

Coping and Quality of Life in Patients with Systemic Lupus Erythematosus: A Review

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Recibido: 11 de agosto del 2015

Aprobado: 26 de octubre del 2015

Cómo citar este artículo: Córdoba, V. y Limonero-García, J. T. (2015). Coping and Quality of Life in Patients with Systemic Lupus Erythematosus: A Review. *Pensando Psicología*, 11(18), 129-139. doi: <http://dx.doi.org/10.16925/pe.v11i18.1223>

Abstract

Background: Systemic lupus erythematosus (SLE) is characterized by uncertain prognosis, severe symptoms and a negative impact on quality of life (QOL) of patients. **Purpose:** The aim of this review is to generate a comprehensive approach in order to improve psychological intervention in these patients. **Methods:** A qualitative review of articles indexed in MEDLINE, PsycINFO and Scopus up to July 2015 was conducted. Articles reporting SLE, coping strategies and QOL were included. **Results:** Twenty-four studies were found, covering different research designs, forms of assessment and intervention. Coping strategies and their relationship with QOL were analyzed in order to describe the best strategies for dealing with SLE. **Conclusions:** There are no adaptive or maladaptive strategies, and the suitability of these depends on the situation that a patient could sustain; nevertheless, an active coping style seems to help preserve the QOL. The main goal of psychological intervention should be to diversify and expand the number of coping strategies used by patients.

Keywords: chronic disease, coping strategies, lupus erythematosus, quality of life, stress, systemic.



Afrontamiento y calidad de vida en pacientes con lupus eritematoso sistémico: una revisión

Resumen

Antecedentes: el lupus eritematoso sistémico (LES) se caracteriza por un pronóstico incierto, síntomas graves y un impacto negativo en la calidad de vida (CV) de los pacientes. **Propósito:** el objetivo de esta revisión es generar un enfoque integral para mejorar la intervención psicológica en estos pacientes. **Métodos:** se llevó a cabo una revisión cualitativa de artículos indexados en MEDLINE, PsycINFO y Scopus hasta el mes de julio de 2015. Se incluyeron artículos que informaban sobre LES, estrategias de afrontamiento y CV. **Resultados:** se encontraron 24 estudios que abarcan diferentes diseños de investigación, formas de evaluación e intervención. Se analizaron las estrategias de afrontamiento y su relación con la CV con el fin de describir las mejores estrategias para tratar con el LES. **Conclusiones:** No existen estrategias adaptativas o desadaptativas y la idoneidad de las mismas depende de la situación que podría estar experimentado el paciente; sin embargo, un estilo de afrontamiento activo parece ayudar a preservar la CV. La principal meta de la intervención psicológica debe ser diversificar y ampliar el número de estrategias de afrontamiento utilizadas por los pacientes.

Palabras clave: enfermedades crónicas, estrategias de afrontamiento, lupus eritematoso, calidad de vida, estrés, sistémico.

Enfrentamento e qualidade de vida em pacientes com lúpus eritematoso sistêmico: uma revisão

Resumo

Antecedentes: o lúpus eritematoso sistêmico (LES) é caracterizado por um prognóstico incerto, sintomas graves e um impacto negativo na qualidade de vida (QV) dos pacientes. **Propósito:** o objetivo desta revisão é gerar um enfoque integral para melhorar a intervenção psicológica nesses pacientes. **Métodos:** realizou-se uma revisão qualitativa de artigos indexados em MEDLINE, PsycINFO e Scopus até o mês de julho de 2015. Foram incluídos artigos que informavam sobre o LES, estratégias de enfrentamento e QV. **Resultados:** encontraram-se 24 estudos que abrangiam diferentes desenhos de pesquisa, formas de avaliação e intervenção. Analisaram-se as estratégias de enfrentamento e sua relação com a QV a fim de descrever as melhores estratégias para lidar com o LES. **Conclusões:** não existem estratégias adaptativas ou desadaptativas e a idoneidade delas depende da situação que o paciente poderia estar experimentando; contudo, um estilo de enfrentamento ativo parece ajudar a preservar a QV. A principal meta da intervenção psicológica deve ser diversificar e ampliar o número de estratégias de enfrentamento utilizadas pelos pacientes.

Palavras-chave: doenças crônicas, estratégias de enfrentamento, lúpus eritematoso, qualidade de vida, estresse, sistêmico.

Introduction

Chronic disease refers to diseases of long duration and slow progress that do not resolve spontaneously and are rarely cured completely, nowadays constituting one of the great challenges of medicine. One of these chronic diseases is systemic lupus erythematosus (SLE), a disorder in which the immune system attacks the tissues and organs of the body, causing inflammation and damage. This most commonly affects women of childbearing age, but also children, adolescents and men, with a prevalence ranging from 20 to 150 cases per 100,000 population, and the 10-year survival rate is about 70% (Tsokos, 2011).

The cellular and molecular mechanisms governing inflammation in SLE remain uncertain (Flesher, Sun, Behrens, Graham, & Criswell, 2010). However, genetic, environmental and hormonal factors are hypothesized to play a key role in prevalence, disease severity and course in different patients (Squatrito et al., 2014; Flesher et al., 2010).

This disease is associated with multiple losses and changes that represent a source of discomfort, such as restriction of activities, increased dependence on caregivers, loss of independence, difficulties in relationships, body image disturbance, risk of miscarriage, neuropsychiatric symptoms such as psychosis, delirium, cognitive disorders and even loss of employment due to physical disability, as well as the commitment of the central nervous system (Cohen, Roberts, & Levenson, 2004).

Therefore, SLE causes a considerable psychological impact, and many of its aspects make it particularly stressful: its chronic and unpredictable course, with sudden exacerbations and remissions, as well as its variable prognosis and the severity of its symptoms (Cohen, Roberts & Levenson, 2004). Regarding the areas of quality of life (QOL) it affects alertness, recreation and leisure, sleep, rest, housework, social interaction, communication, mobility, the ability to work and emotional balance (Lash, 1998; Sperry, 2011). This means that the patient and his family need a great emotional and practical adjustment; this adjustment will be influenced by the cognitive evaluation of the disease.

According to the theory of stress and coping by Lazarus and Folkman (1984), cognitive assessment has a fundamental importance in stress reactions, modulating coping responses and well-being of a person. Moreover, these strategies and their utility are likely to vary and change according to the change of

the disease adaptive tasks. In the case of SLE, the disease has periods of activity and inactivity that affect patient QOL. For example, patients with active SLE reported a worse physical and psychological discomfort than patients with a disease state less active (Dobkin et al., 1999).

Several studies have explored the relationship between adjustment to illness and coping strategies. They concluded that coping strategies focused on the problem are associated with good mental health regardless of the state of disease activity (Bricou et al., 2006), and passive strategies directed toward disengagement predict poor adjustment over time (Stanton, Revenson, & Tennen, 2007).

Stanton, Revenson and Tennen (2007) identified multiple factors that contribute to people's adjustment to chronic disease: socioeconomic status, culture, ethnicity, gender, social resources, interpersonal support, personality traits, the process of cognitive appraisal and coping. From this list of factors, the most likely to be boarded by psychological intervention is coping.

It is noted that cognitive behavioral interventions can modify maladaptive cognitions beliefs and behaviors of patients. The self-help groups (SHG) have had associations with positive results in reducing depression and increasing self-esteem, and interventions aimed at improving active coping and minimizing emotional responses to stress can reduce psychological distress in patients with SLE (Kozora, Ellison, Waxmonsky, Wamboldt & Patterson, 2005).

The goal of medical science increasingly focuses not only in prolonging life, but also maintaining and improving the QOL of the patients, which is defined by the World Health Organization (WHO) as a broad ranging concept that involves the individuals' perception in the context they live, including their culture, goals, expectations and concerns (1997). This perception can be affected by several domains such as health status, as well as social, personal and environmental factors.

According to Centers for Disease Control and Prevention (CDC), health is one of the most important domains of overall QOL, and the concept of health-related quality of life (HRQOL) is proposed to incorporate those specific aspects that can be clearly shown to affect physical or mental health (2000). Since both constructs —QOL and HRQOL—, are often used interchangeably in the literature, this review acknowledges the differences between them and account for both.

Given this premise, the treatment of SLE can't be limited to pharmacotherapy; it must include psychological support to preserve the QOL of sufferers and ease the adaptation to it. This study aims —through a narrative review— to explore the relationship between coping and QOL in patients with SLE, in order to generate a comprehensive approach and make recommendations regarding the psychological improve and the intervention in these patients.

Methods

Two independent investigators carried on an extensive research trying to identify coping strategies and their relationships with QOL in SLE. In order to identify relevant publications, a literature search was performed in MEDLINE, PsycINFO and Scopus databases. While this it was not a systematic review, an extensive search of the scientific literature was undertaken, for which the following keywords were used as search criteria: lupus, systemic lupus erythematosus, coping, coping behavior, coping skills, quality of life and psychological adaptation.

Findings were limited to empirical studies in adults with SLE published in English from 1990 to 2015 (July) that included the concepts of coping and QOL in its objective, whether propose a psychological intervention or not. The abstracts of articles identified were reviewed, and the ones considered relevant were obtained in full text. The full text of these articles was reviewed and in agreement with the second researcher it was examined in order to decide the inclusion and exclusion of studies.

A qualitative analysis of these articles was performed, and the following information was gathered: reference of the study, eligibility criteria, design, participants, measuring instruments, interventions and outcomes.

Results

Selection of studies

This search identified 241 studies (65 MEDLINE, 12 PsycINFO, 164 Scopus). The selection was based on titles, keywords and abstracts resulting in 24 studies published between 1990 and 2015; the others were excluded since they were not empirical, were related to other diseases, the content was not appropriate or were published in a language other than English (table 1).

Table 1
Studies characteristics

Characteristics	Number of studies	%
Year		
1990-1995	2	8,33
1996-2000	4	16,66
2001-2005	6	25
2006-2010	8	33,33
2011-2015	4	16,66
Country		
United States of America	11	45,83
Canada	6	25
Spain	1	4,16
Germany	1	4,16
Korea	1	4,16
Hong Kong	1	4,16
Israel	1	4,16
Italy	1	4,16
Greece	1	4,16
Study design		
Cross-sectional	15	62,5
Prospective	4	16,66
Pre- and post-test	3	12,5
Case study	2	8,33

Note. Compiled by authors.

Quality of life

The review helped to confirm that SLE induces a lasting change in the health and lifestyle of the person, even when the disease is controlled by specific therapies (Rinaldi et al., 2006). QOL and coping were assessed with various instruments (table 2), SF-36 being the most common, while there were a variety of instruments to assess coping. A common finding in the reviewed studies was that the health-related quality of life (HRQOL) of patients with SLE is clearly affected in various dimensions (Kozora et al., 2005; Da Costa et al., 2000; Friedman et al., 1999; Jolly, Peters, Mikolaitis, Evans-Raoul & Block, 2014).

Friedman et al. (1999) found that patients' attitudes toward their illness, fatigue and pain have great impact on their perceived levels of performance, which can be measured by instruments such as the SF-36 rather than objective measures of disease activity, such as specific antibodies or organs affected.

These authors also found that deficits in the QOL in SLE patients of different ethnicities and physical conditions are clearly associated with the perception of functioning, psychosocial and cognitive variables, such as abnormal behaviors associated with the disease, helplessness and worthlessness. The analysis of the results suggested that while many of these associations are common to the entire cohort, some might be specific to each ethnic group.

Two studies found that the sense of coherence (SOC) is a strong correlate of HRQOL in patients with SLE (Abu-Shakra et al., 2006; Hyphantis, Palieraki, Voulgari, Tsifetaki & Drosos, 2011). This construct theory hypothesizes that an individual with a strong SOC maintains and improves health through effective coping with stressors and flexibility, for the purpose of facilitating the adoption of preventive behaviors related to health and eliminating unhealthy ones, while low levels of SOC correspond to individuals with low perceived competence to overcome the health stressors (Hyphantis, et al., 2011). Thus, a person with a strong SOC would be able to cope with stressors related to illness, and therefore enjoy a better QOL (Abu-Shakra et al., 2006).

Coping

As for coping strategies, a study found that strategies classified as avoidant or passive (avoidance, self-blame and wishful thinking), were related to negative consequences for health (McCracken, Semenchuk & Goetsch, 1995), and passive forms of coping were associated with a poor psychosocial adjustment to SLE (Dobkin et al., 1999).

SLE has a fluctuating course with periods of exacerbation and remission. Dobkin et al. (1999) explored the relationship between disease activity and QOL, so that their study showed that in a more active disease state, better mental health was predicted by more education and less emotion-oriented coping, as well as a better physical health was predicted by more emotion-oriented coping in patients. Meanwhile, in a less active disease state, better mental health was predicted by less stress, less emotion-oriented coping, more task-oriented coping and better physical health was predicted by less stress and younger age.

Similarly, another study (Rinaldi et al., 2006) found that patients with SLE used mostly strategies such as acceptance and turning to religion, and less strategies such as planning, suppression of competing activities, restraint coping, focusing on and

venting of emotion, along with strategies focused on the problem, compared with healthy controls.

In the study by Kozora et al. (2005) it was found that, compared with patients with rheumatoid arthritis (RA) and healthy controls, patients with SLE had higher depressive symptoms and psychological distress associated with disengagement and emotional coping styles.

Psychosocial challenges faced by patients with SLE were analyzed through focus groups with the purpose of detecting four key issues (Beckerman, 2011):

1. Feeling depressed for they are not who they used to be.
2. Feelings of depression and anxiety related to coping with the uncertainty of the disease.
3. Physical and emotional fatigue of living with a chronic disease.
4. Coping with the financial strain of the disease.

According to Beckerman and Sarraco (2012), the inability to maintain employment due to SLE, and the expenses of health care and prescriptions can combine and create a series of financial stressors that can result in ongoing conflict for the family. Likewise Auerbach, Beckerman and Blanco (2013) found that socioeconomic coping, lack of friends to rely on, as well as being hospitalized in the past year for SLE also significantly impacted depression and anxiety.

Regarding the possible predictors of coping with the disease, one study found that SLE patients suffering from fibromyalgia also had poorer coping than those who did not suffer from this disease (Akkasilpa, Minor, Goldman, Magder & Petri, 2000). Similarly, attachment can be a predictor of adjustment to disease and QOL, facilitating therapeutic adherence, satisfaction with the doctor-patient relationship and HRQOL (Bennett, Fuertes, Keitel & Phillips, 2011).

Neville et al. (2014) conducted research with SLE patients and healthcare professionals and found that both groups acknowledge the existence of specific needs to cope with the disease, such as specific information and resource needs, barriers to engagement in health care, facilitators for engagement in health care and self-management tools.

Different instruments were used to measure QOL and coping, but while QOL was measured mostly with SF36, the instruments to measure coping vary a lot, as shown in table 2.

Table 2
Measuring instruments of QoL and coping

Measuring instruments	Number of studies	Ref
<i>Quality of life:</i>		
SF36	10	(Dobkin et al., 1999; Rinaldi et al., 2006; Da Costa et al., 2000; Friedman et al., 1999; Abu-Shakra et al., 2006; Bennett, Fuertes, Keitel & Phillips, 2011; Dobkin et al., 2002; Haupt et al., 2005; Dobkin et al., 2001)
WHO QOL-Brief scales	2	(Hyphantis et al., 2011; Abu-Shakra et al., 2006)
Focus groups	1	(Robbins, Allegrante, & Paget, 1993; Beckerman, 2011)
<i>Coping:</i>		
Sense of Coherence scale	1	(Abu-Shakra et al., 2006)
Coping Inventory for Stressful Situations (CISS)	3	(Dobkin et al., 2002; Da Costa et al., 2000; Dobkin et al., 2001; Dobkin et al., 1999)
WCCL-R (Revised Ways of Coping checklist)	1	(McCracken, Semenchuk & Goetsch, 1995)
The Coping Style Inventory (CSI)	1	(Kozora, et al., 2005)
Freiburg questionnaire on coping with illness (FKV)	1	(Haupt et al., 2005)
The Coping Orientation to Problems Experienced (COPE)	1	(Rinaldi et al., 2006)
Lupus erythematosus needs questionnaire (SLENQ)	1	(Auerbach, Beckerman & Blanco, 2013)
LupusPRO	1	(Jolly et al., 2014)
General Health Questionnaire-30 (GHQ-30)	1	(Ng & Chan, 2007)
Coping skills 10 items questionnaire designed by Arthritis Foundation.	1	(Sohng, 2003)
Focus groups	3	(Beckerman, 2011; Beckerman & Sarracco, 2012; Robbins, Allegrante & Paget, 1993)

Note. Compiled by authors.

Some of the reviewed studies measured the effectiveness of psychological interventions administered to patients with SLE; these interventions are heterogeneous in number of sessions and duration, as shown in table 3.

There were two intervention studies that conducted a Brief Supportive-Expressive Group Psychotherapy, originally used as an adjunct to psychological treatment of breast cancer. Dobkin et al. (2002) found that this therapy had no significant impact on any of the psychological aspects of HRQOL that were evaluated, since considered as baseline data, participants in this cohort were carrying the disease very well, used more task-oriented coping than emotion-oriented or avoidant coping, and were satisfied with their social support network. Also this intervention was not designed specifically for patients with SLE.

Meanwhile, the other study (Edworthy et al., 2003) found that this intervention facilitates adaptation to SLE in women who received the intervention, reducing intrusiveness induced by the disease

in different significant domains of life experience, such as social relationships, personal development and intimacy.

Other interventions showed effective results focused in specific areas. For example Sohng (2003), through a group of self-management for patients with SLE, achieved significant improvement in areas such as fatigue, depression and coping strategies. Regarding the psychosocial aspects, Ng and Chan (2007) performed a group intervention that allowed the creation of a platform for patients with SLE where they could share their sorrow and grief about the disease. Significant positive changes in self-esteem, psychosocial functioning, anxiety, depression, difficulty in coping, social dysfunction and sleep problems were found after the group.

Likewise, Navarrete-Navarrete et al. (2010), using a cognitive behavioral treatment achieved a significant reduction in the level of depression, anxiety and daily stress, along with a significant improvement in QOL and somatic symptoms throughout the

Table 3
Psychological interventions to patients with SLE

Ref	Intervention	Study Design	Results
(Dobkin et al., 2002)	Brief supportive-Expressive Group Psychotherapy twelve weekly sessions of 1,5 hours.	Prospective (n=133)	There were no clinically important group differences on any of the outcome measures. Although both groups improved over time on several measures, these changes could not be attributed to the psychotherapeutic intervention.
(Haupt et al., 2005)	Brief supportive-Expressive Group Psychotherapy twelve weekly sessions of 1,5 hours.	Prospective (n=124)	Women who received brief supportive-expressive group psychotherapy experienced significant reductions in illness intrusiveness for two of three domains: 1. Relationships and personal development and, 2. Intimacy. Benefits were evident at sixth and twelve-month follow-ups.
(Haupt et al., 2005)	Psychological intervention combining psychoeducative and psychotherapeutic elements 18 weekly sessions of 1,5 hours.	Prospective (n=34)	The 34 SLE patients improved significantly over a six-month period on most of the psychological measuring instruments applied, such as depression, anxiety, and overall mental burden. The waiting list group showed no significant changes.
(Robbins, Allegrante & Paget, 1993)	Systemic Lupus Erythematosus Self Help Course /SLESH five weekly sessions of two hours	Cross-sectional (n=25)	Culturally determined health beliefs, language of preference, family roles and outreach efforts are the key variables that must be considered in adapting the SLESH Course for the target population.
(Sohng, 2003)	Self- management Course six weekly sessions of two hours	Pre- and post-test (n=41)	This course had effects in reducing fatigue and depression and improving coping skills and self-efficacy.
(Navarrete-Navarrete et al., 2010)	Cognitive behavioural therapy for the treatment of chronic stress in patients with lupus erythematosus. ten weekly sessions of two hours	Prospective, (n=45)	There was a significant reduction in the level of depression, anxiety and daily stress in the therapeutic group compared to the control group and a significant improvement in QOL and somatic symptoms in the therapeutic group throughout the entire follow-up period.
(Ng & Chan, 2007)	Group Psychosocial six weekly sessions of 2,5 hours	Pre- and post-test (n=56)	The study revealed significant positive changes in self-esteem and psychosocial functioning of people with SLE after the psychosocial group program.
(Jolly et al., 2014)	Body image intervention to improve health outcomes in lupus. Ten weekly sessions.	Pre- and post-test (n=10)	The results suggest that the intervention in body image is feasible for SLE populations given that the participants improved on several measures of BI and overall well-being.

Note. Compiled by authors.

follow-up period. Meanwhile, Haupt et al. (2005) developed a group intervention tailored to the specific needs of patients with SLE, integrating psychoeducational elements and retaining the fundamental elements of short-term group psychotherapy. With this intervention patients improved significantly in the period of six months in most psychological measures assessed: depression, anxiety and mental burden. This intervention was effective in reducing long-term dysfunctional coping strategies and wishful thinking, as well as improving QOL in key areas: general

health perception, vitality, social functioning and mental wellbeing.

Jolly et al. (2014) developed an intervention addressed to the poor body image in SLE patients, as it is associated with poor psychosocial wellbeing, abnormal coping behaviors, difficulties forming relationships, an insecure/preoccupied attachment style, low sexual function, risky health behaviors, poor treatment compliance and poor health outcomes. This intervention was cognitive conductual and it improved overall wellbeing and body image.

Regarding cultural differences of patients Robbins, Allegrante and Paget (1993) tried to determine the key variables to be considered in the adaptation of a self-help program for Latino patients with SLE. They conducted focus groups and telephone interviews with patients and families in which several themes came up: cultural beliefs about health, family roles, feelings of lack of self-confidence in speaking English, intimidation, embarrassment, mistrust, shyness and unwelcoming environments as barriers to access self-management programs.

In spite of fluctuations in disease activity, SLE patients, as a group, cope acceptably with the disease over time. However, there is a subset of patients (approximately 40%) that remain in discomfort and they can benefit from psychosocial interventions (Dobkin et al., 2001). None of the studies found significant immunological changes in the index of disease activity (Navarrete-Navarrete et al., 2010; Sohng, 2003).

Discussion

The literature reviewed suggests that there is a benefit for patients receiving psychological treatment in coping adjunct with medical treatment, along with achieving effects such as reduction in anxiety and depression (Navarrete-Navarrete et al., 2010).

Although most studies agree that there are no adaptive or maladaptive strategies, the suitability of these depend on the situation that must be coped with (Rinaldi et al., 2006). The active coping is considered the best predictor of QOL preservation in both the active and inactive phase of the disease (Dobkin et al., 1999).

Using a reduced number of coping strategies increase its maladaptive potential (Rinaldi et al., 2006). For this reason, one of the main objectives in the treatment should be to increase the number of strategies used and diversify them in the purpose to achieve adjustment of the impact that disease activity has on the physical and mental wellbeing (Dobkin et al., 1999).

Several studies agreed that given the impact on HRQOL generated by SLE, a psychosocial intervention is required for the rehabilitation of these patients (Sperry, 2011; Dobkin et al., 1999; Kozora et al., 2005; Rinaldi et al., 2006; Friedman et al., 1999; Akkasilpa et al., 2000). However, the heterogeneity of the interventions described shows the need to standardize treatment for these patients, based on theoretical models of coping with chronic illness.

According to Rinaldi et al. (2006), the understanding of the influence of different coping strategies on HRQOL in SLE patients would help to design an intervention specifically tailored to them. Although this may not be enough, since it also requires modifying the tendency of SLE patients to act in many everyday situations as if they were facing problems related to the disease.

Evidence suggests that cognitive behavioral intervention aimed to transform maladaptive cognitions and behaviors can be very effective for patients with SLE (Kozora et al., 2005). This type of treatment significantly reduces the incidence of psychological and social disorders with SLE and improves and maintains HRQOL. The introduction of therapy from the time of initial diagnosis may be useful, since patients may need to know how to deal with stress more effectively at that time (Navarrete-Navarrete et al., 2010).

The social issues are an important aspect to be considered. Da Costa et al. (2000) indicate that improving QOL in patients with SLE requires a specific orientation towards modifiable psychosocial factors. According to Ng and Chan (2007), social relationships are considered essential in the rehabilitation of people with a chronic disease, as this develops mutual support and patients learn to live with the disease in the community. Regarding this aspect, poor body image is considered an important obstacle for SLE patients to form relationships and it is necessary to include a body image intervention for them in order to improve their quality of life (Jolly et al., 2014).

Similarly, Haupt et al. (2005) observed a low dropout rate that seemed to be related to the integration of key attachment figures in the intervention group. Beckerman's findings (2011) seem to confirm this, since in her study SLE patients gained more strength and coped better with four areas of support: information and education about SLE, family and friends, professional support, and internal support (all of them related to the social aspect). Likewise, Ng and Chan (2007) concluded that through the positive experience of psychosocial group and cohesion achieved by patients, they were able to develop a good social support network, which helped to reduce anxiety and depression.

Despite the above, people with SLE must learn to cope a lifelong condition in which there will always be potential threats and disruption in normal daily activities, severe symptoms and disability, and it is necessary to investigate which psychological

interventions are effective for these patients. So far, relatively few studies have been carried on compared to what has been done with other chronic diseases (Sohng, 2003).

One of the issues of comparing outcomes of effective interventions is the fact that most of the papers reviewed used generic instruments to ascertain QOL and HRQOL, in spite of the existence of several measures designed specifically to assess HRQOL in SLE patients, such as the Lupus Quality of Life (LUPUSQOL), Systemic Lupus Erythematosus-Specific Quality of Life Questionnaire (SLEQOL), and Systemic Lupus Erythematosus Quality of Life questionnaire (L-QOL) (Yazdany, 2011).

Given this literature review, it could be concluded that effective psychological interventions attached to medical treatment for SLE patients would be those which are aimed to promoting active coping, diversifying and expanding the number of coping strategies, including positive reinterpretation as an especial aspect.

These psychotherapies should integrate psychoeducational component about the disease, along with a psychotherapeutic supportive component of cognitive behavioral counseling to modify maladaptive behaviors and cognitions: focusing in self-efficacy and self-esteem, training in problem solving and social skills, as well as the construction and strengthening of a network of social support, including significant attachment figures in order to prevent desertion. All this must start as soon as possible after diagnosis disclosure.

Similarly the particularity of the disease must be considered, with the fluctuations in its activity and symptoms, cultural differences of each patient and the importance of establishing a working alliance between patient and medical staff.

In the present study the authors have tried to lay the foundations in order to develop a better strategy or psychological approach to improve QOL in patients with SLE from the review of the existing literature.

Conflict of Interest Statement

The authors declare no conflict of interest.

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