

Psychological Services for Patients with Systemic Lupus Erythematosus

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Faculty Disclosure

Contributing faculty, Kathleen Holland, PsyD, has disclosed no relevant financial relationship with any product manufacturer or service provider mentioned.

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Audience

This introductory course is designed for psychologists involved in the care of patients with systemic lupus erythematosus.

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Course Objective

The purpose of this course is to provide psychologists with the tools necessary to effectively address the psychosocial needs of patients with SLE.

Learning Objectives

Upon completion of this course, you should be able to:

1. Outline the epidemiology and pathophysiology of systemic lupus erythematosus (SLE).
2. Discuss the diagnosis and medical treatment of SLE.
3. Identify components of the psychological evaluation of patients with SLE.
4. Describe how to select the appropriate psychological services and treatment plan for patients with SLE, taking into account potential comorbid psychiatric disorders.

INTRODUCTION

Systemic lupus erythematosus (SLE) is a rare, multi-system, chronic disease that impacts physical and psychological functioning [1]. This complex autoimmune disorder affects more women than men and is more common among racial/ethnic minorities (e.g., African Americans, Hispanic women) than non-Hispanic White populations [2]. Manifestations of the disease can vary widely and include organ-threatening complications, fatigue, stress, depression, anxiety, and pain [1]. Research has identified specific mental health needs in the SLE population, and mental health professionals providing services to patients with SLE use an eclectic, multi-method approach in the treatment and evaluation of these individuals. Both psychoeducational and psychotherapeutic interventions are required due to the variability of SLE symptoms and the serious complications of this disease. Interventions and therapy should be targeted and sensitive.

AN OVERVIEW OF SLE

Patients with SLE face a cycle of stress and frustration due to the changes in their physical health, their appearance, and their lifestyle that occur as a result of the disease [1]. SLE is an inflammatory autoimmune disorder in which the immune system produces autoantibodies that attack healthy cells, causing inflammation and other complications that can impair organs and systems, including the kidney, skin, blood, and central nervous system (CNS) [1]. As noted, symptoms may include depression, anxiety, impaired joint mobility (and associated movement difficulties), joint pain, vision changes, low-grade fevers, photosensitivity, fatigue/malaise, sleep disturbances, and psychological distress [1]. Stress exacerbates the symptoms of this chronic medical disorder, and symptoms often follow a course of flares and remissions.

Psychological problems may arise at different points in the course of the disease. For example, adjustment reactions are common at the initial diagnosis, while issues related to stress and pain management are ongoing [1]. Psychological services and treatments vary in response to the needs of the individual patient, fluctuations in the disease, stage of the disease, and the debilitating aspects of the disorder [1].

The patient with SLE may also deal with changes in self-image, body image, and self-esteem as a result of the outward signs of the disease, including hair loss, weight gain, and facial rashes. Changes in social relationships may occur, as it can be difficult to plan social activities due to the unpredictable flare-ups and decreased functional abilities. Family relationships can be strained if expectations are not met, and work activity and recreational pursuits may suffer. Cognitive deficits can develop at any point during the course of the disease if there is CNS involvement [3].

EPIDEMIOLOGY

It is believed that there are approximately 1.5 million individuals in the United States with some form of lupus, although estimates of individuals with SLE range from 161,000 to 322,000 [4; 5]. Lupus is more common than other better-known disorders, such as leukemia, multiple sclerosis, cystic fibrosis, and muscular dystrophy, affecting more individuals than all of these diseases combined [1].

Lupus is a significant cause of disability in the United States. Although estimates vary widely between studies, it is estimated that 20% to more than 50% of patients with lupus are unable to work due to their disease and approximately 20% to 32% of patients receive disability benefits [6; 24].

More than 90% of SLE cases occur in women, with most individuals developing symptoms in their childbearing years (15 to 45 years of age) [7]. New diagnoses of lupus in women older than 45 years of age are uncommon [1]. SLE is most common among African Americans, with African American women having three times the incidence of White American women [7]. The incidence of lupus is also greater in Hispanic, Asian, and Native American women when compared with White women [7; 8]. Statistics show that Black and Hispanic women tend to develop the disease at a younger age, are more likely to develop more serious complications (particularly cardiovascular complications and kidney disease), and tend to have a higher mortality rate from the disease as compared to White women [7].

DIAGNOSIS

The exact cause of lupus remains a mystery, but researchers believe that it results from multiple factors [1; 9]. Possible causes may be interrelated and include immunologic dysfunction, genetic factors, hormones, and environmental influences [10; 11]. The diagnosis of lupus may be a challenge for the healthcare provider as well as the patient. A diagnosis of lupus can only be made when an individual shows clinical evidence of multiple organ system disease [12]. It is not uncommon for patients with lupus to have consulted with three to five physicians before a definitive diagnosis of lupus is given [1]. An average delay of two to three years from the onset of symptoms to the time of diagnosis is common [1]. In addition, patients with lupus may have a variety of healthcare professionals caring for them due to multiple organ system involvement and a wide range of symptoms. This may result in confusion and information gaps for the patient and healthcare providers [13].

The antinuclear antibody (ANA) test is the most specific and sensitive test for lupus and is therefore the most commonly used autoantibody test. Ninety-seven percent of patients with lupus have a positive ANA blood test [12]. As noted, lupus is a condition that is often difficult to diagnose due to the significant variation of symptoms among individuals. In 2019, the European League Against Rheumatism (EULAR) and the American College of Rheumatology (ACR) published updated classification criteria for lupus [14]. The EULAR/ACR criteria classifies a person as having lupus if they meet entry criterion of an ANA titer of $>1:80$, followed by additive weighted criteria (seven clinical and three immunologic) in which the patient must meet one clinical criterion and ≥ 10 points between the clinical criteria and immunologic criteria [14].

Four different forms of lupus have been identified: cutaneous lupus erythematosus (CLE), drug-induced lupus, neonatal lupus, and SLE [13]. CLE mainly affects the skin. It is associated with chronic skin eruptions that, if left untreated, can lead to scarring and permanent disfigurement. Drug-induced lupus is associated with ingestion of various drugs that result in lupus-like symptoms. Neonatal lupus is a rare, non-systemic condition affecting infants of women with lupus; symptoms typically resolve within six months. SLE, which affects multiple organ systems as well as the skin, is considered the most common of the four forms.

MEDICAL TREATMENT

The medical treatment of SLE includes a variety of drug interventions to address the many manifestations of the disease, including anticoagulants, anti-inflammatory medications (including nonsteroidal anti-inflammatory drugs [NSAIDs]), glucocorticoids, antimalarials, and immunomodulating drugs [1].

Side effects that may arise as a result of any of these medications, particularly long-term use, are a significant consideration for these patients [1]. In cases of severe lupus kidney disease not helped by pharmacologic intervention, dialysis or kidney transplant may be necessary.

Kaposi was the first to identify the mental changes associated with SLE in 1875 [1]. It has been estimated that 65% of patients with SLE have evidence of cognitive impairment and/or personality changes [1]. Research has been limited on cognitive changes in patients with SLE due to the small sample sizes, so generalization should be guarded.

Health psychologists, neuropsychologists, and psychiatrists evaluating patients with SLE may find that they present as timid, depressed, and/or dependent. Patients may show signs of cognitive confusion, difficulty expressing oneself, and/or memory problems [3]. Administering a mental status exam at each session is essential, as changing disease activity levels are associated with fluctuating psychological symptoms.

Individuals diagnosed with lupus are encouraged to do all of the following [1; 10; 11; 13]:

- Get plenty of physical and emotional rest.
- Maintain a healthy diet.
- Establish an exercise regimen.
- Avoid sunlight.
- Seek prompt treatment of infection.
- Limit stress.
- Set realistic goals and priorities.
- Maintain effective communication with their healthcare providers.
- Develop a support system, including family, friends, healthcare professionals, community organizations, and organized support groups.
- Avoid triggering or aggravating factors.
- Seek regular health care.

Eight to 10 hours of sleep per night along with naps are recommended for patients with lupus. In addition, individuals with lupus should minimize stress to reduce emotional distress, as well as avoid direct prolonged sunlight, especially during the hours of 10 a.m. and 4 p.m. The use of a sunscreen with a sun protective factor (SPF) of 15 or greater that protects against both ultraviolet A and B rays is recommended along with protective clothing such as long sleeves and a hat [13]. Routine exercise is important to reduce fatigue and maintain joint mobility.

LUPUS AS A CHRONIC ILLNESS

Numerous illnesses are considered chronic in nature. Various chronic illnesses include diabetes, asthma, congestive heart failure, and rheumatoid arthritis. Lupus is considered to be a chronic illness due to its cyclical nature of exacerbation and remission of symptoms. Chronic illnesses such as lupus can be challenging to the patient due to the physical, psychological, social, and financial impact of the disease.

When most individuals think about chronic illness, they tend to picture illnesses found predominantly in elderly individuals. Chronic illnesses such as lupus, however, are not limited to a specific age group. In fact, lupus usually strikes individuals in the prime of their life.

Chronic illness and disability not only result in the loss of physical aspects of the individual's life but may also impact the psychological, familial, social, and vocational aspects of the affected individual's life [26]. The impact chronic disease will have on an individual is dependent on various factors, including the nature of the condition, the individual's pre-illness or pre-disability personality, current life circumstances, and the amount of family and social support in the individual's environment [26]. All of these disease factors can impact the patient's perception and experience of lupus. Due to the young age at disease onset, most individuals with lupus can expect to face many years managing their chronic condition.

CHRONIC ILLNESS AND DISABILITY

Both the perception and importance that an individual and his or her family attribute to a chronic illness can affect the individual's ability to accept the condition and make the adjustments necessary to cope [26]. Illness and disability can impact the relationships of the person diagnosed with the chronic illness. Individuals may fear the loss of a relationship secondary to their chronic illness condition; therefore, they may try to conceal the impact of the condition on their life in order to maintain the relationship [27].

Baker and Wiginton found that study participants “expressed concern that others in their lives did not understand lupus and failed to acknowledge the seriousness of their conditions due to the symptoms not being readily apparent” [28]. Family and friends may deny that the disease is a problem, fail to assist the individual, or fail to understand the disease, particularly if the individual shows no outward signs of the disease. Falvo terms this “invisible disability” [26]. Lupus is one such invisible chronic illness. Additionally, some people may be uncomfortable being in a relationship with an individual with a chronic illness like lupus. They may not know what to say, worry about saying the wrong thing, or fear that the chronic disease is contagious.

CHRONIC ILLNESS AND RELATIONSHIPS

Sexuality and interpersonal issues may also be impacted by a chronic illness. Physical limitations, lack of energy, pain, alterations in self-image, or other reactions may impact the sexuality of an individual with lupus [26]. However, a lack of pleasure from sex and presence of sexual dysfunction is not typical in women with SLE [1]. A large survey found that only 4% of women have significant sexual problems related to the disease [1]. Open communication and knowledge regarding the lupus disease process can prevent uncertainty and issues regarding sexuality.

Some individuals with a chronic condition like lupus do not want to burden or inconvenience those around them; thus, they attempt to manage the disease on their own. Individuals with a chronic illness should make families aware of the necessity for adjustments or alterations in roles and tasks secondary to the lupus disease process. Families should be aware of the fact that lupus requires ongoing care and treatment to effectively control the disease. It has been suggested that, compared to women, men may feel more uncomfortable or intolerant regarding a chronic illness such as lupus. This may be due to the fact that women have historically had the primary caregiver role, particularly regarding care of the ill [27].

PSYCHOLOGICAL EVALUATION OF THE PATIENT WITH SLE

Conducting mental health evaluations of patients with SLE is complicated by the varied symptoms and episodic nature of the disease and its impact on major life functions. A number of domains in life are affected by the disease, and throughout its course, SLE can impact a patient's psychological functioning due to socioemotional issues, economic loss, and cognitive changes [2].

When conducting a comprehensive psychological or psychiatric evaluation of patients with SLE, it is essential that premorbid cognitive abilities and personality styles and types are determined. Assessments should include a structured interview, observations, review of medical record, educational history, social history, occupational history, determination of the patients spiritual or religious beliefs, review of prior psychological or psychiatric assessments, the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ), cognitive evaluations, personality assessments, mental health evaluations, and medical imaging (e.g., magnetic resonance imaging) or other scans, as needed. If cognitive test measures are administered, the tools should be sensitive and specific.

The first step of assessing cognitive level of functioning is determining if the patient is medically stable by evaluating disease activity and identifying recent and current complications. As noted, cognitive impairment test scores will fluctuate as a result of natural variations in the disease process, especially if CNS involvement has been detected [3].

Research indicates cognitive dysfunction is not a significant factor in SLE (except with CNS involvement), and cognitive dysfunction is not consistent with or explained by a psychiatric disorder [3]. However, the 40% of patients with SLE who do have CNS involvement are at increased risk for a variety of neurologic and psychiatric abnormalities, including seizures, stroke, psychosis, depression, and even suicide.

In the interpretation of assessment results, the examiner should determine if the findings are the result of true cognitive impairment or if other factors are affecting assessment results. Many factors can influence the results of psychological evaluations, including [2]:

- Pain
- Fatigue
- Complications of the disease
 - Recent organ transplant
 - Seizure
 - Stroke
 - Functional impairments
- Psychosocial stressors
 - Recent divorce
 - Work activity
 - Depression
 - Anxiety
- Personality factors
 - Coping style
 - Resilience to stress
- Situational factors

PSYCHOLOGICAL SERVICE SELECTION

As noted, it is important to parcel out the premorbid level of functioning, disease impact, and stability of the disease to determine if patients with cognitive deficits related to SLE would benefit from the clinical application of the modifiability model for neuropsychology rehabilitation. The neural plasticity mechanisms and the model for neuropsychological interventions and rehabilitation programs may be applicable depending on the deficits identified, the level of disease activity, and stage of the disorder.

A variety of health and behavioral interventions may be used in the treatment of patients with SLE, and practitioners will benefit from the use of a multi-method, eclectic, theoretical approach [16]. It is important to adjust theoretic practices and borrow from both Eastern and Western theories in order to address the symptoms and stages of SLE. Approaches that have been successfully used in the treatment of patients with SLE include:

- Humanist psychology
- Psychoanalytic, behavioral, patient-centered therapies
- Cognitive-behavioral therapy (CBT)
- Emotionally focused therapies
- Existentialism
- Gestalt therapy
- Mindfulness training
- Spiritually based therapies
- Relaxation training
- Traditional psychoeducational interventions

THE PSYCHOLOGICAL TREATMENT PLAN

Following a careful interpretation of the psychological evaluations, a treatment plan is developed. Treatment may include group therapy, individual or family therapy, and/or psychological interventions. As always, therapy should be targeted and sensitive, taking into consideration unmet needs and the impact of the disease on the patient's social, emotional, and physical functioning [16]. Patients with SLE may benefit from a combination of stress and pain management techniques; therapy for adjustment reactions; CBT or other evidence-based treatments for depression, anxiety, and poor self-image; treatment for sleep disturbance; mindfulness training; guided imagery; breathing exercises; relaxation training; and/or exercise therapy.

Considerable emotional support may be required to help patients with lupus to cope with the chronic disease. More than 50% of all individuals with lupus experience emotional problems secondary to their illness [11]. Darner found that women with lupus who had been diagnosed for longer periods of time had a healthier psychosocial adjustment [18]. Therefore, those newly diagnosed with lupus may require more support and interventions to aid in psychosocial adjustment. Some individuals are overwhelmed with having a disease and may find professional counseling to be an important means of managing their condition.

Cognitive mapping has been used to ascertain how women with lupus represent their illness [23]. In one study, 20 female patients with lupus were interviewed in a convenience sample and asked to generate major concepts for the question, "When you think of living with lupus, what words come to mind?" In addition, participants determined

the positive and negative relationship among the identified words or phrases. The concept mapping procedure generated 192 unduplicated concepts. Pain was the most commonly identified concept reported by participants. The report concluded that "although diagnosed with the same illness, women presented with different mental representations of the illness" [23].

Findings indicate that "support groups, self-help groups, and peer counseling...may facilitate the individual's achievement of a positive adjustment to the newly diagnosed illness" [18]. Self-help groups offer patient education on lupus disease management, and it is recommended that those newly diagnosed with lupus receive support via peer groups. It has been noted that "participating in a support group can provide emotional assistance, boost self-esteem and morale, and help to develop or improve coping skills" [10]. Successful support groups can assist patients to gain insights into how to live with their lupus [17]. Support groups provide an avenue for the exchange of feelings and ideas regarding lupus. Robert Phillips, founder of the Center for Coping, stated "self-help or support groups can be incredibly helpful and are some of the best sources of support for people with lupus" [11]. Support groups also restore a sense of autonomy and self-reliance, resulting in a reduction in dependency for the group participants [19]. These groups can provide ideas on how to effectively cope with serious illness and manage problems associated with the condition. Lupus support groups can help members "realize they have the inner strength to cope with existential dilemmas of life as well as the comfort of knowing there are others like themselves" [17]. Gartner states that "in the case of most chronic illnesses, the issue is cure not cure, and the mutual-support group can play a powerful role in helping individuals cope with their illness" [19].

Online social support groups may be an important resource for patients with lupus, especially those who live in rural areas or are unable to leave their homes. Patients may be directed to one of many support groups available online, including Us in Lupus (<https://www.usinlupus.com>) and LupusConnect (<https://www.lupus.org/resources/lupusconnect>).

Referral for specialized care is indicated if patients have evidence of CNS involvement, pain, persistent sleep disturbances, or other complicated issues related to physical or psychological symptoms. A multidisciplinary approach, with close collaboration among the patient's physician, mental health providers, occupational therapist, and other team members, may improve outcomes.

Research indicates that patients with SLE do not always report their needs to their health or mental healthcare providers [20]. In a sample of 112 subjects with SLE who completed the SLENQ, all subjects reported at least one unmet need [20]. African American participants reported a greater number of unmet needs related to health services and information compared with their White counterparts, and older patients experienced more unmet needs related to physical and psychological functioning than younger patients. In total, 98% of the patients had at least one unmet need related to physical health and functioning, most commonly fatigue (90.2%). Psychological and existential needs were reported by 91% of the subjects, and the most common psychological/existential needs were related to [20]:

- Fear of flare-ups (80%)
- Coping with anxiety or stress (79%)
- Decreased functional and social ability (77%)
- Fear of physical disability (74%)
- Depression (71%)

In a separate study, patients who had a higher sense of control were less likely to report distress, including depression and anxiety, related to their SLE than those with lower perceived control [21]. The two most common causes of depression were changes in appearance due to SLE (e.g., hair loss, weight gain) and limitations in physical activities due to symptoms such as multi-joint pain. Other factors found to increase the risk of anxiety and depression included a greater number of flares, chronic symptoms, and socioeconomic hardships (e.g., unemployment, disability leave from work) [21].

In general, patients with SLE report more psychiatric symptoms than general medical inpatients [22]. A study of 326 women with SLE used the Composite International Diagnostic Interview (CIDI), the Systemic Lupus Activity Questionnaire (SLAQ), the Systemic Lupus Activity Measure (SLAM), and the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) to determine the lifetime prevalence of psychiatric disorders [2]. The results indicated that 65% of the sample had a lifetime mood or anxiety diagnosis, and usually more than one disorder was found [2]. The most common disorders were [2]:

- Major depressive disorder (47%)
- Specific phobia (24%)
- Social phobia (16%)
- Obsessive-compulsive disorder (9%)
- Panic disorder (8%)
- Bipolar disorder (6%)
- Generalized anxiety disorder (4%)
- Dysthymic disorder (3%)
- Agoraphobia (1%)

A separate meta-analysis found that patients with SLE were at significantly greater risk of suicide compared with the general population [25]. However, only 40% of patients with SLE seek professional help for psychological disorders [2]. This low mental health utilization rate indicates a need for outreach to this group and a need for additional research on specific, effective psychological treatments and interventions for patients with SLE. Psychological services should be flexible and timely, as patients' needs vary throughout the course of the disease. Prior to diagnosis, patients expected to live a normal life; following diagnosis, they are forced to adjust to the disease's impact on leisure activities, personal/family relationships, and employment. As a result, adjustment reaction disorder is relatively common [1]. Quality-of-life issues and patients' perceived health status also impact adjustment to the disease. Mental health interventions should be timely, flexible, and involve a variety of psychological techniques and therapies, taking into account the severity of the disease, complications, the patient's level and impairment, and the patient's ability to cope.

Some patients will benefit from training in behavioral charting. Identifying patterns and associations between flares, stressors, pain, and physical activities can be helpful and may increase patients' perceived control and hope for the future. Exercise can increase mobility and/or flexibility by helping to build muscle tone and strength, and low-impact and moderate activities, such as stretching, walking, or aqua aerobics, may benefit management of the disease.

A combination of psychoeducational and psychotherapeutic interventions significantly improve outcomes in patients with SLE [16]. Sustained improvements in mood, depression, anxiety, coping skills, overall mental health burden, and overall quality of life have been observed following involvement in a mix of psychoeducational sessions and group and/or individual therapy sessions. Development of coping strategies in patients with SLE can improve their ability to deal with negative emotions and the stresses associated with the disease.

CONCLUSION

SLE is a relatively rare disease, and research has often been limited to small samples. Additional large-sample research is needed in the area of SLE's impact on cognitive functioning and mental health needs. It is known that SLE is costly in terms of both healthcare utilization and impact on a patient's quality of life. Appropriately addressing the mental health issues associated with SLE through patient education programs and psychological interventions has been shown to reduce healthcare costs and lessen the complications of the disease. Patients require a targeted, sensitive, and flexible approach to health and behavioral assessment and treatments [16]. The use of psychological and mental health services by patients with SLE is low, and research has indicated there is a high rate of unmet needs related to psychological functioning in this patient population [20]. Effective psychoeducational and psychotherapeutic programs include stress management, coping skills, pain management, interventions for sleep disturbance, and evidence-based therapies that facilitate adjustment and reduce maladaptive behaviors [16].

RESOURCES

Studies indicate that learning about one's disease process can aid individuals. In addition, it can increase the likelihood of participation in one's care and improve disease outcome [16]. One important voluntary organization that is dedicated to providing such services is the Lupus Foundation of America (LFA). The LFA "brings patients and families together and provides beneficial information about lupus and its treatment" [11]. The LFA has nearly 300 integrated chapters and support groups located in 23 states providing education services, referrals, health fairs, newsletters, publications, and seminars. Support is provided to patients with lupus, families, and friends through the LFA organization [10]. The foundation's website is <https://www.lupus.org>. To increase national recognition for lupus, May has been designated as Lupus Awareness Month.

Other resources of patient education information include:

American Autoimmune Related Diseases Association, Inc.

<https://autoimmune.org>

American College of Rheumatology

<https://rheumatology.org>

Arthritis Foundation

<https://www.arthritis.org>

National Institute of Arthritis and Musculoskeletal and Skin Diseases

<https://www.niams.nih.gov>

National Organization for Rare Disorders

<https://rarediseases.org>

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