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Original Investigation

Analysis of focus groups of Colombian patients with systemic lupus erythematosus: A qualitative look at representations of the disease☆

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ABSTRACT

Systemic lupus erythematosus (SLE) exposes patients to physical, psychological, family, work and social stress factors. The health-related quality of life of these patients is less than that of the general population, and stress is associated with worsening symptoms of SLE. Studying the factors that determine the perceptions of an SLE patient toward their disease would allow understanding the mechanisms by which quality of life is adversely affected, and promote interventions that ensure the well-being of these patients.

Objective: To gain knowledge of the perceptions that SLE patients have regarding their disease.

Methodology: A total of 50 patients (11 of them men) participated in 5 focus groups that were guided by a psychiatrist applying a semi-structured interview. The interview transcripts were categorized into the following 3 phases using grounded theory: open, axial and selective coding.

Results: The results were organized into 7 categories: news of the diagnosis; causes of the disease; functional, social and work consequences; difficulties in establishing a diagnosis; non-pharmacological, alternative treatments, low or non-adherence and rejection of drug treatment; weaknesses in health care identified by the patient; and disease awareness.

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Conclusions: Knowing the perception that SLE patients have of their disease allows the physician, the patient, and the patient's family to take steps toward designing timely and effective interventions for integrated disease management, treatment adherence, and reducing the associated morbidity and costs of medical care.

Análisis de grupos focales en pacientes colombianos con lupus eritematoso sistémico: una mirada cualitativa a las representaciones de la enfermedad

Palabras clave:
Percepción
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RESUMEN

El lupus eritematoso sistémico (LES) es una enfermedad crónica que expone a los pacientes a situaciones estresantes físicas, psíquicas, familiares, laborales y sociales. Se conoce que la calidad de vida relacionada con la salud de estos pacientes es inferior a la de la población general y que el estrés está relacionado con el empeoramiento del LES. El estudio de los factores que determinan la percepción del paciente con LES permitiría conocer los mecanismos que inciden negativamente en la calidad de vida y promover intervenciones que conlleven su mejoría.

Objetivo: Conocer la percepción que los pacientes con LES tienen acerca de su enfermedad.

Metodología: Cincuenta pacientes (11 hombres) con LES y sin otras enfermedades autoinmunes participaron en 5 grupos focales, realizados por un médico psiquiatra mediante la aplicación de entrevista semiestructurada. Utilizando la teoría fundamentada, las transcripciones fueron categorizadas en 3 fases: codificación abierta, axial y selectiva.

Resultados: Se organizaron en 7 categorías: noticia del diagnóstico; causas de la enfermedad; consecuencias funcionales, sociales y laborales; dificultades para establecer el diagnóstico; los tratamientos no farmacológicos o alternativos; baja adherencia y rechazo al tratamiento farmacológico; fallas identificadas por los pacientes en la atención en salud y conciencia de la enfermedad.

Conclusiones: El conocer la percepción que tiene el paciente con LES de su enfermedad les permite al médico, al paciente y a su familia adoptar medidas encaminadas a diseñar intervenciones puntuales y eficaces para el manejo integral, adherencia al tratamiento, disminución de morbilidad asociada y de costos derivados de la atención médica.

Introduction

Systemic lupus erythematosus (SLE) is an autoimmune, chronic, multisystem and complex disease that is associated with a significant economic burden related to the use of resources invested in health care and the loss of productivity of the patient and the caregiver. The prevalence in the United States is 52/100,000 inhabitants, 21/100,000 in Canada and 25–91/100,000 in Europe.[1] The epidemiology in Latin America has been little studied; however, it is known that the disease is more severe in patients of Hispanic origin, low socio-economic strata and lower educational level, with greater renal involvement and mortality than in Caucasian patients.[2–4]

The clinical evolution of SLE is unpredictable, undulating in time with clinical manifestations and sequels that can affect the physical function and the quality of life.[3,5] The above may result in increased morbidity and mortality through accumulated damage in multiple organs and systems. The alteration in the physical, personal, social and family aspects of the patients with SLE can significantly compromise the control of the disease activity, generating higher morbidity and mortality.[6]

Dealing with a chronic disease like SLE constitutes a major challenge for the patient and his family environment. Those who suffer from the disease must confront various stressful situations such as frequent medical evaluations, visits to the hospital, side effects of the treatment, pain, fatigue and anxiety. The above increases the risk of developing behavioral, social and emotional alterations.[7,8]

The perception of the disease is mainly cognitive, which influences the emotional response of the patient to his illness and his behavior to cope with it.[9] Patients with SLE have representations about their disease, which they elaborate through experiences lived personally or by third parties. For these reasons, it is justified to try to know which is the perception that people have of their disease, especially the cognitive (identity,