

“What you always wanted to know about lupus and never dared to ask”: proposal for a patient education program

“O que você sempre quis saber sobre lúpus e nunca teve coragem de perguntar”: proposta de programa de educação do paciente

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ABSTRACT

Introduction: studies on chronic diseases highlight the importance of patient education to promote adherence to treatment and improve prognosis. **Objective:** to know the main questions from patients with systemic lupus erythematosus (LES) as a starting point for the preparation of a Patient Education Program. **Method:** this was a descriptive and cross-sectional study. For six weeks, LES patients treated at the Rheumatology Department of the General Hospital wrote their questions about the disease in a white sheet and placed it in a box. **Results:** 260 consultations were analyzed and 111 sheets were completed, totaling 393 questions with an average of 3.54 questions per patient, which were classified into nine categories: treatment and prevention (18.8%); clinical framework and diagnostic (18.3%); etiology and pathophysiology (17.0%); prognosis and progression (16.3%); concept and epidemiology of the disease (8.1%); general guidelines (6.1%); contraception, pregnancy, and fertility (7.4%); psychological aspects and sexuality (6.9%); and excluded questions (1%). **Conclusion:** it was observed that most of the questions reflected themes often approached during medical consultations. Communication between the doctor, healthcare team, and patient needs to improve, and one strategy would be the development of a patient education program.

Key words: Lupus Erythematosus, Systemic, Health Education; Health Knowledge, Attitudes, Practice.

RESUMO

Introdução: estudos sobre doenças crônicas evidenciam a importância da educação do paciente, para promover a adesão ao tratamento e melhorar o prognóstico. **Objetivo:** conhecer as principais dúvidas de pacientes com lúpus eritematoso sistêmico (LES), como ponto de partida para elaboração de um Programa de Educação do Paciente. **Método:** estudo descritivo e transversal. Durante seis semanas pacientes com LES atendidas no Serviço de Reumatologia do Hospital das Clínicas da UFMG escreveram suas dúvidas sobre a doença em um folheto em branco e o depositaram em uma urna. **Resultados:** foram analisadas 260 consultas e 111 folhetos foram preenchidos, totalizando 393 perguntas, com média de 3,54 perguntas por pessoa, classificadas em nove categorias: tratamento e prevenção (18,8%); quadro clínico e diagnóstico (18,3%); etiologia e fisiopatologia (17,0%); prognóstico e evolução (16,3%); conceito e epidemiologia da doença (8,1%); orientações gerais (6,1%); contracepção, gestação e fertilidade (7,4%); aspectos psicológicos e sexualidade (6,9%); e perguntas excluídas (1%). **Conclusão:** observou-se que a maior parte das dúvidas refletia temas frequentemente abordados durante a consulta médica. É preciso melhorar a comunicação entre médico, equipe de saúde e o paciente e uma estratégia seria desenvolver um programa de educação do paciente.

Palavras-chave: Lúpus Eritematoso Sistêmico; Educação em Saúde; Conhecimentos, Atitudes e Prática em Saúde.

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INTRODUCTION

Systemic lupus erythematosus (LES) is a chronic inflammatory disease, multi-systemic, and with an autoimmune nature. Its multiple and recurrent symptomatology influences the lives of patients in various ways whether through the impaired function of multiple systems and self-image, whether through restrictions on social participation.^{1,2} All these situations directly affect the quality of life of these individuals.

The prognosis of patients with LES has greatly improved in recent years. In 1950, approximately 50% of LES patients died after four years of diagnosis. Today, 80% survive up to 15 years after diagnosis. The increase in survival rates has been attributed to several factors such as early diagnosis, better treatment options, and control of the associated morbid conditions besides extensive knowledge about disease.³

Studies on chronic diseases highlight the importance of education on treatment adherence with consequent improvement in prognosis.⁴ According to the World Health Organization, adherence to long-term therapy is around 50% in the general population of developed countries. It is estimated that this rate is much lower in developing countries mainly due to the lack of resources and poor access to health care.⁵

However, there are a few studies that identify the specific needs in information in people with LES.⁶⁻⁹ Because it is rare, and therefore often unknown disease, there is no representation of LES in the popular imagination, which allows different fantasies about the disease played by patients, its repercussions, and prognosis.¹⁰ Additionally, with the oscillating behavior of LES, with alternating periods of calm and signs and symptoms exacerbation, patients often experience uncertainty about disease progression, and hence, how it will affect their lives.

Because there is little media coverage, LES patients, in general, receive more information about the disease through medical appointments. While the Internet provides different information about the disease, not all sites have reliable texts and sometimes the patient has difficulty in selecting what is really important.¹¹ Thus, knowing the questions and needs of this population, as well as improving the access to knowledge should be the goal of health professionals and institutions dealing with individuals with LES. Information makes the patient an active member in the treatment and prevention of injuries, increases adhe-

sion, and may improve disease progression and prognosis with benefits in the quality of life.¹² The quality of care provided to patients and their families with the appropriate language, conveying confidence, embracement, and more consultation time are factors that can improve adherence.

The objective of this study was to know what are the main concerns of patients, assisted in the LES clinic of the Rheumatology Service at the General Hospital of UFMG that can be a starting point for the development of a patient education project.

PATIENTS AND METHODS

This was a descriptive and cross-sectional study. The project and Informed Consent Form were approved by the Ethics Committee on Human Research of the Federal University of Minas Gerais (November 7, 2014, CAAE 17087313.2.0000.5149). LES patients awaiting consultation at the Bias Fortes Rheumatology Service of the General Hospital of UFMG were invited to participate in the study. An A5 sheet of paper with the statement: "All you ever wanted to know about lupus and never dared to ask! Please write your questions about lupus and deposit in the ballot box. No need to identify yourself" (Figure 1) was delivered to those who agreed to participate. Participants were told to write their questions on that sheet of paper in a free, spontaneous, individual, and anonymous way and deposit it in the box. Patients with visual difficulties or illiterate were allowed their companions to help. The collection of these sheets took place for six weeks.

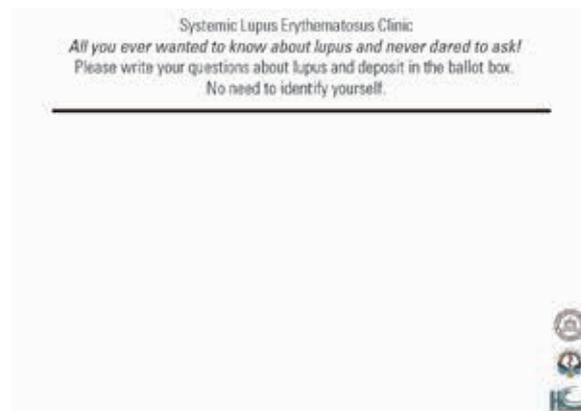


Figure 1 - Sheet with space distributed to patients to freely write their questions.

The researchers were responsible for inviting patients and advising on the importance of the participation of each one so that doctors and scholars in medicine could clear such doubts through medical consultations and the use of graphics and audiovisual, or other educational resources. The absence of any burden or privilege was emphasized to those who participate and, likewise, the absence of sanctions or loss of service to those who rejected the invitation, strengthening the voluntary and consented aspects of the study. Sociodemographic data and LES characteristics of the subjects were not collected.

The ballot box was opened at the end of six weeks, and the questions were categorized according to the subject to which they referred. All questions regarding LES were accepted. Thus, questions on other health conditions unrelated to LES or not understood by the researchers were rejected.

RESULTS

During the study period, 260 patients were invited to participate, and 111 sheets were filled out (42.7% participation) totaling 393 questions, with an average of 3.54 questions per person. All participants had, at least, one question.

The questions were divided into nine categories: general guidelines; psychological and sexual aspects; contraception, pregnancy, and fertility; disease concept and epidemiology; prognosis and evolution; etiology and pathophysiology; clinical presentation and diagnosis; treatment and prevention; and excluded questions. Figure 2 shows these categories in descending order.

The analysis of the profile of the questions raised by LES patients about their illness was based on the survey and categorization of questions by themes, and how these individuals perceived the concepts of health and illness and interpreted their conditions.

Category 1: treatment and prevention

The most frequent subject referred to disease treatment and possibility of prevention. Regarding treatment, the questions were generally related to the drugs used and their adverse effects, duration and choices of therapies. Concerning prevention, they questioned whether there was any way to prevent the disease, about specific diets, and physical activity.

Category 2: clinical frame and diagnosis

The most frequently asked questions in this category were about clinical manifestations: joint pain, skin patches, alopecia, and nephritis. In addition, patients questioned how the diagnosis of LES is performed and how to know whether they have the disease.

Category 3: causes (etiology and pathophysiology)

Patients asked about the etiology of LES and how the disease affects the various systems. Many doubts were direct, with clear questions: “What causes lupus?” “Is Lupus a type of cancer?” “Is Lupus an infection?”.

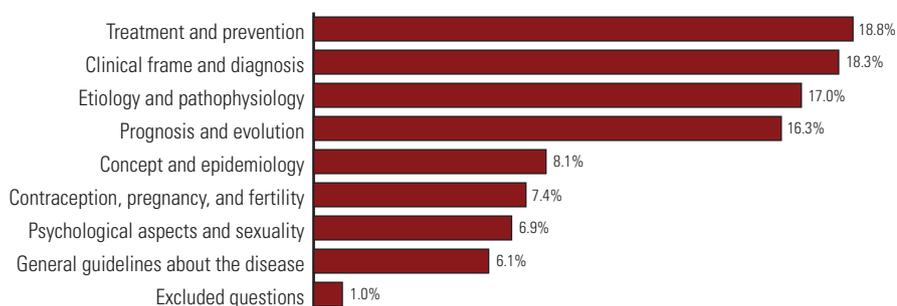


Figure 2 - Distribution of categories related to the questions.

Category 4: prognosis, complications, evolution, and cure

Questions that revealed the fears of patients about the course of the disease and its potential damage prevailed in this category. Questions such as "Is there a cure for Lupus?" Or "How much living time a patient with lupus has?" illustrate this category.

Category 5: Concept and epidemiology

Patients questioned about the higher prevalence of the disease in women than men, and the concept of LES: "What is Lupus?".

Category 6: contraception, pregnancy, and fertility

Most of the questions concerned the possibility of becoming pregnant, fear of bearing a child with the disease, and possible complications during pregnancy. Also, there were questions about contraceptive measures to be used.

Grade 7: psychological aspects and sexuality

Patients addressed the decreased libido, difficulty having sex, mood swings, and lack of interest in daily activities. There were also questions about how LES can influence the emotional life of patients.

Grade 8: guidelines: social benefits, blood donation, and vaccination

Finally, a broader category including less frequent questions. Such questions referred to the possibility of early retirement, which vaccines would be appropriate and which would be contraindicated, and the possibility of being a blood donor even with the disease.

DISCUSSION

The lack of information about the disease, treatment, and impact on life is still a problem for patients with LES that became clear through this study. Although many participants at the clinic are on treatment for a long time – referral service – and a high number of the questions raised were addressed during routine doctor visits, many remain unclear for patients. Moreover, often the patient's opinion about the disease and difficulties in conducting the treatment are marginalized, either by the increasing demand for medical service or care medicalization.

Similarly, in the study conducted in seven centers in the UK by Waldron et al.,⁶ patients with LES said that the information received at diagnosis were inadequate and that they would like to receive more detailed and varied formats of information. The interesting study by Bauman et al.,⁹ states that communication between doctor and patient must meet the patient's expectations, and for that, the expectations need to be known.

According to Araújo and Traverso-Yepezi,¹ LES patients process meanings about the disease through their social relations, the environment where they live, life stories, and experiences. In addition, regardless of the LES diagnostic time, living with the disease can modify these meanings whether by its progression or influences from social networks, for example, by doctors, relatives, or other individuals with LES. This contributes to new doubts to arise and reset at different times throughout life, even if the diagnosis was set a long time ago.

In studies investigating the needs of LES patients that were poorly addressed by healthcare professionals, issues involving symptoms or clinical signs were emphasized as the most frequent.^{8,13} In a French study with 422 LES patients, the issues related to pregnancy (90%), prognosis (80.8%), and treatment (70.4%) were other categories raised.⁷

In this study, the category of treatment and prevention was the one that raised most questions. Questions about drugs largely turned to their side effects. It can be inferred that there is knowledge about the importance of drugs for the control of LES. However, there is still a lack of knowledge by the patients about the effects of each substance on the body. According to Chambers et al.,⁴ in an editorial on treatment adherence in patients with LES, there is a justified con-

cern in patients about the safety and efficacy of drugs, which, in their opinion, directly influence adherence.

In the daily assistance to individuals with LES, the frequent complain about weight gain caused by the use of steroids, even in when used at very low doses, or after being suspended, is observed. These patients also express fear about the side effects of this class of drugs; dose reduction or even discontinuation of use decided by doctors were observed. A similar behavior is observed in relation to immunosuppressive drugs, which is the source of wishful thinking that they would be with cancer despite the clarification during consultations that LES is not a type of cancer.

On the prevention category, questions about how to start a physical activity or what foods worsen the course of the disease were asked. In the qualitative study by Araújo and Traverso-Yépez¹, there are reports of non-adherence to the prescribed diet and drugs being blamed as the cause of major damage, possibly due to the lack of awareness about the importance and effects of each. In the same study, some LES patients often claimed a lack of family support and information about the effects of drugs, beneficial or adverse, used to treat the disease and what is the real importance of nonpharmacological treatment in the development of LES.

The category of clinical manifestations and how to perform the diagnosis was the second in the number of questions. According to Machado et al., because this is a multifaceted disease with broad and still little known clinical manifestations, LES is psychologically represented with some difficulty by patients with no clear delimitation of the popular imagination, thus, allowing the creation of symbolism and mystification. Understanding the representations of these in relation to their situation, to each other, and to society, is knowledge deeply rooted in care.¹⁴ With its many and so variable combinations of manifestations, the meanings of LES also vary and, frequently and erroneously, may be confused with meanings of other health disorders such as cancer and infectious and contagious diseases.¹⁰

According to Araújo and Traverso-Yépez¹, the meaning assigned by these LES patients is related to something bad that came out of nowhere and at any time may bring new exacerbations, worries, and feelings of fear of infecting others. The narratives of participants reveal that the varied physical symptoms and their consequences are what cause more suffering.

Another category of questions on the LES subject was its relationship with changes in psychological as-

pects such as mood swings, lack of interest in daily activities, and sex. In the opinion of Mattje and Turato¹⁰, dissatisfaction with self, which is also kept by the disease, accompanied by a loss of interest in things and even death fantasies, would be related to living chronically with LES. Depression and anxiety¹⁵ have been cited as presenting a relationship between LES and minor psychiatric disorders along with contributing to daily stress by worsening symptoms and contributing to the appearance of cognitive alterations.¹⁶ A study conducted by the Rheumatology Service at the UC/UFGM in 2012 evaluated 34 subjects with LES (94.1% females), identifying which patients presented more depressive symptoms than individuals in the control group. Patients with more depressive symptoms reported more daily stressful events with great intensity and higher scores in anxiety than those with fewer depressive symptoms.¹⁷

The difficulty in maintaining stable emotional relationships, either with partners, their children, other family members, and social and professional groups is observed in LES patients, which results in a negative impact on their quality of life.

CONCLUSION

LES patients generally require more information about their disease and its repercussions in life. In this study, we inferred that most of the questions raised outside the doctor's office often reflected themes brought up during medical visits. The communication between medical, healthcare teams, and patients needs to improve, and the strategy would be to develop a health education program.

Knowing the meanings and questions facing the various phenomena associated with LES is essential for health professionals in order to be able to offer truly effective recommendations. The use of printed materials, illustrated, and with understandable language, as well as videos, in the outpatient settings are certainly instruments that can provide more adherence to the recommendations for prevention and treatment, not only about LES but also its comorbidities.

Identifying the needs of individuals with LES through this study was an essential step in organizing a health education program. The responses to the questions raised are being prepared in the form of booklets and videos that will be used in an outpatient setting of the waiting room at the Lupus Clinic in the Rheumatol-

ogy Service of the General Hospital and during consultations, involving the entire team of professionals that assist individuals with LES: Medical School students, medical residents in Rheumatology, graduate students, rheumatologists, nutritionists, and nurses.

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