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ORIGINAL ARTICLE

UNVEILING THE PERCEPTION OF THE PERSON'S FAMILY WITH SYSTEMIC LUPUS ERYTHEMATOSUS

DESVELANDO A PERCEPÇÃO DO FAMILIAR DA PESSOA COM LÚPUS ERITEMATOSO SISTÊMICO

INAUGURACIÓN DE LA PERCEPCIÓN DE LA FAMILIA DE LA PERSONA CON LUPUS ERITEMATOSO SISTÊMICO

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ABSTRACT

Objective: unveiling the perception of the person's family with systemic lupus erythematosus. **Method:** qualitative study with phenomenological approach, carried out with 10 relatives of people with lupus, Alfenas/MG/Brazil through interviews. The subjects answered the questions: How do you care for a family member with Lupus? How do you feel? The results were presented in categories and analyzed the light of authors who reflected on the subject. The Research Ethics Committee of the Universidade Federal de Alfenas, Protocol n°23087.004756/2008-86, approved the project. **Results:** after analyzing, the speech emerged three categories: Feelings-feelings before diagnosis, at the moment of diagnosis and current feelings; Change of habit after diagnosis and Facing embarrassing situations. **Conclusion:** the perception of families on the care loved carrying Lupus is pervaded by feelings of pain, anxiety, fear of loss, grief, stress, sadness by the restrictions and impossibilities imposed by illness. **Descriptors:** Systemic Lupus Erythematosus; Family Relationships; Emotions; Nursing.

RESUMO

Objetivo: desvelar a percepção do familiar da pessoa com lúpus eritematoso sistêmico. **Método:** estudo qualitativo com abordagem fenomenológica, realizado com 10 familiares de pessoas com lúpus, da cidade de Alfenas/MG/Brasil por meio de entrevistas. Os sujeitos responderam as questões: Como é para você cuidar de um familiar que possua lúpus? Como você se sente? Os resultados foram apresentados em categorias e analisados a luz de autores que refletiram sobre a temática. O projeto foi aprovado pelo Comitê de Ética em Pesquisa da Universidade Federal de Alfenas, protocolo n°23087.004756/2008-86. **Resultados:** após análise das falas emergiram três categorias: Sentimentos - sentimentos antes do diagnóstico, no momento do diagnóstico e sentimentos atuais; Mudanças de hábito após o diagnóstico e Enfrentando situações constrangedoras. **Conclusão:** a percepção dos familiares diante do cuidado do ente portador de lúpus é permeada por sentimentos de dor, ansiedade, medo da perda, pena, estresse, tristeza pelas restrições e impossibilidades impostas pela doença. **Descritores:** Lúpus Eritematoso Sistêmico; Relações Familiares; Emoções; Enfermagem.

RESUMEN

Objetivo: presentación de la percepción de la familia de la persona con lupus eritematoso sistêmico. **Método:** estudio cualitativo con enfoque fenomenológico, llevado a cabo con 10 familiares de personas con lupus, coleccionadas/MG/Brasil a través de entrevistas. Los sujetos respondieron a las preguntas: ¿Cómo te importa para un miembro de la familia con Lupus? ¿Cómo te sientes? Los resultados fueron presentados en categorías y analizan a la luz de los autores que se refleja sobre el tema. El proyecto fue aprobado por el Comité de ética de investigación de la Universidade Federal de coleccionadas, Protocolo N° 23087.004756/2008-86. **Resultados:** después de análisis del discurso surgieron tres categorías: sentimientos- sentimientos antes del diagnóstico, en el momento del diagnóstico y sentimientos actuales; Cambio de hábito después del diagnóstico y frente a situaciones embarazosas. **Conclusión:** la percepción de las familias en el cuidado amado con Lupus es invadida por sentimientos de dolor, la ansiedad, el miedo a la pérdida, dolor, estrés, tristeza por las restricciones y las imposibilidades impuestas por la enfermedad. **Descriptores:** Lupus eritematoso sistêmico; Relaciones familiares; Emociones; Enfermería.

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INTRODUCTION

Systemic Lupus Erythematosus (SLE) is a chronic inflammatory disease, autoimmune in nature that affects multiple organs and is characterized by the presence of autoantibodies. Its etiology is still not completely understood, but studies point to a combination of genetic, hormonal and environmental factors, especially ultraviolet rays, viral infections, sex hormones, chemicals and emotional factors.¹⁻³

Presents clinical manifestations polymorphic and most frequently affects the skin, kidneys, brain and joints; psychosis and depression are the most common neuropsychiatric surge complications.⁴ During the course of the disease, there may be loss of physical function, independence, social interaction and may lead to changes in relations with spouses, with family and with society, suggesting even a social isolation.⁵

Lupus has periods of exacerbation and remission. It focuses predominantly on females at a ratio of 10/1:0 pm for males and usually affects reproductive age, although it can occur at any age.^{6,3}

It is more frequent in countries of southern Europe, Northern Australia and the United States. In Brazil there are few studies that link the incidence of the disease, however a study in Natal that the incidence is 8.7 cases per 100,000 inhabitants/year.⁷ International data show incidence ranging from 1.15 and 9.3 cases per 100,000 inhabitants/year.¹ It is a disease of difficult diagnosis, as a Multisystemic and owning a variable clinical presentation. 11 are proposed criteria for their identification and, for completion of the diagnosis, it is necessary the presence of at least 4 of these criteria.⁸ Treatment includes stimulus control to healthy lifestyle habits, avoid smoking, frequent exposure to the Sun, and the use of systemic corticosteroids, topical, antimalarial, immunosuppressive, among others.⁹

A change in the demographic and epidemiological profile has been setting in the world's population. There is a greater life expectancy, consequently a population aging and a higher incidence of chronic diseases. In this scenario, there is the constant presence of the family as caregiver. With the increase of chronic diseases and with the technological improvement to life extension, the family has increasingly configured as safe harbor, where members will always help to renew their strength and support the hard times.¹⁰⁻¹

Chronic diseases are cause for significant concern for all, since, in addition to limiting

aspects of the disease to the carrier itself, these generate family suffering deep forcing family to develop coping strategies for the new family member's condition.¹⁰ Care often becomes a factor causing stress on family life, leading to physical, mental and emotional stress and in most times, overload of some family members.¹²

The family appears as the first and the primary unit of care for its members, promoting the physical and mental balance. The word caution assumes several meanings to meanings of love, friendship, care and concern. Care does not just mean meet the basic physiological needs of human beings, implies providing support, give love, listen to and understand each other.¹¹

Lupus has a significant psychosomatic dimension, being necessary to consider the stress and psychosocial distress from your triggering, evolution, deterioration and possible control, particularly the effects of these on the carrier and his family.⁴

Parents, spouses, siblings and children may face a great number of changes in their lives when coexist and care for someone with a chronic disease. The patient becomes the priority in care and, by times, family members move away from everyday activities, promoting an entire internal and external restructuring of core family.¹³⁻⁴

Problems and adaptations of those diagnosed have been extensively investigated, however, problems in relation to family members who live with people with lupus, have received little attention. Reflect on the family and the feelings which involve at the moment of caution, must become a focus for nursing assistance, making it the target of actions and interventions proposed by these professionals is essential to overcome the barriers found to provide care to anyone who cares. It is important to know the feelings and the singularities of each family so, direct actions aimed at remedying the difficulties.

It is clear, then, be of great importance to understand how it is for these families live with a family member who has lupus, since this can impose profound changes within the family. For the nurse, becomes indispensable knowledge of feelings that surround this care, allowing the elaboration of plans involving the family and, especially, the caregiver Member.

OBJECTIVE

- Unveiling the perception of the person's family with Systemic Lupus Erythematosus.

METHOD

Qualitative study with phenomenological approach, carried out with families of patients with systemic lupus erythematosus in Alfenas-MG/Brazil. The qualitative methodology is applied in situations where working with relationships and representations, feelings, perceptions and beliefs, as well as research that promotes the investigation of groups, specific segments and delimited by exposing the vision and the interpretations of the speeches of the subjects interviewed.¹⁵

With permission of the Municipal Health Office, registered carriers were identified in basic health units and thus reach out to their family members. Composed this study, 10 relatives of Lupus patients, mostly women.

Inclusion criteria were: have more than 18 years, have basic understanding of conditions guiding question and be the most involved with the care of Lupus.

Upon the authorization of the subject, we setup an appropriate location and reserved, in order to ensure privacy during interviews that were recorded on tape K7. All subjects preferred to perform it in his own home. Before the start of the same was asked to sign the informed consent Form for all subjects. The interviews were conducted from January to April 2009. To preserve the anonymity of these families, we used "I" for interview, followed by numbers according to the chronological order in which they were performed.

We used the following guiding question: how is it for you to care for a family member with Lupus? How do you feel? As discretion to cease the collection of data, we used the saturation or the repetition of lines, indicating that the researcher has achieved the objective proposed, meaning that the phenomenon is elucidated.¹⁶ The data were analyzed in the light of other scholars that reflected on the subject.

Following the phenomenological approach, the speeches were transcribed in full after every interview, followed by successive readings that aimed to extract the units of meaning, which were answers to our questions. The Group of units of meaning emerged three categories and three subcategories: Feelings-feelings before diagnosis, at the moment of diagnosis and current feelings; change of habit after diagnosis and facing embarrassing situations.

The project that originated the study followed the ethical principles and the requirements of Resolution 196/96 of the

National Health Council and was approved by the Research Ethics Committee of the Universidade Federal de Alfenas via protocol n° 23087.004756/2008-86.

RESULTS AND DISCUSSION

Each report is noticeable that the experiences and feelings of the families are in a unique universe. The role of care sometimes manifests itself positively and, on the other, negative way.¹⁷ While being questioned, the family was encouraged to talk about the feelings aroused in caring, so these were organized into categories that reflect the feelings related to the diagnosis, to changes in life habits and to embarrassing situations faced by these.

◆ Feelings

In this category are the speeches that referred to the feelings related to the diagnosis of the disease. These are organized into feelings that relate to moments before diagnosis, in his discovery and in current feelings.

● Feelings before diagnosis

The relentless pursuit by the discovery of the causes of the suffering of their loved one becomes stressful for the family. In this subcategory are expressed the feelings experienced by families when had not yet received the diagnosis of the disease, their fears, doubts and concerns experienced during a period which often becomes confusing and stressful.

Following the speeches, they lay the family's suffering due to the difficulty of making a diagnosis and the disbelief of the facts reported by the carrier.

It was very difficult, you know. When the spots began to appear was the bar. Doctors take long until I discovered it was lupus, we suffered without knowing what exactly [...] (E6)

[...]at the beginning I thought that neither was true when she started to complain that lot of pain, I came to find it until she was lying, I would cry of despair at these moments. (E1)

Because of its clinical polymorphism, the frames are typically complex, difficult recognition, which contributes to the delay in the diagnosis and implementation of appropriate therapy. The delay in making the diagnosis leads the patient to feel frustrated, after describing what is feeling, and the family does not accept or does not share the conviction that something is wrong. The family shares this suffering, because, even without understanding what occurs in fact, all

the emotions experienced by the carrier directly or indirectly affect the family.^{18,8}

Feelings of fear, anguish and anxiety are frequent at this time. The fear appears as a common psychological response in the face of these situations and concerns the lack of diagnosis and the possible loss of loved one.¹⁹

At the beginning, as we we did not know the disease, we were too scared and until we come to think that she would die [...] (E2)

• Feelings at the time of diagnosis

The directions built at the time of diagnosis are different from those in which the person lives with the disease. The feelings experienced at the time of its discovery, most of the time, are related to a sense of loss, suffering, mainly to refer to a disease little known by the general population. However, at the same time experience a sense of relief for the discovery, since the way to make the diagnosis of Lupus is not always peaceful, and sometimes the diagnosis takes months to years to complete.^{7,4}

[...] It was hard and still is, at the time the doctor said she had lupus, I became desperate, I had never heard of this disease and nobody told me what was right. Many thought that the disease was contagious [...] (E3)

[...] When we went to the doctor, he said that she had lupus, I myself over because I had never heard of it and the doctor told me it was serious and had no cure, was a very big blow for me and for my family [...] (E5)

The sense of shock at that moment is present, often centered on the fact that the disease has no cure. It is evidenced a sense of insecurity about how will life from that day on, since the prognosis is uncertain and inevitably will require changes in their lives.⁴

Still realizes that the diagnosis itself was given in a very shallow without many explanations or guidance about the disease. Insufficient communication featuring humanization not offered to patients at the time of care, promoting a correct understanding of the disease and not of care, in addition to an increase in anxiety generated within familiar.¹³

With the exacerbation of clinical symptoms, the family experience a process of intense suffering and sometimes desperation, compounded by the difficulties that arise in the course of this career because of the disease.

[...] I was very nervous to see that situation. My daughter screamed in pain. (E1)

[...] It was too bad because I was very sad to see him feel pain for the whole body,

especially in the knee, hands and feet; He could barely walk. (E8)

Live with and care for a chronic patient allows the caregiver to accompany the evolution of symptoms and understand the constraints of everyday activities caused by these. One of the striking features of clinical Lupus are inflammatory processes in various tissues and organs, which consequently generates pain patients. Inflammatory processes occur in a manner interspersed with periods of remission and exacerbation of symptoms, affecting mainly the skin, joints and central nervous system.²⁰

Frequently, there are tables of joint pain, and arthritis, deforming SYNOVITIS involving the joints in General, leading to a diagnosis of rheumatoid arthritis before the complete and obvious expression of symptoms of lupus. Complaints of joint pain are common in the patient with Lupus since the onset of the disease. These muscle cramps usually occur in 90% of cases, and can cause weakness and loss of stamina.²¹

The mother, as the main character to play the role of caregiver, tends to develop an overprotection to the carrier of the disease, the child who can generate jealousy on the part of other children who do not understand the whole situation experienced by the mother.¹³

[...]I was very nervous when I saw that her brothers have not always understood that I gave more attention to her because she needed, she was ill, needed more from me than they. (E1)

• Current feeling

When asked about the feeling of caring for a family member with lupus, stated that the worst moments were before the discovery of the diagnosis, due to the intensity of the demonstrations, and a lack of knowing how to act in front of the whole situation. Report that with passage of time were getting used to that reality and that currently has not suffered as much as before.

[...]Today it is more difficult, as we have become accustomed with the disease. (E2)

[...] Today is better. Even with all the difficulties. (E4)

[...] Now I have got used to everything, nowadays it is no longer a hindrance. Has always been very good to live with my sister, she is an example for me; she gives me strength to follow in all the difficult moments. (E7)

[...] But today is normal, Lupus is controlled, we live a common life [...] (E8)

[...] Today the Lupus it is controlled, we do not have many problems with it, everything that happened with it taught us a lot, not

all suffering in life is just bad, we learned a lot with the pain also. (E9)

You can see that the caregivers have shown some improvement of the situation imposed by the disease, as well as reporting that the suffering also made them learn, going against what it defines as resilience, which is the ability of individuals must react positively even in the face of adverse situations.^{10, 22}

When a family member triggers a process of dependency, changes the completely family dynamics, resulting in changes of roles and of power relations, reinstituting new relationships of intimacy and reproduction of the family group. It is observed that, depending on the degree of seriousness which people to assign to those conditions, some adjustments may or may not occur within family.^{23,12}

[...]I matured fast because of it, because when my mom went to the hospital to be admitted to the hospital, I had to take the House, I had to leave early from school to come make lunch for everyone from home, I washed clothes and took care of my brother. (E4)

The imminent feeling of loss and the need for care aroused by disease tend to have closer ties and reconnecting individuals of core family.

[...]I think this mother's illness came more people at home; We were very afraid that she died, we learned to have more patience with it all because she struggled a lot, for all at the time of disease. (E2)

The requirements of disease-related changes, changes in affective and practical papers, the loss of certain functions and the fear of the loss of the loved one to death, serve for the family to create a new internal focusing, reconnecting its members.²⁴ There was also testimony that it is noticeable that the disease had not yet been surpassed by members, even after some time.

[...]It was horrible, until today I cry, because it is very sad to see her daughter without being able to do everything that she did before. (E3)

[...]It is very costly; still suffer, because sometimes my mother cannot even eat because it leaves a wound in her mouth. (E6)

Living with the chronic condition is to be inserted into a universe of experiences associated with feelings of suffering, both for the family and for the bearer. This situation becomes stressing because its impact occurs at any time and almost always comes to stay, by changing the healthy condition of the family.²³ The experiences of care in the health-disease process are subjective,

personal and collective dimensions, cultural and universal, making each unique experience to those who experience.¹²

• Changes in habits after diagnosis

Beginning with the first symptoms, followed by the diagnosis and the presence of the disease itself, several changes occur suddenly and drastically in the lives of disabled people and their families. An emotional conflict involving the carrier and your entire family, once the disease is not only seen as a set of symptoms, but has a symbolic representation, moral, social and psychological.²⁵ Lupus sometimes generates interrupt before pleasures and plans made so very common, as we can see from the speeches.

[...]He suffered a lot in seeing her suffering, because she always enjoyed going to the beach, go to the site and after that discovered the disease she was depriving a lot of leave, was very much at home. (E1)

[...]suffered a lot because she did not leave home, so swollen that she was, could not do anything on its own; I arrived to find that she was going to die. It was a very difficult time in my life; I had to stop working out so I can take care of it. (E3)

[...] the doctor said she would need to avoid the Sun, use sunscreen, and eating very well; this left me even worse and worried because she lives with a minimum wage, so she does not have enough money for all this. (E5)

[...] now it is hard, but not because of her, but because she cannot work, and the doctor away for a while. (E7)

A similar situation has also been found by other authors, who have families, they come with chronic illness in their midst, have undergone changes in your routine, such as the withdrawal of employment activities, changes in food and leisure activities.²³ Another important factor is the family income, as it undergoes a significant reduction due to loss of carrier's financial contribution, which, associated to the increase of the expenses resulting from current demands with medication, among others, extends the negative effects on family budget.

• Facing embarrassing situations

Among the manifestations of lupus, we can point out the malar rash is a symptom commonly found among people who have the disease. The Erythema reaches the cheeks and the nose and rear face can be flat or embossed.⁸ although lupus is not a communicable disease, can cause a malaise to the carrier and to the family for fear that

other people have with respect to the lesion on the skin.

Imbued with sadness, the family members reveal feelings manifested when exposed to situations of prejudice that exists in society. Singular and particular issues as social judgment, the stigma and prejudice are key elements in the process of confronting these situations.

[...]I was wrong, because my friends asked me if she had been burned with fat, because of redness on the face. I am evil, by seeing it wrong with the jokes of bad taste, for example, one day his brother told him that she had a face of Jaguar. (E2)

[...]Here the people are very biased; this is another factor that makes it sad to see others looking at it with an air of prejudice, with contempt, not touching for fear of catching the disease. (E3)

[...]I am sad to see that he has embarrassed to leave the House, because that's where everyone was looking, he dies of shame, says that the people is excluding it. (E8)

The family realizes that the loved one is stigmatized, and this causes him pain and suffering since the stigma requires individuals to a situation of no social acceptance by society. Settling differences, that is, on what is considered normal and pathological or deviant considered by the population in General. In situations of illness in which a loved one goes through times when one feels stigmatized your friends and family share with him the feelings of pain.²⁶The stigma may be real or imaginary situations by discouraging the individual in its actions in the community and leading to him feel rejected, and sometimes lead to increased level of anxiety and depression.²⁷

CONCLUSION

It was possible to meet the family's vision and realize that this comes with all the suffering of loved that has the disease, sharing the feelings of pain, anxiety by diagnosis, fear of loss, stress, sadness by the restrictions and impossibilities imposed by illness. We note that the directions given by the interviewees are dynamic and constructed along the process experienced through the peculiarities of each family.

Emphasizes the need to hear the relatives, especially those who are caregivers and who constantly are in close contact with the carrier. These have an experience rich in experiences that need to be valued. Often the attention in our professional practice is usually related to the patient, leaving the caregiver on the sidelines of events.

Accordingly, health professionals must remember that it is up to the family to be part of important way during treatment and that needs to be accompanied and assisted by providing means and spaces to express their fears and anxieties.

Nursing, by being more forthcoming and that encourage the formation of bond with this family, should be able to offer steady emotional support, making it able to detect problems and implement necessary interventions, providing these families a warm and confident for help in coping with the situation experienced.

Upon completion of this study, we believe that it can trigger further thoughts on the subject as well, showing the possibility of constructing new ways to offer a higher quality service in the care given to the family of Systemic Lupus Erythematosus.

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