Revista Brasileira de Enfermagem
REBEn

ORIGINAL ARTICLE

From diagnosis to complications: experiences of those who live with systemic lupus erythematosus

Do diagnóstico às complicações: experiências de quem convive com lúpus eritematoso sistêmico

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How to cite this article:
Souza RR, Marcon SS, Teston EF, Barreto MS, Reis P, Cecilio HPM, et al. From diagnosis to complications: experiences of those who live with systemic lupus erythematosus. Rev Bras Enferm. 2022;75(4):e20200847. https://doi.org/10.1590/0034-7167-2020-0847

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Submission: 07-24-2020 **Approval:** 07-19-2021

ABSTRACT

Objective: To understand how people with lupus experience the diagnosis and how they deal with complications arising from the disease. **Method:** Qualitative study, whose data were collected between February and July 2019, through semi-structured interviews with 26 individuals and submitted to content analysis**. Results:** Three categories emerged that show illness from lupus as a difficult experience, permeated by sadness, fear and suffering, which, in addition to being linked to society's lack of knowledge about the disease, negatively impacts the lives of those who experience it. Furthermore, they show that the time of living with the disease favors the development of self-care strategies and greater therapeutic adherence and, consequently, longer periods of disease remission. **Considerations:** More disclosure about the disease and its implications in the daily lives of those affected is essential, culminating in greater understanding of family, friends and colleagues and improvements in health care and quality of life for these people.
Descriptors: Lupus Erythematosus, Systemic; Diagnosis; Complications; Life Change Events; Autoimmune Diseases.

RESUMO

Objetivo: Compreender como pessoas com lúpus experienciaram o diagnóstico e como lidam com as complicações advindas da doença. **Método:** Estudo qualitativo, cujos dados foram coletados entre fevereiro e julho de 2019, mediante entrevistas semiestruturadas com 26 indivíduos e submetidos à análise de conteúdo. **Resultados:** Emergiram três categorias que mostram o adoecimento por lúpus como uma experiência difícil, permeada por tristeza, medo e sofrimento, que além de estar atrelado ao desconhecimento da sociedade sobre a doença, impacta negativamente na vida de quem o vivencia. Para além disso, evidenciam que o tempo de convivência com a doença favorece o desenvolvimento de estratégias de autocuidado e maior adesão terapêutica e, por consequência, maiores períodos de remissão da doença. **Considerações:** Imprescindível mais divulgação sobre a doença e suas implicações no cotidiano dos acometidos, culminando em maior compreensão de familiares, amigos e colegas e melhorias na atenção à saúde e qualidade de vida destas pessoas.
Descritores: Lupus Eritematoso Sistêmico; Diagnóstico; Complicações; Experiência de Vida; Doenças Autoimunes.

RESUMEN

Objetivo: Comprender cómo las personas con lupus experimentan el diagnóstico y cómo afrontan las complicaciones derivadas de la enfermedad. **Método:** Estudio cualitativo, cuyos datos fueron recolectados entre febrero y julio de 2019, mediante entrevistas semiestructuradas con 26 individuos y sometidos a análisis de contenido. **Resultados:** Surgieron tres categorías que muestran la enfermedad por lupus como una experiencia difícil, impregnada de tristeza, miedo y sufrimiento, que además de estar vinculada al desconocimiento de la sociedad sobre la enfermedad, impacta negativamente en la vida de quienes la padecen. Además, muestran que el tiempo de convivencia con la enfermedad favorece el desarrollo de estrategias de autocuidado y una mayor adherencia terapéutica y, en consecuencia, mayores periodos de remisión de la enfermedad. **Consideraciones:** Es esencial una mayor divulgación sobre la enfermedad y sus implicaciones en la vida diaria de los afectados, que culmine en una mayor comprensión de la familia, amigos y colegas y mejoras en la atención médica y la calidad de vida de estas personas.
Descriptores: Lupus Eritematoso Sistémico; Diagnóstico; Acontecimientos que Cambian la Vida; Enfermedades Autoinmunes; Investigación Cualitativa.

VERSÃO ON-LINE ISSN: 1984-0446

INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic, autoimmune disease that, to date, has no cure, being more frequent in females[1]. Worldwide, the disease affects around five million people[2]. In the United States of America, the prevalence of SLE is 5.8 to 130 per 100,000 population, while in the United Kingdom and Japan it is approximately 40.7 and 19.1 per 100,000 population, respectively[3].

In Brazil, although about 65,000 people live with SLE, most of the population does not have knowledge about the disease. This is possibly related to the scarcity of information and debates on the subject in the mass media. Discussions are still very restricted to health professionals and people already affected[4]. Therefore, due to the lack of information, SLE diagnosis, in most cases, occurs late, as it is based on clinical criteria that are not always clearly present in the initial phase[5], as the symptoms are heterogeneous and of variable evolution[6], plus the lack of information, causing serious and irreversible impairments[7].

Before the diagnosis is established, symptoms can develop rapidly over a few days or slowly over years. For most patients, the diagnosis is given late, triggering serious and sometimes irreversible complications[7]. Thus, and because it is an incurable disease, treatment aims to reestablish immune homeostasis, promote disease remission, prevent organic complications and improve quality of life[5,7].

In the international scenario, studies with people living with SLE have been addressed in different care contexts. More and more researchers seek to understand the origin of the disease and its evolution throughout the illness process. Evidence suggests that self-reported pain and fatigue represent classic symptoms and are present in most of those affected[8-9]. Moreover, some studies have addressed the impact of the disease and its signs and symptoms on health-related quality of life (HRQoL)[10-11] and its relationship with the emergence of neuropsychological diseases, such as depression and anxiety[12]. It is noteworthy that, as it is a chronic disease, it is necessary that individuals, based on their experiences, develop self-management skills for their health-disease process, to control symptoms, reduce crises, mitigate comorbidities and improve quality of life[6].

However, at the national level, little is discussed and investigated about the life experience of those who live with the disease daily, which distances the planning of care actions aimed at the particularities experienced. International studies have already shown that this experience represents a difficult task, which requires constant professional, social and family support[7,13]. Another relevant aspect that involves this experience is the lack of knowledge of society in general about SLE, which can cause significant psychological suffering among patients who, many times, can be judged with stigma and stereotypes resulting from the disease's signs and symptoms, leading to emotional complications and, consequently, worse quality of life[14].

Considering the above, this study is justified: a) by the possibility of expanding the body of knowledge of Brazilian nursing, especially on new technologies of shared care and supported self-care, present in the theoretical framework adopted here, since studies on this topic in the national scenario are scarce; b) need to improve the health care of individuals with chronic conditions, from the moment of diagnosis to the experiences of possible complications arising; c) increase the visibility of this problem to society in general, especially to people with SLE and other chronic conditions, recruiting them to lead their therapeutic processes and care plans.

Thus, the guiding question of this study was: what are the experiences of people with SLE facing its diagnosis and complications?

OBJECTIVE

To understand how people with lupus experienced diagnosis and deal with its complications.

METHODS

Ethical aspects

The study was developed in agreement with the guidelines regulated by the Brazilian National Health Council (*Conselho Nacional de Saúde*) Resolution 466/12. The project was approved by the Institutional Review Board of the *Universidade Estadual de Maringá*. All participants were informed and clarified about the objectives of the study and expressed their agreement to participate in it, signing the Informed Consent Form (ICF), in two copies. To ensure their anonymity, when presenting the study results, extracts from participants' statements were identified with the letter P (participant), followed by a number corresponding to the order in which the interviews were carried out, with the letters M or F to indicate male or female, followed by age, type of lupus, and time since diagnosis (e.g., P 3, F 27, systemic, 4 months).

Theoretical-methodological framework

As a theoretical-conceptual basis, to understand the experiences of people with lupus, the principles and purposes of the Chronic Care Model (CCM) were used[15-17], which refers to two main aspects to be considered in the care of a chronic condition: disease stabilization and self-care supported by the health team. The COnsolidated criteria for REporting Qualitative research (COREQ)[18] guided the description of the study methodology. To systematize and process the data, Bardin's content analysis was used, thematic modality[19].

Study design and place

This is a descriptive study with a qualitative approach, as it was intended to describe the experiences related to the diagnostic process and daily life with a relatively rare autoimmune disease. It was performed with individuals diagnosed with SLE undergoing treatment at the rheumatology outpatient clinic of a university hospital in the countryside of Paraná, Brazil. This clinic is a reference for treatment of rheumatic diseases within the scope of 15th Regional Health, which covers 30 municipalities.

Participant selection

The initial contact with participants took place at the rheumatology outpatient clinic on the day they attended the previously

scheduled medical appointments. Initially, they participated in a cross-sectional study with a quantitative approach, whose objective was to identify factors associated with quality of life in individuals with SLE. For the qualitative aspect, the selection criterion intentionally adopted was the verbal manifestation of greatest interest, willingness to report on their life experience with the disease and residing in the municipality. All 26 individuals approached about the possibility of a future conversation in a more private place, to be defined by themselves, expressed interest and promptly provided the telephone contact number for later scheduling the interview.

Data collection

Data were collected from February to July 2019, through individual interviews and audio recorded after consent. They were carried out at participants' homes, with an average duration of 45 minutes, and were guided by the following guiding question: how is your daily life with SLE from diagnosis to the present day? When necessary, some support questions were used, such as: talk about the process/path until getting the diagnosis – how and when it occurred.

The search for new informants took place until the study objective was reached and no new information emerged in the interviews. The records made in the field diaries, right after the end of the interviews, they helped the researcher to recall singularities and to contextualize excerpts from the testimonies, when she started and deepened the data analysis, in order to facilitate the understanding of the daily experiences reported.

Data analysis

The recorded interviews were fully transcribed and submitted to content analysis, thematic modality[19], following the three pre-established steps. In the pre-analysis, data set organization, transcription and separation were carried out. Then, there was the initial reading of the empirical material with initial identification of relevant aspects from the purpose of this study. In the material exploration, the classification and aggregation of the data was carried out, based on a thorough reading process, with the identification, by means of colors, of common and more specific terms, giving rise to three thematic categories.

RESULTS

Among the 26 participants in this study, nine had a family history of SLE and all of them used continuous medication. Furthermore, 18 of them reported other pathologies, including concomitantly, such as: rheumatoid arthritis (15 cases); lupus nephritis (15 cases); hypertension (13 cases); diabetes mellitus (five cases); fibromyalgia (three cases); anemia (two cases); vitiligo (two cases); chronic renal failure (CRF) (two cases); hypothyroidism (one case); hepatitis (one case); and Antiphospholipid Antibody Syndrome (APS) (one case). Of these, six were undergoing pulse therapy once a month and nine had already undergone this treatment, two were undergoing hemodialysis three times a week and another three had already required dialysis treatment. From the data analysis, three categories emerged, which will be described below.

Early times: from the suffering of diagnosis to resignification of life

Participants in this study demonstrate that the onset of SLE was experienced in a unique way. The time between presenting the first signs and symptoms, which are often nonspecific, and seeking professional help, was also quite variable. The difficulty in establishing the diagnosis in a timely manner stems from the wide clinical spectrum and the different intensity of manifestations in each individual. These are characteristics of chronic conditions, especially chronic diseases, whose courses do not show regular or predictable patterns. In this way, the temporality to seek the health service is related to the impacts that the initial signs and symptoms triggered in affected people's daily lives.

> *It all started with a constant headache, a lot of pain in the body, discouragement, endless tiredness and fainting. I am a truck driver and I started to feel very sick on the road while driving. One day I passed out at the wheel and fell off a bridge with the truck. That day was the last straw for me to see a doctor, it was the limit, because I didn't know what I had.* (P 17, M 38, systemic, 4 years)

> *I started to lose a lot of weight, hair started to fall out, to swell, my tongue started to peel, there are lumps on my face, lumps, lots of infections underneath, I lost my appetite, all those things, fever, a lot of vomiting, I just vomited foam.* (P 21, F 33, systemic, 12 years)

Also, the appearance of signs and symptoms varies, and can be progressive over years or be noticed overnight.

> *I went to bed on a normal day, the next, I got up all screwed up, with my body all red, pus coming out, then as the day went on it increased, it started to itch. Then I looked for a doctor and he found food poisoning, gave me some medicine and sent me home. But, after a week, the wounds started to burst, I started to bleed, so I went back there and he sent me to a rheumatology specialist. When I arrived for rheumatology, they went for biopsies, these things to find out that it was lupus.* (P 24, M 48, systemic with discoid lesion, 28 years)

On the other hand, there were aspects related to the diagnosis that were similar among the interviewees. For example, receiving the news that they have SLE is an experience of suffering, characterized as a feeling of sadness, anguish and fear, mainly because the disease is rare and little known.

> [...] *when I got the news that I had lupus, I cried so much. My God! I was desperate, because, well, I met a girl who has lupus, but I didn't know anything about this disease, I just knew that it was that, except that she was all deformed, full of wounds, so, well, I despaired* [...]. (P 5, F 45, systemic, 7 years)

> *I didn't even know what it was when he said: Look, you will have to undergo treatment for the rest of your life, there is no cure. I thought "I'm going to die, this disease is going to kill me". For me, it was cancer, later I discovered that it attacked from the inside, destroying everything, then it became even more fearful.* (P 15, F 31, systemic, 16 years)

The difficulty and shock of diagnosis contribute to a long and difficult journey towards acceptance and living with the disease.

In addition to this situation, which feeds back and contributes to the disease non-stabilization, people often deal with scarcity of information, lack of knowledge and impotence in the face of diagnosis that are reflected in social isolation as a form of self-protection and/or denial, with friends, neighbors and even family members falling apart.

> [...] *I stayed closed inside the house, closed the curtains and just looked out the window, the neighbors didn't see me, I didn't go to church, my sisters came to visit me, I just spied, because I didn't want to see anyone, they arrived and stayed in the kitchen and I peeked from the room* [...]. (P 14, F 54, systemic, 3 months)

> *At first, there were moments when I wanted to die, I was locked up, I didn't want to see anyone.* (P 15, F 31, systemic, 16 years)

The process of accepting the disease, according to participants, happened over time, and not necessarily because of the work of the team that supported them. It consisted of a process in which there were different learnings, especially regarding the most harmonious coexistence possible with the disease, leading to the acceptance of body self-image and the new demands and care imposed by the disease. This allowed people to re-signify their lives and seek a new normality in their everyday and usual activities.

> *This lupus, for me, is just a phase, each one has a problem to carry, each one has their limitations, but I think like "if we despair, we kill ourselves, destroy ourselves, we get truly sick. So I accept, I accept myself the way I am. Do I have lupus? I do. Do I have skin blemishes? I do. Do I have a lot of wounds? I do. But I won't stop living because of this, these blemishes. I'm not going to stop going to a party because of lupus. Whoever wants to look at me with a disgusted face, go and look, whoever wants to look at me with an ugly face, go and look at me.* (P 8, F 32, systemic with discoid lesion, 10 years)

> *At first, I felt useless, the worst of people, then you get used to it, you learn to survive with it, today, for me, let's say it's normal. Today, I don't have problems anymore, as I've accepted that I have lupus. I fight with it, it fights with me, it's the famous cat and dog fight, I don't give up anymore, no, it won't beat me anymore.* (P 24, M 48, systemic with discoid lesion, 28 years)

In summary, it was possible to observe that the first times of living with SLE were marked by the emergence of signs and symptoms that modified patients' daily lives, leading them to seek professional help to establish the diagnosis. At this moment, there was intense suffering, denial of the disease and withdrawal from the social and family network. However, over time, it was found that acceptance of diagnosis led to a resignification of life, allowing a gradual resumption of usual activities and interpersonal relationships.

Dealing with typical complications of the disease

Participants revealed that, after the impact of diagnosis and acceptance that occurs over time, there is the experience of different situations that trigger suffering, because, considering the involvement of a chronic autoimmune disease, such as SLE, several other serious complications and typical associated diseases emerged. This triggered repeated hospitalizations and even new therapeutic approaches.

> *After I was diagnosed with lupus, I had everything. Today, I have high blood pressure, diabetes, high cholesterol,* [problems with] *thyroid, I had two strokes, glaucoma, kidney stones, liver hemangioma. Wow! There are many problems because of this disease. Last year I had a stroke, I lost all movement in my body on the left side. I also do treatment for anxiety. So, the stroke was a consequence of lupus, diabetes is a result of lupus, high blood pressure is a result of lupus. It's all because of this disease.* (P 2, F 57, systemic, 4 years)

> *Lupus affects everything. Everything happens because of this disease. I already had a lot of lung problems because of lupus and now I have kidney problems. When I did biopsy, I had lupus nephritis, so now I have to do pulse therapy, because my kidneys are a disaster and I'm losing protein in the urine, then I have to do that* [...]. (P 3, F 27, systemic, 4 months)

In this regard, given the emergence of numerous complications resulting from SLE, treatment is meant as the only way to survive with the disease, triggering greater commitment to compliance with therapy.

> *Today, I depend on treatment to live. There's no way to go on without it, either you take it seriously or you can't live* [...]. (P 6, F 52, systemic, 23 years)

> *I'm doing this treatment to be able to live a little longer, because lupus, if you don't take care of it, it ends up with you, attacks diseases in the bones, in the kidneys, so you need the treatment to survive, you have no other option* […]. (P 24, M 48, systemic and discoid, 28 years)

In this category, it was possible to observe that the serious and typical complications associated with SLE are an aspect that has a considerable impact on living with the disease, increasing the suffering in the daily coping with the disease.

Implications of ignorance about the disease in everyday life

In this category, there is another situation that generates anguish and suffering among the participants of this study – the social lack of knowledge about SLE. This has a negative impact on the daily life of people living with SLE, especially due to fluctuation of symptoms and moments of crisis, which are often misunderstood. Thus, the lack of information about the disease can generate criticism, judgment and prejudice by society in general and even the family members themselves.

> *People don't understand what lupus is, not even my mother, because it's like that, sometimes you have a symptom and people think it's nothing, they don't care. You need to be in a bed rolling in pain, screaming in pain, have a fever, need to go to the hospital for people to notice you. We feel pain, tiredness, fatigue and I would like them to at least ask me what is happening. Not to feel sorry for me, but so that I could talk, have someone to talk to, but it's not like that, people don't care, they think it's laziness, joke* [...].

> *I think that people's understanding needs to be improved, it is necessary to disclose more about what lupus is, because it is very little publicized.* (P 1, F 21, systemic, 9 years)

> *Sometimes people ask "wow, but what is this?". I say "it is a disease that is in the blood, it is a rheumatism". Others also ask if they can catch it, because they don't know it, then they are afraid to catch it, people move away because of that, it seems they are afraid to catch the other's disease, but they don't catch it. Even so, people are afraid, that's why most people with lupus prefer to live closed and hidden from the world, I myself avoid leaving home* [...]. (P 15, F 31, systemic, 16 years)

This negative impact is portrayed with even more sadness and suffering when judgments and indifference are expressed by friends and family, revealing the stigma and lack of understanding about the disease and its signs and symptoms.

> *With friends, the situation is even worse. My friends always said "then, when you go to the doctor, you can count on me, whenever you need, you can count on me". But then, when they see the reality, they walk away. People don't care, because they think it's nothing. The person who has lupus is like a clock, there are days when you wake up great, saying good morning to the birds, but there are days when you are in pain, tired, very ill, very sick, and then people think it's nothing much, it's lack of desire to work, it's wanting to lean on others. So, like that, the friends themselves don't see, they don't believe. It's not asking for pity, it's asking for understanding* [...]. (P 1, F 21, systemic, 9 years)

> *My husband doesn't understand me, he thinks it's nothing and lack of things to do, he just complains* [...] *Over the years, I've realized that I never receive a word of encouragement, everything you do is not good, it's no good, he doesn't accept me as I am, nobody does* [...] *I receive criticism and praise never comes. He says I'm a liar, that I make things up, he just criticizes me. I do everything, even bad, sick, stumbling, suffering and even then I'm no good, I'm a liar. God forbid, it's very difficult, if you don't have support at home, where will you get it, from whom?* [...]. (P 6, F 52, systemic, 23 years)

Given the lack of understanding of the social and family network, participants suggested that health professionals include the family in the therapeutic-care process and in decision-making.

> *I feel the need to include the family in treatment, to prepare them too, because there were many times, I asked my mother to come to the consultation with me, so she could hear what I was feeling, so I could show the doctor what was happening inside home. I talked about what was happening and I expected a safer position from them, that they would come to my parents and talk, explain, understand? Trying to talk, but no, they don't talk and it's all vague. The patient really needs to learn to walk with his own legs, but sometimes, when there is something that happens in the family, that affects the patient, there should be a broader conversation, but there is not, I think that is what weighs most. You need to tell my family what can happen to me, explain so they can understand me.* (P 1, F 21, systemic, 9 years)

The reports in this category showed that people living with SLE clamor for greater dissemination of the disease among society in general and also within the family as a strategy to minimize situations of stigma and suffering.

DISCUSSION

SLE has many and varied clinical and laboratory manifestations, so that individuals present different signs and symptoms[1]. This characteristic is one of the main limiting reasons for an early diagnosis. The findings of this study corroborate this evidence, as several participants reported that the diagnosis only occurred after a long time of coexistence, with clinical manifestations and changes in health and search for different professionals. The literature points out that the initial signs and symptoms of SLE can be confused with other pathologies, so that many individuals experience a general malaise for years, before the diagnosis is defined and the treatment started[20].

However, being diagnosed with SLE can trigger great emotional suffering, in addition to social exclusion[17], since it is an incurable disease that requires lifelong treatment, with the adoption of specific self-care measures and changes in habits[20]. This suffering can also be linked to the lack of knowledge about the disease, as observed in the testimonies, since information about SLE is not widely disseminated. In this sense, affected people need information and appropriation of knowledge about the disease, as this is fundamental in the therapeutic plan. The health team must have cultural sensitivity to carry out actions in this direction and support the decisions of users with chronic diseases.

When the diagnosis is established, the person is faced with a whole new world so that understanding the disease only occurs after the illness. However, it was observed that, given the lack of knowledge, the process of accepting the disease is something that is always in progress, and is often permeated by negative feelings, such as sadness, hopelessness, fear and suffering[21]. In addition, due to the inherent characteristics of chronic conditions, each symptom can lead to others, in a vicious circle: chronic condition generates muscle tension, which leads to pain, which triggers stress and anxiety, which leads to emotional problems, which leads to depression, which leads to fatigue, which in turn feeds back into the chronic condition.

However, over time, acceptance can become effective and, thus, feelings of personal appreciation and hope arise, favoring a positive coping with the disease.

Late diagnosis, in turn, favors the appearance of other diseases and some complications[22], which require even more care and medical routines from individuals. Pain was one of the main manifestations mentioned by participants, supporting the results of a study carried out in Africa with 27 individuals with SLE, which identified that it is a constant concern in the daily experiences of people affected by lupus[23].

In this study, it was possible to show that the main pathologies and complications reported by participants were hypertension, diabetes mellitus, anxiety, strong, lung problems, lupus nephritis, among others. A review that included 31 studies and qualitatively analyzed the data found that diseases of the circulatory, respiratory and renal systems represent the most frequent clinical manifestations in people with SLE[22], gradually compromising quality of life. In addition, a national study showed that, in addition to the complications of SLE, diseases of the circulatory, respiratory, digestive and genitourinary systems are the main causes of death in affected individuals[24].

As SLE causes several health complications, treatment is seen as the only way to survive the disease. It differs according to the manifestations presented, taking into account the singularities and degree of commitment of each person[5]. In addition to drug and non-drug treatment, which involves skin care, nutrition, physical and psychological health, some individuals also need to undergo pulse therapy and dialysis treatment, due to the involvement of the renal system[25-26], a common situation faced by people with SLE and which was also evidenced in this study.

Thus, treatment aims to remission the disease and improve quality of life. In this sense, participants demonstrated that they recognize that, in order to keep the disease in remission, adequate therapeutic compliance is essential, which supports the findings of other studies that portray SLE treatment as a permanent disease that requires compliance and care for life[20,27]. Furthermore, the importance of intervention actions focused on disease self-management is highlighted, as they are carried out with other chronic conditions. The feeling of being in control of the disease is something that motivates individuals with SLE[23] to perform self-care.

In the face of such evidence, it is necessary that health professionals, members of the interdisciplinary care team for individuals with SLE, in particular, care mediators, such as nurses, pay attention to the fact that illness from SLE favors the emergence of other pathologies that can negatively impact the quality of life of individuals, in addition to compromising SLE treatment and prognosis[22]. In this sense, we emphasize the importance of the Health Care Network, in addition to Primary Care, with its attributes of accessibility, bonding, and the work of the multi and interprofessional team, with health promotion and disease prevention actions as the great power of elaborating an expanded care plan, which should emphasize therapeutic compliance, regular monitoring and early identification of clinical changes and complications, as well as self-care as pillars for a good clinical prognosis.

It is noteworthy that, in CCM, a care plan must be prepared together with patients and, in addition to following the scientific evidence in relation to care guidelines, consider individuals' singularities, so that they can better understand all actions related to their health. Therefore, it is important for health professionals to be permanently prepared, so that their approaches are in accordance with the new evidence, in addition to being able to use different strategies that support self-care, such as motivational interviewing.

Participants showed, in their speeches, that the diagnosis of SLE and the complications arising from the illness process are difficult situations that require physical and psychological adaptations. In this regard, it was observed that the lack of knowledge about SLE by society in general and, in particular, on the part of family members, negatively influences accepting the disease and the quality of life of people who experience the disease. Often, coexistence at home, work, school, among others, is permeated by conflicts due to the non-recognition of limitations and conditions imposed by illness. This finding corroborates the results of a study that pointed out that this interferes, even with adequate establishment of support for individuals with the disease[14].

The lack of information about the disease, treatment and repercussions on daily life is a frequent problem for individuals with SLE[28], and the lack of understanding extends from the family to society in general, leading the person to an even greater suffering than the one imposed by the grievance. P1's and P15's statements, for example, show that, in addition to this disagreement, people with SLE are judged and experience stigma, due to the manifestations in their appearance. For this reason, people often avoid getting close for fear of being contaminated, and this, in turn, makes individuals with SLE prefer to withdraw from society and from living with family and friends.

In view of this, it is necessary that the general population, as well as family, friends and health professionals, understand that SLE is a chronic condition and what it actually means to live with this disease, what are the consequences arising from their involvement and the difficulties experienced. Knowledge about the disease, treatment and the importance of emotional support are crucial in the process of complying with and accepting the disease, thus contributing to the reduction or absence of feelings such as anguish, anxiety, low self-esteem and shame[26].

This understanding is necessary, as more adequate health care requires a broad view by the interdisciplinary team[26,29] and, in particular, by nurses, who play an essential role in mediation of care. Therefore, implementing educational actions addressing different aspects of the disease and the beneficial effects of self-care and positive attitudes in living with the disease[30], making use of problematizing dialogue, must be carried out, especially addressing the beneficial effects of self-care and positive attitudes in living with the disease[30].

Furthermore, nursing consultations aimed at individuals with SLE and their families make it possible to expand their understanding of the disease, helping to identify needs and expanding the support network. Including the family in the care and monitoring of patients with chronic disease is reflected positively in the understanding of disease evolution and in patients' quality of life[31]. In addition, in CCM, self-care support, family involvement and community resources are essential for people with a chronic condition or disease, together with the team, family and community, to exercise collaborative care management, in that health professionals are no longer prescribers to become partners with people who use health care systems.

Study limitations

A possible limitation refers to the fact that the informants were located from a single health service and, therefore, their results may be subject to local contextual influences. Another limitation is related to the fact that participants were selected based on their willingness to share their experiences with the disease. Therefore, patients with lower communication skills were not considered as potential participants.

Contributions to nursing and health

There is a need for health professionals to welcome individuals and their families, in order to help them understand the SLE and enable the planning of joint care actions that favor quality of life. Furthermore, health education actions, focusing on the dissemination of the main information about the disease, should be developed in different social spaces.

FINAL CONSIDERATIONS

Experiencing illness from SLE is a difficult experience, permeated by periods of exacerbation and remission of the disease manifestations, triggering feelings of fear, anguish and suffering. As it is a rare disease, little known and with diffuse initial manifestations, the time to establish the diagnosis can be too long, delaying the beginning of specific treatment, leading individuals to experience general discomfort, emotional suffering and social exclusion. In addition to suffering from various clinical and laboratory manifestations, individuals also experience several complications and limitations in their daily lives and, in this sense, they recognize treatment as the only way to survive the disease, emphasizing the need for adequate therapeutic compliance, adoption of specific self-care measures and changes in life habits.

Judgment and stigma by family members, friends, co-workers and/or schoolmates, among others, who are unaware of the disease, have a negative impact on the lives of those who experience it. On the other hand, the time spent living with it can enhance self-care and compliance with therapy, restoring positive feelings in individuals, such as personal appreciation and hope. The study is concluded with an emphasis on the need to disseminate the disease and its implications in the daily life of affected individuals, favoring a greater understanding by the family, society in general and improving health care for people with SLE.

FUNDING

Coordenação de Aperfeiçoamento e Pessoal de Nível Superior – CAPES.

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