

DUALITY OF LIVING WITH SYSTEMIC LUPUS ERYTHEMATOSUS: FLUCTUATING BETWEEN “GOOD DAYS” AND “BAD DAYS”

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ABSTRACT

Objective: to learn the perception of individuals with Systemic Lupus Erythematosus about living with the disease.

Method: an exploratory and descriptive research study, of a qualitative nature, carried out with 26 individuals undergoing treatment at the rheumatology outpatient clinic of a university hospital in southern Brazil. The data were collected in the period from February to July 2019, by means of semi-structured interviews that were audio-recorded and subjected to the thematic modality of content analysis.

Results: a category entitled: “Fluctuating between good and bad days in living with Systemic Lupus Erythematosus”, composed of two subcategories that portray that living with Lupus is something unstable/fickle, emerged from the results. This is because, as a result of the periods of remission and exacerbation of the signs and symptoms of the disease, the patients experience a paradox of constant oscillation between ups and downs.

Conclusion: it was learned that individuals with Lupus perceive that living with the disease is marked by an oscillation between good days and bad days, which are related to periods of remission and exacerbation of the manifestations of the disease, respectively.

DESCRIPTORS: Systemic Lupus Erythematosus. Autoimmune diseases. Rare diseases. Nursing. Chronic diseases. Qualitative research.

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DUALIDADE DA CONVIVÊNCIA COM O LÚPUS ERITEMATOSO SISTÊMICO: OSCILANDO ENTRE “DIAS BONS” E “DIAS RUINS”

RESUMO

Objetivo: apreender a percepção de indivíduos com Lúpus Eritematoso Sistêmico sobre a convivência com a doença.

Método: pesquisa descritiva exploratória, de natureza qualitativa, realizada junto a 26 indivíduos em tratamento no ambulatório de reumatologia de um hospital universitário do Sul do Brasil. Os dados foram coletados no período de fevereiro a julho de 2019, mediante entrevistas semiestruturadas, audiogravadas e submetidas à análise de conteúdo, modalidade temática.

Resultados: dos dados emergiu uma categoria temática intitulada: “Oscilando entre dias bons e ruins na convivência cotidiana com o Lúpus Eritematoso Sistêmico”, composta por duas subcategorias, as quais retratam que conviver com Lúpus é algo instável/inconstante. Isto porque, em decorrência dos períodos de remissão e exacerbação dos sinais e sintomas da doença, vivencia-se o paradoxo de uma constante oscilação entre altos e baixos.

Conclusão: apreendeu-se que os indivíduos com Lúpus percebem que a convivência com a doença é marcada por uma oscilação entre dias bons e dias ruins, os quais estão respectivamente, relacionados aos períodos de remissão e exacerbação das manifestações da doença.

DESCRITORES: Lúpus Eritematoso Sistêmico. Doenças autoimunes. Doenças raras. Enfermagem. Doenças crônicas. Pesquisa qualitativa.

LA DUALIDAD DE VIVIR CON LUPUS ERITEMATOSO SISTÊMICO: OSCILANDO ENTRE “DÍAS BUENOS” Y “DÍAS MALOS”

RESUMEN

Objetivo: averiguar de qué manera las personas con Lupus Eritematoso Sistêmico perciben su convivencia con la enfermedad.

Método: investigación descriptiva y exploratoria, de naturaleza cualitativa, realizada con 26 individuos en tratamiento en la clínica ambulatoria de reumatología de un hospital universitario del sur de Brasil. Los datos se recolectaron durante el período de febrero a julio de 2019, mediante entrevistas semiestruturadas, grabadas en audio y sometidas a análisis de contenido, en su modalidad temática.

Resultados: de los datos surgió una categoría temática de título: “Oscilando entre días buenos y malos en la vida diaria con Lupus eritematoso sistêmico”, compuesta por dos subcategorías, que indican que vivir con Lupus es algo inestable/voluble. Esto se debe a que, a raíz de los períodos de remisión y exacerbación de las señales y los síntomas de la enfermedad, se experimenta la paradoja de una oscilación constante entre buenos y malos momentos.

Conclusión: se descubrió que las personas con Lupus perciben que la convivencia con la enfermedad está marcada por una oscilación entre días buenos y días malos, que están relacionados, respectivamente, con los períodos de remisión y exacerbación de las manifestaciones de la enfermedad.

DESCRIPTORES: Lupus Eritematoso Sistêmico. Enfermedades autoimunes. Enfermedades poco comunes. Enfermería. Enfermedades crónicas. Investigación cualitativa.

INTRODUCTION

Systemic Lupus Erythematosus (SLE) is a chronic, autoimmune, rheumatic and inflammatory disease, in which the immune system becomes overactive, gradually attacking the normal and healthy functioning of the human body. It is subdivided into four types: discoid, drug-induced, neonatal, and systemic¹⁻². Its prevalence has been gradually increasing and it is estimated that there are approximately five million people with SLE worldwide, of which 90% are women of childbearing age¹.

SLE can affect various systems of the human body, such as the immune, circulatory, nervous, cardiopulmonary, hematological and renal systems²⁻³. Its clinical spectrum varies from mild to severe, with periods of exacerbation and remission⁴. In addition to that, the individuals have a singular range of symptoms: tiredness, fatigue, arthritis, pain, edema in the upper and lower limbs, Sjogren's syndrome and other skin manifestations⁵. It is noteworthy that the arthritic effects can be observed in more than 95% of the affected individuals⁶. However, fatigue and tiredness are also frequent complaints when SLE is active^{2,7-8}.

People affected by SLE experience many changes in daily life, including, in addition to physical and psychological symptoms, decreased muscle strength, changes in rhythm and productivity at work, limitations related to treatment and changes in body self-image and self-esteem^{4,7,9}. In this sense, for many patients, the disease challenges the future and the meaning of life¹⁰.

The experience of living with SLE is a major challenge for people with the disease, their families and also for the health system, which routinely makes efforts to care for the individuals affected, their complications and treatment⁴. Worldwide, researchers increasingly seek to understand the origin and process of the disease and indicate that its onset significantly impacts on the daily lives of the individuals and their families, in different and broad aspects, covering physical, psychological, family and social health^{2,7,10}.

However, there is still a need for studies that highlight how people living with SLE perceive their daily lives, since getting to know better the subjective face of this disease and understanding the way in which it materializes in the subject's historicity, as well as the anxieties, doubts and fears that accompany it, can positively influence the quality of the care provided by the health professionals. Thus, there is a need for Nursing care that contemplates this understanding, adding practical and technical care, as living with the symptoms and the sociocultural stereotype of the disease produces multiple implications that need to be considered¹¹.

Furthermore, as it is a chronic disease, for comprehensive care to be realized, it is necessary to consider the psychosomatic dimension, since the stress and psychosocial distress factors, for example, can influence its triggering, evolution, worsening and possible control¹¹. Thus, learning the reality experienced by people with SLE can support care planning that prevents or minimizes possible negative consequences for life and health and enhances care aimed at maintaining control of the disease. Given the above, this study aims to learn the perception of individuals with SLE about living with the disease.

METHOD

This is an exploratory and descriptive research study, of a qualitative nature, carried out with 26 individuals with SLE being monitored at the rheumatology outpatient clinic of a university hospital located in southern Brazil. This monitoring takes place by means of periodic appointments every three months, on average, this interval being shortened or prolonged for up to six months depending on the clinical condition of the individual.

In this outpatient clinic, the person with SLE is treated by a rheumatologist and an interdisciplinary team composed of a gynecologist, ophthalmologist, dermatologist, psychologist, psychiatrist and

social worker. The care provided is mediated by the institution's internal organizational flow, which is regulated by the professionals themselves, with the patient being referred and re-referred to a specific specialty, according to the clinical need presented.

The data of this research were collected in the period from February to July 2019. Initially, the participants were approached by the lead author in the waiting room of the outpatient clinic, on the days and times when they attended the service for a previously scheduled medical appointment. At these moments, the individuals were invited to participate in a study with a quantitative approach on quality of life.

Intentionally, during the application of the quantitative data collection instrument, the individuals who, according to the researcher's perception, demonstrated availability and interest in reporting their experience of living with the disease were invited to participate in the qualitative stage. For this stage, the following inclusion criteria were considered: living in the municipality of Maringá or in its metropolitan region and having time availability to receive the researcher in their homes. Individuals affected by other pathologies unrelated to SLE or with speech difficulties were not invited, as this could hinder communication between the researcher and the interviewee. All the individuals invited to the qualitative cut accepted to participate, being asked for a telephone number for later contact.

The interviews were previously scheduled according to the availability of the researcher and of the participants, and were conducted in a reserved place of the house, without the presence of other people and in a single meeting. The interviews were audio-recorded after obtaining due authorization, had a mean duration of 45 minutes and were guided by the following question: "How is it for you to live with SLE?" And, when necessary, two supporting questions were asked: "What are the impacts of SLE on your life?" and "What is your life perspective living with SLE?"

Recruitment of the participants took place gradually, over a period of five months. The interviews were transcribed in full, preferably the same day they were conducted. On this occasion, they were also subjected to a fluctuating reading to include details related to the researcher's impression of the non-verbal communication emitted by the individual, in order to provide better understanding of the context involved and the subjectivity of the answers. New participants were invited until new facts ceased to emerge and the proposed objective of the study had already been achieved. It is noted that the transcribed testimonies were not returned to the respondents for their approval.

All the interviews were subjected to content analysis, thematic modality, following the established stages¹². The pre-analysis included the organization, transcription and separation of the data set and an exhaustive reading of the empirical material with initial identification of the relevant aspects. In the material exploration stage, the data were classified and aggregated based on a thorough reading process, with identification, using different colors, of common and more specific terms and selection of first order codes – directly associated with the quotes and using the interviewees' own words – called *in vivo* codes, which gave rise to the nuclei of meaning and the registration units, and which served as the basis for the subsequent categorization of the data. In the last phase, categorization was carried out, which consisted of grouping the elements according to their similarities and by differentiation, with the subsequent regrouping based on the common characteristics, giving rise to a thematic category and two subcategories.

After authorization was obtained from the hospital, the study was approved by the Permanent Committee of Ethics in Research with Human Beings of the signatory institution. After reading and clarification of doubts, all the participants signed the Free and Informed Consent Form in two copies. To ensure anonymity in the presentation of the results, the extracts from the testimonies were coded with the letter P (Participant) followed by an Arabic number corresponding to the order of the interviews, followed by the letters M or F to indicate male or female gender, and by the indication of the diagnosis time (in years or months) (Example: P17, M, 10 years).

RESULTS

The 26 participants were aged from 18 to 65 years old, 21 of them being female. Regarding schooling, nine of them had less than eight years of study. They all presented cutaneous, articular and psychological manifestations related to the disease, the most common being: presence of joint pain (26); alopecia (21); easy tiredness (18); anxiety (15) and fatigue (14). The manifestations of the disease were varied and related to the diagnosis time, which ranged from four months to 30 years. After the analytical process, a thematic category emerged, composed of two subcategories, which are presented below.

Fluctuating between good and bad days in living with SLE

According to the participants, living with SLE is something unstable and inconsistent. This is because, as a result of periods of remission and exacerbation of the signs and symptoms of the disease, the paradox of a constant oscillation between ups and downs is experienced, that is, living with SLE is marked by the experience of “good days” and “bad days” [*in vivo* codes] (Figure 1).

My life is so full of ups and downs, tumultuous; one day we are fine, the next we are not, it's complicated, one good day, one bad day (P10, F, 6 years). *Lupus is a very crazy thing; there are days when you're feeling good and others, not so much. There's no way to say that tomorrow I will be fine, because I don't know. It's a mystery. Just as things appear, they disappear. It's very strange* (P15, F, 16 years).

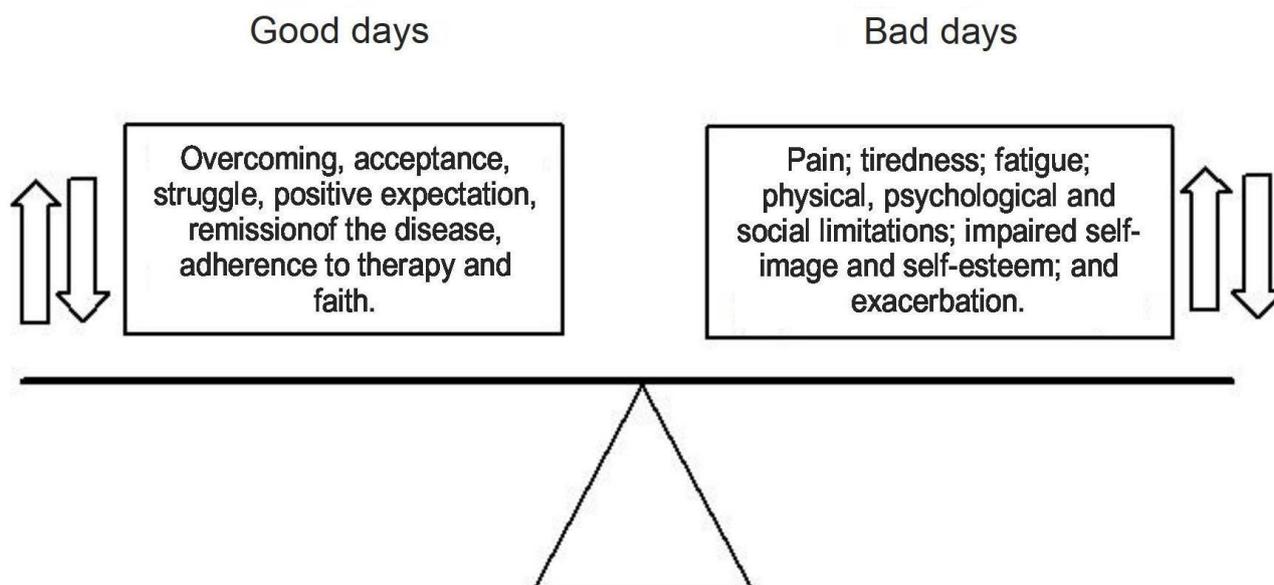


Figure 1 - Graphical representation of the category: “Fluctuating between good and bad days in living with SLE” and its subcategories “good days” and “bad days”. Maringá, PR, 2019.

Good days

Living daily and longitudinally with the disease favors its acceptance process. This has a positive impact on the present time, as people who are in remission of the disease are able to look back and see that they have already faced worse days of intense physical and emotional suffering. And, in this sense, the current days are celebrated for being considered good days, permeated, above all, by feelings of overcoming. *There were many fights, sometimes I keep thinking to myself: did I go through all this? It was difficult, I struggled a lot to get where I got. Today I don't even look the same as 20 years ago* (P18, F, 30 years). *I think that the word that defines me is overcoming, because in the beginning you don't have any information, nor do the doctors; you run after help and they can't help you, they treat things that have nothing to do with your problem, it's very hard. So, after everything I've been through, today I look back and take a breath, I think about it and I'm grateful. Today I have more reasons to be thankful, because I suffered but I overcame it* (P26, F, 6 years).

The emotional aspects directly impact on daily living with SLE. It is observed that care with the emotional aspect helps the acceptance process, adding positivity to the establishment and maintenance of good days. *The emotions affect a lot. So I avoid caring about things and the opinion of others, I try to distance myself from people who stress me out. Because there are people who say unnecessary things, which end up hurting me. They say those things because they don't know what my disease is, because they don't have Lupus, because they don't feel, they don't live, so it's easy to judge without knowing* (P3, F, 4 months).

Furthermore, the consolidation of good days is directly related to therapeutic adherence, because the appropriate treatment helps to reduce symptoms and in remission and, consequently, to live better with the disease. *I'm fine now, very well compared to before, the treatment helps us a lot* (P4, F, 7 years) *If you take care and treat it as you should, you can live a long life with Lupus, but it's like doctors say, you can live with treatment, without it, Lupus is a serious disease that can lead to death* (P3, F, 4 months).

Overcoming of the fears and gestational success also have a positive influence on everyday life, because the disease imposes important limitations in this scenario and often contributes to negative perceptions about building a family. *I'm positive that this child here is a miracle. And I'm amazed, it seems like it's not true; when I heard the heart beating, I had no reaction. With so many bad things I've heard that I couldn't get pregnant, a lot of things, and now I'm here with my miracle. I'm calm and happy* (P8, F, 10 years, 16 weeks of pregnancy).

Furthermore, religiousness and faith in God help the perception of good days, as they favor feelings of peace, tranquility and acceptance, which positively helps to face the disease. *I think that the main foundation is God. I put my cause in the hands of God and I'm calm. From the moment you truly rest in God you see how your life changes* (P8, F, 10 years). *I'm a guy who has a lot of faith in God. He knows everything, He is the one who solves my problems. Then I have faith, it's my structure* (P11, M, 15 years).

Bad days

In detriment to the good days, the periods in which the symptoms of the disease were active were reported as bad, due to the limitations and difficulties imposed on daily life. *The periods when Lupus is active are more difficult. I get very tired, it's difficult to walk, to go to the gym, to go to work* (P1, F, 9 years). *Living with Lupus is bad, it's horrible, because you live in isolation, it requires you to isolate yourself, there are many restrictions. For example: you can't go to the beach, which I always loved. Food and drink restrictions, sometimes you go to a little party and you can't drink anything, you need to limit yourself. I can't go to a park with my son because of the sun, have a stroll during*

the daytime, I have to avoid, now I don't even go to speak the truth. And whether I like it or not, I end up getting in the way of my son's leisure life too; my problem starts to affect him and that's bad, it's very bad (P3, F, 4 months).

The recurrent presence of pain, tiredness and fatigue also exerts a negative influence on daily life. In this sense, the participants pointed out that, on days when pain and fatigue are more intense, living with the disease is difficult. *Some days I can clean like ten houses, but others I can't get out of bed. Pain, tiredness, fatigue; some days it's very difficult (P8, F, 10 years). The biggest problem about Lupus is tiredness; you can do whatever that it will always be there; you can sleep, you can stay at home, it will always be there, it's as if it belongs to you (P1, F, 9 years). People who have Lupus feel a lot of fatigue. It's fatigue all day long; we get that bad feeling, it looks like we are going to faint, we are in agony, wow, I don't even know how to explain it to you. But it's really bad, it's horrible (P9, F, 6 years).*

In addition to that, the participants reported that the winter days are the most difficult ones because the symptoms intensify and contribute to the perception of bad days. *I also had Raynaud's disease, my fingers got white, then red, then purple. This happens in the winter season, followed by tingling, numbness, feeling anesthetized (P4, F, 7 years). Cold is even worse, it seems as if pain worsens, tiredness, everything. The fingers are all purple, very purple; the body freezes very fast, you have to wear a lot of clothes; I wear a glove and I have a thermal boot. It hurts a lot in the cold (P17, M, 4 years).*

Body, skin and joint changes also have a negative impact on daily life, especially on self-esteem, social relationships and leisure. *My hair fell out, my body changed, I got all swollen. I was a beautiful woman, with a nice body, and everything came to an end. Then my family, my husband, my son started to call me ugly; I no longer have beauty, I have no self-esteem, and they treat me like that (P6, F, 23 years). I lost most of my hair, I looked like a man. Wow, it was very sad, I didn't even leave the house; I was ashamed, it's not easy to look in the mirror and see your hair falling out; you feel ugly, you know? Then you take a bath, you lose chunks of hair; you need to have a lot of faith in God or else you end up giving up on yourself, especially me that I care a lot about the way I look. I've always liked to dress up; I thought I was beautiful, then I felt ugly, I looked in the mirror and I felt ugly (P9, F, 6 years). The biggest problem with Lupus is swelling; the right leg is normal, but the left leg is not, the belly is also very swollen. I have varicose veins and stretch marks everywhere, here in the belly. So I'm ashamed of my own body; going out in public, going to a pool is hard, right? And I'm afraid of people (P22, M, 4 years).*

Another manifestation of great impact on daily life and that marks bad days refers to the loss of the libido and other difficulties related to sexual life, which can raise concerns about the discontent of partners and relationships. *In terms of sexual intercourse, I feel a lot of burning, so it's usually months without having intercourse; I often don't even have the desire to do anything, so it's all very complicated, my husband is young and no man likes this (P15, F, 16 years). Lupus also gets in the way of sexual life, I have no desire for anything else. You practically lose all your libido, the desire, you lose everything. As a man, I can't be there. This is something that presses you against the wall, because I consider it wrong, but what can I do if I have this disease? (P22, M, 4 years).*

The individuals also suffer from inability to work, which is directly related to the changes imposed by the disease process. *My life changed after Lupus. Now I'm unemployed and this is very bad; for me, working is important, it makes me feel useful, busy, you fulfill yourself as a person. So working is important for me. And now you see yourself standing there, being a housewife, it's something very displeasing (P4, F, 7 years).*

Furthermore, it is possible to observe that the disease causes a change of roles in family and society life; it is a situation that causes negative feelings of sadness and worthlessness in the individuals, causing them to often experience bad days due to the new role, reflecting the limitations imposed by the disease. *Today I can't work anymore. Let's say that I'm a guy supported by my wife and that is sad, it's depressing, I feel like a useless being, that I'm not able to provide for my family* (P22, M, 4 years).

In addition to the complications and limitations imposed by the disease, feelings of fear and anguish contribute to the triggering of bad days and, in this sense, it is possible to note that the limitations in family planning have negative repercussions in daily life, considering that individuals with SLE are afraid to build a family. *I want to get pregnant but, as far as I know, Lupus has to be controlled and some women sometimes cannot get pregnant because of the medications that can have consequences. I want to get pregnant, but I'm also afraid, really afraid* (P1, F, 9 years). *I had plans to get pregnant this year and the doctor said I can't do it at all. This is the most difficult thing in Lupus because, as women, we feel the desire to get pregnant, and we can't* (P3, F, 4 months). *I'm afraid of having children, I'm afraid of having a child and, when he's 20 years old, I will no longer be here. I did not have a father and I know it's not cool that you have to learn alone with life, how to shave, how to live in society. And I don't want my son to go through this, not having a father by his side is sad, it's difficult. That's why I'm afraid of having children, really afraid* (22, M, 4 years).

In relation to this aspect, the women who have already experienced this moment tell complex stories, which have a negative inference in this experience. *My pregnancies were a tribulation; when I was pregnant with the girl, it was terrible, I had no fluids, she was born at 32 weeks, she had a lot of problems that I thought she wouldn't even make it; and with the boy, he was born at 36 weeks. When I was pregnant with the boy, I had preeclampsia, I got really bad. My pregnancies were very complicated, both children were born premature. It was very hard, very painful, I thought I was going to die* (P6, F, 23 years). *I had problems in all my pregnancies. The first was better, but on the second I had a lot of pain, a lot of fluid loss, then on the last one I was hospitalized for six months until I delivered. He was born at the right time, and healthy, but I suffered a lot and I had two miscarriages too, one was already formed, and the other was spontaneous* (P18, F, 30 years).

DISCUSSION

The results found in this study demonstrated that living with SLE on a daily basis is not a crystallized experience. On the contrary, the individuals reported that it oscillated between good and bad days. Aspects such as accepting the disease and presenting a positive expectation for the future, often based on faith in a higher Being and adherence to treatment, cooperate to maintain the remission of the disease and, consequently, to the consecutive experience of good days, in which the individuals feel more productive, happy and complete.

The reaction to chronic diseases manifests itself in a unique, singular way to each person, although some behaviors, such as difficulty in accepting and adopting new habits, are frequently identified. Having to face a diagnosis without a cure leads the individuals to reflect on complex aspects such as their own existence, losses and death. However, when accepting the diagnosis, they can adopt a posture of research, which leads them to exploit to the fullest the knowledge about their disease, personal conditions and perspectives.

Therefore, not only the way in which the disease manifests itself, but also the way people cope with it throughout their lives is unique. In this sense, acceptance and resilience point to successful ways of dealing with adversity in order to minimize the impact. It was possible to learn that, even in the face of so many complications and limitations, some participants demonstrated that they had overcome and accepted the disease, which favors their clinical management and adherence to treatment, resulting

in an improvement in quality of life and, consequently, in the presence of good days. These aspects were also evidenced in a qualitative study carried out in Australia aimed at describing the experiences and perspectives of adolescents and adults diagnosed with SLE, in which the participants referred to the development of self-confidence and resilience to face the disease¹³.

A phenomenological study carried out in Denmark with 14 women with SLE showed that an important challenge in living with the disease is the constant uncertainty about tomorrow. The periods of symptom intensification are usually unpredictable and the consequent negative changes in functional capacity can interrupt, or intensely hinder, life plans and projects. Thus, the existential experience of staying in motion, advancing in life projects, requires internal efforts, that is, resilience to face the waves in the opposite direction, resulting from the intensification of SLE⁴.

This study also evidenced the relevance of spirituality presented in the reports related to trust in God for a better coexistence with SLE. In a quasi-experimental study on the influence of religious/spiritual exercises on well-being and quality of life in dermatological patients, it was identified that faith represented the foundation for sustaining daily life and presented itself as an important factor in maintaining health, well-being and coping with the chronic condition¹⁴. Thus, it was evidenced that its presence allows the perspectives on life to be positive and that the desire to live is gradually resumed, which, in turn, positively influences the remission of lupus manifestations.

Finally, the experience of pregnancy proved to be a materialization of “overcoming”, even interpreted as a miracle. It is noteworthy that, despite the concern expressed by the women, the experience of pregnancy is relatively frequent, since there is no loss of fertility in SLE¹⁵. However, a possible pregnancy requires prior planning, with the participation of an interdisciplinary team that meets the needs of the women affected and provides support for the pregnancy to occur at a favorable time.

Regarding the experience of bad days, it is observed that, although science has developed efficient ways to control some diseases and circumvent their effects, in the case of SLE, even if medication is available for treatment, there is no guarantee that the disease will remain under control, and even in the face of therapeutic adherence, can present many periods of exacerbation. This is because SLE is a disease of unpredictable course, characterized by periods of remission and exacerbation, which causes existential breakdown in the lives of the individuals⁴. The manifestations resulting from the illness are variable, but a number of studies indicate that physical symptoms, such as sensitivity to the sun, joint pain, tiredness and fatigue are the most common and have a negative impact on daily life^{2,7,9,16}.

Thus, the participants in this study frequently reported the presence of pain and its impact on daily life, corroborating results of national and international research studies^(2,17). It is to be noted that the frequent, and sometimes continuous, presence of pain can cause relevant physical and psychosocial suffering, especially when it is not considered and valued by close people and health professionals. The importance of considering this factor in the planning of the care actions with the families of these individuals is emphasized, as well as in continuing education actions with the team that provides assistance.

Tiredness and fatigue were reported as negative aspects of the disease, as they are often not recognized as SLE complications. Lack of knowledge about these symptoms by those who live with the person with SLE results in frequent misunderstanding and even stigma of disdain. A review that investigated the meaning of illness due to SLE showed that fatigue is recurrently experienced and is present regardless of whether the disease is in an exacerbation or remission phase, negatively interfering in the daily activities¹⁸. In particular, the effect of these manifestations on the reduction of the ability to work and the maintenance of employment are highlighted, which was indicated by a study carried out in the United Kingdom with 393 individuals with SLE¹⁹.

Another manifestation arising from illness due to SLE and that negatively interferes in the daily life of sick people is the change in self-image, resulting from skin manifestations, such as skin blemishes, transient and permanent eruptions and alopecia. The literature shows that the negative impact of these manifestations is significantly greater on women, interfering with self-esteem and personal value^{9-11,20}. However, sometimes, the individuals with SLE feel that these manifestations are not sufficiently valued by the health professionals, as they are related to physical appearance, according to a study carried out on the East coast of the USA²¹.

Some participants in this study reported that alopecia is one of the most impacting skin manifestations because, according to them, its presence causes shame, sadness, isolation and prejudice. Similar results are highlighted in studies carried out in different parts of the world on the experience of living with SLE^{9-11,20,22}. Impaired physical appearance, body shape, hair and skin, among others, often afflict female vanity, in addition to being a reason for discrimination and deprivation of leisure activities to avoid social exposure, which results in a great impact on the women's quality of life^{11,18,23}.

In addition to physical and psychological manifestations, the participants reported changes in sexual life, similarly to what was identified in a study conducted in China, which evidenced decreased interest and reduced frequency of sexual intercourse in individuals with SLE²⁰. In a study conducted with 112 married Indian women, more than 90% of the participants reported problems with desire, arousal and lubrication, which was related to marital dissatisfaction²¹. Among the men, the prevalence of erectile dysfunction is high (69%), according to a multi-center study in Latin America²⁴.

These manifestations are directly related to self-image, which is the individuals' perception of themselves, going through the understanding of their potentialities, thoughts and ideas; and also their self-esteem, which refers to self-discernment as a person and their insertion in the social environment. Therefore, these changes are reflected in social life and social acceptance, which, in turn, has implications on sexuality, not as a sexual act in itself, but as a component of the individual's personality. Personal and social acceptance interferes with quality of life and requires adaptation, which involves complex processes of living with the disease that go beyond the health dimension²⁵.

The physical and psychological manifestations and body restrictions resulting from SLE also have consequences for the professional life, especially when it is necessary to leave work activities, which, in turn, affects the economic condition of the people affected and, consequently, their quality of life^{11,22-23}. In these cases, the loss of professional stability is most of the times directly related to the manifestations of the disease, because the individuals are not always able to work and also because the need to be away from work to go to the routine medical check-ups and appointments is poorly understood by the employers.

Unemployment and the consequent financial dependence on the family members cause a negative burden for the physical, psychological and social health of people with SLE. In a study carried out in the state of Pará-BR that evaluated the impact of rheumatic diseases on productivity at work, SLE had a negative impact on the patients' professional activity. According to the results, 84.2% did not work and, among them, 94.1% reported having interrupted their professional activities as a result of the disease. The results also showed that rheumatic diseases, especially SLE, increase the number of requests for sickness assistance and lead to retirement at an early age²⁶.

Finally, in contrast to the sublime experience of good days, pregnancy also appears as a negative aspect due to the fear of exacerbating the disease and the pregnancy risks resulting from the temporary suspension of some medications. Thus, compared to the general population, in women with SLE pregnancy is at higher risk of obstetric and perinatal complications, such as preeclampsia, fetal loss, intrauterine growth restriction, premature birth and neonatal lupus syndromes²⁷⁻²⁸.

However, planning and regular follow-up with the health team can make all the difference. In China, a study analyzed data from 243 patients with SLE who planned their pregnancies and found that 21.4% of them experienced crises of disease exacerbation; however, in 95.1% of the cases, the births were successful, showing benefits in relation to unplanned pregnancies²⁸. In the same direction, when expressing his concern about having children, the young male participant demonstrated how much the disease is interfering with his psychosocial condition, mainly because he is unable to work. At several moments, this young man (20 years old) demonstrated his low self-esteem and disbelief in the possibility of improving his health condition. It is noteworthy that he has already undergone several hospitalizations and has important limitations resulting from lupus manifestations, despite the short time of the disease (four years).

Thus, considering that SLE is a chronic disease of great physical, psychological and social impact, Nursing professionals become relevant. Thus, the low understanding and acceptance of SLE, aggravated by inadequate social support structures, negatively impact on the personal experiences of those who live with the disease. In this sense, Nursing professionals can act as facilitators in the process of therapeutic adaptation for living with the disease. This is because they are professionals specialized in care, in meeting individual needs, and because they use strategies that can minimize the effects of bad days with previous and later care, and can reinforce attitudes that favor good days, through guidelines and support. Additionally, acting in an empathic, holistic and humanized manner, with welcoming, appreciation and respect for the individualities, favors the reduction of complications and can directly impact on the individual's empowerment²⁹.

The limitations of this study are related to the fact that the participants were located in a single health service and, therefore, are subjected to local influences, and also because the statements were not returned for the participants' approval. However, the results are valid since, in addition to being similar to those of other studies, they allow reflections on the needs that need to be included in the planning of care actions for these individuals and their families.

It is suggested that new research studies investigate the role of the family of the person with SLE, their perception of the disease and the necessary care to keep it under control. This information can support the extended care to the family of these patients and health care planning, in addition to encouraging family participation in the treatment of SLE in an appropriate manner.

CONCLUSION

Living with SLE involves coping with good and bad days, which are directly related to periods of remission and exacerbation of the disease, considering that the active period causes a negative perception of daily life due to the difficulties, limitations and complications imposed. On the other hand, the coexistence time favors clinical management, the acceptance process, overcoming and the possibility of better days. Thus, this study evidences the importance of professional, social and family support to the person with SLE, which can positively contribute to everyday life.

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NOTES

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There is no conflict of interests.

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