

LIFE EXPERIENCES WITH SYSTEMIC LUPUS ERYTHEMATOSUS AS REPORTED IN OUTPATIENTS' PERSPECTIVE: A CLINICAL-QUALITATIVE STUDY IN BRAZIL¹

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This study aimed to know lupus outpatients' life experiences, in terms of the meanings they attributed to several phenomena associated to the process of becoming ill. Systemic Lupus Erythematosus is a chronic inflammatory disease, probably caused by a combination of inborn/hereditary predispositions and environmental factors, which leads to an abnormal stimulation of the immune system. Lupus life experience is associated to important psychosocial adaptation mechanisms of affected people. This work had a clinical-qualitative design and was performed in the dermatology service of a Brazilian General Hospital. The method included purposive sample, and a semistructured interview with open-ended questions was applied. After categorizing the interviewees' discourse, the discussion employed psychodynamic theories. The patients' reactions included the attempt to rebuild their relationships with their own strengths. Lupus patients' familiar and interpersonal conflicts seem to be associated with the idea that family and friends do not understand the nature of the disease.

DESCRIPTORS: lupus; adaptation, psychological; interview, psychological; skin and connective tissue diseases; self concept; qualitative research; psychosomatic medicine; chronic disease

VIVENCIAS CON LUPUS ERITEMATOSO SISTÉMICO COMO RELATADAS EN LA PERSPECTIVA DE PACIENTES AMBULATORIALES: UN ESTUDIO CLÍNICO-CUALITATIVO EN BRASIL

Este estudio objetivó conocer vivencias de pacientes ambulatoriales con lupus, en términos de los significados que atribuyeron a varios fenómenos asociados al proceso de adolecer. Lupus Eritematoso Sistémico es una enfermedad inflamatoria crónica y su causa es probablemente una combinación de predisposiciones congénitas/hereditarias y de factores ambientales, que conducen a un estímulo anormal del sistema inmune. La vivencia del Lupus se asocia a importantes mecanismos psicossociales de adaptación. Este trabajo ha tenido diseño clínico-cualitativo, realizado en un servicio de dermatología de un hospital general brasileño. El método incluyó muestra proposital y una entrevista semidirigida con preguntas abiertas fue aplicada. Después de categorizar los discursos de los entrevistados, la discusión empleó teorías psicodinámicas. Las reacciones de los pacientes abarcaron la tentativa de reconstruir las relaciones con sus propias fuerzas. Sus conflictos familiares e interpersonales parecen ser asociados a la idea de que la familia y amigos no entienden la naturaleza de la enfermedad.

DESCRIPTORES: lupus eritematoso sistémico; adaptación psicológica; entrevista psicológica; enfermedades de la piel y tejido conjuntivo; autoimagen; investigación cualitativa; medicina psicossomática; enfermedad crónica

EXPERIÊNCIAS DE VIDA COM LUPUS ERITEMATOSO SISTÊMICO COMO RELATADAS NA PERSPECTIVA DE PACIENTES AMBULATORIAIS NO BRASIL: UM ESTUDO CLÍNICO-CUALITATIVO

Este estudo objetivou conhecer vivências de pacientes ambulatoriais com lúpus, nos termos dos significados que atribuíam aos vários fenômenos associados ao processo de adoecer. O Lúpus Eritematoso Sistémico é uma doença inflamatória crônica e sua causa é provavelmente uma combinação de predisposições congénitas/hereditárias e fatores ambientais, que conduzem a um estímulo anormal do sistema imune. A vivência do Lúpus está associada a importantes mecanismos de adaptação psicossocial das pessoas acometidas. Este trabalho teve um desenho clínico-qualitativo, realizado no serviço de dermatologia de um hospital geral brasileiro. O método incluiu amostra proposital e foi aplicada uma entrevista semidirigida de perguntas abertas. Após categorizar as falas dos entrevistados, a discussão empregou teorias psicodinâmicas. Concluiu-se que reações dos pacientes incluíam a tentativa de reconstruir os relacionamentos com suas próprias forças. Conflitos familiares e interpessoais destes pacientes parecem estar associados com a idéia de que a família e amigos não compreendem a natureza da doença.

DESCRIPTORES: lupus eritematoso sistémico; adaptação psicológica; entrevista psicológica; doenças da pele e do tecido conjuntivo; auto-imagem; pesquisa qualitativa; medicina psicossomática; doença crônica

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INTRODUCTION

The great imitator's clinical aspects

According to the International Statistical Classification of Diseases and Related Health Problems, in its 10th Revision (ICD-10), Systemic Lupus Erythematosus (SLE), frequently referred to simply as *lupus*, was nosographically conceived within the systemic connective tissue disorders⁽¹⁾. The American College of Rheumatology (ACR) remembers that SLE is called the *great imitator*, because its manifestations vary so widely that it is often erroneously confounded with other disorders, being an important clinical condition that affects several organs: skin, joints, kidneys, lungs, nervous system, and others⁽²⁾. Although Lupus can be a fatal health problem, nowadays, medicine brings us both better expectations, because several therapeutic possibilities are available, and, therefore, better quality-of-life for these patients. SLE is described as a *chronic inflammatory disease*, whose clinical course varies from mild to severe, with alternating periods of remission and relapse.

Lupus affects ten times *more women than men* (in their twenties and thirties and particularly African-Americans and Asians), its treatment varies according to the type and severity of symptoms, and its complex nature requires *the patient's active participation* to maintain a satisfactory health level⁽²⁾. The character of lupus is autoimmune, i.e., the own immune system attacks the individuals' own tissues (*loss of self-tolerance*), representing an *astonishment phenomenon* of Nature: a production of "auto-antibodies" occurs and other immune system cells join the fight, provoking both inflammations (such as vasculitis) and depositions that lead to tissue damage.

The cause is probably a combination of both inborn/hereditary predispositions and environmental factors (biological or physical agents). Nevertheless, ACR mentions that later investigations have suggested that the affection may happen due to a defect in clearing the old and damaged cells from the body, which would then cause an abnormal stimulation of the immune system. It is observed that doctors should diagnose the disease through indicative anamnestic data, confirmed by a series of blood tests. However, unfortunately, due to the great variety of symptoms and their gradual development, lupus is hardly ever recognized. There are no specific epidemiological

studies on lupus in Brazil but, if similar to frequencies in the USA, we should have between 16.000 and 80.000 lupus cases in our population⁽³⁾.

A disease that requires multiprofessional care

Beyond both the so-called conservative treatment and more aggressive therapy, care for lupus patients must also include the management of this disease's *broader health impact* in the affected people's psychological and social life. Clinicians themselves allude that living with lupus surely means learning to deal with a chronic disease that can limit activities, due to fatigue and joint pains, as well as leading with depression, loss of hope, irritability and anger, due to a certain unpredictability of lupus and an occasional lack of response to treatment. Fatigue, particularly, does not seem to be caused by any recognizable factor of an inflammatory or immunological state, but could be a multifaceted phenomenon where several psychosocial factors are strongly related, indicating that fatigue is part of a complex response to chronic disease⁽⁴⁾.

Knowing the meanings ill persons attribute to several phenomena associated to lupus is indispensable to physicians, nurses and other health professionals with a view to offering truly efficacious recommendations. It could be pointless to give a set of medical orders, advices or warnings if the ill people do not place the disease in a central point on their personal value scale. In this sense, a *qualitative study* should always precede a global approach to a certain patient group. Only after interpreting what every symptom, manifestation in general, disease consequence, and limitation in general represent symbolically and existentially to the determined patient profile's psychological and sociocultural life, health professional can be more confident about the successful outcome of treatment.

This will enable clinicians to *better persuade* patients, for example, to maintain an active lifestyle that helps to keep joints flexible and may prevent cardiovascular complications, having them alternate light to moderate exercises with periods of rest or relaxation, in accordance with medical associations' determinations⁽²⁾. Detailed attention must also be given to *how to discuss* the disease with young patients who wish to become pregnant, guiding them to wait for a less active moment in the disease course to have a baby⁽⁵⁾.

Health professionals and patients frequently have different conceptual evaluations about a certain disease because they occupy different sociocultural loci in the clinical setting and bring different emotional demands. A quantitative study with lupus patients and physicians, about their eventual discordances on the assessment of lupus disease activity was performed. In this case study, the disagreement between both groups could have been a result from patients scoring their disease activity based on their psychological and physical well-being, whereas physicians score of the disease's activity was based on clinical and physical signs and symptoms of lupus⁽⁶⁾. As lupus is a serious and multiprofessional health problem, every clinical team member should use qualitative research results to follow lupus patients.

For instance, simultaneously to the role of the rheumatologist, who assumes the responsibility of caring for these patients, interacting with them and their family in order to provide health information, nurses should know how to integrate education, research, management, leadership, and consultation into their clinical roles⁽²⁾, demonstrating a high level of independence and clinical expertise in lupus management. Moreover, the availability of qualitative results can enable clinical psychologists to better assist the patient and family in managing emotional distress and facilitating to live with such painful, chronic, and sometimes disabling disease⁽²⁾.

In the same way, the physical therapist's function could achieve better progress, assisting patients in their recovery and re-entry into the community, home, and work environment, with a high level of self-sufficiency⁽²⁾, when this professional knows the profound psychodynamic and cultural meanings of lupus for patients. If the occupational therapist's mission consists of improving a patient's ability to develop daily activities satisfactorily⁽²⁾, this professional should naturally examine the psychosocial representations of being affected by lupus. Finally, the social worker's role should offer services ranging from several kinds of support to referrals to community resources, which can help to enhance adaptation to lupus conditions, taking into account information about these patients' symbolic understanding of their health problem⁽⁷⁾.

In which terms would lupus be a classical psychosomatic disorder?

In a traditional psychosomatic view and in a strict sense, SLE was considered a psychosomatic

disease, together with other collagen diseases (such as arthritis, polyarteritis, scleroderma, and rheumatoid arthritis). Then, some studies debated on the probable influence of emotions in the course of lupus, cogitated because of the known action of catecholamine in the immunologic complexes⁽⁸⁾.

The renowned Brazilian physician and psychoanalyst Julio de Mello Filho, who frequently discussed the *psychosomatic conception*, particularly attempted to apply this to the global understanding of lupus. According to studies carried out by this author, several overlapping emotional problems were detected in trigger mechanisms of lupus crises, with a predominance of so-called situations or experiences of loss. Nevertheless, these studies did not bring specific aspects. The conclusions suggested that problematic loss was a triggering agent of the disease. In general, this would occur due to the following factors: difficulties to the relational world of who had suffered the loss; ego's overload represented by the mourning process; depression effects that may be installed. Thus, situations of emotional impact could serve as the trigger for disease manifestation. However, this relationship must be proven statistically, with the employment of case-control studies⁽⁹⁾.

On the other hand, as has been well known since Franz Alexander and his contemporaries, the term *psychosomatic* has been subject to great criticism, as it suggests the old and undesirable idea of dichotomy between mind and body⁽¹⁰⁾. For the sake of clarification, we have resumed this question in the following points⁽¹¹⁾. Firstly, this term entails an *emphasis on a dichotomy*. The term, due to being composed by the roots "psych" and "soma", carries the connotation of a division, as if mind and body were two juxtaposed segments or elements; an idea to the taste of the dangerous Cartesian split and, thus, breaking the sense of unit that is desired for Man.

Secondly, *the idea of monodirectionality is embedded*. It implies that the psychosomatic questions would consist of problems "located" in the "soma", under the influence of or originated from characteristics or events in Man's psychic sphere; many people also use the word *somatopsychic*, which would indicate the opposite way. However, neither of both terms brings the idea of a simultaneous global manifestation in human beings. And third, *it induces to the conception of a tight individualization*. The term *psychosomatics* omits important semantic nuclei, which express other dimensions of Man, such as social and cultural ones, as if what we can understand for

both body and soul were constructs, understood independently of Man's relationship with the outer world (other persons, things), with which, actually, he/she lives in permanent contact and exchange.

Finally, we support that *psychosomatics* is both a *word* – before everything else – and has represented a great academic movement determined by historical and cultural factors. Actually, the so-called *psychosomatics* have made reflections and described facts – involving health professionals, researchers and all the population – constructed by *ideas and attitudes* – which attempt to comprehend the Man's global health problems – and that it is not a mere scientific discipline nor a branch of knowledge that would deal with intrinsic explicative mechanisms of the health-disease process.

In view of this picture, it becomes difficult to support the understanding of lupus as a psychosomatic entity, in the sense that it was intended to give to a certain set of diseases, decades ago. A determined characteristic personality of SLE is neither confirmed by literature, nor by daily clinical observation. Alexander himself pointed out that personality patterns “vary to such a degree among patients suffering from the same disease that, at best, one could speak only of certain more or less significant statistical frequencies (perhaps with some exception regarding the so-called coronary-prone personality). The fact that exceptions are so numerous in themselves indicates that most of these correlations are not truly causal in nature”⁽¹⁰⁾.

The imperious need to search for life adaptation

In a broad sense, human adaptation phenomena correspond to concepts that put up at least two delimitations in the psychosocial field. The sociological demarcation refers to group adaptation, understood as the person's capacity of adapting him/herself to interpersonal relationship settings. On the other hand, the psychological boundaries refer to unconscious mechanisms that one seeks internally to defend the ego from negative feelings in a satisfactory way. Actually, lupus is a biomedical problem involved in immunologic system disorders that, in turn, provokes the need to seek all possible types of psychosocial adaptation in its carrier.

Both increased depressive symptoms and distressed mood state in SLE patients have frequently been related to the use of disengaging and emotional

coping styles⁽¹²⁾. A quantitative study that tried to determine if changes in depressive symptoms or anxiety lead to changes in SLE activity observed that depression and anxiety scores accompany changes in patients' assessments of their lupus activity, but did not find evidence to support the hypothesis that psychological distress causes increased SLE activity⁽¹³⁾.

A quantitative study of personality features between adolescents with SLE and a control group, using the Rorschach test, demonstrated a greater difficulty both in interpersonal interactions and self-esteem referring to lupus patients, although they displayed the resources to elaborate the affects and cope with stressful situations⁽¹⁴⁾. Moreover, a cross-sectional study used structured questionnaires to determine the quality of life in SLE patients and correlate it with disease activity. This study found data demonstrating that physical and psychological quality-of-life is more impaired in active lupus, but also concluded that social and environmental quality-of-life does not correlate with the disease activity status in lupus patients⁽¹⁵⁾.

PREMISE AND OBJECTIVE

We depart from the hypothesis that SLE life experience, due to being a strongly disturbing event for patients' personality is functionally associated to this affected people's more important psychosocial adaptation mechanisms. From this idea, this research chose to study lupus outpatients' life experiences, in terms of the *meanings* they attributed to several phenomena associated to both their process of becoming ill and commonly used adaptation mechanisms, in order to *identify and interpret those meanings* from a psychological viewpoint.

METHODOLOGICAL ELEMENTS

We carried out a non-experimental and exploratory study. The research design was *clinical-qualitative*, in line with a humanistic health model, and attempted to give a scientific interpretation to the meanings presented by persons who were interviewed at health services – the ill people's natural setting. The delimitation of the subject led the authors to investigate lupus patients' *perspective* on the importance and severity of their chronic health

problem, in function of the psychological resources that mark their biographical lines. This preserved the *emic* strategy: the respect for the notion of "perspective", i.e., the faculty of seeing all relevant data in a meaningful relationship. Data were collected through *semidirected interviews with open-ended questions*, a suitable mode to assure the in-depth treatment of the matter with the interviewees. All interviews were tape-recorded and later transcribed.

For the sake of adequate sampling, we did not aim for statistical representativeness in relation to the universe of subjects affected by this disorder (as in a randomized study). Instead, we *looked intentionally* for patients, with a life experience that provides the expertise to reformulate, deflect, complement and/or clarify the premises⁽¹⁶⁾. In accordance with these methodological rules, we studied five persons during the first semester of 1998. This number corresponded to the *saturation point*, that is, the moment at which the sample was closed because discourse had become repetitive.

The studied cases came from an outpatient dermatology service at the General Hospital of the Federal University of Mato Grosso do Sul, a state in the Central-West of Brazil. The inclusion criteria for patient selection were: (a) diagnosis of SLE, confirmed by the respective medical team, known for at least one year; (b) clinical, emotional and intellectual conditions to be submitted to a clinical-psychological research interview; and (c) consent freely to participate in this research after explanation about its purpose and signing the respective term. Although patients' gender, age, origin, marital status, family composition, educational level, socioeconomic status, and religion were not considered, eventual variations in these data are presented in the discussion section for the appropriate treatment of any bias.

Interviews were submitted to *qualitative content analysis*, using free floating readings of the discourse to allow the researchers to get familiar with the material. When the categorization technique was finished, the framed topics were discussed according to a psychodynamic view, common in Health Psychology. It is known that, in the qualitative analysis of the text, the frequencies of the analysis units (or other forms of mathematical treatment) do not allow for inferences about its categories. Inductive reasoning is used to consider the phenomena's identification associated to interviewees' discourse, generating interpretations to be generalized to other settings by research users.

RESULTS AND DISCUSSION

Five patients were interviewed sequentially – four women and one man – who related several recent adverse event as well as negative relationship experiences in their lives while talking about their illness. They remembered the types of affective changes in the relation with parental figures, emphasizing complaints regarding to conflicts with the mother. They also lamented situations in which they perceived being rejected in familiar and social contexts. Particular importance was given to health professionals, who were considered incompetent due to the long time to arrive at a diagnosis.

Eventual correlations between these experiences or life events and lupus just could evidently be established through the use of quantitative methodologies, using case-control studies and random sampling. The repetitive complaints about their lives, during the interviews, seemed to be generically linked to the fact of experiencing chronic diseases with such variable manifestations and little predictable progress. However, with the specific goal of discussing the meanings of lupus, qualitative treatment of the interviews led to the establishment of three prominent categories: human experience of the disease, course of life with lupus and relations with the self-concept.

Human experience of the disease

As usually happens with any disease, people affected people by lupus learn to obtain secondary gains. Taking advantage of collagen disease chronicity, the interviewed individuals showed that they manipulated situations in order to gain profits, such as a demonstration of incontestable solidarity from their family circle. This life experience tends towards probable narcissistic needs, with an overvaluation of themselves. In view of such intense psychological demands, it is understandable that professional care is perceived as not enough to treat them or not even to heal them.

Toward the definitive diagnosis communication, the patients seemed to demonstrate feelings of omnipotence, in sense of thinking that they will not be reached by such illness in despite of they have already had the infirmity's traits. Notwithstanding any prognostic that they had received, they seemed to be prepared in any way:

I did not give any importance. I was eighteen years old. Then I let it go through (...) I continued doing the same things that as ever (...) It did not mean a big trouble, something that I could not surpass (E 3).

All the sample's interviewees stated, in any moment, that they would overcome the disease, as a psychological need of avoiding any fragility's self-perception. Even if they had considered themselves as being toward a popularly little known diagnosis, they supposed representing something severe due to a strong psychological load present in the doctor's voice. Therefore, they put themselves automatically to measure strength against this "powerful thing", looking for proofing their narcissistic power to themselves.

I think that I will pass through it (the lupus). I think that it is time for me to give back to the nature-mother the house that great architect had given. I will return to it without lupus, without any sign (E 2).

At first instants, a new disease for their lives represents something cloudy, without a recognizable identity, and so a phenomenon to which it is not known exactly what importance degree should have been done. In the majority of times, it happens due to the fact that lupus is a disease that, being relatively rare in the population, its representation does not inhabit the social imaginary. How can we frame the "stranger"? Toward this picture, a possibility emerges from a negligible objective behavior to the advised cares by doctors, such as avoiding sun exposition or using the medicines obediently.

Nonetheless, facing either the disease real crises or even the important isolated symptoms, such experiences become strongly valorized, and so the patients trend to assume a victims' role. In this case, the suffering regarding this disease may serve as a punishment due to not having accomplished previously the medical prescriptions. Different from the other socially well-known diseases, lupus allows unlike fantasies, since those from a powerful control over events until even over their personal life management.

The life course with lupus

After the appearance of the disease, regarding to these peoples' quotidian changes, they had the need to assert that their physical capacity became decreased, impeding them to keep the same previous life rhythm and generating the distressing conflict between a will of doing things and the its impossibility due to the physical limitations.

On the other hand, during the interlocution, there were some moments of spontaneous reference of having experienced, previously to the current illness, irritability phases accompanied by known sensation of people who seemed always to behave against them. Nowadays, however, they perceive that they deal with their daily problems with calm. In the light of health psychology, there are several possibilities that elapse from this situation. It is probable that, due to both the fact of people being aware about their disease and also the dramatic manner with which they express themselves, using hyperbolic language, they have obtained an interpersonal dealing in which other people speak to them with politeness. It would occur in function of the easiness with which these patients would feel victims. This vicissitude of things makes them feel important compensatorily, representing an emotional gain, overall for whom possibly did not have rewarding life experiences.

They also told that they started to be seen as diseased. They usually imagined that people had come close to them because these ones thought lupus patients could even die soon. Facing this perception, the interviewees demonstrated, paradoxically, suspicion for certain received attentions.

In fact, people treated me as a sick person. And there were many people who thought I was going to die. Upon my soul! People who tried sometimes to please me because they seemed to be convinced of my death.... In my view, it is not love (E 2).

A lament in common among interviewed patients referred to constant vigilance relating to infirmity's eminent crises. In an attempt to keep the disease remission, the necessity of controlling themselves becomes a concern that leads the patients to spend a continuous mental energy. This possibility makes SLE different from other chronic diseases, whose manifestations are always evident, but at the same time cruel: alternately their lives turn around an illness or its phantasm. On the other hand, existing such asymptomatic phases, the necessary healthcares tend to be neglected, in a culturally common posture of non-perseverance for secondary prevention measures. In this way, non-adherence problems emerge: they used to both deceive medical prescriptions and tend to seek the health professionals only in case of great clinical necessity. So, these ill persons can oscillate between the affliction and the carelessness:

You know that you would change, so you must search for having quite patience (E 3).

With lupus emergence, the received attention from both family and friends were redoubled evidently, but it does not discard the idea of that, at the bottom, there is not a significative solidary capacity among people. Although sick persons can distrust of people's sincere intention in helping them kindly, they started telling about their sufferings to whomever they meet, because of the emotional impact, which this disease achieves. Verbalizing about the suffering is not an exception for lupus patients. At last, it is difficult that the received support was enough to them in order to feel comforted.

(...) because I also have very dolorous happenings in my life. I think that it was what marked me more, when I got sick. Then, I did not have support; it lacked much support. Ones did not understand it and others did not strain to understand it for certain (E 1).

In terms of the affectivity, the interviewed persons perceive themselves as different ones, with some peculiar features. They tell that currently they are searching for sublimated affective relationships, from a psychodynamic standpoint, which is, they allege to want someone closer to them, but by preference not having a sexual involvement properly. They prefer proximity in the form of friendship and understanding, instead of a full conjugal involvement. On the one hand, this vital phenomenon can be or not directly related, in causal terms, to a problem provoked by a disease that both restricts corporal movements and leads to a lowering of self-esteem. On the other hand, however, the inhibition or the reduction of the sexual interest can be linked to the own female conditions, which occur commonly both in a certain age group and a in particular cultural context. So it would appear as a mechanism of rationalization in order to try to justify to themselves a not full sexuality:

You want attention, you want affection, you want to chat. Then when one comes already directly to search for sex, it offends, it sorrows, and it hurts. You know... this is my case (E 2).

In social and professional life, this disease was considered a representation of the universe restriction of relationships and activities, due to necessary medical precautions. Lupus represents something powerful, because it is not susceptible to a bigger domain, it is not localizable, it comes by surprise and it causes damage. It symbolizes, therefore, both the loss of a self-control ideal, as well as to feel naked, without defenses toward an evil, which has several faces. In this way, it is an enemy

against which it is not known what kind of weapon should be used. Facing this picture, the reclusion remains as the last defense of who see him/herself cornered. The ambiguity reveals that there is an (unhealthy) satisfaction for having been able to take refuge, but there is also a depression as a psychological reaction that seems to be inexorably an "exit".

The relations with the self-concept

It was dedicated a category to the self-concept question because lupus is a disease that can strongly influence how the patients look, how they feel and how they feel about how they look⁽¹⁷⁾. In the present study, the interviewees' reports coincide with the literature data, which point some features as being very much important for the indispensable rebuilt of their own concept or image. Particular lupus phenomena, such as eruptions on the skin, hair loss, and bloating due to anti-inflammatory treatments lead to the mental representation's unavoidable change regard to their body. New images that reflect the lupus patients in the mirror, day-to-day, can be unappeasable.

However, in a large sense, the corporal self-image is only a part of the global self-concept that marks an individual. According to the clinical experience, it is observed a complex phenomenon that comprehends feelings, conceptions, and mental representation one has of oneself. It is the picture of the own body and other personal fetatures, which a people forms, due to several reasons, in his/her own mind, along the life's course.

(...) sometimes, I then think: if I did not have lost almost ten years as a ill person, I would have made so many things, I would have finished my studies (E 2).

Patients and health professionals know that even in the absence of disease's manifestations, some symptoms, such as fatigue, may abandon who suffers to experience a less active life and invariably to be less able of having pleasures. Lupus' symptoms and signs can symbolize an insidious and imperceptible way of injuring or destroying the personal integrity. Self-concept and self-esteem walk together and these conditions must provoke a reality rereading. From this perspective, the interviewees remarked that their relationships with relatives, friends and all their world social expressed new significations to them.

CONCLUSIONS

Perceived as a multiple faced disease and due to be a medical disorder without a clear delimitation in the popular imaginary, the lupus is psychologically represented with some difficulty by the patients. With its so variable and wide manifestations, the lupus' meanings also vary and these ones can often and erroneously be confounded to other health disorders' meanings. Its indiscriminating character, in consequence marked by several affected organs, can leave the ill persons, at least initially, confused.

The patients' reactions include the attempt of identifying and rebuilding their relationships with their own strengths, but no ever successfully. The disease oscillations interfere with the treatment adherence and the medical prescriptions that may symbolize doubts. On the other hand, these features allow a more effective mechanism of denial than those of an acute illness, for example. To recognize a lupus identity it can spend much time, taking to a late

self-consciousness about its importance for deciding to preserve a good health. The lupus patients' familiar and interpersonal conflicts seem to be associated with the idea that family and friends do not understand the disease nature and the potential causes of fatigue and other indispositions.

Finally, it is recommended to recognize that poor self-esteem may symbolically represent the existential reality of being diseased, as well as a factual sign of clinical depression. Dissatisfaction with themselves, which is maintained with the illness, accompanied by loss of interest in things and even fantasies for death, might be investigated as a problem triggered by lupus chronic life experience in order to establish an adequate treatment.

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REFERENCES

1. World Health Organization [homepage on the Internet]. International Statistical Classification of Diseases and Related Health Problems, 10th Revision. [updated 2003 03 June; cited 2005 June 28]. Available from: <http://www3.who.int/icd/vol1htm2003/fr-icd.htm>.
2. American College of Rheumatology [homepage on the Internet]. Atlanta: Systemic Lupus Erythematosus. [updated May 2004; cited 2005 June 28]. Available from: http://www.rheumatology.org/public/factsheets/sle_new.asp?aud=pat.
3. Sociedade Brasileira de Reumatologia [Homepage na Internet]. São Paulo: A Sociedade. Outras Doenças – Lúpus Eritematoso Sistêmico [Acesso em 28 junho 2005]. Disponível em: <http://www.reumatologia.com.br/doe6.htm>.
4. Omdal R, Waterloo K, Koldingsnes W, Husby G, Mellgren SI. Fatigue in patients with systemic lupus erythematosus: the psychosocial aspects. *J Rheumatol*. 2003 February; 30(2):283-7.
5. Neri F, Chimini L, Filippini E, Motta M, Faden D, Tincani A. Pregnancy in patients with rheumatic diseases: psychological implication of a chronic disease and neuropsychological evaluation of the children. *Lupus*. 2004; 13(9):666-8.
6. Yen JC, Abrahamowicz M, Dobkin PL, Clarke AE, Battista RN, Fortin PR. Determinants of discordance between patients and physicians in their assessment of lupus disease activity. *J Rheumatol*. 2003 September; 30(9):1967-76.
7. Giffords ED. Understanding and managing systemic lupus erythematosus (SLE). *Soc Work Health Care*. 2003; 37(4):57-72.
8. Otto R, Mackay IR. Psycho-social and emotional disturbance in systemic lupus erythematosus. *Med J Aust*. 1967 September; 2(11):488-93.
9. Mello J Filho. *Concepção Psicossomática: Visão Atual*. 9a ed. São Paulo (SP): Casa do Psicólogo; 2002.
10. Alexander F. *Psychosomatic Medicine: Its Principles and Applications*. Reissue edition. New York: W W Norton; 1987.
11. Turato ER. *Tratado da metodologia da pesquisa clínico-qualitativa: construção teórico-epistemológica, discussão comparada e aplicação nas áreas da saúde e humanas*. 2a ed. Petrópolis (RJ): Vozes; 2003.
12. Kozora E, Ellison MC, Waxmonsky JA, Wamboldt FS, Patterson TL. Major life stress, coping styles, and social support in relation to psychological distress in patients with systemic lupus erythematosus. *Lupus*. 2005; 14(5):363-72.
13. Ward MM, Marx AS, Barry NN. Psychological distress and changes in the activity of systemic lupus erythematosus. *Rheumatology*. 2002 February; 41(2):184-8.
14. Santoantonio J, Yazigi L, Sato E. Adolescentes com Lúpus Eritematoso Sistêmico: um estudo por meio do método de Rorschach. *Psicologia: Teoria e Pesquisa*. 2004 Agosto; 20(2):145-51.
15. Khanna S, Pal H, Pandey RM, Handa R. The relationship between disease activity and quality of life in systemic lupus erythematosus. *Rheumatology*. 2004 December; 43(12):1536-40.
16. Turato ER. Qualitative and quantitative methods in health: definitions, differences and research subjects. *Rev Saude Publica*. 2005 June; 39(3):507-14.
17. Lupus Foundation of Minnesota [homepage on the Internet]. Bloomington: The Foundation. Education: Self Image and the Lupus Patient [cited 2005 June 28]. Available from: <http://www.lupusmn.org/Education/Articles/SelfImageandtheLupusPatient.htm>.