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The representation of getting ill in adolescents with systemic lupus erythematosus ☆

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ABSTRACT

Introduction: This study, developed in a federal hospital in the city of Rio de Janeiro, has aimed to analyze the social representation of chronic disease and its treatment, in the perspective of adolescents and their caregivers.

Methods: The sample consisted of 31 adolescents (11–21 years) with systemic lupus erythematosus and 19 caregivers (32–66 years), followed in the pediatrics and in the internal medicine outpatient clinics for a period of six months. Data was collected from the free association of words test, using *chronic disease* and *treatment of chronic disease* impulses, and later submitted to the Multiple Correspondence Analysis using the R software.

Results: The group of adolescents associated the impulse chronic disease with the words *medication*, *bad*, *illness*, *difficulty*, *no cure*, *faith* and *joy*; and in the group of caregivers, to *care*, *treatment*, *no cure* and the word 'no'. The impulse *treatment of chronic disease* was associated, in the group of adolescents, with the words *patience*, *improvement*, *help*, *affection*, *care* and *bad*; and in the group of caregivers, to *caring*, *hope*, *schedule*, *knowledge*, *obedience*, *medication*, *professional* and *improvement*. Caregivers also associated impulses and words according to age: *chronic disease* was associated with the word *care* (over 61 years), *pain* and *impotence* (42–61 years), *treatment* (22–41 years); and *treatment of chronic disease*, with the words *strength* (over 61 years), *professional*, *knowledge* and *improvement* (42–61 years), *affection* and *schedule* (22–41 years).

Conclusions: Considering as subjective and dynamic the experience of getting ill, knowing the representations can contribute to the orientation of conduct and type of psychotherapeutic intervention needed.

A representação do adoecer em adolescentes com lúpus eritematoso sistêmico

RESUMO

Introdução: Esse estudo, feito em um hospital federal na cidade do Rio de Janeiro, teve por objetivo analisar a representação social da doença crônica e de seu tratamento, na perspectiva de adolescentes e de seus cuidadores.

Métodos: A amostra consistiu de 31 adolescentes (11–21 anos) com lúpus eritematoso sistêmico e 19 cuidadores (32–66 anos), seguidos em serviços pediátricos e de clínica médica durante seis meses. Foram coletados dados com a aplicação do Teste de Associação Livre de Palavras, com o uso dos impulsos *doença crônica* e *tratamento da doença crônica*, mais tarde submetidos à Análise de Correspondência Múltipla com o uso do programa de computador R.

Resultados: O grupo de adolescentes associou o impulso *doença crônica* com as palavras *remédio*, *ruim*, *doença*, *dificuldade*, *sem cura*, *fé*, e *alegria*; e o grupo de cuidadores com as palavras *carinho*, *tratamento*, *sem cura*, e com a palavra "não". O impulso *tratamento da doença crônica* foi associado, no grupo de adolescentes, com as palavras *paciência*, *melhoria*, *ajuda*, *afeto*, *carinho* e *ruim*; e, no grupo dos cuidadores, com as palavras *carinho*, *esperança*, *horário*, *conhecimento*, *obediência*, *remédio*, *profissional* e *melhoria*. Os cuidadores também associaram os impulsos e palavras de acordo com a faixa etária: *doença crônica* foi associado à palavra *carinho* of sti (> 61 anos), *dor* e *impotência* (42–61 anos), *tratamento* (22–41 anos); e *tratamento da doença crônica* foi associado às palavras *força* (> 61 anos), *profissional*, *conhecimento* e *melhoria* (42–61 anos), *afeto* e *horário* (22–41 anos).

Conclusões: Considerando a experiência do adoecer como subjetiva e dinâmica, o conhecimento das representações pode contribuir para a orientação da conduta e tipo de intervenção psicoterapêutica necessária.

Introduction

The concept of health has been discussed over the years and, with the creation of the Unified Health System (SUS), health is now considered as a right of all citizens and a duty of the State (Health Organic Law n° 8080/1990, based on Article 198 of the Federal Constitution of 1988). With the increase in the debates prioritizing humanization, in 2004 the Ministry of Health regulated the National Humanization Policy (NHP), aiming to improve relations between professionals, users, hospital and community.[1]

Humanization appears as a transversal policy that intents to overcome the boundaries of the different knowledge and power in the production of health.[2]

With the proposal to humanize care and management practice, the NHP pervades the SUS network from a set of actions and mechanisms[3] – among which we must highlight the attention that refers to a mode of operation of work processes, ranging from the user's reception in the health system and full account of their needs, to the solving of the problem.[3,4]

Regarding the pillars of the attention, one can find the qualification of relations with extended listening and attention to user needs. That is, the attention appears as an intervention tool that involves concern for the quality and the kind of listening that is offered. Being able to hear and make oneself heard is essential so that one can bring up, on the health care scene,

two subjects and a mediator object (suffering, risks, dysfunction), and not a subject-professional and his/her object-user.[5]

Especially in a chronic illness situation – a condition in which the subject has to live with for the rest of his/her life[6] – becomes essential a practice based on the dialogical, interactive and caretaking dimension, where the subject is perceived as an active and co-responsible participant in the process of health production.[7,8]

Knowing the meanings of getting ill, from the study of social representations, may favor the listening ability of the professionals during the caring process, facilitate social communication and guide conducts.[9]

The concept of Social Representation (SR) was defined by Moscovici in his doctoral thesis entitled *La psychanalyse, son image et son public* (1961) and subsequently further developed by Jodelet (2001). Thus, SR would be "a socially developed and shared form of knowledge that contributes to the construction of a common reality to a particular social group".[10,11]

Several authors state that there is successive correspondence between the meanings that each person attributes to the facts in the world shared in common,[12,13] and that the social reality influences the way each person thinks and acts, including on the disease situation.[14–16] That is, the experience of the disease depends on what individuals and social groups understand by disease, and how to place themselves in face of it.[14,17,18]

From this perspective, it is considered that the analysis of the meanings of the disease can help to identify latent feelings

and perceptions of the subjects, in a scenario of getting ill and of care.

The chosen disease was systemic lupus erythematosus (SLE) – a chronic, multisystem inflammatory disease of unknown cause and autoimmune nature, characterized by the presence of autoantibodies,[19,20] and that can lead to physical and/or functional disability.[21,22] According to some studies, 24–59% of SLE patients may have neurological impairment and neuropsychiatric and psychofunctional syndromes.[19–21]

The inclusion of the environment and of social factors in the understanding of SLE patients was shown to be relevant, to the extent that there is a consensus in the scientific community about the multifactorial etiology of SLE, suggesting that this disease has hormonal, genetic, infectious, environmental and psychological causes.[20–23] For many investigators, this latter causation is associated as a major factor for the worsening of the disease.[20,23–25]

From the above, this study aimed to analyze the social representations of chronic disease and its treatment, in the perspective of adolescents and/or their caregivers, hoping to bring a contribution to the attention of adolescents with SLE.

Methods

This study was approved by the Research Ethics Committee of the Hospital Federal dos Servidores do Estado (HFSE) under the opinion n° 456,572.

Data collection was conducted from February to August 2014, in the pediatrics and internal medicine outpatient clinics and in the daycare hospital. All participants signed a consent form.

Inclusion and exclusion criteria

Adolescents aged 11–21 years diagnosed with a well-defined SLE, according to the *American College of Rheumatology* criteria and their caregivers were defined as participants. The classification criteria proposed in 1982 and revised in 1997 are based on at least four of eleven criteria: malar rash, discoid lesion, photosensitivity, oral and nasal ulcers, arthritis, serositis, renal impairment, neurological, hematological and immunological changes, and antinuclear antibodies.[25–28]

As inclusion criteria, only patients with disease duration of at least six months were considered.

Taking into account that different diseases have different impacts on the quality of life of affected individuals, as well as in the perception of the disease and getting ill, the adolescents who had other diseases, in addition to lupus, were excluded, apart from the fact that the type and the intensity of SLE manifestations imply larger or smaller doses of corticosteroids, and that this medication causes psychiatric disorders in the short term, in addition to various adverse effects in the long run, that may interfere in the search results.

The caregivers were not carriers of lupus or any other chronic disease, but their inclusion in the study was important, in order to be aware of the meanings attributed to the getting ill concept for these individuals, for the purpose of comparing the results between the two groups (adolescents and caregivers), considering that the family/cultural background can interfere with the significance process.[12,13]

The sample consisted of 31 adolescents and 19 caregivers (mother, father, grandparents), and the age and level of education were categorized. Age groups: 11–21 years relative to adolescents; over 61 years, 42–61 years and 22–41 years for caregivers. The level of education (LE) was: higher levels of education (over 12 years); high school (10–12 years); elementary school level II (6–9 years); and illiteracy/elementary school level I (0–5 years).

The group of adolescents aged 11–21 years was composed of 4 boys and 27 girls; and that of caregivers with 32–66 years old, 2 men and 17 women. The level of education (LE) varied in each group. The LE of adolescents was: higher level of education, 12.90%, high school, 64.52%, and elementary school II, 22.58%. The LE of caregivers was: higher level of education, 15.79%, high school, 31.58%, elementary school II, 21.05%, and illiteracy/elementary school I, 31.58%.

Our adolescents presented the following SLE classification criteria: discoid lesion, photosensitivity, arthritis, renal impairment, hematological changes, and immunological changes.

Data collection instrument

The tool used for data collection was the Free Association Words Test (FAWT), designed by Carl Jung (1905) in order to obtain the psychological diagnosis on the personality structure of individuals.[29] In 1981, this test was adapted to the field of Social Psychology by Di Giacomo, becoming widely used in studies on Social Representations. In these cases, in order to identify the latent dimensions of representations without filtering censorship in evocation, by setting an associative network between an inducing stimulus and evoked content.[30,31]

The test is performed from the enunciation of inducing stimuli, and analyzed subjects must quickly define words associated with stimuli presented. FAWT is based on a conceptual repertoire that allows unifying semantic universes and highlighting universes of common words, in the face of inducing stimuli and participants in the study.[29–33]

Application method

For a better definition of the inducing stimuli to be used, a pilot study stage was carried out, where we evaluated some stimuli-candidates. From this stage, our defined stimuli were: *chronic disease* (stimulus 1) and *treatment of chronic disease* (stimulus 2). With these stimuli, we considered that it would be possible to obtain the meanings given to the experience of chronic illness as well as to care.

Previously, an explanatory step was conducted, in order to clarify the functioning of the test and familiarize the respondent with the technique, using a fantasy-inducing stimulus and examples of associated responses: as stimuli, "football" and "sun"; and as illustrative answers, "goal," "emotion," "passion," "success," "fame" (stimulus 1) and "happiness," "life," "joy," "beach," "football" (stimulus 2). We emphasized the importance of a quick association, using only phrases or single words and avoiding complete sentences or more elaborate constructions.[30]

The test was administered individually in a private place, to avoid interference and ensure privacy during outpatient consultations in pediatrics and internal medicine outpatient clinic and in the day-care hospital when the adolescents should be receiving intravenous medication. The investigator, having in hand pen and paper, asked the subject to associate five words to each one of the stimuli contained in the questions, "*What comes to your mind when I say chronic disease?*"; and then, "*What comes to your mind when I say treatment of chronic disease?*".

Statistical analysis

The five responses to each stimulus and the personal characteristics of respondents gave rise to a multi-dimensional matrix, whose existing associations could give meaning to the feelings related to chronic illness.

The most common method of analysis used in the literature of social representations is the Multiple Correspondence Analysis (MCA), this being a multivariate technique that makes it possible to describe the associations found in the dimensions of a five-dimensional space on a two-dimensional graphical representation of the different existing interrelations between words or variables. In this case, ACM allowed us to analyze which expressions or words are associated, both for adolescents and caregivers, as well as associations with the variables[29] that, in this study, were age and level of education.

This technique, based on operations in the data matrix, defines proximity and opposition relationships between the words obtained for each stimulus, or with other active variables. The importance of each word or variable, in each of the dimensions or factors, is determined from its weight, called "load factor". The representation in the Cartesian axis of words and variables from these factor loadings and from oppositions and vicinities allows a search for an interpretation of the axes of each dimension related to the problem. With this analysis, one can also verify the levels of participation of the variables in terms of absolute contribution.

Statistical analysis was performed using the FactomineR library, dedicated to the Exploratory Multivariate Analysis of Data[34] of the program R (free software), a tool widely used in statistics.

Results

The words evoked by the test were grouped taking into account semantic similarities and synonyms (by consultation of a dictionary of the Portuguese language)[35] in the singular form of the noun, and with the verb in the infinitive. The words would be retained when appearing with a certain frequency,[29] and in this study words mentioned three or more times were considered. This was done for both groups and for each stimulus, resulting in a final composition of four word lists.

A database was generated for each group and for each stimulus, composed by age, gender, level of education and the five evoked responses.

In the face of the stimulus *chronic disease*, adolescents evoked 147 words, of which 92 were retained (14 different), while caregivers evoked 87 words, of which 57 were retained (9
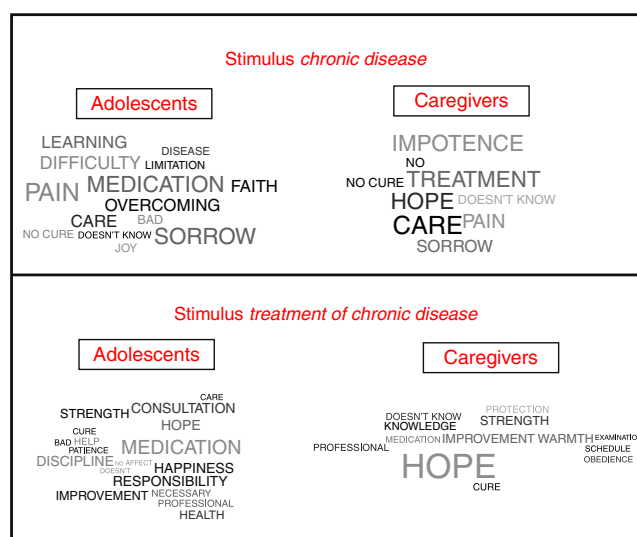

Fig. 1 – Cloud of words in the facemuli 1 and 2.
Source: **http://www.wordle.net/create**.

different). In the face of the stimulus *treatment of chronic disease*, adolescents evoked 148 words, of which 107 were retained (18 different), while caregivers evoked 94 words, of which 70 were retained (13 different). To represent the word frequency, we used a cloud of words produced by an application software available at the site http://www.wordle.net/create.[36]

In the cloud of words, the font size is associated with word frequency. The larger the size of the word, the more often the word was evoked in association with the stimulus. In the clouds, only the words retained (frequency equal to, or greater than, three occurrences) appear, and the different shades or colors are empty of meaning, serving only to facilitate the visualization of words retained (Fig. 1).

From the clouds of words produced by the group of adolescents, there was an association between the stimulus *chronic disease* and the words (in descending order): *sadness* and *pain* (to a greater degree), *medication, difficulty, learning, no cure, care, disease, limitation, faith, joy, bad*; and some adolescents did not know how to nominate. In the face of the stimulus *treatment of chronic disease*, associations emerged with the words (in descending order): *medication* and *strength* (to a greater degree), *hope, improvement, consultation, discipline, joy, responsibility, health, needed, professional, help, care, cure*, the word "no", *patience, bad*, and *affection*.

The clouds of words produced by the group of caregivers illustrated an association between the stimulus *chronic disease* and the words (in descending order): *impotence, treatment, care, pain, hope, sadness, no cure*, the word "no"; and some did not know how to nominate. The stimulus *treatment of chronic disease* appeared associated with the words (in descending order): *hope* (high frequency), *care, improvement, strength, medication, knowledge, schedule, professional, cure, examination, obedience, protection* (sun); and some did not know how to nominate.

In the analysis of MCA results obtained from the first stimulus in the group of adolescents, factors 1 and 2 were selected which, together, explained 21.08% of the variance structure of data.
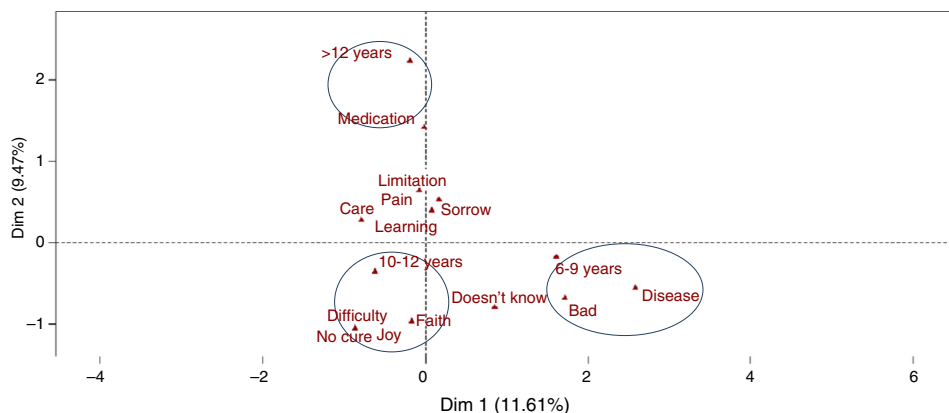
Fig. 2 – Multiple Correspondence Analysis (MCA) – Adolescent group: Stimulus "chronic disease".
Source: software R.

In the visual representation of this result, it was possible to perceive that the adolescents with higher levels of education (above 12 years of study) associated *chronic disease* with the word *medication*; those with high school level (10–12 years of schooling) with the words *difficulty*, *no cure*, *faith*, and *joy*; and those with elementary level II (6–9 years of study) with the words *bad* and *disease* (Fig. 2).

In the analysis of MCA results from the first stimulus in the group of caregivers, factors 1 and 3, which together explained 27.48% of the variance structure of the data, were selected.

In the visual representation of this result, an association between certain words, age and level of education was noted. Older caregivers associated *chronic disease* with the word *care*, while the younger ones with the word *treatment*. As to the associations according to the level of education, it was observed that caregivers with high school level (10–12 years of schooling) associated *chronic disease* with the words *treatment* and *no cure*; those with elementary school II (6–9 years of study), to the word "no"; and those with illiteracy/elementary school level I (0–5 years of study) caregivers, with the word *care* (Fig. 3).

In the analysis of MCA results obtained from the second stimulus, the factors 1 and 2 were selected to report in both groups; these factors explained 15.48% of the variability
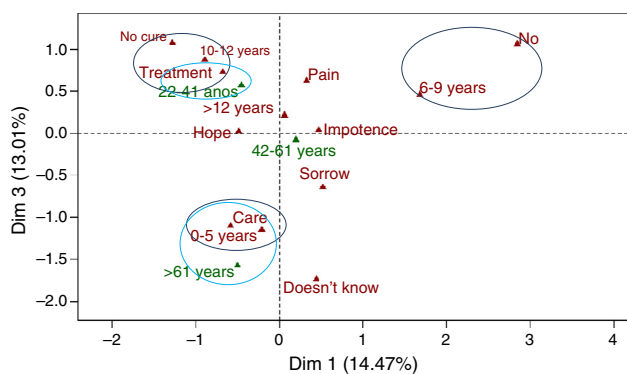

Fig. 3 – Multiple Correspondence Analysis (MCA) – Caregiver group: Stimulus "chronic disease".
Source: software R.

structure of the data obtained in the group of adolescents, and 20.04% in the group of caregivers.

In the visual representation of the result of MCA obtained from the second stimulus in the group of adolescents, a correlation was noted between words and level of education.
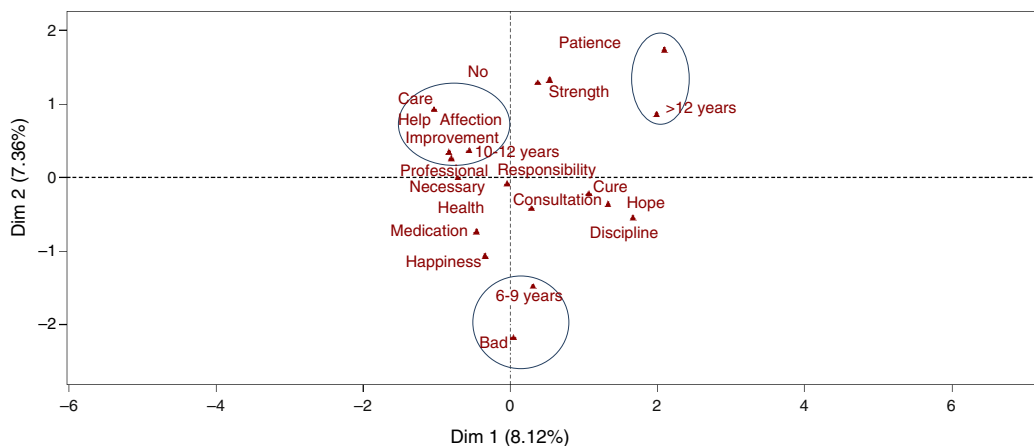

Fig. 4 – Multiple Correspondence Analysis (MCA) – Adolescent group: Stimulus "treatment of chronic disease".
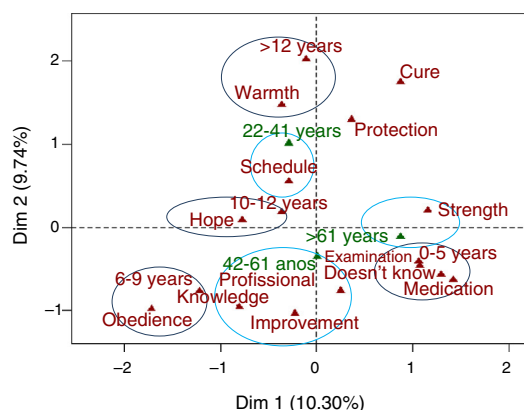*Source*: software R.

Fig. 5 – Multiple Correspondence Analysis (MCA) – Caregiver group: Stimulus "treatment of chronic disease". *Source*: software R.

Adolescents with higher levels of education (above 12 years of study) associated *treatment of chronic disease* with the word *patience*; those with high school education (10–12 years of schooling) with the words *improvement*, *help*, *affection* and *care*; and those with elementary school level II (6–9 years of study) with the word *bad* (Fig. 4).

In the visual representation of the result of MCA obtained from the second stimulus in the group of caregivers, we noticed an association between words, age and level of education. Older caregivers (above 61 years) associated *treatment of chronic disease* with the word *strength*; those aged 42–61 years, with the words *professional*, *knowledge* and *improvement*; and those younger ones (22–41 years), with the word *schedule*. Caregivers with higher levels of education (above 12 years of study) associated *treatment* with the word *care*; those with high school level (10–12 years of schooling) with the word *hope*; those with elementary school level II (6–9 years of study) with the words *knowledge* and *obedience*; and those with illiteracy/elementary school level I (0–5 years of study) with the words *medication* and "Don't know" (Fig. 5).

Discussion and conclusion

The birth of a child is always full of desires, dreams, expectations and meanings – basic hallmarks of its subjectivity, based on the initial mother–baby bond.[37] Although the actual son never matches the imaginary child because this is always idealized, the birth of a child with a disability or illness can affect the mother–child relationship, confirming the mother's fantasies in her ability to beget or not beget a "perfect child".[37–39]

Having a child with a chronic health condition causes changes in family routine and can reflect on family dynamics[13] and also causes an impact on everyday life.[15] A study of maternal representations about the birth of a child with severe organic disease shows that the speech of mothers about their children begins with the health problem of the child, as if they did not find another possibility of symbolization about their child than the disease.[37] For all these reasons, we believe that the inclusion of caregivers – those responsible for the treatment of the adolescent – in this study is important,

and the knowledge of their perception of the disease and of the care offered, and if there is similarity between the meanings assigned by the two groups.

Chronic disease, especially when it occurs in children or adolescents, affects all parties involved (patient, family, professionals) through multiple factors: difficulties and limitations arising from the disease itself, treatment for life, suffering in the face of the social stigma,[13] the narcissistic wound stemming from not having a perfect child,[40,41] economic issues (from the cost of treatment to the education and integration in the labor market),[42] among others.

The psycho-emotional aspect is always present at different levels and times, not just in "psychosomatic" diseases where the emotional aspect comes as a triggering factor, but in the very condition of being ill. Although SLE display an evolution typically marked by periods of remission and exacerbation, suffering the impact of several factors, some authors identify the onset of the disease after situations of "stress" and worsening of clinical activity, preceded by everyday stressors related to interpersonal relationships.[43,44] Others note the influence of emotions and of the environment in the immunity and physical condition of the patients.[45]

Since the experience of getting ill depends on what the person means by disease,[18] and given that the meanings attributed to the facts are influenced by the socio-cultural environment,[14,16,18] we have tried to analyze the social representations of adolescents with lupus and of their caregivers in relation to chronic illness and to treatment, by means of an associative network of words.

From the lists of words produced, we observed antagonistic feelings and perceptions, although some evocations were similar between the two groups.

The associations made by the adolescents in this study, when faced with the two stimuli, illustrated evocations of pain and, at the same time, of the need to fight: sadness, difficulty, overcoming, faith, joy, strength, hope, patience – pointing to the importance of support (family, friends, professionals) in fighting the disease. In their evocations, the adolescents recognized the importance of treatment for the improvement of the disease (*medication*, *consultation*, *discipline*, *responsibility*, *necessary*, *patience*), emphasizing the figure of the professional and of care.

The associations perceived in the clouds of words evoked by caregivers showed the same antagonism: on the one hand, words such as *pain*, *impotence*, *sadness*, *no cure*; and on the other, words like *hope*, *care*, *strength*. The words *medication*, *schedule*, *knowledge*, *obedience*, and the figure of the professional were also evoked, pointing to the importance of treatment adherence and commitment.

Words common to both groups emerged, corroborating the findings of some authors about the influence of the environment in the process of signification in a disease situation[14,16,18]: the stimulus *chronic disease* associated with the words *care/treatment*, *pain*, *sorrow*, *limitation/impotence*; and the stimulus *treatment of chronic disease* associated with the words *strength*, *medication*, *improvement*.

The results of our correspondence analysis in the group of caregivers differed among age groups, probably thanks to the interference of background and experiences with the process of signification. For caregivers, *chronic disease* was associated

with the words *care* (over 61 years), *pain* and *impotence* (42–61 years), and *treatment* (22–41 years). The entailment of *chronic disease* to *care/treatment* points to the perception of a situation that requires a continuous monitoring.[6]

The stimulus *chronic disease treatment* was associated by caregivers with the words: *strength* (over 61 years); *professional, knowledge* and *improvement* (42–61 years); and *affection* and *schedule* (22–41 years). That is to say, the caregivers not only entailed the disease to care, but brought into this scenario the figure of the professional and affections – affection and strength.

It was observed that in the face of the two stimuli, different associations emerged from the level of education in both groups, adolescents associated *chronic disease* with the words: *medication* (over 12 years); *difficulty, no cure, faith*, and *joy* (10–12 years); *bad* and *disease* (6–9 years), while caregivers associated *chronic disease* with the words: *treatment, no cure*, and the word "no" (10–12 years of schooling); and *care* (0–5 years of schooling).

Although some studies show that patients with SLE have a significant rate indicative of psychiatric disorder (anxiety, irritability, depression),[25] the results of our study showed ambivalent feelings and perceptions of adolescents with SLE, relative to the stimulus *chronic disease*: evocations expressing negative and positive feelings, enhancement of therapeutic possibilities, and exaltation of faith in this confrontation. If, on the one hand, these findings brought a poor prognosis for the disease (*difficulty-bad-no cure*), the fact that the disease is treatable (*joy-medication*) prevailed.

Caregivers, despite underscoring the importance of treatment and care, associated *chronic disease* to *pain, impotence*, and *no cure*, perhaps thanks to the burden of responsibility on these individuals, for their responsibility for the treatment of the child, in addition to the concern about the future of the teenager who often have his/her school life disrupted due to constant comings and goings to the hospital.[42]

In general, treatment was seen positively (*improvement, hope, help*), with active participation of the patient (*knowledge, obedience, schedule, medication*). And participants with higher levels of education brought, in common, the valuation of the disease being treatable, the perception of treatment outcome, and feelings of hope and affection in this confrontation. That is, the level of education seems to interfere with the process of signification, in promoting the expansion of the world view, the perception of the limits and possibilities – a result that corroborates the findings of other authors about the experiences, which are individual; but the meanings are influenced by family and sociocultural environment.[14,16–18,46]

The inclusion of the figure of the professionals in the therapeutic scene calls for a reflection on the messages they transmit in the consultations: How can they interfere by offering, or not offering support, strength, care and transmission of information?

In line with some authors, our study shows that the analysis of representations can contribute to extend the ability of listening and the interpretation of the statements and demands of patients,[47] by providing access to the latent meanings of chronic illness. This methodology not only favors the occurrence of a qualified listening to the needs of patients and caregivers, but brings subsidies to actions that offer

psychological support, in order to help the patient's adaptation to SLE, reducing his/her pain and worsening of the disease, improving depression and anxiety, and also the patient's self-esteem and quality of life.[48,49]

Some limitations of the study occurred by lack of sociodemographic characteristics, considering that the patient's housing location produce interesting social and economic data, and the lack of data on the administration and dose of medications used, which could perhaps interfere with the representation of illness by the adolescents, as these are patients with heterogeneous treatments and with adverse events, especially in children and adolescents.

However, the meanings that the person uses to explain the disease provide partial and unfinished pictures, because the reality is dynamic and the experience rather complex.[15] Further studies are required to elucidate various issues, to the extent that there is a range of factors that may interfere with the process of signification.

Conflicts of interest

The authors declare no conflicts of interest.

REFERENCES

1. Brasil. HumanizaSUS: Política Nacional de Humanização: a humanização como eixo norteador das práticas de atenção e gestão em todas as instâncias do SUS. Brasília: Secretaria Executiva, Ministério da Saúde; 2004.
2. Souza WS, Moreira MCN. A temática da humanização na saúde: alguns apontamentos para debate. Interface – Comunicação, Saúde, Educação. 2008;12:327–38.
3. Brehmer LCF, Verdi M. Acolhimento na atenção básica: reflexões éticas sobre a atenção à saúde dos usuários. Ciência Saúde Coletiva. 2010;15:3569–78.
4. Ayres JRCM. Cuidado e humanização das práticas de saúde. In: Deslandes SF, editor. Humanização dos cuidados em saúde: conceitos, dilemas e práticas. Rio de Janeiro: Fiocruz; 2006. p. 49–83.
5. Franco TB, Bueno W, Merhy EE. O acolhimento e os processos de trabalho em saúde: o caso de Betim, Minas Gerais, Brasil. Cad Saude Publ. 1999;15:345–53.
6. Canesqui AM. Olhares socioantropológicos sobre os adoecidos crônicos. São Paulo: Hucitec/Fapesp; 2007.
7. Kleinmam A. The illness narratives: suffering, healing and the human condition. New York: Basic Books Inc.; 1988.
8. Bury M. Illness narrative: fact or fiction? Sociol Health Illn. 2001;23:263–85.
9. Minayo MCS, Assis SG, Souza ER, Njaine K, Deslandes SF, Silva CMFP, et al. Fala galera: juventude, violência e cidadania na cidade do Rio de Janeiro. Rio de Janeiro: Garamond; 1999.
10. Moscovic S. A representação social da psicanálise. Rio de Janeiro: Zahar; 1978.
11. Jodelet D. Representações sociais: um domínio em expansão. In: Jodelet D, editor. As representações sociais. Rio de Janeiro: Eduerj; 2001. p. 17–44.
12. Berger P, Luckmann T. A construção social da realidade: tratado de sociologia do conhecimento. Petrópolis: Vozes; 2006.
13. Bastos OM, Deslandes SFA. Experiência de ter um filho com deficiência mental: narrativas de mães. Cad Saúde Públ. 2008;24:2141–50.

14. Atkinson S. Anthropology in research on the quality of health services. Cad Saúde Públ. 1993;9:283–99.

15. Lira GV, Nations MK, Catrib AMF. Cronicidade e cuidados em saúde: o que a antropologia da saúde tem nos ensinar? Texto Contexto Enferm. 2004;13:147–55.

16. Estevam ID, Coutinho MPL, Araújo LF. Os desafios da prática socioeducativa de privação de liberdade em adolescentes em conflito com a lei: ressocialização ou exclusão social? Rev Psico Porto Alegre. 2009;40:64–72.

17. Oliveira FA. Antropologia nos serviços de saúde: integralidade, cultura e comunicação. Interface – Comun, Saúde, Educ. 2002;6:63–74.

18. Gomes R, Mendonça EA. A representação e a experiência da doença: princípios para a pesquisa qualitativa em saúde. In: Minayo MCS, Deslandes SF, editors. Caminhos do pensamento: epistemologia e método. Rio de Janeiro: Fiocruz; 2008. p. 109–32.

19. Sato EL, Bonfá ED, Costallat LTL, Silva NA, Brenol JCT, Santiago MB, et al. Consenso brasileiro para o tratamento do lúpus eritematoso sistêmico. Rev Bras Reumatol. 2002;42: 362–70.

20. Ayache DCG, Costa IP. Alterações da personalidade no lúpus eritematoso sistêmico. Rev Bras Reumatol. 2005;45:313–8.

21. Appenzeller S, Costallat LTL. Comprometimento primário do sistema nervoso central no lúpus eritematoso sistêmico. Rev Bras Reumatol. 2003;43:20–5.

22. Borba EF, Latorre LC, Brenol JCT, Kayser C, Silva NA, Zimmermann AF, et al. Consenso de lúpus eritematoso sistêmico. Rev Bras Reumatol. 2008;48:196–207.

23. Freire EAM, Souto LM, Ciconelli RM. Medidas de avaliação em lúpus eritematoso sistêmico. Rev Bras Reumatol. 2011;51:70–80.

24. Miguel Filho EC [Tese de Doutorado] Alterações psicopatológicas no Lúpus Eritematoso Sistêmico. São Paulo: Universidade de São Paulo; 1992.

25. Melo LF, Da-Silva SL. Análise neuropsicológica de distúrbios cognitivos em pacientes com fibromialgia, artrite reumatoide e lúpus eritematoso sistêmico. Rev Bras Reumatol. 2012;52:175–88.

26. Tan EM, Cohen AS, Fries JF, Masi AT, McShane DJ, Rothfield NF, et al. The 1982 revised criteria for the classification of systemic lupus erythemathosus. Arthritis Rheum. 1982;25:1271–7.

27. Hochberg MC. Updating the American College of Rheumatology revised criteria for the classification of systemic lupus erythemathosus. Arthritis Rheum. 1997;40:1725.

28. Costallat LTL, Appenzeller S, Bértolo MB. Lúpus neuropsiquiátrico de acordo com a nova nomenclatura e definição de casos do colégio Americano de Reumatologia (ACR): análise de 527 pacientes. Rev Bras Reumatol. 2001;41:133–41.

29. Guerreiro MR, Curado MA. Picar… faz doer! Representações de dor na criança, em idade escolar, submetida a punção venosa. Rev Enfermeira Global Enero. 2012;25:75–91.

30. Nóbrega SM, Coutinho MPL. O teste de associação livre de palavras. In: Coutinho MPL, editor. Representações sociais: abordagem interdisciplinar. João Pessoa: Universitária UFPB; 2003. p. 67–77.

31. De Rosa AS. A rede associativa: uma técnica para captar a estrutura, os conteúdos e os índices de polaridade, neutralidade e estereotipia dos campos semânticos relacionados com as representações sociais. In: Moreira ASP, Jesuino BVCJC, Nóbrega SM, editors. Perspectivas teórico-metodológicas em representações sociais. João Pessoa: Universitária UFPB; 2005. p. 61–128.

32. Coutinho MPL. Depressão infantil: uma abordagem psicossocial. João Pessoa: Universitária UFPB; 2005.

33. Botêlho SM, Boery RNSO, Vilela ABA, Santos WS, Pinto LS, Ribeiro VM, et al. O cuidar materno diante do filho prematuro: um estudo das representações sociais. Rev Esc Enferm USP. 2012;46:929–34.

34. Lê S, Josse J, Husson F. FactoMineR: an R package for multivariate analysis. J Stat Softw. 2008;25:1–18.

35. Dicionário Editora da Língua Portuguesa. Coleção Dicionários Editora, Porto Editora, Edição 2014, ISBN 978-972-0-01866-3.

36. Nuvens de Palavras. Available in: http://www.wordle.net/create.

37. Battikha EC, Faria MCC, Kopelman BI. As representações maternas acerca do bebê que nasce com doenças orgânicas graves. Psicol: Teoria e Pesquisa. 2007;23:17–24.

38. Cullere-Crespin G. A clínica precoce: o nascimento do humano. São Paulo: Casa do Psicólogo; 2004.

39. Belini AEG, Fernandes FDM. Olhar e contato ocular: desenvolvimento típico e comparação na Síndrome de Down. Rev Soc Bras Fonoaudiol. 2008;13:52–9.

40. Freud S. Sobre o narcisismo: uma introdução. Edição Standard Brasileira das Obras Psicológicas Completas de Sigmund Freud, xiv. Rio de Janeiro: Imago; 1976. p. 103–8.

41. Martins BSO. O corpo-sujeito nas representações culturais da cegueira. Rev Psicol. 2009;21:5–22.

42. Resende OLC [Dissertação de Mestrado] O médico e a díade com doença ocular grave. Rio de Janeiro: Fundação Oswaldo Cruz; 2010.

43. Petri M. Systemic lupus erythematosus: clinical aspects. In: Koopman WJ, editor. Arthritis and allied conditions: a textbook of Rheumatology, 26, 14th ed. Lippincott Williams; 2000. p. 377–88.

44. Nery FG, Borba EF, Neto FL. Influência do estresse psicossocial no lúpus eritematoso sistêmico. Rev Bras Reumatol. 2004;44:355–61.

45. Solomon GF, Moos RH. Emotions, immunity, and disease; a speculative theoretical integration. Arch Gen Psychiatry. 1964;11:657–74.

46. Geertz C. A interpretação das culturas. Rio de Janeiro: Livros Técnicos e Científicos Editora; 1989.

47. Favoreto CAO, Cabral CC. Narrativas sobre o processo saúde-doença: experiências em grupos operativos de educação em saúde. Interface – Comunicação, Saúde, Educação. 2009;13:7–18.

48. Cal SF, Borges AP, Santiago MB. Prevalência e classificação da depressão em pacientes com lúpus eritematoso sistêmico atendidos em um serviço de referência da cidade de Salvador. J LIRNNE. 2006;2:36–42.

49. Cal SFLM. Revisão da Literatura sobre a eficácia da intervenção psicológica ao tratamento do lúpus eritematoso sistêmico. Rev Psicol Teoria Pesquisa. 2011;27:485–90.