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ORIGINAL ARTICLE

ACTIVITIES LIMITATION AND SOCIAL PARTICIPATION IN PATIENTS WITH HANSEN'S DISEASE

LIMITAÇÃO DE ATIVIDADES E PARTICIPAÇÃO SOCIAL EM PACIENTES COM HANSENÍASE LIMITACIÓN DE ACTIVIDADES Y PARTICIPACIÓN SOCIAL EN PACIENTES CON LEPROA

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ABSTRACT

Objective: to describe the changes that have taken place in daily life activities and in interpersonal relationships of people with Hansen's disease. **Methodology:** this is a descriptive and exploratory study, with quantitative nature, performed at the outpatient clinic for infectious and contagious diseases at the Giselda Trigueiro Hospital (GTH), Natal/RN, with 22 people with Hansen's disease (leprosy). We made use of a questionnaire and the SALSA and Participation scales for data collection, which were stored by means of Microsoft Excel 2010 and presented in tables and figures. The study project was approved by the Research Ethics Committee of the Onofre Lopes Hospital, under the CAAE nº 0017.0.051.000-08. **Results:** ten patients showed no limitations; 11 showed mild limitation and only one showed moderate limitation in its daily life activities. Regarding the social participation, only three of the interviewees had social restrictions. **Conclusion:** one can indicate the application of the SALSA and Participation scales in health care towards people with Hansen's disease. **Descriptors:** Hansen's Disease (Leprosy); International Classification of Disabilities; Nursing.

RESUMO

Objetivo: descrever as mudanças ocorridas nas atividades de vida diária e nos relacionamentos interpessoais da pessoa com hanseníase. **Metodologia:** estudo descritivo e exploratório, de caráter quantitativo, realizado no ambulatório de doenças infectocontagiosas no Hospital Giselda Trigueiro, Natal/RN, com 22 pessoas com hanseníase. Foi utilizado um questionário e as escalas SALSA e de Participação para a coleta de dados, que foram armazenados por meio do Microsoft Excel 2010 e apresentados em tabelas e figuras. Este estudo teve aprovado o projeto pelo Comitê de Ética em Pesquisa do Hospital Onofre Lopes, sob o CAAE nº 0017.0.051.000-08. **Resultados:** dez pacientes não apresentaram limitações; 11 apresentaram leve limitação e apenas um apresentou moderada limitação em suas atividades de vida diária. Em relação à participação social, apenas três dos entrevistados tiveram restrições sociais. **Conclusão:** indica-se a aplicação das Escalas SALSA e de participação na assistência à saúde às pessoas com hanseníase. **Descritores:** Hanseníase; Classificação Internacional de Incapacidades; Enfermagem.

RESUMEN

Objetivo: describir los cambios ocurridos en las actividades de la vida diaria y las relaciones interpersonales con personas con lepra. **Metodología:** estudio descriptivo, exploratorio, de carácter cuantitativo, realizado en la Clínica de las enfermedades infecciosas en el Hospital Giselda Trigueiro, Natal/RN con 22 personas con lepra. Fue utilizado un cuestionario y las escalas SALSA y de Participación para la colección los datos, que fueron almacenados a través de Microsoft Excel 2010 y presentados en tablas y figuras. Este estudio tuvo aprobado el proyecto por el Comité de Ética en Investigación, CAAE No 0017.0.051.000-08. **Resultados:** 10 pacientes no presentaron limitaciones, 11 presentaron leve limitación y sólo uno presentó limitación moderada en sus actividades de la vida diaria. En relación a la participación social, sólo tres de los encuestados tenían restricciones sociales. **Conclusión:** indica la aplicación de la SALSA y la participación en la asistencia a la salud de personas con lepra. **Descritores:** Lepra; Clasificación Internacional de Deficiencias; Enfermería.

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INTRODUCTION

Hansen's disease (leprosy) is an illness shrouded in taboos and symbolic beliefs, surrounded by a strong stigma throughout its history and that configured one of the most feared diseases of all times. It reveals a history marked by suffering, by the stamp of sin and guilt, by mutilation, by horror on the signs and symptoms and by rejection and isolation.¹

With regard to epidemiology, Hansen's disease has more prevalence in economically disadvantaged areas, where the population is exposed to predisposing factors such as inadequate nourishment, debilitating diseases and overpopulation. It represents a serious public health problem in Brazil, occupying the second place in detection of new cases of Hansen's disease in the world, second only to India. Furthermore, Brazil also is the only American country placed among the 17 countries with a detection rate ≥ 1.000 cases.²⁻³

Chronic infectious disease, caused by *Mycobacterium leprae*, or Hansen's bacillus, which is manifested by means of dermatological and neurological signs and symptoms, Hansen's disease has great potential to provoke physical disabilities that might even evolve to deformities.⁴ The *Mycobacterium leprae* is a compulsory intracellular parasite that has an average incubation period ranging from 2 to 7 years, being that the human being is its main reservoir. It has high infectivity, in other words, is capable to infect a large number of people; however, has low pathogenicity. Accordingly, few people become sick. Its tropism for the cells of the skin, of mucous membranes and of peripheral nerves is the main cause of disabilities resulted from this disease.⁴

The treatment of Hansen's disease is conducted on an outpatient basis, by using the scheme recommended by the World Health Organization, known as Multidrug Therapy (MDT) between 6 and 12 months on average, depending on the operational classification, as paucibacillary (≤ 5 injuries and negative skin smear) or as multibacillary (> 5 injuries and/or positive skin smear). Thus, it is a curable disease.^{2,4}

It is worth highlighting that, in addition to the treatment with MDT, it is necessary to have the accomplishment of activities of prevention, control and treatment of disabilities and deformities activities, since Hansen's disease is strongly influenced by psychosocial repercussions inherent to these

complications. It is understood that the process of illness in our society is usually, in most individuals, a limiting condition, which, in many moments, exposes the subject to some changes in its life. This condition might generate feelings of insecurity and hopelessness in the individual. That is why the issues such as disability, limitations of activities and restrictions of social participation are essential and must be considered as significant components of the health status of a person.^{1,5-8}

The disabling nature of Hansen's disease, its low pathogenicity and the stigma related to its process of illness are determining factors to size and identify the nature of the difficulties faced by individuals. For this purpose, the Brazilian Ministry of Health recommends the use of the evaluation records of disability, the simplified neurological evaluation and the screening, through the use of the SALSA Scale (Screening of Activity Limitation and Safety Awareness) and the Participation Scale, which are validated and are being applied in different regions. These questionnaires must preferably be applied at the beginning of the treatment, at discharge from the MDT and in the period of post-discharge monitoring.^{5,10}

The SALSA Scale was set up on the basis of the International Classification of Functioning, Disability and Health (ICF) and aims at evaluating the extent of activity limitation and the risk of increasing deficiencies during the accomplishment of activities in people affected by Hansen's disease, by diabetes and by other peripheral neuropathies. This is a questionnaire with questions relating to daily life activities (DLA), according to the following domains: mobility (feet), self-care, work (hands) and dexterity (hands). It generates a final score, ranging from 1 to 80, without cut-off points to define standards.^{5,10}

The low score of SALSA usually indicates little difficulty with daily life activities, while higher scores indicate increasing levels of activity limitation. Nevertheless, the score of awareness of risk, which is calculated separately, adding to the options marked with a circle, ranges between 0 and 11, by which the higher values indicate a growing awareness of risks involved in certain activities, but also indicate a greater activity limitation.^{5,10}

The SALSA score is correlated with the age, with the EHF Score (Eye - Hand - Foot) and with the participation score. The EHF score sizes the severity of impairment of physical disability, through the sum of the degree of disability according to each segment (eyes,

hands and feet), left and right, reaching a maximum value of 12.^{5,10}

The Participation Scale is characterized by being an instrument to size the restriction to social participation of people affected by Hansen’s disease, disabilities or other conditions creating stigma. The scale at stake is composed of 18 questions and includes the following domains: learning and application of knowledge; communication; mobility; self-care, domestic life, interpersonal interactions; main areas of life (work, education, employment, economic life, etc.); community, social and civic. Accordingly, it covers the domains listed by the ICF.¹¹

The final score of the scale ranges from 0 to 90, being that, up to 12 points, the individual is considered without restrictions; from 13 to 22 points, mild restriction; from 23 to 32 points, moderate restriction; from 33 to 52 points, great restriction; and from 52 to 90 points, extreme restriction.¹¹

In this context, this study has the following purpose:

- To describe the changes that have taken place in daily life activities and in interpersonal relationships of people with Hansen’s disease.

METHOD

The presented production is part of the results of the research project << *Social Representations of Hansen’s disease: the focus on the stigma in the mental health context* >>, which constituted an exploratory and descriptive research, with quantitative approach. It was performed at the outpatient clinic for infectious and contagious diseases at the Giselda Trigueiro Hospital (GTH), which is the reference unit in the care of patients with Hansen’s disease in the city of Natal, State of Rio Grande do Norte.

In the above mentioned outpatient clinic, people with Hansen’s disease or with sequels are monitored by a multidisciplinary team (dermatologists, physiotherapists, occupational therapists, nursing staff, among other professionals); they receive treatment with Multidrug Therapy (MDT) and for the reactions arising from the disease; they have access to several diagnostic and monitoring examinations for their illness (e.g.: skin smear, biopsy); their communicants are examined and, if necessary, treated; and also have at their disposal a self-help group.

The users are residents of the Metropolitan Region of Natal and of the hinterland of the state. As inclusion criteria, the following points were considered: person who is being

treated with MDT, the period of data collection (From July to September 2011), of both sexes, aged between 16 and 80 years old, classified as paucibacillary or multibacillary.

As for exclusion criteria, we have observed: having completed treatment with MDT and remain under monitoring, within the outpatient clinic, due to sequels or reactions resulting from Hansen’s disease; being a child or adolescent aged up to 15 years, 11 months and 29 days, being an elderly aged over 80 years; being bearer of other morbidities that impair their daily life activities and has no psychic condition to answer the interviews.

22 users were interviewed, representing about 45% of users with active registration in the reference unit and who underwent the treatment regularly. They were addressed at the time in which they arrived to receive supervised dose of MDT, with the help of the nursing staff, within the room intended for the Brazilian National Control Program of Hansen’s Disease (known by its Portuguese acronym PNCH).

In a reserved place, the users were informed about the research objectives and the steps of the interview. After reading the Free and Informed Consent Form (FICF) and appropriate authorization, the interviews were started, which were conducted in three steps: 1) Completion of the questionnaire of identification, through which the data were firstly collected by the information of the interviewee. Subsequently, we completed the information about characteristics of the disease introduced into the records; 2) Application of the SALSA Scale; 3) Application of the Participation Scale.

In order to ensure the privacy of the research participants, they were identified by fictitious names common in the Brazilian society, randomly chosen to not identify them with any specific group or character.

The data were processed by means of Microsoft Excel 2010, presented in tables and figures. The descriptive analysis was performed according to the literature.

The study project was approved by the Research Ethics Committee of the Onofre Lopes Hospital, belonging to the Federal University of Rio Grande do Norte, under the Protocol nº 147/08 project and CAAE nº 0017.0.051.000-08.

RESULTS

Of the 22 research subjects, 14 were male (64%) and eight were female (36%). The age group ranged from 50 to 60 years (36%) and

from 28 to 38 years (23%), with emphasis to three subjects under the age of 18 years. The majority (68%) was comprised of married people or people living in a stable relationship. Regarding the schooling level, one subject had no schooling; nine (41%) participants had incomplete Elementary School, five (23%) had completed Elementary School, six (28%) had incomplete or completed High School; and another subject was attending Higher Education.

The study population was, in its majority, keeping their professional activities; only four people were retired and one was unemployed. The family income was between one and two minimum wages and from three to four minimum wages in 59% (13) and 27% (6) of the interviewees, respectively.

Regarding the characteristics of the disease, 14 cases (64%) were classified as multibacillary (MB) and eight (36%) as paucibacillary (PB). The predominant clinical manifestation was the dimorphic form (borderline), with nine representatives, followed by the tuberculoid form, with eight representatives. The lepromatous form was

present in four of the subjects and one had no defined clinical form. The indeterminate form had no representative.

The application of the SALSA Scale was preceded by the completion of the information form about the customer, which is divided into questions of identification of the customer and registration of disabilities. Next, the Participation Scale was applied. Through the application of this form, it has been possible to identify the presence of other medical conditions concomitant to Hansen’s disease that could hamper the performance of daily life activities, such as carpal tunnel syndrome, diabetes, cataracts, disk Herniation, “bone disorders” and restrictions inherent to the age. The EHF Score was also calculated, ranging from 0 to 5 points, being shown in Table 1 below.

Regarding the use of adaptations/orthotics, only the use of glasses was mentioned, by eight people, of whom, one person showed changes in visual acuity resulting from Hansen’s disease. The absence of ulcers in any area of the body was unanimous among all patients.

Table 1. EHF Score of the study population

EHF Score	n	%
0	11	50%
1	4	18%
2	6	27%
3	0	0%
4	0	0%
5	1	5%
Total	22	100%

The SALSA Score ranged from 14 to 49 points. We have observed a little variation of scores among the interviewees. The punctuations with the highest number of individuals were the one of 17 and the one of 30 points, both with three subjects. The punctuations 22, 23 and 25 points were

represented by two participants for each and the others had only one subject who achieved the punctuation. Table 2 shows the ratio between the SALSA Score and the research subjects.

Table 2. SALSA Score of the study population

Escore SALSA	Sujeitos	
	n	%
14	1	5%
17	3	14%
18	1	5%
20	1	5%
22	2	9%
23	2	9%
25	2	9%
26	1	5%
27	1	5%
30	3	14%
33	1	5%
34	1	5%
35	1	5%
37	1	5%
49	1	5%

The combined analysis between the EHF Score and the SALSA Score (Figure 1) found that the ratio between these two scores shows no regularity, given that the two extremes of

the SALSA Score showed EHF Score equal to zero; and the subjects who showed score 30 showed EHF scores equal to 0, 2 and 5.

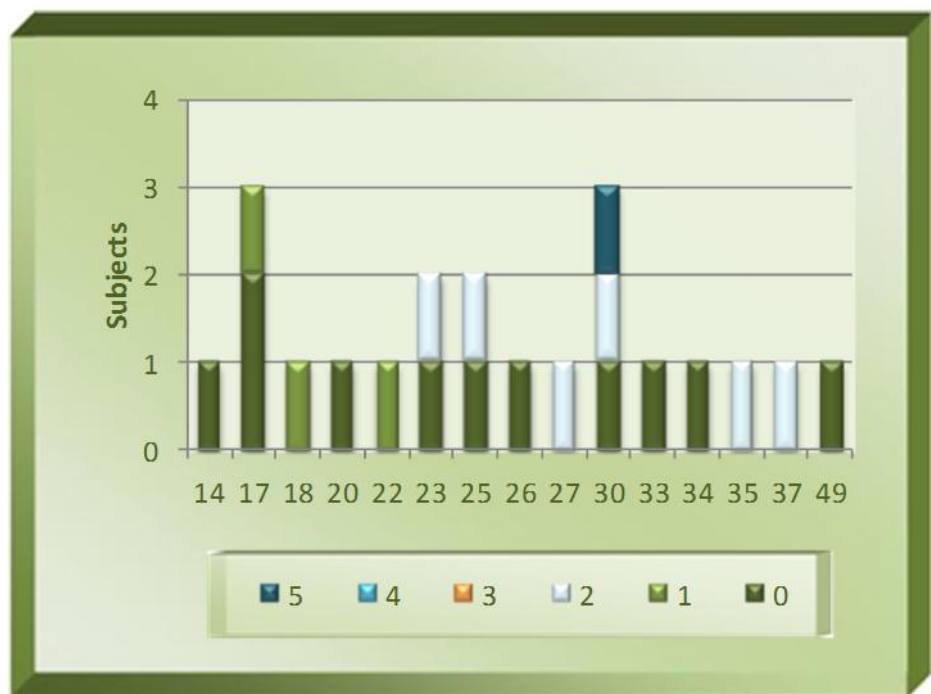


Figure 1. Combined analysis between the EHF Score and the SALSA Score

Regarding the Participation Scale, the majority showed no restrictions, only two had showed restriction and one subject had moderate restriction. In Figure 2, one can note that the subjects who showed mild restriction and moderate restriction also showed SALSA Score with punctuation greater than or equal to 30 points. In contrast, Figure 3, one can observe that the subjects who showed mild restriction and moderate restriction had EHF Score equal to zero and the other who showed mild restriction had EHF Score equal to 2 points.

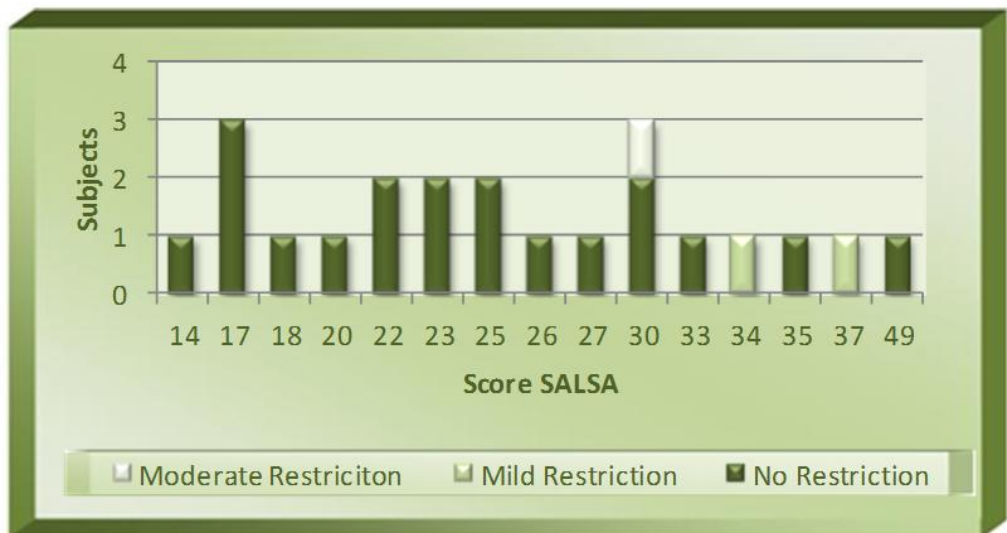


Figure 2. Combined analysis between the SALSA Score and the Participation Scale

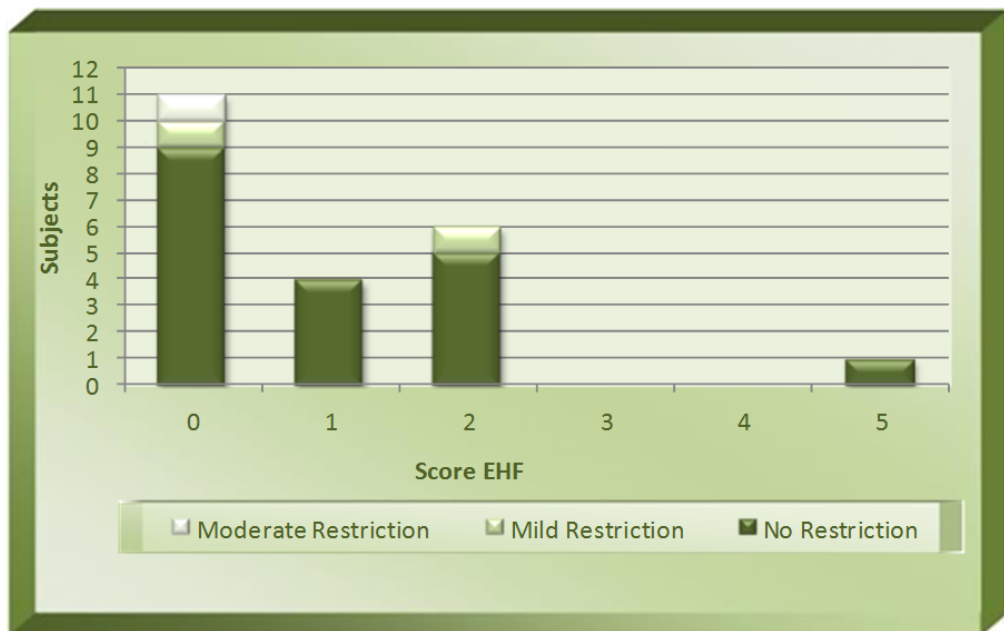


Figure 3. Combined analysis between the EHF Score and the Participation Scale

For didactic purposes, the collaborative group of the SALSA Scale suggests a categorization for the SALSA scores, namely: from 10 to 24 (without limitation); from 25 to 39 (mild limitation); from 40 to 49 (moderate limitation); from 50 to 59 (severe limitation) and from 60 to 80 (very severe limitation)¹¹. By following this categorization, it becomes easier to identify the actual limitations in daily life activities. Thus, in this study, one can verify that ten patients have no limitations; 11 patients show mild limitation and only one patient has moderate limitation in its daily life activities.

DISCUSSION

The SALSA and Participation scales were developed to evaluate the physical limitation and accomplishment of activities in patients with Hansen's disease, diabetes and other peripheral neuropathies, as well as the social restriction in patients with stigmatizing problems. The SALSA Scale is a questionnaire comprised of 20 items that might be administered within ten minutes and provides a standardized measure of limitations in daily life activities related to mobility, dexterity and self-care and of work. The Participation Scale is an instrument comprised of 18 items to measure how respondents rate their participation in comparison to a "peer", defined as "someone similar to the interviewee in all respects, except for the illness or disability."⁶

The study population showed, in its majority, the multibacillary forms, which are frequently responsible for the disabilities and deformities resulting from Hansen's disease, and it is relevant to have the analysis of the ratio between the physical disability and the scores of the scales.^{12,16} We have observed that ten subjects, with the multibacillary forms, showed scores ≥ 25 points in the SALSA Scale and that all those who showed any participation restriction had the most diffuse forms of the disease. In contrast, in this study and in others consulted, this ratio between the EHF scores and the SALSA and Participation scores does not meet the expectations of validation of the scales, because some participants showed unexpected behavior, as previously explained.^{12,17}

Regarding the score of awareness of risk, we have observed that there is a low risk perception among the interviewees, ranging only from 0 to 4 points, which is related to their low activity limitation. Nonetheless, there is a gap in relation to health education and self-care.⁹

The use of the SALSA Scale and of the Participation Scale was easy to apply and might be an excellent instrument to foster the comprehensive care for patients with Hansen's disease, conducted by the multiprofessional team, but it requires the characterization of the life context of the interviewed person, since it does not allow the assertion that the identified restriction is the exclusive result of the Hansen's disease.^{9,16} Nevertheless, we found other researches that worked with the ratio between the process of illness from leprosy and the change in the daily life conditions and interpersonal relationships, through the use of other instruments, which have identified impairments in quality of life of users, especially due to some specific situations of the disease, such as multibacillary clinical form, leprosy-related reaction and disability. These losses provoke great suffering and cause large social and psychological impact.¹⁷⁻¹⁹

When identifying meanings, this study draws attention to the particular way in which each person experiences its process of illness, and indicates the application of the SALSA and Participation scales to improve the quality of health care towards patients with Hansen's disease, with a gaze that goes beyond physical aspects, aimed not only at disease control, but also the prevention of disabilities, encouragement of adherence to treatment and combat against the stigma/social prejudice, in order to minimize the impact of the disease on the individual's life.¹⁸

FINAL REMARKS

When not early diagnosed, the Hansen's disease has great crippling power and carries with itself, even in the present times, a strong stigmatizing factor, which might entail great changes in the lives of affected people. The use of the SALSA and Participation scales in the work routine of the health team, as recommended by the Brazilian Ministry of Health, might foster the prevention of physical and psychosocial disabilities linked to the disease at stake.

Thus, we must alert health professionals and, in particular, nursing, about the need to know these instruments with a view to guiding the care for patients affected by Hansen's disease, thereby seeking to understand the psychosocial conditions that interfere and are determinant in their process of illness. Moreover, we suggest the continuation of permanent education in relation to Hansen's disease, along with health professionals, as a strategy for dissemination and qualification for the use of these scales, both in the

reference centers and in the scope of Primary Care.

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