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Original Article

Functioning and Disability in Leprosy

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This study has been carried out to investigate the frequency of musculoskeletal symptoms in people affected by leprosy and correlate this to their functional capacity to perform daily living and working activities and to their degree of disability. This cross-sectional study was performed on 100 clients who answered a questionnaire on personal and clinical data, the Nordic Musculoskeletal (QNSO), and the shoulder, arm and hand dysfunction (DASH) questionnaires. The mean age was 53.63 years and there was a predominance of men (67%), low education (53%), and multibacillary disease (84%). Physical impairment affected 95% of respondents and 92% indicated pain and/or paresthesia in the arms that interfered in functional capacity. Respondents with musculoskeletal symptoms have more difficulty to perform daily living and working activities compared to those without musculoskeletal symptoms (p-value<0.05). The presence of physical disabilities was not associated with difficulties to perform daily living (p-value=0.29) and labor activities (p-value=0.87). The majority of patients experienced pain and/or paresthesia of the arms, and this was associated with difficulties to perform daily living and working activities. However, the presence of physical disability does not seem to cause major impediments or limitations to perform these activities.

Keywords : activities of daily living; leprosy; disabled people

Introduction

The etiologic agent of leprosy, a chronic granulomatous disease, is *Mycobacterium leprae*. This bacillus is considered an obligate intracellular parasite that prefers cooler regions of the body, infecting the skin and peripheral nerves. Infection does not indicate a subsequent illness always as this bacillus has high infectivity, but low pathogenicity, that is, many more individuals are infected than become sick (Brasil 2009, Garbino

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and Opromolla 2007). About 90 to 95% of the population has good immune resistance against the bacillus (Lehman et al 2006).

The number of cases reported in Brazil in 2014 was 31,064, placing Brazil in the second place in the world ranking in terms of prevalence, only behind India. In 2014, there were 2039 new cases with severe disabilities (Grade II disability) (Brasil 2014).

Monteiroetal (2013) report that, even with all the effort to fight the disease, leprosy is still considered a public health problem due to the number of new cases found in the country; about 20% of patients suffer from physical and/or psychological disabilities and require monitoring by are habilitation team.

Neurological disease may occur both interminal branches of the skin nerves and in the trunks of peripheral nerves, leading to sensory-motor and autonomic changes of the eyes, arms and legs (Lehman et al 2006).

Loureiro et al (2014) states that in leprosy, impairment of the transmission of motor and sensory impulses by peripheral nerves will cause the person to experience disability, especially in the functioning of the hands, as the peripheral nerves of the arms are the most affected.

The sensory alterations or loss in respect to pain, heat or touch prevents individuals from determining shapes and temperatures of objects and surfaces without the aid of vision. This can lead to recurrent burns and injuries and, if left untreated, may lead to the amputation of fingers (Garbino and Opromolla 2007, Lehman et al 2006). Garbino and Opromolla (2007) also state that severe impairment of the ulnar nerve may lead to a claw-appearance of the fourth and fifth fingers which, when associated to median nerve injury, can lead to the claw-hand deformity with loss of thumb opponency movement. The radial nerve is rarely affected, however wrist drop can result from impairment of the in nervation of the extensor muscles of the wrist and fingers (Lehman et al 2006).

Reaction hand is a term used to designate a generalized inflammatory condition expressively manifested in the hands asa response of the body against the presence of the bacillus. Evolution to arthritis, tenosynovitis or myositis in this process may lead to deformities of the fingers and significant impairment in the ability to grip objects (Garbino and Opromolla 2007).

Considering the clinical picture resulting from *M. leprae* infection, where its action in the body or even the response against the bacterium may cause leprosy neuropathies and possibly reaction hand, it is essential to work toward preventing complications and rehabilitating affected individuals to reduce functional disabilities and impaired social participation (Brasil 2008).

Ferreira et al (2012) point out that an evaluation of hand function may help to target prevention and rehabilitation measures, in so far as this assessment indicates the level of functional independence of patients.

Thus, the objectives of this study were to investigate the frequency of musculoskeletal symptoms in people who have or had leprosy and identify their correlation with functional capacity in respect to daily living and working activities and to the degree of disability evaluated by the degree of physical disability classification of the World Health Organization (DPD-WHO).

Methods

Study Design and Ethical Aspects

This is a descriptive survey. The study protocol was approved by the Ethics Committee on Human Research of the Instituto Lauro de Souza Lima, Bauru, Brazil (No. 803 040/14). All participants

agreed to participate and signed informed consent forms.

Sample

The study sample consisted of 100, over 18-year-old people, who were being treated with multidrug therapy (MDT) and /or undergoing rehabilitation for leprosy. Participants were randomly selected during routine neurological assessments in the occupational therapy and physiotherapy sectors and in consultations in the hand and foot clinics of the rehabilitation sector of the Instituto Lauro de Souza Lima. This institute is a referral hospital in Latin America that treats people affected by leprosy. Individuals who presented with morbidities that might contribute to the development of neuropathies, such as hypothyroidism, diabetes, alcoholism, among others, and other skin diseases that were not leprosy were excluded from this study. Furthermore, individuals with mental impairment, or specific developmental disorders of speech and language that might interfere in their communication and under standing during the interview were excluded.

Study variables and assessment tools

A questionnaire was designed to collect data on socio demographic and clinical characteristics, and the degree of disability. Variables included personal data (gender, age, town of residence, marital status, current occupation, and family income), clinical data of the disease (treatment, operational classification and types of disabilities) and degree of disability of the eyes, hands and feet, as recommended by the World Health Organization (WHO).

The DPD-WHO is a measure of loss of protective sensation and visible deformities resulting from neural injury or blindness. It is an epidemiological indicator used to evaluate programs and determine early diagnosis (Brasil 2008). Patients with leprosy are classified as Grade zero (no disability) or Grades 1 and 2 depending on the severity of the disabilities.

The Nordic Musculoskeletal Questionnaire (NMQ) (Kuorinka et al 1987) was used to measure musculoskeletal symptoms; this is a reliable instrument that has been translated and validated for the Brazilian population (Barros et al 2003). The NMQ consists of a picture of the back of the human body divided into nine anatomical regions: (i) neck, (ii) shoulders, (iii) upper back, (iv) elbow, (v) wrist/hands (vi) lower back, (vii) hips and thighs, (viii) Knees, and (ix) ankles and feet (Barros et al 2003). Interviewees are requested to mark regions of pain or discomfort experienced over the previous 12 months on this figure and, in particular, over the previous seven days. Interviewees also provided data on their functional disabilities in daily activities and the need for consultations with a healthcare professional in the previous 12 months due to musculoskeletal symptoms. This questionnaire has been widely used to describe the frequency of musculoskeletal symptoms of different types of jobs (Montrezor and Alencar 2011, Coelho et al 2010, Melo et al 2010, Kotliarenko et al 2009).

To analyze the frequency of musculoskeletal symptoms, functional disability and the participants search for professional help, this study used a scoring system to make the presentation of the results more meaningful. First, the frequencies for each individual and for the different body parts were set down in a table. Then the results were grouped and assigned a score:

0 - Individuals who did not complain of pain or paresthesia;

1- Individuals who had pain and/or paresthesia within the previous 12 months and/or 7 days);

2- Individuals who had pain and/or paresthesia and impaired functional capacity because of symptoms;

3- Individuals who had pain and/or paresthesia, and impaired functional capacity as a result of symptoms who sought professional help;

4- Individuals who had pain and/or paresthesia and sought professional help because of symptoms.

This scoring system not only allowed isolated frequencies to be evaluated, but also identified the presence of musculoskeletal symptoms associated with impairment in the functional capacity of participants. Statistical analysis considered segments of the arms such as the shoulders, upper back, elbow, and wrist and hand.

The Disabilities of the Arm, Shoulder and Hand questionnaire (DASH) was used to evaluate dysfunction of the upper extremities. This instrument, which has been translated and validated for the Brazilian population (Orfale 2003), comprises of 30 questions in three modules: the main module is on activities of daily living (DASH-1). In addition, there are two optional modules on sports and musical activities (DASH 2) and working activities (DASH-3) (Cheng 2006). Individuals report their difficulties to perform activities in the previous week, the intensity of symptoms in the upper limbs, psychological impairment and difficulties in social activities and sleeping. This tool is structured as a five-point Likert scale with scores ranging from 0 (no impairment) to 100 (severe impairment); thus the higher the score, the greater the functional impairment to perform activities. The final score is obtained by subtracting 30 from the sum of the scores of the 30 questions and dividing the result by 1.2. For the optional modules, the scores for each of the questions are summed, 4 is subtracted and the result is divided by 0.16 (Orfale 2003).

Data analysis

Descriptive statistics were used to characterize the study group. The hypothesis of this study was that interviewees with musculoskeletal symptoms (NMQ) and those with physical disabilities (DPD=1 and DPD=2) have higher DASH-1 (activities of daily living) and DASH-3 scores (working activities). This means that these individuals have more difficulties to perform activities compared to interviewees without musculoskeletal symptoms or physical disabilities (DPD=0). Results were evaluated using the non-parametric Kruskal-Wall is test with statistical analysis being performed using the Epi Info software. Significance was set for an α error=0.05.

Results

Sociodemographic, clinical, occupational data and degree of disability of the participants

The participants in this study had a mean age of 53.63 years (Standard deviation - SD:13.97). The majority of the sample were men (67%), married (53%), illiterate or with incomplete primary education (53%), retired (42%) or on disability leave due to illness (32%) and with a family income between 0 and 2 minimum wages (71%).

Regarding clinical classification of the disease, the majority of cases were diagnosed as multibacillary (84%) with 16% diagnosed as paucibacillary; 84% had completed MDT.

Regarding the degree of disability, five patients (5%) had Grade 0, 30 (30%) had Grade 1 and 65 (65%) had Grade 2 disabilities.

Musculoskeletal symptoms and dysfunction of the upper limbs

Table 1 shows the results of the NMQ with individuals grouped as those having pain and/or paresthesia in the upper limb, those with dysfunction due to these symptoms and those who sought professional help. Of the study participants, 96 (96%) had an episode of pain

and/or paresthesia in the upper limbs. Moreover, 92 (92%) reported having limited functional capacity due to the symptoms.

Participants had a mean score of 30.93 (SD:22.52) in the DASH-1 questionnaire (activities of daily living) and 31.98 (SD:32.24) in the DASH-3 questionnaire (working activities).

The evaluation of functional difficulties using the DASH-1 and DASH-3 questionnaires of patients with and without musculoskeletal symptoms in the upper limbs as assessed by the NMQ are presented in Table 2.

Interviewees with musculoskeletal symptom had more difficulty to perform daily living and working activities compared to those who do not have musculoskeletal symptoms (p-value<0.05).

Table 3 shows the results of functional difficulties as identified by the DASH-1 and DASH-3 questionnaires in respect to the DPD-WHO classification (Grades 0,1 or 2).

The presence or absence of physical disabilities does not seem to stop or cause major limitations for patients to perform daily living (p-value=0.29) and working activities (p-value=0.87).

The results of the optional module DASH-2 (sports and playing a musical instrument) are not described in this work due to the small number of individuals who completed this module: of the

Table 1 : Musculoskeletal Symptoms, impaired functional capacity and search for professional help by study participants

Variable	% (n)
No complaints	4.0 (4)
Pain and/or numbness in the last 12months and/or 7 days	3.0 (3)
Pain and/or numbness and impaired functional capacity	4.0 (4)
Pain and/or paresthesia, impaired functional capacity and search for professional help	88.0 (88)
Pain and/or paresthesia and search for professional help	1.0 (1)

Table 2 : Functional difficulties in activities of daily living (DASH-1) and working activities (DASH-3) according to the presence of musculoskeletal symptoms in the body segments representing the upper Limb

	Functional difficulties in activities of daily living (DASH-1)		Functional difficulties in working activities (DASH-3)**	
	Musculoskeletal Symptoms (n = 85)	No musculoskeletal Symptoms (n = 15)	Musculoskeletal Symptoms (n = 12)	No musculoskeletal Symptoms (n = 5)
Median (range)	31.6 (0 - 77.5)	6.6 (0 - 35.83)	50.0 (0 - 100)	0.0 (0 - 31.25)
Mean (standard deviation)	34.55 (22.10)	10.44 (11.30)	42.18 (32.54)	7.5 (13.54)
p-value	< 0.05***		0.04	

** 17 participants responded to DASH-3
*** Kruskal-Wallis

Table 3 : Functional difficulties in activities of daily life (DASH-1) and working activities (DASH-3) according to the degree of physical disability (DPD) classification of the World Health Organization

	Functional difficulties in activities of daily living (DASH-1)			Functional difficulties in working activities (DASH-3)**		
	DPD - 0 (n = 5)	DPD - 1 (n = 30)	DPD - 2 (n = 65)	DPD - 0 (n = 4)	DPD - 1 (n = 4)	DPD - 2 (n = 9)
Median (range)	9.16	30.41	28.33	25.00	31.25	31.25
	(0-58.33)	(0-63.33)	(0-77.50)	(0-68.75)	(0-62.5)	(0-100)
Mean	21.66	31.79	31.25	(35.12)	31.25	33.33
(standard deviation)	(25.00)	(17.90)	(24.36)	29.68	(36.08)	(33.51)
p-value	0.29			0.87		

** 17 participants responded to DASH-3

100 participants, only six responded, which is insufficient for statistical analysis.

Discussion

The individuals participating in this study were mostly men, married and with a mean age of 53.63 years. In other studies, the average age of participants was between 45.8 and 49 years (Cunha et al 2012, Silva et al 2012, Kilet al 2012, Alves et al 2010). The predominance of males was corroborated by other authors sand is probably related to lifestyle as men are considered to be a more active population that sometimes requires relocation to remain in the labor market; this increases the likelihood of coming in connect with the bacillus (Alves et al 2010, Miranzi et al 2006, Monteiro 2012, Monteiro et al 2013, Oliveira et al 2010). Consequently, this population is apparently responsible for higher social costs related to individuals leaving the work force.

Regarding schooling and income, most participants were either illiterate or had incomplete primary education and the family income of participants was, in general, up to two minimum salaries. These results confirm the findings in the literature (Cunha et al 2012, Silva et al 2012, Sousa et al 2011). In addition to these findings, the literature reports that leprosy is associated with large clusters of people with low living conditions and bad health who are there fore more vulnerable to acquiring the disease (Pieri et al 2012).

Seventy-four percent of the patients indicated that they had retired or were on disability leave because of leprosy. However, other published studies report lower percentages for the number of retirees or people on disability leave (Monteiro et al 2013, Ferreira et al 2012, Silva et al 2012, Gonçalves et al 2009). Inability to work is common among patients because leprosy is an europathy, which, in most cases, leads to inflammation of the peripheral nerves, pain, changes in strength, loss of protective sensation and disabilities of the hands and feet, making daily living and working activities more difficult (Monteiro et al 2012).

Most patients in this study were classified as multibacillary and with Grade 2 disability (DPD-WHO), and, most (84%) had completed treatment with MDT. The most common operational classification generally reported in the literature is similar to the results of this study (Cunha et al 2012, Kil et al 2012, Miranzi et al 2010). However, Monteiro et al (2013) investigated the

demographic and clinical characteristics of patients in the State of Tocantins, Brazil and found a larger number of patients with paucibacillary disease (60.3%).

Regarding the prevalence of Grade 2 disability, some published studies differ from the results of this study (Monteiro et al 2013, Silva et al 2012, Miranzi et al 2010, Pieri et al 2012, Gonçalves et al 2009, Do Prado et al 2011). This discrepancy is probably because, in this study, most of the patients were screened in there habilitation department of are ferral hospital for leprosy and thus, it is expected that the individuals would have more severe disabilities.

It was not possible to compare the results for the frequency of musculoskeletal symptoms (NMQ) because, to the best of our knowledge, there are no published studies that used this particular questionnaire for leprosy or other peripheral neuropathies. However, neuropathic pain has been reported frequently in leprosy patients and pain even persists after the regular treatment of leprosy, causing physical and emotional disorders in the patient with consequent in ability to perform daily activities (Reis et al 2013a, Stump et al 2006).

In this study, most patients experienced pain and/or paresthesia and impaired functional capacity, and sought professional help. The persistence of pain for more than three months characterizes a chronic condition and is considered a public health problem (Siqueira and Annes 2013). Prolonged pain can result in altered functional capacity, affecting the performance of activities of daily living, and decreased motivation and self-esteem to carry out working activities (Alencar and Terada 2012, Mango et al 2012, Alcântara 2008).

Only one study that used the DASH questionnaire in patients with leprosy was found in the literature (Pinho et al 2014). In this study, the DASH was used to evaluate neurolysis in the preoperative and postoperative periods of 14 patients with leprosy. One of the objectives of the study was to compare the DASH and SALSA (Screening of Activity Limitation and Safety Awareness) evaluations. The authors justified the use of the DASH because this questionnaire only evaluates impaired functional capacity of the upper limbs (Pinho et al 2014). The results were similar between the SALSA and DASH scales and the authors suggested the use of the latter to complement the SALSA scale.

The current study shows that patients with musculoskeletal symptoms have more mobility disability to perform daily living and working activities. Corroborating these results, Melãoetal (2011) reported that patients with leprosy experience negative impaction their daily lives as the disabilities after leprosy treatment result in functional dysfunction. In another Brazilian state, Monteiro et al (2013) reported that the presence of deformities in leprosy limit the development of activities with physical, social and economic repercussions.

Major functional difficulties to perform daily living and working activities were not observed in patients with disabilities (Grade 1 or 2). The results show that even if patients have physical disabilities caused by leprosy (Grade 1 and 2), this does not prevent them from performing everyday activities, even if they need to adapt to the circumstances (Do Prado et al 2011).

To the best of our knowledge, no published works associate the results of the DASH questionnaire (functional difficulties) with the DPD-WHO classification. However, some studies have sought to associate the limitations in activities assessed by the SALSA scale with the DPD-WHO (Reis et al 2013b, Batista 2010, Ikehara et al 2010, Slim et al 2010, Rafael 2009).

Accordingly, although some published works sought to associate limitations in performing activities with the DPD-WHO classification, it is not possible to determine the sensitivity of the latter assessment tool to qualify the functional performance of patients. This is because an evaluation as Grade 1 or 2 does not define functional dependence, it only identifies changes in body structures that together with other factors, interfere in the functional capacity.

Conclusions

The majority of patients experienced pain and/or paresthesia in the upper limbs. These results associated to the DASH-1 and DASH-3 evaluations show that, in this population, difficulties in performing daily living and working activities are more evident. However, the presence of physical disabilities does not seem to stop or significantly limit patients from carrying out these activities.

Leprosy is a disabling disease, and the results of this study reinforce this finding. There is a growing need to invest in early diagnosis, to combine comprehensive care strategies during treatment, favoring a post-discharge follow-up to maintain functional capacity. It may be important to recognize the need to assess how the patient faces the physical and psychosocial problems resulting from the disease.

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