

## Characterization of the profession/occupation of individuals affected by leprosy and the relationship with limitations in professional activities

SMT Nardi<sup>1</sup>, E Ikehara<sup>2</sup>, HSP Pedro<sup>1</sup>, VDA Paschoal<sup>3</sup>

Received : 09.11.2011 Revised : 22.01.2012 Accepted : 25.01.2012

People who had leprosy stay away from work and have difficulty of employability and to perform their functions or retire early. This study aimed at determining whether there is a relationship between profession/occupation and limitations in activities. This was a cross-sectional study that used the SALSA scale (Screening of Activity Limitation and Safety Awareness) to assess limitations and to classify professions/occupations as low, medium or high risk. Of the 277 people surveyed, 50.2% were men, the mean age was 53.8 years (SD = 16.3), 62.7% had multibacillary, 59.7% had family incomes of 3 minimum wages or less, 58.5% had up to 6 years schooling and 57% did not have paid jobs. As for occupations, 45.8% were considered low, 39.7% medium and 12.3% high risk. Of the total, 49.1% had mild/moderate, 8.7% severe/very severe and 42.2% did not have any limitations. The relationship between limitations in activities and occupational risk indicated that people with severe limitations tend to have low risk occupations ( $p$  value < 0.05). The limitations associated with employability showed that most active individuals have no limitations ( $p$  value < 0.05). Hence, most people who had leprosy have low risk professions/occupations; the limitations favor a shift from high-risk activities and interfere with employability.

**Key words:** Disability evaluation, Morbidity, Leprosy

### Introduction

Over the last decade, the quality of care provided to people with leprosy in Brazil has improved, but studies show that the stigma around the disease and its carriers still persists within society

(Balaiardi 2007, Femina et al 2007). This is shown, for example, by the finding that restriction in social participation affects about 35% of people who have completed drug therapy for the disease (Nardi et al 2011).

---

SMT Nardi, MSc, Researcher

E Ikehara, Bachelor in Occupational Therapy, Specialist in Hand Therapy

HSP Pedro, MSc, Researcher

VDA Paschoal, PhD, Doctor

<sup>1</sup> Regional Laboratory - Adolfo Lutz Institute, Rua Aberto Sufredini Bertoni n° 2325, Maceno, São José do Rio Preto, São Paulo, Brazil, CEP:15060-020

<sup>2</sup> Psychiatry Institute - Hospital da Clinicas- Medicine School of the University of São Paulo, Avenida Dr. Enéas de Carvalho Aguiar n° 255, Cerqueira César, São Paulo, Brazil, CEP:05403-000

<sup>3</sup> Nursing in the Department of Public Health, Medicine School in São José do Rio Preto, Avenida Brigadeiro Faria Lima n° 5416, Vila São Pedro, São José do Rio Preto, São Paulo, Brazil, CEP: 15090-000.

**Correspondence to:** SMT Nardi    **Email:** snardi@ial.sp.gov.br

It is estimated that the physical impairments caused by complications and the chronicity of the disease, as assessed by the World Health Organization leprosy disability grading system (WHO-DG) (Ministry of Health 2008), affect 2 to 3 million people worldwide (Ministry of Health 2011, Lockwood and Suneetha 2005). In Brazil, the percentage of physical disabilities (grade 1 and 2) at diagnosis is of great concern (30.3% of patients), especially as 11% of cases are not even evaluated (SINAN 2009ab). Furthermore, individuals classified as grade 0 i.e. without physical disabilities, are not exempt from limitations in daily activities, indicating that, in Brazil, problems related to physical disabilities due to leprosy may be even greater.

Often, while in outpatient treatment, people who have or have had leprosy report that they need to stop to work or they have difficulties to perform their work and have restrictions in employability (Lima et al 2009, Simões and Delello 2005). It is also disturbing to see these people retire early, a frequently reported situation. Some patients omit mentioning their disease because for fear of being forced to take sick leave or even being fired from their job. All these problems can result from social discrimination, physical impairments and/or the activity limitations stemming from complications of the disease (Balaiardi 2007, Helene and Salum 2002).

Little is known about the profession/occupation of these individuals and whether there is any relationship between their choice of job and activity limitations linked to worsening of impairments or the pain they feel. This study aimed to evaluate the profession/occupation of people affected by leprosy to see if there is any relationship with activity limitations.

### **Patients and Methods**

This is a cross-sectional study carried out in São José do Rio Preto, São Paulo, Brazil. According to the census by the Brazilian Institute of Geography

and Statistics (IBGE) in 2000, the municipality has approximately 400 000 inhabitants, a Human Development Index of 0.834 and social indicators comparable to those of developed countries (Municipal Planning and Strategic Management 2010). This study was approved by the Research Ethics Committee of the Medicine School in São José do Rio Preto (FAMERP) under No. 392/2009.

For this study, we included all patients of both genders and all ages, living in the city that had had multibacillary or paucibacillary leprosy, who started treatment between 02/01/2000 and 31/12/2008 and had completed multi drug treatment at the time of the interview/evaluation. Patients eligible for the study were identified using the Leprosy Project Database (Paschoal et al 2011). All patients were contacted for an interview in 2010 by telephone (up to 3 calls), letters (maximum of 3) or by home visits (2 attempts).

A specific protocol was used that consisted of 20 questions based on the International Classification of Functioning, Disability and Health (ICF) checklist of the World Health Organization (WHO) to collect personal information and the current and past health status of participants. Physical impairments were graded as 0 (no disability), 1 (reduced sensitivity of eyes, hands and feet) or 2 (severe lesions of eyes, hands and feet) at the time of interview using the WHO leprosy disability grading system.

The Screening Activity Limitation and Safety Awareness (SALSA) scale was also utilized. This scale, validated in Brazil and developed based on the ICF, purports to measure limitations in activities of individuals affected by leprosy, diabetes or other peripheral neuropathies. The scale uses scores of from 10 to 80; low scores indicate little difficulty in daily activities and high scores indicate severe limitations. As established by the SALSA Collaborative Study Group (2010), the cutoff point is set so that a score 25 is

indicative of activity limitations. Individuals with SALSA scale scores of 10-24 were categorized as having no activity limitations, those with scores of 25-39 had slight limitations, 40-49 moderate limitations, 50-59 severe limitations and individual with scores of 60-80 had very severe limitations.

Data of the profession/occupation of people affected by leprosy were collected during interviews; the interviewer tried not to influence the respondent while defining prior profession/occupation. Thus, the aim of this work was not to evaluate all daily activities performed by former patients, but to categorize the profession/occupation cited by them as having been their main activity. Due to the difficulty in assessing the entire diversity of professions/occupations and to compare them with other variables of interest, coupled with the scarcity of publications pertaining to this subject and the fact that the classification used by the National Disease Notification System (SINAN) is not appropriate for this study, we chose to categorize professions/occupations as having low, medium or high physical risk. Occupations considered low risk are jobs that do not require intense or constant force or repetitive movements during most of the working day. Examples of this category include lawyer, driver, night watchman, porter, taxi driver, student and pensioner. Medium-risk occupations are those that require repetitive work during about two thirds of the day, as well as those in which the individual carries or moves heavy weights intermittently during the working day, such as salesman, waiter, seamstress, laundress, watchmaker, maid, housewife, mechanic, greengrocer, building site foreman, supermarket cashier, tractor driver, nurse, street hawker, and lathe and machine operators. Finally, high-risk professions were considered those involving intense physical labor or repetitive activities during the entire workday. This category included farm worker, builder, painter, slaughterhouse

employee (butcher), carpenter, tire repair man, general assistant, cleaner, stockroom clerk and rodeo rider.

The computer software, EPI-INFO 2002 (version 3.4.1), was used for statistical analysis. In the descriptive analysis, frequencies were presented for the total and for the following groups: 'without activity limitations,' i.e., those with SALSA scores of less than 25, 'mild to moderate limitations' for those who had SALSA scores between 25 and 49 points, and 'severe and very severe limitations' for SALSA scores greater than or equal to 50 points. The chi-square or Fisher's exact tests were used as necessary and statistical significance was set for a  $p$  value 0.05.

## Results

Of 419 people treated in the period, 277 (66.1%) were contacted and evaluated. The mean age was 53.8 years old (SD = 16.3 years). The socio-demographic, clinical and epidemiological characteristics are shown in Table 1. Of 119 (43%) patients who had paid occupations/professions (i.e., who had paid jobs at the time of interview), 53 (44.5%) had activity limitations and of the 158 (57%) who did not receive wages, 107 (67.7%) had activity limitations. Using the Fisher's exact test, there was a significant correlation between disability and employability showing that most people who were working did not have limitations ( $p$  value < 0.05). Differences in activity limitations were significant in respect to age indicating that the older the individual is, the greater the limitations are ( $p$  value < 0.05).

The professions/occupations most often held by former patients, their respective mean ages, presence of activity limitations and impairments are listed in Table 2. The other professions/occupations reported were: rural workers (n = 5), carpenter (n = 5), unemployed (n = 4), on sick leave (n = 4), guard (n = 4), salesperson (n = 4), cook/kitchen assistant (n = 4), mechanic (n = 3), hairdresser (n = 3), metalworker (n = 3), teacher

**Table 1 : Socio-demographic and clinico-epidemiological characteristics of people treated for leprosy between 2000 and 2008**

Socio-demographic and clinico-epidemiological characteristics (n=277)		
	n	%
<b>Gender</b>		
Female	138	49.8
Male	139	50.2
<b>Age*</b>		
11 to 34 years*	36	13
35 to 54 years	96	34.7
55 years or more	145	52.3
<b>Years of schooling</b>		
Up to 6 years	159	58.5
More than 6 years	118	41.5
<b>Classification</b>		
Paucibacillary	104	37.3
Multibacillary	173	62.7
<b>Occupation/profession vs remuneration</b>		
unpaid	158	57
paid	119	43
<b>Occupation**</b>		
Low risk	127	45.8
Medium risk	110	39.7
High risk	34	12.3
<b>Family income</b>		
Up to 3 minimum wages	163	59.7
More than 3 minimum wages	114	40.3
<b>Disability grade**</b>		
0	168	60.6
1	75	27.1
2	33	11.9
<b>Activity limitations (SALSA score)</b>		
Without limitations	117	42.2
Slight/moderate	136	49.1
Severe/very severe	24	8.7

\* A total of four patients were younger than 18 years old (one was 11, one 12 and two were 13 years old)

\*\* The total differs due to missing data

(n = 3), manicurist (n = 2), pizza cook (n = 2), waste paper collector (n = 2), sales representative (n = 2), businessman (n = 2) and civil servant (n = 2). Of those interviewed, there was only one

**Table 2 : The ten most common professions/occupations and respective mean ages, presence of activity limitations and physical disability grade of people treated for leprosy between 2000 and 2008**

Profession/Occupation			Mean age	With activity limitations		With disability	
			Min-Max	(SALSA $\geq$ 25)		(grade 1 and 2)	
Description	n	%		n	%	n	%
Housewife	48	17.3	56.0 (SD: 14.53) 24 - 84 years	34	70.8	18	37.5
Retired	45	16.2	65 (SD: 10.19) 45- 83 years	32	71.1	29	64.5
Maid	14	5.1	53.1 (SD: 10.11) 40-78 years	12	85.7	5	35.7
Driver	12	4.3	48.7 (SD 12.20) 28 - 67 years	4	33.3	5	41.7
Builder	11	4.0	55.18 (SD: 15.38) 34-81 years	4	36.4	3	27.3
General services	10	3.6	44 (SD: 8.84) 28 - 54 years	6	60	4	40
Cleaner	8	2.9%	51.12 (SD: 7.95) 44 - 66 years	5	62.5	3	37.5
Tradesman	8	2.9	56.5 (SD 12.91) 46 - 82 years	5	62.5	3	37.5
Seamstress	8	2.9	55.1 (SD: 16.52) 32 - 82 years	4	50.0	2	25
Student	7	2.5	16.1 (SD: 5.66) 11 - 27 years	0	0.0	0	0.0

of each of the following professions/occupations: accounting assistant, telemarketing clerk, assistant nurse, massage therapist, esthetician, tractor driver, secretary, shoemaker, sales promoter, painter, packer, deliveryman, engineer, police inspector, caregiver to the elderly; craftsman; beekeeper, goldsmith, bailiff, waiter, gardener, songwriter, railway worker, bus conductor, car accessory installer, machine operator, musician, office clerk, building assistant and assistant assembler. The remaining 22 participants stated that they were not working.

Table 3 shows the distribution of SALSA scores according to occupational risk. On analyzing occupational risk with activity limitations, it was found that people who have the most severe limitations tend to have low-risk activities, while those who do not have activity limitations tend to have high risk occupations ( $p$  value < 0.05). The results suggest that the activity limitations reported by people affected by leprosy may favor a shift from high-risk activities.

**Table 3 : Distribution of SALSA scores according to occupational risk of people treated for leprosy from 2000 to 2008**

Occupational risk	Total*	Activity limitations		
		none n = 115 n (%)	slight/moderate n = 132 n (%)	severe/very severe n = 24 n (%)
low risk	127	43 (33.8)	67 (52.8)	17 (13.4)
medium risk	110	52 (47.3)	52 (47.3)	6 (5.4)
high risk	34	20 (58.8)	13 (38.3)	1 (2.9)

\* The total †differs due to missing data

## Discussion

Although currently there is treatment and cure for leprosy, the stigma associated with this disease still exists in society. This may increase the difficulties experienced by individuals to cope with the disease causing negative repercussions in their social and professional lives (Balaiardi 2007). In the current medical literature, there are several articles that present qualitative reports of patients with leprosy and testimonials about the stigma and prejudice they suffer due to the disease, but there are no works that analyze professions/occupations in respect to activity limitations as assessed by the SALSA scale (Balaiardi 2007, Femina et al 2007, Helene and Salum 2002, Nardi et al 2011).

Information on professions/occupations of leprosy patients is rarely recorded on notification forms. Moreover, when this information is input in SINAN, the Brazilian Information System for Notifiable Diseases, the profession/occupation is categorized according to the sector of the economy in which the patient works and does not identify the condition of this patient in relation to their specific job. A study by Melão and co-workers in 2011 evaluated the records of SINAN and found that the occupation was unknown in 94.4% of the cases. This fact can make it difficult to provide proper care to prevent physical and psychological sequelae related to certain occupational activities performed by the patient.

Because of the number of different types of professions/occupations it is difficult to characterize all in scientific research. For this reason, this study classified occupations in respect to the physical demands of each profession/occupation. This is different to the method chosen by Frazão and Salum, who categorized the types of work in order to emphasize the social status of individuals with leprosy (Helene and Rocha 1998, Helene and Salum 2002) and, therefore, adopted the categories of the IBGE which categorizes work in the 'Services' 'Manufacturing and Construction' and 'Trade' sectors.

Studies over the years show that sick leave for physical and emotional complications arising from leprosy is of concern and thus this is a topic that deserves further investigation. In these studies, commonplace factors that influence the professional activity of persons affected by leprosy include social stigma (Claro 1995, Garcia et al 2003), sick leave and interruption of profession/employment due to sequelae and physical limitations (Balaiardi 2007, Simões and Delello 2005), in addition to the feelings of uncertainty about the future. Also reports of patients who conceal the diagnosis or leave work so as not to suffer discrimination are common, as are physical and emotional changes of patients (Helene and Rocha 1998).

This study adds to the results obtained by other authors by showing that activity limitations are common and people affected by leprosy choose to take low-risk professions/occupations to avoid aggravating their condition. The study sample of this work indicates that there is a predominance of men, in low risk professions/occupations, with little schooling and low family income, with ages greater than 35, who contracted the multibacillary form of the disease, have no physical disability according to WHO-DG but have activity limitations. These characteristics show that most people are in the productive period of their lives but are in medium-to high-risk professions as shown by their low income and because of their little schooling (da Silva et al 2008). Interestingly, our results show that people who are working have no activity limitations but most have low-risk professions. Thus, it is clear that activity limitations encourage people to change from high-risk (or those requiring physical effort) to lower risk activities or to stop working altogether on medical grounds and consequently accept early retirement (Balaiardi 2007, Rolim et al 2006, Sangi et al 2009).

### Conclusion

In conclusion, even after completing multidrug therapy for leprosy, people often suffer from activity limitations. Most participants in this study have professions/occupations that do not require intense or constant forces, nor repetitive movements for most of the working day (low risk professions/occupations), thus, avoiding worsening of their condition. The results suggest that activity limitations may favor a change from high-risk professions/occupations and affect the employability of people who are affected by leprosy.

### Acknowledgements

This work was partially funded by the Paulista Foundation against Leprosy. The authors wish to thank Librarian, Rosangela Kavanami, for her

assistance with the references; Francielle Honorato Alves who corrected the Portuguese version and David A Hewitt for the English version.

### References

1. Balaiardi KS (2007). The Hansen's disease stigma: an account of a group experience with Hansen's disease patients. *Hansenol Int.* **32**: 27-36.
2. Claro LB (1995). Leprosy: Representations of Disease, Fiocruz, Rio de Janeiro.
3. da Silva RC, Lopes A, Guisard CL et al (2008). The history life and work of people with leprosy users of the health service in the state of São Paulo. *Hansenol Int.* **33**: 9-18.
4. Femina LL, Soler AC, Nardi SM et al (2007). Leprosy for Hansen's disease: the effect of this terminology change according to the carriers modifier. *Hansenol Int.* **32**: 37-48.
5. Garcia JR, Macário DP, Ruiz RB et al (2003). Psychosocial considerations about the person with leprosy. In: Prevention of Disability and Rehabilitation in Leprosy (Opromolla DV, Bacarelli R, Orgs), Instituto Lauro de Souza Lima, Bauru, pp25-30.
6. Helene LM and Rocha MT (1998). Identification of some psychosocial aspects in patients with leprosy using computerized analyses resources. *Rev Esc Enferm USP.* **32**: 199-207.
7. Helene LM and Salum MJ (2002). Social reproduction of Hansen disease: a case study in the city of São Paulo. *Cad Saúde Pública.* **18**: 101-113.
8. Lima LS, Jadão FR, Fonseca RN et al (2009). Clinic-epidemiologist characterization of the patients diagnosed with hanseniasis in the city of Caxias, MA. *Rev Bras Clin Med.* **7**: 74-83.
9. Lockwood DN and Suneetha S (2005). Leprosy: too complex a disease for a simple elimination paradigm. *Bull World Health Organ.* **83**: 230-235.
10. Melão S, Blanco LF, Mounzer N et al (2011). Epidemiological profile of leprosy patients in the extreme south of Santa Catarina between 2001 and 2007. *Rev Soc Bras Med Trop.* **44**: 79-84.
11. Ministry of Health (2008). Manual on Prevention of Disability, 3th edn. Secretary of Health Surveillance, Department of Epidemiological Surveillance, Ministry of Health, Brasília.

12. Ministry of Health (2011). General Coordination of the National Leprosy Control: Management Report, January 2009 to December 2010. Ministry of Health, Brasília.
13. Municipal Planning and Strategic Management (2010). Economic Conjuncture 2010. [http://www.riopreto.sp.gov.br/PortalGOV/do/subportais\\_Show?c=146](http://www.riopreto.sp.gov.br/PortalGOV/do/subportais_Show?c=146). Last access on 25th July 2011.
14. Nardi SM, Paschoal VD and Zanetta DMT (2011). Social participation of people affected by leprosy after discontinuation of multidrug therapy. *Lepr Rev.* **82**: 55-64.
15. Paschoal VD, Nardi SM, Cury MR et al (2011). Creation of a data bank for sustainability of leprosy post elimination. *Ciênc Saúde Coletiva.* **16**: 1201-1210.
16. Rolim MA, Colvero LD, Machado AL et al (2006). Meanings associated to leprosy: insight of patients. *Hansenol Int.* **31**: 7-14.
17. SALSA Collaborative Study Group (2010). SALSA Scale Users Manual v 1.1. ILEP <http://www.ilep.org.uk/library-resources/infolep-information-services/subjectguides/salsa-scale/>. Last access on 13th January 2011.
18. Sangi KC, Miranda LF, Spindola T et al (2009). Hansen's disease and reactional states: patient life stories. *Rev Enferm UERJ.* **17**: 209-214.
19. Simões MJ and Delello D (2005). Social behavior study of leprosy patients in São Carlos city state of São Paulo - Brazil. *Rev Espaço Saúde.* **7**: 10-15.
20. Sistema Nacional de Agravos de Notificação - SINAN (2009a). Percentage of new leprosy cases with disability grade assessed in diagnosing States and Brazil [http://portal.saude.gov.br/portal/arquivos/pdf/graf11b\\_casos\\_han\\_incap\\_diag\\_estadosbr\\_011210.pdf](http://portal.saude.gov.br/portal/arquivos/pdf/graf11b_casos_han_incap_diag_estadosbr_011210.pdf). Last access on 9th February 2011.
21. Sistema Nacional de Agravos de Notificação - SINAN (2009b). Percentage of grade 1 and 2 among new cases of leprosy, Brazil, 2001 to 2009. [http://portal.saude.gov.br/portal/arquivos/pdf/graf13\\_perc\\_incapacidade\\_1\\_2\\_br\\_2001\\_2009.pdf](http://portal.saude.gov.br/portal/arquivos/pdf/graf13_perc_incapacidade_1_2_br_2001_2009.pdf). Last access on 9th February 2011.

**How to cite this article :** Nardi SMT, Ikehara E, Pedro HSP and Paschoal VDA (2012). Characterization of the profession/occupation of individuals affected by leprosy and the relationship with limitations in professional activities. *Indian J Lepr.* **84** : 1-8.