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High occurrence of disabilities caused by leprosy: census from a hyperendemic area in Brazil's savannah region

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Summary

Objectives: To describe leprosy-related disabilities, we performed a census including people affected by leprosy in 78 municipalities of Tocantins state in northern Brazil. The study consisted of a review of patient charts, structured questionnaires, and clinical examinations for disabilities of eyes, hands, and feet (August–December 2009), according to WHO standards.

Results: A total of 910 individuals diagnosed from 2006 to 2008 were included (clinical examination and application of questionnaires), but information from patient charts was not available in all cases, resulting in different denominators. The majority (783/858; 91·3%) had completed multidrug therapy. The most common clinical findings included: enlarged/painful peripheral nerves (412/910, 45·3%), namely of ulnar (207; 22·7%), posterior tibial (196; 21·6%), peroneal (186; 20·5%), and radial cutaneous nerves (166; 18·2%); reduction/loss of sensibility 201/907 (22·2%) and

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reduced motor function (185/906, 20·4%). At diagnosis, 142/629 (22·6%) had Grade 1 disability (G1D), and 28/629 (4·5%) had Grade 2 disability (G2D). At the time of the study, 178/910 (19·6%) presented with G1D, and 84/910 (9·2%) with G2D. Disability grading was significantly higher in males ($P < 0·01$). Subjects with G2D showed claw hands (26; 2·9%), followed by plantar ulcers (23; 2·5%), abrasion/excoriation on the foot (12; 1·3%), claw foot (7; 0·7%), and drop foot (7; 0·7%).
Conclusions: Leprosy-related disabilities were common in a highly endemic area. Prevention and rehabilitation measures, especially after release from treatment, should be intensified by the primary health care system. Policy makers need to be aware of an ongoing demand for leprosy control programmes, even in a world of constantly reducing leprosy detection.

Keywords: leprosy, disabilities, epidemiology, prevention, Brazil

Introduction

Leprosy is one of the most ancient infectious diseases of humanity, but still poses a health threat in many countries, with most cases occurring in India, Brazil and Indonesia (in 2015 worldwide: 210,758, Brazil: 26,395).[1] Despite decreased leprosy incidence during recent years, peripheral neuropathy and physical disabilities caused by *Mycobacterium leprae* continue to be a major problem, as they may persist for many years and even worsen after release from treatment (RFT). The proportion of people with visible deformity and/or severe visual impairment (i.e. WHO Grade 2 disability – G2D) among newly detected leprosy cases increased worldwide in recent years, from 3·7% (2005) to 6·6% (2015), and in Brazil from 5·8% (2005) to 6·6% (2015).[1–3] A similar upward trend of the rate of newly detected cases with G2D (7·2% in 2015) has been observed in Tocantins State in Brazil's North region, where this study was performed.[4]

In the current WHO Global Leprosy Strategy for 2016–2020, the reduction of the rate of newly diagnosed leprosy patients with G2D to less than one per million population is one of the aims.[5] This indicator for late diagnosis can be reduced by improving coverage and access in endemic areas and targeting case detection among high risk groups.

The present study forms part of a multidisciplinary epidemiological investigation called IntegraHans MAPATOPI, performed in a hyperendemic region in North Brazil. We present the results of clinical examinations, review of patient charts, and structured questionnaires, regarding impairments and disabilities in a population from 78 municipalities.

Methods

The Brazilian General Coordination of Leprosy & Diseases in Elimination (*Coordenação Geral de Hanseníase e Doenças em Eliminação* – CGHDE) of the Ministry of Health identified several years ago 10 high risk leprosy clusters, in order to focus and intensify prevention and control measures.[6] The present study is a cross-sectional study performed in the so-called cluster 1, within the realm of the IntegraHans MAPATOPI project, a major project performed in the four Brazilian states Maranhão [MA], Pará [PA], Tocantins [TO] and Piauí [PI].[7–9] MAPATOPI includes studies on the epidemiological, clinical, psychosocial,

and operational determinants of leprosy. Details of this project have been published previously elsewhere.[6,9,10]

STUDY AREA AND POPULATION

Tocantins, the most recent state of the Brazilian Federation (created in 1988), is located in the central savannah region. The state is subdivided into 139 municipalities with a total population of 1·5 million.[4] Tocantins is considered hyperendemic for leprosy (58·08 new cases/100,000 inhabitants, 2015).[4]

The study was performed in a census population of 78 municipalities of northern Tocantins that formed part of the high risk cluster 1.[10,11] The target population included all individuals newly diagnosed with leprosy from 2006–2008, living and notified as leprosy cases in the study area. Leprosy cases were identified through the electronic database of the National Information System for Notifiable Diseases (*Sistema de Informacão de Agravos de Notificação* – SINAN).[11] If during field visits patients were identified in the local records that had not been notified in SINAN, we included them in the study.

We did not include the municipality of Araguaína, which forms part of cluster 1, a major city in the region with about 120,000 inhabitants. Araguaína has a leprosy reference clinic and shows different characteristics, as compared to the other smaller municipalities that share mainly rural characteristics. The results from Araguaína (147 leprosy-affected individuals) have been published elsewhere.[12,13]

We excluded those who moved to municipalities outside the endemic cluster, and subjects with mental disabilities or other pathologies, such as anxiety disorder or alcohol abuse, which may interact with clinical examinations or interviews. Relapsed leprosy cases were also excluded.

STUDY DESIGN, VARIABLES AND DATA COLLECTION

The census included all leprosy patients of the study area matching the inclusion criteria. Data collection included review of patient charts, clinical examinations, and the application of structured questionnaires.

Variables included demographic information (age, sex, municipality of residence), and clinical data (clinical form, operational classification, disability grade at diagnosis, mode of case detection, date of diagnosis, date of release from treatment and date of last appearance at the health center for treatment). WHO disability grading was based on examinations of eyes, hands and feet, ranging from 0–2.[14] In detail, the following criteria based on WHO definitions were used - G0D: no anesthesia and no visible damage to eyes, hands and feet; G1D: loss of protective sensibility of eyes, hands and/or feet, without visible damage or deformities; G2D: deformities and/or visible damage to the eyes (shown by lagophthalmos and/or ectropion, trichiasis, corneal opacity, visual acuity less than 0·1 or difficulty counting fingers at 6 meters), visible damage to hands or feet (shown by ulcerations and/or traumatic injuries, resorption, ulcers, drop hand, claw hand or foot, drop foot, ankle contracture). As usual in Brazil, sensibility of eyes was assessed under field conditions, and G1D included reduced corneal sensation.

In close cooperation with the Tocantins State Health Secretariat and the Municipality Health Secretariats, field visits were coordinated; they took place from August to December 2009. Previous to field visits, the Municipal Health Secretariats were informed about the timeframe when the team would perform data collection.

During field visits, first the patient charts and the local notification records were reviewed regarding clinical variables. Then, community health agents invited study participants to be interviewed and examined at the health care centres. If individuals after several attempts did not present at the health care centres, we performed home visits accompanied by local community health agents, with direct individual approach to avoid stigma. Some of them had not spoken about their leprosy diagnosis with their families or neighbours.

Data were collected using pre-tested structured questionnaires for data collection. Clinical examinations were performed according to WHO and Brazilian MoH standards[15,16] and focused on body regions, which are usually infected by leprosy: nose, eyes, upper and lower extremities. The nose was examined with a lamp for leprosy related-lesions (perforation of the nasal septum, dryness). Visual acuity was tested using Snellen charts. Sensibility and peripheral nerve testing was performed (eyes, hands, feet) and peripheral nerves of upper and lower extremities (ulnar, median, radial cutaneous, peroneal and posterior tibial nerves) were palpated, as described in detail elsewhere.[17]

Corneal sensation was tested with a standard dental floss applied on the lateral lower quadrant of the cornea. The Semmes-Weinstein monofilament kit was used to test the sensitivity of hands and feet - six sensory sites on the palmar surface of the hands (three ulnar and three median nerve-innervated areas) and nine topographic sites of the feet.[16] G1D sensory disability was defined if the 2g filament (i.e. the third of the six monofilaments) was not felt, and/or if there was corneal sensory loss.

We applied a voluntary muscle strength test to verify the function of the peripheral motor nerves, with the categories strong, weak and paralysed for eyelid closure, finger and thumb abduction, fifth finger intrinsic position, wrist extension, extension of the hallux and dorsiflexion of the foot.

To reduce inter-observer variation, all questionnaires and clinical examinations were applied by previously trained field investigators who were constantly supervised during data collection. Extensive pre-tests were performed under supervision.

DATA ENTRY AND ANALYSIS

Data were entered twice using Microsoft Office Access® 7 (for clinical data) and Epi Info Software Version 3.5.1 (Centers for Disease Control and Prevention, Atlanta USA) for data from questionnaires and examinations. They were cross-checked, and entry-related errors were corrected. Then, a unique database including all information sources was created. Similar answers to open-ended questions were grouped and categorised. The data were analysed using StataSE® (Version 9.1 for Windows, StataCorp LP, College Station, USA). Variables are presented as absolute numbers and relative frequencies. We applied Fisher's exact test to estimate the significance of the difference of relative frequencies.

ETHICS

The study was approved by the Ethical Review Boards of the Federal University of Ceará (Fortaleza, Brazil) and of the Lutheran University of Palmas (Tocantins, Brazil). The study and field research were permitted by the State Health Secretariat of Tocantins, by the National Leprosy Control Program, and by the involved municipalities. Informed written consent was obtained from study participants. The interviews took place in separated rooms to protect privacy. If there were any clinical findings that required further diagnosis or treatment,

participants were referred to the professionals of the local health centre for treatment or other examinations.

Results

Of the target population of 1,488 people from 78 municipalities, 910 (61·2%) subjects of 74 municipalities were included in data analysis. Four municipalities had not notified any case; 549 (36·9%) subjects of the other municipalities had moved to another city outside the endemic cluster, were not met even after home visits or were not known at the local health centres. In 13 (0·9%) individuals, clinical examinations or the questionnaires were incomplete, and another four (0·3%) refused clinical examination. In addition, eight people (0·5%) did not give their consent to be included in the study. We excluded another four people (0·3%), who had not understood the instructions.

The majority of study participants (783/858; 91·3%) had completed multidrug therapy. The clinical information at diagnosis (clinical form, operational classification and disability grading) collected from the patient health records was often incomplete, resulting in different denominators: 745 (81·9%) with information on clinical form, 864 (94·9%) with information on operational classification, and only 629 (68·4%) with information on disability grading.

Of the total of 910 participants, 478 (52·5%) were males; the age ranged from 5 to 98 years (mean = 41·9 years; standard deviation: 18·6 years); 217 (23·5%) were illiterates, and 250 (27·5%) were living in rural areas. The majority (785; 91·3%) had been released after MDT at the time of the study. A total of 483 (55·9%) had been classified as paucibacillary (PB), and 381 (44·1%) as multibacillary (MB). The most common clinical form was indeterminate (282; 37·4 %), followed by borderline disease (233; 30·9%), and tuberculoid form (151; 20·0%).

At the moment of diagnosis, 142/629 (22·0%) had been graded with G1D, and 28/629 (4·4%) with G2D (Table 1). The clinical examination within the realm of the study revealed 178/910 (19·6%) of cases with G1D and 84/910 (9·2%) of G2D.

Details of the clinical examination are presented in Table 2.

Table 1. Grade of disability at physical examination during study, and at diagnosis, total number and stratified by gender ($n = 910$, but complete data not available in all cases)

	Total	Male	Female	
	N (%)	N (%)	N (%)	*P*-value
Grade of disability at diagnosis (patients' charts)				
Grade 0	459 (73·0)	222 (68·7)	237 (77·5)	0·02
Grade 1	142 (22·6)	81 (25·1)	61 (19·9)	
Grade 2	28 (4·4)	20 (6·2)	8 (2·6)	
Grade of disability during study (clinical examination)				
Grade 0	648 (71·2)	301 (63·0)	347 (80·3)	<0·01
Grade 1	178 (19·6)	117 (24·5)	61 (14·1)	
Grade 2	84 (9·2)	60 (12·5)	24 (5·6)	

Dark grey: Distribution of females with G0D (diagnosis – time of study).
Light grey: Distribution of males with G0D (diagnosis – time of study).

Table 2. General physical examination of the population during the study, total number and stratified by gender ($n = 910$, but complete data not available in all cases)

	Total	Males	Females	
	N (%)	N (%)	N (%)	*P*-value
Nasal examination				
Symptoms relating to nose				
Yes	81 (8·9)	40 (8·4)	41 (9·5)	0·56
No	829 (91·1)	438 (91·6)	391 (90·5)	
Signs - lesions and dryness				
Yes	54 (5·9)	29 (6·1)	25 (5·8)	0·89
No	856 (94·1)	449 (93·9)	407 (94·2)	
Ocular examination				
Symptoms related to eyes				
Yes	324 (35·6)	162 (33·9)	162 (37·5)	0·27
No	586 (64·4)	316 (66·1)	270 (62·5)	
Signs - corneal sensibility; reduction or loss of sensibility on both eyes*				
Yes	70 (7·7)	46 (9·6)	24 (5·6)	0·03
No	838 (92·3)	431 (90·4)	407 (94·4)	
Reduction of visual acuity (<0·1) or difficulty counting fingers at 6 meters				
Yes	50 (5·5)	31 (6·5)	19 (4·4)	0·39
No	860 (94·5)	447 (93·5)	413 (95·6)	
Lid closure (Facial nerve)				
Weak/paralysed	30 (3·3)	21 (4·4)	9 (2·1)	0·06
Intact	880 (96·7)	457 (95·6)	423 (97·9)	
Ocular findings*				
Yes	208 (22·9)	130 (27·3)	78 (18·1)	<0·01
No	699 (77·1)	347 (72·7)	352 (81·9)	
Examination of the upper extremities - symptoms				
Yes	363 (39·3)	184 (38·5)	179 (41·4)	0·38
No	547 (60·7)	294 (61·5)	253 (58·9)	
Evaluation of strength - reduced or paralysed on both hands*				
Yes	148 (16·3)	94 (19·7)	54 (12·5)	<0·01
No	760 (83·7)	382 (80·3)	378 (87·5)	
Abduction of digit V (Ulnar nerve)*				
Reduced	115 (12·7)	68 (14·3)	47 (10·9)	0·02
Paralysed	19 (2·1)	15 (3·2)	4 (0·9)	
Intense	774 (85·2)	393 (82·5)	381 (88·2)	
Abduction of thumb (Median nerve)*				
Reduced	80 (8·8)	50 (10·5)	30 (6·9)	0·12
Paralysed	6 (0·7)	4 (0·8)	2 (0·5)	
Intense	823 (90·5)	423 (88·7)	400 (92·6)	
Extension of the fist (Radial nerve)*				
Reduced	42 (4·6)	28 (5·9)	14 (3·2)	0·02
Paralysed	4 (0·4)	4 (0·8)	0	
Intense	863 (95·0)	445 (93·3)	418 (96·8)	
Nerve Palpation - painful or tender nerve - upper extremities				
Yes	302 (33·2)	187 (39·1)	115 (26·6)	<0·01
No	608 (66·8)	291 (60·9)	317 (73·4)	
Ulnar nerve				
Yes	207 (22·7)	138 (28·9)	69 (16·0)	< 0·01
No	703 (77·3)	340 (71·1)	363 (84·0)	
Median nerve				
Yes	109 (12·0)	68 (14·2)	41 (9·5)	0·03
No	801 (88·0)	410 (85·8)	391 (90·5)	
Radial nerve				
Yes	166 (18·2)	101 (21·1)	65 (15·1)	0·02
No	744 (81·8)	377 (78·9)	367 (84·9)	

Table 2. *Continued*

	Total	Males	Females	
	N (%)	N (%)	N (%)	*P*-value
Evaluation of sensibility - reduction or loss of sensibility - both hands				
Yes	59 (6·5)	41 (8·6)	18 (4·2)	<0·01
No	851 (93·5)	437 (914)	414 (95·8)	
Ulnar nerve*				
Yes	58 (6·4)	41 (8·6)	17 (3·9)	<0·01
No	852 (93·6)	437 (91·4)	415 (96·1)	
Median nerve				
Yes	40 (4·4)	27 (5·7)	13 (3·0)	0·07
No	870 (95·6)	451 (94·3)	419 (97·0)	
Examination of the feet - symptoms*				
Yes	429 (47·1)	222 (46·4)	207 (47·9)	0·69
No	479 (52·9)	256 (53·6)	225 (52·1)	
Evaluation of strength on both feet*				
Reduced or paralysed	100 (11·0)	59 (12·4)	41 (9·5)	0·17
Intense	808 (89·0)	417 (87·6)	391 (90·5)	
Extension of the digit I (Fibular nerve)*				
Reduced	85 (9·4)	50 (10·5)	35 (8·1)	0·06
Paralysed	8 (0·9)	7 (1·5)	1 (0·2)	
Intense	815 (89·7)	419 (88·0)	396 (91·7)	
Dorsiflexion of the foot (Fibular nerve)*				
Reduced	48 (5·3)	29 (6·1)	19 (4·4)	<0·01
Paralysed	9 (1·0)	9 (1·9)	0	
Intense	852 (93·7)	439 (92·0)	413 (95·6)	
Nerve palpation - painful or tender nerve - lower extremities*				
Yes	281 (30·9)	161 (33·8)	120 (27·8)	0·05
No	627 (69·1)	315 (66·2)	312 (72·2)	
Tibial posterior nerve*				
Yes	196 (21·6)	104 (21·8)	92 (21·3)	0·87
No	712 (78·4)	372 (78·2)	340 (78·7)	
Fibular nerve*				
Yes	186 (20·5)	117 (24·5)	69 (16·0)	<0·01
No	723 (79·5)	360 (75·5)	363 (84·0)	
Evaluation of sensibility - reduction or loss of sensibility on both feet*				
Yes	194 (21·4)	136 (28·6)	58 (13·4)	<0·01
No	714 (78·6)	340 (71·4)	374 (86·6)	
Clinical findings – eyes*				
Yes	208 (22·9)	130 (27·3)	78 (18·1)	<0·01
No	699 (77·1)	347 (72·7)	352 (81·9)	
Upper extremities*				
Yes	160 (17·6)	100 (21·1)	60 (13·9)	<0·01
No	747 (82·4)	375 (78·9)	372 (86·1)	
Lower extremities*				
Yes	233 (25·7)	149 (31·4)	84 (19·4)	<0·01
No	674 (74·3)	326 (68·6)	348 (80·6)	
Clinical findings on upper extremities and/or lower extremities and/or eyes				
Yes	405 (44·5)	246 (51·5)	159 (36·8)	<0·01
No	505 (55·5)	232 (48·5)	273 (63·2)	
Clinical findings on upper and lower extremities and eyes				
Yes	38 (4·2)	28 (5·9)	10 (2·3)	<0·01
No	872 (95·8)	450 (94·1)	422 (97·7)	

*data not available in all cases.

Table 3. Disabilities of hands and feet, as detected at physical examination during study, total number and stratified by gender ($n = 910$, but complete data not available in all cases)

	Total	Males	Females	
	N (%)	N (%)	N (%)	*P*-value
Eyes	63/910 (6·9)	41/437 (8·6)	22/410 (5·1)	0·05
Corneal opacity	23/909 (2·5)	17/460 (3·6)	6/426 (1·4)	0·06
Trichiasis	1/910 (0·1)	1/476 (0·2)	0	1·00
Reduction of visual acuity less than 0·1 or difficulty counting fingers at 6 meters	50/909 (5·5)	31/446 (6·5)	19/413 (4·4)	0·19
Hands	26/910 (2·9)	20/458 (4·2)	6/426 (1·4)	0·02
Claw hand	26/910 (2·9)	0/458 (4·2)	6/426 (1·4)	0·02
Abrasion/excoriation	6/910 (0·7)	6/472 (1·3)	0	0·03
Palmar ulcer	2/910 (0·2)	2/476 (0·4)	0	0·50
Drop hand	3/910 (0·3)	3/475 (0·6)	0	0·25
Feet	35/910 (3·9)	23/455 (4·8)	12/420 (2·8)	0·12
Plantar ulcer	23/910 (2·5)	16/462 (3·5)	7/425 (1·6)	0·14
Abrasion/excoriation	12/910 (1·3)	7/471 (1·5)	5/427 (1·2)	0·78
Claw foot	7/910 (0·8)	2/476 (0·4)	5/427 (1·2)	0·27
Drop foot	7/910 (0·8)	7/471 (1·5)	0	0·02
Eyes, lower and/or upper extremities	110/910 (12·1)	74/404 (15·5)	36/396 (8·3)	<0·01
Eyes, lower and upper extremities	2/910 (0·2)	1/477 (0·2)	1/431 (0·2)	1·00
Lower and/or upper extremities	54/910 (5·9)	39/439 (8·2)	15/417 (3·5)	<0·01
Lower and upper extremities	7/910 (0·8)	4/474 (0·8)	3/429 (0·7)	1·00

In general, disabilities detected in this study were more common in males, especially regarding visual acuity, plantar and palmar sensibility, muscle strength of the hands and palpation of the nerves of the upper extremities. Disability grading was significantly higher in males ($P < 0·01$; Table 1).

Table 3 details the findings of physical disabilities. Most subjects with G2D showed strongly limited visual acuity (<0·1), followed by claw hands, corneal opacity and plantar ulcers. Table 4 details the GD at diagnosis, as compared to the assessment during the study; 18·2% presented with a higher GD than at diagnosis, whereas 15·9% improved. The remaining 65·9% maintained their GD, most of them with G0D.

Figures 1a and 1b depict the distribution of subjects with G1D and G2D, stratified by gender and age, at the time of the study. Both genders presented an increase with higher age.

Discussion

This cross-sectional study shows that more than a quarter of the subjects from a hyperendemic area suffered from leprosy-related impairment and that 10% presented visible disabilities (G2D). Tendered or painful nerves were the most common pathological findings, and related to nerve damage,[18,19] which is an indicator for the development of present and future disabilities.[12] The occurrence of damaged peripheral nerves is linked to increased disability, as recently demonstrated in a Brazilian cohort study.[18] At the time of the study, G2D had increased considerably. As a chronic condition, the sensory and nerve evaluation in leprosy cases should be performed as standard at every examination: at time of diagnosis and at time of every examination after diagnosis as well as examination after RFT.

Table 4. Correlation between grade of disability (GD) at diagnosis (patient charts) and during study (clinical examination)

	GD at diagnosis (patient charts)			
	0*	1	2	Total
GD during study (clinical examination)	N (%)	N (%)	N (%)	N (%)
0*	365 (58·0)	86 (13·7)	6 (0·9)	457 (72·6)
1	71 (11·3)	36 (5·7)	8 (1·3)	115 (18·3)
2	23 (3·7)	20 (3·2)	14 (2·2)	57 (9·1)
Total	459 (73·0)	142 (22·6)	28 (4·4)	629 (100)

Light grey: Improvement of GD (diagnosis – time of study).
Dark grey: Worsening of GD (diagnosis – time of study).
To read cross tabulation: at diagnosis 459 (73·0%) patients had no impairments; at clinical examination during study, 365 (58%) were still G0D, 71 (11,3%) became G1D and 23 (3·7%) G2D.

The ulnar nerve is usually the most commonly affected peripheral nerve, followed by the tibial nerve.[20,21] In some studies most of the impairments were seen on the feet, followed by the hands and eyes.[12,22] Independent of the topographic location, prevention measures including self-care activities have to be applied during the entire lifetime to prevent further disabilities.[20]

By intensification of the Brazilian Leprosy Control Program, a continuing reduction of newly detected cases of leprosy has been achieved. These efforts should necessarily be integrated with programs for rehabilitation and prevention of disabilities. Patients with disabilities need long-term special treatment, physiotherapy and instruction in self-care awareness, so that a reintegration in the social and working life is possible. The accessibility to local rehabilitation centres must be guaranteed for every leprosy patient in any stage of the disease. According to official instructions of the Brazilian Ministry of Health and of the State Health Secretariat of Tocantins, every municipality is supposed to provide a specific room for physiotherapy.[23]

The long-term development of disabilities is reflected by the grade of disability (GD) at diagnosis and later moments in time. In both examinations, 365 (58·0%) subjects presented Grade 0 disability (G0D). However, the frequency of current G2D (9·1%) worsened

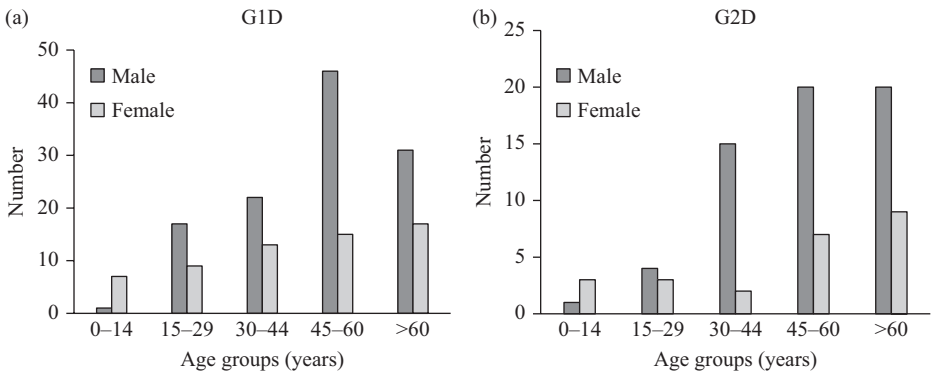

Figure 1a/b. Absolute frequency of the subjects with G1D and G2D, stratified by gender and age group, at the time of the study.

considerably in comparison to G2D at diagnosis (4·4%). The distribution of individuals with G1D showed a higher level in the current evaluation. This shows that the impairments worsened during/after RFT and that secondary prevention measures need to be intensified. In previous studies, a similar trend has been observed.[12,24,25] In an Indonesian study, up to 5 years after RFT there was an increase from 31·0% at diagnosis to 49·0% of patients with G2D.[22] After RFT, the patients are usually out of the monitoring of the health services and not followed up, but during this period leprosy-related sequelae mostly occur. Signs and symptoms often cannot be interpreted correctly by the patients, resulting in delayed diagnosis and treatment, and finally to developing of impairments. The follow-up of patients after RFT has to be systematically integrated into the health services to ensure disease and morbidity management, to instruct in awareness of the disease, and to respond immediately and accordingly if leprosy related sequelae appear.[12,26] Considering the chronic nature of leprosy, these activities should continue, even when the incidence is decreasing. A recent study shows considerable leprosy mortality in Brazil, despite the existence of a preventable and cost-effective treatment. The authors emphasised that sustainable control measures should include appropriate management and systematic monitoring of leprosy-related complications, such as severe leprosy reactions and adverse effects to multidrug therapy.[27] Early diagnosis, the completion of MDT and adequate treatment of leprosy-related reactions prevent the development of disabilities, so that the already existing programmes have to be intensified with focus on these aspects.[25] Furthermore, management, prevention, and socioeconomic rehabilitation should be intensified to further prevent disabilities after RFT.[12,22] Stigma-related aspects should be considered to integrate people affected by leprosy-related disabilities into the workplace and society.[22,28,29]

An additional finding in our study was the predominance of male subjects with pathological results in the clinical examination. This observation coincides with other studies from Brazil and elsewhere.[22,24,29–32] Late diagnosis causes the occurrence of advanced disease, including MB classification or already existing G1D or G2D. Reasons for delayed diagnosis are multiple and may include fear of loss of social and economic life; e.g. loss of work, as demonstrated in an Indian study.[33] In general, late diagnosis is usually more common in males, and the female population shows a more distinct health-seeking behaviour as compared to males.[12,29,31] Due to cultural and socioeconomic factors, Latin American men are considered as the provider, the 'stronger' gender and invulnerable. In rural areas, reduced geographic access to the health system may also be related to delayed diagnosis. Males also often fail to attend consultations because of conflict with working hours. Therefore, several Brazilian Health Care Programs extended the opening times (weekends and at night) of local healthcare centres, with activities focused on the male population.[32,34]

The physical hard work, which in our study setting traditionally is more common in males, comprises a higher risk for developing traumas and lesions especially after RFT, increasing the risk of secondary disabilities in leprosy-affected individuals.[35] In addition, males have been shown to be less aware of disease-specific risks for disabilities.[29] For example, not wearing adequate shoes in case of loss of plantar sensibility may lead to plantar ulcers[36,37] or not interpreting leprosy-related symptoms correctly.[38] A Brazilian study about factors associated with delay in diagnosis revealed that nearly half of the participants did not take their symptoms seriously.[38] Independent of gender, it is important to intensify health education measures to increase the awareness of the disease and to help interpreting leprosy-related symptoms correctly.[38]

In our study, advanced age was associated with higher risk of disabilities, independent of gender. Similar results could be found in other studies.[19,39] Relating to the chronic features of leprosy, the risk of developing disabilities increases with duration of disease, and thus with age.[12,19]

Decentralisation of leprosy control programmes are known to improve case detection and to reduce the number of treatment defaulters. In Brazil, the constant integration of leprosy control into primary health care for several years, based on local municipal healthcare units, supports the relationship and confidence between the health professionals and the patients.[40] The local healthcare centres are important for the day-to-day management relating to diagnosis and treatment, improving early detection of the disease, of reactive episodes and of leprosy-related sequelae. Decentralisation of the health system has also been recommended by WHO.[41]

Limitations

Incompleteness of secondary SINAN and patients' health record data, mainly concerning clinical variables at diagnosis (clinical form, operational classification and GD at diagnosis), may have caused bias; the distributions of GD and gender at diagnosis and at the moment of investigation are based on different population sizes and thus should be interpreted with care. Professionals have to be trained in handling the information health systems and to manage, report and process data collection.[42]

In this study, we focused on clinical examination of the upper and lower extremities, because the interpretation of evaluation of the eyesight is limited, especially in difficult field conditions[43,44]

Inter-observer variation may have occurred, especially regarding the clinical examination. We aimed to minimise this error by applying intensive training and supervision by experienced researchers and clinicians during data collection.

Conclusions

This study performed in a highly endemic area in Brazil shows that the presence of leprosy-related disabilities after RFT is still common. Intensive longitudinal follow-up after RFT has to be integrated systematically into the local health services to prevent the occurrence and progression of disabilities. The access to management, prevention and rehabilitation of the disabilities has to be intensified and guaranteed for every person affected by leprosy. Difficult-to-reach-groups, e.g. working males and rural populations with difficult access to the health system, have to be integrated more intensively into the focus of primary health care. As the first contact people for the patient, professionals from local healthcare units must be permanently trained in detecting leprosy and their sequelae and in transferring the data correctly to the patients' charts and datasets.

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Author contributions

Conceived and designed the study: ANRJ, JH, MFA, CHA, LA, KH, FW, OAC; Preparation of study and field supervision: MFA, JH, LA, ANRJ, CHA; Data collection, entry and management: KH, FW, OAC, LA; Analysis and interpretation of results: KH, JH, MFA, CHA, ANRJ, JR; Wrote first draft of paper: KH, JH; Performed input to paper and approved final version: all authors.

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