

RESEARCH ARTICLE

Associations between occupation, leprosy disability and other sociodemographic factors in an endemic area of Brazil

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Abstract

Background

In Brazil, new leprosy cases with grade-2 disability (G2D) have been increasing. Physical disability has been associated with experienced stigmatization, psychological distress, and social restriction.

Objectives

To identify factors associated with leprosy disability in an endemic area of Brazil focusing on occupational and other sociodemographic factors.

Methods

Between July and December 2015, adult patients with multibacillary leprosy who attended a clinic in Belo Horizonte, Brazil were enrolled. Social, clinical, and demographic factors were collected from an administered questionnaire and medical charts. Occupations were categorized as manual vs non-manual. Descriptive statistics and multivariable logistic regression were performed to study associated factors with disability (Grade 1 disability (G1D) and G2D combined).

Findings

Seventy-three patients were enrolled with 48 (65.8%) presenting with either G1D or G2D at the time of enrollment. Twenty-nine (39.7%) had G2D. About half of the patients ($n = 36$, 49%) reported a manual labor occupation and reactions were common ($n = 53$, 73%). On univariate analyses, older age ($p = 0.048$) and low education ($p = 0.007$) were associated with disability. On multivariable analyses, only low education (primary or less) was associated with disability (OR = 6.34, 95% CI 1.37, 29.26). Greater distance from clinic, income, smoking, marital status, and occupation were not associated.

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Main conclusions

Low education was associated with leprosy disability, consistent with prior studies, and therefore should be a focus for disability reduction programs. While the sample size of this study may have limited detection of associations between disability and social determinants tested, half of the patients reported a manual job, highlighting the need for more extensive studies on associations between occupation, disability, and related injuries.

Introduction

Leprosy is a result of *Mycobacterium leprae* infection, which affects the skin and peripheral nerves. On occasion, leprosy may even develop in the form of silent neuropathy, allowing *M. leprae* bacilli to cause damage long before skin lesions and sensory impairment is noticed. Nerve damage can be irreversible and increases in severity when the infection is left untreated. However, early diagnosis and treatment can prevent permanent nerve damage, consequent disability, and stigmatization that may affect individuals' health and productivity [1].

The World Health Organization (WHO) has reported an increasing number of cases of leprosy with grade-2 disabilities (G2D) and global leprosy strategies have been focused on reducing the number of new cases with visible deformities since 2005 [2]. In 2015, approximately 210,000 new leprosy cases were detected globally, and 14,000 had G2D, exhibiting an increasing trend from 2006 [3]. In 2019, of the approximately 210,000 new cases, 10,813 had G2D. This increase and minor decrease in recent years of disability calls for earlier detection methods and identification of factors associated with nerve damage [4]. Of the 138 countries that reported cases, the clear majority emerged from 14 particularly endemic nations.

Brazil has the second highest number of new cases with G2D, accounting for 89% of the new cases with G2D in the Americas [3, 5, 6]. Brazil reported 2,351 new cases with G2D in 2019, an increase over the reported 2,109 in 2018 and the third consecutive year with an increase [4, 7]. Despite the commitment of both local and global organizations, leprosy continues to be a significant cause of morbidity and disability in Brazil, particularly, where disability present at diagnosis has been reported to be increasing in certain states [8]. New case detection rates have reached high levels of endemicity in 18 out of the 27 Brazilian states, including Minas Gerais, with pockets of hyperendemicity (>40 new cases / 100,000 per year) in many areas [9–15].

G2D is usually permanent, leading to noticeable disability, increased stigma, and associated social isolation. Stigma can then significantly impact the patients affecting their physical, psychological, social, and economic well-being [16]. In a hyperendemic region of Brazil, it was reported that functional limitations due to disability had a significant impact on their performance of other activities and social participation long after completing treatment [17]. Moreover, disability has been associated with Functional Activity Limitations (FALs), psychological distress, and social restriction [18–20]. Furthermore, the more disability one has, the higher psychological distress levels, particularly anxiety and depression are more likely to follow [9, 19]. Investigating factors associated with disability will allow for interventions that may reduce the physical impairments, psychosocial burden and improve the overall quality of life for affected patients.

The WHO Global Leprosy Strategy 2016–2020 emphasized new cases with G2D targeting new cases among high-risk and marginalized groups to reduce G2D at diagnosis with the objective to decrease the G2D case rate to <1 per million population [3, 21, 22]. The new strategy has focused to manage leprosy and its complications and prevent new disability, as one of

its strategic pillars [23]. Given the challenge of decreasing G2D and the overall high prevalence of disability at diagnosis, investigating risk factors may provide data on at-risk populations that can then be targeted for preventative measures.

Prior studies have evaluated factors such as education, rural residency, medical adherence, marital status, and illiteracy [8, 16, 18, 24–28]. While some clinical factors, such as leprosy reactions, are known to be risk factors for disability, in this study, we investigated the role of select social determinants associated with nerve impairment and disability with a primary focus on occupation and distance between residence and clinic. We hypothesized that manual labor and access to care, defined by the distance from the clinic, are associated with a higher occurrence of grade 1 or grade 2 disability. For those with manual labor occupations, a delay in diagnosis or treatment may result from stigma that may discourage this occupational class from seeking treatment in fear of job loss. Other investigated variables include socioeconomic status, race, education, sex, and select clinical factors.

Materials and methods

Study site and population

Between July and December 2015, adult cases (18 years and older) of multibacillary (MB) leprosy who presented for care to a dermatologic reference center in Belo Horizonte, Minas Gerais, Brazil, were enrolled in a study to study risk factors for leprosy reactions [29]. Eligible participants included patients with multibacillary (MB) disease as defined by the World Health Organization (WHO), with some cases of borderline tuberculoid (BT) (5 or more skin lesions), and all cases of borderline borderline (BB), borderline lepromatous (BL) and lepromatous (LL). Paucibacillary (PB) cases were excluded, given low rates of disability. Patients could be at any stage in their treatment—newly diagnosed, on multi-drug therapy (MDT), or following MDT [1]. Those with and without leprosy reactions (Type 1 and Type 2) were included.

Data collection

An in-person questionnaire was administered by study staff, and included questions on demographic topics such as race, marital status, occupation, socioeconomic status, residence (urban vs. rural district), education level, and smoking status. Data abstracted from the medical records included the leprosy type per Ridley Jopling categorization [30], date of original diagnosis, and the presence of disability (Grade 1 or Grade 2) at the time of diagnosis or first appointment at the clinic (if data on disability not available from diagnosis). Disability grade was based on the WHO disability grading system [31] (Table 1).

Manual labor was defined as occupations that rely heavily on physical work and intense strength such as farmers, day laborers, bricklayers, handymen, and fishermen. Those who worked in a less intensive physical environment were grouped as non-manual laborers and included office clerks, housekeepers, and taxi drivers. These assignments follow the standard

Table 1. WHO disability criteria (adapted from Johannes) [31].

WHO disability grading	
Hands and Feet	Grade 0: no anesthesia, visible deformity or damage
	Grade 1: anaesthesia present, no visible deformity or damage
	Grade 2: visible deformity or damage present
Eyes	Grade 0: no eye problem due to leprosy; no evidence of visual loss
	Grade 1: eye problems due to leprosy but vision not severely affected
	Grade 2: severe visual impairment

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form of occupational segmentations in current literature and in the Brazilian National Classification of Economic Activities [18, 32, 33]. Residence demographics were obtained by the distinction between rural/urban on the questionnaire and through measurement of distance in kilometers from the reference clinic to their municipality of residence. Far and near was defined by using the geographical distribution of the data set, with an average of 150 km for the distance to the clinic being determined as the cutoff. Both the median and mean ranged between 139–150 km, respectively, so we thought that 150 km would be a meaningful cutoff to analyze distance from clinic. Furthermore, that would equate to about a 2–3 hour drive by car, which is a moderate distance considering the range from within the same city to 569 km distant. The distance was taken from the reference clinic location to the residence city center. The low-income variable was defined as those earning less than 1X the minimum wage versus those earning more and low education was defined as having received no more than primary education. Primary education is the second stage of education in Brazil for 6 to 14-year-old students. Older age was defined as 60 years of age or older. This categorization is consistent with other studies on leprosy disability [9, 34].

Data analysis

Descriptive statistics and univariate analyses were performed on the main study variables and p-values were calculated to compare those patients with or without disability (Grade 1 or Grade 2 combined) using chi-square, Fisher's exact test, or t-test where appropriate. A p-value of <0.05 was taken as statistically significant. For this paper, we performed a post-hoc analysis to look at this research question of disability, understanding that the original question was looking at risk factors for leprosy reactions [29]. The sample size (48 cases of disability, 25 without disability) was sufficient to detect about an odds ratio of 4.5 assuming that about 15–18% of controls would report being a manual laborer (as per a prior study [27]) and using a power of 0.80 and alpha of 0.05. Given the exploratory nature and secondary data analysis, a larger sample size was not feasible to detect a smaller difference between the two groups in respect to the primary exposure of manual labor. Multivariable logistic regression was performed to calculate adjusted odds ratios on the main study variables. The model included disability (either Grade 1 or Grade 2) as the outcome and manual labor as the primary exposure with covariates including distance to clinic, income, low education (8th grade or less), marital status, age, sex, and race. The model was evaluated for collinearity (by measuring condition indexes), interactions, and confounding. Interactions between the main exposure, hard labor, and each of the other variables were assessed by the chunk test. A change in estimates approach was utilized to determine confounding and variables were dropped from the model if the inclusion of them did not change the point estimate of the main exposure by more than 10% or did not improve the primary measure's precision. All analyses were done using SAS v9.4 (Carey, NC), Tableau 10.3 (Seattle, WA), and ESRI ArcMap 10.6 (Redlands, CA).

Ethics

Ethical approval was obtained from the institutional review boards of Emory University and Faculdade da Saúde e Ecologia Humana (FASEH). Ethical approval was also granted by the Institutional Review Board at Hospital Eduardo de Menezes. All participants provided written informed consent.

Inclusivity in global research

Additional information regarding the ethical, cultural, and scientific considerations specific to inclusivity in global research is included in the Supporting Information (S1 Text).

Results

Of the seventy-three patients enrolled, 65.8% (n = 48) had evidence of disability at the time of either diagnosis or first clinic visit with 39.7% (n = 29) presenting with G2D, 26% (n = 19) with G1D, and 34.2% (n = 25) without disability. About a quarter was female (27.4%, n = 20). The mean age was 51.2 years (± 14.3) and a quarter of them were above the age of 60 (n = 18, 24.7%). Of the total study population, the majority were nonwhite (76.1%, n = 53, Table 2). Despite less than half of the patients residing in a rural location (29.2%, n = 14), almost half of the total study population (45%, n = 32) lived greater than 150 km away from the reference clinic. This range of distance varied from 0 km to 574 km with an average of 151 km, with twelve patients living within the city of Belo Horizonte but many residing at the perimeter of the state (Fig 1). The monthly income was on average above the minimum wage, with only twenty patients overall earning below this benchmark. Most of our patients had received primary education or less (83.3%, n = 60) and 44 of them had a disability. Low education was

Table 2. Main demographic and clinical variables of study population, comparing those with and without disability on univariate analysis, using chi-square unless otherwise noted. Bolded p-values represent significance at a p-value <0.05.

Variable	Disability (n = 48)	No Disability (n = 25)	Total (n = 73)	P-value
Age, years (mean, SD)	53.6 (14.2)	46.7 (13.6)	51.2 (14.3)	0.048*
Age > 60 years	14 (29.2)	4 (16.0)	18 (24.7)	0.22^
Gender, n (%)				
Female	13 (27.1)	7 (28.0)	20 (27.4)	0.93
Grade of Disability, n (%)		N/A	N/A	—
Grade 1	19 (39.6)			
Grade 2	29 (60.4)			
Clinical form of leprosy, n (%)				
Borderline tuberculoid	6 (12.5)	4 (16.0)	10 (13.7)	0.88
Borderline borderline	14 (29.2)	8 (32.0)	22 (30.1)	
Borderline lepromatous	4 (8.3)	1 (4.0)	5 (6.9)	
Lepromatous	24 (50.0)	12 (48.0)	36 (49.3)	
Reaction present, n (%)	36 (75.0)	17 (68.0)	53 (72.6)	0.52
Race, n (%) (1 miss)				
Nonwhite	35 (72.9)	18 (75.0)	53 (73.6)	0.85
White	13 (27.1)	6 (25.0)	19 (26.4)	
Residence, n (%)				
Rural	14 (29.2)	4 (16.0)	18 (24.7)	0.26^
> 150 km from clinic (1 miss)	21 (44.7)	11 (44.0)	32 (44.4)	0.93
Monthly income, n (%)				
< 1 times the minimum wage	16 (33.3)	4 (16.0)	20 (27.4)	0.12^
Smoking, n (%) (1 miss)				
Yes	16 (33.3)	4 (16.7)	20 (27.8)	0.17^
Occupational class, n (%)				
Manual labor	25 (52.1)	11 (44.0)	36 (49.3)	0.56
Marital Status, n (%)				
Married	27 (56.3)	14 (56.0)	41 (56.2)	0.98
Primary education or less, n (%)	44 (91.7)	16 (64.0)	60 (82.2)	0.007

*P-value determined by t-test

^P-value determined by Fisher's exact test.

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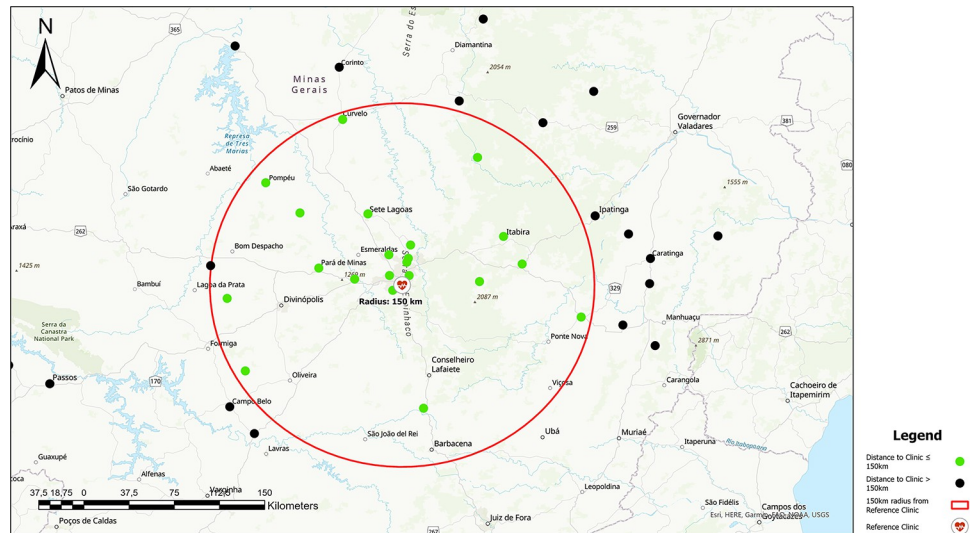


Fig 1. Map of the Brazilian state of Minas Gerais and capital city, Belo Horizonte, patient residences mapped, circle delineating 150km from reference clinic, green markers within radius (ESRI ArcMap).

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associated with disability on the univariate analysis ($P = 0.007$) as was age as a continuous variable ($p = 0.048$). Residence, income, smoking, marital class (married vs not), and occupation were not associated with disability on univariate analysis (Table 2).

Table 3 shows the multivariable logistic regression with variables left in the model after tests of collinearity, interaction, and confounding. The multivariable analysis results show that primary education or less was strongly associated with disability at an odds ratio of 6.34 (95% CI 1.37, 29.26). Patients aged 60 years or older had an odds ratio of disability of 2.10 (95% CI 0.47, 9.47), but the results were not statistically significant, controlling for other factors. The presence of leprosy reaction, rural residence, manual labor, and distance to clinic >150 km was also not significantly associated with disability (Table 3).

Discussion

In our study, we found a high proportion of patients with the MB leprosy who had grade 1 or grade 2 disability. While we did not limit our assessment to patients presenting at diagnosis, 2/3 ($n = 48$) of study participants had objective evidence of nerve impairment at the time of the study. Of those with apparent neuropathy, 60% ($n = 29$) had the most severe, G2D (Table 2). This is consistent with other studies, which show a large proportion of G2D cases at diagnosis in Brazil [24]. Of those with disability in our study, 3/4 were male ($n = 35, 72.8\%$), similar to reported findings across Brazil [14, 24, 35–37].

Table 3. Unadjusted and adjusted odds ratio of factors associated with disability (Grade 1 or 2) left in the final model. Bolded values are significant at an alpha of <0.05. *Defined as either Type 1 or Type 2 leprosy reaction.

Variable	Unadjusted OR	95% CI	p-value	Adjusted OR	95% CI	p-value
Manual labor	1.34	0.50, 3.60	0.56	0.69	0.21, 2.26	0.54
>150 km from clinic	0.96	0.36, 2.56	0.93	0.60	0.18, 1.96	0.40
Primary education or less	5.50	1.46, 20.79	0.007	6.34	1.37, 29.26	0.02*
Age ≥ 60 years	2.16	0.63, 7.45	0.22	2.10	0.47, 9.47	0.33
Presence of “reaction”	1.41	0.49, 4.09	0.53	2.09	0.63, 6.94	0.23
Rural residence	2.16	0.63, 7.45	0.22	2.22	0.52, 9.51	0.28

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The most significant finding in our study was the association between low education (primary or less) and higher occurrence of Grade 1 or 2 disability, with an adjusted odds ratio of 6.34 (95%CI 1.37, 29.26), consistent with other studies [18, 24, 28, 38, 39]. A higher education level often translates to increased health literacy and it is, therefore, not surprising that it acts as a protective factor for disability [34]. With a greater education level, patients may be more informed, have access to care, present to medical care earlier, and avoid nerve function impairment.

While our study did not show an association of disability with manual labor, those with such occupation may be at greater risk of accidental damage while working with disability [40]. Of all the sociodemographic factors, few have looked at occupational roles and types. Occupational studies in Brazil investigating leprosy have considered traditional social factors, such as the human development index and the proportion of people living in households, but none have specifically studied occupation types [34]. However, studies from Southern Asia have shown that occupations categorized as manual work have a significant association with nerve impairments, and manual laborers have significantly more leprosy disability than those with non-manual occupations [27, 41]. Our results showed no association between manual labor and disability, in contradiction to the findings of Withington, Sarkar, et al. [27]. Identifying occupational types with nerve damage could lead to directed treatment strategies of patients with higher risk of disability-related injuries. More than half of our participants had an occupational class defined as manual labor (53%), similar to other studies which have measured this variable. The fact that we did not find associations between disability and manual labor may be due to the small sample size of this study and the fact that there was a considerable amount of disability found in the study. In addition, the actual work performed by the participants may have been varied and perhaps not generalizable across contexts and countries.

Distance to reference clinic as a measure of access to care was also not associated with disability. Access to care was a hard measure to define and absolute distance may not have been an adequate measurement of access. A drive-time area map and a more detailed investigation of transportation barriers may provide a deeper understanding of accessibility. Access to care is likely an under-recognized social determinant of health in regard to leprosy leading to potential treatment delays and further disability.

Lastly, other studies have found that certain age groups are associated with disability [24, 28, 38] and have reported a trend of increased impairment with increased age [26, 27, 41]. In univariate analysis, age (as a continuous variable) was associated with disability but age was not associated with disability on the multivariable analysis. This may be due to overall similar ages of patients in this study.

Limitations of this analysis are the cross-sectional nature of the analysis and small sample size, which is often the case with leprosy given the overall rarity of the disease even in endemic areas. Since the analysis is one-point in time, causation is not possible to assess. The original scope of the study was to investigate the association of leprosy reactions with co-infections [29] but given the large burden of disability in this study sample, we chose to do an exploratory analysis of social determinants of health and disability. While the sample size was only adequate for a finding of a strong association between our primary exposure of manual labor and disability (predicted OR of 6), which we did not find, it was large enough to show the association of education and disability, (at a power of 80% and alpha of 0.05), attesting to the validity of the association in addition to the literature supporting this finding. For further study on occupation, larger samples sizes are needed. In addition, this clinic is a reference center for more severe cases and the degree of disability found may have also limited the delineation of associated factors. Lastly, stigma is an unmeasured confounder in this study and it is difficult to know how that contributed to disability in these participants.

However, our most important finding of educational links to disability supports the need for increased awareness and health campaigns to bring people to care and ensure they understand how to lessen their risk of permanent nerve damage. Also, the high proportion of low education, manual labor, and low socioeconomic status of these patients point to potential health disparities of people with leprosy in Brazil and call for more research and program implementation to address these issues.

Supporting information

S1 Text. Questionnaire on inclusivity in global research.
(DOCX)

S2 Text. Patient questionnaire.
(DOCX)

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Writing – original draft: Juan Cisneros.

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