

# Association between the degree of physical impairment from leprosy and dependence in activities of daily living among the elderly in a health unit in the State of Minas Gerais

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## ABSTRACT

**Introduction:** In addition to the common alterations and diseases inherent in the aging process, elderly persons with a history of leprosy are particularly vulnerable to dependence because of disease-related impairments. **Objective:** determine whether physical impairment from leprosy is associated with dependence among the elderly. **Methods:** An analytical cross-sectional study of elderly individuals with a history of leprosy and no signs of cognitive impairment was conducted using a database from a former leprosy colony-hospital. The patients were evaluated for dependence in the basic activities of daily living (BADL) and instrumental activities of daily living (IADL), respectively) and subjected to standard leprosy physical disability grading. Subsequently, descriptive and univariate analyses were conducted, the latter using Pearson's chi-squared test. **Results:** A total of 186 elderly persons were included in the study. Of these individuals, 53.8% were women, 49.5% were older than 75 years of age, 93% had four or less years of formal education, 24.2% lived in an institution for the long-term care of the elderly (ILTC), and 18.3% had lower limb amputations. Among those evaluated, 79.8% had visible physical impairments from leprosy (grade 2), 83.3% were independent in BADL, and 10.2% were independent in IADL. There was a higher impairment grade among those patients who were IADL dependent ( $p=0.038$ ). **Conclusions:** The leprosy physical impairment grade is associated with dependence for IADL, creating the need for greater social support and systematic monitoring by a multidisciplinary team. The results highlight the importance of early diagnosis and treatment of leprosy to prevent physical impairment and dependence in later years.

**Keywords:** Leprosy (Hansen's disease). Elderly. Dependence.

## INTRODUCTION

A subset of tropical diseases is referred to as *neglected* or *affecting neglected populations*<sup>1</sup>. Leprosy (also known as Hansen's disease in Brazil) is part of this group and can lead to physical impairment and dependence. Its history is also marked by the social stigma it causes. One such example is the mandatory isolation of leprosy patients in the 1930s for prophylactic purposes. Beginning in 1960, the Juscelino Kubitschek government began to transition from this isolationist model to decentralized outpatient care. However, this new model did not affect the residents of the leprosy colonies that

were formed during the isolationist period because they did not acquire the right to leave until the 1980s.

In Brazil, there were at least 36 known leprosy colonies/hospitals, most of which held individuals with severe physical sequelae from leprosy. The subsequent reintegration of these residents into society was extremely complex. Even after the end of compulsory isolation, many individuals chose to remain in the colonies in a metamorphosed form of isolation to avoid experiencing stigma and prejudice that might be found outside the *leprosaria*<sup>2,3</sup>. The survivors of this vertical health policy are now, for the most part, elderly and dependent.

Undiagnosed and untreated neuropathies are the most frequent cause of many disorders of the eyes, hands, and feet in persons with a history of leprosy. Even after achieving clinical cures, patients may present progressive disabilities that can lead to increased vulnerability and dependence<sup>4,5</sup>.

The majority of patients who contracted leprosy during the period of mandatory institutionalization and before the implementation of multi-drug therapy (MDT) carry burdens from the disease. These physical alterations combined with the aging process and other associated ailments often lead to frailty, dependence and loss of personal autonomy<sup>2</sup>.

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The objective of this study was to determine whether the physical impairments and disabilities linked to leprosy are associated with dependence among the elderly.

## METHODS

### Study design

This analytical cross-sectional study evaluated the association between physical impairments and disabilities caused by leprosy and dependence in the basic activities of daily living (BADL) and instrumental activities of daily living (IADL) in elderly affected by the disease.

### Study variables

The outcome variables were BADL and IADL dependence, and the explanatory variables were the standard leprosy grades.

### Study population

The sample was census-based and included elderly persons (60 years or older) with a history of leprosy registered in a former colony-hospital of the Minas Gerais State Hospital Foundation (*Fundação Hospitalar do Estado de Minas Gerais - FHEMIG*) in 2013. To eliminate the possibility of information bias, the analysis was limited to those individuals who did not present signs of cognitive deficits in the data records because this deficit is frequently associated with BADL and IADL dependence.

### Data collection

The degree of physical impairment caused by leprosy was assessed in the patient records, according to the recommendations of the Brazilian Ministry of Health (MoH)<sup>6,7</sup>. These impairments are defined using 'disability grades' by the MoH and the World Health Organization (WHO). We expressly chose to use the term 'physical impairment due to leprosy' as per the guidelines of the International Classification of Functioning, Disability and Health (ICF) given that the disability grading instrument used by the MoH describes alterations in specific body parts but not their functionality. This choice was based on the observation that a majority of authors currently refer to disability as a functional decline<sup>8</sup>.

The MoH data collection instrument to assess physical impairment from leprosy includes the following three grades: 0 indicates no problem with the eyes, hands and/or feet because of leprosy; 1 indicates reduced or lost sensation in the eyes, hands and/or feet; and 2 indicates visible damage to the eyes, hands and/or feet.

The Katz Index<sup>9</sup> was used to evaluate BADL and to determine the level of self-care of older people. This index covers numerous activities, such as bathing, dressing, toilet use, movement, continence, and eating.

We utilized the Lawton Scale<sup>10</sup> to determine IADL because it is an indicator of the capacity of elderly individuals to live alone in the community. This instrument covers activities related to household tasks and needs, such as telephone use, buying

groceries, food preparation, cleaning, laundry, transportation, medication use, and financial control.

For this study, an Excel®, (Microsoft, Redmond, Washington, EUA) database was developed to register the patient evaluations performed in the outpatient sector of a former leprosy colony hospital. The database is updated annually by a multidisciplinary team (i.e., physiotherapists, occupational therapists, psychologists, dentists, speech therapists, and social workers) using the instruments described above. These tools jointly comprise the FHEMIG network protocol for the assessment and annual monitoring of the elderly<sup>11</sup>.

### Statistical analysis

The collected data were organized in a new Excel spreadsheet specifically designed for this study. Subsequent statistical analyses were performed using the Statistical Package for the Social Sciences (SPSS) software, v.19.0, with level of significance fixed at 0.05.

The physical impairment (disability) variable, broken down by standard grading, was analyzed dichotomously. We analyzed grades 0 and 1 as a single set as per a previous study<sup>12</sup>. The variables of dependence in BADL and IADL were also analyzed dichotomously because the objective of the study was to evaluate whether there an association between disability from leprosy and dependence, regardless of the extent.

### Ethical considerations

This study was approved by the Research Ethics Committee of the FHEMIG under case number 296.757.

## RESULTS

Data were collected from 186 elderly persons between the ages of 60 and 96 years with a history of leprosy. The average patient age was 75.2 years (standard deviation -SD =8.1 years); further characterization of the study group is shown in **Table 1**.

The distribution of the elderly broken down by physical impairment because of leprosy (disability grading) and dependence levels for BADL (Katz Index) and IADL (Lawton Scale) are shown in **Table 2**. The majority of the subjects were classified as having grade 2 physical impairment because of leprosy, BADL independence, and partial dependence in IADL.

There is a statistically significant association between the impairment grade and IADL dependence. Among the IADL-dependent individuals, 81.8% were classified as displaying grade 2 leprosy impairment, whereas 61.1% of the individuals who were independent in IADL showed grade 2 impairments (**Table 3**).

## DISCUSSION

Frailty describes the condition of elderly persons with the highest risk of disability, institutionalization, hospitalization, and death<sup>13</sup>. In the national policy for older persons (*Política Nacional da Pessoa Idosa - PNPI*)<sup>4</sup>, the at-risk criteria for frailty are as follows: resident in an institution for the long-term care

TABLE 1 - Characteristics of elderly persons with a history of leprosy in a former colony-hospital of FHEMIG in 2013.

Characteristics	Frequency	Percentage
<b>Age group</b>		
older than 75 years	92	49.5
60-75 years	94	50.5
<b>Sex</b>		
female	100	53.8
male	86	46.2
<b>Type of residence</b>		
ILTC	45	24.2
individual household	141	75.8
<b>Formal education (years)</b>		
up to 4	173	93
5 to 8	9	4.8
more than 8	4	2.2
<b>Amputation of lower limbs</b>		
with amputation	34	18.6
without amputation	152	81.4
Total	186	100.0

FHEMIG: *Fundação Hospitalar do Estado de Minas Gerais*; ILTC: institution for long-term care of the elderly.

TABLE 2 - Distribution of elderly persons with a history of leprosy broken down by levels of physical impairment and dependence (BADL and IADL) in a former colony-hospital of FHEMIG in 2013.

Variable	Absolute frequency	Relative frequency
<b>Physical impairment grade (because of leprosy)</b>		
grade 0	12	6.5
grade 1	25	13.7
grade 2	146	79.8
Total	183*	100.0
<b>Katz index</b>		
independent	155	83.3
partially dependent	11	5.9
dependent	20	10.8
Total	186	100.0
<b>Lawton scale</b>		
independent	19	10.2
partially dependent	147	79.0
dependent	20	10.8
Total	186	100.0

BADL: basic activities of daily living; IADL: instrumental activities of daily living; FHEMIG: *Fundação Hospitalar do Estado de Minas Gerais*. \*Information was unavailable for three individuals (1.6%).

TABLE 3 - Univariate analysis of the association between the disability grade and the level of dependence in basic and instrumental activities of daily living among elderly persons with a history of leprosy in a former colony-hospital (FHEMIG).

Impairment grade	BADL dependence		Total	Pearson's Chi-squared test	P-value
	dependent	independent			
Grade 2	26	120	146	1.05	0.304
Grades 0 and 1	4	33	37		
Total	30	153	183*		
Impairment grade	IADL dependence		Total	Pearson's Chi-squared test	P-value
	dependent	independent			
Grade 2	135	11	146	4.31	0.038
Grades 0 and 1	30	07	37		
Total	165	18	183*		

FHEMIG: *Fundação Hospitalar do Estado de Minas Gerais*; BADL: basic activities of daily living; IADL: instrumental activities of daily living. \*No information for three (1.6%) individuals.

of the elderly (ILTC), bedridden, recently hospitalized, victim of domestic violence, amputee, and/or older than 75 years of age. Studies<sup>15,16</sup> show that frail older persons frequently present comorbidities, advanced age, functional, and/or cognitive dependence, and decreased motor activity, as well as the use of multiple medications.

Considering these descriptions, we observed that a large part of the study population fits the standard risk factors for frailty. Approximately half of the individuals were older than 75 years of age, and approximately one-quarter lived in ILTCs. Of the elderly subjects evaluated in this study, 18.6% had a partial or complete leg amputation because of leprosy. We also observed that a majority of the individuals displayed dependence in activities of daily living, specifically IADL.

In relation to the sex of the study population, we found a greater prevalence of women with a history of leprosy than that observed in other studies<sup>17,18</sup> in which there was no age discrimination. In the wider leprosy literature<sup>5,12,19</sup>, a greater prevalence is seen among men because of their more extensive social contact. It is important to consider the specificities of the group under evaluation because the literature<sup>20,21</sup> describes the feminization associated with the aging process, due to the longer life expectancy of women. Considering these aspects and the results of the study, one perceives that much as in the general population, women affected by leprosy also have greater longevity.

The progression of impairments caused by leprosy can lead to extensive chronic ulcers and severe sequelae that leave the individual unable to perform daily life activities. Thirty-four (18.6%) of the older persons studied had lower limb amputations, which is a common treatment option in leprosy cases<sup>22</sup>.

The percentage of grade 2 (79.8%) impairment of the group under review was greater than the results from other international studies in which the prevalence of grade 3 impairment varied between 17% and 50%<sup>23</sup>. Certain factors, such as the disease evolution before diagnosis and a lack of treatment with MDT and preventive follow-up, are related to a higher grade of physical impairment<sup>24,25</sup>. Nevertheless, it is important to consider the treatment history of each leprosy case. Because of their advanced ages, most of the individuals involved in this study showed signs of the disease in the period before the availability of MDT but during the time of compulsory isolation of leprosy patients. Consequently, the high percentage of grade 2 impairment reflects the absence or delay of treatment. Another aspect to be incorporated in data interpretation is the elevated frequency of physical impairment after being released from MDT treatment<sup>18</sup>. This situation occurs because in the absence of ongoing preventive care, lost sensation can evolve into a higher impairment grade. Previous studies<sup>26,27</sup> have identified the need for rehabilitative measures in conjunction with pharmaceutical interventions to reduce sequelae and to help patients to maintain maximum functional capacity.

Regarding the completion of activities of daily living, the data show that the majority of individuals were independent in BADL, as observed in other studies that characterized the

aged in general<sup>28-30</sup>. The high level of independence (83.3%) of this group, most of whom had some degree of physical impairment, exceeded the average value of older Brazilians in other studies<sup>28-30</sup> and that of patients from other Latin American and Caribbean countries<sup>31</sup>. This phenomenon might be related to greater resilience in individuals who quickly developed strategies to overcome impairment because of leprosy. More extensive patient follow-up performed by a multi-professional team and the exclusion of older persons with cognitive impairments also may have influenced the study results.

As for IADL, independence (10.2%) was lower than other findings in the literature<sup>29,30</sup>. Higher prevalences of independence were observed in research elsewhere in Brazil (33.8%), Chile (30.3%), Argentina (27.6%), and Cuba (26.7%)<sup>31</sup>. Previous studies<sup>28-31</sup> have shown that a low level of formal education, as observed among the study population, is associated with lower scores of IADL independence. This factor, linked with the socio-cultural conditions of this group, may have contributed to the greater dependence in IADL observed in the study.

The association between the degree of physical impairment and the capability to perform BADL (Katz index) was not statistically significant ( $p=0.304$ ). It was not possible to find similar studies that have examined functionality in older persons with a history of leprosy; therefore, no comparison of results could be conducted. Other studies that have evaluated leprosy disability grading and functional limitations because of leprosy using the Screening of Activity Limitation and Safety Awareness (SALSA) scale, regardless of age, did not show statistical significance<sup>12,32</sup>. However, it has been demonstrated that leprosy-related impairment interferes with the ability to complete daily life activities, even if it does not lead to a diagnosis of dependence. One presumes that functional limitation will increase along with the impairment grade. Nevertheless, it is difficult to classify this grade under the standard WHO disability scale given that patients with trophic lesions are included in the same grouping as those with wrist drop, thereby masking the results of impairment<sup>32</sup>.

The association between physical impairment grading and IADL was significant ( $p=0.038$ ), although it was not possible to find data in the literature regarding the assessment of leprosy sequelae in the elderly in relation to IADL. Studies<sup>5,33,34</sup> using the SALSA scale together with the Eye-Hand-Foot (EHF) score found a significant association between impairment and functional limitation. Therefore, it appears that there is a tendency for these patients to become less functional over time because of their impairments and comorbidities. Dependence constitutes an important risk factor for hospitalization, institutionalization, and death in an older population, and it often becomes more impactful than the diseases that lead to it<sup>35,36</sup>. The limitations in IADL contribute to social distancing and, consequently, isolationist tendencies given that IADL are related to the management of one's practical and social life<sup>35</sup>. There is a hierarchy in the process of frailty. First, independence is lost in advanced activities of daily living, and this loss is followed by a loss of independence in IADL and, finally, BADL. Therefore, the study results indicate that the older people in this study are

vulnerable to becoming dependent in BADL. The follow-up and rehabilitation of these patients are essential to prevent disabilities and preserve independence, autonomy and quality of life. In this sense, studies have shown that higher degrees of impairment are directly related to poor quality of life, even among individuals who are clinically cured<sup>37,38</sup>.

This study has certain limitations given that it uses secondary data on the impairment and dependence of older persons (with a history of leprosy) who resided in a former leprosy colony hospital and received care from a multidisciplinary team. These characteristics make any inference impossible for elderly persons affected by leprosy without similar multi-professional care and rehabilitation. Additional research on the functional capacity of older persons affected by leprosy is necessary to analyze how the impairments caused by this disease are associated with functional dependence, including other possible variables associated with this outcome. With more information, it should be possible to focus public policy and rehabilitation projects towards the promotion of an aging process with higher quality of life, preserved independence, and greater autonomy.

Physical impairment because of leprosy is associated with greater dependence in instrumental activities of daily living. This dependence necessitates increased social support and systematic follow-up by a multidisciplinary team. The results reported in this study highlight the importance of early diagnosis and treatment for leprosy to prevent physical impairment and dependence later in life.

## CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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