



## Coping strategies, limitation of daily activities and social participation of elderly people who have or have had Leprosy

### *Estratégias de enfrentamento, limitação de atividades diárias e participação social de idosos que têm ou tiveram hanseníase*

### *Estrategias de afrontamiento, limitación de las actividades cotidianas y participación social de las personas mayores que tienen o han tenido Lepra*

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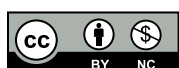
#### ABSTRACT

**Objective:** Evaluate the limitation in carrying (coping) out activities of daily living, social participation and coping strategies of elderly people who have or have had leprosy. **Method:** Were evaluated seventy participants in a Leprosy Reference Center in Brazil, aged sixty years or older in 2017. Sociodemographic and clinical data were collected, as well as the assessment of the World Health Organization's Degree of Disability, and the Salsa, Social Participation and Coping Inventory protocols were applied. The data was entered into an Excel spreadsheet and analyzed using the Epi Info 7.2.6.0 statistical program. **Results:** Among the aged, 91.4% had limitation in daily activities, 48.6% with restrictions on social participation and 64.3% with disability grade 2. The most used coping strategies were: "positive feedback" (70%), "self-control" (67.2%), "problem solving" (65.7%), "social support" (65.7%) and "removal" (62.9%). The prolonged living time and functional adaptation to their activities may justify the use of positive coping strategies, even in the presence of physical disabilities and limitations in daily activities and social participation. **Conclusion:** The data obtained can help the healthcare team to plan and execute effective actions of prevention and rehabilitation, for the elderly achieve better quality of life.

**Descriptors:** Leprosy; Aged; Social participation; Everyday activities; Public Health.

#### RESUMO

**Objetivo:** Avaliar a limitação na realização de atividades de vida diária, a participação social e as estratégias de enfrentamento (coping) de idosos que têm ou tiveram hanseníase. **Método:** Foram avaliados 70 participantes em um centro de referência para hanseníase na região Sudeste no Brasil, com 60 anos ou mais no ano de 2017. Coletaram-se dados sociodemográficos e clínicos, Grau de Incapacidade da Organização Mundial de Saúde, e aplicaram-se os protocolos SALSA, Participação Social e Inventário



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de Coping. Os dados foram digitados em planilha Excel e analisados no programa estatístico Epi Info 7.2.6.0. **Resultados:** Dentre os idosos, 91,4% tinham limitação nas atividades diárias, 48,6% com restrições à participação social e 64,3% com grau de incapacidade 2. As estratégias de enfrentamento mais utilizadas foram: “reavaliação positiva” (70%), “autocontrole” (67,2%), “resolução de problemas” (65,7%), “suporte social” (65,7%) e “afastamento” (62,9%). O tempo de convivência prolongado e a adaptação funcional às suas atividades podem justificar a utilização das estratégias de enfrentamento positivas, mesmo na presença de deficiências físicas, limitações nas atividades diárias e participação social. **Conclusão:** Os dados obtidos podem auxiliar a equipe de saúde no planejamento e execução de ações mais eficazes de prevenção e reabilitação, a fim dos idosos alcançarem melhor qualidade de vida.

**Descritores:** Hanseníase; Idoso; Participação social; Atividades cotidianas; Saúde pública.

## RESUMEN

**Objetivo:** Evaluar la limitación en la realización de actividades de vida cotidiana, la participación social y las estrategias de afrontamiento (coping) de ancianos que tienen o tuvieron lepra. **Método:** Fueron evaluados 70 participantes en un centro de referencia para lepra en la región Sudeste de Brasil, con 60 años o más en el año de 2017. Fueron recogidos datos sociodemográficos y clínicos, Grado de Discapacidad de la Organización Mundial de la Salud, y fueron aplicados los protocolos SALSA, Participación Social e Inventario de Coping. Los datos fueron digitados en hoja Excel y analizados en programa estadístico Epi Info 7.2.6.0. **Resultados:** Entre los ancianos, 91,4% tenían limitaciones en las actividades cotidianas; 48,6% con restricciones a la participación social y 64,3% con grado de discapacidad 2. Las estrategias de afrontamiento más utilizadas fueron: “revaluación positiva” (70%), “autocontrol” (67,2%), “resolución de problemas” (65,7%), “soporte social” (65,7) y “alejamiento” (62,9%). El tiempo alargado de convivencia y la adaptación funcional a sus actividades pueden justificar la utilización de las estrategias de enfrentamiento positivas, aunque en la presencia de discapacidades físicas, limitaciones en las actividades cotidianas y participación social. **Conclusión:** Los datos obtenidos pueden ayudar al equipo de salud en la planificación y ejecución de acciones más eficientes de prevención y rehabilitación, con el objetivo de los ancianos obtengan mejor calidad de vida.

**Descriptores:** Lepra; Anciano; Participación social; Actividades cotidianas; Salud pública.

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## INTRODUCTION

The number of elderly people is constantly expanding, both in developed countries and in developing countries, as is the case in Brazil<sup>(1)</sup>. With a total elderly population of 32,113,490, by 2022, 55.7% of whom are women and 44.3% of whom are men, starting from the parameter of 60 years or older for the aging index. Thus, it is understood that the higher the value of the indicator in the population, the older it is. In 2022, the elderly represented 15.8% of the total population<sup>(2)</sup>.

In addition to the changes that come with aging, some diseases become the main causes of morbidity, disability and mortality in the elderly population. Some of these pathologies can cause physical limitations, such as Parkinson's<sup>(3)</sup>, Alzheimer<sup>(4)</sup>, stroke<sup>(5)</sup>, heart attack<sup>(6)</sup> and risk of falls<sup>(7)</sup>.

Among tropical diseases, leprosy can also cause disabilities and impairments. Thus, although this disease is not included in the list of pathologies typical of the elderly, the people affected by this disease may have physical disabilities in their hands, nose, eyes and feet, as well as experience situations of rejection, stigma and prejudice, as a result of the diagnosis and treatment.<sup>(8)</sup>

Leprosy is an infectious disease, with prolonged evolution and potential for incapacitation, caused by the bacterium *Mycobacterium leprae* and which has a preference for skin cells and peripheral nerves, resulting in sensory, autonomic and motor changes.<sup>(9)</sup> This disease represents a public health problem in Brazil. With the impacts of the post-pandemic on health services, in 2022, 19,635 new cases of the disease were registered and, of these, 8,698 (44.3%) cases began treatment with some physical change or disability in the eyes, hands and/or feet.<sup>(10)</sup> Despite the reduction in the number of new cases in recent years, the country still ranks second in the world with a detection rate of 9.67 per 100,000 inhabitants.<sup>(10)</sup>

Early diagnosis is an important factor in preventing disabilities and controlling the disease. The affected person experiences decreased or loss of sensitivity, sweating, skin lubrication and muscle paresis/paralysis, which can compromise hand function and gait, and consequently interfere with the performance of activities of daily living

(ADLs)<sup>(11)</sup>. Faced with this problem and due to low self-esteem, loss of autonomy, emotional deprivation and lack of opportunities to work, there may be a decrease in social participation related to family and professional life, and a reduction in the intensity of social and religious activities in the community to which the individual belongs.

This condition can generate feelings of insecurity and less worthiness in the individual<sup>(12)</sup>. Therefore, issues such as disability, activity limitation and restriction of social participation must be considered to assess the health status of a person who has or has had leprosy.

Because they are validated, the Salsa Scale (Screening of Activity Limitation and Safety Awareness) and the Social Participation Scale are being applied in different sociocultural scenarios, in order to understand the patient with leprosy, integrally, allowing a better understanding of the physical limitation and social restriction in leprosy patients in treatment and post-discharge<sup>(13)</sup>.

The way a patient deals with a diagnosis of leprosy and the problems arising from the disease will depend on the type of coping he or she uses in his or her daily life. Coping consists of a combination of cognitive and behavioral efforts that can be used by the individual when dealing with specific demands and stressful situations that may be beyond the resources available to the individual<sup>(14)</sup>. In the literature, there are some studies that have identified coping strategies in individuals with chronic diseases, such as diabetes<sup>(15)</sup>, oncology<sup>(16)</sup> and dermatological diseases<sup>(17)</sup>. However, there was a lack of studies that evaluate the coping strategies used by elderly people with leprosy<sup>(18)</sup>, as well as making it possible to understand the relationship between the importance of performing daily activities, social participation and the type of coping strategy used by the elderly. In addition, there is a gap in knowledge regarding the effect of visible disabilities (GIF 2) on the performance of daily activities, social participation and coping strategies used by the elderly.

Therefore, the objective of this study is to evaluate the limitation in carrying out activities of daily living, social participation and coping strategies of elderly people who have or have had leprosy.

## METHOD

This is a descriptive cross-sectional study. Data were collected through interviews and assessment of leprosy cases treated at the Lauro de Souza Lima Institute (ILSL). The ILSL is located in the city of Bauru, with a population of around 380,000 inhabitants, and is located in the interior of the state of São Paulo. The Institute was created in 1933 and named Asilo Colônia Aymorés, a leprosarium, and in 1989 it became a Research Institute. Currently, the Lauro de Souza Lima Institute is a reference in the treatment of leprosy cases for Latin America.

Seventy elderly people affected by leprosy, whether undergoing completed or not drug treatment, with polychemotherapy (PCT), were evaluated, being monitored at the Lauro de Souza Lima Institute (ILSL), Bauru, SP, in 2017, aged 60 years or older, as defined in the Elderly Statute<sup>(19)</sup>. Elderly individuals of both sexes were evaluated, regardless of the clinical form of the disease and the World Health Organization disability grade (GIF-WHO). Thus, the sample was constituted by convenience.

Institutionalized elderly patients and those with intellectual impairment that could hinder communication and understanding with the interviewer were excluded.

To characterize the population studied, a questionnaire was used with personal and clinical data on the disease, collected from the patients' medical records, with authorization from the head of the ILSL medical and statistical archiving service.

All patients were evaluated and the WHO-GIF was established, according to the standards defined by the World Health Organization (WHO). Disability was classified by the highest degree observed in the examination of the eyes, hands and feet: disability grade zero (GIF 0) – no disability related to leprosy; disability grade one (GIF 1) – decreased muscle strength and/or loss of protective sensitivity; and GIF 2 – visible disabilities caused by leprosy.<sup>(20)</sup>

Limitations in performing ADLs were obtained through individual assessment of selected cases using the SALSA Scale, which measures activity limitations in individuals affected by diabetes mellitus, leprosy or other peripheral neuropathies. The application of this Scale is recommended by the National Leprosy Control Program<sup>(21)</sup> and covers four defined domains, based on the ICF (International Classification of Functioning): mobility; self-care; work; dexterity; and an issue related to visual acuity. The cutoff point to indicate activity limitation was considered to be a score  $\geq 25$ , with 10-24 (no limitation); 25-39 (mild); 40-49 (moderate); 50-59 (severe); 60-80 (very severe)<sup>(22)</sup>.

The study subjects also answered questions from the Social Participation Scale, which aims to measure restrictions

on social participation of people affected by leprosy, disabilities and other stigmatizing conditions. This instrument covers eight of the nine domains of the activity and participation component of the International Classification of Functioning (ICF) and is composed of 18 items, with scores ranging from 0 to 90. The eight domains consist of: application of knowledge; communication; mobility; personal care; domestic life; interpersonal interactions; main areas of life; community, social and civic life. The degrees of restriction are classified as: no restriction (0 to 12), mild (13 to 22), moderate (23 to 32), severe (33 to 52) and extreme (53 to 90)<sup>(12,21)</sup>.

Through the Coping Strategies Inventory, it was possible to assess how the patient deals with stressful events resulting from the physiological changes brought about by the disease. The instrument consists of phrases that represent thoughts and actions that may or may not be used by the participants. It was proposed by Folkman & Lazarus in 1985 and translated into Brazilian Portuguese<sup>(23)</sup>. The Scale consists of eight different factors, each assessing the way the individual uses coping strategies: confrontation, withdrawal, self-control, social support, acceptance of responsibility, escape-avoidance, problem-solving, and positive reappraisal. The intensity of the use of strategies can be defined by means of a Scale present in the instrument. This ranges from 0 to 3 points, with 0 being – I did not use this strategy; 1 – I used it a little; 2 – I used it a lot; and 3 – I used it a lot. Therefore, the higher the score, the more the individual uses the strategy. These strategies can be assessed as positive or negative<sup>(23)</sup>.

The authors of this study classified Lazarus and Folkman's Coping Strategies as positive and negative, according to the definitions mentioned in the literature<sup>(23)</sup>. The positive categories were classified as: (a) problem solving (problem solving based on one's attitudes, being able to deal with environmental pressures); (b) acceptance of responsibility (individual engagement in the problem solving/treatment process); (c) positive reappraisal (control of emotions related to sadness, reinterpreting the conflicting situation and generating personal growth); (d) social support (seeking support from people and the environment); negative categories: (e) distancing (the individual avoids confronting the threat, denying the facts); (f) self-control (seeking to control emotions when faced with stressful stimuli); (g) confrontation (based on the individual's active and offensive attitude towards the stressor); (h) escape/avoidance (imagining solutions to the problem, without actually taking concrete steps to solve the situation)<sup>(23)</sup>.

To analyze the coping instrument, the responses (0 to 3) for each strategy were added together and their average calculated. It was considered that the higher the average, the greater the individual's use of the strategy<sup>(23)</sup>.

The data from the instruments were analyzed with EPI-INFO, Version 7.1.1.0, using descriptive statistical analysis to characterize the case series. The Chi-square or Fisher's test was used to verify the association of categorical variables. The Kruskal-Wallis test was used to compare means, considering p-values < 0.05 as significant.

After approval by the Scientific Committee and the Research Ethics Committee of the Lauro de Souza Lima Institute, the researchers invited patients undergoing treatment at the Dermatology and Rehabilitation Outpatient Clinic to participate in this study, providing explanations related to the objectives and clarifying any doubts. Those who agreed to participate in the research signed the Free and Informed Consent Form (FICF) and were individually taken by the researchers to the Occupational Therapy or Psychology Sector to apply the assessment instruments described above. The application of these instruments lasted approximately 60 minutes.

This study was approved by the Research Ethics Committee of the Lauro de Souza Lima Institute (CAAE: 74622917.0.0000.5475) and protocol number 2.334.686, according to the terms of Resolution No. 196/96 and No. 466/2012 of the CEP/CONEP/CNS/MS, National Commission for Research Ethics, which regulates the ethical aspects of research involving human beings. All participants signed the Free and Informed Consent Form.

## RESULTS

The age of the participants in this study ranged from 60 to 93 years, with a mean of 69.4 (SD 8.09). Data regarding gender, level of education, marital status, current occupation, family income, housing, time since diagnosis, treatment completed, operational classification and degree of disability are shown in Table I.

**Table I** – Distribution of sociodemographic and clinical data of participants (n=70), Bauru, São Paulo, Brazil, 2017.

Sociodemographic and clinical data (N=70)	Features	n	%
Gender	Masculine	47	67.1
	Feminine	23	32.9
Age	60 to 79 years old	62	88.6
	≥ 80 years old	8	11.4
Level of education	Literacy (reads and writes)	4	5.7
	Incomplete elementary school	40	57.1
	Complete elementary school	7	10.0
	Incomplete high school	1	1.4
	Complete high school	5	7.2
	Higher education	4	5.7
	Signs name	5	7.2
Current occupation	Illiterate	4	5.7
	Salaried employee	0	0
	Self-employed	3	4.3
	Student	0	0
	Household help	3	4.3
	Retired	53	74.8
	On sick leave	7	10.0
Marital status	Unemployed	4	5.7
	Widowed	16	22.9
	Divorced	8	11.4
	Stable civil union	3	4.3
Lives with	Single	11	15.7
	Married	32	45.7
	Alone	14	20.0
Family income	Parent	1	1.4
	Spouse	33	47.1
	Others	22	31.4
Operational classification	0 to 2 minimum wages	55	78.6
	3 to 4 minimum wages	11	15.7
	5 or more minimum wages	4	5.7
Diagnostic time	Multibacillary	61	87.1
	Paucibacillary	9	12.9
	≤ 5 years	23	32.8
Treatment completed	>5 to ≤ 20 years	17	24.3
	>20 years	30	42.9
GIF-OMS Maximum	Yes	56	80.0
	No	14	20.0
	0	3	4.3
	1	22	31.4
	2	45	64.3

In Table II, the majority of the elderly (65.7%) demonstrated, on the SALSA Scale, mild to moderate limitation in ADLs and 25.8% severe to extreme limitation in their ADLs. The results of the Social Participation Scale show that 51.4% of the elderly were classified as “no social restriction”, 31.4% presented “mild to moderate restriction” and 17.2% with “severe restriction”.

**Table II** – Frequency of classification of SALSA Scale and Participation Scale scores of elderly individuals who had or have leprosy. (n=70). Bauru, São Paulo, Brazil, 2017.

SALSA SCALE										
Classification	No limitation				With limitation of activities					
	No limitation (10-24)		Slight Limitation (25 – 39)		Moderate Limitation (40 – 49)		Serious Limitation (50 – 59)		Extreme Limitation (60 – 80)	
	n	%	n	%	n	%	n	%	n	%
	06	8.5	32	45.7	14	20.0	09	12.9	09	12.9

SOCIAL PARTICIPATION SCALE										
Classification	No restriction				With restriction on social participation					
	No restriction (0 – 12)		Slight Restriction (13 – 22)		Moderate Restriction (23 – 32)		Serious Restriction (33 – 52)		Extreme Restriction (53 – 90)	
	n	%	N	%	n	%	n	%	n	%
	36	51.4	17	24.3	05	7.1	12	17.2	0	-

Table prepared by the authors of this study

There was an association between social restriction and activity limitation, showing that having activity limitation is associated with having restriction on social participation (p-value 0.00).

Regarding the Coping Inventory (Table III), the most used positive strategies were “positive reappraisal” (70%), “problem solving” (65.7%) and “social support” (65.7%), and the most used negative strategies were “self-control” (67.2%) and “withdrawal” (62.9%), regardless of the intensity in which each strategy was used (little; mostly; or almost always). Among the “little used” positive strategies, “acceptance of responsibility” (62.9%) predominated, and as for the negative ones, “escape-avoidance” (57%) and “confrontation” (52.9%) prevailed.

In Table III, when associating coping strategies with current occupation, it was identified that the average of the “social support” strategy is higher in retirees (10.7) and those on sick leave (14.1), but it is not significant when compared to self-employed workers (9.3), domestic helpers (8.6) and unemployed (8.7) (p-value=0.18). Regarding the average of the “responsibility acceptance strategy”, it is higher in retirees (7.3), those on sick leave (7.6) and unemployed (7.0), but it is not significant when compared to the self-employed (2.3) and housewives (4.0) (p-value = 0.36). The average of the “problem-solving strategy” is higher in individuals who perform housewives (13.0), self-employed (13.0) and those on sick leave (12.7), but it is not significant when compared to retirees (10.7) and unemployed (6.5) (p-value = 0.67). The average of the “positive reassessment” strategy varied from 10.0 to 15.2, being lower among self-employed workers and higher among retirees (p-value=0.49).

Individuals with higher education seem to use the “escape/avoidance” strategy less, when compared to people with less education (p-value=0.03), and, on average (8.0), they use the “self-control” strategy less. Therefore, the result clearly shows that those with more education seem to use the “escape/avoidance” strategy less.”.



**Table III** – Average of positive and negative coping strategies associated with the variables studied in elderly individuals who had or have leprosy (n=70). Bauru, São Paulo, Brazil, 2017.

	Variables (N=70)	Coping Strategies – Factors Average							
		Positive				Negative			
		RProb	AR	RP	SS	A	AC	C	FE
Current occupation	Self-employed (n=3)		9.0					10.3	
	Household items (n=3)		13.3					12.7	
	Retired (n=53)		13.5					13.2	
	Absent due to illness (n=7)		14.7					10.3	
	Unemployed (n=4)		15.5					14.7	
	p-value*		0.24					0.72	
Lives with	Alone (n=14)		13.1					11.8	
	Spouse/ Father and Mother (n=33/1)		14.4					13.8	
	Others (n=22)		12.5					11.9	
	p-value*		0.17					0.20	
Diagnostic time	Up to 5 years (n=23)		14.1					11.9	
	6 to 15 years (n=13)		15.0					14.3	
	16 years or more (n=34)		12.7					12.9	
	p-value*		0.65					0.60	
Level of education	Literate (n=13)		14.0					13.5	
	Incomplete and complete elementary school (n=47)		13.9					12.8	
	Incomplete and complete high school (n=6)		14.8					13.0	
	Higher education (n=4)		6.3					11.0	
	p-value*		0.99					0.72	
GIF-OMS Maximum	0 (n=3)		12.7					15.0	
	1 (n=22)		15.7					12.9	
	2 (n=45)		12.6					12.7	
	p-value*		0.36					0.81	
Activity limitation (SALSA Scale)	No limitations (n=6)		14.5					14.2	
	Mild and moderate limitation (n=46)		12.8					13.3	
	No severe and very severe limitation (n=18)		15.2					11.2	
	p-value*		0.9					0.8	
Social Participation Scale	No restrictions		12.9					13.3	
	Mild and moderate restrictions		13.8					12.1	
	Large and extreme restrictions		15.0					12.6	
	p-value*		0.8					0.9	

Legend: RProb – Problem Solving; AR – Acceptance of Responsibility; RP- Positive Reappraisal; SS – Social Support; A – Withdrawal; AC – Self-Control; C – Confrontation; FE – Escape and Avoidance

\*Kruskal-Wallis Test

Table prepared by the authors

Large and extreme restrictions

In Table IV, it was found that the average score on the Social Participation Scale doubles from Grade 0 to Grade 1 and decreases slightly from Grade 1 to Grade 2 (p-value=0.45). However, on the SALSA Scale, the more severe the individual's physical disability (GIF-WHO 1 and 2), the greater their limitation in daily activities (p-value=0.01).

**Table IV** – Average scores of the Social Participation Scale and SALSA Scale according to the WHO Disability Levels. Bauru, São Paulo, Brazil, 2017.

	Grade 0	Grade 1	Grade 2	p-value
Social Participation Scale	8.3 (DP 9.3)	16.8 (DP 15.8)	16.4 (DP 13.1)	0.45*
SALSA Scale	27.7 (DP 3.8)	36.4 (DP 14.7)	44.3 (DP 13.4)	0.01*

\*Kruskal –Wallis test

When associating GIF-WHO with the Social Participation Scale and SALSA, it was observed that patients with mild disabilities (GIF-WHO 0 and 1) present, in percentage terms, more restriction in social participation and less limitation of activities (p-value = 0.62). While patients with severe disabilities (GIF-WHO 2), in addition to presenting restriction in social participation, also present limitation of activities (p-value = 0.01).

**Table V** – Association between Social Participation measured by the Social Participation, Activity Limitation Scale (SALSA) and World Health Organization Disability Levels in the elderly. Bauru, São Paulo, Brazil, 2017.

		Grade 0 (n=3) and Grade 1 (n=22)	Grade 2 (n=45)	p-value
<b>Social Participation Scale</b>	No restriction on social participation (n=36)	14 (20%)	22 (31.4%)	0.62*
	With restriction on social participation (n=34)	11(15.7%)	23 (32.8)	
<b>SALSA Scale</b>	No limitation activities	19 (27.1%)	19 (27.1%)	0.01*
	With limited activities	6 (8.6%)	26 (37.1%)	

Table prepared by the authors

## DISCUSSION

In the present study, the percentage of elderly men was predominant (67.1%). Among the 254,918 new cases of leprosy in Brazil, the majority are also men (55.6%). In 2022, the sex ratio (M:F) increased to 1.3, that is, 13 men for every ten women<sup>(10)</sup>.

The diagnosis time of the elderly was late, over 20 years, demonstrating that the disease may have been contracted during adulthood/productive age. In the literature, there are some situations that justify the delay in the diagnosis of the disease: difficulty in accessing health services; lack of knowledge of professionals about the signs and symptoms of the disease; fear of the patient being socially stigmatized; and late diagnosis, due to mistaken diagnoses.<sup>(24)</sup> In this context, the authors of a study carried out in 2020 identified that healthcare users made 26 consultations to obtain a leprosy diagnosis, in which the average number of consultations to seek healthcare services was almost eight times until the professional presented the leprosy diagnosis<sup>(25)</sup>.

The data obtained in this study indicate that there is a predominance of literate individuals (read and write), but who do not have completed elementary school. In the literature, this is one of the characteristics of the epidemiological profile of leprosy, individuals with a low level of education and knowledge about the disease. In leprosy, the variable “education” is directly associated with existing social inequalities and a population with a per capita family income equal to or less than two minimum wages, with four or more people living in the same space<sup>(26)</sup>, precarious work and low access to assistance programs<sup>(27)</sup>.

The fact that the elderly individuals evaluated were enrolled in a rehabilitation program linked to a leprosy reference center, with a diagnosis time between 5 and 20 years, may explain the occurrence of physical disabilities with GIF 1 and GIF 2 (late diagnosis). In the period from 2013 to 2022, the literature describes that the proportion of



new leprosy cases with GIF 2 totaled 19,218 cases. At the time of the user's diagnosis, the proportion of new leprosy cases with GIF 2 increased from 7.3% (year 2013) to 11.5% (2022), considered a "high" parameter.<sup>(10)</sup>

The multibacillary operational classification was predominant among the elderly individuals investigated in this study. Generally, leprosy transmission occurs through a person who has the multibacillary form and is likely to develop visible physical disabilities (GIF 2). Epidemiological data reveal that, in 2022, the proportion of new multibacillary cases increased to 81.2%, compared to 64.4% in 2013, with a percentage increase of 26.1%.<sup>(10)</sup>

In the present study, it was found that almost all (91.5%) presented some type of limitation in ADLs. However, the elderly perform the activities independently, but with altered grip and gait patterns, resulting from sensory and motor problems. These results corroborate some studies, mainly due to the fact that the participants presented some type of limitation in ADLs and GIF 2.<sup>(28,29)</sup>

Regarding the assessment of social participation, it was observed that almost half of the elderly (48.6%) presented some type of restriction on social participation. Of these, 24.3% presented moderate to severe restriction. When physical disabilities (GIF 1 and GIF 2) are installed or incapacities manifest themselves, the consequences have repercussions not only on daily activities (mobility, self-care, dexterity and manual work), but also have a negative impact on social interactions, leading individuals to social isolation.<sup>(30,31)</sup>

Therefore, in the present study, the data showed that limitation of physical activities led to restriction of social participation. Other studies have also revealed that limitation of activities is common among leprosy patients and was associated with restriction of social participation and advanced age.<sup>(32,33)</sup>

When evaluating positive coping strategies with a percentage above 50%, through the Coping Inventory, "positive reappraisal" was the strategy most used by participants. Elderly people have lived for years or decades with problems resulting from leprosy and were monitored by a multidisciplinary team, which can bring new perspectives and the need to reframe. A study carried out with leprosy patients also used this same strategy more frequently<sup>(18)</sup>. Individuals who use this strategy seek to focus on the positive aspects of solutions, alleviate the emotional burden of conflicts and reflect before acting impetuously<sup>(34)</sup>.

As the second most used strategy, "problem solving" presupposes more appropriate planning to deal with conflict situations with greater adaptive quality. This strategy denotes the elderly person's ability to resolve the difficulties experienced in living with leprosy and the ability to resolve a poorly resolved problem<sup>(35)</sup>. It is interesting to note that in another study, whose sample consisted of adults in the productive phase<sup>(18)</sup>, the "problem-solving" strategy was also one of the most used by those interviewed.

The "social support" strategy was the third most used, in which the individual finds help in the environment and in people to face stigma, difficulties and physical limitations. This strategy includes seeking social support to find solutions, emotional support from friends and family and professional support<sup>(17)</sup>. "Social support" represents a source of support and integration, through the constant coexistence of patients with friends, family and the health team itself<sup>(18)</sup>.

The least used positive strategy in this study was "acceptance of responsibility". It is assumed that the frequent use of the "withdrawal" and "escape-avoidance" strategies are ways of not admitting and not taking responsibility for the problems arising from leprosy, such as fear of transmitting the disease, fear of rejection and social discrimination, fear of losing one's job, feeling of incapacity, among others.

The most commonly used negative strategy in this study was "self-control" (67.2%), a percentage close to that found in another study (72.7%)<sup>(18)</sup>. This strategy is considered negative because the patient has difficulty sharing his/her problems with other people, seeking to control and contain himself/herself, the people and the conditions of the environment around him/her<sup>(36)</sup>. Exercising self-control in the face of possible weaknesses caused by the disease allows the elderly to avoid society perceiving them as having little vitality or weakness<sup>(37)</sup>.

In this context, health promotion seeks to consolidate public health policies, develop a strategy to fight leprosy and its complications, as well as combat discrimination, prevent disabilities and promote the inclusion of users who are monitored by the leprosy program<sup>(38,39)</sup>.

This study aims to contribute to health promotion by supporting health professionals working in the leprosy program, with the aim of updating their knowledge on how to approach patients who have or have had leprosy, contributing to the elimination of the disease and reintegrating users who have completed polychemotherapy into family life and social interaction. To this end, it is necessary to invest in continuing health education, addressing content related to clinical aspects, treatment, epidemiology and rehabilitation, in order to establish a flow of care, understanding the

real needs of the individual and solving their problems. In these cases, the use of participatory methodology seems to be a promising approach for building a new reality<sup>(40)</sup>.

Thus, this study has the limitation of having evaluated elderly individuals who have or have had leprosy and who sought treatment for their comorbidities at a reference center in Latin America. Therefore, these elderly individuals may have previously known about the disease and the limitations caused by it, learning to overcome physical and emotional difficulties through health education. Expanding this study to include elderly individuals from other regions of Brazil and the world who may not have had professional monitoring and family support may therefore offer new perspectives and results on the subject.

## CONCLUSION

Physical disabilities, activity limitations and restrictions on social participation were present in a high percentage of elderly individuals who have or have had leprosy. On the other hand, the coping strategies most used by the elderly individuals evaluated were positive, which can be justified by the time they have lived with the disease and its progression, during the process of redefining the experience with leprosy and the limitations acquired in an attempt to overcome them or modify their habits, their daily routine and quality of life.

Limitations in activities of daily living (ADLs) can restrict social participation, as the patient avoids social interaction due to difficulties or inability to perform daily activities that require preserved neural functions, such as mobility, functionality and physical contact.

Finally, identifying coping strategies in the elderly can help in the investigation of psychological and social factors that interfere in their daily lives, enabling health professionals, with this knowledge, to plan more effective prevention and rehabilitation actions in leprosy.

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## CONTRIBUTIONS

**Gabriela Teixeira Ribeiro de Oliveira, Isabela Boconcelo, Lucia Helena Soares Camargo Marcian and Renata Bilion Ruiz Prado** participated in the conception and design of the project; collection, analysis and interpretation of data; writing of the manuscript text and final review. **Susilene Maria Tonelli Nardi** participated in the analysis and interpretation of data; writing of the manuscript text and final review. All authors approved the final version to be published.

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