

## HEALTH LITERACY OF PEOPLE UNDERGOING TREATMENT FOR LEPROSY IN AN ENDEMIC MUNICIPALITY IN THE AMAZON REGION

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### Highlights:

1. Women, older people, brown people, and low schooling were associated with inadequate health literacy.
2. Health literacy was correlated with mastery of written information.
3. Health actions should take into account the profile of people undergoing treatment for leprosy.

PRE-PROOF

(As accepted)

This is a preliminary, unedited version of a manuscript that has been accepted for publication in *Revista Contexto & Saúde*. As a service to our readers, we are making this initial version of the manuscript available, as accepted. The article will still be reviewed, formatted, and approved by the authors before being published in its final form.

<http://dx.doi.org/10.21527/2176-7114.2024.49.15285>

### How to cite:

Da Silva RG, Nogueira LMV, dos Santos MYS, Rodrigues ILA, Pinheiro AKC, de Farias SNP. Letramento em saúde de pessoas em tratamento para hanseníase em município endêmico da região amazônica. *Rev. Contexto & Saúde*, 2024;24(49): e15285

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## **ABSTRACT**

**Objective:** To evaluate the Functional Health Literacy of people undergoing treatment for leprosy in the Amazon context. **Method:** Quantitative, observational, descriptive study carried out with 23 people undergoing treatment for leprosy in municipal health units and family health strategies in two administrative districts of Belém-PA, from March to May 2023. The Health Literacy Test questionnaire was used. The data was double-entered into a database in Epi-Info 7.2, processed in the Statistical Package for the Social Science 28.0, and analyzed by variance and Spearman's correlation considering the sociodemographic variables and the score obtained in the TLS. A p-value  $\leq 0.05$  was considered. **Results:** Adequate and limited literacy in males, inadequate in females, and significant in browns. People who completed high school had adequate literacy and those with elementary school had insufficient literacy. Adults had adequate literacy and the elderly had inadequate literacy. There was a statistical association between functional health literacy and the level of difficulty in reading medication packaging, understanding written information, self-management, and empowerment. **Conclusion:** The findings point to the need for health education actions that value the profile of people undergoing treatment for leprosy, as well as investment by the education sector to offer schooling to the entire population.

**Keywords:** Health literacy; Treatment; Leprosy.

## **INTRODUCTION**

According to the World Health Organization (WHO)<sup>1</sup>, Health Literacy (HL) is a Social Determinant of Health (SDH) and is related to an individual's ability to find, communicate, process, and understand information about health and how services work. HL is what the person understands about their health condition and how the service works, the actions, and activities made available by the public authorities in this area, covering concepts from the definition of disease to the structure of the care network<sup>2,3</sup>.

There are three main divisions of HL: functional, interactive, and critical. Functional Health Literacy (FHL) corresponds to basic writing and reading skills that work effectively in

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everyday life; Interactive is characterized by the relationship between cognitive skills and more developed literacy which, together with social skills, enable active participation in everyday activities, obtaining information and applying it through different forms of communication in various contexts; and Critical refers to more advanced cognitive skills which, also associated with social skills, enable critical analysis of information and greater control over decision-making<sup>4</sup>. FHL was chosen for this study.

There are also two types of HL: individual and community. The individual expresses a person's ability to understand and apply health information, based on their self-care. Community LS refers to the collective's ability to signal the responsiveness of institutions towards users. Both forms of HL are related to specific health knowledge needs for conscious and qualified decision-making<sup>1</sup>. The conceptions of individual HL and community HL go beyond cognitive skills, as they encompass the interaction of all SDH and the mapping of health conditions at the family, community, and civil society level<sup>5</sup>.

In the context of individual HL, shared health information is important for users to understand the process of becoming ill, transmission, diagnosis, treatment, prevention, and self-care. Low HL is prevalent in low- and medium-development countries, which contributes to higher incidence rates of some diseases and non-adherence to treatment, as people do not adequately process important information to achieve success in control measures<sup>6</sup>.

It is accepted that HL is a pillar of health promotion, since through improved access to information people can make more informed decisions about their health and that of their families<sup>1</sup>. Thus, lack of knowledge about a certain disease, its causes, mode of transmission, and consequences can result in late diagnosis, as well as non-adherence to treatment, resulting in an unsatisfactory prognosis and possible sequelae, as is the case with leprosy<sup>7</sup>.

Classified as an infectious-contagious disease transmitted through prolonged and frequent contact with sick and untreated people, leprosy can cause irreparable damage to those affected, as *Mycobacterium leprae* (*M. leprae*) attacks superficial nerves in the skin and peripheral nerve trunks, especially in the face and neck, as well as affecting the eyes, bones, and spleen in more severe cases<sup>8</sup>.

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The complex framework that surrounds leprosy control requires clear and objective information for people and the community in general, in order to strengthen the conduct of seeking health services in a timely manner, along with following the protocols for diagnosis and treatment, if the disease is already installed. The relatively long treatment time and the need to adopt self-care measures require specific knowledge related to self-administration of medication, especially since not understanding the magnitude of the disease and everything related to it can compromise treatment<sup>7</sup>.

It is important to note that the level of schooling can interfere with HL and this in the person's interaction with health services, reverberating in (non-)adherence to treatment. HL gives people autonomy over their treatment and favors strict control over taking medication, as it is necessary to know your health condition in order to self-manage it in the best way<sup>9</sup>.

Studies show that there is an increase in the risk of falling ill with leprosy among people with less schooling, which is twice as high as among those with a more advanced level of schooling<sup>10</sup>. In addition, the highest prevalence of leprosy is among illiterate people or those with incomplete primary education, which has been pointed out as a cause for abandonment or non-adherence to treatment<sup>11</sup>.

The relationship between schooling and HL has been highlighted, although it is still under discussion. In general, HL is associated with adherence or non-adherence to drug treatment<sup>12</sup>, since the greater the compliance with taking the doses, i.e. the greater the adherence to treatment, the better the HL<sup>13</sup>.

In this regard, a study was identified during the search for scientific literature on HL in the context of leprosy, which concerns stigma among people affected by the disease in a community in rural Nepal<sup>14</sup>. However, it is clear that there is a gap in scientific production on the subject in Brazil, especially in the north of the country. This study aims to assess the Functional Health Literacy of people undergoing treatment for leprosy in the Amazon context.

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## **METHODOLOGY**

This is an observational, descriptive study with a quantitative approach carried out between March and May 2023, in the Amazon region, in the state of Pará, more precisely in the capital Belém, which, to plan and monitor health actions, is divided into eight Administrative Districts, comprising 71 urban neighborhoods. The Municipal Health Units (MHU) and Family Health Strategies (FHS) of the Guamá (GUAAD) and Sacramento (SACAD) Administrative Districts were chosen as the study sites. These are districts with a large number of inhabitants, 342,742 and 274,939 respectively<sup>15</sup>, and which concentrate a significant number of leprosy cases.

The latest stratified data released by the Belém Municipal Health Department shows that 266 cases were registered in 2016, of which 109 were in GUAAD and SACAD. Thus, detection rates were between high and very high, according to the Ministry of Health's parameters, reflecting low levels of living conditions, socio-economic development, and healthcare<sup>16</sup>.

The inclusion criteria were people aged 18 or over, undergoing treatment for leprosy at any stage, registered as a new case, attending appointments regularly, of both sexes, and who could read and write. Given this, 23 people undergoing treatment for leprosy were included in the study, corresponding to 65.7% of the total considered eligible for the study who agreed to take part in the research and who were located during the period established for data collection.

Data collection was supported by the Health Literacy Test (HLT), an HL assessment tool adapted from the TOHFLA<sup>17</sup>, translated into Brazilian Portuguese, and cross-culturally adapted<sup>18</sup>. It consists of three parts and the instrument was chosen because it enables the assessment of two domains of FHL: numeracy with 17 items and reading and textual comprehension with 50 items.

In the data collection process, the instrument was filled in by the participant in the reading and comprehension domain and the researcher collaborated to obtain the data for the numerical domain. To this end, he provided cards with information related to the questions and read them out, as recommended by the instrument. Additional information was obtained

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regarding the socio-demographic profile and possible difficulties faced by the participants in following up on their treatment.

The data was double-entered into a computerized database created in the Epi-Info 7.2 program and the statistical treatment was carried out using the Statistical Package for the Social Science 28.0, with descriptive analysis. Fisher's exact test was carried out to assess levels of FHL and understanding of health, self-management, and empowerment concerning leprosy. A p-value  $\leq 0.05$  was considered.

A score was calculated from the sum of the correct answers given by each participant, with 1 being given for each correct answer and 0 for an incorrect one. Unanswered questions were given a value of 0. The raw score for the numerical part of 0 to 17 was considered and the weighted score used the table used in the original TOFHLA18, which transforms the score to a scale of 0 to 50 points. There was no weighting for the scores of the reading passages and a score between 0 and 50 points was considered for each participant in this domain of the instrument<sup>18</sup>.

Adding up the two parts (numerical and reading), each participant's score ranged from 0 to 100. The final HL classification is presented in three categories: 0 to 59 points, inadequate literacy, which corresponds to the inability of individuals to read and interpret health texts; 60 to 74 points, limited literacy, when reading and interpreting health texts is complicated for the individual; and 75 to 100 points, adequate literacy when individuals can read and interpret most health texts<sup>18</sup>.

This study was approved by the Research Ethics Committee of the Undergraduate Nursing Course at the State University of Pará under protocol number 5.789.456.

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## RESULTS

According to Table 1, the level of FHL was not significantly associated with the sociodemographic characteristics of people being treated for leprosy. Of the total studied, 60.9% (n=14) were males, who had the highest proportions of adequate FHL, corresponding to 62.5% (n=5), while females had 37.5% (n=3). Subsequently, inadequate FHL was more significant among females at 55.6% (n=5). However, 83.3% (n=5) of males had inadequate FHL.

As for the skin color/race variable, 52.2% (n=12) declared themselves to be brown, with 55.6% (n=5) presenting inadequate FHL. Regarding schooling, the highest proportion had completed high school (n=10; 43.5%), followed by completed elementary school (n=9; 39.1%). Among those classified as having adequate FHL, 75% (n=6) had completed high school, and 55.6% (n=5) of those classified as having inadequate FHL had completed elementary school.

The most frequent age group was adults aged between 48 and 59 (n=10; 43.5%) and the elderly aged between 60 and 68 (n=9; 39.1%). Half (n=4; 50%) of the participants classified as having adequate FHL were adults, while those classified as having inadequate FHL were elderly (n=5; 55.6%), followed by adults (n=4; 44.4%), and no young people had inadequate literacy.

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**Table 1** - Analysis of FHL levels according to sociodemographic characteristics of people being treated for leprosy. Belém, PA, Brazil, 2023.

Characteristics	Total 23 (100%)	FHL levels			p-value *
		Appropriate 8 (34.78%)	Limited 6 (26.09%)	Inadequate 9 (39.13%)	
<b>Sex</b>					
Female	9 (39.1%)	3 (37.5%)	1 (16.7%)	5 (55.6%)	0.370
Male	14 (60.9%)	5 (62.5%)	5 (83.3%)	4 (44.4%)	
<b>Race</b>					
White	7 (30.4%)	1 (12.5%)	3 (50.0%)	3 (33.3%)	0.448
Brown	12 (52.2%)	4 (50.0%)	3 (50.0%)	5 (55.6%)	
Black	4 (17.4%)	3 (37.5%)	0	1 (11.1%)	
<b>Education level</b>					
Elementary school incomplete	4 (17.4%)	0	1 (16.7%)	3 (33.3%)	0.144
Elementary school complete	9 (39.1%)	2 (25.0%)	2 (33.3%)	5 (55.6%)	
High school complete	10 (43.5%)	6 (75.0%)	3 (50.0%)	1 (11.1%)	
<b>Age (years)</b>					
23-39 (Young adult)	4 (17.4%)	2 (25.0%)	2 (33.3%)	0	0.403
48-59 (Adult)	10 (43.5%)	4 (50.0%)	2 (33.3%)	4 (44.4%)	

\* Fisher's exact test.

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According to Table 2, among the difficulties mentioned, “removing the medicine from the packaging” was considered not to be difficult by 65.2% (n=15), while 34.8% (n=8) said it was not very difficult.

“Reading the medicine package” was recognized as not being difficult by 52.2% (n=12), including 100% (n=8) of those with adequate FHL and 50% (n=3) with limited FHL. While 88.8% (n=8) of those who demonstrated inadequate FHL said it was a little and very difficult. The association between the level of FHL and the difficulty of reading the medicine package was statistically significant (p=0.001).

With regard to “remembering to take the medicine”, 52.2% (n=12) said it was not difficult, while 43.5% (n=10) considered it to be a little difficult and 4.3% (n=1) very difficult. It should be noted that the need to “replace the medication in time” was recognized as not being difficult by all (n=23; 100%) of the participants. Concerning “taking several tablets at the same time”, 56.5% (n=13) said it was not difficult, 39.1% (n=9) a little difficult, and 4.3% (n=1) very difficult.

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**Table 2** - Analysis of FHL levels according to difficulties in drug therapy for people being treated for leprosy. Belém, PA, Brazil, 2023.

Difficulties in drug therapy	Total 23 (100%)	FHL level			p-value*
		Appropriate 8 (34.78%)	Limited 6 (26.09%)	Inadequate 9 (39.13%)	
<b>Taking the medicine out of the package</b>					
Not difficult	15 (65.2%)	7 (87.5%)	4 (66.7%)	4 (44.4%)	0.250
Not very difficult	8 (34.8%)	1 (12.5%)	2 (33.3%)	5 (55.6%)	
Very difficult	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	
<b>Reading the medicine package</b>					
Not difficult	12 (52.2%)	8 (100%)	3 (50.0%)	1 (11.1%)	0.001
Not very difficult	7 (30.4%)	0 (0.0%)	3 (50.0%)	4 (44.4%)	
Very difficult	4 (17.4%)	0 (0.0%)	0 (0.0%)	4 (44.4%)	
<b>Remembering to take the medicine</b>					
Not difficult	12 (52.2%)	3 (37.5%)	4 (66.7%)	5 (55.6%)	0.675
Not very difficult	10 (43.5%)	5 (62.5%)	2 (33.3%)	3 (33.3%)	
Very difficult	1 (4.3%)	0 (0.0%)	0 (0.0%)	1 (11.1%)	
<b>Replace the medicine in time</b>					
Not difficult	23 (100%)	8 (100%)	9 (100%)	6 (100%)	—
Not very difficult	0	0	0	0	
Very difficult	0	0	0	0	
<b>Taking several pills at the same time</b>					
Not difficult	13 (56.5%)	3 (37.5%)	4 (66.7%)	6 (66.7%)	0.216
Not very difficult	9 (39.1%)	5 (62.5%)	1 (16.7%)	3 (33.3%)	
Very difficult	1 (4.3%)	0 (0.0%)	1 (16.7%)	0 (0.0%)	

\*Fisher's exact test

According to Table 3, 39.1% (n=9) never or sometimes had problems finding out more about their health because of difficulty understanding written information, with 75% (n=6) of those with adequate FHL never having difficulty understanding and 77.8% (n=7) of those with inadequate FHL sometimes not understanding written information.

Also according to Table 3, 26.1% (n=6) sometimes asked others for help when reading health information, 50.0% (n=4) of those with adequate FHL never asked for help and 44.4% (n=4) of those with inadequate FHL always asked for help when reading health information.

In the same table 3, 30.4% (n=7) of those with adequate FHL reported relative safety when filling in forms or forms, 37.5% (n=3) felt very safe and 88.8% (n=8) of those with

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inadequate FHL felt little or very little safe. A statistically significant association was confirmed between levels of FHL and understanding of written information ( $p=0.005$ ), self-management ( $p=0.002$ ), and personal empowerment ( $p=0.01$ ).

**Table 3** - Analysis of FHL levels according to individual HL characteristics of people being treated for leprosy, PA, Brazil, 2023.

Characteristics of individual HL	Total 23 (100%)	FHL level			p-value*
		Appropriate 8 (34.78%)	Limited 6 (26.09%)	Inadequate 9 (39.13%)	
<b>Understanding written information</b>					
Never	9 (39.1%)	6 (75.0%)	3 (50.0%)	0	0.005
Occasionally	4 (17.4%)	1 (12.5%)	2 (33.3%)	1 (11.1%)	
Sometimes	9 (39.1%)	1 (12.5%)	1 (16.7%)	7 (77.8%)	
Often	1 (4.3%)	0	0	1 (11.1%)	
Always	0	0	0	0	
<b>Asking others for help</b>					
Never	4 (17.4%)	4 (50.0%)	0 (0.0%)	0 (0.0%)	0.002
Occasionally	4 (17.4%)	3 (37.5%)	0 (0.0%)	1 (11.1%)	
Sometimes	6 (26.1%)	0 (0.0)	4 (66.7%)	2 (22.2%)	
Often	5 (21.7%)	1 (12.5%)	2 (33.3%)	2 (22.2%)	
Always	4 (14.4%)	0 (0.0%)	0 (0.0%)	4 (4.44%)	
<b>Filling in forms alone</b>					
Extremely	2 (8.7%)	2 (25.0%)	0 (0.0%)	0 (0.0%)	0.011
Very	4 (17.4%)	3 (37.5%)	1 (16.7%)	0 (0.0%)	
More or less	7 (30.4%)	2 (25.0%)	4 (66.7%)	1 (11.1%)	
Little	5 (21.7%)	0 (0.0%)	1 (16.7%)	4 (44.4%)	
Very little	5 (21.7%)	1 (12.5%)	0 (0.0%)	4 (44.4%)	

\* Fisher's exact test.

## DISCUSSION

The highest levels of HL were among males, those with completed secondary education and younger age groups. Those with the lowest levels of HL were women, brown people, with completed elementary school and older. There were significant difficulties in continuing with treatment, such as reading the packaging of the medication, remembering to take the medication on an ongoing basis, removing it from the packaging and swallowing several tablets at the same time. FHL has been shown to be associated with the ability to read

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medicine packaging, understanding written information, self-management and personal empowerment.

Low levels of HL among women have also been identified in other studies, in Brazil with people suffering from hypertension<sup>19</sup> and in Nepal, which investigated the level of HL in patients with Chronic Obstructive Pulmonary Disease<sup>20</sup>. It should be noted that there are controversial opinions in scientific circles about the association of HL with gender, given that the highest proportion of participants in different studies were women. They attribute this to the culture in countries where men avoid seeking medical attention and only do so in extreme emergencies<sup>21</sup>. Therefore, it can be said that the findings on the association between gender and HL are inconsistent worldwide and when it comes to Amazonian women who have a peculiar way of life, which defines eating, working, and social habits.

Skin color may be related to HL since brown individuals were associated with low levels of HL - this relationship may be established with the sociodemographic context since the brown population in the Amazon region experiences remnants of inequities in public policies. Among the studies that analyzed the ethnicity of the participants, it was possible to observe data similar to that identified in this study, with a higher prevalence of self-declared black or brown individuals and low levels of SL<sup>22,23</sup>, in line with this study.

As far as schooling is concerned, the findings are in line with others who have identified an association between schooling and HL, pointing out that people with lower levels of schooling have a greater chance of inadequate HL when compared to those with higher education<sup>24</sup>. These findings suggest that although schooling and HL are different measures, actions that provide formal education can help to reduce the prevalence of low levels of HL. Based on this premise, health services should pay attention to individuals with less schooling, as they are more likely to have HL limitations.

Concerning age, a study carried out in Vietnam found that participants with lower scores on the S-TOFHLA and classified as having inadequate HL were significantly older<sup>25</sup>, similar to the findings of this study. Thus, it is possible to relate low performance in tests that assess HL to increasing age, especially due to declining vision, hearing, cognition, and less access to educational information in the past. Thus, these reflections are similar to two difficulties identified here: reading the packaging of medication, which may be related to

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reduced visual acuity; and remembering to take medication, which may be due to the cognitive decline present among older people<sup>26</sup>.

A study carried out in Altamira, PA (Brazil), points to age and schooling as predictive factors for FHL, as the elderly are more likely to have low levels of FHL due to physiological factors related to aging and social vulnerability. Similarly, those who have completed high school are five times more likely to have adequate FHL compared to those who have not. Furthermore, it reinforces the need to study FHL in the northern region of Brazil, since this is marked by peculiarities that influence the population's health-disease process<sup>27</sup>.

That said, it is necessary for health professionals to be aware of the profile of the demand they meet and to devise strategies to reduce the risks associated with users' limitations. In this sense, Health Literate Organizations (HLOs) encourage the adoption of approaches that involve users, professionals, and organizations in order to promote the provision of effective, individual-centred care. In order to tackle the difficulties related to low HL, the main strategies are clear and effective communication between professionals and users, as well as the use of user-friendly technologies<sup>28</sup>.

Among the difficulties mentioned in self-management of treatment, the difficulty of removing the medication from the packaging may be related to the incapacitating power of leprosy, since the bacillus promotes inflammatory processes and/or immunological responses that impact users' ability to respond to nerve, and motor, sensory and/or autonomic stimuli, with the hands being one of the areas affected by the lesions<sup>29</sup>.

Still among the difficulties, they recognize the discomfort of swallowing several drugs at the same time, which can interfere with treatment, since multidrug therapy uses three drugs, which must be taken simultaneously in the supervised dose, and two drugs in the self-administered daily doses<sup>8</sup>. It is therefore important for professionals to recognize these individual limitations and adopt strategies to minimize the discomfort felt, in order to ensure that the drugs are taken correctly and that all people diagnosed with leprosy continue their treatment.

The results of this study reinforce the correlation between FHL and basic reading and writing skills, such as understanding written information, which influences autonomy and

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empowerment<sup>4</sup>. Thus, it can be said that individuals with lower reading and writing skills are more likely not to correctly follow the information passed on by professionals, which will result in worse health conditions and ineffective use of the healthcare network<sup>4,28</sup>.

In addition, the association between FHL and self-management is healthy, since by developing basic skills within the scope of HL, the individual is able to proactively manage their health, becoming independent, based on the knowledge learned<sup>4</sup>. It is therefore known that HL is an empowerment strategy since individuals who are literate in health become capable of seeking information that helps to control diseases and favors commitment to health in search of a positive outcome<sup>3,30</sup>.

Thus, a study shows that the self-management and empowerment of people undergoing treatment for leprosy are fundamental to the success of the treatment because by becoming self-aware, the individual becomes capable of making informed decisions after diagnosis and practicing self-care that goes beyond traditional treatment since leprosy affects not only the physical and biological, but also the psychosocial, requiring individual, multi-professional and multi-sectoral attention<sup>7</sup>.

As a limitation of the study, it was impossible to include a larger number of participants, given the time allocated to data collection and the dynamics of care for people undergoing treatment, with monthly appointments, when they come to the Health Unit. We also recognize that there is little scientific literature on the subject, reducing the possibilities for a more in-depth comparative analysis. However, this study is a pioneer in describing the Amazonian reality in the field of HL related to leprosy, helping to reduce the knowledge gap on the subject and enabling comparative analysis in future studies.

## **CONCLUSION**

The evaluation of the FHL of people being treated for leprosy in the Amazon region showed that brown women with low levels of schooling and elderly women had inadequate literacy. In addition, the different perspectives highlighted in this study allowed us to confirm that people with limited FHL have difficulties in applying essential health information to self-manage drug therapy, which results from compromised performance of functions and skills

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for decision-making and autonomy, since FHL is related to the ability to read drug packaging, understand written information, self-management and personal empowerment in coping with leprosy.

Thus, it is understood that it is necessary to adopt actions/measures aimed at providing quality information to people in the course of treatment, appropriate to their age group and limitations and that health professionals seek strategies to ensure that this information is properly understood and applied. There is also a need to implement intersectoral policies, especially equal access to schooling, as well as measures to reduce school dropouts.

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Submitted: October 26, 2023

Accepted: May 9, 2024

Published: September 18, 2024

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All the authors have approved the final version of the manuscript.

Conflict of interest: There is no conflict of interest.

There is no financing.

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Editor: Amanda Silva dos Santos Aliança, PhD.

Editor-in-chief: Adriane Cristina Bernat Kolankiewicz, PhD.

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