



**DEVELOPMENT OF A BOOKLET FOR SELF-CARE PROMOTION IN LEPROSY**  
**DESENVOLVIMENTO DE UMA CARTILHA PARA A PROMOÇÃO DO AUTOCUIDADO NA HANSENÍASE**  
**DESARROLLO DE UNA CARTILLA PARA LA PROMOCIÓN DEL AUTO-CUIDADO EN LA LEPRO**

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**ABSTRACT**

**Objective:** to present the development of an educative booklet for self-care promotion in leprosy. **Method:** this is a descriptive study, of the experience-report type, with the development of the booklet in four stages: (1<sup>st</sup>) elaboration and submission of the project to the Research Ethics Committee; (2<sup>nd</sup>) search, in literature, for existing knowledge on the subject; (3<sup>rd</sup>) wheel of conversation with people with leprosy accompanied at a Center of Dermatology and Infectious Diseases; (4<sup>th</sup>) development of the content, guide, graphics and layout for the booklet. **Results:** thematic category emerged from the wheel of conversation “Content for a self-care booklet in leprosy”, considering the main doubts, difficulties and needs of the study participants. The booklet title was “How to take care of the body in leprosy”, with 36 pages, sized 210x148.5mm, printed in couche paper matte 150g/m<sup>2</sup>. **Conclusion:** the booklet developed is an educational material prepared in a participatory manner with the potential to contribute to self-care promotion in leprosy. **Descriptors:** Leprosy; Educational Technology; Self-Care; Health Promotion; Health Education; Primary Health Care.

**RESUMO**

**Objetivo:** apresentar o desenvolvimento de uma cartilha educativa para a promoção do autocuidado na hanseníase. **Método:** trata-se de estudo descritivo, do tipo relato de experiência, em que se realizou o desenvolvimento da cartilha em quatro etapas: (1<sup>a</sup>) elaborou-se e submeteu-se o projeto ao Comitê de Ética e Pesquisa; (2<sup>a</sup>) buscaram-se, na literatura, conhecimentos existentes a respeito do tema; (3<sup>a</sup>) realizou-se uma roda de conversa com pessoas com hanseníase acompanhadas em um Centro de Dermatologia e de Doenças Infecciosas; (4<sup>a</sup>) elaboraram-se o conteúdo, roteiro, ilustrações e diagramação para a cartilha. **Resultados:** emergiu-se uma categoria temática a partir da roda de conversa “Conteúdos para uma cartilha de autocuidado na hanseníase”, considerando-se as principais dúvidas, dificuldades e necessidades dos participantes do estudo. Intitulou-se a cartilha “Como cuidar do corpo na hanseníase”, a qual se apresenta em 36 páginas, com dimensão de 210x148,5mm, impressa em papel *couché* fosco de 150g/m<sup>2</sup>. **Conclusão:** conclui-se que a cartilha desenvolvida é um material educativo elaborado de modo participativo que tem o potencial de contribuir para a promoção do autocuidado na hanseníase. **Descritores:** Hanseníase; Tecnologia Educacional; Autocuidado; Promoção da Saúde; Educação em Saúde; Atenção Primária à Saúde.

**RESUMEN**

**Objetivo:** presentar el desarrollo de una cartilla educativa para la promoción del auto cuidado en la lepra. **Método:** este es un estudio descriptivo, del tipo relato de experiencia, con el desarrollo de la cartilla en cuatro etapas: (1<sup>a</sup>) elaboración y sumisión del proyecto al Comité de Ética e Investigación; (2<sup>a</sup>) búsqueda, en la literatura, del conocimiento existente sobre el tema; (3<sup>a</sup>) rueda de conversación con las personas con lepra acompañadas en un Centro de Dermatología y Enfermedades Infecciosas; (4<sup>a</sup>) desarrollo del contenido, del guion, de los gráficos y del diseño de la cartilla. **Resultados:** emergió una categoría temática a partir de la rueda de conversación “Contenido de una cartilla para el auto cuidado en la lepra”, considerándose las principales dudas, dificultades y necesidades de los participantes del estudio. La cartilla fue titulada “Cómo cuidar del cuerpo en la lepra”, que se presenta en 36 hojas, con un tamaño de 210x148,5mm, impresa en papel *couché* mate 150g/m<sup>2</sup>. **Conclusión:** se concluye que la cartilla desarrollada es un material didáctico elaborado en forma participativa que tiene el potencial de contribuir a la promoción del auto-cuidado en la lepra. **Descriptores:** Lepra; Tecnología Educacional; Autocuidado; Promoción de la Salud; Educación en Salud; Atención Primaria de Salud.

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**INTRODUCTION**

Leprosy represents the main cause of permanent physical disabilities within the infectious-contagious diseases, arising from the deformations, in some cases, which involve the implementation of simple activities of daily life. Therefore, the multiprofessional team from health services should encourage patients to perform the routine and effective care with the body, especially face, hands and feet. Self-care represents one of the potential actions for reducing these disabilities.<sup>1</sup>

There is need for assistance by the multiprofessional healthcare team to strengthen the effective adhesion to self-care by patients with leprosy to encourage and develop the skills necessary for this care. Thus, the care must be understood as an acquired behavior in which people are co-responsible for this practice.<sup>2</sup> Therefore, educational materials that can contribute to this teaching and learning process must be available, so that learning is facilitated through health education actions.

There are several qualities attributed to educational materials, such as representing a systematic set of scientific knowledge that allows planning, executing, managing and monitoring the formal or informal educational process, thus, promoting the construction and reconstruction of knowledge.<sup>3-4</sup>

The booklet is a relatively recent educational material, created in the framework of government campaigns, whose objective is to facilitate access to information of people from different socio-cultural contexts and degrees of schooling. It may have the capacity to bring the facts from the scientific world to the lay public, through various strategies, so that even the reader with little education or with difficulty reading can understand the material content.<sup>5-6</sup>

Several educational materials address leprosy, however, a study analyzed a collection of 276 materials with this theme, including flyers, brochures, posters, booklets and serial albums. It identified that, in great part of the analyzed materials, there is prevalence of a vertical and centralized communication, without distinction regarding cultural diversity of the target public.<sup>7</sup>

Educational materials, including booklets, when elaborated through dialogical relationships between a person with leprosy and the multiprofessional team, through the recognition of knowledge dimensions, sociopolitical and cultural diversity of the population, prove to be necessary resources that allow for expansion of social transformations, generating changes in knowledge construction, boosting and enhancing the various practices in the health area.<sup>8-9</sup>

The findings relating to educational materials related to leprosy highlight the need to strengthen the educational actions about care with innovative educational materials, especially of the booklet type, considering that many of them are still anchored by traditional biomedical practice, with little focus on the stimulation of the patient's participation in the planning and development of these materials. There arises the following question: "How should be prepared a booklet that contributes to self-care in leprosy?".

Recognizing the importance of knowledge construction in a shared form, in which receiver and transmitter exert a horizontal, dialogical and participative role, this study aims to present the development of an educative booklet for self-care promotion in leprosy through the identification of the main doubts, difficulties and learning needs of the target public.

**OBJECTIVE**

- To present the development of an educative booklet for self-care promotion in leprosy.

**METHOD**

This is a descriptive study, of the experience-report type. The study scenario was the region of Cariri-CE, Brazil, in 2016. The booklet was developed in four stages: (1) elaboration and submission of the project to the Research Ethics Committee; (2) search, in literature, for existing knowledge on the subject; (3) wheel of conversation with people with leprosy accompanied at a Center of Dermatology and Infectious Diseases; (4) development of the content, guide, graphics and layout for the booklet.

The booklet of the Ministry of Health "Self-care in leprosy: face, hands and feet" was chosen as reference in the second stage of data collection.<sup>10</sup>

The wheel of conversation took place at a reference service that accompanies people with leprosy, with the participation of 21 participants in the third stage, all people under treatment against leprosy accompanied in the center of dermatology. In the data collection period, there were 42 people under monitoring, being 31 invited to participate in the research through phone contact, because the others had no phone contact on their medical charts. Of the 31 contacted, 26 confirmed their participation in the wheel of conversation and five refused to attend for personal reasons.

The data from the conversation wheel were collected through a predetermined guide, which sought to identify the doubts, difficulties and needs of people with leprosy in relation to the disease and self-care and how the educative booklet should remedy them. Recorded data were

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fully transcribed, and the content was examined.  
There emerged a thematic category.

The booklet was built in the fourth step. A professional illustrator and a graphic designer were hired for the confection of graphics, formatting, configuration and layout of the pages of the booklet. Corel Draw X7 (version 17.1.0.572) was used for the composition of the graphics and layout. Images were treated by means of the program Photoshop CS (version 8.0.1). The writing, language and layout of the booklet were organized according to recommendations for the development of educational materials.<sup>11-12</sup>

The research projected was sent to the Research Ethics Committee (REC) of the Regional University of Cariri (URCA) for assessment, obtaining the Certificate of Submission for Ethical Assessment (CAAE) number 51483715.4.0000.5055.

RESULTS

The study population consisted of 21 people with leprosy: 12 females and nine males. The majority was in the age range from 46 to 59 years, corresponding to nine participants. The marital status married predominated, with 13 people. Most of them had low schooling, since 14 had incomplete Elementary Education and three had never studied. One minimum monthly wage was the prevalent family income, with 13 participants.

Based on the data analysis, there emerged the thematic category “How a booklet for self-care in leprosy should be”, which showed the doubts in relation to leprosy and how the participants wanted them to be remedied in a booklet.

Regarding the booklet content, participants suggested that it should contain information on the onset of the disease, presented in a topic “Did you know?”, which should answer questions concerning the condition of being with leprosy, which symptoms arise after beginning the treatment, leprosy reactions, forms of transmission, as well as aspects related to healthy feeding during therapy, according to the statements below.

*What are the symptoms when we start taking the medicines? (P12)*

*After we are cured, is there any chance of a relapse? (P1)*

*What foods can we eat? (P11)*

*Does numbness end after treatment? (P8)*

*Can an adult transmit the disease to the child? (P20)*

There also emerged aspects related to the diagnosis and results of laboratory tests, according to the reports below.

Development of a booklet for self-care...

*Is there already any blood test to detect leprosy? I heard that on television. (P6)*

*Why do we have to treat it even with a negative test? (P13)*

Concerning the booklet layout, participants suggested the inclusion of color images, because they would make the learning easy and encouraging.

*Colorful is better, we can understand better. (P05)*

*Black and white photo is difficult to understand. (P13)*

The wheel of conversation revealed that the words “disabilities” and “self-care” could hinder the comprehension during the reading, mainly in relation to their meanings in the worked context. The reports below refer to the aforementioned words, respectively.

*Is it the same as crippling fingers and toes? (P03)*

*When you need another person to help you take care of yourself? (P18)*

The planning and preparation of the booklet used the theoretical content available in the literature. The booklet from the Ministry of Health, published in 2014, contributed to this step. The wheel of conversation helped identify the necessary information and their setup in the booklet for self-care promotion in leprosy.

An educative booklet entitled “How to take care of the body in leprosy” was developed, containing 36 pages, sized 210x148.5mm, printed in couche paper matte 150g/m<sup>2</sup>, grouped with two staples. The number of pages is a multiple of four. Both sides of the sheets were used in its printed version. The pages were sequentially numbered in Arabic numerals, from the first text page, on the bottom edge.

The texts of the booklet are predominantly sentences in active voice, as if talking with the reader. The authors sought to use short sentences, with a popular language and easy to read, to facilitate comprehension by the audience.

The font used in the text was Book Antiqua, with sizes 13, 18, 24, 27 and 51. The fonts were black due to the light background of the paper. The keywords of the texts were enlarged, as well as the size, using bold blue- and red-colored markers. The font of the titles beginning sections was two-point larger than the ones of the texts.

The illustrations of the booklet are colored in order to draw the reader’s attention and facilitate learning. Two characters were created, “Pedro” and “Ana”, with profiles of ages according to the findings in this study.

Figure 1 shows the layout of the booklet with its respective elements.



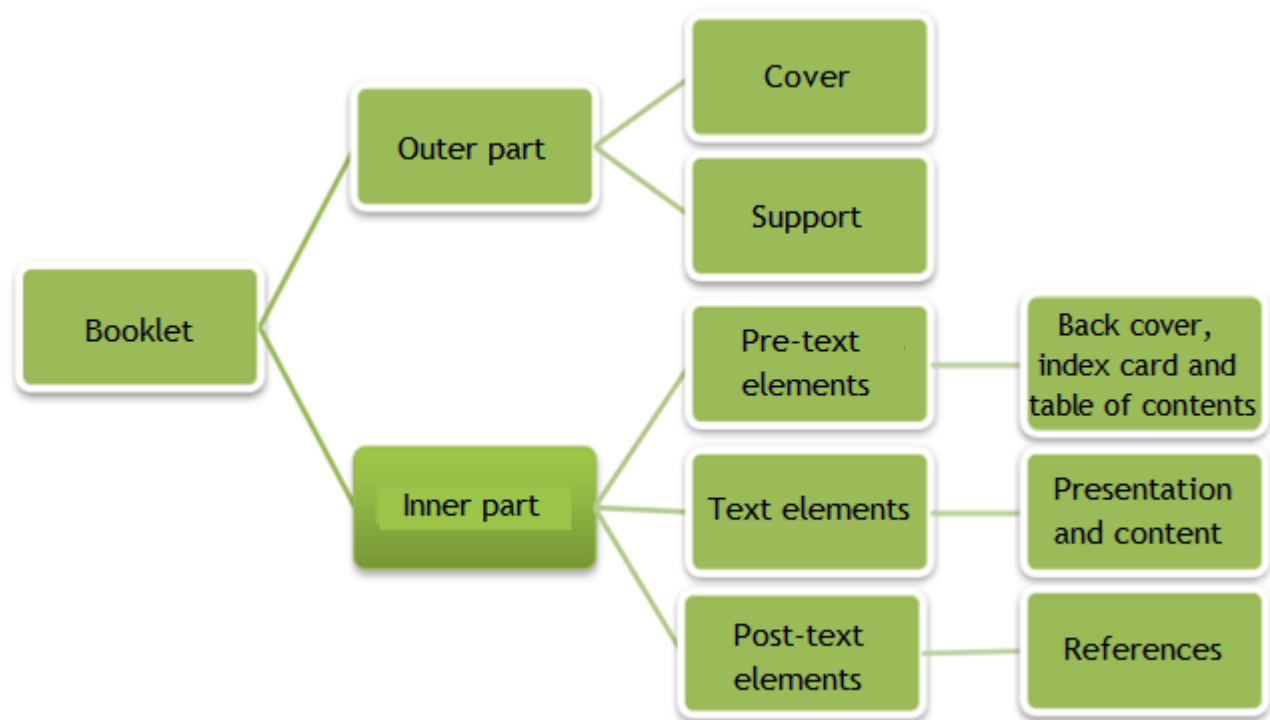


Figure 1: Layout representing the booklet “How to take care of the body in leprody”. Juazeiro do Norte (CE), Brazil, 2019.

The outer part (cover) showed a title and a scenario with two characters in a green place illuminated by the sun, characteristics of the region of the participants. The next page of the booklet (support) contained the coat of the Higher Education Institution linked to the material. The inner part (pre-text elements) contained the back cover with the postgraduate course, title of the booklet, place and year.

The datasheets were placed on the following page after the back cover containing the names of the authors and their respective degrees; technical credits (graphics and layout) and the index card, presenting it on the page following the table of contents, followed by the presentation and content. The end contained the bibliographical references.

The booklet content (text elements) were organized into four topics: **1) Did You Know?** - guidelines about signs and symptoms, transmissibility, encouraging the treatment and demystifying the prejudice; **2) I take care of my face** - the care with the face; **3) I take care of my hands** - self-care with the hands; **4) I take care of my feet** - self-care with the feet.

Contemplating the participants’ suggestions, a story with the two characters with leprosy, “Pedro” and “Ana” was described, who actively guide as they learned to take care of themselves and how to perform the care with the body periodically to prevent complications and disability in leprosy.

Fictitious illustrations and scenarios seek to portray the reality of the patients. The educational material introduced the accomplishment of labor activities by the characters, adopting practices in order to

contemplate actions and occupations reported by some participants of the study.

The term “self-care” was replaced by “care”, considering the difficulty of the participants to understand it. The idea of leprosy causing inability was represented in an assumed manner, considering that the essence of the technology is preventing this circumstance.

DISCUSSION

Leprosy affects primarily the lowest socioeconomic class, with less favorable educational conditions,<sup>13</sup> data reaffirmed in this study. One reaffirms the need for developing an educational technology that is accessible and easy to understand for users of the Unified Health System (SUS) with low schooling.

From the wheel of conversation, the third step allowed knowing the main doubts, difficulties and needs of the target public (people under treatment for leprosy) in relation to self-care with the body. Moreover, this stage also identified a more accessible language to the population.

The findings of the thematic category “How a booklet for self-care in leprosy should be” showed that patients affected by leprosy have fragile levels of knowledge in relation to the disease, especially regarding self-care for prevention of disabilities.

Another study with patients under treatment for the same disease, which assessed the knowledge of respondents, revealed gaps in knowledge, with only inference to the aspect of stigmatized illness and skin care, lubrication of the eyes and use of adapted shoes.<sup>14</sup>

The patients affected by the disease are not the only ones that require guidance and educational actions. A research that sought to

identify the degree of knowledge of household contacts identified results showing that the knowledge about the disease is still scarce.<sup>15</sup> In another study involving residents from a Family Health Strategy that proposed to identify the perceptions related to leprosy, only half of the sample heard about the disease, many are unaware of the health promotion campaigns and most do not know how leprosy is transmitted.<sup>9</sup> These findings show the need to strengthen the monitoring of both patients as contacts and the population in general, as well as a more effective work with educational actions.

Health education is an extremely significant tool in improving the inconvenience caused by leprosy. For an effective self-care, professionals must value the human being in their complexity, encouraging the empowerment of their self-knowledge while reformulating their forms of attention, still vertical and Cartesian, largely hegemonic in the tradition of public health policies.<sup>16</sup>

Primary Health Care (PHC) has a preponderant role in the dynamics of self-care promotion to be provided to the patient with leprosy and, in particular, when such practice requires the use of educational technologies that can be used by both the multiprofessional team as users of UHS, favoring, in this way, best practices for the prevention of disabilities.

The educative booklet constitutes a technology that has demonstrated quite acceptance of professionals and the community in general, since there are studies about the development of this technology addressing different themes.<sup>17-20</sup> The use of this technology has obtained satisfactory results, increasingly awakening the interest of many researchers with the objective of developing and improving it.

The booklet disguises its persuasive purpose, representing an alternative to reach an audience with restricted access to reliable sources of information, either as a result of schooling and poor health care or lack of familiarity with literacy practices involving the reading of printed reports, articles, medical newsletters, among others.<sup>21</sup> In this perspective, by the profile of the study participants, this technology should have the potential to contribute to the advancement of knowledge by part of the target public.

In relation to the booklet prepared in this study, the amount of topics was defined taking into account the guidelines from the literature, which recommend that messages should be presented in a list with at most seven items, once, above this, people may not remember or lose the other topics after the first seven.<sup>12</sup> In this way, only four topics were included in the booklet, related to the main questions found about the

pathology and care that must be performed for the prevention of disabilities.

A colorful booklet was used taking into account the participants' choice. Colorful materials are more effective in the message transmission, in comparison to those printed in black and white.<sup>22</sup> The images should be representative and motivating, with relevant details and properly transmit the information.<sup>12</sup>

Regarding the writing of the booklet, the materials become easier to understand when information is clear and sentences are short, using active voice, which improves the understanding of the public with low schooling<sup>13</sup>. It is essential to include simple language, without technicality, easy to understand, that is attractive and not extensive, with easy-going illustrations and which exceed the needs for information of a given problem-situation.<sup>11</sup>

Some studies stress out that the printed material should always consider the characteristics of the target readers, requiring a planning, assessment and production according to the real needs of the patient. During the preparation of the booklet, the characters were created so that they could represent its audience.<sup>23</sup>

When projecting the image of the target public in a booklet, the reader can feel like part of the situations proposed in the illustrations and imagine experiencing the events. From the moment in which the reader feels like part of the illustrations, he/she may imagine experiencing the reported events and believe he/she might be able to achieve them.<sup>24</sup> This strategy has been used by other researchers and was also used in this study.<sup>25-26</sup>

When directly talking to the target population of the booklet to subsidize the elaboration of the educational material, the actions of self-care promotion included in this material can succeed, once it has been guided in a dialogic relationship of integration between professionals and patients, in a constant shared negotiation, valuing the self-care as fundamental in life and necessary for the well-being and human survival.<sup>27</sup>

## CONCLUSION

The developed booklet is an educational material prepared in a participatory manner that has the potential to contribute to the self-care promotion in leprosy based on the knowledge needs of the target public.

The booklet represents an important resource for strengthening relations between patients and professionals, considering the ability of educational materials to promote autonomy of the subject and establish interactive bonds in the exchange of knowledge, providing improvement of health-disease conditions.

It became an important experience, because it allowed appreciating subjective, cultural and political aspects present in subjects receiving the information. In this condition, the exchange of information should not be unilateral, but in a constructive partnership, in which both sides have representations of their senses, perceptions and practices of life.

The developed booklet needs a validation, considering the contributions of this process to improving the quality of the material.

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