

The production of social discourse on Hansen's disease and health education materials in Brazil: A skin patch as something harmless or a serious disease?

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Summary

Aim: Hansen's disease is endemic in Brazil and government control programmes promote publicity campaigns to increase the detection of new cases through the production and distribution of educative material.

Objectives: This study analyses a set of 276 educational materials produced by governmental and non-governmental organisations that work to control Hansen's disease in Brazil. It describes the content of the materials and the way the issues were approached.

Design: It is a qualitative study that adopts the theoretical and methodological framework of the semiology of social discourse.

Results: Analysis reveals that the relations between the enunciator and recipient of the materials are asymmetrical as a result of the technical and educational language employed. Biomedical information forms the basis for social representations and practices of Hansen's disease, as opposed to historical collective knowledge of 'leprosy'. The prioritised topics are: signs and symptoms of the disease, treatment, stigma, cure and surveillance.

Conclusions: The institutionalisation of public education on Hansen's disease in Brazil was not limited simply to the change of terminology from 'leprosy' to 'Hansen's disease,' but was shaped also by new educational practices. It is recommended that the evaluation and production of new materials be incorporated into the set of activities already carried out in health centres so as to expand the discussion on content, language and the best way to address the disease in the materials.

Introduction

In the 1970s, the renowned Brazilian leprologist Abraão Rotberg began a national and international campaign to substitute the medical terminology of 'leprosy' with 'Hansen's disease' (*hanseníase*, in Brazil) seeking greater social integration of those affected by the disease.¹ During the same period, existing leprosaria were being dismantled throughout the country and the public health network was reorganised towards more regionalised outpatient care. In 1976 Brazil officially adopted the term 'Hansen's disease' and, in the 1980s and 1990s, multi-drug therapy (MDT) was introduced in the public health system to promote decentralized diagnosis, treatment and surveillance services at the primary care level.²

Despite these interventions, Hansen's disease is still endemic in many regions of Brazil. To combat this situation, the Ministry of Health adopted the expansion of household contact examination as a key guideline, and promoted media campaigns with the production and distribution of educational materials. These actions sought to increase "community knowledge of the initial symptoms of Hansen's disease" and inform the population of essential health care services.³ Research has shown that these campaigns are indispensable for the production of new interpretations and images of the disease.^{2,4,5} However, few studies evaluate the ways that these new meanings are produced.⁶

This article aims to analyse the content (proposition) and the types of approaches (utterance) of educative materials produced by campaigns for leprosy control, seeking to understand the different meanings of the disease. The objective was not to cover all social meanings of Hansen's disease, as the process of the social construction of the disease are more complex and involve other dimensions of social life. Materials that are expressly educational are accessed, but they are not the only ways in which social representations of Hansen's disease are produced. In the socio-cultural context of Brazil, mass media plays an essential role in the dissemination of information on the disease. The article is part of a wider study that examines aspects of production, circulation and reception of educational materials on leprosy, discussing how the meanings of the disease are produced by specific social groups.⁷

Material and Methods

This is a qualitative study that investigates the communication processes in the area of Hansen's disease, focusing on the content and condition of the production of educational material developed by control programmes at the municipal, state and federal levels, and by non-governmental organisations (NGOs), over the last three decades. Semi-structured interviews were carried out with 12 state programme managers from the Centre-west, North-east and South-east regions, five healthcare workers dealing with the Primary Care of Rio de Janeiro and three representatives from MORHAN (the Movement to Reintegrate Persons Affected by Hansen's Disease). The forms were collected at this stage and the interviewees were questioned as to the production, process and the prioritised content in educational activities.

Documental analysis was based upon 276 different publications on Hansen's disease.⁸ It was designed according to the physical description of the material (author, editor, state, region, year, page, visual resources and content synthesis) and thematic analysis (classification according to format, target group, objectives, topic). This process resulted in

Table 1. Main issues addressed in the 276 printed materials

Primary topics	Percentage among all materials
1. Definition	55%
2. History	24%
3. Transmission	51%
4. Signs and symptoms	87%
5. Diagnosis	10%
6. Classifications	19%
7. Complication	19%
8. Treatment	83%
9. Socio-cultural dimensions	63%
10. Surveillance	29%
11. Cure	81%
12. Public health services	88%
13. Support services (NGO; social movement)	55%
14. Tuberculosis	4%

the categorisation of 14 main issues and 28 secondary ones, grouped into six semantic areas, as shown in Tables 1 and 2.

The analysis of these categories, sought to reconstruct the devices of enunciation, namely, the mechanisms by which these texts work and produce shared social meanings.⁹ Every device of enunciation is made up of discursive figures or enunciative places.¹⁰ These figures constructed in the discourse can be of three types: *subject of the enunciation*, *spoken subject and referent*. This work aims to analyse discursive entities, instead of real empirical subjects. *The subject of enunciation* is not the author of the text, but the discursive image constructed by the speaker of himself in his speech. Similarly, the *spoken subject* is not the real receptor, but the image that it is built of him. Finally, the *referent* is always a representation. In discourse analysis, we sought to follow the text to show the series, regularities and rules that constitute social discourse and show the relations between them in the social production of the meaning.¹¹

Results and Discussion

In the analysis of the 276 materials, six semantic areas were identified that break down the most common content in the discourse on Hansen's disease: signs and symptoms; treatment and cure; surveillance; definitions; social/cultural dimensions and transmission. The use of these markers facilitated the identification of a 'critical discursive mass,' defined as a set of words – Hansen's disease, anaesthetic skin patch, loss of sensitivity, medications, and cure – that make up a group of new meanings to be incorporated and legitimated as 'truths' in social practices.¹² The main nucleus of Hansen's disease-related discourses expresses a common code about the disease, namely: "Hansen's disease is treatable and curable"; "Go to the health centre closest to your home"; "Light or reddish skin patches with reduced sensation on any part of the body"; "Pain or shocking sensation down any of the nerves of the arms or legs"; "Burning or hurting yourself without the sensation of pain." These materials seek separation from the common social representations associated with leprosy rather than Hansen's disease.

Table 2. Secondary issues addressed in the 276 printed materials

Secondary topics	Percentage among all materials
1.1. Etiologic agent	49%
2.1. 'Leprosy' terminology and related issues	21%
2.1 Reference to Gerhard H.A. Hansen	4%
4.1 Dermatological signs	84%
4.1. Neurological symptoms	82%
6.1. Operational classification	13%
6.1. Clinical forms	11%
7.1. Physical incapacity	29%
7.1. Disability	33%
7.1. Reactions	15%
8.1. MDT	28%
8.1. Self-care	13%
8.1. Prevention of disability	17%
8.1. Surgical corrections	5%
9.1 Social integration	53%
9.1. Prejudice	20%
9.1. Social isolation	11%
9.1. Discrimination	7%
9.1 Fear	4%
9.1. Stigma	3%
10.1. Examination of household contacts	18%
10.1. BCG vaccination	11%
11.1 Contact information of Public Health Centres	29%
11.1 'Call-Health' hotline	9%
11.1 'Tele-health' hotline	5%
11.1. 'Hello-health' hotline	4%
12.1. NGO contact details	19%
12.1. Telehansen (MORHAN) hotline	34%

SIGNS, SYMPTOMS, TREATMENT AND CURE

Dermatological signs are presented in the materials predominantly via photos of parts of the human body (chest, ears, back, arms, hands, buttocks, legs and feet) with skin patches, nodules and characteristic lesions caused by Hansen's disease. It is expected that this form of communication will mobilise the population to suspect the disease and increase case detection. In line with teaching through fear, the representation of the bodies and lesions tends to reinforce the stereotypical representations of the disease or those affected by it.¹³

Neurological symptoms are expressed through the terms of pain, tingling and lost sensitivity, in addition to the information that there may be "hair loss in the eyebrows" (pamphlet 32); "numb skin patches that don't collect dust or perspire" (leaflet 41). A representative image of neurological symptoms is a woman burning herself while cooking as a result of diminished sensitivity (Poster 33, Figure 1).

According one manager this representation refers to the image conveyed in the first media campaign using the term 'Hansen's disease,' in 1988. According to other professionals interviewed, neurological complaints are the most common factor leading individuals to seek health care for Hansen's disease; however, they are the most difficult to diagnose. The general population also has difficulty associating these symptoms with Hansen's disease. Despite this fact, neurological symptoms are given less attention than skin patches and lesions in educational materials.

The association between the concepts of treatment and cure can be seen in pamphlet 53: “A skin patch might be harmless (. . .) Hansen’s disease is curable.” The image of pamphlet 27 (Figure 2) and the information that “MDT is very secure and effective in the

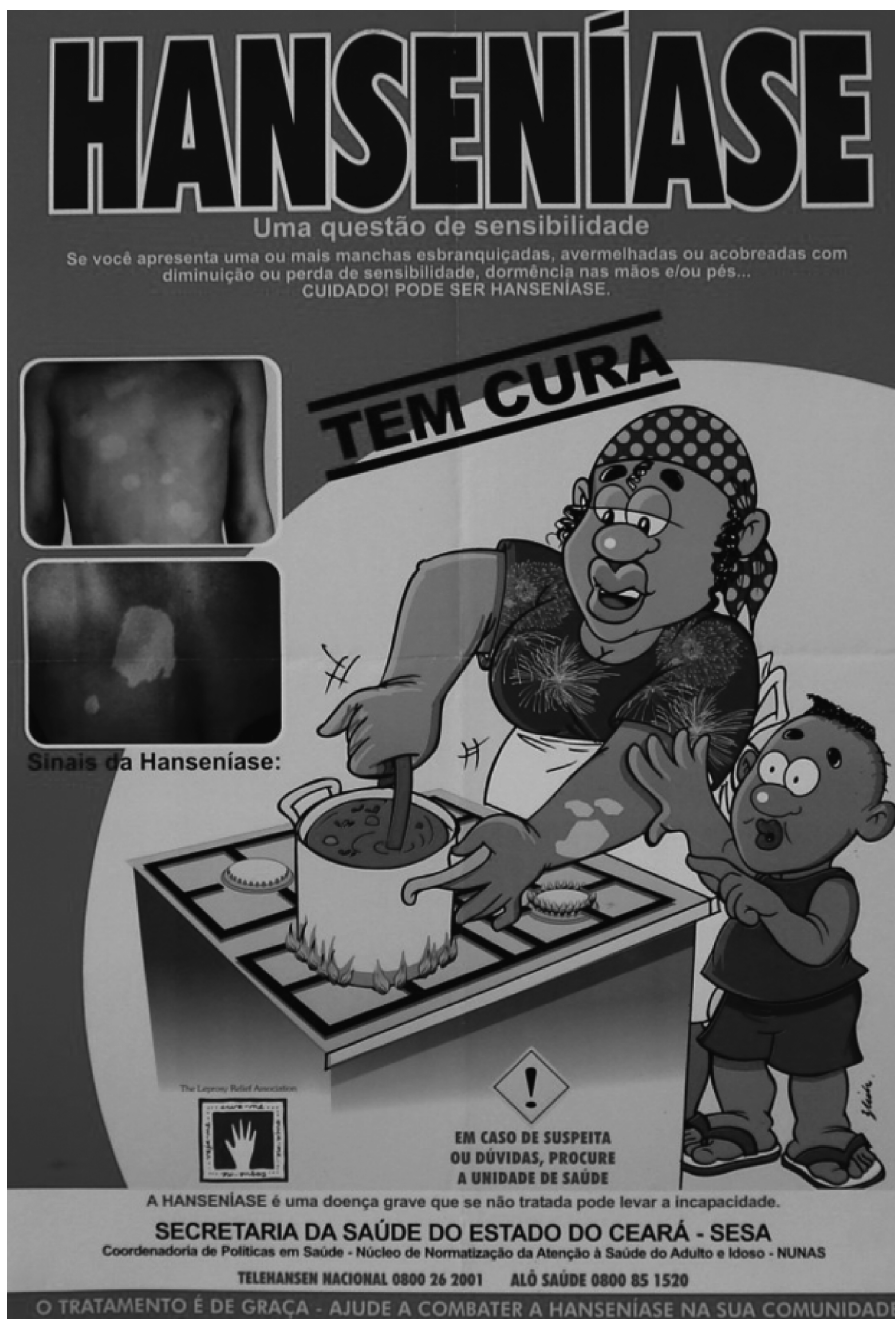


Figure 1. Neurological symptoms, Source: Poster 33/SES Alagoas.

cure of Hansen's disease" (brochure 37), express the new way of referring to the disease and breaking with the past representations of 'leprosy'.

The treatment-cure equation also contributes to the consolidation of the idea that "Hansen's disease is just like any other disease. . . It just needs to be treated!" (leaflet 66). It is possible to find a different perspective, such as the one shown in pamphlet 1: "**A skin patch could be a serious disease (. . .)**". But the emphasis on the severity of the disease is rare in the overall set of materials.

Other forms of representing the disease seek to produce discourse that minimises stigma, prejudice and discrimination. To do so some materials resort to testimonials¹⁴ of 'familiarity' and 'normalcy';¹⁵ the objective is to represent the person as integrated in the social context.



Figure 2. Treatment with MDT, Source: Pamphlet 27/No information.

One example is the use of photos of people taking medications and ex-patients of both sexes, with different ages and race, without physical disabilities.

The production of this social discourse is related to the use of MDT as a new model of treatment. According to one of the programme managers this measure “represents a watershed in the control of this disease.” Treatment shifted from a collective intervention – compulsory isolation of the sick and their social areas by way of institutionalisation in leprosaria – to a more individualised dimension. The active search for new cases by health professionals characterises the new strategy of disease surveillance. In this radical transformation of the standard treatment scheme and in the operations of the health system as a whole, the discipline and adherence of at-risk individuals became the goal. “Correctly follow the doctor’s instructions (. . .) by taking regularly the recommended medications” (brochure 40); “(. . .) treatment is taken at home” (brochure 15).

In the new approach to control, the ‘cure’ became the object of medical care and drug prescription, as exemplified by the phrases: “The cure of Hansen’s disease occurs through the use of medications that provoke the death of bacilli” (pamphlet 7); “The patient receives **release from treatment** upon completion of the prescribed standard doses, without the need for surveillance from health centres (. . .) (leaflet 59). The concept of cure, strictly related to the **destruction of bacilli**, does not take into consideration the subjective, cultural and social effects that the disease and its treatment can cause in the lives of patients. The materials do not address the consequences or side effects of MDT (alteration in skin colour), the use of corticosteroids (excessive weight gain) or other disease outcomes (physical disabilities and permanent sequelae). Such episodes restrict the capacity of patients to undertake daily activities, contribute to the loss of employment and reduce their social interaction. In extreme cases, they can lead to self segregation. In sum, these transformations contribute to changes in self-image and self-esteem, often leading to disbelief of the possibility of being cured.

The political domination of the medical component of health tends to promote a more banal view of treatment and cure, as seen in the following content: “[Hansen’s disease] is **easy** to treat and cure” (pamphlet 15); “The cure of Hansen’s disease is **simple** and **free** at all health centres” (pamphlet 64). White contests the model established by the WHO that fosters the concept of a quick and easy cure with MDT.¹⁶ He questions the extent to which the emphasis on disease cure contributes to diminished stigma associated with the disease. It is recommended that health promotion teams strive to provide better information to patients at the time of diagnosis on possible side effects of the medications and irreparable damage that might be caused by the disease. Such guidance was strengthened by the interviewees.

The topic of disease complications is present in 50% of materials, expressed by the words: reddish urine; sequelae; physical disabilities, deformities, mutilation (claw hands, blindness, etc.). Reactions are described as “acute episodes that can occur (. . .) due to manifestations of the patient’s immunological system” (leaflet 28). This aspect of treatment could be explored more extensively in programme communications, especially when compared with the massive amount of information given on skin patches and lesions, which appears in 88% of printed materials. The approach used for neurological symptoms and complications of the disease is a key issue that cannot be ignored by health authorities, mainly because, in 2007, Brazil was the country with the second-highest number of new cases diagnosed with existing physical disabilities (3,239 cases).¹⁷ This situation is directly related to late diagnosis and the low level of effectiveness of surveillance activities, such as communication and education.

DEFINITION OF THE DISEASE

The producers of materials tend to take a biomedical focus when defining Hansen's disease as "a disease caused by **bacteria** that attack the body's skin and nerves" (pamphlet 17), or as an "**Infectious** disease with prolonged evolution (. . .)" (leaflet 57). The category "etiologic agent" is referred to in 134 (49%) of the 276 materials. This approach seeks to simplify the bacterial conception using terms such as Hansen's bacillus and *Mycobacterium leprae*.

The disease has also been defined by the association between biomedical discourse and historical and cultural aspects. On one hand, the communicator makes reference to the discoverer of the bacillus in order to differentiate leprosy from Hansen's disease; on the other, the term 'leprosy' and its derivatives are often used to contextualise the history of the disease: "Hansen's disease is caused by **Mycobacterium leprae**, the **bacillus** discovered in 1873 by the Norwegian scientist Dr. Gerhard Hansen. That is where the name 'Hansen's disease' comes from although it is also known as: leprosy, morphea, Lazarus disease, and 'skin and blood disease'." (leaflet 57). This association is often more latent: "Hansen's disease has **affected humanity throughout history**. In the past it was present on all continents and left a frightening image of mutilation, rejection and social exclusion on the collective human history and memory" (brochure 11).

However, an opposing tendency is also common in the construction of a new image of the disease and those affected by it without reference to the term 'leprosy'. The subtitle of leaflet 53 - "**Hansen's disease is 30 years old**" - reveals the attempt to erase parts of history by simply giving a new inception point to a disease that dates back thousands of years. The content indicates a lack of coherence in the discursive strategies seen in educational materials; it may confuse the population by producing conflicting meanings and representations of leprosy and Hansen's disease, thereby contributing to the population's lack of knowledge of the disease.

The association between the terms 'leprosy' and 'Hansen's disease' is mentioned in only 22% of the archive and is more common in materials produced by NGOs. The interviewees involved in disease management reported that the change in terminology has led to advantages and disadvantages from different perspectives:

"It could be more motivating [to attract patients] for the health centres to say that they treat Hansen's disease rather than leprosy (. . .). It also remains a very scientific name (. . .). I think it is too radical to prohibit the use of the old name (leprosy) in technical documents. I fear that this change has brought more prejudice against leprosy" (Interview: Manager 2).

"The patient says that it is much better to hear the term Hansen's disease than to hear leprosy (. . .). The history of the disease is a relevant factor, because you introduce something new and then you have to start all over again (. . .). I always tell people that it used to be called leprosy (. . .). We cannot deny that history" (Interview: Manager, 3).

In White's opinion,¹⁸ it is necessary to speak openly to the patient about the connection between the two terms at the time of diagnosis. This dialogue may favour the correlation between existing knowledge and current explanations of the disease, in addition to helping the patient decide how much should be said about the disease and to whom.

SOCIO-CULTURAL ASPECTS

In the materials analysed, the category of socio-cultural aspects is expressed in: social integration, discrimination, fear and prejudice. These issues are addressed mainly in the following phrases: “Don’t discriminate, don’t isolate: give guidance and support” (leaflet 8); “Fear and prejudice still surround patients and can disrupt their treatment” (leaflet 2); “The patient **undergoing treatment** can co-exist with the family, co-worker and society at large” (pamphlet 27). These statements suggest new ways of living, for example, individual treatment and normal family/social life, in opposition to the practice of isolation, adopted in the past.

Prejudice is associated with treatment, as illustrated by these declarations: “A person living with tuberculosis or Hansen’s disease needs treatment, not prejudice” (leaflet 2). Treatment is also the target of **control, elimination** and **cure**: “Hansen’s disease is curable. So is prejudice” (brochure 4). From this viewpoint, information is the answer: “Information is our **single dose** against prejudice in the fight for elimination” (brochure 19). These materials express the hegemony of the universalistic information logic seen in public health^{18,19} which tends to disregard the multiple types of knowledge that influence the formation of concepts and values about the disease.

A minority of materials associates religious discourse with medical knowledge, as exemplified by leaflet 2 that joins the image of Father Cícero, a religious icon of the Brazilian North-east on one side. On the back it has the statement: “Hansen’s disease is curable!” Below that statement, there are two other overlapping boxes, a small black one with a white hand and a larger one outside forming a white frame, with the words: “*see me. . . hear me. . . touch me. . . cure me. . .*”. In this operation, a cure is associated with a miracle, compassionate treatment and pious care.²⁰

Other materials appeal to solidarity: “We can cure Hansen’s disease with love. Much love! Bacurau” (Pamphlet 28). The quotation of words from Bacurau, an ex-patient who founded the Morhan, can be a good example to be followed.

Conclusion

The analysis of the full set of 276 educational materials reveals that the relationship between communicator (producer of the materials) and recipient is predominantly asymmetric, with emphasis on the health professional’s knowledge, constructed upon the use of technical terms that characterise biomedical discourses. This aspect was identified in the focus on signs and symptoms and through the use of photographs of body parts with lesions and nodules, in addition to the emphasis given to an alarmist discourse and an appeal to people’s fears. Nevertheless, there are other materials that show photos of individuals without any visible signs in an attempt to promote a new vision of Hansen’s disease and those who carry it. Both of these approaches are present and compete with one another.

A certain type of dermatological symptoms stand out in the construction of a new disease image, whereas information on reactions, physical incapacity and disability is given lower priority. This reduced emphasis placed on the severity and complications of the disease should be reviewed given that they represent a critical communication point with the general population and care for Hansen’s disease patients.

It is concluded that the institutionalisation of discourse on Hansen's disease has not been limited to the change of names (from 'leprosy' to 'Hansen's disease'), but has been established through a new discursive practice whereby new meanings and practices have been promoted. The biomedical discourse anchors nearly all social representations and practices related to Hansen's disease as opposed to the various sources of knowledge available on leprosy, which leads to a paradoxical situation in communication about the disease.^{2,6,21} The omission of the word 'leprosy' or the dissociation of it with Hansen's disease may prevent the recognition of the disease by the population, since it neglects knowledge and meanings learned socio-culturally.

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