

Hansen's disease: beliefs and taboos of the community health agents

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Abstract

Using critical discourse analysis, this article seeks to understand the discourses on Hansen's disease/leprosy, a stigmatized disease surrounded by knowledge and practices, in the practice of community health agents, based on the premise that these professionals incorporate preconceived representations into their work. The research is structured so as to familiarize the reader with the theoretical aspects of this analysis and the historical path of the professionals in the formation of the discourse. The empirical corpus led to the following categories: "reimoso [harmful] food: food beliefs and taboos"; "alcohol-related beliefs and taboos"; and "leprosy, the disease that makes the body fall apart." We found that the agents believe in the existence of reimoso [harmful] foods and in alcohol as the cause for prolonged treatment, and that the notion that the disease makes the body of affected people fall apart is still circulating. The agents' mistaken technical knowledge may be related to how continuing education occurs.

Keywords: Leprosy. Address. Community health workers.

Resumo

Hanseníase: crenças e tabus de agentes comunitários de saúde

Por meio da análise crítica do discurso, este artigo busca compreender na prática de agentes comunitários de saúde os discursos sobre a hanseníase/lepra, doença estigmatizada e envolta em saberes e práticas, tendo como premissa que esses profissionais incorporam representações preconcebidas ao trabalho. A pesquisa está estruturada de modo a familiarizar o leitor com os aspectos teóricos dessa análise e o percurso histórico dos profissionais na formação do discurso. Do corpus empírico emergiram as categorias: "comida reimosa: crenças e tabus alimentares"; "crenças e tabus relacionados ao álcool"; e "hanseníase, a doença que cai os pedaços". Foi revelado que os agentes acreditam na existência de alimentos reimosos e na culpabilização do álcool para o prolongamento do tratamento e que ainda circula a concepção de que a doença faz cair pedaços do corpo da pessoa acometida. Os conhecimentos técnicos equivocados dos agentes podem estar relacionados à forma como se dá a educação permanente.

Palavras-chave: Hanseníase. Discurso. Agentes comunitários de saúde.

Resumen

Enfermedad de Hansen: creencias y tabúes de los agentes comunitarios de salud

A través del análisis crítico del discurso, este artículo busca comprender los discursos sobre la enfermedad de Hansen/lepra, enfermedad estigmatizada e involucrada en conocimientos y prácticas, en la práctica de los agentes comunitarios de salud, con la premisa de que estos profesionales incorporen representaciones preconcebidas en su trabajo. La investigación se estructura con el objetivo de familiarizar al lector con los aspectos teóricos de este análisis y el recorrido histórico de los profesionales en la formación del discurso. Del corpus empírico surgieron las siguientes categorías: "alimentos remosos: creencias y tabúes alimentarios"; "creencias y tabúes relacionados con el alcohol" y "enfermedad de Hansen, la enfermedad que se desmorona". Se reveló que los agentes creen en la existencia de alimentos remosos y que el alcohol es el culpable de prolongar el tratamiento, y que sigue circulando la idea de que la enfermedad provoca la caída de pedazos del cuerpo de la persona afectada. El conocimiento técnico erróneo de los agentes puede estar relacionado con la forma en que se desarrolla la educación permanente.

Palabras clave: Lepra. Discurso. Agentes comunitarios de salud.

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Leprosy has accompanied the human trajectory throughout history, being incorporated into legends and popular imagination; the scientific explanation for its cause emerged only in the bacteriological era, with the discovery of the causative agent. Nevertheless, people usually refer to it as a disease of the past, especially regarding the so-called “biblical leprosy.” In Brazil, such thought is reinforced by the replacement of “leprosy” with “Hansen’s disease” in 1995, by Law 9,010/1995, which introduced a new perspective on the disease¹.

In this study, the two terms are used separately and juxtaposed – Hansen’s disease/leprosy – according to the context. When addressing historical-cultural aspects and the production of meanings and senses, we adopt the term “leprosy” and its derivatives. When mentioning Brazilian public policies and government programs, we use the term “Hansen’s disease” and related terms. The juxtaposition Hansen’s disease/leprosy, in turn, is employed when these two universes cannot be dissociated.

Hansen’s disease/leprosy is an ancient disease whose first records date back to ancient papyri and most scholars believe it originated in Egypt, but no consensus on this exists². Its history is associated with notions of punishment and impurities, cited in the Holy Bible as a disease of sin and a trial of faith³, always in the sense of purification and not of cure. The Gospel of Matthew (8:2-4), for example, goes as follows: *A man with leprosy came and knelt before him and said, “Lord, if you are willing, you can make me clean.” Jesus reached out his hand and touched the man. “I am willing,” he said. “Be clean!” Immediately he was cleansed of his leprosy. Then Jesus said to him, “See that you don’t tell anyone. But go, show yourself to the priest and offer the gift Moses commanded, as a testimony to them”*⁴.

Despite the discovery of treatment for Hansen’s disease, popular imagination persistently links the disease to the idea of sin, which has contributed to the stigma permeating the disease⁵, shrouded in symbolic taboos and beliefs, since ancient times and for several peoples⁶. “Stigma” is a term used to designate a derogatory attribute or to refer to stereotypes created to differentiate individuals outside the normality standard

imposed by society⁷. Thus, this study is based on the premise that the subjects’ discursive practices and knowledge on Hansen’s disease/leprosy result from a historically construed process.

In everyday health care services, Hansen’s disease is curable and easy to control; from a cultural perspective, however, it refers to symbols, representations, and images collectively construed in different contexts. This, therefore, is a polysemic and multifaceted disease that is a key element for understanding the inevitable association between the physical, psychological and sociocultural dimensions. Understanding the knowledge and actions that permeate health services is thus relevant, since the discursive practices of Community Health Agents (CHA) are socially construed and inevitably incorporated into their work process.

CHAs were institutionalized by the Community Health Agent Program (Pacs), introduced in 1991 by the Ministry of Health (MS) and consolidated as a strategy to reorganize the health care model⁸⁻¹⁰ by implementing the Family Health Program (PSF) in 1994. CHAs – workers exclusive to the Unified Health System (SUS) – are responsible for disease prevention and health promotion by home or community actions, individual or collective, conducted in accordance with SUS directives⁹. These directives establish that CHAs must carry out disease surveillance and systematic monitoring of the population under their responsibility¹¹.

In health care, CHA discourse reflects their way of thinking, being and acting in relation to different aspects of the disease process caused by Hansen’s disease/leprosy, indicating a mutual influence with the setting. Social context and discourses seem thus to be “adaptable” to everyday changes and to the knowledge that the subjects – CHAs – produce about themselves in their relations with the material world¹². In this respect, critical discourse analysis (CDA) proves itself a theoretical-methodological possibility for explaining the discursive phenomena of CHAs.

CDA considers the complexity and interrelations of the discourse, since it determines actions, just as practices can constitute different discourses¹³. In this study, CDA is used as a theory-method to understand the discursive production of CHAs about Hansen’s disease and consequently their social practice. Discourse is defined as a

social practice rather than an individual activity, considered first and foremost as a mode of action by which individuals and collectives act upon the world and upon others, as well as a mode of representation and signification¹³.

Discourses make up the resources used by social agents to interact with each other – cooperating, competing and dominating¹⁴ –, thus featuring ideologies and power relations. Based on the above, we seek to understand the sense of leprosy/Hansen's disease to CHAs within the personal and professional contexts, identifying beliefs, values and taboos that may contribute to the stigma of Hansen's disease in their work.

Method

This is a qualitative, exploratory, and descriptive research conducted in the municipalities of São José de Ribamar, Maranhão, and Floriano, Piauí, both located in Northeastern Brazil. To participate in the study, we selected CHAs working in the Family Health Strategy based on the following criteria: having worked as CHA for more than two years; participation of at least one CHA per basic health unit; and workplace in an urban area. We employed two starting questions: 1) What does Hansen's disease/leprosy mean to you? and 2) What does it mean to work with Hansen's disease/leprosy?

Data was collected by employing a focus group, a qualitative technique used to understand how different perceptions and attitudes concerning a fact, practice, product, or service are formed^{15,16}. Participant selection took place by means of an invitation sent by the municipal primary health care coordinator to all CHAs in the urban area working in the Family Health Strategy to participate in a meeting with the researchers. After explaining the research proposal and its developments, we divided the CHAs who agreed to participate into two groups, with a date and place agreed upon collectively.

The study sample comprised 46 CHAs – 20 from Floriano, Piauí, and 26 from São José de Ribamar, Maranhão – with a mean age of 23 years (minimum age of 22 years and maximum age of 69 years), of which 92.3% were women and 50.1% were aged between 30 and 39 years.

Regarding schooling level, 86.8% reported having complete secondary education, 7.4% reported having or currently attending tertiary education, and 5.8% did not answer nor mentioned another schooling level.

Participants answered a semi-structured interview elaborated by researchers with experience in qualitative research, with the discussions being audio recorded and transcribed by a specialized person, and validated by the main author. The speeches were analyzed using CDA to enable a reflection on the conditions of production and apprehension of meaning, aiming to understand the modes of operation, the principles of organization and the forms of production of their meanings^{13,14,17}.

The discourse analysis of speech content followed the steps proposed by Minayo¹⁷: 1) transcription of material collected in the focus group; 2) skim reading of the material, interspersed with exhaustive listening to the recording, in search of emerging themes, so that affective investments emerge; and 3) construction or mapping of themes (empirical categories).

This study integrates the “Epidemiological, clinical, psychosocial and operational patterns of Hansen's disease in the states of Maranhão, Pará, Tocantins and Piauí: an integrated approach” project¹⁸, linked to the publicly-funded research on neglected diseases promoted by the Department of Science and Technology (Decit) and by the Brazilian National Council for Scientific and Technological Development (CNPq) (Public Notice 34/2008) upon request from the National Program for Leprosy Control (PNCH) involving these states¹⁹.

The study was approved by the Ethics Committee of the Federal University of Ceará (UFC), according to Resolution CNS 466/2012, which regulates research involving human beings²⁰. After explanation, all participants signed the informed consent form.

Results and discussion

Like other serious diseases, Hansen's disease is stigmatized and associated with popular beliefs, especially about what causes it, who contracts it, and how it should be recognized and treated²¹. The following categories emerged

from the CHAs' speeches: 1) *reimoso* [harmful] food: food beliefs and taboos; 2) alcohol-related beliefs and taboos; and 3) leprosy, the "disease that makes the body fall apart."

Reimoso [harmful] food: food beliefs and taboos

According to common belief, one of the causes attributed to Hansen's disease is the intake of certain foods, based on observations made in places where the disease was endemic. The prohibitive practice and institutionalized monitoring referred to by Foucault²² are a constant presence in the CHA guidelines, which are often reinforced and justified by the discourse of other health professionals. Eating certain foods, such as pork, is thus incriminated:

"(...) I told her that it's a disease like any other, that if she followed the treatment correctly, from the second week on she would no longer transmit it (...) the doctor also told her the same thing (...) about the food, I told her not to eat pork – because they say it's *reimoso*, you know? – and duck (...)" (Focus group 7).

In the CHAs' discourse, certain foods are referred to as in popular language and reinforced as harmful, with their exclusion from diet being, therefore, mandatory. Such practice is validated by the physician's and nurse's words, corroborating the discursive practice of the CHA:

"Regarding seafood, I was instructed by the nurse and the physician (...) who treat my husband: he could not eat seafood. Then I even told her that he liked shrimp a lot, right, that every time we [went to] a street market he wanted to buy shrimp. Then she said no, that we should avoid shrimp. I say he can't eat it. I say he can't eat it for prevention, you know? I say he can't eat it" (Focus group 8).

"Pork. I ask him [the patient] to avoid it. Everyone I treat, I ask them to avoid it (...) as they say, let the dust settle so they can eat it (...)" (Focus group 8).

Perpetuating these prohibitions is cruel and decontextualized, since most of the study participants live in coastal communities, where fish and seafood are easily accessible foods. Accordingly, the eating habits of those affected by

Hansen's disease are directly influenced by their social and economic context²³. This brings an important reflection: aren't health professionals perpetuating decontextualized practices? Or: why are health professionals, whom the population has as a reference, so normative in their instructions?

In his work *Discipline and Punish: The Birth of the Prison*, Foucault²² postulates how health services regulate people's lives. Such regulation is exemplified in the following excerpts, which present rules dictated by the CHAs and materialized in representations formed in the interface of the work context with the norms established in the social milieu in which they live.

"Regarding seafood (...) I was instructed by the nurse and the doctor (...) that he could not eat seafood (...) I say he can't eat it for prevention (...)" (Focus group 7).

"Pork. I ask him to avoid it. (...) I ask them to avoid it (...) Let it get better, (...) let the dust settle so they can eat it (...) it's better to avoid it a little until the medication takes effect (...)" (Focus group 8).

"(...) In the communities we visit, I think it's like that, they already know that pork (...) certain kinds of fish (...) they no longer eat it, they come to the stall and say 'I want that fish that 'women who have given birth' eat,' as they say, 'that is not bad for anyone, it's not *reimoso*'" (...) (Focus group 3).

CHAs use the popular terms "*reimoso*" and "*reima*" to describe the "harmful" foods that should be excluded from the diet of patients with Hansen's disease, especially during treatment. "*Reima*" derives from *rheuma*, which designates "bad nature" or a "quality" of food that makes it upsetting to certain states of the body and at certain moments in life²⁴. Foods most cited as *reimoso* – and which should therefore be strictly prohibited – include game (wild animals), pork, scaleless fish and seafood.

"(...) when my family had it [Hansen's disease] they also didn't eat either shrimp, crab or pork" (Focus group 8).

"(...) I always advise the following: (...) eat well because the medication is heavy, have a good diet, you can eat plenty of fruit, (...) vegetables. I always

ask, at my own risk, that the person who uses this type of medication does not eat lemon, because lemon is acidic (...). I always ask, if you can avoid lemon, avoid it (...) lemon is very acidic (...) you can't stop eating properly, because this medication is a strong medication (...)" (Focus group 7).

Food preferences and restrictions are usually of social or cultural origin and, when shared by the same social group, can constitute food taboos, influencing attitudes and behaviors, as well as how social systems represent the world²⁵. These restrictions may thus be related to taboos linked to common belief, causing a prohibited consumption of certain foods because they have *reima* [harmful characteristic] and represent a danger to health^{26,27}.

Alcohol-related beliefs and taboos

Alcoholism is a serious global issue, for it is insidious and interferes with personal care and behavior, impacting health and causing changes in the habits of individuals^{28,29}. The representations regarding alcohol use associated with Hansen's disease that CHAs make of alcoholic individuals come from the collective imagination and are laden with negative value judgments. Alcoholic beverages are also referred to as inappropriate because they interfere with treatment:

"(...) Do not drink, do not drink alcohol (...) if you drink alcohol, the medication is no longer useful, then you will have to start again, if you're a recidivist, then you have to start another treatment (...)" (Focus group 4).

Alcohol use is considered a factor that hinders both adherence to therapy and its regularity³⁰. Consequently, this relation is characterized in the CHAs' discourse as a determinant for prolonging treatment duration, if the patient does not follow the instructions:

"(...) in the case of drinking (...) there are patients who drink (...) they have to stop drinking to take that medication. If the doctor said that he will take this medication [for] six months, if he drinks it will increase to one year, two years (...)" (Focus group 4).

The discourse that prohibits alcohol consumption during Hansen's disease treatment presents contents

centered on biomedical knowledge incorporated into the CHAs' everyday practice, since alcohol consumption is one of the factors associated with non-adherence³⁰. Non-adherence to and irregularity of therapy have always caused concerns for health workers, since they may imply maintenance of the transmission chain and installation of sequelae and complications, as well as the development of resistance to multidrug therapy^{31,32}.

Non-adherence due to alcoholism risk factor can be determined by how professionals address the issue, but also by factors related to the patients' forgetfulness. Thus, the CHA plays a key role in monitoring the treatment of these patients.

"Disease that makes the body fall apart"

CHAs use the expression "disease that makes the body falls apart" when referring to the sequelae, with reports on Hansen's disease-related "loss of fingers" being common in the CHAs' discourse, indicating that these professionals do not understand that this occurs due to lack of preventive care and not as an inevitable sequela.

"(...) Then I said 'My God! (...) isn't that disease where parts of the person fall off? (...)" (Focus group 8).

Health care services require CHAs to inform and instruct the community about the disease and monitor cases; however, it is unclear if they are prepared to conduct these actions and, when they are, if the concern is limited to monitoring the disease, focusing on diagnosis and treatment, or if it includes sociocultural issues related to the disease. One assumes that caring for people with Hansen's disease is not limited to diagnosis and cure, due to the ideological issues within the historical process of the disease. Health agents act thus as mediators between popular knowledge and scientific knowledge regulated by health services³³⁻³⁵, as highlighted in the following speeches:

"(...) it is an infectious disease, (...) formerly known as (...) leprosy. (...) When I was young, living in the countryside, I witnessed a person who died due to lack of care (...) because of this disease, she stayed in that reserved corner, nobody touched her. (...) I witnessed her suffering several times. She had

several wounds, they would even rot (...) due to lack of care, (...) that ugly thing, I said 'my God (...) only those little bones left on her fingers (...)' (Focus group 8).

The dense metaphorical investment historically directed to leprosy is a process full of moral meanings, in which the sense associated with the loss of limbs materializes in the merging between scientific and popular knowledge³⁶. In the CHAs' discourse, popular opinion is often pronounced and mixed with science-based knowledge, especially when it comes to justifying the loss of limbs due to late diagnosis or non-adherence to treatment as prescribed.

"(...) oh, leprosy, oh, if you don't treat it, a part will fall off (...)" (Focus group 4).

"(...) I also treated a young man, I think what happened to him was that a part of his finger fell off, I don't know if it really fell off. But he said that it did fell off. He started treatment early, but he drank, then he said that he started to have wounds, wounds and all that was left was the bone (...)" (Focus group 7).

The image of leprosy immediately evokes its most severe physical symptoms, such as deformities, often mistaken for loss of limbs. Using the term "Hansen's disease" seems, therefore, to attenuate the pathology and differentiate it from leprosy in its consequences. Such is emphasized in its representation as a complex disease, which presents several forms and stages, including in its name.

"(...) in the old days (...) we used to see those people full of wounds: 'So-and-so has leprosy' (...) 'My mother used to say: Look... see, see, he has leprosy...' because there [in the countryside] it was like that. Today we don't have those wounds on the body like that. (...) Leprosy was more serious, when it appeared it was more serious (...) leprosy is already a more advanced disease, (...) much more advanced (...) than Hansen's disease, (...) when it was discovered, it was already in an advanced stage" (Focus group 3).

"(...) there is a stage of the disease where [the sequelae] happens (...) after a while without treatment, it deteriorates. When it reaches

atrophy, it's been a long time. (...) it is in the last stages" (Focus group 4).

The CHAs' knowledge about Hansen's disease may be related to length of service, schooling level, and training³⁷, which highlights the importance of continuing education regarding the disease for these professionals. Moreover, CHAs play a key role in the active search and early detection of cases, since they have closer contact with the population in their territories³⁸. When they mistakenly use words such as "multibacillary," "chronic disease," and "sequela" to designate forms of disease presentation, they are confronting what they consider to be common belief representations.

"Disease with more and less patches (...) with the technical knowledge acquired during their training (...) a chronic, infectious disease. A disease that affects the skin (...) nerves (...) hands, ears, fingers, feet (...) it has many forms, there is multibacillary, the one with more and less [patches], the person feels more pain and feels less pain (...)" (Focus group 3).

"(...) there are three types? As far as I know, according to my training, there are three types (...). There is one [in which] the degree is higher, in the case of nerves (...) Multibacillary? Actually, it is less in the nerves and the highest degree is in the skin, because when it reaches the skin, you get deformed" (Focus group 7).

Other studies showed similar results when reporting that, from the biomedical sciences standpoint, Hansen's disease has treatment and cure; but from a cultural perspective, it refers to negatively charged symbols in a considerable number of societies^{39,40}. Similarly, the metaphors used by CHAs act as representations to understand the inevitable association between the physical, psychological and sociocultural dimensions of Hansen's disease/leprosy.

Final considerations

The practices of community health agents show many conceptual misconceptions, such as the association of the multibacillary form with pain

and the understanding that the disease has several forms – multibacillary, with more and less patches, with more pain and less pain –, including the old formulation: “the disease that makes the body fall apart.” Considering that such social and symbolic constructions help maintain the stigma of the disease, one understands the importance of the knowledge produced in these discourses. Such misconceptions may be related to the methodologies proposed in

CHA training and the lack of continuing education practices based on meaningful learning.

This study sought to reflect on the need to establish continuing education actions that mobilize these professionals to identify strategies that employ multiple languages, approaching the realities experienced in the territories, to modify the current Hansen's disease scenario and overcome disease-centered models.

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