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RESEARCH

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Spirit of leprosy in times of Hansen's disease: knowledge, memories and social representations

Espírito da lepra em tempos de hanseníase: conhecimentos, memórias e representações sociais

Espíritu de lepra en tiempos de enfermedad de Hansen: conocimientos, memorias y representaciones sociales

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ABSTRACT

Objective: to analyze the social representations of Hansen's disease from the perspective of those who experience the disease. **Methods:** a qualitative and descriptive study, based on the Theory of Social Representations. A total of 41 people with Hansen's disease from a reference unit in Pará participated. Information was produced through in-depth individual and semi-structured interviews. The *corpus* was submitted to the IraMuTeQ software. **Results:** the software divided the texts of the interviews into 701 text segments with a utilization of 81.60%. Class 1 contains elements related to the symbolic construction of leprosy, anchored and objectified in the historical memory of ancient leprosy, triggering memories that affect body aesthetics, such as mutilation and deformities. The disease imposed as divine punishment is rescued, and aspects of prejudice and social stigma emerge. **Conclusion and implications for practice:** leprosy reminiscences are still strong and influence patients' treatment, insertion and social life. The dissemination of information about Hansen's disease, the importance of adherence to treatment and its potential for cure must be intensified. This information should not be restricted to discursive content, but rather to images and actions, with activities that mobilize emotions and enable the construction of new representations that distance the image of leprosy from people's daily lives.

Keywords: Social Stigma; Leprosy; Memory; Social Representations; Health.

RESUMO

Objetivo: analisar as representações sociais da hanseníase na ótica de quem vivencia a doença. **Métodos:** estudo qualitativo e descritivo, fundamentado na Teoria das Representações Sociais. Participaram 41 pessoas com hanseníase de uma unidade de referência do Pará. Realizou-se entrevista em profundidade individual e semiestruturada. Os dados do perfil foram tratados com recursos da estatística, e os textuais foram submetidos ao *software* IraMuTeQ. **Resultados:** o *software* dividiu os textos das entrevistas em 701 segmentos, com aproveitamento de 81,60%. A classe lexical 1 contém elementos referentes à construção simbólica da hanseníase ancorados e objetivados nas memórias da antiga lepra, acionando imagens que afetam a estética corporal, como a mutilação e deformidades. Resgata-se a doença como castigo divino, emergindo o preconceito e estigma social. **Conclusão e implicações para a prática:** as reminiscências da lepra são fortes e influenciam a inserção e o convívio social dos doentes. Há que se intensificar a difusão de informações sobre a hanseníase, importância da adesão ao tratamento e seu potencial de cura. Essas informações não devem se restringir aos conteúdos discursivos, mas imagéticos e de ação, com atividades que mobilizem afetos e possibilitem a construção de novas representações que afastem a imagem da lepra do cotidiano das pessoas.

Palavras-chave: Estigma Social; Hanseníase; Memória; Representações Socias; Saúde.

RESUMEN

Objetivo: analizar las representaciones sociales de la enfermedad de Hansen desde la perspectiva de quienes viven la enfermedad. **Métodos:** estudio cualitativo y descriptivo, basado en la Teoría de las Representaciones Sociales. Participaron 41 personas con enfermedad de Hansen de una unidad de referencia de Pará. Se llevaron a cabo entrevistas en profundidad individuales y semiestructuradas. Los datos del perfil se trataron con recursos estadísticos y los datos textuales fueron enviados al *software* IraMuTeQ. **Resultados:** el *software* dividió los textos de la entrevista en 701 segmentos de texto con una tasa de precisión del 81,60%. La clase lexical 1 contiene elementos referentes a la construcción simbólica de la enfermedad de Hansen, anclados y objetivados en las memorias de la enfermedad de Hansen de la antigüedad, desencadenando imágenes que afectan la estética corporal, como mutilaciones y deformidades. La enfermedad es vista como un castigo divino y surgen prejuicios y estigmas sociales. **Conclusión e implicaciones para la práctica:** los recuerdos de la lepra son fuertes e influyen en la inserción y la vida social de los pacientes. Se debe intensificar la difusión de información sobre la enfermedad de Hansen, la importancia de la adherencia al tratamiento y su potencial de curación. Esta información no debe limitarse a contenidos discursivos, sino a imágenes y acciones, con actividades que movilicen afectos y permitan la construcción de nuevas representaciones que eliminen la imagen de la lepra de la vida cotidiana de las personas.

Palabras clave: Estigma Social; Lepra; Memoria; Representaciones Sociales; Salud.

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INTRODUCTION

Hansen's disease, formerly called leprosy, is a neglected tropical disease that is endemic in Brazil, a country that, between 2013 and 2022, reported 316,182 cases of the disease, ranking second in the world in terms of the number of cases.[1] Socioeconomic factors are closely related to the spread of the disease, as Hansen's disease affects, to a greater extent, population groups with lower levels of education and who face barriers to accessing health and social healthcare.[1] This can be illustrated by the fact that India, Brazil and Indonesia account for 81% of global detections.[1]

This is a chronic, infectious and contagious pathology, transmitted by the respiratory system, which presents dermatological and neurological signs and symptoms caused by *Mycobacterium leprosye*.[2] It presents an essentially clinical and epidemiological diagnosis, which occurs through a dermatological examination to identify lesions or areas of skin with altered sensitivity and/or impairment of peripheral nerves.[2] When the presence of the disease is confirmed, antimicrobial treatment is carried out through polychemotherapy with rifampicin, dapsone and clofazimine.[3]

Although it is a treatable and curable disease, it is considered a major public health concern due to the disabling potential caused by the physical changes that the disease can generate, with reduced work capacity, limited social life and psychological problems.[4] A study conducted in Brazil found a 70.4% prevalence of common mental disorders among people diagnosed with Hansen's disease who presented complications due to physical deformities. The study states that prejudice, pain and disabilities secondary to the disease help to explain the impacts on the mental health of those affected as well as the social stigma generated.[5]

However, it is worth noting that the stigma surrounding Hansen's disease is not only linked to physical disabilities, but to the ancient history of segregation of the disease, marked by a long period in which people, at the time called "lepers", were considered impure, sinful, transgressors of the social order, a threat to healthy people, and, therefore, confined in leprosariums or colonies, described as institutions closed to the outside, with high walls, fenced in by wire, surrounded by forests and far from the city.[6-8]

The diagnosis of Hansen's disease for people who experience the illness can activate beliefs that refer to the social memory of leprosy and contribute to negative psychosocial repercussions.[9] Social memory can be understood as a set of social representations (SR) about the past that each group produces, institutionalizes, stores and transmits through the interaction of its members, allowing the interpretation of the present based on reference frameworks linked to the past.[10,11] In a complementary sense, occurrences of memories are observed within SR, through the anchoring of new experiences in pre-existing knowledge, in which the past prevails over the present and memory over deduction.[12]

The relationship between the present and the past of Hansen's disease is still strong, as it is clear that, even with the advances made in Hansen's disease diagnosis, control and treatment, the disease stigma is still clear, caused by prejudice, fear and rejection by society. In this regard, the process of becoming ill with Hansen's disease refers to the social memory of leprosy, and the impact of this is related to the knowledge regarding the past of the disease.[12]

To understand the reality of people living with Hansen's disease, this study adopted a psychosocial approach, because this perspective enables the articulation of individual experience with the constant symbolic exchanges undertaken in the environment of social and institutional relations. Hence, the use of the Theory of Social Representations (TSR) theoretical-methodological framework was considered pertinent.[13]

It is worth highlighting that the concept of SR adopted in this study concerns a form of practical knowledge, socially elaborated and shared, which contributes to the construction of a common reality for a social group.[14]

In this way, understanding the social and cultural meanings of Hansen's disease allows professionals to be closer to the reality of a person affected by the disease, in order to guide health practices in assessing users' real needs and overcoming the limitations of physical-biological treatment. Therefore, this study aimed to analyze Hansen's disease SR from the perspective of those who experience the disease.

METHOD

This is a descriptive study, with a qualitative approach, based on TSR[13] in its procedural approach.[15] The article construction followed the COnsolidated criteria for REporting Qualitative research recommendations.[16]

The study was conducted in four Basic Health Units (BHU) located in the urban area of the municipality of Marabá, state of Pará, Brazil. The units have 12 Family Health Strategy (FHS) teams that offer care by a multidisciplinary team. The units were chosen because they had the highest number of new cases of Hansen's disease registered in 2020 in the state of Pará.

Forty-one people with Hansen's disease participated. The inclusion criteria were being enrolled in the BHU Hansen's disease control program, having a confirmed diagnosis of the disease, regardless of the clinical form, being over 18 years old, and having been undergoing drug treatment for at least one month. The minimum time is justified by participants' familiarity with the institution routines, the disease diagnosis and the therapy instituted.

The exclusion criteria adopted were people with Hansen's disease who had comorbidities associated with dermatological changes, such as lupus erythematosus and pemphigus foliaceus, and those with cognitive changes or communication difficulties that prevented participation in the interviews. The participants approached did not meet these criteria; therefore, there were no exclusions or withdrawals.

The study was developed by professionals with undergraduate and graduate degrees in nursing, one man and three women; among these was the person responsible for data collection who, through a supervised internship developed over a period of three months, had previous contact with the research field and experience in the applied collection technique.

Data production took place from July to September 2020, carried out by the researcher in charge, who did not maintain institutional, labor or personal ties with the institutions and/or the professionals who worked there.

Participants were approached in person, according to their attendance at the BHU, without interfering with work routines of the unit or participants. At the end of the nursing consultation, participants were invited to participate in the study. Those who agreed were directed to a previously reserved room, where only the interviewer and the interviewee were present, with privacy and comfort guaranteed. The research, objectives, benefits and risks, and mechanisms to minimize them were explained. Permission was requested to record the interviews on an electronic device.

The interviews lasted an average of 30 minutes and were recorded in MP3 format. To verify the efficiency of the data collection instrument, a pilot test was carried out with ten patients with Hansen's disease enrolled in one of the four health units investigated in the municipality of Marabá. It is worth noting that those who participated in the test were not included in the final sample of this study.

A semi-structured form was used, consisting of closed-ended questions, in order to characterize the sociodemographic profile of participants and to understand their belonging, and open-ended questions, which explored the object of study based on the following questions: when I say Hansen's disease, what comes to mind? What does Hansen's disease mean to you?

The profile data was entered into Microsoft Office Excel® version 2019 spreadsheets and processed using simple and percentage statistics. After this processing, the results were migrated from a Microsoft Office Excel® spreadsheet to compose the text in a descriptive manner.

The interviews were transcribed in full, following the criteria for *corpus* preparation and lexicographic analysis of the software[17] *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires* (IRaMuTeQ) version 0.7 alpha 2. This software assists in the processing and analysis of dense textual data obtained from discursive texts. For the analysis phase, the Descending Hierarchical Classification (DHC) was chosen, considering the words that presented chi-square ($\chi2$) with significance p-values ≤ 0.01[16] and the text segments (TS) that compose it. The data related to DHC were placed in a table, highlighting words with the greatest statistical association with the lexical class selected for analysis, in compliance with the objective.

The research was approved by the Research Ethics Committee of the *Escola de Enfermagem Magalhães Barata*, *Universidade do Estado do Pará*, under Opinion 3296983/2020. All participants signed the Informed Consent Form before the start of data production. Identity confidentiality was guaranteed through the use of an alphanumeric code, represented by the letter I, for "interview", followed by the cardinal number indicating the order in which the interviews were conducted.

RESULTS

The analysis of the social affiliation of the 41 research participants allowed us to identify that 29 (70.7%) were male and 12 (29.3%) were female. Age ranged from 18 to 59 years, with a predominance of the age group of 29 to 43 years (n=13; 31.7%), followed by the age group of 18 to 28 years (n=11; 27%), between 60 and 75 years (n=9; 22%), and over 79 years of age (n=8; 19.3%). Concerning marital status, 32 (78.1%) lived in a consensual union, and nine (21.9%) were single.

Regarding education, 25 (61%) had incomplete elementary education; 14 (34%) reported having completed high school; and two (5%) reported having completed higher education. Moreover, 21 (51.2%) worked informally; 13 (31.7%) reported not having any professional activities; and six (17.1%) were retired. As for financial matters, 35 (86%) had a family income between one and two minimum wages (35-86%). In relation to religion, 23 (53.7%) declared themselves to be Evangelical, and 18 (46.3%) were Catholic.

The *corpus* was composed of 41 texts, and after processing by the software, it generated 701 TS with use of 81.60% of the analyzed material, distributed in a dendrogram with five lexical classes. To meet the objective in question, lexical class 1 was chosen, which, in light of the vocabulary present in the TS that composes it, was interpreted with the TSR instrument.

Class 1 was organized with 90 TS and 24 analyzable words, making up 15.73% of the total TS that constituted the *corpus*. Considering the most representative words, the number of times they were cited (f - frequency) and the strength of the word for the formation of the class (chi-square test - $\chi2$), according to DHC (Table 1), it was identified that the lexicon with the highest $\chi2$ was represented by "leprosy", followed by "history", "bible", "isolated", which, among others, point to the contextualized and constructed knowledge in the consensual universe, in which the idea of Hansen's disease is anchored in the historical memories of ancient leprosy, a biblical disease.

The elements present in TS indicated that people who experience Hansen's disease, when trying to understand the illness process, still anchor it to leprosy, the target of stigma and prejudice, triggering memories that affect body aesthetics, such as mutilation and deformities.

> [...] *I think there are a lot of people who look at us differently; this is prejudice against those who have the disease. I had it once in the past, and the image I think of is that my fingers fall off, I don't know if there really is a cure for this* [...] (I1).
>
> [...] *at the moment, the illness means a bad feeling, of sadness, because at home, people treat me differently. I don't even feel like going out, because wherever I go, it seems like people are afraid* [...] (I3).
>
> [...] *it is a terrifying, horrible thing, it was even difficult to accept this thing, because, in the past, Hansen's disease was something from another world, it left us covered in*

Table 1 - Descending Hierarchical Classification of class 1 originating from *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*. Belém, Pará, Brazil (n=31).

Words	F	χ2
Leprosy	52	204.69
History	15	82.5
Previously	15	58.46
Listen	20	53.96
Movie	12	53.3
Leper	13	47.6
Bible	9	36.91
Isolation	11	26.69
Fingers-fall	6	20.9
Past	6	20.9
Jesus	7	16.58

Source: report of the software IRaMuTeQ 0.7 alpha 2.0 (2020).

> *ugly wounds, deformed. It scared me, because that was the image I had and I always saw people talking like that* [...] (I4).

Participants associate Hansen's disease with divine punishment and use information circulating in social media, the media, religious organizations or from previous experiences; thus, they objectify and anchor the disease and develop SR about it.

> [...] *the things we watch, we see those movies, that image of the leper from the Bible. We are afraid that what happens to others will happen to us, that they will move away, like what happened to me. It's sad* [...] (I6).
>
> [...] *older people from 59 years old and back know that this is not Hansen's disease, it's leprosy. Those who have it do something wrong in their lives, I don't know if there's a cure or if it just gets better a little* [...] (I35).
>
> [...] *it is a sad disease that makes people feel a lot of pain. We think it is a punishment, because it used to be, and we wonder why it appears in us. The pastor always says that Job's leprosy was given by God* [...] (I16).
>
> [...] *it even meant lack of hygiene, so many pastors say leprosy, and people who don't have knowledge have an impact and continue to have a lot of prejudice. So, they should say the other name* (Hansen's disease) *to reduce this kind of thing* [...] (I34).

TS show how people affected by Hansen's disease were treated in the past, being forcibly removed from their family and social ties to be isolated in leprosariums, which "guaranteed" the safety of the "healthy" and kept them away from "threats".

> [...] *I'm afraid to get close to people sometimes and they'll think it's bad. I'm afraid someone will find out I have the disease and ask me not to get close, you know? There's a lot of prejudice* [...] (I7).
>
> [...] *there are all kinds of people. I think there are people who are prejudiced, I saw it myself, I met people isolated in Imperatriz, in Maranhão, where I spent many years. I remember them being isolated and no one could get close to them* [...] (I17).
>
> [...] *most people are misinformed. With this pain, I pray to God that others don't get it, because Hansen's disease is a prison. I know the history of leprosy very well. Lepers were kept in a shed. People would bring food and hang it on a stick so that no one would get close. I've cried thinking about this story* [...] (I38).

DISCUSSION

Until the 1970s, leprosy was a term associated with different bodily injuries and mutilations, which led to isolation and even exclusion of patients by members of society.[17] Studies show that, to this day, the word carries the connotation that the individual has a health problem that causes disruption to social interaction.[18]

It is worth noting that participants' knowledge about Hansen's disease is not only linked to the clinical aspects of the disease, but also to psychosocial and affective aspects. The results show knowledge constructed based on their previous experiences, culture and relationships within their social contexts. This knowledge is linked to the affective dimension, evidenced by fear and sadness, which influence decision-making in light of what they represent, translated into self-isolation from others.

The images present in TS that translate Hansen's disease, anchoring it to leprosy, support the results of different research on the same topic, relating the figure of a sick person to the "leper of history".[19,20] This negative image associated with Hansen's disease, which still remains in social imagination, suggests that it is related to knowledge and practices of the past, since the phenomenon of SR circulates, intersects and crystallizes in everyday life.[12] And this explains why no mind is free from the effects of previous conditioning imposed on it by its representations, language or culture.[12,15]

It is worth noting that people living with Hansen's disease go through unpleasant situations, influenced by the social image of the disease. Thus, managing prejudices and opinions of third parties (information dimension) about the life of those going through the process of illness begins to be part of the routine. Due to prejudice related to the disease, people diagnosed with the disease experience separation from family members, coworkers and friends, harsh expressions of fear of contagion and segregation.[18,21]

Faced with phenomena that destabilize the physical and social body, a person uses their symbolic framework, constructed and shared culturally, to give meaning to what surrounds them and which generates strangeness.[22] When it comes to historical chronology, Hansen's disease behaves like an ancient health condition reported since biblical times. The writings of the Old and New Testaments remember leprosy as a form of punishment for offenders and a divine consequence motivated by sin; therefore, those diagnosed with the disease were considered abominable, destined for social exclusion and death.[20] It can be seen from the results that these reminiscences continue to circulate and interpenetrate social knowledge about the disease, even today.

The current thinking about Hansen's disease among participants is that it is a bad and fearful disease, related to the biblical marks of antiquity, i.e., to the hegemonic and historically constructed prejudice that serves as the basis for understanding the disease.[23] Memories of the past arise because reminiscences still circulate and feed representations that are shared and are responsible for materializing the imagery of a "leper", highlighting the dimension of information/image and triggering fear, which shows the dimension of affections in SR.[13,15]

In this way, reinforced by history and religious discourse, social exclusion is shown to be one of the characteristics of Hansen's disease anchored in the memory of Hansen's disease that reinforces the stigma and prejudice imposed by the disease.[18] A study carried out in Indonesia identified that the forms of community stigma towards people with Hansen's disease were avoiding meetings, visiting or receiving, greeting, being physically close and even looking at people who had the diagnosis.[24] In the same study, the authors highlighted social expulsions committed, suggestions to leave the community, verbal aggression and non-verbal insults, such as covering the nose and spitting when passing by the residence of someone who had the disease.[24]

These attitudes and behaviors can be called *significant*[25] and trigger psychological consequences that increase the burden of the disease and affect the quality of life and self-care of people affected by it.[26,27] Studies conducted in Nepal and India have shown a high prevalence of symptoms of depression and anxiety in people living with Hansen's disease and victims of the disease stigma, showing that stigma and mental health are significant predictors of quality of life in people facing the diagnosis.[28,29]

Until the 20th century, hospitals that treated Hansen's disease, called Lazarus hospitals and asylums, were mostly supported by the Church, as there were no state-funded institutions that offered treatment.[20] In view of this, religious people controlled people's social roles, associating "leprosy" with divine punishment and sin. For this reason, prejudice still persists in the social contexts in which the patient is included.[29]

In the TS of I34, there is a suggestion to use another name when referring to Hansen's disease. In this regard, it is worth noting that the event that played an important role in understanding the SR of this disease was the change of the name leprosy to the neologism Hansen's disease, aiming to reduce the disease stigma.[14,30]

It is suggested that naming the disease as Hansen's disease lessens the impact of the diagnosis of the disease, as it distances itself from the negative charge present in the previously used expression - leprosy. Thus, the semantic change did not eliminate the coexistence of elements anchored in common sense and that refer to the social memory of leprosy, such as punishment for adultery, witchcraft and sexual immorality,[26] but associated it with content anchored in scientific knowledge about Hansen's disease as a treatable and curable disease as long as it is diagnosed early.[12,14] SR are formed in language, in communication and are sustained in culture, which is why they are difficult to change, especially when it comes to a phenomenon related to a disease with a thousand-year-old history and a strong biblical burden, with characteristics of hegemonic representation,[12] as in the case of leprosy.

Suffering prejudice and feeling fearful of people's gaze in their social context can cause changes in patients that go beyond merely biological aspects. In the TS of I7, mention is made of fear of approaching people and suffering discrimination, which is configured as anticipation of a situation that can generate segregation and distress, which generates the behavior (the action) of avoiding contact with others. This attitude (significant behavior) is configured as self-care.

Self-care goes beyond the body and extends to caring for the soul, which denotes that both dimensions can be affected by ills simultaneously.[31] Thus, the biopsychosocial changes generated by Hansen's disease expose the disease to the gaze and judgment of others (social), which can provoke significant discriminatory behaviors from others towards them, from them towards others (reaction) and from them towards themselves (self-prejudice).

Discrimination against Hansen's disease patients is still a challenge in Brazil. In this regard, the World Health Organization continues to try alternatives to improve efforts in countries with a high burden of the disease, because stigma and discrimination against affected people interfere with early detection of cases and completion of treatment, because revealing the diagnosis can be a factor of social exclusion, depression and job loss, affecting patients and their families.[32]

Affections are one of the bases for SR formation, as they are supported by memories and experiences, since the object induces comments about it.[14] When capturing Hansen's disease SR, when asking people to talk about the disease, they talk about themselves and who they are in the social group they belong to, how they feel and act in the face of the disease,[12,14] making clear the mutual influence of the person and the social group in SR (self-society).

The results lead to the reflection that, although there are ministerial campaigns about Hansen's disease, the image of the disease related to leprosy still remains, and the knowledge that supports it is still shared, keeping it alive in social memories. Therefore, it is necessary to intensify communication about the disease and its treatment, with the dissemination of knowledge and images of people with Hansen's disease, treated and cured, to promote and solidify new SR. However, it is necessary to mobilize the population's feelings in relation to Hansen's disease, since the SR dimensions encompass not only information and opinions, but beliefs and feelings that, together, shape the interpretative field regarding the represented object.[13,15]

FINAL CONSIDERATIONS AND IMPLICATIONS FOR PRACTICE

Hansen's disease SR are still influenced by an incurable disease, leprosy, whose memory triggers images and previous knowledge linked to physical deformities, finitude, segregation and prejudice. This influence is demonstrated by feelings that emerge from the diagnostic confirmation and generate sadness, depression, fear, shame and social isolation, making the process of becoming ill with Hansen's disease even more painful, as these representations guide patients' actions in the face of the disease, having an impact on self-care.

The reminiscences of leprosy are still strong and influence the social integration and coexistence of patients. This aggravates the public health concern, which is not only evidenced by epidemiological data, but also by people's well-being (population). The dissemination of scientific information about Hansen's disease must be intensified, through explanations accessible to the general public, emphasizing the importance of adherence to treatment and its potential for cure. This information should not be restricted to discursive content, but rather to images and actions, with activities that mobilize emotions to enable the construction of new representations that distance the image of leprosy from people's daily lives, which has a negative connotation so that prejudice and stigmas that so affect psychosocial relationships and human health are reduced.

Limitations of this study include the specificity of a region of the country that is strongly influenced by sociocultural factors, which was home to a leper/Hansen's disease colony and where the disease rate is still high. Moreover, the study was conducted with users of 12 FHS teams out of a total of 33 located in the urban area of a municipality in Pará, and could be expanded to include services in other states in the North of the country and also in other states of the federation.

The contribution is evident in the better understanding of the genesis of SR on Hansen's disease in the studied group, which can support similar studies to build a more positive image of the disease, patients and their families. TSR makes it possible to capture the interpretation of subjects and the understanding of attitudes and behaviors of social groups in the face of diseases/illnesses/care, helping to reveal situational contexts that are often hidden and need to be brought to light to enhance healthcare for the population (social groups) with greater acceptance of their demands and minimization of distress.

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DATA AVAILABILITY RESEARCH

Data is available at: https://sucupira-legado.capes.gov.br/sucupira/public/consultas/coleta/trabalhoConclusao/viewTrabalhoConclusao.jsf?popup=true&id_trabalho=10280716

CONFLICT OF INTEREST

None.

REFERENCES

1. Ministério da Saúde (BR). Secretaria de Vigilância em Saúde e Ambiente. Boletim epidemiológico: hanseníase 2024 [Internet]. Brasília, DF: Ministério da Saúde; 2024 [citado 2024 out 21]. Disponível em: https://www.gov.br/saude/pt-br/centrais-de-conteudo/publicacoes/boletins/epidemiologicos/especiais/2024/be_hansen-2024_19jan_final.pdf/view.
2. Kukkaro P, Vedithi SC, Blok DJ, van Brakel WH, Geluk A, Srikantam A et al. Target product profiles: leprosy diagnostics. Bull World Health Organ. 2024;102(4):288-95. http://doi.org/10.2471/BLT.23.290881. PMid:38562197.
3. Brasil. Ministério da Saúde. Secretaria de Vigilância em Saúde e Ambiente. Departamento de Doenças Transmissíveis. Estratégia Nacional para o Enfrentamento à Hanseníase 2024-2030 [Internet]. Brasília, DF: Ministério da Saúde; 2024 [citado 2024 out 21]. Disponível em: https://www.gov.br/saude/pt-br/centrais-de-conteudo/publicacoes/svsa/hanseniase/estrategia-nacional-para-enfrentamento-a-hanseniase-2024-2030/view.
4. Martoreli Jr JF. Aglomerados de risco para ocorrência de hanseníase e as incapacidades em menores de 15 anos em Cuiabá: um estudo geoespacial. Rev Bras Epidemiol. 2023;26(2):1-9. http://doi.org/10.1590/1980-549720230006.2.
5. Li X, Ma Y, Li G, Jin G, Xu L, Li Y et al. Hanseníase: tratamento, prevenção, resposta imunológica e função genética. Imunol Frontal. 2024;15(3):1-18. http://doi.org/10.3389/fimmu.2024.1298749
6. Finotti RFC, Andrade ACS, Souza DPO. Transtornos mentais comuns e fatores associados entre pessoas com hanseníase: análise transversal em Cuiabá, Brasil, 2018. Epidemiol Serv Saude. 2020;29(4):e2019279. http://doi.org/10.5123/S1679-49742020000400006. PMid:32756833.
7. Goffman E. Manicômios, prisões e conventos. São Paulo: Perspectiva; 2020.
8. Souza GC, Oliveira PS, Araujo PN, Santos FL, Silva JP, Santos KS et al. Experiências de estigma social de pessoas que vivem com hanseníase no Brasil: silenciamentos, segredos e exclusão. Saúde Interna. 2024;16(1):60-7. http://doi.org/10.1093/inthealth/ihae005. PMid:38547345.
9. Leano HADM, Araújo KMDFA, Bueno IDC, Niitsuma ENA, Lana FCF. Fatores socioeconômicos relacionados à hanseníase: revisão integrativa da literatura. Rev Bras Enferm. 2019;72:1405-15. http://doi.org/10.1590/0034-7167-2017-0651.
10. Passos ÁLV, de Araújo LF, Belo RP. Hanseníase e envelhecimento: representações sociais dos moradores de um hospital-colônia. Rev Pesq Prát Psicossoc. 2021 [citado 2024 out 21];16(3):1-15. Disponível em: https://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S1809-89082021000300005&lng=pt&nrm=iso.
11. Jedlowski P. Memory and sociology: Themes and issues. Time Soc. 2001;10(1):29-44. http://doi.org/10.1177/0961463X01010001002.
12. Halbwachs M. A memória coletiva. São Paulo: Centauro; 2006.
13. Moscovici S. A psicanálise, sua imagem e seu público. Petrópolis, RJ: Vozes; 2012.
14. Porto CL, Marques MCC. Representações sócio-históricas de uma doença: um estudo sobre cartazes de campanhas para o combate à hanseníase na segunda metade do século XX. Hist Cienc Saude Manguinhos. 2023;30(2):e2023066. http://doi.org/10.1590/s0104-59702023000100066en. PMid:38018637.

15. Jodelet D. Representações sociais: um domínio em expansão. In: Jodelet D, organizador. As representações sociais. Rio de Janeiro: EdUERJ; 2001. p. 17-44.
16. Souza VRS, Marziale MHP, Silva GTR, Nascimento PL. Translation and validation into Brazilian Portuguese and assessment of the COREQ checklist. Acta Paul Enferm. 2021;34(2). http://doi.org/10.37689/acta-ape/2021AO02631.
17. Camargo BV, Justo AM. Tutorial para uso do software IRaMuTeQ (Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires)[Internet]. Florianópolis: Laboratório de Psicologia Social da Comunicação e Cognição; 2018 [citado 2024 out 21]. Disponível em: http://www.iramuteq.org/documentation/fichiers/tutoriel-en-portugais.
18. Jesus ILR, Montagner MI, Montagner MA. Hanseníase, vulnerabilidades e estigma: revisão integrativa e metanálise das falas encontradas nas pesquisas. Unaí: Coleta Científica; 2021 [citado 2024 out 21]. Disponível em: https://portalcoleta.com.br/index.php/editora/article/view/86.
19. Neiva RJ, Grisotti M. Representações do estigma da hanseníase nas mulheres do Vale do Jequitinhonha-MG. Physis. 2019;29(1):e290109. http://doi.org/10.1590/s0103-73312019290109.
20. Costa A. Sangue e fígado: a persistência das imagens simbólicas sobre a lepra a partir do mito do papa-figado. Rev Electron Comun Inf Inov Saude. 2020;14(2):502-14. http://doi.org/10.29397/reciis.v14i2.1896.
21. Souza GC, Oliveira PS, Araujo PN, Santos FL, Silva JP, Santos KS et al. Experiências de estigma social de pessoas que vivem com hanseníase no Brasil: silenciamentos, segredos e exclusão. Int Health. 2024;16(1):60-7. http://doi.org/10.1093/inthealth/ihae005. PMid:38547345.
22. Nascimento RD, Sousa IMC, Melo CPL, Santos DCM. Criação e desenvolvimento de grupos de apoio para o autocuidado em hanseníase em um estado do Nordeste brasileiro. Physis. 2024 [citado 2024 out 21];34(22):1-22. Disponível em: https://www.scielo.br/j/physis/a/zQRKDtW85vbsdBvWFTPFFKK
23. Pegaiani KNA, Pinto NS, Batiston AP, Santos MLM, Cabral KV, Belloc MM et al. Conferências de saúde e a hanseníase: ditos e silenciamentos sobre a doença negligenciada e seus estigmas. Saude Soc. 2023;32(3):e210889pt. http://doi.org/10.1590/s0104-12902023210889pt.
24. Stangl AL, Earnshaw VA, Logie CH, van Brakel W, Simbayi LC, Barré I et al. The Health Stigma and Discrimination Framework: a global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. BMC Med. 2019;17(1):31. http://doi.org/10.1186/s12916-019-1271-3. PMid:30764826.
25. Jesus ILR, Montagner MI, Montagner MA, Alves SMC, Delduque MC. Hanseníase e vulnerabilidade: uma revisão de escopo. Ciênc. Cien Saude Colet. 2023;28(1):143-54. http://doi.org/10.1590/1413-81232023281.09722022.
26. Jodelet D. Loucuras e representações sociais. Petrópolis: Vozes; 2005.
27. Noordende AT, Aycheh MW, Schippers AP. Uma exploração da qualidade de vida familiar em pessoas com deficiências relacionadas com hanseníase, filariose linfática e podoconiose e seus familiares na Etiópia. Trans R Soc Trop Med Hyg. 2020;114(12):1003-12. http://doi.org/10.1093/trstmh/traa090. PMid:33169139.
28. Deps P, Delboni L, Oliveira TIA, Collin SM, Andrade MA, Maciel ELN. Steps towards eliminating Hansen's disease stigma. Int Health. 2023;15(Suppl. 3):iii7-9. http://doi.org/10.1093/inthealth/ihad050. PMid:38118154.
29. Thapa DK, Dahal HR, Chaulagain DR, Karki A, Sharma N, Baral B et al. Stigma, depression and quality of life among people affected by neglected tropical diseases in Nepal. Int Health. 2023;20(15, Suppl3):79-86. http://doi.org/10.1093/inthealth/ihad099.
30. Mangeard-Lourme J, de Arquer GR, Parasa J, Singh RK, Satle N, Mamhidi R. Depressão e ansiedade em pessoas afetadas por hanseníase e filariose linfática: um estudo transversal em quatro estados da Índia. Lepro Ver. 2020;91(4):367-82. http://doi.org/10.47276/lr.91.4.367.
31. Lavantezi M, Shimizu HE, Gaffa V. Princípio da não discriminação e não estigmatização: reflexões sobre hanseníase. Rev Bioet. 2020;28(1):17-23. http://doi.org/10.1590/1983-80422020281362.
32. Barcelos RMFM, Sousa GS, Almeida MV, Palacio FGL, Gaíva MAM, Ferreira SMB. Qualidade de vida de pacientes com hanseníase: uma revisão de escopo. Rev Esc Enferm USP. 2021;55:e20200357. http://doi.org/10.1590/1980-220x-reeusp-2020-0357. PMid:34495209.

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