Original Article

The cure in the collective subject discourse of people on hospital discharge for leprosy cure

A cura no discurso do sujeito coletivo de pessoas em alta por cura de hanseníase

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ABSTRACT | OBJECTIVE: To analyze the social representations of cure in people affected by multibacillary leprosy who were discharged due to cure. **METHODS:** This work is a descriptive and qualitative study, developed in Ceará, Brazil, from January to October 2016. Ten individuals were enrolled in this study, they were over 18 years old affected by the multibacillary form of leprosy and were discharged due to cure. Data collection was performed through a structured recorded interview and analyzed through the Collective Subject Discourse. **RESULTS:** All individuals did not know how to define leprosy, or explain what the disease would be, as well as how the disease would be caused by bacteria. Patients said that, in comparison with the time before the disease, life is different; it is not good and normal. Though, we observed the confrontation of life before and after the disease. **CONCLUSION:** We found key expressions that meant absence of cure in most of speeches from individuals with leprosy reactions and with a high degree of disability. Moreover, the social representations of healing are complex, dynamics and strongly associated with the comparison before and after the disease, the "before" functioning as a reference for the normality of life.

DESCRIPTORS: Leprosy. Social behavior. Hospital discharge. Social stigma. Social Determinants of Health.

RESUMO | OBJETIVO: Analisar as representações sociais de cura em pessoas atingidas por hanseníase multibacilar que receberam alta por cura. **MÉTODOS:** Estudo de caráter descritivo e qualitativo, desenvolvido no Ceará, Brasil, no período de janeiro a outubro de 2016. Os participantes foram dez indivíduos de ambos os sexos, maiores de 18 anos, atingidos pela forma multibacilar de hanseníase, com alta por cura. A coleta de dados foi mediante a entrevista estruturada gravada, e a análise por meio do Discurso do Sujeito Coletivo. **RESULTADOS:** A totalidade dos participantes não soube definir hanseníase, ou explicar o que seria a doença, assim como que a doença seria provocada por uma bactéria. Os discursos denotam que, em comparação com o tempo antes da doença, a vida está diferente, não é boa e normal. Com isso, observa-se o confronto: vida antes e depois da doença. **CONCLUSÃO:** Em indivíduos com reações hansênicas e com grau de incapacidade elevado, foram encontradas, na maioria dos discursos, expressões chave que significaram ausência de cura. Além disso, as representações sociais de cura são complexas, dinâmicas e fortemente associadas à comparação antes e depois da doença, o antes funcionando como referência para a normalidade da vida.

DESCRITORES: Hanseníase. Comportamento social. Alta hospitalar. Estigma social. Determinantes Sociais de Saúde.

Submitted 10/26/2021, Accepted 05/24/2022, Published 07/21/22
J. Contemp. Nurs., Salvador, 2022;11:e4194
http://dx.doi.org/10.17267/2317-3378rec.2022.e4194
ISSN: 2317-3378
Assigned Editors: Cátia Palmeira, Gilmara Rodrigues

How to cite this article: Ribeiro MDA, Silva JCA, Silva LN, Oliveira SB, Lira GV. The cure in the collective subject discourse of people on hospital discharge for leprosy cure. J Contemp Nurs. 2022;11:e4194. http://dx.doi.org/10.17267/2317-3378rec.2022.e4194

Introduction

Leprosy is characterized by skin and peripheral nerves lesions caused by *Mycobacterium leprae*, a bacillus transmitted through airways of infected and untreated people.[1] The disabilities and physical deformities established by the disease are surrounded by a stigma that persists with the pathology: the fear of infection, the presence of traces of isolationism and the religious factor of punishment for sins.[2]

As a result, leprosy fits the definition of a metaphor-disease described by Sontag, as it represents both a medical and social disease due to its historical construction. The idea of dangerousness that permeates between scientific advances and setbacks traditionally evoked by culture still remains.[3] The cure for this disease has been possible since the middle of the XX century, with the emergence of Sulfone, and the combination of antibiotics constituting Polychemotherapy (PQT), a drug cocktail that is recommended by the World Health Organization (WHO) as the standard treatment for the disease.[4] The supervised dose administration schedule should be as regular as possible, every 28 days. If there is no such regularity, healing is compromised and physical disabilities are more susceptible to occur.[1,4]

According to the patient's operational classification in Pauci or Multibacillary, there is a standard treatment regimen that varies from 6 to 18 months with monthly supervised doses plus daily cocktail doses. Thus, a person who is discharged for cure is considered to be someone who completes the multichemotherapy treatment regimen within the established time limits. People who have already completed treatment, according to technical standards, must be removed from the active registry, and discharged on the basis of cure.[1]

Even after cure, people may show leprosy reactions (LR), which are immune reactions against the bacillus and relapses that may occur even after the PQT treatment.[5] Such acute and subacute inflammatory episodes affect both paucibacillary and multibacillary cases. The LR are presented as the main cause of nerve injuries and disabilities caused by leprosy, representing a major problem in the treatment of infected individuals.[6]

The bacillus inactivity as a parameter for hospital discharge is questioned, since even with the bacillus inactive, physical and psychological sequelae continue to cause suffering, in addition to the possibility of LR and disease relapses, which leads to distrust regarding leprosy cure.[7] With PQT strategy there was a need for a disease redefinition, for the demystification of the form of transmission and treatment, however, these tasks are hampered by the stigma attached to leprosy.[8]

Brazil and India account for 80% of leprosy cases in the world. In Brazil, the North, the Northeast and the Midwest are the regions with the highest number of cases.[9] Given the high incidence and prevalence of leprosy in Brazil, we see the need to place the cured individual within this scientific universe. It is known that the notions of disease, health and cure are constructed and characterized by a chain of perceptions, opinions and habits learned and ordered in an understandable sequential logic by society, which goes from the real to the imaginary and constructs explanatory social categories.[10]

This signification is called Social Representation (SR), which is defined as an organized set of practical everyday knowledge, collectively constructed from daily problems and challenges that challenge subjects to take a stand and define their ways of interacting with the social environment.[11] In this way, SR is a tool to improve the understanding of stigma and behavior of people affected by leprosy.[12] In view of what was mentioned above, the objective of this study was to analyze the social representations of cure in people affected by multibacillary leprosy who were discharged due to cure of the disease.

Methods

This manuscript is an exploratory, descriptive and qualitative study, limited to the urban context of Sobral, Ceará, Brazil. In order to delimit the studied population, we first obtained information from the epidemiological service of the Municipal Health Department about individuals who met the inclusion criteria of the study: men and women over 18 years of age living in Sobral, Ceará, who were affected by the multibacillary form of leprosy and who were

discharged due to cure after treatment in the period between January and October 2016. We also adopted exclusion criteria: individuals who were not physically or cognitively able to Interact with the researchers, as well as those who we could not locate for the interview. All volunteers were informed about the study's objectives and procedures, as well as requested permission to record the interview. They confirmed their participation by signing the Free and Informed Consent Term (FICT). Volunteers were identified with the letter E plus the serial number of their interview, for example: E1 – interviewee 1.

Data collection was done in the Leprosy Reference Center in Sobral, Ceará, using a structured interview, which was prepared and applied by the researchers. The limit for data collection occurred due to information saturation and repetition, although we did not consider it relevant to persist in the inclusion of new volunteers in this study.[13] In the studied period, 66 individuals were discharged due to leprosy cure in the studied city, however, 33 patients met the inclusion criteria of this research and composed this study's sample. A total of 10 interviews were performed until data saturation was observed.

The chosen technique for interviews organization and analysis was the Collective Subject Discourse (CSD).[14] We started from the raw transcription of the testimonies extracted from the interviews, which was submitted to an initial analytical work of decomposition that was consisted of the identification of the main Key Expressions (KE) and Central Ideas (CI) and/or Anchoring (AC), present in each of the individuals' speeches. First, the volunteers had to answer questions about how the disease was treated, and then they had to talk about the cure. They were classified according to the degree of physical incapacity, in 0.1 and 2, by analyzing their KE (1).

The study was approved by the Research Ethics Committee (REC 1.878.571) (CAAE 61828616.8.0000.5053) and complied with the ethical principles contained in the National Health Council Resolution 466/12 and the 2013 Declaration of Helsinki.

Results

From the first part of the interview, it was observed that the Basic Health Unit (BHU) is configured as a supplier of medicines and guides the healing process, from this analysis; the CSD described in Table 1 was created.

Table 1. CSD of the sample on how leprosy was treated (Sobral/CE)

KE	CSD
The health basic unit is the provider of leprosy treatment	"I only used the medicine at the health center: I took 1, once a month over there and took it home for the other days (E1, E2, E3, E4, E5, E6, E7, E8, E9, E10). There was one time I needed to buy it because it was not available at the health center, but it was the same one they administered there."

Source: The authors (2016).
KE: Key expressions
CSD: Collective subject discourse

With the analysis of the data, it was observed that the elaboration of the SR of cure in leprosy emerges directly or indirectly from the comparison of life before and after the disease. Cells in the frames were marked in dark color when classified as corresponding to RS of non-curing and in light color when classified as RS of cure. The KE that makes this comparison possible are shown in Table 2.

Table 2. KE of the sample comparing life before and after leprosy (Sobral/CE)

KE OF LIFE BEFORE DISEASE	KE OF LIFE AFTER DISEASE
Life before disease was normal	Life got tumultuous after leprosy.
Life was not difficult	Health care increased after leprosy.
Life before the disease was good	People feel good after treatment.
I did not have problems before the disease	The skin becomes sensitive after the disease.
Life was unfettered	People are afraid of increasing the spots due to disease on the body.
People had good health before the disease	People do not feel good because of the disease's sequelae
	Life changes because it is not the same as before the disease
	There are limitations in activities that were part of the routine
	People feel good because life is the same as before the disease

Source: The authors (2016).
KE: Key expressions

When we analyzed the predominance of KE of life confrontation before and after the disease we synthesized it in two sentences: "*Life was good before leprosy*" and "*Life gets worse after the disease*".

From the comparisons of life before and after leprosy, it was possible to infer the SR that means leprosy cure or not. The key expressions that characterize cure (KE1 to KE6) and absence of cure (KE7 to KE21) were highlighted as shown in Table 3. The perception of cure could be apprehended directly or indirectly by analyzing the interviewees' speeches, from which it was pointed out that 40% (E1, E6, E8, E10) shared SR of cure, while 40% (E5, E6, E7, E9) shared RS of the absence of a cure, and, still, 30% (E2, E3, E4) reported both types of SR.

Table 3. KE of each studied sample on cure or absence of cure of leprosy in Sobral, Ceará (to be continued)

KE THAT PREDICT CURE	KE THAT SUGGESTS ABSENCE OF CURE
KE 1 – People feel good after treatment (E1, E2, E8, E10)	KE 7 – People do not feel good because they cannot work (E5)
KE 2 – People feel good after recovering from the signs and symptoms of the disease (E2, E3)	KE 8 – Because of the disease's reactions people do not feel cured (E2, E9, E5)
KE 3 – People feel happy about overcoming the disease's sequelae (E4)	KE 9 – Constant reactions give instability to people who have had leprosy (E5, E9).
KE 4 – People consider themselves normal after the disease (E6)	KE 10 – Because of the disease's sequelae, people do not feel well (E4, E7).
KE 5 – People feel victorious after treatment (E1)	KE 11 – People do not feel normal because there are limitations in formerly routine activities (E6, E7, E9, E3).
KE 6 – People feel no difference when comparing their life before and after the disease (E1, E2, E3, E8, E10)	KE 16 – People feel dependent on self-care and physical therapy (E7).
	KE 17 – People sometimes feel shaken by the disease (E2, E5).

Table 3. KE of each studied sample on cure or absence of cure of leprosy in Sobral, Ceará (conclusion)

KE THAT PREDICT CURE	KE THAT SUGGESTS ABSENCE OF CURE
	KE 18 – People do not feel good because they depend on others for living (E5).
	KE 19 – People feel different because of extra health care after the disease (E5, E6, E7, E9).
	KE 20 – People feel a difference comparing their life before and after the disease (E5, E7, E9).
	KE 21 – People do not feel normal because they do not do the same as before (E6, E7, E9).

Source: The authors (2016).
KE: Key expressions

The totatily of KEs that describe each situation provides us with information associated with each SR. For the "cured" category, there were 8 SRs that can be summarized in "*People feel normal and the same as before the disease*", while for the "absence of cure" category, there were 11 KEs that dealt with different aspects such as sequelae, limitations and adaptation difficulties to the new way of life (Table 3).

To verify the influence of disabilities and reactions in the elaboration of SR around leprosy, the KEs were classified according to the degree of disability, as shown in Table 4.

Table 4. KE by degree of disability (Sobral/CE)

Degree 0 (E10)	Degree 1 (E2, E3, E4, E7, E9)	Degree 2 (E1, E5, E6, E8)
KE 1	KE 1	KE 1
KE 6	KE 2	KE 4
	KE 3	KE 5
	KE 6	KE 6
	KE 8	KE 7
	KE 9	KE 8
	KE 10	KE 9
	KE 11	KE 11
	KE 17	KE 17
	KE 19	KE 18
	KE 20	KE 19
	KE 21	KE 20
		KE 21

Source: The authors (2016).
KE: Key expressions

We observed that in the absence of disability (degree 0), no KE of the absence of cure was observed, and KE that represents cure of leprosy predominated, while KE related to the absence of cure appeared with increasing degree of disability. Likewise, the classification of KE according to the presence or absence of LR stands for the predominance of representations of the absence of cure (n = 9) associated with the presence of reactions (Table 5).

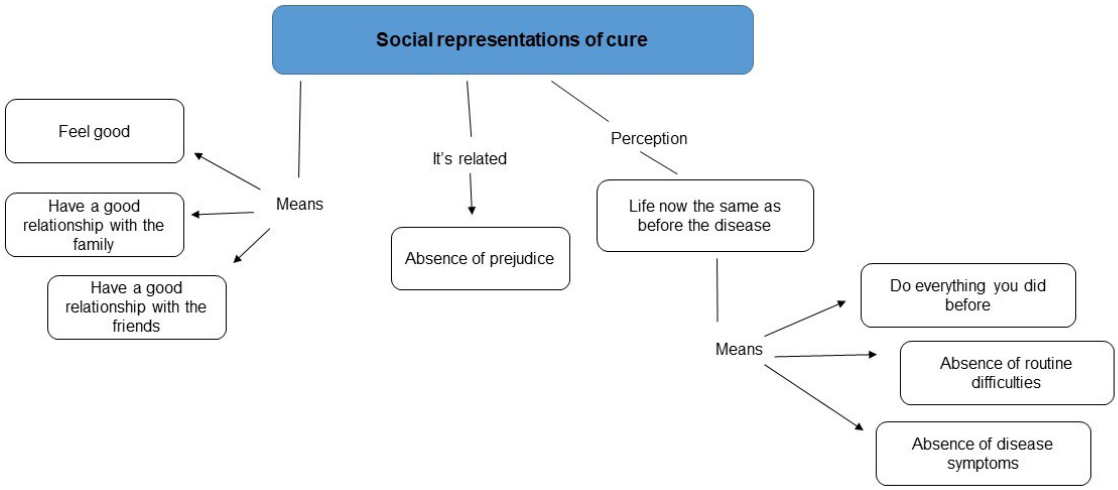
Table 5. KE of the studied sample classified by the presence of absence of leprosy reaction (Sobral/CE)

KE WITH REACTION (E2, E5, E9, E10)	KE WITHOUT REACTION (E1, E3, E4, E6, E7, E8)
KE 1	KE 1
KE 2	KE 2
KE 6	KE 3
KE 7	KE 4
KE 8	KE 5
KE 9	KE 6
KE 11	KE 10
KE 17	KE 11
KE 18	KE 16
KE 19	KE 19
KE 20	KE 20
KE 21	KE 21

Source: The authors (2016).
KE: Key expressions

From the CSD produced, to synthesize the CI and/or AC and the CSD of the SR group that meant cure, a conceptual map was prepared (Figure 1). This map represents the general view of the SR of cure perceived in this study.

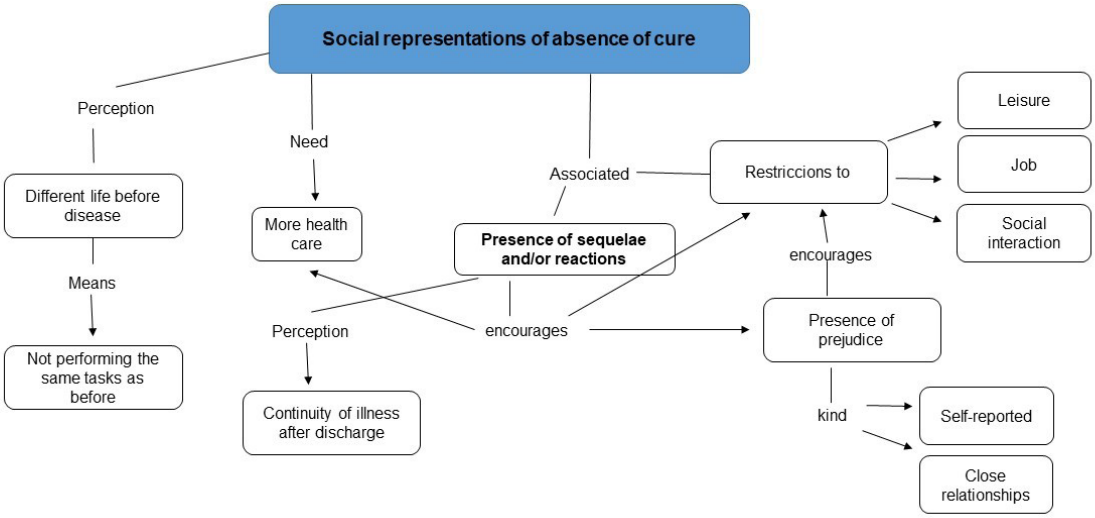
Figure 1. Conceptual map on the social representations of cure in leprosy (Sobral/CE)



Source: The authors (2016).

For the SRs that defined the absence of cure, the CI and/or AC and the CSD were synthesized in the conceptual map below (Figure 2), which established relationships indicated by the analyzed sample. We observed that such relationships are more complex and interconnected than those related to cure.

Figure 2. Conceptual map on the social representations of absence of cure in leprosy (Sobral/CE)



Source: The authors (2016).

Discussion

It is important to point out that all follow-up care, from diagnosis to treatment and rehabilitation of leprosy sequelae, is entirely provided by the Brazilian Unified Health System (SUS – *Sistema Único de Saúde*), in which the Family Health Strategy (ESF – *Estratégia Saúde da Família*) is responsible for providing medication for daily and monthly use. In addition to monitoring and investigating sequelae and the occurrence of LR, patients are also assisted in the aftercare of treatment and guided in the necessary self-care.[15] This confirms the results of this study, in which the biomedical system was the only provider of treatment, however, the literature shows that other sources of cure are sought for diseases' treatment, such as spiritual healing and healing through nature agents.[16]

Comparison of life before and after the disease revealed different particularities of cure of the disease: the limitations of life, the additional medical care, the sequelae, the individual's fear that health might deteriorate again. A survey carried out with women in Cuiabá, Mato Grosso, Brazil showed that LR has a strong impact on personal, marital, family and social life and that pain is the main LR, generating disability and limitations, in addition to leading patients to wonder whether or not they are cured because even after the end of leprosy treatment, they still have symptoms.[17]

Most KE defines cure as the patient returning to the pre-illness state, where there were no difficulties. The cure of leprosy gained a new point of view with the introduction of PQT in the disease's treatment, and the appearance of LR is associated with the irregular intake of drugs during treatment.[18] The emergence of LR leads the patient to believe in the ineffectiveness of PQT and the emergence of adverse reactions during the treatment contributes to treatment withdrawal. For the effectiveness of treatment and patient adherence, the multidisciplinary team must work with the objective of informing and educating the patient affected by leprosy about the possible adverse effects that may arise and clarifying the importance of regular use of the medication.[19]

The volunteers enrolled in this study presented both "cure" and "absence of cure" SRs. This fact may have been influenced by the presence of LR and the emergence of physical disabilities. Another survey identified that LR was confused with reactivation of the bacillus and that patients had difficulties in concluding the diagnosis of leprosy while still at the BHU, which they were transferred to a reference unit for smear microscopy. This fact can delay the start of treatment and worsen the onset of LR. The authors also reported the importance of family involvement in the care of leprosy patients.[20] In our study, a significant portion of studied individuals presented I and II degrees of disability, which may have contributed to the non-cure SR being so present in CSD.

SRs focusing on leprosy result in late diagnosis and treatment, which can lead to physical disabilities and prejudicial behaviors. Leprosy is often associated with the terms contagious, cure, skin disease, stain and treatment. The multiprofessional team that composes the ESF is responsible for carrying out an early diagnosis and helping patients to understand the disease and its treatment, in order to optimize treatment adherence, in an attempt to minimize the SR that may arise with the diagnosis.[21]

The literature estimates that approximately 20-30% of leprosy patients will develop LR or neural damage at some point, with the multibacillary form being more common.[22] The presence of disabilities and deformities caused by leprosy in a cured patient is an indicator that the diagnosis was performed later or that the clinical follow-up was inadequate, increasing the challenges and complexity of disease care.[23] Only one respondent had no sequelae and no disease response, which may have influenced the perception of continuity of symptoms (absence of cure) after PQT, related to LR sequelae, contributing to the SR of no cure present in most of the volunteers' statements.

LR are closely related to the presence of "cure" or "absence of cure" SR[7-8,21], because, when they occur, such immunological reactions result in neural damage, anesthesia and weakness, which is related to the increase in sequelae and deformities. The presence of LR is directly related to the subjective perception of patients who had leprosy quality of life.[24] RH are important in the life of its bearer due to the physical disabilities that they cause and that makes it impossible to return to daily life, from this fact, the SR of not being cured is so present in people who have had leprosy.[25]

From our results, we can conclude that the SR which translates the experience of the disease and curre of leprosy are more strongly associated with the ability to interact with the environment in which one is located, performing routine activities such as work, leisure and activities of daily living, than the elimination of the bacillus of the affected body.[12] A survey[26] conducted in Paraíba evaluated the quality of life of 40 patients with multibacillary leprosy, in which aspects such as pain, medication dependence, negative emotions, and financial resources, among others, negatively influence the perception of quality of life.

We have identified several factors that interact to form a web of individual meanings for people who had leprosy, making the discharge parameter for cure, adopted by the Brazilian Ministry of Health, insufficient given the expectations of these people. Thus, SR of cure were associated with the ability to perform the same functions as before the disease, where life does not change and remains good and normal given daily demands. The SR of absence of cure were associated with the presence of sequelae (disability degrees 1 and 2) and LR and, consequently, greater need for health care or dependence on other people.[27]

Conclusion

This study contributes to a better understanding of the concept of what it means to be cured of leprosy, and provides evidence for strengthen the policy of eliminating the disease as a public health problem, which goes beyond interrupting transmission and inactivating the bacillus. The practical implications of this study for the target population of this research are given by providing adequate support to their individual needs, considering the individuals affected by leprosy with their peculiarities and real needs. SR has been shown to be associated with the presence of physical disabilities and LR can directly affect the individual's quality of life.

Authors contribution

Ribeiro MDA participated in the concept, collection, analysis, interpretation of data and writing.Silva JCA, Silva LN, Oliveira SB participated in the analysis and interpretation of data, writing and critical review. Lira GV participated in the design, interpretation of data and approval of the final version to be published.

Conflicts of interest

No financial, legal or political conflicts involving third parties (government, companies and private foundations, etc.) were declared for any aspect of this submitted manuscript (including, but not limited to grants and funding, participation in an advisory board, study design, manuscript preparation,statistical analysis, etc.).

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