Leprosy: the Present of a Disease from the Past

ORIGINAL

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Abstract

Introduction: Leprosy is one of the oldest and most stigmatizing diseases to affect mankind and is still considered a public health problem in many developing countries.

Objective: To analyze how the social representations of leprosy patients are structured.

Method: The purpose of this study was to analyze how the social consequences of leprosy affect people carrying the disease. A multi-method approach was used, based on the Theory of Social Representations. A total of 100 subjects participated in this study (50 males and 50 females). Data were analyzed using the following software: SPSS (to assess social, economic, and clinical aspects, EVOC, SIMI, and AVRIL (to integrate the structure of social consequences).

Results: The central core for women was "family". In the similitude test, this word was associated with "exclusion". For men, the central core was composed of "family", "work", and "treatment".

Conclusions: The healthcare model must strive to take into account the day-to-day concerns of leprosy patients, with a view towards greater consideration of gender differences and the development of a more humanized care system based on full assistance in order to control this disease.

Introduction

Leprosy is one of the oldest and most stigmatizing diseases affecting humans, and still constitutes a serious public health problem in many developing countries like Brazil.

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This disease can present serious manifestations, which are usually related to a prolonged incubation period from the initial infection to the manifestation of cutaneous lesions. Despite the declining number of new cases detected worldwide, some regions remain endemic, namely: Angola, Nepal, India, Brazil, Mozambique, and the Democratic Republic of Congo [1].

In 2015, there were 20,048 new leprosy cases reported in Brazil, with an incidence rate of 14.2 per 100,000 inhabitants. It is an infectious and contagious disease associated with social inequalities, as it affects the poorest regions of the world. In this context, Brazil remains with two perverse titles: the only country in the world that has not been able to eliminate this disease and the one that concentrates more new cases each year [2, 3].

Leprosy is a curable disease in all its forms, the greatest issue is not biological, rather social and cultural. Even today, the impact caused by the disease interferes with the daily lives of people with leprosy, who need to live with the stigma of the disease [4].

Patients with this disease have difficulty in reestablishing social bonds and values, as well as their self-esteem. They have the need to share their feelings, seeking reintegration in the social context of which they are part [5].

An important way to approach this theme would be the promotion of educational actions for the general population by multidisciplinary health teams in primary care, affirming the value of leprosy patients as members of society, helping them in their reintegration process. In the process of reducing the stigma associated with these patients, the participation of health system managers is essential [5]. In this perspective, we believe that studying the social representations of leprosy patients enables health professionals to better approach the reality of people with this disease, in order to guide health practices, identifying the real needs of users, focusing on broadening the biological reductionist view and advancing towards a collective health care centered on the patients' needs, within a comprehensive and humanized care seeking to strengthen the control of this disease.

Given the relevance described, this research aimed to analyze how the social representations of leprosy are structured and what are their meanings for the patients.

Methods

This is an exploratory descriptive study with multi-method approach based on the Social Representation Theory, which recognizes humans as symbolic animals within a social environment, able to guide the representation that delimits the field of communications and culture with their beliefs and values [6].

Construction of the social object occurs through a structure that provides the basis of the social representation, with great power of articulation, since it is responsible for making the social object understandable within a group, thus being able to guide conducts. There are more flexible elements around this solid structure, but if broken, it can alter the whole representation of the social object. Social Representation Theory can be considered a major theory, to which the Central Core Theory constitutes a complementary approach, providing more detailed descriptions and explanations about the functioning of certain structures compatible with the major theory [7].

To know the social representations of participants regarding leprosy, a two-part questionnaire was designed. The first part with questions to identify the social, demographic, and clinical profile, and the second composed by a free word association test, with the inducing terms: "leprosy", "being a woman with leprosy", and "being a man with leprosy".

The research took place in the city of Fortaleza-CE, Brazil, with 100 subjects divided into two groups: Male Group and Female Group, with 50 participants each.

The following inclusion criteria were adopted: male or female, aged 18 years and older, and having started the treatment for at least three months. Individuals with physical and/or emotional dysfunctions that prevented communication were excluded from this research.

Social, demographic, and clinical data were processed in the Statistical Package for the Social Sciences software, version 16.0, and submitted to simple descriptive statistics.

Data collected through the free word association test were analyzed by the EVOC software – *Ensemble de programmes permettant l'analyse des evocations* (Group of programs for the analysis of evoked responses), in order to identify the central core of the social representation of leprosy for each genre. EVOC software provides the simple frequency of evoked words and the Average Evocation Order (AEO), resulting in a distribution in four quadrants that identifies the central core, the intermediate (first periphery), contrast zone, and peripheral (second periphery) elements of the representation [8].

Furthermore, a similarity analysis was conducted using the SIMI (*Analyse de similitude de questionnaires et de données numériques*) and AVRIL (*Support logiciel graphique de création de graphiques*) softwares, which build the "representational trees" or "filter graphs", graphically expressing the strength of the links among all categories [9].

The study followed the formal requirements of national and international standards for research involving human subjects.

Results

Of the 100 study participants, there were 50 males and 50 females. Women were aged 19-80 years, with an average age of 42 years. Of these, 19 had between 5 and 8 years of education, 27 were married, 24 worked, 35 earned from 1 to 2 minimum wages, and 33 were multibacillary.

As for men, they were aged 17-70 years, with an average age of 40 years. In this group, 17 had between 5 and 8 years of education, 25 were married, 42 worked, 35 earned from 1 to 2 minimum wages, and 41 were multibacillary.

Consequently, the results of this investigation demonstrated that the population is mostly of young adults in full employment, despite the low income. Participants had only a few years of education and more than half were married. Regarding the clinical situation, the majority were multibacillary patients, revealing the lack of epidemiological control of the disease. These data corroborate other studies, such that highlights as factors that favor the maintenance and diffusion of leprosy: low socioeconomic classes, household contact, and ineffective health service [10].

Social Representations of Leprosy

The product of evocations consisted of 500 words, of which 107 were different.
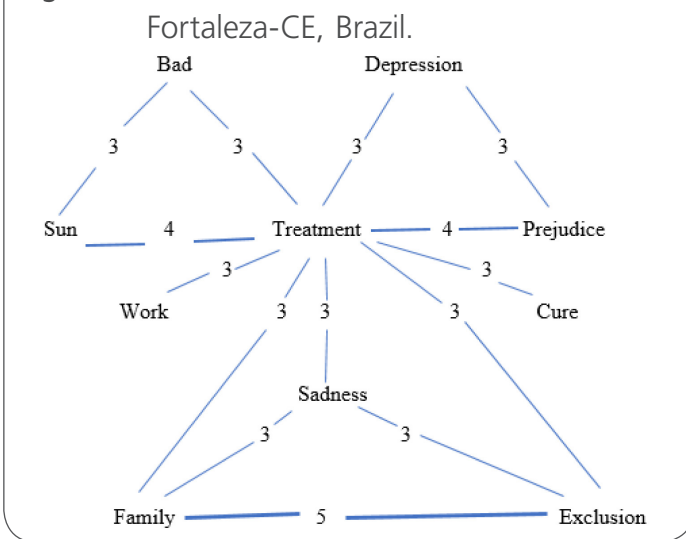
Among the study participants, as the central core of the representation studied for the inducing term "leprosy", the following words emerged: "fatigue", "care", "cure", "unaware", "illness", "pain", "fear", "prejudice", and "bad". The most frequent words were "prejudice", "fear", and "cure". With the same predominance, "ignorance" and "disease" arose, but with less evocation; and in less number, the words "unaware" and "disease".

In the peripheral elements, the word "treatment" was highlighted given the number of evocations. The terms "affliction", "numbness", "spots", and "sadness" were also identified.

As contrasting elements, the words "exclusion", "severe", "leprosy", "normal", and "reaction" emerged. As elements of the second periphery, the words "complexity", "swelling", "patience", "concern", "work", "symptoms", and "shame" appeared.

The corpus of analysis consisted of 250 words evoked by women, of which 87 words were different.

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Figure 1: Maximum tree of 3 co-occurrences. Fortaleza-CE, Brazil.

Only the word "family" was found as a central core element, showing the woman as the main family caregiver. The peripheral elements identified were "work" and "treatment".

As contrasting terms, the words "difficult", "exclusion", "spots", "prejudice", "bad", and "sadness" came out. Regarding the terms emerging in the lower right quadrant, there were "contagious", "cure", and "depression".

Figure 1 was designed to understand the co-occurrences of the elements evoked from the inducing term "being a woman with leprosy".

Maximum tree constitutes the graphic representation of correlation studies. Vertices present the variables, while their connections show the co-occurrence between the elements. Categories connected after applying a filter indicate a stronger degree of connection, related to the number of people who treat such elements in a similar way. This way, one element will be as much more connected to the other, the longer it remains in a set of higher filters [11].

In the representation of **Figure 1**, the maximum tree appears with intermediate connections, whose maximum connection was five, between "family" and "exclusion". Thus, we decided to apply a filter of 3, using the mean co-occurrence. In this figure,

the word "treatment" appears in the center with the greatest number of connections; however, there are few co-occurrences among the eleven terms presented.
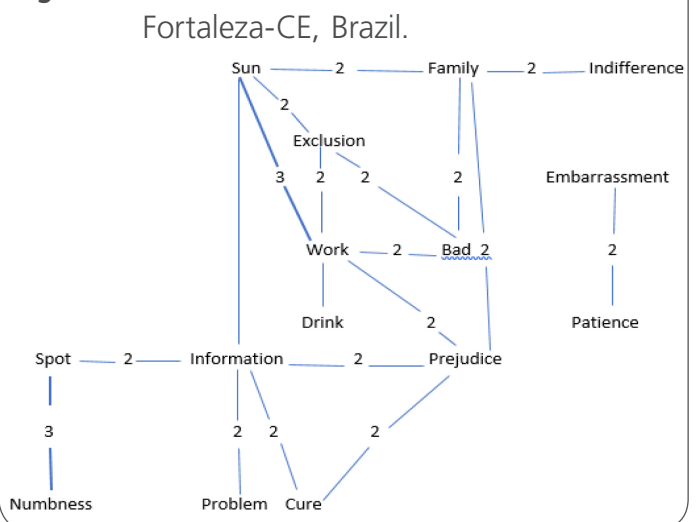
In relation to men, the corpus of analysis consisted of 250 words evoked, of which 144 were different, thus indicating the prevalence of non-synonymous words.

As part of the central core, we found the words: "family", "work", and "treatment", with special reference to the term "treatment", which presented the highest frequency. It was not possible to identify elements of the first periphery.

As contrasting elements, we identified: "exclusion", "information", and "bad". In relation to the second periphery, "drink", "spots", "prejudice", "problem", and "sun" emerged.

To understand the correlation of the elements, the maximum tree was organized in relation to "being a man with leprosy". A smaller filter was chosen, since the greatest connection found was three, in other words, a filter of 2 was applied. Due to the diversity of words evoked, connections were fragile; the connection between "patience" and "embarrassment" did not correlate with the other elements. **Figure 2** presents the evocation of 15 words, with a filter of 2.

Figure 2: Maximum tree of 2 co-occurrences. Fortaleza-CE, Brazil.

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In this phase, the words "work" and "sun", "spots" and "numbness" presented the strongest connections.

Discussion

In Brazil, there are still many cases of delayed leprosy diagnosis, which causes sequelae and disability. Therefore, the primary challenge concerning leprosy remains an early diagnosis of suspicious cases [12].

In the terms evoked and demonstrated, it was identified that the words were marked by negative aspects, particularly the word "prejudice", which represents the dramatic reality these subjects experience. The terms "fear" and "cure" appeared with the same frequency. "Fear" shows a context that expresses the feeling of collapsing towards leprosy, and "cure" emerges as the goal to be achieved. The words "ignorance" and "illness" also present the same frequency of evocations, clearly related by the users' lack of knowledge about the pathology.

The technical language often present in the relationship between professionals and leprosy patients contrasts with the possibilities of the patients apprehending this information. The fragile care process drives the patients to deepen a knowledge/recognition of the disease, considering the singularities experienced by everyone [13].

Considered as an incurable and disabling disease in several societies and cultures, and in different historical periods, it is up to nurses to fight against prejudice, along with health education. This represents one of the primary actions of the nursing care promoted, destroying myths and taboos, and minimizing the fear in the face of the unknown, considering the cultural context in which leprosy is inserted [13].

The word "treatment" gained prominence in the scope of the peripheral elements related to the disease. It is noteworthy the importance of nursing consultation in leprosy, since it actively participates in the search for new cases, interrupts the transmission of the disease, breaks the epidemiological chain, prevents the disease, promotes health, and promotes guidance on the treatment for a better continued care [12].

For women, the word "family" was the central core, reaffirming their historical function of caring for the family. Feminization of the burden of providing care in the domestic environment is a gender issue historically produced and maintained by society, which recognizes women as caregiver par excellence, both for family members who have the disease and those who do not [14].

"Work" and "treatment" were the peripheral elements identified. The word "treatment" was highlighted given the frequency it was mentioned, which might reflect the value of this treatment to women to recover health and change their daily lives, sometimes even intensifying social isolation, a circumstance experienced by the history rooted in the diagnosis, when compared with old-time leprosy.

Prejudice is one of the worst diseases of mankind, and fighting against it requires constant and tireless actions of sensitization, information, and vigilance. Its roots are resistant, even beyond cure [15]. Therefore, when planning educational activities, the health service must not only provide the user with tools to face the disease, but also direct actions to rescue the citizenship and respect for these people.

"Work" may be related to the inability, often caused by leprosy, of remaining active or entering the labor market, which was observed when symptoms associated with the disease were mentioned, such as "pain", "fatigue", and "numbness", in addition to the leprosy reactions that aggravate the situation or the physical incapacities, sometimes installed irreversibly in late diagnoses.

The words "family" and "exclusion" presented the greatest correlation, revealing that the stigma still exists. Stigma consists of every indicative that the individual is different, either by a crime, mad-

ness, or a disease. The term has always been related to the condemnatory sense, leading individuals to social exclusion, banned by their exclusive "guilt", for carrying any of those indications that compromised them [16].

Regarding men, the central core was composed by the terms "family", "work", and "treatment". The word "treatment" presented a high frequency, similar to the group of women. As mentioned, it may be related to the health recovery. This finding corroborates a study carried out with 107 patients on health-related quality of life in a hyperendemic area in Teresina-PI, Brazil, which verified that the determinants of worsening the quality of life of people with leprosy were late diagnosis, multibacillary forms, leprosy reactions, second-degree disability in diagnosis, and prejudice, concluding that leprosy continues to impact the socially disadvantaged classes, hence compromising the work capacity and quality of life of the affected, and perpetuating the stigma associated with the disease [17].

Women, on the other hand, are preoccupied with turning away from the so-called "women's work", as they are unable to perform simple daily activities such as caring for the home, the husband and children, attributing to themselves feelings of "sadness" and "depression". In a society that values beauty, especially of women, having the spotted body is a significant suffering, as it excludes them from the perfection standards demanded by society [18].

The main correlations presented were "spots and numbness" and "spots and sun". "Spots and numbness" are related to the main symptoms of leprosy, even regarding the media. "Work and sun" may be related to the limitation of daily and leisure activities, since the city where this study took place is known as the land of light, due to the sun presence the whole year.

Conclusion

Apprehensions of the social representations of leprosy from the gender perspective enabled to identify different aspects between men and women. While women are more concerned with issues related to the domestic scope, care with the family, and physical image, usually the spots; men, additionally to the concern for the family, which includes providing for their home, are mainly worried about the changes in their daily lives, such as not exposing themselves to the sun and adapting to a routine of medication and health consultations.

This research highlights the importance of public policy actions on leprosy, since there is still need for further progress, mainly in the integration between the three levels of action. Thus, decentralization of the leprosy elimination program would be more efficient if guaranteed customer service at these three levels.

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