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WITHIN THE HABITUS OF THE FORMER COLONY HOSPITAL-SOCIAL
REPRESENTATIONS OF LEPROSY

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RESEARCH

WITHIN THE HABITUS OF THE FORMER COLONY HOSPITAL - SOCIAL REPRESENTATIONS OF LEPROSY

NO HABITUS DO ANTIGO HOSPITAL COLÔNIA - REPRESENTAÇÕES SOCIAIS DA HANSENÍASE

EN LOS HABITUS DEL ANTIGUO HOSPITAL COLONIA - REPRESENTACIONES SOCIALES DE LA HANSENÍASES

Clélia Albino Simpson¹, Francisco Arnoldo Nunes de Miranda², Rejane Millions Meneses³, Icléia Honorato da Silva Carvalho⁴, Ana Michele de Farias Cabral⁵, Vivianne Rafaelle Correia dos Santos⁶

ABSTRACT

Objective: To understand the social representations of leprosy for the former patient of the Getúlio Vargas Colony Hospital, Bayeux/PB/Brazil. **Method:** Study of qualitative and representational approach. **Results:** The habitus was defined through the long and the experienced times in the building of situational behaviors and diversities. The asylum context is revealed through the time. In the realm of religiousness, their illness is understood as a heritage of a divine punishment. The contact with the society as a charity aspect did not reduce the feeling of being excluded by the prejudice and stigma that pervade the patient bearer of leprosy. **Conclusion:** We could infer that, when retelling their lives, the subjects lived a quasi-experimental condition, by recalling striking histories at that context. **Descriptors:** Leprosy, Social representations, Nursing methodological research.

RESUMO

Objetivo: Apreender as representações sociais da hanseníase para o ex-doente do Hospital Colônia Getúlio Vargas, Bayeux/PB. **Método:** Estudo de abordagem qualitativa e representacional. **Resultados:** O *habitus* foi definido através do tempo longo e o tempo vivido na construção de comportamentos situacionais e das diversidades. O contexto asilar é revelado através do tempo. Na esfera da religiosidade, o seu adoecimento é compreendido como uma herança de um castigo divino. O contato com a sociedade como aspecto caritativo não diminuiu o sentimento de excluído pelo preconceito e estigma que permeia o portador de hanseníase. **Conclusão:** Podemos inferir que, ao recontar sua vida, os sujeitos vivenciaram uma condição quase-experimental, rememorando histórias marcantes naquele contexto. **Descritores:** Hanseníase, Representações sociais, Pesquisa metodológica em enfermagem.

RESUMEN

Objetivo: Aprender las representaciones sociales de la hanseníases para el ex-enfermo de la Colonia Getúlio Vargas, Bayeux/PB. **Método:** Estudio de abordaje cualitativo y representacional. **Resultados:** El habitus fue definido a través del tiempo largo y el tiempo vivido en la construcción de comportamientos situacionales y de las diversidades. El contexto asilar es revelado a través del tiempo. En la esfera de la religiosidad su enfermedad es comprendida como una herencia de un castigo divino. El contacto con la sociedad como aspecto caritativo no disminuyó sentimiento de excluido por el prejuicio y estigma que marca el portador de hanseníases. **Conclusión:** Podemos inferir que al contar su vida los sujetos vivenciaron una condición casi-experimental rememorando historias relevantes en aquel contexto. **Descriptores:** Lepra, Representaciones sociales, Investigación metodológica en enfermería.

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INTRODUCTION

Leprosy has been considered as an incurable and disabling disease in several societies and cultures, in all historical periods and even at the contemporaneous time. Claiming that this disease has treatment and cure, frequently, is not enough, since it depends on the imagination that one has about it.

Particularly in Brazil, from the semantic viewpoint, the word “leprosy” has disappeared from the official Brazilians documents, because it was replaced by the word “hanseníase” since 1970. Such an expression is a tribute to the Norwegian Gerhard Armauer Hansen, a physician who, in 1873, discovered the causative bacterium of the infection - *Mycrobacterie leprae*.¹ This official and also structural fact has brought reorganization in the *modus operandi* and in the *modus vivendi* of leprosy patients, whether from the semantic viewpoint or from the treatment-related viewpoint; together, they have reconfigured the coping strategies of the disease through multidrug therapy (MDT) and control and elimination policies, by reducing the prevalence rate of the disease. Thus, the agreement for achieving its elimination diametrically became an international issue, as well as municipal.

Besides the two structural aspects, a third one is placed in a structured way from the struggle and recognition of social movements involved with the cause, especially the Movement for the Reintegration of People affected by Leprosy (known as MORHAN), i.e., stigma and prejudice of the disease. Simply, on the one hand, the leprosy patients were benefited from the new denomination, on the other hand, paradoxically a new and, simultaneously, old ghost is raised, the synonym, leprosy. Leprosy and “hanseníase” are

interfaces of the same reality, which is historically built in the routine of their segregated bearers, excluded and shared in the common sense scope, and this is a perspective contemporaneously built in the rectified realm of science, which is an experts’ field, given that it is individually experienced.

Paradigmatically, in the past, the treatment circumscribed the disease within the colony environment, for being a social issue; nowadays, it takes place in the anonymity of healthcare services under the responsibility of the State and the enrolled territory of the municipality, for being of therapeutic nature. Given the foregoing polarity, one excludes and the other one includes, one stigmatizes and the other one self-stigmatizes, being that the representational centrality remains as a legacy of the history of disease on the mankind as a result of its images and meanings.

Under a new disguise, conceptual and epistemic, leprosy inherits the ontological mark, which is sacred and profane, with purification and punishment, in other words, the myth of leprosy daily translated into stigma and prejudice, in a ghostly perspective that always accompanied the disease. The psychological sense of the term “hanseníase” is more unfamiliar than the original meaning of the term “leprosy”, by being more familiar. In this perspective “contracting ‘hanseníase’ is not just contracting a disease that attacks the peripheral nerves, we also contract a new identity that, not rarely, is far worse than the disease itself.” Since, when one says ‘so-and-so is leprous’, we are assigning it a permanent state. We do not compare such a context to the fact of saying ‘so-and-so has leprosy’.¹

In the current scenario of the medical practice regarding leprosy, the former colony, also

Simpson CA, Miranda FAN, Meneses RM *et al.*

Within the habitus of the...

known as asylum, does not hold the social, segregational and exclusionary function, which is compulsorily determined by the State. Nonetheless, its buildings and geographical spaces integrate the landscape of the cities where they were deployed, regardless of the pioneering initiative of the Brazilian state of Minas Gerais in recommending the use of these spaces as a place of rehabilitation for the population of former asylees that is in the human aging process.

Originally, in the scenario of the former colony, the purpose of the colonies was purely social. There was not a treatment proposal. Patients were forcibly captured and separated from their families. The colonies had an autonomous life, as they were uninterruptedly walled and guarded. The inmates' children were separated from their parents and taken to units known as "preventoriums", where the children were treated with extreme severity, as well as there was submission to physical mistreatments.²⁻³

More recently, we can see an affordable and effective treatment, which has favored the deinstitutionalization of the inmates.³ However, many of the remaining patients present undeniable deformities, being that they no longer adapt themselves to society and labor market. In many cases, resume the daily life after a too long exclusion period is practically impossible. There are still thirty-three partially active colony hospitals, with nearly three thousand remaining people of the regime of compulsory admission.³ From this articulation, by prioritizing the former asylee through the uniqueness of its life history and community participation of those former residents, this study aims to answer the following question: How the former bearers represent the leprosy? Thus, we have drawn the following goal: understanding the social representations of

leprosy from the viewpoint of former patients of the Getúlio Vargas Colony Hospital, Bayeux/PB/Brazil. We have designed our study when using the contributions of the Social Representations Theory, Oral History and Participant Research.

Context is a key aspect of the research, whether because the representations are structured fields by the *habitus* and by the historical contents that pervade the social imaginary, or because they are structural structures of this context and, as such, are social change engines.⁵ The structural issue of social representations is related to the structural structures and the structured structures. Both structures are social products from the individual (re) creations that, usually, lead them back to the representational contents.

Thus, the structures can be located, whether in the diversity order or in the permanencies order, as basic process of social representation.⁴⁻⁵ The permanencies order is the network of representations built by the human being over time that surround a given society as cultural productions.

The diversity order is understood as the representations contained in individuals in their own unique aspects of violence towards the disease. Therefore, "the process of building of the S.R. is made of the personal meanings of the disease, occurs in the interface between permanencies and diversities".⁴

The ability of human beings to interrogate themselves and make use of different territories for reflecting about their identities, clearly demonstrates that, beyond any kind of isolation and individualism, the actual possibility of access to the individuality lies in the presence of others.⁶ Hence, "through the action of social subjects

Simpson CA, Miranda FAN, Meneses RM *et al.*

Within the habitus of the...

acting in the space, which is common to everyone, the public sphere emerges as the place where a community can develop and sustain knowledge about itself, i.e., social representations”.⁶

The asylum-type institutional model while a “private” social space has in the public relation the primary concern with the “sanitary control and confinement of leprosy”, as well as to other diseases of greatest social and historical impact. The adoption of this model under the political and economic influence of the Vargas government, adopted in the 1930s, emphasized the Brazilian industrial production and the hygienic and sanitary character for the patient with leprosy.⁷ We understand that the valorization of the common sense as a dynamic process of symbolic elaboration, enrolled in the consensual and daily universe, shared by psychosocial subjects, seeks to make familiar the unknown from the circulating information, which are mediated by “thinking and dialogicality”.⁸ They both are triggered by interpersonal, intrapersonal and interinstitutional relationships mediated by integrative discursive manifestations of social interaction.

The social representation is a functional world viewpoint which allows an individual or group to give a sense to its behavior and understand the reality through its own reference system, with sights to be adapted and define its place in reality. We note in this statement the constant motion that the former asylee makes towards the adaptive sense, by lending its life story as subject psychosocial to such a process.⁹⁻¹³

METHODOLOGY

It is a qualitative, descriptive and representational study. These aspects are able to incorporate the issues of meaning and intentionality as inherent factors to acts,

relationships and social structures, given that the latter are taken both in their advent and in its transformation, as significant human buildings.¹⁰ Social representations are not mental responses to a social stimulus. They are buildings of the meaning of the social environment, in which stimulus and response are simultaneously formed things, being that both the stimulus and its corresponding responses are determined by the representations built on the stimulus nature and its possible behavioral consequences.

When we decide to choose the analytical resources for comprehending the social representations, in the sequence of content regarding the structured and structural structures thereof, respectively inserted in the permanencies and diversity orders, we have established the following script: 1. Interview transcription 2. Fluctuating reading/listen of the material, by observing: - emerging themes and affective investment 3. Analysis dimensions definition; 4. Network of meanings design. The text of discursive production was recorded on K-7 tape and the context was the space itself of the former colony.

This is a building of the social reality because the representations give meaning to the behavior.¹¹ The life story concerns the experiences and definitions by a person, group or organization, about how such a person, organization or group interprets its experiences.¹⁰ It is a process by which one maintains the presence of an observer before a social situation, in order to perform a scientific investigation. The observer has a relationship, face to face, with the observed subjects and, when participating in their lives, in their cultural scenario, gathers data.

Thus, the observer is part of the context under observation, while simultaneously performs

Simpson CA, Miranda FAN, Meneses RM *et al.*

Within the habitus of the...

changes and is modified by the context itself.¹⁰ We know that changes occur in the lives of investigated subjects, which requires them a rearrangement in their daily lives. We believe in the value of this psychosocial reality comprehension, which, due to its contemporaneity, refers to the possibility of an understanding of “*ex post facto*”, to the extent that twenty-three subjects have participated in the study, in compliance with the recommendations of the Resolution 196/1996/CNS.

This study was approved by the Ethics Research Committee (ERC) from the Federal University of Rio Grande do Norte (UFRN), through the Protocol nº 085/08. All participants were former patients, who lived experiences of inmates in the Getúlio Vargas Colony Hospital, in Bayeux/PB/Brazil. They agreed to participate in the study, because they knew the researchers from other studies, besides the assurance of confidentiality, anonymity and right to refuse. Of these, fourteen are males and nine are females, mostly coming from the Hinterland of Paraíba, low purchasing power, with a high illiteracy rate and an average age of 56 years. We have coded the stretches of speech with the letter “A” to the asylee’s status, followed by the Arabic number as they participated in the study. Data were analyzed based on the discourse analysis.

RESULTS AND DISCUSSION

The Social Representations Theory conceives thought and language exactly as they are used in the common sense and in daily discourses. In contrast to the scientific thinking, which tries to approach the scientific knowledge, the common sense thinking translates representations of natural and social phenomena,

since they seeks the truth through beliefs-based trust, common knowledge and by means of the dialogical rationality power. The aforementioned creeds are rooted in the past, culture, traditions and the language itself.⁸⁻¹²

From this perspective, we have adopted the discourse analysis, which is a discursive formation, not a doctrine, but a device that establishes in the same way and, in the same movement, the set of conditions of its enunciation and advertising.¹² On the articulation between discourse and society, it should be noted that “there has been for a long time a tendency to regard society as a superposition of a solid foundation (the economic factor, social classes) and speeches intended to “translate” (representing, reversing, denying and displacing, among others) this already constituted reality by sense and language, to which they do not overlap in social and economic relations, but consist of a constitutive dimension of these relations.¹²

Initially, the intention was not to use the area of the former colony, but some people have suggested us to go back and talk about themselves at that environment, a few of them still lived there. We have deduced that such a decision closes a way to respond with their presence a singular and peculiar (re) live to report a period lived within that space, rich in meanings and images evoked by memorization of facts still attached to their lives, something that fades away and is worn and yellowed by the time, but remains as a human experience. Most of them expressed emotiveness, watery eyes and faltering voice, even that some of those spaces were familiar and being occupied for other purposes, there was an expression of absence and return to a past that was expressed by assigning a sense of hardship or a ghostly impression. Others, not so much, showed

Simpson CA, Miranda FAN, Meneses RM *et al.*

Within the habitus of the...

a certain degree of resourcefulness and selflessness with the space itself, something apart from their histories, since, as they speak about themselves, did not make clear any apparent affective investment, something emblematically self-denied, like a ghost of the past, something distant, detached from themselves and, therefore, denied.

We could infer that, by retelling their lives as asylees and former patients, the subjects experienced a quasi-experimental condition with regard to the psychosocial factors that confined them. The truth is that all participants lived striking stories in that context, especially, from the biopsychosocial viewpoint. In this regard, we agree that, often, the misunderstanding and the minimization of a phenomenon, far from meaning that it is remote and strange for us, in contrast, are signs of a so intolerable proximity to the point that we should cover and suppress it.¹³⁻¹⁶

Regarding the recall of stories, there are several historical times that permeate the building of social meanings, which enable the development of social representations as forms of practical knowledge that guide the daily actions. Thus, the context can be defined not only by the social space where the action takes place, but also from a temporal perspective in which the short, long and experienced times are edged.⁵⁻¹³ Similarly, individuals select and control their responses, regarded as the most suitable ones, regardless of stimulus, by generating two kinds of behaviors: situationals and representationals.¹⁴

We have analyzed the fragments of these collective and individual trajectories considered as a rescue from the discursive manifestations in the realm of context, structuring of the social representations³⁻⁴ and of the observed behaviors.

¹⁵ Since 1999, the fragments of these collective and individual trajectories are being rescued.¹⁶

Habitus - long and experienced times in the building of situational behaviors - the place of permanencies

The long time is that in which the cultural contents are prevalent in the form of repertoires and collective unconscious; while the short time concerns the socialization and teaching-learning processes, referring to the habitus. Thus, it is characterized by a set of schemas that are learned from the childhood and permanently updated along the social pathway of a person. In the social pathway of a person, situational behaviors are those in which the role of cognitive and evaluative mediations is minimal, and the role of situational factors is maximized.

In the study, the asylum context is revealed over the long and experienced times.¹⁵ The understanding that they have on the disease lead us back to the realm of religion. Their illness is understood and explained as a legacy of divine punishment, through a transmission, as noted in the statements below: “...comes from the time of another century, because in the Bible is written that Jesus healed ten leprous, only one came back to thank Jesus, therefore, this disease still lives in the world due to the lack of gratitude...”A₁. “...I guess my illness is hereditary, because I saw the case of my mother, my father and other sister of mine. I think it already was...”A₁₅.

When talking about the life before the illness, they associated it to the condition of poor children. Accordingly, the relation-poverty is an explanatory building: “... before I get ill, I was very young, I lived in the hinterland along with my father; He was very poor and I cannot even tell you right ...”A₃. “...that is why we lived in a poor condition; you must know where it is

Simpson CA, Miranda FAN, Meneses RM *et al.*

Within the habitus of the...

located, there in the countryside of Campina Grande city..."A₁₅,

The time lived in the colony is a long time which starts in the childhood, pervades all life and reflects in the conformation of a reality present in the memory of those who lived with the disease and the asylum. "...for more than 40 years, right? I'm here, it has been for forty years and one more length that I lived in the colony".A₇. "...when I arrived at the colony, I thought it was good, because I met children like me, so I gave myself, I played too much... I was the age of 10 years..." A₈. "...My childhood was in its entirety lived here ... I'm 66 years old ..."A₁₂. "... I was so young when I arrived, so my first boyfriend was this guy..." A₁₅. ... I was hospitalized in 1946, I married him, he was already sick ..." A₂₃.

Some of them, when talking about their current lives, returned to the lived experiences in the past, especially, the deactivation of the colony, since such a fact caused unrest to the new way of being and living, beyond the limits and the controlled protection provided by the asylum. This fact was very significant in their lives, as highlighted below: "...since childhood, we are cared here, we are already acclimatized here..." A₃ "... I feel...I do not feel well, because of this movement, this deactivation of the colony will be a fight for us ... and it was" A₄. "...this deactivation of the colony will be a hard time for us..."A₇. "...we lived here very quiet, now we live in an unquiet way, violence, alcoholic drinks and other bad things ... they do not give us peace, they steal fruits, even the houses if they can assault..."A₁₀. "...we were very quiet, but now... Not! Not!"A₁₈. "... I see, looking back, that was a controversy for all local inmates, especially those mutilated, who has no family or a place to go ..." A₂₁.

J. res.: fundam. care. online 2013. jul./set. 5(3):104-113

Few of them when returned to the family scope, for a simple and sporadic visitation, the family and friendly groups reacted in an indifferent manner. For others, this return was only imagined, since they never did it, not even for a visitation. "...for my family, I think everyone will welcome me..."A₇. "...as to the others, I do not know ..." A₁₄. "... I went back, still came back there (...) after about six years that I was confined here, I went there along with my father, I was very well welcomed by those people, I was already a teenage girl..." A₂₃.

Regarding the treatment, they demonstrated mistrust, a certain scare, fear and disbelief in particular, i.e., regarding the medication that was used together with dapsone and chamucra oil. As to the multidrug therapy, few of them know, though only know by means of reports of one or another with whom they had contact, at the neighborhood meetings and other community events. "... when I was hospitalized here, the treatment was different, because the medicinal drugs were better, the specific way of the disease came from the EGO itself..." A₁. "... today, I do not give a lot of credit to this remedy in the same way I did to that remedy of CEME, for the treatment of leprosy..." A₅. "...when I need a doctor, I go outside, all my doctors are from there, there in Jaguaribe city ...since the deactivation" A₂₃.

Study participants showed, on the one hand, hold knowledge about the disease from the daily sharing, during the asylum period, on the other hand, an effect of citizenship building facilitated by the MORHAN citizenship, which is a social reintegration movement:

"...we were our own doctors; we often understand the disease better than our own doctors..." A₁. "... the person, when is early

Simpson CA, Miranda FAN, Meneses RM et al.

Within the habitus of the...

treated, can be healed...” A₃. “... I have a sister who lives here in Bayeux city, she lives very well, she is a carrier of this disease, received hospital discharge (...) lives very well, take medications even today...” A₈. “...it is the benefit of the sick person”.

“I cannot say that it is a release, but it is, it is already a walked pathway, right...” A₁₁. “...help, help ... gives more strength...” A₂₀. “...the movement is an organ, a pretty good organ that was deployed, it works for the benefit of the patient, I think it is a very important work what the MORHAN does...”A₂₃.

Habitus - short time in the building of representational behaviors - the place of diversities

The short time is that one which deals with social interactions, in other words, the here-now, mediated by discursive manifestations, of which we highlight polysemy and contradiction. The representational behaviors consist in those determined, at least, by the concrete situation in which they occur and, at most, by pre-situational factors, which are located at the level of attitudes and representations.¹⁵

The contact with society was summarized into sporadic philanthropic visitations of certain religious groups or club of services on celebrative days. This charitable aspect has not diminished the feeling of excluded person by prejudice and stigmas that permeate the person with leprosy, since; somehow, they hoped these people became charity messengers, by expanding the information together the population about the disease and its treatment. *“...the society's staff came here a lot, they brought to us...” A₂. “...in some cases, training like this, a staff to goes out making discourses in schools, by guiding the people so that they lose their prejudice...” A₃. “...I find it*

very hard that they lose this prejudice in relation to the leprosy...” A₄. “...I cannot answer, because prejudice is great...” A₅. “...take off this ignorance from the head of the people, explaining that this disease is not as they think it is...” A₁₀. “...they make a huge beast of it...” A₁₁. “...from some people we can get it off, as opposite to the others...” A₁₂. “...society does not accept us at all, those with leprosy, she does not accept...” A₁₃. “...I saw many cases...”A₁₄. “...it does not accept, only in hospitals...I cite one case, concerning a inmate in the Edson Ramalho Hospital...when they knew about, then they burned the sheet in which he was covered, the bed he lay was thrown away to a dirty place; that is why I...” A₁₉. “...he came here to the colony and died, that boy, the staff did not want him hospitalized there any longer...” A₂₁. “...that is why I say that the society...even today, I think it happens...”A₂₃.

Concerning the performance of healthcare professionals at that time, as asylee caregivers, it was something mechanical, daily and indifferent: *“... we had already a lot of administrators here, all great managers...”A₁. “...the worst administrator who came here was such that it is working now...” A₁₃. “... as to the doctors, I have nothing to say, nobody, to me they are all good, the nurses, doctors...” A₁₂. “...they are there to serve the inmates, right! They came to it, they are here being paid for it...” A₉. “...when I need a doctor, I go outside, all my doctors are from there, there in Jaguaribe city...” “...those patients who needed something are well treated...” A₁₉.*

CONCLUSION

When speaking of leprosy in terms of social representations, it should be clarified two aspects

Simpson CA, Miranda FAN, Meneses RM *et al.*

Within the habitus of the...

of fundamental relevance for the study. The first aspect, of centralizing nature, therefore structural and permanent, consisted in controlling the asylum space, which is segregational and exclusive, with predominance of scientific knowledge and the institution power, in which there was the conviviality of two coexistence domains: institutional and personal(for the patient).

In the institutional domain, the leprous patient under the hygienist protection remained confiscated from the social context, by requiring a new personal reordering before the institutional power and the medical knowledge to the extent that new micro-social relations of power and knowledge about the disease were being built, in a shared conviviality as a way to overcome the difficulties faced within the asylum space. This reordering might be understood as a survival mechanism and, perhaps, defensive.

In the field of the history reported by patients, the treatment was more humanized, since the asylee and patient shared with others its uniqueness, through the bond established by the certification of being with hanseníase/leprosy, in varied degrees of intention, approach, expectations and strangeness, by strengthening the bonds of friendship, parenthood and support.

The second aspect of replacement nature, also a control form, which is considered decentralizing, non-asylum, inclusive and democratic, is enrolled in structural and diversified dimensions. At this aspect, patients are mixed in the healthcare services through the benchmark units of the Leprosy Control Programmes (known in Brazil as PCH).

The actions decentralization makes the leprous more vulnerable to the issues of prejudice and stigmatization, with little or none space for J. res.: fundam. care. online 2013. jul./set. 5(3):104-113

reporting its illness experiences, as well as its probable identity crisis. Some cases are not reported to the family, so that the patient is kept away from family conviviality and social life, throughout the admission period. Hence, the asylum has become private for itself, i.e., something internal to its own existence.

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