

# Social representation of Hansen's disease thirty years after the term 'leprosy' was replaced in Brazil

*A representação social da hanseníase, trinta anos após a substituição da terminologia 'lepra' no Brasil*

Maria Leide Wand-del-Rey de Oliveira  
Professor and researcher, Medical School, Universidade Federal do Rio de Janeiro (UFRJ)  
Ladeira Tabajaras, 126/1008  
22031-110 Rio de Janeiro — RJ Brasil  
mleide@uol.com.br

Carla Maria Mendes  
Psychologist at Secretaria Estadual de Saúde do Rio de Janeiro, Rua Julio Braga, 644  
26135-320 Belford Roxo — RJ Brasil

Rachel Tebaldi Tardin  
Dermatologist, Manager of Plano de Eliminação da Hanseníase of Rio de Janeiro Municipal Health Department  
Rua Ribeiro Guimarães, 220/208  
20511-070 Rio de Janeiro — RJ Brasil

Mônica Duarte Cunha  
Dermatologist, Manager of Plano de Eliminação da Hanseníase of Duque de Caxias Municipal Health Department  
Rua Bento de Vasconcelos, 79/501  
26255-030 Nova Iguaçu — RJ Brasil

Angela Arruda  
Psychologist, professor of Universidade Federal do Rio de Janeiro (UFRJ), Rua Francisco Sá, 38/806  
22080-010 Rio de Janeiro — RJ Brasil

OLIVEIRA, M. L. W.-del-R. de; MENDES, C. M.; TARDIN, R. T. and CUNHA, M. D.; ARRUDA, A.: 'Social representation of Hansen's disease thirty years after the term *leprosy* was replaced in Brazil'. *História, Ciências, Saúde — Manguinhos*, vol. 10 (supplement 1): 41-8, 2003.

Based on the theories of social representation (SC) and Central Core (CC), a structural study was undertaken regarding the neologism *hanseníase* (Hansen's disease), the term adopted by Brazil's Ministry of Health in the 1970s. Carried out during 2001, this study interviewed eight hundred housewives residing in the Rio de Janeiro and Duque de Caxias municipalities. It found that Hansen's disease is part of a process of modernization of common thinking, anchored in the traditional representation of leprosy. This finding is understandable from the perspective that the central structure of a social representation has a historical determination, so short- and middle-term changes are not to be expected. Furthermore, there has been no ongoing investment in social marketing to make the new terminology more widely known. The authors discuss the relation between social representation and the concept of the history of mentalities.

KEYWORDS: Hansen's disease, leprosy, social representation, Central Core.

OLIVEIRA, M. L. W.-del-R. ; MENDES, C. M.; TARDIN, R. T. e CUNHA, M. D.; ARRUDA, A.: 'A representação social da hanseníase, trinta anos após a substituição da terminologia *lepra* no Brasil'. *História, Ciências, Saúde — Manguinhos*, vol. 10 (suplemento 1): 41-8, 2003.

*Baseando-se nas teorias de representação social (RS) e do Núcleo Central (NC), procedeu-se ao estudo estrutural do neologismo hanseníase, introduzido no Brasil, pelo Ministério da Saúde, nos anos 1970. A pesquisa foi conduzida em 2001, em oitocentas donas de casa dos municípios do Rio de Janeiro e Duque de Caxias. Concluiu-se que a hanseníase é parte da modernização do senso comum, mais ainda ancorada na representação tradicional da lepra. Esse achado é compreensível sabendo-se que a estrutura central de uma RS tem determinação histórica, não devendo ser esperadas mudanças de curto e médio prazos. Além disso, não se observou investimento em comunicação social para a divulgação ampla da nova terminologia. Os autores discutem a interface da RS com o conceito de história das mentalidades.*

PALAVRAS-CHAVE: hanseníase, lepra, representação social, Núcleo Central.

### Historical references

Regarding the images and representations involving AIDS and leprosy, Tronca (2000) points out the idea that disease is a linguistic invention to refer to a biological phenomenon, influenced not only by the technology available but also by the historical contexts of all susceptible populations. Although the term 'leprosy' was legally banned (Brasil, 1995) under pressure from the Movement for the Reintegration of Hansen's Disease Patients' (Morhan), it had been in use since the beginning of the 1970s in Brazil (Rotberg, 1972, 1969). This initiative was taken due to strong pressure from Brazilian leprologists, pursuant to recommendations of International Leprosy Congresses (Havana, 1948, and Rio de Janeiro, 1963) concerning minimization of the leprosy stigma (Rotberg, 1975, 1973). For Brazil's Ministry of Health (MoH), leprosy and all correlate adjectives were replaced by the term 'Hansen's disease' (HD) in 1976 (Brasil, 1975), even though the first and only mass media campaign in which the MoH introduced HD concepts and images only took place in the late 1980s (Oliveira *et alii*, 1989).

In general, all information materials from the health sector refer to HD and make no mention of leprosy. The term 'Hansen's disease' is willingly accepted by dermatologists, patients, and the media, despite some controversy still existing among general health workers (Del Fávero, 1973; Andrade, 2001) and, indeed, it is quite unknown to the susceptible population (Feliciano *et al.*, 1977; Maia *et al.*, 2000). It may have started changing after the notable fact that a famous Brazilian singer sponsored a Patients' Movement and, in the past two years, has been playing a major role in introducing HD information on the agenda of different media, which reach more than 80% of the Brazilian population.

### Methodology and theoretical references

This qualitative study also employed a quantitative method for structural analysis. It was conducted among the population from four areas of the Rio de Janeiro metropolitan region during 2001, encompassing the municipalities of Rio de Janeiro and Duque de Caxias, in order to understand whether the popularization of scientific notions of HD have incorporated the traditional stigmatizing knowledge about the category 'leprosy'. A theoretical model considered adequate to explain this question was based on Moscovici (1998), a social psychologist who created social representation theory (SRT). The study endeavors to elucidate how new knowledge is incorporated into pre-existent knowledge, so that scientific issues are transferred to common thinking. To better understand the structural analyses of social representation, a complementary Central Core

(CC) theory was applied (Abric, 1998). This model tries to identify the social-cognitive contents of social representation (SR), identifying two systems of representation: a more stable, consensual, and strict central system, and a more flexible, individual, peripheral system (Sá, 1998, 1995). The CC is responsible for SR command and articulation. Both these theories have been used in Brazil to study AIDS, epilepsy, and similar phenomena in other areas (Jodelet *et al.*, 1998; Tura, 1998) but not in leprosy or HD as yet.

A free-word-association test was used with eight hundred women, mostly housewives, invited to promptly express their associations with the word *hanseníase*. In cases where they said nothing, the word 'leprosy' was proposed. Coded as short one- or two-word phrases, their answers were arranged by EVOC software (Vergés, 1992) in spatial form, which allows us to understand the structural organization of this SR. The word distribution not only takes into account frequency but also the order in which they were evoked and their co-occurrence. The Average Order of Evocations (AOE) is obtained by dividing the word frequencies in each position (the first receiving value 1; the second, value 2; and so on) by the total word frequencies in all positions.

The results can be interpreted by the distribution shown in figures 1 and 2, where each cell has a specific meaning within this representation:

- Upper-left cell: allocation of the most frequent and prompt evocations, meaning CC of SR.
- Upper-right cell: prompt evocations with variable frequencies, meaning close to CC of SR.
- Lower-right cell: allocation of evocations with variable frequencies and order, meaning peripheral system of SR.
- Lower-left cell: allocation of less frequent evocations and variable order, meaning personal attribute with some intermediation with peripheral system.

## Results and discussion

Of eight hundred women<sup>1</sup> (average age of 42; 62% housewives; only 1.8% working in a college-education profession), 436 (54%) promptly expressed their associations with the word *hanseníase* (H group) while 358 (45.1%) expressed associations only when the word 'leprosy' (L group) was offered as a second choice. The magnitude of this relation seems to be modified by education.

<sup>1</sup> Four women did not express associations to both terms; two had leprosy.

**Structure of SR of Hansen’s disease in sample**

Freq.	AOE < 2.4		AOE >= 2.4			
		F	AOE		F	AOE
≥ 83	Disease	190	1.23	Patch	144	2.438
	Leprosy	101	21.50			
	Skin	210	51.733			
< 83	Cancer	34	2.118	Redness	10	3.500
	Dangerous	13	2.38	Pieces fall off	21	3.143
	Sadness	11	52.00	Itching	48	2.958
				Contagious	49	2.776
				Caution	14	3.143
				Cure	76	2.842
				Deformity	10	2.800
				Pain	11	3.000
				Numbness	17	2.647
				Wound	50	2.800
				Serious	12	2.500
				Horrible	10	2.400
				Insensitivity	12	3.167
				Fear	11	2.455
				Prejudice	12	3.500
			Rats	10	2.500	
			Medicine	10	2.800	
			Blood	11	3.364	
			Transmissible	11	2.909	
			Treatment	44	3.205	

Freq. = frequency.

According to the word distribution in the upper-left cell of square 1, which comes from the H group, here the CC is formed of three terms ('disease', 'leprosy', 'skin') that are related to both the HD and leprosy categories. Therefore, 'leprosy' reached the CC of *hanseníase*. Nevertheless, the word 'patch', occupying the upper-right-cell, close to the CC, is more related to HD and is a result of frequent but not prompt evocation. The lower-right cell is formed of many words, related to both categories studied and probably representing a popularization of some scientific notions of HD, co-existing with traditional knowledge of leprosy. It is important to stress the presence of 'cure', 'treatment', and 'numbness', always present in HD learning materials, while the expressions 'pieces fall off', 'dreadful', and 'fear' historically remind one of leprosy. The word 'rat' could be related to leprosy since in the peripheral area of Rio de Janeiro "leprosy is mainly an animal disease," or it might result from some confusion between *leptospirose* (leptospirosis) and *hanseníase* (leprosy), both words that present some pronunciation problems for many Brazilians.

**Structure of SR of leprosy in population group**

Freq.	AOE < 2.2		AOE ≥ 2.2			
	F	AOE	F	AOE		
≥ 51	Dog	87	1.966	Itching	82	2.354
	Disease	144	1.444	Wound	69	2.304
	Skin	91	1.802			
< 51	Cancer	20	1.750	Pieces fall off	36	2.500
	Hurt	13	2.077	Contagious	44	2.386
	Dreadful	28	1.893	Care	10	2.700
	Bad	19	1.737	Disability	11	3.273
	Scabies	10	2.000	Incurable	24	2.542
				Loneliness	12	3.083
				Sore	20	2.250
				Patch	26	2.385
				Fear	10	2.700
				Mycosis	10	2.400
				Rat	14	2.429
				Filth	15	2.800
				Transmissible	16	2.313
			Treatment	11	2.909	
			Sadness	11	2.727	

Freq. = frequency.

In the upper-left cell of group L, the words 'dog', 'disease', and 'skin' in the CC also link to HD and leprosy categories. The words 'itching' and 'wound', occupying the upper-right cell, may cause some discussion concerning their relationship only to leprosy or also to HD. Both are present at the peripheral system of the H group. As in the H group, the lower-right cell of the L group is formed of many words, related to both categories studied. On the other hand, 'cure' is not present, which is reinforced by the word 'incurable'.

In the absence of official information linking HD to 'leprosy', even in the media (Reis, 2000), the relationship of signs, symptoms, and treatment in both categories is seen differently by many people. The collective memory of leprosy is mostly oral and mainly influenced by the individual's social network. An old woman, living in Duque de Caxias, said: "In my state of Minas Gerais, leprosy was a human disease but here it is a dog disease." It must be pointed out that the population of these peripheral areas of metropolitan cities is mainly formed of migrants from different states of Brazil.

Based on the theory of SR, we may conclude that HD is part of a process of modernization of common thinking, anchored in the traditional representation of leprosy. The results of research on social representation carried out in HD patients at a basic health unit in

Rio de Janeiro — despite referring to both categories with no distinction — showed that many of such patients, even under treatment, were really in doubt if their illness was leprosy or not (Claro, 1995). It may be that thirty years is not time enough to consolidate a SR of HD. Furthermore, there has not been an ongoing investment in social marketing to make the new terminology better known.

It is possible to infer that the results presented here can illustrate both the SR theory and the concept of the history of mentalities. As Moscovici (2001) puts it, the notion of collective representation owes much to the research done by historians about mentalities: “The co-existence of various mentalities in the same person in the same époque is essential in the history of mentalities as well as its transformation” (Le Goff, 1976). One mentality begins to disappear when another slowly takes hold.

According to Abric (1998), among the differences of the double system of SR, the most important one is that the central system is independent of the immediate context as its origin is socially and historically determined, thus being stable and resistant to changes in the short term. On the other hand, the peripheral system allows adaptation to and integration into ordinary experiences, and it is possible to be changed. Thus it can also reach the CC, influencing long-term changes. So the peripheral system is the target for health education and therefore the contents of this system must be considered in comprehensive educational processes (Wagner, 1999; Wagner *et al.*, 1999; Spink, 1995).

As already mentioned, the ability for evocation after hearing *hanseníase* was associated with higher educational levels on the part of interviewed women, even among aged ones. As the new terminology is official and definitive in Brazil, besides being very well accepted by the patients, adequate communication with the susceptible population is a valid strategy for dealing with this social context. Le Goff (1996) reminds us that we should work in such a way that a collective memory is useful to freedom and not to human servitude.

#### Acknowledgements

The following took part in this research: L. F. R. Tura; A. Arruda; and K. Blok. (consultants); E. R. Oliveira; R. Eboli; D. Carvalho; V. Bellizzi; A. Pichone; F. Rueda; K. A. Americano; A. Alves (UFRJ medical students: field data collection); and E. R. Oliveira, social worker at HUCFF/UFRJ.

Institutions:  
Universidade Federal do Rio de Janeiro (UFRJ); Secretarias Municipais de Saúde do Rio de Janeiro e de Duque Caxias; Reprehan/IBISS in conjunction with Netherlands Leprosy Relief (NLR) support.

#### BIBLIOGRAPHIC REFERENCES

- Abric, J. C. A. 1998 'Abordagem estrutural das representações sociais'. Em Denise Jodelet e Margot Madeira, (eds.), *Estudos interdisciplinares de representação social*. Goiânia, AB, pp. 27-38.
- Andrade, V. L. 2001 *Estratégia de aceleração da eliminação da hanseníase em todos os municípios do Rio de Janeiro*. GT/Hansen/Conassem.

- Brasil — Ministério da Saúde  
1995 'Lei 9.010 de 29 de março de 1995.' *Diário Oficial da União*, Brasília, DF.
- Brasil — Ministério da Saúde  
1975 'Criação da Divisão Nacional de Dermatologia Sanitária.' Decreto Presidencial nº 76.078 de 4 de agosto de 1975, Brasília, DF.
- Claro, L. B. L.  
1995 *Hanseníase: representações sobre a doença*. Rio de Janeiro, Fiocruz.
- Del Fávero, W.  
1973 'Lepra x hanseníase: editorial.' *Bol. Div. Nac. Lepr.*, Rio de Janeiro, nº 2/4, p. 6.
- Feliciano e Kovacs  
1977 'Opiniões sobre a doença entre membros da rede social de pacientes de hanseníase no Recife.' *Public Health*, 1:2, pp. 112-8.
- Jodelet, D.  
1998 'Representações do contágio e a Aids.' Em D. Jodelet e M. Madeira (orgs.), *Aids e representações sociais — à busca de sentidos*. Natal, EDUFRN, pp. 17-45.
- Le Goff, J.  
1996 *História e memória*, Trad. Bernardo Leitão *et al.*, 4ª ed., Campinas, Unicamp.
- Le Goff, J.  
1976 'As mentalidades: uma história ambígua.' Em J. Le Goff e P. Nora (orgs.), *História: novos objetos*, Trad. Terezinha Marinho. Rio de Janeiro, Francisco Alves, pp. 68-83.
- Maia, M. A. C.; Alves, A.; Oliveira, R. *et al.*  
2000 'Conhecimento da equipe de enfermagem e trabalhadores braçais sobre hanseníase.' *Hanseníase Internationalis*. São Paulo, 25:1, pp. 26-30.
- Moscovici, S.  
2001 'Das representações coletivas às representações sociais: elementos para uma história.' Em D. Jodelet (org.), *As representações sociais*. Rio de Janeiro, Editora da UERJ.
- Moscovici, S.  
1998 'Notes towards a description of social representation in retrospect and prospect.' *European Journal of Social Psychology*, 18, pp. 211-50.
- Oliveira, M. L.; Moreira, M. B. R.; Pereira, G. F. M. P.  
1989 'Multi-media campaign about Hansen's disease.' *Intern. Journ. of Leprosy*, 57:1, sup. 397.
- Rotberg, A. A.  
jan.-mar. 1975 'O pejorativo *lepra* e a grande vítima de grave erro médico-social histórico: a indefesa América Latina.' *Revista Histórica*, 51:101, pp. 295-304.
- Rotberg, A. A.  
1973 'A prevenção moderna da hanseníase: caminhos e obstáculos.' *Bol. Ser. Nac. Lepr.* Rio de Janeiro, 2/4, pp. 107-24.
- Rotberg, A. A.  
1972 'Education on leprosy is a dangerous myth.' *Intern. Journ. of Leprosy*. New Jersey, 40, pp. 79-80.
- Rotberg, A. A.  
1969 'Hanseníasis, the new official name of leprosy in São Paulo.' *Brazil. Derm. Intern.*, 8:1, pp. 41-3.
- Reis, R. M. B.  
2000 'A comunicação da informação em hanseníase e a questão do estigma sob o ponto de vista do discurso da mídia.' Master's thesis in Information Science, Universidade Federal do Rio de Janeiro. (mimeo.)
- Sá, C. P.  
1998 *A construção do objeto de pesquisa em representações sociais*. Rio de Janeiro, Editora da UERJ.
- Sá, C. P.  
1996 *Núcleo central das representações sociais*. Petrópolis, Vozes.

- Sá, C. P.  
1995 'Representações sociais: o conceito e o estado atual da teoria'. Mary Jane Spink (org.), *O conhecimento no cotidiano*. São Paulo, Brasiliense, pp.19-45.
- Spink, M. J. (org.)  
1995 *Conhecimento no cotidiano*. São Paulo, Brasiliense.
- Tronca, Ítalo  
2000 *As máscaras do medo: lepra e Aids*. Campinas, Unicamp.
- Tura, L. F. R.  
1998 'Aids e estudantes: a estrutura das representações sociais.' Em Denise, Jodelet e Margot, Madeira (orgs.), *Aids e representações sociais — à busca de sentidos*. Natal, Editora da Universidade Federal do Rio Grande do Norte, pp. 121-54.
- Vergés, P.  
1992 'Évocation de l'argent: une méthode pour la définition du noyau central d'une représentation.' *Bulletin de Psychologie*, 45:405, pp. 203-9.
- Wagner, W.  
1999 'Social representations and beyond: brute facts, symbolic coping and domesticated worlds.' *Culture and Psychology*, 4.
- Wagner, W.; Duveen, G.; Themel, M.; Jyoti, V.  
1999 'The modernisation of tradition: thinking about madness in Patna, India.' *Culture and Psychology*, 5, pp. 1-29.

Submitted on october 2002.

Aproved on March 2003.