

Fear, infection and compassion: social representations of tuberculosis in Medellín, Colombia, 2007

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SUMMARY

OBJECTIVE: To identify and analyse the social representations (SRs) of tuberculosis (TB) among three groups of people in Medellín, Colombia, with the purpose of contributing to improvements in TB treatment and control programme activities.

METHODS: Cross-sectional study using free word association and evocative analysis techniques in 1049 persons within a structural SR framework.

RESULTS: The terms 'cough', 'contagion', 'illness' and 'fear' were found to be components of the central core in the three groups. In the peripheral system, 'rejection' and 'treatment' were considered modifiable factors. Text anal-

ysis showed that 'fear' and 'compassion' are associated with evocations among patients and their relatives, 'contagion' among lay people and 'isolation' among health care personnel.

DISCUSSION: Fear of infection may have a negative effect on relationships with patients, health care activities, treatment surveillance and family support for patients. A better understanding of patient beliefs and their family environment can improve treatment quality and adherence in the city.

KEY WORDS: tuberculosis; social representations; fear; contagion

TUBERCULOSIS (TB) has a profound impact on individuals, families and society: it tears the social fabric and stigmatises those who suffer from it.¹ TB has caused much damage to humanity in terms of morbidity and mortality across cultures,^{2,3} and it remains the main cause of death due to infectious diseases in adults worldwide.⁴

Colombia reports nearly 11 000 new cases of all forms of TB every year. Public health officials acknowledge it as a major health problem. A total of 11 342 cases were reported in 2008 for an incidence rate of 25.6 cases per 100 000 population.⁵ The TB Regional Plan for the Americas places Colombia in 'scenario 4',⁶ along with other countries with an estimated incidence rate of >50/100 000 and DOTS coverage of <75%.⁶

After health reforms based on the managed competition model were implemented in Colombia in 1993, numerous difficulties occurred in the performance of the TB control programme; bacille Calmette-Guérin vaccination coverage and screening of symptomatic patients decreased, and lower cure rates were reported.⁷

In 2008, 826 cases with a positive acid-fast bacilli smear were notified in Medellín (incidence rate 36.06/100 000). The rates of cure and of default were re-

spectively 54% and 12% (Medellín Health Department, non-published data). These data underscore the difficulties of treatment supervision and patient follow-up faced by the programme at the local level.

Munro et al. published a review of qualitative studies on treatment adherence, with an emphasis on patients' perceptions of TB. One of the issues identified was the influence of community and family support on treatment adherence.⁸ No studies on TB were identified that used free word association.

Traditional approaches to TB control in Colombia focus on programme interventions, but there are very few examples of community participation and social support for patients.⁹ Research studies have covered issues such as patient characteristics, treatment success or failure, and the determinants of disease and desertion.⁸ The connotations TB has for patients, the acknowledgement of the disease and stigma associated with the disease have also been topics of research.

According to Moscovici, the role of social representation (SR) is to help preserve ties among the individuals in a group by directing the actions, behaviours and practices¹⁰ of individuals who, within a specific representation, would show uniform behaviour.¹¹

For Jodelet, SR is 'a form of knowledge, socially built and shared, with the practical goal of constructing

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a reality that is common to a social group; SRs are a guide to action for individuals'.¹² TB control programmes can improve their performance by acknowledging the world view of patients and their families.

The present study used the technique of free word association, as this allows participants to respond without pre-established guidelines, thus facilitating candid responses. This technique, as in the case of knowledge, attitudes and practice surveys, was intended to help TB control programmes by strengthening the promotion and diffusion of programme activities, and social mobilisation through the understanding of patients and their environment.¹³ This study used the structural approach to SR developed by Abric, which allowed us to identify a 'central core' as the basic unit of representation (which determines its meaning and organisation), and which is associated with social norms and values and has been shown to be stable. This approach also has a 'peripheral system' that acts as a defence line for the 'central core' against changes in the social context.¹⁴

METHODS

A cross-sectional study was conducted using evocation analysis, statistical analysis of text¹⁵ and, finally, a qualitative analysis. World views reflected in social interactions were probed for, and ordinary knowledge elaborated, through free word association in patients' discourse. The starting point was cognitive performance where 'some terms are readily brought up to build a representation'.¹⁶

This technique shares some limitations with other techniques dealing with content analysis due to the fact that the categorisation of reality may ignore some of the information and bias the interpretation of the words spoken in favour of the researcher's point of view.¹⁷

A total of 1049 persons aged >15 years were surveyed using a convenience sampling technique. Three groups were defined: 1) patients with TB and their relatives ($n = 212$), 2) health care workers (HCWs; $n = 324$) and 3) members of the general public ($n = 513$). Efforts were made to collect data as rapidly as possible to try and find variations in some of the characteristics of informants with different experiences of TB. Emphasis was placed on the comparison between groups, but the type of sampling limits the extrapolation of results.

Data collection was performed in 2007 by a team working on basic and applied TB research. Each participant was asked to write down eight words evoked by the question: 'What words come to mind when you think of a person with TB?' Associations were elicited spontaneously allowing each person to express elements associated with TB from their own cultural context.

For the structural SR analysis, the frequency and

order of words was quantified to visualise the organisation and construction of the 'central core' as a basis for SR.^{11,14} The 'central core' groups together those words with the highest frequency and the most rapidly associated.¹⁸ The words most readily evoked and with the highest frequency are the core of the SR of TB.

An average of words evoked was calculated for each group, as well as the theoretical categories for the correspondence text analysis to verify relationships among categories within each group.

Data processing was performed using EVOC (Ensemble de programmes permettant l'analyse des évocations) 2003 version (Sarsen Technologies, Marlborough, UK, and XLSTAT (Addinsoft, New York, NY, USA).

RESULTS

Of 1049 people surveyed, 58.9% ($n = 618$) were female; the median age was 30 years (standard deviation [SD] 13.6). A total of 6204 words were collected; the median of words evoked per person was 6 (SD 2.1). A total of 2016 different words were obtained, with an average of 1.9 different words per person. Figure 1 summarises the frequency of evocations in the three groups.

The analysis of evoked words revealed the 'central core' of the SR. Words common to all three groups are highlighted in Table 1.

Among health care workers, words such as 'poverty' and 'overcrowding' were found to refer to patients' socio-economic status. The word 'isolation' appeared in reference to measures taken to contain infection among workers and patients. Transmission of TB in health care institutions is common due to contact between patients and susceptible persons.

Among patients with TB and their relatives, words such as 'sadness' and 'anguish' were found. TB and sadness have become synonymous and have made a place for themselves in the literature and the social fabric.¹⁹

Among the general public, the words infection and lungs referred to contagious bacterial infections involving the lungs. The image of pulmonary TB is

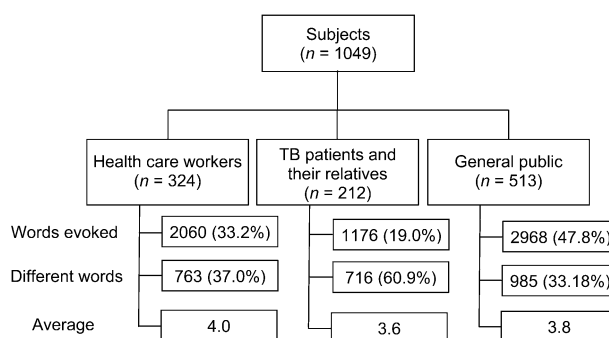


Figure 1 Distribution of population surveyed by words evoked. TB = tuberculosis.

Table 1 Central core prototype (range and frequency) of the SR of a person with TB

Health care workers*			TB patients and relatives [†]			General public [‡]		
Word	n [§]	Range [¶]	Word	n [§]	Range [¶]	Word	n [§]	Range [¶]
Cough [#]	167	2.5	Fear [#]	46	2.5	Cough [#]	142	2.3
Poverty	61	3.9	Sorrow [#]	34	2.2	Illness	131	2.5
Overcrowding	60	3.7	Contagion [#]	27	2.3	Contagion [#]	90	3.6
Contagion [#]	42	3.4	Sadness	23	3.0	Contagious [#]	80	3.4
HIV	42	3.9	Cough [#]	22	3.2	Pain	64	3.6
Isolation	38	3.9	Contagious [#]	16	3.4	Fear [#]	63	3.1
Contagious [#]	36	3.1	Illness [#]	14	1.9	Sorrow [#]	57	2.6
Weight loss	36	3.9	Scare	11	2.9	Ill person	52	1.5
Illness [#]	33	2.5	Pain	9	2.8	Infection	49	3.3
Malnutrition	30	3.1	Anguish	7	3.4	Lungs	48	3.7
Infection	29	3.2	Care	7	2.6	Sadness	43	3.8
Ill person	24	2.5	Sympathy	7	1.3	Blood	35	3.7
Death	22	3.5				Fever	33	3.5
AIDS	22	3.7				Pity	30	3.1
Fear [#]	18	3.8				Scare	15	2.4
Lungs	16	2.5				Disgust	13	2.4
Blood	13	2.8				Neglect	13	3.1
Bacillus	11	3.6				Phlegm	13	3.2
Sorrow [#]	11	2.8				Tiredness	10	3.6
Consumptive	11	2.9						
Poor	10	3.4						
Phlegm	9	3.1						
Skinny	8	3.6						
Old	8	2.5						
Immunocompromised	7	3.4						
Danger	7	2.6						

* Range <4, frequency >7.

[†] Range <3.6, frequency >7.[‡] Range <3.8, frequency >10.[§] Word frequency.[¶] Population average, showing the order in which the word was evoked, i.e., first place, second place, etc.[#] Words common to all three groups.

SR = social representation; TB = tuberculosis; HIV = human immunodeficiency virus; AIDS = acquired immune-deficiency syndrome.

Table 2 Peripheral system prototype (range and frequency) of the SR of a person with TB

Health workers*			TB patients and relatives [†]			General public [‡]		
Word	n [§]	Range [¶]	Word	n [§]	Range [¶]	Word	n [§]	Range [¶]
Expectoration	33	4.1	Death	21	4.1	Death	99	4.4
Fever	31	4.3	Isolation	16	3.7	Treatment [#]	43	4.7
Sputum	20	4.2	Treatment [#]	13	3.8	Isolation	36	4.9
Immunocompromised	17	4.6	Terror	10	3.7	Anguish	28	4.5
Acid-fast smear	15	5.1	Rejection [#]	9	3.8	Hospital	22	5.2
Surgical mask	15	5.0	Depression	7	4.8	Poverty	19	4.5
Adynamia	14	4.5	Suffering	7	4.0	Solitude	19	5.1
Pain	14	4.6	Disdain	7	3.8	Suffering	18	4.4
Treatment [#]	14	5.2				Rejection [#]	17	4.5
Cachexia	12	4.5				Care	15	3.9
Haemoptysis	12	4.4				Paleness	15	4.7
Rejection [#]	11	4.5				Asphyxia	14	5.0
Care	10	4.4				Help	14	4.3
Tuberculin	9	5.1				Medication	14	5.2
X-rays	8	5.9				Danger	14	4.6
Anorexia	7	5.1				Weakness	13	4.6
Secretions	7	5.3				Virus	13	3.8
Sadness	7	6.3				Cigarette smoking	12	4.1
						Pollution	11	4.2
						Flu	11	3.8
						Hospital stay	10	5.2
						Weight loss	10	4.0

* Range ≥4, frequency >7.

[†] Range ≥3.6, frequency >7.[‡] Range ≥3.8, frequency >10.[§] Word frequency.[¶] Population average, showing the order in which the word was evoked, i.e., first place, second place, etc.[#] Words common to all three groups.

SR = social representation; TB = tuberculosis.

entrenched in people's minds: 'that is what infects you'. In this group, words such as 'sadness' and 'pity' are evoked to mean compassion.

Evocative words common in the peripheral system among HCWs generally tend to be related to diagnostics and other tests. Words shared by all three groups are highlighted in Table 2.

Patients and their relatives perceive TB as a lethal disease. Death comes up as a peripheral element. Another word, 'isolation', refers to knowledge about certain factors protective against infection.

Words such as 'death' and 'isolation' were reported among the general public and patients and relatives; in the latter group, terms such as poverty, cigarette smoking and pollution most likely refer to socio-economic status, homelessness and drug addiction as causal factors for TB. In both groups, words such as hospital and medications refer to resources available for treatment of the disease.

A graphic representation was drawn up using a contingency table of 24 theoretical categories, allowing an analysis of associations that reflect the specific meaning of TB for participants in the survey. Figure 2 shows that HCWs are seen as closely related to six attributes: 'cough and sputum', 'isolation and hospital', 'consumption', 'social disease', 'the bacillus' and 'the other'. The group of patients and relatives has five attributes: 'fear', 'compassion', 'rejection', 'bad luck'

and 'loneliness'. The general public has 12 attributes, among them 'low life', 'the ill body', and 'contagion'.

DISCUSSION

The results in the three groups are related to cultural values that reflect collective values.²⁰ Some overlap was found among the central core attributes for the three groups. Five words were found to be common to the three groups: 'cough', 'contagion', 'illness', 'fear' and 'sorrow'. Four categories emerged from these words that reflect the meaning of SR of TB: 'fear', 'contagion', 'illness' and 'compassion'. Some theoretical aspects of these categories are highlighted below.

Illness came up as the first component of the 'central core' for the SR in the three groups. In the correspondence analysis, this was an attribute of the general public and HCW groups:

The disease is described as the quintessential worst event [...] it affects individuals by modifying their energy, mood, family and social behaviour in a negative way.¹⁰

The most frequent word used in the three groups was 'cough' (331 evocations) and it also occupied the first position in all three groups. It is probable that the persistence of this term in the population surveyed is due to the wide diffusion of the characteristic TB symptoms by the media.²¹

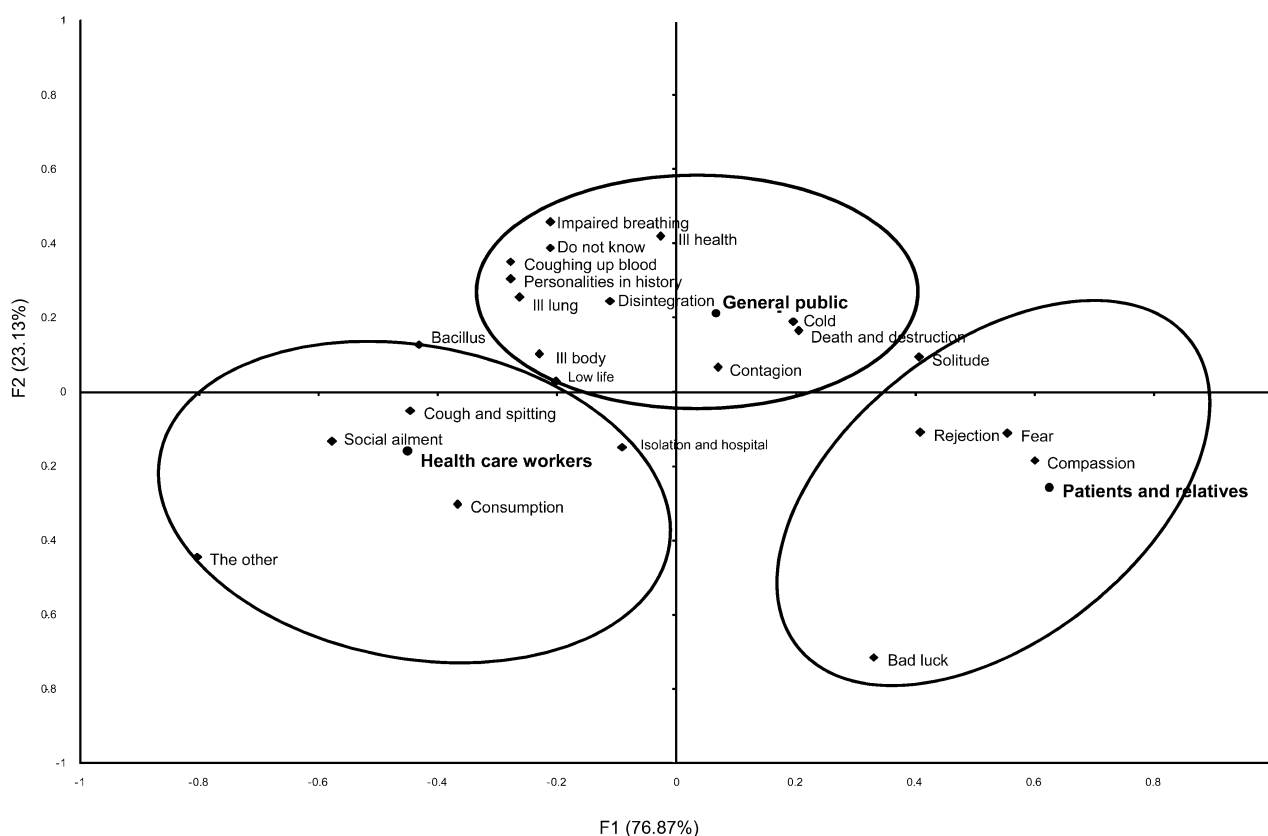


Figure 2 Text correspondences of surveyed groups by associated theoretical categories.

Fear was the second component of the 'central core' of SR in the three groups. In the correspondence analysis, fear came up as an attribute of the group of TB patients and their relatives.

Fear, 'a distressing alteration of mood due to a risk or harm, real or imaginary',²² is often experienced as a sudden emotion in relation to an actual danger.²³ In this study, it is necessary to consider that fear 'weaves links of solidarity and norms of everyday behaviour'.²⁴

Being scared of communicable diseases is a common fear.²⁵ A patient with a positive smear for TB becomes a threat to the neighbourhood's safety and our own. As a result, making the diagnosis of TB public is difficult for patients and their families.

The peripheral components common to the three groups were 'treatment and rejection'. These components are related to fear and its different meanings in the group of patients and their relatives. The implications of a diagnosis of TB are often understated by the medical training and control programmes. A deeper understanding of the fear of TB and collective memory is one of the purposes of this study.

Contagion was the third component of the 'central core' in the SR for the three groups, and it was one of the attributes of the general public in the multiple correspondence analysis.

In the middle of the nineteenth century and at the beginning of the twentieth century, people suffering from TB had an aura of exceptionality, which gave them a certain refinement.²⁶ At the time, TB was a synonym for beauty and sensitive minds.¹⁹ It used to be considered 'interesting', and showed individuality and personal intimacy.²⁷

This belief began to fade when Koch proved the bacterial aetiology of TB. In the twentieth century, when TB was associated with poverty and unhygienic conditions, its romantic aura wore off,¹⁹ and poverty emerged as 'a historical ally of TB'.² New challenges arose to try and explain contagion and to develop effective treatment.

The attributes 'isolation and hospital' emerged as components of the 'central core' among HCWs. Technical procedures,²⁸ such as administrative and environmental controls, can be interpreted as a 'ritual enactment' of the fear of infection.

Londoño points out how recommendations about cleanliness and hygiene in nineteenth century Medellín, used to promote the 'individual use of belongings and food'—fear of infection, 'distrust of others', 'disgust'—may have preceded the spread of disinfection standards in modern bacteriology.²⁹

In this study, the general public feared infection and 'seeing themselves in the place of the patient', and they may fear becoming puppets in the official health care system. Rejection of the patient (a peripheral component of SR) may be related to a deep fear of infection in all the study groups.

Some knowledge, attitudes and practice studies have shown that interpretations of TB may serve to direct people to sources of information and treatment facilities.^{8,30,31}

This study shows that fear of infection may affect the relationship between HCWs and patients in the contexts of treatment supervision and contact screening. The low cure rate and high default rate in Medellín can be explained from several viewpoints. Understanding patient beliefs and language, and their context, may help to improve the quality of treatment in health care services.

Compassion was the fourth component of the 'central core' in the SR for the three groups. This came up as an attribute for TB patients and their relatives in the multiple correspondence analysis. Compassion entails a desire to see others free of suffering. This desire is determined by religious beliefs that promote a feeling of empathy with the suffering of others. TB patients are seen as being weak and prone to suffering from human immunodeficiency virus, weight loss and malnutrition. This view is supported by studies showing that vulnerable people have little resistance to infection or disease by *Mycobacterium tuberculosis*.³²

A different look at TB could allow us to progress to a new conception of control programmes and activities.

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R É S U M É

OBJECTIF : Identifier et analyser les représentations sociales (SR) de la tuberculose (TB) dans trois groupes de personnes à Medellín, Colombie, afin de contribuer au traitement du patient et aux activités du programme de lutte antituberculeuse.

MÉTHODES : Etude transversale utilisant des associations libres de mots et des techniques d'analyse d'évocation chez 1049 personnes au sein d'un réseau structurel de représentation sociale.

RÉSULTATS : On a constaté que les termes « coût », « contagion », « maladie » et « crainte » étaient les composantes du noyau central dans les trois groupes. Dans le système périphérique, les facteurs modifiables consi-

dérés étaient « rejet » et « traitement ». L'analyse des textes a montré que « crainte » et « compassion » sont en association avec les évocations chez les patients et leurs familles, « contagion » chez les non-professionnels et « isolement » dans le personnel de soins de santé.

DISCUSSION : La crainte de la contagion peut avoir un effet négatif sur la relation avec les patients, sur les activités de soins de santé, sur la surveillance des traitements et sur le soutien des familles aux patients. Une meilleure compréhension des croyances des patients et de leur environnement familial peut améliorer la qualité du traitement ainsi que son adhésion au sein de la ville.

RESUMEN

OBJETIVOS: Identificar y analizar las representaciones sociales (SR) que tienen sobre tuberculosis (TB) tres grupos de personas residentes en Medellín, Colombia, con el fin de contribuir al manejo de los pacientes y a las actividades del programa de control.

MÉTODO: Estudio de corte que utilizó la técnica de asociación libre de palabras y análisis de evocaciones de 1049 personas, mediante el enfoque estructural de las SR.

RESULTADOS: Los elementos del núcleo central en los tres grupos fueron: 'tos', 'contagio', 'enfermedad', 'miedo'. En el sistema periférico: 'rechazo' y 'tratamiento', consi-

derados modificables. El análisis textual ubicó que 'el miedo' y 'la compasión' se asocian con las evocaciones de los pacientes y sus familiares, 'el contagio' con los ciudadanos corrientes y 'el aislamiento' con el personal de salud.

CONCLUSIONES: El miedo al contagio puede influir negativamente en las relaciones con los pacientes, en las actividades clínicas, en la supervisión del tratamiento y en el apoyo familiar a los pacientes. La comprensión de las creencias de los pacientes y de su entorno familiar puede mejorar la adherencia y la calidad del tratamiento anti-tuberculoso en la ciudad.
