

Ângela Pôrto

Social representations of tuberculosis: stigma and prejudice

ABSTRACT

Social representations of tuberculosis are analyzed at the turn of the 20th century, focusing on aspects associated to feelings and contradictory manifestations awakened by the disease. The romanticized pattern of experience of this disease was replaced by a more naturalistic vision, though the stigmas and prejudices are reinforced. To this day it is possible to detect some aspects about the way of perceiving tuberculosis, which marked its presence in the past. The persistence of the stigmatization of tuberculosis and of the people who suffer from it consists in a serious obstacle to the disease's control nowadays.

KEY WORDS: Tuberculosis, history. Prejudice. Social medicine. Social representation of disease. Stigma. Literature.

Tuberculosis is a disease represented in ambiguous manners in different moments of history. Until the middle of the 20th century, when the effectiveness of tuberculosis chemotherapeutic treatment was not yet a reality, the disease generated several feelings related to its recovery. These feelings were represented in varied forms, both individually and collectively. Tuberculosis, a deadly disease, was seen as the inevitable result of a life dedicated to the excesses. Thus, it was not in accordance with socially accepted standards, even though it was seen in distinct manners, according to the time in history.

In the middle of the 19th century, those who suffered from tuberculosis had an aura of exceptionality that put them in a position of certain refinement in the eyes of their contemporaries. The concept of tuberculosis pertained to a markedly romantic sensibility, which was spreading about, especially among intellectuals and artists. The word "romantic" is defined as a peculiar sensibility of a certain period of history. Ever since the beginning of the 18th century, it "assumes an 'attractive' nuance, an act that delights the imagination", which comes to "associate with another group of concepts, such as 'magic', 'suggestive', 'nostalgic', and mainly with words that express ineffable states of spirit, the essence of romantic expression."¹⁶ (p.30-4). Common behaviors, routine activities, and established morals appear before the romantic sensibility as obstacles to the creative spirit and expressions of an existential vulgarity that shrouded the most elevated meaning of life. Therefore, the romantic spirit valued everything that referred to an uncommon experience. The disease emerges to poets as an attribute that makes them interesting¹⁸ and many of them start to crave for it, as was the case of Casimiro de Abreu, one of the greatest representations of Brazilian romantic poetry. In a letter that dates back to October 4th, 1858, the poet declares:

Casa de Oswaldo Cruz. Fundação Oswaldo Cruz. Rio de Janeiro, RJ, Brasil

Correspondence:

Ângela Porto
Casa de Oswaldo Cruz/Fiocruz
Av. Brasil, 4036 sala 404
21040-361 Rio de Janeiro, RJ, Brasil
E-mail: aporto@fiocruz.br

Received: 1/30/2007
Approved: 3/27/2007

"I desire a serious, severe, long-term disease indeed, for I am tired of this good health monotony. However, I would like to have the phthisis with all its unexpected incidents; I would like to wither lyrically, always singing the last chants of life, and afterwards, to expire around perfumes under Italy's bluish sky, or around this sublime nature that surrounds Queimado." (quoted by Montenegro,¹² p.27)

The 18th century and the beginning of the 19th century are considered to be a period marked by the definite fall of an old sociopolitical order and the formation of a new order, the bourgeois, which was against exalted passions and connected to the idea of productivity. The romantic feeling will oppose the new values imposed by the new order, psychologically valuing "intimacy, spirituality, and the aspiration to the infinite."¹⁴ (p.52) On the other hand, these traits define a characteristically ambivalent sensibility, that is, marked by states which were simultaneously enthusiastic and melancholic, nostalgic and fervent, confidently exalted and desperate. In fact, the image of the individual projected by the romantic ideal should be understood as an inner projection beyond the reach of the ordinary man. The disease was "interesting", for it was the only one that expressed an individualization process. It was considered as the disease of personal intimacy. "It would also often serve as an opportunity for particularization", "for inner illumination, for the complete individualization."⁶ (p.116-7)

The idea of tuberculosis as an outer manifestation of an "interesting" inner character seems to be associated with the definite overthrow of a type of society. As the old regime fell and the bourgeois order was established, "value and social position were not determined beforehand [anymore], they had to be achieved." This achievement depended, among other possibilities, on the cultivation "of new attitudes towards the disease".¹⁸ (p.39) The sick body acquired an aristocratic aspect as it exposed the disease's visible traits, clearly showing, through these outer peculiarities, an individuality that did not mingle with the average social standards. Intellectuals and artists who suffered from tuberculosis would affirm their condition of exceptional personalities not only through their work, but also through the narcissistic cultivation of the outer testimonies of their malady. The young man who would aspire to a career as a literate should "exhibit a little thinness, pale complexion and cough, as a complement to the intellectual talent sprouting from inside".¹² Tuberculosis was a resource employed by romantic poets as their project of denial of the "concrete world" and as the expression of their disappointment with social life.

Disregarding the suffering of the sick and poor people, piled in slums or concentrated in miserable urban areas, the romantic sensibility encouraged the conception of tuberculosis as a symptom of noble character and artistic geniality. Literature in the first half of the 19th century had the "fever of the sensible souls" as its theme. It is an undeniable proof of the exceptionality of character and artistic and intellectual talents of those with tuberculosis. In this romanticized vision of the disease, the creative genius and the eagerness for accomplishments were explained.⁴ The myth of creativity linked to the disease went on throughout the 19th century. To a certain extent, it is possible to say that it continued past this century. In the 20th century, as the association between tuberculosis and the artistic creation faded away, at least on a theoretical level, the poet Rui Ribeiro Couto grieves to Manuel Bandeira in a letter dated back to May 23rd, 1927. In this letter, Couto reproached himself for not being talented enough to transform his suffering's substance into "a vast artistic work". Curiously, in a letter mailed from Paris and dated back to October 24th, 1931, Couto himself takes again the classic association disease-capacity of creation: "(...) I even feel impressed by this activity, for it is a super-activity, and this characterizes the incubation period of tuberculosis" * Manuel Bandeira had already acknowledged this to his friend when he declared: "in me, the poet is tuberculosis. I am Manuel Bandeira, the Phthisical Poet".** However, this decision to assume his destiny as a phthisical poet would not happen in the romantic way, "with distaste and roses on the pale face"¹ (p.40), as the poet well observed.

The influence of tuberculosis over the mind of those affected by it "is confirmed", says Tulo Hostílio, in *Tuberculose e Literatura* (Tuberculosis and Literature). As he quotes Pereira de Sousa, he argues that the influence "is great, not because of an abnormality of a preexistent mentality, but because of an exaggeration of this preexistent mentality. That is to say, an individual with tuberculosis projects his previous mental attitude more intensely." The willingness for eternity, the "devouring anguish", which makes the sick person's unstable interiority shine, would be a function of "a disease that reaches [...] the lungs and the soul".¹² (p.23) Thus is defined the romantic pattern of the disease's representation. It is a pattern, which sees in tuberculosis signs of a noble character, of artistic and intellectual geniality, as well as the expression of an uncommon individuality. For this reason, such uncommon individuality is indifferent to the principles that value appropriate social behavior as regards the bourgeois way of life. Sick people are not creatures who belong to the world of work and material

* Letter from Rui Ribeiro Couto to Manuel Bandeira. Rio de Janeiro: Arquivo-Museu de Literatura Brasileira da Fundação Casa Rui Barbosa.

** Letter from Manuel Bandeira to Rui Ribeiro Couto. Rio de Janeiro: Arquivo-Museu de Literatura Brasileira da Fundação Casa Rui Barbosa; Década de 20.

preoccupations. The sick person's appearance evokes a spiritualized conception of the disease, which, to a reasonable degree, shrouds medicine's and society's incapacity to treat and overcome it.

When the romantic sensibility starts to present evident signs of its weakness, tuberculosis will tend to appear as the great promoter of moral refinement in its victims. It will be the time of the disease especially conceived as a test of character, through which, as Sontag¹⁸ (p.54) well put it, "the virtuous ones only become more virtuous when they pass away".

Dumas Filho's *A Dama das Camélias* (The Lady of the Camellias – 1852), represents an emblematic example in this case. Marguerite Goutier, necessarily a victim of her dissolute life, achieved, through her disease, the painful and precious knowledge of her moral purity, rejecting Armand's love. This work gained immense popularity in the second half of the 19th century. The chronicle of that time refers to the great impact caused by the elevation of a courtesan to the condition of heroine, who concentrates in her personality the typical traits of a person with tuberculosis. These traits, less physical than moral, reflect the image that the society from the second half of the 19th century had of the phthisic, at the same time that they changed throughout time so as to become some type of coherent behavior as was morally expected back then. Marguerite Goutier becomes a popular heroine as she brought to her body undisguised signs of her moral shame. On the other hand, the suffering caused by the disease is directly responsible for her moral recovery, consolidated in the gesture of rejecting her beloved one. Death comes to providentially reaffirm the courtesan's moral recovery legitimacy, redeeming herself from her condemnable past as well as from the just suffering imposed by phthisis. In the end, "the standard-achievement of tuberculosis in fiction" is found in *A Dama das Camélias*, which is the extreme spiritualization of the disease with the concomitantly sentimentalization of its horrors.¹⁸ (p.54)

However, the work of construction of mechanisms for the productive body's hygienic control was not organized overnight, nor was it developed in a linear fashion. What seems to have happened after the second half of the 19th century was the extension of strategies related to the body's constitution for the working classes, elaborated by the bourgeois in the end of the 18th century. Foucault⁸ well observes in *História da Sexualidade* (The History of Sexuality) that, following the aristocracy's example, the bourgeois also worried about the achievement of its specificity. If, among feudal nobility, this achievement was necessarily dependent on lineage or ascendancy, for the bourgeois the achievement of its specificity was built "towards its descent and the health of its organism".⁸ (p.117)

The bourgeois body, built from biological, medical or eugenic precepts, should be the expression of "the infinite expansion of strength, vigor, health, and life." The bourgeois values its body as its growth and hegemonic project depend on it. Thus, everything that could represent a threat to hereditaryness should be an object of banishment or, at least, of severe treatment, because the class domination was not only achieved on economical or ideological levels – the domination was also a "physical" matter.⁸ (p.118) The bourgeois domination and social expansion project, meticulously elaborated from an entirety of biosocial interventions, gains expression in the collective imagery under the form of worship of agility, physical strength and moral balance.⁴ (p.83)

After the second half of the 19th century, what could be called a body's political economy is reached, which intends, on the one hand, to guarantee the bourgeois class domination and, on the other, to effectively put the working classes in the capitalist socioeconomic order. The conception that will develop around the disease in the collective imagery will be linked to this double goal from then on. Tuberculosis emerges socially not as a physical manifestation of a refined spirituality anymore; on the contrary, its persistence and spread, particularly among the poorer populations, will be a reason for preoccupation as it is a symptom of social disorder. The phthisic brings within himself, in spite of his own displeasure, the sign of evil and destruction. Hence, Coelho Neto portrays the phthisic in one of his chronicles, entitled "*Assassino*" ("Murderer"):

*"That one you see is a sewer of Death. If we had wiser, more provident laws, this monster, instead of walking around here, tainting the splendor of this afternoon with its mourning and compromising life, would be in an asylum, segregated by men. // He is phthisical. (...) He knows he is lost, he says it to everyone and disseminates his evil on purpose."*¹⁵ (p.166-7)

From this time on, the social representation of tuberculosis starts to show more significant changes as the disease is understood by the medical science in an ever more complex fashion. Nevertheless, the persistence of the unfamiliarity concerning its causes and the inefficacy of its treatment justify the collective horror towards the disease, which associates the sick person to an abnormal behavior in relation to social rules. This would be the case of the aristocrat and patient of Dr. Behrens', a character in Thomas Mann's *The Magic Mountain*, who, besides suffering from "brain tuberculosis", lived a scandalous life, to which his doctor shut his eyes.¹¹ Thus, the direct contact of any person with someone who suffers from tuberculosis could mean an unwanted contamination, not only from the medical perspective, but also from the moral one. Consequently, when Hans Castorp has just arrived at Davos-Platz's sanatorium,

he argues that he rose “about five thousand feet to get there...”, to which Setembrini, the humanist who also suffers from tuberculosis, replies “That is what you think. I swear it is only an illusion (...). We are creatures that have fallen really low (...).”¹¹ (p. 72)

The horror towards tuberculosis ends up transforming it into a taboo, an object of prohibition. Its extreme symptom is the sick person’s stigmatization and his consequent isolation. The concept of stigmatization used here is given by Goffman^{9(p.7)}, which is, “the process or the situation of the individual who is incapable of being fully accepted by society.” At the end of the 19th century, death caused by tuberculosis was stigmatizing in a family, for the malady was associated with some obscure hereditary defect, or even with poverty. The sick person saw himself unsuitable for marriage, for the practice of certain activities and even for other family members’ life insurance.⁷ Therefore, the horror towards tuberculosis was less due to the condemnation to physical death than to the condemnation to moral death. As a result, in his statement about the way people faced tuberculosis in the first half of the 19th century in Brazil, José Rosemberg, a specialist in tuberculosis, declares:

“Having tuberculosis was a defect. When there was a case of tuberculosis in the family, it was kept a secret, then: ‘So-and-so has a spot in his lung’, or something of the sort... Nobody talked about tuberculosis, it was not mentioned. When a man was engaged and found out that his fiancée got tuberculosis, he would cancel the wedding.” (quoted by Porto & Nascimento¹⁵)

The relation between tuberculosis and the psychological and moral traits of the sick individual was a great source of fortune in literature. Furthermore, this form of expression seems to have been the adequate vehicle for many illustrious phthisics who looked for some way of understanding the illness that consumed them, an understanding that they could not obtain from the medical knowledge of the time. Around the 1920’s, Kafka declares in a letter to his sister that his disease is only a consequence of his bad morals, as he himself defines as the refusal of contact with others. On the other hand, being sick meant to resolve one’s inner conflicts, based on the impossibility of devoting oneself to literature because of familial and social pressure. The disease appears, then, as an ambivalent event, an announcement of one’s approaching death, but also as an opportunity to feel free and dedicate oneself to one’s favorite activity: literature.¹⁷

A more lyrical phraseology of the condition of someone with tuberculosis appears in Manuel Bandeira’s work. The disease arises as a terrible cataclysm that erases

all possibilities of a socially integrated existence, but which will soon give birth to a long learning process towards a new existence, often lamented as “the life that could have been and was not.” The poems *Epigrafe* (Epigraph – 1917) and *Testamento* (Testament – 1943), the latter, thus, from a very advanced stage of the disease, which he contracted in 1904, reflect in an emblematic form the poet’s feelings related to the impact caused by the disease.*

<i>Epigraph</i>	<i>Testament</i>
<i>I was well born. Being a boy,</i>	<i>My father raised me, since I was a boy,</i>
<i>I was, as all the others, happy.</i>	<i>To be an architect. One day my health was gone...</i>
<i>Afterwards, came the evil destiny</i>	<i>Did I become an architect? I could not!</i>
<i>And turned me into what it wanted</i>	<i>I am a lesser poet, forgive me!</i>

Innumerable passages of Bandeira’s poetic work show the problem of the disease’s threat. Nevertheless, if it seems to be, at the beginning, indecipherable, his capacity to discuss about himself with himself and even with others about the evolution of his condition is remarkable. That is what makes him say to Mário de Andrade, in a letter dated back to May 1924: “Today I am ironically, sarcastically phthisic.”²³ With this ironic spirit, Manuel Bandeira uses his bitterness and transfers his doctor’s verdict at Cladavel’s Sanatorium to his verses:

Fever, hemoptysis, dyspnea and night sweats.

The entire life that could have been and was not.

Cough, cough, cough.

He sent for a doctor:

“Say thirty-three.”

“Thirty-three... Thirty-three... Thirty-three...”

“Inhale...”

“You have a cavity in the left lung and the right lung is infiltrated.”

“Do you believe, doctor, that we could try a pneumothorax?”

“No, the only thing to do is to play an Argentinean tango.”²

At the turn of the 20th century, the evolution of the image of tuberculosis not only arouses problems related to the medical conception as to its origin and

* Porto A. A vida inteira que podia ter sido e que não foi: trajetória de um poeta físico [doctorate thesis]. Rio de Janeiro: Instituto de Medicina Social da UERJ; 1997.

methods of treatment, but also matters that seem to be more important, related to the behavior of the sick and to the collectivity's reaction towards the pathologic phenomenon.

Thus, there is no exaggeration when it is affirmed that the several forms of representation of tuberculosis are nothing more than expressions of the collective will for the reorganization of the social order, kept in check by some type of phenomenon that escapes the instruments developed by society regarding its preservation and perpetuation. On the other hand, it is interesting to observe how images created from the disease's collective existence metaphorically adapt to the treatment of situations considered to be undesirable. Sontag¹⁸ sensibly observes that incurable diseases are quite useful in order to describe negative situations, because they catalyze, due to their incurability, the collective horror when one is facing the danger of falling apart:

*"Any important malady caused by something obscure and that has an inefficient treatment has the tendency to be full of meaning. At first, the objects of deepest fear (corruption, decadence, pollution, anomie, weakness) are identified with the disease. The disease itself becomes a metaphor. Then, in its name (that is, using it as a metaphor), that horror is imposed on other things. The disease begins to describe things."*¹⁸ (p.76)

Fearful of attracting evil to themselves by the mention of its true name, many people end up creating designative resources for the ailment with the objective of disguising it, consequently obliterating its characteristics. It is the case, for instance, of relatives of a sick person who died of tuberculosis, thus referring to the malady that caused the death as "the poor thing was weak in the lungs". Oracy Nogueira observes that sanatoriums' "guests" avoid the pure and simple denomination of their disease, referring to it only by means of metaphors or euphemisms. She analyses expressions such as "*brasileira*" ("the Brazilian one"), "*brasileirinha*" ("the little Brazilian one"), "*branquinha*" ("the little white one"), "*lolose*", "*magrinha*" (the little thin one), "*meu xodó*" ("my dear one"). All of them have an amusing character, denoting the effort of the sick from Campos do Jordão to escape from the "depressing stereotype that exists in the popular mentality."¹³

The use of metaphors or silence around tuberculosis are justified not only because of the great fear of death projected by it, but particularly because it is something considered obscene, that is, "a bad omen, something abominable and repulsive to the senses."¹⁸ (p.13) In his *Memórias* (Memoirs), Nelson Rodrigues tells about

his drama as a sick person and the experience of dread before his own image:

"My bed faced the mirror. I saw around each eye a black halo; my cheeks were sunk; and I had the sensation I was looking at my own corpse. I begged them, for the love of God, to cover the mirror with the sheet." (Quoted by Bertolli⁴, p.245)

The discontinuity that comes with the disease is particularly dramatic to those who suffer from it. The sick, especially the ones with tuberculosis, experience not only the sensation of being separated from social life, but also and, possibly much more tragically, the sensation of separation between their bodies and spirits. What makes the lives of these individuals interesting is the way they try to stand as regards both a world saturated with terrible fantasies about their condition and the physical and mental processes established by the pathology. By means of the testimony of the sick, whether they are illustrious or not, it is possible to follow this unique way of feeling the disease, of being aware of one's own illness and of reorganizing one's life from the advent of tuberculosis.

The 20th century starts with a notorious process of demystification of tuberculosis and the image of the one who suffers from it. Medicine invests heavily in public health policies while the disease, not being an expression of morbid elegance any longer, takes on dramatic contours as it characterizes clear symptoms of social misery. The person with tuberculosis is not a bored dandy or an exceptionally enchanting and exuberant courtesan who can redeem herself, but rather an ordinary man, who lacks resources and lives in industrialized, urban centers. However, the migration of tuberculosis to the poorer social classes does not prevent that some of its most characteristic traits – among them the moral degeneration – continue to be present on the popular level of perception of the disease. The matter is that now the "negative" traits do not symmetrically correspond to the "positive" ones anymore.

Nowadays, Brazil comes in 15th in the ranking that covers the 22 countries which concentrate over 80% of world mortality due to tuberculosis, worsening the statistics with 6,000 annual deaths. Tuberculosis is an infirmity that does not have a cure. Thus, there would be no reason for this disease to be stigmatized to this day. In spite of this, psychologists, anthropologists and sociologists who analyze this infirmity observe that talking about this subject causes discomfort, especially in the poorer communities.* ** The disease is associated to hunger, to the incapacity to provide

*Oliveira JDD. Tísica: Doença dos pulmões e da alma - um ensaio sobre as representações sociais da tuberculose no Morro Santa Marta [master's dissertation]. Rio de Janeiro: Instituto de Filosofia e Ciências Humanas da Universidade do Estado do Rio de Janeiro; 1989.

** Carbone MH. Tísica e rua: os dados da vida e seu jogo. [master's dissertation]. Rio de Janeiro: Escola Nacional de Saúde Pública da Fiocruz; 2000.

oneself and one's family with the minimum resources, and also to the excesses. Alcoholic drinks and parties are the most mentioned excesses, revealing that reckless and immoral behavior is still a considerable cause of a disease that brings about shame. The unclear ideas regarding the infection and the fact that frequent relapses are witnessed by these social groups cause disbelief in the possibility of a cure for tuberculosis. Even when it is said to be a curable disease, there is the belief that "something always remains inside." The sick person with a "spot in the lung" bears a scar that deeply alters his interaction in social groups. Old-fashioned ideas appear as if crystallized in the popular imagery. For the sick person and those involved to actually face

the problem is not an easy task as it may appear to be. Due to prejudice, obstacles come up frequently to the patient, in terms of being responsible for and following his treatment, and to the health care agents, in terms of acting towards communicators' meetings and controlling the disease in the end.^{10,*}

The disease is also feared because it is the expression of something that society believes should be censored and it represents the last stage of human misery. In this sense, the process of stigmatization of tuberculosis and those who have it persists in the popular imagery and as a form of relation between society and the sick person.

* Mendes MCT. A clientela e os profissionais de saúde diante da tuberculose. [master's dissertation]. Campinas: Faculdade de Ciências Médicas da Unicamp; 1998.

REFERENCES

1. Bandeira M. Andorinha, Andorinha. Rio de Janeiro: José Olympio; 1966.
2. Bandeira M. Libertinagem. In: Poesia e Prosa, Rio de Janeiro: Aguilar; 1958. v.1.
3. Barbosa FA. Manuel Bandeira: 100 anos de poesia. Recife: Pool Editorial; 1988.
4. Bertolli Filho C. História social da tuberculose e do tuberculoso: 1900-1950. Rio de Janeiro: Editora Fiocruz; 2001.
5. Coelho Neto HM. Vida Mundana. 2. ed. Porto: Livraria Chardron de Lélo & Irmãos; 1924.
6. Duarte LFD. Da vida nervosa nas classes trabalhadoras urbanas. Rio de Janeiro: Zahar Editores; 1986.
7. Dubos R, Dubos J. The white plague: tuberculosis, man and society. 2.ed. New Brunswick: Rutgers University Press; 1992.
8. Foucault M. História da sexualidade I. A vontade de saber. 2. ed. Rio de Janeiro: Graal; 1979.
9. Goffman E. Estigma. Notas sobre a manipulação da identidade deteriorada. 2. ed. Rio de Janeiro: Zahar Editores; 1978.
10. Gonçalves H. Peste Branca: um estudo antropológico sobre a tuberculose. Porto Alegre: Editora da Universidade Federal do Rio Grande do Sul; 2002.
11. Mann T. A Montanha Mágica. São Paulo: Círculo do Livro; 1986.
12. Montenegro TH. Tuberculose e Literatura: notas de pesquisa. 2. ed. Rio de Janeiro: A Casa do Livro; 1971.
13. Nogueira O. Experiências Sociais e Psíquicas do Tuberculoso. Sociologia. *Rev Didat Cient.* 1949;(2):159.
14. Nunes B. A Visão Romântica. In: Ginsburg, J, organizador. O Romantismo. 2. ed. São Paulo: Perspectiva; 1985.
15. Porto A, Nascimento DR. Tuberculosos e seus Itinerários. *Hist Cienc Saude Manguinhos.* 1995;1(2):129-41.
16. Praz M. A carne, a morte e o diabo na literatura romântica. Campinas: Editora da Unicamp; 1996.
17. Richard L. La Punition par le bacille de Koch. *Mag Litt.* 1982;186:49-50.
18. Sontag S. A doença como metáfora. Rio de Janeiro: Graal; 1984.

Presented at the *Seminário de Avaliação das Estratégias de Controle da Tuberculose no Brasil* (Seminar on Assessment of Strategies for the Control of Tuberculosis in Brazil), held in the city of São Paulo, in September of 2006.