

SOCIAL CONSTRUCTION OF TUBERCULOSIS

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Abstract

A disease caused by a bacteria over 35,000 years old according to paleomicrobiology research, is currently a challenge for all public health systems. Tuberculosis was declared by World Health Organisation one of the world's priorities in a joint effort to eradicate it by 2050. Despite the medical knowledge about the disease, analyzing it from a sociological and anthropological point of view could generate a better understating of the disease, it's social factors and the complexity of the context. Being the leading cause of death among the socio-professionally active population, with approximately 2 million deaths annually, prior to the establishment of certain control and surveillance measures, it is necessary to we understand the social factors and the costs of the disease, elements that increase the risk of infection / death, and what are the needs and services to be addressed. Among the "costs" a patient faces, we can list: long-term and many adverse effects, the high risk of abandonment to resume income-generating occupation, the risk of developing antibiotic resistance, lowering family incomes, entering the vicious circle of poverty by lowering family incomes and increasing vulnerability.

In the following, a series of information on national and international contexts, behavioral, sociological, anthropological and medical therapies and theories of TB are presented, in the desire to identify the main social factors belonging to the universe of the field of study. At the same time, a great emphasis is placed on risk factors, on the needs of TB patients but also on vulnerable groups. By understanding the whole social, economic, cultural and medical context, new directions of study and new recommendations for practitioners in this field can be outlined in the prevention, control and surveillance of a contagious disease.

Keywords: tuberculosis, anthropology, sociology, Mason model, Romania, health, disease.

1. Introduction

Although tuberculosis is curable and case management is relatively simple when access to healthcare is easy, often the illness is fatal to poor people in rural and urban environments in developing countries. (Farmer apud Ember, 2004) Beyond the clinical and medical aspects, questions arise about the economic, social, family, organizational aspects of the disease universe. At the same time, an analysis is needed between the aspects of anthropology, medical sociology and other social disciplines in order to explain and identify certain patterns in tuberculosis in Romania.

The sociologist and anthropologist Paul Mason, following several researches conducted between 2010-2015, proposes a dynamic social model, an explanatory model of the descriptive and explicative factors and explanatory elements of the disease, disease which is over 95% in developing countries. This model addresses health problems, taking into account the social, cultural and historical factors to understand human health and disease experiences through an interpretative and critical approach. Although the proposed solutions are at an individual level, they are at the intersection of a cumulus of factors that ultimately lead to the public health system.

1.1. Global TB cotext

Analyzing the "Global TB Report 2016" published by the World Health Organization, based on

the data reported by each monitored country as well as estimates of unreported cases, the global situation in 2015 was as follows:

- 10.4 million new cases, (56% men, 34% women and 10% children, with 1.2 million (11%) cases of HIV-TB coinfection;
- 480,000 cases with antibiotic-resistant forms: rifampicin resistance (RR), isoniazid resistance and rifampicin (TB-MDR), and finally resistance to all line I and II drugs, the latter form (TB-XDR);
- 1.4 million deaths due to illness, plus about 0.4 million deaths among HIV-TB people. All these statistics place tuberculosis first in terms of deaths from infectious disease and among the top ten causes of death worldwide.

1.2. Tuberculosis in Romania

Regarding the fight against TB in Romania, progress has been observed over the last few years in terms of country indicators and the infrastructure has developed as a result of international funds for TB issues: Global Fund to Fight HIV, TB and Malaria, EEA and Norwegian Funds, World Bank funds as well as other international donors.

Due to the international support, the PNPSCT has made a remarkable increase in the detection and treatment of the disease with some notable results, such as:

- Increase in detection of cases above international targets of 75%;
- Decrease in population incidence from a historical maximum in 2002 to 142.2 per 100,000

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inhabitants to 79.9 in 2012;

- Increased therapeutic success rates, usually over 80% for all forms of susceptible tuberculosis and implicitly a decrease in the number of deaths caused by the disease. (PNPSCT, 2016)

The World Health Organization, according to its mission, is defined as an international forum for the role of a "guardian" of global public health and working globally to achieve the maximum potential in terms of the safety and health of the population. GLC is a mechanism, a WHO structure, made up of international specialists who oversee the implementation or facilitate the access of troubled countries to TB-MDR case management. GLC, through its missions, provides technical assistance, expertise, assessments of the status of reforms as well as easy financial mechanisms. (WHO, 2000)

According to the report of the last mission to assess the TB-MDR, conducted by the World Health Organization (GLC) in May 2016, tuberculosis remains a public health problem in Romania and continues to be a threat with all the progress has been made in the last 20 years. From the data collected, it can be noticed that during the last decade, the figures have been steadily decreasing. The incidence of TB among the population, at 100.00 inhabitants, decreased from 142.2 (30,985 new and recurrent cases) in 2002 to 71.7 in 2015. Also, the TB mortality rate (excluding HIV-TB coinfections) fell to 5.7% in 2014.

The critical issues raised by the GLC mission are related to the increase in the number of resistant MDRs but also to other challenges, including the lack or reduced number of kits for rapid testing, the incomplete or non-existent treatment for patients with resistant forms, the deficiencies in the system as long-term hospitalization and higher per capita costs, control of ineffective infections at hospitals and laboratories, which increases the risk of infection of healthcare personnel, lack of control over treatment (DOT) in ambulatory, poor medical and social services coverage high risk of non-adherence, lack of prevention and education activities among vulnerable groups, lack or low number of staff and specialized and non-specialized medical personnel.

According to the National Control Strategy TB 2015-2020, in Romania, the categories that are at high risk of developing the disease are LTBI persons, children under 5, HIV-infected persons (especially those untreated), consumers substances (especially drugs) and people suffering from other conditions (silicosis, diabetes, cancer, kidney disease, autoimmune diseases, etc.). There are also certain categories of population with a higher risk for the general population to contact / develop the disease:

- Close contacts of a person with contagious TB;
- People migrating from areas with high levels of TB;
- Groups with high levels of TB transmission: homeless, injecting drug users (IDUs), HIV-infected people (HIV);

- Those working with people at high risk for TB in establishments or institutions: hospitals, shelters for homeless people, correction units, elderly homes, residential homes for HAVs, etc.

In developed countries, even if the number of cases is decreasing, TB directly affects vulnerable groups with low socio-economic status, substance users, people in high-impact regions, the elderly and all those living in institutions: dormitories, asylums, prisons, hospitals, day centers, etc. (Grange apud Ember, 2004)

Considering the contagiousness of the disease but also the increase in the number of patients with antibiotic-resistant forms, the lack of medication needed for them, the lack of psychosocial support and the bureaucratic and inadequate legislation for these cases, tuberculosis remains a threat to public health (both in Romania and international level). As regards the control of bacillus infections, there are a number of universal recommendations that can prevent transmission or infection. One of the most common recommendations is to ventilate the spaces and allow the penetration of ultraviolet rays to penetrate the rooms. Ultraviolet are the most effective form of destruction of these microbes and UV lamps are the most effective equipment for controlling TB infections in the health system.

2.1. Tuberculosis in Antropology

In the fight with the disease / illness, depending on the cultural specificity, at the individual level there may be problems at the somatic, mental and / or suffering level for reasons of "fate" and / or "misfortune". While individuals are confronted with these problems, the medical system has to cope with troubles related to work, finances, etc. All these aspects intervene and can be addressed separately or integrated in their complexity. (Hahn and Ember, 2004)

A common critique of disease / illness dichotomy is that both are localized or experimented on an individual level, but they cannot be analyzed without context. For this reason, researchers make a direct correlation between these individual sufferings and issues related to processes, events, social order, public health issues and / or inefficiency of health systems. (Waitzkin apud Ember, 2004)

As historians have shown that epidemics are social events that beyond the medical aspects require understanding of the social systems through which disease has multiplied, the anthropological studies of emerging infections seek to explain and understand how these epidemics are integrated into economic relationships and anchored in systems social. Social relationships shape exposure to risks, transmission, and susceptibility, which causes epidemics to cause pathogenic social relationships. (Ranger & Slack et al., 2004)

Anthropologist R. Shrestha-Kuwahara dedicates an entire chapter on tuberculosis to the Encyclopedia of Medical Anthropology, in which he reviews the main

studies and researches in the field analyzing the subjects as a whole. Starting from this synthesis, the author tells us that transmission of TB, disease development and treatment take into account many complex factors from the biological and social sphere. By identifying and examining how these factors, anthropologists and sociologists by applying different methods and approaches to disease and their factors, have contributed to understanding correlations in structural, behavioral and socio-cultural TB control. (Shrestha-Kuwahara, 2004)

Historically speaking, Shrestha-Kuwahara has gathered data demonstrating the existence of the disease since antiquity by discovering bacilli in mummies in Egypt dating back to 5,400 years ago. There is also archaeological evidence, through the study of bone DNA, which demonstrates the transmission of disease through migration from one continent to another, a phenomenon also described during the discovery of the American continent of the middle Ages. Anthropologists and sociologists have discovered that over time there have been numerous references to TB through art, thus discovering that the approach has undergone distortions over time: from a romantic way and the copying of paleness by nobility to associating disease with poverty, misery and immorality. From the seventeenth century to the nineteenth century, progress has been done in understanding pathology and clinical manifestations, understanding the social, economic and political context, and improving public policies by stating here the control of eating, improving sanitation and living conditions, patient isolation in the sanatorium and going to pasteurization of milk to avoid the transmission of *M. bovis* bacilli. (Shrestha-Kuwahara, 2004)

Until recently, the hypothesis of researchers in the field was that tuberculosis occurred 10,000 years ago with the domestication of animals and the occurrence of mutations in *M. bovis* DNA that could then be transmitted to humans, but with the research of the field of paleomicrobiology *M. tuberculosis* DNA was found to be more than 35,000 years old, being a much older pathogen than previously believed to have occurred long before the sedentarisation processes of the populations. (Stone Apud Burke, 2011)

Between the late nineteenth and twentieth centuries there have been recorded major advances in TB control. In 1882 Robert Koch discovered *M. tuberculosis*, the bacillus responsible for the development of the disease, and who will also be called the Koch bacillus. In 1940, streptomycin was discovered, a powerful antibiotic that progressed in treating the disease, but developed very fast resistance. In the 1950s, the principle of a treatment scheme involving the combination of several antibiotics was introduced and a few years later was discovered the isoniazid, the antibiotic "miracle" and very effective when administered in the right schemes. In the presence of streptomycin and isoniazid are still antibiotics basic

treatment regimens throughout the world only important findings are antibiotics line II and Group V, antibiotics used for treatment of resistant forms of TB-RR or MDR-TB and have adverse effects for all patients (hearing loss, partial loss of vision, jaundice, liver failure, renal failure, etc.). (Davis and Shrestha-Kuwahara, 2004)

With the discovery of these treatment regimes, social scientists have begun to study other social dimensions, addressing issues of compliance or adherence to treatment, behavioral studies that have shown the importance of patients' rights to be involved in treatment decisions but also causal analyzes, social relationships, or cultural factors. Since 2000, the WHO has introduced a new concept regarding the relationship of TB patients with the community in an attempt to empower local authorities and communities to better respond to patients' needs and to counteract the DOTS strategy of discontinuing treatment. At the same time, there are new directions of study regarding the increase in the number of cases with resistant forms, as well as concerns about opportunistic HIV-TB infections. (Rubel & Moore and Shrestha-Kuwahara, 2004)

In order to see improvements in tuberculosis control, it is necessary to place this disease in the social context and actions should be extended to spheres related to social inequalities, improving education and developing a patient-centered treatment paradigm: are the services necessary for the patient, complementing the medical treatment? The chapter on TB issues in the Encyclopedia of Medical Anthropology makes a review of all social and cultural research into TB control, opening up a series of topics that require further analysis of the search behavior of healthcare, adherence to treatment, stigma, the structure of health programs, and the supplier-beneficiary relationship. (Rober and Buikstra apud Burke 2011) The failure to explain the social context has become the biggest limitation in tuberculosis control as a result of the change in the prevention paradigm of the 1940s, where control means adequate housing, richer nutrition, and living conditions improved and replacing them only with drug treatment with antibiotics has changed reporting mode. (Lonnroth apud Burke, 2011)

According to medical definitions, tuberculosis is a disease that mainly affects the lungs but is not limited to this organ but can also occur in other organs and parts of the body. The route of transmission of the bacillus is the air way and thus through coughing, sneezing, saliva, sang, a contagious person releases through aerosols TB germs that can survive for a few hours if they have a favorable environment. By ingesting these germs a healthy person becomes infected and the human body can respond by encapsulating bacilli and keeping them latent throughout their lives. In the second situation, under conditions of immunosuppression and / or successive infections, the bacillus finds a favorable environment thus developing active tuberculosis. Symptoms of the disease are persistent cough, fever, night sweats and weight loss,

and by being similar to other diseases, the time of diagnosis can be postponed for several months, which can lead to infection of others. WHO estimates that a patient can infect between 10 and 15 people within one year. (WHO, 2017)

Although TB is a contagious disease, it is not easily transmitted. WHO guidelines show that only one-third of people exposed to bacilli become infected over a long period (several hours or days). There is a very high risk of transmitting the infection between the diagnosis and the negative (the patient is no longer contagious), which usually lasts for two weeks. Any person who comes in contact with an infected person by inhalation of bacilli may become infected, but the likelihood of developing the disease varies from person to person and takes into account, first of all, the immunological level of the disease. Infected but not developing disease is called LTBI and is a latent infection with TB that is not symptomatic and is not contagious. WHO estimates that about 20% of the world's population is infected with latent TB and the probability that these people develop lifetime disease is 10% (1 in 10). (WHO, 2017)

Homeless people, drug users, HIV-positive people, vulnerable groups as a whole viewed from a systemic perspective are a consequence of social changes that have dismantled the welfare state, which has contributed to increasing social inequalities and rising poverty. In this way, tuberculosis reappears as a public health problem in developed countries, countries where this problem was believed to have been eradicated. (Draus apud Blake, 2011)

2.2. A new explanatory model - Mason Model

The conceptualization of elements of sociology and medical anthropology offers useful methods in examining the dimensions of public health at the expense of the biomedical paradigm, by recognizing cultural experiences as central forces shaping human interactions. In this way, TB researchers can develop new models of understanding health, illness, treatment, with new skills in understanding the sociocultural dimensions that impact on TB patients, thus contributing to the development of new procedures to reduce diagnostic time, increasing the efficiency of the services offered, and ultimately stopping the contagious disease. (Mason, 2015)

Mason thus presents a model of seven key concepts that highlight the social dimensions of tuberculosis through anthropological and sociological approach, conceptions emerging from the conceptualization of the three levels of analysis: personal, interpersonal, and structural. (Mason, 2015)

As regards the individual level, it is worth noting that illness is not just a diagnosis, but rather a sum of social experiences that the patient faces during the illness. At the conceptual level, the disease can also be seen as an interruption of the biography in the sense that for a period of time the patient is self-employed as a pause, in a difficult moment of life, moment that

influences his social relations, the level of income, daily activities and quality of life. (Mason, 2015) The seven key concepts presented by Mason can be summarized as follows:

Stigma. As noted above, TB is a curable disease but in most current societies, simple diagnosis with TB can place patients in a social vulnerability due to stigma towards disease / sickness. Effects are difficult to quantify and foresee but can be manifested by the resilience of certain suspects in going to a medical check or resisting diagnosis, decreasing or lack of adherence to treatment, social isolation, and obviously, in extreme cases, suicide.

Biographical interruption is a concept that explores how patients with chronic (or long-lasting illness such as TB) develop, analyze and reinterpret their past, present, and future in narrative form. This method generates valuable information about the personal, social and adaptive processes through which a person with a chronic illness lives.

Medicalization. In the biomedical paradigm, all social and physical problems are seen as biological in nature, thus there is a medical treatment for any problem that has arisen. With the discovery of antibiotics, anti-TB treatment has changed its approach from treating patients to nursing homes and providing social support by involving the community in patient issues to an individualistic approach where the patient is responsible for healing by self-administering the treatment.

Treatment oversight opens up a new perspective on ethnographic and cultural studies, which are considered to be the best way to measure the quality and effectiveness of the DOT.

Gender is very important in the broad context of tuberculosis discussion because it correlates with the results in terms of active detection, diagnosis, treatment and adherence to it. The link is more to how gender is built socially by virtually influencing lifestyle and behavior in accessing medical services, behaviors that directly influence life expectancy.

The **technological imperative** opens a new subject in the social sciences about the use of technology and how much it helps us. Living in a technology paradigm is often considered to be the most efficient methods, but studies have shown that there are situations where technology is only used for it, even if it does not bring any extra information. This is the case for clinical trials conducted in India, which are still used, although the inefficiency of these technologies has been demonstrated, consuming resources without scientific justification.

The **human body or body in front of TB** refers to the link between the risks of developing tuberculosis and latent TB infection. One third of the population lives with latent TB (LTBI) and public health policies should take into account the reduction in risk factors that can turn the infection into disease.

In outlining this model, Mason also reviews the main theories that can explain the phenomena and

processes in the field of tuberculosis. As far as sociology and health sociology are concerned, the concepts of health and disease terms are related to cultural factors, such as medicalization, dominant discourse, individualism, media, victim's blame, system blame, social control and surveillance. Starting from this conceptualization, it is worth mentioning that it is necessary to understand how general information about disease is built as a constructive social construct based on social, economic, political and cultural interactions. As regards social parks on health and illness, tuberculosis as a field of study has shown close links with topics such as class and social status, social inequality, gender, marginalization, social exclusion or ethnocultural history. (Mason, 2015)

Going into the structuralist and organizational area, studying tuberculosis can not exclude analyzes and research on the way in which health structures are organized and functioning. The organization of systems is directly influenced by social values regarding social and individual responsibility, prevention versus treating a disease but also the way in which the economic environment influences the medical act in practice. From here, complex comparisons or analyzes can be made to demonstrate the links between basic medical coverage and certain indicators such as infant mortality, maternal mortality at birth etc. (Mason, 2015)

The last dimension related to TB is concerning the patient travel and how it addresses the disease, the role of sociologists being to answer a number of questions such as: what is the link between the social

class and the health of a person? What are the social forces that predispose some people to develop TB? What is the social response to this disease? But the individual one? Also, answers to other questions regarding patient categories are needed, including diagnosed patients, latent TB patients and also patients with active but non-detectable TB. (Mason, 2015)

3. Conclusions

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The conceptualization of elements of sociology and medical anthropology offers useful methods in examining the dimensions of public health at the expense of the biomedical paradigm, by recognizing cultural experiences as central forces shaping human interactions. In this way, researchers can develop new models of understanding health, illness, treatment, with new skills in understanding the sociocultural dimensions that impact on TB patients, thus contributing to the development of new procedures to reduce diagnostic time, increasing the efficiency of the services offered, and ultimately stopping the contagious disease. (Mason, 2015)

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