

## The Perception of Patients about Tuberculosis Disease in Terms of the Society and Psycho-Social Status

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**Abstract:** As a contagious and dangerous disease, tuberculosis continues in all periods of history and today its existence and risk status even in developed countries. Tuberculosis is disease which is spreading rapidly, difficult to diagnose and difficult in the treatment of versions named as “resistant tuberculosis” and regardless to socio-economic conditions tuberculosis is a threat risk for first the people themselves and their close neighborhoods and then the whole society. Awareness and consciousness of societies against the disease is not the desired level. The perception and evaluation of the infected people by their social environment differ among societies, additionally these people encounter mostly with psychological oppression and social exclusion causing adverse effect in the treatment of the disease. In our study, the spread of tuberculosis rather than its treatment, wounds opened in the community and the adverse effects revealed by tuberculosis will be discussed. Furthermore, spreading areas of the disease in the community, social environment factors in infection stage, areas the disease most spread to, reproduction, sheltering and protection places of the germ and socio-psychological situations of infected persons will be evaluated in the study. It is observed that clustering among tuberculosis patients among themselves and their solidarity is causing social stratification in the society and that troubles occur in their relationships including with their families and with other peoples. When treating the disease, taking in to consideration of these reflections in the society and long-term and permanent solutions are also important.

**Key words:** Tuberculosis • Phthisis • Society • Social Change • Social Disintegration • Social Exclusion

### INTRODUCTION

As old as human history and still persisting all over the world, Tuberculosis (TB) is a human life threatening, strange and interesting disease. There is the demand of humanity for thousands of years on the basis of his profession to live more healthy and longer. The studies on health issues and the obtained results are now a lot away compared to the former decades. Social dimensions of health problems, especially in cases of contagious diseases to affect society were barely understood in the last century. This topic is continuing as a debate between modern medicine and regional medicine.

As stated by Alfred Grothjohn [1] in 1915 “Someone’s disease does not only concern to that person; it concerns at first his/her family, relatives and gradually the whole society. Only cause of the diseases is not biological-physical-chemical factors. The underlying socio-economic and cultural factors should be investigated”, it is expressed that the health services is needed to handle in the societal dimension.

There have been important diseases threatening world history and societies in every period time. Among these the ones with contagious, not having an exact treatment and high spread risk have always been a nightmare for the societies. One of these diseases is Tuberculosis. Tuberculosis is an infectious disease caused by mycobacterium tuberculosis or TB bacillus.

Although the microbes that cause TB disease was discovered in 1882, adequate information about the natural evolution of the disease has been illuminated only in the last 50 years by the very crucial studies.

Tuberculosis disease is a struggle for life between single-celled creature, tuberculosis germs and the most advanced creature, humankind. The purpose of this struggle for the germs is infecting humans with the disease and ensuring the continuation of their own species by transmission of the disease to other people. On the other hand, the purpose of the infected human body is to take precautions and to mobilize its all protective forces in order to avoid the illness.

If the human body defeats the germs, the germs cannot find the opportunity to reproduce themselves, so the disease cannot develop. On the contrary, if the germs prevail, they reproduce themselves so that the disease appears. New victims will be caught by spreading germs with the cough of the infected patient. Eventually they extend the infection to other people. This situation concerns the entire society with infectious properties by its feature as a social disease. Thus a vicious cycle of tuberculosis lasted for thousand of years.

Today in this struggle of both sides, their powers in that struggle, fighting strategies and tactics have gained explanation in detail. The aim is to destroy the TB germs and to clean the world from these insidious germs. In our era, TB is not a dangerous disease. Today, it is not expected to diagnose the disease as in the past to have hemoptysis or severe cough. After the discovery of the germ and drug, moreover the improvement of the social conditions and precise precautions by medicine, the disease tend to reduce.

Rather having a socio-economic origin, the occurrence of tuberculosis has its roots in poverty and besides this fact difficult working conditions, unsuitable housing conditions, poor nutrition and low life standards have crucial roles in the occurrence of tuberculosis [2]. High infection rates, long term treatment, the isolation of patients and their families from society, false beliefs about the occurrence of TB and neglect of patients affect the achievement of the treatment.

In the societies or families in which the disease occurs, both the patient and his/her community experience several effects in addition to social disintegration. The understanding of the existence of precise treatment destroyed the idea that TB is extremely dangerous, thus there have been a psychological relief among the people. Even the patient without losing hope provides a rapid progress by resisting the disease. This lethargy causes the germ to reproduce itself more quickly by blocking the precautions taking at the proper time.

#### **The History and Social Evolution of Tuberculosis:**

Known as the oldest disease in the human history, tuberculosis is one of the most common diseases in the present day [3]. In the 3-4 thousand years B.C. and Neolithic period, the symptoms of TB in human bones show how old the disease is. As the first time, the existence of tuberculosis in humans has been detected in the Egyptian mummies. The mummies with Pott disease died three thousand years before Christ. As in the old periods when the disease had been diagnosed with the symptoms, the disease was believed as God's bad

revenge. In some tribes in Africa in that period, especially to protect them from this disease and to get the treatment, there had been sacrifice, magical healing and religious rituals. In Greek and Roman civilizations, to cure the patients' clergy had the role of medicine and religious shrines had the role of hospitals. In those religious shrines religious rituals were performed to cure the patients. The father of medicine, born 460 years earlier than Christ, Hippocrates has been explained the first symptoms of the disease. However the actual symptoms of TB were described 133 years after the birth of Jesus by Arrete in Cappadocia. These scholars reported the cause of TB as the injuries in the lungs. They told that "Injuries occur after the long-term cough and hemoptysis". Continuously increasing fever at night falls sometimes during the day. It causes fatigue and weakness, pulse is weak and soft. The sleep is disturbed and the patient's color is pale. These scholars wrote the continuing symptomatology in many pages such as the color of the sputum is varying.

In the medieval ages, cow milk, donkey milk, goat milk and especially healthy breastfeeding were recommended to the TB patients. In the 18<sup>th</sup> century, the most important discoveries in the diagnosis of tuberculosis were the percussion examination[4]. During the industrial revolution in Europe in 18<sup>th</sup> and 19<sup>th</sup> centuries, the number of deaths from TB was too much. The first precautions in order to prevent the disease had no scientific basis. In this period, for the diagnosis of the disease several studies had been conducted.

A. Villemin was proved experimentally in 1865 that tuberculosis is infectious. Thus it was stated that the disease concerned all individuals of the society. The bacillus, as being the cause of this disease affecting people for thousands of years, could be identified by the German bacteriology expert Robert Koch just in 1882. However, Koch's discovery was discountenanced by his community. At first, big compliments were told, but then the negative responses came [5]. When Koch insisted about his discovery, it was adopted by applying on some patients. Nevertheless, the regression of the disease has been after the development of effective drugs against TB.

Although in developed countries TB is almost entirely taken under control, in less developed countries it continues still its effects. The statistics of the World Health Organization indicates that today up to 20 million tuberculosis patients are living in the world and these patients may have the condition of infecting other people. The decrease of TB cases in developed countries is pleasing in terms of the history of medicine.

In Turkey before 1945 tuberculosis, named as “*ince hastalık*” in public, was in the first place. In those days the people dying because of TB was around 25-30 in hundred thousand. This atmosphere was largely reflecting the health services in Turkey and in that period sanitariums were founded, sympathetic treatments were applied. After intensive works on those days, effective drugs were found and by widely using the BCG vaccine until today, beside the decreasing number of patients with TB, the mortality rate of TB dropped 8 to 10 in hundred thousand.

#### **Contagion of Tuberculosis and the Social Environment**

**Factor:** Tuberculosis which is a disease caused by the germs of Tuberculin is a kind of decay. The germs moved by the respiratory track in to the lungs find a chance of life in there. This contagion by overgrowth of germs is called infection. The contamination in Tuberculosis appears by the respiration of the small droplets caused by coughing, sneezing and talking of the infected patients. Each droplet contains one or two microbes. These dangerous droplets can not be seen macroscopically. This is because the size of five million of them is small enough to create a volume like a pin head [6].

Droplets are dangerous in closed areas where the air flow is not available. In the social environments of transient social relationships like the cafes, schools and other indoor areas, the disease is more contagious. Most germs are in gloomy and humid places. Long club-shaped germs, called bacillus, come out with mucus of the patients of pulmonary tuberculosis. When they coughed up, small nucleate bubbles spill to the air. Through inhalation, it infects other peoples. A small nucleate bubble carries up to 1000-2300 bacillus. It spreads to one meter distance from the person who coughs. Millions of bacillus spill over around by coughing and mucosa. The contagiousness of tuberculosis was found to be caused by airflow.

People have to control in general their behaviors and actions in terms of health in their social environment. They should provide a healthy environment for their community by acting according to environmental conditions. Health, as not only the absence of disease and disability, is a complete well-being condition both physically and mentally. By taking into consideration health of people and community, humans with tuberculosis should not go to the collective areas and throw sputum randomly around.

#### **The Emergence and Most Common Areas of Tuberculosis:**

Tuberculosis is related primarily with poverty, malnutrition, poor living conditions and dirty environments. Unclear and germ hiding areas matter also for this disease. Since not only medical reasons but also social conditions cause tuberculosis, it affects societies and gives rise to high mortality rates [7]. The meeting delegation about medical aspects of nutrition in Ministry of Health induced by United Kingdom so that rather than as a physical factor, heart disease and tuberculosis need to be thought as risk factors. Actually tuberculosis germ always exists. However when this bacillus cannot find a suitable host, it ceases to be harmful.

When in societies, the environments and cases suitable for the occurrence of this disease have taken under control, the self-treatment will occur and the disease will disappear. The factors affecting the occurrence of tuberculosis are heavy working conditions, inadequate and unbalanced nutrition, poor housing and environmental conditions (in a residential building that is timid, poor warming without sunshine and infrastructure and an environment with ecological pollution) and stress [8]. It is also very important in which the age group the disease occurs. The disease is seen frequently in age group between 16-35 years. The children are in the second place and the elderly are in the third place. The socio-psychological structure of human appears to be a causative agent in the disease. Too much thinking is also known as a cause of tuberculosis. Moreover the disease is seen in love stories of young people. In cases when young people cannot come together with beloved ones, they cannot stop thinking about the phenomena and beloved one and they disappear in the inner world, so the disease affects them quite easily. It is advised to people who are thoughtful, “If you think too much you might be tuberculosis”. The basic philosophy of tuberculosis is common in a sense among people.

The cause of Turkish films being so popular is love with the infectious tuberculosis. Today the answer of the following question “Why people like these movies that much?” which cannot be answered by many researchers is tuberculosis. As called politely, it is melancholic love. Tuberculosis in Turkey was being released of being a danger. Turkish movies, songs and Turkish music also do not exist anymore. The reason of lasting musical Indian movies in India is the continuing Tuberculosis from hundreds of years.

Epidemiological investigations show that in rich countries the areas where tuberculosis is seen are usually the districts of immigrant groups. In most parts of the US, through the 19<sup>th</sup> century the mortality rates of tuberculosis was always falling, but around 1860, it went up for a while in New York City, Boston and Philadelphia. The most obvious explanation of this was the mass migration and the unpleasant greeting of the Irish people thrown from their homes across the Atlantic. It is statistically identified that people without roots, like replacing from home to home and work to work are more prone to the TB.

Until this century, likewise the old women, doctors believed mostly that TB is about deprivation which is also type of consuming Keats and is about a sense that formed by unrealized and not going to be realizing desires. Richard Morton who wrote a thesis about this issue said that: "I have often witnessed that the disease of the lungs has taken its roots from long-lasting and painful passions". By repeating the same claims, Australian doctor Leopold Augenbrugger who introduced percussion technique in the lung diseases, associated the disease with "sorrow of the mind, especially unpredictable longings concerned with nostalgia. Interestingly, after these claims were fallen out of grace in a century, Sir William Osler argued the same claims. "To predict the emergence of lung tuberculosis, it is also important to know the inside of the head of humans likewise inside the lungs".[9]

Falling into despair by feeling sadness, as the people are failing to achieve their targets about the same issue in which they concentrate their sorrow and thoughts, are propelling them into the disease. From this perspective, beside the methods of modern medicine, improvement of the events with social and psychological contents and their origins is also a treatment method.

**Psychology of Human with Tuberculosis and Individualism:** Until recent, people with tuberculosis gave way to despair and concealed his disease by becoming unsocial. The patient became upset about his situation, given by the suffering of the disease he worried himself and perhaps prepared to his own death with sorrow. After psychological influence and social pressure, even suicides were seen. Since in each disease there is psychological influence, in tuberculosis this rate is much higher. Because of its epidemic nature, the fear of exclusion of people raises the need to hide the disease.

Besides thinning, Tuberculosis is crushing the body; the soul is feeding itself from this crush, as the disease is progressing the human spirit is growing until fitting to any grave. Fatigue, slow death, with tears of blood is being desirable; the taste of life is being desired in long lasting death bed with excruciating tunes. In this spirit human is lost from life. He/she propels to loneliness. He/she sees himself/herself like almost not a member of the society, but like a criminal against the whole society. The tuberculosis already psychologically kills humans. It is said in society continuously: "Do not think much, you can be tuberculosis". It is seen more widely among lovers and beloveds. Introverted feelings not shared with anyone else, pushes people to this disease.

Kafka, before two months of his death in 1924, wrote to a friend from the sanitarium: "It is not possible by talking to learn obvious things. Because, if the conversation is about laryngeal tuberculosis ... in everyone, shyness in speech, evasiveness and dull eyes are dominant". This presents the psychological dimension of the disease.

Katherina Mansfield wrote to her log before a year of her death in 1923: "A terrible day ... awful pains and weakness. I was not in a position to do anything. My weakness was not just physical. To get well I had to treat first of all my personality... I had to do this alone and as soon as possible. Katherina Mansfield, not just believing the cause of her sickness being personality, but also by curing her personality, she believes that her hopeless and chronic disease in her lungs.[10]

TB patients today in our society can conceal their situations or can observe themselves as incompatible personalities and as socially excluded peoples. A patient we talked to was feeling really excluded from the society. Although the disease can be treated, as you say that do not upset, feel no despair, he/she still in a sense of "wonder if!" weakens himself/herself psychologically. Some of them by knowing that they are TB patients concede the death and want to live without revealing their situation. Actually these people are pushed to neglect by the effect of negative factors arising from the general structure of the society. When the patient observes that people are avoiding from him/her, he/she feels more ill and the treatment is delayed. Once after the death of patient with TB, the disease commonly was kept secret from the adjacent and even from the children.

TB is interpreted as a disease of excessive contrasts. Like a gray pallor and sudden flushing, patient's changing situation between overactivity and recession. This up-and-down course is laid out with cough. This persistent

cough is the symptom of TB. The patient with TB is dropped off, burned out. Especially pneumonopathy by disrupting the life quality creates a sense of more insufficiency more than any other chronic disease. Therefore, pneumonopathy shows a more strong relationship with psychiatric disorders than any other neurological or somatopathic diseases [11].

Tuberculosis is a disease which makes people individual, separates from the environment and stands out like a relief. What makes TB so interesting and romantic, but also makes it cursed and a source of horror. In the past, major outbreaks can be transmitted to each individual of the affected society and even the whole society could be encompassed. Whereas TB isolates the people from the society, it elects people. Regardless of how widespread in the community, it has been always the mysterious disease of the humans. Despite the reluctance of individuals, TB is a disease revealing the intense desires of human which wanted to be hid.

**Tuberculosis and Reflections on Society:** Interact to meet the social needs and share a common culture, a union consisting of large number of people is called society. Each society has a structure. The whole social relations organized in a society are called social structure. Social structure is always dynamic.

Diseases are always present in the social structure. The health of a person is not just important because of his individuality but also because of his part in the society. People hold themselves responsible for other peoples' health besides their healths.

From this point of view, the patient with TB compels himself to take precautions in order to not spreading the TB germs. Moreover, a family with a TB patient keeps its distance to the society. The society also keeps the distance to the family. To the houses with TB patients are not visited. A separate room in the house is prepared to the TB patients, who are waiting their turns in the hospitals, their kitchen and stuff are separated and he is not having contact with the house dweller. They become cleaning addict because of the disease. The cause of the contamination is believed as dirtiness. The exclusion and blaming of people are worried about.

The patients within same situation in the social structure want to find a separate place. This causes the social disintegration. Once after the death of the TB patient, concealing the disease from the children was a common attitude. Even the doctors and families having sufficient information about the disease of the patients did not talking.

It is believed that tuberculosis is causing pleasure and increase in sexual desire. TB is bringing an extraordinary seductive attraction. However these symptoms are often deceptive in TB patients. The patients' viability and the joy caused by a mental and physical destruction is a diseased joy, the pink cheeks are the symptom of fever and the vitality can be the messenger of forthcoming death. By this way the booming of energy can be harmful for the patient himself and his environment. This situation affecting the social structure puts the negative condition of the patient in the society.

**Tuberculosis and Social Change:** Social change means the change in networks between institutions, social role patterns and relations of people in a society's social system. According to a sociologist, social change is important alterations arising in social structure. In healthy societies, social change means direct proportionally the changes in the structures of human. There is a many reason for social change. Some of them are; inventions, discoveries, technologies, ideas, beliefs, industrial developments, wars, natural disasters and historical events.

All societies are in a permanent changing process. Each changing brings new problems. Each culture has not the same capability and aggregation for trying to solve this problems, producing new solutions and adapting to these [12]. There are lots of reason of social changing. Inventions, investigations, technology, ideas, beliefs, developments of industry, wars, natural disasters, problems of health, historical event are some of them.

In societies where TB is seen, there is a difference between the healthy state and diseased state of the society attracting the attention. As an infectious disease, if tuberculosis is transmitted to some people in a society, it is concerned to spread to the whole society. A social change in that society occurs. As a consequence of revealed situation of this health disaster, a change in society arises. A healthy society displace with a community that is sick, fighting with the disease and taking precautions. In the II. World War, it is obvious to observe this situation in Turkish society. The social change arising from the social mobility in the society requires new precautions against this disease.

**Tuberculosis and Social Disintegration:** As a result of social change in a society with TB, there occurs a distance and a disconnection between consumptive and healthy people. In this situation, social control collapses

in the society while disorders occur in the social structure. Any control can be provided. While corruption of cooperation in society, danger of continuity of unity and discipline are experienced, disorganization originates as a result of this disorder. Sociologists interpret this disorders occurring in poor neighborhoods in big cities and in health as social disintegration.

Furthermore, the society cannot keep up with the rapid changes arising from fear and panic about TB in the society. The lag behind with rapid changes in society is considered as social disintegration. While this situation persists, the diseased people, against their isolation from the society, absolutely create a sense of unity and self-defense.

**Tuberculosis and Social Exclusion:** The first use of the concept social exclusion in social policy is stated commonly in the social exclusion literature in 1974 by Rene Lenoir, Social Affairs Minister of France [13]. As being a more European notion, revealing by the problems of globalization, social exclusion seems to have a quick introduction into the social policy literature since the end of 1990s.

There is a continuing debate on the concept of social exclusion, on what is its exact meaning and on whether it has a universal validity in the context of time and space among the developed and developing societies; and in the near future this debate seems not to come up to an end.

The consideration of social exclusion as a multidimensional social deprivation process requires the involvement of social, political and cultural factors to this process. To illustrate, in European Union the factors constituting this process is thought as follows; lack of income-tax and social protection, consumption and loans, access to education, health, unemployment, working conditions, housing, no benefit from homelessness, health and social services.

Within this context, social exclusion is tried to measure with the indicators about income that is developed at the union level, employment, education and health, accordingly social exclusion phenomenon is also revealed in a sense [14]. Social exclusion is a concept related with poverty, as a functional analysis means, having a multidimensional/scientific perspective for exclusion phenomenon and by this way it reveals the dynamic character emphasizing the processes leading to exclusion [15].

TB patients feel themselves excluded from the society and lonely and they experience this first in their families. The predominant cognitive/emotional reactions against TB are personal anxiety, social exclusion and social factors [16]. Because of misunderstandings socially from the past, TB has become a quite scary disease. Social exclusion and labeling is triggered this fear. The feature of infection of TB is well known and sometimes the isolation of the patients is unnecessarily prolonged. More than half of the patients in researches were observed as they stated that they hide their disease from their work places and friends because of the fear of exclusion. This causes high anxiety levels among patients after the occurrence of the disease.

**Tuberculosis and Social Integration:** In ancient times, when there is any remedy of TB is available and when the relations with healthy people are abandoned, the changes and disintegrations were leading a social integration among diseased people. An organization or solidarity was occurring between TB patients against the other groups and communities in a society. Eventually, among the people who are sharing the same life style and the same fate, there occurs a compulsory integration.

Today, medical and psychological developments of both the vaccine (BCG) and drugs and other treatment methods has ceased TB to be a mortal and incurable disease. In the societies from the last century, there is no exact TB outbreak in public. On the other hand, our short term observations show that there is a better solidarity among TB patients. They know each other much better. There is the need of profiting from each other's experiences in improvement methods. Even it is possible to come across a communication by means of communications among long distance patients.

Although the Tuberculosis dispensaries stand for duties like helping other dispensaries, interposing in economical reasons and medical instruments for TB patients, at the same time these associations are contributing in meeting the patients with each other and in taking precautions as coordinated. This is important to provide a social integration.

Since the infectious diseases had been considered as social diseases, there is a sensitive situation for the disease and patients in the society. It may be a social duty to take care of them, not to exclude them and not to leave them under psychological pressure. It cannot be possible that the whole treatment is medical; self-confidence, ownership in the society and mobilization of moral values can also be applied as a kind of treatment.

**Tuberculosis and Social Mobility:** It is believed that TB is a wet disease and the patient can be cured by change of air. The disease of wet and cold cities. The doctors suggest their patients change of air and to go to places with high and dry climates.

In such a situation, in the places, where TB patients are, is a social mobility. The TB patients break their ties with places where they are living and start to an endless quest for the place where they can have their health back. Since the beginning of XIX century, TB has become a new reason to exile.

There were some places good for the TB patients. These were for example Mediterranean or Islands of South Pacific. The doctors of Keats recommended moving to Rome. Chopin moved to West Mediterranean Islands and Robert Louis Stevenson preferred to exile to pacific [9]. TB resisted for long years to the developing medical sciences. By succumbing in the last century, medicine eliminated such fears of TB.

People with TB have broken their ties with the places where they lived once. They are in a never-ending quest to regain their health. Since the beginning of XIX century, TB has become a new reason to exile. The patients with TB were often used to travel to last a lifetime. In patients with TB there occurs a social mobility within the same social strata. This social mobility is upwards mobility, because the status of people changes. As being before a strong man switches this time to a patient. Afterwards it can be seen roles of patient in that people. A social integration occurs among people having the same disease. First social disintegration occurs by exclusion of TB patients from the society and than social integration arises from cohesion among them.

## CONCLUSION

Tuberculosis, as threatening people and considered as being important by the people at the every stage of human history, is today not a mortal disease and ceased to be dangerous with the contribution of modern medicine. Nevertheless, the number of deaths from Tuberculosis in the world is not a few to overlook. In every stage in human history, desperate diseases affected societies in every aspect (Social, psychological, economical). Besides the medical dimensions, psychological dimensions of the diseases had augmented the danger.

Until the last century, TB had threatened the whole societies without separating supervisors from officers. While people with TB were fighting with the disease and

death, on the other hand they were struggling with the social pressure. After the definition of the causing tuberculosis by Robert Koch in 1882 and the determination of the disease as an infectious disease, a relaxation had occurred among societies until a new cureless disease derived. After the lethal drugs against the disease germs and the factors leading the societies infected are improved, TB ceased to be not longer a fear factor. It can be seen that all countries in the world have allocated financial and medical funds by means of a lot of time and place. By conferences, panels, discussions and meetings it is tried to provide a public consciousness and instead of a negative atmosphere in the society, a hopeful social structure had tried to achieve. Since TB causes fluctuations in any kind in the societies, it sometimes arise social disintegration, sometimes social integrations and also social mobility. Affecting country's economy and patient's financial structures, this disease has lost his rapid increase in recent years; mortality rates are decreased and saved from being an instrument of state policies.

The treatment of the disease is provided sometimes with medical and other times with other methods. For example, the treatment of a infectious disease is provided by the drugs of modern medicine, on the other hand the treatment of a patient who caught the disease after a love story is psychological. Since the doctors' negative attitudes like inappropriate methods by acting to the patients as a business client instigates the disease, on the opposite conditions the elimination of the disease by approaches of (patients) psychology and social behavior can be provided. The certain periods of progress of the disease are also directly relevant with social, political, cultural and economic conditions.

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