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DERLEME
REVIEW

Treatment of tuberculosis in Turkey in terms of medical ethics

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SUMMARY

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Having a history as old as the history of humanity, Tuberculosis (TB) is a serious disease and it is regarded as an important a public health problem not only for its medical aspect but also for its social and ethical aspects.

As a result of the discovery of the cure for TB and the improvement of humans' living conditions, the TB problem was believed to be solved and a relaxation in the battle against TB was observed around the world by 1980s.

World Health Organization (WHO) declared a state of emergency for the battle against TB in 1993. According to the "Global Tuberculosis Control 2014" which was published by WHO, TB remains one of the world's deadliest communicable diseases.

This article argues that tuberculosis is one of the most important neglected topics in medical ethics as regards individual obligations to avoid infecting others, coercive social distancing measures, third-party notification, health workers' duty to treat contagious patients, and justice. The purpose of this article is provide a picture of the current situation of TB treatment in Turkey in terms of medical ethics.

Key words: Infectious diseases, history of medicine, medical ethics, public health ethics

ÖZET

Türkiye'de tıp etiği bağlamında tüberküloz tedavisi

İnsanlık tarihi kadar eski bir geçmişe sahip tüberküloz, sadece tıbbi yönden değil aynı zamanda sosyal ve etik açıdan önemli bir halk sağlığı sorunu olan, ciddi bir hastalıktır.

Tüberküloz tedavisinin bulunması ve insanların yaşam koşullarının iyileşmesi sonucu, tüberküloz sorununun çözüldüğüne inanılmış ve tüm dünyada 80'lerden itibaren tüberküloz mücadelesi gerilemiştir.

Dünya Sağlık Örgütü (DSÖ) 1993'te acil olarak tüberkülozla mücadeleye başlamak için bir bildiri yayınlamıştır. DSÖ'nün raporu "Global Tüberküloz Kontrolü 2014"e göre, tüberküloz hala dünyanın en çok öldüren infeksiyon hastalığından biridir.

Bu makalede tıp etiğinin ihmal ettiği önemli konulardan biri olan tüberküloz, başkasına hastalığı bulaştırmadan kaçınma konusunda bireylerin sorumlulukları, baskıcı sosyal dışlama, üçüncü kişilere bildirme zorunluluğu, sağlık çalışanlarının bulaşıcı hastalıkları tedavi etme görevi ve adaletten bahsedilecektir. Bu makalenin amacı tıp etiği bağlamında Türkiye'de tüberküloz tedavisinin var olan durumunu ortaya koymaktır.

Anahtar kelimeler: Bulaşıcı hastalıklar, tıp tarihi, tıp etiği, halk sağlığı etiği

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INTRODUCTION

Tuberculosis (TB) is a disease which is as old as humanity and it is a social disease as much as a medical one (1-3). Although Robert Koch discovered the active substance of the disease in 1882, the cure for TB was developed as late as mid-twentieth century. As a result of the discovery of the cure for TB and the improvement of living conditions by industrialization, it was believed that TB will no longer be a threat (4). However, as a result of the growing resistance of the disease which was caused by the unconscious use of antibiotics, the susceptibility of HIV carriers to TB –the number of HIV carriers with TB is more than TB carriers without HIV-, and the socioeconomic disparities had retained the position of TB as a global health threat (5). According to WHO's "Global Tuberculosis Control 2014" report TB remains one of the world's deadliest communicable diseases (6).

Although it is a curable disease for more than 50 years, TB is still an important threat for public health for it is an air-borne disease and it developed drug-resistant strains. However, there are not sufficient amount of research on TB and the ethical aspect of the issue is not discussed in detail (1). The purpose of this article is to provide a picture of the current situation of TB treatment in Turkey in terms of medical ethics.

The History of TB in Turkey

In order to understand the current situation in Turkey, we should look into the historical development of the subject. During the reign of Abdulhamid II whose father and grandfather dies from TB, various steps were taken to tackle the disease, studies of Koch were followed closely, and the production and application of tuberculin took place in the Ottoman Empire. The primary quantitative data about TB was from Besim Omer Pasha's research on the TB ratios in İstanbul and Izmir which were conducted in 1906. According to this, the annual death rate from TB was 9-10% (7). However these studies had not expanded beyond individual efforts. The Ministry of Public Health and Welfare, which was founded after the establishment of the National Assembly in 1920, opened two sanatoriums in Burgazada and Buyukada is the largest of the nine islands comprising the Princes' Islands in the Marmara Sea, close to İstanbul. However, the limited resources were allocated to battles against malaria, syphilis and trachoma which were more widespread during this period (8).

The struggle against TB was conducted by associations for battling against tuberculosis (BAT) until a planned national policy was developed. The first BAT which was established in the republican period was Izmir Association for Battling against Tuberculosis (1923). Second association was established in Balıkesir in the same year. The third BAT, which was established in İstanbul in 1927 is widely regarded as the continuation of the Ottoman Association for Battling against Tuberculosis which was established in 1918 (8).

The Central Sanitation Institution (CSI) which was established in 1928 and the educational section of this institution, Sanitation School, have important roles in the battle against TB. With the new laws which were enacted in 1930 (Public Health Law, Regulation of Battle against Tuberculosis Dispensaries, Law of Ministry of Public Health and Welfare, Law of Prosecution of Public Servants, laws and regulations on private hospitals, etc.), the battle against TB was no longer only an endeavor which was embarked on by civil initiative, but also an issue which has a place in the agenda of the government (8).

The planned period of the battle against TB have started by the increase in the ratio of death by pulmonary tuberculosis after the World War II. The "Law of Municipal Revenues" and the "Law of Battle against Tuberculosis" were enacted in order to create a legal status and regular financial support for BATs. Local associations for battle against tuberculosis came together first time in the 1st Tuberculosis Conference which was organized in the period of Behcet Uz. The new association organized a nationwide stamp campaign to fund-raising and generated a great income. 1950s are important years for the battle against TB because of the developments like the initiation of cooperation between universities and association, the production of BCG vaccine in CSI and its approval by World Health Organization (WHO). The production of BCG vaccine was followed by a vaccination campaign. WHO provided financial aid for the BCG vaccine campaign. Approximately 7.7 million person whose tuberculin test gave negative result were vaccinated between 1953 and 1959. The participation rate for the vaccination campaign was 90%. The number of dispensaries (a clinic offering medical care only to people who diagnosed with TB) had risen from 8 to 72 between 1950 and 1962. According to the data provided by the ministry, the death rate in 1950 which was 152 out of 100.000 had declined to 94.1 in 1954 and then to 76.7 in 1960. By 1980 the rate of death from TB was 8.8 out of 100.000 (8).

As a result, active campaigns, vaccination, public screening and economic development have resulted with a great decline in TB cases. Currently the unit which deals with TB in the Ministry of Health is demoted to a department, which caused budget cut and the decline in the number of personnel. In addition, the Sanitation School where the personnel for TB department in the ministry were acquiring education was closed. CSI stopped the production of BCG vaccine in 1998 for reasons of high cost and lack of technology. Turkey had her share in the worldwide relaxation in the battle against TB since 1980s. Flaws in the TB-related services had increased by 1990s because of political instabilities and economic problems (8).

TB in Today's Turkey

The statistics of tuberculosis patients are collected and reported by Tuberculosis Control Department all over the country. Tuberculosis patient data was sent monthly from tuberculosis dispensaries in the overall statistics; statistics were computed by Tuberculosis Control Department at the provincial and country levels prior to the year 2005. The data of each registered patient to the TB dispensaries has been collected, analyzed and reported on an individual basis each year since 2005 in Turkey (9).

Activities of the year 2010, the data of tuberculosis cases of the year 2009, the treatment outcomes of tuberculosis cases of the year 2008 and the second year treatment outcomes of multi drug resistant tuberculosis cases of the year 2007 were presented in 2011 report, because of carrying out of the diagnosis and treatment of tuberculosis patients in long-term programs.

Today, the National Tuberculosis Control Program is applied in Turkey in line with the global TB control program of WHO. Turkey initiated the "Tuberculosis Suppression Program" as a part of the "Berlin Declaration" which was accepted in 2007. The Direct Observation Treatment (DOT) program which is one of the main components of the battle against TB was initiated as a pilot program in 2003 and incepted nationwide by June 2006. The drugs of TB patients who are registered in the dispensaries of battle against tuberculosis are provided free of charge by Department of Battle Against Tuberculosis (DBAT). In addition, TB drugs were started to be distributed by first, second and third level healthcare institutions of DBAT without asking for any kind of social assurance. The second choice TB drugs have been distributed

since January 2008. Although information about TB was collected as aggregate data before, individual data started to be collected since 2005 and they have been published as annual reports since 2007 (10).

For Tahaoglu et al. drug resistance has become a major problem in the treatment of tuberculosis (11,12). Resistance rates in Turkey are high because treatment approaches are often inappropriate, rates of treatment completion are low, and therapy is not directly observed. Despite a relatively stable number of new cases of tuberculosis each year, resistance to rifampin is growing, as is multidrug resistance.

According to WHO's Global Tuberculosis Control Program 2013 Report, the average TB incidences by 2009 in WHO Europe Region-which includes Turkey- was 47 out of 100.000 while it was 29 out of 100.000 in Turkey. The average TB incidence worldwide in 2009 was 137 out of 100.000. However Vidinel and Turkish Medical Association (TMA) argue that TB is a threat for young population in Turkey and points that the abandonment rate in drug-resisting cases is high (9.6%) curing ratio is low (64.6%). Therefore, TB is still a major problem for Turkey unlike what the numbers tell (7,13).

According to the January 2012 dated Tuberculosis Report of TMA, the new programs for transforming the healthcare system in Turkey, which were implemented in line with global policies, had downgraded the position of the dispensaries of battle against tuberculosis and assigned additional duties to family physicians without clarifying the details of the process. In addition, as a result of the new family physicians program, additional problems have emerged in finding qualified personnel for dispensaries and providing standardized healthcare services. According to TMA the successful picture of Turkey in TB control in WHO reports was the outcome of the "old" central vertical TB control program which comprises dispensaries of battle against tuberculosis. Therefore, TMA argues that the new adjustment which closed 33 dispensaries and provides one dispensary for every 500.000 population is not an appropriate policy. The Report gives examples from developing and underdeveloped countries where health reforms had negative influences on TB control and points that more serious problems will emerge for the units which are responsible for the battle against TB with the "Transformation in Healthcare" which orients healthcare institutions to provide services with commercial concerns (13).

Anti-TB Dispensaries

In order to grasp the subject, it would be beneficial to look into the structure of the struggle against TB in Turkey (14). The associations of struggle against TB, their dispensaries and the Ministry of Health are the two units which actively take part in this subject. The needs of dispensaries (costs of building maintenance, water, electricity, telephone and heating; salaries of contracted attendants) whose personnel were appointed by the Ministry of Health were provided by the associations during the periods when associations were strong. Dispensaries are managed by the ministry since the income of associations has decreased considerably recently. However the organizational changes in the ministry had their impact on the dispensaries. Today they are connected to the public health centers. Being connected to two institutions has created management problems.

Anti-TB dispensaries are responsible for coordinating the struggle against TB, patient follow-up, contact scanning, distribution of medicine, the management of DOT (directly observed treatment) and collecting statistical data. There is a computer program which works online and connects anti-TB dispensaries for data collection. Each health personnel have their own passwords to access this online system. Patient files are kept in closed envelopes and the access of third parties to these files is prevented carefully.

Problems of anti-TB Dispensaries

In order to enable follow-up, the information about the patients who are diagnosed with TB in another health institution is given to the anti-TB dispensaries of the region where these patients reside. Until few years ago, the anti-TB dispensary which is informed about the subject was sending a letter of invitation with an envelope which has the emblem of the dispensary. In case the patient cannot be reached, the headman of the neighborhood would be informed about the situation. These practices carry the risk of stigmatization and social exclusion. Today, letter-sending is rarely practiced since it is much easier to access people via cell phones. In case person who are diagnosed with TB or carry the risk of the disease cannot be reached at via cell phone, family physicians are informed. In rare cases when there is nothing to do but to send a letter to the patient, a plain envelope without any emblem is used.

Another ethical dilemma which is experienced in anti-TB dispensaries is about DOT. Physicians who

work in anti-TB dispensaries are aware of the importance of DOTs, but they also know that appropriate solutions for patients should be developed in order to have a functioning system. For example some patients do not want to come to the dispensaries every day for taking their medication for economic reasons, work-related concerns or fear of stigmatization. Others cannot visit dispensaries for they have patients or kids to be taken care of at their home. In some other cases, there can be a lack of personnel or vehicle which is necessary to provide the medication of bedfast or elderly patients who live alone. In such special cases, one of the family members is educated for following DOT. Financial aid is provided for the patients who have economic problems. In Ankara, patients are followed via internet though this application is still limited. The DOT follow-up of patients who can use internet and prefers to be followed via internet is executed by using cameras which are provided by the institution in case they do not own one. The institution also provides training to their personnel who will get in contact with the patients via internet at the pre-determined hours. Although it is not used widely, patients reported that they are satisfied with this method.

Another problem which is emphasized is the fact that experienced personnel of Anti-TB dispensaries started to shift to other branches as a result of the changes in health policies. It is believed that the functioning of dispensaries is influenced negatively by these changes and this situation had its reflection on success rate of treatment.

The personnel of anti-TB dispensaries are only in contact with TB patients thanks to the vertical organization model. Therefore they can develop intimate and strong connections with patients and their relatives. A relationship based on trust between the dispensary personnel and patients and their relatives contributes positively to the adaptation of the patient and the success of the treatment. In addition, such close relationship enables the physician to take decisions and develop solutions which are convenient for the specific conditions of each patient and case.

Another ethical problem which is experienced in anti-TB dispensaries is contact scanning. Family members and colleagues who are in close contact with the patient who is diagnosed with TB must be

scanned for the sake of public health. In order to hinder the stigmatization and exclusion of the patient during the process of scanning family members and colleagues, the information about the situation of the patient is given only to those who are close family members and in managerial positions in the workplace. However, the existence of patients who lost their jobs because of TB proves that contact scanning process is not always successful in that front.

Compulsory Treatment-Detention-Isolation-Quarantine

Another ethical problem related to TB treatment is enforcement of compulsory treatment for the prevention of the enhancement of drug-resistance and the protection of public health and the applications like detention, isolation and quarantine. Although they appear as the violation of the right for autonomy, these practices should be considered under a different heading since they have their place in law.

In Turkey, laws give authority to the Ministry of Health for detention and compulsory treatment. Family physicians have the authority to demand for a decision from Provincial Public Health Commission for the involvement of police force for detaining a patient who resist against treatment (15).

Information about literature shows us in many countries like Turkey, patients with TB were deprived of their autonomy and lacked the opportunity to influence the delivery of their own health care. Patients were never given reasons why their treatment was organized in such a way, and nor was the inherent element of force or involuntariness ever explained or justified (16).

A decision of Ankara Provincial Health Commission in 2009 can be given as an example for a decision for detention and enforced treatment in Turkey. With this decision the patient was brought into the hospital by security forces, observed by a psychiatrist and detained in the hospital under the surveillance of a security guard 24 hours a day. In addition, in order not to victimize the family of the patient, district governorship and municipality provided food, clothes, fuel, stationery equipment, medical equipments and financial aid to the family (17).

In addition, Turkish Ministry of Health is conducting workshops which focus on the education of patients

who resist against treatment, methods for following these patients, planning of detainment procedures and determining the standards of patient rooms. Another issue which is discussed in these workshops is the calculation of the number and cost of beds for TB patients.

When implemented for a disease like TB which is related to poverty and alienation, quarantine and isolation can cause accusation, stigmatization and discrimination. If DOT is possible for TB, isolation is a preferred method. Detention and isolation should never be a routine part of TB program since in most cases the main problem is the lack of qualified TB diagnosis and healthcare services rather than patients' resistance against treatment. Forced detention and isolation should be resort in rare cases which threatens public health. In addition, there are certain points which should be taken into consideration in these practices. Persons must be sick and be in a position to infect others. The spaces which are used for detainment must be clean and livable. Persons' bodily freedom should not be constrained and their needs for food, clothing, accommodation and medical care should be met. They should be treated justly and they should not be discriminated because of their condition. Detention should not be used as a method of punishment. Procedures should comply with the process. Persons should not be detained longer than it is necessary (18,19).

It is believed that there are very few studies on the effectiveness of forced detention and more studies should be conducted about this issue in which there is a conflict between public health and rights of individuals (20).

In 2010, the WHO published Guidance on Ethics of Tuberculosis Prevention, Care and Control to guide stakeholders in implementing TB control programmes. These guidelines emphasize the overarching goals of TB care and control programmes, which are (19):

- to achieve universal access to high-quality diagnosis and patient-centred treatment
- to reduce the human suffering and socio-economic burden associated with TB
- to protect poor and vulnerable populations from TB, TB/HIV and MDR-TB
- to support development of new tools and enable their timely and effective use

- to protect and promote human rights in TB prevention, care and control.

The guideline identifies ethical values that are important to TB care and control, such as “social justice and equity”, “common good”, “respect for patient autonomy”, “participation” and “transparency” in decision-making processes, and “effectiveness”.

The Legislative Framework of TB Treatment in Turkey

In Turkey the 1593 numbered Public Health Law stands as the foundational regulation about TB (21). The related articles of this law specifies that the Ministry of Health is responsible for taking precautions against TB and the services will be provided free of charge. The 432nd article of the Turkish Civil Code specifies the practices like compulsory treatment and detention (22). Laws allow the Ministry of Health to conduct compulsory screening in enrollment to school and army and employment processes in accordance to the protocols signed with the Ministry of Education, the Ministry of Defense and Social Security Institution.

News on a TB outbreak in a school in Bolu in February 14, 2012 which took its place in the media is important to understand the information of society about TB (23-25). The Ministry of Health and the Turkish Thoracic Society had to make a press release to correct certain expressions used in these news which might cause panic (26,27). The press release of the society points that the news that the infected person was fired will cause stigmatization and exclusion. In addition, these news give the impression that the disease cannot be cured and even if it is cured, infected persons will still be a threat for others. These news display the inadequacy of the level of knowledge about the disease in society. The Ministry of Health has some studies to produce informing pressed materials which can also be found in internet but it is believed that these efforts do not have their reflections in the entire society (28).

In conclusion, the level of success in TB control during the first decades of the republican period had declined in Turkey as a result of the worldwide relaxation in TB control policies. It should not be forgotten that TB is a disease with significant social repercussions; society should be informed about the issue and the vertical organization which had given successful results in the past should be preserved.

CONCLUSION

Medical and research ethics which was developed in the postwar period focused on social benefit by providing access to welfare and information. The medical institution of the postwar period was not very much interested in the threat of infectious diseases for public health and neither were they have willingness to develop drugs to postpone or even avoiding the death of previously healthy young adults. The history of biology and humanity was forgotten in the industrial age and we believed that it is unthinkable that infectious diseases can be a threat for us. We believed that epidemics belong to history; they can be cured by a miraculous drug which is already in our pharmaceutical arsenal and they are limited to the known diseases of the developed world. However, AIDS and TB which follows it showed that this is not the case. The appearance of AIDS at the beginning of 1980s indicated that the conviction that developed industrial societies are exempt from epidemics is just an illusion. In addition, it was realized that developments which did not take into consideration ethical concerns can bring about additional risks. As a result, the importance of public health for protection against epidemics is noticed in developed countries, especially the United States.

Challenging medicine, science, public health and legal system, HIV/AIDS forced medical staff, patients and the society to take part in an ethical struggle. However, it was quite interesting to see that similar concerns have not arisen about TB. Although the debates on the conflict between civil liberties and public health were ignited by AIDS, the spread of similar concerns into the field of TB was an important development. AIDS-related debates functioned as a catalyst in these debates. On the one hand there was the concern for protecting public health for the benefit of the society; and on the other, there were civil liberties. There were radical differences between the basic ethical values, perception and fields of movement of civil liberties and public health.

In fact no other disease caused debates on the ethical principles in such wide spectrum. HIV infection and AIDS provided a model for evaluating almost all basic ethical principles in medicine. It is possible to use this model to develop the ethical aspect of TB. Various issues ranging from identifying the infected patients and searching for an effective treatment method to treating the disease or the feeling pity for

the ones who could not be saved had to be reevaluated ethically. These debates also include the conflict between civil liberties and public health, incentives for the development of new drugs and the allocation of limited resources, conflict between privacy and the revealing of reality, discrimination and exclusion. AIDS continue to challenge many issues of medical ethics like the responsibility of the physician for treatment, privacy, informed consent, right to acquire healthcare, decisions for limiting treatment and research on vulnerable groups. AIDs and TB will surely be important models for the above-mentioned ethical issues.

A multi-faceted and inter-sectoral approach is necessary for successful treatment and control of TB. It is important to develop bold policies by taking into consideration the health system and social determinants. Health policies which are only treatment-centered would be ineffective for TB. Practices which locate preventive medicine into forefront would be more successful. Organization of the material resources of diagnosis and healthcare and the use of TB drugs, provision of the convenient infrastructure and computer network for accelerating tests and the education of sufficient number of personnel are important aspects. It is meaningless to expect from TB programs to tackle all social problems. Studies for controlling TB should be conducted with a comprehensive approach by maintaining cooperation between different sectors (19). Publication of brochures and books, education of society -especially women-, provision of institutional support and incentives for research on this field are few of necessary steps to be taken (29).

The effectiveness of the methods of the battle against TB should be followed up and local interests, ideas, beliefs should be taken into consideration while making decisions. Society should participate to the decision-making processes. Transparency, equity, problem-solving and clarity of the processes of the battle against TB would increase the possibility of success. All TB-related medical costs should be met by governments. Treatments should be sensitive to gender. It is important to study on groups such as destitutes, refugees, asylum-seekers, immigrants, convicts, mineworkers, homeless, addicts since they are more susceptible to TB. Furthermore, social, cultural and anthropological studies which inquire the social and structural determinants of the disease and educate individuals and the public about this disease should be conducted (29).

For the case of Turkey, it is believed that vertical organization which produced successful results in the earlier decades of the republic should be preserved and developed. Since policies for the transformation of health system encourages privatization, policies on fields which are not profitable like TB should be developed meticulously and covering of the costs of diagnosis and treatment by governments has become more important. In addition, education of the public is important. It should not be forgotten that TB feeds social injustice, special attention should be paid for vulnerable groups, only treatment-centered studies are not sufficient and that the issue should be approached in a comprehensive manner.

CONFLICT of INTEREST

None declared.

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