

Stigma and Discrimination in Treatment of Patients with HIV Co-Infection - Tuberculosis in the Osh Region of Kyrgyz Republic

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ABSTRACT

Despite the downward trend in the incidence rate, the situation in Kyrgyzstan is complicated by the spread of drug-resistant tuberculosis and tuberculosis (TB) combined with human immunodeficiency virus (HIV) infection. Stigma and discrimination are among the strongest negative factors affecting the lives of people affected by tuberculosis, leading to many patients not seeing doctors or dropping out of treatment. This article is devoted to an important issue, the study of the manifestation of stigma and discrimination in patients with HIV - infection combined with tuberculosis, which leads to a delay in diagnosis, early initiation of treatment, an increase in the reservoir of the source of tuberculosis infection, including drug-resistant tuberculosis among population. The publication contains a thorough and detailed analysis of the complex of social and medico-biological actions necessary to prevent the spread of HIV infection and tuberculosis.

Keywords: Treatment, HIV, Stigma and Discrimination, Co-Infection, Tuberculosis

INTRODUCTION

Practical recommendations have been developed for the implementation of programs for the formation of prophylactic settings for HIV-infected people concerning tuberculosis infection, taking into account the characteristics of a particular region the Karasu district of the Osh region of the Kyrgyz Republic. To determine the level and nature of stigma in patients and their relatives, a questionnaire was conducted among 100 HIV-infected patients with newly diagnosed TB who are receiving anti-tuberculosis treatment.

In recent years, some success has been achieved in psychiatric practice, but tuberculosis remains a threat to humanity. Globally, in 2012, there were 8.6 million cases of tuberculosis, of which about 1.3 million died.

According to the WHO, about a third of the world's population two billion people were infected with *Mycobacterium tuberculosis* and are at risk of infection. The upward trend in the incidence continues to this day. According to 2015 WHO report, there were already 10.4 million new cases of tuberculosis worldwide.

In a total number of cases, 5.9 million were men with a specific weight of 56% and 3.5 million women were 34%. The number of sick children under 14 years old was 1.0 million were 10%. Among all new cases of tuberculosis, those with HIV infection were 1.2 million [5], while tuberculosis is the main cause of mortality in HIV-infected and makes up about 30%. The increase in the incidence of tuberculosis in patients with HIV - infection has led to the fact that today tuberculosis is the main opportunistic infection in HIV - infected.

According to WHO reporting data, 27 countries in the world have a high burden of multidrug-resistant tuberculosis (MDR- tuberculosis) and the Kyrgyz Republic belongs to one of them, this was a predisposing fact for the planned studies. Thus, according to the National

Tuberculosis Program (NTP), in 2014 the number of MDR-TB patients detected was 1370, in 2013 were 1160 cases. While, for 2011 were 835, for year 2012 were 904, i.e. in the country there is a situation with a steady increase in multidrug-resistant tuberculosis [5].

Scientists define stigma as a certain negatively assessed by society sign that determines the status of a person and the behavior of others concerning him. Stigma and discrimination are the strongest negative factors affecting the lives of people affected by tuberculosis, due to which many patients with tuberculosis do not go to doctors or drop out of treatment, which in turn leads to a lack of awareness of the disease among the patient's close contacts with tuberculosis thus contributing to the spread of the disease. The presence of serious self-stigmatization in many patients with HIV infection and tuberculosis has been shown, which includes awareness of stereotypes, agreement with them and they are projecting onto themselves.

Stigma is a socially constructed phenomenon that devalues a person and negatively affects stigmatized people. If the disease is stigmatized, the patient becomes afraid of the social and economic consequences of the diagnosis, and because of this, patients are reluctant to seek and complete medical care. Stigma and fear of discrimination, as a rule, lead to delays in receiving medical services [5-8]. Many studies on stigma indicate that its existence prevents people from seeking medical attention, leading to delayed diagnosis and early initiation of treatment. These dangerous consequences of stigma contribute to an increase in the reservoir of the source of infection with HIV infection and TB, including drug-resistant TB, among population [8, 9]. TB patients were characterized by a loss of interest and motivation for life, a decrease in vitality and psychological stability [5]. They may find themselves socially excluded from family, friends

and other members of society, fired from their jobs, expelled from educational institutions. In addition, stigma and self-stigmatization are created by a lack of knowledge about the disease, prejudice about the transmission of infection, and fear associated with death.

Therefore, the manifestation of stigma and discrimination in patients with HIV - infection and tuberculosis in the Kyrgyz Republic has been little studied so far and requires more thorough research to develop practical recommendations on the implementation of programs for the formation of preventive-type settings for various population groups with infection with tuberculosis. It is necessary to analyze the complexity of social and medico-biological actions necessary to prevent the spread of the disease, as well as reduce stigmatization and discrimination against patients with tuberculosis, which will lead to an increase in patients' referral to medical and preventive institutions, and increase their treatment adherence.

METHODS AND MATERIALS

To achieve the research goal, a combination of qualitative and quantitative strategies was used. A prospective cohort study was carried out with the inclusion of a retrospective model and secondary analysis of information located in the databases of the national center for phthisiology, the Osh regional tuberculosis dispensary and the Karasuu tuberculosis dispensary. The following methods of collecting information were used for the study:

- 1 Analysis of documents and statistics: Within the framework of the study, an analysis of statistics relevant to the goals and objectives of the study was carried out;
- 2 Analysis of data from registration logs of TB patients TB02;
- 3 Analysis of the data of the electronic tracking database of RO AIDS and OOTSBS: Upon obtaining official access to the journals, all data were transferred to the developed database in Excel. As part of the study, data from 2017 -2019 of TB02 journals were analyzed;
- 4 A survey of patients with pulmonary tuberculosis was carried out to identify and determine the level and nature of stigma and discrimination in the treatment of DR tuberculosis.

The complexity of HIV/AIDS related stigma is often cited as a primary reason for the limited response to this pervasive phenomenon [9].

To determine the level and nature of stigma in patients and their relatives, a questionnaire was conducted among 100 newly diagnosed TB patients who were receiving anti-TB treatment and their analysis was carried out. Before the survey, informed consent was obtained from patients to participate in this study. The questionnaire consisted of sections:

- Socio-demographic characteristics of TB patients - 4 questions;
- Risks of TB - 18 questions;
- What measures did your family members begin to take after they learned about the disease - 8 questions;
- What measures did your family members begin to take after they learned about the disease -14 questions;
- External stigma-11 questions;

- Discrimination against PLHIV by organizations and institutions - 8 issues;
- Internal stigma - 7 questions;
- Self-discrimination of a TB patient - 10 questions;
- To eliminate stigma and discrimination against TB patients, 5 questions are required.

The median age of the patients was 36.5 years (age range 15-69 years). Most of the patients were male - 60.0%. All the data obtained were entered into excel and processed on a computer using a program for analyzing statistical information - epi info and Statistics 6.0 with the calculation of relative values (in shares %).

The following factors have been tested by scientists in different countries in diverse cultural communities and be important both for TB patients' access to health services and for treatment adherence. The question of the influence of social, cultural and economic factors on the success of the prevention and treatment of tuberculosis in the Kyrgyz Republic has been repeatedly raised in several domestic studies. At the same time, the characteristics and mechanisms of influence of such factors in cultural context of the Kyrgyzstan are still not clear; the values of individual factors on the effectiveness of tuberculosis treatment and prevention are not "weighed".

Meanwhile, this kind of analysis seems to be very relevant, since today, despite progress in the fight against tuberculosis, Kyrgyzstan is still among the 30 countries with the highest burden of multidrug-resistant tuberculosis (MDR-TB) in the world and is one of the 18 countries of high priority on TB in the WHO European Region.

Factors Affecting TB Patient Utilization and Treatment Adherence were subdivided into following levels:

Level 1 - socio-economic, cultural conditions and natural environment as risk factors

- the level of economic development of society (GDP per capita)
- migration processes
- TB incidence rate in the country

Level 2 - working and living conditions as risk factors

- income level/poverty
- employment / unemployment
- physical conditions of the dwelling (housing density, water supply norms and sanitation)
- imprisonment/homelessness

Level 3 - psychosocial risk factors

- social exclusion
- depression

Level 4 - individual lifestyle as a risk factor

- smoking/drug use
- alcoholism
- malnutrition, low body weight

Along with the indicated risk factors [10, 11] and conditions, it is customary to highlight the key biological risk factors: gender, age, employment. Research purpose is to study the manifestation of stigma and discrimination in patients with tuberculosis and to analyze the complexity of social and medico-biological actions necessary to prevent the spread of tuberculosis. The prevalence of HIV infection per 100,000 population in the Kyrgyz Republic as of January 1, 2021, is 157.5. Three regions occupy the first 3 places: Osh city 365.4, Chui region 288.4, Bishkek 205.

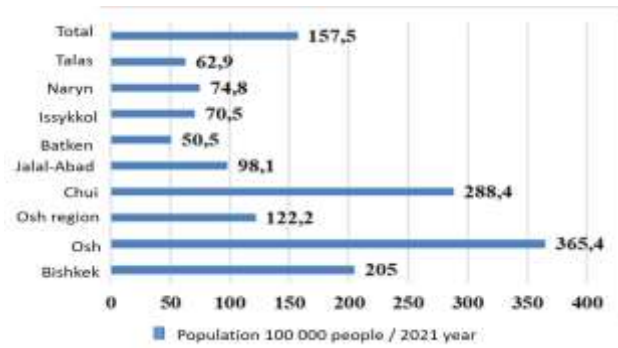


Figure 1: Prevalence of HIV infection in the Kyrgyzstan per 100,000 population (2021).

In the Kyrgyz Republic, as in the rest of the world, a decrease in the incidence and mortality rate from tuberculosis was noted over the past 10 years. However, the incidence of MDR-TB, both among newly diagnosed and retreated cases, is one of the highest in the world (27% and 60%, respectively, according to WHO data for 2016).

The main reasons for such a high incidence of MDR-tuberculosis are social, economic and medical factors. They relate to gaps in the quality of care at inpatient and outpatient levels.

Labor migration plays an important role in the deterioration of the epidemiological situation of tuberculosis in the country: there is evidence of a higher prevalence of TB among migrants, as well as a high proportion of late access to medical care, which leads to advanced forms of the disease. The second factor worsening the epidemiological situation is HIV-associated tuberculosis. The increase in the number of morbidity in patients with co-infection is associated with an improvement in the coverage of HIV-infected with dispensary observation, as well as an improvement in screening diagnostics in HIV-infected patients.

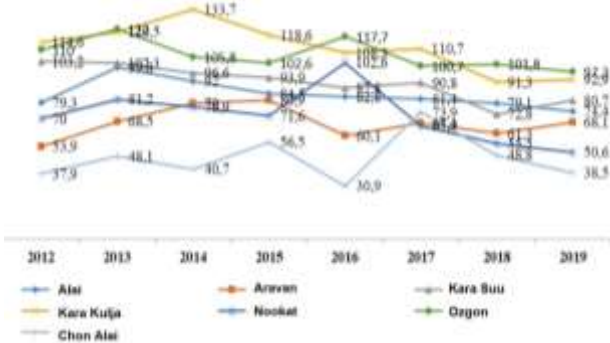


Figure 2: Tuberculosis incidence per 100 thousand population in Osh region, Kyrgyzstan.

Figure 2 analysis shows a tendency towards a pronounced decrease in the incidence in the Alai region from 114 to 92, in the Karasuu region from 103 to 80.1 and in the Uzgen region from 110 to 97, but in the Aravan region, one can see the opposite trend and an increase in the incidence from 53 to 68.1, a slight decrease in the disease in other regions. When analyzing the incidence of TB in the Karasuu region, there are positive shifts, but at

the same time, despite the positive changes in the epidemic process in the fight against tuberculosis, there are peculiarities in the development of the current epidemiological situation of tuberculosis.

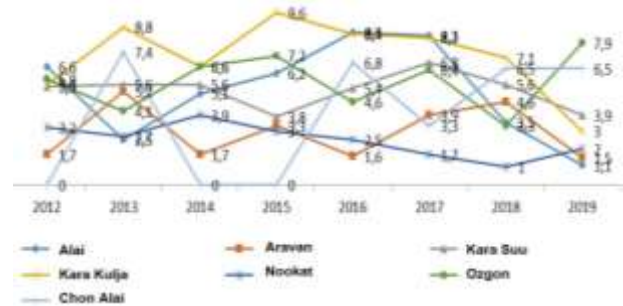


Figure 3: Mortality from tuberculosis for period 2012-2019 in Osh region, Kyrgyzstan.

Every year in the world, including in the Kyrgyz Republic, there is a tendency towards an increase in the incidence of drug-resistant tuberculosis. The number of patients with MDR-tuberculosis has increased by 47 times compared to 2005, and by 2 times compared to 2010. Assessment of stigma and discrimination in treatment of HIV + tuberculosis co-infection.

Table 1: Patients' socio-demographic characteristics.

Criteria	Patients	Abs.No.	B %
Sex	Males	60	60
	Females	40	40
Age	15-19	1	1
	20-29	26	26
	30-39	48	48
	40-49	19	19
	50 and older	6	6
Education	Secondary	53	53
	College	28	28
	Higher	19	19
Job	Full employee	26	26
	Part time	11	11
	Housewife, on maternity leave	12	12
	Full (self-employment)	8	8
	Casual / part-time jobs (self-employment)	3	3
	Unemployed	40	40

Semi-structured interviews were conducted with patients with HIV / TB co-infection, including those with interruptions in treatment for HIV or tuberculosis or interrupted treatment. Semi-structured interviews should be able to gain in-depth information on factors that influence the risk of delays in treatment, interruptions and disruptions from treatment, including groups of men and women. For a qualitative analysis of the data, a written transcript of all received records, notes of researchers and audio recordings of interviews were made. In the analysis of patients participating in the survey, men accounted for 60%, women - 40%. When distributed by age share was made up of young people of reproductive and working age. So the largest number were patients aged 30-39 years, in second place at the age of 20-29 years, in third place at the age of 40-49 years, and a small number in adolescence 1%

and 6% in middle age, i.e. e. 50 and older. More than half of the respondents, 53% had secondary education, 28% specialized secondary and only 19% had higher education. In a survey of respondents' employment, more than half of 55% are unemployed, 11% have part-time work and only 34% have full-time employment.

Table 2: Comparative characteristics of risks in patients with HIV / TB coinfection (men and women).

Comparative characteristics	Males	Females
Risk of getting ill	1	1
Risk of impoverishment	1	1
Risk of losing wage earner	1	
Risk of interruption of treatment due to hard physical labor	1+3	
Risk of interruption of treatment due to high reproductive activity		1
Reproduction prohibition		1
Risk of domestic violence and neglect		1
Risk of potency loss	1	
Risk of losing a partner/family		1+2
Suicide risk	2	2
The risk of social isolation	2	2
Risk of insults and humiliation and discrimination in public space	2	2
Risk of becoming of scammers victim	2	2
Risk of losing friends	2	2
Risk of job loss	3	3
Radiation risk	4	4
Risk of poor quality medical services	4	4
Risk of sexual harassment		4
Risk of medical service rejection for TB	4	4

According to the questionnaire survey, the risks compared in patients with co-infection of men and women. The risk level was determined on a subsequent scale: 1) moderate risk; 2) the risk is significant; 3) high risk; 4) the risk is very high. In contrast to women, men reflected the risks of losing the breadwinner status, interruption of treatment due to hard work, and the risk of losing potency. In contrast to women, men reflected the risks of losing the breadwinner status, interruption of treatment due to hard work, and the risk of losing potency. Women noted the risks of interruption of treatment due to high reproductive activity, prohibition on reproduction, domestic violence and neglect, sexual harassment and loss of a partner or family.

Other risks in men and women were similar and moderate risks voiced by patients - these are the risks of getting sick, becoming impoverished. Significant risks included - suicide, social isolation, becoming a victim of scammers, losing friends, as well as the risk of insults, humiliation and discrimination in public space. Job loss categorized as high risk, and men identified the risk of treatment interruption due to heavy physical labor. Both men and women identified the risks of radiation exposure, poor quality medical services, and the risks of refusing medical services for HIV or tuberculosis to be very high risks.

The family of a patient with HIV - infection or coinfection with HIV + tuberculosis is a key area, on which the timeliness of the patient's treatment, and the continuity of treatment, and the prognosis of recovery itself largely depend.

Table 3: What measures did your family members start to take after they learned about the disease

Measures	Males	Females
None	16	25
Become more attentive to my health (monitor nutrition, etc.)	24	17
More often offered their help	56	40
Always wash your hands before eating	56	38
They began to ventilate the room	54	31
I was freed from household chores	44	38
Regularly undergo fluorographic examination	54	39
I do less housework	51	38
Allocated separate dishes for me	36	38
They gave a separate room or part of the room, separating it with a screen or curtain	34	31
Do not buy meat, milk in spontaneous markets	24	23
They began to keep my things separate	24	22
Began to wear a mask	15	9
They began to make me wear a mask	11	9

In international research practice, the study of the behavior and relationships of family members of a patient with HIV infection or HIV/Tuberculosis co-infection, their strategies for adapting to the disease of a family member represents a whole layer of knowledge and becomes the basis for the development of special measures to support the family environment of a tuberculosis patient.

Family members providing home-based care for people with HIV / TB infection carry out a significant amount of work: they clean and process living quarters, prepare food, monitor the timeliness of food and medicine intake, and support the patient psychologically. As a rule, such a load is performed by women wives, sisters, mothers and daughters. Most often, women also take care of a seriously ill relative in a hospital. If a minor child falls ill in the family, the burden of caring falls mainly on the mother, as well as measures to prevent the disease among other family members. If an adult woman or an adult man falls ill in a family, then their children, especially daughters and/or daughters-in-law, bear full responsibility for the care and attention. One of the most critical is the awareness of the patient's family members and they noted how psychologically difficult it was for them to understand and accept the diagnosis, how they suffered, seeing the suffering of a loved one, cried, suggesting negative scenarios for the development of the disease.

After the relatives find out the diagnosis, many of them immediately change their usual way of life: they begin to pay more attention to sanitation and hygiene of the home, to be more tolerant and attentive to the patient, and to be more sensitive to the health of other family members, especially children. Thus, 41% of the patients surveyed answered that family members have become more attentive to their health. More than 90% answered positively to questions such as:

- offered their help more often
- always wash your hands before eating
- began to ventilate the room more often, freed me from household chores
- regularly monitored the fluorographic examination
- I do less housework.

- 2/3 of patients

When analyzing external stigma, they can be divided into 2 categories:

- they are conducted by family members
- and the people around.

Family Stigma:

1 The highest percentage belongs to psychological pressure from the partner 18%.

2 Sex partners in 15% refused to have sexual intercourse 15.1%

3 Not allowed to participate in family affairs 3%

Stigmas carried out by people around patient are:

1 Often, discrimination was carried out against the attitude of not only the patient but also all members of the household 16%.

2 Discrimination was carried out not only by the surrounding people but also sometimes by other patients 11%.

3 They insulted, learned about themselves gossip 16%.

4 Physically harassed and sometimes physically abused 1.9%.

5 They did not allow participation in meetings and other events 1%.

Both organizations and institutions are discriminating against patients with HIV / TB co-infection. The most frequently encountered is the refusal to find a job 14%. There were cases of dismissal from work 5.2% and if they did not dismiss, then they changed their labor duties 6.8%. As they lost their jobs, as well as stigma and discrimination from neighbors, they had to change their place of residence. They denied medical services, especially in private medical centers. In parallel with external stigma, internal stigma is often encountered. About 40% of patients felt guilty, ashamed and blamed themselves. Self-esteem decreased in 31% of patients, and a few patients blamed others for their illness 16 %.

CONCLUSION

Serious attention should be paid to the problem of stigmatization and discrimination among patients with HIV/TB co-infection by partners and close social environment, as well as discrimination against their family members. It is obvious that to reduce these negative manifestations, it is necessary to work in local communities (especially in rural areas) to raise public awareness. Strengthen work on the implementation of anti-tuberculosis programs, including educational work among the population at different levels.

Another relevant group is patients with HIV / TB co-infection who are subject to additional factors of stigmatization and discrimination (former and current injecting drug users, people with non-traditional gender identities, persons formerly in the penitentiary system).

Introduce counseling and training work with family members of a patient with HIV / TB co-infection. Correction of manifestations of internal stigma and self-discrimination

(especially self-limitation of access to health services), including taking into account gender and cultural characteristics, should become a separate topic of support for patients with HIV / TB co-infection. Implementation of the VOT program (via online video) in parallel with the DOT program.

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