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EVALUATION OF SOCIO-ECONOMIC FACTORS, INCLUDING GENDER-SPECIFIC FACTORS AFFECTING RECEIPT OF MEDICAL SERVICES BY TB PATIENTS IN THE KYRGYZ REPUBLIC

FOR USAID'S TB DEFEAT PROJECT

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Content

LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ATO	Anti–tuberculosis Organization
CCTC	City Center for Tuberculosis Control
CITI	Collaborative Institutional Training Initiative
FGD	Focus Group Discussion
FMC	Family Medicine Center
GDP	Gross Domestic Product
HIV	Human Immunodeficiency Virus
IRB	Institutional Review Board
KR	Kyrgyz Republic
MDR	Multidrug Resistance
MH	Ministry of Healthcare
NCP	National Center of Phthisiology
PH	Primary Healthcare
PNFA	Person of No Fixed Abode
RHP	Rural Health Post
RMIC	Republican Medical Information Center
TB	Tuberculosis
USAID	United States Agency for International Development
VHC	Village Health Committee
WHO	World Health Organization

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ACKNOWLEDGEMENTS

This report was commissioned by USAID's TB Defeat Project to expand the evidence base which will be the base for targeted interventions for elimination of a set of social, cultural and economic factors, including gender–specific ones that affect receiving medical services by tuberculosis patients and generally the effectiveness of the fight against tuberculosis in the Kyrgyz Republic.

The authors would like to express their appreciation for the ideas, time and other forms of support provided to the research team by specialists and staff of the USAID's TB Defeat Project: Ainura Ibraimova, Ainura Kadyralieva, Dilorom Kasymova, Aigul Alymkulova, Anara Kendjebaeva, Elmira Abdrakhmanova, medical staff of the Bishkek City Center for Tuberculosis Control (CCTC), Jalal-Abad City CTC, Tuberculosis Control hospitals in Kemin and the Bazar-Korgon rayons. In particular, we express special appreciation to the staff of the National Phthisiology Center (NPC) Atyrkul Toktogonova and Altynai Baytelieva, for their invaluable assistance in collecting field data, as well as to interviewers Sharipa Mamytova, Asel Shayildayeva, Giuliaym Toktogonova and Adinakhan Aldozova.

INTRODUCTION

Life circumstances of tuberculosis–afflicted people are often rooted in social problems not related to medicine. To date, healthcare programs in the sphere of prevention and treatment of tuberculosis accounted for the "social context" of patients in a discriminatory manner, attributing the risk of disease to vulnerable[1] groups of population and linking the increase in incidence with low awareness of the population. Specific policy measures to combat tuberculosis poorly reflected the diversity of social circumstances of patients' lives, inactively used the opportunities and rarely took into account the risks of social status, cultural patterns and value orientations of tuberculosis patients.

Draft Program of the Government of the Kyrgyz Republic on Public Health and Health System Development for 2019–2030 "Healthy person – a prosperous country" has significantly changed approaches to public health issues, having formulated the key goal as "strengthening people-centered systems that ensure public health and provide quality services aimed at maximizing the health of the population and individuals, reducing health inequalities, providing financial protection." The implementation of this goal is planned to fulfill a set of key tasks, including the development of the public health service, PHC, the improvement and rationalization of the hospital system and laboratory service. The tasks and principles planned by the Program are coordinated with the main international standards in the field of human rights to health, including the right to participate in health protection management.

In the international research practice of studying the extent of the spread of TB, the 4-tier model of determinants of health, developed by Swedish scientists G. Dahlgren and M. Whitehead[2], was widely used, which fixes the following significant factors for the spread of TB:

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

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

Level 2 – working and living conditions as risk factors

- level of income/poverty
- employment/unemployment
- the physical conditions of the dwelling (occupation density of housing, standards of water supply and sanitation)
- detention in prison/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

Also, along with these factors and risk conditions, it is common to identify key biological risk factors: gender, age, HIV status, diabetes.

[1] Persons belonging to social groups at high risk of tuberculosis: people of no fixed abode, migrants, refugees, internally displaced persons living in inpatient social services and social assistance institutions for persons of no fixed abode and occupation

[2] G. Dahlgren and M. Whitehead, "Policies and strategies to promote social equity in health," Institute for Future Studies, Stockholm, 1991, here cited from the source: The Impact of Socioeconomic Factors on Tuberculosis Prevalence in Latvia, available at https://pdfs.semanticscholar.org/1385/792c75fd51d05168e1c8e157090cb5320a31.pdf (retrieved on 26.02.2018). It is important to note that the article contains studies that tested the impact of all these risk factors in different countries' cultural contexts.

These factors have been tested by scientists from different countries in the context of diverse cultures of communities and have confirmed their importance both in TB patients turning to health services and in compliance to treatment.

The question of the impact of social, cultural and economic factors on the success of TB prevention and treatment in the Kyrgyz Republic has been repeatedly raised in a number of local studies[3]. At the same time, the characteristics and mechanisms of the influence of such factors in the cultural context of the Kyrgyz Republic are still not clear; the values of individual factors on the effectiveness of treatment and prevention of TB are not "weighed." Meanwhile, this kind of analysis is very relevant, since today, despite progress in the fight against tuberculosis Kyrgyzstan is still among the 30 countries with a high burden of multidrug-resistant tuberculosis (MDR-TB) in the world and is one of the 18 high priority countries on TB in the WHO[4] European Region.

Review of statistical data and the results of studies related to the incidence of tuberculosis in the Kyrgyz Republic make it possible to draw conclusions regarding the understanding of the socioeconomic factors of receiving medical services for TB patients:

1) Despite the decline in registered patients and mortality rates in the last 10 years, the incidence of MDR-TB among new and re-treated cases is one of the highest in the world (27% and 60%, respectively, according to WHO for 2016). The key reasons for the high incidence of MDR-TB are multiple factors, including those associated with gaps in quality of care at the inpatient and outpatient levels. These quality gaps lead to late detection of drug-resistant strains of TB, treatment with inefficient schemes, and a low rate of compliance to treatment among patients[5].
2) The burden of labor migration can manifoldly worsen the epidemiological situation of tuberculosis in the country: there is evidence of a higher prevalence of TB among migrants, as well as a significantly higher proportion of cases of tuberculosis[6] in this category of Kyrgyzstani citizens.
3) There is a gap in the incidence rate of men and women, as well as the possible gender differences in the rate of decline in morbidity in recent years. In particular, during the period from 2009 to 2016, a higher incidence rate among men persisted, but the decline was more dynamic among men (the rate of decline was 16 per 100,000 for men and 3.5 per 100,000 for women); thus, the ratio of the incidence rate of men and women slightly decreased. The incidence rate for men has been declining since 2013, while for women the incidence rate began to decline only in 2015 (see Figure 1).

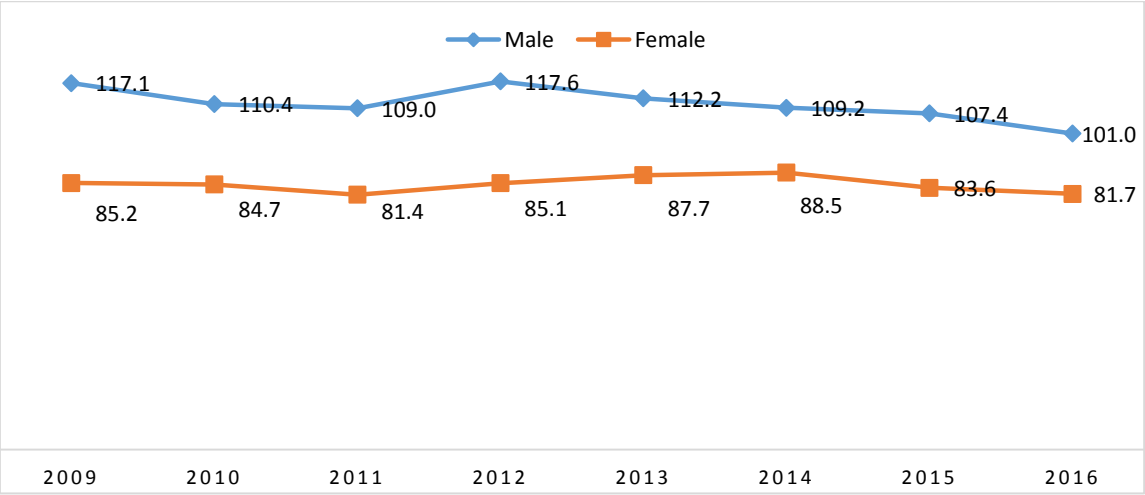
Figure 1. Gender disaggregated morbidity per 100,000 people. RMIC data

[3] Study of risk factors of lost to follow-up of DR-TB patients on second-line treatment: KNCV Surveys Results; What are diagnostic barriers among newly diagnosed Pulmonary TB patients in Kyrgyzstan: patient delay. S.Sokolovsky. Assessment of Gender Issues in the Kyrgyz Republic. Stop TB Partnership, 2016; and others.

[4] WHO. 2017. TB-REP mission to Kyrgyzstan, June 6-8, 2017 http://www.euro.who.int/ru/health-topics/communicable-diseases/tuberculosis/news/news/2017/06/tb-rep-mission-to-kyrgyzstan,-68-june-2017

[5] Technical report. Study of the medical care provided to patients with tuberculosis and their satisfaction in the Kyrgyz Republic. 2014, USAID - Center for Health Policy Analysis of the Kyrgyz Republic.

[6] 481 to 1,500 per 100,000, which is higher than the prevalence of tuberculosis in the countries of the Central Asian region. See in more detail: One-time study of risk factors of tuberculosis disease among migrants in Central Asian countries. Center for Global Health Studies in Central Asia - Columbia University, 2015



1) Statistics for 2009-2016 make it possible to note the unevenness of trends in reducing the incidence of tuberculosis in the regional context. In particular, the rate of decline in morbidity and mortality varies from region to region. For example, in Jalal-Abad oblast, the incidence rate was significantly lower in 2009 than in Osh, Naryn and Talas oblasts, but in 2016 the statistical picture in these three areas improved and in 2016 Jalal-Abad oblast shows the fourth highest incidence rate in the country, after Chui oblast and Bishkek and Osh cities (see table 1). During the analyzed period, the incidence rate was especially significantly reduced in Naryn, Osh, Batken and Talas oblasts; in Osh city and in Issyk-Kul oblast, the decline was slower. Such differences in the rate of change in the regional epidemic pattern for TB require additional detailed study and "weighing" of the influencing social and economic factors in each specific case[7].

Table 1. TB incidence rate dynamics by regions of the KR per 100,000 people. RMIC data

Region	2009	2010	2011	2012	2013	2014	2015	2016	Dynamics since 2009 until 2016
Batken Oblast	82,7	81,8	78,9	90,3	90	86,1	72,7	67,1	–15,6
Jalal-Abad Oblast	84,5	82,9	81,4	84,8	80,7	85,3	76,5	84,9	0,4
Issyk-Kul Oblast	67,4	67,1	67,7	70,1	70	64	58,5	60,4	–7
Naryn Oblast	98,6	103,5	95,2	105,1	90,5	98,2	84,8	77,3	–21,3
Osh Oblast	99,5	90,3	87	89,5	97,4	90,7	91,2	83,9	–15,6
Talas Oblast	98,8	105,9	107,9	96,9	106,5	101,9	95,9	83,7	–15,1
Chui Oblast	144,1	142,8	133,9	144	132,3	129,2	141,7	135,2	–8,9
Bishkek city	110,9	105	107,1	118,9	121,6	118,9	115,1	101	–9,9
Osh city	98,2	83,5	86	95,7	83	103,1	89,7	92,5	–5,7

2) The dynamics of mortality of TB patients is also uneven in the regions: the greatest decrease in mortality in recent years could be achieved in large cities – Bishkek and Osh, while in Naryn, Jalal-Abad and Talas oblasts, the rate of decline is relatively slow.

Table 2. TB mortality rate dynamics by regions of the KR per 100,000 people. RMIC data

Region	2009	2010	2011	2012	2013	2014	2015	2016	Dynamics since 2009 until 2016

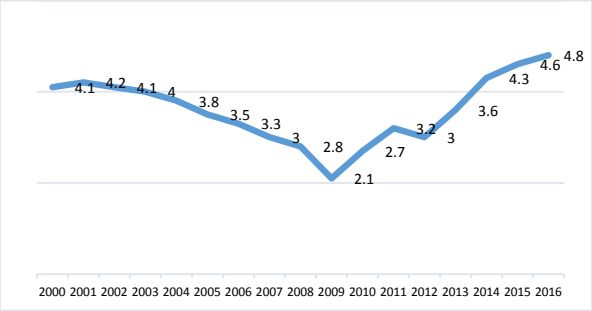
[7] in the scientific literature there is even evidence of dependence of the frequency and forms of tuberculosis on the regions of the republic. see A. Ibraeva, Reproductive function of women living with tuberculosis in Kyrgyzstan, 2012. Author's abstract of the dissertation for the Doctoral degree in Medicine. http://medical-diss.com/medicina/reproduktivnaya-funktsiya-zhitelnits-kyrgyzstana-bolnyh-tuberkulezom#ixzz58nFbj6Ja

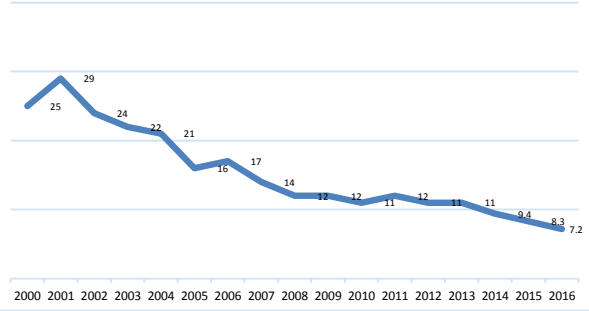
Batken Oblast	4,2	4,8	4,7	6,4	8,4	3,2	3,7	2,8	
Jalal-Abad Oblast									–1,4
Issyk-Kul Oblast	5,2	5,1	6,5	5,4	3,5	5,6	5,5	4,5	–0,7
Naryn Oblast	8,4	7,2	8,7	6	5,5	8	4,1	4,6	–3,8
Osh Oblast	7,7	7,7	12,5	12	10,4	5,9	8,7	7,2	–0,5
Talas Oblast	7,2	5,2	4,8	4,7	4,7	4,9	4,7	5	–2,2
Chui Oblast	8,8	11,7	12	10,5	9,5	7,3	5,6	7,9	–0,9
Bishkek city	11,8	13,2	15,3	13,6	13,6	10,6	10,5	9	–2,8
Osh city	14,4	13,9	11	10,2	10,4	7,3	5,9	5,8	–8,6
	10,4	11,7	7	10,1	8,8	8,6	6,2	4,3	–6,1

3) Kyrgyzstan is one of the countries with a high combined level of tuberculosis and HIV infection. The statistics show that since 2000, there has been no steady decline in the prevalence of TB among HIV-infected people, and there has been steady growth in the last three years. Experts from the Association of the harm reduction program "Partner Network" believe that although "tuberculosis remains the leading cause of death among HIV-infected people, half of cases of tuberculosis leading to death remain unidentified."

Figure 2. Prevalence of TB + HIV in Kyrgyzstan per 100,000 people. WHO data

Figure 3. Mortality from TB in Kyrgyzstan per 100,000 people. WHO data





4) A number of academic studies have focused on investigating the impact of socio-demographic factors, individual lifestyle on the incidence and treatment of TB[8] in Kyrgyzstan, and provide evidence of how poor nutrition and plight were significant factors in the spread of TB in sample groups. They, in particular, provide data on the risks of childhood and adolescent tuberculosis incidence and the instability of statistics on diseases in these categories of patients[9]. Due to a number of factors, especially psychosocial studies in Kyrgyzstan, there was almost no research, except for the study of the homeless population group, in which the issues of depression and social exclusion did not act as a background factor in the history of the disease[10].

The main objective of this study is to identify the impact of socioeconomic and cultural factors, including gender relations, on the behavior of TB patients and MDR-TB patients and their decisions regarding their health, which implies active seeking medical help, diagnosis, counseling, treatment and compliance to treatment.

[8] For example, E. Moldobekova. Epidemiological features of the incidence of tuberculosis in urban residents and the organization of treatment and prevention activities at the level of primary health care. Thesis for the Doctoral degree in Medicine. Bishkek, 2014

[9] This is also evidenced by the speeches of responsible health workers in the media https://24.kg/zdorove/6928_tuberkulez_borba_postfaktum/ ; https://ru.sputnik.kg/video/20170605/1033692363/deti-v-bishkeke-vse-chashche-boleyut-tuberkulezom-sanehpidnadzor.html . The authors of this report did not have access to statistics on the age cohort of patients.

[10] E. Moldobekova. Epidemiological features of the incidence of tuberculosis in urban residents and the organization of treatment and prevention activities at the level of primary health care. Thesis for the Doctoral degree in Medicine. Bishkek, 2014

The logic of this report is based on a detailed study of the set of challenges, barriers, discrimination and stigma that are encountered by a patient with TB during the "disease – tuberculosis treatment" life cycle and in relation to which they develop "survival strategies" in the following key institutional environments/zones:

A) family and family environment,

B) local community (neighborhood or any other type of social organization of everyday contacts and relations in the area of residence),

C) work collective or sphere of employment,

D) the scope of obtaining medical services.

The authors of the report used the concept of risks and insecurity to analyze the set of challenges and discrimination of a TB patient and tracked the risks associated with each of the above institutional environments in a patient's life.

One of the key aspects and innovative components of this study is the calculation of standardized indicators of stigma on the scales "attitude of patients" and "attitude of the local community" to tuberculosis patients[11]. The definition of indices allowed a deeper exploration of the psychosocial factor component, including stigma and (self)stigmatization in the TB patients' environment.

STUDY METHODOLOGY

To achieve the research objective, the project used a combination of qualitative and quantitative strategy and used the following methods of information collection:

1. Analysis of documents and statistics

In the framework of the study, an analysis of normative legal acts, research projects, statistics, relevant to the goals and objectives of the study was carried out.

2. Analysis of the data of the TB Patients TB02 registration log

The analysis of the logs made it possible to study the sex–and–age and territorial differences in the time between obtaining the analyses results and initiating the treatment of various groups. With official access to the logs, the researchers moved the log data to the developed database in Excel format in medical institutions. Within the framework of the research, the 2016 data from six TB02 logs were analyzed:

– FMC #14, Bishkek

– FMC #1, Bishkek

– Log of registration of people belonging to the "of no fixed abode" category in the Bishkek City CTC

– JAOCTC named after Bauer

– Log of registration of Patients with TB in Bazar-Korgon rayon, Jalal-Abad Oblast

– Log of registration Patients with TB in Kemin rayon, Chui Oblast

3. Survey of the population having experience of treatment/prevention of tuberculosis

[11] the methodology for calculating indices was borrowed from international practice. For more details on the methodology, see the appendix.

The survey of the recipients of the services allowed collecting and analyzing information on the respondents' value judgments about the quality of the work of medical workers in the performance of state functions, the level of stigmatization and empowerment[12] among people with TB.

The study covered four regions of Kyrgyzstan – the cities of Bishkek and Jalal-Abad; Chui (Kemin rayon) and Jalal-Abad Oblast (Bazar-Korgon rayon). Data collection took place from August to September 2017.

City/rayon	Place of data collection
Bishkek city	NCP, CCTC
Kemin rayon	Republican hospital of palliative care for TB patients, FMC of Kemin rayon
Jalal-Abad city	JAOCTC named after Bauer, City Tuberculosis Dispensary, FMC #1, 2, 3, 4, 5
Bazar-Korgon rayon	FDG #9, FMC of Bazar-Korgon rayon, Bazar-Korgon Tuberculosis hospital

A total of 320 respondents were interviewed among the population groups experienced in the treatment of tuberculosis or members of their families: 80 respondents in each sample region with equal distribution by sex. All respondents were selected by the convenience sampling method with the help of medical personnel, VHC members and other community activists.

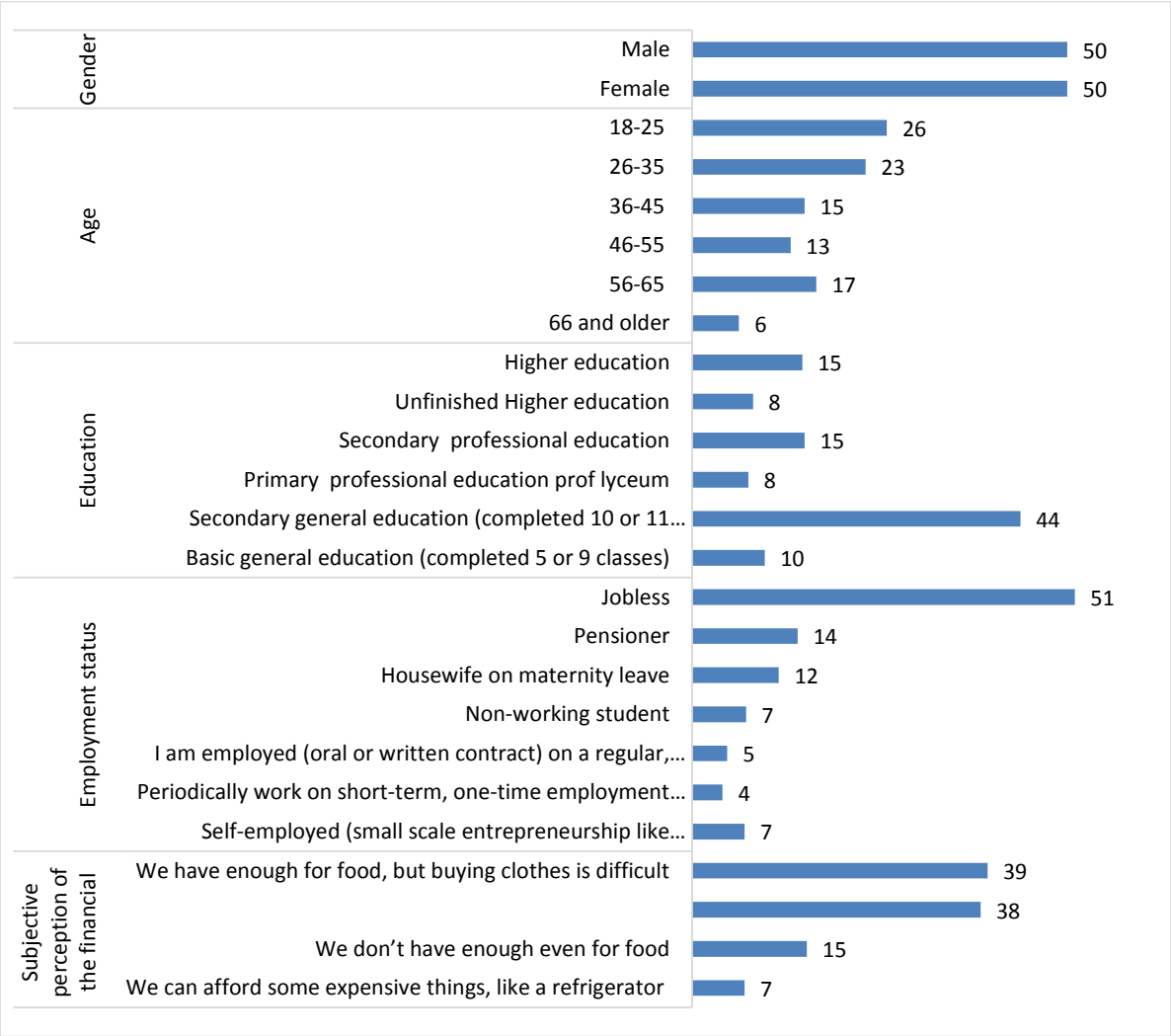
To measure the level of stigmatization in the survey, the "Tuberculosis-related stigma" scale, developed by a group of scientists in 2008 and tested in a number of countries[13], was used. In addition to the Stigma Scale, the Empowerment Scale[14] was also calculated during the data analysis (for more details and the procedure for calculating both scales, see Appendix 1). The questionnaire was designed in Russian and translated into Kyrgyz. Both versions were used in the survey, depending on the preferences of the respondent.

Figure 4. Socio-demographic characteristics of respondents who took part in the survey (%), N=320

[12] In recent decades, the term empowerment, which is translated into Russian as "widening of rights and opportunities" is increasingly being used in international development policies and in strategies to combat poverty. There are many definitions of the term and different definitions have a common approach: empowerment refers to the process of people's awareness of the possibilities and responsibility for actions in the interests of their own health or other issues important to their lives and actually participating in the planning process

[13] Van Rie, A., Sengupta, S., Pungrassami, P., Balthip, Q., Choonuan, S., Kasetjaroen, Y., Strauss, R. P. and Chongsuvivatwong, V. (2008), Measuring stigma associated with tuberculosis and HIV/AIDS in southern Thailand: exploratory and confirmatory factor analyses of two new scales. Tropical Medicine & International Health, 13: 21–30. doi:10.1111/j.1365-3156.2007.01971.x http://onlinelibrary.wiley.com/doi/10.1111/j.1365-3156.2007.01971.x/full

[14] Koren, P. E., DeChillo, N. & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. Rehabilitation Psychology, 37(4), 305-321.



4. Semi-structured interviews with service providers

In each village semi-structured interviews were conducted with representatives of medical institutions working in the field of facilitating access to medical services for TB and MDR-TB patients, such as nurses of DOT offices, family doctors, phthisiologists and feldshers in the RHP. Interviews with service providers made it possible to assess the quality of the work of medical staff in the provision of services.

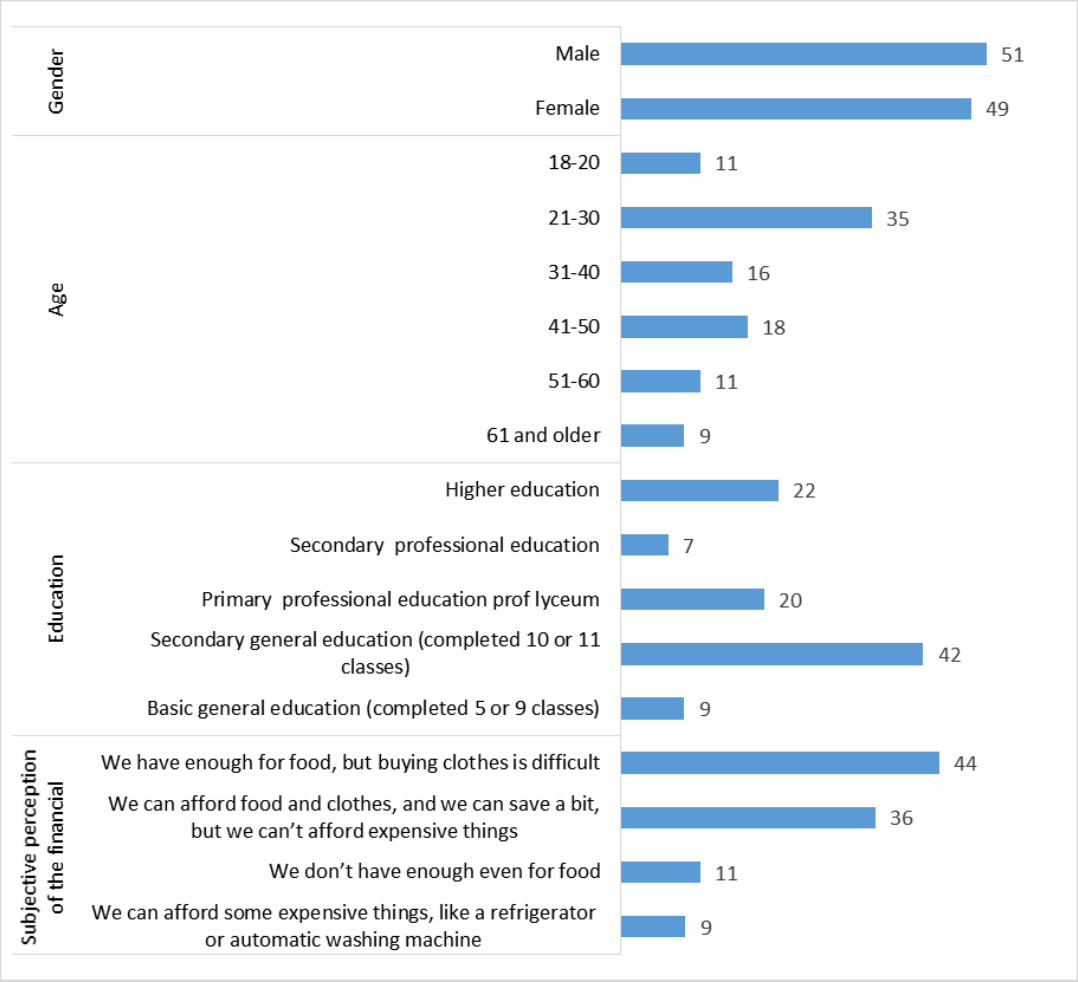
In general, 20 semi-structured interviews with service providers were conducted. The selection of respondents was carried out by the method of judgments about the expert's competence level.

For qualitative analysis of the data, a written decoding of all received records, notes of researchers and audio recordings of the interview was done.

5. Focus-group discussions (FGD) with patients/persons cured of TB, or having experience in the treatment of tuberculosis

FGD allowed to obtain in-depth information on the main tasks of the study. In total, 4 FGDs were conducted: 2 FGDs were organized and conducted in the cities of Bishkek and Jalal-Abad (separately with men and women). All respondents were selected by the convenience sampling method with the help of medical personnel, VHC members and other community activists. All discussions were audio-recorded for further analysis. Also, the decoding of audio recordings of all conversations was carried out, which was used for qualitative data analysis.

Figure 5. Socio-demographic characteristics of FGD participants (%), N=45



6. Semi-structured interviews with patients who have interruptions in the treatment of tuberculosis or who have interrupted treatment

The interviews provided in-depth information on the factors that affect the risk of late treatment, interruptions and disruption of treatment, including groups of men and women. In total, 8 semi-structured interviews were conducted: 2 in each region (1 with a man and 1 woman). For qualitative data analysis, a written decoding of all received records, notes of researchers and audio recordings of the interview was done.

7. Semi-structured interviews with family members of people with TB

The interview provided in-depth information on the facts of discrimination and stigmatization of people with TB. In total, 8 semi-structured interviews were conducted: 2 in each region. All respondents were selected by the convenience sampling method with the help of medical personnel, VHC members and other community activists. For qualitative data analysis, a written decoding of all received records, notes of researchers and audio recordings of the interview was done.

ETHICAL EXPERTISE

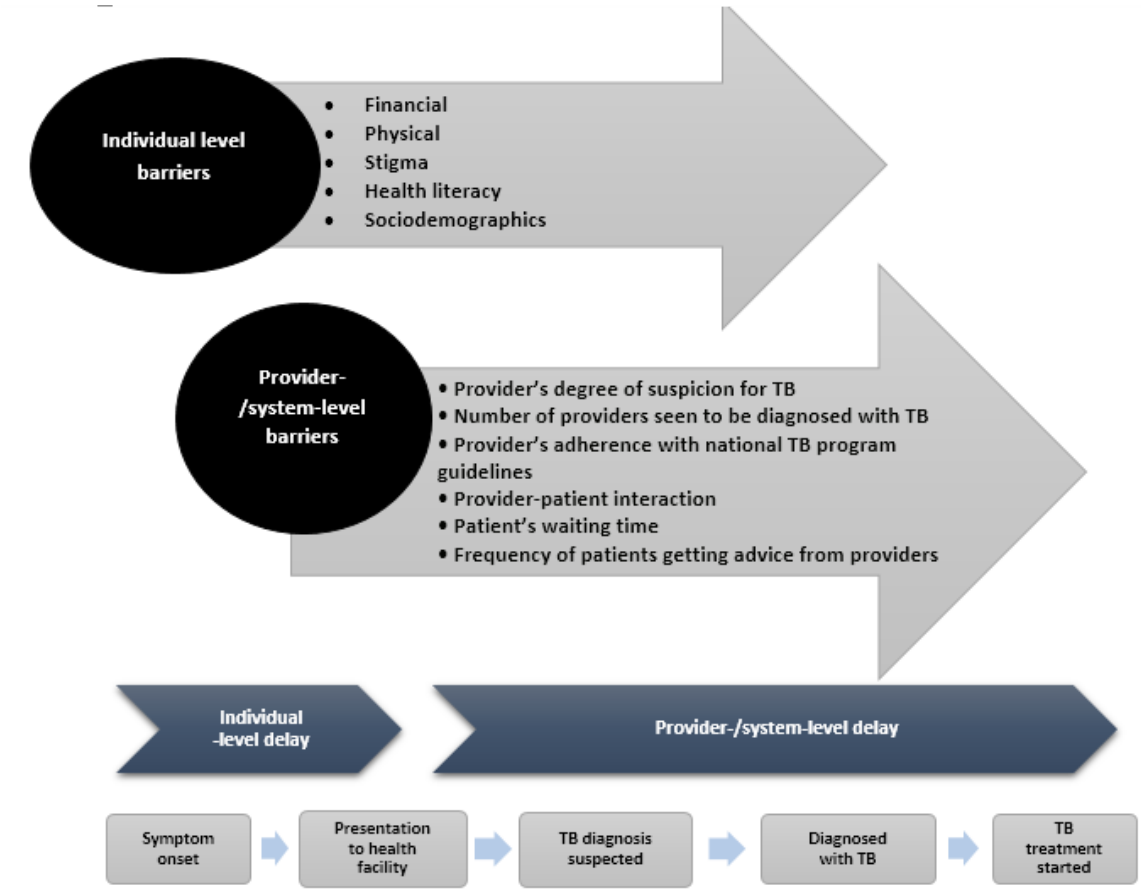
Two positive conclusions of ethical examination were received for the study due to the special sensitivity of the research subjects. The first approval of the ethical committee after consideration of all the necessary documents was received from the ethical committee at the research and production association "Preventive Medicine" MH KR (extract from protocol No. 3 as of June 9, 2017). Further documents for the study were submitted to the Abt Associates Institutional Review Board. Only after receiving the final approval from the ethical committee in the United States (Abt IRB #: 0947) was the full-scale study started. Also, it should be noted that the entire research team, during the course of the

ethical examination at the IRB, received CITI (Collaborative Institutional Training Initiative) certificates, indicating the successful completion of the course on ethical principles of the study.

LIFE ENVIRONMENT OF A TB PATIENT: (IN) SECURITY AND LIFE STRATEGIES

The study of barriers and delays in the provision/receipt of medical services for TB patients in international practice presents the following conceptual framework:

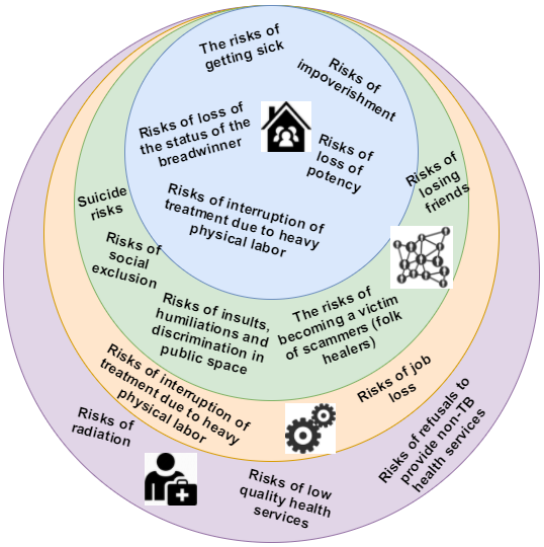
Figure 6. Conceptual framework illustrating barriers and delays that limit access to diagnostic assessment and treatment of TB[15].

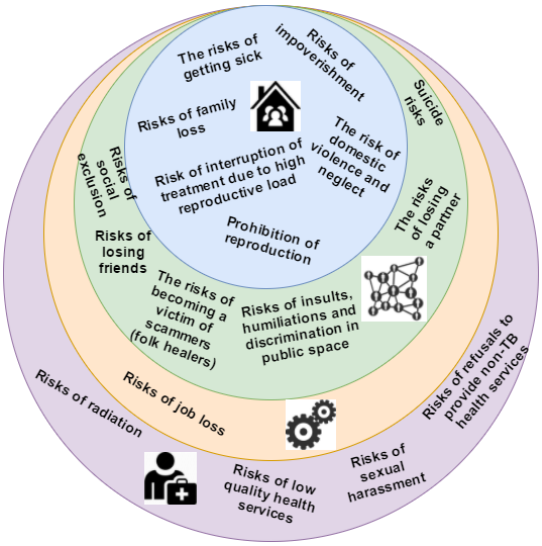


The data of our study showed significant variability in barriers and delays, depending on such socio-demographic characteristics as gender, region of residence, and sometimes family status. On the basis of subjective assessments and the described personal life experience of the respondents of this study, the risks and (in)security of men and women with TB in the institutionalized spheres allocated for analysis and significant for a patient were schematically visualized as follows:

Figure 7. Risks and (in)security of male (on the left) and female (on the right) TB patients in different institutional environments.

[15] Wei-Teng Yang, Celine R. Gounder, Tokunbo Akande and others. Barriers and Delays in Tuberculosis Diagnosis and Treatment Services: Does Gender Matter? Hindawi Publishing Corporation, Tuberculosis Research and Treatment. Volume 2014, http://dx.doi.org/10.1155/2014/461935





Family

The family of a patient with tuberculosis is a key area on which the timeliness of the patient's treatment, and the continuity of the treatment, and the prognosis of recovery largely depend.

In international research practice, studying the behavior and attitudes of family members of a patient with tuberculosis, their strategies for adapting to a family member's illness, represents a whole layer of knowledge, and becomes the basis for developing special measures to support the family environment of a TB patient[16]. In the present study, the respondents, members of a TB patient's family, were also included in the sample, and the data obtained for the first time in the Kyrgyzstani context raise the most problematic and risky areas for adaptation of a patient and his/her family environment to illness and treatment.

Family members providing care for TB patients at home, carry a significant burden: clean and cleanse the living quarters, prepare food, monitor the timeliness of food and medicine intake, support the patient psychologically. This load, as a rule, is performed by women – wives, sisters, mothers and daughters. Care for a seriously ill relative in a hospital is most often done by women. If a minor child is ill in a family, the burden of care mainly falls 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 care and tendance.

One of the most critical is the awareness among family members of a patient with tuberculosis, because a correct understanding helps them not only to reduce the risks of spreading the infection, but also improves the psychological atmosphere and stimulates proper treatment. It is important to note that almost all interviewed respondents – relatives of TB patients – noted how psychologically it was difficult for them to understand and accept the diagnosis, how they suffered, seeing the sufferings of their close one, wept, anticipating negative scenarios of the disease development. As one respondent from Kemin noted: *"It was very difficult for us, we were shocked. When a person first hears this, it's very scary, it turns out. Not only me, my husband himself hardly walked. We all cried for a whole month. About a month we cried, thought that people with this diagnosis do not live, we thought that he would die. Then*

[16] Joyce T. Sukumani, Rachel T. Lebese, and others. Experiences of family members caring for Tuberculosis patients at home at Vhembe district of the Limpopo Province. https://curationis.org.za/index.php/curationis/article/view/54/47 ; Samal J, Dehury RK. Role of families in tuberculosis care: A case study. Muller J Med Sci Res 2016; 7: 150-2.; Samal J. Family perspectives in the care and support of tuberculosis patients: An Indian context. J Assoc Chest Physicians 2017;5:67-9.

we heard that even cancer can be cured, and that this disease is curable. Only after this we... Now we are already used to it, but for 2-3 months we were suffering"[17].

After relatives find out about the diagnosis, many of them change their habitual way of life immediately: they pay more attention to sanitation and hygiene of the home, are more tolerant and attentive to the patient, more sensitive to the health of other members of the family, especially children. As one of the respondents (Kemin), the wife of the ill man, described, for the first time she and her daughter did not just "scrub" the house every day, but they also soaked the patient's clothes in chlorine without end. The woman noted that later many of her husband's clothes were unsuitable for wearing. At the same time, some respondents noted in their interviews that they did not allocate separate dishes, towels and a room for a family member suffering from tuberculosis, because it felt awkward, although they considered such measures mandatory. Thus, the respondent from Bazar-Korgon, the daughter of a man with tuberculosis, admitted that despite the patient's requests, she does not separate his dishes and seats him to eat with all members of the family, so as not to offend his feelings: *"He himself began to separate from others. I tell him, father, do not do this. And he objects, tells us to separate his dishes. I do not listen to him, if I put his dishes separately he can think to himself... So I mix his dishes with ours. I do not separate"*[18].

Almost all respondents – relatives of TB patients – are poorly informed about the details of the diagnosis and treatment of their ill family member, do not fully understand the importance of timely intake of medications, the inadmissibility of interruption, as well as the prognosis of the treatment duration. Only one respondent – the wife of the TB patient, who turned out to be a certified nurse – knew all the details and nuances of diagnosis and treatment of the disease. Despite her husband's steady form of TB, they managed to achieve recovery, and the woman is sure that this is due to strict treatment regimen. She herself did injections and drips to her husband, gave pills according to the schedule, took him for analyses/tests on time to track the dynamics, tracked the weight and other symptomatic characteristics of the effectiveness of treatment. The woman remembers that more than once did the man want to stop taking pills because of side effects (severe nausea), but she always persuaded him to continue treatment.

The family role of a TB patient and his/her social status determine the attitude and involvement of the family circle in diagnostics and treatment. If a husband falls ill in the family, the whole family "gets sick" and empathizes, "endures" his mood worsening, and the work load of women and girls is increased to provide sanitization for the home in order to prevent tuberculosis among other family members.

Interviews with TB patient's family members showed that they may experience shame, resentment, guilt for their relative's illness, and sometimes anger. It is especially difficult for family members to accept the situation when, despite their efforts to care for a sick relative, the condition of a close one may worsen. For example, one of the respondents (Bishkek) is forced to take care of her seriously ill sister in the hospital. She regretfully said that the sister has been treated for several years now and is now in very serious condition. The respondent was concerned that there was a risk of getting sick herself, noted that she had small children and a husband who constantly warned her about the rules of hygiene and prevention of infection. She also admitted how psychologically difficult it is to take care of seriously ill relatives: *"My sister has become more nervous since she fell ill, she curses a lot. Capricious. She gets worried and nervous because of little things. It's hard for me, too. For example, my health is normal, when I take care of her, she does not allow me to go outside. But I want to go outside, I am*

[17] Аявай жаман болдук, шок болдук. Биринчи укканда аявай жаман болот экен киши. Ии мен эмес куйөм өзу аран жүрдү, биз баарыбыз ыйлап эле калганбыз бир айдай. Бир айдай ыйлап жүрдүк биз ойлогонбуз, ии муну менен вообще жашабайт го, өлуп калат го деп ойлогонбуз. Анан кийин эле угушубузча мындан дагы рак айыгат экен, бул оору деле айыгат экен дегенде гана биз өзүбүз эметип калдык. Азыр көнүп калдык, а так 2-3 айдай вообще кыйналып жүрдүк.

[18] өзүнөн өзү бөлүп баштады. Анан мен айтам, ата, койңузчу, антпеңиз, ушинтип эме кыламда. Антсең деле, жок дейт, силер жан нерсесиңер, кой менин идишимди өзүнчө бөлүп кое бергиле деп. Мен ага эме кылбаймда, бөлүп койсом, мисалы атам ичинен дагы ойлонот. Анан мен аралаштырып эле эме кылам. Мен мисалы, бөлбөйм..

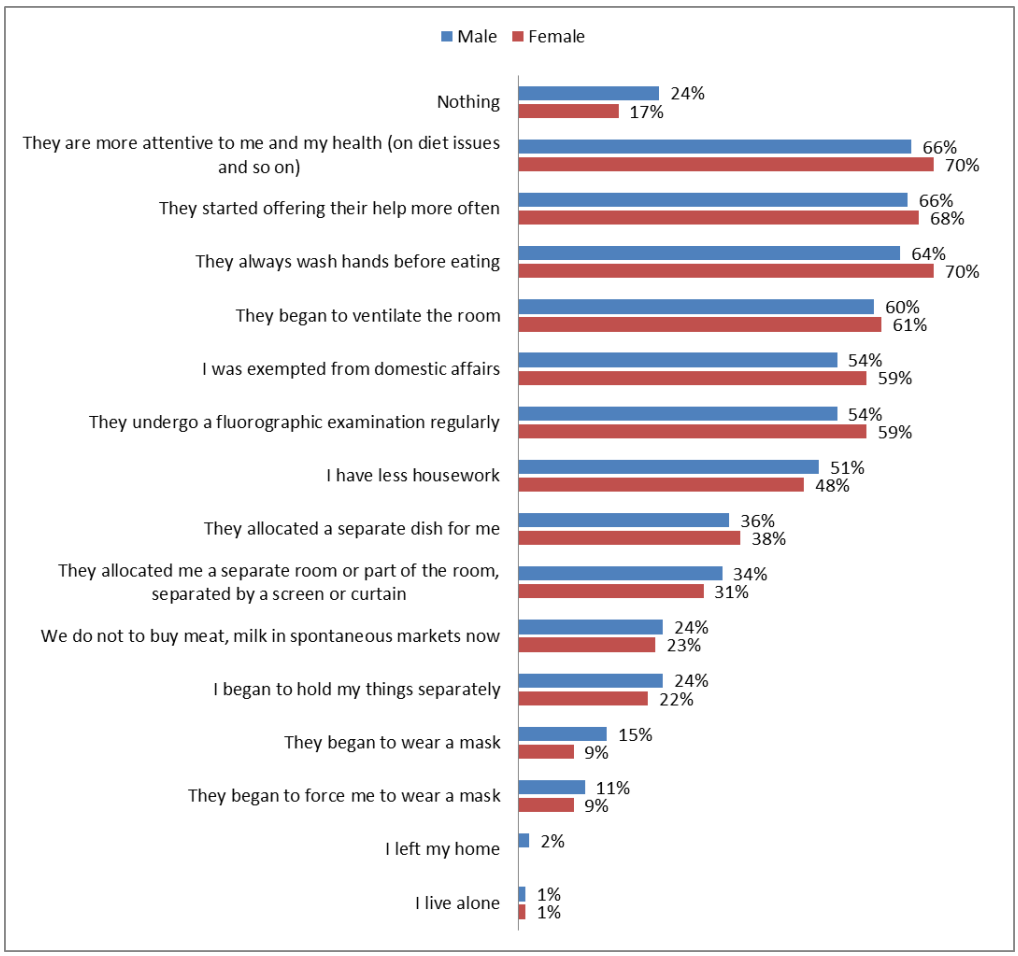
healthy after all. I think to myself – you are sick and suffering, and so you do not go outside, but I'm healthy. How can I not go outside?! I don't tell her, I'm just thinking to myself"[19].

The expectation of participation and the patients' perception of the contribution of family members to their recovery often differ from the perception of their family circle that cares for them. So, for example, the perception of a patient's relatives about the measures being taken is a picture of serving and self-sacrifice, which does not include questions of care for their own health, nor questions about the labor contribution of the patient.

To the question about measures taken by family members after they learned about the disease respondents from the TB patient category presented the following range of responses (see Figure below): a) strengthening measures on preventive healthcare and to prevent infection (a more thorough approach to sanitation, hygienic measures – washing hands, ventilating the premises, requiring/adherence to wearing a mask, as well as separating the dishes and the patient's living space from the rest of the family, more frequent medical monitoring of the health of family members); b) provision of a "preferential" household work regime for a sick family member; c) demonstration of caring for the patient and psychological support for him/her (offering help, caring for the patient's nutrition, etc.). It is interesting that the respondents gave a little more attention to such responses as: they began to keep my things separate, gave me a separate room, began to wear a mask, began to force me to wear a mask... Women emphasized measures such as: release from domestic affairs, washing hands before meals, a more attentive attitude to the health of the patient and caring for her...

Figure 8. Responses to the question: "What measures did your family members take after they learned about the illness?" (N=313, except for 7 respondents who answered "I live alone" and "I left home," men N=155 and women N=158)

[19] Эжем ооруганы көп нервтенет, урушат. Капризная. Кичине нерсе болсо кайгырып калды. Мага дагы кыйын. Мисалы, менин ден соолугум нормальный анан мен карап жатканда ал мени эшке чыкпа дейт. Менин ден соолугум болгондуктан мен эшике чыккым келет ал жак бул жактарга баскым келет. Анан мен ичимен айтам сиз го ушинтип ооруп кыйналган үчүн айла жок чыдап атам деп. Менин ден соолугум нормальный кантип эшике чыкпайм. Айтпам просто ичимен ошентип ойлоном..

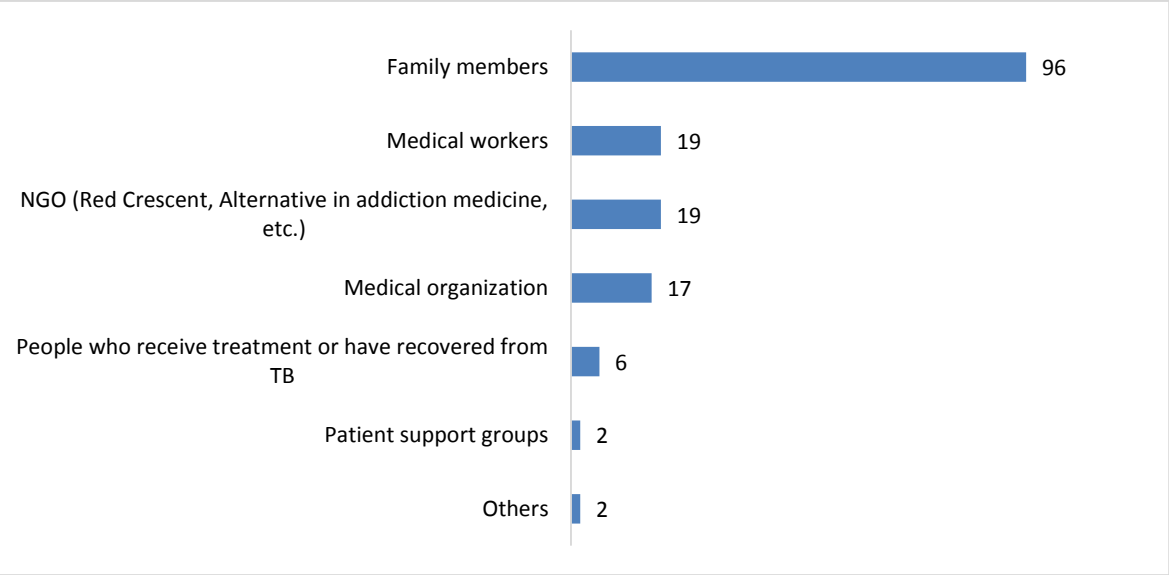


A significant proportion of the information obtained in our study describes the perception and attitude of a TB patient to their family environment. The overwhelming majority of respondents said that the family[20] was a "fortress" for them, hiding from stigma and discrimination of the outside world, the family provided tendance and care for the patient.

First of all, the respondents noted the material and financial support of the family, without which the patient with tuberculosis, being the breadwinner of the family, could not survive during the (partial) loss of ability to work. Among all the subjects who provided material assistance, it is family members who are the most significant support structure in all regions, on average for 96% of respondents.

[20] Respondents sometimes included only the closest circle of blood relatives in the scale of the family, sometimes the family acquired the character of an extended group of relatives, including cousins and second cousins.

Figure 9. Who helped you financially when you found out about your diagnosis? (N=288, the number of respondents who answered that they were helped financially) (%)



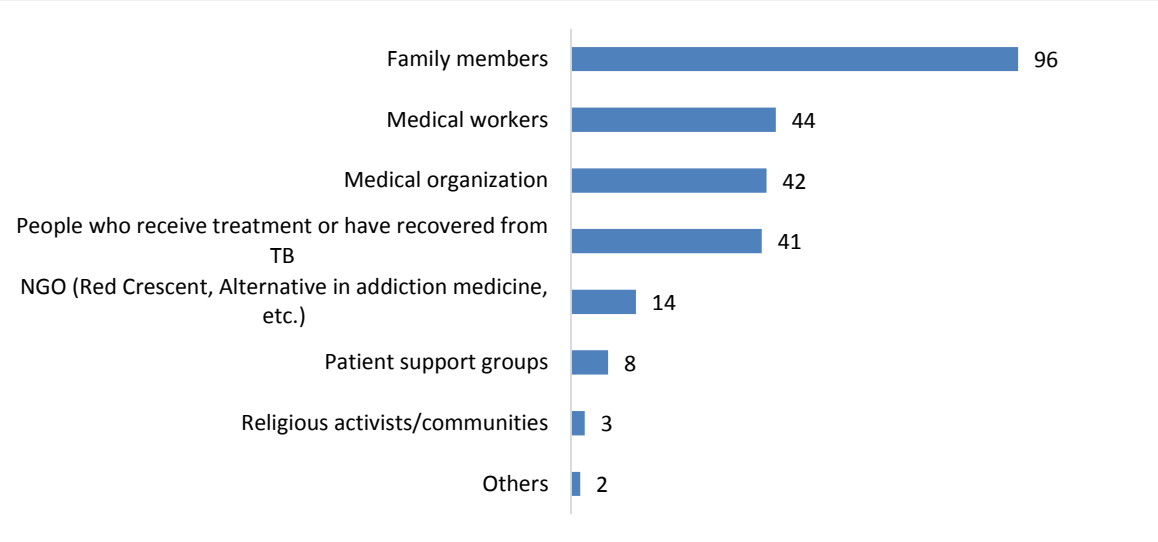
The breakdown for patients who received only outpatient or only inpatient treatment, and those who received both types of treatment, indicates that TB patients receive assistance both in inpatient treatment and in outpatient or mixed care, primarily from family members. The family helps financially in almost 100% of cases of inpatient treatment and at the level of 96–97% in the case of outpatient treatment, that is, the illness of a family member becomes a financial burden for his family. In the interview, respondents were informed that in cases when the main breadwinner in the family was ill (mostly the husband), the parents of the wife provided material support to the whole family of the sick. Also, often the material support of the patient and his family is carried out by brothers and sisters on both sides.

Table 3. Who supported you financially when you have learnt about your diagnosis? (%)

	Men			Women		
	Only outpatient treatment (N=26)	Only inpatient treatment (N=27)	Outpatient and inpatient treatment (N=86)	Only outpatient treatment (N=37)	Only inpatient treatment (N=26)	Outpatient and inpatient treatment (N=86)
Medical workers	2	9	25	5	13	14
Family	25	27	80	36	26	83
People who receive treatment or have recovered from TB	1	1	9	2	1	3
Patient support groups	0	1	2	2	0	1
NGO (Red Crescent, Alternative in addiction medicine, etc.)	3	6	19	4	2	22
Others	1	0	5	0	0	2

The majority of respondents received psychological assistance from various sources, however, in this case, as well as with material assistance, the main support was provided precisely by the members of the family[21] (96%).

Figure 10. Who helped you psychologically when you found out about your diagnosis? (N=301, the number of respondents who answered that they were helped psychologically) (%)



The assessment of psychological support of the family given by TB patient respondents, taking into account the type of treatment – inpatient, outpatient or mixed – is as follows:

Table 4. Who helped you psychologically when you have learnt about your diagnosis? (%)

	Men			Women		
	Only outpatient treatment (N=29)	Only inpatient treatment (N=28)	Outpatient and inpatient treatment (N=91)	Only outpatient treatment (N=39)	Only inpatient treatment (N=24)	Outpatient and inpatient treatment (N=90)
Medical workers	12	16	47	19	21	51
Family	29	28	82	38	24	87
People who receive treatment or have recovered from TB	9	15	43	10	8	39
Patient support groups	0	2	11	3	0	9
NGO (Red Crescent, Alternative in addiction medicine, etc.)	3	4	16	3	1	15
Others	0	1	6	2	0	2

Thus, according to the respondents' estimates, the family provides financial and psychological support equally.

The respondents' high assessment of the psychological help of the family paradoxically does not exclude the problems of discrimination, psychological pressure on the patient within the family. So, for a young man, tuberculosis is associated with the risk of losing/destabilizing the status of the breadwinner, the head of the family and feeling guilty. In the focus group in Bishkek, a young man said that he feels very

[21] In general, apart from the family, three other main sources of psychological assistance were noted: a medical worker in PHC (44%), a medical organization (42%) and people who receive treatment or were cured from TB (41%). The highest proportion of respondents who noted a medical worker and a medical organization as one of the main sources of psychological support is in Kemin rayon and Jalal-Abad city, and the smallest in Bishkek.

uncomfortable, because not bringing money home, he feels the need for at least a participation in the household in terms of labor contribution. But the performance of heavy physical work around the household (chopping wood, bringing water from a stand pipe, putting away hay, etc.) is also problematic for him because of taking medication, or rather – it requires a special mode of work and rest. Because of the complexity of explaining this situation to his relatives, the sick man feels guilt and rejection. Respondents in the Bishkek's male focus group confirmed that when they had to sleep during the day after taking medication, often family members perceived it with a lack of understanding, negatively, as confirmation of their laziness, idleness.

If a young woman – a daughter-in-law – gets ill, the family circle may not be loyal to her and even exercise violence: daughters-in-law talked about their mother-in-law's attempts to drive the sick women out immediately after diagnosing the illness or increasing discrimination and violence during the treatment, including *prohibition of reproduction*, *economic violence* (do not give money for transportation costs or for radiographic examinations and other expenses for medical services), *physical violence* (doctors talked about scandals and beatings of women by their husbands even in the hospital under the pretext that they are hospitalized to take time off from homework), etc. In some cases, when a young woman was very ill, she was sent to the home of her parents or siblings who were taking care of them.

For a young woman, her family roles particularly affect the timeliness of access to medical services and treatment. Among the respondents of our study, the presence of young children became a critical factor for a young woman: some women could not go for examination and subsequent hospitalization or full-time outpatient treatment because they had no one in their family to entrust the care for their young children. At the same time, the presence of small children in some cases forced the woman to fight for the right to go to a tuberculosis hospital due to fear of infecting children if she was treated at home. Fear of infecting children reinforces (self)stigmatization and psychological suffering of women with tuberculosis.

Thus, the family role and status of a patient with tuberculosis, their perception of role expectations are a significant correlator of attitudes towards illness and behavior in obtaining medical services. For example, for some men, the family was perceived as an incentive for healing and recovery, as men emphasized their responsibility for fulfilling the traditional role of the family breadwinner. One of the respondents during the FGD in Bishkek, in response to discussions about the multiple side effects of medication, about the severe mental and physical state after taking medication, commented as follows: *"I think this is because they (other respondents) are still young and do not understand that it is necessary to survive by all means, to continue to feed the family. I need to marry off my daughters, marry off my son. When I'm taking medicine, I'm thinking about it, and not that it makes me nauseated and that it's hard for me. Whatever they give me to take, whatever the treatment, I will still complete the treatment."* At the same time, according to one of the respondents, the same dedication to family roles did not allow her father to seek medical help on time: he could not go to the doctors, as he and his wife took care of several of the grandchildren left in their care by children who left for labor migration.

Family circle can not only fail to provide psychological support to a sick family member, but also stigmatize them. Therefore, respondents expressed the opinion that patients with tuberculosis are often afraid to inform even their family members about their illness (more than 50% of such responses are for both male and female respondents; see the table below). The patient's fears are associated with the expectation or real practices of isolating a patient in the family when the family does not want to eat and drink with the sick family members (more than 60% of responses for both women and men). More than 18% of respondents said they know someone who was forced to leave their family because he/she was sick with TB. In the discussions, opinions were often voiced that in case of a woman's illness husbands abandon them. In the focus groups of women in Jalal-Abad and Bishkek, the overwhelming majority of women said that after learning about the diagnosis, the husbands or grooms left them forever, or talked about the experience of other women they knew. In men's focus groups, the very idea that a wife can abandon her husband on the basis of the "tuberculosis" diagnosis seemed unacceptable and contrived even in a hypothetical situation.

Table 5. The share of respondents, who agreed with the statements, by gender and residence region

		I know someone who was compelled to leave the family because he/she is a TB patient	Some people cannot want to eat or drink with members of the family with TB status	Some TB people feel guilty because their family is compelled to take care of them	Some TB people are afraid to tell to members of the families of their TB status
Kemin N=80	Men (N)	10	24	32	18
	Men (%)	25%	60%	80%	45%
	Women (N)	10	24	26	15
	Women (%)	25%	60%	65%	38%
	Total (N)	20	48	58	33
	Total (%)	25%	60%	73%	41%
Bishkek city N=80	Men (N)	4	28	32	32
	Men (%)	10%	70%	80%	80%
	Women (N)	7	22	28	24
	Women (%)	15%	55%	70%	60%
	Total (N)	11	50	60	56
	Total (%)	13%	63%	75%	70%
Jalal-Abad city N=80	Men (N)	13	34	32	23
	Men (%)	33%	85%	80%	58%
	Women (N)	10	38	31	25
	Women (%)	25%	95%	78%	63%
	Total (N)	23	72	63	48
	Total (%)	29%	90%	79%	60%
Bazar-Korgon N=80	Men (N)	0	13	11	15
	Men (%)	0%	33%	28%	38%
	Women (N)	2	16	16	19
	Women (%)	5%	40%	40%	48%
	Total (N)	2	29	27	34
	Total (%)	3%	36%	34%	43%
Total for sample N=320	Men (N)	27	99	107	88
	Men (%)	17%	62%	67%	55%
	Women (N)	29	100	101	83
	Women (%)	18%	63%	63%	52%
	Total (N)	56	199	208	171
	Total (%)	18%	62%	65%	53%

It is important to note that the indicators that testify to (self)stigmatization and discrimination in the family vary by region: respondents in Bazar-Korgon spoke less about the facts when someone was forced to leave the family because he/she was sick with TB, feelings of guilt towards members of the TB patient family, about the fear of telling about their diagnosis, as well as about the experience of separating the patient from a family meal. These figures among respondents from Jalal-Abad and Bishkek indicate a more unfavorable family environment and psychological atmosphere. As a

hypothesis, it is possible to propose a positive impact on the perception of TB patients and reduce stigma as a result of activities that contribute to reducing stigma and discrimination against tuberculosis patients through raising public awareness, which at the time of the study were conducted in the Bazar-Korgon district[22]. This hypothesis is also evidenced by a number of other indicators that significantly differentiate the views of Bazar-Korgon respondents from respondents from other regions. In particular, the answers to questions about the impact of the status of TB patient on the role possibilities of women and men in the family have regional differences. Thus, 80% of male and female respondents in Jalal-Abad believe that women's TB is especially dangerous for others, while only 6% of Bazar-Korgon respondents agree with them and about a third in Kemin and Bishkek. Thus, it was probably the conducted awareness-raising campaign in Bazar-Korgon that helped to reduce stigma and discrimination against women and men sick with TB[23].

Table 6. The share of respondents, who agreed with the statements, by region of residence

About women		Kemin	Bishkek	Jalal-Abad	Bazar-Korgon	Kemin	Bishkek	Jalal-Abad	Bazar–Koron	About men
Women's TB is especially dangerous to family and society	N	24	23	64	5	23	17	64	5	Men's TB is especially dangerous to family and society
	%	30%	29%	80%	6%	29%	21%	80%	6%	
Some people consider that a woman who used to have a TB status cannot be good...										Some people consider that a man who used to have a TB status cannot be good ...
... mother	N	26	7	33	9	25	5	33	9	... father
	%	33%	9%	41%	11%	31%	6%	41%	11%	
... wife	N	25	7	33	5	21	7	33	4	... husband
	%	31%	9%	41%	6%	26%	9%	41%	5%	
... homemaker	N	24	9	27	5	22	8	28	5	... master of the house
	%	30%	11%	34%	6%	28%	10%	35%	6%	
... daughter-in-law	N	25	11	29	17	23	8	29	18	..... son-in-law
	%	31%	14%	36%	21%	29%	10%	36%	23%	
... earn well	N	38	23	29	18	41	24	30	18	... earn well
	%	48%	29%	36%	23%	51%	30%	38%	23%	
Some people consider that one should not marry a woman who had a TB status	N	32	20	29	18	35	22	28	17	Some people consider that one should not marry a man who had a TB status
	%	40%	25%	36%	23%	44%	28%	35%	21%	
Some people consider that a woman who used to have a TB status, cannot give birth to a healthy child	N	35	16	29	5	31	14	31	4	Some people consider that a man who used to have a TB status, cannot have a healthy child
	%	44%	20%	36%	6%	39%	18%	39%	5%	

Despite some of the abovementioned negative assessments of family influence on the diagnosis and treatment of a TB patient, their assessments of their own power in the family as a whole were very optimistic (see Table 7).

Table 7. The level of empowerment at the family level, by gender and region (possible values 0–3; the higher indicator corresponds to a higher level of empowerment) (N=320, men N=160, women N=160)

[22] For more details, see reports on the communication campaign carried out by Door Media.
[23] The proposed hypothesis on the effectiveness, positive impact of the information campaign on the perception of TB patients and the disease itself requires additional focused research and analysis.

		I can easily use the family budget if I need to pay for medical services and/or buy drugs	I can openly discuss TB and other health issues with my family
Kemin	Men	2,1	2,5
	Women	2,2	2,6
	Total	2,1	2,6
Bishkek	Men	2,2	2,5
	Women	2,3	2,6
	Total	2,3	2,5
Jalal Abad	Men	2,3	2,4
	Women	2,3	2,3
	Total	2,3	2,3
Bazar-Korgon	Men	2,8	2,7
	Women	2,6	2,5
	Total	2,7	2,6
Total for sample	Men	2,4	2,5
	Men	2,4	2,5
	Women	2,4	2,5

As can be seen from the table, respondents expressed confidence that they can freely discuss their health and diagnosis with their relatives, and also expect them to finance the costs of medical services from the family budget, if necessary. In general, such confidence is found among respondents from all regions of the study, but among the respondents from Bazar-Korgon the assessment of power in the family is slightly higher than in other regions and the average for the regions.

Local community

Most of the respondents from Kemin, Bazar-Korgon and Jalal-Abad stressed the exceptional importance of the local community in their lives and the fear of being excluded, discriminated by the local community. The threat of being subjected to social exclusion, dropping out of networks of local community interactions is perceived in the rural community or in the realities of small towns as the worst punishment and test. As one of the respondents notes, the wife of a patient with TB: *"Everyone is hiding. Openly declaring (about the disease) does not even cross my mind. You do anything for people not to find out about his illness, we are afraid that people will stop coming to us. That we cannot go to anyone, that they will stop inviting us to visit – these are the apprehensions, we have such thoughts"*[24].

Measurements of the subjective perception of the local community's attitude showed:

- The overwhelming majority of respondents with TB prefer to keep their disease secret from the community.
- Almost half of those whose community is informed of their health status regret it and would prefer that they did not know.
- In a larger proportion, information about the health status was disseminated not by the patient himself but by others – his relatives, social or even medical workers or unidentified sources.

Respondents' answers to questions about the perception of the attitude of the local community vary by region. So, the largest number of respondents who answered "yes" to the question "Do villagers or your neighbors know that you have TB?" are respondents from Kemin and Bazar-Korgon (moreover, while in Kemin more men answered yes to this question, in Bazar-Korgon more women did so). The source of

[24] Бүт эле жашырып эметкен кишилер, анан эмне болуп ачыкка чыгып менин мээме деле кирген жок азырчы. Эптеп эле киши билбесе экен ооруганын, биз коркконубуз үйгө киши кирбей калатко. Биз бирөөнүкүнө кире албай калабызго, бизди коноко чакырбай калышатко деген эле ой кетет

information about the patient's diagnosis was most often the TB patient him/herself in Bishkek (women 100%) and in Bazar-Korgon (women 72% and men 68%), while in Kemin and Jalal-Abad the proportion of respondents who informed the local community was less than a quarter and less than one seventh, respectively. It is noteworthy that the proportion of those who regret that the local community was informed of the patient's illness was the lowest in the Bazar-Korgon district, which indirectly indicates a low level of stigma and discrimination against a patient with TB.

More often than not, in Jalal-Abad and Kemin relatives acted as distributors of information about TB, which probably was uncontrollable for the patient and was most likely undesirable for him/her. In Bazar-Korgon rayon, the proportion of relatives as sources of information about the disease was the least in comparison with other regions, and the respondents themselves were more often the source of information about them having TB, which also indirectly indicates a relatively low level of stigma and discrimination against TB patients.

Table 8. Subjective perception of the attitude of the local community

		Do your fellow villagers or neighbors know about your TB status?		**If know, whence did they have learn about it?**					**If they do not know, would you like them to know about it?**	
		Yes	No	From me	From relatives	From a medical worker	From a social worker	D/k	Yes	No
Kemin N=80	Male (N)	30	10	6	16	0	0	8	12	18
	Male (%)	75%	25%	20%	53%	0%	0%	27%	40%	60%
	Female (N)	18	22	5	5	1	0	7	2	16
	Female (%)	45%	55%	28%	28%	6%	0%	39%	11%	89%
	Total (N)	48	32	11	21	1	0	15	14	34
	Total (%)	60%	40%	23%	44%	2%	0%	31%	29%	71%
Bishkek N=80	Male (N)	7	33	3	3	1	0	1	2	5
	Male (%)	18%	83%	43%	43%	0%	0%	14%	29%	71%
	Female (N)	3	37	3	0	0	0	0	2	1
	Female (%)	8%	93%	100%	0%	0%	0%	0%	67%	33%
	Total (N)	10	70	6	3	1	0	1	4	6
	Total (%)	13%	88%	60%	30%	0%	0%	10%	40%	60%
Jalal-Abad N=80	Male (N)	16	24	2	13	0	0	1	6	10
	Male (%)	40%	60%	13%	81%	0%	0%	6%	38%	63%
	Female (N)	19	21	3	14	0	1	1	4	15
	Female (%)	48%	53%	16%	74%	0%	5%	5%	21%	79%
	Total (N)	35	45	5	27	0	1	2	10	25
	Total (%)	44%	56%	14%	77%	0%	3%	6%	29%	71%
Bazar-Korgon N=80	Male (N)	22	18	15	4	0	0	3	16	6
	Male (%)	55%	45%	68%	18%	0%	0%	14%	73%	27%
	Female (N)	25	15	18	4	1	0	2	17	8
	Female (%)	63%	38%	72%	16%	4%	0%	8%	68%	32%
	Total (N)	47	33	33	8	1	0	5	33	14

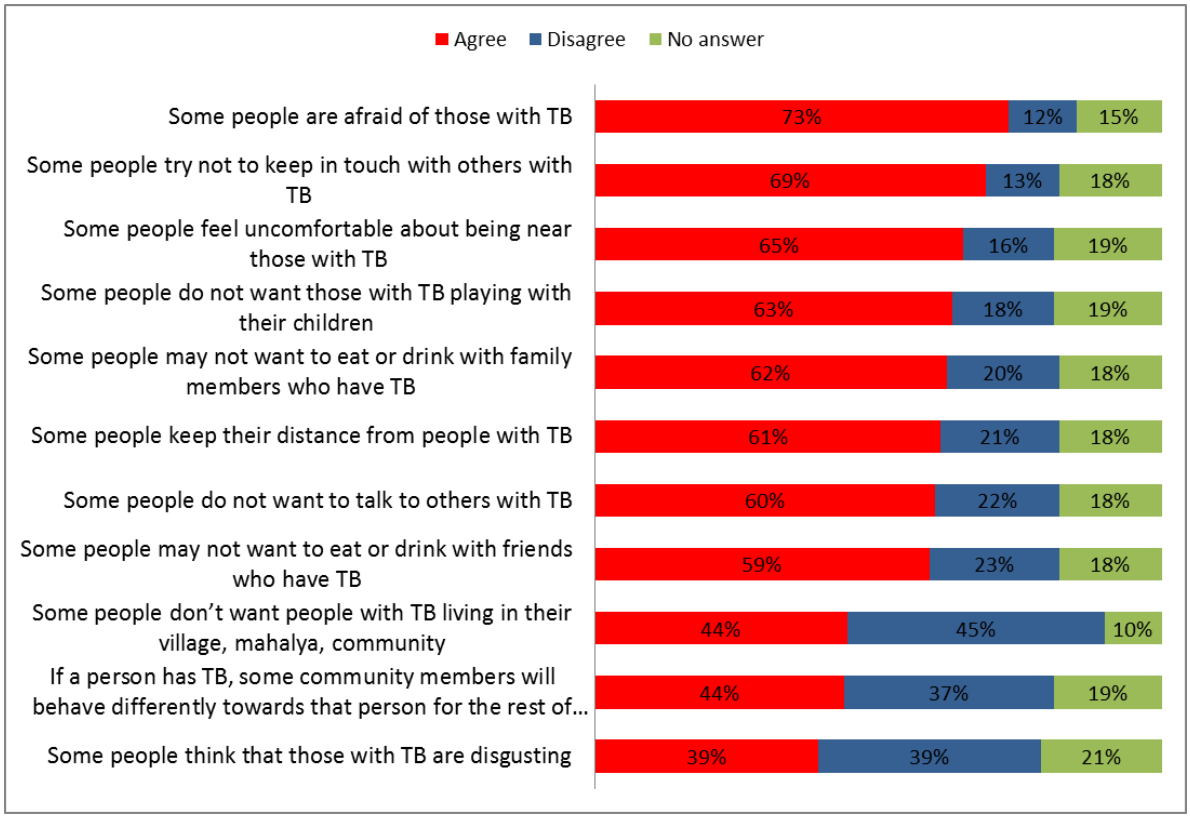
Total for sample N=320	Total (%)	59%	41%	70%	17%	2%	0%	11%	70%	30%
	Male (N)	75	85	26	36	0	0	13	36	39
	Male (%)	47%	53%	35%	48%	0%	0%	17%	48%	52%
	Female (N)	65	95	29	23	2	1	10	25	40
	Female (%)	41%	59%	45%	35%	3%	2%	15%	38%	62%
	Total (N)	140	180	55	59	2	1	23	61	79
	Total (%)	44%	56%	39%	42%	1%	1%	16%	44%	56%

Thus, a reduction in the level of stigma and discrimination of TB patients, an increase in the confidentiality of TB patient's diagnosis for social workers and health workers in Bazar-Korgon rayon testify to the possibility of changing attitudes and behaviors in relation to TB patients and their treatment given an adequate information impact.

Due to the fact that stigmatization is assessed by respondents everywhere as the heaviest burden of a patient with TB, a special scale "Stigma associated with tuberculosis" was used for measurement in the study and the data were subjected to factor analysis in order to determine the key causes and consequences of stigma in relation to a TB patient.

The calculation of indices on the scale of stigma included a number of statements for respondent's evaluation from the point of view of an individual and from the point of view of a community. The figures below represent the comparative "indices" of consent levels on the stigma scale – from the community's position on TB and from the position of patients towards TB[25].

Figure 11. Level of agreement with the statements on the scale Attitude of the community towards TB patients (N=320)



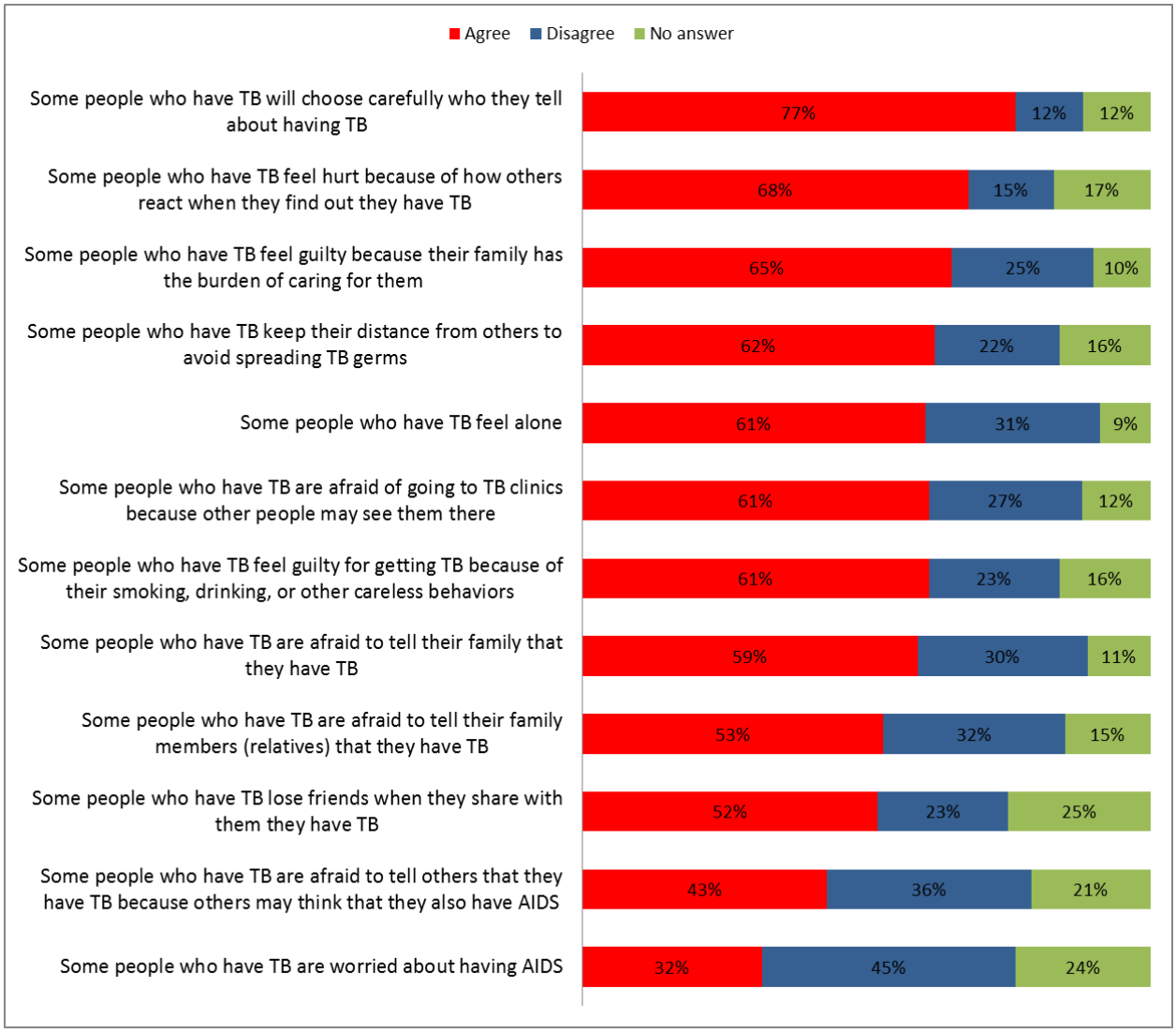
Even a cursory look at the results of assessing the statements on "Community's attitude towards TB Patients" testifies that the main cause of stigma is related to respondents' fears of accidental infection.

[25] The statements in the diagram are presented according to agreement degree.

It is no coincidence that one of the respondents in FGD in Jalal-Abad said that she envies people with deadly cancerous diseases – no one is afraid to get infected from them, everyone feels love for them, sorrow, at least pity. A woman from Bazar-Korgon recalled that when information about her tuberculosis spread in the local community, most villagers stopped greeting her. *"At first I was puzzled that they did not even want to say hello. I cried a lot then, I thought, why did they do that. There were even days when I wanted to kill myself. But then I imagined the fate of my children and decided that I should live for their sake"*[26].

Statements on the *"Patients' attitude towards tuberculosis patients"* scale are projective questions and allow to identify a set of attitudes and opinions of TB patients about other patients, an idea of their perceptions in society. Respondents' answers to the statements on the scale show that TB patients suffer from loneliness and self-stigmatization, feel guilty, are afraid of infecting their loved ones and are worried about the similarity of their disease stigma with other stigmatized diseases (such as AIDS, for example).

Figure 12. Level of agreement with the statements on the scale Patients' attitude towards TB patients (N=320)



The indices calculated on the basis of assessment of the statements on both scales, are standardized indicators of stigma that range from 0 to 50. High rates correspond to a high level of stigma.

[26] Биринчи, буларга эмне болду, мен менен сүйлөшкүсү келбейт, учурашкысы келбейт деп, ошол малда ыйлап калат болчумун, эмнеге мынтип атышат деп. Өзүмдү өзүм өлтүргүм келген күндөргө барып аттым. Бирок балдарымдын күнүн элестетип, балдарым үчүн жашашым керекмин деп кайта...

Table 9. The standardized indicators of stigma – "indices" by the Attitude of the community towards TB patients and Attitude of patients towards TB patients scales

		Attitude of the community towards TB patients	Attitude of patients towards TB patients
Kemin	Men	27,7	27,6
	Women	27,9	28,6
	Total	27,8	28,1
Bishkek	Men	30,2	30,9
	Women	30,2	28,9
	Total	30,2	29,9
Jalal-Abad	Men	34,3	31,8
	Women	33,5	30,5
	Total	33,9	31,1
Sample	Men	30,9	30,4
	Women	30,9	29,5
	Total	30,9	29,9

Calculations of standardized indicators of stigma – "indices" for tuberculosis patients show a stigmatization level above average and make up 30.9 points on the *"Community's attitude towards tuberculosis patients"* scale, and on the *"Patients' attitude towards tuberculosis patients"* scale – 29.9 points[27]. The difference in answers by gender is not significant. Regional differences cannot be considered significant, although the difference between the generalized index in Jalal-Abad and in Kemin is almost 7 points on the "community's attitude *towards tuberculosis patients*" scale. Data on Bazar-Korgon are not presented due to the high proportion of respondents who found it difficult to answer the question[28].

A comparison of the standardized indicators of stigma obtained during this study demonstrates that they are slightly higher than those calculated from the results of studies in South Thailand and Mexico[29]. However, the difference as a whole is not significant, the level of stigmatization of TB patients seems to be approximately the same in all three countries.

Table 10. Comparative table of standardized indicators of stigma by countries (vary from 0 to 50, high values correspond to high level of stigma)

Country	Period of data collection	Sample	Scale: Attitude of the community towards TB patients	Scale: Attitude of patients towards TB patients
South Thailand	August 2004– December2005	204 TB patients registered in eight hospitals	27,9	27,6
Mexico	January– February 2009	217 respondents in 5 states of Mexico	28,9	28,3
Kyrgyzstan	August– September 2017	170[30] respondents in Bishkek and Jalal-Abad cities, and	30,9	29,9

[27] Standardized indicators of stigma range from 0 to 50. High rates correspond to a high level of stigma. Data on Bazar-Korgon are not presented due to the high proportion of respondents who found it difficult to answer the question

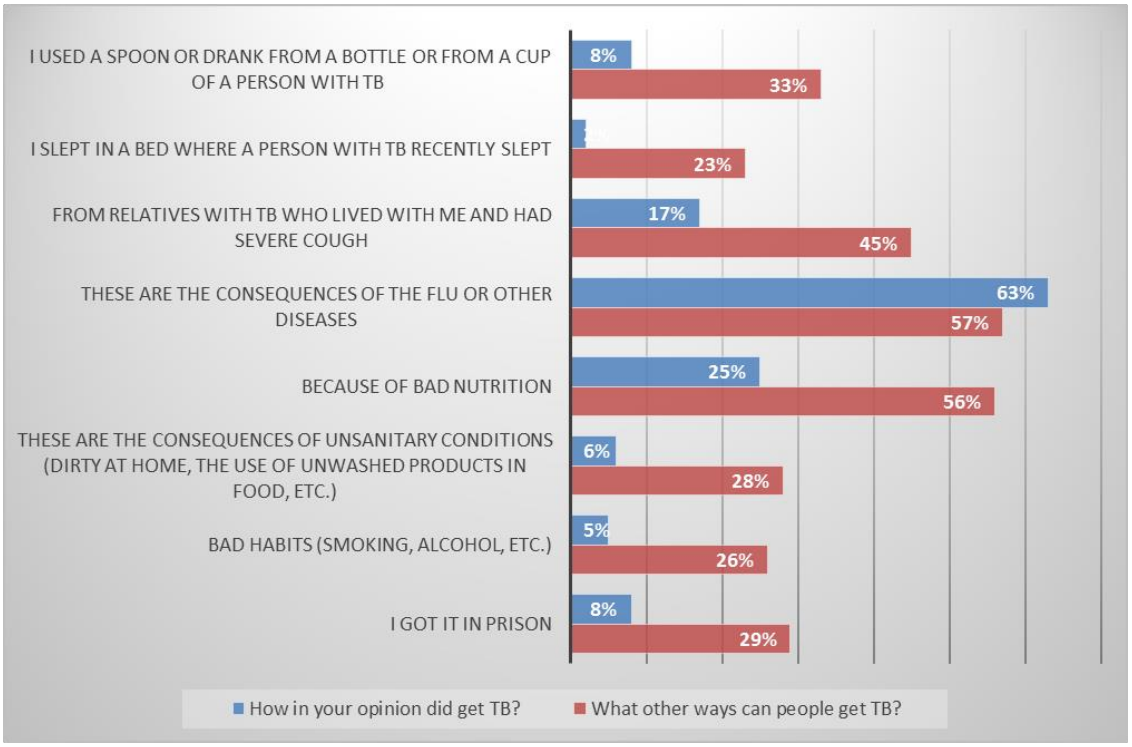
[28] although field workers did not note difficulties in understanding the statements, the majority of respondents chose the option "I find it difficult to answer," at least for 1 statement.

[29] The Stigma Index was developed in Thailand and adapted in Mexico and Kyrgyzstan. The validity of the index was confirmed in studies in South America in 2016, in Brazil in 2016, in the United States in 2015 (only the HIV/AIDS stigma index).

[30] 120 respondents found it difficult to reply to at least 1 statement of the index and were disqualified for further analysis

The definition of indices of stigma demonstrates that stigma works both as an external and as an internal mechanism. In other words, while suffering from stigmatization, opposing the stigma of TB patients in relation to themselves, at the same time TB patients themselves share discriminatory and stigmatizing attitudes towards other TB patients. This phenomenon is especially well reflected by a diagram comparing the assessment of the causes of the illness that the respondent identifies for him/herself and for other TB patients.

Figure 13. Causes of TB disease (N=320)



One of the consequences of stigmatization is often forced withdrawal from the local community, as life in isolation becomes morally unbearable[31]. About 18% of respondents indicated that they knew someone who had to leave the community because he/she was sick with TB. The share of such respondents is higher in Jalal-Abad and lower in Bishkek and Bazar-Korgon, where the share of those who found it difficult to answer the question is the highest (84%).

Table 11. The share of respondents who have agreed with the statement: I know someone who had to leave the community because he/she turned out to have TB

Region	%
Kemin (N=80)	25%
Bishkek (N=80)	14%
Jalal-Abad (N=80)	29%
Bazar-Korgon (N=80)	3%
Total for sample (N=320)	18%

[31] The study to assess VHC activities in 2017 (Impact Assessment of the "Community actions on health issues" project, the Swiss Red Cross) includes a case in Kemin when a young woman was forced to leave her parents' home in Bishkek after a local health worker released information about her TB affliction (no definition of "TB status," this can enhance stigma).

Work colleagues

The sphere of labor and employment is one of the key problems for tuberculosis patients, on the one hand, because for patients with tuberculosis having permanent employment, work symbolizes health and social integration, on the other hand, because unemployment is axiomatically perceived as the most important social factor in the spread of tuberculosis. In international practice, many studies are devoted to the study of the relationship between the status of the unemployed and getting ill with tuberculosis[32]. Familiarity with the reports of a number of such studies shows that the unemployed status, as well as the factors and conditions associated with this status (poverty, alcoholism, drug addiction, excessive smoking, etc.) directly correlate with the level of tuberculosis spread.

In the present study, the share of the unemployed among the respondents was quite high (51% of the survey respondents identified themselves as unemployed, except for such statuses as "housewife", "periodically working on short-term contracts"), including:

- 27 unemployed citizens, 4 pensioners and 4 students (out of 45 participants in four focus groups). 10 respondents, who stated that they have a job, mainly belonged to the groups of "precrariate (workers with a risky workplace)" – representatives of short-term working professions (4 people), had the status of private entrepreneurs (2 respondents), or worked being hired by private individuals on a "permanent" basis,
- Among 8 interviewed patients with tuberculosis, none of the respondents had a permanent job at the time of being diagnosed with TB,
- Of the 320 survey respondents, 84% were not employed at the time of the survey.

International research also established a direct link between the status of the unemployed, delays in accessing medical services and interruptions in treatment. In this study, some respondents who discontinued treatment stated that the inability to provide for a family's livelihoods forced them to take a break as soon as they felt better; several respondents expressed regret that the disease progressed after a heavy workload – most often participation in the construction of housing.

Discussions around the experience of labor migration of TB patients are interesting. The traditional point of view is that migrant workers from the Kyrgyz Republic who live in Kazakhstan or the Russian Federation live in crowded conditions, do not eat well and that is exactly why the risks of tuberculosis are very high. Indeed, among FGD participants, a considerable number of respondents had experience working in labor migration in Russia and it was there that they learned about their illness. As many respondents said, they left for work, feeling that they are full of health and strength and are able to bear the burdens of physical labor and the hardships of life in a foreign land. But in conditions of stress and deprivation of labor migrant life, their immune status fails, and they become infected with tuberculosis. As one of the respondents in Bishkek's FGD noted, the biggest problem is that they are exporting not just tuberculosis, but MDR-TB, which, as the male FGD assured, was never "natural" for Kyrgyzstan.

At the same time, one of the respondents from Bishkek and some doctors believe that there is likely another pattern of incidence: people who have migrated to labor migration are already infected but do not undergo medical examinations and are unaware of the disease. Work in Russia for migrants is always associated with undergoing medical examinations and therefore our citizens immediately determine their health status. This point of view is supported by arguments based on the data of the Russian FMS, which among other facts asserts that labor migrants from Central Asia, while being poorly informed about the disease itself, know very well and understand that the tuberculosis detected in Russia means forcible deportation and prohibition of entry into the future[33].

Prospects for employment and income-generating activities after recovery among respondents are assessed highly pessimistically. Some respondents believe that tuberculosis inevitably leads to disability

[32] For example, Przybylski G., Dąbrowska A., and others. Unemployment in TB Patients – Ten-Year Observation at Regional Center of Pulmonology in Bydgoszcz, Poland https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4228860/; V. Zakharenkov, I. Viblaya. Negative links between the health indicators of the population and the unemployment rate in Novokuznetsk city. https://cyberleninka.ru/article/v/negativnye-svyazi-pokazateley-zdorovya-naseleniya-s-urovnem-bezrabotitsy-v-g-novokuznetske

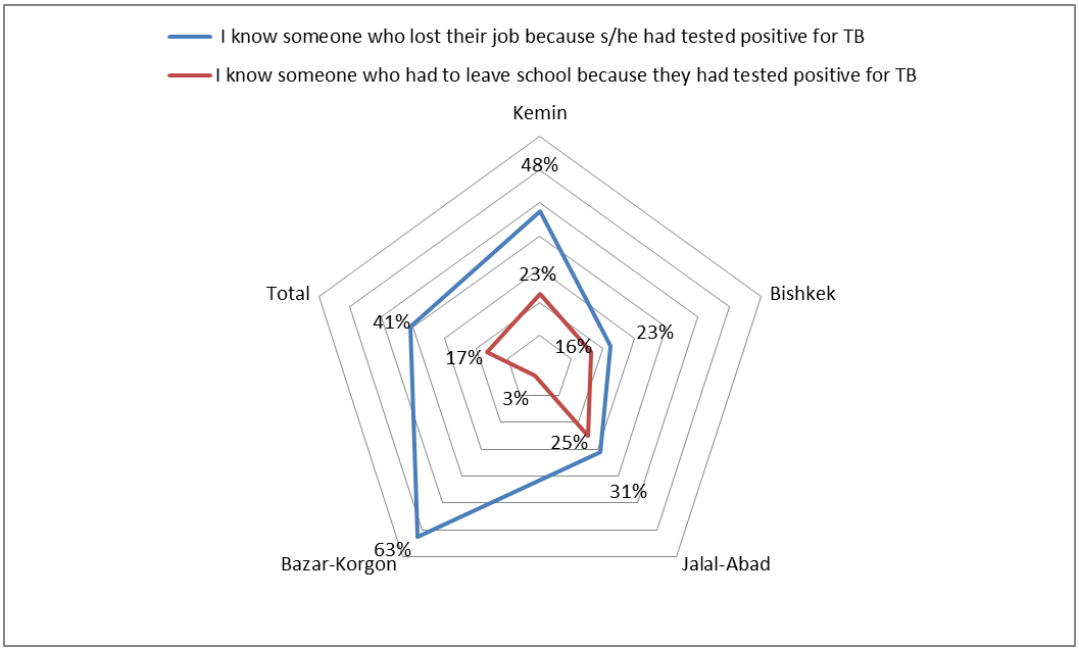
[33] http://www.fergananews.com/articles/9124

and that tuberculosis patients can never become adequate subjects of the labor market. A 47-year-old man, a respondent from Kemin, believes: *"We cannot earn anything, we really cannot work. Even if people do not know that you are a tuberculosis patient, but you do not have enough strength."* This setup is also supported by the TB patients' close circle. One of the respondents, the wife of a TB patient, said: *"The husband will not be able to work for another 18 months until the end of his treatment, and even then he will not be able to work on a good (paid) job. It would be nice if they could allocate something like a pension"*[34].

Young female respondents from the Bishkek focus group very much wanted to find a job, but on the whole they did not believe that they would be able to find their professional niche, since they believe that any employer, even with the slightest information about their disease, even after recovering, will not hire them.

Negative attitudes of respondents are justified by their knowledge of cases, when specific people lost their jobs due to stigma and discrimination of TB patients. Thus, about 41% of respondents said they knew someone who lost their job, because he/she was sick with TB (also many talked about forced change or full withdrawal from school – 17% of respondents knew someone who was forced to leave school because he/she was sick with TB).

Figure 14. Level of respondents' agreement with statements (N=320)



Media reports, legal forum-portals also inform the public about such cases when a member of a certain company, institution due to TB disease was forced to resign "by choice" and even the payment of the sick leave according to labor legislation was not made in full[35].

Sphere of medical services

The sphere of medical services in the life cycle of a TB patient respondent is central, and covers the diverse aspects of life, not only of TB patients, but also medical professionals, since it is interaction with them that provides patients with TB chances of a better recovery.

[34] Жолдошум жанагы дарысы буткончо 18 ай жумушка жарабайт деп атпайбы, андан кийин деле жакшы жумуштарга жарабайт. Почти жумушка жарабай калат деди да Атыркуль эже чи. Мисалы пенсия сыяктуу кылып чыгарып берсе деп ойлогонбуз.

[35] http://law.kg/question/nezakonnoe-uvolnenie/

Life cycles of a TB patient – from disease and diagnosis to recovery – are determined by a combination of factors, including:

- the quality of the provided medical services, including the material and physical conditions of medical institutions, staffing, the motivation of medical workers to work effectively,
- TB patient's understanding of peculiarities of the disease and treatment, compliance to treatment and motivation for a full cure,
- establishing cooperation between the medical worker and the patient and patient compliance[36] with medical prescriptions based on trust,
- social factors, including loyalty of the family environment and the environment of other TB patients, the level of stigma and discrimination in different communities

Since the quality of medical services depends to a large extent on the social well-being, satisfaction with the working conditions of the health workers themselves, in the framework of this study, in-depth interviews with medical workers were conducted on the conditions of their work, the features of interaction with patients and the local epidemiological situation related to tuberculosis. Conducted interviews allowed to formulate a list of current problems in the work of medical professionals:

- Lack of modern diagnostic technological equipment in polyclinics and hospitals (for example, a computerized tomograph that would accurately determine all foci and infiltrates or modern X-ray equipment in each FMC, so that old and technologically obsolete devices do not work beyond their technical capabilities and provide quality services, etc.)
- Lack of adequate safe sanitary conditions in the workplace of medical workers (medical worker respondents said that there are no showers, no separate dressing rooms where one could store their belongings, the crowdedness of doctors' and nurses' offices, etc.)
- The increased risk of contracting tuberculosis, the mortality of patients, the high frequency of "severe" patients and frequent "breakdowns" in their treatment without special psychological relief and rehabilitation of medical workers lead to their psychological burnout[37]
- Subjective feeling of injustice of wages, taking into account risks to health of medical workers themselves
- Lack of recognition of TB as an occupational disease and, accordingly, absence of compensation mechanisms in cases of contracting the disease.

The problems expressed by medical workers indicate the insecurity of their workplace, low professional motivation to work effectively and reduced social well-being of medical personnel in the system of antituberculous medicine[38]. One of the medical workers from Jalal-Abad confessed: "We come to work every day in the hope that we will escape this risk of contracting tuberculosis and we can safely retire." Another medical worker from Bishkek says: "Let's be honest that the staff does not receive a large salary. And some work in two places. And the staff... the low potential of tuberculosis service. And people work for such a salary, and those who value their intellect finds another job. You know it's

[36] This term, in the narrow sense, means compliance to medical recommendations by the patient, WHO provides a more comprehensive formulation: "the degree of correspondence of the patient's behavior with regard to the use of the medicine, following the advice on dietary or lifestyle changes according to prescriptions and instructions of the doctor"

[37] In the study of Russian scientists N. A. Stogova, O. N. Kalinina, an assessment of professional burnout in phthisiatricians was carried out, which refers to the process of development of chronic stress of moderate intensity, which causes personal deformation of a professional. It is shown that modern work load lead to the formation of emotional burnout syndrome in 16% of phthisiatricians, which can adversely affect the health of the doctors themselves, the quality and effectiveness of their work. The authors note that one of the causes of EBS is communication with patients not adhering to treatment, abusing alcohol, drugs, as well as working with chronic incurable and dying patients. See: https://cyberleninka.ru/.../meropriyatiya-po-povysheniyu-priverzhennosti-lecheniyu-bolnyh-tuberkulezom-v-rossiyskoy-federatsii%20(1).pdf

[38] the review of measures to increase compliance to treatment of tuberculosis patients in the Russian Federation, conducted by T. Pyanzova and I. Vejnina, notes the importance of motivating health workers to work effectively. The authors give an example of Dagestan, where in order to improve the effectiveness of treatment for newly identified patients with pulmonary tuberculosis, material incentives were provided to medical workers of anti-tuberculosis facilities for an effectively cured case of tuberculosis. This allowed a 1.3-fold increase in the cessation of bacterial excretion, 1.4-fold in the closure of the decay cavities among newly diagnosed tuberculosis patients and a 3.6-fold reduction in the frequency of premature discontinuation of treatment. See details in: https://cyberleninka.ru/.../meropriyatiya-po-povysheniyu-priverzhennosti-lecheniyu-bolnyh-tuberkulezom-v-rossiyskoy-federatsii%20(1).pdf

disappointing. Here, the guy was sitting, he worked as a waiter in Moscow. He came, and expects that we give everything to him, lay out everything for him. But he came, so grand. Later, after he stayed in the hospital and left, I asked him: How much did you earn in Moscow? He says: A thousand dollars. You see, he did not want to work and study here. Work, for example, as a nurse for 8 thousand soms. He chose another profession, he chose another country, he chose a different salary."

Despite these negative factors in the work of medical workers, in the survey respondents rather highly assessed the professional behavior of contact staff as a component of assessing the quality of medical services. In the regional division of the assessment, there are small differences: the highest scores were given by patients to medical workers from the Bazar-Korgon district, the lowest ones by patients from Jalal-Abad (see table 12).

It is important to note that the respondents' positive assessments of the quality of services following the results of the survey were discordant with the results of qualitative methods – interviews and focus of group discussions[39]. Respondents in interviews, and especially in focus groups, often expressed very critical assessments of health professionals and the healthcare system overall. Respondents in Jalal-Abad perceived the possibility of a frank conversation in FGD as a kind of therapeutic procedure – almost all women wept during the conversation, remembering especially traumatic events of their treatment. In the course of the discussion, the respondents even shared their experience in very sensitive areas, touching upon the topic of sexual harassment by a medical worker, insults to the person, physical assaults of children sick with TB, extortions by in-patient medical staff and many other flagrant violations of patients' rights. TB patient respondents told about how "evil" medical workers in the hospital are, how they do not hide their fear of getting infected and are disgusted with patients with active forms, how they neglect to perform their duties. In one of the hospitals, according to the respondents' testimony, a phthisiologist could go weeks without inspecting his patients and/or not paying attention to the results of their analysis results, etc.

In addition to assessing the behavior of the contact medical staff, an assessment of the material environment for the provision/reception of services was included in the evaluation of the quality of services. In this section, the patients also gave high scores, with a slight decrease in assessments in Jalal-Abad (for inpatient and outpatient treatment) and Kemin (only for inpatients).

Table 12. Assessment of the quality of services (average values: 5 points as a maximum and the percentage of respondents having marked the responses)

	Inpatient treatment					Outpatient treatment				
	Kemin N=61	Bishkek N=38	Jalal-Abad N=73	Bazar-Korgon N=73	Total for sample N=245	Kemin N=77	Bishkek N=79	Jalal-Abad N=39	Bazar-Korgon N=68	Total for sample N=263
Material environment of providing and receiving medical services										
Ward condition	3,9	4,2	3,7	4,3	4,0					
Illumination in wards and premises	3,8	4,2	4,1	4,4	4,1	4,2	4,0	3,5	4,1	4,0
Temperature in wards and premises	3,9	4,3	3,9	4,3	4,1	4,2	4,0	3,5	4,1	4,0
Cleanliness in wards	4,1	4,4	3,9	4,4	4,2	4,2	4,1	3,6	4,1	4,0
Food	3,8	4,1	3,5	4,2	3,9					
Shower/bath	3,5	3,9	3,3	4,2	3,7					
Condition of toilets inside buildings	3,6	4,0	3,4	4,0	3,7	4,0	4,0	3,4	4,2	4,0
Access to a drugstore	3,8	4,2	3,7	4,2	3,9					
Quantity of chairs for waiting persons						4,0	4,0	3,4	4,1	3,9
Assessment of the conduct of contact staff										

[39] It is likely that this discrepancy in the estimates is due to the lack of privacy in conducting interviews

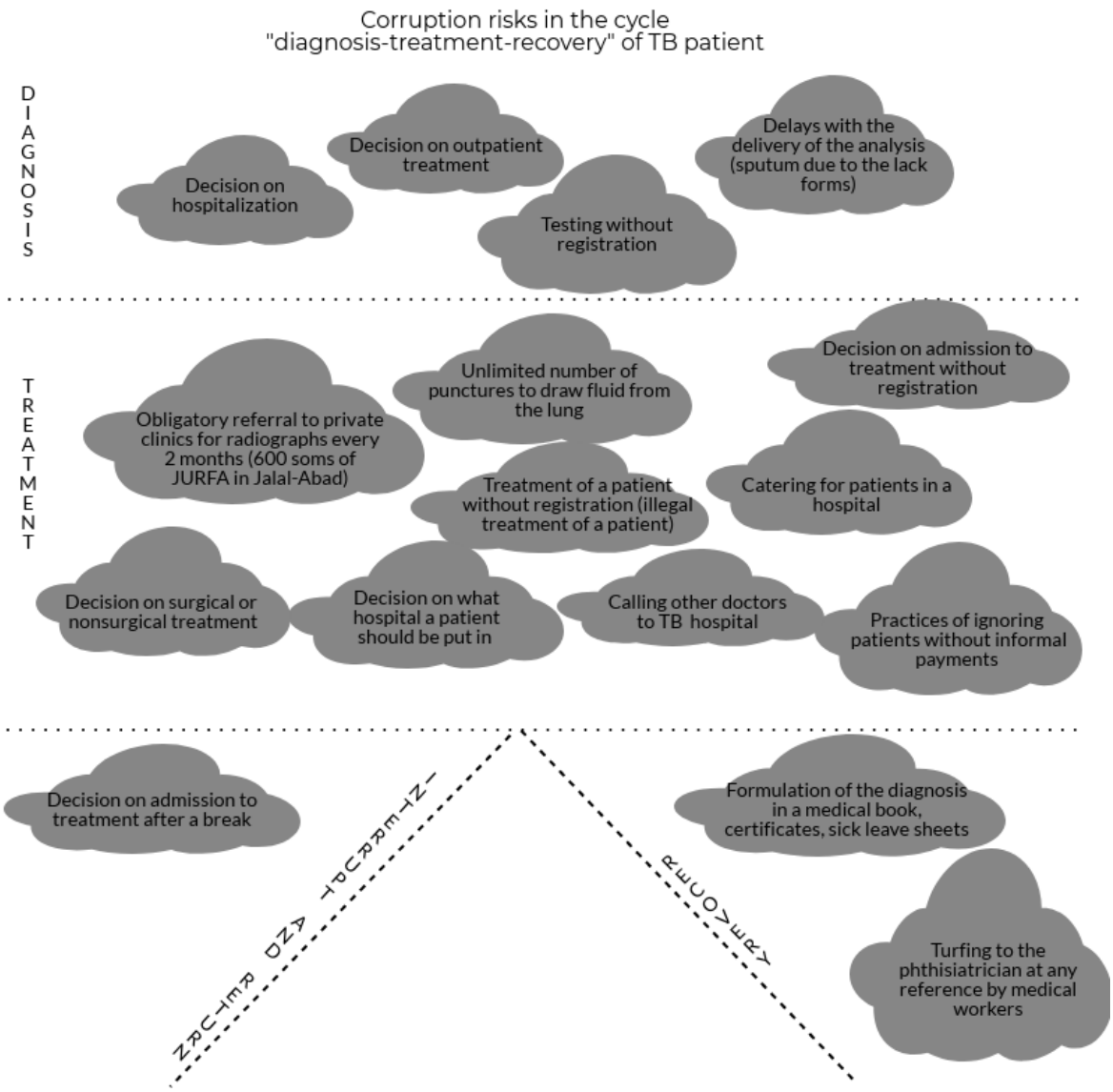
Attitude of the attending medical doctor	4,2	4,3	3,8	4,4	4,2					
Attitude of staff nurses	4,2	4,3	3,8	4,4	4,2					
Information on the disease development	4,1	4,2	3,9	4,3	4,1					
The medical worker did not provide training / informing / psychological consultation						100%	85%	92%	100%	100%
The medical worker was polite						100%	99%	92%	93%	97%
There were conflicts with a medical worker						96%	95%	97%	100%	97%

In order to examine in more detail the realities of patients' life in the field of medical services and understand the contradictory assessments, an attempt is made to study step-by-step the interaction of medical workers and patients throughout all service provision/reception cycles: a) the diagnosis; b) the appointment of a therapeutic strategy and treatment; c) interruption of treatment; d) recovery (or relapse and a new cycle of services, or fatal outcome).

At each of these stages, a patient faces a number of barriers, including corruption risks. Based on the data, specific stories of TB patients, a generalized scheme of corruption risks, abuses and human rights violations in the field of healthcare services was created, which accompanies TB patients from diagnosis to recovery[40].

Figure 15. Scheme of corruption risks and abuses in the sphere of medical services

[40] The figure is discussed in more detail below, in the description of each of the cycles



Diagnostics

Early diagnostics of tuberculosis faces two main problems of the healthcare system: self-medication of diseased patients and seeking medical advice not through official procedures, but through “acquaintances” or informal payments and, accordingly, receiving services with a violation of the diagnostic algorithm. Both problems, as the respondents testify, are associated with subjective attitudes and perceptions, in particular, with the expectation of patients to provide poor quality of medical services and waste of time and money. In one case, a woman in Bishkek noted that she does not have a residence permit in the city and she has to apply informally, because otherwise she will be sent to apply at the place of residence. But treatment even for informally paid services not attributed to FMC, as she now believes, does not guarantee the quality of medical services. In any case, as the respondent says, she could not get an official opinion on the X-ray image, having turned with fever and coughing to the nearest polyclinic. The doctor who took payment for the consultation sent her for an X-ray and, according to the results of the image, orally reported pneumonia, prescribed a 10-day course of antibiotics injections. Two weeks later, when the woman was already in the tuberculosis hospital and she was diagnosed with MDR-TB, she could not even show the image and prove the fact of the contact with the primary care physicians.

The experience of those who turned to primary healthcare physicians by the rules, according to testimonies, also did not always turn out to be smooth. Here, according to the testimonies of our

respondents, there are high risks that medical specialists, due to lack of professionalism or negligence, can make a mistake and diagnose another disease and prescribe antibiotic treatment. For example, among the participants of the Bishkek FGD there were several women with this experience. All these participants testified that they had been prescribed antibiotic ceftriaxone[41], expectorating syrups; bronchitis was most often diagnosed. One respondent was prescribed a so-called "hot" injection. Such treatment usually took from a few days to a week or more. A pre-diagnosis was usually based on an X-ray, in which physicians "saw" signs of bronchitis or pneumonia.

One of the male FGD respondents in Bishkek shared his experience being diagnosed: "At first, it was kind of like my heart ached. Checked in a hospital, they said the heart is normal. The next day I went and decided to get an X-ray image "for myself." The doctor, for some reason, did not send me for an X-ray. They said that I have pneumonia. He was sent to the attending doctor, and he sent me for tests. On Monday I gave phlegm [for testing]. I came at noon the next day, the result was positive. Then they were sent to the tuberculosis hospital on Bokonbaev street. Well, there, too, it was confirmed"[42].

As soon as there was a suspicion of tuberculosis, the patients were immediately sent to specialized medical institutions, where the final diagnostic was carried out.

However, here, in the opinion of the respondents, there were risks of incorrect diagnosis: sometimes the stability of the tuberculosis form is determined only after 1-2 months after the beginning of therapy, some respondents reported longer periods – up to 6 months of therapy, which was ineffective, because they had a drug-resistant tuberculosis.

Analyzing the stories told by the respondents, it can be noted that patients in their turning for medical services are mostly not informed about what they are entitled to and act under the influence of certain stereotyped attitudes and ideas that provide their behavioral choice with rationality. For example, an Uzbek woman from Jalal-Abad was absolutely sure that physicians are disloyal and practice discrimination based on ethnicity. When she heard during the FGD in Jalal-Abad that other respondents, Kyrgyz by ethnicity, also faced red tape, extortion from medical workers, she was sincerely amazed.

Thus, the majority of respondents share a stereotypical opinion about the corruption of physicians, the need for informal payments and therefore, in case of some "inconsistency" with the requirements of the medical system (for example, they are not assigned to a FMC) – they immediately rush to solve the problem by informal payments or through social networks. If they do not have such resources, then based on the logic of the inevitability of informal payments, those respondents who assess their financial situation as poor, with a lack of finance for basic needs, are forced to remain without access to medical care until the most critical state of health.

Another example of the impact of insufficient awareness of the rights and pressures of stereotypes and myths on the patients' behavior is the cases of respondents, who explain why they choose a strategy to treat tuberculosis illegally, without registration, receiving medicines and services from phthisiologists and nurses of specialized tuberculosis clinics at commercial prices. Such respondents saw on the experience of their relatives that it is possible to lose work in case of official registration as TB patients, to face discrimination and social exclusion, which will eventually lead to being forced from work or become a barrier to employment. Given that in a significant proportion of cases, people in Kyrgyzstan have risky employment[43], the goal of keeping employment and income available is fully justified in explaining the costs of "illegal" treatment.

[41] Here there may be variations from the cephalosporin series

[42] Мен биринчи жүрөгүм ооругандай ооруду. Больницага барып текшерттирсем жүрөгүм нормальный экен. На следующий день барып для себя деп рентгенге түшсөм биринчи пневмония деп чыкты. Врач мени жиберген эмес эмнегедир. Врачтарым болсо лечащий врачка барып тапшырып кел деди. Анализдерди берип кой деди. Ну там макротага берип койду на понедельник алып келесиң деп. Понедельник тапшырдым. Эртең түштө келесиң деди. Түштө келсем результат положительный чыгып калды. Потом отправили туберкулезный больницага Боконбага. Ну, там тоже чыкты.

[43] Risky employment is a term that indicates the employment relationships that can be terminated by the employer at any time, also deregulation of labor relations and an inadequate, restrained legal and social guarantee of employment.

In the framework of this study, the task of comparing subjective evidence of respondents with more objective and reliable data from medical records was also difficult.

The study of 6 registration logs (TB02) for 2016 showed the presence of problems related not only to the low operational value of the log filling format, but also with the standardization and rigorous careful registration of a patient and recording the beginning of the treatment time. In total, during the study period, data on 742 patients was registered in 6 logs:

Table 13. Number of cases recorded in diaries

Logs	N
FMC #14, Bishkek	190
FMC #1, Bishkek	125
People belonging to the "Of no fixed abode" category, Bishkek	84
CCTC, Jalal-Abad city	85
Bazar-Korgon rayon, Jalal-Abad Oblast	123
Kemin rayon, Chui Oblast	135

The data in the logs for registration of history and treatment of patients are not complete: in 76 cases (10%) there is no start of treatment date, in 4 cases there is no registration date, and in 2 cases there is no registration date and the start of treatment date. More than half (58%) of patients started treatment before registration, that is, they were given a registration number with a delay: it is possible that patients applied to the primary level of health care or turned to specialized hospitals themselves. The proportion of such patients is greater in the Jalal-Abad CCTC and in Bazar-Korgon rayon.

Table 14. Dates of registration and beginning of treatment

		FMC #14, Bishkek	FMC #1, Bishkek	People "Of no fixed abode," Bishkek	Kemin rayon	CCTC, Jalal-Abad	Bazar-Korgon rayon	Total
No date of registration and beginning of treatment	N	1	0	0	1	0	0	2
	%	1%	0%	0%	1%	0%	0%	0%
No date of registration	N	0	1	0	0	3	0	4
	%	0%	1%	0%	0%	2%	0%	1%
No beginning of treatment date	N	19	3	37	7	3	7	76
	%	10%	2%	44%	8%	2%	5%	10%
The patient began treatment prior to registration	N	88	63	39	27	94	118	429
	%	46%	50%	46%	32%	76%	87%	58%
Date and registration and treatment coincide	N	48	36	4	22	17	0	127
	%	25%	29%	5%	26%	14%	0%	17%
The patient was registered prior to the beginning of treatment	N	34	22	4	28	6	10	104
	%	18%	18%	5%	33%	5%	7%	14%
Total	N	190	125	84	85	123	135	742
	%	100%	100%	100%	100%	100%	100%	100%

70% of patients were given registration numbers with a delay of more than 1 week, and almost every fourth patient (24%) started treatment with a delay of more than 1 week after registration.

Table 15. Period of time between the beginning of treatment and registration

	Period of time between beginning of treatment and registration		Period of time between registration and beginning of treatment	
1–7 days	127	30%	80	76%
8–30 days	172	40%	13	13%
More than 30 days	130	30%	11	11%

Total	429	100%	104	100%

Regionally, Bazar-Korgon rayon has the highest proportion of patients, who were registered with a delay of more than 1 week (86%), and in Jalal-Abad, the proportion of such cases was 51%.

Table 16. Delay in assigning of a registration number

		FMC #1, Bishkek	FMC #14, Bishkek	People "Of no fixed abode," Bishkek	Kemin rayon	CCTC, Jalal-Abad	Bazar-Korgon rayon	Total
1–7 days	N	32	14	13	6	46	16	127
	%	36%	22%	33%	22%	49%	14%	30%
8–30 days	N	29	26	19	7	29	62	172
	%	33%	41%	49%	26%	31%	52%	40%
More than 30 days	N	27	23	7	14	19	40	130
	%	31%	37%	18%	52%	20%	34%	30%
Total	N	88	63	39	27	94	118	429
	%	100%	100%	100%	100%	100%	100%	100%

The shares of patients who started treatment after 1 week are approximately equal, except Bazar-Korgon rayon, where out of 10 patients who started treatment after registration, 8 started treatment with a delay of more than 1 week. However, because of the small number of patients in this category, it is difficult to draw conclusions from the data.

Table 17. Delay in the beginning of treatment

		FMC #1, Bishkek	FMC #14, Bishkek	People "Of no fixed abode," Bishkek	Kemin rayon	CCTC, Jalal-Abad	Bazar-Korgon rayon	Total
1–7 days	N	28	18	3	24	5	2	80
	%	82%	82%	75%	86%	83%	20%	76%
8–30 days	N	3	2	1	3	0	4	13
	%	9%	9%	25%	11%	0%	40%	13%
More than 30 days	N	3	2	0	1	1	4	11
	%	9%	9%	0%	4%	17%	40%	11%
Total	N	34	22	4	28	6	10	104
	%	100%	100%	100%	100%	100%	100%	100%

According to specialist medical workers who helped researchers understand the registration logs, in some cases, the logs recorded a violation of diagnostic algorithms. In particular, microscopy was conducted in the overwhelming majority (94%) of cases, but in 6% of cases the microscopy was not performed, mainly in Bishkek, among people of the "of no fixed abode" category. The diagnostic algorithm was not observed in 37% of cases when microscopy was performed only in PHC, such cases are most common in Bishkek's FMC and in Kemin rayon.

Table 18. Microscopy in patients with pulmonary TB

		FMC #1, Bishkek	FMC #14, Bishkek	People "Of no fixed abode," Bishkek	Kemin rayon	CCTC, Jalal-Abad	Bazar-Korgon rayon	Total
Only PHC	N	63	37	1	58	40	14	213
	%	44%	39%	1%	85%	39%	15%	37%

Only ATO	N	70	51	59	5	60	76	321
	%	49%	53%	73%	7%	58%	82%	55%
PHC and ATO	N	4	5	0	2	2	0	13
	%	3%	5%	0%	3%	2%	0%	2%
Neither PHC, nor ATO	N	5	3	21	3	1	3	36
	%	4%	3%	26%	4%	1%	3%	6%
Total	N	142	96	81	68	103	93	583
	%	100%	100%	100%	100%	100%	100%	100%

At least in 223 cases out of 583, the results of Xpert and microscopy coincided. In 47 cases, the results of Xpert were more accurate than the results of microscopy. In 22 cases, the results of the microscopic examination were positive, and Xpert – negative, which, according to experts, who helped researchers study the logs, may be the result of the incorrect work of medical workers.

Table 19. Results Microscopy and Xpert

		Xpert					Total
		Pos	Neg	No result/invalid/error	Incorrect code	No data	
Microscopy	Positive	126	22	0	7	85	240
	Negative	47	97	1	17	131	293
	PHC neg, ATO pos	1	0	0	2	2	5
	PHC pos, ATO neg	1	0	0	0	0	1
	Incorrect code	3	0	0	1	4	8
	Tests were not done	3	1	0	1	31	36
Total		181	120	1	28	253	583

Treatment

During the interviews and FGD respondents admitted that the choice of treatment was difficult for them. Some respondents said that they wanted to receive treatment on an outpatient basis, for example, because they had no one to leave their young children with, or they wanted to keep their diagnosis secret from colleagues and acquaintances, while others, on the contrary, insisted that it was important for them to isolate themselves from relatives and friends, in fear of infecting them. Sometimes, respondents said that they had to pay informal payments to get doctors' permission for the necessary treatment regimen (either outpatient or inpatient).

Assignment of a hospital for treatment for some respondents was also problematic. Sometimes, the respondents were sent to the hospital far from their place of residence: Bishkek residents to Kara–Balta or Kemin residents to Bishkek. This remoteness became a heavy burden for a patient's family, and relatives were forced not to visit the patient every day. For the very patient, who was worrying about their diagnosis very much and experiencing a sharp reduction in the circle of communication, this remoteness exacerbated the feeling of loneliness. Therefore, many patients and their relatives were again forced to turn to friends or pay for the opportunity to be assigned to the most suitable hospital for them.

Sometimes it is not the remoteness of the dispensary, but information about the treatment regime and the reputation of the institution influenced the attempt to be treated in a specific dispensary. For example, one respondent said: *"They sent me in the direction of Dordoi. Well, not in the direction of*

Dordoi, but to the tuberculosis hospital. I refused, and went to the tuberculosis institution. I already read all the information and did not want to go to that hospital, because, firstly, there, according to rumors, the reviews are not so good. Secondly, all the city homeless people stay there. And that it stinks there, unsanitary conditions. And I heard it all, that there is no necessary supervision of the doctors. People take pills, it does not matter whether one took them or not, they go for a walk. But, I was not happy with such a [medical] treatment. I came to the institution and began to cry: "Take me in." Because, I'm urban and you can only do that. It's not right that they put urban people so far away from the city. And on the contrary, those who are not urban stay here. This is not right and I said, take me in. I found the best doctor. She is in the department, the head, Russian"[44].

All respondents noted the first days of taking prescribed medications as the most traumatic, mostly because many medical workers did not explain possible side effects and consequences. The respondent shared her experience of extreme stress from the fact that at the beginning of the treatment she did not know about the effects of the medication: *"I was given these 4 pills. And I took these pills and, those who took them probably know that when you go to the toilet everything is red. And I think that... Everything is exactly like that in red, I tell the doctor. Nobody told me anything. He says it's medicine and that's how it works. I experienced very strong stress and then this on top of it. I stayed for three days".*

One girl told that she "was almost unconscious, did not understand what was happening around her and was surprised how in that condition she did not get hit by a car in those early days of outpatient treatment." But the biggest problem, which was voiced by almost all patients, regardless of gender, is nausea and vomiting, headaches and dizziness, pain in the legs, liver problems, and sometimes hepatitis. Appealing to medical workers about the side effects of the main treatment was not always effective: medical staff prescribed cheap but free medicines, but they usually did not help. Several women and girls said that they are trying to develop a strategy for taking medication, nutrition, to cope with nausea and other side effects on the body, very few patients buy drugs on their own to reduce side effects.

Patients who are in contact with TB patients often do not become a source that inspires trust, in many ways because of disinterested behavior towards patients, often patients noted discriminatory and stigmatizing behavior of medical workers. For example, doctors, not having elementary skills of psychological counseling, often say words that are offensive to patients, further worsening their stressful state of health. For example, according to one of the respondents from Bishkek: *"When I was diagnosed, I thought: Lord, did I really live and work so long to die from tuberculosis. And I came to the hospital. We also had a doctor. Accordingly, I gave the phlegm [for a test] on the same day. He takes the results and says ... and I already lost all hope, all my life and such: "You have a magnificent form of tuberculosis". I felt even worse and did not know what to do. And he says, put on a mask, you're, it turns out, contagious."*

One of the key topics for discussion in all FGDs is the issue of stigma and discrimination. Respondents told stories about how they lost friends, how they were forced to be alone. Many respondents talked about their subdued, depressed psychological state, about suicidal moods, irritation and internal aggression, anger at everyone. During the discussion of these problems in the Bishkek group, almost a third of the participants heard for the first time about the psychological support provided, about the meetings of the support groups. For young girls, the beginning of taking medication was associated with worries about their appearance, about their psychological state. In one of the FGDs, a girl told that from taking the pills her face turned red and this set her fiance's relatives against her. Other girls said that because of the treatment, their skin color significantly darkened, and they lost their external appeal.

Older women expressed more concern about the risks of their children and other family members getting tuberculosis, how high the financial costs of the disease and treatment are: the need for periodic testing, monitoring the health of children and the spouse, how much the support of relatives and family means. So, one of the respondents emphasizes that, despite the free treatment, even periodic medical control is too expensive or very burdensome: "I live in Kemin. And the first time I was sent – I spent

[44] Spelling and vocabulary of respondents are provided without changes

1000 soms on fluorography and on the transportation. I still did not show [send for testing] my husband and children. I just do not have enough money."

Men's groups and male respondents talked more about intolerance to certain medications, how difficult it is to take dozens of pills daily without an exact end date.

The topic of corruption and corruption risks in the system of antituberculous care was popular. Respondents talked about poor nutrition (comparatively in dispensaries in Vorontsovka, near the Dordoi market and at the institute on Akhunbayev street). In Jalal-Abad, according to the testimonies of the respondents, the patients prepare themselves a hot meal in the courtyard on open fire, male patients do not cook because of cultural stereotypes, and it is because of the meager diet that they interrupt their treatment. Respondents said that medical personnel constantly imposed on patients the purchase of various unnecessary things, even local newspapers (in Jalal-Abad), that they had to solve the problems of repair works, arrangement of their patient rooms on their own.

A separate topic was the topic of trust to medical workers, their competence and ethical principles in working with patients. The majority of FGD respondents rated medical workers as unprofessional or unmotivated, disinterested in the correct and effective treatment of TB patients. More than once, patients told stories about personal experience when a doctor became a barrier for timely and correct diagnosis, adequate treatment and prospects for recovery. A story of a young woman from the Jalal-Abad FGD, who believes that she fell ill with tuberculosis in 2014, when she had all the main symptoms of TB: a fever for two weeks, coughing, sweating, weakness and an abrupt decrease in weight. But then the doctors of the tuberculosis hospital did not recognize the diagnosis of TB, they insisted on pneumonia and the woman received a course of antibiotics, after which she became better. Tuberculosis that was identified this year is virtually asymptomatic, but it is already a resistant form.

The Internet often becomes an alternative to medical opinion and recommendations: respondents told dozens of stories when they did not trust the opinion of their doctor, began to look for ways to solve health problems and found approaches and recipes that our doctors do not practice. That is why, in the opinion of the respondents, trade in "folk remedies" for tuberculosis treatment is flourishing and very often patients are resorting to these means.

In the respondents' opinion, the residents of rich countries do not have any problems with tuberculosis: they have an easy, fast cure for good, and the medications do not cause any side effects. That is why, during the focus group discussion, the fact that the moderator did not put on a mask caused a storm of unrest and interrogation by the respondents. One of the respondents bluntly explained: "So you are working for an American company, apparently they provided you with a secret medicine that protects against tuberculosis infection and therefore you do not need to follow security measures?"

One can consider symptomatic from the point of view of lack of trust in doctors the discussion in two male focus groups about a global experiment that is being carried out on citizens of poor countries (including the Kyrgyz Republic) to test new drugs and schemes for medical treatment against tuberculosis. For some respondents, the essence of such an experiment is not for medical purposes, the task may be to develop biomedical destruction weapons. Not always were the respondents ready to identify the subjects interested in the "experiment", they named the American, Israeli and Chinese (intelligence) structures. It is noteworthy that the topic of the drug experiment was discussed in the media of the KR around the same period, the reason for the critical articles were the deaths of two TB patients in the NCP, presumably from using in the treatment a drug that is unlicensed in the Kyrgyz Republic, manufactured in Kazakhstan. The fact that this topic was initiated by the respondents in the FGD can testify to the influence of media sources on the credibility of medical workers, as well as the negative consequences of a lack of information about diagnostics and medical treatment among patients and the general population.

The sphere of medical services is a complex space in which TB patients interact not only with medical workers, but also with other patients. Communities of patients in inpatient hospitals are becoming "collectives," in which a certain culture of relations is formed towards treatment, care of health and healthy lifestyle, patterns of interaction with medical workers are established, etc.

Respondents from all the surveyed inpatient TB services told dozens of stories about mutual support, exchange of information or conflicts between patients in hospitals. For example, according to the stories of women from the Bishkek FGD, in a hospital in Bishkek, patients form groups of "resistance" to medical workers in response to stigma and discriminatory attitudes. The pattern of behavior of "resistance" includes such samples as evening trips to Korean cafes for eating "dog soup" in accordance with "national" recipes, drinking alcohol at night, sabotaging drug intake (which go down the toilet), demonstrative "intimidation" with infecting nurses for the fun of the whole department, etc. In another tuberculosis hospital, patients in the ward solidarize and collectively practice "alternative" methods, etc. At the same time, there is no evidence of solidarization of TB patients in hospitals or of those receiving ambulatory treatment.

Interruption of treatment (breaks)

The most problematic in the treatment of tuberculosis for many patients is the uncertainty of the treatment cycle and the uncertainty of the probability of recovery. One of the young men in FGD in Bishkek said that he was hospitalized three years ago. Then the doctors predicted that the treatment would last 8–10 months and the recovery would be achieved. But after one year of treatment in the hospital, the patient changed the hospital ward to a parental home, and the treatment did not stop for a single day. Having not achieved progress, a few months later, the young man was forced to return to the clinic again, to undergo a surgery, and by the time of our conversation he despaired that he would arrive at any result at all. In the conversation, he noted that he had decided that if before the onset of winter colds there was no progress, he would leave the hospital and stop treatment...

Discussions in FGDs with TB patients showed that they interpret the interruption of treatment as evidence of poor contact and poor relations between patients and health workers. In particular, according to the patients, very many of those who interrupted treatment did not really understand all the possible consequences of this behavior because they did not have the full information that medical workers were supposed to provide them.

Discussion with the doctors about the limited awareness of patients about the treatment regimen, about the necessities and needs of a patient, the priorities of outpatient treatment for patients without drug-resistant TB forms, and the reduction in hospitalization period for all patients showed very important aspects of the attitudes and values of medical workers, their "confrontation" and a lack of understanding of the essence of the healthcare reform and, in particular, the anti–tuberculosis service.

Firstly, many medical workers with whom in-depth interviews were conducted are supporters of repressive methods of providing medical services and do not support the prioritization of outpatient treatment. As one of the respondents stated, *"You know, in Kazakhstan for instance, there is a law on forced isolation. Isolation exists both in Europe and America, because the public health issue must stand above individual people who do not want, those who do not want. If you do not want to be treated, if you do not want to fulfill your duty, to be treated, to not infect. Why do people around you have to suffer. Please, then, be in another place, as Kazakhstan reacted. They built more fences. Morbidity there dropped immediately... Our police does not have laws that would lock up (those who interrupted the treatment). But see, as long as there is no mechanism, a patient knows that they will not lock him up anywhere. Moreover, when they commit a crime having tuberculosis, right away they go: they cannot take me somewhere, I am sick. They know their rights here. I'm here, they cannot lock me up there. Forced isolation behind fences in Kazakhstan, up to a certain level, I think, would be effective. Because practice shows, yes – democracy, human rights, but democracy for one and against the rest."* Another respondent shared his assessments of treatment regimens and treatment standards introduced by the clinical protocol "Classification of cases and treatment of tuberculosis": *"We mainly try to treat outpatiently. Why do we have a lot of them now? Because three years ago a project appeared, which said that outpatient treatment can be done, so we now have so many. Nobody at home takes medicine on time, as they would have done in a hospital. Some forget, sometimes they do not eat on time, sometimes they leave for a visit, to go to a toi [feast]. At first he would interrupt for one day, then on an ongoing basis. They take one day, do not take another. If one takes for 10 days and then does not take*

for a day, a resistant form will develop. Therefore, we now have so many resistant forms of TB. Here the main reason: well, you did it outpatiently. To come for a medicine you need to spend 20 som on transportation. Here nobody will come every day spending 20 soms to take medicines. To spend 20 som every day, you have to earn them first. No way is outpatient treatment suitable for us. We even cannot find out what form they have – active, inactive. For example, today you give your phlegm, and you will get out of a closed place, and after lunch you can already get phlegm from an open place. In general, only god knows when it will be open"[45].

Secondly, one of the interviewed doctors believes that talking to patients to tell them about the treatment regimen, the importance of adherence to treatment is useless, because mostly patients are young, uneducated and do not understand the information. The respondent notes: "We talked with patients, there's no use. Because classes, and so on, and when you show pictures, they are more fun, pictures are for the level of children. Out population's ability to perceive information now..., but it is youth who get sick. Ability to perceive is low. Therefore, I do not know in what form we should communicate, in the form of comics, yes, probably. By the way, have you seen the terrible pictures on packs of cigarettes? Is there any effect?"

Thirdly, medical professionals suppose that the WHO–promoted standards correspond to the European mentality and way of life. In our context, the principles included in the clinical protocols can be detached from reality. More than once in an interview they voiced a proposal: if we work according to European standards, why do not we get a European salary?

The limited communication and lack of understanding of the patient's treatment can often lead to depression and cause a patient to believe that medication is useless, that the illness is virtually incurable and on this basis interrupt treatment. Some respondents, especially men, said that as soon as they felt better, they decided to leave for labor migration, start working to fulfill their traditional role of breadwinner. In such cases, poverty is combined with a lack of understanding of the prospects for health and ability to work.

According to the respondents' testimony, substitution and supportive therapy are also of great importance, which medical workers do not carefully assign to patients. As one of the patients whose mother is a medical worker noted, there are very effective drugs that reduce the side effect of anti–tuberculosis treatment: antiemetics, hepatoprotectors or to support the gastrointestinal tract, kidneys. She was supported by another participant, whom her friend – the pharmacist's dispatcher – helped to find effective medicines that doctors never advised... The desire to avoid community stigma sometimes also causes a treatment interruption. An example of a week–long treatment interruption for a man who, along with his wife, is terrified of publicizing the diagnosis in the local rural community, shows how even understanding the negative consequences of discontinuing treatment did not become an effective motivation due to the risk of dissemination of information about the man's TB diagnosis among neighbors and friends. In the life of this man, there was a time when his wife had to fulfill her "duty" of the daughter-in-law in the environment of her husband's relatives for a week, serving the wedding of close relatives, and in order to keep the boundary of safety from discrimination and social isolation could not admit that she needed to travel to the regional center for medicines for her husband. The man himself preferred to interrupt the treatment, fearing that one of his acquaintances could see him when receiving medicines (in the daily life his wife goes to get medicines).

[45] Жалпысын үйдөн лечение кылганга аракет кылабыз. Биздин территориябызда көбөйүп кеткенинин себеби, анткени мындан үч жыл мурун амбулаторно лечение кылса болот деген проект чыккан. Ошонун айынан бизде аябай көбөйүп кетти. .. Дарыны эч ким өз убагында иче албайт. Больницада жаткандай. Бири үйдө унутат, кээде тамак ичпей калат, кээде коноко кетет, кээде тойго кетет. Бир күн перерыв болуп туруп, кийин туруктуу формага өтө башташат. Бир күн ичип, бир күн ичпей, он күн ичип, бир күн ичпей койсо туруктуу формага айланат. Ошонучүүн ушул мезгилде туруктуу форма аябай көбөйүп кетти. Негизги себеби, амбулаторный кылды, мисалы бул жер ичинде эле күнүнө 20 сомдон жол кире кылып, дары ичкенге эч ким барбайт. Күнүгө 20 сом жол кире кылып барыш үчүн, 20 сом табыш керек. Амбулаторный условияда лечение эч качан болбойт. Алардын открытый, закрытый билиши да кыйын болот. мисалы, бир күн какырык тапшырганда бир күн жабык жерден чыккан болсо, түштөн кийин ачык жерден чыгып калышы мүмкүн. Ал кайсы малда ачылып калышын Кудай гана билет.

Stigma and discrimination in the family is one of the reasons for interruption: among the respondents there were two young women who stopped taking medication as soon as they felt better, because their mother-in-law tried to drive them away from the family, as it happens to sick, unsuitable daughters-in-law. By stopping medication, women tried to demonstrate their recovery and restored working capacity in the household.

In-patient facility

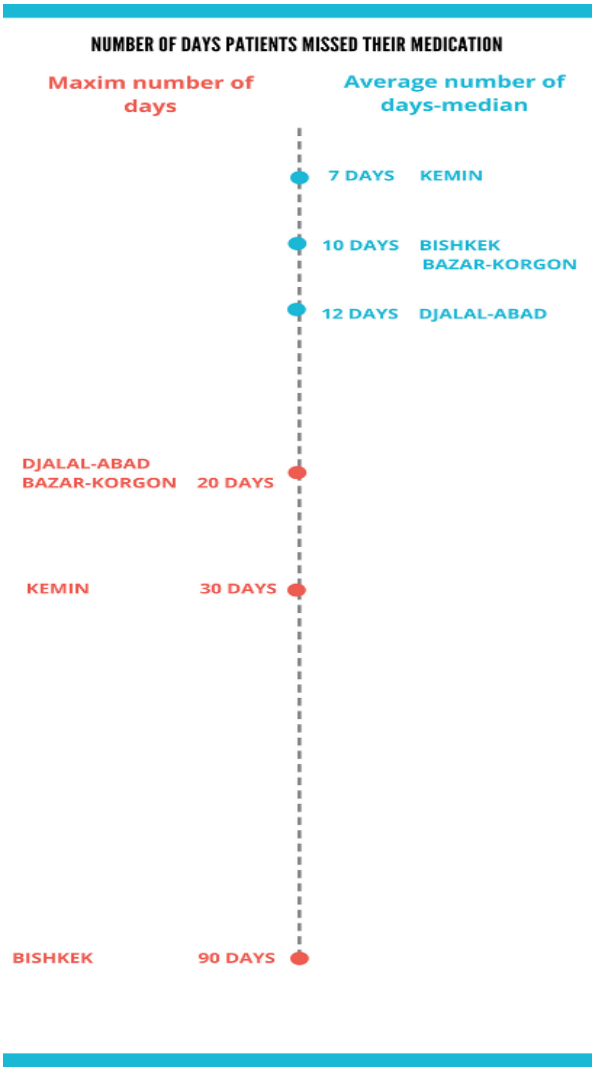
Out of 320 respondents, 245 (77%) underwent in-patient treatment. Out of those who received inpatient treatment, 23 people (9%) answered that they had interrupted treatment while undergoing treatment at the hospital. Below is the socio-demographic characteristics of respondents who interrupted treatment compared to the general sample. In Kemin, the proportion of interrupted treatment is relatively high compared to other selective settlements. In connection with the small number of those who interrupted treatment, making conclusions on the sex, age difference and educational level is difficult. The share of unemployed respondents among those who interrupted the treatment is lower than in the general sample. Unmarried, divorced respondents and respondents with low incomes were more likely to interrupt treatment.

Table 20. Socio-demographic characteristics of respondents who interrupted treatment in the hospital, compared with the structure of the total sample

		From the number of patients who interrupted treatment in the hospital (N=23)		All sample (N=320)
		N	%	%
Valid	Kemin	11	48%	25%
	Bishkek	3	13%	25%
	Jalal-Abad	2	9%	25%
	Bazar-Korgon	7	30%	25%
Sex	Male	11	48%	50%
	Female	12	52%	50%
Age	18–28	9	39%	34%
	29–39	3	13%	21%
	40–49	4	17%	16%
	50–59	5	22%	14%
	60+	2	9%	15%
Education	No formal education	1	4%	1%
	Elementary education (4 grades or fewer)			0%
	Incomplete secondary (5–9 grades)	4	17%	10%
	General secondary (10–11 grades)	11	48%	44%
	Secondary technical education (vocational school)			8%
	Specialized technical (training college, technical college)	2	9%	15%
	Incomplete higher	3	13%	8%
	Higher	2	9%	15%
Employment	I work for hire (contract) on a permanent, long-term basis (with the exception of maternity leave)			5%
	Periodically I work on short-term contracts	1	4%	4%
	I am engaged in private business, entrepreneurship	3	13%	3%
	I am engaged in agriculture and/or animal husbandry	1	4%	2%
	I am self-employed	1	4%	2%
	Non–working pensioner	2	9%	14%
	Non–working student	2	9%	7%
	Housewife, on maternity leave	4	18%	12%
	Unemployed	9	39%	51%

Subjective perception of wellbeing	We do not have enough money even for food	6	26%	15%
	We have enough food for food, but it is problematic to buy clothes	10	44%	39%
	We have enough money for food and clothes, but not enough to buy expensive things	4	17%	38%
	We can afford to buy expensive things like a refrigerator, a washing machine	2	9%	3%
	We can afford to buy anything	1	4%	4%
Marital status	Not married	8	35%	28%
	Married	10	44%	48%
	Civic marriage		–	3%
	Divorced	4	17%	10%
	Widow / widower	1	4%	10%
	REFUSE TO ANSWER			0%

Figure 16. Duration of treatment interruption among patients from different regions (median and maximal interruption)



Skipping taking medication among respondents who interrupted treatment varies from 1 to 90. Because of the presence of "throwing away" that is an uncharacteristically high value for the sample (1 respondent indicated 90 days), the median is the more suitable statistical parameter for determining the average duration of missed treatment.

On average, 23 respondents discontinued treatment for 7 days, and women in hospitals missed treatment for a longer period (see table 21).

Table 21. Number of days when medication was skipped for inpatient treatment

Gender	N	Minimum	Maximum	Median	Average
Male	11	3	20	5	7

Female	12	1	90	10	18
Total	23	1	90	7	13

The three most common reasons that respondents give to explain breaks are: due to adverse reactions of the body to taking prescribed medications, because they are tired of taking pills and because they began to feel worse and due to family circumstances (of an undefined nature). Women mentioned more causes of treatment interruption than men and more often stopped treatment, as they did not trust medicine, because of side effects and because they began to feel worse.

Table 22. Reasons for interrupting inpatient treatment, by sex (Multiple responses)

	Male	Female	Total
Got tired of drinking pills, I decided to take a break from the treatment	3	3	6
	27%	25%	26%
I do not trust these drugs, they can completely undermine my health	0	3	3
	0%	25%	13%
Medications are not effective, cannot cure TB	0	1	1
	0%	8%	4%
Due to occurrence of adverse reactions	4	7	11
	36%	58%	48%
I began to feel worse, and I refused to take medications	1	3	4
	9%	25%	17%
I did not want relatives to find out about the disease	0	1	1
	0%	8%	4%
I do not trust medical workers	1	0	1
	9%	0%	4%
For family reasons	2	2	4
	18%	17%	17%
To undergo heart examination	1	0	1
	9%	0%	4%
Went on a bender/binge drinking	1	0	1
	9%	0%	4%

Thus, the answers about the reasons for the interruption show that the issue of trust in the competence and professionalism of the medical personnel causes a whole list of reasons (variations in the answers in this category: mistrust in medicines, evaluation of medicines as ineffective, emergence of adverse reactions and deterioration of well-being and mistrust in physicians), they are followed by the issue of patients' awareness of the consequences of interruption: patients complained in the interview about the weakness of control by medical workers over taking medications and that, taking them for a long time patients get "tired" and do not realize the harmful effects of such a repose for the body. And finally, stigma is not unimportant: sometimes, a break occurs because the patient, trying to avoid stigma, "demonstrates" the absence of disease to relatives and friends by stopping taking the medications.

Women more often than men decided to resume treatment, or decided to do so under the influence of their relatives. Men more often mentioned female medical workers, 1 male also mentioned his employer.

Table 23. Who persuaded to resume inpatient treatment, by sex (Multiple responses)

	Men	Women	Total
I decided on my own	7	11	18
	64%	92%	78%
Medical workers	6	3	9
	55%	25%	39%
My relatives	1	3	4
	9%	25%	17%
Employer	1	0	1

	9%	0%	4%

Outpatient treatment

Out of 320 respondents, 266 (83%) were treated as outpatients. Out of those who underwent outpatient treatment, 28 people (11%) responded that they had discontinued treatment. Below is the socio-demographic characteristics of respondents who interrupted treatment compared to the general sample. In Kemin, the proportion of interrupted ambulatory treatment is also the highest among 4 regions. Men are more likely to discontinue treatment than women. The proportion of respondents with higher and incomplete higher education is lower among those who interrupted treatment than in the general sample. In general, working respondents and respondents with low incomes responded more often that they interrupted treatment. It is interesting to note that the proportion of married respondents among those who discontinued treatment is higher than in the general sample, which may be yet another confirmation that the family does not always mean loyal attitude and support, and the family role and social status of a TB patient can be a factor, which burdens, complicates the treatment of the patient.

Table 24. Socio-demographic characteristics of respondents who interrupted outpatient treatment and structure of the general sample

		From the number of respondents, who interrupted outpatient treatment (N=28)		All sample (N=320)
		N	%	%
Valid	Kemin	16	57%	25%
	Bishkek	3	11%	25%
	Jalal-Abad	5	18%	25%
	Bazar-Korgon	4	14%	25%
Sex	Male	16	57%	50%
	Female	12	43%	50%
Age	18–28	7	36%	34%
	29–39	5	18%	21%
	40–49	6	21%	16%
	50–59	2	7%	14%
	60+	5	18%	15%
Education	No formal education	1	4%	1%
	Elementary education (4 grades or fewer)	3	11%	0%
	Incomplete secondary (5–9 grades)			10%
	General secondary (10–11 grades)	15	54%	44%
	Secondary technical education (vocational school)			8%
	Specialized technical (training college, technical college)	6	21%	15%
	Incomplete higher	1	4%	8%
	Higher	2	7%	15%
Employment	I work for hire (contract) on a permanent, long-term basis (with the exception of maternity leave)	4	14%	5%
	Periodically I work on short-term contracts			4%
	I am engaged in private business, entrepreneurship	1	4%	3%
	I am engaged in agriculture and/or animal husbandry	1	4%	2%
	I am self-employed	2	7%	2%
	Non–working pensioner	4	14%	14%
	Non–working student	2	7%	7%
	Housewife, on maternity leave	3	11%	12%
	Unemployed	11	39%	51%

Subjective perception of wellbeing	We do not have enough money even for food	8	29%	15%
	We have enough food for food, but it is problematic to buy clothes	12	43%	39%
	We have enough money for food and clothes, but not enough to buy expensive things	6	21%	38%
	We can afford to buy expensive things like a refrigerator, a washing machine	1	4%	3%
	We can afford to buy anything	1	4%	4%
Marital status	Not married	7	25%	28%
	Married	16	57%	48%
	Civic marriage	1	4%	3%
	Divorced	2	7%	10%
	Widow / widower	2	7%	10%

Skipping medication among survey respondents interrupting treatment varies from 2 to 730 days. Because of the presence of "throwing away" that is an uncharacteristically high value for the sample (1 respondent indicated 730 days), a more appropriate statistical parameter for determining the average duration of the skipped medication is the median. Thus, on average, 28 respondents interrupted treatment for 7 days, and men missed outpatient treatment for a longer period.

Table 25. Number of days when medication was skipped for outpatient treatment

Gender	N	Minimum	Maximum	Median	Average
Male	16	2	730	9	56
Female	12	3	30	6	8
Total	28	2	730	7	35

The three most common causes are: due to the occurrence of adverse reactions from taking medications, because I'm sick of taking pills and for family reasons.

Women often stopped treatment, as they began to feel worse and due to the occurrence of adverse reactions. Men more often than women named such reasons, as taking pills was a nuisance for them and due to change of a residence.

Table 26. Reasons for interrupting outpatient treatment, by sex (Multiple responses)

	Male	Female	Total
Got tired of drinking pills, I decided to take a break from the treatment	5	1	6
	31%	8%	21%
Due to occurrence of adverse reactions	6	5	11
	38%	42%	40%
I began to feel worse, and I refused to take medications	1	3	4
	6%	25%	14%
Due to change in the place of residence	2	1	3
	13%	8%	11%
For family reasons	3	2	5
	19%	17%	18%
Did not have money	1	0	1
	6%	0%	4%
Went on a bender/binge drinking	1	0	1
	6%	0%	4%
Went to Issyk-Kul to take rest	0	1	1
	0%	8%	4%
Medical worker did not give me/allow me	0	1	1
	0%	8%	4%

Women more often than men decided to resume treatment under the influence of medical workers, relatives, or they took this decision on their own. Only men mentioned relatives of the wife and their employer. 1 man still did not resume treatment – until the interview the interruption of treatment was 10 days.

Table 27. Who persuaded to resume outpatient treatment, by sex (Multiple responses)

	Men	Women	Total
I decided on my own	13	10	23
	81%	83%	82%
Medical workers	4	4	8
	25%	33%	29%
My relatives	2	2	4
	13%	17%	14%
Relatives of the spouse	1	0	1
	6%	0%	4%
Employer	1	0	1
	6%	0%	4%
Did not recommence the treatment yet	1	0	1
	6%	0%	4%

Recovery/relapse/lethal outcome

Patients talk little about recovery, it seems that the very "picture" of the future recovery is not clear. Pessimism is largely due to the fact that among patients there is little awareness, there are almost no role models of patients who have successfully healed. Also a high share of uncertainty about how much recovery is stable and irreversible, how possible are the relapse of the disease; these become both a factor in the weakening of treatment goals, and the cause of treatment interruption.

Some patients said that they had been in the hospital for a long time and met many people who had recovered several years ago and returned with a relapse, only now with a drug-resistant form, they were convinced that this disease is incurable. That it eventually leads to death, only a little later, in the next phase of exacerbation.

Data from the registration logs of 2016 also confirm that relapses or previous cycles of treatment of associated diseases (in cases of pulmonary TB it is pleurisy, pneumonia, etc.) have a high frequency.

Table 28. Forms of TB and the determination of cases

	New case	Relapse	After ineffective treatment	After loss for observation	Other previously treated	History of previous treatment is unknown	No data
The pulmonary form of TB	380	72	25	52	28	20	6
	65%	12%	4%	9%	5%	3%	1%
Extrapulmonary TB	119	11	3	4	0	0	2
	86%	8%	2%	3%	0%	0%	1%
Incorrect code	0	0	0	0	0	0	14
	0%	0%	0%	0%	0%	0%	100%
No code	0	1	0	1	0	0	4
	0%	17%	0%	17%	0%	0%	67%
Total	499	84	28	57	28	20	26
	67%	11%	4%	8%	4%	3%	4%

Some patients stressed that the proximity of the hospital (in the Dordoi area) with resuscitation and the opportunity to observe almost daily how patients die from tuberculosis, led to the thought of uselessness of treatment, caused depression and despair.

According to the respondents, the medical workers also do not contribute to strengthening hopes and belief in the recovery of patients. One patient who had a long interruption in treatment explained her decision with despair: "If you take such strong chemistry. Firstly, the nausea is constant. On top of that sometimes eyesight worsens, hearing, liver, stomach. Sometimes there are even such deterioration in speech development. And many people, how much time I was treated for XDR. Honestly, I went to the doctor. And I ask: What is the percentage of recovery. I do not know, they get sick almost 150 times, get sick and get to this stage (XDR). And she told me so, thanks to her for that: For those similar to you – 20 out of 100%. And then when she told me this, I said to myself that I took so much chemistry. I tried so hard, so that something happened – a change. But, there was still no change. I left. I did not take anything for 3–4 months. I said, if nothing helps, then there is no point. Yes, basically, that's it. And only after 4 months, when they put forward new drugs called "Dedafimin"[46]. And when the doctors said that really, they said that if you take them there will be good results. And I thought only about this for 15 days. After that, I started to take medicine. I realized that this medicine is much more effective and does not have side effects. And, ultimately, if you take these medicines, then there is an option of recovery."

Evaluation of the possibility of patients to influence the morbidity/curing of TB

The abovementioned problems and risks associated with the diagnosis, treatment and recovery of TB patients create a background for the perception of the opportunities and powers of patients to influence the change in the existing situation, and improve the TB service. The study measured the empowerment indices, which allowed to measure the patients' possibilities in two directions: a) the opportunitoes to gain access to quality services and understanding services for TB patients, and b) opportunities for other TB patients to obtain the necessary services, influence on improving the quality of services and on decision–making to improve healthcare services.

Table 29. Level of empowerment among TB patient in interaction with health workers and the system of providing medical services, by sex and region (possible values are 0–3, high value corresponds to a higher level of empowerment)

Region		I go to the doctor on a regular basis to go through medical examinations and inspection	I am in constant contact with doctors by whom I am treated and/or consulted	I immediately tell health workers if I do not like something in the service	I understand well the system of services that is offered to people with TB
Kemin	Male	2,8	2,7	2,4	2,3
	Female	2,7	2,8	2,3	2,4
	Total	2,7	2,8	2,4	2,3
Bishkek	Male	2,7	2,8	2,4	1,7
	Female	2,7	2,6	2,4	1,9
	Total	2,7	2,7	2,4	1,8
Jalal-Abad	Male	2,5	2,4	1,4	1,6
	Female	2,3	2,3	1,3	1,5
	Total	2,4	2,3	1,3	1,6
Bazar-Korgon	Male	2,9	2,9	2,7	2,7
	Female	2,6	2,7	2,6	2,4
	Total	2,8	2,8	2,7	2,5
Total for sample	Male	2,7	2,7	2,2	2,1

[46] the name of the medicine is written according to the respondent's words.

	Female	2,5	2,6	2,2	2,1
	Total	2,6	2,6	2,2	2,1

The obtained indicators demonstrate that the components of the index represent unequal opportunities for patients: for example, constant contact with a medical staff member, getting consultations and medical examinations/screening is part of the real practice of TB patients, and they assess their possibilities in these aspects highly. But with regard to the feedback on the quality of the provided health services and, in particular, the knowledge about the range of services provided by the system, patients assess their possibilities lower. In some regions, especially in Jalal-Abad and Bishkek, these components of the empowerment index are especially reduced. An interesting exception in the obtained data is again Bazar-Korgon rayon, in which all components of the index are at the level of high capability. Again, as a hypothesis, the authors of the report would like to link this exception to the impact of the information campaign that recently passed in the area and allowed local residents, especially TB patients, to be more knowledgeable and to know their rights and authorities. In this regard, the relevance of assessing the impact of the Bazar-Korgon information campaign and drawing lessons is an urgent need for strengthening the capacities of patients.

The empowerment index in interaction with the local community and local authorities received the lowest assessments, the indicators for the regions and the country as a whole mainly correspond to the low level of opportunities. It can be stated that at the political level, both men and women, regardless of their regions of residence, feel less protected, less able to influence the situation. Patients consider their chances to help other people with TB receive medical and other guaranteed services, use their own experience of treatment to improve the quality of TB services being low; it is even less possible for them to directly address local authorities in order to strengthen their activities to improve medical services in the field of anti–tuberculosis activities. The answers of the respondents have regional specifics: Bazar-Korgon and Kemin respondents showed a slightly higher level of confidence in their authority.

Table 30. Level of power at the level of interaction with the community and decision makers (political level), by sex and region (possible values are 0–3, high score corresponds to a higher level of empowerment)

Region		I help other people with TB status to receive services necessary for them	I speak with representatives of local authorities how it is possible to improve medical services	My knowledge and experience of TB treatment can be used for improvement of quality of services for people with TB status
Kemin	Male	1,9	0,4	1,6
	Female	1,9	0,8	2,1
	Total	1,9	0,6	1,8
Bishkek	Male	1,2	0,7	1,0
	Female	1,2	0,4	0,9
	Total	1,2	0,6	0,9
Jalal Abad	Male	1,5	0,5	0,7
	Female	1,5	0,7	1,0
	Total	1,5	0,6	0,8
Bazar-Korgon	Male	1,8	1,4	1,6
	Female	2,0	1,2	1,7
	Total	1,9	1,3	1,6
Total on sample	Male	1,6	0,8	1,3

	Female	1,6	0,8	1,4
	Total	1,6	0,8	1,3

CONCLUSIONS

Assessment of socio-economic factors, including gender-specific factors affecting receiving medical services by tuberculosis patients in the Kyrgyz Republic revealed the following challenges in the efforts to improve the epidemiological situation related to tuberculosis in the country:

1. **high level of stigma and discrimination** to which TB patients are exposed in all key life spheres – in the family, community, workforce and in the area of receiving medical services.
2. **abundance of discriminatory practices, including the stigma against TB patients among medical workers, which demotivates patients to continue treatment, reduces the credibility of medical workers and the system as a whole**.

   In the course of the study, a number of complaints were received from patients about sexual harassment, ignoring patients and failing to provide medical services, personal insults and limiting patients' choice of outpatient treatment or hospitalization, violation of patients' right to non-disclosure of the diagnosis. Verification of the reliability of such complaints is beyond the scope of the study.

3. **low level of awareness…**
   - among patients about the standard treatment regimen for TB, about the treatment prognosis and the inadmissibility of interruption of treatment, about the mode of life after recovery
   - among patients and their families about the rights in the sphere of receiving medical services
   - among family members of TB patients about the most favorable mode of TB support for a patient receiving inpatient and/or outpatient medical services
4. **the negative impact of cultural stereotypes on the behavior of TB patients' families and communities** (in particular, the respondents' views on the possibility of continuing marital relations, the reproductive rights of TB patients, the decline of the status of men in the family as they are unable to perform the role of breadwinners, etc.).
5. **lack of compliance** (adherence to the medical prescriptions of the patient's treatment), conditioned not only by the socioeconomic factors in the life of patients themselves, but also for reasons caused by the healthcare system itself.
6. **problems of documenting and analyzing data to improve the effectiveness of management decisions in the field of anti-TB service**.

1.1. Stigma and discrimination remain one of the main problems that TB patients face in the life cycle process associated with the disease of tuberculosis. Stigma determines the patient's attitude to the disease, to other TB patients, to the treatment regimen, to interaction with society.

- Despite the fact that TB patients assessed the family environment in terms of protection, care and support, many of them are discriminated against and stigmatized in the family. Particularly affected by discrimination and stigma in the family are young women – daughters-in-law, for whom the diagnosis of tuberculosis means the risks of loss of family, spouse, prohibition of reproductive ability, etc. It is also especially difficult for male TB patients to live with the diagnosis because it destabilizes traditional family roles and the status of men as a breadwinner, earner, head of household.
- Perception of changes in the behavior of family members after the TB diagnosis is significantly different depending on gender: men mostly note aspects related to the safety measures among family members: family members began to keep my things separate, put me in a separate room, began to wear a mask, made me wear a mask. Female respondents tend to note more care for them – I was released from domestic affairs, offered help, began to wash my hands before

eating, they became more attentive to my health, began to look after me. The revealed gender difference in perceptions is most likely due to the difficulty of the men's psychological adaptation to a decline in the status in the family.

- Conducted in Kyrgyzstan for the first time according to the international methodology, measured according to the standardized "Patient's attitude to tuberculosis patients" scale allowed to calculate the stigma index. The value of the index on this scale was 29.9 points, which corresponds to the level of stigma above average. Respondents' answers to the statements on the scale demonstrate paradoxical things: on the one hand, TB patients suffer from loneliness, feel guilty, are afraid of infecting their loved ones and suffer from the attitude towards TB patients the same as towards other stigmatized categories, e.g., people living with HIV. At the same time, they themselves share and accept discriminatory and stigmatizing assessments and attitudes towards other TB patients.
- The fact that the stigma index has an equal above the average value, without gender specificity, reflects the existence of discriminatory practices and stigma against both women and men.
- Measurement and calculations on the standardized "Community Attitude toward TB Patients" scale show an above-average stigma level of 30.9 points. This indicator, as well as the indicator "Patient's relationship to tuberculosis patients", is similar to the stigma index in South Thailand and Mexico, which may indicate a universal stigma for infectious diseases such as tuberculosis.
- There is a gap in expectations of care and involvement of a patient's family circle and patient's perception of it, assessment of the assistance provided by the family circle. So, in the patient's expectations, family members should demonstrate images of service and self-sacrifice, in reality, relatives put issues and measures on their own safety in the first place, and secondly worry about the economic costs associated with treating a TB patient.
- Family role and social status of a TB patient determine the attitude and involvement of the family circle in diagnostics and treatment, and also correlate with the behavior on receiving medical services.
- Stigma and discriminatory practices in the labor market undermine the chances of recovered TB patients to be integrated into employment and income-generating activities and reinforce the orientation on disability as the most successful strategy for income access. Negative attitudes toward employment prospects in the future are related to others' experiences and media discourse, which testify to the reproduction of stigma and discrimination throughout the life of a TB patient, even after recovery.

2.1. The study revealed a low level of patient awareness of the standard treatment regimen for TB, treatment prognosis and inadmissibility of treatment interruption, and the life regimen after recovery. Medical workers pointed to constant information activities, an abundance of visual information literature in medical institutions at the stands, information boards. But patients often had no idea when they complete the intensive phase and go on to supporting one, nor about what their personal prospects for recovery are, etc. Frequently patients who returned after treatment interruption regretted their lack of knowledge in the past about the consequences interruption of treatment. The patients also testified that the beginning of treatment could be less traumatic for them, if they were informed in advance of the influence and possible side effects of the prescribed therapy.

2.2. The study revealed a low level of awareness among patients and their families of rights in the area of receiving medical services. Due to lack of understanding and knowledge of rights, patients often "solved" their need with informal payments. Thus, a low level of awareness is a factor that stimulates corruption risks.

2.3. The study demonstrated that family members of TB patients are poorly informed about the most favorable mode of TB support for a patient receiving inpatient and/or outpatient medical services. Patients' family members' awareness is critically important for a proper understanding of the safety of TB prevention measures, reducing the risks of spreading the infection and creating a favorable psychological atmosphere, incentives for treatment compliance. In practice, they often involuntarily

became catalysts for treatment interruption, instead of being a family support system it turned into a disloyal environment for TB patients.

2.4. The weakness of targeted information channels from medical structures or other relevant state/public structures is compensated by informal channels of information in hospitals and around outpatient facilities in TB patient communities; moreover, the media and the Internet become leading providers of information on the disease – healing and recovery. Within the framework of the study, separate evidence was obtained of the effective impact of various media channels: 1) the media, which covered the discussion of the death of two patients in the NCP, presumably from the side effects of an experimental drug; 2) the targeted information campaign to reduce stigma and discrimination against TB patients conducted during the period of data collection by media company Door Media, commissioned by the USAID's TB Defeat Project.

3.1. In some cases, when an influential/respected family member (father, mother) is ill with tuberculosis, other family members ignore the requirements of strengthening preventive measures for the safety of other family members, preferring, contrary to rational arguments, cultural traditions and standards of respect for elders.

3.2. In cases when traditional activities are carried out in the community (*ash* or *toi*), the TB treatment regimen of a patient receiving out-patient treatment is usually violated. Traditional values and rituals are prioritized as more significant, and the interruption in treatment is underestimated.

4.1. The number of interruptions from treatment, cases of ineffective treatment and practices of referring to "alternative" therapies, as well as independent substitutions/prescriptions of supporting medications among survey respondents and according to agency statistics indicate problems of the patient-doctor relationship, a weak adherence to treatment of a significant share of patients. Thus, we can talk about the patient's lack of compliance.

4.2. The lack of compliance is due to the problems of financial support for the livelihoods of the patient and his/her family environment, the psychological atmosphere in the family and community, the levels of stigma and discrimination in the family and community, possibly personal characteristics (including the psychological type) of the patient.

4.3. At the same time, the lack of compliance is due to a lack of trust towards medical workers and the system of health services provision in general, the stigmatizing and discriminatory attitude of medical workers towards tuberculosis patients, disinterestedness/psychological burnout of specialists, and the weakness of the communicative competence of the medical worker. Probably, in this connection, the lack of methodological developments in communication between a doctor and a TB patient is of no little importance.

4.4. The study of the opinions of medical workers revealed a reduced social well-being of medical personnel in the TB service system, low professional motivation to work efficiently, largely due to unfair remuneration and working conditions that correspond to all norms of infection control.

4.5. An important aspect that forms the patient's compliance is the regime of latent rejection of new policies in the treatment of tuberculosis by some medical workers who are obviously committed to the old management approaches in the field of medical services. These respondents internally disagree with the idea of prioritizing outpatient treatment, providing services in accordance with the needs and necessities of the patient, introducing a patient–centered approach model.

5.1. Despite a large number of studies on the spread of tuberculosis in the Kyrgyz Republic, the study of statistics and studies on various aspects of the TB epidemiological situation revealed **a lack of knowledge and understanding by the management structures of healthcare of causal mechanisms of key processes and phenomena in the field of antituberculous medicine**. Insufficient knowledge and understanding is due to the lack of research on a number of issues and topics, as well as **problems of departmental documentation and data analysis**. The existing deficit of analytical studies includes (but does not exhaust) questions of compliance of TB patients, mortality from TB, peculiarities of treatment and recovery of different categories of TB patients, etc.

RECOMMENDATIONS

1. To eliminate the lack of knowledge and understanding of ongoing dynamic processes in the field of antituberculous medicine, it is advisable to study the following topical issues and topics:
    - Factors contributing to/preventing the reduction of gaps in the rate of decline in the incidence and mortality from TB in different regions of the country,
    - The impact of the labor migration factor on the tuberculosis epidemiological situation in the country is an undeveloped subject, despite the availability of data indicating a higher prevalence of TB among migrants, as well as a significantly higher incidence of tuberculosis in this category of Kyrgyzstani citizens;
    - Uneven rate of decline in the incidence rate among men and women, which leads to a reduction in the gap in the incidence rate of men and women, but there are not enough data to analyze the causes of trends, including disaggregated data on the types and forms of tuberculosis that affect men and women.
    - There is no research in the country into the impact of a patient's psychological type on compliance to TB treatment and strategies for working with different patient psychological types.
    - The country does not apply an analysis of the mortality of patients from TB (confidential audit), which does not allow to understand a significant proportion of TB patients' deaths.
    - The need to assess the perception and acceptance of new rules of work according to clinical protocols and ethics of addressing and interacting with patients.

2. Develop and adopt a set of measures to increase patient compliance, including:
    - Training, informing and counseling patients, especially non-compliant risk groups.
    - Monitor the impact on a patient's behavior of a variety of ways that would help patients take medication on time.
    - Develop and implement compliance monitoring – diaries of patients, regular monitoring of key indicators of the state, etc.
    - Development and adoption of guidelines for communication with patients on the most important issues of treatment regimens, followed by training of contact medical staff
    - Further work to educate clinicians on the clinical protocols for the classification and treatment of TB so that regional health workers are aware of new policies, but also that they accept policies, value-based consent.
    - Develop clear mechanisms for receiving and responding to patient complaints, especially in cases of stigma and discrimination by medical workers, and eliminating systemic barriers to the realization of the right to health.
    - To make additional measurements on the impact of the territorial accessibility of the DOT rooms on patient compliance to the prescribed treatment.

3. Raising patients' awareness, informing their family circle and community
    - To promote stories of successful recovery and full integration of the cured women and men into the community, the workforce and so on through various media channels.
    - It is advisable to study and disseminate the experience of the information campaign on reducing the stigma and discrimination against TB patients by Door Media, commissioned by USAID's "Defeat Tuberculosis" Project, during our field study, as this study shows evidence of a positive difference in stigma and discrimination in Bazar-Korgon.

APPENDIX 1. DEFINITION AND CALCULATION ORDER OF STIGMA AND EMPOWERMENT SCALES

Stigma scale

For the computing of the stigma scale there was used the Van Rie HIV/AIDS–Related Stigma Scale to measure the social and psychological constructs of stigma associated with tuberculosis and HIV/AIDS at both the community and patient/individual level in a developing county.

The items represent the key causes of stigma (fear of casual transmission, willingness to interact with affected individuals, and moral values of blame, shame, responsibility, guilt, punishment and judgement) and key consequences of stigma (negative feelings and emotional reactions towards affected individuals, isolation, discrimination and disclosure). The scale consists of 43 indicators / statements using 4-bit Likert scale to measure people's attitudes to these allegations. The scale consists of two factors that were conceptually identified as «Community Perspectives toward Tuberculosis» (11 statements) and "Patient Perspectives toward Tuberculosis" (12 statements). The initial total score (SSraw) was calculated for each of the scales as the sum of the answers for all statements for a specific scale.

Computation of standardized summary stigma scores

Four-point Likert responses to individual items were scored with 0 representing the least (strongly disagree) and 3 representing the most (strongly agree) stigma. A raw summary score (SS_{raw}) was computed for each scale as the sum of scale item responses. Because the four scales had different numbers of items, raw summary scores were mathematically transformed into a standardized summary score (SS_{50}) such that the level of stigma on each of the four stigma scales would lie between 0 and 50, with higher scores representing higher levels of stigma. This was achieved using the formula $SS_{50} = (SS_{raw} \times 50)/(n \times 3)$ where n represents the number of items in the respective scale and 3 equals the maximum score that can be achieved for each individual item. Summary scores were only calculated for individuals that responded to all items of the respective scale. The mean and standard deviation of the SS_{50} in the study population were calculated and the distribution of SS_{50} for each of the final scales was assessed.

Statements for computing of scale index «*Community Perspectives toward Tuberculosis*»

Some people prefer not to have those with TB living in their community

Some people keep their distance from people with TB

Some people think that those with TB are disgusting

Some people feel uncomfortable about being near those with TB

Some people do not want those with TB playing with their children

Some people do not want to talk to others with TB

If a person has TB, some community members will behave differently towards that person for the rest of his/her life

Some people may not want to eat or drink with friends who have TB

Some people try not to touch others with TB

Some people may not want to eat or drink with relatives who have TB

Some people are afraid of those with TB

Statements for computing of scale index «*Patient Perspectives toward Tuberculosis*»

Some people who have TB feel hurt of how others react to knowing they have TB

Some people who have TB lose friends when they share with them they have TB

Some people who have TB feel alone

Some people who have TB keep their distance from others to avoid spreading TB germs

Some people who have TB are afraid to tell those outside their family that they have TB

Some people who have TB are afraid of going to TB clinics because other people may see them there

Some people who have TB are afraid to tell others that they have TB because others may think that they also have AIDS

Some people who have TB feel guilty because their family has the burden of caring for them

Some people who have TB will choose carefully who they tell about having TB

Some people who have TB feel guilty for getting TB because of their smoking, drinking, or other careless behaviors

Some people who have TB are worried about having AIDS

Some people who have TB are afraid to tell their family that they have TB

Empowerment scale

The scale of empowerment of the Family was originally designed to measure the level of empowerment of parents of children with mental disorders. In this study, it was adapted to measure the empowerment of patients with TB in three ways: (a) Attitude (what patients feel and believe in); (b) Knowledge (what patients know and what they can potentially do); and (c) Practice (what patients actually do) on three levels: (a) Family; (b) the Services System; and (b) Communities / Policies.

Computation of scale

For each individual statement, the values were from 0 to 3, where 0 means the lowest level of empowerment, and the value 3 is the highest. A higher score corresponded to a higher level of empowerment. In particular, the average for each type of manifestation of empowerment was calculated.

Statements for computing of Empowerment scale index

I can easily use the family budget if I need to pay for medical services and / or buy drugs

I can openly discuss TB questions and other health related issues with my family

I visit the doctor on a regular basis, do medical examinations and check ups

I keep the constant contact with doctors who have been treated and / or consulted me

I immediately tell medical workers when I do not like something in their service

I have good understanding of the system of services that is offered to people with TB

I help other people with TB to get the services they need.

I speak with representatives of local authorities on how to improve medical services.

My knowledge and experience of TB treatment can be used to improve the quality of services for people with TB.

APPENDIX 2. LIST OF REFERENCES

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