

**ASSESSING
THE SATISFACTION LEVEL
OF TUBERCULOSIS PATIENTS
IN REGARDS TO
MEDICAL SERVICES AND COMMUNITY
SUPPORT DURING TREATMENT**



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ACRONYMS

AIDS – Acquired Immune Deficiency Syndrome
CESCRGC 14 – Committee on Economic, Social and Cultural Rights (CESCR) General Comment 14
DOT – Directly Observed Treatment
DR-TB – Drug-Resistant Tuberculosis
DS-TB – Drug-Susceptible Tuberculosis
ECDC – European Centre for Disease Prevention and Control
EEA – European Economic Area
EECA – The Eastern Europe and Central Asia Team
(The Global Fund to Fight AIDS, Tuberculosis and Malaria)
EU – European Union
FG – Focus Group
HIV – Human Immunodeficiency Virus
ICESCR – International Covenant on Economic, Social, and Cultural Rights
MDL – Moldovan Lei
MDR-TB – Multidrug-resistant tuberculosis
PCC – Patient/Person-Centred Care
PNCT – The National Program for TB Control
RM – Republic of Moldova
SMIT – Moldovan National Association of Tuberculosis Patients
TB – Tuberculosis
TB-REP – TB Regional EECA Project for Health System Transformation and Financing Reform to Scale up Drug-Resistant TB Control
UDHR – Universal Declaration of Human Rights
VOT – Video Observed Treatment
WHO – World Health Organization

Executive summary and priority recommendations

Although the Republic of Moldova faces serious challenges related to both TB and especially drug-resistant TB burden, having one of the highest rates of MDR-TB in the WHO European Region, it has also made significant strides in reducing TB incidence and improving access to diagnostics and DR-TB treatment. In recent years, it has even piloted fully ambulatory MDR-TB treatment and strengthened peer and community-based support. There is still much to be done, but there are many promising collaborations and projects which show that Moldova is not only taking the problem of TB seriously, but is open to innovative, patient-centred approaches.

This report was completed as part of the “Together for TB Control” project initiated by the Moldovan National Association of TB Patients (SMIT) and supported by The Centre for Health Policies and Studies with funding from the Global Fund to Fight AIDS, Tuberculosis, and Malaria through the regional program EECA (TB-REP). It provides important information that is often not solicited, namely what is working and what needs improvement in TB services from the perspective of people who are currently being treated for TB. The report is intended for decision makers in Moldova from the national to local levels. It should also be of interest to other countries in the region as it complements already existing data regarding the experiences of patients and their feedback on how to improve TB services, including data recently collected in Romania. [1]

The data presented in this report were gathered using survey and focus group methodologies. Data were collected on a variety of issues, from basic demographic information to the challenges of having the disease and completing treatment. The report even includes data on the challenges that follow completed treatment, such as the inability to return to one’s former occupation due to a loss of lung capacity, or permanent adverse reactions such as hearing loss caused by injectable antibiotics used for the treatment of drug-resistant TB. Though this research is based on a relatively large sample size, additional, in-depth research in Moldova will be necessary to better understand the problems affecting people with TB, particularly their struggles with adverse reactions, and the financial and emotional toll that hospitalization causes especially for the poorest people, and what types of support will be the most useful to ensure that everyone in Moldova has access to quality, patient-centred TB care.

In order to achieve the best treatment outcomes and the least disruption

to people's lives, eliminate the catastrophic economic consequences that frequently accompany TB disease, and make the Moldovan public health system as effective and cost-efficient as possible, we sought the perspectives of affected communities. Their input is necessary to ensure that care is meaningfully accessible and that the right to health is respected. This right is guaranteed by the International Covenant on Economic, Social, and Cultural rights (ICESCR), of which Moldova is a signatory. [2]

Some of our most important findings

The experience of TB greatly disrupts people's lives. The disease not only causes physical suffering to the person, who has it, but can also result in great emotional distress, alter a person's role in their family, damage a person's social networks, and lead to catastrophic financial consequences. This is especially true when the primary breadwinner must undergo treatment and is unable to work. Many respondents reported that the disease and treatment cost them their jobs and made it difficult for them to find work. This situation is worsened by the fact that there is little financial support available to people with TB and their families in Moldova. Additionally, even after a person has been cured of TB, they often suffer from the permanent lung damage, hearing loss, and other conditions caused by the disease and its treatment.

Respondents identified their families as their main source of support. However, as noted above, the experience of TB, particularly when people are hospitalized and removed from their social networks, can weaken the very social supports they rely on, and lead to them losing their social role. About one third of respondents reported feeling a lack of control in their lives due to the strains the disease puts on their finances and social networks. The people who were most likely to express this were respondents from rural areas, with incomes below 1000 MDL and between 50 and 59 years of age. This lack of control is especially true for people with DR-TB, who face many months of hospitalization. During this time, family finances, child care needs, and other responsibilities may fall on other household members who are unable to bear this burden alone. Therefore, while, according to respondents, the family may be the most important source of support, it is also put under great strain by the disease.

Almost 40% of respondents had treatment interruptions. 26% percent of them had interruptions lasting 8 to 30 days, and an unacceptably high 16% had interruptions that lasted longer than 30 days. Interruptions like these endanger a person's chances of being cured and can result in the development

of additional drug-resistance, which would further complicate their treatment.

A common theme in both the survey responses and focus groups discussions was adverse reactions to treatment. These were explicitly identified by respondents as the number one reason that they discontinued treatment. If all of the interruptions that are likely to have been due to adverse reactions are combined (liver issues, feeling too sick, being told by the doctor to stop treatment, etc.), these reactions account for nearly half of all treatment discontinuations. They far outnumbered other reasons, including work, migration, or family problems. This is not surprising considering how common adverse reactions are, especially for people with DR-TB. Unfortunately, palliation of adverse reactions and TB symptoms is not adequate in Moldova. During the WHO TB Program Review in 2013, it was found that ancillary medications were only freely available while people were hospitalized. WHO recommended that these medicines be freely available for the entire duration of treatment. [3] However, this problem has also been reported by our research participants (three years after the WHO TB Program Review), so it has not been resolved, or at least not in all sites.

TB is still stigmatized in Moldova. About one third of respondents reported feeling discriminated against or stigmatized because of their illness and ignored by society in general. Those feeling the most stigmatized, as well as the most helpless, tend to be those who were already economically vulnerable when they became ill, and those who have suffered from the economic burden and disruption of social relationships caused by TB disease.

One of the most important findings of this research, which is not at all surprising given the situation described above, is that people with TB want treatment options, and overwhelmingly prefer treatment on an ambulatory basis (almost 70% of respondents) despite the fact that nearly three quarters were hospitalized at the time of the survey. In this case, patient preference for ambulatory treatment is similar to that which has been recently expressed by current and former TB patients in neighbouring Romania, who strongly support ambulatory treatment and desire a variety of options including Video Observed Treatment (VOT). [4]

In addition to more patient-centred, community-based treatment, people expressed a desire for better communication from medical staff. They generally had positive opinions of the training of doctors and nurses, but many felt that they needed more information and explanation of their health status and treatment options. They wanted staff to be open and available and to ask how they felt and if they were experiencing adverse reactions to treatment. This is important because one of the things that people were least satisfied with is the prescribed treatment. Moreover, they wanted explanations for when diagnostic tests and other processes took longer than expected. It may be

that the doctor also does not know when to expect the results, but greater openness is appreciated nonetheless. Though respondents wanted a more open communication, they also complained about a lack of confidentiality. It should be noted that people with TB have a right to privacy and that nothing about their health should be shared with anyone without their consent. This is especially important because of the stigma associated with TB.

Priority recommendations

- The suffering that TB disease and treatment inflict can be limited by adopting a patient-centred approach to treatment. Based on the survey responses and focus groups discussions, as well as on WHO guidelines and best practices from other places, we recommend adopting a community-based treatment and support model that provides people with TB options that allow treatment to better fit their lives.
- Community-based treatment and support should aim to remove barriers to treatment identified in this research, by making it as close and convenient to the patient as possible. People with TB should be made aware of the different ways of accessing treatment and support, such as in-home treatment, VOT, and any other options that patients and their families deem acceptable.
- Patients' families are their top source of support. These families should also receive appropriate support while patients are being treated. A needs assessment should be done to determine the best approach in terms of economic, social, and psychological support for people with TB and their families.
- For people with TB who have families, ambulatory treatment is highly recommended. Once a person is placed on correct treatment, they rapidly become non-infectious. All efforts should be made to provide the necessary support to allow people with families to remain at home unless there is an extraordinary clinical reason for them not to.
- Adverse reactions are a major cause of treatment disruption. All people with TB have a right to palliation of symptoms and adverse reactions to treatment. To accomplish this, all ancillary medicines should be available free of charge, regardless of whether a person is hospitalized or not.
- Hearing loss caused by injectable second-line drugs is permanent and interferes with people's ability to work and communicate with their

families. WHO guidelines should be followed, which call for hearing loss to be monitored and, in cases of intolerance to the injectable, for the latter to be replaced with another drug.

- People with TB have a right to privacy. This should be respected. Information about their health should not be shared without their consent. Sensitive information should not be given in open spaces where others might hear.
- With patients' consent, mediation and education should take place for their families. These discussions could be led by medical staff, local elected officials, social workers, psychologists, representatives from NGOs and other qualified people.
- Medical staff should make themselves available for discussions with patients regarding their treatment options, their progress, and especially any adverse reactions they are experiencing. Patients want medical staff to invest time to create an atmosphere of open communication. This could reduce treatment interruptions and ultimately yield better treatment outcomes.

CONTEXT

Despite notable progress over the last decade, tuberculosis continues to be a public health problem in most of the countries in the European Region. Countries outside the European Union (EU) and the European Economic Area (EEA) show high incidence rates of TB. At the same time, some of the highest incidence rates of drug-resistant TB are found in the EU/EEA region. [5] People from vulnerable groups are the most likely to become infected with TB, Socio-economic factors and co-infection with HIV are the determinants of the disease. Conversely, when direct and indirect costs are considered in low and middle-income countries, TB often has devastating economic consequences on families because it reduces the annual household income by about 50%. [6, 7]

Statistical data collected at the international, European, and national level

According to the World Health Organization (WHO), 10.4 million people became ill with TB disease in 2016. [5] About one quarter (approximately 1.7 billion people) of the world's population is infected with tuberculosis [5], and between 5 and 15% of those infected will develop active tuberculosis. However, certain groups of people are at a much greater risk, such as those living with HIV, or suffering from diabetes, malnutrition, and any condition that impairs the immune system, or those who use tobacco. For example, people living with HIV are estimated to have a 20-40 times greater chance of developing active TB as people without HIV in the same country. [8-10]

Globally, in 2016, an estimated 600,000 people developed rifampicin-resistant- and MDR-TB. However, only 153,000 (26%) of these people were actually diagnosed, and even fewer were put on appropriate treatment. [5] 1.7 million people die of tuberculosis each year. 95% of deaths occur in low and middle income countries. 190,000 people died of drug-resistant TB in 2016, with more than half of these deaths occurring in India, China and the Russian Federation. [5] TB is the 9th leading cause of death in the world and is the number one cause by a single infectious agent, resulting in more deaths than HIV/AIDS. It is also the main cause of death of people living with HIV/AIDS. [5]

Within the WHO European Region, TB incidence rates vary dramatically by country. However, the region is home to the majority of the countries in the world with the highest incidence rates of drug-resistant TB and to a regional treatment success rate for MDR-TB of only 54%. [5] In the region, as well as

in Moldova, there is an upward trend in rates of MDR-TB. [5] While drug-resistant TB leads to many deaths, so does drug-susceptible TB. The table below compares tuberculosis mortality rates in European countries according to the latest data. [11] The data below suggest that, on average, the mortality rate within the European Region is 5.2% of its total number of TB cases, while within the EU this figure is 0.8%. The Republic of Moldova has a rate of 12.6%, which is double the average within Europe. The rate in Romania is 6.4 times higher than the EU level. Ukraine has an index of 14.3, higher than Moldova by two units.

**Table 1. Tuberculosis mortality rates in European countries
(according to WHO / HFA Database data, April 2014)**

Country	Index	Country	Index	Country	Index	Country	Index
Austria	0,4	Latvia	3,2	Croatia	1,03	Romania	6,4
Belarus	7,3	Lithuania	6,1	Finland	0,6	Russia	14,3
Bulgaria	1,9	Malta	0,4	France	0,5	Ukraine	14,2
Czech Republic	0,4	Moldova	12,6	Germany	0,2	EU	0,8
CIS	13,9	Netherlands	0,1	Greece	0,4	Europe	5,2

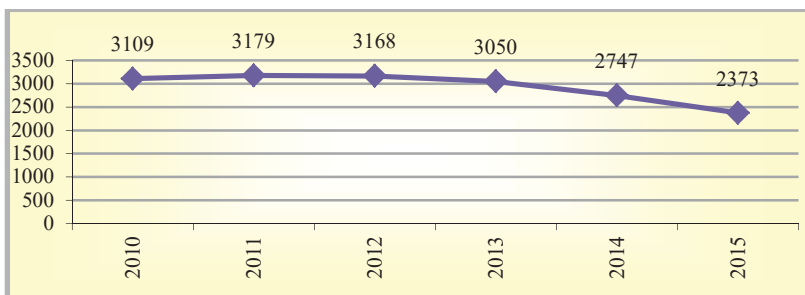
**Table 2. Tuberculosis mortality rates in European countries –
deaths per 100,000 people
(according to WHO / HFA Database data, April 2014)**

	M	F			
Austria	0,6	0,2	Lithuania	11,6	1,9
Bulgaria	3,2	0,7	Malta	0,6	0,2
Czech Republic	0,6	0,2	Moldova	23,5	3,0
CIS	24,0	5,6	Netherlands	0,2	0,1
Croatia	1,5	0,7	Romania	11,4	1,8
Finland	0,8	0,5	Russia	25,6	5,2
France	0,8	0,4	Ukraine	25,7	4,5
Germany	0,3	0,2	EU	1,4	0,4
Greece	0,5	0,2	Europe	8,8	2,1
Latvia	6,0	1,1			

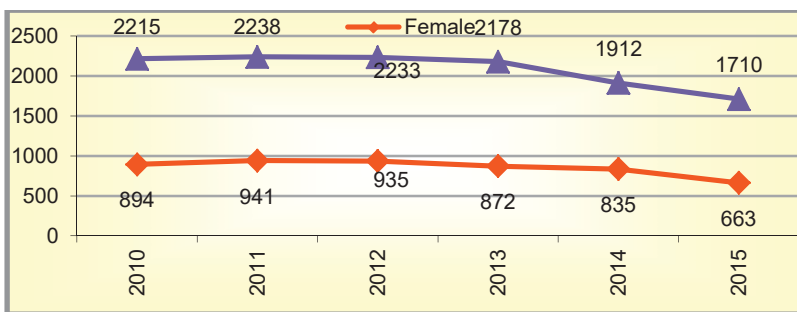
In conclusion, although countries in other parts of the world have greater TB mortality than Moldova, its mortality rate remains among the highest in the European Region. The mortality rate among men in Moldova is particularly high, being nearly eight times greater than that of women.

During recent years, there have been a number of positive outcomes in the Republic of Moldova in terms of reducing the burden of tuberculosis, thanks to the measures undertaken within the national program for TB control (PNCT). These include reducing the incidence of TB (a 23% reduction between 2011 and 2015) and ensuring universal access to TB diagnosis and treatment. Advances in the availability of diagnosis and treatment, as well as PNCT participation in several local and international research efforts, including research on new TB drugs, fully ambulatory MDR-TB treatment, and video observed treatment, to name a few, are all examples of the ambitiousness of the Moldovan PNCT and evidence of strong partnerships with local and international partners. Nevertheless, the Republic of Moldova still faces a serious TB problem, which is complicated by high rates of drug resistance. The website <http://statbank.statistica.md> shows the following statistical data on active tuberculosis morbidity in the Moldovan population [12]:

Diagram 1. Active tuberculosis morbidity in the RM by year, 2010-2015



Active tuberculosis morbidity in the RM by year and gender, 2010-2015



For 35-40% of the cases diagnosed annually, microbiological tests yield negative results; another 40% are diagnosed late, which leads to an increased risk of serious complications. Late diagnosis is a major challenge in Moldova and was also identified in the last WHO review of its TB program as contributing to the spread of infection. The review noted worse outcomes for people not diagnosed until they had severe forms of pulmonary TB. [3]. Moldova's high poverty rate and potentially difficult access to health care in many rural areas contribute to this problem.

In the Republic of Moldova, national programs and various projects aimed primarily at ensuring the health of the population and stopping the spread of tuberculosis are being carried out. One of these projects is «Together in Controlling Tuberculosis: Streamlining TB and MDR-TB control by strengthening a favourable environment for ambulatory treatment», which is part of the regional TB-REP project. The latter is focused on promoting the introduction of new treatment and support models for tuberculosis patients and is implemented by the Moldovan National Association of Tuberculosis Patients «SMIT»¹. These projects are part of a larger, global trend towards TB care that respects human rights and aims to improve treatment outcomes and to limit the physical, emotional, and financial damage that often accompanies TB disease and treatment.

Ambulatory care

The shift towards ambulatory care, even for people with drug-resistant TB, is part of these activities, but is not by far the only concern. Since 2011, the World Health Organization (WHO) MDR-TB treatment guidelines have recommended that people with TB, including drug-resistant varieties, be treated primarily on an ambulatory basis. [13] This recommendation is repeated in the 2016 revision of the guidelines. [14]

Ambulatory care refers to treatment and care outside of hospitals on an outpatient basis. It can take many forms, from requiring people with TB to

¹ The Moldovan National Association of Tuberculosis Patients «SMIT» (Moldova Society against Tuberculosis) emerged as a result of the need to strengthen and protect the rights of people with tuberculosis. SMIT promotes the creation of a partnership between patients, medical staff and community in order to improve the health of people with TB and to increase the efficiency of the health care process, to carry out measures to support and promote public participation in health care decision-making and to encourage cooperation between representatives of health care, civil society organizations, government and business.

arrive at a TB dispensary on the grounds of a hospital at a set hour, to more flexible models where a treatment supporter might observe treatment by coming to a patient's home or place of work, or even through Video Observed Treatment (VOT) whereby a mobile phone application allows a patient to make a video of themselves taking their pills to be watched by the treatment supporter at a later time. There is strong evidence that ambulatory care in most, if not all, of its forms, is more cost-effective than traditional hospitalization. In fact, recent research in South Africa found that various models of ambulatory care reduced costs by 36-42%. [15] It has also been shown to be effective in a variety of settings, even among HIV-positive people with DR-TB. [16-18] A pilot study of fully ambulatory DR-TB treatment in Moldova yielded treatment outcomes similar to standard hospitalization. [19] This result is in keeping with a 2013 meta-analysis of treatment outcomes which found no statistical difference between ambulatory and inpatient approaches. [20] While there are many types of ambulatory and community-based models of care available, it is important to note that different types may be appropriate for different patients. Outcomes will be best when the care is designed around the needs of the patient.

Patient-Centred Care²

Patient³-Centred Care (PCC) is the first pillar of WHO's END TB Strategy. [22] PCC is a holistic approach that places the patient and their family at the centre of care by making it as convenient as possible to them. It also means understanding the motivations of each patient and providing them with education and counselling tailored to their circumstances, all within the context of local social, structural and cultural factors. This is more complicated than simply offering patients a menu of choices. It requires understanding a patient's priorities and needs. PCC also does not mean that all responsibility is placed upon the person with TB. According to WHO's treatment guidelines and recent ethical guidance, treatment should be accessible, acceptable, affordable and appropriate. Patients should have choices about the location of treatment, when patient-centred DOT is used, and the individuals who will be doing the observing. [23, 24] PCC should be grounded in human rights and ethical norms which recognize that governments and health systems have

² See the TB-REP project brochure on People-Centred Care [21]

³ Sometimes called People-Centred Care

ethical (and in most cases) legal responsibilities to respect, protect, and fulfil the right to health. [25]

Human rights and ethics

The right to health is established in several human rights documents beginning with the Universal Declaration of Human Rights (UDHR). [26] It is also expressed by article 12 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR) which was ratified by 166 countries, including the Republic of Moldova. [2] Article 12.1 of the ICESCR states that the countries which are party to this Covenant should “recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” It continues by stating that the full realization of this right shall include, among others, “(c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;” and “(d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.” [2]

The right to health is further elaborated by the United Nations’ Committee on Economic, Social and Cultural Rights (CESCR) General Comment 14 which is the authoritative interpretation of Article 12 of ICESCR. [27] The CESCRGC 14 considers accessibility to health care, stating: “Health facilities, goods and services have to be accessible to everyone without discrimination.” According to the CESCRGC 14, there are four overlapping dimensions of accessibility. The first stipulates that “health facilities, goods and services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.” The CESCRGC 14.30 declares that “States parties have immediate obligations in relation to the right to health, such as the guarantee that the right will be exercised without discrimination of any kind (art. 2.2).” Secondly, goods and services in health facilities must be physically accessible—that is, “within safe physical reach for all sections of the population, especially vulnerable or marginalized groups.” Special mention is made of rural residents’ right to accessible health facilities, goods and services. The third dimension of accessibility is economic affordability. The CESCRGC 14 states that “health facilities, goods and services must be affordable for all....including socially disadvantaged groups. Equity demands that poorer households should not be burdened with health expenses as compared to richer households.” The fourth dimension is information accessibility. This means that individuals

have a right to information about their health. [27] This right is part of the reason why WHO's Ethics Guidance for the END TB Strategy (hereafter the WHO TB Ethics Guidance) states that "there is a duty to give individuals information and counselling about TB prevention, diagnostics, treatment and care services." [24]

Given Moldova's obligations under the ICESCR, it is important that TB treatment and support reach all people, regardless of whether they live in rural areas or are members of other vulnerable groups. This includes ensuring that these services are equitably accessible and do not burden people with TB and their families with direct and indirect economic costs. This is not only legally required, but also an important part of the WHO TB Ethics Guidance. [24] The data collected as part of this project suggests that there is significant room for improvement in the areas of physical and economic accessibility. There are also opportunities to increase information accessibility for people with TB and their families. The data that follows will provide the Moldovan PNCT and local and international partners with the information needed to inform policy ensuring that all people in Moldova with TB have meaningful access to care that addresses their needs and minimizes damage and disruption to their lives caused by TB and its treatment.

Hospitalization

One of the greatest burdens on people with TB that was identified in other countries is the long and unpredictable duration of hospitalization and the economic and emotional distress that it brings. However, in much of the Euro WHO region, long hospitalization is standard practice, regardless of a person's clinical and socio-economic state. For example, in Romania, the most recent WHO TB Program Review described extensive and unnecessary hospitalization, including for people with non-severe and non-infectious TB. [28] Similarly, Moldova's last WHO TB Program Review found "systematic hospitalization of all infectious and most non-infectious TB patients". [3] While there are some severe clinical states that justify extended hospitalization, it is not recommended for the majority of people with TB. [14, 23] In addition to being clinically unnecessary, it removes people with TB from support networks which are important for their economic and emotional well-being. It also disrupts the ability of a person with TB to contribute to the economic and emotional support of their family. This issue was studied at length in Romania, where it was found that people were disrupting treatment due to the

indirect costs of remaining hospitalized, especially if they were the primary breadwinners of their families. [29] This was also a problem for women who, despite requiring TB treatment, faced expectations of childcare and other household duties, along with having to work to supplement the family income. [30] One of the main findings of a recent consultation in Romania funded by the European Centre for Disease Prevention and Control (ECDC) was that people with TB wanted options for their treatment. These included fully ambulatory treatment for DS and DR-TB, Video Observed Treatment (VOT), in-home DOT, and traditional hospitalization followed by DOT at a local clinic or doctor's office. [4] The interviews and focus groups conducted during the WHO review of Moldova's TB program in 2013 yielded similar results, with many people discussing how disruptive TB treatment and especially hospitalization were in their lives. However, a less common, but important, perspective came from some elderly and poor respondents who supported hospitalization because of the food it provided and because they could not afford to heat their homes in the coldest winter months. [3] Insights like this are crucial for the development of effective, patient-centred care. The concerns of people who support hospitalization reinforce the need to understand local specificity as it relates to both health services and social welfare supports, which in Moldova, as in much of the world, do not guarantee that a person will be spared of cold or hunger. This is a need that is made obvious by the experiences of people with TB and that offers a valuable caution that a "one size fits all" model of ambulatory care will not be economically accessible to some of the poorest and most vulnerable people in Moldova. We hope that our findings, which capture the experiences and needs of many people with TB, will be considered alongside the growing body of research highlighting the effectiveness and acceptability of well-designed, community-based treatment and support programs, so that locally appropriate solutions can be created for Moldova.

I. METHODOLOGY:

1.1 Description of study

This study examines and evaluates the satisfaction level of patients with tuberculosis in the Republic of Moldova in regards to medical services and community support during treatment. At the same time, this study is a record of patients' demand for improved quality of and access to these services and support.

This study was carried out by the Moldovan National Association of Tuberculosis Patients «SMIT» and was qualitative and quantitative, as well as descriptive and analytical in nature. It consisted of a national survey of 230 people with TB during the period October - December 2016, and of four focus groups conducted between April and June 2016 in four district centres and comprised of a total of 29 people with TB. Each focus group discussion included 7-8 participants and was guided by a moderator. Discussions were informal and relied on information provided by the group, as well as by the moderator. Participants had the opportunity to speak when they wanted and express divergent opinions, with or without providing arguments or examples. The quantitative part of the study was based on a probabilistic selection of those surveyed. The process of selecting respondents was uniform at the national level. Respondents were questioned wherever they were located. Survey takers made an effort to carry out the interviews face-to-face, assuring respondents that the data they provided is confidential and that their names or surnames will not appear anywhere. All efforts were made to ensure privacy during the interviews. However, due to the large number of interviews conducted in hospitals, there were occasions when interviews had to be interrupted by medical staff.

These two data collection tools were meant to examine a series of issues, ranging from patients' satisfaction levels, their problems and ways of expressing concerns, the people whom they called upon and who supported them, their perceptions of stationary and ambulatory treatment, their communication with other patients, their community etc., their interactions with the primary health care services (AMP) and specialty medical services, interventions, directly observed treatment, causes of treatment interruptions, etc.⁴ This multi-dimensional approach allows for an analysis of the relationship between patients and services, and, at the same time, for a consideration of patients'

4 The field operators trained to carry out this study were members of the SMIT team: Pavel Rucșineanu, Stela Draguțan, Georgeta Andrieș, Alexandrina Reaboi, Natalia Baranova and Aliona Chistol.

perceptions of their disease and needs (micro perspective) as a starting point for the transformation of services and institutions (macro perspective).

The results of this study, which included patients' descriptions of their needs and suggestions for improving TB services, will contribute to the ongoing development of tuberculosis control programs aimed at rendering more efficient the services provided to people with TB in the Republic of Moldova. This study, which assessed patients' emotional state and identified their needs and expectations in regards to available services and support, will guide the design of new ways to develop socio-medical services.

1.2 Objectives

The goal of this study was to collect information from patients about their most significant issues and needs, the changes they experienced with the onset of illness, the way they evaluated the services they had access to, and their expectations regarding these services. In addition, the study explored the sphere of support networks to get a picture of the several forms of support that exist.

In order to collect information which could contribute to the improvement of services, this study included:

- ✓ Assessing patients' satisfaction levels;
- ✓ Assessing patients' problems and needs;
- ✓ Assessing existing medical and psychosocial support and assistance;
- ✓ Assessing patients' attitudes towards stationary and ambulatory treatment;
- ✓ Assessing the quality of directly observed treatment;
- ✓ Assessing patients' interaction with other patients, community, etc.

1.3 Methodology: qualitative research

Four focus group discussions were held, each of which included 6 to 8 people. Focus group participants were selected according to the following criteria:

- Patients with TB;
- Patients with MDR-TB;
- Language spoken: Romanian, Russian;
- Districts of residence: Briceni, Florești, Rîșcani and Nisporeni.

Table 3. Distribution by number of participants, district of residence, and gender, 2017

No.	No. Participants	District centre	Structure
FG 1	6	Nisporeni	6 Men
FG 2	8	Rîșcani	1 Woman and 7 Men
FG 3	8	Florești	2 Women and 6 Men
FG 4	7	Briceni	1 Woman and 6 Men

Tables 4-9. Socio-demographic profile, 2017

Gender	Participants
M	25
F	4

Marital status	Participants
Married	16
Unmarried, divorced, widowed, etc.)	13

Studies	Participants
Secondary	19
Vocational	7
Middle School	3

Age groups	Participants
18-29 years old	3
30-44 years old	11
45-59 years old	12
60+ years old	3

Area of Residence	Participants
Urban	9
Rural	20

Occupation	Participants
Employed	3
Unemployed	19
Retired, disabled	4
Homemaker	3

About 85% of the participants in the FG discussions were men. Participants were predominantly between 30 and 59 years of age at the time. Most of them resided in rural areas, and the majority of them had a secondary education.

All group discussions were organised according to a moderation guide developed on the basis of the study objectives. Each group discussion was about 90 minutes long. The participants in the focus group were assured that they could speak freely and openly, and so everyone had the opportunity to express their ideas and opinions.

1.4 Difficulties and limitations of qualitative research

The findings and conclusions of this study reflect the experiences of the interviewees and cannot be extrapolated to all people with TB. However, given the relatively large sample size of this study, its methodological rigor, and the similarities between its data and those which have been collected in other countries, especially recent data from Romania, which shares with Moldova many of the same challenges and patient characteristics, we are confident that the data collected in this research is a good representation of the actual situation in Moldova. Nevertheless, there are areas where additional and more in-depth research would be useful to better understand the experiences of people with drug-susceptible and drug-resistant TB in Moldova. This could include in-depth qualitative research focused on people who have been unsuccessfully treated, and on vulnerable groups such as people who have been incarcerated, the very poor, people who use drugs and alcohol, and migrants (especially those who are poor). This research would help ensure that future efforts to make care more patient-centred address the needs of all people with TB.

1.5 Methodology: quantitative research and sample structure

Method used: Opinion poll among TB patients.

Sample universe: 230 respondents / nationally selected TB patients.

Sample type: targeted, random, probabilistic, stratified.

Table 10. Socio-demographic structure of the sample of respondents, 2017

Variable	Group	No. of respondents	Percentage
Gender			
	Male	184	80,0
	Female	46	20,0
Age groups			
	19-29 years old	39	17,0
	30-39 years old	59	25,7
	40-49 years old	61	26,5
	50-59 years old	50	21,7
	Over 60 years old	21	9,1

Education	No Stud. / incomplete secondary education	64	27,8
	Grades 1-8	53	23,0
	Prof. School / high school	89	38,7
	Higher education	24	10,4
Nationality	Moldovan / Romanian	181	78,7
	Russian / Ukrainian	40	17,4
	Other	9	3,9
Occupation	Agriculture	76	33,0
	Industrial production, construction	66	28,7
	Service industry	39	17,0
	Education / Health	8	3,5
	Unemployed	41	17,8
Income	100-1000 MDL	65	28,3
	1001-2500 MDL	41	17,8
	2501-5000 MDL	35	15,2
	More than 5000 MDL	12	5,2
	Does not know / does not answer	77	33,5
Area of residence	Urban	148	64,3
	Rural	82	35,7
Total		230	100,0

According to the table above, which shows the structure of the sample, 80% of the interviewees were men. The sample included virtually all age groups. However, most of the interviewees were between 30 and 59 years old.

Respondents' education levels were quite varied. The sample included people with no education or an incomplete secondary education, as well as with a university education. About 80% of respondents were Moldovans/ Romanians, while the rest were mainly Russians/ Ukrainians.

At the time of the interviews, most of the respondents were working in agriculture (33%), 29% in industrial production/ construction, 17% in the service industry etc., and 1 out of 5 respondents did not have a job.

A third of respondents had a monthly household income below 1000 MDL⁵; a fifth were in the income category of 1001 MDL - 2500 MDL, and one

⁵ As of February 2018, one US dollar is about 17 Moldovan Lei (MDL). One Euro is about 20 MDL.

third of respondents either did not know what their household income was or refused to answer this question.

Two thirds of surveyed respondents were living in urban areas at the time.

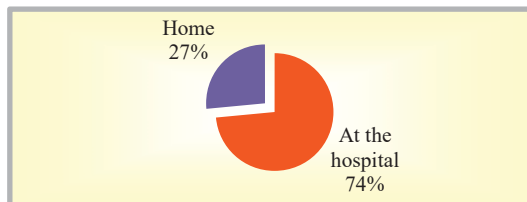


Diagram 3.
The distribution of
people undergoing
ambulatory and
stationary treatment,
2017 ⁶

As the diagram shows, about three quarters of respondents were hospitalized at the time of this study. 86% of those hospitalized came from rural locations.

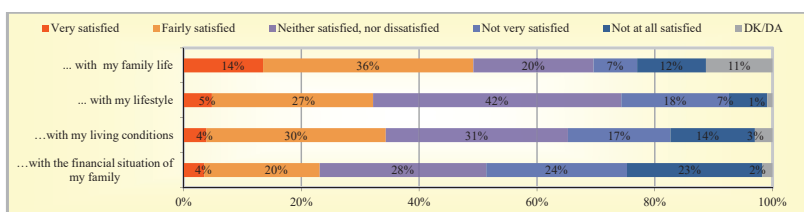
⁶ Values in diagrams have been rounded and may not equal 100%.

II. RESPONDENTS' KNOWLEDGE OF AND ATTITUDES TOWARDS TUBERCULOSIS AND TREATMENT

2.1 General views on life

Respondents' general views on life were assessed with the help of a series of questions taking into account the psycho-emotional, social and physical aspects of their lives.

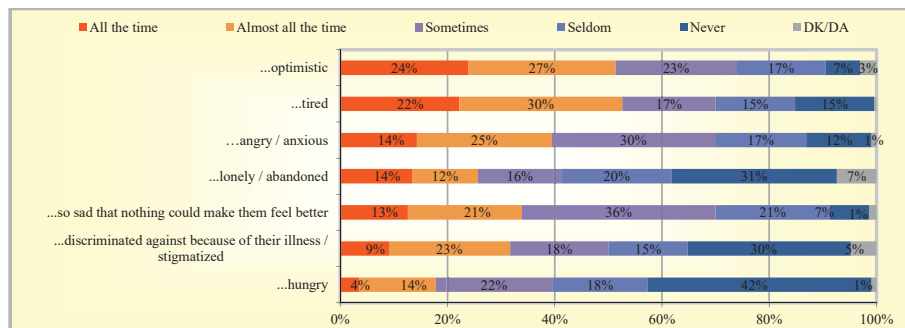
Diagram 4. Respondents' general satisfaction level, 2017



The diagram above reveals respondents' levels of satisfaction with several aspects of their lives. About half of respondents were satisfied with their family relationships. However, 1 out of 5 patients declared that they were not very or not at all satisfied with their family life. The most satisfied with their family lives were young people aged 19-29, with a university education and a household income of over 2500 MDL. Those most dissatisfied with their family lives were people aged 40-49.

Almost half of respondents said they were neither satisfied nor dissatisfied with their lifestyles. 1 out of 3 respondents was dissatisfied with their living conditions. A third of respondents were satisfied with their lifestyles. As far as their financial situation is concerned, interviewees tended to be dissatisfied with their incomes. The worst off were respondents over 60 years old, who were unemployed and who were predominantly from urban areas.

Diagram 5. Respondents' emotional states in the last 30 days, 2017



Respondents were asked about their moods in the last month. The most prevalent was a feeling of fatigue. 52% of patients experienced it at least almost all the time. 34% of respondents suffered from sadness with the same frequency. 42% of patients felt abandoned and alone in the face of life's obstacles at least sometimes. It is promising, however, that 51% remained optimistic.

About a third of respondents always or almost always felt discriminated against / stigmatized because of their illness. This was mostly felt by young people between 19 and 29 years old, with an 8th grade education and a household income below 1000 MDL per month, and whose main occupation was agricultural work.

Also, according to the focus group discussions (FG), some patients felt discriminated against by their community due to their disease.

My neighbours tell me not to get close to them, because it is transmitted through the air! [FG1 - M2]

If they know you have it, «take him away, stay here». At any rate, there is always someone who thinks of the worst. [FG3 - M6]

I know people with TB who always change their place of residence because their neighbours ignore them and even their children cannot go to school because people know who they are and do not want them in their school. [FG3 - M2]

We have encountered many cases where people do not want children in their school or kindergarten because their parents are TB patients. This especially happens in villages. [FG4 - M4]

There were even respondents whose family members rejected them.

I don't sleep with my wife because she said I'd give her the illness. [FG1 - M2]

If I drink from a cup, they do not want to sit with me at the table. [FG4 - M3]

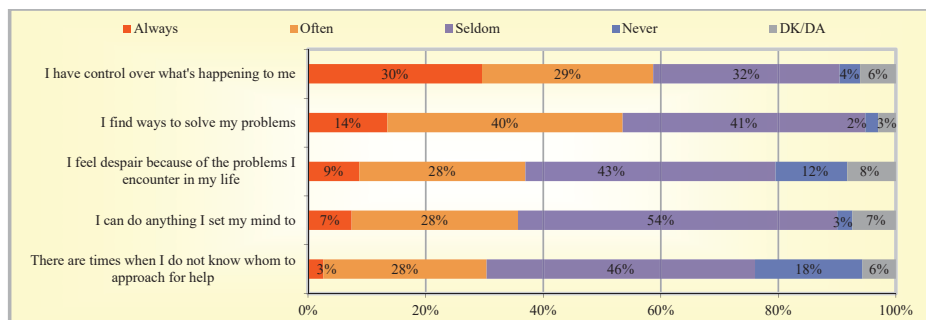
Others joked about it, saying that doing so made it easier for them to live.

However, it is important to note that these jokes are only possible because of the stigma that TB carries in Moldovan society.

I'm proud to have this illness! When I see that the line of people is long, I cough and everyone steps away, they suddenly hold you in high esteem! [FG1 - M5]

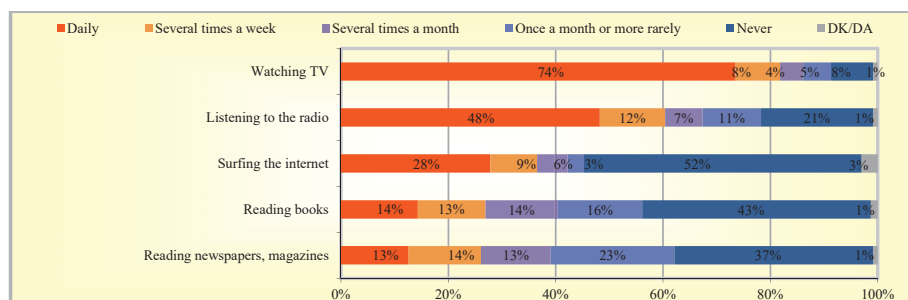
I look at the bright side, there are also advantages to this disease, if someone comes to visit me and I do not like him, I tell him I have TB and he quickly disappears from my yard. [FG4 - M1]

Diagram 6. Respondents' perceptions of their level of control over the things that happen in their lives, 2017



As the chart above indicates, about half of respondents thought they had complete control over the things that were happening to them and found the means to solve their problems. However, about a third of respondents found it difficult to cope with the challenges they were encountering in their lives, and said they felt powerless before them. Most of these respondents were living in rural areas, had incomes below 1000 MDL and were 50-59 years old.

Diagram 7. Frequency with which respondents accessed sources of information, 2017



Respondents' main source of information was television; more than two thirds of respondents watched TV daily. About half of respondents listened to the radio daily. The sources of information used most rarely were books and newspapers. But this is not just typical of respondents in this study. According to the Barometer of Public Opinion conducted by IPP twice a year, the Moldovan population in general does not read and mostly uses TV and the Internet as sources of information. [31]

Table 11. Types of physical activity that respondents engaged in to maintain their health (in percentages), 2017

Multiple answers	Yes	Daily	2-3 times a week	1-2 times a month	Rarely	Never	DK/DA
Walks in the outdoors	99,1	88,3	8,3	0,4	1,7	0,4	0,0
Physical exercise	49,1	15,7	12,2	2,2	11,3	7,4	0,4
Massage	29,1	1,7	5,2	0,4	8,3	13,5	0,0
Physiotherapy	21,7	0,0	0,9	1,7	4,3	14,3	0,4

The type of physical activity respondents engaged in most often was walking in the outdoors. 9 out of 10 patients did this every day. Half of respondents did physical exercise. For one third of them, physical exercise was part of their daily schedule. Two thirds of patients were getting massages in order to improve their health. 1 out of 5 patients said they were undergoing physiotherapy, only very rarely.

Table 12. Things respondents most wanted, 2017

<i>Out of a total sample of 230 respondents. Respondents were able to provide one answer.</i>	No. of responses	Percentage
Health	181	78,7
Treatment	13	5,7
A good life	8	3,5
Recovering one's health	1	0,4
Happiness	3	1,3
A job	6	2,6
Money	1	0,4
A family	1	0,4
A home	1	0,4
DK/DA	15	6,5
Total	230	100,0

What respondents wanted most in life was to undergo treatment and to be healthy (84.8%).

Table 13. Problems that respondents were worried about, 2017

Out of a total sample of 230 respondents. Respondents were able to provide three answers.

	No. of responses	Percentage
Poverty	48	20,8
Prices	54	23,5
Crime	90	39,1
Hunger	69	30,0
Indifference, being ignored by people	72	31,2
The possibility of having no one to support them in old age	70	30,4
Disease	126	54,8
Being physically / mentally dependent (on other people)	52	22,6
The future of their children	46	20,0
A war in the area	15	6,5
DK / DA	48	20,9
Total	690	300,0

Most respondents were worried about disease (in more than half of cases – 54.8%), followed by crime (39.1%), and by people's indifference to what happened to them (31.2%).

The respondents who were most worried about disease were men of working age (between 30 and 59 years old) who had been employed before becoming ill. This concern was likely related to the expectation, especially in rural areas, that men financially support their families. A long-term illness like TB interferes with this ability.

Table 14. The main things respondents did not want, 2017

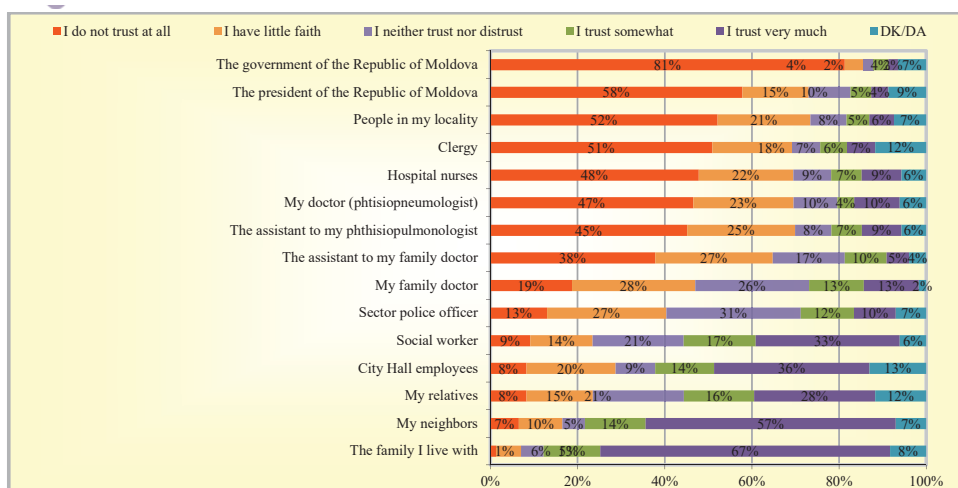
Out of a total sample of 230 respondents. Respondents were able to provide one answer.

	No. of responses	Percentage
Disease	105	45,7
No one knowing about this disease	43	18,7
Death	21	9,1
Loneliness	10	4,3
War	7	3,0
Disappointment	3	1,3
The future of their children	3	1,3

Catastrophe	2	0,9
Hunger	2	0,9
Invalidity	1	0,4
Not having a place to live	1	0,4
Loved ones to be sad	1	0,4
Being contagious	1	0,4
Being bedridden	1	0,4
Betrayal	1	0,4
Poverty	1	0,4
DK/DA	27	11,7
Total	230	100,0

The thing that most respondents did not want to happen in their lives is TB. They were not only referring to themselves but to other people as well, saying that they would like no one in the world to have to face this disease (64.4%).

Diagram 8. Respondents' levels of trust in their community, 2017



According to the diagram above, the people and institutions respondents trusted the most were the family they were living with (67% had a lot of trust), followed by their neighbours (57%) and, by a wide margin, by their relatives (28%), the Mayor's Office, their social worker etc.

At the opposite end of the spectrum, the people and institutions respondents

trusted the least were the government of the Republic of Moldova (81% of patients did not trust it at all), followed closely by the president of the country (58%), and by people in their locality (52%). Paradoxically, respondents expressed a fairly high level of distrust in the church (51%). While, generally speaking, this institution enjoys the greatest trust from people, more than half of respondents had no trust in clergy. Also, according to the table above, interviewees expressed a higher level of distrust in hospital staff than in the medical staff in their locality. 47% did not trust hospital doctors at all, compared to 19% who distrusted their family doctor.

2.2 Perceptions of and attitudes towards tuberculosis

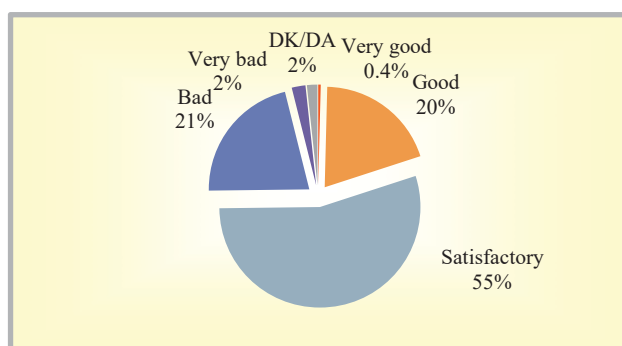


Diagram 9.
Respondents’
assessment of their
own health, 2017

More than half of respondents claimed their health was satisfactory (55%), about 23% believed it was bad or very bad, and 20% thought it was good. Those most dissatisfied with their health were people between 40 and 49 years old.

Among the first symptoms of tuberculosis, which made the participants in the FG discussions wonder, were difficulty breathing, convulsive cough, and loss of appetite.

I felt sick, I had no appetite, I thought it was my stomach [FG2 - M2]

I was suffocating. [FG4 - M4]

When they sent me away from here, I could not eat, I was suffocating I would mostly sit, I could not sit, I would kneel, I would lie down. [FG4 - M2]

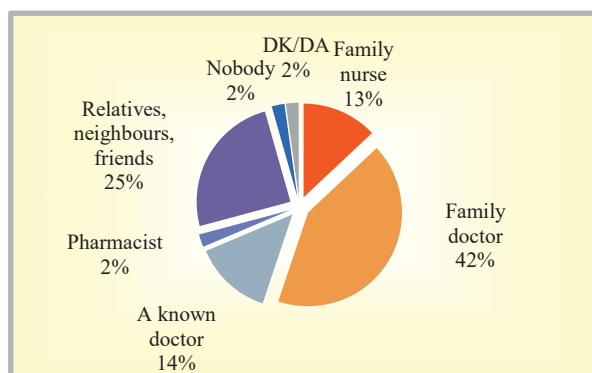


Diagram 10.
The first person
respondents contacted
in case their health got
worse, 2017

When they were feeling worse than usual, more than half of patients contacted medical staff: the family doctor (42.0%), a doctor they knew (14%), the nurse (13.0%). 25.0% of respondents contacted their relatives, neighbours, friends.

Table 15. Diseases that respondents suffered from, 2017

Out of a total sample of 230 respondents. Respondents were able to provide three answers.

	No. of responses	Percentage
Tuberculosis	56	24,3
Foot/ Leg problems	10	4,3
Hepatitis	7	3,0
Vision problems	7	3,1
Blood pressure	6	2,5
Stomach problems	5	2,1
Headaches	5	2,1
Hearing problems	5	2,1
Colds	4	1,7
Kidney problems	4	1,7
Liver problems	4	1,8
Gastritis	4	1,8
Nervous system problems	3	1,3
Diabetes	3	1,3
Pulmonary pleurisy	3	1,3
Arthritis	3	1,3

Pancreas problems	3	1,3
Ulcer	2	0,9
Osteochondrosis	2	0,8
Psoriasis	2	0,9
Intestinal irritation	1	0,4
Paralysis	1	0,4
Chronic pyelonephritis	1	0,4
Cardiac diseases	1	0,4
Radiculitis	1	0,4
Heart problems	1	0,4
Epilepsy	1	0,4
Impotence	1	0,4
Back problems	1	0,4
Haemorrhoids	1	0,4
Dental problems	1	0,4
Cancer	1	0,4
Autism	1	0,4
DK/DA	539	234,3
Total	690	300,0

When asked about their current diseases, only 1 out of 4 respondents mentioned TB (24.3%). Although, at the time of the survey, all respondents suffered from a form of TB, many reported other illnesses. It is important to note that many of the conditions reported by respondents were likely adverse reactions to TB treatment, such as hearing loss, pain in the feet, headaches, stomach aches, and other gastrointestinal problems.

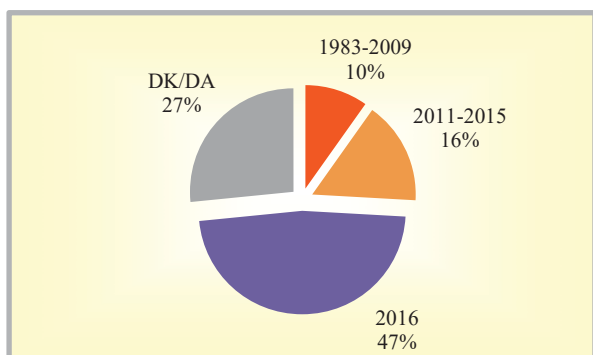


Diagram 11.
Year of falling ill with
TB, 2017

According to the diagram, about half of respondents (47%) said the disease appeared during the year 2016. Most of them were men from rural areas and between 50 and 59 years old.

16% of respondents said they contracted tuberculosis between 2011 and 2015, and 10% between 1983 and 2009. 27% did not know how to answer this question or did not want to respond.

Participants in the FGs reported that their first reaction upon finding out that they had TB was emotional pain. Some of them became severely depressed at the thought they had children to raise. The first thing that came to the minds of other participants was that they would die. This thought made them get into a state of shock.

I was diagnosed last week. I was told it was found and could be tuberculosis. To be honest with you, I cannot express what was in my soul when I first heard, I felt pain. I have two children at home, to be honest with you I fell into a depression. [FG2 - M1]

It was a shock for me. [FG2 - M2]

How can you possibly feel when you are sentenced to death? [FG4 - M4]

When I was in Chişinău at the hospital, I got sad. I'm ill and at home, [I have] three children. [FG3 - M5]

I was in shock, I could not speak, I could not explain anything, I was crying. [FG2 - M1]

Many of the FG participants found out they had TB after they returned from work abroad.

I came from abroad, I came home. I did construction work there for a long time, and when I came back here in Moldova, I was forced to get an X-ray exam at the company I worked. That's how I found out. [FG1 - M4]

I went to Odessa, where I worked for 11 years at a «bakery», and that is where I got it! Yes, I did not realize I had it until the last day, until I went to the hospital. Then the company shut down, and I went away. Then I stayed, I stayed in Ukraine! [FG1 - M5]

Some of the participants in the discussion believed that improper working conditions brought them to the brink of illness.

Yes, I worked, I worked in Moscow, I was sleeping where I could. [FG2 - M6]

When it is windy and you are working in construction, you should not be "covering roofs" if you have this disease. [FG1 - M5]

Others found out they had TB accidentally.

I, for one, can say that I had no way of knowing. My leg, my toes, hurt. I came to the hospital, where I was forced to get an X-ray exam, and when I took it, it showed a spot on my lungs. [FG1 - M6]

I was forced to get a big X-ray in the hospital. And there they ... diagnosed me with pulmonary tuberculosis! Well, "I was forced" is a way of saying. They didn't force me ... they asked it of me: do you want to undergo treatment or not? [FG1 - M4]

I still did not realize it. I was in Moscow and I got an X-ray, and they told me I had TB. I came home, I sort of thought it was a joke, I did not feel bad, whenever I smoked - I coughed. I was smoking 2 packs of cigarettes a day. [FG2 - M7]

Some respondents were not properly diagnosed. One reason for this is that not all district medical centres have phthisiopulmonologists. After a course of treatment, local specialists referred the patients to specialists:

For roughly two months I was treated for pneumonia. There is no specialist, at first I received treatment at home, then in Briceni. After that, once I arrived in Bălți, I was diagnosed and placed on DOTS from the very beginning. [FG3 - M2]

I stayed in Camenca for a day, then they said to me: «Go to Florești, it cannot be treated, it's tuberculosis. I had no feeling towards it, because I did not know of such a disease. [FG4-M5]

The doctor here sent me to Chișinău. While I was in the hospital, I kept feeling sick. Now I have 9 months of treatment left, it's different, but it's a problem anyway. [FG1-M1]

2.3 Perceptions of tuberculosis treatment

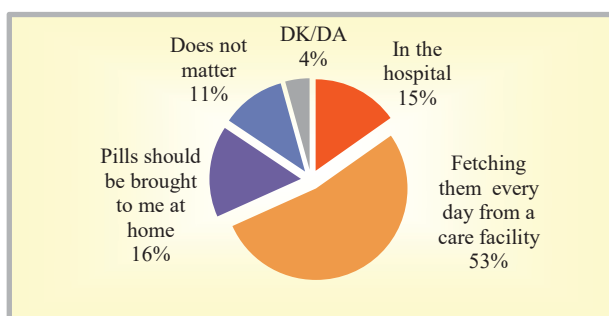


Diagram 12.
The methods of treatment (ambulatory / stationary) that respondents preferred, 2017

According to the diagram, when asked how they would like to follow their treatment, 69% of respondents opted for ambulatory treatment, with 53% preferring to fetch their pills daily from a medical care facility, and 16% answering that they would like their medicines to be delivered at home. At

the same time, 1 out of 10 patients said that it did not matter to them where they underwent treatment (11%) and 15% opted for hospital treatment. It is important to note that the options offered in the survey did not cover the range of patient-centred ambulatory treatment possibilities. The fact that 53% of respondents preferred to fetch their treatment daily, which is a difficult thing to do, shows a strong desire for ambulatory treatment options. If patients had access to more flexible, patient-centred options and were able to alter treatment times and sites depending on their work schedules, this number might have been even greater.

Participants in the FG discussions were asked where they would like to follow treatment. Their opinions were divided: most preferred to follow ambulatory treatment, i.e. at home, but some patients preferred to go to the hospital because everything there seemed more organized to them.

Ambulatory or at home [FG1 - M4]

Depends on the illness of each person [FG2-M5]

At home! [FG1 - M7]

At home you can eat what you want! In the hospital you don't know what you are going to eat... [FG1 - M2]

At home... [FG3 - M3]

At home!... [FG4 - M5]

In the hospital I thought of myself as gravely ill because there were people all around me with severe tuberculosis, it is easier for me to receive my treatment at home. [FG3 - M5]

It is 100% better to receive the treatment at home, at home even the walls treat you.[FG3 - M4]

If you have something to eat at home and a person to take care of you then home is better, but if you are like me and you do not have anyone, then the hospital is better. [FG4 - M1]

One of the main reasons why participants preferred to undergo treatment at home was the strict hospital rules, which made them uncomfortable. Another reason is that they would have nothing to do in the hospital and would get bored.

At the hospital I receive the morning pills and at 11:00 the door already closes and you cannot go anywhere, except the toilet. I can't do it this way, you want to walk and can't. At home you can go for a walk even at night, if you want. [FG3 - M1]

At the hospital, once you have swallowed your pills, you have nothing to pass the time, it's annoying, at home you can go here and there, you have something to do. [FG3 - M4]

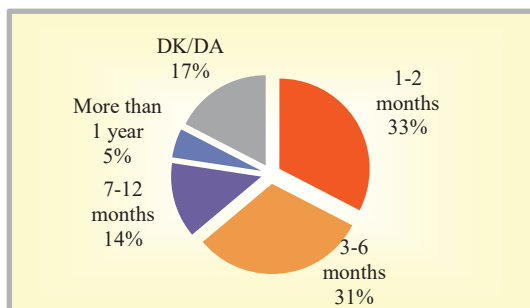


Diagram 13.
Duration
of treatment, 2017

The diagram shows that most respondents knew how long they had been treated for TB. One third of patients (33.0%) had been treated for about 1-2 months.

1 out of 3 interviewees had been following anti-TB treatment for about 3-6 months (31.0%). 1 out of 5 had been treated for more than 6 months (14.0%). Among those who had been treated for more than half a year were mostly men aged between 30 and 39 / 50 and 59, with household incomes between 1001 and 2500 MDL, with no education or with an incomplete secondary education.

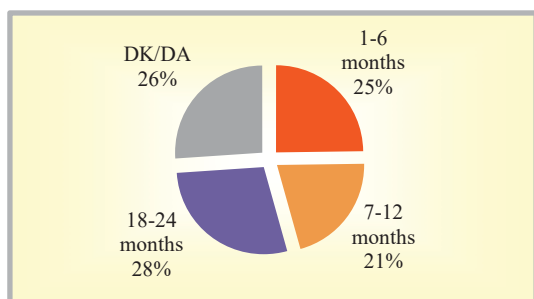


Diagram 14.
Respondents'
knowledge of
treatment duration,
2017

Respondents' answers to the question „how long should treatment last?“ demonstrate that they were very poorly informed about what stage of treatment they were in and, generally speaking, about all the stages included in a course of treatment and about what follows treatment.

While 17% of patients answered DK / DA to the question „how long have you been treated?“, 26% of respondents answered DK / DA when asked how long they needed to be treated. Thus, 1 out of 4 patients did not know how long they needed to be completely treated. This state of ignorance and uncertainty about tomorrow made respondents feel helpless in the face of life's problems.

Most of them were people who had been employed when they became ill and now had an income of less than 1000 MDL per month.

There were also respondents who knew how long they needed to be treated and even mentioned the period of time that their treatment required: between 1 and 6 months (25%), 7 and 12 months (21%), 18 and 24 months (28%).

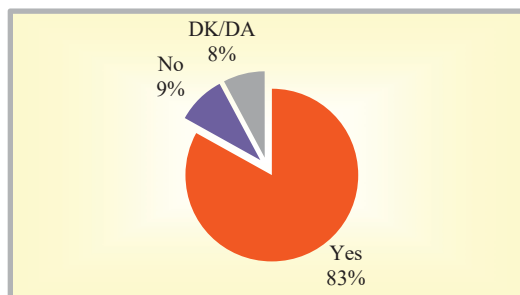


Diagram 15.
Respondents’
confidence that they
will be healed of
tuberculosis, 2017

Respondents’ answers tended to be positive, with 83% of them believing they would recover. The most optimistic among them were educated young people between 19 and 29 years old who had been employed when they became ill.

However, 1 out of 10 patients thought they had no chance of recovery (9%). These were mostly men between 30 and 49 years old with incomes below 1000 MDL.

Table 16. Factors that, according to the respondents, contribute to healing, 2017

<i>Out of a total sample of 230 respondents. Respondents were able to provide three answers.</i>		No. of responses	Percentage
Food		30	13,0
Personal hygiene products		92	40,0
Procurement of public transportation tickets		103	44,8
Money		99	43,1
Encouragement / attention from medical staff		84	36,6
Possibility of home treatment		78	33,9
Encouragement / Attention from relatives		57	24,8
Mental health counselling		71	30,9
Legal counselling		23	10,0
DK/DA		53	23,1
Total		690	300,0

As the table above suggests, some of the main factors which respondents believed would increase their adherence to treatment and contribute to their rapid recovery are: purchasing public transportation tickets (44.8%), money (43.1%), personal hygiene products (40.0%), etc.

It was mostly men from urban areas that needed public transportation tickets. People who needed personal hygiene products were women between 50 and 59 years old. While all respondents needed money, this was more important for the age segment of 30-39.

One of the perceptions of the FG participants regarding their TB treatment was that they had to take a multitude of pills and that treatment would last a long time. For these reasons, many were going through an emotional breakdown. However, patients were well aware that, if they discontinued treatment, the consequences would be more severe.

How long would I get treated... my entire life or what? [FG1 - M3]

If I receive this medication, my sin is that, if I stop taking it, then it will be worse. Worse ... [FG4 - M6]

There are too many pills, sometimes you get sick just seeing them ... [FG3-M2]

You take TB pills, then you take some for the heart and pancreas ... and so on.

There are too many, maybe if they had made them into a single dose a day or even once every 2-3 days. ... [FG4-M4]

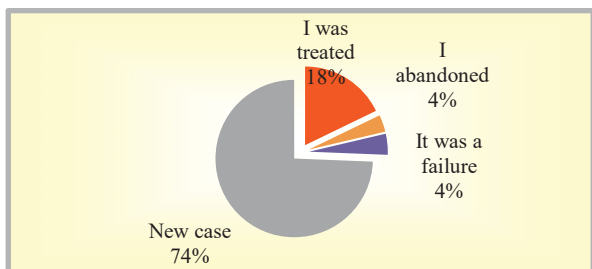


Diagram 16.
Results of previous
course of treatment,
2017

26% of respondents said that they had previously suffered from tuberculosis. 1 out of 5 patients (4%) said they had been successfully treated, 4% admitted that they had abandoned treatment out of their own initiative, and another 4% said that, in their opinion, the treatment they had been given had failed.

III. RESPONDENTS' SATISFACTION WITH MEDICAL SERVICES

3.1 Directly observed treatment (DOT)

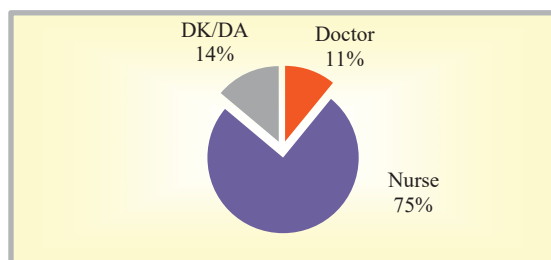


Diagram 17.
The people supervising respondents while they took medication, 2017

The people supervising patients while they took pills were mostly nurses and doctors. 75% of respondents took their medicine in the presence of a nurse and 11% in the presence of a doctor.

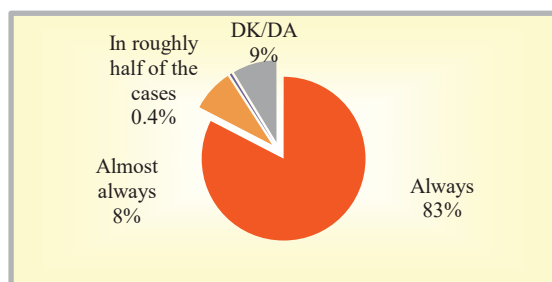


Diagram 18.
Frequency of directly observed treatment, 2017

91% of interviewees said that someone always or almost always supervised them when they took their tuberculosis pills. 9% of respondents refused to answer this question or did not know how to answer it.

3.2 Satisfaction with medical services provided in stationary care facilities

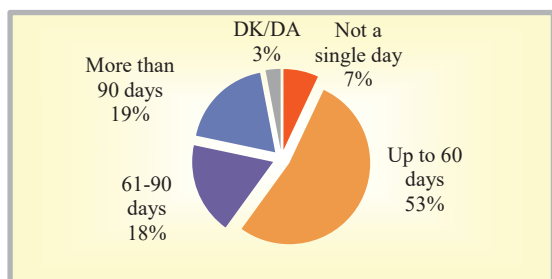


Diagram 19.
Duration of respondents' stationary treatment, 2017

	Very bad →→→→→→→→→→→→→→→→→→ Excellent										DK/ DA
	1	2	3	4	5	6	7	8	9	10	99
The attending physician's professional expertise	3,5	1,7	0,9	0,9	3,5	2,2	5,2	14,3	28,7	32,6	6,5
Nurses' professional expertise	3,0	0,0	0,9	2,2	3,5	2,2	7,0	12,6	30,0	32,2	6,5
Doctors' behaviour towards respondents	3,0	1,3	0,9	0,9	6,1	2,2	7,4	11,3	31,7	27,4	7,8
Nurses' behaviour towards respondents	2,6	1,7	0,4	0,4	6,5	3,5	7,8	9,6	31,7	27,4	8,3
The clarity of the information that doctors provided to respondents about their illness	8,3	0,4	0,4	1,7	2,6	6,1	10,4	15,2	23,5	23,5	7,8
The timeliness of the staff's involvement in solving respondents' problems	7,8	0,4	0,4	1,7	2,2	4,8	8,3	15,2	24,3	22,6	12,2
The staff's openness to helping respondents as effectively as possible	6,1	0,9	0,9	3,0	3,5	6,1	10,0	15,7	24,3	18,7	10,9
The staff's availability to listening to respondents	6,5	0,4	1,7	2,2	4,8	2,6	5,7	15,2	27,0	22,2	11,7
The method used by staff in solving respondents' health problems	6,5	1,3	0,9	0,9	6,1	3,0	7,8	13,5	24,8	19,1	16,1

Respondents found most satisfying the professional expertise of their attending physician and of the nurses in the hospital. About 75% of interviewees gave these two aspects grades ranging between 8 and 10. Respondents were less satisfied with how they communicated with their doctors - it seems that not all doctors were sufficiently clear when providing patients with information about their health. Medical staff should be more involved in delivering treatment and counselling patients. Respondents emphasized the professionalism of hospital personnel but, at the same time, had higher expectations of the staff in terms of their openness and availability to listening to them and helping them.

It seems that medical staff were behaving correctly from a professional point of view, but patients felt that their communication with staff was greatly lacking; specifically, they were interested in staff knowing how they felt and what the adverse effects of their anti-TB treatment were. Patients' perception was that, sometimes, some procedures were taking too long for no good reason.

Table 18. Respondents' requests for improving the quality of medical care in stationary facilities, 2017

<i>Out of a total sample of 230 respondents. Respondents were able to provide three answers.</i>	No. of responses	Percentage
Hiring a psychologist	2	0,9
Other treatment regimens	4	1,7
Better treatments	4	1,7
Comfort	5	2,2
Good food	12	5,2
More extensive explanations	3	1,3
Faster treatment	3	1,3
Nice behaviour	30	13,1
Professionalism	6	2,6
Attention	4	1,7
Treatment at home	4	1,7
Quality sheets	2	0,9
New mattresses	2	0,8
Everything needs to be improved	3	1,3
Hospital conditions	1	0,4
TVs in patients' rooms	5	2,2

Fewer patients in each room	2	0,8
All is good	3	1,3
Massage	2	0,9
DK / DA	593	257,8
Total	690	300,0

Respondents said that they would like hospital staff to be nicer to them. Another complaint expressed by interviewees had to do with the quality of hospital food. It should be noted that the number of respondents who did not provide an answer exceeded two thirds of the total number of interviewees.

Participants in FG discussions had different opinions regarding their satisfaction with hospital services: while some had remained very satisfied with their interaction with medical staff and with the latter's respect, advice, support, and answers to questions, others were completely disappointed by the medical staff with whom they had interacted.

I am satisfied ... [FG1 - M4]

I am satisfied [FG1 - M1]

Well, we are all satisfied [FG1 - M2]

Yes, very satisfied. They would take me where I needed to go. I tell you, I could not walk, they would walk with me while holding my hand, they would take me, they would bring me farther in a wheelchair. [FG4 - M2]

The doctor told me this: do you want to live? Then take pills ...and behold! [FG1 - M5]

My daughter took me to Chişinău, I went there, the doctor - if you know her, I thank her very much - gave me a good room, I received the entire treatment. [FG2 - M9]

It was clear to me, everything was clearly explained to me. Here are the tests this and that After they did the tests, I had to get the results. They made me clearly understand everything on the film, they explained everything to me. There were no misunderstandings. [FG2 - M1]

In Chişinău I was at the hospital at the Institute, every morning when the doctor came, he would make us understand every morning what TB is, what is being treated and how, and that it is treated, practically every morning. [FG2 - M3]

The doctor would quickly tell us anecdotes, he would come in the morning and tell us a couple of jokes and raise our courage against the disease. [FG3 - M2]

The doctor would tell me «come on, take the pills»! No, I do not want to! But

he would say they were so good! And I thought they were indeed good.. I was taking them since I could not say anything to him. Then they fed me for a few days. And then God gave me health and I am alive now. [FG4 - M5]

If I was feeling bad, I could not get up, he would come and tell me: are you eating? No, I could not eat. «You're going to eat,» he would look at me and sing to me. [FG1 - M3]

Here in Bălți they showed us respect, I do not know how it was elsewhere. I was in the unit on the 4th floor, they showed us respect. And the nurses were nice to us. They wouldn't yell at us «come back, put it back or down.» In short, they were nice to us. If I could not go get an injection, they would tell me they were coming to me. [FG3 - M5]

Some patients said that medical staff did not care about them.

When I was hospitalized, they wouldn't even really look at us. [FG2 - M4]

I do not have a good opinion of the hospital staff, the conditions are good, but the staff is aggressive. [FG3-M1]

Sometimes you call the nurse and tell her the person next to you is suffocating, and her answer is that he is only pretending. [FG3 - M5]

I was a witness to 3 patients dying because of the negligence of the medical staff. [FG4 - M2]

You run to the doctor and tell him that there is a patient there throwing up blood, but he ignores that person and says that he can't help them at all. [FG4 - M4]

You enter such a hospital as you would a prison, knowing that you may never come out. [FG3 - M5]

In Bălți it's good, but in Vorniceni the food is even better, it's just that the attitude of the staff is very bad, you do not know how to act towards them. People on one shift come and tell you: keep your cups in the cabinet. The next day, people on another shift say: put them on the table. This is how they pick on everything. [FG3 - M4]

Sometimes, medical staff would recommend to patients that they buy some medicines with their own money. Patients felt as if these were not necessary at all, or that no one had considered that, unemployed as they were, they had no money to buy these medicines.

Then they told me I needed more vitamins, and not... the percentage that is medically needed... Yes. Yes you need them ... buy them ... we'll administer them here, we'll help you take them. We are already out of those that the state gives for free, we don't have any more of them. - But with what money can I buy them if I do not work ... [FG1 - M1]

But with what money can I buy them if I do not work ... [FG4 - M3]

When I was hospitalized, there were a lot of drunkards. [FG1 - M3]

Some participants believed that hospitals of this kind should be built in the rest, near a pond, where they could go fishing, for example.

Hospitals of this kind should be built in the forest, so you can walk around, rather than stay indoors day and night. [FG3 - M1]

3.3 Satisfaction with ambulatory medical services

Table 19. Respondents' assessment of the quality of services provided by their primary health workers (in percentages), 2017

	Very bad ➡➡➡➡➡➡➡➡➡➡➡➡➡ Excellent										DK/DA
	1	2	3	4	5	6	7	8	9	10	99
The level of comfort in the waiting room and the doctor's office	4,8	0,9	0,4	1,7	0,4	9,1	10,4	22,2	18,3	21,3	10,4
The attention paid to respondents by their family doctors	5,7	1,3	0,4	1,7	2,2	5,2	8,3	16,1	28,3	22,6	8,3
The attention paid to respondents by nurses	4,3	0,9	0,4	1,7	5,2	3,9	7,4	15,2	31,7	18,7	10,4
The behaviour of respondents' family doctors	3,9	2,2	0,9	0,9	5,2	2,2	8,7	13,5	25,7	23,9	13,0
Nurses' behaviour	3,5	1,3	0,4	1,3	5,7	1,7	7,8	18,7	27,4	19,1	13,0
The prescribed treatment	7,0	2,2	2,2	0,4	1,7	4,3	7,4	17,8	25,2	14,3	17,4
Confidentiality	7,0	4,8	5,2	2,2	7,0	3,5	7,4	10,9	21,7	16,1	14,3
Advice given	5,7	2,2	0,4	0,9	3,5	5,2	7,4	14,8	24,3	17,0	18,7
Referral to doctors of other specialties	3,9	1,7	1,7	2,6	2,2	3,5	8,3	12,2	27,4	15,7	20,9

Professional expertise of respondents' family doctors	3,9	1,7	1,3	0,9	3,0	6,5	7,8	10,9	27,8	19,6	16,5
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The aspects of ambulatory treatment which most dissatisfied respondents were the treatment prescribed to them and the lack of confidentiality that they had experienced. The aspects respondents appreciated the most were emotional in kind, namely the advice given to them (18%), the attention paid to them by ambulatory medical staff (18.7%) and the latter's behaviour towards them (26%). They also highly appreciated the professional expertise of their family doctor.

Table 20. Respondents' requests for improving the quality of ambulatory medical services, 2017

Out of a total sample of 230 respondents. Respondents were able to provide three answers.

	No. of responses	Percentage
Appropriate behaviour	28	12,1
More extensive explanations	4	1,7
Help from the Mayor's Office	1	0,4
No need for anything	9	3,9
More attention	2	0,8
Confidentiality	6	2,6
Good doctors	2	0,8
Salary of medical employees	4	1,7
Some staff should be fired	5	2,1
High performance devices	2	0,8
Repairs	1	0,4
Triage of patients by the severity of their illness	1	0,4
Treatment at home	2	0,9
Possibility of taking medication in several rounds	1	0,4
Free treatment	1	0,4
DK/DA	621	270,0
Total	690	300,0

Two thirds of patients did not express their opinion on what should be improved about ambulatory services. However, some other respondents

requested that ambulatory medical staff show more appropriate behaviour and respect confidentiality. There were interviewees who were more categorical in their responses. They believed that such medical staff should be dismissed (5 responses).

Many participants in the FG discussions were satisfied with the attitude of the medical staff they were interacting with during their ambulatory treatment.

Very fast! I entered, came out and left. Yes, they acted very responsibly towards me, I'm happy about that! [FG1 - M4]

And another example from me! Regarding the medical assistance. I ring the doorbell, I'm in, I'm in right away, I take the pills and 'that's all'. [FG4 - M6]
She is a very kind doctor, she respects me and I respect her. [FG4 - M3]

What can I tell you... the first doctor was always there encouraging me and telling me that everything is decided, we pray to God. [FG3 - M2]

At the same time, there were situations where medical staff seemed uncaring to patients, sometimes letting them wait outside their office for no good reason.

Stay in the hallway, I'm drinking tea now. [FG4-M3]

In some cases we are told, «Do not enter until I call you.» [FG3-M4]

Sometimes we are told that they need to undress and put on their white coat. [FG2-M10]

Some patients said that, because of their health problems, they would like to be offered a week's or 10 days' worth of pills on a single visit.

And my legs hurt. Maybe it's possible for them to give me ten days' worth or so, until I get back the strength in my legs to walk in this dust! [FG1 - M6]

Why don't they give us a week's worth of pills, so we don't have to go back and forth every day ... [FG4 - M3]

There were not enough medical personnel in some ambulatory care facilities, which made it impossible for patients to take their pills at the same time every day. This was a source of discomfort for them.

They should either give them to me in the morning or in the evening. [FG1 - M6]

Either only in the evening or only in the morning! I want to follow a regimen! [FG4 - M2]

Today they are working in the morning, tomorrow – in the afternoon [FG1 - M6]

He works in several areas, in other villages! [FG3 - M1]

Sometimes patients were asked to cover some costs.

Take me, for example. When I went to the family doctor, I had no insurance

policy ... and since I had no insurance policy ... how - To do it this fast, it has to be done as an emergency! And he referred me to Chişinău, I went there, I paid for it. They told me to get that X-ray, yes, I paid. But then, I stopped paying anything, and they immediately committed me to the Diagnostic Centre. [FG1 - M1]

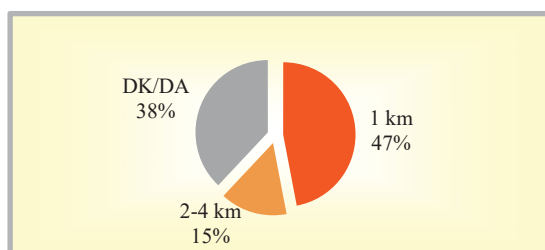


Diagram 20.
The distance that respondents had to cover to the clinic where they got their daily treatment, 2017

For nearly half of respondents the distance from their home to the clinic where they got their treatment was under 1 kilometre (47.0%).

15% of patients were travelling about 2-4 kilometres, and 38% of respondents could not estimate the distance they had to cover to their clinic..

3.4 Interruption of treatment

Diagram 21. Share of respondents who interrupted their treatment, 2016

24% of patients admitted that they had had interruptions in their treatment. These were mostly men aged 30-39 who had been employed when they became ill, and who had incomes below 1000 MDL per month. Most of these men come from urban areas. The most faithful to treatment seemed to be young women from rural areas, aged 19-29, with monthly incomes between 1001 and 2500 MDL.

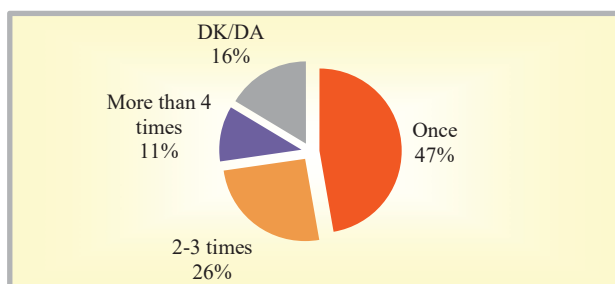


Diagram 22.
Number of treatment interruptions, 2017

When they were asked how many times they had discontinued treatment,

half of the respondents who had said they had mentioned they had only done so once (47.0% of 55 respondents). 1 out of 4 patients said they had interrupted their treatment about 2-3 times (26.0%) and 1 out of 10 respondents (11.0%) had discontinued theirs more than 4 times.

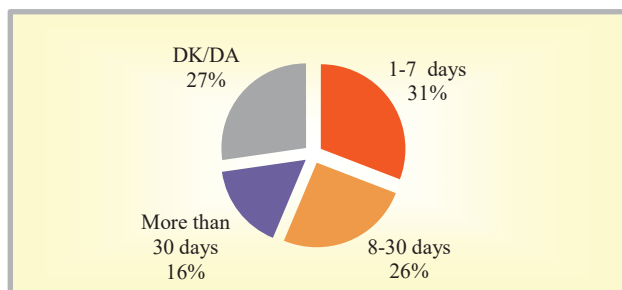


Diagram 23.
Duration of treatment interruptions, 2017

The duration of treatment interruptions varied from patient to patient: 3 out of 10 patients (31.0%) had interrupted treatment for up to one week, 26% had had treatment interruptions that had lasted between 8 and 30 days, and a fairly high percentage (16, 0%) had discontinued treatment for more than 30 days (2 out of 10 patients). It should be noted that 27% of respondents did not want to answer this question.

Two clear profiles of people who discontinue treatment emerge from these statistics:

- Women have treatment interruptions that last for up to one week;
- Men with incomes below 1000 MDL and generally from urban areas, are more likely to interrupt treatment for more than 30 days.

Table 21. Factors that caused the interruption of treatment, 2017

<i>Out of a total sample of 55 respondents (those who had discontinued treatment). Respondents were able to provide three answers.</i>		No. of responses
Broken leg		1
Job		6
Being fed up with treatment		3
Liver problems		1
Migration		2
Holidays		1
My own irresponsibility		5
Adverse effects of treatment		10

I was feeling sick	9
Out of my village / country	3
Family problems	2
Financial problems	3
Surgery	1
Inappropriate behaviour in the hospital	1
Doctor's orders	3
Distance to ambulatory care facility	1
Total	55

Respondents had discontinued treatment because, among other things, their health had worsened as a result of the adverse effects of medication. If responses suggesting adverse reactions or symptoms of TB (highlighted in the chart) are added together, they account for 25 out of 55 answers or 45%. These adverse reactions and symptoms account for treatment discontinuations far more than any other factor such as work, migration, or financial problems. These findings are further supported by the FG responses which described their anti-TB treatment as highly toxic, i.e. with serious adverse reactions. Another important finding of the FGs is that ancillary medicines—those which prevent or ease adverse reactions or TB symptoms were still not always available for free in both in and out-patient settings, despite a recommendation to do so by WHO in 2013. [3] Providing these medicines is an important part of a patient-centred approach. Failing to do so can pass the cost to people who may not be able to pay out of their own pockets.

I take the «pills» and my feet hurt and I cannot breathe. [FG1 - M6]

When I take «pills» I walk around like I'm drunk! [FG1 - M6]

My hand hurts; when I wake up in the morning, my pelvis hurts... [FG1 - M4]

Either your heart hurts or your legs hurt or you're nauseous ... The other pills I've been taking are even worse ... and sometimes my heart stops too! The pills are very strong. [FG1 - M3]

The pills that we receive daily affect the bones ... [FG1 - M4]

Yes, my legs hurt. [FG1 - M5]

For a while after the beginning of treatment, nothing hurt. After some time, my spine started to hurt. [FG1 - M4]

My liver hurts a lot because of these tuberculosis pills. They do not give us liver pills, we need to buy everything with our own money, which is very little. [FG3- M5]

Sometimes, your head hurts and your eyesight becomes foggy because of the pills. [FG3 - M2]

IV. SOCIAL CONTEXT

4.1 Respondents' main sources of support

Table 22. The main person who provided support in times of need, 2017

Out of a total sample of 230 respondents. Respondents were able to provide one answer.

	No. of responses	Percentage
A family member	136	59,1
A relative I live with	20	8,7
Someone who is not my relative (neighbour)	8	3,5
A relative I do not live with	4	1,7
A doctor	21	9,1
A nurse	2	0,9
A friend	6	2,6
Somebody else *	4	1,7
I do not talk to anyone about my problems	25	10,9
DK/DA	4	1,7
Total	230	100,0

* The category „Somebody else” includes answers that totalled less than 1% of all responses: other medical staff – 0,4%, God – 0,9%, a niece – 0,4% etc.

For more than half of respondents (59%), their families were their main source of support when some problems or special situations arose.

On the other hand, 1 out of 10 respondents preferred not to talk to anyone about the problems they had. These were mostly men aged 30-39 with a university education, who had been employed and had had a household income of over 5,000 MDL per month before getting sick.

Generally, however, it should be noted that patients had a higher trust in people who were close to them, than in medical staff, social workers or local public authorities.

4.2 Family support

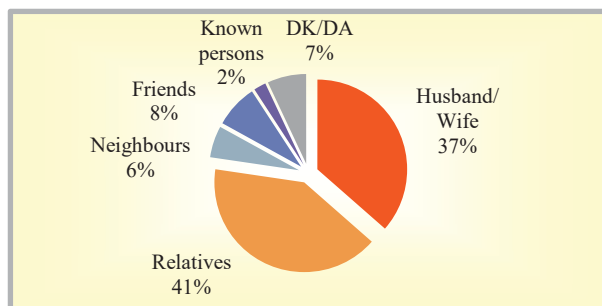


Diagram 24.
The people with whom respondents interacted during ambulatory treatment, 2017

4 out of 10 patients most often communicated with their spouse. Half of respondents most often communicated with their relatives / neighbours (about 47%).

Patients most often found support within their family. According to the FG discussions, the family members who supported them the most were: their wife, husband, children and closest relatives. It is important to note that since 80% of the survey respondents were male, the category of husband/wife was actually referring to a wife in the majority of cases. This is further supported by the FG responses of men who referred to their wives and other female relatives (such as daughters) as their sources of support, and by other research. [30]

My wife! [FG1 – M4]

I have a daughter-in-law! [FG1 – M2]

For example, my wife works but I work too! You have to work. If you sit around doing nothing, money won't grow on trees. [FG1 - M4]

My wife came to Chişinău regularly. We don't live very close to each other, but she would come every 2 weeks. [FG4 - M2]

Can you imagine that, apart from my wife, no one thought I would survive? Even the doctors were sceptical! As you can see, I have come back to life. [FG4 – M5]

My children help me too. [FG2 - M6]

The behaviour of respondents' families towards them was assessed according to three principles: respect, attitude and acceptance.

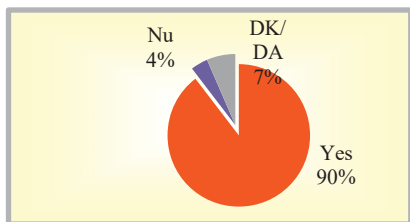


Diagram 25. Respect, 2017

Almost all respondents felt very comfortable around their families. 90% of them were shown respect by their families. Negative responses (4%) were mostly given by patients who were living alone. 7% did not know what answer to give or refused to give one.

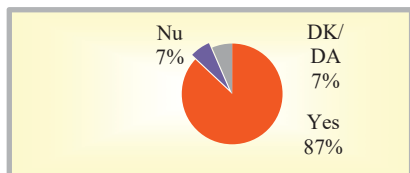


Diagram 26. Attitude, 2017

87% of respondents mentioned their family as the primary environment in which they felt safe and their opinion was listened to. However, 1 out of 10 patients could not say the same thing.

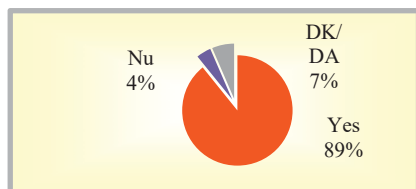


Diagram 27. Acceptance, 2017

9 out of 10 respondents (89%) said their families accepted them as they were. 4% of respondents had been rejected by their families after being diagnosed with TB.

Before becoming sick, some respondents had been the only source of income for their families, a factor which had influenced intra-family relationships. Due to these patients' illness, their families lost their financial support. The interviewees talked about losing their role on the labour market (as a result of illness and the need to follow treatment) as a very serious problem in their lives, but also about their feeling of helplessness and about having to give up fulfilling a variety of roles for their families.

It's good for you that you're already old, but I'm young and I have little kids in

kindergarten, what do I do?[FG1- M4]

I have little kids; two of them are in kindergarten. I must work. I cannot just rely on their mother. You can't live otherwise. I can't move up in life if I only earn a thousand MDL per month. [FG4 – M4]

How can things be better? For example, you used to earn 5,000 MDL per month, now you earn one thousand per month. This is how things are! Things have changed. Yes, we earn less than we spend. [FG1 – M4]

This thousand MDL per month is not enough. You just spend it on medicine. [FG1 – M7]

4.3 Community support

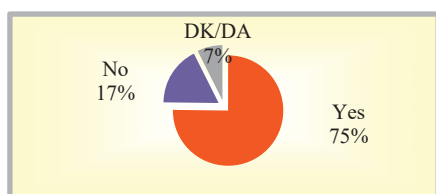


Diagram 28. Respect, 2017

Two thirds of respondents (75%) felt respected by their community as regular citizens with equal rights. However, 2 out of 10 patients (17%) said they were not treated like everyone else.

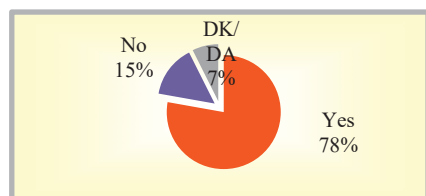


Diagram 29. Attitude, 2017

More than two thirds of respondents (78%) believed that their community listened to them and took them seriously. About 15% of respondents felt ignored by others.

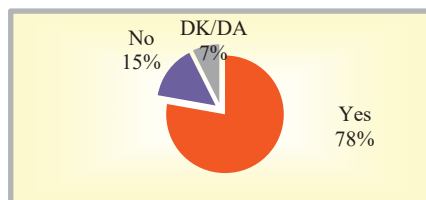


Diagram 30. Acceptance, 2017

About two thirds of respondents (78%) felt accepted by their community as they were.

15% of respondents felt rejected by their community. 7% could not give an

assessment or refused to respond.

According to FG discussions, patients most often enjoyed the support of the doctor they interacted with throughout their treatment.

How...the doctor... [FG1 – M7]

I have a lady doctor!... Beautiful... She gives me pills. [FG1 – M2]

Some received additional support from their neighbours.

I have good neighbours, who come over and ask me how I am, and if I have been taking my pills. [FG1 - M1]

I can sit down and talk with my neighbours, we say jokes, and this helps you move on. [FG1 - M1]

Some patients did not receive any help or support.

I, for one, receive no help from anyone, neither from my neighbours, nor the city hall ... I've been all alone since having this disease. [FG2 - M4]

4.4 Communication with other patients

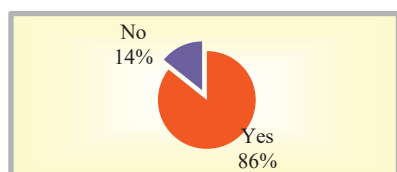


Diagram 31. Respondents' communication with other patients, 2017

Communicating with other patients helped respondents get through this difficult time more easily. 86% of respondents said they were talking with other patients on a regular basis while only 14% were not communicating with others.

Table 23. Impact of respondents' communication with other patients on their desire to be treated, 2017

Out of a total sample of 197 respondents. This sample includes those who answered «Yes» to the question “do you communicate with other patients?”. Respondents were able to provide three answers.

	No. of responses	Percentage
I began to want to get treated.	35	15,2
My desire to get treated has not changed	89	38,7
I realized I was not alone, which strongly encouraged me to get treated	27	11,7

I started to skip some pills	1	0,4
I started to encourage other people in my position	16	7,0
I've lost trust in medical staff	6	2,6
Something else	1	0,4
Nothing	16	7,0
DK/DA	6	2,6
Total	197	100,0

38% of respondents said that their desire to get treated did not change. For 15.2%, communicating with other patients made them want to get treated. 11,7% realized that they were not alone, which encouraged them to get treated. For 7% of respondents, communicating with other patients made them want to encourage their peers. Talking with other patients helped respondents get through this difficult time of their life more easily. The fact that they were not the only ones in this situation made them feel more secure and confident that they would be able to recover. The most communicative patients were men with an 8th grade or high school education and, more often than not, from rural areas.

Table 24. Respondents' reasons for not communicating with other patients, 2017

<i>Out of a total sample of 33 respondents. The sample includes those who answered «No» to the question "do you communicate with other patients?" Respondents were able to provide three answers.</i>	No. of responses	Percentage
Lack of free time	3	9,1
I don't really know anyone	13	39,4
I do not want to talk to anyone	6	18,2
DK/DA	77	33,3
Total	33	300,0

However, there were 33 patients who were not communicating with others. 4 out of 10 patients who were undergoing ambulatory treatment did not personally know anyone with a similar illness. One third of this sample of respondents refused to answer this question.

V. RESPONDENTS' SOCIO-ECONOMIC STATUS

Table 25. Respondents' main sources of income, 2017

<i>Out of a total sample of 230 respondents.. Respondents were able to provide three answers.</i>	No. of responses	Percentage
Salary	66	28,7
Income from work as a day-labourer or occasional income	56	24,4
State benefits (for children, illness, unemployment, etc.)	36	15,7
Dividends, rents, interest	1	0,4
Income from agricultural production	6	2,6
Income from own business	5	2,1
Financial aid from children, parents, and/or relatives, who work abroad	29	12,6
Pension	57	24,7
Other sources	6	2,6
I don't know	9	3,9
Did not answer	419	182,1
Total	690	300,0

Respondents' main sources of income were: their salary (29%), their pension (25%), and occasional earnings (25%). Other respondents stated that they were getting by on state benefits (15.7%), financial aid from children, parents, and/or relatives that were working abroad (12.6%), and what they were earning by working in agriculture and from their own business (4.7%).

Table 26. Number of people in respondents' households, 2017

<i>Out of a total sample of 230 respondents.</i>	No. of responses	Percentage
1 person	48	20,9
2 people	59	25,7
3 people	46	20,0
4 people	34	14,8
5 people	23	10,0
6 people	8	3,5
7 people	3	1,3
Did not answer	9	3,9
Total	230	100,0

1 out of 5 respondents (20.9%) was living alone. 1 out of 4 patients (25.7%) was living with one other person. Other respondents were part of families consisting of three or more members. Respondents who were living alone were mostly men aged 40-49, with incomes below 1000 MDL, and from urban areas.

Table 27. Respondents' occupational fields, 2017

Out of a total sample of 230 respondents.

	No. of responses	Percentage
Agriculture	76	33,0
Industrial production, construction	66	28,7
Transportation, telecommunication	24	10,4
Other services and sales	15	6,5
Education, culture, research, design	6	2,6
Health care	2	0,9
Unemployed	41	17,8
Total	230	100,0

33% of respondents were working in agriculture, 28.7% in industrial production and construction, 10.4% in transportation and telecommunications, 6.5% in services and sales, 2.6% in education, culture, research and design, and about 1% in health care. 17.8% of respondents were unemployed.

Table 28. Respondents' educational levels, 2017

Out of a total sample of 230 respondents.

	No. of responses	Percentage
No studies	13	5,7
Incomplete high school education	51	22,2
Grades 1-8	53	23,0
Vocational school	79	34,3
High school	10	4,3
Specialty high school	13	5,7
Higher education	10	4,3
Master's, doctorate	1	0,4
Total	230	100,0

40% of respondents had graduated from a vocational school or specialty high school. 45.2% had an 8th grade or incomplete high school education. 4.7% had a university education, master's, or doctorate. 5.7% of respondents said they had no studies.

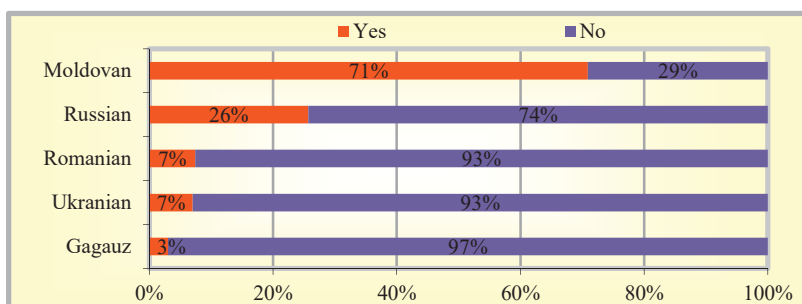
Table 29. Respondents' ethnicities, 2017

Out of a total sample of 230 respondents.

	No. of responses	Percentage
Moldovan	179	77,8
Romanian	2	0,9
Russian	17	7,4
Ukrainian	23	10,0
Gagauz	6	2,6
Other	3	1,3
Total	230	100,0

77.8% of respondents were Moldovan, 10% Ukrainian, 7.4% Russian, 2.6% Gagauz, and 0.9% Romanian. 1.3% were of other ethnicities.

Diagram 32. Languages spoken by respondents, 2017



71% said they speak Moldovan; 26% Russian; 7% Romanian; 7% Ukrainian; and 3% Gagauz.

Table 30. Respondents' denominations / religions, 2017

Out of a total sample of 230 respondents.

	No. of responses	Percentage
Orthodox Church, The Metropolitan See of Moldova	215	93,5
Orthodox Church, The Metropolitan See of Bessarabia	2	0,9
Catholic	2	0,9
Protestant	1	0,4
Adventist	2	0,9
Atheist	2	0,9
DK/DA	6	2,6
Total	230	100,0

94.4% of respondents were Orthodox. About 1% were Catholic. The same percentage was comprised of Protestants and Adventists, respectively. About 1% said they did not adhere to any religion. 2.6% of respondents did not give an answer.

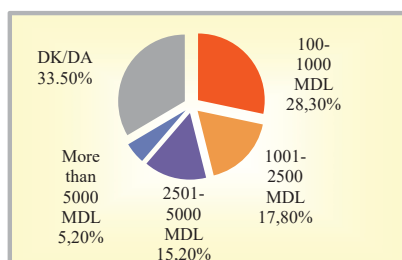


Diagram 33.
Respondents' average household income, 2017

The household income of about one third of respondents (28.3%) ranged in the last month between 100 and 1000 MDL. 17.8% had an income of 1001-2500 MDL, 15.2% earned 2501-5001 MDL, and 5.2% had an income larger than 5000 MDL. One third of respondents (33.5%) did not know what their income was or refused to answer this question.

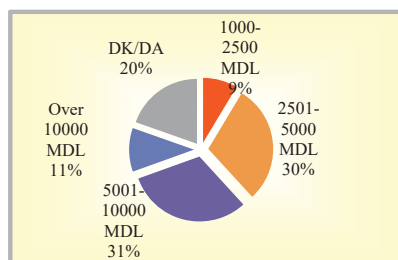


Diagram 34.
Income required for a decent living, according to respondents, 2017

For 30% of respondents, the income needed for a decent living would be between 2501 and 5000 MDL per month, 31% believed they would need between 5001 and 10000 MDL, 11% thought it would take more than 10,000 MDL to secure a decent living, and 20% of respondents did not know what income they would need for a decent living or refused to answer this question.

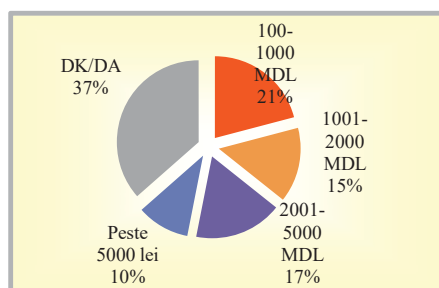


Diagram 35.
The minimum income
respondents believed they
would need to survive, 2017

1 out of every 5 patients (21%) would not be able to survive with an income of less than 1000 MDL, 17% would need a minimum income between 2001 and 5000 MDL, 15% believed the minimum income to be 1001-2500 MDL, 10% estimated the minimum income at 5000 MDL. 37% of those interviewed did not know how to answer this question or refused to do so.

FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS FOR THE ORGANISATION OF MEDICAL AND ASSISTANCE SERVICES

Main findings

- ✓ Half of respondents were satisfied with their family relationships. However, 1 out of 5 patients said they were not very happy or not at all happy with their family life. The most satisfied with their family life were mainly young people aged 19-29, with a university education and a household income of over 2500 MDL.
- ✓ The most dissatisfied with their family life were people aged 40-49. 1 out of 3 respondents was dissatisfied with their living conditions. A similar number of respondents were satisfied with their lifestyle. 52% of respondents were experiencing a state of fatigue, while 34% were feeling sad. More than half of respondents reported feeling lonely or abandoned.
- ✓ About one third of respondents felt stigmatized or discriminated against all the time or almost all the time because of their illness.
- ✓ The most common occupations of people in this study were in the fields of construction and transportation.
- ✓ Many people lost their jobs while they were sick. It was then difficult for them to find work. This was especially a concern for people who had worked in construction and other physically demanding jobs.
- ✓ About half of respondents thought they were in control of the things that were happening to them and found the means to solve their problems. About one third of respondents found it difficult to deal with life-threatening situations and said they were powerless in the face of life's challenges. Respondents from rural areas, aged 50 to 59, and with incomes below 1000 MDL were the most likely to feel this way.
- ✓ Respondents' greatest desire was to be cured of TB and to stay healthy.
- ✓ Half of survey respondents said that sickness/TB was their greatest concern, followed, by a wide margin, by crime and people's general indifference.
- ✓ When they were asked about their current disease, only 1 out of 4 respondents focused on suffering from TB disease itself. Other respondents referred to the other conditions they were suffering from, including pain in their legs and feet, vision problems, hearing loss,

headaches, stomach problems, etc. It should be noted that many of these reported problems were likely adverse reactions to anti-TB drugs.

- ✓ Respondents' main source of information was television. Half of respondents listened to the radio daily. The least utilized sources of information were books and newspapers.
- ✓ The people respondents trusted the most were the family members they were living with (67%), followed by their neighbours (57%) and, by a wide margin, by their relatives (28%), by employees of the Mayor's Office, their social workers etc. At the other end of the spectrum was the government of the Republic of Moldova, which 81% of patients did not trust at all, followed by the country's president (58%), and by people in their locality (52%). It is paradoxical that respondents declared a fairly high level of mistrust of the church (51%) given that, in national polling, it is one of the most trusted institutions. [31]
- ✓ People with TB wanted treatment options, with almost 70% of respondents preferring ambulatory treatment (53% wanted to take the drugs at a nearby site while 16% wanted to receive them at home).
- ✓ While the majority of respondents preferred ambulatory treatment, 15% expressed a preference for hospitalization. This may be due to poverty, a lack of a support network at home, or a feeling that they would receive better care in a hospital. However, if ambulatory care is sufficiently patient-centred, the majority of these concerns can be mitigated with additional support.
- ✓ Some focus group participants expressed a dislike of the strict rules that one must follow while hospitalized. These led to boredom and frustration, and interfered with people's family and work lives.
- ✓ 83% of respondents thought they would eventually recover. However, 1 out of 10 patients thought they had no chance of recovery. These included men aged 30-49, and with incomes below 1,000 MDL.
- ✓ In order to get healthier, respondents, especially men, said they needed public transportation tickets. Women aged between 50 and 59 needed personal hygiene products. Virtually all categories of respondents needed money, but especially people between 30 and 39. Other desired services included psychological and legal counselling.
- ✓ Almost all participants in the study (93%) were hospitalized at any time during their treatment. More than half followed hospital treatment for up to 60 days. 1 out of 5 respondents underwent hospital treatment for more than 90 days.

- ✓ Men aged 30-39 / 50-59, with a household income between 1001 and 2500 MDL and with no studies or an incomplete secondary education were the most likely to have been treated for more than six months.
- ✓ Almost 40% of respondents had treatment interruptions. 26% percent of them had interruptions lasting 8 to 30 days, and an unacceptably high 16% had interruptions that lasted longer than 30 days. Interruptions like these endanger a person's chances of being cured and can result in the development of additional drug-resistance, which would further complicate their treatment.
- ✓ The main causes of discontinuation included worsening of health status and adverse reactions to treatment. Respondents reported loss of vision, hearing, heart and liver problems, pain in their feet, headaches, and gastrointestinal problems. All of these are well-documented adverse reactions of anti – TB medicines, especially those used to treat DR-TB. One of patients' perceptions was that there were too many pills and the duration of treatment was too long. For these reasons, some were unable to cope psychologically with the treatment.
- ✓ People with TB would like alternative treatment methods, which would involve shorter treatments with fewer pills.
- ✓ For nearly half of participants, the distance from their home to the clinic was up to 1 kilometre. 15% were covering a distance of about 2 to 4 kilometres. 38% were unable to assess the distance to the clinic.
- ✓ People who assisted patients taking pills were nurses and doctors in most cases. In two thirds of cases, nurses observed treatment, and for 11% of respondents, the attending physician did.
- ✓ Respondents were the most satisfied with the professional training of both doctors and nurses. About 75% gave it marks ranging from 8 to 10 (10 being the most satisfied).
- ✓ The respondents were less satisfied with the communication between themselves and medical staff. In most cases, they did not feel that doctors were explicit enough when providing information to them about their health status. Respondents wanted greater openness and availability, and for medical staff to ask for their opinions and listen to how they felt, especially regarding the adverse reactions to treatment. When results or information were delayed, respondents expressed a desire to know why. They also said they wanted to know when they can expect more information in order to better plan their lives.
- ✓ As for hospital services, respondents' opinions were divided: some

remained very satisfied with their interaction with medical staff, and with the latter's respect, advice, support, and answers to questions while others were completely disappointed with the medical staff they interacted with.

- ✓ The qualities and aspects of ambulatory treatment that respondents appreciated the most were emotional in nature, namely counselling (18%), the attention paid to them by medical staff (18.7%) and the latter's behaviour towards them (26%). Another aspect they greatly appreciated was the expertise of their family doctor. However, the aspects respondents were most dissatisfied with were the prescribed treatment and the lack of confidentiality.
- ✓ Respondents asked for improvements in the quality of food during hospitalization. This was a common request, which deserves consideration due to the long durations of hospitalization that are still common in Moldova. If such hospitalization is necessary, food of good amount and quality should be available. This is particularly important as TB is associated with poor nutrition. Additionally, quality food can improve the spirits of patients and ease some of the boredom of long-term hospitalization.
- ✓ There is very little financial support especially for families where the person diagnosed with TB was and is the main income earner in the household.
- ✓ More than half of respondents (59%) identified their family as their most important source of support.
- ✓ 9 out of 10 respondents said they were accepted as they were by their families. Two thirds of respondents felt respected by their communities as ordinary citizens with equal rights. However, 2 out of 10 respondents said they were not treated like everyone else.
- ✓ 4 out of 10 patients most often communicated with their life partner. Almost half of respondents most often communicated with relatives and neighbours.
- ✓ Communicating with each other helped patients get through this difficult period more easily. 86% of TB respondents communicated with other patients on a regular basis.

Conclusions and recommendations for the organisation of medical and support services

In this report, we sought to assess the satisfaction level of tuberculosis patients in regards to medical services and community support during treatment as it is very important to understand the expectations of people who use TB services. The medical system and support services should be continuously developed and integrated in a way that ensures universal access to quality, patient-centred care for all people affected by TB. An important conclusion of this research is that TB disease greatly disrupts the lives of people who have it, but also those of their families and social networks.

There are some fundamental aspects that characterize the lives of patients as they experience tuberculosis:

- a. a major change in health status;
- b. patients' material/ financial problems and impoverishment, which the disease causes or accentuates
- c. the role of healthcare;
- d. the role of patients' families and communities in their recovery process.

The interview and survey data show that, beyond the suffering caused by TB and its treatment (which can be worse than TB symptoms, especially for drug-resistant TB), the most serious problems faced by patients are material in nature, as well as related to family and community support (the disease sometimes leads to patients losing fundamental social roles). Families are the main source of social support for people with TB. Health care and community care also play an important role in their lives.

In this context, it is essential that there be mediation and education for families of TB patients meant to help them understand their important role in the treatment process. These discussions can be initiated by health workers, local elected representatives, social workers, representatives of NGOs, and any other people who could be of influence in this respect. It is important for patients' families and spouses to know that even simply talking with their loved ones can contribute to the latter's wellbeing. Therefore, ambulatory treatment is absolutely appropriate for patients with families.

Confidentiality statements are intended to protect patients from the impact of stigmatization. At the same time, patients' personal data are of great help to people whose mission is to support them (NGOs, the police etc.). Medical staff, local elected representatives, social workers, and society in general should develop anti-stigmatization messages and publicly showcase examples

of people who have been cured of TB while fostering respect and a friendly attitude towards people with TB and their friends and relatives during and after treatment.

If a TB patient was the only wage earner in their family prior to becoming ill, there is a major risk that they will not complete treatment since they will feel like they have no choice but to continue to provide for their family. Moreover, it is well known that women bear a heavy burden when it comes to caring for family members. Ethnographic data from Romania also supports this conclusion. Stillo found that women were not only caring for relatives with TB (sometimes getting the disease themselves) but also delaying and interrupting treatment in order to care for their families. [30]

This socio-economic burden of TB can be reduced through an analysis of the financial situation of the patient's family, which may require the involvement of several community actors that would guarantee a basic monthly support in the form of cash, food, personal hygiene products, and, in the case of people undergoing ambulatory treatment, transportation tickets.

People who follow treatment should be allowed to work if they feel good and if a committee of specialists have given their approval for them to do so. At the same time, they should be counselled and provided with educational and employment support or job-retraining, if necessary, to facilitate their employment. This would help them continue to support their families, as well as provide them with a sense of self-worth. Whenever possible, ambulatory treatment arrangements should be flexible enough to accommodate working people and those who have schedules which require them to work or perform childcare/household duties at particular times. This flexibility can limit disruptions in a person's home life and help them maintain as much normalcy as possible.

The human suffering caused by TB can be mitigated by providing psychological and legal counselling services to people with TB at the start of and during treatment. People with TB need to be informed about all possible options for treatment. The choice must belong to the person being treated. Moreover, they should undergo ambulatory treatment from the beginning as long as a review of their case has found that they feel good or satisfactory and that there is no documented clinical reason for why this should not happen. This is in keeping with the results of this research as well as with WHO guidelines. [14, 23] As discussed prior, there is a great deal of data from around the world, including from Moldova, that demonstrate the acceptability, effectiveness, and cost-efficiency of well-designed community-based care and support.

At the same time, if the patient and clinician agree that inpatient treatment is best, the rules guiding hospital stay should be reasonable, and the length of stay should be minimized as much as possible. The conditions of hospitalization should respect a patient's need for privacy, personal space, and control over their time. It is advisable that the patient be given the alternative to receive the medicines when it is most useful and convenient for them, and that the food provided be of a quality and quantity that is in keeping with the treatment they are undergoing.

It is essential that enough time be provided for discussions with patients. The language used in the communication, counselling and education process must be clear and simple. It should be understandable to people with TB and their relatives. Discussions between health care staff and patients about the latter's physical and psychological health should become the norm. In addition, consultations with specialists in other areas of medicine (including dentistry) should be easily available to patients to ensure they have their other health issues addressed as well.

The timely treatment of adverse reactions is especially important. This will increase adherence to treatment by making it more bearable. Within patients' communities, medicines can also be administered by other trustworthy institutions (police, post office, public local authorities such as the town hall, NGOs, social services, etc.). For some people, VOT may be an appropriate way to maximize adherence to treatment. For patients who travel to DOT sites, the distance between them and the delivery point of the medicines must be reasonable as it is difficult for some people to cover even short distances to TB clinics, especially in poor weather. In order to guarantee the quality of DOT, the health care professional must ensure that the individuals entrusted with administering treatment perform their duties (telephone conversations, private meetings, etc.).

Protecting people with TB and promoting human rights in the prevention, care and control of TB should be supported by developing informative materials on healthy lifestyles among migrants (main meals of the day, healthy foods, recommended physical activities, etc.). These materials should be accessible in health centres, mayor's offices, border checkpoints, railway stations, etc. When working with people with a higher risk for TB, particular attention should be paid to those who do physically demanding work such as agriculture or construction.

Thus, it is necessary to reiterate that integrated and quality medical treatment should include not only medical therapy (as short as possible, and

involving a small amount of pills and proper monitoring and treatment of adverse reactions), but also effective communication between patients and health care staff, as well as support that addresses the medical, economic, social, psychological, and spiritual needs of people with TB and their families.

In conclusion, a holistic, patient-centred approach which considers medical issues as well as other needs and concerns of people affected by TB (as long as they are willing to share them) is the best strategy in maximizing positive treatment outcomes and minimizing the stress and discomfort of people with TB and their families. This patient-centred approach entails that community support mechanisms be strengthened and as closely integrated with TB and public health services as possible. This way, people with TB benefit from services, which are designed to accommodate their lives and experience continuous support, which addresses all of their needs and respects their human right to accessible, quality health care.

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