



PROGRAMUL DE COOPERARE ELVEȚIANO-ROMÂN  
SWISS-ROMANIAN COOPERATION PROGRAMME

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# *Mapping of Romanian TB Patients' Needs Report*

*June 2014*

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# Mapping of Romanian TB Patients' Needs

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## Report

Bucharest, June 2014

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## Abbreviations

AMRTPS	Association for MDR-TB Patients Support
DOT	Directly Observed Therapy
FG	Focus group
GLC	Green Light Committee
Global Fund	The Global Fund to Fight AIDS, Tuberculosis and Malaria
MoLFSPE	The Ministry of Labor, Family, Social Protection and the Elderly
MoH	Ministry of Health
WHO	World Health Organisation
NTP	National Tuberculosis Program
TB	Tuberculosis
MSR-TB	Multidrug-resistant Tuberculosis
XDR-TB	Extensively drug-resistant Tuberculosis



## Executive summary

Starting from an analysis model called “The patient journey map”[1][2], the present evaluation follows the TB and MDR-TB patient on the road from “life before diagnosis”, through experiences of diagnosis, hospitalisation, treatment, all the way to resuming everyday life.

For each stage, the patients’ needs were revealed, in context – together with information about the patients’ medical and emotional experiences, focusing on the turning points in the patient’s journey when these needs can be particularly noted.

The analysis was based on data collected through: sociological survey among the TB patients from the pulmonology hospitals in Bucharest and Bisericani (Neamț County), focus-groups with TB and MDR-TB patients and their families in five locations, focus-groups with professionals in other three locations and four interviews with representatives of public institutions having a role in the development and implementation of TB prevention and control in Romania.

The results suggest that, for a successful track of the TB patient (concluded with complete recovery and social integration), one must address the risks that the patient is exposed to even before contracting the disease (proximity to infected people or who had the disease, difficult life conditions, lack of housing, stress, a general poor health etc.)

As for diagnosis, the most pressing need identified is to have a rapid result and to reduce uncertainty: the patients have difficulties in coping with delayed, sometimes even wrong diagnoses and they do not receive clear explanations about their health problems, what’s coming next, how they can be treated correctly.

During therapy, the patient’s main needs are related to medical, social and psychological support necessary for the successful completion of the treatment. They need support in order to overcome the side effects of medication, to procure the drugs and paramedical supplies for co-morbidities and side effects. Without the confidence that their families will have the necessary resources while they’re gone, the patients who are the main income providers in a household will do whatever is necessary to shorten the hospitalisation periods and to avoid becoming a burden for their families.

TB patients’ quality of life should be considered not only during treatment, but after recovery as well. Since they are mostly people of working age, measures to ensure their maintenance and their reintegration into the labor market are necessary, especially for MDR and XDR patients who must spend many months hospitalized.

## Context

In 2013, more than 15,000 cases of tuberculosis (TB) have been diagnosed in Romania.

According to the statistics provided by the National Tuberculosis Control Programme (NTP), 30,000 people with TB, MDR-TB and XDR-TB were under treatment in Romania in 2011, of which 65% were men.[3] An analysis conducted in 2008 indicates the following profile of patients with TB in Romania: most likely male, aged between 41-60 years, from urban areas, with middle school education, unemployed and with an income below 600 lei per month.[4]

Under-diagnosis of patients with resistant tuberculosis combined with high estimates of the number of such cases is perhaps the most serious problems the Romanian system of tuberculosis prevention and control is facing today. According to estimates by the World Health Organization (WHO), about 800 new MDR/XDR-TB cases should be diagnosed annually in Romania, but in reality only about 400 new cases of multi-drug resistant tuberculosis (MDR-TB) and extensively-drug resistant tuberculosis (XDR-TB) are identified.[5][6]

In Romania there is little systematically collected information about the conditions (social, personal, medical) that expose sensitive TB patients at risk of developing MDR-TB or having an unfavourable disease evolution after the TB diagnosis. More recent studies in the area of TB explore mainly the knowledge and practices regarding tuberculosis in the general population [7][8] and the groups considered vulnerable to infection (the homeless, prisoners and drug users).[9][10][11] One study published in 2010 and conducted among TB patients in Maramures County [12] showed that patients consider that their therapeutic success and quality of life depend, mainly, to satisfying the following needs: material and psychological support, especially from the family; reducing discrimination against people with TB in the community and in hospitals.

### General epidemiological data

The latest evaluation mission of the multi-drug resistant tuberculosis management in Romania was carried out by the WHO - Green Light Committee (GLC), in March 2014. According to the report, Romania is still on the list of 18 high-priority countries in the WHO European Region with regards to Tuberculosis, but lately there has been progress with the Tuberculosis control.

The data centralised by NTP suggests a steady decline of tuberculosis indices in our country: the TB incidence decreased from 142.2 per 100,000 in 2002 (with 30 986 new cases and relapses) to 73.3 per 100,000 inhabitants in 2013 (15 629 new cases and relapses). Excluding cases of coinfection with HIV, tuberculosis mortality rate decreased from 6.9% in 2010 to 5.9% in 2012. 1,249 people died from TB in 2012. Incidence of TB varies across the country and is relatively influenced by socio-economic status of the regions, with higher values in the east, west and south and lower in the center and northwest. The number of cases of tuberculosis receiving therapy in 2012 was about 29,000.

Apart from improving the situation regarding the diagnosis and treatment of drug-susceptible TB, the GLC Mission report draws attention to major challenges posed by drug-resistant tuberculosis. MDR-TB and XDR-TB are major obstacles to the functioning of the Tuberculosis Control Program. Based on the data from the National Drug Resistance Survey for first-line drugs conducted in Romania in 2003-2004, the WHO estimates a total of 800 cases of MDR-TB every year in Romania (2.8% of new

TB cases and 11% of relapses). The report states that the national data do not fully reflect the real situation as less than 50% of new cases and relapses are tested for drug resistance. Regarding the cases of XDR-TB, these represent an estimated 9.9% of new MDR-TB cases and 11.6% of retreated MDR-TB cases.

The report cites as factors with negative impact on TB control in Romania the very long period for diagnosis and therapy initiation, incomplete treatment and poor patient management. Lack of strategies to increase patient adherence to treatment remains also a decisive factor in the growth of drug-resistant tuberculosis reservoir.[6]

The treatment for sensitive or resistant tuberculosis in Romania is free, regardless of ethnicity, race, religion, gender or age. Often, however, vulnerable or minority populations such as Roma people, have difficulty accessing health services in general, including those for tuberculosis, both in terms of diagnosis and treatment. From this point of view it should be noted that TB patients' rights fall within the general concept of patient rights. Specifically, they are presented in the Patients' Charter for Tuberculosis Care (The Charter) developed by WHO and the World Care Council [13] and are summarized as follows:

- The right to treatment: the right to free and equitable treatment without discrimination, the right to receive medical advice, centring on patient needs.
- The right to dignity: the right to be treated with respect and dignity, including the delivery of services without stigma.
- The right to information: the right to information about what healthcare services are available, the right of access to medical information which relates to the patient's condition and treatment and to a copy of the medical record, the right to meet, share experiences with peers and other patients.
- The right to choose: the right to a second medical opinion, with access to previous medical records, the right to accept or refuse surgical interventions if chemotherapy is possible, the right to choose whether or not to take part in research programs.
- The right to confidence: the right to have information relating to the medical condition kept confidential and released to other authorities contingent upon the patient's consent.
- The right to organize: the right to join, or to establish, organizations of people with or affected by tuberculosis, the right to participate as "stakeholders" in the development, implementation, monitoring and evaluation of tuberculosis policies and programs.

## Methodology

### Objectives

The Association for MDR-TB Patients' Support and the Romanian Angel Appeal Foundation aim to develop a bill providing measures to improve the quality of life of people affected by tuberculosis in Romania - i.e. patients with TB and MDR-TB and their families. To this end, it was planned to identify specific health and social needs of this target group, in terms of:

- Access to appropriate diagnostic and treatment services;
- Ensure therapeutic success;
- Access to support (medical, social, psychological, community) for their integration in the active life (work, school, participation in community activities).

## Data collection

Data collection was carried out using both quantitative and qualitative methods.

**Sociological survey** based on a semi-structured questionnaire, administered during February - March 2014, to TB patients in TB hospitals in Bucharest and Bisericani. The choice of hospitals in Bucharest and Bisericani (Neamț County) was dictated by the proximity and the high number of patients they serve. Profile of respondents is presented in Table 1:

Table 1. Profile of respondents to the sociological survey

Indicators	Values		
Average monthly income per family member (N=64)	557 Romanian lei		
Residential area (N=79)	Urban – 53%	Rural – 47%	
Age group distribution (N=79)	<b>Age group</b>		
		<b>n</b>	<b>percentage</b>
	15-25	9	11%
	26-35	14	18%
	<b>36-45</b>	<b>22</b>	<b>28%</b>
	46-55	15	19%
	56-65	12	15%
>65	7	9%	
	Youngest: 17 years old/ Oldest: 83 years old		
Gender (N=79)	Male – 70%	female – 30%	
Imprisonment record (N=63)	Yes – 14%	Nu – 86%	
Dependant children (N=63)	Yes – 19%	Nu – 81%	
Employment status (N=80)	<b>Unemployed/stay-at-home – 44%</b> Retired/disabled/with handicap – 21% Employed on permanent contract– 15% Working without an employment contract (including day laborer) – 10% Employed on fixed-term employment contract– 6% Unemployed – 3% Pupil/student – 1%		

**Focus groups (FG) with patients (TB and MDR/XDR-TB), with their families and professionals** involved in TB prevention and control. In all, **five focus groups with patients** (and families) registered and / or admitted to lung disease hospitals were held in Leamna (Dolj County), Moroeni (Dâmbovița County), Ilfov County and MDR-TB centers in Bucharest and Bisericani (Neamț County). **Three focus groups were held with specialists** from the MDR centers in Bucharest and Bisericani and Ploiești Hospital (Prahova County). Recruitment of patients and family members was achieved through the medical and psychosocial staff involved in the care and

treatment of these patients. Although there were initial patient recruitment criteria (age, gender, residence and employment status), the final selection of the 44 patients was performed taking into account:

- Their availability (patients who were hospitalized at the time of the FG and their families and outpatients available at that moment were invited to the FG)
- Willingness to participate (all patients signed a consent to participate)
- Medical situation (only the inpatients with a medical condition allowing participation were invited, for a discussion of about 2 hours, held in a hospital room, outside the ward where they were hospitalised).

Although we aimed to have one or two family members in each group, their participation depended on their presence (as companions) on the day of the focus groups. In total, 5 family members participated in focus groups (in Bucharest and Ilfov County).

The distribution of focus groups on locations and participant profile is shown in Table 2.

*Table 2. Distribution of focus groups on locations and participant profile:*

	TB/MDR-TB patients and family members	Professionals
<b>Bucharest</b>	9 MDR-TB patients and 2 family members	7 specialists (pulmonologists, Psychotherapist)
<b>Ilfov County</b>	8 TB patients	
<b>Bisericani (Neamț County)</b>	9 MDR-TB patients	
<b>Ploiești (Prahova County)</b>		7 specialists (NTP County Manager, ambulatory doctors, doctors from sanatoriums)
<b>Moroeni (Dâmbovița County)</b>	8 TB patients	
<b>Târgoviște (Dâmbovița County)</b>		7 specialists (NTP County Manager, ambulatory doctors, doctors from sanatoriums, ambulatory nurses)
<b>Leamna (Dolj County)</b>	8 TB patients	

Interview invitations were sent to experts, representatives of the structures responsible for the prevention and control of tuberculosis: Ministry of Health, National Tuberculosis Control Programme, Ministry of Labour, Family, Social Protection and the Elderly, National Institute of National Institute of Medical Assessment and Work Capacity Rehabilitation (under the Ministry of Labour), National Health Insurance House, Institute of Public Health and the Bucharest Office of the World Health Organization. Finally, interviews were conducted with representatives of the National Tuberculosis Control Programme, Ministry of Health, National Institute of Medical Assessment and Work Capacity Rehabilitation.

All three methods explored, quantitatively and qualitatively, the following topics:

- The respondents' experience and perception regarding the access to and the use of: TB diagnostic services, TB treatment services, social support services for people affected by TB.
- Respondents' perception on the adequacy of existing services to the needs of people affected by TB.
- Recommendations for TB diagnosis and treatment services and social services for people affected by TB.
- Socio-economic profile of patients with TB and TB-MDR/XDR.

## Data analysis

We used an analytical framework that explored simultaneously all three data sources (sociological survey, focus groups and interviews with experts) and sought to identify patient needs for the following stages of the TB experience:

- Life before diagnosis;
- Diagnosis experience;
- Initiation of treatment and hospitalization;
- Treatment adherence after hospitalization.
- Resumption of normal life.

Each stage was followed from the **patients' perspective** (and family members where data were available), as well as from the **specialists' point of view**.

For each stage the following aspects were emphasized and illustrated with quotes and figures extracted from the survey:

- **Facts and figures** - which contextualize the patient's experience at that stage;
- **Patient medical care experience** - describing typical experiences during the disease progression, treatment, interaction with the medical system;
- **Patient's emotional experience** - that captures patient's emotions in each of the outlined stages;
- **The needs identified** by patients, family members or professionals in the study;
- **Turning points** - i.e. those critical moments in which specialists could and should act to positively influence the health and emotional experience of the patient.

The analysis is based on the model "The Patient Journey Map". This method chronologically identifies and describes the key steps in the experiences of patients suffering from a disease and highlights the less effective aspects of the system (or systems) that affect their lives during the disease.[1]

## Study limits

The type of analysis used has an operational and practical purpose and aims to draw a profile as detailed as possible for the patient affected by tuberculosis, highlighting a variety of needs and experiences.

The detail level of the profile and its representativeness, however, are limited by the amount of data collected and the recruitment method of study participants. Convenience recruitment was used for selecting the sociological survey and focus groups respondents and the interviews were conducted only with respondents who expressed willingness to participate in the study.

## The TB patient's journey

### Life before diagnosis

#### Facts and figures

The interviewed patients are mostly men, adults (> 35 years), living in low-income families and come, almost equally, from urban and rural areas.

#### Patient's medical care experience

The patient experiences fatigue and weakness, which they attribute to physical labor, stress or co-morbidities (e.g. diabetes) and cough, attributed to chronic smoking.

"I was mowing the hay and felt tired... today like this, tomorrow the same, the day after tomorrow... smoker... it's from the cigarettes. I started coughing and a month has passed, two..." (Patient, Moroeni).

When the symptoms (fatigue, cough) come and go, the patient attributes them to burnout or a strong cold, and takes action in this perspective.

"... I was feeling depressed but that I attributed to the job, as starting from November I had stopped going to work. And for the holidays I walked around, went shopping, bought gifts, I did some chores... no symptoms at all, only cough. And on January 2, at night, in my sleep, I coughed and I felt that I had something in my mouth, I spat blood ... and it was ... a little, not a lot ... on the napkin." (Patient, Moroeni)

The patient believes that AIDS and cancer are the worst possible health problems.

The patient knows that tuberculosis is "the poor man's disease", that smoking, repeated exposure to hot and cold (even exposure to air conditioning) can cause lung diseases, including tuberculosis.

#### Patient's emotional experience

The patient leads an active life and feels the pressure of family and social responsibilities.

"I used to walk where my wife and I worked, doing cleaning work in the hallways of apartment buildings, on Calea Victoriei, all the way to Matache market, in summer, before going to the hospital, I used to drink a beer or two, help farmers unload watermelons at the market ... worked hard, sweat, go home, go to bed, didn't eat, tired..." (Patient, Ilfov)

The patient believes that staying in good health depends on having a healthy lifestyle, but, more largely, on good luck.

"The young people, that's what I wanted to say, should take good care of them otherwise it's a shame... One needs will, strong, strong will, and a little luck. Will is not enough if you don't have luck." (Patient, Bucharest)

### The needs identified

Information on tuberculosis (what it is and how it acts on the body), ways of transmission and prevention methods.

Measures to reduce or prevent burnout (physical, psychological) of people of working age

### Turning points, which can be addressed to positively change subsequent patient experience

The patient learns that an acquaintance or a relative is sick or has been sick with tuberculosis, but does not know or learn more about the disease and the means of transmission. The patient's belief (that tuberculosis is "the poor man's disease") may conflict with the reality of the socio-economic profile of the person who got sick.

The patient starts to feel really sick, especially to cough, to lose appetite and lose weight.

## Diagnosis experience

### Facts and figures

After diagnosis, only 8 of the 78 respondents stated that they received support from other professionals (social worker, psychologist, and priest) in addition to the doctor.

### Patient's medical care experience

When accessing medical services for diagnosis, the patient is in an advanced stage of disease.

"What can I say, until August last year I had no problem with TB, with this, my brother was, and working at the car wash, in two weeks it exploded suddenly, I began to lose weight, I could not walk, kept coughing, I lost weight, from 52 kg I got to 43, I could not make any kind of effort, I walked ten steps and had to rest, and the colleagues from work sent me to the doctor." (patient, Ilfov)

Diagnosis disclosure (especially to patients who develop MDR-TB or to those who relapse) is not always accompanied by information that the patient can understand, about the disease, its causes and treatment requirements.

"They told me that I must be urgently hospitalized. Did not even allow me to leave the hospital. They took me straight to Stejaris, where we have [the sanatorium], but I did not know what TB was. I had no idea. So I was thinking: a disease, I got sick with something. Until I started reading booklets, stuff, what I was explained at admission, that it can be cured. When I heard that it can last for months, I thought, it's not that easy. It can take even longer depending on how your body reacts." (Patient Bisericani)

"I didn't know anything, I only knew that one can die of TB and when I found out that I had TB, I started crying, I had a neighbor who died of TB, and when they said I had TB, they did not say what kind of TB." (Patient, Ilfov)

"I think the doctors do not know how to be clear when they say something to the patient." (Patient, Bucharest)

"[...] The doctors went to university, they can't be wrong. But if they do it [diagnosis disclosure], they do it as a job, soulless. Like the car mechanic, he changed a washer ... goodbye." (Patient, Bucharest)

TB diagnosis can take from about three weeks (for TB) to three to four months (for MDR-TB). After the MDR-TB diagnosis, the patient feels that, all that time, he was given the wrong treatment unnecessarily.

"I, for four months, took those pills for nothing. Me, I took four pills, but there are others who take more. There should be something faster." (Patient, Bisericani)

"With regard to diagnostic problems... My opinion is that if you have therapy, diagnostic problems are a little alleviated, in the sense that you can settle for what you have, that is traditional methods, to which, in principle, we have access without surprises, without limitations; the great disadvantage of traditional methods is the long duration pertaining to the biological peculiarities of the microbe... Until last summer we never had access, in a significant manner, to anything other than the traditional methods... [...] We are delayed in terms of diagnosis and treatment by at least two generations." (Specialist, Bucharest)

The patient becomes confused about the severity of the disease and starts questioning the doctors' professionalism when is encouraged to be discharged from the hospital pending the diagnosis outcome or for the holidays (Easter, Christmas, New Year's Eve), although this practice is guided by hospitalization standards for the patient who has not yet been confirmed for MDR-TB:

"Why, for example, I was positive and they let me go home for Easter. So the doctor knew that I was positive and said: you go home for four days. If I had said: let me go to the store, he would have told me I was a walking time-bomb." (Patient, Bucharest)

"I spent Christmas in the sanatorium, during drug testing. That much will I had, that they would say: if you want to go home for the holidays and come back after, leave, or we'll give you a reference to go to Bucharest. I said no. [...] I said I have a family that I must protect" (Patient, Bucharest)

"I was admitted to the [hospital] on Alexandriei Road [...] That was no hospital; it was a camp

for some of us, poor unsuspecting people, among which I was as well. It was freedom and I said that's fine. I could go when I wanted, to do whatever I wanted, which I realize now that it was not good." (Patient, Bucharest)

"Length of stay for common tuberculosis, on average, countrywide, is of 32-35 days; physicians are forced to discharge and readmit..." (Specialist, Bucharest)

Patient referral to other investigations or medical services can be difficult when the TB medical staff is not aware of these services (eg services for drug users, for the homeless), or when the investigations to which the patient is referred require payment.

The patients without identity papers have difficulties with being taken into immediate evidence to the TB services, especially when they can not provide any proof of their identity.

"When a patient without identity papers comes, even though he has a known personal identification number, whether it's written on a piece of paper or has a photocopy, and we can see that it expired in 2009, regardless of the time he comes in, we call the police, who have a device ... [...] There is this procedure that works, for obtaining the data, but for patients with tuberculosis would be great if someone helped them get identity documents because, here in Bucharest, we are more lenient, we are faced with this situation and maybe access some services easier, but it's very hard to send a patient who has no identity papers, no evidence that he's insured, to be admitted and stay hospitalized for 4 months in another hospital." (Specialist, Bucharest)

### **Patient's emotional experience**

The experience of diagnosis has a negative psychological impact on the patient, as he feels fear, anger, and low self-esteem.

"[When I was diagnosed] it was like a blow to the head." (Patient, Bisericani)

"[When I was diagnosed] I said I would buy a tent and isolate myself with my bacillus. I would just pitch it in the woods." (Patient, Bisericani)

"[Diagnosis] was a disaster for those who did not know what it means this disease. Misfortune." (Patient Bisericani)

"When he told me [the diagnosis], I wanted to beat him up." (Patient, Bisericani)

"Many [patients outside of Bucharest] think that it must be the final stage when they hear «I go to Bucharest» [MDR-TB center]. But they don't know that here is where MDR-TB treatment

is provided.” (Patient, Bucharest)

“[When I was diagnosed I thought of] the fear that I might not get cured. That it is a fatal disease. Especially when I was told about MDR. So I heard from patients, not the doctors, that MDR is the final stage of the disease. That was nothing! Then I had MDR. Now when they said I have XDR! What is XDR?” (Patient, Bisericani)

The lengthy MDR-TB diagnosis subsequently makes the patient feel responsible for spreading the disease.

“So, to diagnose such a disease after 60 days is enormous, because in those 60 days one might kill a million people.” (Patient, Bucharest)

### The needs identified

Rapid diagnosis of MDR/XDR-TB infection.

Active involvement of family physicians in the referral of TB suspects to diagnostic services and in identifying the contacts of people diagnosed with TB.

“[It is necessary] to increase the awareness of family physicians that tuberculosis is still a health problem in Romania and the patient with respiratory symptoms, not the one coughing for three days that he does not want to treat, but the one who has been coughing for three weeks despite intensive antibiotic treatment - that one should be suspected for tuberculosis and sent to a specialist consultation. The family doctor has to collaborate to identify all close contacts that can be controlled and to receive prophylactic treatment where appropriate.” (Specialist, Ploiesti)

### Turning points, which can be addressed to positively change subsequent patient experience

Patient sees the family doctor, having symptoms of possible infection with tuberculosis.

Diagnosis disclosure of infection with sensitive TB or MDR-TB

## Initiation of treatment and hospitalization

### Facts and figures

**The most difficult experiences during treatment:** "to be hospitalised" (60%), "to be away from the family" (35%), "to sit and do nothing"(30%) and " to cope with side effects" (30%).

### Patient's medical care experience

The patients have long hospitalisation experiences, which can last from two months (for sensitive TB) to two years or more (for MDR-TB).

If the disease relapses, the patient has had multiple experiences of prolonged hospitalization.

Lack of correct and complete therapy for the MDR-TB patient.

“We are delayed in terms of diagnosis and treatment by at least two generations.” (Specialist, Bucharest)

“The [MDR-TB] patients from programmes [the Global Fund<sup>1</sup>], had access to six drugs, while from the National Programme<sup>2</sup> [of Tuberculosis Control] one could have access only to 4 at best; the programme [the Global Fund] ensured continuity for two years for each individual, while those in the National Programme were left to luck...” (Specialist, Bucharest).

“The programme [NTP] could only provide a minimum of four drugs that were a minimum of treatment but only for a category of patients: those with TB; or, for those with MDR-TB, but with incipient forms with limited resistance, because, if they became XDR, it was out of the question... And the drugs provided by the Global Fund were not compatible drugs for XDR treatment, which was again automatically out of the question...” (Specialist, Bucharest).

### **Patient’s emotional experience**

The patient is stressed by long periods of hospitalization and treatment, in which it is inactive and can not contribute to family and work obligations (may lose job and income).

“Such a long leave, so far away ... so my daughter is in the 12th grade. I was thinking only of her, even in the early days, I felt I was going crazy ... there is a graduation exam, a college exam next... some tutoring lessons ... the support from family and former colleagues helped me a lot because I was determined to stay one week at most, to finish those injections I had for the bleeding and to ask to be discharged and sent to Bucharest, to be closer to home.” (Patient, Moroeni).

The patient feels discouraged when he is told about the duration of treatment and the need to stay for a while (short or long) in the hospital.

The patient is encouraged by the interaction with a specialist who can provide psychological counseling or just the opportunity for a frank discussion about how it feels, physically and

<sup>1</sup> The Tuberculosis Programme financed in 2007-2014 by the Global Fund to Fight AIDS, Tuberculosis and Malaria. The program has received an amount of €2 million in order to provide the necessary treatment for a number of 800 patients with MDR-TB.

<sup>2</sup> The National Tuberculosis Control Programme is financed from the budget of the Ministry of Health and the National Health Insurance House. The amount allocated under the program in 2013 was 3.3 million.

mentally.

"I heard when I came that there will come a psychologist and help with boosting the morale. That no matter how tough one is, let's face it, at some point one might fall, and not everyone has the strength to stand up and then an helping hand there, a finger here, help one stand up and say: there is a way for the future. It's hard to walk into a place where you feel that you have no way out." (Patient, Bucharest)

### The needs identified

Social support for patients who experience long periods of inactivity due to hospitalization.

Psychological support to overcome stress caused by prolonged hospitalization.

### Turning points, which can be addressed to positively change subsequent patient experience

Communication of treatment duration.

The patient exhibits early concerns about the hospitalization impact on his family and professional life and the economic situation.

## Treatment adherence after hospitalization

### Facts and figures

13 out of 80 respondents (16%) said they had discontinued the treatment at least once (seven for one week, three between 2 and 4 weeks, three more than a month)

**Reasons for discontinuation:** "I felt sick" - 30% "felt better" - 23%, other reasons - 47% (e.g., "I was out of town", "I refused to go to the clinic anymore").

**The main needs for the successful completion of treatment:** family support (46%), better nutrition (32%), money / welfare / income (23%).

### Patient's medical care experience

After being discharged from the hospital, the patient can get home, to the local dispensary, only to discover that not all the drugs that have been prescribed are available.

"The main difficulty is to ensure the appropriate treatment: in our department, there are certain drugs that we give and later, when the patient is discharged from the hospital and goes to various places in the country, I do not mean necessarily Bucharest, let's say that Bucharest is somewhat covered, but in many dispensaries there are big problems with the second line drugs supply." (Specialist, Bucharest)

Treatment adherence, especially after discharge, decreases without the material resources that ensure adequate nutrition and housing for the patient, purchase of medical supplies (such as syringes), drugs for co-morbidities and for TB medication side effects management.

“Look, I gotta go to work. And then I have two choices: either I go to work and take the treatment, but do not know whether it will be effective as that I will be tired from work and relapse. Or I let them [family] automatically go live in the street.” (Patient, Bucharest)

“One of the most powerful side effects is hearing loss, currently many of the patients have this side effect. It’s a challenge for us to do this investigation and the cochlear implant is very difficult and is made with great efforts from the patient, I think this should be considered and we need more help with it.” (Specialist, Bucharest)

The treatment, especially for MDR-TB, has physiological side effects that are difficult to bear.

“My guts are ruined, my bones are gone, I ache everywhere, I have diarrhea, everything. What else? Nausea, like pregnant women, there is nothing left; I'm torn on the inside.” (Patient, Bisericani)

“[...] Lack of appetite and I see that the more hospitalizations I have, the increasingly worse it is, it's enough to see the pills and I already feel nausea, without taking them. They already make me sick; I do not need anything anymore.” (Patient, Bisericani)

“I feel sick from my pills. They gave me injections and all for nothing. As soon as I see them, as soon as I take them, I feel sick.” (Patient, Bisericani)

When the patient feels that it can not cope physically with the treatment anymore, it interrupts it.

“What can I say, my only chance, if there is one, is to be able to finish my course of treatment. If I can cope with it. If not, I have no choice but to come back here or to the doctor... Here I might take it. It's not that I don't have the will, at some point the body no longer accepts the drugs, and I take them... So it will take the treatment for a year, and then that's it. Or nine months. After that I can not take it anymore. At first I said that's it, it's OK and I'm cured... I suffered much more than... I should have completed the treatment.” (Patient, Bucharest).

The co-morbidities management influences the adherence to TB treatment.

“Yes [I gave up treatment] in 2006 when I had. I had finished the injecting drugs and I was negative. I had to take pills but I gave up. Three times a week, and I did not take them because I was going to work. When I knew I had injections, then I took the treatment.” (Patient, Bisericani)

"I had the shingles, the doctors have discontinued it for 10 days. I had surgery, they discontinued for 10 days, I had heart pains, they discontinued for 10 days, whatever else I had, they discontinued." (Patient, Bisericani)

Family stability and support from the close ones favour adherence to treatment.

"More help, for me, the children are at my brother's and I have not given them to strangers. They are at home, they are together, and this helped me a lot because I feel better psychologically and I have the willingness to take the treatment. Very much!" (Patient, Bisericani)

The patient does not benefit from the involvement of all the professionals in the community who could support the implementation of DOT.

"[...] the social worker should know what it is paid for, it should know that it has some tasks and, at least once a month, should come here [to the TB dispensary] and ask [who takes the medication and who does not]. We should know each of them, we should work together. After all, what does «social worker» mean?" (specialist, Targoviste)

### **Patient's emotional experience**

The TB treatment has psychological side effects that are difficult to cope with, such as depression.

"When I take the drugs, I feel I lose... I don't know ... my brain." (Patient, Ilfov)

Lengthy treatment and the large number of drugs to be taken generate therapeutic fatigue.

"Yeah, well, I have a heart condition as well and take pills for it too. And I'm sick of pills, better make a soup out of them and eat them all at once and that's it." (patient Bisericani)

"I knew I was sick, but I was not aware of the disease, it often disgusts you, you become sloppy, you don't have something to hold on, to fight for something. You don't have a motivation." (Patient, Bucharest)

### **The needs identified**

Support measures and services in order to increase the adherence to the TB treatment, in particular MDR/XDR-TB.

Identification and active tracking of patients at risk of non-compliance to treatment (through cooperation between the Ministry of Labor and the Ministry of Health, to ensure the provision of material support, the effective activation of the DOT system and involvement of social

workers in the community).

Free access for patients to complete and properly administered treatment (including subsidized syringes, saline solution and adjuvant treatment);

“The medication should be permanently ensured in all units carrying out TB control activities, in order to avoid situations where we are out of stuff, no X-Ray available, no money for the antibiogram and thus time is lost in treating the patient. [It is necessary] to identify a way to cost effectively facilitate the patient access to treatment after discharge, namely the opportunity to come to the TB clinic or to the family doctor's office, with as little cost as possible.” (Specialist, Ploiesti)

Patient access to psychological support services and social assistance.

Effective management of side effects (physical and psychological) of the treatment.

### Turning points, which can be addressed to positively change subsequent patient experience

On treatment initiation, an assessment of the patient's condition (social, psychological, medical) may suggest an increased risk of non-adherence.

The patient discontinues therapy for the first time.

The patient has the first relapse.

The patient exhibits side effects to treatment.

## Resuming normal life

### Facts and figures

**The main concerns of the patients after the completion of treatment:** 40% of respondents fear that after completing the treatment they could get sick again, 28% that they will no longer be able to practice the same profession, and 16% that they will no longer be hired by anyone due to the disease.

**Solutions to personal concerns:** lifestyle changes to prevent future illness (28%), finding a job (20%), financial support from the state (18%), proper and complete treatment (14%), psychological support from family or a specialist (14%), periodic medical examination (12%), information and education on TB (9% ).

### Patient's medical care experience

For the patient, it is a challenge to change the lifestyle and to protect himself in order to prevent a relapse.

The patient feels he no longer has the same strength and energy, as before becoming ill.

### **Patient's emotional experience**

The patient feels that the diagnosis disclosure to peers will damage its image in the community, given the association between tuberculosis and poverty (tuberculosis is seen as the "poor man's disease").

"Now I want to talk about something, actually the perception of tuberculosis we all grew up with: poor man's disease, as you said. And given this, some patients would rather not tell anyone about the diagnosis, keep it secret." (Patient, Moroeni)

The patients fear rejection from peers once they reveal why they were hospitalized or why they took treatment in ambulatory.

"In general, I understand it's a dangerous disease and that they should avoid us and we should protect them, but to be rejected... I do not know." (Patient, Bisericani)

The TB patient feels safe, encouraged, especially when it receives family acceptance and support.

"For us, it matters that the family and relatives understand... the rest..." (Patient, Ilfov)

"When my mother heard «Oh, my God, it's a dangerous disease...» instead of encouraging me, she discouraged me and that ... [...] My brothers said they would not come anymore, for fear they would get sick... and I told them I was negative, negative, and they did not understand." (Patient, Ilfov)

Diagnosis disclosure, however, can be a traumatic experience.

"I have not told anyone, only to my family, husband, child, mother and so on. I chose to tell a friend, she was my soul mate, this girl, and when I told her, she stopped calling me; 45 days I've been admitted here, she's no longer interested in me. And for this I will not tell anybody anymore. I get cured, OK, I die, well, nobody cares." (Patient, Bucharest)

The patient fears that reinsertion on the labor market will be difficult, due to the low work capacity and the stigma associated with TB.

"And we must find a solution to help them [the TB patients]. We treat them and then we send them out in the world. And now, you go. But what do you do out in the world? You look around, you are simply confused, because you think - what job can I find? For office work, I'm not good enough, I didn't study, right? I can't start now at 30. Or I could, but it may be too late or... I don't know. Maybe I wouldn't even find [a job]. In construction I can't work anymore [...] I mean I could, but it would worsen [my illness] and I could go back to where I came from. I do not want to come back! A security guard ... I don't know if I would be fine. In a pub, I could not work [because] I have to avoid smoke, to avoid a lot of things..." (Patient, Moroeni)

### **The needs identified**

Revision of the paid sick leave period from 1 to 2 years - as a special measure of protection, especially for patients with MDR/XDR-TB, thus facilitating therapeutic success. Currently, under the law, patients with surgical treatment of pulmonary tuberculosis and osteoarticular tuberculosis are eligible for up to 18 months of medical leave.

Access of people affected by TB to psycho-socio-professional services offering professional skills assessment and, where appropriate, professional re-orientation and requalification training (qualification and requalification courses).

The access of people affected by TB to recovery services that ensure the possibility of retraining for physical effort - so that at the end of the sick leave the patient is ready to resume work.

Measures to reduce social stigma and discrimination associated with TB.

### **Turning points, which can be addressed to positively change subsequent patient experience**

The patient completes the treatment and fears the disease will relapse.

The patient understands (before or after completion of treatment) that they do not have the same capacity to work as before they became ill.

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