

TB Stigma Assessment in Ukraine

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ABSTRACT

TB stigmatization is among the most significant social factors hindering equal access to the health care services for people with tuberculosis (PWTB), preventing them from seeking care and continuing treatment and resulting in poor health outcome and human rights violation. Personal factors, family, health care, community settings and legal environment were studied to assess how stigma affects people-centered care in Ukraine being amongst the thirty countries with high MDR TB burden.

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List of Abbreviations

ACSM: Advocacy Communication and Social Mobilization
CO: Charitable Organization
HIV: Human Immunodeficiency Virus
MP: Local Deputy
MDR TB: Multidrug-Resistant Tuberculosis
MoH: Ministry of Health
NGO: Non-Governmental Organization
PLHA: People Living with HIV/AIDS
PWTB: People with Tuberculosis
RC: Regional Coordinators
TB: Tuberculosis

Introduction

Ukraine is one of the thirty countries in the world with some of the highest prevalence of multidrug-resistant tuberculosis [1]. The burden of TB epidemic is made worse by the HIV epidemic: one in four patients with TB is living with HIV [2]. In 2019 Ukraine's TB morbidity has registered at 60.1 per 100,000, with estimated MDR TB morbidity at 29 per 100,000 [3,4].

In order to reach the targets, set under the State Strategy for Strengthening the National TB Care Provision it is important to eliminate the barriers which prevent the TB patients from accessing medical care services at every level: from screening for TB to provision of care and support [5]. In this respect overcoming stigma and discrimination is vital and without it patient-centred services cannot function successfully [6]. In the process of medical care delivery stigmatisation is of the most significant social factors which hinders equal access to the health care services. There is a global call to fight TB associated stigma. The first-ever UN General Assembly high-level meeting on tuberculosis in 2018 endorsed a political declaration to accelerate progress towards End TB targets in 2022, this includes eliminating stigma and all types of discrimination associated with tuberculosis [7].

Stigmatisation is a complex process which is shaped by institutional and community norms, interpersonal factors and attitudes. In a wider sense TB associated stigma is a process which begins when a particular trait or characteristic of an individual or a group is identified as undesirable or disvalued, as a result the stigmatised individual adopts a set of self-regarding attitudes which include shame, disgust and guilt which produces a set of behaviours that include hiding the stigmatised trait, withdrawing from interpersonal relations or increasing risky behaviour [8]. Stigmatisation differs from discrimination in a sense that the latter is characterised by socially excluding the person and violating the person's rights as a result of stigma. The stigma associated with tuberculosis has a negative effect not only on the patient but the patient's family, is a source of shame, fear and isolation, which hinders the treatment [9,10].

Stigmatisation goes beyond individual barriers to medical care and often extends to the structural components which requires both personal interventions involving the patients together with the medical care providers and interventions at the level of medical care facility and the society at large. Despite the concerted large scale effort applied by the government agencies, NGOs and international organisations and significant progress in strengthening TB testing, prevention and treatment, still there are strategic gaps in raising awareness about TB-associated stigma. Prevalence of stigma and discrimination, types thereof and impact on accessing medical care have not been studied in full in Eastern Europe and Asia, which includes Ukraine. The study was commissioned by the CO 100% LIFE and carried out by the European Institute of Public Health Policy, in cooperation with the Public Health Centre of the MoH of Ukraine and the CO TB People Ukraine.

The assessment includes important national data on the scale and level of TB associated stigma which could potentially inform interventions aimed at eradicating unequal access to medical services for TB patients and supporting patient-oriented approaches in prevention, testing for TB and treating the disease.

Methodology

The overarching aim of this assessment is to analyse the extent to which TB-associated stigma prevents the patients from accessing TB testing services, treatment and prevention services as well as its impact on the process of service delivery. The study also aims to developing recommendations on eradicating TB-associated stigma in Ukraine.

The study has set the following objectives:

- assess the level and scale of the anticipated and experienced stigma as well internalised stigma among people diagnosed with TB;
- assess the level and scale of secondary stigma, i.e., stigma experienced by TB patients and stigma experienced by the family/caregivers of people with TB;
- evaluate the level of anticipated TB stigmatization of people with TB at community level and the level of stigma reported by community representatives;
- analyse the level and scale of anticipated stigma which exists in health care settings towards people with TB and towards health care providers working with TB patients;
- analyse to what extent institutionalised stigma which exists in the framework of current legislation and policies as well as stigma in the mass media could harm or protect people with TB;
- obtain data needed for developing recommendations on eliminating TB-associated stigma with aim to reducing vulnerability to TB infection, scaling up access to the TB services, and improving the treatment success rate.

The study has analysed the experiences and views of the five key populations:

- People with TB. The population includes adult patients (≥ 18 yo) who registered in the 2019 State TB Registry as first time TB patients or patients with relapsed TB infection.
- Family and close contacts of people with TB disease. This key population includes the family members, other close contacts and caregivers of people living with TB who provide support in the process of screening for TB and TB treatment. The survey included both men and women, parents or children of participants with TB. The age cap was set at ≥ 18 yo.
- Community representatives. This group includes community leaders identified by the research team and the people working in close vicinity to the TB clinic. The survey was conducted exclusively inside the communities located in the oblasts covered by study.
- Medical care providers. The research included the doctors and medical nurses at the Primary Care clinics and specialised clinics which provided TB testing, prevention and/or treatment for TB infected patients.
- Stakeholders. This key population included programme managers coordinating the efforts to fight TB at the global, national and regional level, law experts, politicians, MoH of Ukraine representatives, the media, donors, representatives of medical facilities, NGOs and representatives of communities of people who had experienced TB.

The sample of people who had experienced TB was intended as random and representative of the geography at the level of macro-regions, it is reflective of the share of people living in the cities and rural areas, age and gender and includes representatives of all key populations. The sample population of patients was developed based on the 2019 statistics on TB patients available from the Public Health Centre of the MoH of Ukraine. The sampling for

other key populations was uniform. Three family members of a TB patient, 3 community representatives, and 17 medical providers were selected from each specific oblast. Overall, the study engaged 1,437 participants, representative of 15 Ukrainian oblasts and the city of Kyiv, including 1,101 people who had experienced TB, 45 family members of TB patients, 43 community representatives, and 248 medical care providers. Also 15 stakeholders participated in two focus groups; all of the stakeholders were based in Kyiv.

The survey was conducted during the COVID-19 pandemic, the recommendations on social distancing measures were in full force and as a result the data was collected remotely. The four key populations, including people with TB, their family, community representatives, and medical providers were interviewed by phone using a standardised questionnaire as presented in the TB Stigma Assessment Handbook, which was adapted for Ukraine [11]. The data collection was conducted by independent interviewers (7 women and 6 men) using the Qualtrics 13 programme, the interviewers underwent special training on the survey methodology, approaches to collecting data by phone, and ethics. The majority of interviewers came from the TBpeopleUkraine and had personally experienced TB. The stakeholders were interviewed during two focus groups (7-8 participants) which were remotely organised in Kyiv.

In the regions recruiting of people with TB disease was organised by the survey's Regional Coordinators, i.e., medical professionals employed by the TB clinics with access to the TB Patients' Registry. In the beginning of the study the RCs have created primary e-lists of patients corresponding to the survey criteria; the encrypted patients' depersonalized lists were forwarded to the study headquarters using a secure system of data transfer. The survey data manager ascribed personal identification numbers to each clinic, randomly selected the patients' numbers specific to the region and formed a new depersonalized e-list of randomly selected respondents. The data manager forwarded the list to the RCs from respective regions, the RCs used the patient IDs from the TB Registry to connect with the selected respondents using the approved protocols on collecting data and offered them to participate in the study. If the potential participant has not expressed any interest in the study, the RC would make a note in the e-list of randomly selected respondents and move on to the next candidate. The patients who participated in the survey were engaged to recruit the family members, in the process the interviewer would suggest the client to engage their family and offered to contact the study team in case they were interested. The medical providers were recruited by the RCs, the RCs were used to engage the medical staff at the TB clinics and Primary Care clinics in the cities covered by the survey which engaged the clinic's patients and their families.

The local community representatives were selected using two methodologies:

- independent interviewers engaged into the survey random people whose professional activities placed them in close proximity to the TB clinic;
- community representatives (members of the HIV and TB Coordination Councils, local MPs) were selected by the Head of Team via the civil society representatives located in the regions covered by the survey.

The stakeholders were selected based on the recommendations provided by the Core Group established by the National TB and HIV Council's ACSM Working Group.

The Core Group is an ad hoc advisory panel which was created in the project's framework with the aim to engage a wider circle of stakeholders and provide expert support to TB Stigma Assessment in Ukraine. The Group members were government officials and NGO representatives, including international civil society organisations and people affected by TB (ten organisations in total). The Core Group meetings were facilitated by TB Expert under the Public Health Centre of the MoH of Ukraine leadership; the Group has endorsed the study's protocol and provided recommendations used to adapt the study guidelines initially developed by the Stop TB Partnership; the Core Group was fully engaged in discussing the study's milestones. Following the Group's recommendations, the survey methodology initially developed by the Stop TB Partnership was extended to include a larger number of medical care providers -from 40 to 248 participants, the move was intended to reflect the newly implemented changes which came into force in Ukraine as a result of the medical reform and help cover both specialised TB care and the primary care clinics which now find most TB cases and provide outpatient care to the TB patients.

All of the digital data was downloaded from Qualtrics to MS Excel. The data was validated through running a logical test to detect doubles and missing values. The list of indicators selected for analysis reflected the international TB stigma assessment implementation handbook:

- Indicators used to identify the «stigma radar» associated with TB, e.g. comprehensive analysis of self-stigma, secondary stigma within the family, anticipated stigma within the community and in the health care community;
- specific manifestations or dimensions of stigma within each key population;
- indicators of experienced stigma along the TB journey, including the ones which inhibited PWTB from seeking and receiving care;
- stigma indicators observed by the key populations along the TB journey;
- indicators used to assess the legislative and political climate and its impact on stigmatization and discrimination of PWTB.

The stigma scales are an adapted version of the following tools: Van Rie, et al questionnaire which was used to evaluate stigma faced by PWTB and communities; R. A. Arcêncio, et al questionnaire which was used to assess secondary stigma experienced by the family of PWTB; Corrigan, et al questionnaire which was used to evaluate the nine dimensions of stigma [12-14].

The analysis of quantitative data was mostly statistically-descriptive, e.g., calculations of frequencies and percentages, mean values and standard errors in the aggregated scale of stigma. Indicators to assess stigma were analysed in respect to PWTB and health care providers. In respect to the rest of the key populations this type of analysis was not applicable due to the insufficient sample size. In dealing with quantifiable resultative variables, e.g., the total score of self-stigma, the discrepancies between populations were identified by using a multiple linear regression used to simultaneously analyse the impact of several variables. The results are presented as an adjusted mean difference as compared to the reference group, its 95% confidence interval and p values. For the categorical binary resultative variables, e.g., present/absent experience of stigma, the indicator analysis was performed using multiple linear probability models. This helps assess the adjusted percentage discrepancy (prevalence) related to a specific phenomenon in a population, its 95% confidence interval and p values. The confidence interval indicates that if this analysis was repeated many times over, in 95% of studies the actual discrepancy

between the means or percentages within a population will stay within the same interval. Confidence intervals which exclude the null value and $p < 0.05$ indicate that there are statistically significant discrepancies between populations. The quantitative data analysis was performed in the R programme, ver. 3.5.2 (Copyright (C) 2018 The R Foundation for Statistical Computing).

Results

The level of self-stigma in PWTB was measured by using a set of 12 statements describing the attitude towards TB disclosure, feelings of guilt, social isolation and so on. Practically all of the respondents have clearly expressed their views on the statements and under one percent of the respondents have either refused to answer or could not specifically tell. Over half of the respondents have identified with the feelings of guilt for letting down their family; reported being hurt by a negative reaction after a disclosure; fearing disclosure of TB status; and limiting social contacts with aim to preventing spread of TB. Over one quarter of respondents (27%) have supported statements on associated TB and HIV stigma, saying that after finding out that they have TB the others may think that they are also infected with HIV. The PLHA respondents (54%) also identified with the statement that if the others find out about TB, they may also assume HIV. One in seven respondents (14%) associates disclosing their TB status to the family with the feeling of fear, and every fifth respondent (20%) associates visiting a medical clinic for TB care with the feeling of fear because at the clinic they could be seen by someone they know and who could find out about their TB status. Overall, only 3% of respondents have not indicated any self-stigma associated with tuberculosis and contradicted all of the 12 statements.

In general, the women felt more self-stigma compared to the men. There is a link between self-stigma associated with tuberculosis and age — older respondents felt more self-stigma. Patients with extra-pulmonary TB usually exhibited less self-stigma compared to the people diagnosed with pulmonary TB. This could be explained by the fact that pulmonary TB is more infectious and the patients with pulmonary TB were afraid of spreading the infection further and felt isolated as a result. At the same time there was no discrepancies in the level of self-stigma between the patients diagnosed with drug-sensitive and drug-resistant TB — out of the number of respondents who could accurately name their diagnosis. Also, there was no correlation between the directly observed treatment model and the level of self-stigma associated with tuberculosis. The highest levels of self-stigma were registered among such key populations as the PLHA and low-income populations in the cities and rural areas.

Over one third of PWTB (39%) have reported personally experiencing stigma along the TB journey which prevented them from accessing medical services (Diagram 11). In the majority of cases the respondents have reported experiencing stigma while visiting medical clinics (18%). In total, 9% of respondents have reported experiencing stigma at a TB clinic; another 9% — at a Primary Care clinic and 2% at other medical facilities. One in ten respondents has experienced stigma associated with tuberculosis at work (11%) and in the community, in a neighbourhood setting (10%). Only 5% of PWTB reported being stigmatised by the family.

The patients who self-administered TB treatment without any outside supervision have reported more stigma in a family setting. Only 5% of the total number of respondents have experienced stigma in a family setting, but in people who self-administered TB treatment one in every eight respondents (12%) have reported

being stigmatised by the family. In key populations people with low-income and at-risk populations due to underlying health conditions, including people with disability, patients with diabetes and people with mental health issues had higher levels of stigma compared to the respondents who did not identify with these groups. Stigmatisation in a work setting is more prevalent in the South of Ukraine compared to other regions. The patients who were in treatment at the time of the survey reported more stigma in a work setting compared to the respondents who completed their treatment.

Secondary stigmatisation is mostly marked by the fear of being infected and status disclosure. Out of the overall number of families surveyed 59% were afraid of getting TB. Over half of the PWTB family members (52%) in the survey chose not to disclose their family member's status. The feelings of guilt and shame were less prevalent — 20% would use euphemisms when discussing tuberculosis with the infected person, and 14% felt ashamed that their family member was infected with TB. Every seventh respondent (14%) in the PWTB family has reported that that being seen by someone they know at a TB care facility is associated with the fear of status disclosure.

The registered level of anticipated stigma within the community was quite high, it was mostly manifested as limiting contacts because of the fear of being infected. Over 90% of the responding community representatives have confirmed the statement that people with TB are feared, the other community members try to keep their distance, refuse to share food and drink, do not want their children to have any contact with PWTB. A large proportion of community representatives believes that the change in the attitude towards people with TB is long term, 74% confirm that if a person has had TB some society members will continue to treat them differently for the rest of their life. Two thirds of community representatives (63%) confirm that some people believe that it is best if people with TB have left their community altogether.

The medical care providers are convinced that the anticipated stigma associated with tuberculosis is widespread within the medical community. An overwhelming majority (90%) have confirmed the fact that there are medical providers who would support quarantining TB patients during the more intense stages of treatment. Eighty-eight percent of the respondents have expressed support for mandatory TB treatment. Almost three quarters (73%) say that some health care providers try to avoid TB patients. Compared to the primary care setting, specialised TB care exhibited higher levels of stigma.

In the population group a larger proportion of respondents supported the following statement: «Some health care providers believe that patients with TB are a hazard to others», «Some health care providers do not want to be around patients with tuberculosis», «Some health care providers are anxious about providing medical care to PWTB», «Some health care providers dislike providing medical care to PWTB» and «Some health care providers become angry with PWTB». According to the Stop TB Partnership recommendations, the assessment of the legal and policy environment in TB focused on the seven TB rights most relevant to living with TB or with the most cases of rights violations. A desk review was conducted to perform the assessment. The review's findings were discussed on two focus groups which aimed to assessing the extent to which the legal and policy environment in Ukraine could harm or protect people diagnosed with TB. The focus group participants made different suggestions as to eliminating stigma and discrimination

in legislation; some experts believed that special clauses on the rights of people with TB must be introduced to the health care legislation and respective legislation regulating specific areas, like education and labour laws. Other experts were convinced that the rights of people with TB are part of the human rights and there is no need in developing a special set of regulations for PWTB. Instead the rights of people with tuberculosis should be afforded the same level of protection as the other human rights. The researchers believe that systemic stigma in legislation will be eradicated as a result of introducing the human rights approach to into the methodology in which legislation is developed and implemented.

Conclusion

The overwhelming majority of people with TB (97%) show signs of self-stigma. These signs are not always recognised for what they truly are. Often the respondents try to avoid anticipated stigma by not disclosing their TB status to their family or in the community. However, the need for non-disclosure indicates self-stigma and anticipated stigma. Non-disclosure of the status is hardly an effective means of fighting stigma as it increases social isolation and limits opportunities in which PWTB could receive support. PWTB often identify with several key populations, where each identity can be a source of stigma. Each tenth PWTB has identified with five or more key populations, including people with disability, low-income populations, PLHA, former inmates and so on. Addressing TB-related stigma is not enough, the process requires developing interventions which could address multiple stigma and mitigate its effects on accessing medical care for people with tuberculosis.

TB-related stigma diminishes post-treatment but is never gone completely. In this study PWTB in post-treatment at the time of the interview did not show as many signs of stigma and were more willing to discuss experienced stigma compared to the respondents who remained in treatment at the time of the interview. Experiencing stigma along the TB journey could prevent PWTB from entering care. In total 39% of PWTB reported that experienced stigma acted as a barrier to accessing TB diagnostic, entering care and receiving support. The reports mostly referred to stigma in a health care setting, in community and at work. Secondary TB-related stigma in the family was mostly perpetuated by the fear of TB infection and concerns that someone from the community will learn that a family member has TB. At the same time secondary stigma in the family in most cases did not prevent the family from supporting their family members with TB, as they continued to provide support in the family and during hospital visits.

The level of anticipated TB-related stigma in the community is dangerously high. Two out of three community representatives agreed with a statement that some residents do not want people with TB living in their community. It is especially significant when three quarters of respondents believe that having TB has long term consequences regarding how PWTB are viewed in the community. Communities often fail to differentiate between people with TB and people who have had TB, and stigma can continue even post-treatment. Stigma in the community is directly associated with self-stigma in PWTB and secondary stigma in the family when the fear of status disclosure and its possible consequences served as a source for both types of stigma. Addressing stigma in the community would have direct consequences for self-stigma and secondary stigma.

Anticipated stigma is prevalent in the professional community of health care providers, its level measured at 63%. At the same time

experienced stigma due to working in TB care is less prevalent: 30% of health care providers were stigmatised in a work setting, in community and family. Usually TB care providers, especially physicians have experienced higher levels of anticipated stigma and enacted stigma compared to primary care providers.

The experts assessed the level of harm in the legislative and policy environment at 54% and 81% respectively, where 0 indicates no harm and 100 — extreme harm to PWTB. The key gaps identified in legislation and policies include lack of laws and policies and/or unwillingness to implement them with aim to protecting the right to freedom from discrimination, right to access information, right to access services, right to privacy, right to informed consent and so on.

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