

Helping People with Tuberculosis in Ukraine Stay in Treatment

Findings from a Qualitative Analysis of a Social Support Program

In 2014, the United States Agency for International Development (USAID) mission in Ukraine asked

MEASURE Evaluation to launch an impact evaluation to study two interventions conducted by the Strengthening Tuberculosis Control in Ukraine (STbCU) project to (1) provide social support services to improve tuberculosis (TB) treatment adherence; and (2) improve the integration of TB and HIV services, to reduce mortality through early diagnosis and treatment of TB- and HIV-coinfected clients. MEASURE Evaluation designed two independent but complementary studies to evaluate the impact of these STbCU program efforts: the social support study and the TB-HIV integration study. Both employed a mixed-methods approach, with a quasi-experimental quantitative evaluation design complemented by qualitative descriptive work to inform the findings. This brief summarizes the results of the qualitative research conducted for our evaluation of the social support program.

Background

Ukraine has one of the world's highest rates of multidrug-resistant tuberculosis (MDR-TB) (Acosta, Kaluski, & Dara, 2014). It has an estimated 40,000 cases of tuberculosis (TB) each year (PATH, n.d.), with 7,855 new cases of MDR-TB reported in 2014 (Ukraine Center for Disease Control, 2014). Treatment default rates are high, as is the rate of TB and HIV coinfection.

Under the STbCU project, the Ukraine Red Cross Society (URCS) implements the home-visiting social support program for TB clients who are vulnerable to treatment default. Nurses conduct daily home visits to directly observe client treatment and to encourage them to fully adhere to TB treatment. The evaluation of this project aimed to gather information on the individual- and system-level

facilitators and barriers to client adherence to treatment and to recommend ways to improve future programs.

Strengthening Tuberculosis Control in Ukraine

USAID in Ukraine is testing strategies to combat the problems posed by multidrug-resistant tuberculosis and HIV. One such mechanism is the STbCU project, in partnership with the Government of Ukraine and national and international stakeholders, with additional funding from the United States President's Emergency Plan for AIDS Relief (PEPFAR). Its goal is to decrease the country's TB burden and to improve the quality of TB services, including detection and treatment of TB and multidrug-resistant and extensively drug-resistant TB. It also aims to provide prevention and treatment support to counter the rapid growth of TB and HIV coinfection. The project began in March 2012 and ended in April 2017. It built on more than 10 years of USAID's TB assistance in 10 priority geographic areas.

Research Approach

This qualitative research addresses the following questions:

1. What aspects of outpatient TB treatment make adherence particularly difficult for clients in at-risk groups?
2. What aspects of the social support program are most important to those receiving program services, and what works best for ensuring adherence?

We conducted 36 in-depth interviews with three stakeholder groups: 21 clients, 11 providers, and four program coordinators. All interviews were digitally recorded, transcribed, and translated by a professional transcription service. The transcribed files were imported into a software program (ATLAS.ti, version 7.5.17) to analyze the qualitative data, including the identification of themes and subthemes.

Study Findings

Aspects of Outpatient TB Treatment that Made Adherence Difficult for Patients

Several themes emerged from the **interviews with clients** on aspects of outpatient TB treatment that made adherence particularly difficult for them prior to joining the social support program:

- Weakness and side effects from medicine
- Length of time required daily to receive outpatient treatment at a health facility (HF)
- HF hours of operation
- Fear of getting re-infected with another TB strain at an HF



- Transportation expenses
- Stigma
- Lack of motivation to get treated

The social support program later addressed most of these barriers by bringing TB medication to client homes. Although

Before, I had to go from home to hospital, wait in line, look for a place to sit if I get nauseous. This way, I take the pills. If I feel dizzy, I go home and lie down for an hour. Then I get up, do whatever I need to—I can go sit on a bench next to my apartment and rest. [Client]

medicine side effects remained one of the biggest challenges for clients, respondents reported that participation in the home visit program made handling some of the side effects easier.

Other challenges to treatment adherence **reported by providers and clients** were alcohol abuse; length of the treatment regimen; clients feeling better during the course of treatment and thinking they could stop; denial of having TB; depression; and loss of hope.

We noted that stigma related to having TB was a cross-cutting

theme discussed by respondents in all categories. In addition to being one of the barriers to treatment adherence, stigma negatively influenced clients' quality of life and their well-being.

Most Important Aspects of the Social Support Program

The two most important aspects of the social support program **mentioned by clients** were the convenience of having TB medication delivered daily and the support provided by URCS nurses. Themes describing the convenience for clients were:

- Time, effort, and money saved
- Help dealing with side effects
- Minimized number of visits to the HF
- Flexibility in the time of day and place for meetings with nurses
- The opportunity to have uninterrupted treatment

Clients likewise appreciated that the nurses provided

She [nurse] cheers me up. Sometimes, I wake up in a bad mood for the entire day. When I meet her, she starts asking questions about my health, and cheers me up. And I realize that not everything is that bad and someone cares about me. This is the most important thing. [Client]

emotional, informational, and motivational support and tangible assistance. It was important to clients that the nurses cared about their well-being and treated them as equals and that clients received individual attention. Clients mentioned the importance of understanding the consequences of not getting treated and the benefits of staying free of MDR-TB. Clients also expressed their appreciation for the social support program's efforts to treat them and thereby reduce the TB epidemic in Ukraine.

Relationship of Clients and Nurses and Nurses' Qualities

Clients described the program as successful, attributing this to the dedication and efforts of the nurses. Both clients and nurses described their relationships as open and based on trust and mutual respect. Many clients considered a nurse to be a close friend or like a family member whom they could trust.

- Clients described the nurses as sincere, approachable, responsible, flexible in scheduling, open to communication, being “positive,” and having good energy.
- Other qualities described were excellent interpersonal communication skills; caring about clients and wanting to help them; gaining clients' trust and building rapport; using individual approaches to clients; building clients' self-esteem; and treating them as equals.

If the program is replicated or scaled up in the country, this close relationship between clients and nurses—along with the nurses' skills, qualities, and characteristics—will need to be in place.

From time to time, I buy bread and milk for some of my patients. Simply, I see the living conditions in which they live and try to help them in any way I can. They try to earn money wherever there is an opportunity... Sometimes I simply bring them a bottle of jam. I do not give them money, because they can spend it on something else. In contrast, whenever I bring them food, I know that they will eat it and no longer be hungry. [Nurse]

Facilitators of and Challenges to Providing the Social Support Program

Nurses discussed several factors that facilitated their work:

- Participation in TB trainings
- High-quality supportive supervision
- Their own passion for fighting the TB epidemic
- Support from other nurses working on home visits
- Good working relationships and ongoing collaboration with HF staff and TB services
- Support from clients' family members and close relatives
- Simplicity of reporting forms
- Proximity to clients' homes
- Previous experience working for the URCS

The nurses did not report many work-related challenges. Among those mentioned were working with clients who abuse alcohol, absence of food incentives for low-income and unemployed clients, and inability to detach from the clients' problems. Findings from the interviews with **program coordinators** confirmed the information provided by nurses.

Key Findings and Recommendations

Key findings and recommendations for USAID/Ukraine are:

1. The social support program's outpatient treatment strategy addressed most of the treatment adherence barriers that clients faced. Participation in the social support program allowed clients to avoid travel to clinics, which addressed logistical barriers associated with travel time and costs, wait time at HFs, and stigma and fear of further infection. The program nurses also supported clients to handle the side effects of the medicine as well as depression.
2. Clients appreciated and valued the social support program and felt that it helped them to stay in treatment. Clients reported that they were often isolated from society and felt lonely; it was therefore important to have someone in their lives who cared about them. In future, staff in any program such as this one should be trained in ways to gain client trust and build close client relationships and should have similar skills and qualities as the nurses working for this URCS social support program.
3. To improve this type of program, we recommend providing food parcels or food certificates to low-income and unemployed clients to support their

treatment. We also recommend providing counseling for nurses to address any work-related challenges to ensure their own well-being. Future programs need to address TB-related stigma in society.

The full evaluation report on the STbCU Project impact evaluation will be available at www.measureevaluation.org

References

Acosta, C.D., Kaluski, D.N., & Dara, M. (2014). Conflict and drug-resistant tuberculosis in Ukraine. *The Lancet*, 384(9953), pp.1500–1501. Retrieved from <http://linkinghub.elsevier.com/retrieve/pii/S0140673614619140>

PATH. (n.d.). Ukraine TB and TB/HIV projects. Retrieved from http://www.path.org/publications/files/HIV-AIDS_Ukraine_tb_fs.pdf

Ukraine Center for Disease Control. (2014). Ukraine national tuberculosis statistics. [Online]. Retrieved from <http://ucdc.gov.ua/pages/diseases/tuberculosis/surveillance/statistical-information>