

Attitudes Toward Tuberculosis Services Among People Living With HIV and AIDS (PLHA) in Ukraine

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Background

Since 2003, PATH has been implementing a USAID-funded project entitled, “TB Control Partnership in Ukraine,” which aims to roll out DOTS to regions within Ukraine with the highest tuberculosis (TB) and HIV burdens. Both TB incidence and mortality have risen sharply in Ukraine in the last ten years. The increase in mortality rates is likely due to late detection and multidrug resistance, and the burgeoning HIV epidemic will likely drive TB incidence upwards in the coming years. The latest data show that 10 to 15 percent of TB patients are HIV-infected and about 30% of PLHA may have active TB, while more than half of AIDS-related deaths are attributable to TB”. Available data suggests that PLHA delay seeking care until the TB disease is advanced.



Methods

This study was a part of wider research conducted at the project's initial stage to gather baseline data on knowledge, attitudes, and practices regarding TB among both the general population as well as specific populations particularly vulnerable to TB infection in the two project locations. This report focuses on two sets of data gathered as part of the wider effort:

- Exit interviews with 312 TB patients who may or may not be HIV-positive at 11 facilities (9 in Donetsk and 2 in Kyiv City).
- Five focus group discussions (FGD) with PLHA (3 in Kyiv City, 1 in Mariupol, and 1 in Makiyivka).



Results of FGDs

Awareness about TB and perceived risk of getting infected were low among all FGD participants. Many participants were not fully aware of the risk of airborne transmission of TB. Typically, only individuals who had learned about TB from personal experience or from infected friends or family members articulated a more accurate perception of risk.

Stereotypes and misconceptions about TB prevent HIV-positive persons from suspecting that they may have TB, thus resulting in delays in seeking effective diagnosis and care. Some of the stated beliefs that prevent people from seeking timely care included the following:

- TB treatment is expensive.
- It is not unusual for people with HIV to be more susceptible to fever, persistent cough, and fatigue, so it is not worth going to the doctor every time.
- Antiretroviral therapy provokes activation of TB bacteria.
- X-rays can cause serious damage to one's health.
- TB doctors do not know enough about HIV to treat co-infected people correctly.

“They do not know which course AIDS takes when accompanied by TB. In the x-ray, it may look like plain bronchitis or lung inflammation. If the doctor is competent and knowledgeable about HIV, he will see that it is surely TB. But an ordinary phthisiotherapist will say, ‘It is just lung inflammation.’ I encountered such situations on three occasions.”

The FGD data suggest that most HIV-positive persons tend to avoid going to medical institutions for as long as possible. They frequently practice self-treatment, use folk medicine, or are unable to see the type of specialist that they want. Many turn to the recommendations of friends who also have HIV.

“I have had a persistent cough for a long time, but I do not go—I do not go to the hospital because that would be a headache.”

“I personally go there once every half a year—or undergo analyses—visit specialists, so as to know where I stand. And when I have fallen ill or gotten a sore throat, I just go to the pharmacy, buy all the [necessary] medications and undertake self-treatment. It's because going to the hospital is unrealistic; the doctors won't understand us.”

Some of the main factors underlying PLHA's attitudes towards medical institutions include:

- Stigmatization of PLHA on the part of medical staff. According to participants, stigma is exhibited through demand for payment at “increased” rates for professional advice, diagnostics, and treatment of any disease; insistence on purchasing specific, expensive medications directly from the doctor; refusal to provide medical care; and indifferent or insulting attitudes. Some doctors have conveyed their feeling that treating people with HIV is a waste of time and money.
- Little or no confidence in the qualifications of medical staff, particularly in their ability to treat opportunistic infections in PLHA.

“You go to one doctor and you listen to him; then you go to a different doctor... I do so myself because I don't trust them. And when there are two or three results, I make a generalization on my own and decide what to do.”

- Apprehension that doctors might not respect the confidentiality of PLHA.

“The mother of my classmate is our cardiologist; if I come there, the whole district where I live will know about it. Everything stops there; it's better not to go.”

- Shortage of money. Most participants were not aware that TB diagnosis and treatment are free, or they doubted that this could be true.
- The decline of medical institutions overall and of TB dispensaries in particular. FGD participants vividly described awful conditions and obsolete, depreciated equipment at hospitals and TB dispensaries, as well as a lack of elementary medications and materials.

Exit interview results

The medical education system in Ukraine does not teach a model of client-provider communication that includes psychological support and counseling. Consequently, most doctors have no counseling or communication skills training. Research results showed that many of them are not familiar with a service approach that includes counseling the patient and often their interpersonal communication skills are inadequate.

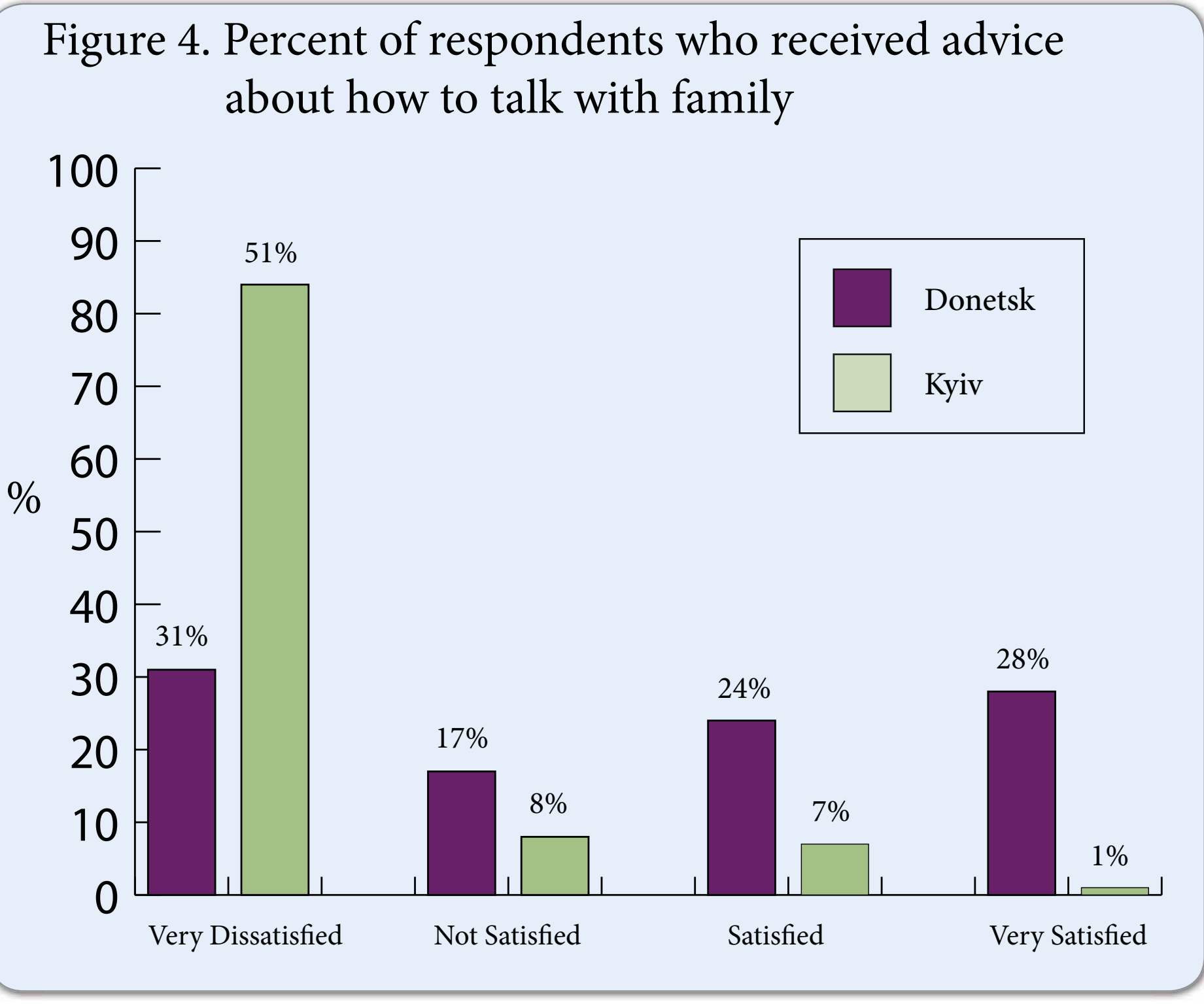
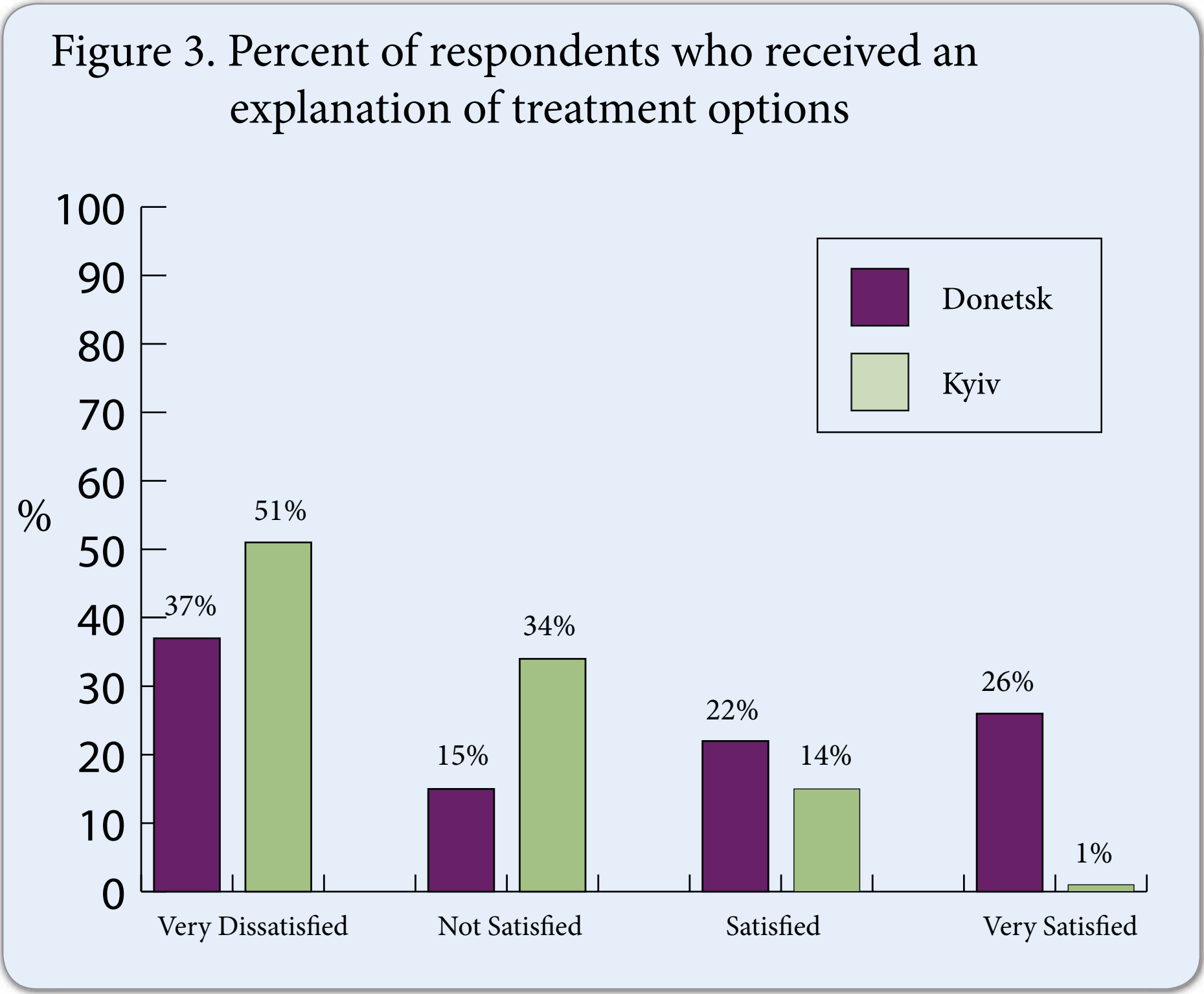
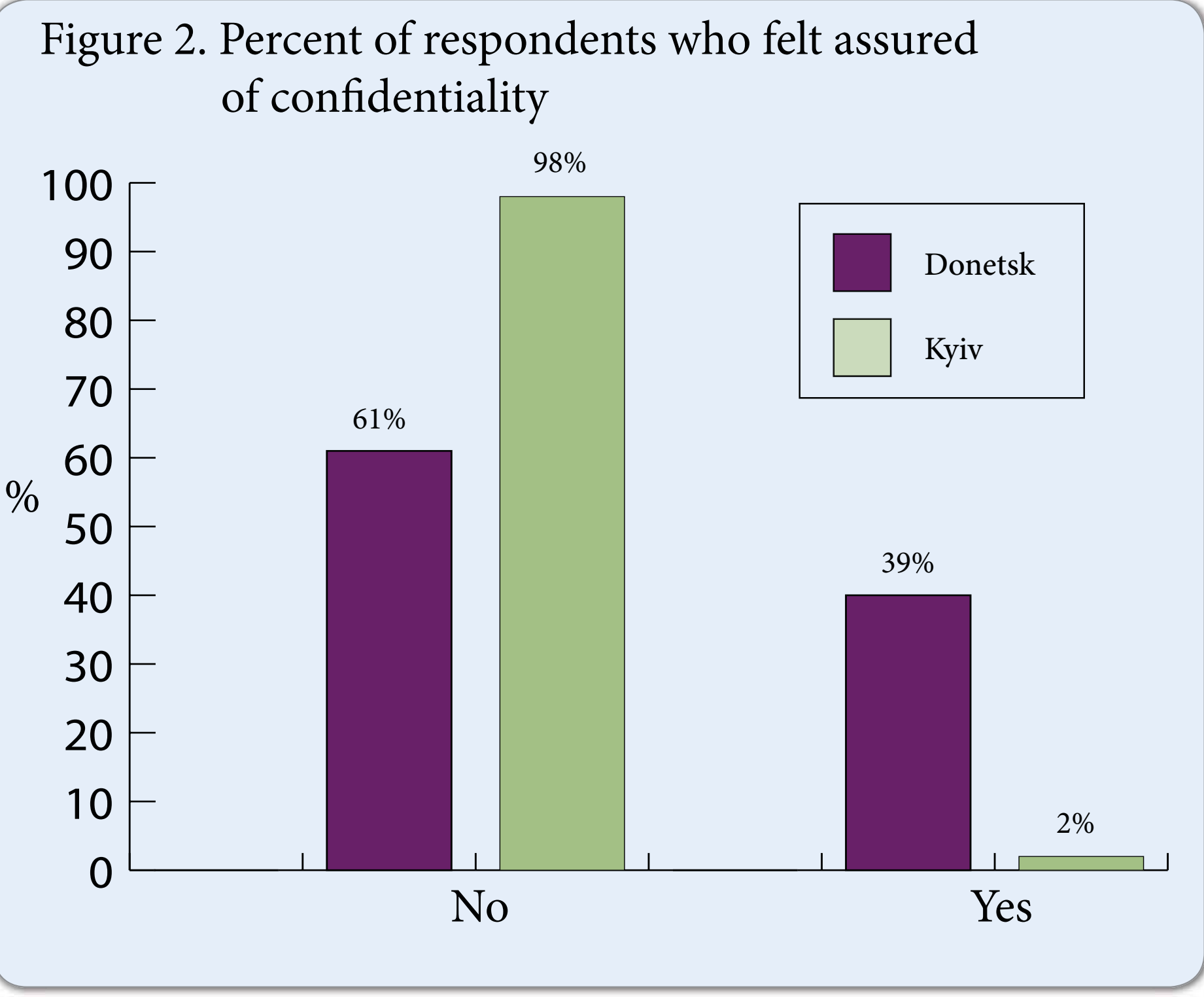
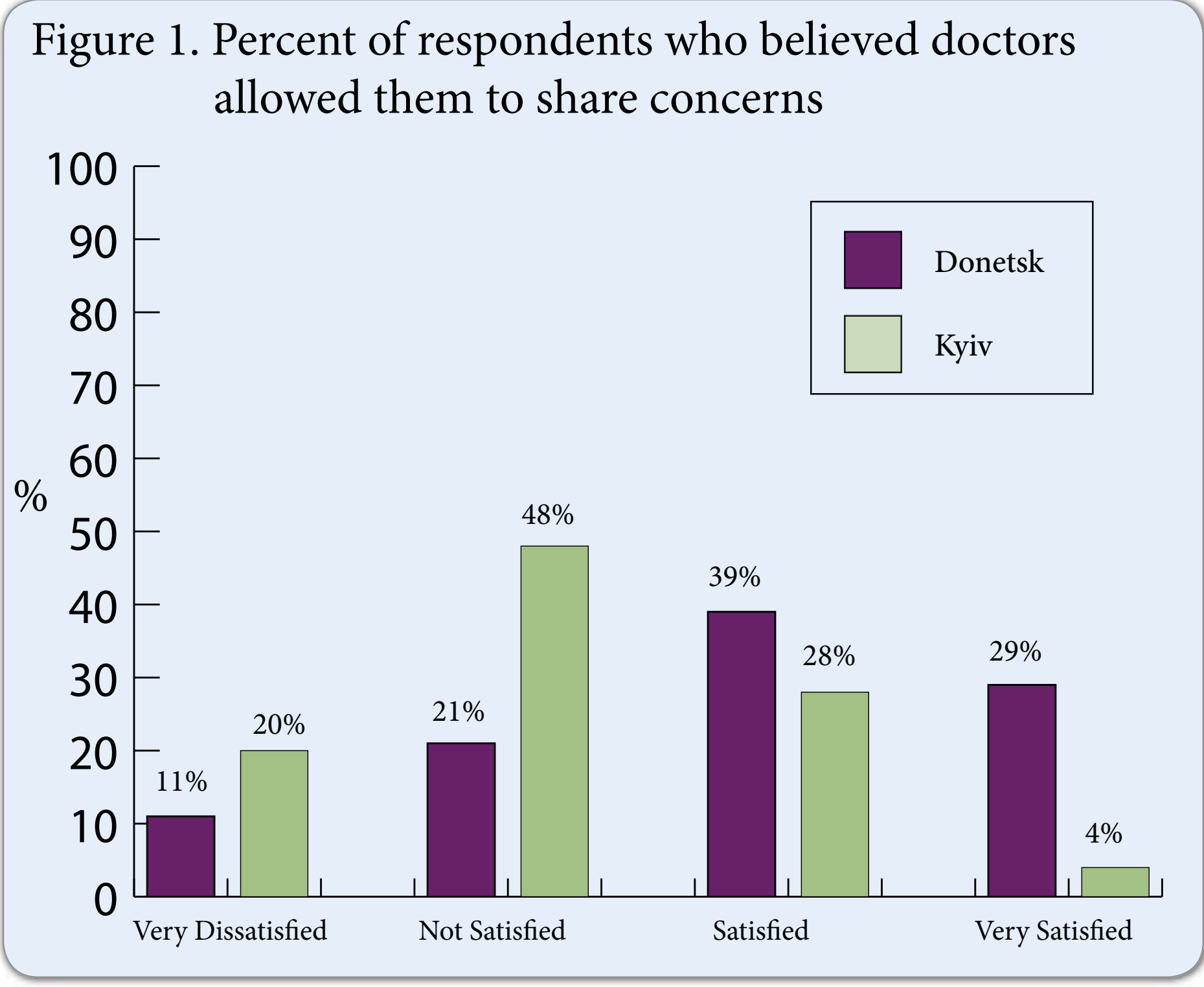
For each question, the survey participants were given the choice of the following four possible answers: 4 very satisfied, 3 satisfied, 2 not satisfied, and 1 very dissatisfied.

When asked to evaluate the doctor's ability or willingness to allow sharing patients' concerns and questions about their overall health, 34% of the respondents said they were satisfied, whereas 34% said they were not satisfied (Figure 1).

Seventy-nine percent of the respondents said they were not verbally assured of confidentiality, including 61% of respondents in Donetsk and 98% of respondents in Kyiv (Figure 2).

Overall, the majority of respondents were very dissatisfied (43%) or not satisfied (24%) with their providers' ability or willingness to explain the treatment options available to them (Figure 3).

Also, the majority of respondents (57%) stated they were very dissatisfied with their doctor's ability or willingness to provide them with advice about how to talk with their families about TB (Figure 4).



Conclusions

Our results suggest that delays in seeking care and failure to follow medical advice may be due to perceived declines in Ukraine's public health service, insufficient qualifications of medical personnel, and the high level of stigmatization of PLHA by medical personnel. People

with HIV also do not seem sufficiently aware of their heightened personal risk of contracting TB because of their HIV status, the symptoms of the disease, the possibility of free diagnosis and treatment, and their legal rights as patients.

The results of this research indicate that TB educational campaigns as well as improved clinical services are

urgently needed. Simultaneously, the training of medical personnel in general health facilities and TB institutions in counseling skills, including voluntary counseling and testing (VCT), is essential. More emphasis on VCT is needed so that providers recognize that counseling is an essential part of good care.