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RESEARCH AND EVALUATION REPORT

Accessibility of Antiretroviral Therapy in St. Petersburg and Orenburg City, Russia

DECEMBER 2008

This report was prepared by University Research Co., LLC (URC) and Stellit of St. Petersburg, Russia, for review by the United States Agency for International Development (USAID). It was authored by M.M. Rusakova, I.N. Gurvich, A.A. Yakovleva, E.M. Vinogradova, V.A. Odinokova, K.Y. Eritsyan, A.F. Makhamatova, M.A. Sidorenko, and N.M. Marudova. The data collection for this research was carried out under the USAID-funded Quality Assurance Project; the report was produced by the Health Care Improvement Project, which is made possible by the support of the American people through USAID.

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ABBREVIATIONS

AIDS	Acquired immunodeficiency syndrome
ART	Antiretroviral therapy
ARV	Antiretroviral
CSW	Commercial sex worker
HCI	Health Care Improvement Project
HIV	Human immunodeficiency virus
IDU	Injection drug user
MPTF	Medical and preventive treatment facility
NGO	Non-governmental organization
PLWHA	People living with HIV/AIDS
QAP	Quality Assurance Project
RAS	Rathus Assertiveness Schedule
URC	University Research Co., LLC
USAID	United States Agency for International Development

EXECUTIVE SUMMARY

The Russian health care system seeks to provide ART to all patients who need it, and antiretrovirals have recently become sufficiently available to do so, but uptake is low. The Quality Assurance Project (QAP) contracted with the Russian non-governmental organization Stellit to identify and measure the factors preventing people with HIV/AIDS (PLWHA) from seeking, accepting, and adhering to antiretroviral therapy (ART). This report presents findings, based on focus groups of PLWHA and interviews with experts, explaining the low uptake among "hidden" groups: injection drug users, commercial sex workers, and others with HIV/AIDS.

Study subjects, none then on ART, resided in St. Petersburg and Orenburg City, where both Stellit and QAP were seeking to improve the quality of care for PLWHA and where the incidence and prevalence rates for HIV/AIDS are high. The study examined ART refusal from several angles: demographic, reasons for refusing ART, psychological determinants, attitudes of the closest member of the person's social environment, etc. Appreciable differences were found between the two cities.

Regression analysis enabled study managers to assess the level of influence of various factors on refusal to seek or adhere to ART and on a range of other behavior indicators of HIV-positive patients regarding ART. The factors were clustered and analyzed as eight categories: social group, drug abuse, alcohol abuse, individual experience, microsocial factors, macrosocial factors, personal psychology, and cognitive behavior. In addition to clarifying understanding of the underlying causes of ART refusal, this approach also facilitated the development of recommendations specific to each city.

Drug abuse was associated with the refusal to seek ART in both cities, probably because accepting ART would require drug cessation; it had slightly less influence on the desire to start ART if deemed necessary. Alcohol abuse was the second most important factor negatively influencing ART adherence, especially in St. Petersburg. The third most influential factor was individual experience in seeking medical care: In this case, ART was often refused due to severe treatment intolerance (manifested as pain) and lack of belief in ART's efficacy. Satisfaction with care in non-specialized facilities notably impacted ART adherence in St. Petersburg. Focus group results showed that at initial disease stages, the most important consideration for PLWHA was not health care system features but rather personal contact with a doctor, trusting the doctor, and absence of signs of negative attitude from medical personnel. Positive experience led to more frequent medical facility visits and higher treatment adherence. Among microsocial factors, non-adherence was strongly associated in Orenburg with beliefs held by HIV-positive friends that HIV infection does not exist, while other attitudes of HIV-positive friends were more influential in St. Petersburg. Among macrosocial factors, the influence of mass media on refusal to seek ART was significant only in St. Petersburg. In Orenburg, trust in media information positively influenced a desire to start ART if deemed necessary. Personal psychological variables and cognitive behavior determination factors were examined but found to be the least influential.

The study's recommendations are organized by target groups: 1) the general population, 2) the medical and social care system for PLWHA, 3) those socially closest to PLWHA, and 4) individual PLWHA. With differences between the cities and among the targets, the study urges that mass media campaigns address appreciable misunderstandings in the PLWHA population relative to HIV/AIDS and ART. Widespread beliefs were found indicating denial of the existence of HIV, credence that disease is punishment by God, failure to believe that ART is effective, and unwillingness to abandon drug and alcohol abuse to become eligible for ART. Recommendations for the medical and social care system call for interventions to reduce HIV-related stigma among ART providers, improve interpersonal communication between providers and PLWHA, and achieve better coordination between government and non-government providers. The study urges health care providers to work with PLWHA self-assistance groups and with families of HIV-infected persons through family psychotherapy. Finally, the study acknowledges that treatment of drug dependency is a necessary precondition for ART initiation but that this requires improvement in the quality of drug abuse care for persons with HIV/AIDS.

I. INTRODUCTION

This report presents the results of a study conducted by Stellit (Regional Non-governmental Organization for Population Welfare Social Projects), a Russian non-governmental organization (NGO), in 2006–2007 at the initiative of the Quality Assurance Project, then managed by University Research Co., LLC (URC), with funding from the U.S. Agency for International Development (USAID).

St. Petersburg and Orenburg are among Russia's cities with the highest incidence of new HIV cases and the highest HIV prevalence rates in the population. By January 1, 2006, the HIV prevalence rate in St. Petersburg was 625.8 per 100,000 (0.6% of the population) and in Orenburg 1,053 per 100,000 (1.0% of the population). A priority objective of the Russian health care system is to provide antiretroviral therapy (ART) to all HIV-positive patients who need it. The latest generation of antiretrovirals (ARVs) make it possible to prolong the lives of HIV-positive patients and improve health. In 2005–2006, several federal projects (in particular, the GLOBUS Project) set the goal of eliminating the shortage of ARVs by providing a sufficient supply. However, the number of HIV-positive patients receiving appropriate treatment remains extremely low, falling far short of the estimated number of persons requiring ART. As a result, most of the ARVs purchased via these projects are unclaimed.

This study's objective was to discover the barriers preventing HIV-positive persons from accessing specialized medical care, specifically ART, and to develop recommendations to increase ART availability and treatment adherence in HIV-positive "hidden" patient groups: injection drug users (IDUs), commercial sex workers (CSWs), people living with HIV/AIDS (PLWHA), and PLWHA in self-registration groups. The study conducted structured interviews with 551 members of these groups in St. Petersburg and Orenburg City. It also conducted structured interviews with focus groups of either PLWHA (26), subject experts (32), or individual project coordinators and heads of organizations. The study also reviewed literature on ART adherence issues, including evidence-based and theoretical studies, from Russian and foreign scientific sources.

The study results are intended for specialists at the Regional Center on Prevention and Fighting AIDS and Associated Infectious Diseases of St. Petersburg and Orenburg, for non-governmental organizations planning and implementing programs to prevent HIV and increase availability of ART, for the Department for Surveillance over HIV Infection (of Rospotrebnadzor), as well as international organizations working in public health in the Russian Federation.

II. PROBLEM OF ACCESSIBILITY OF ANTIRETROVIRAL THERAPY

The availability of treatment for HIV-infected patients has attracted significant attention of foreign investigators but has been less studied by the Russian scientific community. Most important at this stage of Russia's HIV epidemic is the process by which HIV-infected persons seek specialized medical care, including starting on ART care. Also important is why patients discontinue ART and later want to renew it. Global research has addressed how to achieve high levels of ART adherence by patients already enrolled in ART, but not issues related to seeking care in the first place. Good adherence is achieved by high coverage of those requiring medical and social care and fully available medicines.

A literature review identified the following factors influencing ART adherence among HIV-positive patients:

- Youth and higher education are associated with better adherence.
- Living with other people or the presence of extended family lowers adherence.

- Depression is the most widespread impairment to adherence: Multiple studies demonstrate a direct link between depression in patients and unsatisfactory HIV treatment outcomes.
- "Self-effectiveness," that is, a feeling control over the success of one's own actions or a belief that one's actions will generate desirable results, significantly influences ART adherence. This characteristic increases a patient's motivation to take ARVs, thus increasing adherence.
- A belief that ARVs have unpleasant side effects is a main reason for refusing ART. Many patients believe that complications caused by ARVs can outweigh the therapeutic benefits. A person is more adherent to the treatment if he/she is sure that despite side effects, compliance can prevent the occurrence of negative outcomes for his/her health.
- Social support can also influence adherence. Persons close to patients on ART can increase adherence by direct support: by improving the patient's self-effectiveness and by lowering stress and depression. Attending physicians can be among the most important sources of social support. Patient adherence increases when the doctor provides clear explanations, informs the patient in detail about potential side effects, and provides motivational and emotional support. Higher adherence has been observed in clinical settings when doctors spend more time counseling and helping patients adapt treatment regimens to their lifestyles.
- Multiple studies demonstrate that drug abuse is one of the most important factors inhibiting ART adherence. Viral suppression rate in IDUs is considerably lower than in patients who stopped using drugs or never used them. Complicated regimens for taking ARVs require changes in IDU lifestyle, such as eliminating drug use and improving nutrition, and failure to make such changes results in lower adherence. Another factor that decreases the adherence of IDUs is social stress and discrimination, which lower the probability of qualifying for medical care. IDUs' unstable social situations also contribute to lower adherence.

Our literature review showed that several different cognitive, emotional, and behavioral strategies can be effective in improving adherence. Psychotherapeutic strategies can optimize social and emotional support. One effective psychotherapeutic method is motivational interviewing, a client-oriented approach that increases internal motivation to change and reduces ambivalence. Behavioral strategies can reinforce key practices, such as systems reminding patients to take drugs on time or to seek more frequent testing for viral load. However, educational programs that are unsupported by other types of interventions show poor effectiveness. High educational level has a positive influence on outcome; its effect is unstable in cases with only a single intervention.

Experience indicates that a combined program of methadone-replacement therapy and needle exchange among drug users is effective in increasing ART adherence. Self-assistance groups are considered to be one of the most effective methods for decreasing risky behavior and for forming positive attitudes about one's health among injection drug users on ART. Russian publications state that the most effective approach to manage ART patients who are drug users is to develop systemic, multilevel mechanisms that stabilize and normalize all aspects of a person's life: health (both physical and psychic), social (employment, social insurance), and personal relationships (forming partner and family relations).

We reviewed 110 publications (six of them Russian) issued as monographs or international journal articles published during 1996–2007 that focused on HIV/AIDS and related issues (including *AIDS, AIDS Behavior, AIDS Care, AIDS Patient Care and STDs, American Journal of Addiction, Clinical Infectious Diseases, HIV Clinical Trials, HIV Medicine Journal of the Association of Nurses in AIDS Care, AIDS Journal, Journal of the American Medical Association, Journal of Acquired Immune Deficiency Syndromes,* etc.). This study included all the factors that foreign researchers identified as influences on treatment adherence.

III. METHODOLOGY

A. Study Population

When a person first learns that he/she is HIV positive, he/she will psychologically accept or reject this information based on his/her experiences. Psychological acceptance of the diagnosis and subsequent behavior are largely determined by personal psychological protection mechanisms. In the case of dominant, "repressive" mechanisms, the person will reject the diagnosis. If "creative" mechanisms dominate, the person will become actively involved in social activities in informal organizations (for instance, communities of people living with HIV/AIDS). If "reaction" mechanisms dominate, the person will develop multiple neurotic signs, in particular, excessive attention to one's own health, or "hypochondria."

Thus, HIV-positive persons can be distinguished from the viewpoint of their behavior as potential patients as:

- "Hidden" or at-risk groups within the main population; these group members go almost unnoticed by specialized medical facilities;
- "Activists," who fight for their rights, including the right to high quality medical services, in particular, ART; and
- "Hypochondriacs," who care for their own health, taking various medications and visiting medical facilities.

This study focused on the "hidden" group of HIV-positive persons since they are not receiving but are potential recipients of specialized medical-social services that increase ART availability and adherence. The last two types often receive specialized medical services, including ART, and therefore are not addressed in this study. The study population was defined as males and females aged 14 to 49 who had been diagnosed as having HIV but were not taking any ARVs at the time of the study.

B. Sampling and Data Collection

The main study sample was formed from PLWHA in "hidden" groups: IDUs, CSWs, PLWHA being treated in hospitals, and PLWHA from self-assistance groups. Subsamples were determined during data collection.

The IDU subsample included males and females aged 14 to 49 who had experience with injection drug use. The presence or absence of drug use at the time of the study was not considered since it did not represent any determinative values for the objectives of the study. Respondents for this subsample were selected through social networks of drug users by the "snowball" method. After preliminary coordination with an interviewer and mobile and stationary sites set up for the study, interviewing was conducted in places where IDUs gather.

The CSW subsample included males and females aged 14 to 49 with experience in selling sexual services, particularly on city streets. Actual participation in selling of sexual services at the time of the study was not considered for the same reason noted above. As with the IDU subsample, selection of respondents was conducted through social networks (the snowball method).

The PLWHA in-hospital subsample included males and females aged 14 to 49 with HIV-positive status being treated in specialized city hospitals (AIDS Center branches or infectious disease hospitals).

The self-assistance PLWHA subsample included males and females aged 18 to 49 who visit self-assistance groups for persons with HIV. Samples were formed using the "snowball" method, and persons representing the PLWHA community were actively involved in information distribution.

Qualitative data were collected through individual interviews and focus groups. In St. Petersburg, two focus groups were conducted with HIV-positive persons who had been recruited based on information from 1) Department 20 of the S.P. Botkin City Infectious Disease Hospital #30 and 2) a support group for HIV-positive persons: Nadezhda (Hope), which is connected to the Salvation Army. In Orenburg, one focus group was conducted with HIV-positive persons who had been recruited based on information from the Positive Initiative.

Individual interviews were held with experts familiar with focus group participants. In St. Petersburg, the experts included heads of organizations and project coordinators from the organizations that provided information on and access to the focus group participants, as well as medical and social workers involved with those participants. In Orenburg, the experts included staff of the main therapeutic and preventive facilities directly or indirectly providing medical care to people with HIV. Table 1 gives the number of study participants in St. Petersburg and Orenburg by category.

The interviewers received training on the interview process and its possible issues. All study interviewers had previous experience in behavioral studies. In St. Petersburg, the focus group work was organized by a specialist in psychology experienced in working with risk groups.

Table 1. Number of persons in various categories by city

Location	HIV-positive persons	HIV-positive focus group participants	Experts interviewed
St. Petersburg	266	14	22
Orenburg	285	12	10
TOTAL	551	26	32

C. Tools

Stellit developed a questionnaire, "ART Accessibility for PLWHA," specifically for the study. It has sections on: awareness of and opinions on HIV infection (five questions); awareness of ART (12 questions); experience with ART (seven questions); opinions on ART held by "people in the closest social environment"[1] (seven questions); use of mass media sources (nine questions); attitude toward health and medical care (15 questions); personal and psychological features (six tests to be completed without assistance); sexual behavior and marital status (10 questions); addictive behavior (19 questions); help and support (four questions); and social and demographic data (four questions).

For the qualitative part of the study, Stellit developed an interview guide to obtain expert opinions and a focus group scenario to solicit and record opinions of the focus group participants.

D. Mathematical and Statistical Data Processing

The study's mathematical and statistical data processing and data analysis consisted of two stages. The first stage included calculating prime distributions, expressed as percentage, mean, or median values; standard deviations; and semi-interquartile range. The data are presented in distributions with value assessment between the cities by Kramer's V criterion (for indicators measured on nominal scales) and by Student's t-criterion (for indicators measured on ordinal scales).

The second stage involved a multivariate analysis using multiple step-wise regression analysis (binary logistic regression). This method of multiple statistical analyses is designed to study interactions of one

[1] "People in the closest social environment" refers to those who have the closest and most influential relationship with the study participant. These people may be family members, friends, and/or associates in a similar situation.

variable (dependent) and several others (independent). Regression analysis is often used to forecast results using several preliminary measured parameters. In this study, this technique enabled us to assess the value and intensity of influence of various factors on refusal to seek ART and on a range of other behavior indicators of HIV-positive patients regarding ART.

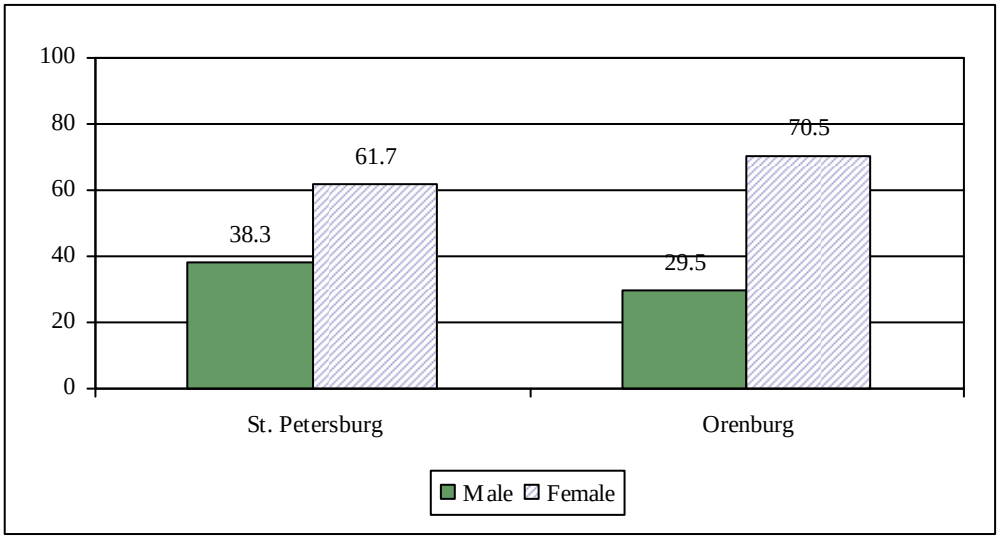
Qualitative data were processed as follows: To analyze expert interview results, the expert answers were coded and presented in tables where columns correspond to items of the interview guide and rows to the opinions of each expert. Next, answers to interview questions were categorized. To analyze the focus group results, the records of the focus groups were coded, analyzed, and generalized. Analysis of results obtained by qualitative methods exhibited high correspondence with the results of interviewing HIV-positive persons using the questionnaire. Along with that, the qualitative data enabled us to find some important details that supplemented the quantitative analysis results and facilitated better understanding of the quantitative results.

IV. RESULTS

A. Social and Demographic Features

The study sample of HIV-positive persons contained many more females than males, with the preponderance of females being more evident in the Orenburg subsample than in St. Petersburg's (Figure 1).

Figure 1. Gender distribution of interviewed persons, percentages



With regard to age, participants 25–29 years old were the largest group of respondents in St. Petersburg, followed by those 20–24 years old; the reverse was true in Orenburg. St. Petersburg respondents were slightly older than those in Orenburg (Figure 2).

With regard to education, those who had completed high school or a vocational or specialized school predominated in both cities. In St. Petersburg a higher percentage than in Orenburg had completed only elementary school or less (18.1% versus 13.3%), and a higher percentage had completed higher education (22.2% versus 17.2%); in Orenburg a higher percentage had completed secondary education (41.4% versus 39.8%) (Figure 3).

Figure 2. Age distribution of respondents, percentages

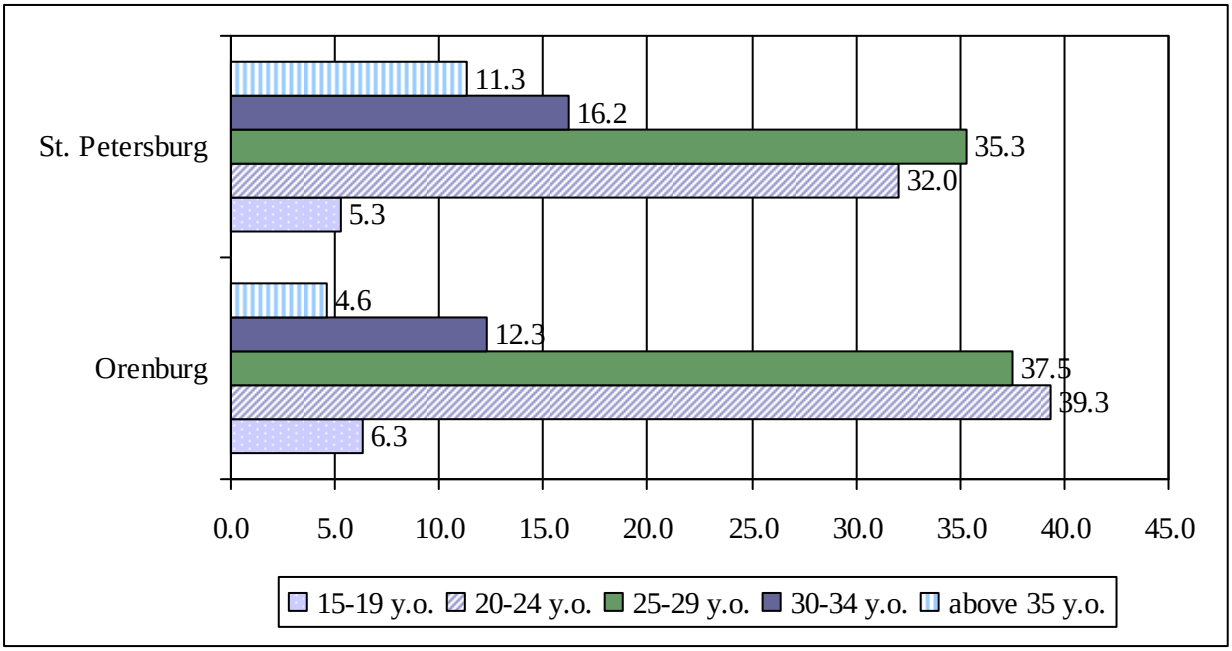
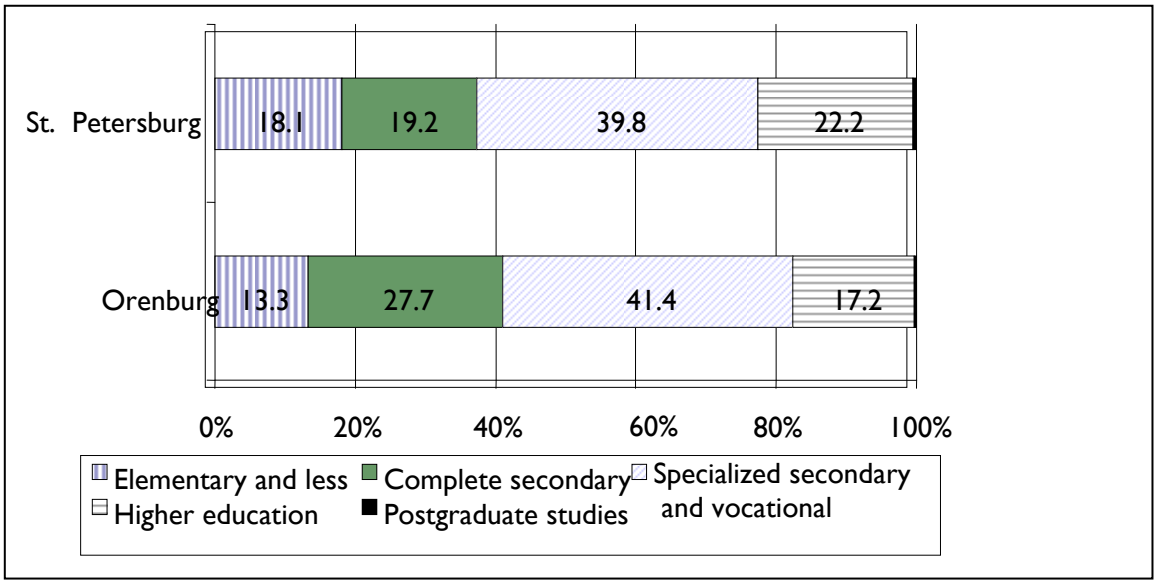
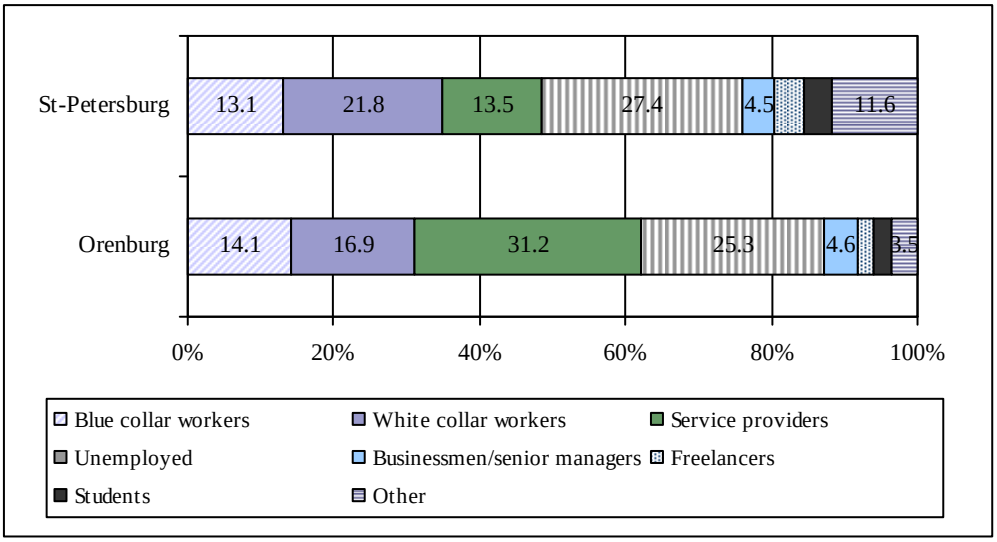


Figure 3. Educational attainment of respondents, percentages



With regard to social groups, the most frequent in the sample were unemployed or service providers. The sharpest difference between the cities was the percentage of service providers, with Orenburg (31.2%) having double that of St. Petersburg (13.5%) (Figure 4).

Figure 4. Social groups, percentages



B. Focus Group Participants' Behavior Relative to ART

The specialized facilities in both cities were attended by slightly more than 20% of the respondents seeking ART care (Figure 5). ART was administered to 72.1% of St. Petersburg's respondents visiting doctor offices and just under half (48.3%) of Orenburg's (Figure 6).

Figure 5. Visiting doctors for ART, percentages

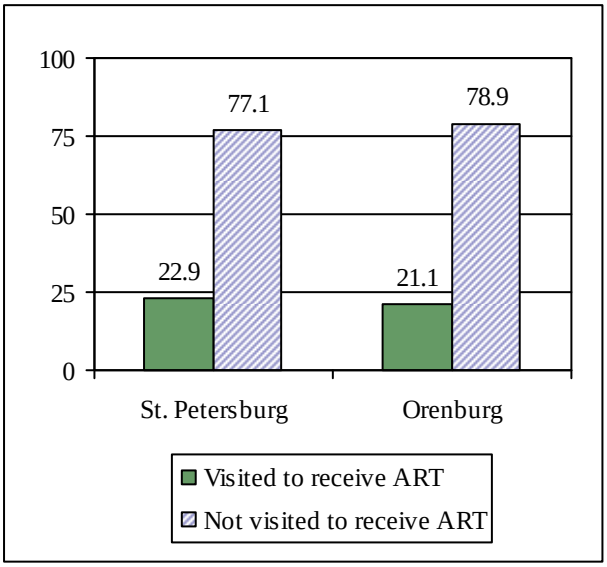
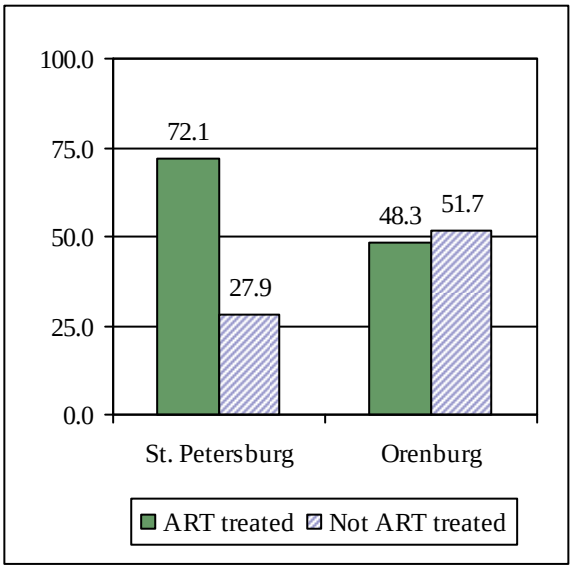
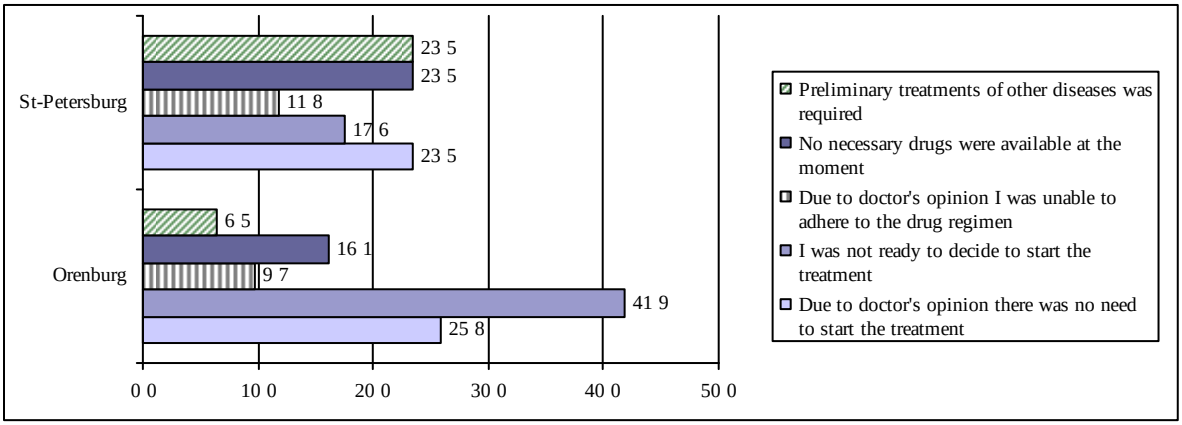


Figure 6. ART administration, percentages



The reasons why ART was not prescribed to those seeking it are statistically significant between the St. Petersburg and Orenburg samples (Figure 7). Orenburg had a higher percentage of PLWHA who were not ready to decide to start taking drugs, while St. Petersburg had a higher percentage that needed treatment for other disorders before starting ART or who needed drugs that were not in stock.

Figure 7. Reasons why ART was not administered to those seeking it, percentages



Note that the sample included only patients not taking ARVs at the time of the interview. Figure 8 shows that in Orenburg most sample members had stopped taking drugs on their own initiative, while in the St. Petersburg sample it was mostly the doctor's decision or stock-outs that caused cessation. The desire to restart ART was considerably higher in St. Petersburg (90.9%) than in Orenburg (72.4%) (Figure 9).

Figure 8. Reasons for ceasing ART, percentages

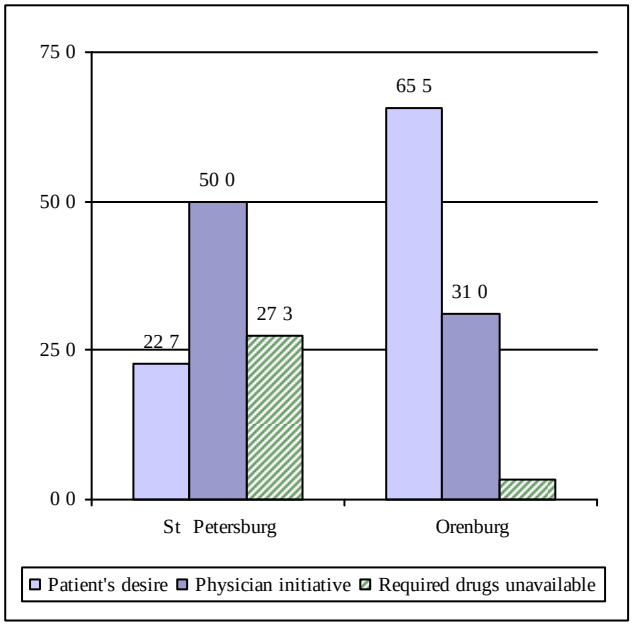
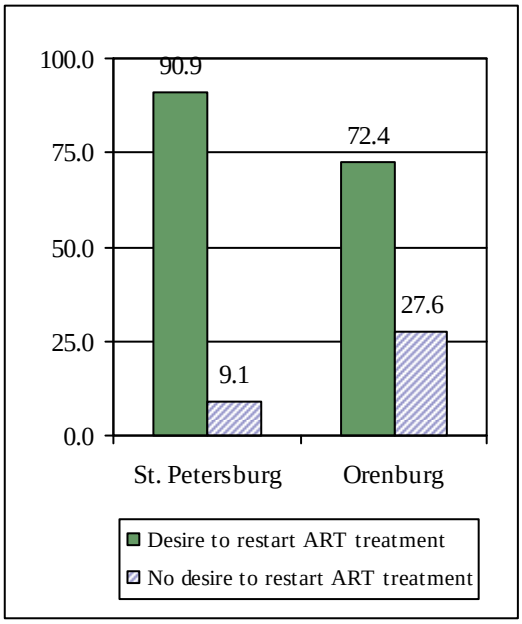


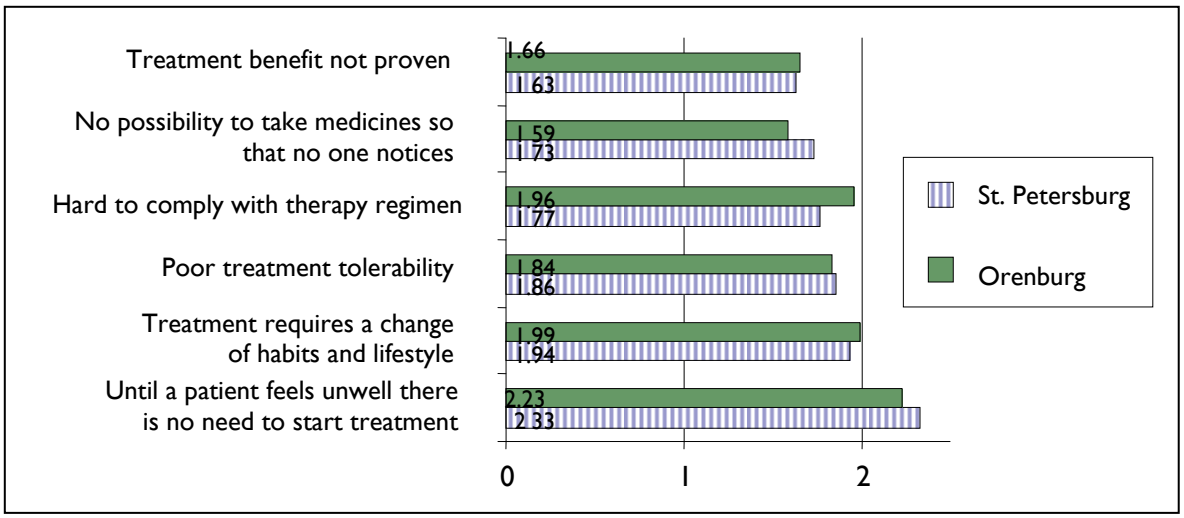
Figure 9. Desire to restart ART, percentages



The main reasons for refusing to seek ART care are in Figure 10. In order of decreasing frequency of appearance, the reasons were: 1) if feeling well, there is no need for treatment; 2) it requires a change of habits and life style; 3) it is hard to tolerate treatment; 4) it is hard to follow regimen requirements for taking pills; 5) it is impossible to take pills such that no one notices; and 6) benefits of therapy have not been proven.

Less frequent were irrational reasons for refusal of treatment, such as "the infection is a punishment for sins," "to get treatment means to resist God's will," and "HIV infection does not exist, it is a fiction of greedy doctors and pharmaceutical companies."

Figure 10. Reasons for refusing to seek ART



Over half the respondents whose doctor had said they needed ART wanted to start (Figure 11). The general attitude toward ART was that it is more positive than negative: more likely to help than not (Figure 12).

Figure 11. Desire to start ART if doctor says it is needed, percentages

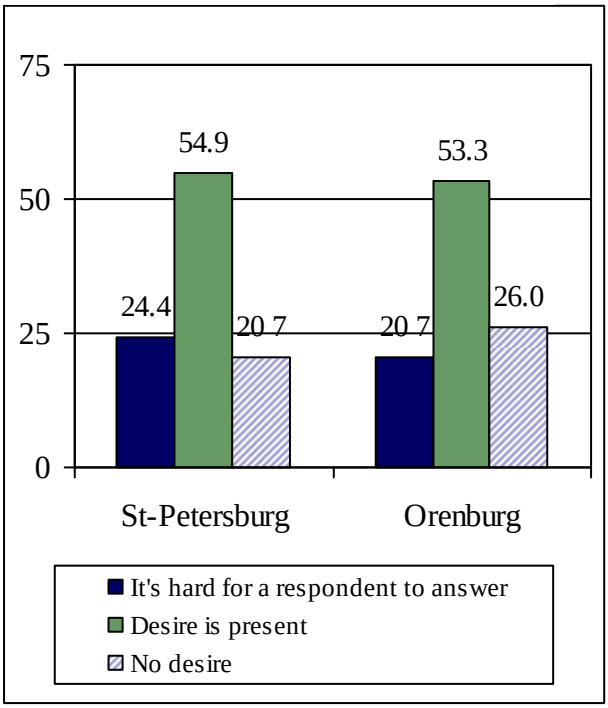
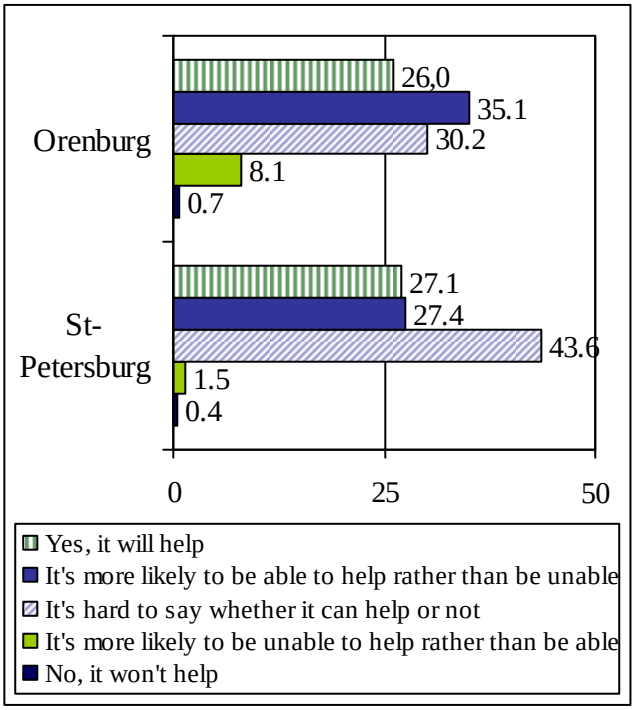


Figure 12. Attitude about whether ART will help, percentages



The study showed that the visit rate for seeking ART was extremely low. Among those visiting, only a small proportion of patients were not administered ART for objective reasons, namely, the absence of indications. In St. Petersburg, ARV stock-outs often caused the non-administration or cessation of treatment. A stock-out could last for a considerable period, even for several visits by a single patient.

Not being ready to decide whether to start taking medicines and cessation of treatment at the patient's initiative were more characteristic of Orenburg patients than St. Petersburg's. Both characteristics could be caused by an inability to recognize and accept diagnosis. A significant role is played here by the younger age and lower education level of the Orenburg respondents: Both are factors that studies show negatively influence ART adherence.

The refusal of HIV-positive patients to come for treatment was associated with their notable negative attitudes toward the treatment process, particularly their ideas on poor treatment tolerance and issues related to regimen adherence. The next most important reason for refusal to visit a doctor to access ART was linked to low familiarity with ART, specifically, a belief that if one feels well, there is no need to start treatment. Belief in the efficacy of ART and readiness to start if necessary occurred in only about half our sample. Similar findings presented in the focus group analysis. The St. Petersburg focus group participants expressed the following doubts and apprehensions related to ART: fear of missing a drug dose, a belief that ART is very harmful, necessity to change lifestyle, and no information on the possibility of taking ART due to a planned pregnancy. These participants also expressed doubts and apprehensions related to experience in specialized facilities: fear of diagnosis disclosure, fear of interruption of ART supply, belief that ARVs are administered to too many of patients without indications, belief that the latest generation drugs that do not have many side effects are not available, and belief that there are not enough ARVs for all in need.

The Orenburg focus group revealed that the main reasons for refusal of treatment were absence of symptoms and fear of side effects. Their main apprehensions in regard to taking ARVs were uncertainty that the ARVs would be available permanently and at no cost.

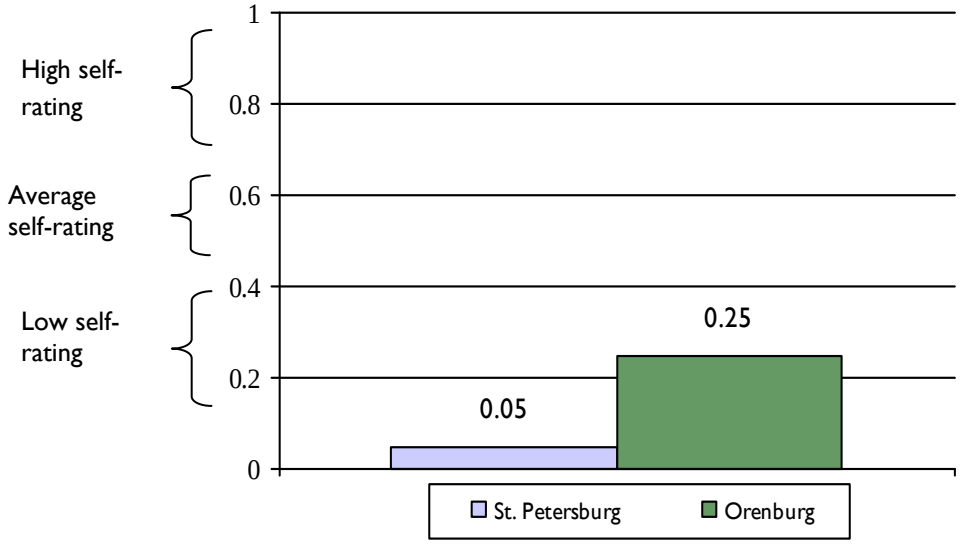
The experts gave different opinions as to why HIV-positive persons refuse ART:

- Objective circumstances related to changes in quality of life and lifestyle: treatment regimen, side effects, frequent contacts with doctors and fear of diagnosis disclosure, and (in St. Petersburg) remote location of medical facilities.
- Experts from both cities agreed that patients' personal characteristics and psychological status, in particular the unimportance to IDUs of maintaining their health and subjective well-being, contributed to ART refusal. St. Petersburg experts mentioned the issue of diagnosis acceptance, and Orenburg experts talked about inadequate mental status caused by intake of psychologically active substances.
- The awareness level among HIV-positive persons of the medical and social care system was also reported as a factor. St. Petersburg experts emphasized a low level of trust of official medicine, fear of interruption of the drug supply, and ignorance of ART availability. Orenburg experts noted distorted and incorrect information in mass media sources.
- Orenburg experts noted doubts about the effectiveness of treatment and correctness of diagnosis as issues for some patients.
- St. Petersburg experts cited low effectiveness of care for HIV-positive persons in general, including ineffective systems of medical and social rehabilitation.
- Orenburg experts noted stigma and discrimination in regard to HIV-positive persons as factors causing ART refusal.

C. Personal Mental Characteristics

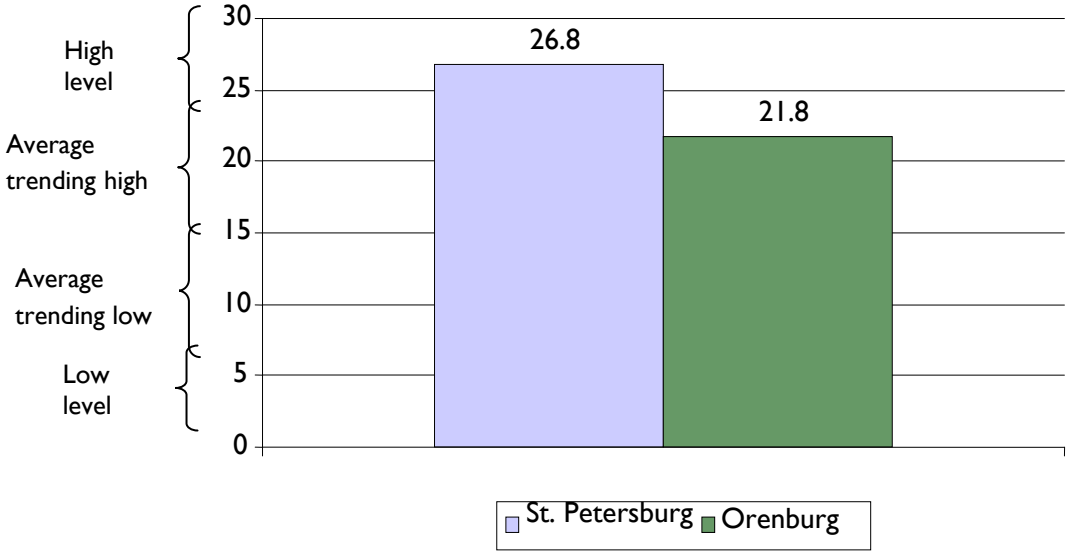
Self-rating by HIV-positive respondents in both St. Petersburg and Orenburg was extremely low compared to standard ratings (Figure 13).

Figure 13. Self-rating, mean



Mean scores of anxiety[2] indicate that the St. Petersburg respondents had a high degree of anxiety, and Orenburg's had a medium degree trending to high (Figure 14).

Figure 14. Anxiety score, mean

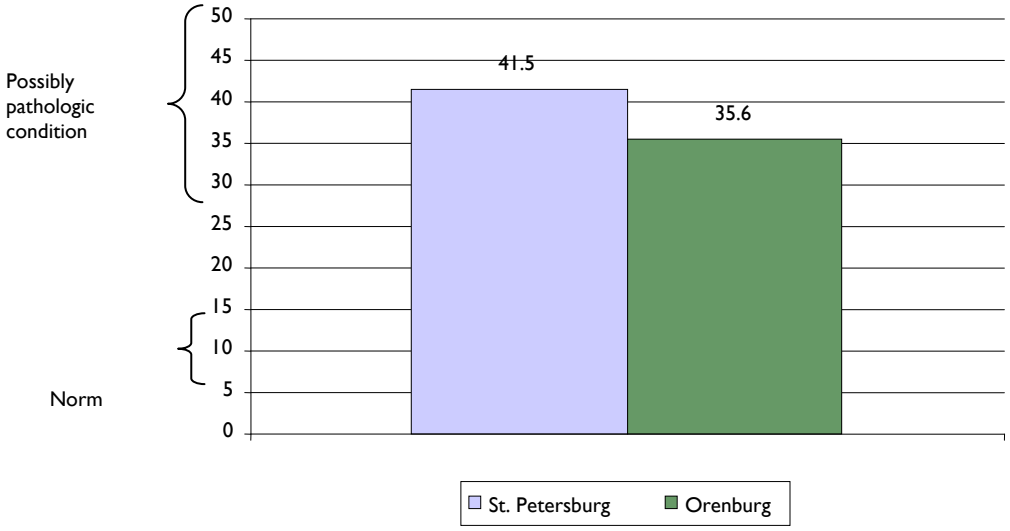


In both St. Petersburg and Orenburg, respondents had high mean neuropsychic adaptation (Gurvich-Semichov)[3] scores (Figure 15).

---

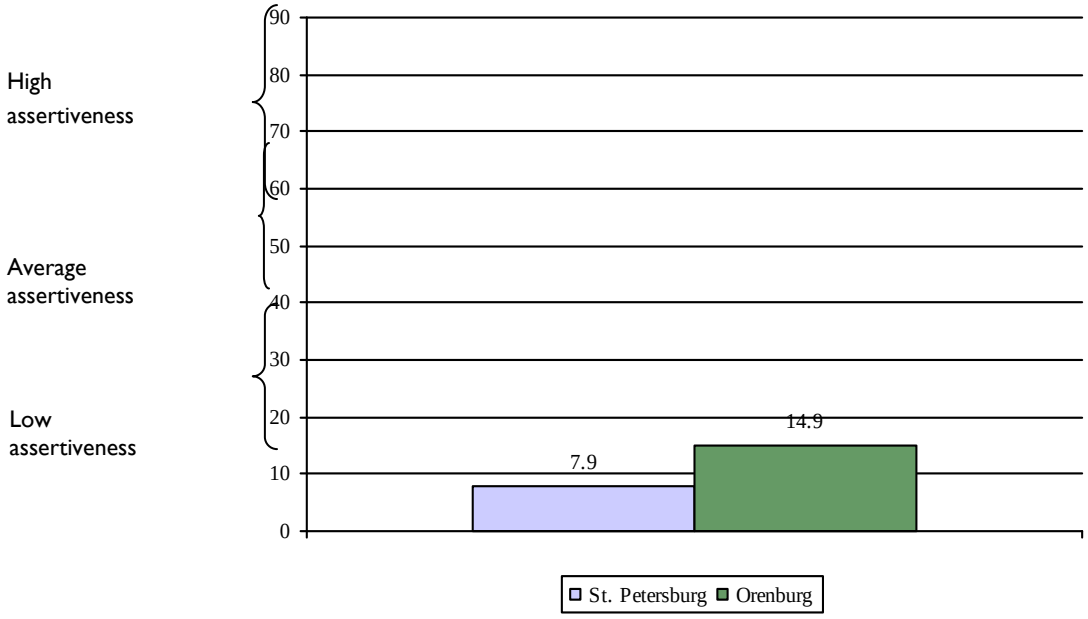
[2] JA Taylor. 1953. A personality scale of manifest anxiety. *Journal of Abnormal and Social Psychology* 48:285–90.
[3] IN Gurvich. 1999. Социальная психология здоровья [Social psychology of health]. St. Petersburg, Russian Federation 609–23.

Figure 15. Neuropsychic adaptation, mean



Respondents in both subsamples exhibited extremely low self-assertion and confidence behavior characteristics on the assertiveness (Rathus Assertiveness Schedule (RAS))[4] scale (Figure 16). The Orenburg respondents had nearly twice as high an assertiveness rate as the St. Petersburg's. Low self-assertion and high assertiveness, high anxiety, and intense neuropsychic disadaptation indicate reactive depression, i.e., depression in response to psychic trauma.

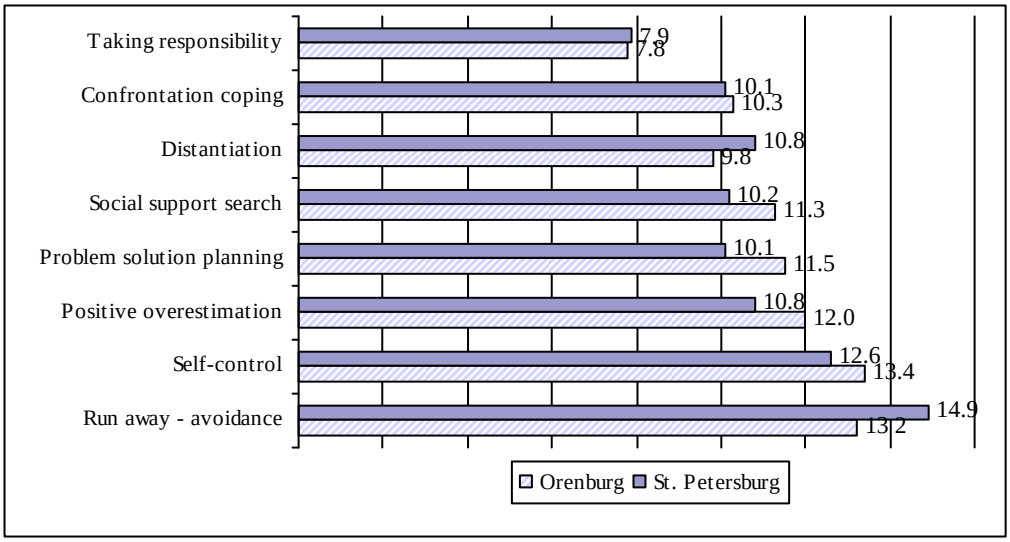
Figure 16. Assertiveness, mean



[4] SA Rathus. 1973. A 30-item schedule for assessing assertive behavior. *Behavior Therapy* 4: 398–406

Strategies to overcome serious life challenges: The study found that the respondents used many ineffective strategies to overcome serious life challenges (Figure 17).

Figure 17. Strategies for handling serious life challenges, mean



Run away/avoidance: In this strategy, people facing a complicated situation try to avoid the problem: They hope for a miracle rather than take action. The strategy is characterized by selectivity of attention: The person is inclined to switch attention from resolving problems to lighter, more pleasant things or to routine and/or unimportant issues. This strategy uses traditional methods to avoid psychologically unpleasant situations: day-dreaming, overeating, alcohol, drug abuse, etc.

Self-control: In this strategy, respondents recognize the presence of a stress-inducing situation but do not attempt to change it actively. They try to suppress emerging emotions and control their feelings. Thus, their main effort is directed to controlling their emotional status. Such an approach does not resolve the situation and instead increases internal tension, thereby distorting the perception of the situation.

Positive reassessment: In this strategy, respondents focus on the positive aspects of the situation. They interpret their environment in positive terms that allow them to perceive the problem as less stressful. Such behavior allows them to diminish internal discomfort and emotionally adapt to the situation. This strategy is most effective when one cannot change a situation with available resources; however, it distracts one from resolving specific, practical problems; focuses on selected aspects of a problem; and tends to ignore some important aspects.

The strategies favored by St. Petersburg respondents to overcome serious life challenges included "distantiation" (an attempt to fence off problems and suppress undesirable emotions) and "run away/ avoidance." Orenburg respondents favored self-control, search for social support, planning for problem resolution, and positive reassessment. The "search for social support" strategy means that a respondent seeks information (advice and additional information), emotional support (approval and understanding), and other help (financial and other resources). This is an effective strategy for changing both emotional status and the situation. The "problem resolution" strategy means that a respondent addresses a problem by applying an analytical approach, developing an action plan, and following the plan rigorously.

Respondents used such strategies as "confrontation coping" and "responsibility acceptance" less frequently: They were not inclined to press their opinion or fight for their interests. They do not accept responsibility for the emerging situation and are not inclined to consider their own negative experience.

Significant regional differences here draw our attention. For instance, the St. Petersburg respondents had more symptoms of reactive depression (lower self-rating and assertiveness, higher anxiety and

intensity of neuropsychic symptoms) than Orenburg's. The Orenburg respondents more often chose effective strategies to overcome a stressful situation, such as social support and planning for problem resolution.

D. Addictive Behavior

Most respondents drank alcohol-containing beverages previously and in the year before the survey (Figure 18).

Figure 18. Alcohol intake rate, percentages

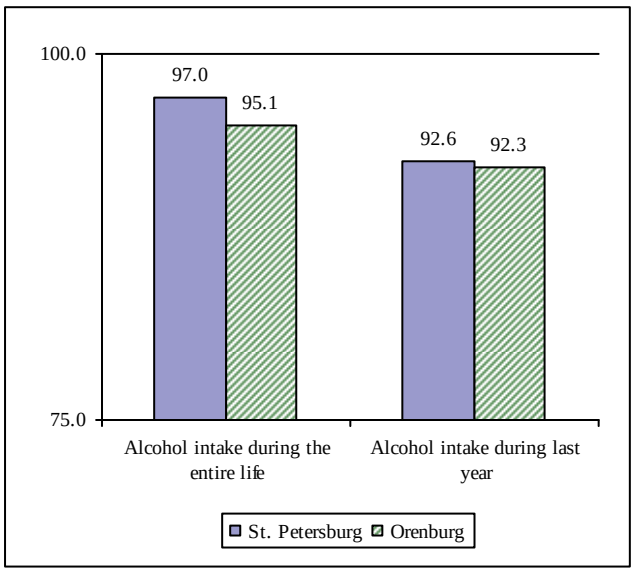
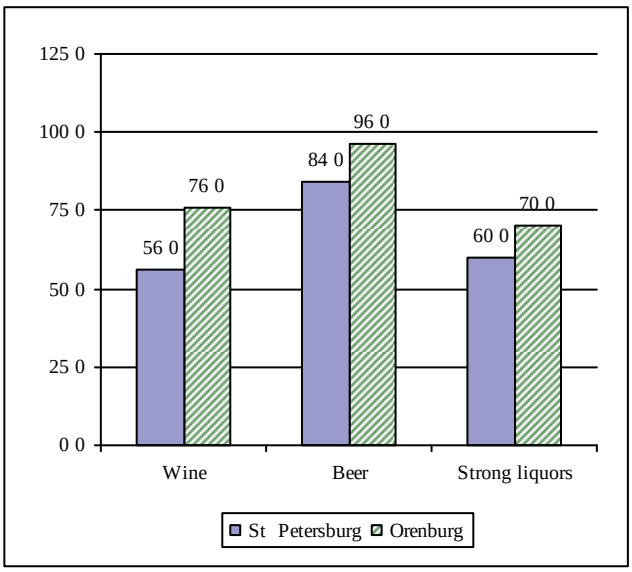
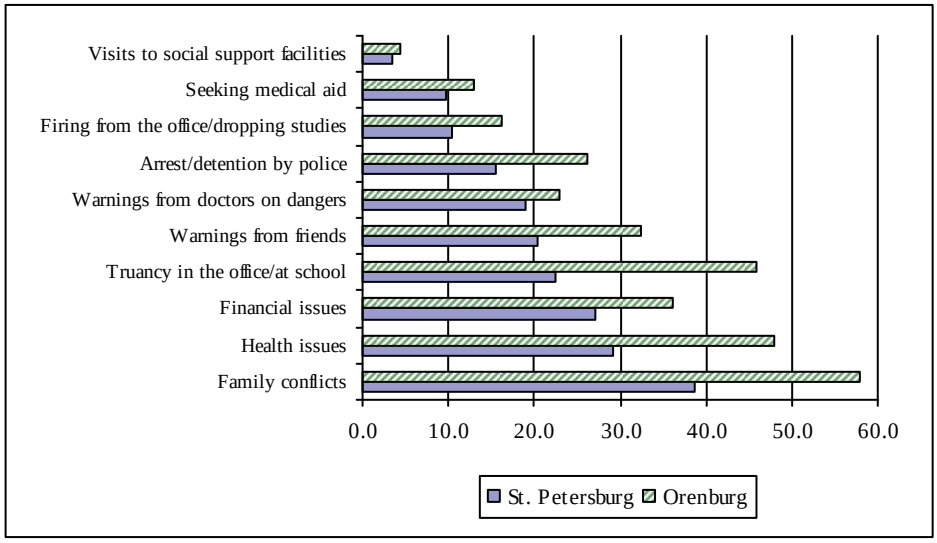


Figure 19. Alcohol intake during the last year by type of alcohol, percentages



Both cities' respondents used beer, wine, or strong drinks (Figure 19), while Orenburg's had a higher frequency of negative social consequences of alcohol abuse (Figure 20).

Figure 20. Rate of negative social consequences of alcohol abuse, percentages



St. Petersburg respondents exhibited a much higher proportion of persons who used injection or non-injection drugs than Orenburg's (Figure 21). The St. Petersburg respondents had a higher rate of negative social consequences of drug abuse (Figure 22) as well as higher drug use rate during the last year, last month, and prior to the survey (Figure 23).

Figure 21. Drug abuse rate during lifetime, percentages

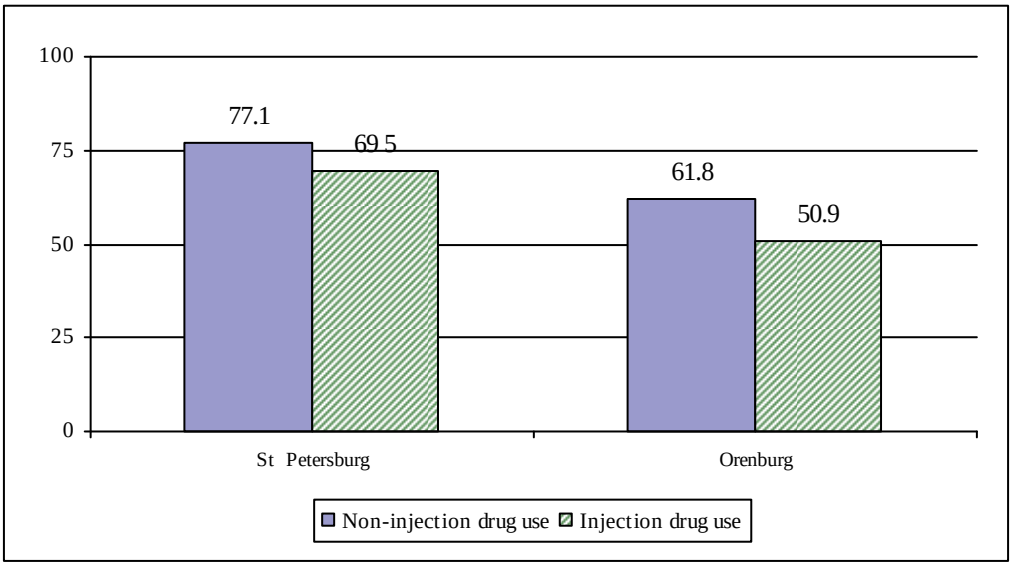


Figure 22. Rate of negative social consequences of drug abuse, percentages

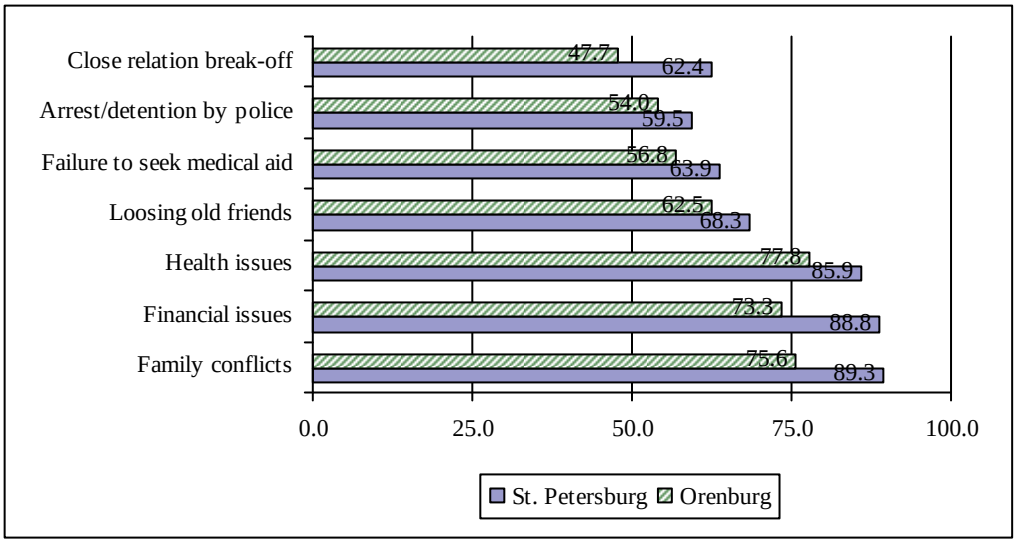
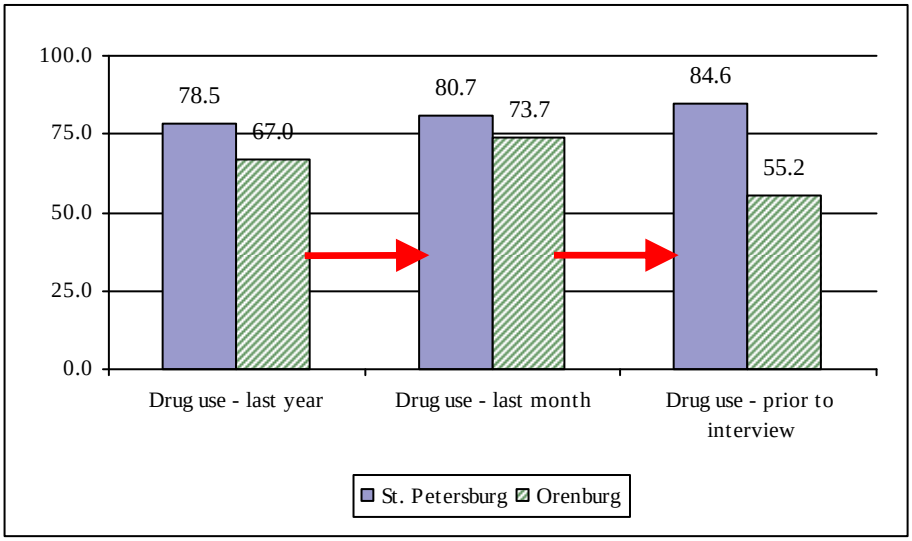
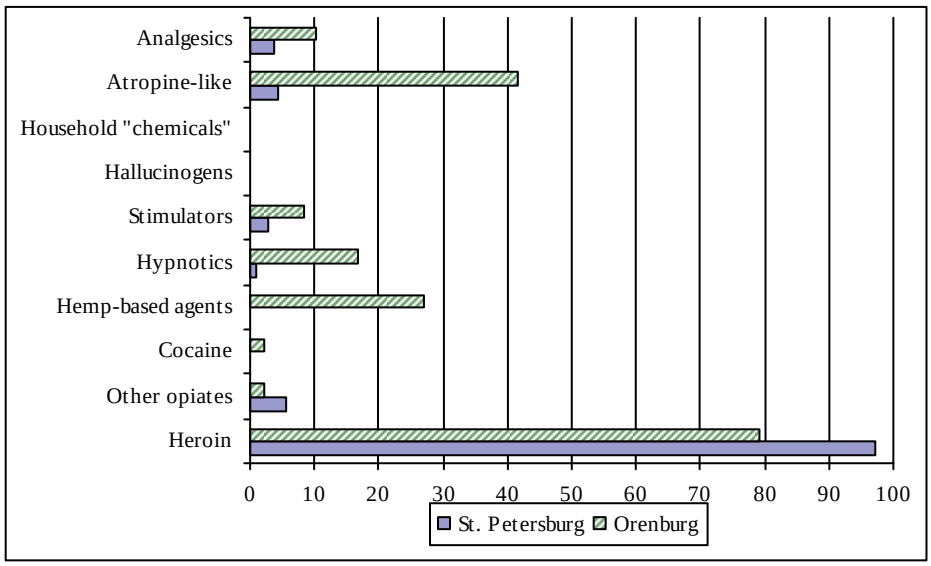


Figure 23. Actual drug abuse rate, percentages



Most drug users in both cities use heroin. In Orenburg they were more likely to use several types of drugs simultaneously, probably because many in this sample used other types of drug-containing substances besides heroin prior to the study: atropine-like agents, hemp-based agents, hypnotics, and stimulators (Figure 24).

Figure 24. Types of drugs used before the study, percentages



E. Individual Experience

Pain syndrome was present in almost two-thirds of HIV-positive persons in both cities (Figure 25); St. Petersburg respondents rated the pain intensity higher (Figure 26).

Figure 25. Pain syndrome, percentages

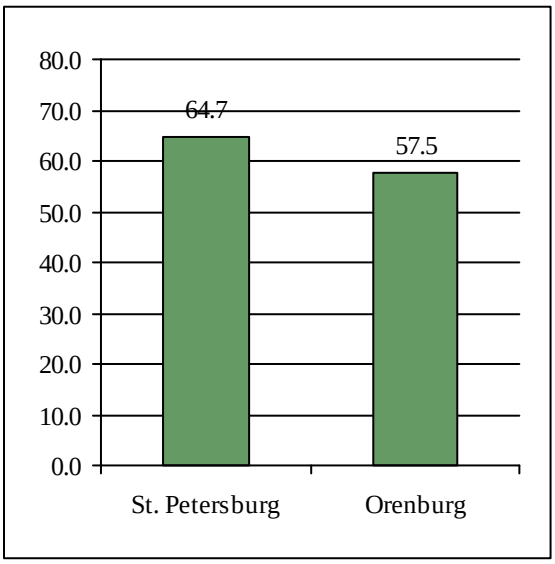
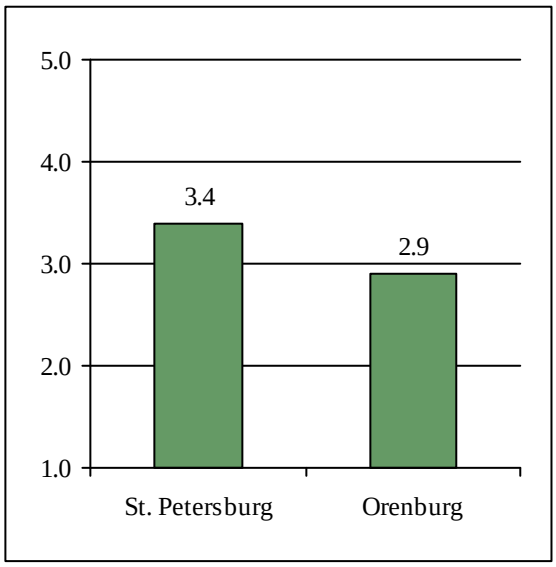


Figure 26. Pain syndrome intensity (points), mean



1 – slightly noticeable pain, 5 - hardly tolerable pain

In this study, complaints of pain-like sensations not linked to trauma or body wound were used as an indirect marker of the stage of the HIV infection in respondents.[5] The results indicated a more advanced HIV stage in the St. Petersburg respondents than in Orenburg's.

Respondents from both cities visited medical and preventive treatment facilities (MPTFs) often. About half of respondents in both had visited non-specialized MPTFs (Figure 27). Non-specialized facilities attracted more respondents than specialized ones (Figures 27 and 28), and specialized facilities in St. Petersburg attracted more respondents than those in Orenburg (Figure 28).

Figure 27. Visits to non-specialized MPTFs

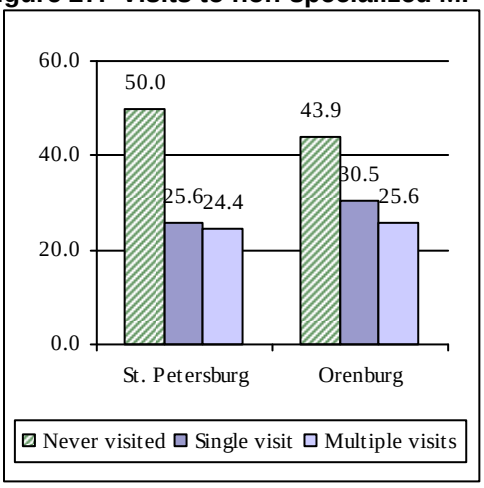
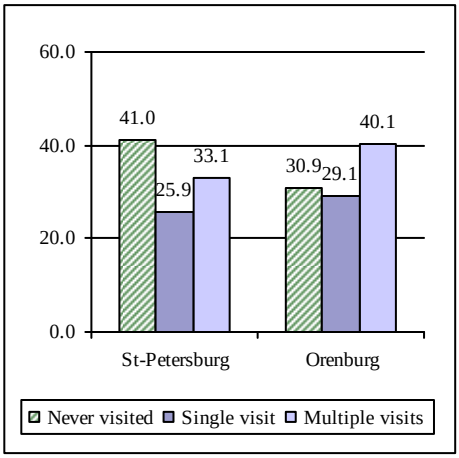


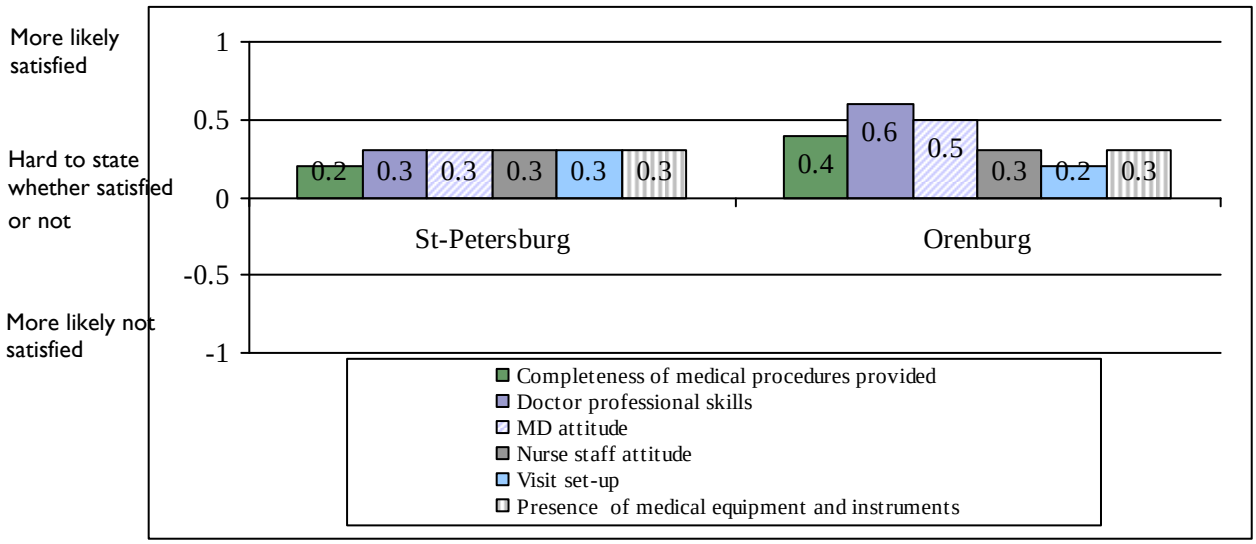
Figure 28. Visits to specialized MPTFs during the during the last year, percentages



[5] The most common syndromes noted in HIV/AIDS patients and mentioned in modern studies are painful sensory peripheral neuropathy, pain induced with advanced Kaposi sarcoma, headache, oral and pharyngeal pain, abdominal pain, thoracic pain, arthralgias and myalgias, and painful dermatologic conditions. HIV-infected women felt pain more frequently than HIV-infected men. Women more often complained of high intensity pain, of specific pain characteristic of opportunistic infections, and of cancer disorders in pelvic organs and the genitourinary tract. Y Swica and W Breitbart. 2002. "Treating pain in patients with AIDS and a history of substance use." *Western Journal of Medicine* 176 (1):33–39.

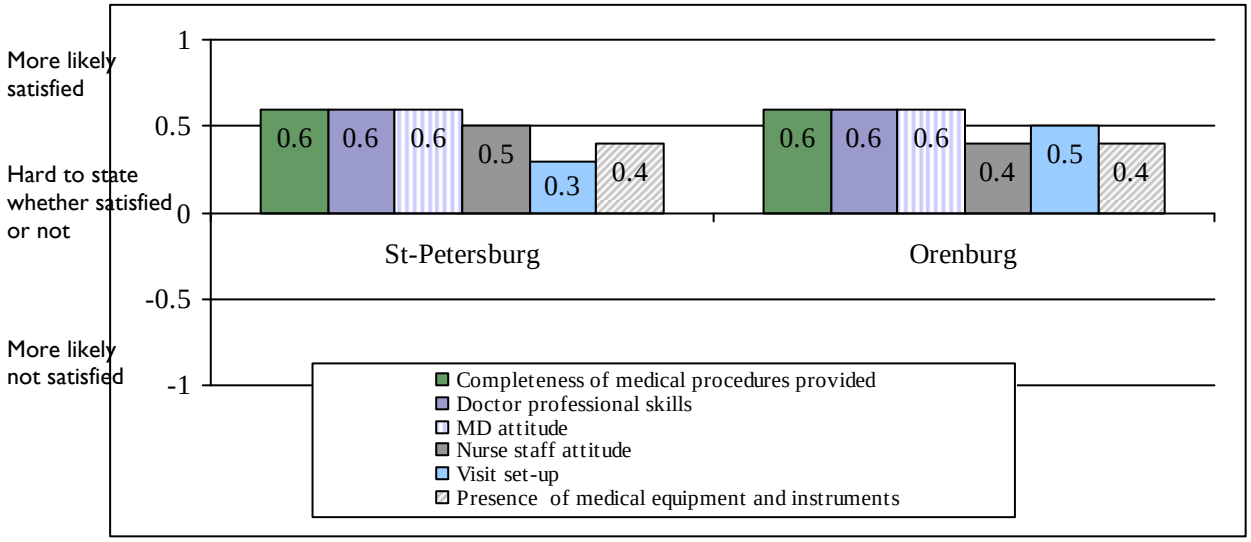
Figure 29 shows that Orenburg respondents were more satisfied than St. Petersburg's with the medical care quality in non-specialized medical facilities, especially for completeness of care and doctor skills and attitude. Orenburg respondents were less satisfied with the visit set-up. The St. Petersburg respondents were least satisfied with the completeness of care and showed average satisfaction with all other assessment criteria.

Figure 29. Satisfaction with care in non-specialized MPTFs (scores), mean



Satisfaction with care was higher at specialized MPTFs than at non-specialized ones. The highest satisfaction scores in both cities were with care, doctor's skills, and doctor's attitude (Figure 30).

Figure 30. Satisfaction with care in specialized MPTFs (scores), mean



Respondents in both cities reported negative communication experience in non-specialized MPTFs where they were diagnosed with HIV or treated for concomitant disorders. St. Petersburg respondents reported negative attitudes of PLWHA toward some aspects of the HIV care system in specialized facilities.

The focus group results show that at the initial disease stages in both cities the most important consideration for PLWHA was not health care system features but rather personal contact with a doctor, trusting the doctor, and absence of signs of negative attitude from medical personnel at all levels. Positive experience led to more frequent medical facility visits and higher treatment adherence.

F. Cognitive Behavior Determinants

Awareness of HIV/AIDS in general was sufficiently high in both cities' respondents, although it was somewhat higher in St. Petersburg (Figure 31). Awareness of ART was lower than desirable (Figure 32), and correct understanding about it (Figure 33) was very low in both localities.

Figure 31. Rates of awareness of HIV/AIDS (13-point scale), mean

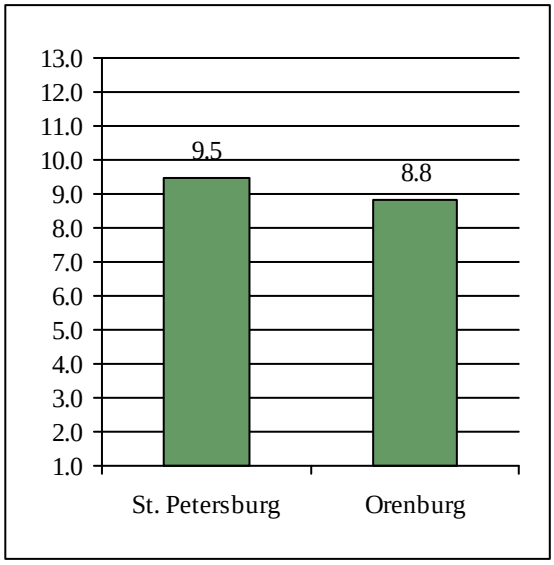


Figure 32. Knowledge of existence of ART, percentages

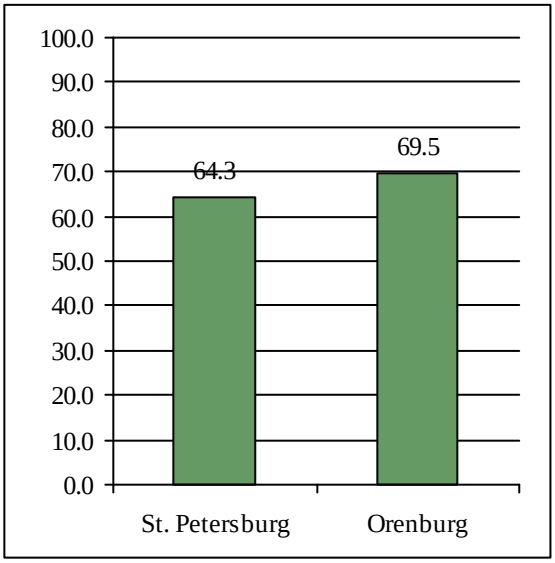
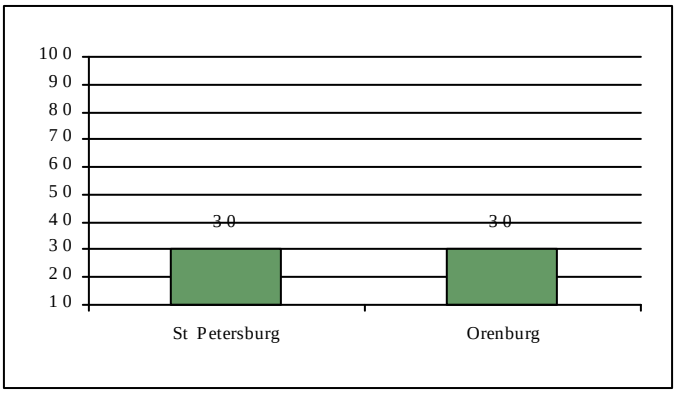
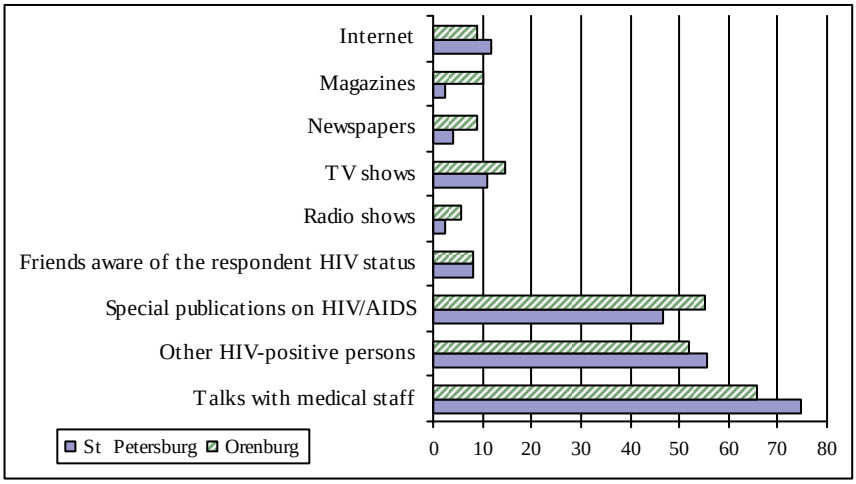


Figure 33. Rates of correct understanding of ART (10-point scale), mean



Respondents said their main sources of information about ART were health care workers, other HIV-positive persons, and specialized publications (Figure 34).

Figure 34. Sources of information on ART treatment, percentages



Importantly, the results in this section indicate that even though one of the main sources of information on ART is health care workers, both the awareness and understanding among HIV-positive persons in both cities are extremely low.

G. Microsocial Effects on Behavior (Closest Social Environment)

About 40% of HIV-positive respondents were registered as married or married by common law, with most living with their marriage partner (Figure 35). The partner was also HIV-infected in about half the cases (Figure 36).

Figure 35. Marital status, percentages

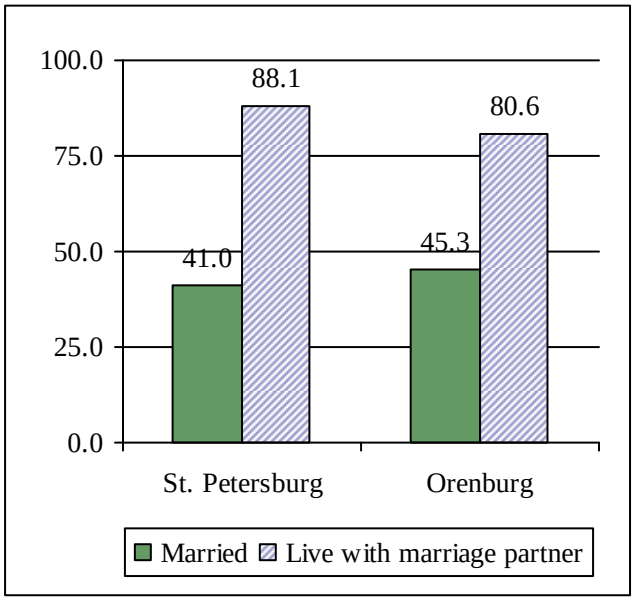
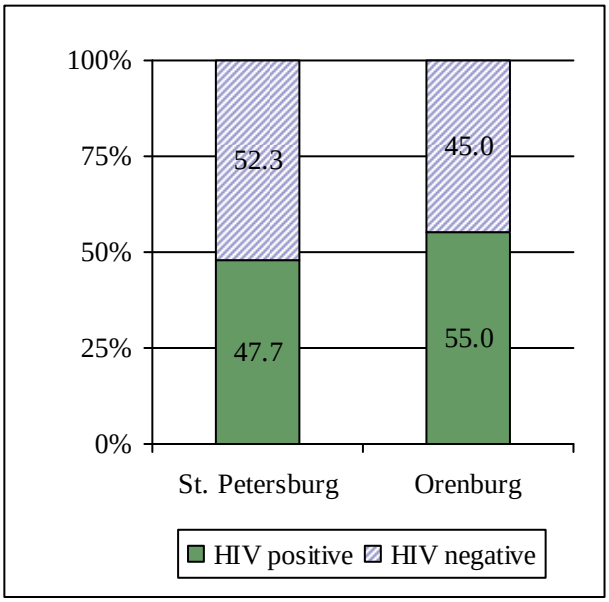
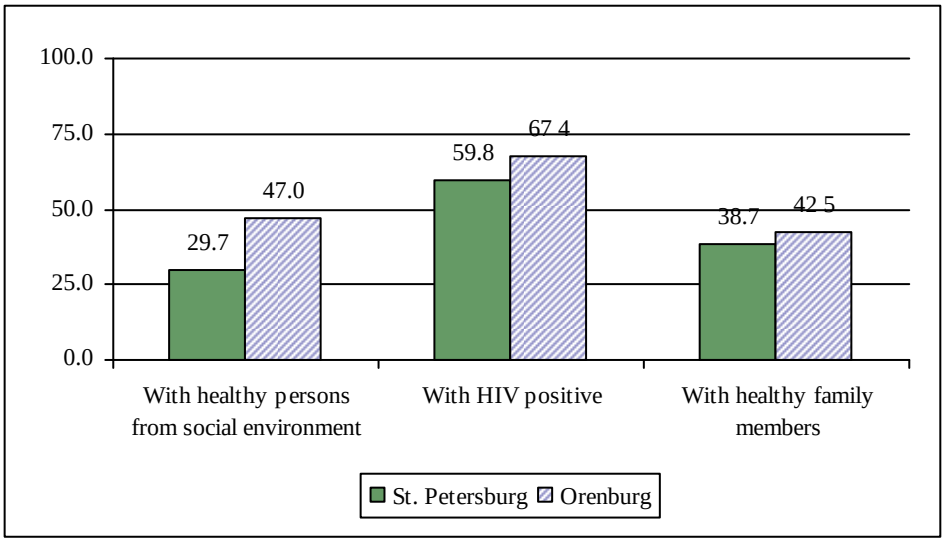


Figure 36. Partner HIV status, percentages



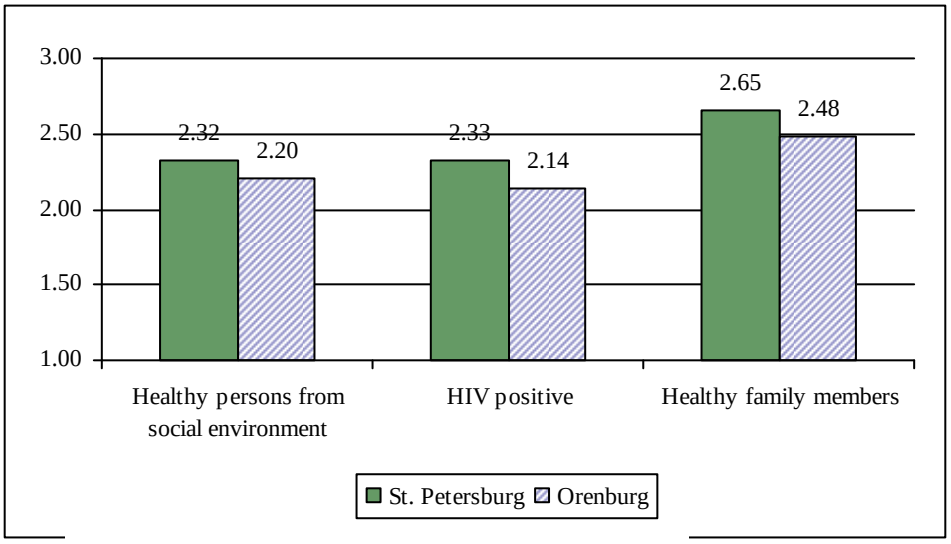
In both cities, respondents discussed treatment issues more frequently with other HIV-positive persons socially near to them than with uninfected family members or other uninfected persons (Figure 37).

Figure 37. Discussion of HIV treatment issues with HIV-infected and uninfected persons, percentages



Respondents believed that family members' attitudes toward ART tended to be positive while their beliefs about attitudes of other socially close, healthy persons and other HIV-positive persons were more neutral (Figure 38). Overall, the St. Petersburg respondents thought the attitudes of all these groups were slightly more positive than did the Orenburg respondents.

Figure 38. Attitude toward ART use among members of the closest social environment, percentages



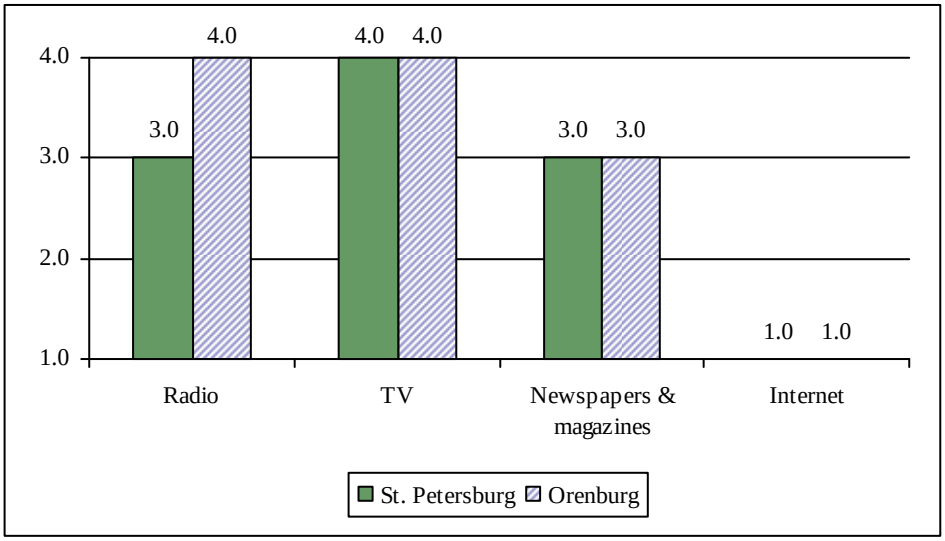
1– Negative, 2 – Neutral, 3 – Positive

Thus, though HIV-positive persons were more eager to discuss treatment issues with other HIV-positive persons, the most social support for ART administration came from healthy family members.

H. Macrosocial Behavioral Effects (Mass Media)

The most frequently used mass medium was television in both cities and radio in Orenburg (Figure 39). The Internet was seldom used.

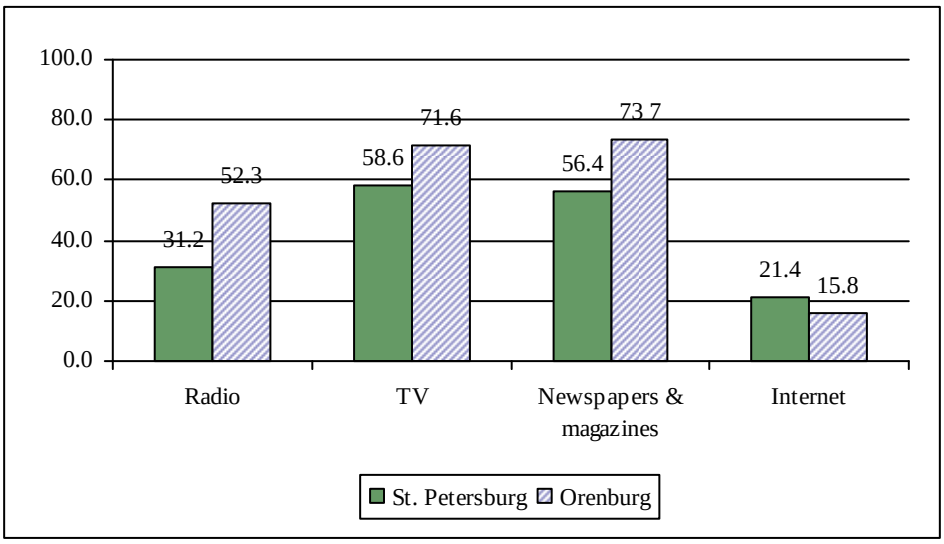
Figure 39. Rate of turning to mass media during the last month, mean



1– None, 2 – Less than once/week, 3 – About once/week, 4 – Every day

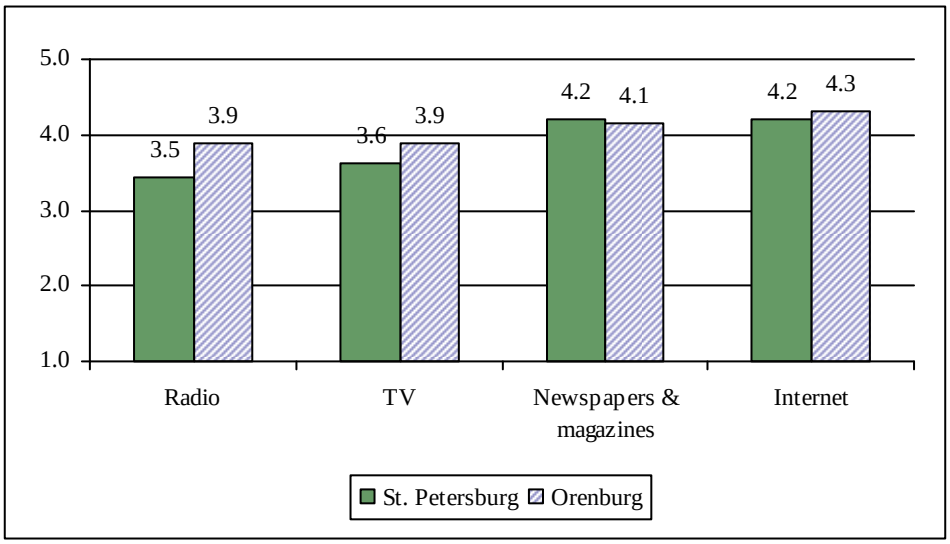
Respondents in both cities saw specific HIV/AIDS messages on television and in printed mass media most frequently and on the Internet least frequently (Figure 40). The Orenburg respondents saw HIV/AIDS messages in mass media more often than did St. Petersburg's.

Figure 40. Received messages on treatment for HIV/AIDS in mass media during the last year, percentages



However, respondents in both cities trusted the rarely used information channels (Internet and printed materials) slightly more than the frequently used ones (Figure 41).

Figure 41. Trust rate for messages on HIV/AIDS treatment from mass media



1– Minimal, 5 – Maximal

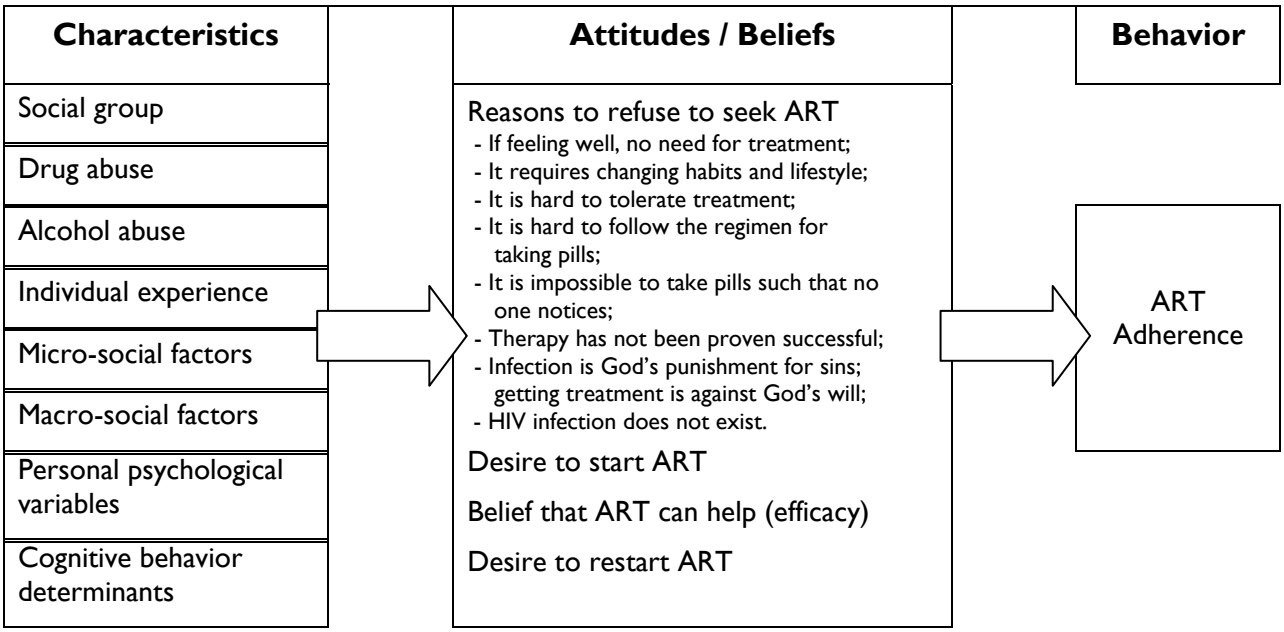
I. Summary: Influence of All Factors on Behavior

A stepwise multiple regression analysis was used to assess the influence of different factors on ART adherence and care-seeking behavior. This method identified the extent to which different behavior-influencing factors were associated with the care-seeking behavior, both separately and in combination with other factors.

Figure 42 presents the logic of how the regression analysis (over 80 regression models) was used to assess the influence of the many variables characterizing eight factor groups on care-seeking behavior for ART and its various components, as defined by 11 indicators of behavior and attitudes such as reasons for refusal of seeking ART, desire to start taking ARVs, belief that ART will help, and desire to renew ART if it was interrupted). The eight factor groups consisted of: social-group assignment, characteristics of drug and alcohol abuse, individual experience, microsocial factors, macrosocial factors, personal psychological variables, and cognitive behavior determinants.

The regression models identified factors that statistically influenced the given behaviors, including R^2, which shows the magnitude of the factors' effects. For example, the regression analysis identified the main factors influencing refusal to seek ART care, desire to start taking ARVs, and a positive attitude toward ART. Statistical relationships obtained via multivariate regression analysis are defined as being significant at the $p \leq 0.05$, $p \leq 0.01$, and $p \leq 0.001$ levels. (Percentages in parentheses following a particular characteristic refers to the variance of the dependent variable explained by the characteristic.)

Figure 42. Framework of the multivariate regression analysis



Social group

Our analysis indicates that low education level was a significant factor in the refusal to seek ART in both study cities. Older people were more likely to refuse to take medicine due to concerns regarding disclosure of their HIV status, and younger people refused due to their immaturity and external type of control. Men were less inclined to seek ART due to non-rational reasons: a belief that HIV does not exist, that it was invented by greedy doctors and pharmaceutical companies, that health status can be maintained with the help of various natural means not using any "chemicals," or that the efficacy of treatment had not been proven.

Drug abuse

Drug abuse was a main factor negatively influencing ART adherence in both cities, according to our analysis. Part of this influence was due to the association of such abuse with the refusal to seek ART in St. Petersburg and Orenburg.

Drug abuse was associated with the refusal to seek ART equally in both cities, likely due to the necessity to change one's habits and lifestyle. However, the influence of drug abuse on other accessibility indicators differed by the respondent's city. In St. Petersburg, drug abuse influenced the refusal to seek ART due to beliefs that the treatment is hard to tolerate, that the regimen is hard to follow, and/or that HIV does not exist. In Orenburg, drug abuse influenced the refusal to seek ART because the patient feels fine and/or believes that ART has not been proven, that one cannot escape one's fate, and/or that one's health status can be maintained with various natural means (naturopathic belief).

Drug abuse had slightly less influence on the desire to start ART if deemed necessary (explaining 12% of the variance in St. Petersburg and 43% in Orenburg) and if the patient believed in ART efficacy (12% in St. Petersburg and 22% in Orenburg).

Alcohol abuse

We found alcohol abuse to be the second most important factor, after drug abuse, influencing ART adherence. Alcohol abuse explains 45% of the variance in the refusal to seek ART in St. Petersburg, but only 17% of the variance in Orenburg. In both cities, severe alcohol abuse (reported frequent intake of strong liquors) resulted in refusal to seek ART due to myth-like ideas: that HIV infection is God's punishment for sins and getting treatment means resisting God's will and that HIV does not exist.

Alcohol abuse can lead to poor treatment tolerance, and in St. Petersburg this reason was given frequently for not seeking ART. Other important links in St. Petersburg between alcohol abuse and the refusal to seek ART included: issues related to following the treatment regimens, belief that the effectiveness of ART has not been proven or that HIV does not exist, feeling healthy, and having doubts about the treatment. In Orenburg, the influence of alcohol abuse on refusal to seek ART was higher than in St. Petersburg only in the belief that HIV infection is God's punishment for sins and getting treatment means resisting God's will.

The desire to start ART was more influenced by alcohol abuse in St. Petersburg (15%) than in Orenburg (3%). The influence of alcohol abuse on respondents' belief that one will benefit from ART was in the range of 11–12% in both cities.

In both cities frequent and high-consumption episodes of beer and strong liquors diminished one's positive attitude about ART and the desire to be treated. Rare and low-consumption rates of beer were related in both cities to more a positive attitude toward starting ART and facilitated confidence that ART will help.

Individual experience

Pain and resulting experience in seeking medical care were the third most significant factor for ART adherence, explaining 25% of the variance in the refusal to seek ART in St. Petersburg and 40% in Orenburg. This factor influenced refusal of ART due to severe treatment intolerance and to a belief that ART's efficacy has not been proven.

In both cities persons with frequent and intense pain were more likely to refuse to seek ART for irrational reasons: HIV infection is a punishment for sins or does not exist. However, in St. Petersburg, this relationship was more highly correlated with: feeling well, a belief that one can't escape one's fate, a belief that HIV infection is God's punishment for sin and getting treatment means resisting God's will, and doubt in ART efficacy. In Orenburg the most important factors were: belief that HIV does not exist and that health status can be maintained with various natural means.

Satisfaction with medical care provided in non-specialized facilities notably impacted ART adherence among the St. Petersburg respondents, whereas Orenburg respondents were more influenced by the attitudes of junior medical staff in non-specialized MPTFs and by the presence of pain.

Microsocial factors

The reasons for not adhering to ART were strongly associated in Orenburg with the belief by HIV-positive friends that HIV infection does not exist (14%) and with other attitudes of HIV-positive friends in St. Petersburg (19%). In both cities, belief in the efficacy of ART was strongly associated with a similar belief among HIV-positive friends. In St. Petersburg, belief in the effectiveness of ART by healthy family members was associated with a desire to restart the treatment (48%).

Our analysis indicates that marriage status may affect adherence either positively or negatively. For instance, St. Petersburg respondents indicated that the HIV-negative status of a marriage partner was associated with refusal to seek ART since accepting ART would necessitate changing habits and lifestyle; however, the marriage partner's negative status was also linked to a desire to start ART if deemed

necessary. In Orenburg, a partner's HIV-negative status was also linked to refusal to seek ART but was due to the belief that one cannot escape one's fate. The marriage status influence was 5% in St. Petersburg and 7% in Orenburg.

Macrosocial factors

The influence of mass media on refusal to seek ART was significant, but only in St. Petersburg where the trust of mass media influenced such reasons as: issues with adherence to a treatment regimen, necessity to change one's habits and lifestyle, and belief that health status can be maintained with various natural means. In Orenburg, trust in information from mass media positively influenced a desire to start ART if deemed necessary (19%).

Personal psychological variables

Underdeveloped self-control and strategies for overcoming life challenges that rely on a search for social support facilitated the refusal to seek ART in St. Petersburg (7%). In Orenburg, high self-control and low self-rating against a background of no depression and underdeveloped confrontation-coping skills facilitated refusal to seek ART treatment (5%).

Cognitive behavior determinants

This group of factors was associated with ART care-seeking and adherence at a level of 9% in St. Petersburg and 6% in Orenburg. Low awareness of HIV/AIDS influenced the reasons for refusal to seek ART, mainly due to doubts about its usefulness. ART awareness contributed considerably to reasons for refusal to seek ART in St. Petersburg and somewhat less in Orenburg.

V. RECOMMENDATIONS

Based on this study, we estimate that the ART adherence rate in the studied populations could be increased by two to five times if the suggested recommendations were implemented, depending on the presence or absence of previous treatment experience.

The recommendations include increasing the rate of primary visits by PLWHA seeking ART, increasing the rate of ART restart after being independently interrupted, and maintaining ART adherence. We have grouped the recommendations by target: 1) the general population, 2) the medical and social care system for PLWHA, 3) those socially closest to PLWHA, and 4) individual PLWHA. The most successful ART adherence improvement measures will likely be those that will carefully manage activities targeting individuals.

Since the differences between the St. Petersburg and Orenburg samples are extremely important, only a few recommendations are common to both cities and careful attention should be given to local circumstances when designing improvement activities. Local conditions to take into account include personal characteristics and behavior peculiarities of the high-risk groups and medical and social circumstances.

A. Measures Directed at the General Population

For both cities

In Russian society, unlike in Western ones where ART adherence is widely recognized as important, HIV infection control and AIDS treatment issues still have not attracted sufficient public attention. This means that there are not yet developed in the general population cultural predispositions for securing ART adherence. The study points to the need for mass media campaigns in both cities to address appreciable misunderstandings about HIV/AIDS treatment in both the PLWHA population and the general population.

The leading method to attract members of the target population to seek ART in both cities is a mass media campaign. Its main objective should be to increase the number of PLWHA who seek ART by increasing their awareness of ART. An important precondition for the success of such campaigns is the validity and objectivity of the information they provide. Such objectivity can be ensured by involving highly experienced HIV/AIDS treatment specialists in the development of the information programs.

We recommend using television to provide information on ART availability and adherence because television has high coverage in the target population. The Internet and printed publications should also be used for messages aimed at increasing ART adherence in the target population. Information should cover the efficacy of ART and the structure and capacities of the medical and social care systems for PLWHA living in each city. It is necessary to systematically assess the effectiveness of the campaigns.

For special emphasis in St. Petersburg

Because PLWHA in St. Petersburg have low trust in television, we recommend greater use of the Internet and printed publications in this city. The St. Petersburg campaign should provide information that will improve acceptance of PLWHA and thereby reduce stigma.

For special emphasis in Orenburg

The mass media campaign for Orenburg should provide information on the capacities of the medical and social care system for PLWHA. It should aim to increase acceptance of ART. Radio and television broadcasting in particular should be used to disseminate information on the importance of ART adherence and on ART availability.

B. Measures Directed at the Medical and Social Care System

For both cities

Develop and implement educational programs for medical staff, both doctors and nurses, in all medical facilities providing care for PLWHA. An objective should be to improve awareness of the disease and to develop tolerance toward PLWHA. Simultaneously, in all medical facilities providing care for the target groups, develop and implement programs for social and psychological training of medical staff, including skills for communicating with PLWHA.

For special emphasis in St. Petersburg

Create a beneficial therapeutic environment: It is important that the experience of HIV-infected persons, including patients with AIDS, be emotionally positive in their contacts with medical facility staff, because such contacts serve as the basis for a perception of ART's effectiveness. Therefore, medical facilities providing care to PLWHA should develop and implement a set of interventions for developing emotionally positive experiences among visiting PLWHA who come into contact with facility staff.

Create more positive settings for PLWHA to contact a doctor: It is important to alleviate patient fears related to negative experiences in specialized facilities: disclosure of diagnosis, interruptions in drug supply, absence of clear explanations about indications for taking individual medications, and the use of obsolete treatment methods. The education program for doctors and nurses in medical facilities providing such care should address these issues. To increase patient trust in health care workers, facilities should assure the steady availability of drugs and prevent overcharging.

Enlarge the network of medical care for PLWHA by further involving non-specialized MPTF so that treatment sites will be as close as possible to patients' residences.

Increase patient awareness of the possibility of obtaining medical care in specialized federal facilities.

It is strongly recommended that the structure of medical and social care of HIV-positive persons and AIDS patients be improved continuously with regard to referrals, development of interaction between state and public organizations, and among public organizations themselves, while being careful not to duplicate functions.

Implement measures to increase ART adherence in non-specialized MTPFs to the same degree as in specialized ones.

Provide adequate drug supplies for treatment of HIV/AIDS-associated diseases. This may require a substantial increase in supplies.

Increase the effectiveness of the current system of medical and social rehabilitation of HIV-infected persons and AIDS patients, particularly the development of a system for their social support.

For special emphasis in Orenburg

Take action to ensure that PLWHA have a positive emotional experience in their contacts with medical facility staff, since a negative experience generates negativistic and naturopathic attitudes about the disease.

Provide detailed explanations of the side effects that ARVs can have for some patients and secure a reliable drug supply.

Fully implement measures to increase trust of PLWHA in the professional skills of medical doctors and specialists in regard to diagnosing disease/infection and administering therapy.

In non-specialized MPTFs, improve the quality of pre- and post-test counseling when patients are tested for HIV.

Work more closely with medical workers in penitentiary facilities to improve the provision of medical care to HIV-infected prisoners.

Increase the capacity of medical facilities to reduce queues in doctors' offices, thereby increasing the availability of specialized medical care.

Implement measures to increase ART adherence in non-specialized MPTFs to the same degree as in specialized ones, particularly in regard to junior medical staff.

C. Measures Directed at the Closest Social Contacts

For both cities

To increase availability of ART, foster positive attitudes about ART by working with communities of HIV-infected persons, especially their leaders. NGOs of HIV-infected persons and AIDS patients in Russia are, in fact, self-assistance groups, and require systematic state support.

To achieve stable administration of ARVs, develop effective social support by working with families of HIV-infected persons (family psychotherapy).

For special emphasis in St. Petersburg

To achieve the restart of administration of ARVs after discontinuation, develop effective social support by working with families of HIV-infected persons (family psychotherapy).

Further develop and support the functioning of peer-to-peer practice via selection, training, and creation of an incentive system for peers.

An effective activity with communities of HIV-infected persons can be visits of specialists to PLWHA self-assistance groups.

D. Measures Directed at Individuals with HIV/AIDS

For both cities

Older people should receive enhanced guarantees of confidentiality of their HIV status.

When working with PLWHA, it is good practice to foster their desire to increase their level of education.

Since male patients often refuse ART for irrational reasons, it is advisable counsel them by applying practices of cognitive (rational) psychotherapy. Psychotherapy care to drug users should develop motivation for health improvement (to develop self-protective behavior). Drug users usually place a low subjective value on health and so egocentric motives should be used.

ART should be started immediately after signs that control over drug dependence has been achieved; such a start is possible in cases of "standard" drug use.

At the very beginning of psychotherapeutic interventions with HIV-infected persons with severe alcohol abuse, one should immediately correct irrational concepts about HIV/AIDS such as negation and fatalism.

Moderate use of alcoholic beverages should not be considered as a contraindication to starting ART. However, if a pattern of alcohol abuse is strongly exhibited, the necessary precondition for ART adherence is alcohol abuse treatment.

To facilitate ART adherence in persons with pain at the initial treatment stages of ART, it is necessary to control it effectively while simultaneously using psychotherapeutic methods to correct fatalist and negativistic attitudes toward the disease.

For special emphasis in St. Petersburg

The start of ART can be facilitated with the use of special methods to remind new patients of the need to take pills and to counsel women with about issues related to treatment and pregnancy.

An important initial objective for psychotherapeutic interventions should be the development of subjective-personal acceptance of the HIV/AIDS diagnosis.

A necessary precondition for the start of ART is treatment of drug abuse. This requires improvement in the quality (for psychotherapeutic constituents) of drug abuse care for PLWHA. During psychotherapeutic sessions for persons with drug abuse, significant attention should be paid to correcting irrational concepts exhibited with negation.

At psychotherapeutic sessions for persons abusing alcohol, the alcohol intake pattern should be considered. Wine consumers need, first of all, evidence-based rationale for the efficacy of treatment with rational psychotherapy methods.

Interventions for HIV-infected persons that facilitate success of ART include a considerable amount of psychiatric care, including psychotherapeutic and psychopharmacological treatment. The main topics for such interventions include: Treatment of reactive affective disorders, anxiety control, and treatment of neuropsychic disadaptation conditions. Fields of psychological correction of PLWHA behavior that are required for ART adherence include: Development of skills for self-affirmative (assertive) behavior, development of self-control skills, and development of stress-handling behavioral strategies such as seeking emotional and social support.

For special emphasis in Orenburg

Treat (and correct) personal disorders in PLWHA when ART is indicated, as well as polynarcomania that emerges in this process.

During the psychotherapeutic treatment of drug-abusing persons, stress correction of fatalistic and naturopathic ideas.

The main focus of psychological treatment of PLWHA behavior that is required to attain ART adherence should be to develop a confrontation strategy to successfully overcome this problem.

E. Conclusion

Bringing to life a set of recommendations requires the development and implementation of targeted programs with the involvement of a wide range of specialists: sociologists, communications and public relations specialists, journalists, clinical and social psychologists, narcologists, psychotherapy specialists, and psychiatrists. With differences between the cities and among the targets, the study urges that mass media campaigns address appreciable misunderstandings in the PLWHA population and general population relative to HIV/AIDS and ART. The medical and social care system needs to implement interventions to reduce HIV-related stigma among ART providers, improve interpersonal communication between providers and PLWHA, and increase coordination between government and non-government providers. While recognizing that treatment of drug dependency is a necessary precondition for ART initiation, improvement in the quality of drug abuse care for persons with HIV/AIDS is also needed.

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