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Barriers and Facilitators of HIV Care Engagement: Results of a Qualitative Study in St. Petersburg, Russia

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Abstract

Russia has a large HIV epidemic, but medical care engagement is low. Eighty HIV-positive persons in St. Petersburg completed in-depth interviews to identify barriers and facilitators of medical HIV care engagement. The most commonly-reported barriers involved difficulties accessing care providers, dissatisfaction with the quality of services, and negative attitudes of provider staff. Other barriers included not having illness symptoms, life stresses, low value placed on health, internalized stigma and wanting to hide one's HIV status, fears of learning about one's true health status, and substance abuse. Care facilitators were feeling responsible for one's health and one's family, care-related support from other HIV-positive persons, and the onset of health decline and fear of death. Substance use remission facilitated care engagement, as did good communication from providers and trust in one's doctor. Interventions are needed in Russia to address HIV care infrastructural barriers and integrate HIV, substance abuse, care, and psychosocial services.

Keywords

Russia; persons living with HIV (PLHIV); HIV-positive; HIV medical care; HIV services; HIV care linkage and retention

INTRODUCTION

Antiretroviral therapy (ART) produces viral suppression which reduces AIDS-related illnesses and early death. In addition, viral suppression reduces the likelihood of virus transmission from infected persons to others (1,2). This has given rise to the concept of ART treatment as a strategy for reducing downstream HIV incidence (3). However, the full public

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health benefits of HIV treatment-as-prevention can only be achieved when a high proportion of persons living with HIV infection (PLHIV) in the community are aware of their HIV-positive serostatus, enter and remain in medical care, are prescribed ART at an early infection stage, adhere to antiretroviral regimens, and remain virally suppressed. Some points in the HIV "treatment cascade" (4) have been well-studied, but others have been neglected. For example, considerable attention is being directed to interventions to link persons newly-diagnosed with HIV infection to medical care (5,6). However, linkage models for newly-diagnosed PLHIV usually do not reach persons diagnosed at some point in the past who never entered care, who dropped out, or who became lost to care. Much remains to be learned about how to reach and encourage medical care engagement or re-engagement among PLHIV who are out of care.

In most countries, including the United States, substantial proportions of PLHIV in the community are not presently in medical care for their HIV disease (7,8). However, the picture of HIV care engagement in countries of the former Soviet Union is especially dire. 907,607 HIV infections were officially diagnosed in Russia by 2015 (9). However, treatment cascade data indicates that only 12% of Russia's total estimated number of PLHIV were receiving ART for their disease in 2013, and a scant 9% achieved viral suppression (10), with ART coverage lower in Russia than in sub-Saharan Africa (11). In St. Petersburg, Russia's second largest city, fewer than one-third of PLHIV are presently in medical care (12). Other post-Soviet countries share similar profiles of low HIV care engagement (13). In this light, it is troubling but not surprising that negative health outcomes and HIV-related mortality in Russia remain very high and that, unlike in most other world regions, HIV incidence continues to rise.

A number of studies have identified factors associated with poor HIV medical care linkage, engagement, and retention. Some of these barriers are structural including poor care access, health system barriers and policies, and poor treatment by providers (14–17), as well as housing instability and poverty (18–20). Others are individual-level characteristics including substance abuse (15,19,21,22); younger age (22–24); depression and mental distress (14,17,19); having less advanced HIV disease (22,25); and misconceptions about HIV treatment (26). By contrast, factors found to facilitate HIV care linkage, engagement, and retention include integrated social and health care services and perceived support from providers (15,19,27–29); case management and care navigation (19,28,30); housing assistance (31,32); social support (19,33); and perceiving a responsibility to take care of one's family (18).

Most studies examining factors associated with engagement in HIV medical care have been undertaken in Western countries. Even though HIV incidence in post-Soviet countries is high and continues to increase, and even though levels of medical care engagement are very low, little research has sought to explore reasons why PLHIV in the region are not in care. In addition, most prior studies have used quantitative measures to identify factors associated with care nonengagement. An alternative but complementary approach—and one not often employed in past studies—is to use qualitative methods to learn about reasons why HIV-positive persons themselves report that they did not enter or have dropped out of medical care.

This study was conducted in St. Petersburg, Russia with a population of 4.2 million. 58,105 HIV infections were diagnosed in St. Petersburg between 1987 and October 31, 2013 (12). However, the true number of people infected with HIV is likely to be much greater. Prior to the mid-2000s, Russia's HIV epidemic was almost entirely among persons who inject drugs (PWID), and a large number of newly-diagnosed HIV infections are still among PWIDs. Sexual HIV transmission increased in the mid-2000s. Approximately 40% of incident HIV infections are now attributable to sexual transmission (9). Over the past decade, the gender proportion of newly-diagnosed HIV-positive persons has been approximately 60% males and 40% females.

The HIV medical care system in Russia is centralized. Typically, each jurisdiction in the country has a single specialized care provider located in its central city. In St. Petersburg and its surrounding area, HIV care is regularly provided by specialized care centers and also—less commonly—by infectious disease hospitals and residence-based district clinics. HIV medications are normally prescribed at no cost although only for PLHIV whose CD4+ counts are ≤350, and some providers are reluctant to prescribe ART for current drug users. ART in Russia employs regimens more cumbersome than those now used in the West, and medications are sometimes changed or substituted due to supply interruptions.

The purpose of the present study was to gain an understanding of barriers and facilitators of HIV medical care engagement in Russia from the perspective of PLHIV themselves. These findings can help to guide the development of programs to improve the delivery of care to PLHIV with the aim of improving HIV-related health outcomes and decreasing future disease incidence.

METHODS

Setting and Participants

Participants were recruited from May, 2013 to May, 2014 using multiple strategies to maximize diversity with respect to exposure mode, gender, and age. Announcements were posted on PLHIV-oriented web sites such as discussion boards, online forums and social network communities oriented to PLHIV. Outreach volunteers with a needle exchange program distributed flyers with study information and the telephone numbers to their clients. In addition, we partnered with community programs that reach and serve HIV-positive persons. Their volunteers or staff verbally announced an opportunity to participate in the research study during their program activities. Some participants were recruited through HIV medical service providers where individuals were approached directly by study staff. A small number of participants were recruited through chain referral by already-entered participants. Announcements included study information and the study telephone number so that the interested persons could call and be screened for eligibility. Eligibility criteria were being HIV-positive and at least 18 years of age.

The study sample (n=80) consisted of 48 males and 32 females, and included PWIDs (n=57 representing 36 males and 21 females), men who have sex with men (MSM, n=3 males), and persons reporting heterosexual exposure (n=20 including n=9 males and n=11 females). This sample size was selected because it was large enough for a broad range of themes to emerge until saturation was reached. Participants' mean age was 34 years. No participants who volunteered and met eligibility criteria were excluded from participating. Of the 80 participants, 20 reported being out of care (defined as not having an HIV medical care visit in at least the past 6 months) and 60 reported being in care. Among the 60 who were in care, 30 said they had always been in care and 30 reported a history of being out of care in the past. The mean duration of participants' HIV-positive serostatus knowledge was 8.4 years.

Interview Procedures

Study procedures were approved by the IRBs of the Medical College of Wisconsin, USA and Botkin Hospital for Infectious Diseases, Russia. Written informed consent was obtained from all participants. In-depth interviews that lasted 60–90 minutes were conducted at the project office by research staff experienced in carrying out qualitative interviews with PLHIV. Participants received a $30 incentive payment for the session. Staff members did not know or have other contact with participants and were trained to carry out interviews using a guide developed for this study. The interviews were semi-structured and followed a standardized guide covering a range of topics but that also allowed flexibility to probe participant responses and explore emerging topics in greater depth (34). The interviews elicited detailed information about participants' (a) history of HIV diagnosis and experience when initially engaging in the HIV medical care system; (b) relationships, living circumstances, life history, and other personal and social experiences prior to care engagement as well as barriers and facilitators related to entering and remaining in HIV medical care; (c) perceptions, attitudes, and experiences with the HIV health care system and its personnel; and (d) HIV serostatus disclosure, social support, adverse events, and coping.

Data Analytic Procedures

Interviews were audio recorded in Russian and transcribed verbatim with participants' personal identifiers removed. Accuracy of verbatim transcription was ensured by verifying each transcript's content against the audio recording of the original interview by a second staff member, allowing for the correction of errors. After verification, each transcript was entered into the MAXQDA 11.0.2 (VERBI GmbH, Berlin, Germany) computer program for qualitative data analysis. All data that could be meaningfully categorized within central questions of interest were transcribed verbatim into a summary table for each participant.

The first 30 interview data summaries were independently analyzed by two senior co-investigators to identify key themes. Initially, each rater created a separate taxonomy of the themes that emerged for each of the questions of interest. Following the approach recommended by Spradley (35) to establish reliability, the two raters then worked collaboratively to develop a single taxonomy. Discrepancies were discussed and resolved. Decision trails were noted and documented to assure that interpretations were supported by the data (36,37). All 80 interview data transcripts—including those from the 30 interviews used to develop the taxonomy—were coded using the final taxonomy. Direct quotes were used to ensure that the results accurately conveyed the respondents' main points.

The paper describes care engagement barriers and care engagement facilitators. Care barriers were reported only by participants who were presently out of care. Care facilitators were reported by all participants. Those presently in care described what actually helped them to engage in care and out-of-care participants described what would help them to engage in care.

RESULTS

Table 1 shows how frequently major categories of care barriers and facilitators were cited by study participants based on data derived from the analysis.

Barriers Reported by Out-of-Care PLHIV

Two main themes emerged within the domain of barriers to care. These were dissatisfaction with HIV medical services and also individual-level psychosocial barriers including the influence of substance abuse.

HIV medical service-related barriers

Difficulties accessing care providers: Ninety percent of participants presently out of care cited difficulty in accessing services as a barrier. Russia’s HIV care infrastructure leaves little room for PLHIV to choose their doctor or provider. In this context, PLHIV often described a variety of barriers related to the care infrastructure and their care appointments.

> “I came several times and waited honestly for three hours, but it was just all—I had not enough nerves, just couldn't sit and wait, and I left the place. It was many times. Really, I’m not keen on coming there.”
>
> (Female, 35)

> “These are disadvantages: no specialists to work and queues. I called the [provider] and learned that there was hardly a chance to break through, it was unreal. Last year, an appointment was scheduled for two months before the visit.”
>
> (Male, 50)

> “[It is] one hour by minibus to the [provider]; at the [provider], it takes about an hour and a half, perhaps, two if not more. Plus, one needs to come for the first time to take an appointment ticket, then return. To come for the second time, to give a blood sample and return. To come for the third time, to get lab results. That is to say there are three trips… damn them…”
>
> (Male, 33)

Thus, participants reported having to frequently return on multiple visits for laboratory work, reported long clinic waiting times, and expressed frustration with the care system. In addition, several participants said they had legal problems in establishing their residence within the jurisdiction of the agency providing AIDS care.

Dissatisfaction with the quality of providers’ services: Seventy-five percent of participants not presently in medical care reported feeling mistreated by providers because their doctors did not interact with them properly and showed little interest in their problems. Some participants were not satisfied with the quality of counseling they received.

> "She [the doctor] asked me just a single question, that's it. Here is your referral. 'See you in half a year,' that's it. She asked neither 'what?', nor 'how?', nor 'how do you feel?' Well, maybe in passing there was 'do you have complaints?' You might see what kind of [patients] sometimes come. Of course, she [the doctor] won't smile at everybody. So, she has her own attitude, to behave indifferently."
>
> (Female, 35)
>
> "I don't like the uncertainty of doctors, they know the real situation and they cannot promise anything. They mostly do not believe in what they are talking about."
>
> (Male, 31)
>
> "How to say, doctors put a distance at once, like a wall."
>
> (Male, 30)
>
> "When I learned about [my] status, nobody explained to me anything in our village. I thought I would be alive for half a year or one year and then would crawl to a cemetery."
>
> (Male, 50)

Negative attitudes held by HIV care staff: One-third of out-of-care participants described past negative experience when interacting with HIV medical staff. PLHIV often felt stigmatized based on a history of discrimination, perceived negative attitudes by care providers because of their HIV status, and observed excessive safety precautions taken by medical workers. These experiences sometimes created negative expectations about treatment in future care visits. As a result, some participants postponed or entirely refused to begin HIV medical care.

> *Interviewer:* "Were you referred anywhere after you were informed about [your] HIV-diagnosis?"
>
> *Participant:* "I was offered to when I talked to them. Well, first of all, I do not believe in [the effectiveness of] our medical care system. I feel very negative about people in white lab coats because I do not believe them."
>
> (Male, 50)
>
> "You know, when I came to my gynecologist in the outpatient clinic or to a dentist and told them that I was HIV-positive, and then I felt their negative attitude and rejection."
>
> (Female, 33)
>
> "When they made the puncture, the doctor took a step back right away, she put on a robe just like a space suit. It made me laugh."
>
> (Male, 33)

> "There are doctors… they put on ten latex gloves… It is okay if they do it silently, but somebody can even speak out something like 'Watch out, you can dribble with her blood, God forbid.' I felt like not a human being but some monster…"
>
> (Female, 31)

> "There were some nurses in the hospital. They discussed me like 'rubbish came.'"
>
> (Female, 30)

Very few participants attempted to address these problems such as by changing care providers. Although technically possible, changing one's provider is very difficult and normally not encouraged by providers. Thus, skipped appointments or even quitting HIV care were common.

Individual-level barriers to HIV care—This theme included a variety of individual issues, problems, and perceptions including the belief that therapy is not needed if one's present health is good; low personal value of health leading to a lack of care of oneself and little interest in treatment; care misconceptions; treatment-related fears; life crises; internalized stigma of being an HIV-positive person; and the interference of substance abuse with care engagement.

Perceived good present health and the absence of HIV illness symptoms: When asked why they were not in the HIV medical care and the treatment system, participants often referred to their perceived good state of health. They expressed the belief that one does not need treatment in the absence of symptoms, discomfort, or alarming health issues.

> "Now I feel good, full of energy, I have no tiredness or dizziness. I have no bad symptoms. I feel like a normal, healthy person. Only if one of the symptoms appears, I would turn to my physician."
>
> (Female, 33)

> "I am not a disciplined person. If I have an opportunity to let things slide, I would certainly let them slide, that applies to my health also. That is to say, if I feel good, I would not think about doing anything."
>
> (Male, 31)

> "I do not go to any medical service. This is my position: if I feel something is wrong with my health, then, perhaps I would go to the hospital. Frankly speaking, I'm not a hospital visitor."
>
> (Male, 50)

Current life difficulties, stresses, or crises: Life difficulties and stresses interfered with engagement and retention in medical care. Among the most frequently reported difficulties were not having time for care visits due to work schedule conflict or having a young baby, social instability such as loss of one's job, bureaucratic problems associated with care provider assignment, or incarceration:

> "My wife and mother tell me: 'Come on, [visit your doctor]!' It is difficult to explain to them that I cannot afford missing even one working day due to [my] hard financial situation."
>
> (Male, 39)

> "I have a little baby. So, that's why I have no opportunity to visit doctors and 'make analyses' [receive blood tests] regularly."
>
> (Female, 35)

Some participants had life crises that demanded greater attention:

> "I have personal barriers. This year was very hard because several deaths happened one after another and there were funerals after funerals... So, this year unsettled me. And now I spend my time only for my work and family."
>
> (Female, 37)

Low value placed on one's own health: Some participants expressed indifference toward their HIV diagnosis, placed low value on their health, and were unwilling to adjust their everyday lives to new routines that would be required if they chose to follow anticipated HIV medical care requirements:

> "I am 50. Should I take ART? If I take the therapy, I would need to refuse fried food, alcohol and smoking, some other things. No, I do not want these limitations for me. If I were 20 years of age, I would have thought about it. But, not at this age. I do not want to do such things."
>
> (Male, 50)

> "I do not take any treatment. I have a daughter. Thank God she is healthy and everything is fine. I want nothing more in this life. ART? I am not interested in all this."
>
> (Male, 33)

> "I feel too lazy to get up early in the morning for 'taking analysis' [blood work] which requires an empty stomach. Well, maybe that's it."
>
> (Female, 37)

Internalized stigma and worry that one's HIV status would become known: Internalized stigma over being HIV-positive and psychological denial of one's diagnosis often resulted in sustained anxiety over the possible breach of confidentiality related to receiving care. PLHIV who expressed internalized stigma also often indicated that they would not attend specialized care institutions or accept treatment even when they had serious health problems:

> "Every time, I became horror stricken… what if I meet somebody from my [group of] acquaintances? Who knows who might appear there? As for the local outpatient clinic, I visit it even more rarely than [my provider]. Because in the local outpatient clinic, one can come across acquaintances for sure."
>
> (Female, 31)

> "I cannot be hospitalized because they may report about it to my work. I work in the police."
>
> (Female, 29)

Fears over learning about one's true health status: Psychological refusal to accept one's diagnosis was also common. Some expressed fear that clinical tests might not confirm their perceived good present state of health. They were unwilling to learn about their true health state.

> "At the beginning, I was afraid. I thought they would tell me something terrible. I feel good. And I thought that if I listen to them, I would just become upset."
>
> (Female, 31)

> "The fear. One day, I went to the [provider] with my friend who got medical care there. I came in and thought, well, I would register also… Suddenly a panic fear appeared while I was standing in line. I ran out in tears. I thought, I was stronger because I am a man… I went away and just could not come back there again."
>
> (Male, 29)

Substance abuse: Both narcotics and heavy alcohol use emerged as barriers to care engagement. More than half of participants said that they missed medical care visits, terminated care, or missed medication pick-up appointments due to heavy drinking and drug use. For example, several interviewees attributed not entering HIV medical care to their substance abuse:

> *Interviewer:* "After you learned that you are HIV-positive, what did you do?"
>
> *Participant:* "Nothing. I had no changes. At that moment, I took drugs deeply, in other words, I had a very strong addiction. So, I lived further the same way as before."
>
> (Female, 31)

Some participants reported that alcohol or drug abuse was associated with long periods of treatment interruption and missed medical appointments:

> "Therapy interruption was because I began using drugs. Before, I was taking [therapy when I was] in remission, then I discontinued… Now I do not remember, I discontinued, but then there was a long therapy interruption, for about three months."
>
> (Male, 29)

> "Well, first of all, I tend to have a bloody drinking bout once in five months, because I [normally] don't drink. And, I cannot control [it], I forget [everything] when I am in an alcohol condition. My organism very quickly gets poisoned. It is very difficult to take tablets. I begin vomiting and, in five days, I stop this stuff. Well, that's how alcohol strongly influences [me]."
>
> (Male, 43)

Finally, drug addiction led other participants who had been in medical treatment to drop out of medical care and stop taking ART:

> "I started to take drugs after I was released from prison. When I was released, I visited a doctor and then, after a while, I started to take drugs, and of course I gave it all [HIV treatment] up."
>
> (Female, 33)

> "At the beginning, I visited my infectious disease doctor once in a while, then more and more seldom. And, consequently, all this came to an end after a while. I just stopped visits. The reason was taking drugs. Sometimes, I felt too lazy to go for medications. Then, sometimes, my withdrawal did not let me go to a doctor, and of course one would not go anywhere when they felt so badly."
>
> (Male, 30)

> "So I, then, during 2004–2005, began taking ART and took it for two and a half years. In two and a half years, [I] quit, because [I] began using drugs, and for about two years [I] did not take ART or visit a doctor."
>
> (Male, 34)

Other individual-level barriers: Additional barriers reported by a fewer number of participants included worries and fears about committing to a lifetime of ART medication, lack of understanding about ART and denial of HIV illness, and long-term or severe depression.

Facilitators of Medical Care Engagement and Retention

The interviews of participants who were presently engaged and remained in HIV medical care were analyzed to identify factors that facilitated service integration and maintenance. Out-of-care PLHIV also responded to questions regarding what they thought would help them engage in HIV care. Their opinions were also analyzed and are included in this presentation.

Individual-level facilitators of HIV care—The most frequently-cited reasons to engage and stay in HIV care were personal in nature. These included caring about one's health and family, perceived support received from other HIV-positive persons in the community, the need to get treatment due to worsening health and fear of death, cessation of substance abuse, and reporting positive personal experiences with HIV medical providers.

Taking care of one's health and one's family: For persons in HIV care, taking care of oneself and one's health, as well as perceived responsibility to family members, were the motives most frequently cited for treatment engagement.

> "I said right away that there was no need to delay medical care access. I need to start treatment and control the process by myself. Because it is very important."
>
> (Male, 29)

> *Interviewer:* "What do you think, what helps you to stay in medical care?"

> *Participant:* "I'm interested in my health. That's it. I want to live. Not just 'to live', but to live like a healthy person."
>
> (Female, 34)

In addition, the desire to have a family and to remain healthy to care for one's children in the future also helped retain PLH in care.

> "I have a wife and a child. My mom is alive. I have a family who I should think about. I would like to live more and to see our child go to school. This supports [me] very much."
>
> (Male, 37)

> "I am to have a family and baby. Just for having them in the future, I wanted to improve my health."
>
> (Female, 30)

> "I went for medical care when I had gotten pregnant. I need my baby to be healthy. The baby's health was the only reason."
>
> (Female, 34)

> "We just wanted a child with my wife. We decided to visit a doctor together—me and she—in order to have a healthy baby."
>
> (Male, 30)

Support from the PLHIV community: A small number of participants said that their own internal and independent self-management capacities gave them the discipline needed to enter and remain in medical care. However, social support was much more often identified as critical to facilitating HIV care engagement among persons who were in care. PLHIV not presently in care also felt that support from other HIV-positive persons would help them to engage in care services. Both in- and out-of-care participants described the PLHIV community—including self-support groups or seropositive friends—as important resources of information regarding HIV infection as well as available services. Many also said they gained emotional support from HIV-positive community members and cited this support as helping them accept their own status.

> "Self-support groups are very useful. People from there consult, help, and talk about the necessity for visiting specialists. They motivate [me] to do that. I was looking for such groups where I could talk with people freely, without keeping that secret."
>
> (In-care female, 38)

> "For the first four years, I was very upset, I was feeling myself as an outcast. I had no information about HIV, so I secluded myself. Later, I started talking with people who were defending HIV-infected people's rights."
>
> (In-care male, 43)

> "I am intending to visit a doctor. I guess I will go to the [provider] with my friends for company. That is in my plan."

(Out-of-care female, 31)

Finally, the community of other PLHIV was seen as a source of personal exemplary stories and cases of successful care engagement. This motivated some participants to make contact with care providers and consider treatment initiation.

> "Time is running out for me. I am always talking with people; all of them are taking ART. So, I think about the same, meanwhile."

(Out-of-care female, 31)

In addition to care engagement support provided by other members of PLHIV community, some participants said that the support of non-PLHIV friends and relatives helped them to enter and remain in care.

Observable decline of health and fear of death: The desire to live—as well as the fear of death—were often cited as reasons to initiate medical care engagement. This motivation was important, especially for participants who had experienced life-threatening health problems, who had infirmities caused by HIV infection, and among those who had seen other people dying.

> "It took only four years for my disease to progress to the AIDS phase with many serious opportunistic infections. After such complications, after being almost dead, everybody will value each leaf and each green grass under foot. But, now when I receive therapy, I think that such a bad situation will not happen."

(Female, 36)

> "I know people who have 25 CD4 cells or even less. They look really bad. I did not want the same for myself. I am afraid of death, of being in hospitals, I do not want it all."

(Male, 31)

> "I am 32 years old and still have nothing in my life except health problems. I would like to have a future, a family, a wife. I want to love and to live."

(Male, 32)

When asked what leads them to visit an HIV doctor and initiate treatment, out-of-care participants also said that it would be an observable decline of health and feeling sick:

> *Interviewer:* "What kind of reasons would motivate you to start treatment?"
>
> *Female Participant:* "If the doctors say me that I have 10 or 3 CD4-cells, or even less."

(Female, 31)

> "Only in quite an exceptional case, when I will be urged to put on diapers or I will be fastened to a bed. I do not want to communicate with doctors at all. All those stories about CD4, how many do you have of them, are bullshit!"

(Male, 33)

Cessation of substance abuse: Many participants either currently or previously used drugs. Cessation of substance abuse—by receiving treatment in a rehabilitation center, by having long-term substance abuse remission, or even having short-term breaks from drug use—helped these participants overcome barriers to HIV care engagement, enhanced their desire to live and care about their health, and served to initiate HIV care visits and begin treatment.

> “I tried to solve another problem before my [care] engagement. At first, I wanted to quit using drugs. HIV infection treatment was in second place. I learned details about [drug] treatment over a couple of months; later, I visited the [HIV care provider] and started to get information.”
>
> (Male, 31)

> “I was treated [for my drug] dependence in a rehabilitation clinic. When I came out of the clinic, I changed my mindset and I got registered with the [HIV care provider].”
>
> (Female, 30)

> “One day, I decided to visit a doctor. I became more serious about my health; I got much more mature and quit using drugs. I went to the [HIV care provider] to visit all the specialists.”
>
> (Female, 34)

Positive experiences with medical providers and trust in one’s doctor—

Nearly half of participants explained that positive experiences with HIV medical care systems helped them to stay in care. These participants described contact with their care physicians as stable, supportive, and trustful, and emphasized the personal importance of this relationship. Doctors’ positive attitudes, their support, as well as the perceived high quality of consultation were crucial factors for care engagement and retention.

> “It is very important, of course, it seems to me, communication with doctors, moral support first of all. It means that if a doctor explains something to you, tells something about your disease, and supports you, it will be easier for you to cope with it, of course.”
>
> (Male, 33)

> “I lost weight for some unknown reasons. Thanks to my doctor in the local clinic, she called me all the time to find out my news. She convinced me to do [HIV] lab analysis. Finally, she made me do that. I did the analysis.”
>
> (Male, 32)

> “I called my doctor. I was not able to visit her just to show her my sore throat or something else. If I have questions for her, she can say something to me by phone. So, I can talk with her without further visits. It’s very important for people with HIV at the first stage in care engagement.”
>
> (Female, 38)

> "I believe, first of all, one should trust in one's doctor. Without that trust, nothing will get done."
>
> (Male, 32)

Additional factors enabling medical care engagement described by smaller numbers of participants were receiving effective pre- and post-HIV test counseling at the time of diagnosis, convenient and accessible location of care providers, trust in HIV medical treatment.

DISCUSSION

Reductions in HIV-related illnesses and early death can only be achieved when PLHIV enter, remain, and adhere to medical care that provides contemporary antiretroviral medications. In addition to poor health outcomes among PLHIV, the benefits of treatment-as-prevention are largely not being achieved because so many HIV-positive persons in Russia are not engaged and retained in medical care, because relatively few are on ART regimens, and because most have not achieved viral suppression (10). Prior research has established high levels of psychosocial distress, continued substance abuse, and stigma experienced by PLHIV in Russia (38). This is the first study carried out in Russia that interviewed HIV-positive persons from the community and elicited their own HIV care experiences, particularly factors that supported or interfered with care engagement. Some of the study's findings—especially associations of substance abuse and social support with care engagement—are consistent with findings of past research conducted in other countries (15, 19, 22, 33). However, this study identified other factors that were more unique or more pronounced among PLHIV in Russia.

Barriers related to HIV care infrastructure were among those most frequently cited. In Russia, HIV care is highly centralized, leaving very few choices about where persons can get medical treatment. Thus, dissatisfaction with services may lead persons to completely drop out of the care system rather than seek an alternative provider. In addition, ART is normally prescribed in Russia to individuals with CD4+ counts ≤350. Therefore, and unlike in most of the West, entering the care system often does not lead to immediate ART initiation. PLHIV may have less interest in regularly attending medical appointments when their antiretroviral treatment is delayed. Delaying ART initiation also erodes the benefits of early treatment to avert downstream transmission, a factor that likely contributes to Russia's high HIV incidence. Recent guidelines by the World Health Organization now recommend immediate ART initiation upon diagnosis and regardless of CD4+ count (39). If adopted, these guidelines will eliminate long monitoring periods before treatment initiation.

Among other infrastructure and systems barriers were not only inconvenient provider access such as location or working hours but also issues related to stigma, concerns over confidentiality of services, and negative attitudes or reported mistreatment by medical personnel. In contrast, participants who were satisfied with services and who felt well-treated by their doctors indicated that this helped them to remain in care. Efforts are needed to improve the quality of services and infrastructure, meet the specific needs of patients, interact with patients in ways that do not increase stigma, and ensure confidentiality.

Substance use—particularly the heavy use of alcohol and use of injected drugs—was also a barrier to HIV treatment retention. Participants reported that remission from in substance use, receiving treatment in rehabilitation centers, or simply having a short-term break from drug use all facilitated their care engagement and retention. In Russia, the use of opiate substitution therapy is illegal, drug treatment approaches are not contemporary, and harm reduction programs are limited. Substance abuse not only fuels HIV transmission but also interferes with efforts to engage HIV-infected persons in care and support their treatment adherence. There is a clear public health need in Russia to improve and integrate drug and HIV treatment services and use multidisciplinary approaches that target both substance abuse and HIV care needs.

Other factors associated with care engagement involved a variety of individual issues, perceptions, values, and priorities. Among these, one's current state of health influenced whether participants engaged in or postponed treatment. Many participants explained that they felt well, did not have illness symptoms, and therefore did not perceive the need for HIV treatment. In contrast, participants in care cited deteriorating health and fear of death as reasons for initiating and remaining on ART. Care engagement was also facilitated by motivation to take care of oneself, the desire to live a longer life, and a sense of responsibility to loved ones. Social support from other PLHIV in the community helped some participants accept their HIV-positive status and motivated them to integrate into the care system.

Barriers to care engagement included low personal value placed on one's health and having more pressing priorities, particularly among persons facing other life difficulties, stresses, or crises. Some participants cited stigma and fear of disclosure of their HIV status as barriers to visiting care providers because they might meet other HIV-positive persons who know them. Finally, some participants cited fear of learning "bad news" about their health from declining laboratory tests as a reason for avoiding care appointments.

The study has several limitations. Participant recruitment was based on self-referral by persons who saw study announcements on specialized websites, who used community services, and who could be recruited through outreach or by chain referral. Participants recruited in other ways may have reported different factors related to their HIV medical care engagement. In addition, while interviews were conducted by experienced professionals who encouraged participants to openly share their experiences, social desirability bias was still possible and some barriers may have been underreported. Finally, St. Petersburg is a large city, has a very large PLHIV community, and has an HIV care and service infrastructure that is more advanced than in most of Russia. Thus, factors related to care engagement might be different in other areas of the country.

This study's results underscore changes needed to improve the HIV care engagement situation in Russia. Philbin et al (40) and Latkin et al (41) have conceptualized macro-, meso-, and micro-level strategies to improve HIV prevention and care. This conceptualization can be applied to efforts to improve HIV care in Russia. At the macro-level, changes are needed to make the care infrastructure system more efficient, client-oriented, flexible, and trusted. In addition, early treatment initiation is needed to implement the strategy of treatment-as-prevention in Russia as well as to motivate PLHIV to enter care and receive active treatment. Campaigns to reduce HIV-related stigma in Russia are needed, including among care providers. At the meso-level, there is an urgent need for improved and increased services and a greater number of providers in the field of substance abuse treatment. More effective coordination between substance abuse and HIV care providers, and the development of multidisciplinary service teams, are very important in Russia because substance abusers are one of the country's most HIV-affected populations. In addition, care providers and HIV self-support groups and nongovernmental organizations must increase their mutual collaboration to address individual-level client barriers. At the micro-level, interventions are needed to improve the psychosocial well-being of persons living with HIV in Russia, address patient misconceptions about the need for treatment, and increase the perceived benefits of HIV treatment.

Although viral suppression cannot be achieved without ART, its availability alone is not sufficient to ensure individual and public health benefit. Comprehensive HIV care also requires testing to diagnose HIV infection early; services to ensure care linkage and retention; early initiation of ART; counseling and support for medication-taking adherence; and integrated services to meet other needs of PLHIV including high-quality substance abuse treatment, mental health, housing, and social services. In Russia, challenges remain in most of these areas.

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Table 1

Prevalence of Barriers and Facilitators to HIV Care Engagement Reported by Study Participants*

Barriers reported by out-of-care PLHIV (n=20)	**% (n)**	**Facilitators reported by in- and out-of-care PLHIV (n=80)**	**% (n)**
HIV medical service-related barriers		**Positive experiences with medical providers and trust in one’s doctor**	45% (n=36)
Difficulties accessing care providers	90% (n=18)		
Dissatisfaction with the quality of providers’ services	75% (n=15)		
Negative attitudes held by HIV care staff	35% (n=7)		
Individual-level barriers to HIV care		**Individual-level facilitators of HIV care**	
Perceived good present health and the absence of HIV illness symptoms	60% (n=12)	Taking care of one’s health and one’s family	75% (n=60)
Current life difficulties, stresses, or crises	75% (n=15)	Support from the PLHIV community	66% (n=53)
Low value placed on one’s own health.	50% (n=10)	Observable decline of health and fear of death	61% (n=49)
Internalized stigma and worry that one’s HIV status would become known	55% (n=11)	Cessation of substance abuse	49% (n=39)
Fears over learning about one’s true health status	40% (n=8)		
Substance abuse	55% (n=11)		

* Note: Because most participants reported multiple care barriers and facilitators, column totals exceed 100%.