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Lost-to-Care and Engaged-in-Care HIV Patients in Leningrad Oblast, Russian Federation: Barriers and Facilitators to Medical Visit Retention

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Abstract

Sixty-nine percent of the 1.5 million Eastern Europeans and Central Asians with HIV live in the Russian Federation (RF). Antiretroviral therapy (ART) is effective but cannot help those who leave treatment. Focus groups with patients who dropped out of ART for ≥ 12 months (Lost-to-Care, LTCs, n=21), or continued for ≥ 12 months (Engaged-in-Care; EICs; n= 24) were conducted in St. Petersburg. Structural barriers included: stigma/discrimination; and problems with providers and accessing treatment. Individual barriers included: employment and caring for dependents; inaccurate beliefs about ART (LTC only); side-effects; substance use (LTCs, present; EICs, past); and depression. Desire to live, social support, and spirituality were facilitators for both; EICs also identified positive thinking and experiences with ART and healthcare/professionals. Interventions to facilitate retention and adherence are discussed.

Keywords

HIV; AIDS; Retention; Attrition; Russian Federation; positive psychology

INTRODUCTION

Sixty-nine percent of the 1.5 million HIV+ Eastern Europeans and Central Asians live in the Russian Federation (RF) (UNAIDS, 2010), where ~150 cases reported daily (Pokrovsky, 2009), and 21–29% of those with advanced HIV receive antiretroviral therapy (ART; WHO,

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2011). In the RF, HIV is mainly transmitted through injection drug use (IDU) (Lioznov, Ruutel, et al., 2011), and treatment occurs only at regional centers and infectious disease hospitals. Guidelines recommend ART for CD4<350 and/or viral load>100,000 and/or opportunistic infection and to prevent maternal transmission (UNAIDS, 2009; Lioznov et al., 2011; Ministry of Health, 2006). ART is effective (Detels, Tarwater, et al., 2001) but cannot benefit those who leave treatment. In former Soviet states, incorrect information, prejudice against ART, and low physician trust (Rusakova, Gurvich, et al., 2008) could be related to past totalitarianism and suspicions of governmentally influenced medical decisions (Aronson, 2007) and are compounded by stigma and misperceptions (Balabanova, et al., 2006).

Individual, structural, and socio-cultural factors influence retention (Wringe, Roura, et al., 2009; Geng, Nash, et al. 2010). Individual and structural barriers and culture-specific attitudes are important; they have been examined mostly in Africa and South Asia but not much in former Soviet states (Caldwell, 1993; Mimiaga, Safren et al., 2010; Spicer, Bogdan et al., 2011; Wolfe, 2007); this is a gap in the literature. This study used focus groups to identify facilitators and barriers to retention among patients who left treatment vs. those who remained. A qualitative approach was chosen to enable participants to explain why they remained or left inform future research.

METHODS

Design

Focus groups were conducted at Pavlov State Medical University, recruited from Leningrad Regional AIDS Center and Botkin Hospital for Infectious Diseases. The University of Pennsylvania's and Pavlov's IRBs approved the study.

Participant Selection and Recruitment

Physicians identified participants through chart review: LTCs began ART but missed all appointments during the past 12 months and received no treatment elsewhere; EICs kept ≥90% of appointments, with no documented adherence problems and had a CASE Adherence Index score>10 (Mannheimer et al., 2010). Participants were≥18, gave informed consent, and received 1,000 rubles(~US $32).

Measurements and Analysis

Participants completed a survey and the Center for Epidemiologic Studies Depression Scale (α=.85-.90) (CES-D; Radloff, 1977), which is commonly used in healthcare and has been translated into many languages. Two EIC (n=11; n=13) and LTC (n= 13; n=8) focus groups were conducted with an interpreter, recorded, and transcribed. Topics included facilitators and barriers. Quotes were content analyzed for themes and subthemes (Strauss & Corbin, 1997); results were based on consensus (Tables 3 and 4).

RESULTS

Demographics

Participants were Caucasian (M=34; range=21–60). Approximately half were male; married or living with a partner; two-thirds had completed some college. Most were employed (Table 1).

Substance Use and Treatment

LTCs and EICs reported similar, low alcohol use,[1] but 27% of all, and more LTCs than EICs [38% vs. 17%], used drugs in the past 6 months. However, more LTCs reported having been treated for drug/alcohol problems [76% v. 42%], and more LTCs reported that drugs [33% v. 4%] or alcohol [52% v. 17%] had ever interfered with ART. (Table 2).

Both groups showed depression on the CES-D [M=19.31(SD=5.61)]. The atmospheres of the groups were different: LTCs seemed depressed; they spoke slowly and quietly; EICs did not.

Barriers

Structural Barriers

Stigma/Discrimination: All participants described stigma and discrimination from family, friends, colleagues, physicians, and authorities including police. Stigma was the perception that HIV+ people are addicts, deviants, or criminals and not associating with them.

Problems with Healthcare Providers: LTCs described providers as incompetent, untrustworthy, withholding information, self-interested, lacking compassion, and unwilling to help. EICs mentioned providers' lack of knowledge and negative attitudes but continued treatment because they thought it helped. Three LTCs, but no EICs, concluded it is better to not disclose HIV status to providers.

Treatment Infrastructure: Both groups reported treatment and drug availability at few, understaffed, locations, waiting lists; unavailability of viral load tests; ART shortages. Some reported unavailability of ART in prisons and non-HIV inpatient units.

Individual Barriers

Employment, Caring for Others: Employment and responsibilities for dependents were problematic.

Inaccurate Beliefs about ART: LTCs had inaccurate beliefs about ART (ineffectiveness, addictive potential, harmfulness). One stated that his physician did not prescribe the best medications. Another attributed having fewer colds on ART to a "psychological" effect. No EICs reported inaccurate beliefs.

[1]This could reflect under-reporting due to a cultural perception of regular alcohol use as normative, as rates of alcohol abuse are known to be high in the RF (Zaigrayev, 2010).

Practical Problems with ART: Both groups reported difficulty accessing ART due to inconvenience, price, and shortages. Four LTCs and one EIC reported privacy concerns. Both groups reported side effects and drug interactions. LTCs stated that physicians were unwilling to change regimens despite side effects, whereas EICs' physicians did so.

Substance Use: Both groups identified substance use as a barrier and stated that active users are denied treatment. LTCs provided personal stories of how substance use leads to poor ART adherence, whereas EICs spoke of past or others' experiences.

Depression: Both groups spoke about depression, particularly when diagnosed, and how their drive to take ART is diminished with hopelessness.

Facilitators—Although barriers were similar, EICs reported facilitators more frequently. LTCs did not report some facilitators described by EICs.

Desire to Live: Desire to live was the most important facilitator identified across groups, particularly among EICs: Many mentioned wanting to be with loved ones, which reflects greater connectedness.

Social Support: Many EICs mentioned social support: family or friends picking up or reminding them to take medications. They were more "accepted" by HIV-uninfected friends and borrowed ART from HIV+ friends. One LTC mentioned that family gave him reminders, but it was "annoying."

Spirituality: Several LTCs and EICs mentioned spirituality as personal resource or used by others with HIV. In general, more EICs than LTCs reported belonging to faith communities, which reflects greater engagement.

Healthy/Drug-Free lifestyle: Some EICs and LTCs mentioned a healthy diet and drug-free lifestyle. Frequently, stopping substances enabled patients to re-engage.

Organizational Strategies: Many EICs used alarms, containers, etc. However, LTCs mentioned making medications a "habit" or coping by having a regular schedule. One LTC mentioned an organizational strategy but still could not take ART.

Thinking Positively about ART: Importantly, EICs believed that ART is helpful; increases quality of life, and discontinuation would be harmful and described optimism as beneficial. LTCs mentioned they tried not to think about HIV at all—and that choosing to ignore it was best. No LTCs mentioned positive thinking. EICs coped by accepting their diagnosis and thinking positively, and LTCs coped by suppressing thoughts and emotions.

Positive Experiences with ART: Many EICs–but no LTCs-spoke about positive experiences (feeling better, improved test results) with ART.

Positive Experiences with Healthcare: Several EICs-but no LTCs-described positive treatment experiences, including education and skills, support groups, social and family support in treatment and adherence, and physicians who made exceptions.

DISCUSSION

HIV+ people in the Leningrad Region face many barriers but have some facilitators. Overall, LTCs perceived barriers as insurmountable, while EICs perceived them as challenges. EICs were realistic but seemed more hopeful and optimistic. LTCs' isolation, and EICs' greater connectedness, optimism, and positive thinking, were expressed verbally and non-verbally. LTCs-but not EICs-expressed inaccurate beliefs about ART.

Qualitative techniques enabled access to the views of HIV+ individuals in the Leningrad Region on many factors associated with treatment. Limitations include the retrospective nature of the study; using an interpreter; focus groups instead of interviews as interviews may have revealed more detailed information, and a convenience sample rather than random selection.

Findings were unique because of treatment infrastructure problems and distrust of physicians but recalled those from HIV positive IDUs in Ukraine where stigma, police discrimination, inaccurate beliefs about ART, substance use, and privacy were barriers (Mimiaga et al., 2010). Facilitators and barriers in other cultures may differ. An African study found that transportation problems, poverty, and lack of food led to poor retention, but social support enhanced it (Geng et al., 2010).

CONCLUSIONS

Further research in other former Soviet States is necessary, but the barriers mentioned by participants are amenable to change, and addressing them should be an urgent priority in the RF and other places with high HIV prevalence. Many HIV-infected individuals benefit from ART in the Leningrad Region; however, more could benefit if the barriers are addressed.

Potential strategies to address structural barriers include: increasing treatment locations and staff; assuring a more reliable ART supply; ensuring ART availability in prisons and non-HIV hospitals; public education to reduce stigma by pointing out that HIV is treatable and that treatment helps individuals and reduces transmission by lowering viral load. For individual barriers: evidence-based approaches to treat depression and change inaccurate beliefs about ART; Evidence-based addictions treatment including recovery-oriented groups. One potentially helpful approach is Life Steps (Safren, Otto, 1999; Safren, Radomsky, et al., 2002), a brief Cognitive-Behavioral intervention to address inaccurate beliefs, skills building, and adherence; it has been adapted for use with HIV+ IDUs in Ukraine. EICs' hopefulness, optimism, spirituality, and connectedness are important, and a module encouraging them could help. Further research could explore low trust in physicians and test an adapted Life Steps intervention plus substance use treatment.

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Table 1

Background and demographic characteristics reported by mean, standard deviation, frequencies, and percentages for the *EIC* and *LTC* groups and for the entire sample

		EIC n=24	**LTC n=21**	**All N=45**
Age	Mean	33.5(SD=7.3)	33.8(SD=7.2)	33.6(SD=7.1)
Gender	Male	13(54%)	11(52%)	24(53%)
	Female	11(46%)	10(48%)	21(47%)
Race	White	24(100%)	21(100%)	45(100%)
Sexual Orientation	Heterosexual:	17(71%)	15(71%)	32(71%)
	Homosexual:	7(29%)	4(19%)	11(24%)
	Bisexual	0(0%)	2(10%)	2(<1%)
Marital Status	Single-Never Married	8(33%)	5(24%)	13(29%)
	Living with Romantic Partner	9(38%)	4(19%)	13(29%)
	Married	2(8%)	8(38%)	10(22%)
	Separated	2 (8%)	1 (5%)	3 (1%)
	Divorced	2(8%)	3(14%)	5(11%)
	Widowed	1(4%)	0(0%)	1(<1%)
Education	Secondary School	2(8%)	1(5%)	3(75%)
	Some College	18(75%)	16(76%)	34(76%)
	Bachelor's/Advanced Degree	4(17%)	4(19%)	8(18%)
Employment	Full-time Student	1(4%)	0(0%)	1(2%)
	Unemployed	6(25%)	7(33%)	14(31%)
	Employed Part or Full-Time	17(71%)	14(67%)	31(69%)
Route of Transmission				
	Needle Sharing Only	9(38%)	13(62%)	22(49%)
	Sexual Activity Only	10(42%)	5(24%)	15(33%)
	(Males: Sex with Males)	5	4	9
	Needle Sharing and Sexual Activity	2(8%)	1(5%)	3(7%)
	Other	3(13%)	2(10%)	5(11%)
CES-D Scores		18.12(SD=4.57)	20.67(SD=6.44)	19.31(SD=5.61)
Number of Close Friends		6.4(SD=7.9)	3.1(SD=2.8)	4.8(SD=6.2)

Table 2

Self-reported alcohol and substance use over the previous 6 months for the *EIC* and *LTC* groups and for the entire sample

Alcohol and Substance Use during the Past 6 Months	**EIC n=24**	**LTC n=21**	**All N=45**
Alcohol Use			
Drank ≥3 times/week	2(8%)	2(10%)	4(9%)
Binge drank	6(25%)	7(33%)	13(29%)
Drug Use			
Used any drug(s)	4(17%)	8(38%)	12(27%)
Marijuana	1(4%)	5(24%)	6(13%)
Opiate Painkillers	3(13%)	3(14%)	6(13%)
Heroin	2(8%)	1(5%)	3(7%)
Stimulants	1(4%)	2(10%)	3(7%)
Cocaine (Powder)	0(0%)	1(5%)	1(2%)
Benzodiazepines	0(0%)	1(5%)	1(2%)
Hallucinogens	1(4%)	0(0%)	1(2%)
Other	0(0%)	4(19%)	4(9%)
Treatment			
Ever treated for drug or alcohol abuse	10(42%)	16(76%)	26(58%)

Table 3

Barriers and Facilitators

Barriers	
Structural	Stigma and Discrimination Problems with Medical Providers Treatment Infrastructure
Individual	Employment, Caring for Others Inaccurate Beliefs about ART Practical Problems with ART Side-effects Substance Use Depression
Facilitators	
Desire to Live Social Support Spirituality Healthy/Drug free Lifestyle Effective Organizational Strategies Positive Thinking about ART Positive Experiences with ART Positive Experiences with Healthcare/Professionals	

Table 4

Structural Barriers Quotations.

Barrier	LTC or EIC	Quote
Stigma and Discrimination	LTC	"People, even my husband, are afraid of being in the same room." (Female, 24) "There is so much stigma and discrimination. We cannot even discuss tolerance. I only tell the people who are closest with me…." (Male, 30) "Security guards suspect us of having drugs– They want to search and read the [medication] insert, so I'm reluctant to travel… Many people hide their status from their families –Friends become enemies. The response to disclosing your status is obvious: If they don't beat you, you will become an outcast." (Male, 60)
	EIC	"The average person… thinks that if you have HIV, you must be a drug user or gay. People would prefer not to hire me, would prefer not to be my family, because of my HIV." (Female, 29) "I started discussing my status with people, and out of 15 friends, only 2 remained." (Male, 40)
Problems with Medical Providers	LTC	"Each medical chart is labeled with a triangle, and everyone knows its' meaning. Doctors won't touch you." (Male, 60) "If you tell the ambulance you have HIV, they won't come." (Female, 31) "Medical staff, after an MRI, started scrubbing it, when I was just lying there in my clothes, and no blood was taken." (Female, 24) "It's a huge problem to show up at a regular outpatient clinic, even a fee-per-service clinic. The better option is not to tell doctors about HIV." (Female, 28) "My doctor called to ask me to come in, but it was not out of concern for me but because they needed to meet their 'quotas' for the month." (Male, 35)
	EIC	"I had many ART failures. I felt so bad. I had to quit working. The doctors refused to change my regimen… I had Neuropathy. I couldn't walk. I had lypodystrophy and anemia… For 3 years I… was feeling bad." (Female, 33) "I wouldn't go the gynecologist because of her condescending attitude. Eventually, she changed." (Female, 26)
Treatment Infrastructure	LTC	"There are a limited number of providers. It's a monopoly. They mistreat people. Often, I am denied access to healthcare because I have no passport or IDs." (Male, 35) "If we are in a hospital but not an AIDS facility, they treat us like outcasts. I had 20 cells and was given preventive TB medicine. And now ART is given only by commission, and I'm on a waiting list." (Female, 33) "I was on ART but couldn't get medications in prison. We can't bring medications." (Male, 36)
	EIC	"There's a shortage of doctors. Sometimes I don't get medications but just vitamins. The newly diagnosed struggle with access, as the supply is minimal. We have to wait in lines every 1–2 months. You have to make an appointment, show up, wait, then get the prescription, and go to a special counter." (Male, 34) "For about a month, ART was not available, and I developed resistance. I had to switch regimens." (Male, 40) "I remember how difficult it was for me to go to appointments, wait in lines, and keep going back for medications. But when I started seeing the benefits, these hardships became less important." (Male, 28)
Too Busy: Employment, Caring for Others	LTC	"We need more doctors. I have a little girl. I have to make an appointment one month in advance, and I can't always find childcare. This makes me miss." (Female, 31)

Table 5

Individual Barriers Quotations.

Barrier	LTC or EIC	Quote
Inaccurate Beliefs about ART	LTC	"Medications don't work. It didn't have any impact on my immune status, improve my health or CD4 count, or decrease my viral load. So I stopped taking it." (Female, 33) "HIV medications are addictive, so I don't take them. As far as I know, we cannot kill any virus, so does it actually help?" (Male, 35) "Doctors abuse their power to prescribe medications for which they are being compensated, but not the most helpful ones." (Female, 24) "I'm upset about using ART; My CD4 increase was miniscule. I felt even worse. I didn't get colds or infections so regularly. Perhaps it was just psychological. It doesn't work." (Female, 33)
Practical Problems with ART	LTC	"They only dispense one month of medications. It's difficult to get them this regularly due to time constraints." (Male, 31) "The incompatibility with medications for other illnesses is a big problem." (Female, 31) "I have to explain to the police what these medications are for." (Female, 38) "Guests open my drawers, and the pills are labeled 'Medicine for HIV'." (Male, 39) "I work, and this prevents me from taking medications in a timely manner. I don't want to cause unpleasant conversations. I work long hours, and they don't give you enough medications when you get them. If I go on long trips, it doesn't work. I'm not able to take them no matter what." (Male, 28)
	EIC	"For about a month, ART was not available, and I developed resistance. I had to switch to another regimen." (Male, 40) "People at work watched me take my medications. They asked me what is wrong with me. I had to make things up, like I am taking medications for allergies. I had to resign because I was so discriminated against." (Male, 35)
Side-Effects	LTC	"I quit because of very severe side-effects. I was diagnosed in prison. They were choosing medications based on availability. I haven't been able to take ART with the harsh side-effects." (Female, 31) "Side effects always get in the way. The ones that bothered me most were rashes and jaundice. Hepatitis C and HIV treatment are very hard together." (Female, 31)
	EIC	"I developed lypodystrophy but wanted to take ART. I was admitted, and they changed my regimen." (Male, 40) "Of course there are side-effects, but this resolved. I developed anemia, and my doctor modified my regimen." (Female, 26)
Substance Use	LTC	"Drunk people aren't good at taking medications." (Male, 60) "We have nothing to take these medications with except vodka… If I abuse alcohol for long, I get confused and disoriented." (Male, 39) "When I was drinking, I had to choose between drinking and ART." (Female, 38) "Heroin interferes big time." (Male, 31) "Whenever I use drugs, I'm not motivated to take ART." (Male, 30) "I stopped ART when I started using drugs. One doctor said that if I was drinking, I shouldn't take ART. Whenever I'm on drugs, I don't need anyone to talk to me…. I was on drugs without ART, and I had many chances to die without suicide." (Male, 32)
	EIC	"Often, drug use is a barrier… I derive this from my experience, but when I started ART, I was no longer a drug user. But friends usually remember to take their medications when they get their next fix. Alcohol gets in the way. A couple of drinks – you're fine, but abusing alcohol, getting drunk, you will forget." (Male, 33) "I had a friend abusing drugs who refused to take ART because it interfered with drugs." (Male, 40) "It's very difficult for the average person to get an HIV medical appointment, but if you take drugs, it's almost impossible." (Female, 29)
Depression	LTC	"I quit taking ART because… I was very depressed."(Female, 33) "Often, [ART] isn't a priority –Often, I don't want to live. When my CD4 cells are very low, it's hard. I'm getting discouraged."(Female, 33)
	EIC	"Being diagnosed was like a head injury. I wanted to commit suicide. I felt like I had a label on my head that said HIV. Later, I decided against suicide." (Female, 35) "ART makes mental health worse. There's depression, and there's a temptation to leave everything and forget about it." (Female, 36)

Table 6

Facilitator Quotations

Facilitator	LTC or EIC	Quote
Desire to Live	EIC	"A desire to live keeps me taking my medications." (Male, 33) "It was a strong desire to live – We were weak, but all of a sudden, I learned that ART would prolong my life. I took it and started to improve." (Female, 26) "My little one is an incentive." (Female, 36)
	LTC	"I've decided to live to the age of 80 like all my relatives."(Male, 60)
Social Support	EIC	"My daughter reminds me–She doesn't understand what kind of pills. My husband too."(Female, 36) "My loved ones remind me."(Male, 29) "No one has rejected me. I'm grateful."(Male, 32) "Many friends who know about my status are supportive, and I don't experience negativity." (Male, 28) "Support from friends means a lot."(Male, 35) "I ask my friends to call and text me. Peers and support groups in the hospital helped me. I have new interests and new friends. I try to help others… accept their diagnosis."(Female, 26) "I joined a support group, and many are aware of my status – I'm comfortable, which enhanced my adherence – It's the support of the people around me."(Male, 29) "We keep an eye on each other taking lifelong medications."(Male, 28) "I use the internet to find and exchange pills with friends."(Female, 33) "I borrowed pills from others. I was helped by peers and support groups in hospital. I have new interests and new friends. I try to help others."(Male, 34)
	LTC	"Sometimes, loved ones remind us to take medications and ask how we're feeling. It's annoying." (Male, 39)
Spirituality	EIC	"I got baptized at 24, and my life changed. I became a different person. I became strong. I went to church and saw a Priest. He gave education about HIV. He told people to take ART. Everyone at the church loves him. The church really helps me."(Female, 26) "I like Mantras in the evening to get rid of negative energy."(Male, 28) "I'm an Atheist, but in the hospital, there was a chapel, and people prayed there, and I saw they were helped."(Male, 40)
	LTC	"Going to church made me feel better. When I found out I had HIV, I was looking for ways to cope, and I tried to go to church once or twice per week, and this made me feel much better." (Female, 24)
Healthy/Drug Free Lifestyle	EIC	"For a long time, I was on drugs. But once I got clean, I got to know people who were taking good care of themselves, taking medicine, and I learned from them."(Male, 29)
	LTC	"The change was: I got sober and started thinking more of my health. I was also imprisoned and evaluated my health behind bars. I want to live for 5 more years. I'm sober now. I need to know what's going on in my body, and when the times comes when to start therapy, but I need to know for sure the time is right."(Male, 36) "We increase our fruit and vegetable intake and do physical exercise."(Female, 33)
Positive Thinking about ART	EIC	"Nine months after my diagnosis, I was ready for acceptance. I have a positive attitude. I like to be seen by my doctor. She's there for me. I take medications for my own sake."(Male, 28) "I was upset but decided not to focus on the negative."(Male, 36)- "I'm sure that positive attitude improves immunity. Medications help without any doubt. It's better not to miss; if I forget to take a pill, I will take it hours later."(Male, 40) "I take ART due to improved quality of life. We can't give the virus any opportunity."(Male, 33) "HIV medications are my life… a continuation of my life."(Male, 57) "Taking medications is like a lifestyle."(Male, 35) "ARTs are important to be able to live."(Female, 33) "If I miss doses, I may develop resistance."(Female, 26)
	LTC	"I try NOT to think about my HIV. I just accept it."(Female, 33) "I have no time to think about my HIV. I try to stay busy not to think about it. I have no emotions related to quitting treatment."(Female, 33)
Positive Experiences with ART	EIC	"Taking my medications is based on experience. I observed positive effects, so it kept me taking my medications."(Male, 32) "All of the sudden, I learned that medications will prolong my life – I took medications and started to improve."(Female, 26)
Positive Experiences with Healthcare/Professionals	EIC	"I've been attending group for years – this is where I learn everything – pre – post-test counseling, diagnosis, prognosis… They referred me to a social worker, and I started to improve. This is where I spend my leisure time."(Male, 29)

Facilitator	LTC or EIC	Quote
		"At the ____, there was no difficulty. I like my doctor. She is there for me. I take medicine for my own sake." (Male, 28) "For half a year, I lived in Southern Russia – for the first time I got a 3 month supply. I gave power of attorney to my friend, and he picked them up for me."(Male, 40) "I am able to call my doctor. My friends help me to pick up pills."(Female, 33) "Support and explanation relieves my tension around taking medications."(Female, 33)