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# Social Maladaptation of Teenagers with HIV Through Discontinuation of Antiretroviral Therapy<sup>1</sup>

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## Abstract

**OBJECTIVES:** The aim of this article is to identify the causes of antiretroviral therapy (ART) interruption by teenagers and to determine preventive solutions. **THEORETICAL BASE:** The article is theoretically based on international and Ukrainian studies of adherence to ART formation. **METHODS:** HIV-positive young men and girls aged 14-19 years took part in the survey. The data were collected by defining focus groups and a Google-form questionnaire. **OUTCOMES:** It was found that ART influences self-perception, behaviour, communication, life-style and identity of a teenager living with HIV, thus affecting the context of their socialization. The factors that lead to discontinuation of ART by adolescents (inconvenient treatment plans, side effects, non-acceptance of diagnosis and restrictions, incomplete information on ART and unreliable sources of such information, conflicts with parents and stigmatization of children living with HIV) were identified. **SOCIAL WORK IMPLICATIONS:** Training parents and health care workers to be able to explain to the child the peculiarities of ART; training children in life skills with regard to their HIV status and ART; teaching parents the communication skills to deal with teenagers; setting up support groups for children and their parents; organizing support

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campaigns in communities to counteract stigmatization; providing social services to families of children living with HIV.

### Keywords

HIV, teenagers, socialization of children living with HIV, prevention of HIV, antiretroviral therapy (ART), adherence to ART

## INTRODUCTION

From the onset of the HIV epidemic in late 1980s until the beginning of 2022, 84.2 million [64–113 million] people have been infected with the HIV virus, and about 40.1 million [33.6–48.6 million] individuals have died of HIV. According to World Health Organization (WHO), globally, around 38.4 million [33.9–43.8 million] people were living with HIV at the end of 2021. Currently, worldwide an estimated 0.7% [0.6–0.8%] of the adult population aged 15–49 years live with HIV (World Health Organization, 2022), although the burden of the epidemic continues to vary considerably between countries and regions.

Ukraine, the largest country in Europe, continues to have one of the highest HIV prevalence in the region of Eastern Europe and Central Asia (EECA) (Skrzat-Klapaczyńska et al., 2022). According to official statistics, for the period from 1987 to April 2022, 341,084 cases of HIV infection among citizens of Ukraine were officially registered in the country, including 114,487 cases of AIDS and 49,751 deaths from diseases associated with AIDS. As of April 1, 2022, 144,206 HIV-infected citizens of Ukraine were under medical supervision in health care institutions (the rate of 382.1 per 100,000 population), including 44,675 patients diagnosed with AIDS (118.4 per 100,000 population) (Public Health Center, 2022). The data from the most recent serological monitoring showed that in 2021 only every second individual living with HIV was aware of their HIV status and was linked to the medical facility (Public Health Center, 2022), and even though the epidemic is mostly driven by injectional drug use (Meteliuk et al., 2020; Sazonova et al., 2020), the prevalence of HIV remains extremely high in blood donors (Tolstanov et al., 2014) and men who have sex with men (Trickey et al., 2021). During 2018, 50 new cases of HIV infection, 24 cases of AIDS, and 9 cases of death from diseases associated with AIDS were registered daily in Ukraine (Public Health Center, 2022). The proportion of children with congenital HIV also remains rather high. As of April 1, 2022, over 4,000 children have been registered as born from HIV-positive women.

Antiretroviral therapy (ART) is the only means of treatment of HIV infection (Aguilar-Company et al., 2022). It involves daily intake of a lifelong combination of medications and is recommended by WHO for every individual living with HIV (Wattanasirikosone, Modnak, 2022). Systematic ART also ensures proper quality of life of people with HIV: their state of health status allows them to not limit themselves in work, leisure time, and interactions. ART not only helps to preserve or even restore people's immunity but also minimizes the risks of infecting others. Unless diagnosed and treated in a timely manner, the condition can severely impair the quality of life of the infected person, leading to AIDS, the phase of HIV-infection where the body of the infected person loses the ability to counteract diseases that present no risk to healthy people. Discontinuation of ART significantly increases the risks for both HIV-infected individuals and their sexual partners.

Over the past five years, Ukraine has made significant progress in the treatment of HIV-positive people. The coverage with ART almost doubled (from 56,000 to 103,000 people), as well as adherence to treatment after 12 or more months from its initiation increased from 69% to 88%. As of April 1, 2022, 103,194 individuals were receiving ART in Ukraine, among whom 2,606 patients are children under 18 years old (Public Health Center, 2022). However, ART will only be effective



if the patients are committed to the treatment, a state in which they are motivated and able to fully adhere to a treatment regimen prescribed by healthcare providers. Poor adherence to ART leads to interruption of treatment, which totally nullifies its positive outcomes and may be associated with individual issues of a person living with HIV (Kim, 2014).

Multiple research shows that children with any chronic illness are prone to be at greater risk for mental health issues, including depression, anxiety, and feelings of isolation (Hein et al., 1995). Children living with HIV have additional risk factors in complexity of their illness and treatment as well as in the adverse psychological outcomes and circumstances. Studies conducted worldwide demonstrate that the prevalence for mental health disorders in children with congenital HIV infection vary from 55% to 61% (Leserman, 2000). The most commonly observed disorders are anxiety followed by attention-deficit hyperactivity disorders, conduct disorders, oppositional defiant disorders, and mood disorders (Mellins et al., 2009). Social work is one of the tools that can form adherence to ART in an individual living with HIV, prevent him/her from interrupting treatment, and provide assistance in overcoming personal issues. Social worker's support while receiving ART helps to accept the diagnosis, find the motivation to take antiretroviral drugs, understand the treatment regimen and align person's lifestyle with the receipt of ART, and get psychological support related to the difficulties with adaptation to life-long treatment. Provision of social services will help to overcome complex life circumstances that may cause mental health problems and thus distract from treatment. However, for this, social workers should possess relevant knowledge on the reasons for ART interrupting as well as have a clear understanding of a mental state of a person living with HIV ready to start ART.

The relevance of the research is supported by the fact that in recent years Ukraine has been leading Europe for the growth rate of the HIV infection, a disease mainly caused by reckless behaviour.

## **The subject of research**

One of the groups of people living with HIV who show the highest risk of ART discontinuation is preadolescent and adolescent age of individuals. Currently, there are a total of 4,000 HIV-positive children registered in medical institutions, 2000 of which are teenagers. Organizations that provide social and health services to such children and their families face high rates of treatment interruptions in children 12–19 years old and do not have efficient means of responding to such cases.

According to the only study conducted in this area in Ukraine, the reasons for interruption of ART by both adults and children are adverse side effects of ART medications, willingness to take a break from their use, disbelief in the effectiveness of ART, lack or unavailability of medications, fear of HIV status disclosure to others, and just forgetfulness (Balakireva et al., 2019). However, during this study, the specific reasons for ART termination specifically among adolescents were not considered.

The research team explored this problem in the context of the socialization of a child living with HIV. Socialization was determined as the process of an individual's entry into society, during which he acquires certain social status, integrates into the system of social relationships, obtains social experience as well as develops social qualities of the individual. It was assumed that interruption of ART among teenagers happens not only due to the peculiarities of their treatment course but also due to general issues of socialization among people of this age and the specific children's reaction to information about their HIV status and the associated restrictions. In turn, interrupting ART can deepen the social maladjustment of a teenager - a condition in which he has limited opportunities to meet needs and development due to aggravation of personal problems and deterioration of physical and mental health.

## **Research focus**

This article aims to identify the causes of ART interruption by adolescents and to come up with preventive measures.



### Objectives:

- To reveal specific features of socialization of a child with HIV, related to their HIV status and the need for systematic antiretroviral therapy
- Define the attitude of HIV-positive teenagers to ART and the associated problems
- Identify the factors that cause adolescents to discontinue ART
- Develop recommendations on how to make HIV-positive teenagers more inclined to ART and lower the risk of discontinuation

## METHODOLOGY

We suggested combined research implemented in several stages with the use of quantitative and qualitative research methods (Table 1).

Table 1: Survey structure

Method	Stage of the study	Description
Focus group	<b>A quality research survey</b> 14 HIV-positive boys and girls 14-19 years of age who are members of the public association “Youth Organization Teenagers of Ukraine”	<ul style="list-style-type: none"> <li>- Peculiarities of socialization of a child living with HIV</li> <li>- Opinion about ART</li> <li>- Side effects and negative consequences of the therapy</li> <li>- Reasons for interruption of therapy</li> <li>- Reasons for returning to ART</li> </ul>
Google Form Questionnaire	<b>Representative survey</b> 67 persons with HIV-positive members of the public association “Youth Organization Teenagers of Ukraine”, namely 43 were girls and 24 boys aged 12-19	<ul style="list-style-type: none"> <li>- Opinion about ART</li> <li>- Sources of information on ART</li> <li>- Negative effects of ART</li> <li>- Experience of discontinuation</li> <li>- Causes of discontinuation</li> <li>- Factors of discontinuation</li> </ul>
Round table discussion	<b>Verification of results</b> VI All-Ukrainian forum of pupils of the PA “Youth Organization Teenagers of Ukraine” NGO	<ul style="list-style-type: none"> <li>- Discussion of the survey results with the participants</li> </ul>

During the first search stage, the goal was to get reliable information about the socialization of children, adolescents and young people living with HIV, their attitude to ART and their experience with it.

Research methods: focus group, qualitative analysis of the obtained data.

At the second stage a representative survey of children with HIV was conducted in order to determine the factors of ARF interruption and determine ways to prevent it. The method used was survey questionnaire and quantitative analysis of the data obtained. The survey was carried out remotely using a Google-form. The questionnaire consisted of 30 questions with answer options about the participants' perception and attitude to living with HIV and ART, problems caused by ART use, experience of therapy interruption in adolescence, and possible ways to stop it. The main target group of the interview included children and young people aged 12–19 who live with HIV and are members of the NGO “Youth Organization Teenagers of Ukraine”. The total reached 67 persons selected based on their availability. The invitation to respond to the questionnaire was sent to all participants of the organization that met the eligibility criteria. The responses of all those who agreed to fill in the questionnaire were taken into account.



At the third stage, the goal was to verify the results of the study and the conclusions made by discussing them with the study participants and experts. Methods: focus group, round table.

The selection of a mixed-methods approach was related to the need to assess the socio-psychological and socio-cultural conditions of socialization among adolescents, which may be interrelated with the interruption of ART, evaluation of adolescences' reasons for ART interruption, their vision of this issue and possible ways to overcome it. Qualitative research at the first stage was intended to provide an opportunity to clarify hypotheses regarding factors related to socialization in adolescences, while the quantitative approach at the second stage was to test these hypotheses, and at the third stage to interpret the obtained results and design recommendations to address the problem.

## RESULTS AND DISCUSSION

At the first stage of the research, a focus group was conducted with HIV-positive teenagers who receive social support from the PA "Youth Organization Teenagers of Ukraine". 14 HIV-positive young men and girls took part in the focus group. The focus group discussion lasted for about 2 hours with a break.

During the focus group, a number of narrative and reflective questions were discussed, in particular:

- How do you feel about ART? What does it give you?
- Where do you get information about HIV and ART? What sources of information do you trust the most? Why?
- What difficulties did you have related to receipt of ART?
- How did taking ART affect your lifestyle? Relationships with others?
- Why might your peers have decided to stop or give up ART for a certain period of time?
- If you have had such situations, please describe your own experience? What made you stop taking ART medications? How did it affect your life? What prompted you to return to treatment?
- What can be done to help your peers adhere to ART?

In the course of the focus group the children appeared to be very interested and open-minded. Many participants shared their personal experience with the positive HIV status, interactions with their parents, peers and professionals, and even tragic incidents in their lives that were somehow related to HIV. The focus group results showed that their socialization is significantly affected by three factors: awareness of their being different from other children, the need for regular use of ART and the stigma that can result from disclosure of their HIV status.

Based on the discussion with FG participants, the following features of their socialization related to HIV status were identified:

- The vast majority of people were infected with HIV at birth are on ART from early childhood and have to adhere to a rigorous treatment regimen.
- A large number of children who lost their parents are brought up in foster care or in institutional care.
- They learn about their HIV status mostly over their teenage years, and it stirs controversial feelings.
- Some of them are mad at their parents for infecting them and not informing them of their status.
- Children are concerned about the risk of disclosure of their HIV status on the one hand, and on the other hand, they need to share their experiences with others.

The discussion in the focus group was mainly about the ART. According to the results of the discussion, children have a generally positive attitude towards ART and an understanding of its effects. They consider therapy as a prerequisite for a healthy life. Below are a few expressions that were said during the focus-group discussion: *"An inevitable part of our life... Without it, our life is not a life, but a struggle ..."*; *"It helps to find a way to stay afloat, ... It helps to live well and not to worry too much about your health..."*; *"If you do not take the medicine, in the worst case – you die, if you do not*





*change your mind...*”. But some people express distrust to the information about its properties and doubts in its necessity saying, for example, *“I tried it a lot of times. And so far nothing happened to me... That is why my attitude towards the therapy is generally neutral...”*. Dislike of therapy in such children is reinforced by a general distrust of any information from adults and an attitude towards it as a limitation that needs to be overcome.

In the course of the focus group, side effects and negative consequences of the therapy were discussed. Most of the participants of the group mentioned them. First and foremost, the following were mentioned:

- Negative somatic sensations and psychiatric reactions to the medications (headache, nausea, vomiting, nightmares, and hallucinations). Respondents noted, *“I think everyone has at least one ‘side effect’...”*; *“The mildest are headaches and incomprehensible dreams. A typical person doesn’t have such dreams, I think...”*; *“When I was a child, when I first started therapy, I suffered a lot from hallucinations... I had such obvious hallucinations that they followed me up to the age of 11...”*.
- The children said, *“The therapy was a way of life, and I had to adapt my way of life to it. I had to take the therapy... at 8 in the morning and at 8 in the evening. At 8 in the morning it is impossible to wake up to have it during the school holidays”*. It is especially painful in childhood and adolescence, because in order to take therapy you have to forgo spending time with friends, entertainment, rest.
- Fear of status disclosure when seen taking medication (if someone notices and asks uncomfortable questions). One of the girls said, *“My friends are asking me what this is. I did not know how to explain it...”*.
- The control by the adults was intense. At the same time, according to participants’ comments, fear of disclosure was reinforced by adults themselves, by their cautions about the need to maintain their status secret. For example, *“Your family, those who support you, are somehow oppressive. You feel nasty...”*.

During the discussion, three of the participants shared their own experience of discontinuation. It was first of all related to:

- Unmanageable treatment regimen and bad side effects (*“I started taking the therapy and I felt constantly nauseated, I take a pill and throw up... and it is so big and I have to take two of them, and I have to take them in the morning... So I “gave up” on them and did not take for a year”*)
- Unwillingness to accept the diagnosis after the child’s HIV status has been disclosed, not being ready to accept the fact that you have this disease and that you have to restrict yourself during your life (*“When you are told, you just feel hatred, and you can avoid taking pills to get back at everyone.”*)
- The disclosure of the child’s status by peers (peers, teachers) and stigmatization that followed, or fear of it (*“The teacher told everyone at school that I have the status...”*). After that everyone began to make fun of me... and I did not take pills for two years...”, *“I was going to go to the camp... I did not take pills with me, so there would be no questions about what I was carrying in packs”*)
- Conflicts with parents and desire to get rid of their supervision, to make decisions independently, to protest against pressure from parents (*“I stopped for the first time when they told me I had HIV. My mom started to pressure me... I had a really bad relationship with her.”* *“Well, more often it was a rebellion... On one side: Oh, I’m fed up with everything, I don’t want it anymore, and on the other - you know what you have to...”*)
- A wish to experiment, to see for oneself whether the therapy is really as important as they say it is (*“My second case is an experiment: what will happen if I don’t take the pills?”*). At the same time non-acceptance of the diagnosis was often connected with difficult relationship with parents, being upset with them or the guardians.



The reasons that made the participants resume the therapy were a separate subject for discussion. The participants with experience of discontinuing therapy mentioned the following reasons:

- Significant deterioration of health, fear of death, which the youngster experienced (“I spent over a month in hospital... and I finally realized that I could die just because I don’t take pills...”)
- Sense of responsibility for themselves, their future children, other people who worry about them, love and support them (“I remembered what it was like, I remembered how I felt because my parents did not bring me up well, I saw them die, and I realized that I have to accept it because I want to have children and raise them at least until the age of 18”)
- The explanations and opinions of parents, doctors, and other people. Especially important were the opinions of the people living with HIV and had a similar experience of interrupting the therapy (“They just told me that I had 15,000. I said ‘Well, that sounds like a lot. But they say a lot is millions!’ And I do not have enough. I started taking pills again, every day at a precise time, and my condition stabilized to the stage where HIV is not detectable in blood at all...”, “I was told off at the hospital, then I went to the centre, and there was a guy who was older than me, who explained everything in detail: what is happening in the body, how the therapy works... And it had a good effect, I started taking therapy always, constantly...”).

Analysis of the results of the focus group discussion allowed adjusting the hypotheses of the study:

- Teenager’s termination of treatment is caused by severe adverse effects and an inconvenient treatment regimen
- Teenager’s decision to terminate treatment may be related to incorrect information about ART and negative attitudes related to unreliable sources of information about it
- Teenager’s termination of treatment can be caused by conflicts with parents or guardians, teenage protest reactions, stigmatization by peers
- Teenager’s self-esteem and self-confidence can also be moderating factors

For hypothesis testing, we developed a method of questionnaire survey, the results of which could be presented quantitatively and by means of statistical analysis to determine the severity of certain factors of ART interruption and to provide recommendations for its prevention. The survey questions were aimed at assessing the respondents’ experiences regarding ART termination and its reasons. Among possible reasons for ART termination, the survey included an assessment by the participants of: inconvenient treatment regimen and severe adverse effects; fatigue from treatment; non-acceptance of one’s HIV status and negative attitude towards it; not understanding the need for treatment and not realizing the risks of its interruption; conflicts with parents (or guardians) and excessive control and restrictions on their part; the teenager’s fear of disclosing their HIV status to others; stigmatization by others after disclosing the status; protest against treatment as externally imposed by adults; the desire to experiment with the refusal from treatment and to test its true consequences. In addition, the survey included questions aimed at evaluating whether the following possible factors of ART interruption are present: (a) attitude to living with HIV as a significant event in their life; (b) HIV awareness and the impact of this knowledge on daily life; (c) the experience of disclosing their HIV status and its consequences; (d) attitude to ART and understanding of its effect on the body and on the course of the disease; (e) sources of information and its content regarding ART; (f) presence and severity of adverse side effects of ART and inconveniences associated with it; (g) self-assessment of their own personality and relationships. The attitude of adolescents to different ways of maintaining adherence to ART was studied separately. In order to confirm the effect of the above listed factors, study participants’ responses were compared regarding having and not having ART interruption experience using the means of determining statistical significance between the groups. The study confirmed the overall positive attitude of teenagers to ART. Less than 10% of respondents questioned its usefulness. The vast majority of the participants have a generally correct understanding of the positive effects of therapy, only a few of the participants are doubtful about it (Fig. 1).



Figure 1: Attitude of HIV-positive teens towards ART

ART helps me survive	70%	It helps maintain a certain level of immunity that is sufficient for survival	94%
ART helps me to maintain a certain state of health and avoid deterioration of my health	52%	It helps other people from being infected by HIV	82%
I am glad that ART exists	46%	It helps restore the level of immunity that is sufficient for survival	73%
Regular ART helps protect others	18%	ART helps avoid the illnesses an HIV-positive person may get	72%
Hard to say	5%	ART helps treat the illnesses an HIV-positive person may get	46%
I am not sure ART is necessary and useful	3%	ART helps the body get rid of the virus	8%
ART causes inconveniences and problems in my life	2%	ART has a negative effect on the human body and the organs	8%
The adverse effects of ART prevail over its benefits	0%	ART does not have a significant influence on the human body	%
The distribution of positive replies to the question: "What do you think about ART?", % (N=67)		The distribution of positive replies to the question: "What is the effect of ART on the body of an HIV-positive person?", % (N=67)	

The study showed that the main sources of information on ART for adolescents were parents and guardians (85% of respondents) and physicians (82%). A quarter of the respondents tried to independently find information about HIV on the Internet (both on medical resources and on general information sites), searched for relevant literature, and talked about it with other people living with HIV; 21% of respondents received information about HIV at trainings.

Most of the patients (56%) did not remember negative effects of ART or could not recognize them. Others reported uncomfortable side effects (25%), intrusive supervision by parents or guardians (22%), uncomfortable treatment (up to 18%) and fear of stigmatization (15%).

26.9% of study participants reported their own experience of ART interruption in the course of the survey (Table 2). Those who reported this experience had more than two cases of interruption in the majority of cases. The most common reasons for treatment interruption, as admitted by the respondents, was being tired of the therapy and the desire to live a normal life, uncomfortable treatment plan, lack of knowledge or awareness of risks associated with discontinuation of therapy, conflicts with parents, and protests against being pressured towards treatment.

Table 2: Experience of participants regarding ART interruption (N=67)

Parameters	Experience of ART interruption			
	So		Ni	
	n	%	n	%
<b>Total number</b>	18	26.9	49	73.1
<b>Sex</b>				
Women	13	30.2	30	69.8
Men	5	20.8	19	79.2
<b>Age</b>				
12-15 years old	4	13.8	25	86.2
16-19 years old	13	35.1	24	64.9

According to the responses of participants with relevant experience, the most common reasons that made them discontinue the therapy were feeling tired of the therapy and the desire to live a normal



life (44%), uncomfortable treatment plan (39%), lack of awareness or ignorance of risks associated with discontinuation of therapy (33%), conflicts with parents and protests against treatment (28% each). Factor analysis allowed us to identify three groups of interrelated reasons that, in the opinion of participants, triggered their decision to discontinue ART (Fig. 2). We called the first group of reasons “HIV withdrawal” (uncomfortable therapy regimen, feeling of discomfort due to IDU status, withdrawal from therapy and desire to lead a normal life), the second group - “Protest against treatment” (protest against the imposition of treatment, confrontation with parents, lack of awareness of the risks of discontinuation due to the absence of side effects of therapy for the teenager); the third - “Fear of disclosure” (afraid that others will find out about their HIV status being unaware of the risks of interruption and absence of conflicts with parents). The groups of factors above have been admitted by the participants of the survey.

Figure 2: Reasons for discontinuation

HIV Withdrawal	Protest against treatment	Fear of Disclosure
Uncomfortable treatment plan	Protest against being pressured into treatment	Fear of disclosure of their HIV status
Feeling lost due to the HIV status	Conflicts with parents	Lack of information or unawareness or the risks related to the therapy
Feeling tired of the therapy and desire to live a normal life.	Lack of information or awareness of the risks related to interruption of the therapy	Absence of conflicts with parents
	Absence of grave side effects	

Statistical analysis of the differences in participants’ responses to the questionnaire depending on their experience of treatment discontinuation allowed us to identify the factors that triggered their decision to stop taking medications (Table 3). According to the data we received, these factors were: the existence and number of side effects; the inconveniences associated with taking ART; an uncertain attitude to ART; lack of parental explanations and consultations from physicians; failure to obtain information from books, the internet, and training, and communication with others living with HIV; lack of information or incomplete information about side-effects and how to manage them; relatively low (compared to others) self-esteem of the teenager.

Table 3: Causes of ART interruption (N=67)

Factor	Experience of ART interruption				P-value*
	Yes		No		
	n	%	n	%	
<b>Total number</b>	18	26.9	49	73.1	
<b>Occurrence and number of side effects</b>					
None	8	44.4	42	85.7	0.001
Nausea, vomiting	6	33.3	4	8.2	0.010
Adverse psychological reactions	5	27.8	0	0	0.000
<i>Average number of observed side effects</i>	<i>0.89</i>		<i>0.14</i>		<i>0.000</i>
<b>Inconveniences of taking ART</b>					
None	6	35.3	31	63.3	0.045
Uncomfortable therapy schedule	4	23.5	1	2	0.004
The need to explain to those around what is happening	5	29.4	7	14.3	0.164
Excessive supervision by parents (guardians)	9	52.9	6	12.2	0.001
<i>Average number of inconveniences</i>	<i>1.44</i>		<i>0.76</i>		<i>0.074</i>



<b>Unsure attitude towards ART</b>					
Objecting to the fact that ART allows you to live a full, quality life.	9	50	12	24.5	0.046
Questioning the need for and benefits of ART	2	11.1	0	0	0.018
Objecting to the fact that ART protects from opportunistic infections	4	22.2	1	2	0.020
Objecting to the fact that ART helps the body to avoid HIV	14	77.8	21	42.9	0.037
<i>Average number of correct responses regarding the efficiency of ART</i>	2.6		3.1		0.057
<b>ART Awareness</b>					
Absence of an explanations from the parents	6	33.3	7	14.3	0.081
Absence of medical consultations	5	27.8	5	10.2	0.074
Lack of information or receipt of incomplete information on side effects and ways to manage them	4	23.5	3	6.2	0.048
<b>Self-assessment</b>					
(on a 10-point scale)					
<i>Will power</i>	5.9		7.9		0.003
<i>Emotional state</i>	6.0		7.3		0.014
<i>Confidence</i>	5.8		7.5		0.008
* Significance of differences according to $\chi^2$ criterion for nominal scales and U by Mann-Whitney for metric scales					

While responding to the questionnaire, the participants assessed which of the suggested measures could prevent their peers from interrupting ART. In the opinion of the vast majority of patients, these measures could include a calm explanation why the therapy is needed and how it works. More than a third of the patients also reported the following in connection with ART interruption:

- Parental control
- Kind relationship with parents (guardians), other family members
- Knowledge of specific examples of people who have tried to discontinue therapy or withdraw from it
- Trustful relations with professionals (physician, psychologist, social worker), who can listen, consult, support

The results of the research and conclusions were presented and discussed at the IV All-Ukrainian Forum with the participation of active members of the youth organization “Teenagers of Ukraine”, including those who live with HIV. During the discussion, the participants suggested that inaccurate information about ART is the main reason for the teenagers’ misconceptions and negative attitudes towards ART: “*Maybe someone explained it incorrectly, or they just didn’t understand it... Everyone has a different understanding, that’s why some people see it differently.*” Participants said that most children living with HIV receive information about ART from their parents (guardians) and doctors, but not all parents and doctors themselves have the correct information and know how to present it to their children: “*Parents may not know much and will only tell you what they know*”, “*Not all doctors [general practitioners] are well aware of this. Some still stigmatize you*”. The participants of the discussion agreed that the best source of information is professionals who specialize in HIV research and treatment, as well as other people who live with HIV and have correct knowledge and experience in treatment.

In the opinion of the participants of the discussion, many more children have experience of ART interruption than indicated during the survey: “*I think at least once everyone has forgotten or done something [that prevented them from taking the therapy]. You just have to sit at home all the time and wait until it is time to take the pills.*” Some of the respondents could either not remember some short-term interruptions or be reluctant to report them in the questionnaire.



The participants mostly agreed with the identified reasons for the interruptions. Among reasons that, in their opinion, could have contributed to interruption, the participants emphasized the fact that their parents were not telling their children about their HIV status and about the fact it was ART that they were taking. Because of this, the children were not very diligent about it: *“When I didn’t know about my status, my mother gave me the pills and said it was for my immunity. But I thought to myself: “If it’s for my immunity, it’s not a big deal, I can skip it”.*

The participants have emphasized the importance of complete and correct information about ART for due diligence. However, in their view, each person perceives the information individually, not all calm explanations have the desired effect, there are those who trust only their own experience or the experience of other acquaintances: *“I also think it’s either my own experience or the experience of people who haven’t been taking the pills and had something terrible happen to them. If your grandparents or someone else tells you to take the pills, and you do not want to, you will not do it, but if you see an example, either your own or someone else’s, then it will have an effect”.*

Thus, in the course of the discussion with the participants of the PA “Youth Organization Teenagers of Ukraine” forum, the findings of the research were confirmed regarding the impact of incorrect information about ART on the interruption of the ART, unreliable sources, interactions with parents and siblings, teenage concerns and reactions; recognized the importance of training doctors and parents on how to properly communicate information about HIV and ART to children and how to reach teenagers living with HIV, provide support from peers, more experienced and trained people who also are also HIV-positive status and have experience of taking ART.

## CONCLUSION AND RECOMMENDATIONS

The results of our survey demonstrated that ART affects self-perception, behaviour, interpersonal communication, way of life, identity of a teenager living with IDU, and affects the context of their socialization. These results are somewhat unique because multiple studies showed that self-efficacy, self-perception behaviour and other important social factors are positively correlated with adherence to ART (Langebeek et al., 2014; Jones et al., 2015), however most of these studies are conducted among adults and very few among children and adolescents, and there is not a lot research available on the effect of ART on these factors. Various studies revealed the role of social support in adherence to ART, especially that coming from close family members such as parents and/or caregivers (DiMatteo, 2004; Dulmen et al., 2007). A recent study from Thailand demonstrated that family and social relationships significantly contribute to better adherence to ART, overall health outcomes, and quality of life (Rotheram-Borus et al., 2010). However, even though there is research showing the importance of self-perception, behaviour, and interpersonal communication (Poudel et al., 2015; Nabunya et al., 2020), there is still a gap in examining of how family factors, such as family cohesion, child and caregiver interactions, and a child’s perceived support from parents and caregivers, are associated with ART adherence self-efficacy among adolescents living with HIV as well as the opposite direction on the effect of ART on these social factors.

Another important result of our study is that the risk of interruption of ART is related to (a) uncomfortable treatment plan, side effects, (b) failure to accept the diagnosis and a general withdrawal from treatment and limitations, (c) incomplete information on ART from unreliable sources of such information, (d) confrontational and uncooperative relationship of the teenager with their parents and doctors, and (e) stigmatization of children living with HIV. Multiple studies from across the world show that among adult populations the most common factors associated with interruption of ART are mostly health-care-provider-related conditions like loss of health documents or enacted discriminatory behaviour of healthcare workers (Tabatabai et al., 2014) as well as those related to the ART-related characteristics such as duration of ART, ART regimen and uncomfortable clinic working hours (Wen et al., 2018). However, there are individual barriers



such as changing life circumstances (Bisnauth et al., 2021). However, this is not exactly true about children and adolescences. Most findings from other international studies on this issues suggest that timely disclosure of their HIV status has a positive impact on their adherence to ART and psychological health (Amankwah-Poku et al., 2021). Overall, children and adolescences are more vulnerable to ART related difficulties since they are not the decision makers themselves and have to relate to parents or caregivers. Thus, the results of our research will contribute to development of interventions tailored specifically for the prevention of ART interruption among children and adolescences in Ukraine.

Based on our findings and relevant review of similar studies from across the world, we suggest the following preventive measures of ART interruption that can be carried out by the means of social work provided by non-governmental organizations and state social services that support adolescents living with HIV and their families:

- Training of parents and health care workers to be able to explain to their children the peculiarities of their HIV status and ART. Since it has been confirmed that the comprehensiveness of knowledge about HIV and ART is an important factor in retention of ART, and parents (or guardians) and health professionals serve as valuable sources of information whom adolescents trust, and their readiness for frank communication with adolescents in an understandable for them language will ensure a conscious attitude and adherence of adolescents to ART and awareness of the risks of its interruption.
- Teaching children the life skills that would take into account their HIV status and ART. This will improve the ability of adolescents to rapidly respond to difficult life circumstances, resolve conflicts, assert themselves, find support group, refer for help, and protect themselves from stigmatization as well as increase their self-confidence. Adolescents will not need to respond to difficult situations by refusing ART
- Teaching parents the communicative and psychological support skills, which will reduce the severity of teenagers' protest reactions among which is refusal from treatment
- Organizing support groups for children living with HIV and their parents. This will increase opportunities for adolescents and their parents (guardians) to receive psychological support, and provide adolescents with the opportunity to learn about the experiences of their peers and elders who have the same HIV status and have gone through therapy interruption
- Organizing support campaigns in communities aimed at combatting stigmatization of children with HIV
- Providing social services to families of children living with HIV, aimed at getting them help in overcoming difficult life circumstances, protection of their rights and representation of their interests, as well as integration into local communities.

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