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## Barriers to Enrolling Women Injecting Drugs (WID) and IDU (Injective Drug User) Female Partners with Hepatitis C in Hepatitis C Elimination Program, Tbilisi, Georgia



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### ABSTRACT

Hepatitis C treatment in Georgia has been limited for years due to the high price of treatment and diagnosis. However, later in April 2015, with the support of US partners and pharmaceutical company Gilead, unique hepatitis C elimination program was launched in Georgia. Its aim is rapid detection of all infected people, their treatment and minimization of new instances of the disease by means of effective preventive measures. Even though the state program for elimination of hepatitis C has been operating in Georgia for three years already, with treatment received by more than 45,000 people, currently there are still 100,000 infected people. Therefore, it is important to detect them as soon as possible. An estimated 19,000 people who tested positive in rapid tests were reported in harm reduction programs. They are not included in the treatment program. The priority of the program is to enroll these people in the treatment. Screening tests are free of charge throughout the country.

## INTRODUCTION

Hepatitis C is one of the most challenging and large-scale disease in the modern world. 71 million suffer from chronic hepatitis C worldwide; most people with chronic infection develop hepatic cirrhosis or cancer; every year up to 399,000 people die from liver diseases related to hepatitis C; in Georgia approximately 150,000 people suffer from chronic hepatitis C. Most of them are not aware of their disease; more than 95% of people suffering from this disease can be treated with anti-virus drugs. As a result, the rate of mortality from hepatic cirrhosis and cancer may reduce;

Currently, there are no vaccines against hepatitis C, but efforts continue in this direction.<sup>1</sup>

Georgia is one of the countries with high prevalence of hepatitis C. Georgia has the highest incidence of hepatitis C<sup>2</sup> among the countries in Eastern Europe and Central Asia. Based on the results of seroprevalence study of hepatitis C conducted by the Disease Control and Social Healthcare Center in 2015-2016, hepatitis C is prevalent among general population (Anti HCV 7.7% and RNA 5.4%)<sup>3</sup>. Reasons for the high incidence of the disease have not been properly studied. One of the reasons could be the collapse of health care system in 90s, as well as negative impact of low quality healthcare services on safe injection practices, poor control and epidemiological surveillance of infections and blood safety in medical institutions over years. All these factors, coupled with widespread syringe exchange among IDUs, lead to higher incidence of hepatitis C in general population<sup>4</sup>.

Despite the scarcity of epidemiological surveillance data, it has been proven that IDUs are at a high risk of hepatitis C. Based on the data of Behavioral Surveillance Survey - BSS conducted in 2014-2015, 66.2% of IDUs are infected with hepatitis C<sup>5</sup>.

Hepa Plus report showed that 100% of people with hepatitis C were involved in risky behavior in the past, and most of them still continue to do so no matter whether they are aware or not of the risks associated with such behaviors<sup>6</sup>.

## MATERIALS AND METHODS

The study was conducted over 7 months, from November 15, 2017, to June 15, 2018, Qualitative study was conducted as part of this research. Where used in-depth interview and focus group discussion method. In-depth interviews were conducted with 30 women injecting

drugs and IDU's female partners, whereas focus group consisted of ten medical specialists who have worked with women infected with hepatitis C for many years. After ethics approval, respondents were recruited by program officials until required number was reached. Interview was conducted with beneficiaries infected with hepatitis C who were available for the researcher and agreed to participate in the research. The age range for interviews was 22 to 70, Selection criteria included: age 18 years or above, voluntary involvement, and Georgian speaking.

## RESULTS

In most cases, women participating in the research stated that they were going to enrol in the elimination program in the near future. However, most of them find it difficult to specify exact dates. In some cases, women find it difficult to state one specific reason as to why they have not yet enrolled in the program. However, when looking more into the details, we can identify certain factors which are more or less common for respondents participating in the research.

Importantly, 40% of respondents stated that they had been infected by their spouses. Although it is known that there is a low risk of sexual transmission of hepatitis C, there are still many cases when family members are believed to be the possible source of infection. In one of the cases, a respondent thought that his child was the source of infection.

50 % of respondents are injecting drug users who believe that they were infected by exchanging syringes or other injection equipment; interestingly, many IDUs think that drug itself can be infected, i.e. the infection can be transmitted through drugs.

IDU respondents are less likely to perceive themselves stigmatized. They are ready to state their status openly thinking that it is normal and should not be surprising to anyone whereas IDU's female partners believe that after disclosing their status they will be looked down on as people using drugs or having other risky behaviors. The community will not understand it. That is why they try to conceal their status, sometimes even from their family members.

Respondents are better informed about the results of treatment than about the process of treatment. As they are not yet enrolled in the treatment process, they do not know exactly where they should go, which tests they will have to take. They just know that they will need to pay additionally for the tests though they do not know exactly how much they will have to

pay.

Some of the respondents spoke about the negative effects of the treatment, such as physical weakness, mood swings or increasing agitation, insomnia. One of the described negative effects was also the fact that no alcohol could be consumed during the treatment because it could damage the liver; respondents spoke about cases when their acquaintances or relatives were unable to endure the treatment and had to leave it halfway.

Based on the findings of the research, we can note several obstacles. Factors preventing inclusion in the elimination program which were identified during the research can be divided into the following categories:

Financial - one fourth of respondents stated they could not join the elimination program due to financial problems.

Biological - there are cases when women refrain from treatment due to the possible side effects of medications Biological - there are cases when women refrain from treatment due to the possible side effects of medications. Psychological - the most important barrier revealed during the research. More than 50% of respondents say that the problem lies only in them and if they make up their mind, they will undergo treatment. Most beneficiaries say that they will start treatment in the near future. However, it should be mentioned here that they are unable to specify exact dates, or explain what they are going to start the treatment. The fact that hepatitis C has no symptoms is cited as one of the reasons for not starting treatment. The respondents believe that treatment is not urgent and necessary as they do not experience any inconvenience. They also emphasize that they will start treatment once they make up their minds.

Based on the nature of the research, it was important to consider not only the opinion of respondents with hepatitis C but also the opinion of specialists who have a long experience of working with women infected with hepatitis C and to some extent, participate in hepatitis C elimination process in harm reduction services and/or studies.

A focus group was organized to obtain information from medical specialists. We received valuable information from medical specialists about obstacles to enrolment in hepatitis C elimination program, possible counterindications to treatment and needs for additional services.

The focus group also noted that although the medications used to treat hepatitis C in the elimination program are less likely to cause side effects and are mostly effective, sometimes treatment is counterindicated due to the following symptoms: headache, stomach ache, nervous disorder, depression, and anemia. It was also mentioned that sometimes side effects from treatment could actually be an abstinence symptom as drug users stop using drugs and/or alcohol during the treatment. This causes symptoms characteristic of abstinence. However, patients, their family members and close friends think it is a side effect from medicine and form a negative opinion of the treatment process.

Specialists note that sometimes expectation of side effects is higher than it is in reality. Patients have preconceived ideas that the process of treatment will be complex, though later they admit that they feel well and have no side effects from the medication.

Barriers to enrolment in hepatitis C elimination program which were described by medical specialists complement the barriers described by respondents of the research during the in-depth interview.

According to specialists, one of the obstacles is the fact that tests necessary for enrolment in the elimination program require additional financial resources as IDUs and IDU's partners are financially vulnerable groups. Their priority is to find/consume drugs. Thus, they cannot afford to pay for treatment.

However, the main obstacle is a psychological factor, i.e IDUs are focused only on using drugs; very often they do not see any need for treatment as hepatitis C has no symptoms.

They were also concerned that at the first stage patients with stage 4 and 3 fibrosis enrolled in the treatment. These patients had acute liver failure, so death rate among them was high. IDUs believed it was caused by the treatment and feared that the treatment could be fatal.

The specialists described common misconceptions among patients with regard to enrolment in the program, for instance, the misconception that the recent growth in liver cancer is the result of treatment or, in the case of IDUs, the belief that use of drugs after treatment could be fatal.

In general, medical specialists who dealt with IDUs, both men and women, share the opinion that it is difficult to obtain IDU's consent for treatment, that is why they always need a specialist or social worker to accompany them in the course of treatment.

## CONCLUSIONS

- Women injecting drugs and IDU men's female partners with hepatitis C have sufficient knowledge about the ways of hepatitis C transmission. They are also aware of hepatitis C elimination program.
- The infected women are not aware that hepatitis C elimination program will not last forever and that it will not be available in Georgia in several years.
- Unlike Women injecting drugs with hepatitis C, IDU men's infected female partners have a higher degree of stigmatization which to a certain extent prevents them from enrolling in the elimination program.
- Unlike men, women with hepatitis C feel more stigmatized. (Similar result was reported by Hepa Plus in research of 2017 - Assessment of knowledge about HIV/AIDS, dependence and behavior among injecting drug users with hepatitis C in Tbilisi).
- IDU men's female partners state that their main source of information about hepatitis C is the Internet.
- The main source of information about hepatitis C among Women injecting drugs is trainings in service centers implementing harm reduction programs, including leaflets distributed by them and communication with social workers.
- Financial problem is one of the factors preventing enrolment in the elimination program, though it is not the most important one.
- Very often infected women are unaware of the amount of financial resources required for enrolling in the elimination program.
- Psychological factor is considered to be a main obstacle, such as fear of side effects from medication, inability to take a decision and give up drugs.
- The barrier to enrolment in the elimination program could be misinformation from incompetent sources, such as myths spread among IDUs about ways of hepatitis C transmission and side effects of treatment.
- Another barrier to enrolment in hepatitis C elimination is that the issue becomes less

relevant and receives lower level of media coverage.

## LIMITATIONS

Our study was limited due to selection bias and small sample size.

## ACKNOWLEDGMENTS

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