

Community Outreach Listening Activity People co-infected with HIV and HCV in San Francisco

SUMMARY REPORT

BACKGROUND AND METHODOLOGY

This Community Outreach Listening Activity (COLA) was conducted through one-on-one interviews with people co-infected with HIV and Hepatitis C virus (HCV) and providers who serve clients co-infected with HIV/HCV. The SF EMA HIV Community Planning Council uses COLAs to proactively gather and disseminate relevant information to and from people living with HIV and at highest risk for HIV. The content of this document offers context and factors to consider regarding the needs of people co-infected with HIV and HCV in San Francisco.

According to the most recent HIV Epidemiological Report, “*HIV Epidemiology Annual Report 2016*”, overall, among the 2,056 persons newly diagnosed with HIV in San Francisco in 2010-2014, 8.3% were co-infected with HCV. Hepatitis C virus (HCV) causes liver infections that increase morbidity and mortality outcomes for persons living with HIV. The HIV Epidemiology report indicated that the demographic profile of those co-infected with HIV/HCV are more likely to be female and transgender persons, African American, MSM and MSM-PWID, and aged 50 years and older. Persons at-risk for HCV are those who inject drugs, transfusion and hemodialysis recipients prior to consistent testing, and PLWH¹.

CDC research shows that about one quarter of HIV-infected persons in the United States are also infected with HCV. Thus, coinfection with HIV and HCV is common (50%–90%) among HIV-infected injection drug users. HCV is one of the most important causes of chronic liver disease in the United States and HCV infection progresses more rapidly to liver damage in HIV-infected persons. HCV infection may also impact the course and management of HIV infection. The treatment for (HCV) infection has evolved substantially since the introduction of highly effective HCV protease inhibitor therapies in 2011².

In 2017, the Community Engagement Committee of the San Francisco HIV Community Planning Council (HCPC) discussed potential target populations for four Community Outreach Listening Activities. The Committee chose people co-infected with HCV and HIV as one of their target populations.

COLAs traditionally function as focus groups that dovetail off of an existing support group. Council staff conducted research on HIV/HCV support groups in San Francisco and found that there was currently no

¹ The HIV Epidemiology Report 2016 (pp. 1-22. Rep.). (2017). San Francisco, CA: San Francisco Department of Public Health. <https://www.sfdph.org/dph/files/reports/RptsHIVAIDS/Annual-Report-2016-20170831.pdf>

² Viral Hepatitis. (2017, September 26). Retrieved October 25, 2017, from <https://www.cdc.gov/hepatitis/populations/hiv.htm>

existing support groups with attendance rates that would support a COLA session. Providers notified Council staff that support groups have disbanded because so many people were clearing of HCV with the new treatment options. In consultation with the Community Engagement Committee, Council staff altered the traditional COLA format and conducted two one-on-one interviews with people living with HIV/HCV and two one-on-one interviews with providers who work with clients co-infected with HIV/HCV.

Interview Structure

- 1) Explanation of role and functions of HCPC.
- 2) Discussion regarding individual challenges, in particular barriers to care.
- 3) Description of RWPA HIV service categories.
- 4) Discussion regarding utilization of service categories and challenges with HIV service utilization.

Participants

- One co-infected HIV/HCV participant currently undergoing treatment for HCV
- One co-infected HIV/HCV participant who is awaiting HCV treatment
- One provider who works with clients who are HIV positive and have cleared of HCV
- One provider who works with clients who are co-infected with HIV and HCV

FINDINGS

1. Benefits and Navigation

- Both providers expressed challenges with their clients being eligible for treatment through Kaiser. One provider noted that Kaiser is mandating substance use counselling for substance users seeking HCV treatment.
- Participants noted that the timeline for when someone has tested positive, been approved by insurance and have been treated for HCV has improved drastically.
- A provider noted that there is a subset clients who are in HCV/HIV co-infected PWIDUs who are not connected to Ryan White services. They expressed that there was a gap in care for this high-risk population.

2. Case Management

- One participant expressed the difficulty of retaining a case manager, they noted that they were concerned about re-enrolling in ADAP.
- One participant commented that they feel that many of their past case managers have been burnt out and don't truly care what happens to them.
- A provider noted that their clients utilized their case managers for a myriad of services, such as mental health and substance use counselling. They expressed that the vulnerable population they work with does not have the bandwidth to attend therapy or support groups.

3. Substance Use

- One participant expressed the importance of substance use counselling and treatment. They noted that they use substances to numb the emotions that come up with life challenges. They stated that they will undergo HCV treatment once they are clean and able to stay med adherent.
 - A provider noted that some of their most vulnerable clients are only connected through the methadone clinic.
4. Psychosocial Support
 - Participants expressed that importance of support groups and care navigators for alleviating isolation.
 5. Primary Medical Care
 - One participant felt stigmatized by their primary care doctor due to their substance use.
 6. Mental Health
 - A provider noted that a side effect of HCV is the buildup of ammonia in the brain which can cause mental health issues such as foggy brain, confusion and delirium.
 - One participant felt that it would not be useful of their time or the mental health provider's to seek mental health treatment due to their substance use. They expressed that they cannot truly improve their mental health while under the influence of substances.
 7. Food
 - Participants noted that providing more liquid nutritional supplements would be helpful due to needing to eat while taking medications and not being to eat some solid food due to dental challenges.

QUOTES FROM PARTICIPANTS

"I've had Hep-C since 1986 and I didn't get treated because I saw how bad the side-effects of Interferon were. I'm waiting until I get sober to go on the new treatment because it's hard for me to take one pill a day."

"Before treatment, I had a lot of side-effects. I had liver pain and I didn't have an appetite. I've been on treatment for 4 weeks and I already have more energy and I am feeling less sick."

"Support groups make me feel less isolated. I heard of the new Hep-C treatment through an in-service at a support group."

"Challenges that my co-infected clients face are similar to the challenges that my HIV clients face; lack of stable/adequate housing, resources for daily needs, getting to appointments."

"There is not enough support for the aging HIV population. There is a lot of discussion around not feeling that as they age they will have the support system to care for them."

"After injecting for 10 years, you have a 90% chance of contracting HCV."

“Stable housing is essential for HCV treatment.”

“There’s a refusal in the health systems to recognize gay men who participate in rough sex, BDSM etc. as high risk for HCV.”

“There is stigma with HCV and HIV, clients talk about feeling doubly burdened. However, HCV stigma is lessening because people are becoming cleared and feel more comfortable talking about it. Talking about the improvements has been shaking off the horribleness of the treatments during the 90s.”

“Some of the health issues my clients face are clogged arteries, high blood pressures, depression and fatigue. I’m not sure if these symptoms are related to HIV and aging or long-term side-effects of past HCV treatment, or a combination of both.”

“HCV treatment and education are getting people to shift their habits. There is a limited amount of re-infection among my clients.”

CONCLUSIONS

1. HCV treatment side effects and the timeline of when someone can get approved by insurance and receive treatment has improved drastically.
2. The access of HCV treatment at Kaiser is a barrier for clients who are substance users.
3. There is a subset of HIV/HCV co-infected people who inject drugs who are not connected to Ryan White services.
4. Case managers are difficult to retain due to burnout.

PROVIDER RECOMMENDATIONS

1. Increase the availability of mobile nurses and the co-location of services
 2. Providing additional incentives for HCV treatment
 3. Expand HCV testing and treatment into shelters, SROs and encampments
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