Talking About Hepatitis C: FAQs From Young Adults Who Inject Drugs

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Introduction. *Young adults who inject drugs and live in rural communities are at high risk for hepatitis C virus (HCV) infection. Recent changes in HCV treatment must be communicated within these communities to improve access to care and reduce HCV transmission.* Methods. *Field workers in the ¡VÁLE! Hepatitis Treatment and Integrated Prevention Services study identified frequently asked questions (FAQs) posed by young-adult participants at high risk for HCV during screening and educational sessions. From 2016 to 2018, 183 young adults (44.3% women; 85.8% Latino/a) younger than 30 years who inject drugs and reside in Rio Arriba or Doña Ana counties in New Mexico were enrolled. The research team compiled deidentified questions during field enrollments.* Results. *FAQs were reviewed and categorized into four major domains, including risk/prevention, screening, treatment, and reinfection. FAQs were addressed by a team of medical and public health professionals, using the most current research and recommendations.* Conclusions. *These FAQs address important gaps in HCV knowledge among young adults who are at high risk for infection. The FAQs also highlight the importance of risk reduction counseling provided by frontline public health providers as well as access to safe and effective HCV treatments for young adults who inject drugs.*

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INTRODUCTION

Approximately 3.5 million Americans are chronically infected with hepatitis C virus (HCV) (Edlin, Eckhardt, Shu, Holmberg, & Swan, 2015). The majority of newly acquired HCV infections occur in young adults who inject drugs and reside in rural areas of the United States, making this group an important focus for

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health promotion efforts (Centers for Disease Control and Prevention [CDC], 2017; Suryaprasad et al., 2014; Valdiserri et al., 2014; Zibbell et al., 2018). Meanwhile, safe and effective medications for curing HCV have recently been approved (Vermehren, Park, Jacobson, & Zeuzem, 2018). These exciting developments offer, for the first time, the opportunity to substantially affect the epidemic of HCV by curing the virus in large numbers of patients, including people who inject drugs.

In this new era of HCV treatment, public health initiatives are needed to dispel misconceptions about HCV in populations at high risk for infection. Frontline public health providers should be equipped with up-to-date information about HCV in order to offer effective counseling in the field, particularly among young adults who inject drugs. In the *¡VÁLE!* Hepatitis Treatment and Integrated Prevention Services study, we enrolled 183 young adult patients (44.3% women; 85.8% Latino/a) who inject drugs and reside in rural New Mexico between 2016 and 2018. We collected a series of frequently asked questions (FAQs) about HCV from study participants. Here, we offer these questions alongside up-to-date, evidence-based responses to each question that other providers and educators can apply in their own work.

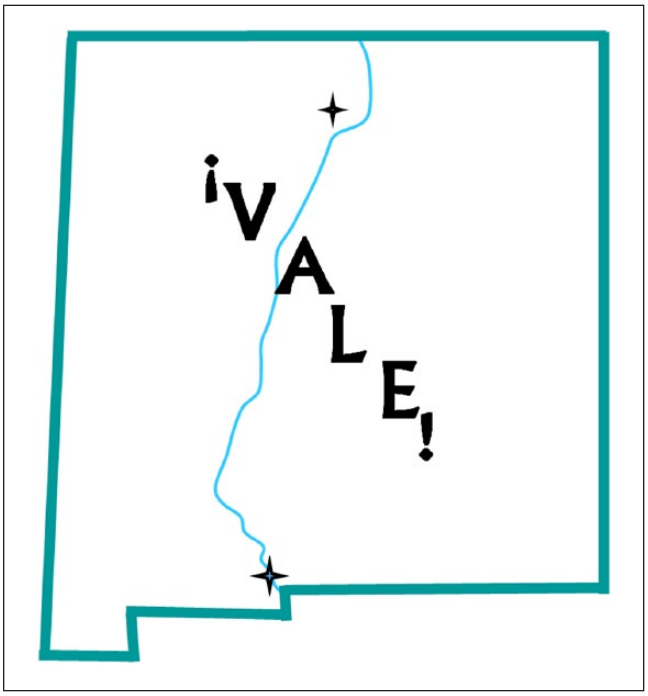

FIGURE 1 ***¡VÁLE!*** **Study Logo Showing Study Site Locations (Doña Ana and Rio Arriba Counties) Superimposed on a Map of New Mexico**

RESEARCH SETTING AND METHODS

¡VÁLE! Field Environment and Study Recruitment

¡VÁLE! study staff traveled to two field enrollment sites in rural New Mexico in a mobile clinic van. The primary study site was located in Rio Arriba County (Figure 1) at the Santa Fe Mountain Center, which hosts a syringe services program and is colocated with other preventive, recovery, and treatment programs for persons who inject drugs. Study staff recruited potential participants with in-person engagement at the center, distributing written study information and answering questions in person. Staff at the Mountain Center did not directly recruit participants for the study but referred interested clients to study staff and placed study informational materials (e.g., flyers and study cards) in visible places at the center.

A secondary, short-term study site in Doña Ana County (Figure 1) was located at a clinic offering medication-assisted treatment for opioid use disorder and a drop-in center offering access to multiple services, including syringe exchange and case management. Similar engagement procedures were followed at this site. Flyers and study materials were posted at study sites and at locations (e.g., drop-in centers, local medical clinics, and community bulletin boards) that provided services to potential study participants. These materials included general information about the study, opportunities for free HCV testing, dates and times the study team would be present, and ways to contact study staff for more information.

¡VÁLE! Study Procedures

Eligible participants were 18 to 29 years old with self-reported injection drug use in the past 90 days. After providing consent, participants underwent screening for HCV using a rapid point-of-care antibody test (anti-HCV; OraSure© Technologies; Bethlehem, PA) and a blood test for HCV ribonucleic acid (RNA) to confirm active infection status, as well as screening for human immunodeficiency virus (HIV) and hepatitis B virus (sometimes abbreviated as HBV). For the purposes of this article describing work among young-adult patients, we have opted against the use of the HBV acronym, since it may be confused with another virus of clinical importance in this patient group—human papillomavirus or HPV.

All participants received counseling regarding infection prevention, referrals to local services, and resources for prevention, drug treatment, and behavioral health

TABLE 1
Characteristics of *¡VÁLE!* Study Participants (*n* = 183)

Characteristic	n *(%)*
Sex	
Female	81 (44.3)
Male	102 (55.7)
Race	
White/Caucasian	125 (68.3)
Native American	13 (7.1)
Black/African American	5 (2.7)
Other	37 (20.2)
Unreported	3 (1.6)
Ethnicity	
Hispanic or Latino/a	157 (85.8)
Ever tested for hepatitis C	111 (60.7)
Have health insurance	161 (88.0)
Education	
Less than high school	63 (34.4)
High school diploma or GED	71 (38.8)
Some college	35 (19.1)
Associate's degree or trade school	7 (3.8)
Bachelor's degree or graduate degree	3 (1.6)
Unreported	4 (2.2)

care. Participants were interviewed using a structured questionnaire about sociodemographic characteristics, risk exposures, injection drug use history, and selected health care utilization measures.

Participants were asked to return to the enrollment site to receive their HCV RNA results within 2 weeks. If HCV RNA test results were positive, indicating active HCV infection, participants underwent a one-on-one HCV education session and received a referral for HCV care. Participants were all asked to return for follow-up HCV testing and interviews every 3 months for 1 year.

FAQ Collection

¡VÁLE! study staff collected a series of FAQs about HCV that they encountered from study participants at various study visits, including visits for screening, laboratory test results, follow-up, and education sessions. These FAQs were organized into four categories: risk/prevention, screening, treatment, and reinfection. Responses to each question were developed using the best available professional literature as well as clinical and public health expertise in HCV prevention and management.

Ethics Approval

The University of New Mexico Institutional Review Board reviewed and approved the study, including all study procedures, data collection, HCV testing, and referrals to care. All FAQs are presented without identifiable details about study participants.

TOOLS OF THE TRADE: HCV FAQS

Characteristics of the overall *¡VÁLE!* study population are shown in Table 1. FAQs in each of the four domains are explored below.

Risk and Prevention

Participants expressed interest in assessing their own risk for infection as well as the risk of transmitting the virus to others in their families or social circles. In a number of instances, participants had previously been misinformed about how HCV is transmitted and prevented.

Q. How did I get HCV? Am I contagious?

A. *HCV is spread when the blood of a person with HCV comes into contact with the blood of a person who does not have HCV.* In the United States, it is most often spread through unsafe injecting practices, such as sharing contaminated injection equipment or other contaminated materials (e.g., syringes, cottons, cookers, and water). Less commonly, HCV may also be spread through sexual activity (most often in HIV-infected men who have sex with men), intranasal drug use (which may cause bleeding inside the nose), perinatal transmission from mother to fetus, nonsterile tattoo equipment, shared razors, and toothbrushes, or after other accidental blood contact.

HCV can survive outside the body on contaminated surfaces for days or weeks, if these surfaces are not properly sterilized. *HCV can remain infectious in a syringe for as long as 2 months!* Bleach disinfectants are much more effective than other household detergents/disinfectants (e.g., Dawn dish soap, Lysol cleaner), rubbing alcohol, or hydrogen peroxide. Rinsing syringes with water, beer, or wine is *not* effective in killing HCV.

The safest approach is never to share materials that may be contaminated with blood—such as needles, injection equipment, toothbrushes, razors, smoking devices, and intranasal devices. Ensure that all injection equipment is kept out of the reach of other household members, especially children, and dispose of all

used injection equipment in a safe, puncture-resistant container. If injecting with a member of the same household, everyone should maintain their own injection equipment. If dividing drugs, ensure that the syringe used to divide is new.

References: Binka, Paintsil, Patel, Lindenbach, and Heimer (2015); CDC (2016, 2018); Doerrbecker et al. (2011); Hagan et al. (2010); Hahn et al. (2002); Paintsil, He, Peters, Lindenbach, and Heimer (2010); Palmateer et al. (2014)

Q. Can I spread HCV to others in my household? Can I spread HCV to my partner?

A. Yes. It is possible for a person with HCV to spread the disease to other people living in the same household. Infrequently, *HCV may be transmitted by sharing personal items contaminated with blood (e.g., toothbrushes, razors).* Although HCV has been detected in saliva, there is no evidence that the virus is spread or acquired through saliva or kissing.

The risk for HCV transmission to a sexual partner is relatively low compared with transmission via unsafe injection practices. However, forced or traumatic sex, exposure to genital sores or cuts, or exposure to blood during menstruation may increase the risk. Oral sexual contact may have the lowest potential for HCV transmission. Some sexual practices (e.g., unprotected anal sex, use of sex toys), the presence of other sexually transmitted infections, and the use of other noninjection drugs have also been associated with increased risk for sexually transmitted HCV in studies of HIV-infected men who have sex with men. Thus, *it is important to practice safer sex* among partners to prevent sexual transmission. Partners should also be aware that despite having a sexual relationship with another individual, *sharing injecting equipment—not sexual intercourse—remains the highest risk for HCV transmission no matter who your partner is, which means that even sexual partners should not share injection equipment.*

References: CDC (2018); Ferreiro, Dios, and Scully (2005); Gambotti et al. (2005); Ghosn et al. (2004); Götz et al. (2005); Luetkemeyer et al. (2006); Marincovich et al. (2003)

Q. Is there a vaccine for HCV?

A. *Not yet.* There is currently no vaccine to help prevent HCV, although some experimental vaccines are now being tested by researchers and may be available in the future.

Reference: Steckelberg (2017)

Screening

¡VÁLE! participants requested information about obtaining and/or interpreting HCV-related laboratory tests. Such questions are also common among public health practitioners and clinical providers. It is important for frontline public health providers to know about HCV screening methods in order to provide accurate counseling to patients about this particular infection.

Q. My rapid HCV screening test is positive, but my confirmatory test is negative. What does that mean? Is my HCV dormant?

A. The rapid HCV test is an "antibody" test. It measures your body's response to HCV but not the amount of HCV in your blood. If you have been exposed to HCV before, your body will produce antibodies against the virus, which remain detectable even if the virus is no longer present in your blood.

The confirmatory test measures whether there is HCV in your blood by detecting the virus (HCV RNA) instead of the antibody. It tells you whether the virus is present.

In other words, *the rapid test measures your body's memory of HCV, while the confirmatory test measures whether or not the virus is still present in your body.*

Some people's bodies clear HCV on their own (up to 25% of cases), and some others are cured of HCV after treatment. In these cases, where the virus has been cleared or cured, the confirmatory test will be negative. *If your confirmatory test is negative, the virus is not "dormant"; the virus is gone.*

References: CDC (2013, 2018)

Q. What is a "window period?"

A. The window period is the time after HCV exposure that it takes the body to produce enough antibodies to show up on a rapid screening test. This period usually lasts about 2 to 3 months. During the window period, it is possible to be infected without having a positive rapid-screening antibody test.

Reference: CDC (2018)

Q. How often should I be screened for HCV if I have risk factors for infection?

A. *Yearly testing is recommended for all patients who inject drugs*. More frequent screening may be considered if a new exposure is suspected, keeping in mind that the antibody screening test may not be positive until about 2 to 3 months after the new infection occurs (due to the window period described above).

Reference: American Association for the Study of Liver Diseases and Infectious Diseases Society of America (AASLD/IDSA) HCV Guidance Panel (2015)

Q. If I had HCV while I was pregnant, should my child be tested?

A. *Yes.* Although the risk for mother-to-fetus transmission is low, your child should be tested. Treatment recommendations for children are likely to evolve and improve over the coming years, so determining your child's HCV status will help inform future decisions about starting treatment.

Reference: CDC (2018)

Treatment

¡VÁLE! participants expressed significant interest in HCV treatment, posing insightful questions about treatment risks and benefits as well as treatment availability for people in special circumstances (e.g., kidney problems). Often, participants reported not seeking treatment for their HCV infection due to certain behaviors or practices, such as current injection drug use.

However, HCV treatments, including those treatments available for patients who inject drugs, have changed substantially in the past 1 to 2 years.

Q. Can people cure themselves?

A. People with new HCV infections have a small chance—up to 25%—of clearing the infection on their own. *For most people, however, the infection will not go away on its own*; those people will have a chronic (long-term) infection and will need medication to cure it.

Reference: CDC (2018)

Q. How is HCV treated? What are the side effects of treatment?

A. HCV treatments have changed a lot in recent years (Table 2). *HCV can be treated with prescription pills*, which are sometimes called direct-acting antivirals or DAAs. These pills need to be taken every day as prescribed in order to cure the infection. Most DAAs need to be taken for 2 to 3 months without interruption. HCV can be cured in almost all (>90%) people who complete this treatment. The pills usually have few or no serious side effects. Up-to-date treatment guidelines can be accessed at any time at https://www.hcvguidelines.org/.

References: AASLD/IDSA (2018); AASLD/IDSA HCV Guidance Panel (2015); CDC (2018)

Q. Why should I be treated if I'm not sick?

A. *Everyone with chronic HCV should be treated, except in very rare circumstances* (e.g., people with an advanced terminal illness). The new treatments are safe, effective, and well tolerated. There are potential benefits of treatment for you and those around you:

1. *Long-term benefits for you*: Curing HCV before you feel sick may prevent serious complications of the infection, such as liver failure and liver cancer, in the future.
2. *Short-term benefits for you*: Some people notice that they feel better immediately after treatment, even though they didn't notice feeling sick before. This is because HCV can cause other symptoms, such as fatigue and joint pain, which may improve after treatment. In our own clinical experience, some people also report feeling happier or more hopeful after their HCV is cured.
3. *Benefits for others*: Curing HCV can prevent spreading the virus to other people.

References: AASLD/IDSA HCV Guidance Panel (2015); Cacoub et al. (2016)

Q. Can I receive treatment while I am still injecting drugs?

A. Yes. The new treatments are safe and effective for people who are still actively injecting drugs. *In fact, treatment is recommended for all infected people, including people who inject drugs.* Currently, access to HCV medications can vary widely from state to state. Up-to-date information about HCV treatment access in each state can be reviewed at https://stateofhepc.org/.

References: AASLD/IDSA HCV Guidance Panel (2015); National Viral Hepatitis Roundtable and Center for Health Law and Policy Innovation at Harvard Law School (2018)

Q. Can I receive treatment if I have kidney problems?

A. *Yes.* Treatment is now possible for people with kidney problems, including people who are on dialysis.

Reference: AASLD/IDSA (2018)

Q. Can I receive treatment if I have a history of hepatitis B virus infection or HIV infection?

A. *Yes.* Treatment is possible for patients with a history of hepatitis B infection or those with HIV infection. A

TABLE 2
Side-by-Side Comparison of New and Old Hepatitis C Virus (HCV) Treatments

New HCV Treatments	*Old HCV Treatments*
Pills only	Shots and/or pills
Few mild/moderate side effects	Many moderate/severe side effects
Treated in 2 to 3 months	Treated in 6 to 12 months
Very high chance of cure	Relatively low chance of cure
Safe for people who currently inject drugs	Not safe for people who currently inject drugs
Safe for people with kidney disease[a]	Not safe for people with kidney disease
Recommended for all people with chronic HCV, with or without symptoms[b]	Recommended for specific subgroups of people with chronic HCV

[a]At least one treatment regimen is available for people with kidney disease, including people on dialysis. [b]Treatment is not indicated for people whose life expectancy does not exceed 6 months due to other illnesses.

specialist with experience treating these infections should help oversee the treatment plan.

Reference: AASLD/IDSA (2018)

Reinfection

Reinfection is of utmost concern for individuals who inject drugs. *¡VÁLE!* study participants consistently inquired about whether HCV treatment conferred immunity and, if not, how to avoid reinfection during and after treatment.

Q. What is reinfection?

A. Reinfection is a new infection with HCV after a previous HCV infection was cleared spontaneously or cured with treatment. *Patients who have cleared or cured the infection once are* not *immune from getting infected again.*

There are 7 major types of HCV and more than 60 subtypes found in different places throughout the world. Infection with multiple types or subtypes—at one time or at different times—is possible. Thus, antibodies formed after infection with one subtype do not provide future immunity against HCV.

References: Blackard (2012); Smith et al. (2014)

Q. Can I be reinfected during or after treatment?

A. Yes, you can be reinfected during or after treatment. However, diagnosis of reinfection can be tricky. *It's important to know that your rapid screening test may stay positive for at least 10 years, even after HCV treatment and cure. Thus, a positive screening antibody test does not mean that you have been reinfected. If reinfection occurs, this can only be determined with the confirmatory test that detects the presence of virus in your blood* (see "Screening" section above).

Reference: Toyoda et al. (2005)

Q. What can I do to keep from being reinfected or from reinfecting someone else?

A. It is important for everyone—including patients who are currently being treated for HCV or who have been treated for HCV in the past—to avoid potential exposures to the virus by following the recommendations in the "Risk and Prevention" section above.

Highlights and Resources for Frontline Providers

Frontline providers and health educators should be prepared to convey up-to-date information about HCV risk/prevention, screening, treatment, and reinfection to the communities they serve. The FAQs above may help providers anticipate and respond to questions from young adults in their communities.

Our study group plans to integrate these FAQs into our educational materials (e.g., using infographics or flash cards) for future fieldwork and to share what we have learned with other public health stakeholders in our community and region (e.g., using web-based postings or tools). Key points for providers and health educators to reinforce in patient education include the following:

1. Avoiding potential blood-to-blood exposures is the hallmark of preventing HCV infection and reinfection. Counseling should be reinforced at every possible opportunity (e.g., screening, treatment, or

posttreatment evaluations and during visits to syringe services, sexually transmitted infection clinics, behavioral health support groups, or other public health interactions).
Related resources for frontline providers: The FAQs provided here, along with those offered by national, state, or local public health entities may aid with the counseling process (CDC, 2016, 2018).

2. HCV is now a curable condition, and treatment is recommended for patients who inject drugs. Treatments have become much more effective and much easier to tolerate compared with therapies used in years past (Table 2). Currently, however, access to these medications varies from state to state.
Related resources for frontline providers: The contrast between new and old treatments shown in Table 2 may help ease patient concerns about pursuing treatment. Frontline providers can directly review treatment guidelines and state-specific treatment access information on readily available, regularly updated websites (AASLD/IDSA, 2018; National Viral Hepatitis Roundtable and Center for Health Law and Policy Innovation at Harvard Law School, 2018). Providers are also encouraged to identify screening and treatment referral sites in their areas of practice to assist with patient counseling.

Although our study did not encounter specific questions about the use of herbs, supplements, or medical cannabis, such questions may be encountered by other frontline providers and clinicians. Providers may find the National Institutes of Health LiverTox database (https://livertox.nih.gov/) helpful to support discussions about the impacts of herbs, supplements, and medications on liver health.

CONCLUSIONS

Young adults who inject drugs and reside in rural areas of the United States are at high risk for HCV infection. The combination of operative prevention programs, including syringe services with effective counseling strategies employed by frontline providers, and access to safe, effective treatment regimens for affected patients could have a dramatic impact on this epidemic. As the questions posed in this study show, young adults often have important and insightful questions about HCV. Frontline providers should be prepared with equally important and insightful responses.

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