# BREAKING DOWN BARRIERS TO CARE

ALICIA STIVALA, FNP CALLEN-LORDE COMMUNITY HEALTH CENTER NEW YORK, NEW YORK

## HEPATITIS C : GLOBAL IMPACT AND ELIMINATION 2030 WHO HCV ELIMINATION Goals:

- Mortality reduction 65%; Diagnosis 90%; Incidence Reduction 80%; Treatment coverage 80%
- Hepatitis C and B are the leading causes infectious disease of mortality globally
- National incidence on the rise
- Providers who can diagnose and treat can increase treatment uptake and reduce incidence, morbidity and mortality
- Microelimination is key for macro impact!

#### STIGMA AND HEPATITIS C

#### Goals:

- Understand how common myths about HCV and HCV treatment are barriers to treatment uptake
- Discuss how patient fear and stigma from time of diagnosis through treatment and even after cure can be a barrier to linkage to care
- Promote patient empowerment and education as tools to overcome such barriers
- Clinical staff can learn how simplified HCV treatment guidelines can be used to swiftly and effectively eliminate HCV in their clinical settings with current treatments, while providing psychosocial support and continued harm reduction to prevent re-infection

HEPATITIS C – A LIVER DISEASE THAT CAN CAUSE CIRRHOSIS AND MORTALITY, WITH OTHER **IMPACTS:** 

- Mental / Psychological
- Social
- Stigma and fear due to lack of adequate information
  - For <u>healthcare professionals</u>, patients, family members, and communities
  - Education about the achievable goal of <u>cure</u> – total, definitive elimination of the virus is fundamental

### HCV STIGMA

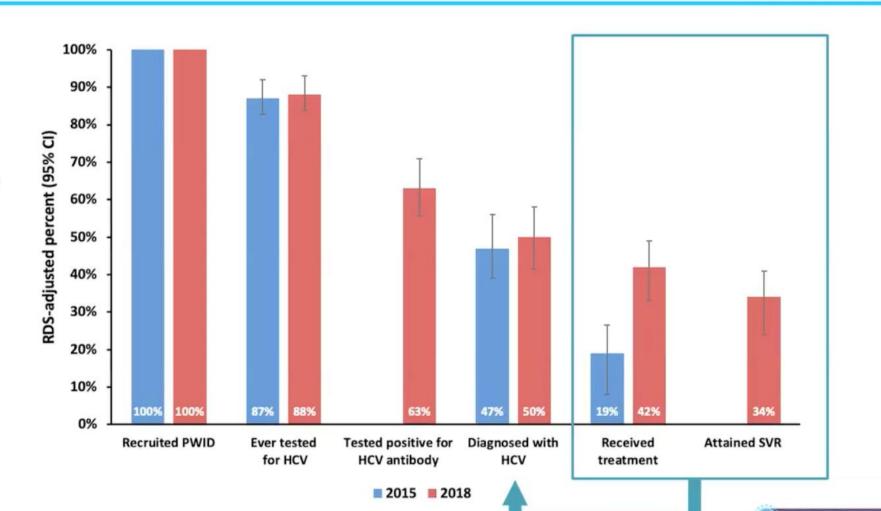
HCV infection diagnosis often leads to:Increased anxiety and depression

- Fear of transmission
- Social isolation
- Reduced intimacy in relationships

## What's wrong with this picture

Progress toward closing gaps in the hepatitis C virus cascade of care for people who inject drugs in San Francisco

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#### INTRAVENOUS DRUG USE AND STIGMA

- Since more than 90% of HCV is transmitted via syringe sharing, HCV is associated with persons who inject drugs (PWID)
- Blame and shame on users for transmission is common
- HCV and HIV share a route of transmission, HIV being another stigmatized virus
- Stigma denoting shameful intimate relations and deviations from what is considered "normal" behavior has a long history within infectious disease, in particular HIV and HCV

#### RISKS OF STIGMA ON PATIENT CARE

- Marginalization of patients
- Influence of course (delay in or avoidance of treatment)
- Healthcare workers may adopt judgements
- Check in with own beliefs and stereotypes Adopt non-judgmental, universal approach to care for all patients, regardless of risk factor for HCV
- Changing healthcare provider behavior will prevent patient isolation, withdrawal and increase retention and follow-up

### VANCOUVER STUDY OF PWID (N=50)

- Stigma identified as a barrier to health care access
- Stigma reduction identified as key motivator of HCV cure
- Even after cure, stigma played a prominent role in post-treatment care
- Shame around HIV co-infection, ongoing substance use, poverty and housing issues cited
- Stigma and criminalization may interfere with re-infection prevention efforts

GOODYEAR T, BROWN H, BROWNE AJ, HOONG P, TI L, KNIGHT R. "STIGMA IS WHERE THE HARM COMES FROM": EXPLORING EXPECTATIONS AND LIVED EXPERIENCES OF HEPATITIS C VIRUS POST-TREATMENT TRAJECTORIES AMONG PEOPLE WHO INJECT DRUGS. INT J DRUG POLICY. 2021 OCT;96:103238. DOI: 10.1016/J.DRUGPO.2021.103238. EPUB 2021 APR 23. PMID: 33902968; PMCID: PMC8881088

#### ADHERENCE IS IMPORTANT, BUT DIRECT ACTING ANTIVIRALS (DAAS) ARE FORGIVING: TREAT ACTIVE USERS

- PWID or on opiate agonist therapy
- 190 participants in 8 countries; 97% completed treatment
- 24% had <80% Adherence
- 13% had > 7 days nonadherence
- SVR overall was 93%
- ✓ Of the 25 that had nonadherence for > 7 consecutive days, 84% completed treatment with SVR

 No Stat difference in SVR between those who did/did not miss 7 consecutive doses

CUNNINGHAM EB, HAJARIZADEH B, AMIN J, LITWIN AH, GANE E, COOPER C, LACOMBE K, HELLARD M, READ P, POWIS J, DALGARD O, BRUNEAU J, MATTHEWS GV, FELD JJ, DILLON JF, SHAW D, BRUGGMANN P, CONWAY B, FRASER C, MARKS P, DORE GJ, GREBELY J; SIMPLIFY AND D3FEAT STUDY GROUPS. ADHERENCE TO ONCE-DAILY AND TWICE-DAILY DIRECT-ACTING ANTIVIRAL THERAPY FOR HEPATITIS C INFECTION AMONG PEOPLE WITH RECENT INJECTION DRUG USE OR CURRENT OPIOID AGONIST THERAPY. CLIN INFECT DIS. 2020 OCT 23;71(7):E115-E124. DOI: 10.1093/CID/CIZ1089. PMID: 31677262.

#### PUBLIC HEALTH NEEDS TO DESTIGMATIZE PWID

- DAAs are transforming the health and wellbeing of some PWID. HCV-related policy must include public health investments, including anti-stigma efforts and improvements to the social welfare system in which patients navigate
- Goals should include advancing equity in PWIDs' post-treatment trajectories and outcomes
- Clinicians may consider allotting time to address common misconceptions about HCV when educating patients about HCV infection, which may counterbalance the stigmatizing impact of greater HCV-related knowledge

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#### PROVIDER EDUCATION MYRIAD BENEFITS OF SUCCESSFUL HCV TREATMENT

- Negative HCV RNA after treatment that is sustainable = CURE (SVR)
- Negative HCV RNA in liver, no detection of genotype
- Reduce risk of transmission to others
- Normalization of transaminases = reduction of inflammation in liver
- Visual changes on ultrasound, contour of liver can become regular
- Cure of HCV-related conditions (porphyria cutanea tarda, polyneuropathy, urticaria, cryoglobulinemia, splenic lymphoma)

#### PROVIDER EDUCATION EVEN MORE BENEFITS OF SUCCESSFUL HCV TREATMENT

- Decrease in Fibroscan reading
- Reduce risk of progression to cirrhosis
- Reversal of cirrhosis in some
- Reduce risk of HCC and of HCC progression
- Reduce risk of recurrence after transplant
- Improve quality of life
- Reducing psychological impact of disease
- Reduce stigma of disease
- Reduce mortality

#### STIGMA AND TREATMENT UPTAKE

- Stigma has been identified as an important mediator of health behaviors, such as disease disclosure, treatment uptake, and medication adherence
- 95.5% of patients with hepatitis C virus (HCV) infection experience some degree of perceived disease-related stigma from others
- Addressing deficits in HCV-related knowledge may ameliorate HCVassociated stigma and lead to increased engagement of patients in the steps across the HCV care continuum

SAINE ME, SZYMCZAK JE, MOORE TM, BAMFORD LP, BARG FK, FORDE KA, SCHNITTKER J, HOLMES JH, MITRA N, LO RE V 3RD. THE IMPACT OF DISEASE-RELATED KNOWLEDGE ON PERCEPTIONS OF STIGMA AMONG PATIENTS WITH HEPATITIS C VIRUS (HCV) INFECTION. PLOS ONE. 2021 OCT 5;16(10):E0258143. DOI: 10.1371/JOURNAL.PONE.0258143. PMID: 34610030; PMCID: PMC8491913.

#### PSYCHOSOCIAL, EDUCATIONAL AND TREATMENT APPROACHES SHOULD BE IN TANDEM

- Highly-effective, all-oral direct-acting antiviral therapies revolutionized HCV treatment
- Elimination of HCV as a public health threat is now feasible
- State-based Medicaid programs, and experiences of stigma in healthcare continue to be barriers to HCV treatment
- Reduction of stigma is a motivator to undergo HCV treatment
- Experiences of stigma may persist beyond completion of treatment and achievement of cure
- Psychosocial approaches must complement treatment interventions in elimination

### Factors Associated with reinfection

- Active injection drug use1, 2, 3
- Younger age1, 2
- Needle and syringe sharing3
- Mixed heroin/amphetamine injecting 2, 3
- Low confidence in ability to avoid reinfection2
- Housing insecurity2,4
- Spousal and common-law relationships with injection partners PWID2, 5

12 1. Hajarizadeh 2. Akiyama et al CID 2020 3. Midgard IJDP 2021, 4. Cunningham et al CID 2021, 5. Akiyama JID 2022 Slide adapted from Dr. Seun Falade-Nwulia





# HCV reinfection as a positive indication of high-risk population treatment access

#### Strategies to address HCV reinfection among people who inject drugs

Acknowledge DAA treatment of high-risk PWID populations will produce HCV reinfection

Discuss HCV reinfection risk prior to, during and following DAA therapy

Explore injecting partner relationships, with HCV screening of regular partners

Optimize harm reduction strategies, including overdose prevention

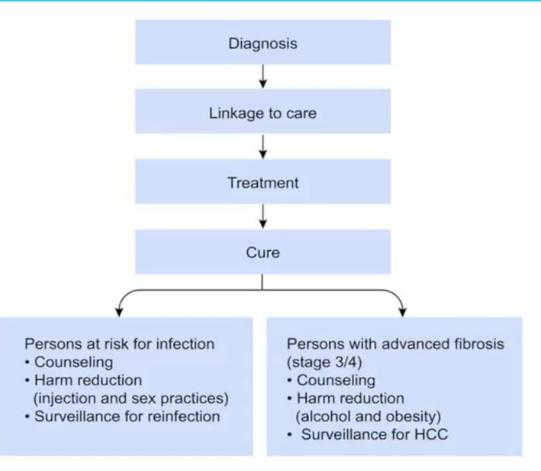
Monitor for HCV reinfection with annual HCV RNA assessment

Retreatment without stigma and discrimination



#### The HCV care continuum does not end with SVR

Characteristic	Follow-up After SVR
No advanced fibrosis (Metavir stage F0-F2), no or low risk of HCV reinfection	<ul> <li>Standard medical care, as in someone without HCV</li> </ul>
Advanced fibrosis (Metavir stage F3 or F4)	<ul> <li>Ultrasound surveillance for HCC every 6 mos ± AFP</li> </ul>
Moderate to high risk of HCV reinfection	<ul> <li>Harm reduction</li> <li>HCV RNA every</li> <li>12 mos</li> </ul>





## Hepatitis C: State of Medicaid Access Report Card

### lowa

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Estimated Number of Individuals Living with Hepatitis C: 12,6001

Grade	Summary		
	Liver Damage (Fibrosis) Restrictions: Iowa does not impose liver damage restrictions.		
	Sobriety Restrictions: FFS and all MCOs require at least three months' sobriety from alcohol and substance use, documented by a urine screen.		
D	Prescriber Restrictions: FFS and all MCOs require a liver, infectious disease or digestive disease specialist to prescribe or consult.		
R-		F2 or greater IS RESTRICTIVE.	
	<b>Recommendations to Improve Patient Access:</b>	Should be removed!	
	<ul> <li>Remove sobriety and prescriber restrictions.</li> </ul>		
	<ul> <li>Maintain transparency regarding hepatitis C co programs.</li> </ul>	verage requirements and parity across FFS and MCO	
	Grade Rationale: Despite removing liver damage restrictions, Iowa continues to have severe sobriety and prescriber restrictions. With these in place, very few people with hepatitis C have access to treatment.		

#### PATIENTS WITH HIGH LEVELS OF UNDERSTANDING OF HCV MAY HAVE HEIGHTENED PERCEPTION OF STIGMA

- Patient education about HCV natural history and treatment alone is not enough
- Patients may still harbor misinformation that creates fear and anxiety
- Clinicians should spend time inquiring about patients' beliefs about themselves, transmission risk and their peers/partners in relation to their HCV infection status
- Allotting time to dispel common misconceptions, such as HCV transmission through casual contact (e.g. shaking hands, working with someone who has HCV) may also help to reduce perceived stigma

Target your patient populations with clear messaging that will reach them. Graphics are helpful, and language that is non-judgmental is key.

# **HEPATITIS TESTING DAY**

Hepatitis A and B have vaccines, but Hepatitis C does not. It is important to get tested for Hepatitis C because there are often no symptoms.

Hepatitis C (hep C) is a serious, but curable liver disease. There are often no symptoms, so the only way to know if you have it is to get tested. Hep C is generally transmitted through blood-to-blood contact, but can be passed sexually.



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## **HEPATITIS C PREVENTION**

#### Wear a condom for anal sex

Anal sex increases risk for sexual transmission ofhep C. Hep C can be found in semen and rectal fluids. If you choose not to use a condom for anal sex/bareback, use extra lube.



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# HEPATITIS C PREVENTION

#### Using drugs? Don't share or reuse supplies

Use sterile needles, syringe, water, cotton, straws, plungers or lube injectors when you use or mix drugs. Do not share or reuse. If you are pushing any substances into your bottom or a vein, make sure you mix and insert them into yourself, so that you can be sure it is not contaminated or used. If you must share needles and syringes, lower the risk of HIV and HCV transmission by cleaning with water, then bleach, then water.

# CALLEN-LORDE

Resources with excellent graphics for education and stigma reduction https://harmreduction.org <u>National Harm Reduction</u> <u>Coalition</u>



#### Hepatitis C Basics

#### For People Who Use Drugs



With safer injection and harm reduction tips inside.

You can take steps to prevent getting hepatitis C. If you have hepatitis C, new treatments can cure it and keep your liver healthy.

Injection drug use is the most common way people get hepatitis C. If you share injection equipment with someone who is infected with hepatitis C, this puts you at risk. Even a tiny amount of blood— so small you can't see it—can contain the virus. This is why hepatitis C can be passed on (transmitted) by sharing any equipment that may have come in contact with someone's blood while injecting.

If you are getting high, you can protect yourself and others from getting hepatitis C. Getting tested, talking about your status, and injecting safely can reduce your risk of contracting or passing the virus onto others.

Distributed by Harm Reduction Coalition

www.harmreduction.org 212-213-6376

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#### Safer Injecting Strategies

Use Sterile Injection Equipment. Avoid Reusing or Sharing.

Your blood may end up on any item you touch or use when injecting, including syringes, cookers, cottons, water, and ties. Use new, sterile equipment each time you inject.

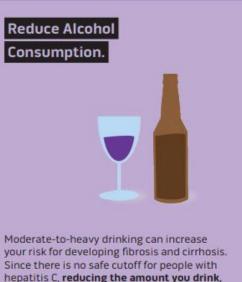
If You Must Reuse Equipment,

Then Mark Yours.



Avoid sharing any injection equipment. The virus is alive in blood outside the body. If you must reuse, keep a set of works with markings on it so you know it's yours.

#### Liver Care Tips



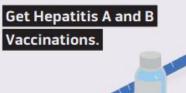
#### **Review Your Medications** and Supplements.



Discuss all over-the-counter, prescribed medications, and herbal supplements with your doctor because some may be hard on your liver.



If you must share a syringe, then clean it with bleach and sterile water. Step 1: Rinse the syringe with sterile water. Step 2: Rinse the syringe with bleach. Step 3: Rinse again with (new) sterile water.



or not drinking at all, is the safest option.

There is no vaccine for hepatitis C, but there are vaccinations for hepatitis A and hepatitis B. If you have hepatitis C, get vaccinated for both hepatitis A and B to protect your liver.

#### **Get Emotional** Support. Because of the stigma attached to

hepatitis C and injection drug use, it's not always easy disclosing your status to friends, family, and even healthcare providers. Accessing hepatitis C services and support groups can be helpful for gathering resources and sharing your feelings in a safe, nonjudgmental, and confidential environment.

#### **Articles referenced:**

Cunningham EB, Hajarizadeh B, Amin J, Litwin AH, Gane E, Cooper C, Lacombe K, Hellard M, Read P, Powis J, Dalgard O, Bruneau J, Matthews GV, Feld JJ, Dillon JF, Shaw D, Bruggmann P, Conway B, Fraser C, Marks P, Dore GJ, Grebely J; SIMPLIFY and D3FEAT study groups. Adherence to Once-daily and Twice-daily Direct-acting Antiviral Therapy for Hepatitis C Infection Among People With Recent Injection Drug Use or Current Opioid Agonist Therapy. Clin Infect Dis. 2020 Oct 23;71(7):e115-e124. doi: 10.1093/cid/ciz1089. PMID: 31677262.

Marinho RT, Barreira DP. Hepatitis C, stigma and cure. *World J Gastroenterol.* 2013;19(40):6703-6709. doi:10.3748/wjg.v19.i40.6703

Goodyear T, Brown H, Browne AJ, Hoong P, Ti L, Knight R. "Stigma is where the harm comes from": Exploring expectations and lived experiences of hepatitis C virus post-treatment trajectories among people who inject drugs. Int J Drug Policy. 2021 Oct;96:103238. doi: 10.1016/j.drugpo.2021.103238. Epub 2021 Apr 23. PMID: 33902968; PMCID: PMC8881088.

Saine ME, Szymczak JE, Moore TM, Bamford LP, Barg FK, Forde KA, Schnittker J, Holmes JH, Mitra N, Lo Re V 3rd. The impact of disease-related knowledge on perceptions of stigma among patients with Hepatitis C Virus (HCV) infection. PLoS One. 2021 Oct 5;16(10):e0258143. doi: 10.1371/journal.pone.0258143. PMID: 34610030; PMCID: PMC8491913

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