HOW TO TALK WITH INMATES ABOUT HEPATITIS C

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DISCLOSURE

- I do not have any relevant financial relationships with any commercial interests.
LEARNING OBJECTIVES

1. Understand current hepatitis C treatment access trends in prisons and jails.

2. Get equipped with helpful messages and techniques for communicating with inmates about hepatitis C treatment.

3. Be able to talk to inmates about other, non-treatment health interventions for someone with hepatitis C.
MY BACKGROUND TO TALK ON THIS SUBJECT

- Hepatitis Education Project, 501c3 in Seattle
  - Unique agency
  - Community-based, non-judgmental
  - Work *directly* with most marginalized populations
    - Unique understanding of stigma and also of the patient perspective

- Two correctional education programs
  - Work directly with offenders and medical staff
  - Reach 1000+ inmates per year
  - Have heard (almost) every question, complaint, opinion, challenge, frustration, conspiracy theory out there
WHAT'S UP WITH HEP C (HCV)?

- Most common blood-borne pathogen in US
- Disproportionately affects correctional populations (understatement!)
- New treatments cure 95%+ but at huge price tag
- Prisons and jails seen as ideal venue for public health interventions for HCV...
  - Identifying cases, education, staging, prevention
  - Treatment as prevention
  - ...but prisons and jails are not (designed to be) public health institutions
Understanding Hepatitis C Treatment Access

- 50% of HCV patients are still undiagnosed
- Almost all HCV patients are candidates for treatment
- Very expensive medications
- Prioritization of patients is taking place in the community and in corrections
- Provider capacity to treat still lags in both community and corrections
- Most exclusion criteria for patients are resource-, not clinically-based
- Patient choice is often greater in community, but many don’t have access to healthcare or financial resources
UNDERSTANDING HEPATITIS C TREATMENT ACCESS

- **Bottom line:**

Despite advances in therapy, HCV treatment is still very difficult to access, especially for marginalized populations. Despite a constitutional right to healthcare, resource and capacity issues are still preventing most prison systems from treating HCV robustly despite the widely accepted public health benefits of doing so.
Is it true I can get hepatitis C from my own blood?

What’s going to happen to me?

They’re going to wait until I’m on the verge of death before they treat me.

I want to take care of this while I’m here.

They don’t care who lives or dies in here.

I can’t afford treatment outside.
OH YEAH, THIS CAN HAPPEN...
REAL PEOPLE AND REAL EMOTIONS

- Fear
- Uncertainty
- Frustration
- Mistrust
- Urgency
The Unfortunate Reality

More incarcerated people interested in hepatitis C treatment
Incarcerated people have constitutional right to health care (“community standard”) Major community health benefit

Prisons forced to prioritize due to lack of resources and capacity

*Most people with hepatitis C in prison won’t get treated while incarcerated*
How do we explain this in ways that...

- Are accurate
- Are understandable
- Encourage healthy changes
- Reduce fear/uncertainty

Of course, we can't always do this
Basic HCV Counseling Messages

Any patient who has tested positive for hepatitis C antibodies should be counseled to:

- Get a viral load test to confirm chronic infection
- Reduce/eliminate alcohol
- Avoid drugs, including OTC’s containing acetaminophen. Discuss any new medications with provider
- See medical provider regularly for monitoring or treatment workup
- Practice prevention – even among others with HCV
- Eat well and exercise (car analogy)
- Get vaccinated for hepatitis A and B
- Harm reduction perspective!
UNDERSTANDING THE OFFENDER POINT OF VIEW OF DELAYED/DENIED TREATMENT

- Hepatitis C is scary
- Many inmates know someone who has died from HCV
- Inmates often inherently mistrust prison staff
- Hepatitis C is highly stigmatized
- Prison is a time of reflection and redemption for many
- Prison is an opportunity for many to get healthcare
- Navigating healthcare system on outside is difficult (even for us!)
- Many worry about friends and family
DISCUSSING WHY YOU CAN’T TREAT

- **Validate feelings** of frustration, uncertainty, and fear

- **Provide medical facts** about HCV disease progression and urgency of treatment
  - Slow-progressing
  - Doesn’t progress in all patients
  - Recent infection = lower chances of liver disease (currently)
  - *Don’t neglect seriousness of HCV and importance of treatment* at earliest possible time, but do work to ease feelings of panic

- **People are smart** – **explain macro-level issues**
  - Newness of and transition to new medications
  - Expense of new medications and limits of correctional healthcare budgets
  - Prioritization of patients – many are sick and/or have been waiting

- **Offer alternatives** – what *can* be done?
  - Be realistic about what can and can’t be done in your facility
  - Emphasize importance of treatment on release and offer resources
HCV: Non-treatment Health Interventions

- Regular testing and confirmatory testing
- Patient counseling and education
  - Help patients understand what their diagnosis means
  - Counsel patients on health interventions
  - Counsel patients to learn as much as they can about HCV and prepare for treatment when available
  - Harm reduction strategies
- Prevention and accurate routes of transmission in prison and community
- HAV/HBV Vaccination
- Staging, monitoring
HCV: Non-Treatment Health Interventions

- Chemical dependency treatment (if applicable)
- Prepare for future treatment as much as possible
- Evaluate insurance and patient assistance options
- Bring medical records home
- Any release planning/case management/linkage to care resources
- Referrals to local community resources
DISCUSSION:
APPLYING COMMUNICATION SKILLS
As providers, case managers, counselors, etc. working in corrections, what are some communication skills you use to communicate with inmates?

Especially those who mistrust the system?

What about those who are afraid?
“YOU’RE JUST GOING TO LET ME DIE IN HERE AREN’T YOU?”

I recognize you may be scared and frustrated

Hepatitis C is not a death sentence

It’s true that treating HCV early is best, but treatment is not immediately urgent for most people

Hepatitis C treatments are new and expensive, and we are working to treat many people who may have been waiting a long time

Just because you are not being treated now does you will not get treated in the future

Here is how you can prepare for treatment in the future (offer tangible resources – take home medical records!)

Here is what we are going to do for you: (Monitor, educate, vaccinate, workup, plan for release, etc.)
FINAL THOUGHTS

- Honesty and authenticity go a long way
- HCV treatment access is an amalgam of *systematic* problems
- Stay on top of this issue as it will be a major one for a some time to come
- Don’t forget that the people in khakis or jumpsuits are human beings
HEP
HEPATITIS EDUCATION PROJECT

• Direct services
• Patient Support
• Education
• Advocacy

HEP has worked in the correctional setting since 2001.
Launched by Hepatitis Education Project in 2013
Growing network of experts
What we do:
- Connect network partners to each other through email communication, webinars, and in-person meetings.
- Host an annual meeting each year in March.
- Provide quarterly webinars on relevant topics.
- Develop educational materials for incarcerated people about hepatitis.
- www.hcvinprison.org
HEPATITIS C
IN PRISON AND JAIL

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