

Investigating Patient Attitudes towards Hepatitis C (HCV) to Guide Implementation of Primary Care-Based HCV Treatment

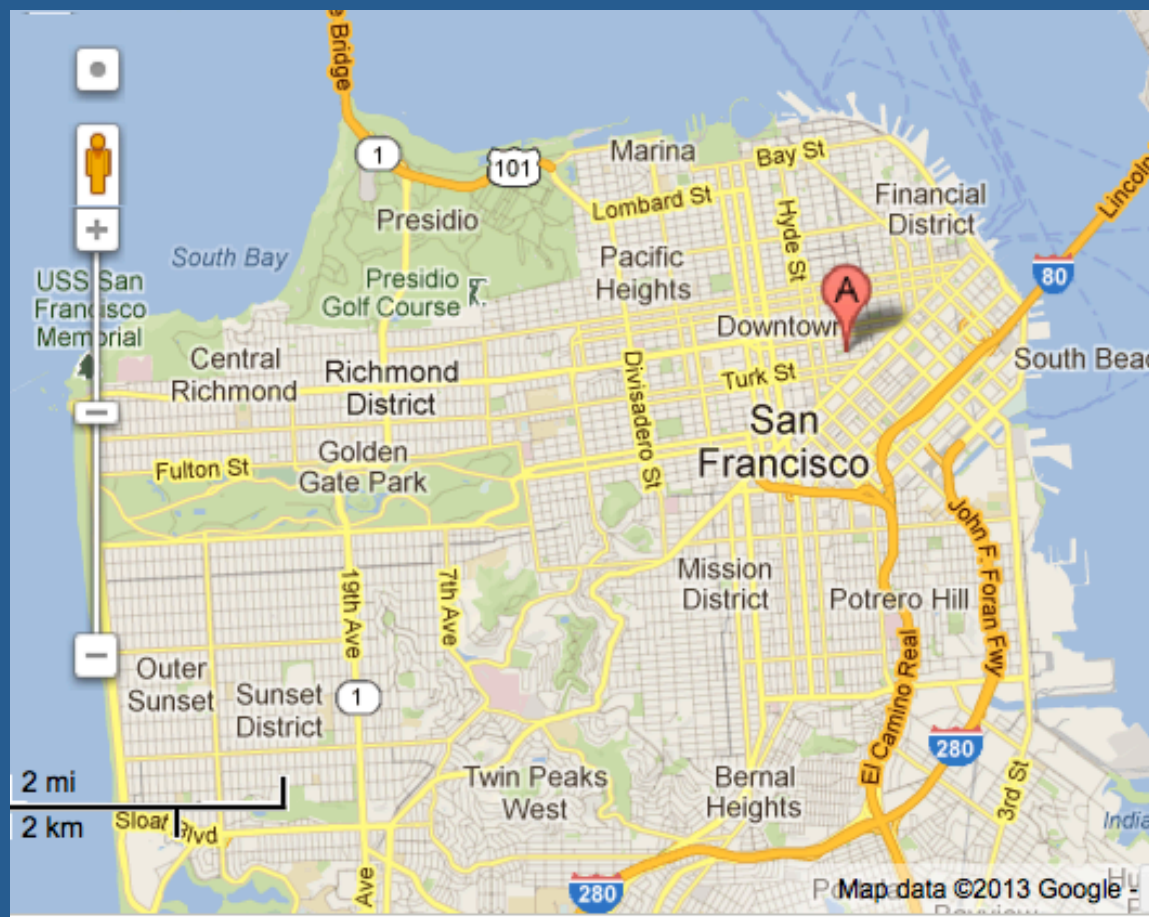


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Objectives

1. Outline the risks for infection and the burden of HCV in homeless populations
2. Delineate strategies for starting a primary care-based education and support group
3. Describe patient-identified barriers to HCV treatment in the underserved setting
4. Outline the fundamental elements of a primary care-based treatment program



The Housing and Urban Health Clinic

The Housing and Urban Health Clinic is dedicated to providing culturally competent, multidisciplinary medical and psychiatric health services tailored to serve the unique needs of adult patients living in both supportive and independent housing in San Francisco.

- **HUHC Demographics**

- Total active adult patients : 1757 (71% male, 29% female)
- 92% between ages 18-64

- **Housing status**

- Primarily living within the Tenderloin, Civic Center, SOMA and surrounding neighborhoods
- Supportive housing (5 RN-supported bldgs with CM/SW services)
- SF DPH: Direct Access to Housing (DAH)
- Homeless (streets and shelters)
- Single Room Occupancies (SROs)

The Richardson Apts
365 Fulton # Gough



EMPRESS HOTEL

This place is pure emotion . . .

Stories of the Homeless

*Struggles with Demons
and Addiction*

*"If you weren't mentally ill when you
became homeless, you're going to be
mentally ill. . ." —Lynn*

144
EMPRESS HOTEL

NFN
NATIONAL FOSTER NETWORK

144 Eddy
@ Mason

The Plaza Apartment
998 Howard @ 6th



**Mission Creek Senior Community
Dedication & Open House
October 10, 2006**

225 Berry
@ 4th St



1. Outline the risks for infection and the burden of HCV in homeless populations

The Hepatitis C Virus

- Bloodborne viral pathogen
- Risk factors for infection: injection drug and crack cocaine use, low income, history of incarceration, mental illness, African Americans, Latinos, Baby Boomers
- Long term sequelae:
 - Cirrhosis
 - Decompensated liver disease
 - Hepatocellular carcinoma
 - Death

The Hepatitis C Epidemic

- Approximately 170 million people infected worldwide
(Armstrong et al., *Annals of IM* 2006)
- Hepatitis C-related deaths exceeded HIV-related deaths in 2012
(Ly et al., *Annals of IM* 2012)
- Estimated 17,000 new infections in the US in 2010
(CDC, *Viral Hepatitis Surveillance – US* 2010)
- CDC Birth Cohort (1945-1965) HCV Screening Recommendation
(Smith et al., *MMWR* Aug 2012)

HCV Screening Guidelines

- **Persons born during 1945-1965 (1 time)**
- **Intravenous drug users, including those who injected only once and do not consider themselves to be drug users.**
- **Persons with conditions associated with HCV infection including those with:**
 - HIV infection
 - Hemophilia (when having received clotting factor concentrates prior to 1987)
 - Hemodialysis (ever)
 - Unexplained abnormal aminotransferase levels
- **Recipients of transfusions or organ transplants prior to July 1992 including those who:**
 - Were notified that they received blood from a donor who later tested positive for HCV infection
 - Received a transfusion of blood or blood products
 - Persons who received an organ transplant
- **Children born to HCV-infected mothers**
- **Health care, emergency medical and public safety workers after a needle stick injury or mucosal exposure to HCV positive blood**
- **Current sexual partners of HCV-infected persons.**

Note: People who have rough sex or multiple sex partners have higher rates of hepatitis C, although CDC does not specifically recommend screening for these groups.

Hepatitis C in the Homeless

- HCV Ab (+) prevalence at Health Care for the Homeless Clinics:
 - Overall prevalence: 31%
 - Among IDUs: 70%

(Strehlow et al., J of Health Care for the Poor and Underserved 2012)

- Homelessness is independently associated with HCV infection

(Stein & Nyamathi, Drug Alcohol Depend 2004)

The Treatment: a Cure

- 6-12 months of Interferon and Ribavirin (+/- Telaprevir/Boceprevir)
- Significant side effects
 - Nausea/vomiting/diarrhea
 - Malaise, weakness, fatigue, muscle aches
 - Rash
 - Anemia
 - Irritability, depression, suicidality, anxiety
- “Contraindications”
 - Psychiatric disease
 - Substance abuse
 - Lack of social supports

“They don’t treat people like us.”

“The possibility of achieving future cost savings, particularly for disadvantaged groups, raises the question: can we afford not to improve the accessibility of treatment for hepatitis C?”

(Clark et al., *NEJM* 2012)

2. Delineate strategies for starting a primary care-based education and support group

The Housing and Urban Health Hepatitis C Initiative

- Leadership
 - Kelly Eagen, MD (HUHC)
 - Jocelyn Poulin, RN (HUHC)
 - Laura Starbird, RN (UCSF School of Nursing Student)
 - Suzanne Hufft, MSW (DPH)
 - Jana Drakka (Soto Zen Buddhist priest)
- Partnerships:
 - UCSF School of Nursing (Collaborator: Carmen Portillo, PhD, RN)
 - UCSF Positive Health Project's "Hepatitis C: A Primary Care Initiative"
 - The Empress Hotel (a Direct Access to Housing SRO in the Tenderloin)
- Funding - SF Bay Area Collaborative Research Network



"I go to the groups because, um, sometimes healing is more than just taking a pill, you know. Energy from a pill might change the biochemical structure of a being, while energy from a conversation changes the chemical structure to different sound waves, or whatever."

- Group participant



* Used with participant permission

Weekly Support and Education Group

- Recruitment at HUHC, affiliated SROs, word of mouth referrals
- Start date: April 2012
- Average weekly attendance: 5-10 participants
 - Approximately 55 total participants to date
- Monthly Calendar
 - Week 1: MD-led teaching session
 - Week 2: Guest presentation
 - Week 3: Peer advocate
 - Week 4: Self-care (mindfulness, stress management, harm reduction)
 - Week 5: Community field trip, other


“The group is like my safety net.”

Curricular Topics

- Hepatitis basics
- Transmission
- Serum testing
- Know your status
 - The Pocket Card: Ab, VL, genotype, imaging
- Symptoms of HCV infection
- Cirrhosis and long term complications
- Co-morbidities (DM/HTN/HLP)
- HIV and HCV co-infection
- The liver biopsy
- Treatment (DAAs, INF, ribavirin)
- Patient's experience of treatment
- Nutrition and HCV
- OTCs with liver disease
- Herbal supplements
- Acupressure and acupuncture
- Stress management
- Mental health
- Substance abuse and harm reduction
- Alcohol and marijuana with HCV
- Sex and HCV
- Mindfulness
- Yoga
- Exercise and HCV

A few more things...

- Resources:
 - Patient education books
 - Liver model
 - HCV Pocketcards
 - Videos
- Keep an attendance record (but no attendance requirements!)
 - Incentives for regular attendance
- *Food... Food... Food...*



KNOWLEDGE IS POWER

MY INFO

Hep C antibody test

positive

negative

unknown

Hep C Viral Load

_____ copies/iu

Hep C Genotype

1 2 3 4 (circle one)

Liver Image

ultrasound

ct scan

_____ results

First steps to creating a group...

- Identify a champion (or champions).
 - Include clinical and non-clinical team members
- Partner with a local institution.
 - health clinic, community-based organization, housing facility, religious entity
- Recruit widely in the places where your target population can be found.
 - shelters, clinics/hospitals, dining facilities, substance abuse treatment programs
- Look for funding from small grants or your partnering institution's budget.
(It's not expensive!)
- Create a library of resources.
 - Patient education books (*HCV Advocate*, OASIS clinic, VA treatment workbooks)
 - Videos (OASIS)
- Pick a weekly day and time in a meeting place convenient for your participants. Be consistent!
- Listen to the ideas and interests of your participants.

3. Describe patient-identified
barriers to HCV treatment in the
underserved setting

Data Collection

- Literature review of patient experiences during HCV treatment
 - Limited published data regarding patients' pre-treatment perceptions of HCV and treatment
- 12 participant interviews
 - To analyze patients' pre-existing knowledge, attitudes and beliefs regarding HCV
 - To gather feedback from our target population to guide the development of a primary care-based HCV treatment program

The Interviews

- 20-40 minute interviews at HUHC
- Recruitment from HCV group participants and HUHC patients
- \$20 gift cards for participation (Walgreens/Safeway)

Interview Participants

- 67% male
- Age 36 to 59 (mean 49.8)
- Ethnicity :
 - 6 white
 - 3 African American/black
 - 2 American Indian/Alaska Native
- Housing:
 - 10 in Apartment/SRO
 - 3 clinic-affiliated housing
 - 1 Homeless/Streets
 - 1 Transitional/Sober Living
- Case Management
 - 67% have case manager
- Mental Health Support:
 - 50% have MH provider
- Medical Care:
 - All have medical home/clinic
 - 10 HUHC
- Treatment History:
 - 1 current HCV treatment
 - 1 previously treated x4 weeks
- Mode of Infection:
 - 59% (7) needles
 - 8% (1) blood transfusion
 - 33% (4) unknown

Lack of HCV Knowledge

Theme	Quote
What is hepatitis C?	<i>"It was kind of a surprise to me; I didn't know what it was."</i>
I'm going to die	<i>"I thought I was going to die right then and there. I was like, shocked. How did I get this, you know?"</i>
Indifference	<i>"I didn't think a lot of it then. I kind of let that go. And it seemed like the medical team I was being treated by had no urgency."</i>

Awareness of Symptoms

The most commonly reported symptom was fatigue (75%)

Theme	Quote
+ symptoms related to wanting to be treated	<i>"I just want my energy back, you know. I just want to feel good about myself."</i>
- symptoms related to not wanting treatment	<i>"I think I would do it if I was being affected by hep C, but I'm really not."</i>

Stigma of Infection

Theme	Quote
External stigma	<i>"I remember talking to my parents about it and they disowned me. They were like, 'what? Jeopardizing this family? You're not our kid.'"</i>
Internal contamination	<i>"I'm ashamed of it... I sure wish my eyes would be clear like yours."</i>

Fear of Interferon

Theme	Quote
Peer discussions focus on negative effects of interferon	<i>“most the people I’ve talked to – well, you’re not gonna talk about it a lot if it was easy to go through. But you’re gonna hear all the complaints about it, of course.”</i>
Interferon unrealistic without stable housing	<i>“And I’m like, I’m homeless, whatever, I’m not doing chemotherapy or whatever, cuz I know that it can make you sick”</i>
Wait for interferon-free regimen	<i>“They’d have to get rid of the interferon, have...different drugs.”</i>

Social Stability

Participants wanted to achieve stability – with housing, substance use, and relationships – before beginning treatment

Theme	Quote
Housing – Somewhere to rest	<i>“I’d be willing to try the medication if, and only if, I’m inside somewhere so if I get sick, whatever, I can lay down, go to sleep, and don’t have the cops rousing me.”</i>
Substance use – Harm reduction	<i>“I would think that people need to be practicing some sort of harm reduction. Because a lot of people who have this are not gonna stop using drugs. And they need to be treated.”</i>

More Suggestions

Theme	Quote
Food access	<i>"I live in an SRO and I have a lot of cooking issues... my diet is limited"</i>
Flexible access to clinic	<i>"There could be a set date where I could just drop in"</i>
Adherence support	<i>"I'm seen at the clinic every day, and so I'm constantly monitored and that's the best way to get through treatment, is when somebody sees you every day."</i>

Support is Key

- All participants expressed an interest in attending a support group.
- When asked what the most important thing to help succeed in HCV treatment would be, participants stressed peer support.

“I think the only thing I would need is the support group that I go to on Mondays.”

4. Outline the fundamental elements of a primary care-based treatment program

Primary Care-Based Treatment

- Supportive clinic administration and staff
- Treating Provider
 - IAS-USA Viral Hepatitis Management trainings
 - Local mentor experienced in HCV treatment
- RN Champion
 - Weekly medication dispensing → easy access to clinic during treatment
 - Regular phone or in-person check-ins, ongoing hepatitis education
- Local consultant (hepatologist or infectious disease specialist)
 - Complex cases
 - Adverse reactions and complications
- Psychiatric partner for pre-treatment evaluation and ongoing care as needed
- Social work evaluation
 - Housing
 - Insurance
 - Food access
 - Support systems
 - Transportation
- Local support groups, peer advocates, substance abuse counseling and harm reduction groups

“Your Hepatitis C Treatment Starts Today”

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