Hep B Moms Project
A postpartum patient navigation program for women living with hepatitis B

Farma Pene & Liz Tang
New York City Department of Health and Mental Hygiene
Viral Hepatitis Program
September 18th, 2019
Background

- **Over 230,000** New York City (NYC) residents are living with chronic Hep B infection.
- New York State (NYS) law mandates testing all pregnant women and reporting positive results.
- **1,256** pregnant women reported with Hep B in 2017.

Why perinatal women?

- Only 1 in 5 pregnant women with Hep B receive appropriate follow up after delivery
- Half of providers do not educate women about hepatitis B or refer to specialty care
- 1 in 4 women with Hep B have flares after delivery

Sources: Chang et al. 2015; IOM Report 2010; ACOG Practice Bulletin, 2007; February 8, 2018; AASLD 2018 Hepatitis B Guidance.
Birth Countries of women with hepatitis B who delivered a child in NYC, 2017

China 53%

Western Africa 15%

Other 21%

United States 5%

Caribbean 6%
Hep B Moms Patient Navigation Project

- **Goal**: Increase maternal engagement in Hep B medical care after delivery
- **Population**: Adult postpartum women in NYC
- **Intervention**: Telephone patient navigation program
- **Research**: Required full IRB approval and informed consent from participants
- **Duration & Funding Source**: 2 years, Gilead Sciences grant
- **Staff**: 1 full time Chinese-speaking and 1 French- and Wolof-speaking navigators. 2 part-time grad school interns
Program Workflow and Evaluation

**Preparation**
- Navigators receive referrals
- Review patient demographic information
- Review lab results
- Review provider information

**Intervention**
- Outreach
- Informed consent
- Assessment
- Culturally appropriate linkage to care
- Health education
- Assistance to overcome barriers
- Reminders
- Follow up

**Evaluation**
- Did the intervention increase the proportion of women who received follow-up hepatitis B monitoring within 6 months of delivery?

**Impact**
- Increase self-efficacy
- Increase Hep B knowledge
- Decrease stigma
- Improve patient-provider communication
- Enhance referral process
- Increase contact screening and vaccination
Participant Characteristics & Program Outcomes

There were unique barriers faced by Chinese-born versus other participants, encompassing both educational and health care needs

- **417** enrolled, **99%** foreign-born
- **23%** uninsured/temporary insurance
- **81%** of those enrolled for at least 4 months have attended an appointment for Hep B care after delivery
- **5%** referred their contacts

Languages Spoken:
- Mandarin: 54%
- English: 20%
- Cantonese: 15%
- Wolof: 3%
- French: 2%
- Spanish: 2%
- Russian: 1%
- Uzbek: 1%
Characteristics of Chinese-speaking participants

- Follow-up with PCP at FQHC or private practice
- Most patients can make appointments
- Have a health insurance representative
- Work or travel outside NYC
- Communicate by call, text, weChat, email
- Aware of spouse’s Hep B status
Total Chinese-speaking participants: 272/417

- 78% preferred speaking in Mandarin and 21% preferred speaking in Cantonese
- 3% unable to fill out forms
- 11% needed help to make appointments
- 6% needed additional referrals for health insurance or pharmacy, etc.

Most participants used Low-income health insurance

Most participants could contact their providers by themselves

- Uninsured: 6%
- Private insurance: 9%
- Temporary Medicaid: 18%
- Low-income insurance: 67%

- Referral provided and accepted: 3%
- Navigators made appointments for patients: 9%
- Patients made their appointments: 70%
Barriers to care for Chinese-speaking participants

**Schedule Appointment**
1. Difficult to schedule appointments due to travel/work schedule
2. Some private practices only take walk-ins and no next appointment scheduled

**Access to care**
1. Difficult to provide required documents to apply for low-cost medical services
2. Misinformation about sliding fee scale
3. Copayment/deductible

**Hep B Knowledge**
1. Does not understand the importance of routine monitoring
2. Believes that Hep B medication is not safe if taking it long-term or while breastfeeding
Common concerns & questions of Chinese-speaking participants

- Side Effects of Long-term Hep B medication
  - Would the baby take the medication at the same time if I am breastfeeding?

- Vaccine and Immunity
  - For people with immunity, how long does the immunity last?

- Routine follow up
  - My viral load is low, do I need to follow up?

- Diet and Lifestyle
  - Can I use cooking wine?

- Spread HBV to others
  - Can I breastfeed my baby?

- Lack of informal support for child care
  - Would it affect my green card application if I get health insurance?

- Immigration policy changes
Characteristics of Other Participants (1)

- Mostly uninsured
- Experience language access barriers
- Low health Literacy
- Mostly communicate by phone
- Receive most of their care at H+H (public) hospitals and FQHCs
- Patients need full appointment scheduling
Characteristics of Other Participants (2)

Health Literacy

- English-speaking: 83%
- No English: 17%
- Low Health Literacy: 33%

Appointment

- Need help scheduling appointment: 49%
- Scheduled appointment for patient: 60%
- Additional referral: 12%

157 Participants
Barriers to Care for Other Participants

**Language**
1. Language services are not available
2. Low quality translation from interpreter services
3. Difficulties communicating by text
4. Can’t make appointments

**Access to Care**
1. Undocumented
2. Unaware of low-cost health services
3. Difference between temporarily insurance and regular insurance

**Hep B Knowledge**
1. Does not understand the risks of Hep B
2. Lack of knowledge of medications and blood tests
3. PCP versus specialist
Common concerns & questions of Other Participants

- Being stigmatized by family or partner
- How to get documents to provide to hospital for low cost care (sliding fee scale)
- Concerned health insurance will damage green card application
- Concerned that Hep B is causing other health issues
- Will my kids be ok after vaccinations?
- What is so dangerous about B and where does the virus come from?
- Is it too late to get vaccinated?
- What can I eat to make sure the virus stays low?
- As a person living with Hep B, can I work in health care?
- Since the virus is low, does it mean it is going away?
Lessons Learned

- Navigation services and health education are important for postpartum women.
- Accessing free and low-cost health care is complicated.
- Maintaining close relationships with federally-qualified health centers and public hospitals is critical.
- A patient’s language needs are not always met by interpreter services at hospital or health insurance companies.
- Focusing on the person (not the disease) is less stigmatizing.
- Patients often have limited Hep B health literacy and need guidance.
Thank you!

The Hep B Moms Project is supported by the great work of:

Jessie Schwartz & Interns: Jialiang Li & Faiza Nasir

Perinatal Hepatitis B Prevention Program
Julie Lazaroff, Ariba Hashmi & All the Public Health Advisors

Check Hep B Patient Navigation Programs
Umaima Khatun & Nirah Johnson

Check Hep B Patient Navigation Partners and their Patient Navigators
And many others!