Understanding and Combating HBV-Related Stigma and Discrimination

November 1, 2017
Hep B United: A National Coalition

Dedicated to reducing the health disparities associated with hepatitis B by increasing awareness, screening, vaccination, and linkage to care for high-risk communities across the United States.

- 30+ local coalitions & national organizations that focus on the Asian American & Pacific Islander communities.
- Voices for local and national advocacy

hepbunited.org
We know that many populations impacted by HBV face stigma.

Stigma is defined as a “mark of disgrace,” either real or perceived, that sets someone apart from others.

Those that feel stigma can feel shame, hopelessness, loneliness, social isolation, and much more.

This can lead to being treated differently from others in one’s family and community, discrimination, etc.
Speakers

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Addressing HBV Stigma
At Charles B. Wang Community Health Center (CBW)
A Federally-Qualified Health Center in New York City

Janice Lyu
Senior Hepatitis B Program Associate
Charles B. Wang Community Health Center

- Federally Qualified Health Center
- NCQA level 3 Patient-Centered Medical Home
- Multidisciplinary care- primary care (adult, pediatric, OB/GYN), mental health, specialists, optometry, dental, social work
- 4 clinical sites across Chinatown, Manhattan and Flushing, Queens
- Serve more than 50,000 patients and 275,000 service visits in 2015
- Focus on medically underserved and Asian Americans
  - Staff fluent in many languages, including Mandarin, Cantonese, Taishanese, Shanghainese, Fujianese, Vietnamese, and Korean
- Research and Evaluation Department
- Health Education, Marketing & Communications Departments
How many chronic hepatitis B (CHB) patients do we see?

- **8540** CHB Registry
- **4115** Active* patients
- **1,130 (27%)** Uninsured patients
- **550 patients in HBCP**

*Active CHB patients were seen for an annual physical or follow-up visit from 9/1/15 to 9/1/2017

**HBCP = Hep B Care Program for high risk uninsured CHB patients include care management and subsidized imaging tests
Hepatitis B Programs

• Hepatitis B Care Program (HBCP) est. 2009
  – Case management for high-risk uninsured adult patients with HBV
  – Over 550 patients (Manhattan and Flushing) enrolled
  – Patients are referred by providers and found using internal HBV registry report
  – High-risk enrollment criteria:
    • On treatment
    • Have family or personal history of HCC or cirrhosis
    • Meet other high risk HCC screening criteria (Asian M > 40yo, Asian F > 50yo, African/Black > 20yo)
Hep B Moms Program

• Goal to prevent perinatal transmission and fill the gaps between transitions of care (OB/HBV provider/Delivery hospital/Pediatrician)
• Tested early in pregnancy and assessed for existing care and if not, referred to CBW IM
• Patients are identified from Women’s Health OBGyn Care Management report run biweekly
  • Care Manager provides face-to-face counseling
  • Links patients to hepatitis B care during and after pregnancy
Overview of Primary Care Model for Hepatitis B Care at CBWCHC

Specialist: GI or ID

Hep B Program Director/Departmental Hep B Champion

Hepatitis B Program Manager

Patient

MH specialist MH issues associated with hep B, substance abuse, etc.

Education & Training

Health System Support

EMR Tools: Forms, Reminders, Registry

Procedures and Protocols
HBV Stigma at CBW

Cause:
- Lack of knowledge and misconception
- Having no visible chronic hepatitis B symptoms

Effect:
- Neglecting care
- Lack of communication
- Making assumptions and suspecting
- Fears
Protocols and Education for Providers

• Updated Guidelines and Protocols Uploaded on Central Medical Protocol Portal
• Monthly Internal Medicine/Provider meetings
• Monthly Hepatitis B Collaborative meetings
• CME Providers Education Seminars/Training
Hep B Education Reminders in EMR

<table>
<thead>
<tr>
<th>Pre Diabetes</th>
<th>DM</th>
<th>Hepatitis B</th>
<th>HTN</th>
<th>Hyperlipidemia</th>
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<tbody>
<tr>
<td>Explained to pt that HBV is a chronic disease</td>
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<td>Patient education given on:</td>
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<tr>
<td>[ ] F/U MD regularly</td>
<td>[ ] Avoid liver injury</td>
<td>[ ] Avoid self medication</td>
<td>[ ] Avoid transmission factor</td>
<td>[ ] Household screening</td>
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<td>Comments:</td>
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Previous HepB Tracker Status: renewed and given (12/28/2018 2:44:11 PM)

HepBTracker: 

Documents Flowchart

Orders

Histories

Protocols

Graphs

Handoffs

Registration

Uptake

Dec ID: 75

Properties: IM FU Visit at C, IM_4 on 09/10/2016 10:07 AM

Hepatitis B

Patient education given on:

F/U MD regularly: Need to have bloodwork routinely to monitor viral load and liver health

Avoid liver injury: Avoid alcohol and smoking, healthy diet and adequate rest

Avoid self medication: Herbal supplements and OTC meds may harm liver, notify MD if taking

Avoid transmission factor: Do not share toothbrushes, razors, nail clippers, or any other object that could possibly become contaminated with blood

Healthy Lifestyle: Be physically active and adequate rest

HepBTracker: patient did not bring tracker to visit 09/10/2016

Pt verbalized understanding and educational pamphlet given By: AM
Care Manager Duties

- **Create a safe environment for patients to raise questions/fears/concerns about HBV**
- **Assess knowledge about HBV**
- **Phone or in-person HBV education and case management**
  - Work with provider for optimal treatment plan
  - Monitor patient’s HBV visits and their progress using database
    - Track patient’s blood work and follow up appointment dates
  - Re-engage non-adherent patients
    - Call if did not show up or canceled appointment
    - Provide education and reschedule appointment
- If unable to reach by phone, send HBV specific reminder letter Track HCC U/S screening referrals
  - Assist in scheduling appointment
  - Assist in follow up imaging if needed (CT or MRI)
- Track staging fibrosis referrals (Elastogram/Fibroscan)
- Record patient’s treatment status in database
  - Assist in applying for medication through Patient Assistance Program
  - Check that patient is adherent to medication
Household Contact

• Weaved into care manager’s and provider’s HBV education
• Ask about family history/status of household contacts
• Encourage communication with family and friends
• Encourage households to get screened
  – Offer 1st time screening for free
Patient HBV Education Tools/ Resources
Hep B Mom Roadmap

IF YOU HAVE HEPATITIS B, PROTECT YOUR BABY
USE THIS CHART TO TRACK YOUR CARE AND YOUR BABY’S CARE

If you have hepatitis B, the virus can be transmitted to your newborn through your blood at birth. The baby can then carry this serious disease for a lifetime. To prevent infection, make sure your baby is protected with immunizations. Also, see your doctor regularly to take care of your hepatitis B and avoid liver damage.

DURING PREGNANCY
- Get blood tests.
  - Hep B Viral Load
  - Liver tests
  - Hep B e antigen
- If your disease is severe, your doctor may talk to you about taking hepatitis B medication.
- Make sure your spouse and those living with you are tested for hepatitis B.
- See a doctor regularly for hepatitis B.

AT BIRTH
- Tell the staff at the hospital you have hepatitis B.
- Baby must receive 2 shots within 12 hours of birth to protect from infection.
  - One shot of hepatitis B immunoglobulin (HBIG)
  - 1st shot of the hepatitis B vaccine

AFTER DELIVERY
- 6 MONTHS
  - Make sure your baby receives the 3rd shot of hepatitis B vaccine. This shot should not be given before 6 months, or baby will not be fully protected.

- 9-12 MONTHS
  - Make sure baby gets a blood test to check if he or she is protected after the shots. This is special for babies born to mothers with hepatitis B.
  - HBsAg
  - HbsAb
  - Check the test results:
    - Protected
    - Not Protected
    - Infected
  - *If baby is not fully protected from hepatitis B, the doctor will repeat the vaccine.

IF YOUR BABY IS CARED FOR IN CHINA
- The caretaker must tell the new doctor that baby’s mother has hepatitis B. It is very important to make sure the baby gets the 2nd and 3rd dose of the vaccine.
- Your baby must get the 3rd shot at 6 months and not earlier.
- Ask the doctor to test your baby by 15 months to check if he or she is protected from hepatitis B. This is not done for all babies, so the caretaker should request it because it is important for your baby. Keep a copy of the results.
- When your child returns to the United States, bring your child’s vaccination records from China, and schedule a check up for your child. Immunization records are needed for children to enter to school.

Charles B. Wang Community Health Center

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Protecting Your Baby From Hepatitis B
What Pregnant Women Need to Know

Charles B. Wang Community Health Center

http://www.cbwchc.org/HepatitisB.asp

Hepatitis (HEP-ah-TY-tis) B is a serious liver disease caused by infection by the hepatitis B virus. If not cared for or treated, a hepatitis B infection can lead to cirrhosis (liver scarring), liver damage, and liver cancer.

Hepatitis B is called the “silent killer” because most people with the disease do not know they have it until they develop serious problems. People with hepatitis B can spread the virus to others even if they do not have any symptoms.

Why should I be concerned about hepatitis B?
Asians are at high risk of getting infected. About 75% of people with chronic hepatitis B infection in the world are Asian.

Among Asians, the most common way the virus spreads is from mother to baby. If a mother has hepatitis B, her blood and body fluids are likely to infect her baby during birth.

Even if a mother does not have hepatitis B, her child can still get infected by:
- Contact with infected blood and body fluids through breaks in the skin, such as bites, cuts, or sores.
- Contact with objects that have blood or body fluids on them such as toothbrushes or razors.
- Having sex without a condom with someone who has hepatitis B when the child grows up.

Hepatitis B virus is NOT spread by:
- Sharing food or drinks
- Sharing eating utensils or cups
- Sneezing or coughing
- Kissing or hugging
- Saliva, sweat, tears, urine, or stool
Thank you!

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Understanding and Combating Stigma:
A Toolkit for Improving Care and Support for People Affected by HBV

November 1, 2017
Beverly Quintana, Communications Manager, AAPCHO
About the Association of Asian Pacific Community Health Organizations (AAPCHO)

• National association of 33 community health organizations serving Asian Americans, Native Hawaiians and Pacific Islanders (AA&NHPIs)
  – 28 of which are Federally Qualified Health Centers (FQHCs)

• Dedicated to improving the health status and access of these medically underserved communities
AAPCHO Hepatitis B Activities Overview

1. Increase awareness about the impact of hepatitis B on AA&NHPIs and other at-risk populations, through thought leadership and advocacy work with:
   - Hep B United coalition
   - AAPCHO member health centers and broader network

2. Develop and disseminate resources and tools to improve hepatitis B prevention, care and treatment
Hep B United and AAPCHO Network

- Hep B United
  - National coalition raising profile of hepatitis B and liver cancer as an urgent public health priority
  - National Summit, coalition-building, mini-grant program, webinars
  - Meetings with policymakers
  - #justB Story campaign to combat stigma

- AAPCHO network
  - Community health centers
  - National and local CBO partners
New Toolkit to Address HBV-Related Stigma

Understanding and Combating Stigma: A Toolkit for Improving Care and Support for People Affected by HBV


- Curriculum to help community-based organizations and health facilities work with patients, staff and community members to combat and address stigma and discrimination experienced by people living with or most vulnerable to the hepatitis B virus (HBV)

- Acknowledgements and thanks to contributing reviewers
What’s in toolkit and why was it developed?

- Collection of participatory educational exercises
  - Learner-centered, participatory approach
  - Built around discussion and small group activities

- The aim of these exercises is to facilitate open discussion on HBV-related stigma and what we can all do to promote a change in attitude and practice
Who can use this toolkit?

Anyone can use this toolkit. You might be a:
- HBV health care provider or educator
- Community member or member of a community-based group
- Someone living with or who knows someone who is affected by HBV (partner, child, parent, or friend)
- Someone who can use the materials in this toolkit to adapt them for use to train other groups (media, policymakers, other community-based organizations, etc.)

Currently being pilot-tested by AAPCHO and Hep B United partners
Excerpt: Short Intro ➔
Straight to Modules

HBV, Stigma and At-Risk Groups

Combating HBV Stigma in a Health Care Setting

Table of Contents

Introduction

MODULE A - Understanding and Confronting Stigma

MODULE B - More Empathy and Less Fear

MODULE C - “Us” vs. “Them”

MODULE D - Understanding Stigma in Your Family and Community

MODULE E - Combating Stigma in a Health Care Setting

MODULE E - Taking Action to Combat Stigma

APPENDICES
**Hepatitis B**

**What is Hepatitis B?**
Hepatitis B is a liver disease that is caused by the Hepatitis B virus. Just like HIV, only a fraction of people who get Hepatitis B get infected for life. Some people may experience liver failure, cirrhosis, or even liver cancer.

**How is Hepatitis B spread?**
Hepatitis B is spread when an infected person comes in contact with blood or body fluids from a person who has the disease. This can happen through sexual contact, sharing needles or other forums where someone can be exposed to the virus.

**How is Hepatitis B treated?**
There is no cure for Hepatitis B. Treatment focuses on reducing symptoms and preventing complications from the virus. This can include medications and other medical treatments.

**Prevent Hepatitis B**

<table>
<thead>
<tr>
<th>TRUE</th>
<th>FALSE</th>
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</thead>
<tbody>
<tr>
<td>1. Hepatitis B is spread through direct contact with infected blood.</td>
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<tr>
<td>2. Hepatitis B cannot be spread through the air.</td>
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<tr>
<td>3. Hepatitis B cannot be spread through sharing meals, bowls or utensils with someone who has the disease.</td>
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<tr>
<td>4. In 12 Asian Americans has Hepatitis B.</td>
<td></td>
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<tr>
<td>5. Many people with Hepatitis B don’t have symptoms and don’t look or feel sick.</td>
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</tr>
<tr>
<td>6. A Hepatitis B blood test is the only way to know if you are infected with the virus.</td>
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<tr>
<td>7. The CDC recommends that people born in Asia or the Pacific Islands be tested for Hepatitis B.</td>
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<tr>
<td>8. Treatments are available that can help prevent serious liver damage from Hepatitis B.</td>
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<tr>
<td>9. Most people infected with Hepatitis B were infected at birth or in early childhood.</td>
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<tr>
<td>10. Hepatitis B is the leading cause of liver cancer among Asian Americans.</td>
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Excerpt: “Combating Stigma in a Health Care Setting” Module
Exercise D1 - Stigma in the Household

OBJECTIVES:
- Participants will be able to:
  - Understand forms of stigma in a household with a person living with HBV.
  - Identify ways to address stigma and create a healthier and more supportive household environment.

ACTIVITIES:
- Divide participants into groups and give each group a picture.
- Ask the group to write down notes to answer and discuss:
  - "What do you see in the picture? What do you think is happening? Does this happen in your family/household?"
  - "How does it affect you? How does it affect the people living with HBV in your house?"
  - "What can you do to address this stigma and create a more supportive household?"
  - "As a person living with HBV, how would you want your family members to treat you and make you feel comfortable?"
  - Report back to the group.

Summary:
Explain how stigma in the family/household takes many forms including isolation, blaming, and judging those living with HBV. The first step to combating stigma is to identify and acknowledge it, then work together to solve it.

Some examples of stigma in the household:
- Separation of utensils—plates, cups, spoons.
- Burn or discard clothing and other things used by person living with HBV.
- Physical isolation (e.g., forced to sleep alone or in a separate room).
- Minimum physical contact. No hugging. Told not to touch/play with children.
- Treated as a burden (e.g., extra money needed for treatment, extra time for care and management).
- Judging, Blaming, Condemning. Made to feel s/he has disgraced family.
- Partners/spouses of people living with HBV are assumed to be HBV positive.
- In-laws blame spouse for HBV (HBV exaggerates tensions with in-laws).

TIME:
1 hour

MATERIALS:
- Selection from stigma pictures (Appendix 1)
- Note pads
- Pens and markers

Excerpt: “Understanding Stigma in Your Family and Community” Module
Thank You

Understanding and Combating Stigma: HBV Toolkit
HBVStigmaToolkit@aapcho.org - feedback for improvements appreciated!

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AAPCHO
www.aapcho.org
Thank You!

Connect with us!

Hep B United
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AAPCHO
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Hepatitis B Foundation
www.hepb.org