Hepatitis B Stigma and Discrimination: Looking for a home.

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Presentation rationale

- World Hepatitis Summit, Glasgow, September 2015
  - 90 countries
  - To do: “to upscale the world’s response to hepatitis and to address the need for a global forum to examine public health approaches to the disease.”
- Opening Session
  - Jazzy de Lister, Dee Lee,
  - Representatives from Georgia, The Gambia, Egypt, Uganda, France, India, United Kingdom, and China.
It’s not the disease that’s scary,  
it’s the response that is scary.  

(Chinese man, 30-35yo, Guangzhou)
Public policy responses

- Draft global health sector strategy on viral hepatitis, 2016-2021
  - *End policies and practices that condone or encourage stigma and discrimination against people at risk for hepatitis or living with hepatitis,*
- Regional Action Plan for Viral Hepatitis in the Western Pacific
  - *Stigma and discrimination should be specifically addressed in the National Action Plan.*
- National Hepatitis B Strategy 2014-2017
  - Objective: *to eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people’s health*
Stigma, Discrimination and Hepatitis B - Definitions

- **Stigma**
  - “the individual who is disqualified from full social acceptance” (Goffman, preface, Stigma: Notes on the Management of Spoiled Identity)

- **Discrimination**
  - Unjust or prejudicial *treatment* of a person or group on the grounds of specific characteristics for example, race, gender, sexual orientation, disease
Stigma, Discrimination and Hepatitis B - Impact

- Higher levels of stigma = Lower levels of social support and poorer physical health
- Reduces health service access
  - Testing and diagnosis
  - Monitoring
  - Treatment
- Rights denied to people with hepatitis B
  - The right to employment
  - The right to marry
  - The right to freedom of movement
  - The freedom from inhuman and degrading treatment

From: HIV- and AIDS-Related Stigma, Discrimination, and Human Rights: A Critical Overview
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Some hepatitis B intersections

- Complex condition
- Migration, CALD + health access
- Indigenous + health access
- Priority of health
- Poor diagnosis
- Asymptomatic condition
Stigma, Discrimination and Hepatitis B – National Hepatitis B Strategy

- Prevention
- Testing
- Management, care and support
- Workforce
- Enabling environment
- Surveillance, research and evaluation

Quality heath care provision for the whole population
Stigma, Discrimination and Hepatitis B – Prevention

- Vaccination
- Access to health services
  - People who inject
  - Indigenous people
  - People from CALD backgrounds

- My daughter, she’s only two and a half ... we just found out a year ago that she’s got hepatitis B, she was born here. (Vietnamese born woman, mid 30s)
Stigma, Discrimination and Hepatitis B – Testing

- What limits quality health care to people with hepatitis B?
- Inadequate testing
  - They didn’t give me any information ... all I know is that it was hepatitis B. (Chinese born man, mid 20s)
  - I wasn’t sure what does it mean hepatitis B ... in our language we say ... this skin is yellow. (Afghan born man, early 20s)
  - In grade 3, 9 years old, I was dragged into a room ... 15 – 18 of us were invited into another room, and said that “yes, you guys are hepatitis B carriers” (Chinese man, 30-35yo)
Stigma, Discrimination and Hepatitis B – Management, care and support

- What limits quality health care to people with hepatitis B?
  - “I didn’t know there was treatment. Can it help them?” (Community nurse, Torres Strait)

- General practitioners' knowledge and management of viral hepatitis in the migrant population. (Guirgis et al., 2012)
  - 123 GPs responded to questionnaire
  - 42% lacked confidence in interpreting hepatitis C serology
  - 20% lacked confidence in interpreting hepatitis B serology.
  - 20% were unaware of hepatitis B treatment
  - 54% agreed that there was stigma attached to hepatitis B or hepatitis C
Stigma, Discrimination and Hepatitis B – Management, care and support

- Hepatitis B Knowledge and Practices among Chinese and Vietnamese in Brisbane 2009
  - People with hepatitis B from China more likely to know that there was a treatment
  - People with hepatitis B from Vietnam - more likely to be currently seeing a doctor (81% versus 56%).
  - People with hepatitis B from Vietnam - more likely to be managed for hepatitis B (56% versus 11%).

- Investigating General Practice and Hepatitis B (2012)
  - Not everyone wants to wait in the hospital system with the stigma [that] this is a hep B clinic. But they can go to general practice and go and sit outside, and you’re not different with anyone. (GP)
Stigma, Discrimination and Hepatitis B – Enabling environment

- The bad

  - Canada - 31% were ashamed; 47% unwilling to discuss hepatitis B; 52% thought hepatitis B could be transmitted by sharing food (Sociocultural factors that potentially affect the institution of prevention and treatment strategies for hepatitis B in Chinese Canadians, Wu et al., 2009)

  - US - Chinese immigrants - 60% believed people with hepatitis B could put others at risk and therefore should avoid close contact with others; 36% of people with hepatitis B felt that they bought ‘trouble’ to their family, however, participants with a family member with hepatitis had greater knowledge and a lower degree of stigma (Characterizing hepatitis B stigma in Chinese immigrants, Cotler et al., 2011)
Stigma, Discrimination and Hepatitis B – Responding

- Stigma is associated with misconceptions about transmission and low levels of knowledge, but it is more than a lack of knowledge
- We need to better understand the non-clinical factors that facilitate access to hepatitis B testing, vaccination and treatment
- With hepatitis B – explore how racism, social and economic inequality, and the experiences of migration affect access to health services
- Are health seeking behaviours influenced by discriminatory attitudes and practices towards people affected by hepatitis B in their country of origin?

Who wins from stigma?
A human rights framework for addressing stigma and discrimination

- National education campaign
- Create supportive environments
- Provide information on redress for discrimination
- Health care worker training
- Identify and redress legal barriers

Individually to move from stigma to entitlement
Thank you

Jeanne Ellard, ARCSHS

Lead author, Stigma, Discrimination and Hepatitis B: A review of current research