

Hepatitis B Stigma and Discrimination: Looking for a home.

Jack Wallace, Australian Research Centre
in Sex, Health and Society.

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

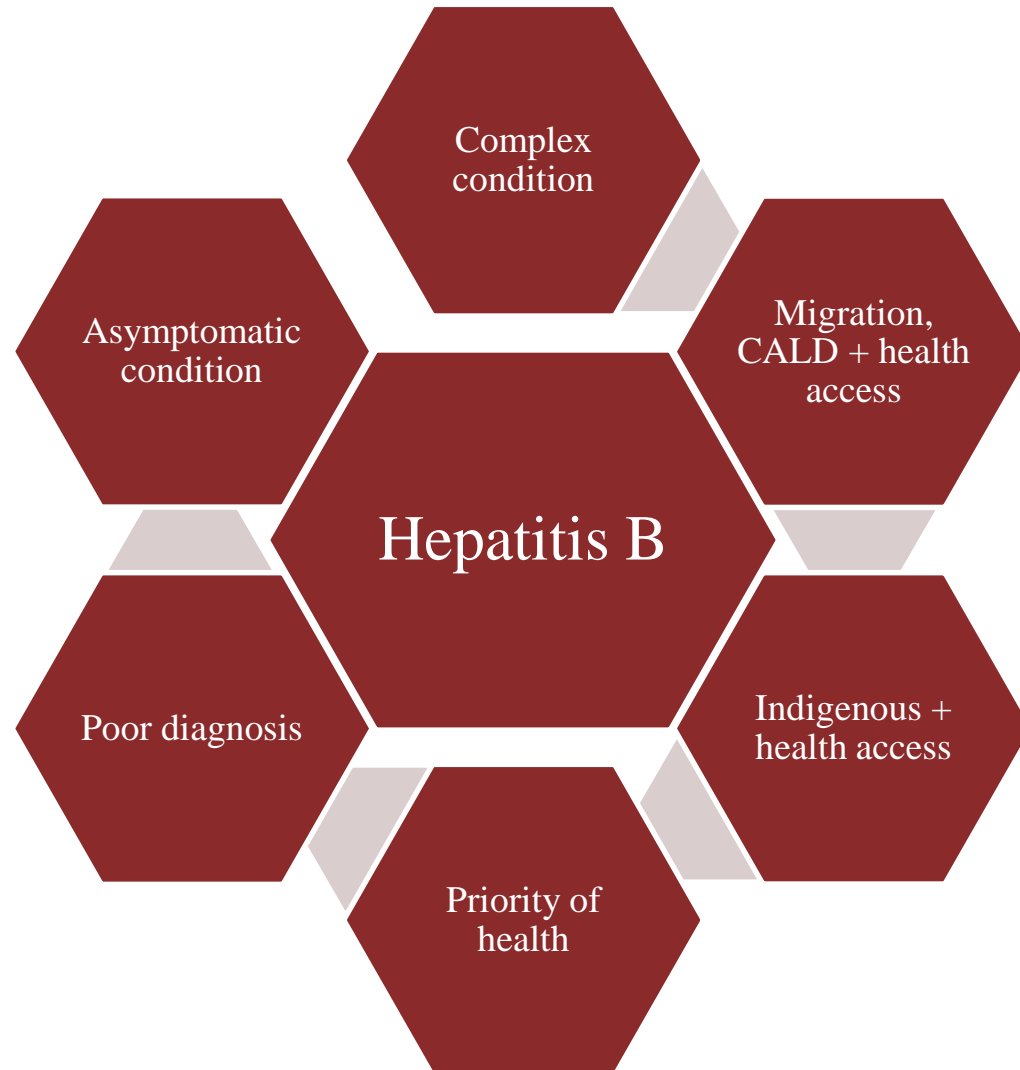
Stigma, Discrimination and Hepatitis B - Impact

- 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

Literature interest

Infection + stigma	No of articles
HIV	3589
AIDS	2482
Hepatitis C	104
Hepatitis B	49

Some hepatitis B intersections



Stigma, Discrimination and Hepatitis B – National Hepatitis B Strategy

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

Quality health 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 brought ‘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

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

