



Viral Hepatitis: Using social sciences to reduce the burden.

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The Context: People are dying from viral hepatitis

- We have interventions to reduce the burden:
 - Prevention – viral hepatitis transmission is preventable
 - Hepatitis B vaccination
 - Screening of blood supply
 - Needle and syringe programs
 - Infection control
 - Screening
 - Is available for hepatitis B and hepatitis C
 - Treatment
 - Hepatitis B can be controlled
 - Hepatitis C can be cured

The Context: People are dying from viral hepatitis

- With 1.75 million attributable deaths in 2010, chronic liver disease is a leading cause of human mortality
- In AP, hepatitis kills 3 times more people than HIV/AIDS and 9 times more than malaria
- 1.3 million of these deaths are due to chronic viral hepatitis – comparable to the burden of HIV/AIDS, tuberculosis and malaria
- Between 1990-2013:
 - 35.6% increase in cirrhosis of the liver secondary to hepatitis B
 - 67.3% increase in cirrhosis of the liver secondary to hepatitis C
 - 51.6% increase in liver cancer deaths due to hepatitis B
 - 290.8%* increase in liver cancer deaths due to hepatitis C

Social Research and Viral Hepatitis

- Systematic investigation of the personal and social impact of viral hepatitis
- Our focus is on the lived experience of people with viral hepatitis from diagnosis to treatment
- Reframe viral hepatitis from a solely clinical issue
- Identifies gaps in service delivery
- Aiming to reduce the burden of viral hepatitis

Screening

- Needs assessment of people with hepatitis B (Australia)
 - No consent
 - No information upon diagnosis
- Needs assessment of people with viral hepatitis (China)
 - Screening done by schools, universities, employers
 - No information upon diagnosis
 - No confidentiality or anonymity
- Investigating General Practice and hepatitis B (Australia)
 - No screening protocols used/poor GP knowledge
- Charting Health Impacts study (Australia)
 - 57% of 170 survey participants received no information on diagnosis

Screening

- *The teacher went to paste the results onto the blackboard on the front of the class ... and then you go and check the board whether you are short sighted, whether you are this or that (Female, 25-30yo, hepatitis B, Shanghai27).*
- *I didn't ask for it, just through a normal blood test. (Australia)*

Clinical Management

- Hepatitis B Patient and Clinical Practice Survey (Australia)
 - Poor knowledge of the infection
 - 35% didn't know transmission routes
 - 52% knew there was treatment available
- Needs Assessment of People with Viral Hepatitis (China)
 - Treatment decisions are essentially economic
 - Familial infection adds complexity
- A Situational Analysis of Chronic Hepatitis B in the Torres Strait (Australia)
 - *I didn't know there was treatment available. Can it help them? (Nurse)*

Clinical management

- People with hepatitis C noted the following issues helped people decide against treatment:
 - Impact treatment will have on family/ friends and/or on work
 - Can't commit myself to a long treatment program
 - Wanting to have children in the near future
 - Costs associated with treatment
 - Because of feeling well
 - Treatment success rate is not good enough
 - Side-effects of treatment

Conclusions

- Individual stories can provide collective knowledge – these need to be recognised and acted upon.
- Overwhelming numbers hiding individual stories
- Accessibility of findings for a lay audience

Thank you

- Behzad Hajarizadeh, Jacqui Richmond, Ros Le, Jeanne Ellard, Lizzie Smith, William Mude.