

Australian Research Centre in Sex, Health & Society

## Psychosocial health among people with chronic hepatitis B in Australia

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## Project background

- An estimated 218,000 Australians live with Chronic Hepatitis B (CHB)
- Barriers to clinical management of CHB include a low rate of diagnosis, poor access to services, poor adherence, fear of receiving bad news and perceived stigma
- Data on psychosocial health of Australians with CHB is scarce
  - International evidence suggests people with CHB experience poorer psychosocial health and increased prevalence of anxiety and depression.

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## Project Objectives

- To investigate knowledge, and attitudes of people with CHB to clinical management.
- To identify the broader social and psychological barriers to clinical management.
- To assess hepatitis B-related concerns, anxieties, confidences and other factors affecting the psychological and social health of people with hepatitis B.

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## Methodology

- Study conducted in two phases using qualitative and quantitative methods
- Phase 1: Semi-structured interviews with 10 people with CHB and 13 clinicians
  - The purpose phase one was to obtain information to inform the development of the phase two questionnaire.
- Phase 2: Self-administered questionnaires were available in English, Chinese and Vietnamese languages
  - Face and content validity evaluated by an expert panel and a pilot study

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## Methodology

- People with CHB attending four public liver clinics and one private general practice in three Australian jurisdictions, were invited to complete the self-administered questionnaire
- Section 1 - demographic & background characteristics
- Section 2 - hepatitis B knowledge & clinical management
- Section 3 - clinical experiences and feelings about hepatitis B including emotional coping strategies and disclosure

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## Results

- 93 people with CHB completed the survey
  - 24% response rate
- Mean age - 45 years; 57% were male
- 93% were born overseas
  - 75% were born in South- or North-East Asia
  - 1% identified as Aboriginal or Torres Strait Islander
- 45% rated their English as “not good” or “no English literacy”
- 48% had higher than high school education
- 53% were employed

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## Hepatitis B-related anxieties

- 76% (n=71) reported at least one of seven hepatitis B-related anxieties:
  - 56% (n=52) concerned about developing liver cancer
  - 53% (n=49) concerned about infecting other people
  - 47% (n=44) concerned about developing liver diseases

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## Hepatitis B-related anxieties

- Higher hepatitis knowledge was associated with more hepatitis B-related anxiety
  - Respondents with hepatitis B-related anxiety demonstrated higher hepatitis B knowledge (mean: 58) compared to those experiencing no anxiety (mean: 43;  $P=0.006$ )
- Respondents who understood the natural history of CHB (higher mean knowledge score) were more worried about developing liver cancer
- No association between demographic factors and being worried about developing liver cancer or infecting others

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## Impact of hepatitis B

- 34% indicated they did not like to talk to anyone about their hepatitis B
- 25% had changed the way they lived their life
- 19% thought about having hepatitis B all the time

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## Impact of hepatitis B

- Significant associations were found between 'Not liking to talk to anyone about hepatitis B' and:
  - being scared of hepatitis B ( $p=0.001$ )
  - being worried about infecting other people ( $p=0.003$ )
  - feeling sad or hopeless because of hepatitis B ( $p=0.009$ )
- No association between with demographic factors

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## Impact of hepatitis B

- Significant associations were found between respondents reporting hepatitis B changing their life and:
  - being scared of hepatitis B ( $p=0.001$ )
  - being worried about infecting other people ( $p=0.001$ )
  - worried about getting liver cancer ( $p=0.002$ )
  - feeling sad or hopeless because of hepatitis B ( $p=0.003$ )
- No association with demographic factors

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## Emotional support

- Key person helping respondents to cope emotionally with hepatitis B:
  - Health professional including General Practitioner (GP), specialist at the liver clinic, nurse at the liver clinic, and counsellor or psychologist (34%)
  - Family members, friend, and work colleagues (21%)
  - No one (18%)

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## Emotional support

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- 78% (n=25) reporting a health professional as the key emotional support had at least one hepatitis B-related concern or anxiety
- 85% (n=17) who nominated a family member/friend/work colleagues had at least one hepatitis B-related concern or anxiety
- 71% (n=12) who had no one helping them cope had at least one hepatitis B-related concern or anxiety

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## Hepatitis B disclosure

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- 75% had disclosed to family members
- 67% had disclosed to their GP
- 25% had disclosed to friends
- 11% had disclosed to colleagues
- 7% had disclosed to no one

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## Summary

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- The results of this study demonstrate the significant impact hepatitis B has on the psychosocial health of people with CHB:
  - Feeling concerned and anxious as a result of having hepatitis B is common
  - Having higher hepatitis B knowledge can lead to more hepatitis B-related fear and concern
- To support people with CHB, care and management needs to move beyond the clinical assessment, to address the specific concerns and impact of hepatitis B on individuals' lives

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## Acknowledgements

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- Financial support for this research has been provided by Bristol-Myers Squibb through the Coalition to Eradicate Viral Hepatitis in Asia Pacific (CEVHAP).
- We acknowledge the support of the individuals that participated in the study, and the individuals and organisation that assisted in recruitment: Dr Sally Bell, Prof Alex Thompson, Dr Robert Chen, Dr Tin Nguyen, Carmel Miller, Mary Dafalis, Suzanne Polis, Dr Simone Strasser, Catherine Stevens, Margaret Fitzgerald, Suresh Sharma, Dr Jill Benson, Dr Nicole Allard, A/Prof Ben Cowie, Cheryl Sendall, Dr Chris An, Dr Thu Ngo, Wendy Anderson, Yvonne Drazic.

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