Hepatitis B-Related Concerns and Anxieties Among People With Chronic Hepatitis B in Australia

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Abstract

Background: The psychological wellbeing of people with chronic hepatitis B (CHB) may be negatively affected due to the chronic and transmissible nature of the disease, and possible serious complications (e.g. cirrhosis and liver cancer). There are limited data investigating concerns and anxieties among people living with CHB.

Objectives: This study examined feelings about having hepatitis B among people with CHB, including hepatitis B-related concerns and anxieties.

Patients and Methods: Using convenience sampling, people with CHB attending four public liver clinics and one general practice in three Australian jurisdictions between April and September 2013 completed a self-administered questionnaire about their feelings about having hepatitis B.

Results: Ninety-three people completed the survey. Mean age was 45 years, 57% were men, and 93% were born overseas (75% from Asia). Seventy-six percent of participants reported having hepatitis B-related concerns and anxieties. The most common concerns were of developing liver cancer (57%), and infecting other people (53%). Thirty-five percent of participants were unwilling to talk to anyone about their hepatitis B while 25% changed how they lived as a result of having hepatitis B. Lower educational level was associated with feeling scared of hepatitis B (adjusted Odds Ratio [OR]: 4.04; 95%CI: 1.09, 14.90; P = 0.04), and an unwillingness to talk to anyone about hepatitis B (adjusted OR: 4.41; 95%CI: 1.09, 17.83; P = 0.04). Very good English proficiency was associated with a higher likelihood of participants changing how they lived (adjusted OR:12.66; 95%CI: 2.21, 72.42; P < 0.01), and seeing life differently as a result of having hepatitis B (adjusted OR: 21.10; 95%CI: 3.70, 120.19; P < 0.01). Health professionals were the key person for 34% of participants in helping them cope with having hepatitis B, while 18% reported that no one supported them.

Conclusions: Hepatitis B-related concerns and anxieties are prevalent among people with CHB. Clinical management of people with CHB must address their psychological support needs as an essential component of comprehensive care.

Keywords: Anxiety, Educational Status, Hepatitis B, Infection transmission, Liver cancer, Psychological Stress

1. Background

Chronic diseases affecting physical health generally also impact on psychological health (1). For people with chronic hepatitis B (CHB), psychological wellbeing may be negatively affected because of possible concerns and anxieties due to the transmissible nature of the disease, lifelong duration of treatment, the likely serious consequent complications of the infection (e.g. cirrhosis and liver cancer), social marginalisation, and possible stigma associated with an infection that can be transmitted sexually. There are several reports of poorer psychosocial health including increased prevalence of anxiety and depression (2-5) and impaired quality of life (6-10) among people with CHB, while people with more advanced liver disease showed greater impairment of their quality of life (11, 12). Therefore, an exclusive focus on liver health and the biological outcomes of CHB underestimates the true individual burden of the infection. It is important to understand the impact of hepatitis B on psychological health to provide comprehensive care to people with CHB.

Data describing psychological health including hepatitis B-related concerns and anxieties among Australians with CHB is scarce. Only one qualitative study interviewing 20 people with CHB reported a significant fear of the future or of dying among several participants (13).

2. Objectives

As part of a larger research exploring barriers to treatment, knowledge, psycho-social health and clinical experiences of people with CHB living in Australia (14, 15), this current study examined feelings and attitudes about hav-
ing hepatitis B among people with CHB living in Australia, including hepatitis B-related concerns and anxieties.

3. Patients and Methods

3.1. Study Population

This study was an observational cross-sectional study. Using convenience sampling, people diagnosed with CHB attending one of four public liver clinics in three Australian jurisdictions (Victoria, New South Wales, and Northern Territory) and one private general practice clinic in New South Wales, were invited to participate in the study between April and September 2013. Participants were invited to complete a self-administered questionnaire, with assistance in completing the questionnaire provided upon request by either the project coordinator, or clinic nursing or administrative staff. Completion of the questionnaire was deemed as providing informed consent. Ethics approval for the study was obtained from La Trobe University human ethics committee (approval number: HEC12-013) and local ethics committees at all study sites which conforms to the provisions of the declaration of Helsinki.

3.2. Study Questionnaire

The content of the questionnaire was informed by a literature review and data gathered from semi structured interviews conducted with 10 people with CHB and 13 clinicians, including six gastroenterologists, two infectious disease physicians, two general practitioners (GPs) and three hepatology nurse consultants. The draft questionnaire was revised by the research team through consensus. Face and content validity of the questionnaire was assessed during a pilot study with five people with CHB. The questionnaire was available in English, simplified Chinese and Vietnamese languages, chosen to reflect the demographic profile of people with CHB in Australia (16).

The first section of the questionnaire included questions about socio-demographic factors and background characteristics, and the second section included questions assessing hepatitis B knowledge. The third section of the questionnaire collected data on the feelings and attitudes about having hepatitis B among participants, the people to whom they had disclosed their hepatitis B, and their views of community perspective of people with CHB. This paper reports data from the sections on socio-demographic and participants’ feelings and attitudes about having hepatitis B.

3.3. Statistical Analysis

The internal consistency of the questionnaire was assessed using Cronbach’s alpha. Distribution of the variables was expressed as frequency and percentage for categorical variables, and as mean and standard deviation for continuous variables. Categorical variables were compared using Chi square and Fischer Exact tests in univariate analysis. In multivariate analysis, logistic regression was used, adjusted for gender, age, region of birth, educational level and English proficiency. In all cases, comparisons were two tailed, and a P < 0.05 was considered statistically significant. The data analyses were performed using STATIA software version 12 (College Station, TX, United States).

4. Results

4.1. Participant Characteristics

Ninety-three individuals completed and returned the survey (response rate: 24%). The characteristics of the participants are summarized in Table 1. Over half of participants (57%) were men, with an age range from 22 to 77 years and a mean age of 45 years. The large majority of participants (93%) were born overseas with most (75%) born in South- or North-East Asia, and only one participant (1%) identifying as Aboriginal or Torres Strait Islander. Most participants (n = 89; 96%) had access to Medicare and/or private health insurance.

4.2. Hepatitis B-Related Concerns and Anxieties

Participants were asked to select from a series of options about how they felt about having hepatitis B, including any hepatitis B-related concerns, anxieties and confidences and of the impact of hepatitis B on their life (Table 2). The overall reliability coefficient of the questions was 0.79, using Cronbach’s alpha. The most common hepatitis B-related concerns nominated by participants were of developing liver cancer (57%) and infecting other people (53%). Seventy-one participants (76%) reported having at least one of the seven hepatitis B-related concerns or anxieties listed in Table 2. About one-third of participants (35%) did not like to talk to anyone about their hepatitis B, while about a quarter changed how they lived (25%) and saw life differently (24%) as a result of having hepatitis B.

The distribution of participants’ feelings and attitudes about having hepatitis B were compared by gender (Table 2), age (Table 3), region of birth (Table 4), educational level (Table 5) and English proficiency level (Table 6). A significantly higher proportion of women (22%) compared to men (8%; P = 0.04) felt that they did not deserve to have hepatitis B (Table 2), although the association between gender
and having this feeling was not significant in the multivariate analysis (women vs. men; adjusted odds ratio [OR]: 3.63; 95% CI: 0.87, 15.24; P = 0.08). No significant difference was found in the distribution of participants’ feelings and attitudes about having hepatitis B across the age groups (Table 3).

A significantly higher proportion of participants born in non-Asian countries (52%) compared to those born in Asia (29%; P = 0.04) did not like to talk to anyone about their hepatitis B (Table 4). However, the association of region of birth and this attitude was not significant in the multivariate analysis (non-Asian vs. Asian; adjusted OR: 2.71; 95% CI: 0.75, 9.71; P = 0.13). Similarly, a significantly higher proportion of participants born in non-Asian countries (39%) compared to those born in Asia (18%; P = 0.04) stated that they saw life differently as a result of having hepatitis B (Ta-

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### Table 1. Background Characteristics of the Study Participants

| Value                                      | No. (%) | n = 93 |
|--------------------------------------------|---------|--------|
| **Mean age, y (SD)**<sup>a</sup>           | 45 (13) |        |
| **Gender**                                 |         |        |
| Female                                     | 40 (43) |        |
| Male                                       | 53 (57) |        |
| **Region of birth**                        |         |        |
| Australia, New Zealand                     | 8 (9)   |        |
| South-East Asia                            | 36 (39) |        |
| North-East Asia                            | 34 (37) |        |
| Europe                                     | 4 (4)   |        |
| South Asia                                 | 3 (3)   |        |
| Africa                                     | 3 (3)   |        |
| Middle-East                                | 2 (2)   |        |
| Other regions                              | 3 (3)   |        |
| **Educational levels**                     |         |        |
| Did not attend school                      | 5 (5)   |        |
| Primary school                             | 11 (12) |        |
| High school                                | 32 (34) |        |
| Higher education (including TAFE and university) | 45 (48) |        |
| **Self-rated English language proficiency**|         |        |
| No English                                 | 7 (7)   |        |
| Limited                                    | 35 (38) |        |
| Good                                       | 30 (32) |        |
| Very good                                  | 20 (21) |        |
| Not specified                              | 1 (1)   |        |
| **Occupational status**                    |         |        |
| Employed (including self-employed)         | 49 (53) |        |
| Student                                    | 8 (9)   |        |
| Home duties                                | 13 (14) |        |
| Retired                                    | 7 (7)   |        |
| No job                                     | 15 (16) |        |
| Not specified                              | 1 (1)   |        |

<sup>a</sup> Eight participants (8.6%) did not report their age (missing value).
Table 2. Distribution of Participants’ Feelings and Attitudes About Having Hepatitis B by Gender

| Hepatitis B-related concerns or anxieties | Total, No. (%), n = 92* | Women, No. (%), n = 40 | Men, No. (%), n = 52 | P Value |
|----------------------------------------|-------------------------|------------------------|---------------------|---------|
| I worry about getting liver cancer      | 52 (57)                 | 23 (57)                | 29 (56)             | 0.87    |
| I worry about infecting other people   | 49 (53)                 | 22 (55)                | 27 (52)             | 0.77    |
| I worry about developing liver disease  | 44 (48)                 | 20 (50)                | 24 (46)             | 0.71    |
| I am scared of hepatitis B             | 30 (33)                 | 13 (32)                | 17 (33)             | 0.98    |
| Hepatitis B makes me feel guilty       | 14 (15)                 | 8 (20)                 | 6 (12)              | 0.26    |
| I did not deserve to get hepatitis B   | 13 (14)                 | 9 (22)                 | 4 (8)               | 0.04    |
| I often feel sad or hopeless because of hepatitis B | 13 (14) | 6 (15) | 7 (13) | 0.83 |

- Hepatitis B-related confidences

| I feel confident that hepatitis B can be controlled with treatment | 43 (47) | 17 (42) | 26 (50) | 0.47 |
|-------------------------------------------------------------------|---------|---------|---------|------|
| I feel confident there will be a cure for hepatitis B in my lifetime | 28 (30) | 13 (32) | 15 (29) | 0.71 |
| Hepatitis B does not cause me any problems                         | 17 (18) | 7 (17)  | 10 (19) | 0.83 |
| Having hepatitis B does not worry me                               | 15 (16) | 6 (15)  | 9 (17)  | 0.77 |

- The impact of hepatitis B on participants’ life

| I do not like to talk to anyone about my hepatitis B | 12 (15) | 12 (30) | 20 (38) | 0.40 |
|------------------------------------------------------|---------|---------|---------|------|
| I changed the way I live my life                      | 23 (25) | 9 (22)  | 14 (27) | 0.61 |
| I see life differently                                 | 22 (24) | 9 (22)  | 13 (25) | 0.78 |
| I think about hepatitis B all the time                | 17 (18) | 8 (20)  | 9 (17)  | 0.74 |
| I rarely think about my hepatitis B at all            | 17 (18) | 8 (20)  | 9 (17)  | 0.74 |

*One participant (1%) did not select any of the options (missing value).

Percentages indicate column percentages.

Compared to participants with high school or tertiary education, a significantly higher proportion of those with primary school education or less felt scared of hepatitis B (62% vs. 26%, respectively; P < 0.01), felt they did not deserve to have hepatitis B (31% vs. 10%, respectively; P = 0.04), and were unwilling to talk to anyone about their infection (62% vs. 29%, respectively; P = 0.01; (Table 4)). In multivariate analysis, lower education was independently associated with feeling scared of hepatitis B (primary school/lower vs. high school/tertiary education; adjusted OR: 4.04; 95%CI: 1.09, 14.90; P = 0.04), and an unwillingness to talk to anyone about hepatitis B (primary school/lower vs. high school/tertiary education; adjusted OR: 4.41; 95%CI: 1.09, 17.83; P = 0.04). Alternatively, a significantly higher proportion of participants with high school or tertiary education (53%) compared to participants with primary school education or lower (25%) were worried about developing liver disease (P = 0.04; (Table 5)). However, no significant association was found between educational level and worries of developing liver disease in multivariate analysis (high school/tertiary education vs. primary school/lower; adjusted OR: 3.41; 95%CI: 0.80, 14.44; P = 0.10).

Compared to participants with self-rated limited or good English proficiency, a higher proportion of those with very good English proficiency stated changing the way they lived (45% vs. 26% vs. 10%, respectively; P = 0.02), and seeing life differently as a result of having hepatitis B (60% vs. 17% vs. 10%, respectively; P < 0.01; (Table 6)). In multivariate analysis, very good English proficiency was independently associated with a higher likelihood of changing the way they lived (very good English vs. good/limited English; adjusted OR: 12.66; 95%CI: 2.21, 72.42; P < 0.01), and seeing life differently as a result of hepatitis B (very good English vs. good/limited English; adjusted OR: 21.10; 95%CI: 3.70, 120.19; P < 0.01).
Participants were asked to nominate the most important person helping them cope emotionally with having hepatitis B. Thirty-four percent (n = 32) reported health professionals (i.e., GP, specialist at the liver clinic, nurse at the liver clinic, and counsellor or psychologist), 20% (n = 21) reported family members, friends, or work colleagues, 18% (n = 17) reported multiple persons, and 18% (n = 17) reported no one helping them cope with having hepatitis B. Additional responses included other people (1%; n = 1), and not sure (1%; n = 1), while 5% (n = 5) did not respond. Among participants reporting a health professional as their key support, 78% (n = 25) reported having at least one of seven hepatitis B-related concerns and anxieties. This proportion was 85% (n = 17), and 71% (n = 12) among participants nominating family/friends/colleagues, and no one helping them cope, respectively. The difference between the three groups was not statistically significant (P = 0.61).

5. Discussion

This study is the first to provide quantitative data exploring the feelings and attitudes of Australians with CHB about having hepatitis B, including hepatitis B-related concerns and anxieties and demonstrates that a high proportion of participants had hepatitis B-related concerns and anxieties affecting their perspective toward life. Academic educational level was associated with participants’ attitude toward discussing hepatitis B with others, and a fear of hepatitis B. English proficiency was associated with a participant’s attitude in changing how they lived and seeing life differently as a result of having hepatitis B.

Most participants (76%) reported having hepatitis B-related concerns, with worries of getting liver cancer and infecting other people being the most common concerns, a finding reported by other studies (17-20). Other hepatitis B-related fears and concerns have also been reported among people with CHB in several other studies (3, 5, 10, 13, 17-19, 21-23) with these psychological stressors possible predisposing factors to developing psychiatric disorders, particularly depressive disorders. In one study among people with CHB, having hepatitis B-related concerns were associated with the presence of major depression (3). In another study, people with CHB exhibited higher cortisol response to a standardized psychosocial stressor, and also...
higher levels of anxiety and depression after the stressor than people without CHB, suggesting a higher sensitivity to the psychological stress and greater distress in this population (2).

Our findings showed that having hepatitis B affected participants’ social behaviour, perspectives and attitude toward their life. About one third of participants reported an unwillingness to discuss their hepatitis B with anyone, and about a quarter of participants declared they saw life differently and had changed the way they lived their life as a result of having hepatitis B. Changes in social behaviours, life style and the way they live due to a chronic disease are expected among patients living with a chronic disease. However, some additional negative attitudes among people with CHB coupled with misconceptions about hepatitis B transmission occurring through sharing foods, utensils, kissing and hugging (14, 20, 24, 25) may result in social isolation of people with CHB and consequently impair their social health. In a study from the United States, 43% of people with CHB reported dating less since they had been diagnosed with hepatitis B and 52% felt overwhelmed about dealing with hepatitis B (18). Taken together, these data indicate that a clinical assessment of CHB needs to extend beyond the usual virological and biological evaluations, and acknowledge psychosocial issues as an important component of care.

The findings support the specific provision of emotional support and/or counselling services for people with CHB to address concerns about their health and social life. These services could be made available as soon as people

### Table 4. Distribution of Participants’ Feelings and Attitudes about Having Hepatitis B by Region of Birth

| Value | Born in Non-Asian Countries, No. (5%)a, n = 23 | Born in Asian Countries, No. (5%)a, n = 69 | P Value | Born in Asian Countries |
|-------|------------------------------------------------|---------------------------------|--------|------------------------|
|       | China, No. (5%)a, n = 30 | Vietnam, No. (5%)a, n = 22 | Other, No. (5%)a, n = 17 | F Value |
| Hepatitis B-related concerns or anxieties | 12 (51) | 40 (58) | 17 (71) | 0.63 |
| I worry about developing liver disease | 9 (39) | 35 (52) | 14 (47) | 0.33 |
| I am scared of hepatitis B | 7 (30) | 23 (35) | 8 (57) | 0.78 |
| Hepatitis B makes me feel guilty | 5 (22) | 9 (13) | 3 (18) | 0.75 |
| I did not deserve to get hepatitis B | 4 (17) | 9 (13) | 2 (12) | 0.75 |
| I often feel sad or hopeless because of hepatitis B | 4 (17) | 9 (13) | 2 (12) | 0.75 |
| Hepatitis B-related confidences | 10 (43) | 33 (48) | 5 (30) | 0.72 |
| I feel confident that hepatitis B can be controlled with treatment | 6 (26) | 22 (32) | 4 (23) | 0.60 |
| I feel confident there will be a cure for hepatitis B in my lifetime | 6 (26) | 22 (32) | 4 (23) | 0.60 |
| Having hepatitis B does not cause me any problems | 4 (17) | 9 (13) | 2 (12) | 1.00 |
| The impact of hepatitis B on participants’ life | 4 (17) | 9 (13) | 2 (12) | 1.00 |

aPercentages indicate column percentages.
Table 5. Distribution of Participants’ Feelings and Attitudes about Having Hepatitis B by Educational Level

| Value                              | Primary School or Lower, No. (%)<sup>a</sup>, n = 16 | High School or Tertiary Education, No. (%)<sup>a</sup>, n = 76 | P Value |
|------------------------------------|-----------------------------------------------------|------------------------------------------------------------|---------|
| Hepatitis B-related concerns or anxieties |                                                      |                                                            |         |
| I worry about getting liver cancer  | 9 (56)                                              | 43 (57)                                                   | 0.98    |
| I worry about infecting other people| 7 (44)                                              | 42 (55)                                                   | 0.40    |
| I worry about developing liver disease| 4 (25)                                              | 40 (53)                                                   | 0.04    |
| I am scared of hepatitis B         | 16 (62)                                             | 20 (26)                                                   | < 0.00  |
| Hepatitis B makes me feel guilty   | 5 (31)                                              | 9 (12)                                                    | 0.06    |
| I did not deserve to get hepatitis B| 5 (31)                                              | 3 (18)                                                    | 0.04    |
| I often feel sad or hopeless because of hepatitis B| 3 (19)                                              | 40 (53)                                                   | 0.69    |
| Hepatitis B-related confidences    |                                                      |                                                            |         |
| I feel confident that hepatitis B can be controlled with treatment | 4 (25)                                              | 39 (51)                                                   | 0.05    |
| I feel confident there will be a cure for hepatitis B in my lifetime | 5 (31)                                              | 23 (30)                                                   | 1.00    |
| Hepatitis B does not cause me any problems | 3 (19)                                              | 14 (18)                                                   | 1.00    |
| Having hepatitis B does not worry me | 3 (19)                                              | 12 (15)                                                   | 0.72    |
| The impact of hepatitis B on participants’ life |                                                      |                                                            |         |
| I do not like to talk to anyone about my hepatitis B | 10 (62)                                             | 22 (29)                                                   | 0.04    |
| I changed the way I live my life   | 3 (19)                                              | 20 (26)                                                   | 0.75    |
| I see life differently              | 3 (19)                                              | 19 (25)                                                   | 0.75    |
| I think about hepatitis B all the time | 3 (19)                                              | 14 (18)                                                   | 1.00    |
| I rarely think about my hepatitis B at all | 3 (19)                                              | 14 (18)                                                   | 1.00    |

<sup>a</sup> Percentages indicate column percentages.

Table 6. Distribution of Participants’ Feelings and Attitudes about Having Hepatitis B by English Proficiency Level

| Value                              | English or Limited English, No. (%)<sup>a</sup>, n = 42 | Good English, No. (%)<sup>a</sup>, n = 29 | Very Good English, No. (%)<sup>a</sup>, n = 20 | P Value |
|------------------------------------|------------------------------------------------------|----------------------------------------|------------------------------------------------|---------|
| Hepatitis B-related concerns or anxieties |                                                      |                                        |                                                |         |
| I worry about getting liver cancer  | 24 (57)                                              | 15 (52)                                | 13 (65)                                        | 0.65    |
| I worry about infecting other people| 23 (51)                                              | 15 (52)                                | 11 (55)                                        | 0.94    |
| I worry about developing liver disease| 17 (40)                                              | 15 (52)                                | 12 (60)                                        | 0.32    |
| I am scared of hepatitis B         | 16 (38)                                              | 8 (26)                                 | 6 (30)                                         | 0.52    |
| Hepatitis B makes me feel guilty   | 8 (19)                                               | 2 (7)                                  | 4 (20)                                         | 0.29    |
| I did not deserve to get hepatitis B| 6 (14)                                               | 4 (14)                                 | 3 (15)                                         | 1.00    |
| I often feel sad or hopeless because of hepatitis B| 7 (17)                                               | 3 (10)                                 | 3 (15)                                         | 0.74    |
| Hepatitis B-related confidences    |                                                      |                                        |                                                |         |
| I feel confident that hepatitis B can be controlled with treatment | 17 (40)                                              | 13 (45)                                | 11 (55)                                        | 0.18    |
| I feel confident there will be a cure for hepatitis B in my lifetime | 14 (33)                                              | 9 (30)                                 | 5 (25)                                         | 0.46    |
| Hepatitis B does not cause me any problems | 8 (19)                                               | 5 (18)                                 | 6 (30)                                         | 0.32    |
| Having hepatitis B does not worry me | 6 (14)                                               | 4 (16)                                 | 4 (20)                                         | 0.40    |
| The impact of hepatitis B on participants’ life |                                                      |                                        |                                                |         |
| I do not like to talk to anyone about my hepatitis B | 13 (30)                                              | 8 (28)                                 | 8 (40)                                         | 0.75    |
| I changed the way I live my life   | 11 (26)                                              | 3 (10)                                 | 9 (45)                                         | 0.22    |
| I see life differently              | 7 (17)                                               | 3 (10)                                 | 12 (60)                                        | < 0.01  |
| I think about hepatitis B all the time | 10 (24)                                              | 4 (14)                                 | 3 (15)                                         | 0.58    |
| I rarely think about my hepatitis B at all | 8 (19)                                               | 4 (14)                                 | 5 (25)                                         | 0.95    |

<sup>a</sup> Percentages indicate column percentages.

are diagnosed with hepatitis B, particularly given previous findings of people with CHB describing their diagnosis as ‘shocking’ with considerable confusion and fear for their future due to lack of a proper pre- or post-test discus-

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lines on management of CHB (28, 29) recommend counselling services for people with CHB but there is no data about the proportion of patients receiving these services or of the efficacy of counselling and emotional support currently provided. In this current study, while health professionals were key in supporting most participants cope with having hepatitis B, more than three quarters of those reporting a health professional providing this support still reported having hepatitis B-related concerns or anxieties with this proportion being comparable with other participants seeking support from other people or from no one. These findings suggest the need for a systematic improvement in how support is being provided by health professionals.

While several of the hepatitis B-related including feeling guilty for having hepatitis B or being scared of hepatitis B are unrealistic, being concerned about developing liver disease including liver cancer is realistic. Ensuring that this concern motivates an individual to access clinical services, rather than reducing access as a result of a fear of hearing bad news, highlights the importance of a sophisticated and culturally appropriate approach to counselling or the provision of information. This reflects the findings of another Australian study that conducted focus groups with people from the Chinese community reporting that improving awareness of the link between CHB and liver cancer could motivate people for testing, while a perception that there was no cure for CHB and the belief that liver cancer has a poor prognosis was a barrier to testing (30).

A lower academic educational level among participants in this current study was associated with an unwillingness to talk about hepatitis B to others, and of being scared about hepatitis B. Insufficient knowledge or misconception about hepatitis B is one explanation for an unrealistic fear or reluctance to talk about hepatitis B with others. Previous studies have shown a positive association between academic education and knowledge of hepatitis B among people with CHB (14, 20, 24, 25) and a lower educational level can be a surrogate marker for less knowledge about hepatitis B. This hypothesis is supported by our findings indicating a higher proportion of participants with higher education were realistically worried about developing liver disease. Providing accessible, accurate and low literacy resources about hepatitis B for people with CHB is needed. Perceived stigma associated with being infected with hepatitis B and concerns about social rejection (13, 23, 26, 30-33) are other possible reasons for feeling scared of hepatitis B and an unwillingness of people with CHB to publicly discuss their condition. Further research is suggested to assess this hypothesis.

English proficiency of the participants in this study was associated with higher likelihood of changing the way participants lived and seeing life differently as a result of having hepatitis B. It is possible that those with higher levels of English proficiency were able to more easily access health promotion resources, or access a broader range of resources to assist in making lifestyle changes.

In this current study, no association was found between region of birth and having hepatitis B-related concerns. However, in univariate analysis, a higher proportion of participants born in non-Asian compared to Asian countries were unwilling to talk to anyone about their hepatitis B and saw life differently as a result of having hepatitis B. One study from the United States also reported a more accepting attitude toward hepatitis B among Asian, compared to non-Asian people with lower likelihoods of having hepatitis-B related concerns, and re-evaluating their lifestyle, as well as a lesser impact of CHB symptoms on their daily lives (18). This study interpreted these findings as either American-Asians denying the seriousness of their condition or a hepatitis B knowledge gap in this population (18). Another potential explanation for a more accepting attitude toward hepatitis B among Asian people is related to the inter-generational nature of hepatitis B in most Asian families with the infection consequently being perceived as “benign” or “normal” (30, 33). Despite common features of hepatitis B epidemiology and some common cultural similarities in several Asian countries, our data indicated differences in some feelings and attitudes about hepatitis B among participants born in different Asian countries. These similarities and differences should be considered in providing emotional support or counselling services for people with CHB.

This study is the first Australian study providing quantitative data describing the feelings and attitudes of people with CHB of having hepatitis B. There are limitations. While providing questionnaires in Chinese and Vietnamese languages reduced a selection bias toward people with good English proficiency and assisted in recruiting a more representative study population given the demographic profile of people with CHB in Australia (16), the response rate was suboptimal with the findings susceptible to a selection bias toward people more confident in communicating feelings. Participants were recruited in clinical settings and are not representative of the population with CHB in Australia, particularly considering that only a minority of this total population having been diagnosed and receiving clinical care (34, 35). While Aboriginal and Torres Strait Islanders are estimated to be 9% of the total population of people with CHB living in Australia, only one participant in this study identified as a member of these communities (34). The lack of representation of Aboriginal and Torres Strait Islander people in this study reflects the poor access of these populations to clinical services.
and highlights a need to develop innovative and culturally appropriate models of care to improve access to CHB clinical management for these populations, and for further research to identify the barriers to clinical services (36, 37). No data about liver disease stage and time of CHB diagnosis were collected in this study and it is probable that having more advanced liver disease and longer duration since CHB diagnosis will affect a patient’s psychological response to hepatitis B. The small sample size limits the power of subgroup analyses, and as such, some analyses failed to show statistically significant associations with marginal P values.

In conclusion, a range of hepatitis B-related concerns and anxieties were identified among people with CHB in this study, with CHB having impact on their perspective and attitude toward life. Lower educational level was associated with feeling scared of hepatitis B, and an unwillingness to talk to anyone about the infection. Very good English proficiency was associated with a higher likelihood of participants changing how they lived, and seeing life differently as a result of having hepatitis B. Clinical assessment and management of CHB is required to recognize and address the psychological health and social life needs of people with CHB. Culturally appropriate counselling or emotional support should be made available for people with CHB at diagnosis and could address the most common concerns, including feeling worried about getting liver cancer and infecting other people. Further studies are needed to identify how best to support people with CHB manage their hepatitis B-related concerns effectively.

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