Hepatitis B testing and diagnosis experiences of patients and primary care professionals in Australia

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Background and objective

A significant proportion of Australians with chronic hepatitis B (CHB) remains undiagnosed and unaware of their risk of liver disease and cancer. This study explored the hepatitis B testing and diagnostic experiences of people with CHB, general practitioners (GPs) and primary care nurses.

Method

Semi-structured interviews were conducted with people who have CHB (n = 19), GPs (n = 14) and nurses (n = 5).

Results

The majority of patient participants with CHB were not provided with information prior to being tested, and were shocked to receive a diagnosis. Neither GPs nor nurses noted Australia's *National hepatitis B testing policy* as guiding their practice, and hepatitis B contact tracing was poorly executed.

Discussion

Patient participants' diagnostic experiences did not correspond with national policy recommendations. GPs and nurses need resources to provide accurate information when testing and diagnosing hepatitis B, and clear guidance about their role in contact tracing.

hronic hepatitis B (CHB) is the leading cause of primary liver cancer in Australia, which is one of the few cancers associated with increased mortality over the past 10 years.¹ Of the 239,167 Australians with CHB, only 62% have been diagnosed (n = 148,284), meaning that 38% are unaware of the opportunities to reduce their chances of developing serious liver disease, including liver cancer.² Historically, Australia's public health response to CHB has focused on vaccination, neglecting the complex issues related to improving testing, diagnosis, contact tracing and clinical management of people with CHB.

There is significant cultural and linguistic diversity among people with CHB in Australia; approximately 56% were born overseas,³ with Chinese and Vietnamese being the most common languages spoken by people with CHB.⁴ Cultural understandings of CHB play a role in framing the meaning of the infection, particularly for people from culturally and linguistically diverse (CALD) communities.5-8 The impact of an inadequate diagnostic process means that people with CHB may have poor knowledge about transmission, implications of the infection and availability of treatment, which subsequently affects their engagement in ongoing clinical care.9,10

Australia's Second national hepatitis B strategy 2014-2017 set a target of diagnosing 80% of people living with CHB in Australia by 2017;11 current estimates indicate this will not be achieved. Primary care practitioners, namely general practitioners (GPs) and primary care nurses, are often tasked with the role of identifying risk factors for chronic disease and implementing best practice guidelines.12 However, in the case of hepatitis B, it has been reported that GPs have poor knowledge, specifically in interpreting hepatitis B serology results, and experience systematic barriers to testing people at risk of hepatitis B.13,14

Australia's *National hepatitis B testing policy* promotes confidential, voluntary testing with informed consent, and outlines the process for providing the test results.¹⁵ Testing and diagnosis are fundamental to reducing the burden associated with CHB, and are the cornerstone of Australia's response to CHB.¹¹ However, no formal dissemination or evaluation have ever been conducted to identify whether GPs and/or nurses are aware of, or systematically use, this policy.

Each Australian jurisdiction has developed a contact tracing procedure. These local procedures are primarily based on the recommendations of the *Australasian contact tracing guidelines*,¹⁶ which frame hepatitis B as a sexually transmissible infection (STI) or bloodborne virus (BBV) acquired in adulthood through sexual activity or sharing drug injecting equipment. While the guidelines emphasise the need to be attentive and sensitive to cultural diversity, there is no specific discussion of hepatitis B. The guidelines suggest household and sexual contacts of people with CHB should be traced back six months prior to the onset of acute symptoms, which is not relevant to hepatitis B infection acquired at birth.

At the population level, diagnosis of CHB followed by appropriate vaccination of at-risk contacts can effectively reduce transmission.¹⁷¹⁸ At an individual level, an effective diagnosis is a critical step for a person to understand and reduce the impact of the infection. This study sought to understand the processes of testing, diagnosing and contact tracing from the perspective of people with CHB, GPs and nurses, to inform the development of effective health policy and Australia's effort to increase the diagnosis rate of CHB in Australia.

Methods

Qualitative, semi-structured interviews were conducted with people who have CHB, and GPs and nurses who selfidentified as having a high hepatitis B caseload, defined as at least one patient per month. Patient participants were from a range of rural, regional and urban communities across Australia. A convenience sample of people with CHB and primary care practitioners were recruited through community health centres, advocacy and support groups, and primary healthcare newsletters publicised to GPs and nurses.

Interviews with people who have CHB explored reasons for testing, who did the testing, what information was provided, and if and how they disclosed their infection to others. GPs and nurses were asked which patients they tested for hepatitis B and why; if and what types of pre-test and post-test information was provided; and how potential contacts were traced. All interview themes were based on previous research and policy recommendations from the *National hepatitis B testing policy*.^{9,11,14} The semistructured design of the interview structures allowed the interviewer to follow concepts and themes as these presented.

Interviews with people who have CHB (n = 19) were conducted over the phone and face-to-face, and lasted between 20 and 40 minutes; seven interviews were conducted through an interpreter. Nineteen interviews, lasting approximately 20 minutes, were conducted with GPs and nurses over the phone, with one face-to-face interview.

All participants were reimbursed for their time, and consented to audio recording of the interview. The research gained ethics approval from La Trobe University's Human Research Ethics Committee (reference number 14-034). Pseudonyms of participants have been used throughout.

Data analysis was based on a hybrid process of inductive and deductive thematic analysis involving theory-driven (ie based on the research questions and existing literature) and data-driven (ie themes drawn from data)¹⁹ coding. Data were managed in NVivo 10 and coded separately by two authors. This process of inter-rater reliability involved each reading and re-reading the data to identify emerging themes, and comparing these to achieve shared understanding and meaning of the data. Themes included emotional responses to diagnosis and cultural appropriateness of the testing process. Data were coded separately by two authors to ensure coding consistency using NVivo 10. All authors discussed the resulting themes.

Results

The findings describe experiences of testing, informed consent, being diagnosed and contact tracing from the perspectives of people with CHB, GPs and nurses.

Demographics

Nineteen people with CHB (male = 11; female = 8), 14 GPs (male = 8; female = 6)

and five nurses (female = 5) were interviewed about hepatitis B testing. Patient participants with hepatitis B were broadly representative of the Australian cohort living with hepatitis B with regard to gender and country of birth. More male than female patient participants were recruited to this study, reflecting the higher prevalence of CHB among males.²⁰ The patient participants' country of birth reflects the cultural diversity of the hepatitis B epidemic globally, with 11 born in south-east Asia, the global region with the highest prevalence of CHB.²¹ Table 1 provides demographic information for participants with CHB. Table 2 contains clinical and geographic characteristics for the primary care practitioners.

Testing

Patient participants with CHB reported being tested for the following reasons:

- Born in a high-prevalence country (n = 7)
- Routine blood donation testing (n = 4)
- Part of a general check-up (n = 2)
- Presenting with symptoms or feeling unwell (n = 4)
- Having a family or household member with CHB (n = 2).

Claudette, aged 18 years, immigrated to Australia from Sierra Leone, and asked her GP to conduct regular health monitoring. She was subsequently diagnosed with CHB.

I went to my doctor and I told him I wanted to start having regular check-ups ... and I did at first, and when I went for

the results, he said I had (hepatitis B). Arka, aged mid-30s, was one of two patient participants tested for hepatitis B in response to a family member being diagnosed with CHB:

I had a blood test when I was about 18, and my doctor did a test for hepatitis ... because my dad had it and he found out

I was a carrier of (hepatitis B). GPs and nurses based their decision to test patients for hepatitis B on the basis of their place of birth, risk factors (eg men who have sex with men, people who inject drugs, sex workers, or those training to be a medical professional),

Pseudonym and age	Children	Country of Birth	Time since	Gender	Reason for	Relationship
rseudonym and age	Children	Country of Birth	first diagnosis (approximately)	Gender	testing	status
Akra, early 30s	No	Cambodia	10–15 years	Man	Family member with hepatitis B	De facto
Ayana, mid-20s	Yes	Somalia	8 years	Woman	Unwell	Married
Baw Mu Thaw, early 30s	No	Burma	4 years	Man	Refugee testing	Single
Brian, late 40s	Yes	Australia	30 years	Man	Family member with hepatitis B	Married
Carmi, early 70s	Yes	Philippines	5 years	Woman	Other illness	Married
Claudetta, aged 18 years	No	Sierra Leone	6 months	Woman	Unassigned	Single
Eh Soe, early 40s	Yes	Burma	3 years	Man	Blood donation	Married
Hser Eh, early 40s	Yes	Burma	1 year	Woman	Refugee testing	Married
Htoo Gay, mid-20s	Yes	Burma	8 years	Man	Family member with hepatitis B	Married
Kaw Moo, late 20s	No	Burma	1 year	Man	Refugee testing	De facto
Lah Doh, mid-20s	Yes	Burma	10 months	Man	Refugee testing	Divorced
Lena, mid-40s	Yes	Switzerland	30 years	Woman	Blood donation	Married
Long, early 40s	Yes	Thailand	10 years	Woman	General check up	Married
Madhav, early 30s	No	India	7 years	Man	Blood donation	Married
Malcolm, early 50s	Yes	Australia	25 years	Man	Unwell	Single
Paw Say Wah, early 20s	No	Burma	8 months	Woman	Refugee testing	Single
Rebecca, late 40s	No	Australia	16–25 years	Woman	Unwell	Single
Rodney, early 60s	No	Australia	26–50 years	Man	Unwell	Single
Tha Wah, mid-40s	Yes	Burma	26–50 years	Man	Refugee testing	Married

symptomology, or whether they had a family member with CHB or liver problems.

I tend to risk profile people ... anyone who is married to anyone from Asia or Africa – automatically high risk. If you received a blood transfusion in the past

... and whether they're immigrants.

Peter, GP, Australian Capital Territory
GPs working in settings with a high
caseload of refugees routinely tested
patients for hepatitis B.

Most of the ones we see are newly arrived immigrants. They get the ... standard refugee screening, which has it built in automatically. The other main ones we'd test would be people that we think are at risk because they're relatives of people from the same community. – Joseph, GP, Victoria Dash worked in a drug rehabilitation facility and tested all people who disclosed a history of drug injecting.

When we get a new patient ... we just ask whether they know if they're hepatitis B positive or not, whether they've had the vaccine. – Dash, GP, New South Wales

Informed consent

The National hepatitis B testing policy states that 'informed consent should be obtained for hepatitis B testing, except for rare occasions', and that this process should include the 'pre-test provision of all appropriate information'.¹⁵ Despite this, few patient participants reported being provided with information before testing or at the point of diagnosis. This resulted in many patient participants feeling shocked, with very little understanding about continued monitoring, transmission or whom they should inform. Ayana, aged mid-20s, who was diagnosed after the development of the testing policy, explained:

I didn't have an understanding of [hepatitis B], either in my own culture and language (or) in English. And when he (GP) first saw me, he's like, 'Sorry, you've got hepatitis B' ... there was ...

	Current hepatitis B case load	State	General practitioner (GP)/primary care nurse	Gender
Aamil	<1 per month	WA	GP	Man
Dash	High	NSW	GP	Man
Feng	High	VIC	GP	Man
Holly	High	QLD	Primary care nurse	Woman
Jackie	High	VIC	Primary care nurse	Woman
James	<1 per month	VIC	GP	Man
Jasmine	High	NT	GP	Woman
Jenny	High	VIC	Primary care nurse	Woman
Joseph	High	VIC	GP	Man
Karen	Low	VIC	GP	Woman
Laylah	<1 per month	WA	GP	Woman
Meg	High	VIC	GP	Woman
Meka	Low	ACT	GP	Woman
Noah	High	VIC	GP	Man
Peter	Low	ACT	GP	Man
Sarah	High	VIC	Primary care nurse	Woman
Susanne	Medium	NSW	GP	Woman
Tammy	Medium	NSW	Primary care nurse	Woman
Thomas	High	VIC	GP	Man

no discussion about it and what that meant for me. It was a bit of a shock,

but I really didn't understand it. Because of the complexity of CHB and the frequent low health literacy and English proficiency of many affected populations, one GP explained that he did not always provide much information before testing.

Most of the patients we see aren't aware of the concept of bloodborne

viruses and have very little health literacy. So we actually don't provide them a lot of information before we test them. – Noah, GP, Victoria

Being diagnosed

Many patient participants reported being repeatedly diagnosed with CHB. The time since the patient participants' first CHB diagnosis ranged from 10 months to 25 years. A large proportion of patient participants indicated that a lack of awareness about hepatitis B prior to their diagnosis meant they did not have the capacity to clarify what the diagnosis meant.

Before coming here I don't know about hepatitis ... so don't know what to ask. – Lah Doh, aged mid-20s

I didn't know much about the condition in the first place for me to ... ask

questions. – Mahdav, aged early 30s For some patient participants, their lack of understanding was confounded by their GPs' lack of concern about CHB. For Long, aged late-40s, being informed that she had CHB was shocking, and the lack of information provided to her had significant implications.

I'm really shocked and ... I'm going to die earlier than another person because I got a liver problem and I will die in pain. But the doctor explain to me ... I know you worry, you stress, but you

cannot do anything. Three patient participants received comprehensive information at diagnosis. Paw Say Wah, aged early 20s, noted the following.

They told me I have hep B and we may need to see you every six months to know the condition and when there is

increase and decrease in the virus. Hepatitis B diagnosis has social and clinical implications. Malcolm reflected that he would have appreciated receiving information about the risk of sexual transmission of hepatitis B because, without it, he 'didn't bother dating after [receiving the diagnosis]'. While Malcolm's experience was more than 30 years ago, one young woman, diagnosed in 2014 was also concerned about establishing relationships.

[My GP] said it's like [if I] have sex with anyone, I have to, you know, tell them because it's an STD. – Claudette, aged 18 years

GPs provided varying levels of information to patients at the point of diagnosis. Joseph reported that 'telling someone they have hep B is never a one-consult job'. Aamil, a GP from Western Australia believes that explaining the disease course was the most important issue to be addressed:

You first explain the nature of the condition, that it's a viral infection and, actually, it's a chronic infection.

Other GPs explained the importance of communicating about the virus in plain language so the patient understood the importance of continued monitoring.

The main message is the importance of lifetime monitoring. We go over that again and again ... it tends to be caseby-case. It's not a standard pro forma. – Joseph, GP, Victoria

While several patient participants with CHB described the shock of being diagnosed, only one GP recognised an emotional response to the diagnosis.

They probably still need to digest the information in small bites, which we have to do when people get bad news. – Meg, GP, Victoria

Primary care nurses were more likely to be involved after the GP had given the result to the patient.

We usually get involved only once the ... positive result has come about and they might let us know or the patient

will let us know. – Jackie, Nurse, Victoria Jenny who is a nurse in Victoria reported developing care plans for people with CHB and providing education on transmission and lifestyle changes.

They all usually have about a 45-minute appointment with me, initially. And then I have a care plan template ... Do they drink? If anyone is single, I talk to them about safe sex.

Several nurses noted the importance of cultural sensitivity when providing information about hepatitis B. Holly, a nurse working with Aboriginal and Torres Strait Islander communities in northern Australia noted a lack of appropriate resources, particularly in contrast to other chronic diseases.

There hasn't been any particularly well thought out, culturally appropriate educational programs for hepatitis B. They've done a lot on ear health and renal health and diabetes.

Contact tracing

Contact tracing seeks to reduce hepatitis B transmission and ensure that family, household and sexual contacts are tested and immunised. Patient participants with CHB described varying experiences of contact tracing, including an uncomplicated process of informing their close contacts about their diagnosis.

All family and friends. ... I told them and they got tested. In my opinion, I think I should tell [them]. I can't remember if doctor told me to tell them. – Tha Wah, aged mid-40s

The need to inform family members of a positive hepatitis B result can have significant implications, including multiple members of the family being diagnosed, some of whom live overseas.

My only brother who lives in LA is also hep-B positive ... when I went home to the Philippines, my younger sister ... found out she is also hep-B positive, which means three of us have been hep-b positive not knowing it – Carmi, aged early 70s

There was some confusion among GPs as to whether they, a specialist clinician, or the health department were responsible for contact tracing:

I don't usually routinely do this ... I'm not quite sure about that. – Dash, GP, New South Wales

For others, contact tracing was a standard part of their practice.

When they are diagnosed, I always advise the family, close family should get a check also. – Feng, GP, Victoria Jenny, a nurse from Victoria described the systematic in-house procedure for contact tracing that had been developed by her organisation:

When [they see] me for the care plan, I print out the consent for the contact tracing. And then we put all the family members down ... and the nurses all help me contact the ... family members, if they need serology, etc. We're picking up the new hep B patients that way. The complexity of contact tracing was highlighted, particularly in the context of few resources. Usually it's about 20 to a house out here ... we just don't have the resources to do it ... we try and put notes on people's records saying, 'in a household with a hepatitis B person, vaccinate if they come in' – Jasmine, GP, Northern Territory

Discussion

There are clear policy expectations in Australia describing the process for hepatitis B testing and diagnosis. None of the patient participants with CHB reported being tested in a manner that reflected these expectations, and neither the GPs nor nurses noted the *National hepatitis B testing policy* as a resource that informed their practice.

The systematic provision of information prior to testing is inconsistent. The impact was noted by patient participants with CHB who described the shock and, for some, confusion they experienced upon diagnosis, and its negative impact on their ability to absorb information from the health professional. There was a marked difference between patients who had effective conversations with their GP about CHB and those who left the GP appointment with a poor understanding of the virus, or feeling scared. The burden of inadequate information left this latter group feeling apathetic, and sometimes restricted their relationships with others for fear of transmitting the virus.

Numerous studies indicate that GPs' knowledge of hepatitis B is poor, particularly regarding ordering and interpreting tests, and understanding the link between CHB and HCC.^{9,13,14} GPs in this study believed that providing basic information about CHB and its effect on the liver was the most important aspect of diagnosis, as this supported patients' engagement in ongoing clinical monitoring. However, the complex disease course of CHB, its largely asymptomatic presentation, the stigma associated, and the lack of knowledge among GPs created barriers to individuals participating in ongoing monitoring. A recent qualitative study of people of

Somali ethnicity in the UK reported that a lack of understanding of CHB was the major barrier to engagement in testing and contact tracing activities.²² It is critical that effective methods to support patients' understanding of CHB (eg low health literacy resources, exploring the implications of infection) are developed and disseminated to primary care practitioners.

There is little clarity regarding the process of contact tracing and testing patients' family, household and sexual contacts. Contact tracing practices used by GPs and nurses differed greatly, and there was confusion about whose responsibility it was to lead the process. Given that significant numbers of people with CHB in Australia are not engaged in regular clinical monitoring, developing a broader model of contact tracing is advisable. To implement a consistent approach to testing, diagnosis and contact tracing for other notifiable diseases, the Federal Department of Health, in consultation with the Communicable Diseases Network Australia (CDNA), has developed a series of national guidelines (SoNGs).²³ At the time of publishing, a hepatitis B SoNG had not been developed to guide jurisdictional public health units in Australia on the process of testing and diagnosing hepatitis B.

Several nurse-led interventions have been implemented around Australia in an attempt to improve testing and diagnosis rates,^{24,25} and contact tracing.²⁶ A report on a multidisciplinary approach, including primary care nurses, GPs and refugee health workers at one community health centre, describes the systematic tracing of family and household contacts (n = 420) of patients with CHB (n = 122).²⁷ Most contacts were already immune, but around 12% were unprotected and 8% had CHB, demonstrating the role contact tracing can have on identifying undiagnosed people.

A significant limitation of the current contact tracing approach is the lack of differentiation between acute and chronic infection, with issues including the need for lifelong monitoring and disclosure not addressed. A model that moves away from an emphasis on acute or infectious disease to one that more forcefully addresses the personal, social and cultural issues that frame a hepatitis B diagnosis would have greater impact.

This research focused on GPs and nurses with a high caseload. Knowledge about the disease course, best practice around informed consent and need for contact tracing may be lower in the general population of primary care practitioners in Australia. This is a potential constraint of the research and should be taken into account when interpreting the results.

The National hepatitis B testing policy emphasises the need to provide culturally appropriate counselling and education during testing and diagnosis, and provides detail as to how GPs and nurses should execute this work.¹⁵ However, consideration of the structural issues (eq skills, time, communication) that might inhibit the implementation of culturally competent healthcare are not acknowledged. Future research needs to focus on trialling interventional strategies to support the implementation of the National hepatitis B testing policy in primary care, to improve the quality of the diagnostic experience for the patient, and to further explore the patient's needs at the point of diagnosis.

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