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Challenges to the effective delivery of health care to people with chronic hepatitis B in Australia

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Abstract. *Background:* The complexity of the hepatitis B natural history and its prevalence in specific populations in Australia challenges the capacity of the health system to deliver health care effectively to affected people. This study explores the challenges in delivering health care to people with chronic hepatitis B (CHB) in Australia. *Methods:* We conducted a grounded theory based qualitative study in which data were gathered from 70 in-depth interviews with government program officers, clinicians and health and community workers across Australia, and four focus group discussions with 40 health and community workers from the communities most at risk of CHB. *Results:* A systematic approach to screening populations at risk, including people born in countries with intermediate or high prevalence of CHB; consensus on clinical guidelines; development of a shared care framework for CHB involving general practitioners; and effective communication between patients and health professionals were identified as essential. Workforce development, particularly for primary health care professionals, and developing the knowledge and capacity of health professionals to communicate effectively with people with HBV were described as other major factors in reducing the barriers to CHB treatment in Australia. *Conclusion:* To improve the clinical management of people with CHB in Australia, the health system needs to encourage the screening of people at risk, improve access to clinical services, and the knowledge and communication skills of primary health care and community health service providers. This study supported developing a shared care model and related infrastructures including training programs, referral pathways and clinical guidelines.

Additional keywords: access, health system, public health, qualitative research, screening.

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Introduction

The hepatitis B virus (HBV) is a major public health problem of international significance. More than 2 billion people have been infected with HBV, of whom over 360 million are chronically infected. This is resulting in significant morbidity and mortality and causing an estimated 500 000 to 700 000 deaths each year worldwide.¹ The HBV vaccine is funded through the Immunise Australia Program, with the universal infant dose commencing in 2000 and the adolescent catch-up program from 2002.² While this program has reduced acute HBV infection, HBV has been the underlying cause of 46 deaths per 10 000 person-years from 1990 to 2000 in Australia.³ This is 1.5 times greater than the age- and sex-adjusted population. The epidemiological pattern of HBV infection observed in Australia is similar to that found in several industrialised countries in North America and Europe,^{4–7} with the burden in Australia being greater among discrete culturally and linguistically diverse (CALD) communities.⁸

The complexity of HBV and its interaction with specific populations provides challenges to the capacity of the health

system to deliver health care effectively to affected people in Australia. A study in New South Wales (NSW) reported that 79 children with chronic hepatitis B (CHB) were referred to specialist clinics during 2000–07, while 930 infected children, the majority of whom were chronically infected, were notified to the NSW Health Department. This suggests missed opportunities to intervene early in the natural history of CHB.⁹ Another study conducted in two large teaching hospitals in Sydney in 2003–06 reported that while all hepatitis B surface antigen (HBsAg) positive mothers had evidence of positive serology in their records from an earlier pregnancy, only 3.5% had been clinically assessed for CHB and subsequent liver disease, and 93% of these mothers had no documentation of referrals for further follow-up for their infection during or after pregnancy.¹⁰

The current study is one component of an extended project to develop a comprehensive response to hepatitis B, and aims to identify the challenges and barriers in health care delivery to people with or at risk of CHB in Australia.

Methods

This qualitative study used in-depth interviews and focus group discussions.

To capture a diverse spectrum of views, a purposive sample of health professionals providing direct and indirect health or community support services to people with or at greater risk of hepatitis B as well as health policy makers were recruited. A sampling frame was constructed by stratifying participants into four professional groups including government program officers, clinicians, community support workers and community-based health workers. The breakdown and more details of the participants' professional backgrounds are summarised in Table 1.

Semi-structured in-depth telephone or face-to-face interviews were undertaken by three researchers with 15 program officers (11 by telephone), 30 clinicians (23 by telephone) and 25 health or community workers (14 by telephone). The location of the interviews was determined by the participant and took between 15 and 40 min. Interviews stopped when no new themes emerged.

Four focus groups, with 10 participants in each session and facilitated by two experienced moderators, were held in Victoria, NSW, South Australia and Queensland with staff and volunteers of organisations providing health and social support services to the communities most at risk of HBV infection. Participants in the focus groups included community or health workers working with 12 different CALD communities, Indigenous communities and refugee health services and were recruited through organisations with established links with the communities most affected by CHB in Australia. Focus group discussions took between 60 and 90 min.

The theme list for the interviews and focus groups sought to identify the gaps and challenges relating to caring for and managing patients with CHB, how to address these challenges, participants' perspectives of the met and unmet needs of people with CHB, and how these needs are addressed with an emphasis on health care delivery. In addition, specialists were asked at what point in the clinical course they would prefer to receive referrals from general practitioners (GPs) and of their perspective about developing a model of shared care in which specialists, GPs and nurses are actively involved in the management of patients with CHB. The main theme list in each interview and focus group was customised to focus on the interviewee's field and scope of expertise.

All interviews and focus group discussions were recorded, transcribed and verified. Transcripts were analysed by using Nvivo 8 (QSR International Pty Ltd, Melbourne, Vic., Australia) following the principles of grounded theory,¹¹ with coding conducted by two researchers independently with inconsistencies discussed to reach consensus. Analysis commenced after the first few interviews were conducted, with initial interview transcripts read and open coded. This enabled a review of the data as they were being collected and allowed researchers to change the interview theme list to include emerging themes and issues that could be explored in following interviews. Focus group data were compared with interview data, ensuring data and methodological triangulation.

The proposal was approved by the La Trobe University Human Research Ethics Committee and Southern Health Human Research Ethics Committee (Victoria). All participants consented to having their interview recorded, and were informed of the interview process and of the confidentiality of their information.

Table 1. Professional details and jurisdiction distribution of participants to individual interviews

NSW, New South Wales; Vic., Victoria; SA, South Australia; WA, Western Australia; NT, Northern Territory; Qld, Queensland; Tas., Tasmania; ACT, Australian Capital Territory

Profession ^A	Number	Jurisdiction
Program officer	15	
Government health department ^B	9	National, NSW, Vic., SA, WA, NT, Qld, Tas.
Ministerial advisory committee	6	National
Clinician	30	
Gastroenterologist	20	NSW, Vic., SA, WA, Qld, ACT
Infectious diseases physician	6	NSW, Vic., NT, Qld, ACT
Nurse	4	SA, WA, Qld, ACT, Vic.
Health or community support workers ^C	25	
Hepatitis Council	8	NSW, Vic., SA, WA, NT, Qld, ACT, Tas.
Indigenous health service	7	NSW, Vic., SA, NT, Qld
National advocacy organisation ^D	3	National
Peer-based injecting drug user group	3	Vic., NT
Social or clinical researcher	4	NSW, Vic., SA, WA

^ASeveral participants have multiple responsibilities and are listed according to their profession.

^BPopulation Health Division and Office for Aboriginal and Torres Strait Islander Health in Australian Government and Sections of blood-borne viruses, communicable disease policy and prisoner health services in State and Territory governments.

^CHealth workers are those providing clinical or non-clinical health services, and community support workers are those providing community support services through community- and government-based organisations.

^DRepresenting people with or at risk of HIV and hepatitis C.

Results

Emergent themes identified through interviews and focus group discussion included screening, workforce development, clinical guidelines, shared care and engaging with people with CHB.

Screening

Many participants believed that only a minority of people with CHB had been detected.

'We are seeing a really small fraction of all the hepatitis B that is out there. So there's a lot of undiagnosed, unmonitored, unfollowed, unreferred hepatitis B, which means that we get late referrals and tumour referrals.' (Clinician)

While Aboriginal and Torres Strait Islanders are over-represented in the numbers of people estimated to be infected with HBV in Australia, one clinician working in a region with a significant Indigenous population noted that they made up less than 1% of their CHB patients. One program officer working with Indigenous communities noted that *'they'd never heard of anyone treated for their hepatitis B'*.

Screening within some Aboriginal and Torres Strait Islander communities was recognised as challenging due to inadequate resources available to health services working with these communities.

'We don't recommend screening because we know we can't treat it [because of insufficient resources].' (Health worker)

'People who work in Aboriginal communities are snowed under with the day to day stuff... people are reluctant to say that you should be screening for hepatitis B.' (Program officer)

Two clinicians suggested that a perceived stigma associated with hepatitis B discouraged individuals at risk of infection and GPs to undertake testing. However, this perspective was not reflected in comments from other informants.

'We don't have our head around the cultural aspects of this... there's hepatitis B infected individuals who don't want to come forward for testing because of the stigmatisation.' (Clinician)

'You seem to run into a cultural issue that the Asians don't like being told they've got hepatitis B. It's a shameful thing, and... even the Asian GPs don't really want to screen for it.' (Clinician)

Concerns about the lack of any systematic approach to screening and diagnostic processes for hepatitis B undertaken by the Department of Immigration were discussed by several participants.

'If they see a cut or a scar on your body then they test for hepatitis B.' (Community support worker)

'Interpreters are not used in a routine manner in this screening so that pre-test counselling would be minimal.' (Health worker)

One health worker was concerned about the processes undertaken by the Department of Immigration in informing people that they had been diagnosed with hepatitis B and described the process as:

'A standard letter which they (Department of Immigration) pop in a section [saying] "you've got hepatitis B... Go and see someone at your own cost." It's really confronting. They've just applied for asylum and their absolutely terrified that health will be connected to their refugee claim.'

Workforce development

There was a perception that while community and health services were responding effectively to the needs of people with the hepatitis C virus (HCV), the populations affected by CHB were more diverse and used the health care system in different ways.

'A lot of people with hepatitis C will be engaged with drug and alcohol services, who know quite a lot about it... whereas with hepatitis B, it's a much more diverse range of people with it... [It could] be Joe Blow who comes in for his blood pressure check who might have it because he grew up in a community where it was endemic... so he won't have access to people who are familiar with the referral pathways.' (Program officer)

The complexity of the impact of HBV infection is challenging for health and community workers who increasingly need to become more literate about hepatitis B. There were several instances when community and program workers disclosed their lack of knowledge about hepatitis B:

'I've done hepatitis B 101 three times and every time that I think I've got it, I try to explain it to someone else and I realise that I haven't got it.' (Program officer with professional nursing experience)

'Even the natural history; I'm not clear about it... To be honest, I don't even know if treatment is available.' (Community support worker)

Examples of lack of knowledge from within health departments were also noted, with one community support worker being told by a departmental officer that *'carriers are at no risk of liver cancer'*.

Hepatitis B serology is complex and our participants frequently noted that the capacity of GPs to interpret this

serology and respond to advances in treatment is limited. One specialist thought *'It's something of a mystery to them (general practitioners).'*

'I think GPs most likely manage hepatitis B quite poorly as well: (a) because they don't know about the disease, and (b) don't really know how to refer someone.' (Clinician)

Increased migration from countries with a high prevalence of HBV over the past 30 years has fundamentally changed the populations in Australia most affected by CHB. There were concerns that as the majority of people with CHB were infected overseas at birth, GPs needed support in responding to this changing infection pattern:

'I think as GPs, we're used to the horizontal transmission of hepatitis B. We're used to adults who get the virus and then clear the virus. It's really important in the expectations you have of the virus... and the outcomes.' (Clinician)

One program officer felt that professional development among GPs should be generated by specialists: *'I think it's up to the gastros (gastroenterologists).'* She gave an example of this, with renal clinicians undertaking the education of GPs after identifying that late referrals were resulting in an increased number of people requiring dialysis.

Clinical guidelines

Throughout the interviews, hepatitis B was described by many clinicians as being complex. One specialist noted:

'General gastroenterologists find hepatitis B extremely complex and don't necessarily understand the disease or its treatment, which results in switching and changing medications without a rationale and can result in resistance.'

During the interviews, clinicians regularly highlighted uncertainty about some concepts related to CHB management such as 'who needs treatment', 'resistance to treatment', 'availability of the HBV DNA assay', 'monotherapy versus combination therapy' and 'role of liver biopsy in management'. A need for consensus clinical guidelines was highlighted several times by the participants.

'The treatment algorithms are still evolving and we don't yet know when we should start treatment and what we should start with, and if our current regimes are ideal drugs to use... It is still controversial and you can't get consensus.' (Clinician)

Such a lack of consensus among professionals reflected significant challenges in communicating about hepatitis B to people from CALD backgrounds:

'If you think about the number of hepatitis B specialists who argue about the natural history

of hepatitis B [and] cannot agree amongst themselves, and then you try to tell this person about these nuances through an interpreter.' (Community support worker)

Shared care

There were varied responses to questions about the development of a shared care framework in which specialists, GPs and nurses would be actively involved in the management of patients with CHB. Clinicians from jurisdictions that had significant experience with hepatitis C shared care programs were more likely to support a similar model in CHB management. This perspective was not universal, with one clinician identifying that *'Shared care is a poisonous phrase among some hepatologists'*.

However, there was support for shared care from some specialists, given the long-term nature of CHB treatment:

'Hepatitis B is more suited to shared care than hepatitis C... Hepatitis B treatment will last for years for most people. It's ridiculous that people who are stable need to come back to a tertiary clinic every three months for what? To say hello, get a script written and get another set of liver function tests and viral load done and sent on their way... that's not a good use of resources.' (Clinician)

Specialists were asked for their perspective on the role of GPs within a shared care model and although there was support for this involvement, the majority of clinicians felt that more work needed to occur beforehand.

'Who should treat or when someone should be treated? What's the role of the gastro, the role of the GP, the role of the nurse? There is no consensus and I think that's where things need to start.' (Clinician)

'There needs to be some mechanism by which gastroenterologists [and GPs] can come to some shared understanding and agreement, and that will be phenomenally difficult.' (Clinician)

Of 16 specialist clinicians asked about the indications for patient referral, six suggested referral of HBsAg-positive people, four suggested HBsAg-positive people with abnormal liver function, with the remainder suggesting at the point of a positive HBV result, positive HBV DNA or anyone with abnormal liver function. This diversity demonstrates the need for agreed referral pathways, as one health worker noted.

'At the moment, [there] is such an ad hoc approach to managing and referring hep B in general practice. [We] need [a] national approach and guidelines.' (Health worker)

Engaging with people with CHB

Effectively communicating with people at risk of or who are chronically infected with hepatitis B was described by participants as important for developing clear understanding of

infection, treatment protocols, expectations and compliance. One community support worker felt that clinical specialists were not in the best position or did not have the time to effectively provide complex information about CHB to individuals, particularly in the 'crucial 20 minutes you get with the gastro'.

Several respondents described their experience when poor communication between clinicians and people, particularly those from CALD backgrounds, resulted in some people with CHB not engaging with the health care system.

'There were three people... who just disappeared... because they didn't understand the communication.' (Program officer)

'I saw a couple of African families and... I couldn't get messages across to them clearly. The interpreter service was letting us down, and then they just drifted off into nowhere land... They're not coming into any other part of the service, not being referred back for further follow-up.' (Clinician)

Language was identified by several clinicians as the most important barrier in doctor-patient communication, particularly when patients were coming from countries with a different understanding of liver disease. One clinician reported the impact of not communicating to patients in their own language:

'Even if the doctor tries to tell them the problem, they cannot perceive the concept and unless you explain it to them in their own language... they have little concept of the disease... They have no idea what the treatment is and what the treatment does.'

Communications challenges not only relate to language, but also to understanding of health, dynamics between clinicians and patients, and literacy.

'It's not about translating word for word what has been written in English... but it's accommodating for cultural issues as well.' (Community support worker)

Several clinicians described patients, particularly people with Asian heritage, as being 'compliant'. Other clinicians noted this compliance as a barrier to effective communication.

'They are sitting there nodding saying "Yes, yes, yes, thank you very much," but they don't understand, they won't say "What's that mean?"' (Clinician)

'They're easy to deal with but it doesn't mean that they're doing what they say they are doing.' (Clinician)

CHB is rarely eradicated by treatment, and is usually monitored and managed over a lifetime. This challenges an expectation of western medicine that treatment equals a cure. The processes used in hospitals, such as initial assessment and monitoring, were noted as confusing for some populations.

'Sometimes they expect to be treated immediately the first time they see the doctor and they don't fully understand that we have to fully assess their disease status before... and we are constrained by the government regulations.' (Clinician)

Nursing staff were recognised, particularly by specialists, as playing an important role in providing information, and managing patient expectations and follow-up. Two clinicians reported:

'Nurses are exceptional at being able to monitor and discuss a lot more openly and deeply [the] natural history of the virus.'

'I really need a nurse involved to track [my patients] and make sure they do come back, as we have increasing number of people on therapy... you want to use your manpower to ensure there is compliance and follow-up.'

Because CHB treatment and management is long-term, liver clinics need to consider developing recall processes to manage the patient's care adequately over this timeframe:

'Hepatitis B is about lifelong treatment, and lifelong monitoring, and I don't think that we have the systems in place in this clinic to do that effectively... We've got the clinical staff, but we haven't got a well-defined recall system.' (Clinician)

Discussion

A systematic approach to screening populations at risk, consensus clinical guidelines and the development of a shared care framework were identified in this study as essential to providing effective health care to people with CHB in Australia. Workforce development, particularly for primary health care professionals, and developing effective communication between health professionals and people with or at risk of CHB were described as the other major factors.

The early identification of CHB is essential for infected individuals to receive the necessary care to prevent or delay onset of liver damage, and to interrupt ongoing transmission by vaccinating susceptible household contacts and sexual partners. Many participants in this study noted that a minority of the people with CHB in Australia have been detected, given inadequate screening of populations at risk. This perspective is supported by a study estimating that less than 2% of Australian people in the immune tolerant or immune control phase of HBV infection, where there is a low risk of disease progression but where clinical monitoring is important, were recognised and managed.¹²

Population level testing for HBV infection meets established public health screening criteria.¹³ The United States Centers for Disease Control (CDC) recommend expanding HBV screening to include all persons born in high and intermediate endemic regions with HBsAg prevalence of >2%.¹⁴ The CDC report recommends that HBV screening be integrated in

prevention and care settings that serve populations at higher risk of infection. Studies from the USA, with its similar epidemiological pattern to Australia, strongly suggest the need for an intensive HBV screening program for immigrants from endemic regions.^{6,15} Screening for HBV in Australia should be part of the health care check of migrants from countries with intermediate or high HBV prevalence, with an understanding that a positive diagnosis is not used as a barrier to immigration. While the Department of Immigration can play an important role in this regard, our participants reported the approach to screening by this department was non-systematic and unproductive.

Although one specialist identified that the stigma associated with HBV in some CALD communities affected the willingness of GPs to undertake testing or screening, this perspective was not reinforced by any other participants. Many of the people with CHB that we interviewed volunteered that their diagnosing doctor was from an Asian background, and that household and family contacts had been vaccinated.¹⁶

Workforce development was identified throughout the study as vital for implementing an effective response to hepatitis B. The audience for this development includes clinicians, nurses, government and other public health workers, and staff and volunteers from community-based agencies working with at-risk communities. Several participants identified a need for professional training for primary health service providers, especially GPs, to improve their skills in CHB management, particularly relating to their capacity to interpret serology and respond to developments in monitoring, referral and treatment. In another study examining experiences of people with CHB, patients reported a low confidence in the professional knowledge of GPs.¹⁶ While GPs were not interviewed for this study, our survey in one Melbourne-based Division of General Practice revealed that 70% of the 95 GPs responding to the questionnaire reported needing to strengthen their professional skills in managing people with CHB.

Hepatitis B is complex both for professionals and for people with CHB. Our participants reported that understanding serology, natural history and treatment all provide challenges for populations at risk and professionals working in the area. Clinical guidelines have been developed by the American Association for the Study of Liver Diseases,¹⁷ European Association for the Study of the Liver¹⁸ and the Gastroenterological Society of Australia (GESA).¹⁹ Collaboration with the communities most affected by CHB in Australia and GPs in future versions of the GESA guidelines will increase their practicality within the Australian health system.

There is a need to develop a model of shared care in CHB given the limited capacity of liver clinics and the chronic nature of the disease. Liver clinics are currently operating at capacity as a result of government support for increasing access to pharmaceutical treatment for people with HCV, and alternative forms of clinical management for CHB, such as shared care protocols need to be developed. While the long-term nature of CHB management supports the need for shared care, the barriers to its implementation raised by clinicians included the lack of referral pathways and the skills of GPs in relation to CHB. Effective models of care for CHB need to

be developed in consultation between people with CHB, the communities most affected, GPs, nurses and specialists, and need to be cognisant of the needs for training programs, referral pathways and clinical guidelines.

The cultural diversity of people most affected by CHB provides unique challenges for the health system. Many participants in this study reported inadequate communication between people with CHB and health professionals, particularly clinical specialists. Limited proficiency in English was described as a significant barrier to effective communication with people with hepatitis B. This barrier was seen to affect the expectations and behaviours of patients in relation to clinical management. A study investigating hepatitis B knowledge and exposure in several migrants and refugees in Australia reported that only 25% of Cambodian participants considered themselves proficient in English.²⁰ Similar barriers have been reported in other countries with a multi-ethnic pattern of people with CHB.²¹ Communities can be supported by government to play a role in reducing language barriers and modifying the expectations of people with CHB through providing culturally and linguistically appropriate educational materials and interpreters, and using bilingual physicians.²¹ Cultural competency was not directly named by participants in this study but was reflected in interviews when participants discussed patient compliance and their understanding of western medical models. Further investigation of cultural competency of clinicians in relation to the populations most at risk of CHB is required.

The chronic nature of HBV infection and the long-term process of treatment and monitoring of people with CHB make regular follow-up challenging for both patients and clinicians. This has also been identified as a challenge by primary care physicians in Singapore.²² A CHB registry can be used as a tool for public health programs and clinical management to facilitate regular follow-up. Such a registry can collaborate with perinatal HBV prevention programs to collate data on women and infants with chronic infection and to identify outcomes for infants born to infected women who might have been lost to follow-up.¹⁴

To summarise, this study found that the Australian health system needs to improve the detection and management of people with CHB to reduce its long-term impact on individuals and the community as a whole. These improvements need to include the professional development of health care and community support workers, and to develop strategies to facilitate patient–doctor communication. The study supported developing a shared care model and relating infrastructures such as training programs, referral pathways and clinical guidelines to ensure appropriate clinical management of people with CHB in Australia.

Conflicts of interest

None declared.

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