

# Women with hepatitis B: how mothers with chronic hepatitis B understand and experience the prevention of mother-to-child transmission interventions in Victoria, Australia

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## ABSTRACT

**Background.** Mother-to-child transmission (MTCT) of hepatitis B can be prevented with targeted interventions; however, MTCT continues to occur in Australia and globally. This qualitative research investigated how mothers with chronic hepatitis B (CHB) understand and experience interventions for the prevention of MTCT of CHB (PMTCT-CHB) in Victoria, Australia. **Methods.** Semi-structured interviews were conducted with women with CHB. Participants were recruited through purposive and snowballing sampling. Interviews explored the women's experience of care for themselves and their infants aimed at PMTCT-CHB. Interviews were conducted over the phone with a qualified interpreter where required. The consolidated criteria for reporting qualitative research framework was used with data thematically analysed. This study was co-designed with mothers with CHB through a Community Advisory Group established for this research; coordinated and supported by LiverWELL and the researchers. **Results.** Sixteen women were interviewed. Although most women understood the purpose of hepatitis B vaccination, there were significant gaps in information and education provided to mothers regarding PMTCT-CHB. These gaps included understanding of the extent of protection of vaccination, breastfeeding with CHB, post-vaccination testing for infants and lack of clarity of the woman's own hepatitis B status. There was notable fear and worry associated with hepatitis B transmission, with emotional support for mothers identified as a major gap in service delivery. Additionally, some women experienced stigma and discrimination due to their hepatitis B and refugee status. **Conclusions.** This study explored how mothers with CHB understand and experience interventions to prevent MTCT. Our findings reveal substantial gaps in delivery of information and care in the context of PMTCT-CHB in Victoria. Our findings can support development of evidence-based interventions and systems to improve healthcare for mothers with CHB and their infants, and thereby reduce possible CHB transmission and other negative outcomes, including stigma and discrimination.

**Keywords:** community health, health service, health systems, liver cancer, maternal health, mother-to-child transmission, vaccination, viral hepatitis.

## Introduction

Globally, mother-to-child transmission (MTCT) is the predominant cause of transmission of chronic hepatitis B (CHB). Most commonly, transmission occurs during birth. Neonates who are infected with hepatitis B have a higher risk (95%) of developing CHB, compared with most adults who are exposed to the virus (5%), which is why prevention of MTCT of CHB (PMTCT-CHB) is fundamental for hepatitis B elimination (Navabakhsh et al. 2011; World Health Organization 2021).

Globally, and in Australia, there is a commitment to eliminating viral hepatitis as a public health threat by 2030, and in the *Third National Hepatitis B Strategy 2018–2022*, PMTCT is identified as a key priority (Australian Government Department of Health 2018; World Health Organization 2020). Optimal PMTCT-CHB involves screening all pregnant women for hepatitis B, viral load testing of all women with CHB in the second trimester

and antiviral treatment in the third trimester for women with a high viral load ( $>200\,000$  IU/mL; [World Health Organization 2020](#)). Additionally, infants should receive timely hepatitis B immunoglobulin, HBV birth dose and complete the series of infant hepatitis B vaccination. Post-vaccination testing for all children born to mothers with CHB is recommended ([World Health Organization 2020](#)). These interventions prevent MTCT in 90–95% of cases ([Giles et al. 2013](#)), of which 15–40% would have gone on to develop liver disease, such as hepatocellular carcinoma, as adults without clinical intervention ([Lavanchy 2004](#)).

In Australia, an estimated 226 566 people were living with CHB in 2018 ([MacLachlan et al. 2020](#)), with most either born overseas in countries with intermediate or high CHB prevalence or being Aboriginal and Torres Strait Islander people. In 2017, 77 714 women gave birth in Victoria, and of those, 687 (0.9%) were identified as living with CHB, and eight infants were identified with CHB between 2009 and 2017 ([Deng 2021](#)). Despite the availability of effective PMTCT interventions, hepatitis B MTCT continues to occur both in Australia and globally. MTCT factors identified include poor adherence to PMTCT-CHB guidelines; inadequate viral load testing during pregnancy; minimal post-vaccination serological testing for children born to mothers with CHB; poor CHB status and vaccination uptake recording and reporting; and incorrect understanding of hepatitis B transmission routes by obstetricians ([Giles et al. 2004, 2013](#); [Markey et al. 2017](#); [Shen et al. 2019](#); [Deng 2021](#)). Additionally, provision of antenatal and postnatal care is fragmented with hepatitis B antenatal screening usually completed within primary care, perinatal and neonatal care in hospitals, postnatal care by maternal and child health services, and infant vaccination by GPs or councils in community settings. Women living with CHB need access to specialised care during pregnancy, and continuous coordinated care to improve PMTCT-CHB outcomes ([World Health Organization 2020](#)).

Universal hepatitis B testing in pregnancy provides a key opportunity to link women with CHB into longer-term ongoing care ([Roder et al. 2021](#)). The USA has nationally coordinated, state-run comprehensive programs to reduce MTCT of hepatitis B. For example, the *New York Perinatal Hepatitis B Prevention Program* ([New York State Department of Health 2011](#)) and the *Arizona Perinatal Hepatitis B Prevention Program* ([Arizona Department of Health Services 2018](#)) coordinate and promote policy to test all pregnant women and their families, provide education about CHB, and promote vaccination to ensure all pregnant women receive appropriate care and management. The New South Wales Government developed and implemented a similar program, the *Neonatal Hepatitis B Prevention and Vaccination Program* ([NSW Health 2017](#)), to coordinate the cascade of care of women with CHB and their infants. Other than NSW, there are no centrally coordinated hepatitis B perinatal programs in Australia and, therefore, the

incidence of hepatitis B MTCT in Australia remains unknown. There is some evidence of hepatitis B MTCT in Victoria and Queensland ([Shen et al. 2019](#); [Deng 2021](#)).

This research aimed to explore how mothers with CHB understand and experience PMTCT-CHB in health services, and will provide knowledge and insights into existing gaps to guide future considerations for PMTCT interventions in Victoria.

## Methods

This qualitative study conducted semi-structured interviews with women with CHB. Participants were recruited from public hospital hepatitis clinics, community health centres, and through the professional networks of the researchers via purposive and snowballing sampling. Due to the 2020 COVID-19 pandemic, all interviews were conducted by phone with an interpreter where required, and electronically audio recorded and transcribed after receiving verbal consent. Interviews ranged between 30 and 95 min, and explored an in-depth understanding of the perspective of the mother's lived experience of care provided in the context of PMTCT-CHB. This included their experience of service delivery, how and what hepatitis B information and education was provided to them, and their understanding and experience of vaccination provided to their child.

The inclusion criteria were women with CHB, aged at least 18 years, able to consent and gave birth in Victoria in the past 10 years. Due to difficulties in recruiting participants as a result of the COVID-19 pandemic, we included one woman who gave birth 11 years ago; and another woman who gave birth overseas, but had most of her maternity appointments in Victoria.

The consolidated criteria for reporting qualitative research, COREQ ([Tong et al. 2007](#)) framework (Supplementary material Appendix S1) were utilised, and data were coded and thematically analysed using NVivo 12 software (QSR International Pty Ltd, Melbourne, Vic., Australia).

This study was co-designed with mothers with CHB through a Community Advisory Group established for this research; coordinated and supported by LiverWELL, a non-government viral hepatitis organisation and the researchers.

## Data analysis

Analysis used a grounded theory approach ([Strauss and Corbin 1990](#)), and data were categorised into themes identified through the interviews. Interviews were conducted by researcher NY, guided by a semi-structured interview guide (Appendix S2). Data coding and thematic analysis using NVivo software were undertaken by researchers NY and JW, who independently analysed and coded the transcripts to identify themes, and cross-checked this analysis to reach

consensus. Data saturation was reached by the end of the interviews.

## Ethics

The study was approved by the Melbourne Health Human Research Ethics Committee, HREC Reference Number: HREC/58472/MH-2019 (Parkville, Vic., Australia), and received site-specific approval by *Cohealth* (Footscray, Vic., Australia).

If clinical issues and/or questions arose during the interview, the interviewer provided participants with CHB information brochures to address knowledge gaps, and referred them to their clinician and/or GP.

## Results

Sixteen interviews were conducted. Participants included 15 women who had given birth in Victoria in the previous 11 years (plus one participant who gave birth overseas, but received the majority of her maternity related appointments in Victoria). Participants ranged from ages 18 to 59 years, overall spoke 10 languages, seven requiring an interpreter, and all were overseas born with 11 participants born in Asia and five born in African countries (Table 1). All participants had arrived in Australia after 2002, and most were diagnosed with hepatitis B either through migration arrival screening ( $n = 4$ ) or antenatal screening ( $n = 5$ ). Other settings included refugee camp screening and routine family- or GP-initiated screening. Most participants gave birth in maternity hospitals (public,  $n = 14$ ) and (private,  $n = 2$ ). Educational background ranged from primary to tertiary education. Table 1 describes participants' demographic characteristics.

Major themes identified through the interviews related to: (1) being diagnosed; (2) understanding of hepatitis B; (3) understanding of hepatitis B vaccination and transmission; (4) navigating the healthcare system; and (5) hepatitis B-associated fears and concerns.

### Being diagnosed

Hepatitis B testing and diagnosis mostly occurred in pre-migration and/or post migration arrival screening or at antenatal screening ( $n = 9$ ), demonstrating the importance of these routine screening approaches for diagnosing hepatitis B in Australia (Allard et al. 2021).

When I give birth that's when I find out. I'm very shocked. I didn't know that. (Tham)

When we had arrived to Australia, we had to have the blood test, and the doctor found that I have hepatitis B. (Bennu)

Although all participants were engaged with a health care provider for their CHB care and management at the time of interview (either through a GP or a specialist physician), most reported receiving little to no hepatitis B information during their diagnosis and throughout their ongoing care, and several did not recall details about the information they had received at the time of their diagnosis.

He [diagnosing doctor] didn't tell me anything. He just requested for some blood tests. After that, he not...he recommended me to the (hospital). (Aarif)

### Understanding of hepatitis B

The chronic nature of hepatitis B was described by several participants with some accurate and inaccurate understanding of hepatitis B.

It's a disease that grows, progress in time, that there is no medicine about it, there's no treatment towards it, it's a forever disease. (Fatou)

One participant demonstrated lack of understanding of her hepatitis B status, as she was told she is a 'hepatitis B carrier' when diagnosed, but was unsure what this meant. As explained by Yuri, a Korean mother with tertiary education.

They say it's like I'm the carrier, means that I have it, right? (Yuri)

The asymptomatic nature of CHB was confusing for several participants, and impacted on their acceptance and understanding of the infection. Some associated lower virus level (viral load) with being well, but lacked clarity and understanding of what this means.

I don't even know what the symptoms are...I never experienced anything. And the doctor told me 'you have hepatitis B but it's very low'. There is a percentage or something they measure, and she said it is very low. (Fatima)

Although most participants demonstrated little understanding of the long-term health implications of CHB, several participants associated CHB with liver cancer and this risk motivated them to continue ongoing care and management.

I'm afraid for myself because I know it would affect my liver, and yeah, it would cause cancer and so on. I know I must, yeah, keep check. (Fatou)

Most participants asked the interviewer important, clinical questions about CHB and their care, suggesting that these questions were not previously addressed by their healthcare

**Table 1.** Demographic characteristics of interview participants.

Number	Pseudonym name	Age range (years)	Country of birth/region	Education	Year of arrival	Context of diagnosis	Years since diagnosis	Known family history of CHB and/or liver cancer	No. of children	Last pregnancy (years)	Public or private birthing hospital	Required an interpreter
1.	Ayan	30–39	Somalia	Primary	2010	GP initiated	9	No	1	Currently pregnant	Public	Yes
2.	Fatima	18–29	Eritrea	Primary	2017	Refugee camp	8	No	2	2	Public	Yes
3.	San	30–39	Thailand	Secondary	2006	Arrival screening	14	No	2	1	Public	No
4.	Zaynab	30–39	Sudan	Secondary	2006	Arrival screening	13	Unsure	5	5	Public	No
5.	Thawda	18–29	Myanmar	Primary	2016	Arrival screening	4	Yes	3	1	Public	Yes
6.	Amal	50–59	Sudan	Primary	2005	GP initiated	1	Unsure	9	9	Public	Yes
7.	Amala	40–49	China	Primary	2016	Antenatal screening (overseas)	16	Yes	4	<1 year	Public	Yes
8.	Lin	18–29	China	Tertiary	2014	Family initiated (overseas)	20	Yes	2	4	Public	No
9.	Rosa	18–29	Philippines	Secondary	2015	Antenatal screening	2	Yes	1	1	Public	No
10.	Tham	30–39	Vietnam	Secondary	2004	Antenatal screening (overseas)	13	Yes	2	10	Public	No
11.	Jessica	30–39	China	Tertiary	2013	Antenatal screening	4	No	2	2	Private	No
12.	Aarif	30–39	Bangladesh	Tertiary	2011	Family initiated (overseas)	15	Unsure	1	Currently pregnant	Public	No
13.	Hla	30–39	Myanmar	Primary	2015	Antenatal screening	5	Unsure	4	2	Public	Yes
14.	Fatou	30–39	West Africa	Secondary	2003	GP initiated	7	No	1	6	Public	No
15.	Bennu	40–49	Myanmar	Primary	2008	Arrival screening	12	Yes	5	11	Public	Yes
16.	Yuri	30–39	Korea	Tertiary	2008	Routine screening (overseas)	10	No	1	Currently pregnant	Private	No

At the time of the interview.

provider, or that they were uncomfortable with raising these questions with their healthcare provider, as highlighted by Ayan.

How can I know where the virus is (level of virus) . . . It's a very bad disease. Does it ever go away, naturally? Has there ever been someone who has got rid of it? (Ayan)

### Understanding of hepatitis B vaccination and transmission

Knowledge of hepatitis B transmission and the protection provided by infant vaccination varied widely across the participants. Nine participants (out of 16) understood the principles and importance of infant vaccination.

It builds the immune system against the hep B, I believe. (Yuri).

To stop this virus being passed . . . to my daughter. (Ayan)

In the other participants ( $n = 7$ ), there was confusion and uncertainty about the purpose of the vaccination and the extent to which it protected the newborn.

You know, it's to, um, prevent your kid or anyone to get it. That's – you know, that's what it's for. But I'm not 100% sure. (Rosa)

Two women were unaware whether their children were vaccinated at birth or not, and confused the routine infant heel prick blood test conducted at birth to screen other serious medical conditions to be hepatitis B antibody testing.

They said there's a chance of me passing it on to the child and they did the test as when she was born and she doesn't have it, just me. So they did that test, yeah and she doesn't have it which is good. (Fatou)

Most participants reported they were advised breastfeeding is safe immediately after birth. However, two participants reported they were advised by their health care provider not to breastfeed or to delay feeding their infant for concerns of transmission.

[Via interpreter] The nurse told her very clearly that baby had to have the hepatitis B vaccination and can't be breastfed for 24 h. (Amala)

### Navigating the healthcare system

Navigating the Australian healthcare system during and after pregnancy for participants with low English proficiency was noted as challenging, particularly coupled with participants' low health literacy and complex experiences of migration

and pregnancy. Some participants were managed for their CHB by a specialist physician within a tertiary hospital, and some by their local GP for their ongoing CHB care. However, most maternity hospitals did not discuss the woman's CHB during routine and postnatal care, and participants reported little to no engagement from the maternal and child health services in their hepatitis B-related care.

They focused on the baby . . . but I didn't talk to them about my hep B and they didn't either. (San)

When participants were asked what hepatitis B information or care was provided to them at the maternity hospitals, Fatima's response reflected that of several other participants:

They didn't really give me or get involved with my hepatitis B, I mean they know I have it . . . it's in my history. They do blood test at each pregnancy. But they don't provide any information on hep B. (Fatima)

Most participants reported little to no relevant hepatitis B resources were provided to them. Both verbal and written information at antenatal and postnatal appointments were also reported to be poor, and not always well understood by participants. As explained by Amal, the complex description and clinical nature of hepatitis B was not always understood well, even when an interpreter was provided.

Sometimes I don't understand well what they are saying . . . even if there is an interpreter . . . sometimes I forget. (Amal)

Most women were unaware that hepatitis B post vaccination testing to confirm immunity is recommended for their infants. One participant attempted to test her child but was unsuccessful.

We tried to go a few times . . . twice or three times . . . yeah, they needed two nurses to do it . . . they said maybe it's better if you go to the hospital. (Rosa)

Women who learnt that (through the interview) CHB post-vaccination testing was recommended for their infant expressed reluctance to ask for CHB testing. Yuri explains below that she will only test her child if her GP advises.

I'm not sure if I'm asked to do that [test child post hepatitis B vaccination]. I do that, but everything is in GP hand, you know . . . If GP ask me to do that, I'll do that, but I'm not going to do that, um, as long as they're not asking me to do that. (Yuri)

Several women reported a lack of emotional support for pregnant women, as expressed by Zaynab of the importance



of social and emotional support for women, particularly after birth.

They need to support for emotion... that's important one, because sometimes we will feel down, you know, and up... you need somebody to [provide] right information for – they understand. Because if you tired, you stressed, affect your body and then affect you liver and that's when they get worse and worse. That's why I think the emotion, that's important for me. (Zaynab)

## Hepatitis B-related fear and concerns

In spite of the availability of hepatitis B vaccination and that family members had been vaccinated, several women remained concerned about transmission, with a strong emphasis on not sharing personal items, including toothbrushes and nail clippers, due to fear of blood transmission, including those that reported their infants were vaccinated.

The doctor said that we can cause this disease to our family member by sharing our personal items, so the doctor told me not to share the personal items with the family members. So it can be blood-to-blood transmission. Yeah. So, the doctor said that we cannot share the needle, the nail-cutter... I don't share personal belongings with them. (Bennu)

Although most participants understood vaccination to be a protective measure, participants continued to express fear of MTCT. San, a Karen mother of two diagnosed 14 years earlier, was extremely concerned about transmission, and emphasised wanting her newborn baby to be bathed prior to the hepatitis B vaccination to prevent blood transmission via the vaccination needle.

Just that my, my blood, uh, is on the baby [at birth] ... so they need to wash off, uh, the blood on the baby first. (San)

The psychosocial burden associated with the intergenerational nature of CHB transmission was highlighted by several participants, and the desire to protect their children and break the cycle of hepatitis B transmission within the family. The burden and worry of MTCT, and losing family and friends to hepatitis B-related liver cancer for participants coming from high prevalence and mortality countries of origin was also significant.

Now I got hepatitis B and my husband also go it. I don't want to pass it to my children. I feel so sorry for them. I don't want them to get hep B. (Thawda)

I saw a lot of people dying with this disease, even my friends. Even my close friends did die from this disease. That's why I'm worried. (Fatou)

Several participants ( $n = 3$ ) reported experiences of stigma and discrimination in health service provision (both overseas and in Australia), and marginalisation within their own families.

My mum knew about it, but then her character was a bit different towards me like she would tell me – tell other people... not want us to eat together and yeah... but I just didn't understand why she is acting like that. (Fatou)

...the health practitioner in the hospital asked my husband are you really sure you're going to marry her because she's got hep B... and my mother-in-law in [China] she actually boil water... every single time. You have to sanitise all this, just in case of oral transmission. (Lin)

## Discussion

This study explored perspectives of mothers with hepatitis B, and their experience and understanding of interventions for PMTCT-CHB. The diagnosis of hepatitis B occurred at a complex stage of life during either antenatal screening and/or pre- or post-migration screening. The shock of the diagnosis was coupled with: little to no CHB information; a lack of social and emotional support; poor understanding of CHB; and ongoing concerns regarding MTCT and liver cancer. These findings give insight into the perspectives of women with hepatitis B, and provide rich data that can be used to inform improvement of services provided to mothers with CHB. It is essential that the PMTCT-CHB in maternal settings is as effective as possible to eliminate CHB, and to ensure mothers are well informed and supported.

Previous research indicates there is a poor understanding of CHB by people who have already been diagnosed (Wallace *et al.* 2011; Allard *et al.* 2018). Most people with CHB in Australia were born overseas or are Aboriginal and/or Torres Strait Islander people. This intersectionality 'refers to the ways in which different aspects of a person's identity can expose them to overlapping marginalisation' (Crenshaw 1989). Thus, this presents opportunities and specific challenges in health delivery and communicating complex biomedical health information, as understandings of health, the body and CHB differ across cultures (Mude *et al.* 2020; Le Gautier *et al.* 2021). Marginalised communities experience low health literacy, which is associated with poorer health outcomes and engagement with healthcare services (Berkman *et al.* 2011).

Stopping MTCT of hepatitis B is imperative to reach viral hepatitis elimination as a public health threat by 2030, a goal sought by the Australian Government and the World Health Organization. Appropriate pre- and post-testing information, routine informed consent, linkage to ongoing care, and infant post-vaccination testing follow up should

be a priority. Tools and training to improve verbal and written communication with women with CHB include cultural safety training for health care professionals. A person-centred care approach, and tailored CHB and pregnancy resources in various languages could assist patients better understand their CHB status and long-term consequences of CHB. Clear explanation of protection afforded by CHB vaccination could reduce unnecessary worry associated with being infectious. One strategy that can be utilised by health care providers is the 'teach-back' method, which asks patients to explain information in their own words to improve understanding and retention of information, and should be considered as best practice (Tran et al. 2019). Broader health promotion campaigns co-designed with affected communities could assist with CHB messages and broader community understanding.

Healthcare services need to be supported to provide holistic care. A coordinated approach to supporting maternity services, and women with CHB and their infants should be considered to ensure equity in access to PMTCT-CHB interventions, and quality of engagement and linkage to CHB care, such as the USA programs.

Our study was limited by recruitment of participants who were already engaged in care and community recruitment affected by the COVID-19 restrictions in Victoria. This also affected our capacity to recruit women from Aboriginal or Torres Strait backgrounds. Additionally, this study does not represent the intersectionality and diverse experiences of all mothers with CHB. Some data were transcribed via the interpreters rather than direct translations of women's voices, which might affect the interpretation of their words.

## Conclusion

This study identifies significant gaps in the knowledge of and poor experience in the health system of women with CHB accessing maternal health services. These gaps occur at both an individual and system level regarding the information and support provided to women with CHB. A comprehensive and coordinated response, including CHB training and resourcing, and person-centred and culturally safe care, are needed to appropriately respond to the needs of mothers with CHB and their infants, and prevent MTCT and the subsequent burden of CHB.

## Supplementary material

Supplementary material is available [online](#).

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**Data availability.** The authors confirm that the data supporting the findings of this study are available within the manuscript. Data cannot be shared in accordance with ethics approval.

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