

ENGAGING COMMUNITIES AFFECTED BY HEPATITIS B

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Abstract

The impact of chronic hepatitis B infection on the health care system is increasing. To effectively reduce this burden, the health care system needs to understand how people and the communities most affected respond. Through talking with people with chronic hepatitis B and health workers, the National Hepatitis B Needs Assessment highlights significant gaps in the health care system response to chronic hepatitis B. This article highlights some of these gaps, including poor diagnostic processes, lack of information available about chronic hepatitis B for people who are infected, the need for workforce development (particularly for health and community workers involved with communities most at risk) and issues relating to access to treatment for chronic hepatitis B. The Australian health care system needs to develop effective coordinated responses to chronic hepatitis B before its burden can be reduced.

The burden of chronic hepatitis B in Australia falls heavily on specific communities, and while there are gaps in the data, there is increasing evidence that the health care system is beginning to understand its long-term impact. As many people with hepatocellular cancer have been infected with chronic hepatitis B, it is important to understand how people respond to this infection and whether they have the knowledge and skills to reduce their risk of cancer.

The National Hepatitis B Needs Assessment was undertaken by the Australian Research Centre in Sex, Health and Society at Latrobe University in 2007¹ and its report provides a starting point for discussing the needs of people with chronic hepatitis B in Australia. The project was funded by an unrestricted educational grant from Bristol Myers Squibb through the HBV (Advancing the Clinical Treatment of Hepatitis B) group.

Information for this national assessment was collected through semi-structured telephone and face to face interviews with: people who have had hepatitis B (n=20); clinicians including gastroenterologists, hepatologists, infectious disease physicians and general practitioners (n=30); health department program and policy officers (n=15); and workers from community based health services, including peer-based injecting drug user groups, hepatitis councils and people living with HIV/AIDS organisations (n=25). Four focus group interviews were held with community and health workers from culturally and linguistically diverse communities, including refugee health services (n=40). A questionnaire was distributed through the Northern Division of General Practice (Victoria) to 500 general practitioners. Ethics approval for the needs assessment was obtained from La Trobe University Human Ethics Committee and the Southern Health Human Research Ethics Committee (Victoria). Quotes from participants in the needs assessment are used throughout this article to highlight some of the issues raised in the report.

The following assumptions were made about chronic hepatitis B in the report:

- The burden of liver disease on the health care system is increasing.
- Hepatitis B is a chronic disease, with chronicity mostly discussed using clinical language and concepts.
- Populations most affected by chronic hepatitis B do not have the same understanding of the body, the blood or the liver as those used in the western health system.
- People with knowledge and understanding about their infection are more likely to engage in health promoting activity.
- Barriers to access the health system exist for the populations most affected by chronic hepatitis B.

Community beliefs and understanding of hepatitis B

The majority of people with chronic hepatitis B come from culturally and linguistically diverse communities, whose understanding of the body is based on their own cultural experience and framed by a different understanding of the body from that used in western medicine.

Hepatitis B is a complex virus. Providing often technical and complex information about hepatitis B into languages and concepts understood by people from culturally and linguistically diverse backgrounds is challenging. One study done among a Cambodian community in the United States highlights these challenges.² Hepatitis B pamphlets targeting the Cambodian community and written in Khmer, the principal Cambodian language, used the term “liver disease” (rauk tlaam), or “swollen liver disease” (rauk hoem tlaam) for “hepatitis B.” Rauk tlaam was chosen by translators as the more appropriate Khmer term for hepatitis, as this phrase was thought to best capture the organ damage expressed by the word “hepatitis,” as derived from the Greek. The distinction “B” was routinely

dropped and considered unnecessarily confusing. When the understanding of Cambodian people's comprehension of these terms was measured, the authors found that *rauk tlaam* was meaningless to 82% of respondents and Cambodian refugees often associate liver disease with heavy alcohol use, rather than the hepatitis B virus.

Both language difficulties and certain health beliefs and practices significantly influence health literacy, including access to health services. While many people in the broader community do not understand what the liver is or what it does, there are common understandings of basic western medical concepts, which provide a common language from which to start a dialogue about health. This is often not the case of people with chronic hepatitis B. One clinician reported to the needs assessment that people with hepatitis B "really have very little understanding of their disease...partly because their background concept of health and liver, and what it does, is minimal."

Diagnosing chronic hepatitis B

A person with hepatitis B finds out that they are infected after receiving a blood test, primarily from a general practitioner. The health sector has learned from responses to other blood borne viruses that a pre and post-test discussion fundamentally influences how people respond to receiving a positive diagnosis. A supportive diagnostic experience can mean that an individual can incorporate chronic hepatitis B infection into their lives and respond in effective ways. These effective ways can mean making dietary changes, reducing alcohol intake or having their infection monitored by a general practitioner or specialist, thereby reducing the impact of the infection.

There were several people with hepatitis B who reported not providing formal consent to be tested for hepatitis B: "I didn't ask for (the test), just through a normal blood test".

Several people with chronic hepatitis B said they were provided with limited or no information at the point of a chronic hepatitis B diagnosis and several described the event as shocking. This shock of finding out that they have chronic hepatitis B can be significant and may not allow people to comprehend any additional information beyond the diagnosis if this had been provided: "Nothing that I remember – if there was (information provided) it didn't stick". One person with hepatitis B assumed that their positive diagnosis equalled cancer: "I think it was like a cancer or something".

Refugee workers reported people newly arrived in Australia receiving correspondence from the immigration department notifying that they had been diagnosed with chronic hepatitis B: "A standard letter which they pop in a section (that says) 'you've got hepatitis B'". Providing a chronic hepatitis B diagnosis through the mail is the antithesis of what occurs in diagnosing infection with other blood borne viruses.

The National Hepatitis C Testing Policy released in 2007,³ describes the purpose of a pre-test discussion being to "prepare individuals for hepatitis C testing and to sufficiently equip the person requesting the test such that she/he can give informed consent". The policy notes that

test results should be delivered to the patient as soon as possible after results are received from the lab. It is strongly recommended that test results be given in person. These processes recognise the psychological and social impact that infection with a blood borne virus can have, and that the diagnostic event provides an opportunity to give information to people that effectively minimises the impact of infection, and reduces the risk of further transmission.

Given the lack of systemic testing protocols for hepatitis B, there was a wide variation in responses to being diagnosed with chronic hepatitis B. As noted previously, this included one person assuming they had cancer; while another person reported that they "didn't know that hepatitis B could be problematic ... I don't think that was explained to me".

The majority of people with chronic hepatitis B come from culturally and linguistically diverse backgrounds and many have little or no knowledge of the Australian medical system or of the language used within the system. Good English language skills were seen by one person with chronic hepatitis B as important in accessing basic and reliable information: "If you don't speak English, nobody tells you nothing".

Seeking information about hepatitis B infection

In the context of a lack of information provided to people with hepatitis B at the point of diagnosis, and a paucity of accessible and relevant information about living with chronic hepatitis B generally, several people with chronic hepatitis B reflected a poor understanding of their condition and/or had a fatalistic view of their options:

- "Only one thing I know is that there is no medicine."
- "I had hep B not much just a little bit, just carrier and no treatment."
- "I've got it ... there's nothing much I can do, it's up to the virus."

In responding to the lack of information being provided at the point of diagnosis, people with hepatitis B reported seeking guidance from a range of sources – "I had to ask a couple of people, because the people that I did ask didn't have all the information ... the doctors, they didn't have enough time to go through the specific questions". Identifying information which is accurate and credible is important if people are using it to base decisions about their health.

Being infected with chronic hepatitis B occurs within the broader context of a person's life. Several people interviewed for the needs assessment came from significantly disrupted backgrounds and were engaged in a process of establishing their lives in a new country. Responding to chronic hepatitis B was not a clear priority for some. One community worker noted that for refugees – "Hepatitis B is not the dominant thing on their mind, it's creating a life here is far, far, far more important".

Hepatitis B is a global issue and while vaccination programs are not effectively implemented in other countries, chronic hepatitis B will remain a key issue.

Organisations funded to provide services to populations most at risk of chronic hepatitis B have unique challenges, including an increasing number of clients coming from a broader range of cultural backgrounds. One community worker reported the increasing breadth of cultural diversity within their client group: “The service I coordinate have currently over 50 different countries of origin in our client group”. The implications of this cultural diversity for delivering information about chronic hepatitis B to people with differing understandings of the body, blood and the liver are significant.

Knowledge of hepatitis B among health workers

While the lack of information for people with hepatitis B is self-evident, another factor highlighted in the needs assessment was community based health workers reporting an increased number of requests for information from clients about chronic hepatitis B.

There were significant gaps in the level of knowledge about hepatitis B by people with hepatitis B, and this extended to people working with communities with higher prevalence of chronic hepatitis B. One community worker noted their significant lack of knowledge about chronic hepatitis B and the available options related to treatment: “Even the natural history - I’m not clear about it, and to be honest, I don’t even know if treatment is available”.

Several workers noted that responding to these requests required professional skill development so they could effectively explain to their clients issues related to what is a complex virus: “Hepatitis B is so bloody complicated”. Another public policy professional noted that even with their prior nursing experience, understanding and providing information about hepatitis B was challenging: “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”.

Several health professionals noted the need for increased workforce development to improve their skills. The complexity of hepatitis B and its sequelae, and differing understandings of some aspects of hepatitis B among clinicians and other health workers further complicates communicating about hepatitis B to people from culturally and linguistically diverse backgrounds. As one community worker noted: “If you think about the number of hepatitis B specialists who argue about the natural history of hepatitis B [and] can not agree amongst themselves; and then you try to tell this person about these nuances through an interpreter”.

Access to hepatitis B treatment

An essential group of clinicians that need to be engaged to reduce the impact of hepatitis B infection are general practitioners. The role of general practitioners in reducing the burden of chronic hepatitis B was identified by a public policy professional as “diagnosing the unrecognised pool (of hepatitis B),” which a clinician suggested could be done through “screening for hepatitis B (as) part of the routine health care check of populations who are high risk”.

Access to treatment services by Indigenous people, who make up about 16% of people infected with chronic hepatitis B, was noted as lacking. One clinician working in a region with a significant Indigenous population noted that Indigenous people made up “less than 1% of their patients, while another reported absolutely no contact with Indigenous populations”. One of the few clinicians interviewed for the needs assessment who was in contact with Indigenous people described “people dying early from end-stage liver disease and that’s complicated by alcohol use”. This clinician noted that hepatitis B “is actually a killer and a lot of people aren’t being referred in”.

While general practitioners were identified as having a role in screening for chronic hepatitis B, it was also noted that specialists, particularly those providing treatments which suppress the immune system, needed to be more proactive in checking their patients’ hepatitis B status before instituting treatment. One clinician noted that “there are high risk areas of medical therapy that impact on hepatitis B and there’s very little awareness among clinicians involved in delivering those therapies ... I have been told by a medical oncologist and a haematologist ... ‘we can’t screen everyone for hepatitis B’ ... and I just asked ‘why not?’”

Treating people with hepatitis B

Several clinicians talked of the challenges in treating and managing people from culturally and linguistically diverse communities with chronic hepatitis B. One challenge related to the power dynamics that occur between clinicians and patients. Having patients understand how treatment works, and what to expect from treatment is important and leads to clinicians engaging with patients in meaningful ways. As one clinician noted: “You’re much more likely to get people who want to be treated and stick to their therapy if they understand what they are doing and they think it’s good for them”.

One perception from clinicians was that people with hepatitis B were compliant and followed what the specialists told them, but there was also an awareness that this may not always be the case: “They are sitting there nodding saying ‘yes, yes, yes, thank you very much’ but they don’t understand, they won’t say ‘what does that mean?’”

The impact of patients with chronic hepatitis B coming from highly disrupted backgrounds can challenge the health care system, and one clinician reported the impact of “huge social disruption and post traumatic stress ... psychological problems that clearly we don’t address very effectively in our clinic setting”.

Conclusion

The health care system in Australia has a history of responding effectively to blood borne viral infections. Our national responses to the transmission of the human immunodeficiency virus, and of hepatitis C, showed the capacity to engage and develop partnerships effectively with marginalised communities and reduce the burden of infection of these viruses on the broader community.

There are significant gaps in the health care system response to chronic hepatitis B throughout the trajectory from diagnosis to treatment. Current diagnostic testing protocols for hepatitis B are inadequate. Diagnostic testing needs to be provided in meaningful ways so that when a person is diagnosed with chronic hepatitis B, they understand what the diagnosis means and have the knowledge, skills and willingness to effectively respond.

The unaddressed needs of people with chronic hepatitis B highlight the requirement for workforce development within the health care system. This education needs to range from improving the capacity of community workers to provide fundamental information, through raising the awareness of hepatitis B among communities most at risk, through to improving the capacity of specialists to work effectively with patients from a broad range of cultures and experiences.

There are significant gaps in access to treatment services, particularly for people from Indigenous communities. Indigenous people are estimated to make up 16% of people with chronic hepatitis B infection and yet only two of 30 clinicians reported seeing patients who

were Indigenous. The public hospital system is learning to effectively engage with people from culturally and linguistically diverse backgrounds, but more needs to be done.

Health care systems need to be resourced to engage and develop relationships with communities most at risk of chronic hepatitis B. These relationships are necessary to develop effective and efficient interventions that reduce the burden of infection on individuals infected with chronic hepatitis B, communities most at risk of infection and the broader community.

References

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