Perceptions of liver cancer and hepatitis B in the Victorian Vietnamese community

Summary Report

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Executive summary

Chronic hepatitis B infection is a leading cause of primary liver cancer in Australia. In the last few years, primary liver cancer has been identified as the fastest increasing cause of cancer death in Australians. Liver cancer deaths related to chronic hepatitis B (CHB) infection are preventable. The early detection, treatment and monitoring of CHB can slow disease progression and significantly reduce the risk of developing liver cancer.

A key target in the Federal government’s Second National Hepatitis B Strategy is to reduce the proportion of people undiagnosed by increasing testing rates. Little is known about how the Vietnamese community would perceive and respond to messages that focus on encouraging them to test for hepatitis B in order to reduce the risk of liver cancer. Cancer Council Victoria (Cancer Council) undertook four focus groups with a total of 35 people to determine perceptions of this message, in particular whether promotion of the link between CHB and liver cancer would motivate or deter people from being tested.

The research identified the following themes and observations:

The main barriers to testing and vaccination of hepatitis B include:

- The perception that the issue of **hepatitis B was less of a concern in Australia than in Vietnam**. Associated with this was a perception that hepatitis B is associated with lifestyle factors (diet, hygiene).

- Poor knowledge about vaccination and/or previous vaccination and testing experiences may **reduce/minimise any concern about hepatitis B related health issues**.

- **Perception of low susceptibility in relation to liver cancer**. Liver cancer was thought to be a consequence of an unhealthy lifestyle, specifically related to drinking and diet.

- An **assumption that their GP will inform them of, and carry out, any necessary tests**.
The main motivators to testing and vaccination

- **Improving awareness** that hepatitis B prevalence is high within the Vietnamese community living Australia.

- **Improving awareness** of the link between hepatitis B and liver cancer.

- **Increasing understanding** that there are treatments for chronic hepatitis B that can reduce the risk of serious liver disease and/or liver cancer.

Based on the findings, the follow recommendations were made in relation to the development of awareness and communication campaigns:

- Communications need to increase **awareness of the link between hepatitis B and liver cancer**.

- **A comprehensive communication strategy will need to involve general practice.** It cannot be expected that testing will be primarily patient driven based on the significant trust placed in the role of GPs. **GPs need to recommend testing.**

- Communications need to include a **specific, blatant and detailed call to action** (to dispel any misunderstandings and to enhance self-efficacy in the required action).

- Additional information materials need to clearly explain who needs vaccination, how to check if one has been vaccinated and how long it is effective for.

- Campaigns need to be effectively designed to reach a range of age groups.
Background

Chronic hepatitis B infection is a leading cause of primary liver cancer in Australia.¹ In the last few years, primary liver cancer has been identified as the fastest increasing cause of cancer death in Australians.² Five year survival for liver cancer is poor, and in Victoria most die within a year of diagnosis.³,⁴

Liver cancer deaths related to chronic hepatitis B (CHB) infection are preventable. The early detection, treatment and monitoring of CHB can slow disease progression and significantly reduce the risk of developing liver cancer.⁵ However, CHB management as a cancer prevention strategy faces a range of barriers. Almost half of the 218,000 people with CHB are undiagnosed, the majority of those who require clinical treatment are not receiving it, and there is poor awareness of the virus amongst the affected community.⁶,⁷

Chronic hepatitis B disproportionately affects migrant and refugee communities, specifically those born in hepatitis B virus endemic areas such as East and South-East Asia, the Pacific, and Sub-Saharan Africa.⁶,⁷ The Australian Vietnamese communities have one of the highest CHB prevalence rates, and Vietnamese born Australians also have a 6 to 12 times greater risk of developing liver cancer.⁶,⁸,¹⁰ Australian studies have identified low levels of understanding about how hepatitis B is transmitted, prevented, and treated in Vietnamese communities.¹¹,¹² General practice has a crucial role in diagnosis and management; however poor knowledge within affected communities combined with lack of knowledge among general practitioners about hepatitis B has also been identified as a major challenge for effective health care.¹²

A key target in the National Hepatitis B Strategy is to increase hepatitis B testing to reduce the proportion of people undiagnosed.⁷ Previous qualitative research undertaken by Cancer Council Victoria identified the promotion of the link between liver cancer and hepatitis B would be a useful tool in increasing testing rates in the Victorian Chinese community.¹³ It was hypothesised that a similar approach could be undertaken with the Vietnamese community however; there was little evidence to substantiate this possibility. This project sought to build the evidence base for health promotion initiatives which emphasise the link between liver cancer and hepatitis B in order to promote behaviours that will reduce the burden of liver cancer.
Research approach

Cancer Council Victoria commissioned *Michael Murphy Research* to conduct qualitative research to investigate the project based on the aims and objectives outlined below.

**Research objectives**

The overall aim of this research was to provide insights for the development of messages about chronic hepatitis B (CHB) that encourage behaviours to reduce the risk of liver cancer within the Victorian Vietnamese community.

Specifically, the objectives of this project were:

- Identify and explore knowledge and awareness of CHB and liver cancer within the Victorian Vietnamese community.
- Explore how the Vietnamese community perceive the link between CHB and liver cancer.
- Identify barriers and enablers to testing for CHB.

**Exploratory focus groups**

Four focus groups were conducted, a total of 35 attended across the four groups (15 men and 20 women). Groups were conducted in Footscray and Springvale. Participants were recruited through contacts within Vietnamese community groups. Participants were given a voucher as an incentive.

Recruitment criteria included:

- Participants were aged between 20 and 50 years of age.
- Participants were born in Vietnam.
- Participants were excluded if they had student visas.

Three of the groups were conducted predominantly in Vietnamese, using an interpreter. One group (Group 2) was conducted in English with a group of participants who were fluent in English. The moderator was limited to only speaking English.

Each of the groups included people from a range of ages, and as such it is not possible to draw definitive conclusions about age differences. Participants were not asked to disclose their hepatitis B status.
Analysis and reporting

This analysis is based on a review of the transcriptions from the group recordings. A thematic content analysis was conducted, addressing each of the research objectives and themes that were emergent from the data. A sample of quotes has been included to illustrate the findings. While this report includes some quotes from the groups, as they are based on the translations, they should not be regarded as direct and verbatim quotes from the participants.

The limitations of this research need to be acknowledged. Firstly, it was a small project, with only four group discussions, and as such the results cannot necessarily be generalised to the whole Australian Vietnamese community. Rather, they should be understood as reflective of the participants themselves. Secondly, each of the groups included participants from across the age range, and as such it is not possible to make clear age-based distinctions. The findings of this project also need to be understood in light of the observation that it was quite common for participants in these groups to report having been vaccinated for hepatitis B. The vaccinated participants believed that hepatitis B was not something they needed to worry about, and consequently the insights of these participants into the barriers to testing and vaccination were limited.

And thirdly, this analysis has been based on the translated components of the discussions, which is likely to have limited the data available. That is, the discussions were not verbatim translated, hence not everything that was said in the groups was available for this analysis.

Ethics

This research was approved for an exemption from formal review by the Human Research Ethics Committee at Cancer Council Victoria.
Overview of findings

The following section provides a summary of the key findings and themes identified during the research.

Exploration of understanding and perceptions of hepatitis B and liver cancer

Awareness of liver cancer

- There was some awareness and understanding of liver related diseases, such as liver cancer, cirrhosis and hepatitis. Although it was apparent to the researcher that liver disease was not as high on the list of concerns as was observed within the earlier Chinese community research.

- Several participants talked about knowing people, amongst their family and within their community, who had liver cancer, and that this had prompted them to realise that liver cancer was a particular concern for the Vietnamese population.

  “I don’t think I would have thought it was related to my community until it happened to my dad.”

Perceptions of causes and susceptibility

- Overall, liver cancer was thought to be a consequence of an unhealthy lifestyle, specifically related to drinking and diet. Drinking excessive amounts of alcohol was seen as the main cause of liver disease generally, and of liver cancer specifically.

- There was also a common perception that liver cancer was related to diet in general. Some commented that they believed liver cancer was high in Asian populations because of their diet. On the other hand, several participants commented that they did not think of themselves as being at risk of liver cancer because they ate well.

- Questions were raised in some of the groups about whether liver cancer had a genetic component, with some commenting that they had heard of families where liver cancer was in several generations.
“I remember the day when I was still living with my mum back in Vietnam, in my village where we live, there are many men who drink a lot and every time when my mother saw them, she say okay, just keep drinking and some day you will get liver cancer.”

Perceptions of treatment and prognosis for liver cancer

- There was a common belief that liver cancer prognosis was quite poor. This was typically based on what they had learned through close associations (family, friends) who had been diagnosed with the disease. This perception of poor prognosis was understood to be at least partly associated with late diagnosis.

Hepatitis B awareness

- There was some awareness that hepatitis was common amongst Vietnamese people, although this was not universally known, and in fact was quite a surprise to some participants.
- The general perception was that hepatitis B was more of a problem for people living in Vietnam than for those who had moved to Australia. This perception stemmed from linking hepatitis transmission to poor hygiene.
- Awareness tended to be about hepatitis in general, and specific knowledge of the different types of hepatitis infection was poor. While participants understood that there were different types of hepatitis, they were commonly unsure of the difference between them in terms of transmission, treatment and seriousness.

“Sharing things in dinner, especially man in Vietnam, because they drink a lot, sharing a glass, they don’t drink their own glass, they use only one and the glass will go around, or they eat meat that is not well cooked, or they don’t observe hygienic principles in cooking food and sharing things.”

“In my opinion, the reason why hepatitis A B and C is so popular in Vietnam is living conditions in Vietnam are so hard, and most people, patients there are very poor. When they are poor they are more susceptible to these illness, and even when they discover that they’ve got the problem, they have no means and no money to pay for services, so they just get by without any treatment until the problem develop into liver cancer.”
Perceived cause and susceptibility

- There was a general understanding that hepatitis was an infectious disease that could be passed from one person to another.

- Hepatitis B was commonly thought to be transmitted through sharing of food and eating utensils. Participants talked about the practice of shared food bowls, and believed that this was the reason that hepatitis B was common amongst the Vietnamese community.

- Some participants talked about having known of people who had hepatitis B and who had not passed it on to other family members. Based on these observations, they were somewhat confused about the idea of hepatitis B being infectious.

- There was some awareness that hepatitis B could also be transmitted through body fluids (saliva, blood, sexual fluids, perinatal).

  “We know that the disease is very easy to get because of the infection, it can be infectious, but we have no idea how we got it.”

Perceived stigma

- There was little sense of stigma being associated with hepatitis B. While there was some understanding that people with hepatitis B were likely to have lifestyle challenges, related to alcohol, poor diets, drug use and/or sexual issues, participants appeared not to stigmatise the disease at all. Those with hepatitis B were regarded with sympathy.

- There was awareness that hepatitis B was quite common, which in part normalised the disease, and contributed to it not being particularly stigmatised.

- Participants consistently reported that there was no obvious factor that would prevent them from discussing the topic of hepatitis B amongst family members, or in these group discussions.

Hepatitis B – perceptions of prognosis and associations with liver cancer

- There was some understanding that hepatitis B could lead to chronic liver problems such as cirrhosis, and that this was the possible link with liver cancer. However, it was also apparent that there was limited knowledge regarding how hepatitis B was linked with liver cancer.
Two participants reported that they had been diagnosed with hepatitis B, and they both believed that regular blood tests and monitoring by doctors would assist with the prevention of liver cancer. Those who had family members with hepatitis B also mentioned that it’s a chronic disease that can be managed.

“Actually, very hard to understand, hepatitis B, because I have seen some people who were diagnosed with hepatitis B and they have been living healthily for more than nearly years, they never show any sign of sickness or anything, so that’s what we don’t know how the problem, the disease develop.”

Testing and vaccinations

Participants were asked whether they had been tested and/or vaccinated for hepatitis B.

- While specific numbers were not counted, a high number of participants reported that they had been tested and vaccinated. Vaccinated people believed hepatitis B was not something they needed to worry about.

- It was also apparent that some were not sure whether they had been tested or vaccinated for hepatitis B (it may have been done back in Vietnam).

- There was also some confusion about the need for repeated testing, with various stories of people being tested and not being provided with clarity about the results of their tests as to whether they had been effectively immunised.

It appears from this research that there may be three different groups in terms of their experiences of hepatitis B testing and vaccination. A more comprehensive research study would be required to make this conclusion definitive. The groups that appeared to be reflected in this research were:

1. Those who have regular (e.g. annual) health checks through their GP, during which they believed their GP would include tests for hepatitis B if it was warranted. This appeared to be more common amongst the older participants.

2. Those who had tests and vaccines when they went travelling. This appeared to be more common amongst the younger participants.

3. Those who underwent a comprehensive health check before immigrating to Australia, and they now believe they have been vaccinated or that no further tests are required.
When prompted to discuss why they would get vaccinated, the main motivations for vaccination, in no particular order, were:

- That it had been recommended by a GP.
- Having partners or family members with hepatitis B.
- Travelling, especially back to Vietnam.
- Knowledge that hepatitis B is a contagious disease.
- Knowledge that hepatitis B is associated with liver cancer.

“A few years ago our family doctor told me that there are vaccinations available and he advised us to go, and the whole family, we went to have. We think the best thing is to prevent, so we do whatever we need to to prevent diseases.”

Experience with medical system

Participants were asked about their perceptions of the Australian medical care system, specifically in the context of general practice (GP). Participants generally felt very positive about the Australian health system, and expressed feeling fortunate to have a system that provides so well, with many health services offered free of charge. As a result, participants reported their GP as the main health service that they seek.

It was common to mention that they would go to a GP for yearly check-ups. They believed that the yearly check-up and any blood test tests included anything that was important or necessary, and that their doctors would make the most appropriate decisions for them as to what tests they needed. From this perspective, they did not feel that it was their role to decide which tests they should have or to suggest to their GPs what tests to carry out.

“For me I go and get a blood test done every year, and then from that blood test I get the information … to see whether you have cancer, not specifically for any cancer, but just cancer.”
Communication preferences

Participants were prompted to discuss how they access health information and the most effective ways for health information to be delivered to them.

- There was a consistent belief that the GP was the primary source of health information, and a belief that for the Australian Vietnamese community to get the message that it is important to test and vaccinate for hepatitis B, GPs would need to be promoting this directly.

Other sources included:

- Internet, with a general response that using the Google search engine was the primary way to seek out health information.

- Other electronic media, including television and radio.

- Amongst the group who had more English speakers (and tended to be younger), participants commented they were not linked into the Vietnamese community, but that they saw themselves as part of the mainstream population. Hence, this group felt they would be unlikely to be affected by communications that used Vietnamese community and language channels.

- Participants were also keen that it was more of a community wide push, which involved community organisations and/or groups organising the events or activities.

“*I’m just thinking my mum, she’s in an association for the elderly, they are always very good at distributing and talking about these things, so the Chinese whisper aspect, it just spreads. I hear more about what they do through my mother.*”

“And I think the other way is your GP should introduce it to the patients, or their clients, and said have you had this test, better than keep it silent, and only giving you an answer when you ask them, so your GP is playing a very important role.”
Summary of research findings

The main barriers to testing and vaccination of hepatitis B include:

- The perception that the issue of hepatitis B was less of a concern in Australia than in Vietnam. Associated with this was a perception that hepatitis B is associated with lifestyle factors (diet, hygiene).
- Poor knowledge about vaccination and/or previous vaccination and testing experiences may reduce/minimalise any concern about hepatitis B related health issues.
- Perception of low susceptibility in relation to liver cancer. Liver cancer was thought to be a consequence of an unhealthy lifestyle, specifically related to drinking and diet.
- An assumption that their GPs will inform them about, and carry out, any necessary tests.

The main motivators to testing and vaccination

- Improving awareness that hepatitis B prevalence is high within the Vietnamese community living in Australia.
- Improving awareness of the link between hepatitis B and liver cancer
- Increasing understanding that there are treatments for chronic hepatitis B that can reduce the risk of serious liver disease and/or liver cancer.
Recommendations for awareness campaigns and communication designs

- Communications need to increase **awareness of the link between hepatitis B and liver cancer**.

- A comprehensive communication strategy will need to reach **general practice**. It cannot be expected that testing will be primarily patient driven based on the significant trust placed in the role of GPs. **GPs need to recommend testing**.

- Communications need to include **a specific, blatant and detailed call to action** (to dispel any misunderstandings and to enhance self-efficacy in the required action).

- Additional information materials need to clearly explain who needs vaccination, how to check if one has been vaccinated and how long it is effective for.

- Campaigns need to be effectively designed to reach a range of age groups.
Recommendations

In working towards liver cancer prevention in affected communities, Cancer Council Victoria, and other interested agencies should:

1. Use liver cancer prevention messages in communication and awareness campaigns to increase the diagnosis and management of chronic hepatitis B in Vietnamese communities.

2. Focus test key campaign messages with the Vietnamese community to ensure the call to action is culturally relevant and influential.

3. Continue to identify and implement strategies that enable GPs to appropriately test and manage people most at risk of developing liver cancer from chronic hepatitis B. These include but are not limited to:
   a) researching and advocating for systems and procedures that enhance clinical practice
   b) implementing communication campaigns and educational initiatives to increase their understanding about the prevention of hepatitis B related liver cancer.

4. Investigate perceptions of liver cancer and hepatitis B in other at-risk communities to identify:
   a) the barriers and enablers to hepatitis B testing
   b) how the promotion of the risk of liver cancer impacts on the lived experience of a person living with chronic hepatitis B and community groups who have complex needs.

5. Continue collaborations with community groups and peak organisations representing culturally and linguistically diverse groups to ensure affected communities can be actively involved in the public health response to hepatitis B and liver cancer prevention.
References


