Hepatitis B testing and diagnosis experiences of people with hepatitis B and health professionals

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Background

- Chronic Hepatitis B (CHB) disproportionately affects people from culturally and linguistically diverse communities and Aboriginal and Torres Strait Islander people
  - 44% have not been diagnosed
  - 87% of people with CHB are not receiving any clinical management¹

No evaluation has been conducted to identify whether General Practitioners (GP) or practice nurses systematically use the policy.
Background

• Research suggests that people with CHB have limited understanding of their infection:
  – They receive little or no information at the point of diagnosis
  – Little understanding of the implications of being infected
  – Base their health care decisions on poor or inadequate information
Aim of the study

• To explore the experiences of hepatitis B testing and diagnosis from the perspective of people with CHB, General Practitioners (GPs) and practice nurses.
Methodology

• Qualitative semi-structured interviews were conducted over the phone and face-to-face with:
  – people with CHB (n=19)
    • 7 interviews were conducted with an interpreter
  – High case load GPs (> one patient per month) (n=15)
  – practice nurses (n=5)
Results

• Hepatitis B testing was initiated by a health professional during routine screening:
  – blood donation (n=4)
  – general health check (n=2)

• OR presence of a risk factor such as:
  – country of birth (n=7)
  – Family/household member with CHB (n=2)
  – symptoms/feeling unwell (n=4).
Results

I went to my doctor and I told him I wanted to start having regular check-ups ... when I went for the results, he said I had (hepatitis B).

(Claudette, 18 years old)
Results

• GPs and practice nurses based their decision to test patients for hepatitis B on the basis of:
  – country of birth
  – cultural identity
  – family history of CHB or liver problems
  – experience of symptoms
  – identification with a priority population such as men who have sex with men, people who inject drugs, sex workers, or if they were entering a medical profession.
Results

I tend to risk profile people ... anyone who is married to anyone from Asia or Africa - automatically high-risk. If you received a blood transfusion in the past ... and whether they’re immigrants.

(Peter, GP, ACT)
Results

• National Hepatitis B Testing policy notes “informed consent should be obtained for HBV testing, except for rare occasions” and that this process should include the “pre-test provision of all appropriate information”

• Few participants with CHB reported being provided with information before testing or at the point of diagnosis
Results

I didn’t have an understanding of it, either in my own culture and language (or) in English. And when he (GP) first saw me, he’s like, “Sorry, you’ve got hepatitis B.” But, I wasn’t expecting it so there was … no discussion about it and what that meant for me. … It was a bit of a shock, but I really didn’t understand it.

(Ayana, mid-20s)
Most of the patients that we see aren’t aware of the concept of blood-borne viruses and have very little health literacy. So we actually don’t provide them a lot of information before we test them.

(Noah, GP, VIC)
Results

• Time since participants’ first diagnosis ranged from 10 months to 25 years
• Participants lack of understanding about hepatitis B prior to diagnosis meant they had limited capacity to ask questions clarifying what the diagnosis meant
Results

Before coming here I don’t know about hepatitis or disease so don’t know what to ask.

(Lah Doh, mid 20s)

I'm really shocked and ... I'm going to die earlier than another person because I got a liver problem and I will die in pain.

(Long, late 40s)
Results

• Information provided by GPs at diagnosis varied
  – Most felt referral to a liver specialist was the most important aspect of diagnosis
  – Plain language explanations were critical so the patient understood the importance of referrals and continued monitoring

• Information about the virus, specifically the natural history was very important
  – Response consisted of providing a pamphlet or other written material
Results

…the main message is the importance of lifetime monitoring. We go over that again and again … we might talk to them about who’s going to follow them up, whether it’s going to be me or a specialist, whether there’s any chance that they might need treatment and so on … telling someone they have hep B is never a one-consult job.  

(Joseph, GP, VIC)
Results

• Lack of culturally appropriate resources:

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

(Holly, Nurse, QLD)
Results

• Primary care nurses tend to became involved in hepatitis B patient after diagnosis:

_We usually get involved only once the ... positive result has come about..._  
(Jackie, Nurse, VIC)

• Nursing role focuses on:
  – Developing care plans for people with CHB
  – Providing education on transmission and lifestyle
Conclusion

• The National Hepatitis B Testing policy clearly outlines how hepatitis B should be tested and diagnosed
  – No participants reported being diagnosed in line with these expectations
  – No health professionals noted the testing policy as a resource informing their practice
Conclusion

• Barriers to individuals participating in ongoing monitoring and surveillance:
  – Shock and stigma associated with diagnosis and hepatitis B
  – Lack of hepatitis B knowledge among primary health practitioners

• Building the capacity of individuals to participate in their chronic disease management is an important role of primary care
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