Uncovering the experiences and needs of patients with chronic hepatitis B infection at diagnosis: a qualitative study

Abstract:
This study aimed to explore the experiences and needs of patients with hepatitis B at diagnosis. A qualitative methodology was used. Nine focus groups (n=44) were conducted to explore: patients’ feelings and reaction to the diagnosis; encounters with healthcare professionals; and their needs. Transcribed data were analysed thematically. Most patients felt unprepared, anxious and distressed. This was attributed to poor patients’ knowledge; doctor’s emphasis on disease complications; and associated stigma. Information about the disease was lacking and patients wanted to know more about the disease and available treatment options. There was a feeling of ‘passivity’ among patients because no active treatment was available at diagnosis. Therefore, patients missed both surveillance visits and starting antiviral treatment. There is an urgent need to provide sufficient education about hepatitis B to newly diagnosed patients; address their emotional needs; and emphasise surveillance and treatment. We then discuss possible strategies on addressing these needs.
Abstract:

Patients with hepatitis B face uncertainty at diagnosis. Information and support they receive at the early stage of the disease determine their adherence to follow up and treatment. This study aimed to explore the experiences and needs of patients with hepatitis B at diagnosis. A qualitative methodology was used. Nine focus groups (n=44) were conducted to explore: patients’ feelings and reaction to the diagnosis; encounters with healthcare professionals; and their needs. The transcribed data were analysed using a thematic approach. Most patients were not prepared for the diagnosis and many felt anxious and distressed. This was attributed to poor patients’ knowledge; doctor’s emphasis on disease complications; and associated stigma. Information about the disease was lacking and patients wanted to know more about the mode of transmission, natural progression of the disease, complications and treatment options. There was a feeling of ‘passivity’ among patients because there was often no active treatment available at diagnosis. This resulted in patients defaulting surveillance visits and missing the opportunity to start antiviral treatment. Therefore, there is an urgent need to: provide sufficient information and education about hepatitis B to newly diagnosed patients; break ‘bad news’ to patients with sensitivity; address their emotional needs; and emphasise on the rationale and importance of surveillance and treatment. This may entail public awareness campaign, implementation of pre- and post-test counselling and educating doctors on how to communicate the diagnosis and management to patients accurately and sensitively.

Keywords: consumer health information, hepatitis B, chronic illnesses, focus group, qualitative research

Introduction:
Hepatitis B is the most common viral hepatitis and cause of cirrhosis and liver cancer in the world, in particular among the Asian population. Recent advances in hepatitis B treatment reaffirmed the importance of regular surveillance and early detection of active disease so that effective antiviral treatment can be instituted. Timely intervention reduces the risk of complications significantly.

However, the adherence to follow-up visits after diagnosis remains low. This is partly attributed to the fact that most patients are asymptomatic and the disease progression varies from individual to individual. Patients’ perception of hepatitis B, the information they receive and their experiences with healthcare providers at diagnosis often shape their adherence to follow-up and treatment. It is therefore important to explore the barriers patients face at diagnosis that might influence their decision for future treatment and follow-up.

Besides the risk of clinical complications, hepatitis B, like most chronic diseases, might have an impact on patients’ emotional and social well-being. So far, research studies have focused on the experiences patients who have been living with the condition for some time. Few looked at their experiences at diagnosis.

This study, therefore, aimed to explore the experiences and needs of patients when they were first diagnosed with chronic hepatitis B.

**Methods:**
In this study, we used a qualitative approach to capture the experiences of people with chronic hepatitis B when they were first diagnosed. Qualitative methodology aims to explore the behaviour, interactions, meanings, values and experiences of people in the ‘natural’ context. We invited patients with hepatitis B, who participated in a hepatitis B survey at an outpatient hepatology clinic in the XXX (an urban tertiary hospital in Malaysia), to participate in focus group discussion. Focus group discussion enriches the data by encouraging group interactions.

We used purposive sampling to recruit the patients, taking into consideration their age, gender and ethnicity. Each focus group comprised four to six participants who were grouped according to their preferred language, i.e. English, Malay or Chinese, as Malaysia is a multi-cultural country. A semi-structured topic guide was developed by the researchers based on literature review and expert opinions. It covered three main topics, namely: healthcare experiences at diagnosis and during follow-up; physical, psychological and social impact of hepatitis B on patients; and healthcare needs of patient with chronic hepatitis B. The topic guide was developed in English and translated into Malay and Chinese. Trained facilitators conducted the focus group discussion in the respective language. This paper only reported the healthcare experiences and needs of the patients when they were first diagnosed with the illness.

The authors conducted the FGDs using the topic guide. Written informed consent was obtained from the participants prior to the FGD. The facilitators used open-ended, non-directive questions to facilitate the group discussion. Participants were encouraged to talk openly and voice out their views. The group discussion was audio-recorded with permission and field notes were taken by a note-taker. This research project was approved by the XXX ethical committee.
The audio-recorded interviews were transcribed verbatim and the transcripts were used as data for analysis. The data were managed by NVivo 2, a computer assisted qualitative data analysis software. A thematic analysis approach was used.

The researchers familiarised themselves with the data by reading the transcripts repeatedly. While keeping in mind the research questions (‘what are the experiences and needs of patients with hepatitis B infection?’) and guided by the key topics in the FGD guide, main themes were extracted from the data and they formed the ‘nodes’ for further coding. All researchers coded the transcripts using the same framework to ensure consistency. Subsequently, the coded nodes were summarised into subthemes and reported as shown below. No new themes emerged after six focus groups (two in English, two in Malay and two in Chinese). We conducted three additional focus groups, one in each language, to ensure saturation of the themes.

Two researchers coded the first three transcripts independently to ensure dependability. The researchers used a reflexive approach to ensure the analysis was as credible as possible. Any disagreement with the analysis was discussed and consensus reached at the researcher’s meeting.

Results:

Forty-four (44) patients with chronic hepatitis B infection participated in nine focus groups. Their socio-demographic profile is show in Table 1. The patients were diagnosed to have
hepatitis B infection either through active screening or being detected accidentally during blood donation, medical check-ups and hospital admissions. Family history of hepatitis B played a significant role in prompting the patients to go for screening.

Three main themes emerged from the focus group discussion and they were categorised as follows:

- Patients’ feelings of, reactions to and coping with the diagnosis
- Patients’ encounters with the healthcare professionals at diagnosis
• Patients’ needs at diagnosis

1. Patients’ feelings, reactions and coping strategy at diagnosis

Patients’ feelings and reaction to the diagnosis

The emotional reaction from the patients at diagnosis varied considerably, ranging from ‘shocked’, ‘disbelief’, ‘upset’, ‘scared’, ‘anxious’, ‘not surprised’ to acceptance.

‘I just wanted to do a routine blood test. I got a shock, you know. I couldn’t sleep. I was so depressed. I was anxious.’

47-year-old woman

‘I didn’t believe the results initially. I told them it was wrong.’

47-year-old man

‘What to do, have to accept it.’

28-year-old man

How patients felt depended on how much they knew about the condition. Those who were unaware of the complications of hepatitis B were less distressed and more likely to delay in seeking treatment. Those who were aware of the complications such as liver cancer were more anxious.
‘First, I don’t know anything about it. I didn’t feel anything. I didn’t feel sad. Just ordinary.’

26-year-old man

‘When I delivered my first child, I already knew I had hepatitis B. But, I just act as if I didn’t have and… I was giving birth like one a year. The doctor scolded me and said that I could pass the illness to my children. I didn’t know that hepatitis B could become chronic.’

26-year-old woman

‘I feel like it was, oh Hepatitis B, straight away it’s going to be cancer of the liver and that’s it, you know.’

47-year-old woman

Few were willing to discuss openly about their condition because of fear of being discriminated by or causing anxiety to their social contacts. There was a stigma associated with hepatitis B.

‘I didn’t dare to let anyone know. I was afraid that people will be scared of me. I only let my family members know. I didn’t even let my friends know.’

62-year-old woman

‘I didn’t tell my family… and friends. I myself take the responsibility…like my friends will be worried like sharing food… so I’ll control it myself.’

23-year-old man
‘So I told them I got hepatitis B, better don’t drink mine. I can drink yours but you cannot drink mine.’

54-year-old woman

Patients’ coping with the diagnosis

At diagnosis, patients with hepatitis B coped by not thinking about the condition and its potential complications.

‘Emotionally, I can cope because I try to keep myself occupied all the time so I don’t want to think about it. I don’t want to think that hepatitis B can actually progress with time.’

61-year-old man

‘I wanted to be positive. I mean I don’t want to think that I have a disease.’

51-year-old man

‘I was young, that time was twenty; so the idea of having cancer didn’t even come to me – because I was so young and active.’

60-year-old man
Some viewed hepatitis B as a disease with ‘no cure’. Treatment of hepatitis B was viewed as opportunistic depending on when the patients have active disease. There was a sense of ‘passivity’ in the way the patients viewed hepatitis B.

‘This disease cannot be cured. If we think too much, it’ll make us more ill. When I knew about the diagnosis, I just said, ‘Really?’ That’s it.’

43-year-old man

Others adopted a more pro-active attitude and searched for information regarding hepatitis B.

‘Doctor told me and I quickly searched for information and read about the disease. I also read the notes from my roommate who was a student nurse.’

23-year-old man

2. Patients’ encounters with the healthcare professionals at diagnosis

How the diagnosis was communicated

The patients had varying experiences with the healthcare professionals when they were first diagnosed with hepatitis B. Some felt that the doctors were trying to allay their anxiety by reassuring them that the condition was benign.
‘The doctor said liver cancer takes many years, may be 30 to 40 years, or may be
liver cancer won’t develop at all. The doctor said, it’s not easy to get cancer – it’s
like striking lottery.’ 62-year-old woman

Others became more anxious after the doctors discussed the diagnosis with them.

‘He (the doctor) told me ‘Do you know that hepatitis B can cause cancer?’ He didn’t
say that to motivate me; he said it in a way as if I could infect others… like I am
going to die now.’ 26-year-old woman

Information and arrangement for follow-up

Post-test counselling was inconsistent; some received medical advice and follow-up while
others only received brief advice from the pharmacists or laboratory technicians. Some did
not receive any counselling but sought information on their own via newspapers, books,
friends and families.

‘So my friends told me it’s quite serious. We must take care. I cannot drink alcohol.
That’s all’ 46-year-old woman

‘In fact, when I came to know about this disease, I just know the results from the
report. No doctor explained to me. I found out that the antigen means I am a
carrier.’ 23-year-old man
There was no uniform follow-up practice after the patients were diagnosed with hepatitis B infection.

‘In fact, I wasn’t told to check every six months.’

60-year-old man

3. Patients’ needs at diagnosis

The patients highlighted their needs, in particular their desire for emotional support and information about transmission, prevention, complications, available treatments and prognosis.

‘At the end, still a big question. More questions than answers.’

58-year-old man

‘What can I do? What can I eat? What can’t I eat?’

23-year-old man

‘He just say you are a hepatitis B carrier. I did ask the question as in so is there any medicine that I can take and all that. There is nothing you can take. So that’s about it.’

36-year-old woman

‘For me, I’d like to know more like after 10 years what happen; after 20 years, what happen; when we can have the medicine and what treatment.’

32-year-old woman
Patients with hepatitis B highlighted the difficulty in accessing accurate information about the diagnosis and treatment. There was variation in how, who and what information was delivered at the time of diagnosis. Some of the information provided was inaccurate.

‘First, I don’t know anything about this (hepatitis B). Then only I ask the doctor how (it can be transmitted). Then only he told me I can get it from having sex. Another thing is food, you can get it from food outside. Some more drink beer.’

26-year-old man

‘Still there were all kinds of thoughts of how this disease is going to infect other people. At the beginning, people said through saliva. So we kept separate bowls, spoons, everything also separate.’

58-year-old man

There is need to deliver health information in a manner that can be understood by the patients.

‘The doctor explained but I don’t really understand what they are talking about. Somehow I know it’s not very harmful at this (early) stage.’

21-year-old woman
Discussion:

The patients in this study were not ready for the screening outcome and many were emotionally distressed by the ‘bad news’. This was partly attributed to the lack of knowledge and how the diagnosis was communicated to them. Patients wanted to know more about the disease, its transmission, complications, treatment and prognosis. However, accurate information was not easily accessible. There was also a wide variation in how patients were counselled and managed at diagnosis, and followed up subsequently. Currently, few clinical practice guidelines on management of chronic hepatitis B provide guidance on patient counseling at the time of diagnosis (4,5).
Many studies have focused on the update of hepatitis B screening; little attention was paid to the pre- and post-test counseling \(^{(1,2)}\). People experience considerable anxiety when they undergo screening. This is often due to inadequate knowledge about: the condition and its complications; the predictive value of the tests; and the treatment options and follow up plan if tested positive \(^{(20)}\). As a result, people who are screened positive are uncertain about what they should do next. This issue is particularly common in countries, including Malaysia, where screening could be performed at commercial laboratories and no medical advice is provided. The emotional distress experienced by the patients in this study highlighted the importance of pre- and post-test counseling and follow up for people who are undergoing hepatitis B screening. The information should include: the need for a repeat serological test if screened positive; natural progression of hepatitis B; importance of regular surveillance for timely antiviral treatment and early detection of complications.

In this study, the patients’ encounters with the healthcare professionals affected their initial reaction to the diagnosis and influenced their subsequent help-seeking behaviour \(^{(21)}\). Inappropriate reassurance creates unrealistic expectation while overemphasis on the disease complications causes unnecessary anxiety. Diagnosis of hepatitis B is ‘bad news’ to patients and it should, therefore, be communicated with sensitivity. This requires the doctor to explain the diagnosis, complication and management in a balanced and realistic manner \(^{(22)}\).

Another major concern patients had at diagnosis was how the disease was transmitted and whether they could infect their family and friends. They were unaware that vertical transmission is the most common mode of transmission locally. Many still believed that hepatitis B could be transmitted via saliva and they avoided sharing food and utensils with their close contacts. As a result, most patients would only disclose their hepatitis B carrier
status to their immediate families but not their friends and relatives. Dispelling this myth is crucial to destigmatise hepatitis B, remove self-imposed social restriction and reduce emotional distress. Public awareness campaigns and continuing professional education should stress on the common route of transmission according to the disease epidemiology in the region (1). Information on hepatitis B should be made easily available in hospitals and the primary care setting.

In addition, the patients were unaware of the treatment options of hepatitis B and adopted a ‘passive’ attitude towards the treatment. This is partly due to the lack of definitive treatment for hepatitis B at diagnosis when the disease is inactive. There is also no evidence to advocate lifestyle changes and prescribe specific medications for chronic hepatitis B at diagnosis if there is no active disease (3). This is in contrast to other chronic diseases, like diabetes and hypertension, where lifestyle modification and medications are often instituted at early stage of the disease. As a result, patients may not see the necessity and urgency to be followed up regularly, especially when they are asymptomatic and there are cost implications. It is, therefore, important for the healthcare professionals to explain to the patients that regular monitoring will help in early detection of disease activity and complications. This may improve patients’ adherence to follow up and treatment later.

There are a few limitations in this study. Firstly, the patients recruited in this study had been diagnosed with hepatitis B for an average of more than ten years. There might be recall bias when they discussed their experience at diagnosis. However, judging from the patients’ ability to describe and recollect their feelings and encounters with the healthcare professional with considerable details, the chances of recall bias is less likely. Furthermore, the patients were able to describe the change in their feelings and
healthcare experiences over time; this is helpful to for them to identify their healthcare needs at diagnosis.

Secondly, this study was conducted in an outpatient hepatology clinic of an urban tertiary hospital. The research findings are restricted to patients with hepatitis B who have secondary education and easy access to health information and services. The findings are not transferable to patients who are less educated and in the rural setting, where their informational access might be less and the impact of the hepatitis B on their emotional and social well-being might be different. Further studies are needed to explore the experiences and needs of patients from a different socio-economic background.

Thirdly, although the use of focus group discussion encourages interaction among participants by creating group dynamics, some participants may not be comfortable in sharing their personal experience with the group, in particular pertaining to sexual and relationship issues. Individual in-depth interviews may be used to overcome this limitation and the interview findings served as a form of triangulation. This should be considered in future studies.

This study highlights the need to provide timely and accurate health information for patients during screening and at diagnosis. This requires the healthcare professionals to be trained to provide routine pre- and post-test counseling when conducting hepatitis B screening. The healthcare professionals should also be sensitive to the emotions of the patient when breaking ‘bad news’. Appropriate reassurance and step-wise patient education over a few consultations may be needed to avoid information overload and causing patient anxiety. However, the importance of regular surveillance and availability of antiviral treatment should be explained and emphasized at the early stage of diagnosis.
Addressing the information needs of patients with chronic hepatitis B at diagnosis is one way of ensuring that patients are adherent to follow ups and less likely to miss the opportunity in receiving timely antiviral treatment.

**Conclusions:**

This study found that the emotional and social well being of patients with hepatitis B were affected at diagnosis. There was a wide practice variation in how patients were counselled, treated and followed up at diagnosis. There is, therefore, an urgent need to address patients' informational, emotional and social needs when the diagnosis of hepatitis B is made. Healthcare strategy must be developed and implemented to standardise patient education at diagnosis to reduce practice variation in care provision for patients with chronic hepatitis B.

**Statement of Interests:**

None
References:


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Table 1. Socio-demographic profile of the focus group participants.

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### Mean number of years after diagnosis

\[12.63 \pm 7.76\] (years) \((n=41)\) (1 – 30)