Current Issue

ORIGINAL ARTICLE

A qualitative study of hepatitis B carriers' understanding of their chronic infection

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Abstract

Aim: : This study aimed to determine hepatitis B (HBV) carriers' understanding of the etiology, pathology, monitoring and therapy of their chronic disease.

Methods: A qualitative study using focus group discussion (FGD) and a semi-structured guideline to explore HBV carriers' understanding of their disease.

Result: Thirty-nine asymptomatic HBV carriers of both genders, three races (Chinese, Malays and Indians) and aged 22–75 years were recruited in eight FGDs. Most carriers were aware of the viral origin, its effect on the liver and the main modes of transmission. Confusion of HBV with hepatitis A and transmission with shellfish was common. All had and were aware that the blood and liver ultrasound investigations were to detect liver complications but failed to recognize the need for regular monitoring in view of previous 'normal' results. They were also unaware of the current strategy in the use of anti-viral therapy and relied mostly on their doctors for HBV-related information.

Conclusions: HBV carriers had fragmented understanding of their disease. They were less aware of the significance and need for regular disease surveillance or the availability of anti-viral therapy for definitive treatment, and were dependent mostly upon their doctors for health education.

Key words: anti-viral therapy, disease surveillance, hepatitis B carriers, understanding

Introduction

An estimated 350 million people worldwide are chronically infected with hepatitis B virus (HBV), resulting in over one million deaths annually due to progression to cirrhosis and/or hepatocellular carcinoma (HCC). Chronic HBV infection is also endemic in Singapore and affects 4%[1] of the local multi-racial population who are carriers of the virus.

Due to the local fees-for-service healthcare system, these HBV carriers can select their preferred sites of review in the management of their chronic disease. They can be followed-up either in primary care centers, such as government-subsidised polyclinics or private family physician clinics, or secondary healthcare institutions such as specialist clinics in government-aided or private hospitals. An earlier study carried out by the same authors reported primary care physicians' perceptions that HBV carriers' lack of understanding led to poor compliance with disease monitoring.[2]

Objective

This qualitative study aimed to explore hepatitis B carriers' understanding of their chronic HBV infection in terms of the disease etiology, pathology, monitoring, therapy and source of information. The results would allow physicians to gear their patient education towards filling the gap of knowledge and motivating patients towards better compliance to disease surveillance.

Method

The authors used qualitative research methods[3] to explore HBV carriers' understanding of their chronic disease through focus group discussion[4] (FGD). The SingHealth Polyclinics Ethics Committee approved the study.

The sampling frame included adult HBV carriers above 21 years-of-age, of both genders, inclusive of the three main races in Singapore (Chinese, Malays and Indians) and followed up in primary and secondary care medical centers. Participants from this sampling frame were selected for each FGD using a variety constructs in order to capture a wider spectrum of views. Those who had or were currently receiving anti-viral therapy were excluded. The authors perceived that the views of this group of HBV carriers could be affected by their anti-viral therapy.

The HBV carriers were approached by investigators and a research nurse during their consultation at polyclinics and Changi General Hospital and were informed of the next scheduled FGDs. Follow-up calls were made to the potential participants to confirm their participation approximately 3 days prior to the FGD.

Nurse manager SL Cheah, a trainer in qualitative research in SingHealth Polyclinics, facilitated all the FGDs to allow free-flow discussion, which could be biased or inhibited by the presence of a physician. A research coordinator assisted in the note-taking during each FGD. The questions in the semi-structured guideline explored HBV carriers' awareness, reaction and experience (abbreviation 'CARE') of their chronic infection (Table 1). The facilitator was allowed to modify or expand the guideline according to the line of discussion and issues raised during the FGDs.

The purpose and objectives of the study were explained to the participants at the onset of the FGD and confidentiality of their identities was ensured. Each participant signed a consent form and was required to fill in basic socio-demographic data. Each focus group was audio-taped, which lasted between 45–90 minutes. Detailed notes of each session were taken. Participants were encouraged to speak freely and described their experience of being HBV carriers. They were reimbursed for their travelling expenses.

The study was terminated with saturation of ideas after eight FGDs. The tape-recorded interviews were transcribed in their entirety into text files. The transcripts were read and checked independently by the investigators to ensure consistency.

The qualitative data were analyzed after all transcripts were read several times and simultaneously coded, using the software NUD*IST Version 6.0TM.4 Potential conceptual and content-related themes were formulated in the analysis. The quotes included in the results were typical views expressed by the participants in each FGD and were used to exemplify emergent themes.

Results

Socio-demographic background of participants

A total of 75 HBV carriers were approached, of which 39 participated in the FGD. Their profiles are described in Table 2. The majority were male, Chinese, with age ranging from 22 to 75 years. The mean age was 44.0 years (SD 12.4 years). They were diagnosed as HBV carriers for a period of 1–23 years and were managed by government-aided polyclinics and by a hepatitis clinic in a district hospital.

HBV carriers' understanding of their disease were categorized by the authors into etiological agents, mode of transmission, pathology, awareness of disease surveillance through blood and imaging investigations, therapeutic options and source of disease information.

Etiological agent

The majority of the participants were able to identify the etiological agent of the disease as 'a virus' but none could describe the morphology of the virus. Although several participants indicated that more than one viruses could lead to the development of hepatitis, the majority of them were confused between hepatitis A and B, from the way they described the mode of transmission. Few participants mentioned the 's' and 'e' antigen on the virus. One participant, who could do so, mistook it for 'hepatitis E'.

> 'All of us have very vague idea of hepatitis. We are always mixed up with A, B and C.' FGD6

> 'It is said that for hepatitis B, clams and oysters could be one source for that disease.' FGD8

Mode of disease transmission

Participants were able to identify the blood-borne or 'body fluid' mode of transmission of the disease.[6] Participants in two FGDs compared HBV infection as similar to AIDS transmission. Many mentioned that it could be sexually transmitted and through contaminated needles, shaver blades, toothbrushes and tattooing. Mother-child transmission was also brought up in the FGD when participants queried about their origin of the infection. This was most pertinent in participants with family history of HBV infection. There were participants who were aware that they could have been infected since birth but participants in two FGDs attributed it erroneously to a 'genetic' disorder. There were queries as to why only certain siblings were infected and others were non-carriers despite being from the same family. Nonetheless, most participants had their family members screened for HBV and were relieved to discover that most of their relatives, especially spouses, were immune to the virus.
Participants often mistook hepatitis A for HBV and blamed previous consumption of shellfishes such as cockles and oysters as the source of their HBV infection. A significant number of participants indicated that sharing kitchen utensils and food could also transmit HBV. An internet-savvy participant highlighted that the coating of peanuts could also cause HBV from web-based information that he encountered. Another attributed his infection to contaminated water in the jungle, which he had during army training.

> 'Once I asked a colleague who is also a carrier on how he got infected. It was genetic!' FGD8

Pathology

All participants were aware that HBV could lead to liver cancer and cirrhosis (described as 'hardening of the liver')[7] and ultimately death. Although two participants had previous acute HBV infections and could describe the clinical signs and symptoms of hepatitis from their experience, the majority of them were asymptomatic carriers. The former mentioned about yellowing of the eyes and skin in jaundice but were less aware of other symptoms such as hepatomegaly, fever, malaise and constitutional symptoms. Few participants in two FGDs perceived that HBV caused them to 'feel sick', 'feel tired' or to be 'weakened'. Most considered themselves to be 'healthy'.
The participants used a variety of metaphors to describe their current 'asymptomatic' state of health. Many appeared contented when their doctors told them that the HBV in them was 'not active' or was 'sleeping'. In contrast, they were fearful of an 'active' virus, which they perceived would cause liver damage, complications and ill health.

> 'If you are a carrier, the virus will stay there and won't do anything to you but once your body gets weak, it will come out to do all sorts of things (harm).' FGD8

> 'It is liver infection … that can cause liver hardening and cancer if it is active. If it's not active, it should be quite ok.' FGD4

Disease surveillance

All the participants had blood and imaging investigations as instructed by their physicians from both the hospital and the polyclinics. However, the frequency of blood and imaging investigations varied between the participants in all FGDs. Most were told to undergo annual or half-yearly blood test monitoring[8] and were aware that the tests assessed the 'liver function'. Few mentioned about 'liver enzymes' but none was able to describe the significance and relationship of the enzymes to liver function. None was aware that the liver enzymes such as alanine transaminase (ALT) was one of the determinants for eligibility for anti-viral therapy.[9] Several participants mentioned that their doctors had attempted to explain the blood tests but they could not understand them due to the 'medical language' used.
The participants, especially the female carriers, expressed anxiety whilst waiting for their results to be reported by their doctor. Most carriers were contented if they were told that their results were 'within the normal range'. On the other hand, fear was prevalent if their readings were beyond the stipulated range printed on the laboratory result slip. Some carriers would insist on keeping records of their blood results so as to monitor the trend of the test results. The majority appeared to be less compliant with follow-up after several years of investigations, which showed 'normal' results.
Similarly for imaging investigations, the participants were told to undertake yearly or 6-monthly ultrasound scans of their liver.[10] They were unaware of the need for both the blood and imaging investigations or rationale behind the frequency of the investigations. Some were concerned about the 'fatty liver' report of their previous ultrasound scan but did not receive any explanation of the significance or its possible health impact. They associated the 'fatty liver' to fat intake in their diet and were told by their doctors to take on a low fat diet. Nonetheless, it appeared that HBV carriers in this study continued their blood and imaging investigations periodically, but often not according to their schedule, largely out of fear of development of liver complications.

> ‘All of us are very ignorant over the investigations.’ FGD1

‘Therapeutic options

The participants in all FGDs were disappointed that there was ‘no cure’ for the disease as pointed out by their doctors. Many were unaware of any anti-viral drugs [11], targeted at HBV infection and several of them pointed out that the drugs were in the ‘research phase’ and would not result in total recovery of the disease. Two participants were previously approached by their hepatologists to take part in drug trials but neither agreed and expressed relief that they were not involved in these clinical trials. However, all the participants were unaware of possible drug intervention during the reactivation phase of the disease. They were more concerned and apprehensive of the cost, side-effects and the lack of efficacy. One senior participant expressed disappointment, as he perceived that he was being rejected from any drug treatment due to his age. Some participants were taking ‘liver pills’, mostly vitamin supplements to ‘detoxify the liver’. In all FGDs, participants reported that they had been warned against taking herbs by their doctors and most denied current consumption of any traditional medication. Only in one FGD was liver transplant mentioned as an option for treatment.

> ‘The medicine is not fool proof, so you are taking chance. That’s what people worry about hepatitis B. There is no medicine to cure it.’ FGD6

Source of disease information

Participants in each FGD admitted that they lacked adequate knowledge of the disease but most made no attempts to find out more than what their doctors told them during the consultation. Participants sought additional information from health magazines, books and the internet. They also obtained information from relatives and friends but expressed greater reliance on medical professionals’ expertise, especially those of hospital specialists. Participants refrained from asking doctors for more information as they perceived that their doctors were busy. They were also concerned that they might not comprehend the doctor’s explanation. However, participants expressed willingness to obtain health education on HBV from trained nurses, if offered by the health institution.
Although there was an HBV support group in Singapore, all participants, except for one, had not heard of it. Nonetheless, that sole participant did not participate in the support group due to ‘lack of time’.

> ‘Heard from the doctor that my virus is dormant. It’s not reproducing but the virus is still inside my liver.’ FGD7

Discussion

The authors noted that the HBV carriers in this study did not have a clear and wholesome picture of their chronic infection. Many HBV carriers misunderstood the etiology of the disease. Whether it was due to carriers’ ignorance or the past failure of healthcare professionals to educate their patients is secondary. What is more important now is for healthcare professionals to introduce programs or processes in their clinics to rectify erroneous perceptions and promote awareness of the etiology and viral mode of transmission.
Most HBV carriers relied on their doctors to provide them with relevant information but unfortunately the knowledge gained was at best fragmentary. Reports[2,12] by the same authors showed a gap of communication between HBV carriers and their physicians. Those who sought additional information themselves from other sources were not necessarily better acquainted with the disease; the information could be erroneous or misinterpreted by the HBV carriers, who might not have the ability to understand the medical terms used. This calls for trained healthcare professionals to play a more proactive role in HBV-specific health education. Both physicians and nurses could disseminate the HBV-specific information to HBV carriers and their families in multiple ways: one-to-one consultation; incorporation of health education into clinic protocols; provision of health education material; establishing monitored HBV web-sites; open public talks; and the mass media. Carriers should find, amongst these multifaceted health education programs, ample opportunities to clarify their doubts and address their concerns.
Medical professionals should also look into new strategies in their consultations with carriers. Instead of a pessimistic fatalistic approach which focuses on complications, they should emphasize to HBV carriers that regular surveillance provides opportunities for definitive drug therapy if HBV reactivation is detected by the vestigations.[13,14]
The majority of carriers were still unaware of therapeutic options with antiviral medications, even less so on the selection criteria for such drug interventions. HBV carriers should be entitled to such information and to understand their options. Ultimately it would be their shared decision with their doctors before embarking on definitive treatment of their disease.

Limitations

This paper aimed to provide an insight into the understanding of the disease amongst HBV carriers but this qualitative method did not allow the results to be extrapolated to the entire population of HBV carriers in Singapore.

Conclusion

HBV carriers in this study had fragmentary knowledge of their chronic disease and were often confused with the mode of transmission and the etiological agent. Few recognized the clinical relevance for regular disease surveillance and were mostly unaware of anti-viral therapy against HBV due to lack of explanation from their doctors. Medical professionals should raise their level of disease awareness through appropriate and specific health education.

Acknowledgments

The authors are thankful to all the HBV carriers who contributed to the study. They are also grateful to the research nurse, Vasanti, who rendered her assistance during the FGDs and diligently transcribed all the voice recordings. The study was supported by a research grant from SingHealth Research Council to establish an HBV carrier database in SingHealth Polyclinics.

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Table 1 Questions guideline for hepatitis B carriers

1. Knowledge
What do you know about the Hepatitis B virus?
What do you understand by the term “HBV Carrier”?
How does it affect your body? (liver function)
What harm does it cause? (complications such as cirrhosis, cancer)
How does it spread to other persons?

2. Attitude

How do feel about having the infection?
Does the infection interfere with your daily living?
Do you take any preventive measures to avoid spread of the disease?
Do you inform your family members/close friends of your condition?

3. Reaction
Do you take any medication to try to control the infection?
Do you seek alternative therapy?
Do you seek religious support?

4. Concern of their condition
What are your main concerns about the viral infection?
What do you do to address these concern?
Do you have any concern with the blood tests?

5. Expectation in their management
Who is your regular doctor who looks after your HBV infection?
Are you satisfied with the follow up management by your doctor?
Did the doctor explain to you the nature of the infection?
Do you understand the doctor's explanation?
What are your doubts about the infection that you would like to find out or clarify?
Is there anything that you think should be included in the consultation?
Do you follow up regularly with your doctor?
Where is your preference in the follow up? GP/ polyclinic or specialist in hospital? If so why?
Are you aware of the HBV support group? If there is such a group, will you participate? What benefits do you think you can get from the support group?

Table 2 Socio-demographic background and profile of participating hepatitis B carriers

Variable	Frequency *n* = 39	Percentage (%)
Race of HBV carriers		
Chinese	33	84.6
Malay	4	10.3
Indian	2	5.1
Gender of HBV carriers		
Male	24	61.5
Female	15	38.5
Age group		
<= 40 years	19	48.7
>= 40 years	20	51.3
Health institutions of HBV carriers		
Government restructured hospital	12	30.8
Restructured polyclinics	27	69.2

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