

A qualitative study of health-seeking behavior of Hepatitis B carriers

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ABSTRACT

Introduction: Asymptomatic Hepatitis virus (HBV) carriers are often followed up at primary and secondary care centers in Singapore. Compliance to disease monitoring is perceived to be a barrier in their management. The study used qualitative methods to determine the health-seeking behavior of HBV carriers. Understanding such behavior will enable the attending physicians to optimise their care and promote regular disease surveillance.

Methods: Data were collected from 39 HBV carriers from primary and secondary healthcare centres, with different demographic profiles in eight respective focus group discussions (FGD). A nurse conducted the FGDs using a semi-structured guideline. The qualitative data were analysed using standard content analysis technique.

Results: There was evidence of doctor hopping among the HBV carriers in seeking the follow-up of their disease. Cost of review and investigations and preference for specialists' care appeared to be determinants of the sites of disease monitoring. Compliance to follow-up seemed to be sub-optimal, arising from apathy, denial, perceived inconvenience and cost of review. A significant proportion of the carriers had tried alternate therapy, took liver supplements but most found them to be ineffective. Most carriers had adopted healthier lifestyle after their diagnosis with regular exercise, smoking cessation and alcohol abstinence.

Conclusion: Many HBV carriers' inadequate understanding of the disease resulted in indifferent or inappropriate health-seeking behavior towards their disease management. There is room for health education for these carriers to enhance their awareness of the disease and improve compliance to disease monitoring.

Keywords: chronic Hepatitis B infection, focus group discussion, disease monitoring, health education, health-seeking behavior

INTRODUCTION

Chronic hepatitis B virus (HBV) infection is endemic in Singapore, and affects 4%⁽¹⁾ of the local multi-racial population who are carriers of the virus. They are at higher risk of developing liver cirrhosis and hepatocarcinoma⁽²⁾. Reports show that early detection of these complications may improve prognosis in mortality and morbidity^(3,4) but this can be achieved through regular disease surveillance and to ensure that hepatotoxic substances do not further compromise the liver. However, compliance to disease monitoring is an issue in the management of HBV carriers in primary care. This is compounded by the patients' health-seeking behavior and the use of traditional medication in the Asian context. This qualitative study aimed to explore the Hepatitis B carriers' health-seeking behavior in relationship to their chronic infection. This will allow medical professionals to provide patient-centered health education and to seek ways to modify their behavior towards optimal self-management of their disease.

METHODS

The authors used qualitative research methods⁽⁵⁾ to explore the HBV carriers' understanding of their chronic disease through focus group discussion (FGD)⁽⁶⁾. 39 HBV carriers, who had been managed by government-aided polyclinics and by the hepatitis clinic in a district hospital, were recruited. Those who had or were currently receiving anti-viral therapy in the previous six months were excluded. A variety sample was constructed to include adult HBV carriers above 21 years of age, both genders, all the three main races in Singapore, and sites of follow-up in both the primary and secondary care settings in order to capture a wide spectrum of views.

The HBV carriers were approached by the investigators and research nurse during their consultation at the polyclinics or hospital and were informed of the next scheduled FGD. Follow-up calls were made to the potential participants to confirm their participation about three days prior to the FGD. The 2nd author (SLC) facilitated the FGD, based on

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a semi-structured discussion guideline to ensure uninhibited discussions. The guideline explored HBV carriers' awareness, reaction and experience of their chronic infection. The questions covered in this paper focused on their health-seeking behavior, which included their views on consultation with their doctors, disease monitoring, use of alternative or traditional therapy, and other health-seeking behavior.

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 audiotaped with participants' permission, and each session lasted about 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 transport allowance for travelling to the FGD sites.

The study was terminated with saturation of ideas after eight FGDs. The tape-recorded interviews were transcribed in its entirety into text files. The transcripts were read and checked independently by the investigators to ensure consistency. The qualitative data were analysed using standard content analysis technique. All transcripts were read several times and simultaneously coded to explore potential conceptual and content related themes. The data was coded using a qualitative data analysis software NUD*IST Version 6.0TM⁽⁷⁾ and grouped into broad themes determined by the authors. The quotes included in the results were typical views expressed in each FGD to exemplify emergent themes.

RESULTS

The participants comprised of 39 HBV carriers and their profiles are described in Table I. The majority were males, Chinese, with ages ranging from 22 to 75 years. The mean age was 44.0 years (SD 12.4 years). They were diagnosed to be HBV carriers for a period ranging from one to 23 years. The authors organised the themes derived from the FGDs into doctor consultation, disease surveillance and use of alternative or traditional therapy (Table II).

All the participants were followed-up at least for a period of time in either primary care or hospital specialist clinic, or even both settings due to the local fees-for-service healthcare system. Their doctors were their main source of medical information. Some participants had switched their follow-ups with different doctors in both private and restructured

Table I. Demographical background and practice 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		
<or = 40 years	19	48.7
>40 years	20	51.3
Health institution of HBV carriers		
Government restructured hospital	12	30.8
Restructured polyclinic	27	69.2

Table II. Themes regarding the health-seeking behavior of HBV carriers.

Topic	Themes derived from the FGD
Doctor consultation	<p>Follow-up at either primary or secondary healthcare centres or both</p> <p>Tendency to doctor hop</p> <p>Preference for specialist's review due to perceived expertise and confidence</p> <p>Cost of consult and investigations and satisfaction with care appeared to be other determinants of follow up sites</p>
Disease surveillance	<p>Variable compliance to disease monitoring due to inadequate understanding of the rationale and frequency of follow-up</p> <p>HBV carriers with family history of HBV-related liver complications seemed to be more compliant</p> <p>Appointment and recall system served as useful reminders</p> <p>Denial, long waiting time, perceived inconvenience, cost of investigations and absence of symptoms were barriers to disease monitoring</p>
Alternative and traditional therapy	<p>Common practice to use alternative or traditional medicine to "detoxify the liver" or to "boost body's immunity" to HBV</p> <p>Use of liver supplements such as vitamins was prevalent</p> <p>Most carriers discontinued alternative or traditional medications after period of time after discovery that such therapy was not effective.</p>
Lifestyle changes	<p>Most carriers claimed to adopt healthier lifestyle activities upon advice by the doctors such as alcohol abstinence and smoking cessation.</p> <p>Some carriers claimed to be easily fatigued and excused themselves from sporting activities</p> <p>A minority continued their usual alcohol or smoking habits despite awareness of potential hepatotoxicity.</p>

health institutions of both primary and secondary care settings.

A small group of participants indicated their preference to be followed-up by the specialists in the hospital. They perceived that specialists would be more knowledgeable in the management of their condition.

"In the polyclinics, most of the doctors are GPs. They may know about the liver but they might not know in thorough details, which is why I prefer a specialist. These doctors are doing their research on liver." FGD 3

However, cost was regarded in all FGDs as a key factor which determined the sites of follow-up. Other factors included satisfaction with the care of their respective physician, accessibility of facilities such as waiting time prior to the consultation, and cost of investigations at the individual medical centres.

"Specialists want to send you for more tests, like the DNA test; it can end up quite costly. That's the difference." FGD 4

The frequency and regularity of follow-up in the disease monitoring varied between participants in all FGDs. A small proportion of them appeared to be compliant with their medical review especially those from the hospital. The hospital doctor's emphasis on the need for regular monitoring seemed to be the prime motivating factor although most had variable level of understanding of the frequency and need of follow-ups. Those who had family history of HBV-related complications and those with abnormality in their investigations were strong motivating factors.

"I follow up every six months without fail. I make an effort." FGD 7

Another factor was the hospital's appointment system and sending reminder by letter and even short message system (SMS) through mobile phone. Participants from the polyclinics did not have a structured reminder system and were informally reminded of their follow-up with a priori provision of the laboratory form for blood investigations for the next review.

"If the doctor gives you an appointment date, you definitely have to be there." FGD 8

The majority of the participants were ambivalent in their decision to comply with the follow-up. They were keen to know if their livers were functioning normally despite the infection and at the same time, hesitant and reluctant to attend the review for fear of detection of any abnormality from the blood and imaging investigations. Other deterrents included the long waiting time prior to the consult, perceived inconvenience, and costs of investigations and perception of well-being from previous series of

normal investigation results. No participant indicated fear of venepuncture or needle phobia.

"Very troublesome getting yourself poked every six months, then go for this ultrasound. People like me, I speak for myself, hate to go to hospital. Going there is not a good thing, try to get away from it." FGD 8

A minority of HBV carriers was not receptive to disease surveillance. This could stem from their perception that there was absence of symptoms and definitive treatment for the chronic infection and that the disease was "inactive", and thus disease monitoring would be futile. Some also viewed other activities of daily living such as work were more pertinent to their needs, thus assumed higher priority and took precedence to disease monitoring.

"I knew it (HBV) in the 80s, I checked up for three years; I didn't bother anymore. My liver is quite dormant, they are sleeping quietly so I don't want to bother (laugh)". FGD 6

Denial of the chronic infection was prevalent in several FGDs. The participants chose to avoid finding out their liver status and thus defaulted on their follow-up.

"Some people refuse to go for the result because they find it stressful. I was one of them." FGD 5

The use of alternative therapy and health supplements appeared to be common practice amongst the participants although a proportion of them denied taking any of these. Most of those who took herbs and traditional medications, often through the recommendation of relatives and friends, discontinued after variable period as they discovered that they were ineffective in eradicating the HBV. Books on herbs were another source of information.

"A friend introduced Lingzhi (type of fungus) to me. Cost a few hundred dollars. I tried it but no effect at all." FGD 1

Those who continued alternative therapy perceived that the alternative medicine "detoxify the liver" or enabled the liver to effectively purge the body of toxins. The herbs or traditional Chinese medication mentioned in various FGDs included 'Meticil', "Jetapar", "Man tian xin", "Pian zhi wan" and Lingzhi". Several of the participants grew the herbs such as "Man Tian Xin" themselves or bought them from the market or Chinese medicinal halls.

For the few who were on regular health supplements such as multi-vitamins and liver tonic such as Essentiale® and Liverite®, the aim was to "strengthen the liver" and to boost their immunity system.

"I took a lot of liver supplements to boost up my immunity." FGD 3

One participant claimed to have regularly embarked on a specific "liver detoxification" programme, comprising of a regime of olive oil, lemon juice, zenthel (an anti-helminthic drug) and Epsom salt over a period of several days. Another participant reported the use of dried toad ("Lai ha ma") skin to wrap around the waist to "remove the poison" from the liver.

Most of the participants had adopted healthier lifestyle upon diagnosis of their carrier status and largely attributed this to doctors' advice. This included moderation or abstinence of alcohol and smoking cessation to avoid further liver damage, and embarking on a regular exercise programme to promote health. One participant changed his eating habit to include raw food in his diet frequently. However, the attempt to adopt healthier lifestyle was not universal. A few participants claimed to feel more tired after they were diagnosed with chronic HBV infection, leading to reduction of exercise instead. A minority of them continued smoking and usual alcohol intake, despite their awareness of the potential risk of hepatotoxicity.

DISCUSSION

There was widespread perception of ineffective treatment for chronic HBV infection. Rather than merely monitoring their disease, it would be natural for the HBV carriers to seek various modalities of therapy to treat their condition. Likewise, for those with faith in western medicine, the HBV carriers would at least consult various doctors in an attempt to find a solution to their problem. This could result in unnecessary and repetitive investigations, wastage of health resources, increased anxiety, discontinuity and dissatisfaction of care.

The use of traditional medication, partly attributed to the perceived lack of effective "Western therapy", has its potential risk of aggravating the liver condition and should be discouraged. Even the use of liver supplements, perhaps safe from the pharmacological perspective, promotes a false sense of security and has a negative impact on the compliance to disease monitoring. In contrast, the change of lifestyle towards healthier activities, such as exercise and proper diet, should be advocated to all HBV carriers. Smoking cessation and alcohol intake moderation should be reinforced in the follow up visits. However, the myth of liver detoxification in chronic HBV infection should be dispelled. The carriers should be discouraged from adopting extreme change in lifestyle and potentially risky liver detoxification practices, which were of unproven benefits.

It is vital for medical professionals to understand such health-seeking behavior for this group of patients

and to act accordingly. Educating and ensuring that these carriers understand the natural history of the disease, the rationale for disease surveillance^(8,9) and the current pharmaceutical therapy⁽¹⁰⁾ for chronic HBV infection would be three key areas in the management of the disease in primary care. The authors believed these key messages would reduce the anxiety levels of these carriers, promote adherence to regular disease monitoring and trim wastage of health resources and individual health expenditure.

As in all areas of medicine, primary healthcare professionals should also keep up with the advancement of science and medicine, including anti-viral therapy against HBV. Sharing the latest updates with their patients would enhance the latter's confidence in the doctors' management of their condition. This is most pertinent as another report by the same authors showed that advice by doctors constituted the main source of information for the patients.

Understanding the health-seeking behavior of the HBV carriers would provide an invaluable insight into their self-management of their chronic disease. Rectifying such behavior could promote disease monitoring of asymptomatic HBV carriers in primary care. This would reduce the burden of the hepatologists in tertiary institutions, who could devote their energy and resources to carriers with established liver complications.

In conclusion, HBV carriers seek consultation in both primary and secondary healthcare centres for their chronic disease. Compliance to disease monitoring was generally sub-optimal due to the widespread perception of ineffective treatment of the disease. It also led to use of alternative therapy and lifestyle changes. Most HBV carriers were more conscious of adopting activities to promote their health through exercises, smoking cessation and moderation of alcohol intake.

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