Qualitative Interviews on The Diagnosis Process of Hepatitis B Among 50 Patients in Chongqing, China

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Qualitative interviews on the diagnosis process of hepatitis B among 50 patients in Chongqing, China

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Abstract

Objective: To identify the obstacles preventing and controlling hepatitis B and put forward suggestions for its prevention and treatment by describing the discovery process of hepatitis B patients.

Methods: We conducted face-to-face interviews with 50 hepatitis B patients in Chongqing, China from July to August 2019 by constructing a thematic analysis framework, which included interviewees' social demographic characteristics, diagnosis approach, signs and symptoms at the time of discovery, feelings after diagnosis, and doctor's instructions. **Results:** Most of the patients were firstly found hepatitis B via physical examination when patients were asymptomatic or had no obvious symptoms.

The majority of them were shocked, frightened, and at a loss when they were diagnosed. The patients could remember doctor's instructions on keeping healthy lifestyle, but they had very little impression about doctors' reminding about regular liver function test. Failure of regular follow-up to liver function test brought irreversible loss for certain patients. **Conclusions:** Most of the patients were found hepatitis B passively. The patients need professional mental help after the diagnosis to overcome the negative emotion. The doctors' instruction should emphasize more on the importance of regular follow-up to liver function test besides health lifestyle.

Key words: Hepatitis B ;discovery process ;qualitative research

Background

Hepatitis B infection is becoming a global public health problem, which leads to a large disease burden. Chronic hepatitis B has a long course, many complications, and easy recurrence and may even lead to cirrhosis and liver cancer[1]. In fact, chronic hepatitis B and C infections are thought to be responsible for about two thirds of all cases of liver cancer globally. At the same time, early detection, diagnosis, and treatment are of great significance for reducing the incidence of liver cancer and improving its cure rate[2].

China has a large number of hepatitis B cases. Thus, the widespread epidemic of hepatitis B has brought a heavy economic burden on patients, families, and society and has affected social development. Hepatitis B is one of the outstanding public health problems in China at present[3]. In 2016, the WHO proposed to eliminate hepatitis B, and China is also a major contributor to the global goal of eliminating hepatitis B in 2030[4-6]. Recent studies have shown that the incidence of hepatitis B has greatly decreased[7,8], but approximately 120 million people in China remain as hepatitis B virus (HBV) carriers[9]. Moreover, Chongqing Municipality has 3,000,000 urban residents with a high prevalence of hepatitis B (707.97/100,000)[10,11]when compared with other countries such as Europe, Singapore, and Japan[12-14]. As a large country affected by hepatitis B, China will make great contribution to the goal of eliminating hepatitis B worldwide in 2030[15]. However, the prevalence of hepatitis B in China is high, and the treatment and diagnosis rates are low[16,17]. A study has shown that hepatitis B is found to be insidious[18]. Therefore, occult hepatitis B is easily overlooked. In order to achieve the goal of eliminating hepatitis B by 2030, We should make some suggestions and take measures to improve the diagnosis and treatment rates and reduce the prevalence rate.

HBV is transmitted through mother-to-child, blood (including minor wounds to skin and mucous membranes), and sexual contact[19]. A patient can be diagnosed with hepatitis B according to epidemiological information such as blood transfusion, contact history of hepatitis B infection, and family members with HBV infection and pathogenic examinations including the five tests of hepatitis B and ultrasonic diagnosis. Understanding the diagnosis process of hepatitis B is necessary and important for controlling this important public health problem.

Analyzing and summarizing the ways of disease discovery and the problems existing in the treatment process are important to determine the early characteristics and help us better formulate targeted countermeasures. In this article, we report the findings of a qualitative study that examined hepatitis B patients' pathogenesis, symptoms, test results, and doctors' orders in a hospital in Chongqing, China. This study to some extent makes up for the gap in the way hepatitis B is detected; emphasizes the importance of raising public awareness and achieving early detection, diagnosis, and treatment; and provides evidence for targeted strengthening of preventive measures.

Materials and methods

Study design

Chongqing is located in Western China, and many researchers have investigated the prevalence of hepatitis B in this region. Some studies have described a downward trend in the prevalence of hepatitis B among young people and an upward trend in the elderly[20-22]. Through literature searches in China and abroad, previous studies on hepatitis B have not described the discovery process to prevent it. An in-depth qualitative investigation was conducted in Chongqing Municipality from July 2019 to August 2019. Hepatitis B patients who were seen for follow-up visits were recruited from hospitals.

Data collection

A total of 50 participants were included through convenience sampling. All the interviews were conducted face-to-face by three interviewers (one acted as the main interviewer, and others took detailed notes) from July 2019 to August 2019. The interviewing group listed the outline of the problem in advance. The research investigated six aspects including social demographic information, way of discovery, test results, signs and symptoms at the time, feelings at diagnosis, and doctor's orders. Social demographic information includes gender, age, education, occupation, marital status, residence, and whether there are any carriers in the family. The interviewees' questions and answers were recorded by using qualitative research group interviews, and the recordings were analyzed afterward. Before each interview, participants were informed about the purpose of the study, their right to withdrawal at any time, and the possible risks and benefits of study involvement. Each interview lasted about 60 min. To ensure that patients' personal privacy is confidential, their names are erased.

The semi-structured interview was conducted according to the guidelines and regulations of the ethics committee of Chongqing Medical University, which focused on but were not limited to the following qualitative interview questions:

1. What are your medical treatment process and experience of hepatitis B?
2. What is your cognition of hepatitis B and your daily life?
3. What is the attitude of your family members toward your illness, diagnosis, and treatment?
4. How does hepatitis B affect your life, work, and social relations?
5. What are your current concerns about hepatitis B? What do you expect from future treatments?

Data analysis

Qualitative research was used to determine the significance of data. The transcripts were reviewed

repeatedly by two researchers, and after discussion by the research team, a thematic framework was established. Then, other researchers analyzed the data. All the recorded interviews, discussions, and recordings were first transcribed from verbatim into Mandarin Chinese by one researcher. Another researcher was responsible for checking the accuracy of transcription through notes. In addition, the researcher analyzed the data and used the topic analysis method to analyze the detailed interview/discussion notes line by line.

Results

Interviewee social demographic information (Table 1)

A total of 50 hepatitis B patients were collected and included in this study. Social demographic information among patients registered in the projects is shown in Table 1. The age of interviewees is mainly 30–39 years old, and the proportion of patients under 19 and over 60 years old is very small. The ratio of male-to-female respondents was 3:2. The education background of interviewees is mainly in junior high school, senior high school, and undergraduate course, of which junior high school education accounts for 24% at most. The major occupations are workers, the number of which is 12. Most of the patients live in Chongqing, and approximately half of the respondents have carriers in their homes.

Table 1. Interviewee Social demographic Information

Demographics	N(%)
Age (years)	
≤19	1(2)
20-29	8(16)
30-39	15(30)

	40-49	11(22)
	50-59	12(24)
	≥60	1(2)
	No record	2(4)
Gender		
	Male	30(60)
	Female	20(40)
Education		
	primary school	2(4)
	junior high school	12(24)
	High school	8(16)
	Undergraduate	9(18)
	master's degree	4(8)
	no record	15(30)
Occupation		
	barber	1(2)
	driver	1(2)
	company representative	2(4)
	Officer	4(8)
	self-employed laborer	5(10)
	worker	12(24)
	Salesman	3(6)
	Farmer	4(8)
	Civil servant	4(8)
	Student	2(4)
	Teacher	3(6)
	Enterprise personnel	3(6)

	retiree	2(4)
	No job	2(4)
	Cleaner	1(2)
	No record	1(2)
Location		
	Chongqing	35(70)
	Sichuan	5(10)
	Guizhou	2(4)
	Hunan	4(8)
	Other places	1(2)
	No record	3
Does the family have a carrier		
	Yes	26(52)
	No	21(24)
	No record	3(6)

Discovery path of hepatitis B

As shown in Table 2, patients can use six categories to discover hepatitis B. Approximately half of the patients' hepatitis B status was detected by physical examination, followed by family/doctor's influence. Patients who discovered their hepatitis B status through blood donations and application for health certificates were the lowest. The detailed physical examination methods are also divided into six categories. The number of patients who discovered their hepatitis B status through college entrance examinations and routine physical examination of enterprises is five each.

Table 2. Categories used by patients to discover their hepatitis B status

	N
Discovery path of hepatitis B	

Physical examination	22
Family/doctor's influence	8
Influence of friends and neighbors	7
Examination after mild disease symptoms	6
Other disease examinations	5
Blood donation/application for health certificate	2
Specific classification of physical examination	
Health examination	4
Antenatal examination	4
College entrance examination	5
Employment examination	2
School routine physical examination	2
Routine physical examination of enterprises	5

Specific medical examination classification

(1) Physical examination: Of the 50 patients included, 22 patients were found to have been diagnosed with hepatitis B during various medical examinations. Five patients were detected in college entrance examination/routine physical examination of enterprises. Two patients were detected in employment examination and school routine physical examination (see Quotes 1–4 in Table 3).

(2) Family/doctor's influence: Eight patients went to the hospital to test themselves after their family members were sick or went to test for hepatitis B on the advice of a doctor. Eventually, they found out that they had hepatitis B. Among them, three were detected under the influence of a doctor. The remaining five were identified after family's influence (see Quotes 5–6 in Table 3).

(3) Influence of friends and neighbors: Seven of the interviewees went to the hospital to test for hepatitis B after they discovered that their neighbors/friends had hepatitis B and finally confirmed that they also had hepatitis B (see Quote 7 in Table 3).

(4) Examination after mild disease symptoms: Six patients were diagnosed with the disease after showing mild symptoms, including fatigue, nausea, vomiting, and weakness. At the same time, the main manifestations of hepatitis B in the early stage were fatigue, nausea, and abdominal distension (see Quotes 8–9 in Table 3).

(5) Other disease examination: A small number of patients were diagnosed with hepatitis B while they

were examined for other diseases. One patient said: “the disease was first found during a blood test in a hospital because of a cold, and was eventually diagnosed in 2017 when he was examined for a cerebral hemorrhage” (see Quote 10 in Table 3).

(6) Blood donation/application for health certificate: Only patients found out that they had hepatitis B as they donated blood or applied for health certificate. They all described that they did not know when they had hepatitis B (see Quote 11 in Table 3).

Patient's signs and symptoms before diagnosis

Through interviewing, many patients had no obvious symptoms related to hepatitis B before diagnosis. One patient said, “At that time, the body did not have any discomfort, so I didn’t feel much.” The early symptoms of patients mainly include nausea, decreased sleep quality, fatigue, and indigestion (see Quotes 12–13 in Table 3). Before diagnosis, patients were asymptomatic or had no obvious symptoms, which were similar to the symptoms of other diseases, so they were easy to be ignored. Many years later, the failure of regular follow-up of liver function examination has brought irreversible loss to some patients

Feeling of the patient at the time of diagnosis

When they were diagnosed with hepatitis B, most people were shocked, scared and at a loss. Among the interviewees, 10 patients explicitly mentioned how they felt at the time of diagnosis. Six of them had no obvious symptoms, and four had an obvious sentiment of fear, stress, and nervousness. In the early stage of hepatitis B, the patients had no obvious symptoms, and their lives were not affected. Thus, many patients did not have obvious feelings at the time of diagnosis; they thought that it does not matter and had a good mentality. One patient described, “At that time, when I didn’t know about the disease, I didn’t feel much about it, and the doctor said it was nothing serious” (see Quotes 14–15 in Table 3).

Patients feel fear and anxiety after learning that hepatitis B is currently incurable through the

Internet and other methods, so they become even more stressed. One patient said: “I was found to have cirrhosis at that time, so I was getting scared because it was close to liver cancer. After all, I was still young, and my child had just started working.”Some patients also feel uneasy and frightened because they are afraid that the disease will be transmitted to their families and inherited to their children. One patient said: “I was found to have cirrhosis at that time, so I was getting scared because it was close to liver cancer. After all, I was still young, and my child had just started working.” However, as time goes by, their fear, tension, and other negative emotions about hepatitis B will decrease (see Quotes 16–17 in Table 3).

Doctor’s advice to the patient

Patients can remember the doctor's instructions on maintaining a healthy lifestyle, but they have little impression of doctors reminding them to have regular liver function tests. Almost all of the patients mentioned that their doctor gave advice on life and diet rather than taking medicine and regular follow up visit. One interviewee said, “we should ensure a regular life, pay attention to rest, and do not engage in excessive physical activities in life.”The dietary suggestions include less oil and salt intake and avoiding eating cold, hard, or fried food and drinking alcohol. Early asymptomatic patients should be re-examined regularly. If their condition are not serious, no medication is needed. Patients are suggested to take their medicine regularly and undergo regular physical examination to prevent the disease from further developing into liver cancer. When patients had advanced liver cirrhosis and liver cancer, doctors suggest improving the patient’s symptoms and prolonging the survival time. During our interview, some patients said that their doctors did not mention these suggestions(see Quotes 18–21 in Table 3).

Table 3. Related quotes in the results section

Key Points	Quotes
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discovery process	Detected by physical examination	<p>Quote 1:</p> <p>“I was infected with hepatitis B during the college entrance examination.” (YA 09,34 years old, female patient) “It was detected during prenatal examination.”(YA 27,57 years old, female patient)</p> <p><i>Quote 2:</i></p> <p>“It was discovered in the physical examination in 1994 or 1993. It has been found for more than twenty years. There are no symptoms and no care about it.”(YA 20,48 years old, female patient)</p> <p><i>Quote 3:</i></p> <p>“while I went to work in Guangzhou, it was normal. Since last year, transaminase was found to be elevated in the physical examination.”(YA 11,53 years old, female patient)</p> <p><i>Quote 4:</i></p> <p>“Because of the need for a health certificate two years ago, I had abnormal liver function after a blood test, and was diagnosed at the First Affiliated Hospital of Chongqing Medical University. "(YA 38,30 years old, male patient)</p>
	Find out after family / doctor's influence	<p>Quote 5:</p> <p>“After graduating from high school, due to my father got sick, I went to check and found out that it was hepatitis B.”(YA 35,46 years old, male patient)</p> <p>Quote 6:</p> <p>“At that time, my mother got hepatitis B, and the doctor suggested that I also check it out. At the time of high school, the doctor did not recommend medication. "(YA 16,29 years old, male patient)</p>
	the influence of friends and neighbors	<p>Quote 7:</p> <p>”In 2009, I went to the county hospital for physical examination.because many people in the village had this disease at that time, and many people died of liver cancer, so I wanted to go for physical</p>

examination and found that I was sick.”(YA 03,40 years old, male patient)

Examination
after mild
disease
symptoms

Quote 8:

“In 2004,I felt uncomfortable,and the main manifestation is soft feet . I went to the hospital to check out and was told my liver function was abnormal.

”(YA 32,male patient)

Quote 9:

“I have symptoms and feel uncomfortable. I thought there was some stomach problems. I was diagnosed with hepatitis B. ”(YA 41,55 years old, female patient)

Found out
during other
disease
examination

Quote 10:

“In 2017, it was detected because of a brain stasis, but it was not detected at first. Later, it was detected by a blood test in a county hospital because of a cold. ” (YA 08,51 years old, male patient)

Blood
donation/Apply
for health
certificate

Quote 11:

“while donating blood on the local village street, take a small amount of blood for examination. then because the blood test fails, I was told that I had hepatitis B.”(YA 01,42 years old, female patient)

Patient's
symptoms and
signs

Quote 12:

“At that time, the body did not have any discomfort, so I didn't feel much.Later, it was found hepatitis B .”(YA 01,42 years old, female patient)

Quote 13:

“I had a bad stomach and not a good night's sleep two years ago. At that time, I didn't go to check due to I lived in a rural area and I didn't pay too much attention to these diseases and relaxed my vigilance.It feels like it doesn't matter to my body, it just feels that my digestion is not good and my stomach is swollen.”(YA 08,51 years old, male

patient)

The feeling of
the patient

Quote 14:

“At that time, when I didn't know about the disease, I didn't feel much about it, and the doctor said it was nothing serious.”(YA 01,42 years old, female patient)

Quote 15:

“At that time, I didn't know what hepatitis B was, I thought it was a minor disease, and I didn't have that consciousness for many years.”(YA 41,55 years old, female patient) “No feeling, is because I do not feel any physical discomfort, so I do not pay attention.”(YA 11,53 years old, female patient)

Quote 16:

“I was found to have cirrhosis at that time, so I was getting scared because it was close to liver cancer. After all, I was still young, and the child had just started working. But now I'm very cheerful, and I'd like to talk about this with others.”(YA 09,44 years old, female patient)

Quote 17:

“At that time, I was really depressed while I was found to have hepatitis B, because a search on the Internet found that hepatitis B could not be cured, which scared me a lot. It was really a bit scary.”(YA 36,50 years old, male patient)

The doctor's
impressive
advice

Quote 18:

“The doctor said to have a reexamination every six months.”(YA 42,50 years old, male patient)

Quote 19:

“At that time, the doctor told me that I was the carrier of hepatitis B virus. It didn't matter much. I didn't need to pay much attention. After starting the treatment, the doctor ordered that I should pay attention to my diet while I go back. Do not eat

cold, hard foods, oily things, or things that are bad for my liver.”YA 01,(42 years old, female patient)

Quote 20:

“After finding out the virus, I didn't pay attention to the diet as usual. I never paid attention to it. The doctor said that more attention should be paid to rest. Don't drink, don't stay up late, sleep well. I'm used to living in the countryside.”(YA 11,53 years old, female patient)

Quote 21:

“The doctor suggested that we should go home to rest and not go to work. In our daily life, we should not eat stimulating food, cold food, hard food or fat food.”(YA 39,54 years old, male patient)

Discussions

This study showed that huge barriers exist in the prevention of hepatitis B in the southwest of China. First, physical examination is the main method to discover hepatitis B. However, few people take the initiative to check themselves, and the vast majority go to physical examination because of the demand of enrollment and employment. Second, although most patients have carriers in their homes, very few people check for hepatitis B under the influence of their families. In addition, the doctor's advice to patients mainly focused on diet and lifestyle, and the patients were not satisfied with the follow-up and review.

Our research revealed that very few people took the initiative to conduct health examinations. Nearly half of the interviewees found out that they had hepatitis B through physical examinations, but physical examinations were carried out due to the needs of school enrollment, employment, and birth examinations. In 2010, relevant national departments explicitly cancelled the “hepatitis B five” inspection in entrance and employment medical examinations, and individuals with HBV should not be

prohibited from admission and employment. This policy means that hepatitis B will not be checked in the five-indicator test in general examinations. Therefore, unless the patient's liver function is damaged, hepatitis B will not be detected, and to a certain extent, the carrier cannot be detected early. We recommend that residents should pay attention to detecting abnormal liver function, and medical workers should advise patients to seek medical treatment and treatment. At the same time, health education should be provided to residents, and residents should be encouraged to take the initiative to check the two and a half pairs, instead of detecting hepatitis B when abnormal liver function is found. The purpose is to allow patients to discover the abnormal state of their body as soon as possible, which further emphasizes efforts to prevent hepatitis B with early detection, diagnosis, and treatment.

Our findings indicated that more than half of hepatitis B patients have carriers in their families. Some studies have shown that hepatitis B has obvious family inheritance[23,24], and family members and hospitals have a certain positive role in recommending hepatitis B screening[25,26]. Thus, we recommend family-based diagnosis and treatment and mobilization of special populations to achieve the goal of early detection, diagnosis, and treatment. Studies have shown that individuals' understanding[27,28] and awareness of hepatitis B are still low[29,30]. The patients themselves do not pay enough attention to hepatitis B[31]. The current main measures are increasing investment in public health and advocating extensive inspections of residents to increase the detection rate of hepatitis B in order to achieve the goal of early detection, diagnosis, and treatment[32]. The difference between our study and other studies is that we are mainly concerned with patients with hepatitis B and their families. When one person discovers hepatitis B, we mobilize families for examination and advocate standard follow-up treatment. Because the mutual supervision of members of the extended family is conducive to adherence to follow-up and standardized treatment, it is conducive to better management of the

disease, achieve the goal of eliminating hepatitis B by 2030 proposed by the WHO in 2016[33], and reduce hepatitis B mortality as soon as possible.

Our study found that patients' recommendations on regular review and follow-up are not clear, which is an important issue in the prevention and treatment of hepatitis B. The most influential recommendations for patients are lifestyle and diet. Other studies have found that most patients in China find themselves in the middle and late stages of the disease when they are suffering from hepatitis B[34] and have symptoms such as nausea and fatigue[35]. Influenced by the environment and other factors[36], they are likely to develop into liver cancer and reduce their quality of life[37]. Therefore, we recommend that doctors be trained to emphasize that patients should pay attention to their own condition and pay attention to follow-up and review. The public health department conducts health education and propaganda to the public and encourages the public to undergo the five-indicator test for hepatitis B in the hospital.

Our research has several limitations that must be acknowledged. First, due to limited time, manpower, and financial resources, the survey scale is relatively small. Second, the participants are all patients from hospitals. Therefore, the conclusions drawn may not be generalized to other parts of China, but they can provide some opinions and suggestions for the prevention of hepatitis B.

Conclusion

Our findings suggest that a considerable gap exists between the early detection and timely treatment of hepatitis B and the current discovery process of hepatitis B patients. A large number of problems and obstacles include not actively performing physical examinations and home carriers failing to actively prevent and treat the disease, and patient's inadequate influence on follow-up and

review limits the prevention and control of hepatitis B. Therefore, interventions on improving the testing rates of the five-indicator test are needed. Moreover, the family-based diagnosis model should be focused, and attention should be paid to their condition as early as possible to control further development. Our findings also suggest that the training of medical workers should emphasize on the importance of regular review and follow-up of hepatitis B and providing health education to the public.

Declarations

Ethics approval and consent to participate.

Sample collection was approved by the Ethics Committee of Chongqing Medical University and informed consent was obtained from each involved individual.

Consent for publication

Not applicable since no individual data was included in the manuscript.

Availability of data and materials

Authors are not able to share their raw data since participants disclosed very sensitive information. Participants were told that the transcripts will be read by Interviewers only, and this prompted their trust. However, authors are willing to share codes generated from the data on request.

Competing interests

None.

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Authors' contributions

All authors contributed equally to the study and all authors have read and approved the manuscript.

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Data availability statements

All data generated or analysed during this study are included in this published article

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