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## Meanings and Experiences of a Case of Chronic Hepatitis B Virus Patient: A Qualitative Study Exploring the Marco-Perspective of People Living in Ho Chi Minh City, Vietnam



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### ABSTRACT

The study aims to explore the situation of a Hepatitis B carrier's meanings, lived experiences in relation to the chronic infection, meaning (significant) of Hepatitis B virus, experiences of Hepatitis B infection and coping strategies. This study used depth interviews with qualitative research methods to explore chronic HBV patient's understanding of the disease. The participant can absorb medical knowledge about Hepatitis B including causality, prognosis, prevention and rehabilitation through media, books, and so on. In this study, the participant, for religious support, she visited Buddies temples every week with the purpose of praying. The study found that the participant with CHB had a poor understanding of their infection, and had reservations about the capacity of health professionals to cure her of CHB. Medical professionals should raise patients' awareness of the disease through appropriate and specific health education.

## INTRODUCTION

Hepatitis B virus (HBV) infection can cause a potentially life-threatening viral hepatitis and lead to chronic HBV (CHB) infection which is defined as the hepatitis B surface antigen (HBsAg) seropositive for at least 6 months. Although there are advanced strategies for preventing and treating CHB, the disease has become one of the major health concerns in the world due to its high prevalence and fatal complications particularly cirrhosis, liver failure, and hepatocellular carcinoma (HCC) (1-3). Additionally, there are about 350 million people with CHB and approximately three quarters of those reside in the Asia-Pacific area where a majority of the populations has low to intermediate gross national income per capita (2-4). Among those, Vietnam, a developing country, has been considered as a high-endemic country with the substantial burden of CHB and HCC. This is compounded of the patients' meanings, experiences, and the use of traditional medication in Vietnam. The aim of this study is to explore the situation of Hepatitis B carrier' meanings, lived experiences in connection with the chronic infection, meaning (significant) of Hepatitis B virus, experiences of Hepatitis B infection and coping strategies that the patient develop to survive or live with CHB.

## MATERIALS AND METHODS

The methodology of this study is to use in-depth interviews with qualitative research methods. Interviews had been carried out with one participant in Southern of Vietnam who are the author's relative.

Firstly, the researchers approached the CHB carrier and asked for her permission to conduct this study. The researchers described the aims of this research and inform her what steps will be done. Secondly, the researchers conducted all interviews for how the patient were diagnosed and explored her awareness, reaction and perspective on the effects of having Hepatitis B on her life. Therefore the interviews happened naturally and she felt comfortable to talk about their own experiences. The researchers had used in-depth interviews four times a week for three weeks via telephone. As a result, the researchers explored her experiences, and other clear information such as her life, her situation, and so on. With the purpose of deep and comprehensive health seeking behaviors, all interviews were conducted in Vietnamese language and for about 45-60 minutes per time. These interviews were recorded via mobile phone and transcribed into text files. The

CHB patient was encouraged to speak freely and describe their experiences of being a CHB carrier. The results of this study were recorded after analyzing the qualitative data.

The questions in form of loose-structured or opened and ended questions were developed to ask for two different kinds of information: meaning (significant) of Hepatitis B virus, and experiences of Hepatitis B infection. The questions (see *Appendix 1.*) were first written in English and then were translated into Vietnamese by the authors. Part I consists of five questions focusing on the meanings of HBV regarding the knowledge about Hepatitis B virus, the perception of a HBV carrier, the interpretation of blood tests, and illness complication. Part II concerns the lived experiences of those who are afflicted with HBV infection, including the feelings of being infected HBV, the involving effects on her daily lives, the coping strategies, prevention or limiting transmission, and adaption to the daily life.

## **RESULTS**

### **Socio-demographic background of the participant**

The participants a CHB patient and her profiles are described as follows: Mrs. N was female, 51 years old; she was diagnosed as a CHB carrier for about 20 years and was followed up by Medical University Center in Ho Chi Minh City about ten years ago. The participant lives in Sothern Province of Vietnam. She is a teacher in a junior school, and she has a family consisting of her husband, daughter, and son. Every week, she teaches about 15 hours. About twenty years ago when she knew that she got CHB at the age of 31, her financial condition was so poor because she had to earned money to nourish her children. She had worked a part-time job as a tailor for ten years.

### **Major themes**

Two major issues identified through the interviews and discussion by telephone, include the meaning (significant) of Hepatitis B virus and experiences of Hepatitis B infection.

## MEANING (SIGNIFICANT) OF HEPATITIS B VIRUS

Two decades ago, the participant was lack of knowledge, information and understanding of Hepatitis B virus and in terms of her real meanings, she expressed very vague ideas of Hepatitis B. She indicated that various virus types could lead to development of hepatitis, and she was confused between types and the mode of transmission. She told, “Many years ago, I had very vague ideas of hepatitis. I always mixed up hepatitis A, B, C, D and E with each other. It is said that clams and oysters could be one source of hepatitis”. In her point of view about “symbols” of HBV, she was not sure what did hepatitis B virus mean... she had seen her yellow skin, fatigue then she asked some friends because she believes that they have more knowledge. She got the answer that “... it means that yellow skin, yellow eyes or fatigue”. Several friends did not give her any information ... all they know was that it was hepatitis B; other her friends said that it was a cancer or something like this. At that time, she felt worried and stressful, she herself asked about how much time she will live, and how would she takes care children and her daily life in the future.

Her psychological phenomenon was shocking, being disappointed and falling down when her doctor prescribed the blood test. Many years after when finding extensive knowledge of Hepatitis B virus, she informed, “In Mekong River region, some channels have “Health Dialogue Program: From Doctors to Patients” with two times per month – they want to help citizens in this area can understand clearly about various diseases.”

In conclusion, we are normally conceptualized our illness in term of medical definition including obesity, stroke, hyperactivity, and so on. As we all know, people realized that they have same pattern. At first, the patients have no clear image, the more they met their doctors or medical professionals, the more they server, write, and collect information from medical journals and watch television.

### **The perception of Hepatitis B virus carrier**

In her perception, when she was firstly a carrier, her symptoms were not clear and blurred. She felt awkward, stressful such as blamed, labeled and stigmatized, awarded and anxious when she communicated with other people. Then, she got more knowledge from her doctor, friends, relatives, neighbors and media and told that “Hepatitis B carriers are a term used to describe

those who have HBsAg in their blood for more than 6 months. Most of them such as my friends and neighbors have no symptoms and are unaware of their status as a Hepatitis B carrier. Unfortunately, these otherwise healthy people (not HBV patients) can infect others without knowing it". When comparing the different phase of her life, it differs clearly from her thought and her knowledge is deeply through diversified ways. She herself knew that she was belonging the high-risk group to the spread of HBV.

### **Meanings and significance of the blood tests**

In the sense of the patient, only numbers of blood test indicators did not signify something important because we cannot interpret differentiate. After training and absorbing knowledge from doctors, nurses or pharmacists, these patients can interpret by themselves. The interviewer tells, "Previously, I usually visit my doctor every 3 months to check blood tests. After that, I often check liver functional indicators (AST, ALT, HBV-DNA or AFP) every 6 months". According the results of parameter in the blood test, if they are abnormal, patients can evaluate state of the liver as hepatitis-experts and physicians emphasized on the need for the frequency and regularity of follow-up in CHB.

### **Illness complication**

Firstly, the perception of participant about illness affects through feelings. Illness complication is showed not only through the relation between liver functions and damages but also the state of her liver function. Chronic hepatitis patients are at increasing risk of having serious liver diseases such as liver cirrhosis and liver cancer. Regarding HBV, the term "active virus" could be explained that it is easily passed from people to others. Thus, reducing the chances for this virus to spread is one of methods to prevent this disease. Once the virus is active, it is extremely fearful and can cause liver damages, complications and illness very easily.

### **Inform family members or close friends**

About twenty years ago, her feelings and emotions before and after her husband had known her disease were different. On the other hand, an important issue was identified through the fear of rejection or stigma at individual level and community level. She shared with researchers that "I didn't let my children know because they were only 5-years-old son and 8-years-old daughter ...

I didn't want them to ... go to school and tell anyone because kids are kids ...They cannot understand what was happening with their mother". She did not let her husband know for a long time...because she did not want to make their lives changed. After about five years when her husband knew her situation, he found the latest information about HBV and shared all with her. She became a very positive person and never let anything get her down.

## **EXPERIENCES OF HEPATITIS B INFECTION**

### **Feelings, emotions and interference of HBV patient with her daily life**

By far the most common cited cause of hepatitis B was food-related, linked to access, contamination or cultural practices. Deleterious food, raw and dirty food, lack of food and consuming non-indigenous food were all considered putative factors. In Vietnam, they are fearful...because if each person eats separately then there is less transmission.

### **Copings strategies**

A perception of HBV for people with CHB and health professionals were the key role in her believes. Besides, she gave more information about preventive measures to avoid spread of the disease, such as "...should avoid having sex with anyone (especially any sex without a condom) until they have been fully immunized and the immunization has worked (checked by a blood test)". In order to avoid the HBV transmission, we should not share any injecting equipment such as needles, syringes, razors, toothbrushes, and so on that may be contaminated with blood.

### **To seek alternative therapy**

The patient took herbs and traditional medications, often through the recommendation of her relatives and friends, and then discontinued taking them for some reasons, for instance the participant discovered that herbs or functional food (products from many pharmaceutical companies: BONAGIC<sup>®</sup>, MEGARIN<sup>®</sup>, HEP-FORTE<sup>®</sup>, etc...) were ineffective in eradicating the HBV... Books on herbs were another source of information. 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 patient chose foods that can be easily digested and do not put extra load on the liver like simple soups, chicken broths, or baked potato for CHB patients. It is important to maintain the patient's healthy body weight, prevent her from gaining or losing weight. She also kept some healthy snacks handy like hard-boiled eggs, fruits, nuts, carrot sticks, celery sticks or some instant breakfast mixes.

For religious support, she told that she did not have any religion. However, she went to Buddies temples every week with the purpose of praying for safe and sought for her family and praying for her disease. She hoped that her status, which means the HBV virus will be not active, will be always good.

### **Prevention or limiting transmission and adaptations to the daily life reality**

Not only the participant but also many people considered HBV infection similar to AIDS transmission. Many mention that it could be sexually transmitted and through contaminated toothbrushes, tattooing or shaver blades. However, the participant changed her opinion about this disease after getting more knowledge about Hepatitis B virus.

### **To control the infection by medications**

Similarly, for imaging investigations, the participant was told to aware of the need for both the blood and every 6 months and additional tests including alpha-fetoprotein, ultra-sonographic liver examination or rationale behind the frequency of the investigations.

## **DISCUSSION**

The study provides insight into the understandings and responses to CHB infection by an individual with CHB. Patients often found knowledge of HBV through specialists, doctors, books, journals, and the internet; however, they did not realize that Hepatitis B virus is huge roles in society nowadays. Now, patients can absorb adequate knowledge of HBV including causality, prognosis, prevention and rehabilitation.

In Asian countries including Vietnam, the whole family often eats together, they even stick their chopsticks or spoons right into the common dishes. This cultural practice was seen as the primary cause of the disease and the main mode of transmission. Although Vietnamese people

have gotten more knowledge about HBV transmission from media and newspapers but they still scare and keep off people related to HBV.

The use of alternative therapy and health supplements appeared to be a common practice. The use of traditional medication has its potential risk of aggravating the liver condition and should be discouraged. From the pharmacological perspective, using liver supplement products promotes a false sense of security and has a negative impact on the compliance with disease monitoring. Conversely, changes of lifestyle towards healthier activities, such as exercise, no drink and a healthy balanced diet should be advocated to all CHB carriers. The carriers should be discouraged from adopting extreme changes in lifestyle and potentially risky liver detoxification practices, which were of unproven benefits.

## CONCLUSION

In conclusion, the study was to provide qualitative information describing meanings and experiences of a chronic Hepatitis B virus patient in Southern Vietnam. This information included meaning (significant) of Hepatitis B virus and experiences of Hepatitis B infection. The HBV patient had fragmentary knowledge of the chronic disease and was often confused with the mode of transmission and the etiological agents. Medical professionals should raise the level of disease awareness through appropriate and specific health education program.

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### APPENDIX 1. Questions guideline for Hepatitis B carriers

<b>A. MEANING (SIGNIFICANT) OF HEPATITIS B VIRUS</b>	<b>B. EXPERIENCES OF HEPATITIS B INFECTION</b>
1. What do you know about the Hepatitis B virus?	6. How does Hepatitis B virus spread to other persons?
2. What do you understand by the term “HBV Carrier”?	7. How do feel about starting the infection (spread, concerns, and threat)?
3. How do the HBV and liver affect your body? What harm does it cause? (complications such as cirrhosis, cancer)	8. How is interfere of CHB with your daily living?
4. Who are informing your family members/close friends of your condition? Why did (not) you talk with them?	9. Do you take any preventive measures to avoid spread of the disease?
5. What do you have any concern with the blood tests?	10. Do you take any medication to try to control the infection?
	11. Do you seek alternative therapy?
	12. Do you seek religious support?

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