



# Psychological Reactions among Patients with Chronic Hepatitis B: a Qualitative Study

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## ABSTRACT

**Introduction:** Hepatitis B is the most prevalent type of viral hepatitis. Psychological reactions among patients with hepatitis B infection is considerably different and affects their decision about treating and following up the disease. The present study aims at explaining the psychological demonstrations experienced by these patients.

**Methods:** In this qualitative study, a total of 18 patients with hepatitis B (8 women and 10 men) were selected by purposive sampling method. Data were collected by unstructured in-depth interviews during 2014-2015 in the medical centers of three cities in Iran. All interviews were recorded, typed and analyzed by the conventional content analysis approach.

**Results:** By analyzing the data, the main theme including psychological instability, with three sub-themes emerged: grief reaction (stupor, denial, anger and aggression), emotional challenges (worry and apprehension, contradiction with beliefs, fear of deprivation, fear of stigma, waiting for death and prognosis ambiguity) and inferiority complex (social withdrawal, sense of humiliation and embarrassment and sense of guilt and blame) were acquired.

**Conclusion:** The findings indicate that patients with hepatitis B experience various psychological reactions that need to be controlled and managed by themselves or healthcare providers. Thus, implementation of health interventions with emphasis on psychological care to prevent problems and execution of educational and consultation programs about hepatitis especially by medical centers and mass media is seems necessary.

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## Introduction

Despite the access to effective vaccination against hepatitis B, this disease is still a major health problem in the world and there are almost 350 million chronic Hepatitis B Virus (HBV) infection carriers<sup>1</sup> of whom 75 percent are Asian.<sup>2</sup> HBV is the tenth leading cause of death worldwide.<sup>3</sup> According to recent studies, 3 percent of Iran's population are estimated to be HBV carriers and it varies from 1.23 to 3.6 percent in different parts of Iran.<sup>4,5</sup> HBV is an

infectious disease that can be transmitted via different forms including vertical (from mother to child) and horizontal (from blood transfusion, dental services, sexual contact, substance abuse and etc.).<sup>6</sup>

Like other chronic diseases, in addition to clinical complications of hepatitis B, the patients' psychological and social health is also at risk.<sup>7-9</sup> Generally, stressful incidents and chronic diseases that threaten life are followed by psychological reactions.<sup>10</sup> Many patients are not ready to hear about their diseases and

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become skeptical and doubtful.<sup>11</sup> Catching chronic hepatitis B virus infection has several negative impacts on different psychological, social and emotional aspects of patients life apart from physical effects.<sup>12</sup> Moreover, psychological problems are prevalent among patients with chronic hepatitis B virus infection, in as much as anxiety and depression among them are significantly more than healthy people.<sup>13</sup>

Generally, patients with hepatitis B are less healthy than the normal people in terms of emotion.<sup>14</sup> Diagnosis of HBV leads to depression, anxiety, fear, worries about stigma and declines the quality of life of infected patients, especially within the first three months of diagnosis.<sup>15</sup> Fear of transmitting the disease to the family, friends and colleagues as well as fear of the stigma are of the most substantial negative impacts of Hepatitis C virus infection. The patients are also accused of socially unaccepted behaviors and debauchery and there is the risk of rejection if the disease is revealed and that is the reason they feel ashamed and guilty.<sup>16</sup>

Insufficient knowledge among patients' about Hepatitis potentially leads to tension and conflict. Moreover, inaccurate information about the source of infection, controlling the infection, prognosis, progression and the disease complications especially at the time of diagnosis may leads to psychological distresses.<sup>16</sup> In a study, emotional reactions of hepatitis B patients were reported to be resulted from patients' lack of awareness, physicians' emphasis on disease complications and stigma.<sup>11</sup> Information about psychological distresses of these patients increases our ability to help them cope with treatment and self-care.

Despite the precautions about prevalence and complications of hepatitis, little attention has been drawn on its psychological aspects and treatment. There are few studies with the focus on psychological issues in patients with HBV infection that are mostly limited to anxiety and depression disorders and are often based on instruments such as standard or researcher-made questionnaires.<sup>17,18</sup> Moreover,

studies in various societies show different results regarding the psychological reactions of patients with hepatitis B<sup>11,14,15</sup> which indicate that this issue is context-oriented. On the other hand, examining the human sentiments with numerical and quantitative values are difficult and it seems that for analyzing sentimental responses, qualitative researches are more effective than quantitative ones.<sup>19</sup> Since the influence of dominant culture in Iranian society and the psychological reactions of HBV infected patients in Iran have not been examined yet, the present study applies qualitative research approach to investigate the experiences and various aspects of psychological reactions of patients with hepatitis B.

## Materials and methods

The present qualitative research is conducted using conventional content analysis. This method is usually used to describe a phenomenon when the existing theories and researches pertaining to the intended phenomenon are limited.<sup>20</sup> The inclusion criteria for choosing a participant in this study were: absolute HBV infection and at least 6 months passed the diagnosis, having no severe physical and psychological problems, and having the ability to communication.

This research was conducted in the year 2014-2015. A total of 18 participants were purposively selected among the two genders with different economic and social status and then were interviewed. The interviews were held in medical centers of Babol and Tabriz as well as Amol Gastrointestinal and Liver Diseases Research Center. These places were chosen in consultation with the participants and also as result of accessibility of the samples for the researchers. Each interview lasted between 30-105 minutes.

Before holding the interview, the participants were assured that their participation in this research was voluntarily and their confidentiality would be followed when using the information. The participants then signed an informed consent and the

ethical permission for conducting the research was received from the ethics committee of Tabriz University of Medical Sciences (Ethic cod: 5/4/2949).

The interviews continued until data saturation occurred and no new information emerged from last interviews. In this study, data saturation occurred after holding 14 interviews and the next interviews were held to ensure the data is saturated. The interviews were held face to face with open and deep questions. For instance, they were asked "what was your reaction after you were informed about the disease diagnosis?", "Explain your emotions and reactions after you learned about the disease." Then depending on participants' responses more specific questions were proposed. For example, explain more about ..., would you give an example for ..., and do you mean ....

Content analysis was used to analyze the data in this study. First, each interview was tape recorded and then typed word by word in the first occasion and coded with using MAXQDA 10 software. The data analysis was done simultaneously with data collection. The transcript of each interview was read several times and by breaking down the text, themes were extracted, coded and categorized as the smallest meaningful constituent units. In order to ensure the correctness and stability of the data four criteria including credibility, dependability, confirmability and transferability were used in accordance with Lincoln and Guba criteria.<sup>21</sup>

In addition to long-term involvement, the research participants' reconsideration was used to provide the credibility of the data. The interview transcripts were returned to the participants after coding. Dependability was also provided by continuously recording the researcher's activities about the circumstances of data collection, data analysis and presenting excerpts from the interview transcripts for each of the categories. Moreover, the extracted categories were given to a number of individuals who did not take part in the research but had the characteristics of the participants. For achieving conformability of

the findings, the researcher tried to acquire the data without involving his personal beliefs and opinions during the interviews and followed the principles of an open and in-depth interview. Also, some other colleagues who were expert in analyzing qualitative data were consulted about the correctness of the interpretations and the process of coding. Using the mixed method, that is, interviewing and taking field notes and well sampling with maximum variation helped the transferability of the data.<sup>20</sup>

## Results

The participants of the present study were 18 patients with HBV infection whose demographic characteristics are mentioned (Table1). The patients' ages ranged between 23 to 50 years and their mean age was 35 year.

In this study, the patients were mostly diagnosed accidentally after a blood donation or in case of female ones, during the routine pregnancy tests. In accordance with the findings of the present study, the participants' responses and their experiences of psychological instability are presented in three sub-themes and their subcategories as followings (Table2).

### **1. Grief Reaction**

Usually the patients go through several stages before they accept diagnosis of hepatitis. Diagnosis of hepatitis is unexpected for most people and causes them to lose their control on themselves and experience stupor, denial and rejection of the disease, anger and aggression after diagnosis.

#### *1.1. Stupor*

Following diagnosis of the disease and facing an unexpected phenomenon, most of the patients feel shocked and experience stupor. In this regard the participants said:

*"The day I found out about my illness in the laboratory I got shocked. After two days I was still stunned, didn't know what to do." (P17)*

*"...they called me and told me I had hepatitis and I was also pregnant. When they said that, I got*

**Table1.** Demographic characteristics of participants

Participant (Number)	Age (years)	Gender	Occupation	Education	Marital status	Length of the disease	Form of transmission
1	32	Male	Farmer	9 <sup>th</sup> grade	Married	5 years	Dentistry
2	24	Male	Driver	9 <sup>th</sup> grade	Married	7 months	Tattoo
3	37	Male	Self-employed	12 <sup>th</sup> grade	Married	1 year	Unknown
4	24	Female	University student	Master's degree	Single	5 years	Mother to child
5	42	Male	Self-employed	Master's degree	Married	15 years	Unknown (probably dentistry or hairdresser)
6	49	Male	Employee	Bachelor's degree	Married	13 years	Unknown (probably blood transfusion)
7	50	Male	Labor	9 <sup>th</sup> grade	Married	2 years	Unknown (probably hairdresser)
8	38	Female	Housewife	9 <sup>th</sup> grade	Married	10 months	Mother to child
9	23	Female	Seamstress	12 <sup>th</sup> grade	Married	6 months	Unknown (probably hairdresser)
10	26	Female	Housewife	12 <sup>th</sup> grade	Married	6 years	Mother to child
11	32	Female	Housewife	Associate degree	Married	11 years	Mother to child
12	45	Male	Labor	Elementary school	Married	14 months	Dentistry
13	26	Male	Labor	Bachelor's degree	Single	7 years	Unknown
14	34	Female	Housewife	Elementary school	Married	10 years	Dentistry
15	37	Female	Housewife	9 <sup>th</sup> grade	Married	3 years	Unknown
16	47	Male	Employee	Bachelor's degree	Married	14 years	Unknown
17	28	Female	Housewife	12 <sup>th</sup> grade	Married	6 years	Mother to child
18	35	Male	Employee	12 <sup>th</sup> grade	Married	5 years	Unknown

**Table2.** Themes, subthemes and codes related to psychological instability among patients with HBV infection

Themes/Subthemes	Codes
<b>Psychological instability</b>	
<b>Grief reaction</b>	
Stupor	Patient's confusion in the first few days of diagnosis—patient's sense of shock and astonishment after diagnosis
Denial	Visiting several doctors in order to be certain of diagnosis of the disease—recourse to several laboratories to be certain of the positive test result
Anger and aggression	Patient's anger after infection—aggression and quarrel with the blood donation staff— throwing the shaving machine because of anger—Why me?
<b>Emotional challenges</b>	
Worry and apprehension	Patient's deep worry after infection— high anxiety because of the probability of disease progression— Patient's apprehension and anxiety because of the probability of disease transmission
Contradiction with beliefs	Patient's sense of debt to others, lying (concealing the disease) as a cardinal sin, sense of debt regarding the religious trainings, make amend following the concealment of the disease (considering the call of conscience)
Fear of deprivation	Fear of losing job—fear of losing marriage opportunities—Patient's concerns about disgrace
Fear of stigma	Patient's fear of being exposed—fear of being looked upon like HIV infected patients—with disclosure of the disease, its news spreads throughout the neighborhood
Waiting for death	Sooner or later I'll fall down somewhere and die—Hepatitis causes premature death—the end of the world—Hepatitis has no treatment
Prognosis ambiguity	Nothing is definite—patient's constant stress of disease relapse and progression—patient's worry about impairment—worry of the probability of liver failure
<b>Inferiority complex</b>	
Social withdrawal	Patient's negative self-image and social withdrawal—patient's unwillingness to interact with others— avoidance of going to parties
Sense of humiliation and embarrassment	Patient's sense of shame and embarrassment in front of the spouse, the family and others because of being infected by hepatitis—feeling humiliation and embarrassment by people's question about the method of infection
Sense of guilt and blame	Self-blaming for negligence in vaccination—patient's regret after infection because of neglect in taking preventive measures

*shocked and believe me that the phone dropped from my hand." (P10)*

### **1.2. Denial**

Some of the patients refuse to accept the disease in the first few days of diagnosis and believe that there is a mistake and the diagnosis is wrong. The patients stated in this regard:

*"I thought the doctors were making mistake, maybe the test result was wrong, or the doctor was giving the wrong diagnosis, so after visiting doctor X I visited several other doctors, and they all said the same thing." (P17)*

*"Two days later I went again to take a test, thinking it might had been mistaken, so I went to the Health Center laboratory and took another test ..., and there too they said that yes you are infected." (P10)*

### **1.3. Anger and aggression**

Anger and aggression were other reactions of the patients that were caused by different reasons. The participants stated that:

*"During pregnancy my doctor's behavior changed after I was infected and I got angry and depressed every time I visited her." (P17)*

*"In the first few days when I was sad, once I was shaving and I got upset in a moment and threw my razor on the floor." (P12)*

## **2. Emotional challenges**

Infection by Hepatitis caused extensive psychological reactions in patients and was followed by emotional challenges and feelings such as anxiety, worry, apprehension, fear and unworthiness.

### **2.1. Worry and apprehension**

Worry and apprehension are prevalent reactions in confrontation with this disease and one of its main reasons has been fear of unknown things. The patients said:

*"It's most likely that one day it will relapse, so a kind of anxiety and worry is always with you." (P10)*

*"This disease has occupied my mind, I ask myself if it left untreated and remain in my body, what do you want to do and what would your future be like? These things occupy my mind and are my worries." (P13)*

### **2.2. Contradiction with beliefs**

When the patients went to the healthcare centers, they initially tried to tell the personnel about their infection with the disease. But as they found that by revealing their disease they would be stalled and their affair would not be properly attended to, they decided to conceal the disease. On the other hand, concealing the disease made the patients feel worried, guilty and in debt to their fellow men.

*"When we go to a healthcare center or when we enter the society and conceal our disease, we are practically lying. Not only is it a cardinal sin, but also it is against morality. Unfortunately, the context is not provided and those who are infected by the virus are not willing to reveal their disease. On the other hand, they are worried about denying their disease and not to transmit it to others." (P16)*

### **2.3. Fear of deprivation**

Most of the patient considered infection by hepatitis equal to social life restrictions and deprivations and were worried about losing their social positions and their jobs. In this regard they stated:

*"I fear I won't be employed in the future. What if they learn about my disease and take a test for employment?" (P4)*

*"I fear, I want my disease to be a secret, because I fear that people would not communicate with me or approach me or dine with me if they find out." (P15)*

### **2.4. Fear of social stigma**

Another important and considerable worry of the participants was fear of being exposed. In this regard a participant said:

*"I'm afraid of any incident, I'm so afraid of people finding out and the way they will look at me, like the way they look at someone who has HIV." (P8)*

### **2.5. Waiting for death**

The majority of the participants believed that hepatitis B was an incurable disease and causes premature death. The participants said in this regard:

*"It's been two years and my sister doesn't take a test, she says leave me to be in my sense and let me die, she says when one is to die let her die, she expects a premature death." (P17)*

*"In the early months of diagnosis I thought I got to the end of the world, as if sooner or later I'll fall down somewhere and die." (P5)*

### **2.6. Prognosis ambiguity**

A group of the patients had an ambivalent perception of living with this disease, constant worries and anxieties about disease relapse and progression as well as impairment and they were ambivalent about their future. A participant said:

*"I myself get sad spontaneously, what happens? I have void thoughts, nothing is definite! What would I do if it won't cure and stay in my body? What about my future?" (P14)*

### **3. Inferiority complex**

Inferiority Complex, declined self-confidence and sense of abashment were of patients' other reactions and were specified by social withdrawal as well as sense of humiliation, embarrassment, shame and blame.

#### **3.1. Social withdrawal**

After the diagnosis, some of the patients isolated themselves strictly and distanced themselves from their friends, relatives and colleagues. A participant stated in this regard:

*"I withdrew from my friends and my companions, I've limited my conversations, I try to stay away as much as I can, for example in a place where a group is seated I try to sit somewhere else and make excuse that I don't want to trouble them, since the diagnosis I've tried to manage myself and not to mingle with others." (P5)*

#### **3.2. Sense of Humiliation and Embarrassment**

Sense of humiliation and embarrassment was another important sub-theme and the participants stated that because of people's negative attitude towards this disease they were ashamed of mentioning it among their friends, relatives and colleagues.

*"...I felt it was something embarrassing and shameful, because it's a disease that can be transmitted to others." (P17)*

*"I'm ashamed of my husband and his family fearing lest my disease relapse and disable me, and I'm ashamed of my husband for having hepatitis." (P10)*

### **3.3. Sense of guilt and blame**

A number of participants felt guilty and culpable for being infected with this disease and neglected in taking preventive measures. A participant said in this regard:

*"I myself was so negligent in this case too and I curse and blame myself for not pursuing vaccination." (P17)*

## **Discussion**

The psychological reactions among patients with chronic hepatitis B virus infection are examined in this study. The patients in this study were not ready for the consequences of screening and suffered emotional distresses for hearing "bad news". In accordance with the participants' responses and their experiences of psychological instability, the findings of this research are presented in three main categories and their associated primary concepts including: grief reaction, emotional challenges and inferiority complex concepts.

Diagnosed with HBV, the participants of this study stated symptoms similar to that of dying patients and since they confronted this disease without previous preparation and had a bad mental image of hepatitis in their minds; hence, they suffered self-alienation, stupor and confusion. These stages are almost similar to the stages introduced for the first time by Kubler-Ross regarding dying patients.<sup>22</sup>

According to a quantitative study in Malaysia, emotional reactions of patients with chronic hepatitis B virus infection at the time of diagnosis were considerably diverse and varied from getting shocked, disturbed, frightened and anxious to acting normal and accepting the disease.<sup>11</sup> In another study with participation of patient

with chronic hepatitis C virus infection, some of the patients reported that they were shocked or surprised after the disease diagnosis.<sup>23</sup> In addition, the result of present study showed that some of the patients refused to accept the disease diagnosis and denied it in the first few days. In order to get sure about the accuracy of the diagnosis they consulted different doctors and different laboratory. In this regard, Tan and Cheah reported that one of the obstacles in the way of managing patients with chronic hepatitis B virus infection during primary care provision was denial of disease by the patients.<sup>24</sup> It occurred as a result of society's inappropriate view towards this disease and the patients did it in order to preserve their previous social statuses. Another reaction of the patients during the first few days of disease diagnosis was excessive anger and fury which were sometimes accompanied with aggression. In another similar study conducted in Malaysia, the results showed that patients with chronic hepatitis B virus infection displayed emotions and reactions such as disbelief, disturbance and anger at the time of diagnosis.<sup>11</sup> Since the participants of this study were selected with the maximum variety and stated their several years of experiences, the findings are varied and include different concepts. Despite others studies that focus on patients' psychological reactions merely at the time of diagnosis<sup>11</sup> or psychological complications such as anxiety and depression in these patients<sup>14,18</sup> the present study goes further and in addition to the mentioned issues it addresses other psychological reactions such as fear of deprivation, sense of blame and criticism, sense of guilt, expectation of premature death and prognosis ambivalence in the patients.

Another significant problem experienced by the majority of the participants was anxiety and apprehension following confrontation with the disease and its associated ambiguities. Apprehension and worry are prevalent reactions in

confrontation with this disease and one of its most important reasons is fear of unknown facts. Altindag et al., argue that since chronic hepatitis B virus infection is a serious and life-threatening disease, the patients feel anxious and are vulnerable and then move towards depression.<sup>25</sup> Moreover, in other similar studies, the prevalence of anxiety and depression among patients with chronic hepatitis B virus infection was considerable.<sup>11,18,25</sup>

The participants have complained about the constant fear of transmitting the disease to their family members, relatives, friends and colleagues and the fear of deprivation of social positions and supports as well as fear of social stigma. The results of another study showed that AIDS related stigma causes psychological distress and has negative effects on patients' social communications and psychological health.<sup>26</sup>

In a study conducted by Ng et al., patients with chronic hepatitis B virus infection did not tend to explicitly talk about their disease because they were afraid of being victimized by discrimination and social stigma.<sup>11</sup> Enescu et al., also reported that the most important fear among the patients with chronic hepatitis B virus infection had been fear of disease transmission and social stigma.<sup>15</sup>

The results of this study showed that the patients were suffering from low self-confidence and had a negative mental image of themselves; as a result, they felt humiliated, embarrassed, guilty and blameful, and avoided communicating with others. Stewart et al., study points out the low self-confidence, lack of positive image and sense of guilt and shame among patients with chronic hepatitis C.<sup>16</sup> In addition, in another study the primary reactions of patients with HCV included fear, denial, embarrassment, sense of guilty, despair, depression and anxiety for death.<sup>23</sup>

As a result of their short knowledge of hepatitis B disease and because they believed they were infected by a deadly and incurable disease, the participants were

afraid of the imminence of their death. In other studies the majority of patients had also short knowledge of Hepatitis B.<sup>27,28</sup> Another study in the United States indicated that the majority of patients with hepatitis B felt lonely and disappointed and had recurrent thoughts of premature death.<sup>29</sup> Moreover, chronic hepatitis B virus infection is followed by serious problems and decreased quality of life.<sup>30</sup> The results of other studies have also demonstrated that depression, social isolation, stigma, job dismissal and economic problems have been of examples of patients' challenges caused by disease complications as well as fear of unknown things among the patients and their families.<sup>12,31,32</sup>

Limitation of the present study was the participants' disinclination to participate which mostly caused by the associated social stigma of this disease. Moreover, since HBV infection is a disease that can be transmitted via sexual intercourse, during the interview some of the participants were not comfortable when they were talking about their experiences.

## Conclusion

Regarding the results of this study, the majority of patients was not prepared at the time of diagnosis and experienced various psychological reactions that need to be controlled and managed correctly. In addition, the patients' confrontation with professional personnel's can affect their primary reactions at the time of diagnosis.

Therefore, ongoing education of the patients, the medical staff and the population at risk with the use of appropriate informing strategies and standard education and consultation programs before and after screening test by the medical centers and the mass media are recommended. Moreover, psychological health improvement programs in medical centers for improvement of patients' self-efficacy and self-confidence should be planned and implemented to prevent the

incidence and continuance of severe emotional reactions and enable the patients to properly manage their emotional reactions at the time of diagnosis with the use of self-management programs including appropriate behavior, stress management, fear management and relaxation techniques.

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## Ethical issues

None to be declared.

## Conflict of interest

The authors declare no conflict of interest in this study.

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