

# A Qualitative Study on Marital Challenges of Chronic Hepatitis B Patients

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## Abstract

**Background:** Hepatitis B is a life-threatening viral infection that is mainly transmitted through blood; due to the presence of this virus in semen, vaginal fluids, and saliva, the possibility of transmission among couples during marital life still exists.

**Objectives:** This study was conducted to specify the patients' perception of their marital problems.

**Methods:** In this descriptive qualitative research conducted in Iran, 32 patients with chronic hepatitis B were selected through purposive sampling. The data were collected through semi-structured interviews and field notes during 23 months in 2015 and 2016. The interview transcripts were coded by using MAXQDA10 software®. The utilization of thematic analysis approach was to extract categories and themes.

**Results:** Participants of this study were in the chronic and inactive phase of hepatitis B. Participants' age varied from 24 to 57 years. Three major themes were extracted: premarriage challenges, conjugal life with suffering, and lack of marital adjustment.

**Conclusions:** Like other chronic diseases, chronic hepatitis B causes numerous marital challenges for the carriers of the disease. The partners of patients with hepatitis B can be used as self-care facilitating agents in the family to promote self-care of these patients and help better manage their marital challenges.

**Keywords:** Hepatitis B, Chronic, Marital, Marriage, Qualitative Research

## 1. Background

Chronic infection with HBV is a prevalent health problem with 2 billion infected people worldwide (1) and more than 350 million chronic carriers of the disease (2). HBV is mainly transmitted through contact with infected blood or semen (3). In highly endemic areas, HBV is most commonly transmitted from infected mother to her infant; however, sexual transmission is more common in low endemic areas. The risk of infection is higher in people with multiple sexual partners, and those who have a history of other sexually transmitted infections (4). In 2016, the prevalence of hepatitis B in the general population of Iran was 2% (5). Hepatitis B is mainly transmitted through intrafamilial transmission in Iran (6). Besides household contacts, marital relations between spouses is one of the factors influencing HBV transmission between them. The number of HBS Ag positive carriers among hepatitis B patients' spouses was higher than individuals whose spouses were HBS Ag negative in factors like age of marriage, frequency of sexual intercourse, and use of condom (7).

When one spouse is diagnosed with a chronic disease, it causes considerable distress not only to him/her but also to the his/her spouse. Hence, it will affect the marital re-

lationship (8). Marital dissatisfaction has been reported in various chronic diseases such as diabetes (9), chronic renal failure (10), Crohn's disease (11), and multiple sclerosis (12). Although either physical symptoms of this disease or the side effects of treatment have led to reduced quality of marital relations between couples, hepatitis B is separated from other diseases for several factors including the risk of transmission to sexual partner through unprotected sexual relations and to other healthy members through household contact (3), feeling of social stigma (13), psychological consequences (14), the struggle for self-care (15), and susceptibility to hepatic cirrhosis and hepatocellular carcinoma (16). There has been a growing interest in understanding how chronic illness affects sexual functioning and relationships among chronic patients in the marital dyads (17). Several studies on sexual functioning disorders and chronic diseases found in the literature were quantitative, and most of them focused on sexual dysfunction rate associated with the disease, treatment, and long- and short-term side effects. On the contrary, there is a lack of qualitative researches on reporting sexual health of males and females with chronic diseases that consider their subjective experiences (17). Because a few studies exist on marital problems in patients with chronic hepatitis

C (18-20), knowledge on marital problems of HBV carriers is limited. As hepatitis B infection is a confidential and unparalleled experience, to have a detailed understanding of the patients' marital challenges, which are the most confidential secrets of private life, using a qualitative approach will be helpful. A deep understanding of patients' marital problems is useful in suggesting proper plans to couples to help enhance the quality of life of patients and promote self-care.

## 2. Objectives

The present study aimed at exploring marital problems of Iranian patients with chronic hepatitis B according to their lived experiences.

## 3. Methods

**Design:** this was a qualitative study that used narrative interviewing and thematic analysis and was conducted during 2015 and 2016. Braun, Clarke, and Terry (2014) stated: "Thematic analysis is a method for identifying, analysing, and interpreting patterned meaning or themes in qualitative data." Thematic analysis consists of 6 steps: familiarization with the data, coding the data, searching for themes, reviewing themes, defining and naming themes, producing the report (21).

The research was conducted in the gastroenterology and hepatology research center of Guilan University of Medical Sciences, Iran, and for greater access to samples, health service centers affiliated to Guilan University of Medical Sciences and Guilan blood transfusion organization were asked to help. To select patients, the researcher frequently went to the above-mentioned organizations and presented the invitation cards to the participants. If the patients wished to participate in the study, they would contact the research center, using the provided contact number on the cards, and referred to the center. Participants of this study were from different regions of Guilan province.

**Participants:** the selection criteria for selecting the participants involved a history of hepatitis B infection for 6 months or more, taking HBS Ag confirmatory test, living with family members, not suffering from other chronic diseases such as diabetes, renal failure, and other diseases such as AIDS and hepatitis C. Hearing and speech problems, and unwillingness and inability of the individuals were the exclusion criteria in the study.

### 3.1. Data Collection

Purposive sampling was performed on patients of different age, gender, and educational backgrounds as a maximum variation to obtain rich data. The method of data collection was individually conducted semi-structured interviews. All interviews were conducted by the corresponding author, who is a Phd candidate in nursing education and is experienced in providing counseling to patients suffering from hepatitis. The interview was started with an open-ended question: "When and how did you find out that you are infected with hepatitis B?", "Does it have an influence on your marital life?" Then, to clarify the concepts of the study, the patients were asked some follow-up questions according to their answers: "Can you explain more?" or "Can you express it more clearly with an example?" Sampling continued until data saturation, and 32 patients participated in the study. Each interview took 40 to 120 minutes; the average time was 57 minutes.

### 3.2. Data Analysis

All interviews were conducted and simultaneously recorded by the researcher, and then transcribed and typed word by word. To obtain a deep understanding of the collected data, the transcripts were read several times, while listening to recorded voices; afterwards, the data were encoded and analyzed. Each transcript of the interviews was imported into MAXQDA 10 software® to organize and categorize information from the participants. Merrill and West's (2009) thematic analysis model was used to analyze the content of interviews. Then, transcripts were coded, and the codes were later compared. In the next stage, they were classified into categories, and finally the themes were extracted (22).

### 3.3. Rigor

To ensure the rigor of study, Guba and Lincoln assessment criteria were used (23). Prolonged engagement with the data, member check, and data triangulation with a maximum variation in sampling were used. The conformability of the findings was measured by the help of 2 external experts who were familiar with qualitative research.

### 3.4. Ethical Considerations

Sampling process was conducted after obtaining approval from a local ethical committee, a referral from the University to enter the research context, and observing ethical issues including informed consent of the participants, confidentiality of their personal information, and maintaining anonymity. The place and time of the interviews

were determined by participants' agreement. The interview was conducted in a quiet room in the research environment, where the participants could comfortably and easily talk to the researcher.

Results: Participants of this study were in the chronic and the inactive phase of hepatitis B. Most of the participants (53.1%) were male, and 43.8% were in 24 to 35 age group; of the participants, 87.5% were married, and most of them (37.5%) had a high school diploma. Most of the patients had suffered from hepatitis B, ranging between 1 to 30 years. All demographic features are demonstrated in [Table 1](#).

Analysis of findings from in-depth interviews with participants in the study revealed the following 3 themes that are summarized in [Table 2](#).

### 3.5. Premarriage Challenges

The remarks of single and married participants in the study indicated that their infection of HBV, negative attitude of ordinary people towards the disease, and the presence of discriminatory practices in the society have prevented them from marrying at an appropriate age and to a desired partner. This theme contains the following categories:

#### 1) Posing a Dilemma

One of the problems heard from most single participants was choosing whether to marry or not. Because despite a strong desire to marry, the fear of being rejected by the person made the carrier hesitant to choose to marry. One educated young female said:

"To tell you the truth, I have been thinking about the issue for quite a while. If I do not tell my future husband the truth and he does not get the vaccination, it will cause a problem, because someone has proposed to me and we are planning to marry. However, I always feel stressed over whether he will accept my disease or not, or get the vaccination. I am always anxious, and think, if he knew about my disease, he would never marry me." (p 14)

#### 2) The Bitter Experience of Telling the Truth

Other HBV carriers had a bad experience of telling the truth to their selected partner before marriage. They believe that most people are reluctant to marry chronic carriers of hepatitis.

A female talked about her experiences of celibacy, "I lost one of my best suitors, who claimed he had loved me for 3 years, when I was honest and told him that I have the disease. It was a big psychological blow. When he found out about the disease, he no longer wanted to see me." (p 6)

#### 3) Conjugal Life with Suffering

The remarks by participants revealed that they have been deprived of the pleasure of peaceful marital life during their conjugal life because of the disease, its consequences, and lack of necessary support, and the poor acceptance of the disease among their family members. These include as follow:

#### 1) The High Cost of Self-Care

The remarks by some patients showed that the chronic nature of the disease and long term self-care by the patients have led to paying high costs for treatment and the couples' resentment in the case of financial restrictions in the family.

A female whose husband is also infected said,

"I was prescribed a test and was told to have a regular checkup every 6 months, and my husband has to have a checkup every 3 months. However, honestly, because of the high costs of the tests we did not do it, but because the cost of the tests would set us back financially, we finally decided to give up."

#### 2) Feeling Displeasure From the Partner's Reproaches

The remarks by participants showed that their long-term infection of the disease has caused them to expect more support from their partners because when a warning is given by the healthy spouse, even in the cases of the possible risk of transmission of the disease to family members, it causes displeasure for the other who is a patient. One female participant said,

"Sometimes I am hurt by my husband's behavior. One day I used his parents' nail clippers at home. My husband got really angry and told me I wanted to infect others with my disease. His behavior hurts me." (p 6)

Some other patients feel the displeasure of recalling bitter memories of family disputes because of the disease. Since these kinds of disputes do not seem unlikely during marital life, this long-term feeling causes disturbance in couples' intimate relationships.

#### 3) Marital Life with Embarrassment

Spouses, whose infection has been diagnosed earlier than their mate, always blame themselves for the infection of their partner. According to these participants, these individuals have a guilty conscience about their spouse's disease, a sense of embarrassment, and are very concerned and worried about the consequences of their disease. One patient with a family history of hepatitis in maternal relatives, whose HBV infection was confirmed in her first pregnancy, said,

"First, I realized that I am carrying the virus then my husband had a test, which confirmed that he is carrying the virus too. I feel guilty about transmitting the infection to my husband. This is the only thing that bothers me. It won't bother me if I have any trouble, but I am really worried about my husband because I do not want anything to

**Table 1.** Demographic Characteristics of Participants

Participant No.	Age, y	Gender	Marital Status	Length of Disease, y	Education
P1	40	Male	Married	14	Diploma
P2	47	Female	Married	4	9thgrade
P3	27	Female	Married	6	Diploma
P4	41	Male	Married	10	Diploma
P5	29	Male	Married	1	Associate degree
P6	34	Female	Married	11	Master's degree
P7	41	Female	Married	3	9thgrade
P8	49	Male	Married	30	Diploma
P9	28	Male	Married	1	Diploma
P10	25	Male	Single	7	Bachelor's degree
P11	37	Female	Married	12	9thgrade
P12	28	Female	Single	11	Associate degree
P13	28	Female	Married	4	Diploma
P14	29	Female	Single	12	Master's degree
P15	34	Male	Single	6	Associate degree
P16	52	Male	Married	25	Diploma
P17	34	Male	Married	11	Diploma
P18	42	Female	Married	5	9thgrade
P19	45	Male	Married	30	Diploma
P20	40	Male	Married	14	Diploma
P21	26	Female	Married	1	Associate degree
P22	37	Female	Married	10	Master's degree
P23	50	Male	Married	20	Bachelor's degree
P24	43	Male	Married	6	Diploma
P25	38	Male	Married	19	Diploma
P26	31	Female	Married	1	Diploma
P27	24	Female	Married	2	Bachelor's degree
P28	42	Male	Married	1	9thgrade
P29	47	Male	Married	1	9thgrade
P30	54	Female	Married	5	Illiterate
P31	26	Female	Married	3	Associate degree
P32	57	Male	Married	15	9thgrade

happen to him.”(p3)

#### 4) Concealing the Disease from Family Members

Although emotional support for couples would help to solve the problems, the patients' remarks show that they have concealed their disease from their partner for many years because of many reasons such as fear of the consequences of disclosure and fear of creating panic in the family, the possibility of rejection by the partner, and the dis-

ruption of family friendly atmosphere. This has caused anxiety and living with apprehension due to concealing the disease.

A male patient with over 20 years of infection speaks about concealing his disease from his wife because of the fear of creating anxiety and disturbing the peaceful family atmosphere: “I mostly care about my disease by myself; I have said nothing about it to my family members because

**Table 2.** Themes and Categories Related to Marital Challenges of Patients with Chronic HBV Infection

Themes	Categories
Pre-marriage problems	Posing a dilemma
	The bitter experience of telling the truth
	The high cost of self-care
Conjugal life with suffering	Feeling displeasure from the partner's reproaches
	Marital life with embarrassment
	Concealing the disease from family members
	Dissatisfaction in marital relationship
Lack of adjustment between couples	Spouse misunderstanding about the nature of the disease
	Fear of marriage breakup

I thought it would cause stress for them. It would take a long time to convince them that my disease is not a threat to them.” (p 8)

Couples are even determined to conceal their wife or husband's disease from their in-laws family because of fear of rejection and discriminatory behaviors during times of family visits. One of the infected females said, “Due to fear of the disclosure of our disease, my husband and I decided not to say anything about our disease to my husband's family to not make them fearful.” (p 26)

#### 5) Lack of Adjustment Between Couples

Fear of disease transmission through marital relations, inappropriate understanding of the nature of the disease, and couples legal reactions in the case of awareness of the partner's disease have led to lack of adjustment between participants in this study. This theme includes 3 classes as follows:

##### 1) Dissatisfaction in Marital Relationship

Some participants were not satisfied with their sexual relations with their partners due to fear of transmission of their disease. One infected female said,

“I do not feel good about intimate relations with my husband because they say the disease is transmitted through sexual relations, and I am always worried about him because I do not want to infect him, as my husband got the vaccination a long time ago.” (p 2)

Another participant said, “Although my husband has been vaccinated and they say he won't get infected after vaccination, I really worry because they say it is possible for the virus to become active again. Does it cause any problems in my sexual relations? What should I do to make sure there won't be any problems?”(p 21)

#### 2) Spouse Misunderstanding About the Nature of the Disease

It is usually told to the patients' relatives during the clinical visits by doctors that this disease is transmitted through blood, like other blood infections such as AIDS; thus, most people have a conception of hepatitis similar to what they have about AIDS. A male patient, who is a father, said,

“My wife is really worried that I die like AIDS patients. I am gripped by fear as like AIDS patients I may transmit my disease to someone else.” (p 20)

#### 3) Fear of Marriage Breakup

After one of the partners is diagnosed with hepatitis, the healthy partner always boasts about his or her legal right to obtain legal separation. Even in some cases, the couples are worried about other relatives' interfering after the disease diagnosis.

One patient said, “My husband says his mother has told him to divorce me because I have this disease, but he sympathizes with me. He won't divorce me.” (p7)

One of the females who has recently gotten married and reached an agreement about her disease with her husband, said, “My biggest problem is that if my in-laws find out about my disease, my life will be destroyed.” (p 27)

The same fear is also observed in statements of married males.

“My wife constantly reminds me about her health. She says that she has the right to make decisions about her life. She says that she did not do anything when she realized about my disease because our baby had been born.”(p20)

## 4. Discussion

Long-term marital problem experiences of chronic hepatitis B patients are presented in 3 themes including premarriage challenges, conjugal life with suffering, and lack of marital adjustment using thematic analysis. There is a limited number of studies considering the relationship between chronic infection with HBV and marital problems, and most of them have dealt with the effects of the drugs on marital satisfaction in a quantitative way (24).

HBV carriers participating in this study suffered from premarriage challenges. According to cultural and religious conventions of Iranian society, males and females select each other at the age of marriage, and they undertake marital life as wives and husbands after official and legal formalities. It seems what single HBV carriers are suffering from is the presence of discriminatory behaviors against hepatitis carriers, which is seen in different communities, and Iranian society is not an exception. In a study in Thailand, 70% of university students were scared of telling their friends about their status (25). Premarital screening for

HBV in Iran revealed that one-third of people tend to reject the selected person in the case of his/her being diagnosed positive for hepatitis B (26).

The experience of conjugal life with suffering in the present study is compatible with the findings of a study in Pakistan, revealing near half of married patients report changes in the partner's behavior after diagnosis of hepatitis (27). A study on hemodialysis patients in China showed that patients and their partners had a great deal of stress and this stress negatively influenced their marital satisfaction (28).

Concealing the disease from the family was one of mentioned experiences of the patients. Similar to this finding, 31% of Asian immigrants living in Canada were ashamed of having hepatitis B, and 53% of them were reluctant to talk about their disease with family members and friends (29). In another study, hepatitis C patients concealed their disease from relatives because of misunderstandings in the society on how infection occurs and maintaining the existing relationships with children in the family (30). However, the study conducted on AIDS patients in Iran showed that more than half of the patients confided in their mothers and sisters and talked to them about their status and received more support from their families (31). It seems that if disease disclosure to the partner results in suitable acceptance from him/her, it can reduce the patient's pain and suffering and promote the couples' individual capacity to overcome challenges resulting from the disease.

In this study, infection of one of the partners can result in lack of adjustment between couples. While participants of this study were inactive carriers of HBV and did not receive any kind of antiviral medication, the findings of the previous study on marital adjustment in Iran showed no difference in marital adjustment between chronic active hepatitis patients, inactive carriers, and healthy individuals in the country (32). High prevalence of dissatisfaction with sexual life and sexual dysfunction was found in chronic hepatitis C patients in Brazil, and it was related to factors such as symptoms of depression or taking antidepressants (18). Decreased sexual function due to either disease or hepatitis C treatment, fear of disease transmission, or lack of sexual interest were observed in hepatitis C patients; regardless of the underlying reasons, decreased sexual function leads to worse sexual relations in partners (19).

In the present study, what leads to dissatisfaction in marital relations of patients with HBV seems to be fear of disease transmission to the wife or husband during sexual intercourse. Similar to other studies, hepatitis B patients had the fear of infecting their loved ones in addition to fear of liver cancer and their lives being threatened by the dis-

ease (33).

The results of this study revealed that married patients regard disintegration of marital life as fearful. The results of a study showed that only wives' illness onset is associated with risk of divorce, while either husband or wife's illness onset is associated with risk of widowhood (34).

According to research of the last half a century, low marital life quality, measured subjectively or objectively, can lead to poor health (35). Desirable marital quality contributes to maintain couples' physical health (36). On the contrary, middle-aged marital conflict is a significant risk factor for psychological and physical health among the middle-aged and elderly (37).

HBV infected members of a family have lower life quality than other healthy members (38). The relationship between health-related quality of life and various aspects of marital adjustment in patients with chronic viral hepatitis shows the particular role of family (24). Health care providers play an important role in provision of effective health care interventions to improve the compatibility of couples with chronic illness. Seeking professional help for problems in sexual relationship and practical sexual problems were seen among individuals with chronic diseases (39). Couple-based interventions on various diseases such as cancer, arthritis, cardiovascular disease, and chronic pain are more effective than any kind of psychological patient-based interventions or conventional care (40).

Chronic HBV infection is the leading cause of cirrhosis and hepatocellular carcinoma around the world (41). A study on the candidates for marriage in Iran showed a low prevalence of HBV. On the other hand, HBV test is optional in premarital screening program of Iran (42). Hepatitis B screening for identifying the HBV carriers seems to be effective for marriage candidates to decide to marry with full awareness and taking preventive measures in the case of disease transmission to their partner. Also, women of childbearing age who are HBV carriers should pay more attention to their self-care and regular control of their viral status so that they can reduce perinatal or mother to child transmission (43).

Individual features of patients such as having family support is effective in treatment regimen of chronic hepatitis C (44). Thus, to promote self-care of hepatitis B patients with better management of marital challenges, the patients' partners can be deemed as self-care facilitating agents in families with hepatitis B patients to manage the disease better.

This study was the first research work through qualitative approach exploring Iranian marital problems of patients with chronic hepatitis B. One of the main points of this study can be the utilization of a qualitative approach that adheres to a naturalistic view, which is free from pre-

dices and restrictions existing in positivistic view in quantitative approach. All interviews were conducted by a single interviewer, and data analysis was performed under the supervision of external observers. Some participants had the disease for more than a decade.

The present study had several limitations. First, the patients suffering from hepatitis B were reluctant to reveal the illness and were absent in medical care treatments due to the feeling of stigma. Since talking about marital problem is the most personal live experience, expressing problems in this regard was not easy. Thus, the participants in this study were invited by the researcher, who gained the trust of the patients by creating a favorable research atmosphere, where bilateral relations would be based on trust, privacy, and confidentiality during the project. Besides, as this study was of a qualitative nature and had a limited number of participants, the obtained results can not be generalized to the whole population of chronic hepatitis B carriers.

#### 4.1. Conclusions

Like other chronic diseases, chronic hepatitis B causes numerous marital challenges for the carriers of the disease. To prevent such challenges, it is better to inform the couples about their partners' disease after diagnosis through offering supportive measures by health care providers to manage the chronic disease challenges instead of managing marital challenges. Regular implementation of consultations by professionals, who are familiar with the nature of the disease, in premarriage stage is helpful for hepatitis B carriers.

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#### Footnote

**Conflict of Interest:** The authors declare no conflict of interest in this study.

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