



Physical, Psychological, and Social Challenges in Patients with Hepatitis B Infection

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Abstract

Context: Hepatitis B is the most prevalent chronic viral infection in humans, which imposes limitations on patients and has many physical, psychological, and social consequences due to its chronic nature. The purpose of this study was to evaluate the physical, psychological, and social challenges of patients with hepatitis B virus (HBV).

Evidence Acquisition: First, a set of keywords, including hepatitis B, challenge, physical, psychological, and social, were searched in databases, such as Google Scholar, PubMed, SID, Magiran, and IranMedex. Then, the articles published between 2009 and 2019 were reviewed according to the inclusion and exclusion criteria in two stages - the title and the abstract in the first stage and the whole paper in the second stage. Finally, 34 articles were selected out of 1426 articles.

Results: The articles used in this study were as follows: descriptive and cross-sectional studies (10 articles), review studies (9 articles), qualitative studies (9 articles), cohort studies (3 articles), randomized controlled trials, mixed-methods studies, and field studies (one article each). Most studies had considered patients with hepatitis B with an emphasis on physical issues (10 articles), social stigma (7 articles), psychological reactions (5 articles), the discovery of patients' experiences (3 articles), and discrimination (2 articles). In 25 studies, the samples were patients with HBV.

Conclusions: It is necessary to understand and support the patients to treat them properly and help them live with minimum challenges and limitations. Therefore, it is necessary to consider educational and counseling programs to identify different aspects of this disease.

Keywords: Challenge, Hepatitis B, Physical, Psychological, Social

1. Context

Hepatitis B is a systemic disease caused by the Hepatitis B virus (HBV), and liver cirrhosis and hepatocellular carcinoma (HCC) are among its important consequences. Annually, 80% of HCC cases, which is the fifth prevalent type of cancer with 630 thousand cases each year and the second cause of death due to cancer worldwide, is associated with HBV (1). According to the World Health Organization, more than 350 million people around the world are chronic carriers of the virus (2). In Iran, the prevalence of this virus has been reported to be between 0.87 and 8.86% in various provinces, where the highest and the lowest prevalence rates were found in Golestan and Kurdistan (and Kermanshah) provinces, respectively (3). Hepatitis B is a blood-borne infection and is highly transmissible through body fluids, including tears, saliva, urine, and semen (4).

The majority of HBV patients do not have adequate

knowledge and understanding of the disease, its etiology, transmission pathways, and treatment methods. They do not have access to appropriate information resources to understand the disease, improve their health, and protect their families (5). In a study, hepatitis B infection significantly reduced the physical, mental, and social health of the patients, even without liver cirrhosis and liver cancer. Also, it had social (lack of close and intimate relationship) and mental consequences and was followed by decreased quality of life (6).

Concerns and anxiety about Chronic Hepatitis B (CHB) are common among the affected patients. In the study by Hajarizadeh et al., 76% of CHB patients had concerns and anxiety. Their most common concerns were liver cancer (57%) and transmission of the disease to others (53%). Moreover, 35% of them were not willing to talk about their disease with other people (7). According to another study, 75%

of patients reported that they had to change their lifestyle because of the disease, 66% of them were afraid of transmitting the disease to others, and 51% of married patients said that their marital relationships were affected (8).

Overall, hepatitis B patients appear to face reduced social support, fear of community, and decreased support of family and friends. In addition, most of these patients are deeply concerned about the association between this disease and drug abuse and try to hide it (9). Since the prevalence of hepatitis B in Iran is significantly high, and it has consequences, such as malignancy and imposes financial burden for the patients and their families; therefore, it is very important to know the challenges associated with this disease for educational and health plans. Despite a large number of global studies on this subject, few studies have been conducted in Iran. Therefore, this study was done to provide an integrative review of the Iranian and international studies on the physical, psychological, and social challenges of patients with hepatitis B.

2. Evidence Acquisition

This review was performed in three stages, including literature search, data evaluation, and data analysis based on the Broome method (10, 11). Keywords, including hepatitis B, challenge, physical, psychological, and social were searched using the databases of IranMedex, Magiran, SID, Google Scholar, and PubMed, and 1426 articles and abstracts were obtained. This study was approved by the Ethics Committee of Babol University of Medical Sciences (Ethics code: IR.MUBABOL.REC.1399.214).

The inclusion criteria included articles on Hepatitis B-related challenges in adults of both sexes published between 2009 and 2019 and the accessibility of the full-text version of the article. Short report cases, book summaries, editorial reports, introductions and forewords to books and journals, and conference reports were removed from the study due to their inability to answer the research question.

The studies on other types of hepatitis (other than hepatitis B) and those irrelevant to the challenges of hepatitis B disease were not examined. The articles were selected in two stages. In the first stage, articles on other types of hepatitis were removed, and in the second stage, the whole article was studied. Then, those conducted on physical, psychological, and social challenges of hepatitis B patients were selected, and finally, 34 full-text articles published in Iran and other countries were included.

In the first stage, 1426 articles were acquired. In this stage, the titles, and if necessary, the abstracts of the articles were reviewed, and in the end, 185 articles were selected. In the second stage, the full text of the articles was

studied, and 150 articles were excluded because they had not considered the physical, psychological, and social challenges of hepatitis B patients. Finally, the current review assessed 34 published articles.

The results of articles on physical functioning, physical role functioning, bodily pain, and general health perceptions were considered as the physical challenges of hepatitis B. Studies that addressed the vitality, social role functioning, emotional role functioning, and mental health aspects were considered as the source for psychological challenges (12) and those focusing on the individual and social effects of hepatitis B, such as the impact on employment choices, economic opportunities, and the development of intimate relationships were regarded as the source for social challenges of hepatitis B (13).

Two independent reviewers (A.Z. and M.Q.Q.) read the abstract and included studies according to their content. In case of any disagreement, a third reviewer decided after reading the title and the abstract (S.R.J.A.). At the analysis stage, the information collected from the study(s) included the author(s), year of publication, the purpose of the study, main study concepts, study methodology, research environment, sampling method, response rate, validity, and reliability of the study. This information was regularly gathered in a file and used as raw data for this review. During the data collection, no interpretation was used, and the main terms of the articles used by the author were adopted. The validity and the analysis were confirmed in two ways: 1) by two researchers who worked independently during the analysis process; 2) two researchers agreed upon the results of the analysis, and if a problem occurred, they discussed it and came to a conclusion.

3. Results

The included articles were as follows: descriptive and cross-sectional studies (10 articles), reviews (9 articles), qualitative studies (9 articles), cohort studies (3 articles), randomized controlled trials, and mixed methods studies and field studies (one article each). Most studies had addressed patients with hepatitis B with an emphasis on physical issues (10 articles), social stigma (7 articles), psychological reactions (5 articles), the discovery of patients' experiences (3 articles), and discrimination (2 articles). In 25 studies, the samples were patients with hepatitis B.

The data collection tools used in the examined studies were interviews (11 studies), questionnaires (7 studies), patient records (7 studies), group discussion (2 studies), and information form (one study). Most of the studies had used descriptive statistics (frequency and percentage, mean, and standard deviation) and analytical statistics (logistic regression analysis, t-test, chi-square, Mann-Whitney,

ANOVA, Kruskal-Wallis, and Fisher exact tests). Moreover, 9 qualitative studies had used thematic analytical methods and content analysis. The included studies had considered physical, psychological, and social consequences related to hepatitis B patients. Therefore, the results are presented in three sections, including studies of the physical, social, and psychological problems of patients with hepatitis B:

3.1. Physical Challenges

Regarding the side effects of drugs in the treatment of viral hepatitis with antiviral drugs, a study showed that the majority of antiviral drugs used in the treatment of hepatitis B and C have been associated with side effects. The most common physical side effects of antiviral medications included flu-like symptoms, shivering, fever, arthritis, headache, weakness, anemia, neutropenia, platelet decline, and gastrointestinal disorders, such as nausea, abdominal pain, and constipation (14).

In a clinical trial on the effects of antiviral therapy with Tenofovir on fibrosis and liver function in patients with CHB based on statistical tests, no significant changes were observed over a 6-month follow-up and treatment (15).

In a population-based cohort study in Turkey, liver fibrosis was emphasized as one of the serious complications of hepatitis B (16). Another study linked the prevalence of liver fibrosis to the severity of non-alcoholic fatty liver disease in CHB patients (17). The elderly and diabetic people were found more likely to have serious hepatitis B complications, such as HCC (18). Alcohol consumption, cigarette smoking, and exposure to aflatoxin by CHB patients were among the most important risk factors of HCC (19).

Subic and Zoulim reported that only 10% of the patients with hepatitis B were diagnosed, and approximately 1% of them received adequate treatment. Barriers in the diagnosis and treatment included low knowledge of HBV and HBV-related diseases, inadequate screening and referral system, limited treatment due to restrictions on access to drugs, costs, and long-term treatment (20). Also, a cohort study in Taiwan showed that the use of nucleoside analogues was associated with a reduced risk of HCC recurrence among hepatitis B patients after liver resection (21). Cai et al. showed that high levels of gamma-glutamyl transferase, younger age, high waist-to-hip ratio, and high body mass index were direct risk factors for non-alcoholic fatty liver disease in CHB patients (22). In a review article, liver complications and extrahepatic manifestations of patients with HBV infection were addressed to be acute and chronic hepatitis, hepatic cirrhosis, HCC, glomerulonephritis, nephropathy, polyarthritis, cutaneous manifestations, and cryoglobulinemia (23).

3.2. Social Challenges

Several studies have been conducted on the social challenges of patients with hepatitis B, with social stigma and discrimination reported as the most notable challenges. In a qualitative study using the grounded theory, the process of social interactions in patients with HBV infection was investigated, which showed that “maintaining normal social interactions” after diagnosis of a disease was a major concern for patients. Strategies that patients used to respond to this problem included hiding the disease from others, taking care of themselves and others, and compromising with the disease (24). In another study, concepts, such as fear of the patient in society, social stigma, and low support from the authorities, were extracted. According to the results of this study, various contextual and cultural factors make people afraid of hepatitis, avoiding close interaction with them (25).

Confronting the stigma induced by HBV infection as a “blind spot” was investigated in a study, where stigma and poor knowledge of the disease were introduced as the obstacles in the diagnosis and treatment of HBV infection. Stigma has a negative impact on seeking help, screening, and disclosure of the disease and is a major obstacle for the successful implementation of prevention, diagnosis, and treatment of HBV, which was highlighted as a “blind spot” and indicates the lack of data and opinions in this area that requires further investigations (26). In another study, the HBV patients’ experiences of social stigma were divided into two main themes: the external concepts of a social stigma (feeling ashamed and being blamed and discriminated) and the internal concepts of a social stigma (feelings of rejection, avoidance, and despair). The social stigma of these patients was due to the low knowledge of these patients and the community members and was more severe in the earlier stages of the disease (9).

In another study in China, the experiences of CHB patients showed that social stigma was significant in these patients so that they lost their job opportunities because of the disease. They were not allowed to work in restaurants and felt unwanted by their spouses, resulting in some troubles for their families (27). In his study, Nwokediuko cited many challenges for the effective management of HBV infection, including stigma, lack of proper referral system, lack of diagnostic facilities, treatment problems, lack of public knowledge, lack of surveillance programs, the weak political will of the governments, and lack of proper statistics of the patients (28). A study in Vietnam reported that psychological consequences caused by viral hepatitis were followed by manifestations, including negative self-image, social guilt and shame, disruption of social relationships, and barriers in the prevention, testing, and treatment of the disease (29).

In a review article, the hepatitis B patients' experiences of stigma in Asia had been analyzed. In this study, stigma was identified as a major obstacle for disease management (30). In another study, the highest incidence of HBV-related stigma in Chinese immigrants regarding the fear of infecting others was due to the patients' low levels of knowledge (31).

Stigma experiences in hepatitis B and C patients in Islamabad and Rawalpindi, Pakistan, included influencing relationships with friends, relatives, spouses, healthcare workers, and the people at the workplace. In this study, stigma was reported associated with disease transmission (66% of patients) and marital relationships (51% of married patients) (8). In another study on stigma and discrimination in patients with chronic hepatitis in Iran, the results showed that the disease was a major challenge for patients, their families, the nurses, and the healthcare personnel (32).

Discrimination in the daily lives of HBV patients in Beijing migrant workers had been investigated in a study in which fear of being infected with HBV was one of the main causes of discrimination in these patients (33). The results of another study in China showed that not only the hepatitis B carriers can suffer from physical problems but also they experience discrimination and stigma. It was also stated that fear of being infected leads to discrimination (34).

3.3. Psychological Challenges

Regarding the psychological challenges of patients with CHB, a qualitative study was found entitled "The Psychological Responses in CHB Patients". The main theme extracted from the data was the psychological instability in patients. In this study, the patients' initial psychological responses to the diagnosis of the disease included confusion, illness denial, and anger. The emotional challenges also included worry and anxiety, conflict with beliefs, fear of being deprived, fear of stigma, and a vague future image. Other psychological responses included feelings of inferiority, embarrassment, guilt, and blame (35). In another study, the Hepatitis B-induced anxiety in CHB patients in Australia had been investigated. About 76% of patients reported that they had hepatitis B anxiety. The most common concerns were liver cancer (57%) and transmission of the disease to others (53%) (7). In a study by Ng et al., patients with CHB were not ready when they were diagnosed with the disease and were often anxious, which was due to the lack of knowledge and the physicians' emphasis on disease complications and stigma (36).

In a qualitative study titled "Experiences of Hepatitis B Carriers in Confronting the Disease", the main theme extracted from the data was the "effort to actively expand in-

teractions". Subsidiary themes included disease concealment, underestimation of the disease, normalization of social behavior, self-care behaviors, coping with illness over time, and adherence to religious beliefs and teachings (37). In another study, the results showed that psychological issues and the quality of life were important factors in hepatitis B and C patients (38). In a study by Mohammadi et al. entitled "Self-Care Efforts in Patients with Chronic Hepatitis", three themes were obtained, including effort for information seeking, negative attitudes about the disease, and inadequate resources (39). Fear of transmitting the disease to the child during pregnancy is one of the major challenges for patients. In a review article, Yogeswaran and Fung examined the challenges associated with chronic hepatitis B during pregnancy. They emphasized that the diagnosis and treatment of CHB during pregnancy is critical (40).

4. Discussion

The most important physical, psychological, and social challenges of people with hepatitis B are listed in this article. Each challenge seems to affect the other aspects of the patient's life. Psychological treatments have been provided in similar fields to treat physical, psychological, and social problems (41-43).

Although this review identified various issues related to physical, psychological, and social challenges in CHB patients, it did not show an extended overview of these challenges based on well-known theoretical models.

The majority of studies examined in this study reviewed the concepts of physical issues in patients with CHB, such as HCC, liver cirrhosis, and liver fibrosis merely through descriptive or retrospective studies. As a result, there is an absolute lack of studies with qualitative, experimental, or mixed methods since they have not been widely used in this area. In addition, few studies have been done on the development of concepts related to the physical, social, and psychological challenges as qualitative studies. The lack of empirical studies and mixed methods studies on psychological and social challenges, as well as the absence of theoretical frameworks in the studies reviewed, are the greatest disadvantages of these studies, which affect the validity of their results.

In a review of the studies examining the challenges of patients with CHB, these challenges had often been mentioned, but their causes had been addressed less frequently or superficially. However, validation of the results of these studies requires further investigation in experimental, qualitative, or mixed methods studies to find more precise causal relationships between the studied phenomena. Moreover, appropriate strategies should be consid-

ered to use the results of in-depth and extended studies and investigations to prevent these challenges in patients with CHB.

Considering the issues discussed as well as the findings of the reviewed studies, the following solutions are suggested for reducing the physical, psychological, and social challenges of CHB patients:

- Most patients were not prepared to hear “bad news” when diagnosed with the disease and had the feeling of anxiety and distress, which was largely caused by the patients’ poor knowledge and the physicians’ emphasis on complications and stigma of the disease. The patients were anxious due to the fear of being victimized and fear of losing social interaction and social stigma. They were also hesitant after the diagnosis of the disease about what to do in the future. Since there are no educational or counseling centers in Iran to meet the informational and educational needs of the patients, it is very important to establish such centers for the authorities to take action.

- Lack of proper information presented in the mass media, such as radio, television, and newspapers about the different aspects of the disease, can cause panic and worry in the patients and society. At the onset of the disease, the patients face many physical, psychological, and social challenges and are in real need of proper education and information to adopt appropriate strategies to cope with the disease.

- It is imperative for authorities to highly consider and supervise the governmental and non-governmental service providers to severely punish centers that discriminate between the patients and do not do their tasks or postpone it.

- The patients were aware of the supportive, advisory, and training roles of the professional staff at the time of diagnosis and referral to health centers. However, several patients reported that some of the attitudes and behaviors of the staff seemed completely offensive, discriminatory, and unexpected. Therefore, modifying the nature of this type of attitude or dealing with patients respectfully should be a top priority.

- Since patients and others people in the society have low levels of awareness about the disease, which has a great impact on people’s attitudes and the way they interact with the patients, it is recommended that health care providers and managers take measures for training and improving people’s levels of knowledge to improve the living conditions of patients and prevent the spread of the disease.

- The control and follow-up of hepatitis B impose high costs on the patients who are often individuals with a low socioeconomic status. Therefore, this factor should be considered by the authorities in different aspects, such as considering treatment subsidies or through the health insur-

ance system to help, by which patients can follow up and control their disease in a timely manner. Effective psychological treatments have been provided in Iran to address drug dependence and hepatitis C (44). This trend should be implemented for treating the psychological problems of hepatitis B.

- Based on the findings of this study, the patients reported that they had difficulty in finding a job in the public and private sectors and faces discrimination and rejection in recruitment tests simply because of the disease. Therefore, it is recommended that the government revise and repeal the pertinent laws and regulations and pass appropriate laws to protect these patients.

5. Conclusion

Patients with CHB experience many different physical, mental, and social problems. Understanding and supporting these patients is essential for effective treatment and making them able to live with minimal challenges and limitations. Healthcare managers and caregivers need to consider necessary plans to support their patients to deal with physical, mental, and social problems.

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Footnotes

Authors’ Contribution: Qanbari Qalehsari and Ali Zabihi analyzed and interpreted the data. Ali Zabihi drafted the manuscript. Ali Zabihi, Seyedeh Roghayeh Jafarian Amiri, and Qanbari Qalehsari revised critically the manuscript for important intellectual content.

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