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Contextual Factors Affecting the Social Interactions of Hepatitis B Carriers

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ABSTRACT

BACKGROUND AND OBJECTIVE: Hepatitis B is a great problem all over the world and due to its chronic nature influences on different aspects of life and affects people with many challenges in social life. Therefore, this research was conducted with the purpose of demonstrating and explaining the contextual factors affecting the social interactions of hepatitis B carriers.

METHODS: Using qualitative content analysis approach, a number of 18 chronic carriers of hepatitis B who referred to healthcare and counseling centers of cities of Babol, Amol and Tabriz were selected purposefully and were interviewed from 2014 to 2016 using unstructured and in-depth questions. All of the interviews were recorded, transcribed word by word and then were qualitatively analyzed.

FINDINGS: With data analysis, three main categories with subclasses including “rejection” (pathophobia, social stigma), “inadequate support” (lack of support, disease perception disorder and economic pressure) and “patient as the center of transmission of incurable disease” (contagiousness and incurability of the disease) were obtained.

CONCLUSION: According to the results of this study, various underlying and cultural factors lead to fear of people from hepatitis patients and avoiding close interaction with them.

KEY WORDS: *Context, Interpersonal Relations, Hepatitis B, Carrier State, Qualitative research*.

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Introduction

Hepatitis B is a major health problem in the world and one of the top ten causes of death in humans (1-4). Hepatitis B is a major cause of cancer and cirrhosis of the liver throughout the world (5). In the general population of Europe, the incidence of hepatitis B was reported to be between 0.1% and 5.6% (6). The prevalence of HBV infection in the Middle East is 2 to 5 percent depending on the region (7).

Recent research results show that the overall incidence of hepatitis B infection in Iran is less than 3% (8). According to a systematic review in 2008, the prevalence of hepatitis B in Iran was 14.2%, which varies across provinces (9). The most common ways of transmitting this disease are the transmission of mother to child, sexual relations, the use of injectable drugs and blood transfusion (10-12). Chronic hepatitis B disease usually requires management and monitoring throughout life (13).

Despite extensive efforts to provide health services to chronic patients, there are still some deficiencies in the quality of provision of health care to these patients (14). Also, people's awareness of hepatitis B disease is low and people have misconceptions about the disease. Low awareness of the people strongly affects their social interactions with hepatitis B patients (15). The results of a study showed that people do not have a positive attitude toward patients with hepatitis, and this leads to blame patients and ultimately leads to lower self-esteem and creating a challenge for patients and their families (16).

Another study showed that patients had experienced blame, violence, aggression and ugly social interactions by friends, health care staff, family and workplace (17). The majority of carriers of hepatitis B have no proper understanding of the disease, etiology, ways of transmitting disease, and care and treatment (18). In Wallace et al., The majority of participating patients did not have a good understanding of hepatitis B and stated that they did not have adequate resources for understanding and improving the health of patients and families (19). Studies have shown that chronic diseases have negative effects on self-esteem and interpersonal and social interactions (20). In a qualitative study, it has been shown that the risk of hepatitis B significantly decreases the physical, psychological and social health of patients It has social and psychological consequences and a decrease in the quality of life (21, 22). Regarding the chronic course of hepatitis, the set of environmental and existing factors leads to the emergence of issues and situations, and people show behavior or feelings toward patients this disease can have a large impact on the various dimensions of the person's life, especially the social interactions of the patients with others.

Methods

This qualitative study was carried out with a content analysis approach approved by the Tabriz University of Medical Sciences, with a code of 59.4 / 5, during two years (2014-16) on 18 carriers of hepatitis B after being informed by written consent. This method is generally used to describe a phenomenon that theories or research on the phenomenon is limited (23). Patients with a definite diagnosis of HBV viral infection and after at least six months of diagnosis, lack of severe mental disorders, ability to communicate and lack of severe physical problems were included.

The main criterion for the diagnosis was the HBsAg test and the doctor's approval. 18 participants were selected by targeted method and interviewed with deep and semi-structured interviews. The participants were selected through the introduction of experts from the centers, which had a list of patients in each region. The place of interview was determined by the opnion of the participants, health centers in Babol and Tabriz, and Liver and Digestive Disease Consulting Center in Amol city. The duration of each interview was 30 to 105 minutes and depended on the current situation and the interview. Participants were assured that the participation in this study was optional and that information would be used in compliance with the rules of confidentiality. Interviews continued until data saturation and lack of access to new information.

In this study, a set of open questions and pre-designed and related to the research topic to guide the flow of the interview were used. Include your experiences with Hepatitis B disease. How are people's views about hepatitis B disease? How do people interact with patients with hepatitis? What are the limitations of patients in the community? With the advancement of the study and the initiation of data analysis, classes have been created that determine the direction of the subsequent interviews and, given the response of the contributors to more specific questions, such as what you mean ... Explain this item .... Take an example. And so on. Content analysis was used to

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analyze the data. Initially, each interview was recorded by an audio tape, then all the words were typed word-by-word at the earliest opportunity and coded by MAXQDA10 software. Data analysis was performed simultaneously with data collection. The text of each interview was studied several times and, by breaking each text, the smallest meaningful constituent unit was extracted, coded and categorized. In the results section, the participant was shown with the letter "P".

Results

The study participants included 18 patients with HBV infection (10 males and 8 females) aged between 23 and 50 years old with an average age of 34.49±0.44 years and a mean duration of disease (43.3% 5.85±0.year). The way of transmission was unknown in 9(50%) patients, in 5 patients (27.8%) was from mother to child, in 3 patients (16.7%) was dentistry and in 1 patient (5.5%) was through tattooing. In this study, the diagnosis was often accidentally followed by blood donation and in female patients during routine pregnancy tests. The underlying factors affecting the social interactions of the hepatitis B carriers were expressed in three main categories and several subtypes and primary concepts (table 1).

Rejection: An undesirable and criminal attitude toward these patients and rejection behaviors from relatives, community, and health care personnel leads to blame and discrimination.

Pathophobia: Participants' experiences show that people's awareness of hepatitis B is low and patients around are avoiding the patient due to fear of getting an HBV infection. "From the point of view of society, all people are afraid of the disease, they are afraid, they are afraid of transmitting disease to them." (7P)

A public escape from a hepatitis patient: All contributors have said that there is a kind of panic among people in relation to hepatitis patients. "People flee from hepatitis patients, even if they encounter the patient, they come close to the person to shake hands, but they do not kiss us." (7P)

Avoidance behavior of family members: One of the common avoidance behaviors, especially from family and relatives, was the separation of devices such as spoons, glasses and utensils, especially, early in the diagnosis of the disease. "¬ ... Early in diagnosis of the disease, they separated the plate and food containers, for example, they did not use my glass." (13P)

Social stigma: In this study, people with HBV infection have often spoken of the concept of social stigma.

Stigma: Some contributors have said that people in the community, because of the inadequate view of the disease, look at it like AIDS and have erroneous judgment. "Others think what kind of person is and in what way it has taken the illness or is thinking about it badly, for example, they say they are addicted or have a special sexual relationship"(13P).

Look blaming: Patients stated that most people looked negative towards hepatitis patients and blamed them. "... Some people say because you are sick, do not come near us. They said, "Because you're sick, do not use my spoon and do not eat infront of us ..." (12P).

Inadequate support: One of the other main categories related to the conditions or field of influence on social interactions of patients was the factors related to inadequate support and limitations of their living environment.

Table1. Effective factors on the social interactions of the hepatitis B carriers

Main classes	Sub classes	Basic concepts
Rejection	Pathophobia	A public escape from a hepatitis patient
		Avoidance behavior of family members
	Social stigma	stigma
		Look blaming
Inadequate support	Lack of support	Inadequate government support
		Low news media
		Undesirable social support
	Disease perception disorder	Low awareness of people-patient personnel
		The false belief of people- patient -personnel
	Economic pressure	Costly disease
		Economic Poverty of Patients
Patient as the center of transmission of incurable disease	Contagious disease	Transmitting the disease to family members
		Transmission of disease to others
		Ways for disease transmission
	The severity of the illness	Incurability of the disease
		Probability of disease activation

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Lack of support: The majority of contributors have repeatedly, directly or indirectly emphasized the inadequacy of social support for patients with hepatitis B as one of the underlying problems of these patients.

1.Inadequate government support: One of the major problems for patients with hepatitis B has been inadequate government support. "... Since hepatitis is very costly, the government needs to take into account the facilities ..." (17P)

2.Low news media: One of the important reasons for the problems of these patients is the lack of information on hepatitis in the community. "I feel that if the media open and educate more about this disease, it will not happen again."(17P)

Undesirable social support: Another problem for patients with hepatitis B was poor community support. "The reason people behave badly about patients with hepatitis, maybe they think that the disease is being transmitted to them, and this thought is wrong, they have to support so the patient does not despair of life."(18P)

Disease perception disorder: The findings of this study showed that the level of understanding of patients, community members and health care staff about hepatitis B disease was low. Patients, especially at the early diagnosis of the disease, did not have the necessary knowledge about the disease.

Low awareness of people-patient personnel: The level of awareness of people about hepatitis B disease was low and most of them considered hepatitis B disease the same as AIDS. "I think that the bad behavior of others towards me is due to their low awareness, if they are well aware they will not be treated like this." (17P)

The false belief of people- patient -personnel: According to contributors, people's attitudes toward hepatitis B disease are often the same as AIDS. "People think about hepatitis like AIDS and avoid them." (13P)

Economic pressure: One of the most important issues for patients with hepatitis B is the economic problems associated with the disease.

Costly disease: Patients should spend a lot on follow up and treatment. "This disease is somewhat expensive, is a costly disease." (17P)

Economic Poverty of Patients: The majorities of patients are low-income businesses and have not had the proper financial support to treat their illness. "The cost of this disease is too high, and many people can not afford it because hepatitis B disease is very expensive."(17P)

Patient as the center of transmission of incurable disease: Due to the chronicity and the ability to transmit through the vertical and horizontal of the hepatitis, the disease can affect the different dimensions of the life of the patients.

Contagious disease: The possibility of transmission of disease to family members and others has caused limitations in the social interaction of patients with family members and community members.

The transmission of disease to family members: There was no good interaction between them in some patients due to the fear and the possibility of transmission of disease to family and spouse. "It was just like when my spouse told me you had hepatitis and we can not live together. This disease may be passed on to me. "(3P)

Transmission of disease to others: Contributors stated that fear of transmitting illness was one of the reasons why people were fleeing from them. "If others get informed about the disease, the relationship will be less, because they think the disease will be transmitted to them "(1p).

Ways for disease transmission: The similarity of the way of transmission of hepatitis and AIDS has caused patients have problems with their interactions. "People think about hepatitis like AIDS, from the perspective of the society hepatitis and AIDS, are equally recognizable, and people are avoiding patients."

The severity of the illness: In most cases, hepatitis B virus can exist in the body for many years and the patient does not find a liver problem. Also, in some people, the disease may recur again and the activity of the virus begins again.

Incurability of the disease: In this study, some contributors stated that hepatitis is an untreated disease that affects their various dimensions of life. "I was crying and upset, I said that the disease is cancer, permanent and deadly." (17P)

Probability of disease activation: In the absence of treatment, follow-up tests and self-care, the disease may progress again. "I was afraid and I was worried that the disease might become active again and the liver stops working and be a trouble for my families."(2P).

Discussion

The results of this study showed that there is a kind of panic among people in relation to hepatitis patients, and people were afraid of patients for various reasons, such as lack of awareness and misconceptions and misunderstandings, and avoided close interaction with them. As in the present study, Hopwood's study also has issues such as tagging, discrimination, exclusion or dismissal, insulting, and humiliation of the most commonly occurring behaviors in patients with chronic hepatitis (24). According to the results of the studies, low awareness of the people and their negative attitudes are the basis for the formation of false and

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unknown fears (25, 26), therefore, the officials of the organization have to organize educational classes in order to promote the level of public awareness.

In this study, among the common avoidance behaviors of the family and relatives of the patient was to separate the equipment, such as spoons, glasses and dishes of the patient and avoiding close contact with patients. In this study, it was shown that patients were not aware of the vertical transmission pathways of the disease, and the majority of patients believed that hepatitis B disease was transmitted through saliva and should avoid eating with patients, sharing the dish, and communicating closely with patients (26). Contributors stated that social stigmatization of this disease was due to a lack of awareness of the community.

In another study, the low level of public information about HBV infection and inappropriate understanding of the ways of transmitting the disease and the fear of transmitting disease to others resulted in unsatisfactory social behaviors (25). With regard to the above, patients are faced with issues such as stigma, discrimination, blame, etc. while interacting with others, and, given the existing cultural and social environment, can provide psychological support to patients in the community and in the health care system it can be of particular importance. Participants in interviews repeatedly emphasized the low or no social support of hepatitis patients as one of the main problems of these patients. The results of a study showed that support of family, friends, health care personnel and public and private institutions was essential for these patients (27). One point to be taken into consideration is that discriminating between patients and not performing medical and dental services for patients with hepatitis is not only contrary to the basic rights of humans and especially patients, but also ethically is not acceptable. Therefore, monitoring of public and private service centers and dealing with offenders is imperative for authorities to focus on. In this study, one of the important underlying factors was the low level of information about hepatitis.In the study of Hassanpour Dehkordi et al., The lack of information was referred to by the media, and there was no central point for patients with hepatitis to go there and to meet their educational and information needs (28).

Failure to properly inform by media about this disease can cause fear and panic among the patients and the community. The economic problems associated with the disease, the costs of follow-up tests, treatment, travel costs etc. were one of the most important problems for patients, and they were faced with complicated conditions. Other studies also found that most of the patients did not have a good financial position due to lack of job or dismissal from work (28, 29). Unlike AIDS patients who benefit from state-sponsored aid, hepatitis patients should pay for their illness, and some have been reluctant to treat their illness due to lack of adequate funding.

Therefore, with regard to the high cost of hepatitis B and the economic weakness of most patients, governments should prioritize issues related to hepatitis patients. An important feature of hepatitis B disease is the transmission of disease and its chronicity. In the study of Mohammadalizadeh et al., the most common concern of chronic hepatitis patients were, transmission of disease to family members (80.6%) and transmission of disease to others (66.7%) (30). As with the results of this study in another study, the important concern of patients with hepatitis B was the risk of transmitting disease to family members and friends, and thus avoided close communication with others (24). Other features of the hepatitis B disease are incurable and the possibility of disease progression. In the study of Lee et al., The majority of hepatitis B patients had negative emotions that they had a chance of disease progression (25). In another study, all patients considered chronic hepatitis B disease as an incurable disease, and the majority of patients had fear of transmitting disease to family members and others (31). In this study, patients were unwell due to the incurable and the possibility of exacerbation of the disease that had a negative effect on communication with others. The limitations of this study were probably the lack of positive attitudes about hepatitis B disease due to the conditions of the interview. According to the findings of this study, low level of people's knowledge and inappropriate understanding about ways of transmitting disease and fear of transmitting disease to others leads to inconvenient social behaviors with these patients and patients were confronted with such things as stigma, discrimination, blame, and so on. Public media, such as radio, television and newspapers, can play an effective role and have proper planning for infectious diseases, especially for hepatitis B, and to provide accurate information. Considering government support programs, the community, the media and personnel have a special place in the lives of patients.

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