



## Hepatitis-related stigma in chronic patients: A qualitative study



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### ABSTRACT

*Background:* Hepatitis is one of health problems throughout the world. It has numerous consequences on patients' life. Stigma, depression, social marginalization and financial problems are some of the challenges in these patients.

*Aim:* The purpose of this qualitative study was to examine hepatitis-related stigma and discrimination in patients living with chronic hepatitis in Iranian society.

*Methods:* This present study was designed as a qualitative method, and this article shows up the results of a qualitative research study undertaken with patients living with hepatitis in Iran. The study uses a content analysis method. A purposive sample of 18 patients was chosen. Data were collected through a semi-structured interview and field note that the researchers will take during participants' observation. Data analysis process was performed on the texts which were generated from verbatim transcripts of the participants interviews.

*Results:* Participants were between 18 and 61 years old. The main theme, Stigma, emerged from three themes during the process data analysis in this study. These themes were including fear to lose of family and social support, fear to present in public and fear of transmission.

*Conclusions:* This research indicates that stigma presents major challenges not only for patients living with chronic hepatitis but also for nurses, other healthcare practitioners, family and social networks, institutions and society. The researcher suggests that interventions to reduce or eliminate stigma should require individual, structural, cultural thought, society and systemic changes.

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## 1. Introduction and background

Hepatitis is a systemic and chronic viral infection which involves the liver. Hepatitis B is one of the common types of hepatitis and it is considered as one of the world's health problems (Mohammadi, HassanpourDehkordi, & NikbakhatNasrabadi, 2013). According to the published reports, it is estimated that between 350 and 400 million people suffer from hepatitis B around the world (Alavian, Hajarizadeh, Ahmadsad-Asl, Kabir, & Bagheri-Lankarani, 2008; Sievert et al., 2011). The prevalence rate of hepatitis B varies largely in different countries ranging from 1.2 to 9.7% (Sievert et al., 2011). In Iran, it is estimated that currently 1.5–2 million Iranians suffer from hepatitis B (Saki et al., 2013). The incidence rate of hepatitis B is estimated to be 2.14% of general population. In addition, the incident rate of hepatitis B among Iranian men and women is reported to be 2.55% and 2.03% respectively (Saki et al., 2013).

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Hepatitis C is another type of hepatitis causing chronic disorders in liver (Khan et al., 2013). It is estimated that about 180 million people around the world are infected with hepatitis C virus (Mohd Hanafiah, Groeger, Flaxman, & Wiersma, 2013). Like hepatitis B, the prevalence of this type of hepatitis varies globally ranging from 1% to 5% of the general population (Sievert et al., 2011). In Iran, the prevalence of hepatitis C is reported less than other eastern mediterranean region countries, and its prevalence rate is estimated about 1% of general population. Hepatitis C has high mortality rate among other types of hepatitis and causes at least 20% of deaths in patients with hepatitis (Alavian et al., 2009).

The chronic nature of hepatitis has many consequences on patients' life in particular during possible transmission of the disease to vulnerable people. In the published literature, there are many examples of persons with hepatitis being evicted from their homes, their jobs, and rejected by their families, friends and neighbors. Stigma, depression, social marginalization and financial problems are some of the challenges in these patients which occur due to the complications of the disease and unknown fear in the patients and their families (Cotler et al., 2012; Kraus, Sehter, Csef, & Scheurlen, 2005; Mohammadi et al., 2013). Stigma and discrimination has been reported in association with chronic hepatitis in the literature (Cotler et al., 2012). However research on hepatitis stigma and discrimination is limited in the literature (Butt, 2008).

Stigma is one of the major problems influencing the self-care activities (Treloar, Rance, & Backmund, 2013). It is an important attribute of the experience of living with chronic diseases (Bockting, Miner, Swinburne Romine, Hamilton, & Coleman, 2013), particularly when it is associated with the possible transmission of the disease to vulnerable people (Stangl, Lloyd, Brady, Holland, & Baral, 2013). The experience of stigmatization has been identified by researchers as one of the most significant issues facing people who are hepatitis C positive (Treloar et al., 2013). Stigmatization of people who suffer from hepatitis C within health care is a concern not only because of its pervasiveness across all health care disciplines (Butt, Paterson, & McGuinness, 2008).

There are also widespread reports of discrimination against people who suffer from hepatitis C in nursing homes, health care settings, hospitals and clinics (Butt et al., 2008). In one research study majority of respondents with hepatitis C reported that they had been discriminated by health care workers (Zacks et al., 2006). In another study involving only injection drug users (IDUs) with hepatitis C, more than 90% of the respondents indicated they had experienced discrimination enacted by health care staff (Harris, 2009).

In the last 20 years, most of the research on chronic disease stigma and discrimination has focused on the attitudes of uninfected persons toward people living with HIV/AIDS, the role of stigma in HIV/AIDS-related laws, health care policies, interventions to increase tolerance, and understanding why HIV/AIDS is so highly stigmatized (Greeff et al., 2008).

Little knowledge is available in the literature about hepatitis-related stigma and discrimination, and there are limited studies using a qualitative method to examine hepatitis-related stigma and discrimination in patients living with chronic hepatitis particularly in Iran. Therefore, it needs to conduct more studies to expand the knowledge of hepatitis-related stigma and discrimination. The purpose of this study was to explore hepatitis-related stigma and discrimination in patients living with chronic hepatitis.

## 2. Materials and methods

A descriptive qualitative research method was used to conduct the present study, and it took place from March 2012 to May 2013.

### 2.1. Participants and recruitment

Selection criteria of participants were aged between 18 to 61 year-old, living with chronic hepatitis B or C for at least 6 months, able to participate in the face-to-face interview; and consent to participate in the study. Participants recruited through a purposeful sampling method from counseling office in the health care centers. Participants were recruited through different recruitment strategies including poster and flyer distribution, key people and direct contact in the health centers. Posters and flyers were distributed at counseling offices in the health centers, local hepatitis service organizations and medical clinics. Information on the posters and flyers briefly stated the nature and purpose of the study and encouraged interested participants to contact the researcher.

The first contact with the study participants was made by the principle researcher. The researcher explained the level of involvement of participants and answered to any potential questions of the participants. The researchers also explain the need for audio-taped interview in order to have an exact recording of their experience that would assist the researchers in analysis of data. Also the risks and benefits of the study, measures taken to ensure confidentiality, the voluntary nature of participation, ability to withdraw from the study without penalty and research data protection procedures were discussed during the informed consent process.

Participants were 18 people (83% male and 17% female) with chronic hepatitis, aged between 18 and 61 year-old ( $37 \pm 4.25$ ). Table 1 presents more demographic characteristics detail of participants.

### 2.2. Data collection process

In this study, data were collected through a semi-structured, in-depth interview and field note that the researcher's took during participants' observation. The location for the interviews was in a quiet room in the counseling office in health centers or local hepatitis service organizations. The participants informed that they could have a close family member or friend during the interview, if they preferred. In addition, participant completed the consent form prior to the audio-taped interviews. The researchers began the interview with an informal talk. The purpose of this informal talk was to establish relationship with the participants in order to build trust. There is no formal protocol to follow with specific questions asked.

Following questions were used as guiding questions during interviews. "What does hepatitis mean to you?"; "Did you face difficulty in relation to your illness?" "What should the attitude towards hepatitis management be"? "How has hepatitis affected your life"? And how is your social life affected by your disease. Towards the end of every interview, the researchers afforded each participant the opportunity to add anything to the discussion by asking the following question: "Is there anything else that you feel is relevant and you would you like to add?"

The interview sessions ranged from 40 to 65 minutes. Each interview transcribes verbatim into a word processor as soon as possible. Following verbatim transcription, the researchers read the transcripts while listening to the tapes to check accuracy of texts prior to analysis. Then the researchers commenced the data analysis process on the written transcripts.

### 2.3. Data analysis

Data analysis was done through a constant-comparative thematic analysis. The first stage of the analytic process was preparation of an interview guide including broad and open-ended questions which enabled the participants to express their viewpoint comprehensively. In the second stage, all the transcripts were read several times, and all transcripts were examined line by line to identify the participants' descriptions of thought patterns, feelings, and actions related to the themes mentioned in the interviews. Then the text about the participants' experiences of having hepatitis was extracted and brought together into one text, which constituted the unit of analysis. The text was divided into meaning units that were condensed. The condensed meaning units were abstracted and labeled with a code. The codes derived were formulated in words used by the participant; this was an attempt to maintain the semantics of the data. The codes were sorted into categories and sub-categories, which constitute the manifest content. The tentative categories were discussed by researchers and revised. What differed between the researchers was their judgment about what comprised familiar and un-

**Table 1**  
Characteristics of the participants.

Participants interviewed (N = 18)	
Gender	
Male	15 (83%)
Female	3 (17%)
Age (year)	
Mean	37 ± 4.25
Education	
Did not complete high school	11 (61%)
High school diploma	6 (33%)
Postsecondary	1 (6%)
Source of infection	
Needle-stick or work exposure	1 (6%)
Illicit drug use	10 (55/5%)
Blood transfusion	2 (11/11%)
Unknown	5 (27/4%)
Economic status	
Week (less than \$200 per month)	10 (55%)
Moderate (between \$200 to \$500 per month)	6 (33/8%)
Good (more than \$500 per month)	2 (11/2%)

familiar sensations and actions. A process of reflection and discussion resulted in agreement about how to sort the codes. Finally, the underlying meaning, that is, the latent content, of the categories, was formulated into a theme.

#### 2.4. Study rigor

Researchers utilized the assessment criteria of Guba and Lincoln. For this purpose, numerous methods were used to examine the credibility of data such as check member, peer debriefing, searching for disconfirming evidence and prolonged engagement with data. Transferability was considered by having a team. The final categories were determined by the entire study team. The research methods were employed and carefully elaborated that readers could follow the research process. Finally conformity was assessed by researcher attempts to mention all steps of the research, to enable reader to pursue data.

#### 2.5. Ethical approval

The study had been approved by the Ethical Committee of Tehran University of Medical Sciences. Participants ensured about keeping personally identifiable information confidential and to keep the transcriptions anonymous and the audiotapes secured. Participants also filled out a written agreement for participation to the study and recording the interviews. All the participants signed a written consent form at the beginning of the interview.

### 3. Results

In the process of data analysis, stigma was the main theme that emerged from the participants' interviews. Stigma emerged from three sub-themes including fear to lose of family and social support, fear to present in public and fear of transmission.

#### 3.1. Fear to lose family and social support

Fear to lose family and social support was one of the consequences of stigma in the participants. Participants believed that they would lose the support of family and friends if their family knew that they have hepatitis. Therefore they were always feeling that they would be humiliated by family members and friends if they know the participants' illness. For example, one of the participants told me:

*When I found out that I had hepatitis, I was worried ....I cried frequently and didn't know how to inform my husband about my status. I was worried about what he would think, that maybe I had contacts with other men. I was thinking that it could be shame to have hepatitis from my family perspectives.*

Participants' fear had diverse meaning and perception of lost family and social support. For some of the participants, lost family and social support was changing the way their family members and friends behaved with them. As a participant said, "My wife didn't communicate with me. Didn't have meal with me, avoided me and was severely frightened...". However, it was a threat for some other participants that they would be divorced. The following manuscript has been taken from one of the participants. He pointed out that "She divorced me when she knew I have hepatitis. ....I thought hepatitis is like flu, I did not assume that people like my wife recognize hepatitis as a embarrassing illness!!!".

Fear to lose social support was expressed as fear of the misbehavior and misconduct of healthcare professionals. Participants explained that they were feeling that health professionals do not like to look after patients with hepatitis. Therefore they would neglect them if they know they have hepatitis. The following text from one of the participants provides a typical example.

*As soon as my surgeon found out that I have hepatitis, he got reluctant to do surgery. At that time, I thought how bad is my illness that my surgeon does not like to do surgery any more!*

Other participants added that

*When I had fracture in my leg, I was admitted to the hospital. After admission, I said to the doctor that I have hepatitis. He did discharge me from hospital right away and asked me to go to governmental hospital. I was feeling bad after discharging from hospital. I went to another hospital and did not tell the health professional about my illness.*

Participants will easily solve their problems when they are supported by others. Additionally, husbands and family are important sources of encouragement, also health professionals, including nurses, are significant roles in the acceptance and support.

#### 3.2. Fear to present in public

Majority of participants believed that publics had a negative attitude towards hepatitis. Therefore they were unwilling to go to public and be socialized. For example, the following statements were taken from one of the participant's interview.

*People think that hepatitis is look like a dragon! Because of such negative perception among people, I prefer to stay home and not going out. I always get uncomfortable when I see people stare me. That is why I keep my illness as a secret.*

*"Because people think hepatitis means stigma, I always send my mother, instead of running the errand myself to the Health centers to fetch my drugs.*

Some of participants pointed out that hepatitis has destroyed their social life and they insisted that public avoid to interact with people who suffer from hepatitis. This quotation is taken from one of the participants.

*"People think hepatitis is something worse than drug addiction and vampire. ....People cannot stand a patient with hepatitis."*

Negative feelings and moral judgments of those with hepatitis by healthcare providers, family, friendship networks and society serve as socially surrounded controls that set the person separately from society and hide his or her disease.

#### 3.3. Fear of transmission

Stigma was a consequence of fear of transmission. Participants believed that fear of transmission among family members, relative and friends originated from lack of knowledge about the transmission of routes of hepatitis.

*I always was going out with my friends for coffee and dinner. ....since I told them that I suffer from hepatitis, everybody refuse to go out with me. They also avoid shaking hands with me. Even if I see them in coffee bar or restaurant, they suddenly leave there. They don't know shaking hands is not the way to transmit hepatitis. ....you know it's not just my friends, I know even my brothers are unwilling to shake hands with me.*

One of the participants added that his wife gets very upset when he held or kissed their baby. He also explained that she avoids children to eat meal when I am eating. The following excerpts are an example which was declared by one of the participants. "When my wife found that I have hepatitis, she try to keep a distant with me. She ask me to use disposable cutlery and dishes. She discards them after I used."

Participants were always concerned if their family members, relatives and friends were infected with hepatitis; they would be embarrassed. "I



can understand from the way my wife look at me that she is worried about virus transmission. I explained her that the virus doesn't transmit if I use condom."

#### 4. Discussion

In this study, one of the themes was fear to lose family and social support that contributed to stigma for chronic hepatitis patients. Participants' statements about access to care and support resources were insufficient (Maria et al., 2010). The family is an important source of care and support for patients with hepatitis (Maman et al., 2009a). The results of the current study were similar with other studies (Greeff et al., 2008; Holzemer et al., 2007). Also Fife and Wright reported that women with HIV/AIDS are hesitant to access health care for fear of discovery. They are unwilling to take medications and nursing service that identify them as being ill and require explanations. They feel obliged to tell the health care professional but worry that their confidentiality will be breached or the provider will reject and mock them (Fife & Wright, 2000).

The participants in this study were hesitant to inform others about their illness because they fear rejection by family members, relatives and friends. This was not limited to family members and friends but also included health care providers and employers. This hesitancy presented a barrier to their seeking health care and both formal and informal support. Taking medications and maintaining employment while not disclosing their hepatitis status required that they make choices regarding medication (Cotler et al., 2012). Therefore, these challenges had the potential to limit their access to health care, social support, medications and employment. Previous studies have described how poor access to health-related resources is associated with stigma and is a powerful expression of stigma in settings where communities feel overwhelmed in caring for people with HIV (Maman et al., 2009b). The nurses who provide counseling or therapy to chronic hepatitis people can help them make informed decisions about the risks and benefits of status concealment. Chronic hepatitis people who feel seriously stigmatized and use more hiding strategies will likely experience increased stress and risk closing off access to the social support needed to facilitate adaptation to the illness.

Fear to present in public was another sub-theme to lead hepatitis-related stigma. The result showed that stigma management was highly dependent on social context. In this study, most of the participants remarked that the stigma has devastated their life, making them frustrated, depressed and isolated. They insisted that they were hiding their own disease. The results of the study are consistent with previous research showing that hepatitis patients seek to find hiding strategies to protect themselves from stigma (Bockting et al., 2013; Treloar et al., 2013).

Fear of transmission was the most common report cited the withdrawal of care, support, or services by health care practitioners. It involves refusing to care for the person with chronic hepatitis by health professionals. For example, some participants indicated that nurses and doctors were reluctant and took a step back when they found out that they suffer from hepatitis. Findings in other research indicated that the majority of patients are not given dental services. Other studies, also, suggest that the health professionals who deal with hepatitis or HIV patients are discriminatory and unwilling to provide health service to patients with hepatitis. In relation to difficulties in patients' access to health services, studies found out that health professionals behave differently with patients who have hepatitis (Stangl et al., 2013; Treloar et al., 2013).

Nurses and health team have important role to help these group of patients to adapt with their own illness. Patients with chronic hepatitis need counseling for a range of issues including being labeled, inadequate knowledge, hopelessness, physical, economic and psychological difficulties. However hepatitis-related stigma hides them to seek for health care support and counseling. Other studies also revealed that people who experience stigma, need health professional support (Bockting et al., 2013; Maman et al., 2009a). In addition, it has been revealed in many studies that lack of knowledge, frustration, physical, economical

and psychological challenges can intensify the effect of stigma on patients (Butt et al., 2008; Mohamadpour, 2010).

#### 5. Conclusion

Stigma is a complex social construct that is influenced by biopsychosocial, cultural and economic factors. Chronic hepatitis-related stigma is an emerging concept with relevance to the stigma of other infectious diseases. However, the central and distinctive features of chronic hepatitis-related stigma in Iran are lack of health care and support system special in patients living with chronic hepatitis, inadequate or loss of knowledge, and negative attitude. Chronic hepatitis-related stigma indicates that stigma presents major challenges not only for those with chronic hepatitis, but also for health professionals, family and social networks, institutions and community. The researcher suggests that interventions to reduce or eliminate stigma will require individual, structural, cultural thought, society and systemic changes. Health care system team should develop interventions in order to eliminate the chronic hepatitis-related stigma and reduce fear of hepatitis among people in the community through public education.

#### Conflict of interest

The authors of the present work declare no conflict of interest.

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