

## Iranian Patients with Chronic Hepatitis Struggle to Do Self-Care

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**Abstract:** Background: Hepatitis is a systemic infection which has many consequences on patients' life because of its chronic nature. Patient involvement in doing self-care is crucial for patients with chronic hepatitis in order to change their behaviours towards a healthy life style and to increase the own quality of life. The purpose of this study was to explore how chronic hepatitis patients to do self-care activities. Methods/Design: This present study was designed as a qualitative method. It is undertaken with patients living with hepatitis in a metropolitan city in the Iran. A purposive sampling method was used to recruit 18 participants. The study participants were at least 18 year-old. Data was collected through a semi-structured interview. Data analysis process performed on the texts which generate from verbatim transcripts of the participants interviews by using thematic content analysis. Results: The core-theme for the study was struggling to do self-care activities. There were three themes derived from data including seeking information with difficulties, negative perspectives of hepatitis among people and insufficient resources. Conclusion: Chronic hepatitis presents major challenges for patients with chronic hepatitis to do self-care activities. Providing appropriate information, changing negative perspective of society on hepatitis and provision sufficient facilities help Iranian patients with chronic hepatitis to do self-care activities appropriately.

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### 1. Introduction

Hepatitis is defined as a chronic systemic infection which involves liver. It is a common health problem in developed and developing countries. Hepatitis B and hepatitis C are the two common types of chronic hepatitis (Brenner et al., 2008). Hepatitis B is considered as one of the worldwide health problems. There are about 400 million people who suffer from chronic hepatitis B globally (McMahon, 2008). The prevalence rate of hepatitis B varies largely in different countries ranging from 1.2 to 9.7% of general population (Adams et al., 2010). In Iran, the incidence of hepatitis B has been reported 3.5% of the general population in the last report (Alavian et al., 2007a). It is estimated that there is currently 1.5–2 million Iranians suffering from the chronic hepatitis B (Alavian et al., 2007b).

Hepatitis C is another type of chronic hepatitis. World Health Organization reports that there is about 170 million people with hepatitis C in the world. Like hepatitis B, the prevalence of this type of hepatitis varies globally ranging from 1 to 5% of general population. In Iran, its prevalence is less than other countries in Eastern Mediterranean Region. The prevalence rate of this type of hepatitis is 1% of general population. Hepatitis C have high mortality rate among other types of chronic hepatitis. Hepatitis C causes at least 20% of deaths in patients who suffer

from chronic hepatitis (World Health Organization, 2003).

Because of the chronic nature of hepatitis, it has many consequences on patients' life. Depression, social marginalization and economical difficulties are some of the problems in these patients which occur due to the complications of the disease and unknown fear in the patients and their families (Kraus et al., 2005). Since the most undesirable effects of chronic hepatitis can be controlled by self-care behaviours (Sakhayi, 2005), self-care measures have an essential role in the management of patients with hepatitis. The involvement of these patients in self-care programs helps them to change their behaviours towards a healthy life style and to increase their own the quality of life.

The theory of self-care was developed by Orem in 1956 (Akyol, 2007). She points out that self-care activities can help individuals to maintain and promote their own health. Orem understands human and environment as a unity which has mutual effects on each other. She believes that humans should care themselves independently and be responsible for their own care. For Orem, individuals can learn self-care and dependent care behaviours within a socio-cultural context (Lin et al., 2004).

Performing self-care activities and measures is essential in patients with chronic hepatitis (Walsh and

Walsh, 1989). And influence on the severity of hepatitis (Pojoga et al., 2004). Self-care activities also can decrease the duration of hospitalization and re-admission (Gary, 2006). In addition, doing self-care activities increases self-confidence and use appropriate adaptation mechanisms in patients with chronic hepatitis. Consequently, the feelings of hopelessness, fear, distress and mental pressure reduce in these patients (Reisi, 1997). There is limited knowledge how self-care is and how people who suffering from chronic hepatitis do self-care activities. The purpose of this study is to explore how patients with chronic hepatitis experience self-care in their daily life.

## 2. Methods and Design

A qualitative research method was applied to conduct this study. The study was approved by the Ethical Committee of Tehran University of Medical Sciences .A purposeful sampling method was used to recruit eligible participants from a large clinical setting into the study. Eligible participants were individuals who suffered from hepatitis B or hepatitis C; they were at least 18 year-old and were agreed for face-to-face audiotape interview. In order to recruit participants, the researchers identified eligible patients as potential participants and contacted with them. In the first contact, the researcher explained participants' level of involvement and answered to their questions. The researchers also clarified the need for audiotape interview for an exact recording of their experience which audiotape interview assists the researchers in analysis of data. At the end of first meeting, the researcher organized another meeting for face-to-face interview with participants who were happy to be involved in the study. Recruitment of the participants continued until data saturation was reached. Finally, eighteen participants were recruited.

A written Consent Form filled out and signed by the participants. For recording interviews, they declare their agreement. The participants were ensured that their remarks will be maintained as secret and no one but those involving in the research could have access to them. The participants' names are known only for the researcher and referees, as a result pseudonyms used in this study. The participants were ensured to have permission to stop participation whenever they want.

Data was collected through a face-to-face semi-structured interview with each participant and field note that the researchers took during participants' observation. Using open-ended questions during interview provided the opportunity for the researcher to engage with participants and rich disclosure. The location for the interviews was at the discretion of each participant. The participants informed that they

could bring a close family member or friend with them to the interview meeting, if they desired. In addition, the participant Consent Form was completed by each participant prior to commencing the interview.

In order to establish rapport with the participants and build trust, the researchers began the interview process with an informal talk and allow the participants to be comfortable with the researcher and the data collection process. At the beginning of each interview, the researcher asked the participants to talk briefly about their illness and daily life. The question posed was: "Please tell me about your illness and its effects on your daily life?" Then the participants asked to explain their needs and the activities which they do for these needs.

As the interview was semi-structured, there was no formal protocol to follow with specific questions to be asked. However a certain specific questions used during data collection process to keep the interview focused on the research purpose. Examples of these questions are: "How long are you suffering from hepatitis?"; "Did you face difficulty in relation to your illness?" Towards to 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?" After this the interview was concluded.

One session, which took 40 to 65 minutes interview, was done to collect data from each participant. Each interview transcribed verbatim into a word processor as soon as possible to allow data analysis on the written transcripts. Following verbatim transcription, the transcripts were proof read while the researchers were listening to the tapes in order to check accuracy prior to analysis. The verbatim transcriptions were consecutively analysed. For this purpose, the researchers commenced the process of collecting data and thematic content analysis in parallel.

At the first step, the researchers were involved to have a comprehensible sense of the transcriptions. Then the researchers did open coding on transcriptions. The researchers examined data line by line to identify the participants' descriptions of thought patterns, feelings, and actions related to the mentioned themes in the interviews. The derived codes were formulated in the words used by the participation to maintain the semantics of the data. Open coding continued until categories emerged. The researchers carried out the consequent coding to categorize the derived codes. For this purpose, the codes were sorted into categories through constant comparison between categories, codes, and interview

protocols. Then the researchers fitted the categories into a larger category in order to make a core theme.

Different strategies were used for rigor in this study. The strategies were reflexive debriefing, prolonged engagement of the researcher with the data and member checking. In addition, randomly selected transcripts were exposed to an independent audit trail to confirm categories and verify that sufficient data existed to support the study themes.

### 3. Results

The core theme which emerged in the data analysis process was 'struggling to do self-care activities'. For all participants, self-care was playing a significant role in their life. As one of the participants said to me "It's me to do some things to look after myself. I could not expect someone else help me to look after me". Another participant points out "I know well, even having the best treatment from health setting is not useful as much as doing something to look after myself".

Although they were aware how self-care can help them, they were struggling to do self-care activities. This is a typical statement from one of the participant that shows how she was struggling to receive useful information to look after herself. She states that "I don't know how I can help myself or I should look after myself while no one [Health professional] talk to me about these issues. Everybody [Health professionals] says different things to me". The following quotation has been taken from another participant. He expresses "I like to do everything that can help me to get better, but when people treat me like rubbish. ...I doesn't like to do anything when I feel that I am rubbish".

Struggle to do self-care activities in this study emerged from three sub-themes including 'seeking information with difficulty', 'negative perspective of society' and 'insufficient resources'. The following section discusses these sub-themes.

#### Seeking information with difficulty

Seeking for knowledge was the first sub-theme which extracted from participants statements. For participants in this study, lack of knowledge due to inaccurate information was a source which caused the participant to have trouble to do self-care activities appropriately. For example, one of the participants told me that I'm married, but I have no information about a safe sexual activity. One of my friend said to me that it doesn't matter if you have no safe-sex with my wife because she has not AIDS and I should consider safe-sex when I have partner with AIDS. I don't know where I have to find this information.

Following quotation is from another participant. "...I asked been to separate my cutlery to keep others

safe. But I am always worried about myself'. Participants were seeking for a wide range of information in regards to physical, psychological and social issues. This excerpt is from another participant. He says "I don't know what I have to do for looking after myself. I don't know what I have to eat; what I have to do when I am in public; what is good and what is bad for me".

Although participants were keen to obtain accurate and proper information, some of them had inaccurate information about self-care measures. Having inaccurate information was hindering the participants to look after themselves appropriately. As an example, one of the participants stated "...the staffs in the Hepatitis Consultant Centre said to me that I never get cure, so why I have to see my doctor regularly every six months if I never get cure". Another participant said to me "I have been informed that hepatitis is a disease which patients should limit their social relationship".

The participants believed that health professionals do not spend enough time to teach them. Thus it was the main reason why they receive inappropriate or insufficient information. This excerpt is one of the example that health professional did not provide information appropriately to the participants. "...there are too many patients in the Hepatitis Counselling Centre. Health professional has no time to talk to us". The following quotation is another example that one of the participants think he did not received enough information. "I have been asked to use condom when I have sexual contact, but I don't know why I have to use it because I am already sick".

#### Negative perspective of hepatitis among people

Another sub-variable that impacts on participants' self-care activities was negative perspective of hepatitis among people in the Iranian society. Most of the participants believed people have negative perspective to hepatitis and patient with hepatitis. They believed that hepatitis is a dreadful phenomenon from Iranians' perspective. One of the participants who was thinking that AIDS is a dreadful disease pointed out that "People suppose that hepatitis is the same as AIDS, I hate it". Another participant said to me "Iranians accept individual who is addicted more easily than someone who suffers hepatitis".

Negative perspective of people in the Iranian society on hepatitis causes a disillusioned feeling among participants. This quotation has taken from one of the participants. "Hepatitis is not a physical illness. All of my life is affected by hepatitis. It makes me really unhappy when I see people are not communicating me because I have hepatitis". For

some of the participants, negative perspective of society on patients with hepatitis was an important factor which influence on their self-care activities. "I always ask my mother to go to the health centre to collect my medication because I did not the way treat me appropriately. Sometimes I ask myself why I have to take the medication if I could not feel okay to go there."

Participants had explained the experiences of isolation; stigma and insult in their story due to negative perspective of people to hepatitis. The following excerpts are examples of these experiences by the participants. "I'm deadly afraid to get pointed by others. If someone suffer from a disease other than hepatitis, she/he lets others to know that without any consideration, but I am scared to tell people around myself about my illness, even my close friends, because they will stop to have relationship with me. [This is why] I don't like go out". Another participant pointed out "I am terrified to say people that I have hepatitis because they run away from me".

One of the participants says how she had been stigmatized due to hepatitis. "I got hospitalized for leg fracture. I told the doctor I have hepatitis. He didn't perform surgery for me. I was forced to leave that hospital without surgery". This is an example of insult experience by the participants. "People consider patients like me as rubbish and call us 'risky people'. I heard it when one of my colleagues was whispering to another one". Following statement from one of the participants is an example how the participant had been insulted. "One day my brother was arguing with someone while I was next to him. The person who had argument with my brother said to him 'go to the hell with your brother that has hepatitis'. I felt it is shameful if you have hepatitis".

#### **Insufficient resources**

An insufficient resource is another sub-variable of struggle to do self-care activities. An insufficient resource is a broad range of problems which represents several factors including limited health care facilities, difficult access to health care services and financial resources. The participants say that the provided health care services were not enough to support their need. One of the participants told me that "the Hepatitis Counselling Canter do not do anything for us. They just ask us to go there every six months. When I go there, they do really nothing. I spend my time to go the Hepatitis Counselling Canter to know how my health condition is, but my doctor says to me you are okay. I know he see many patients, but I like him to talk to me and let me know what I should do for myself". The participants had difficulty to have access health canter services. They

believed that there is limited facility and service to support patients who suffer hepatitis. This statement is one of the typical instances that the participant had difficulty to get information due to limited facility. "The consultant in the Hepatitis Counselling Canter said I don't need sexual education because I am single. ...Since there is just one educator in the Centre, sexual education is given only for married clients".

One of the typical examples of financial problem is coming in the following excerpt. "The cost of hepatitis treatment is high and I have no enough money to follow treatments and the stuffs which I need them to protect myself and others". Another participant staid to me that "Because of prescribed medication is expensive, I did not follow my prescription".

#### **4. Discussion**

Hepatitis B and hepatitis C are chronic conditions which have negative effects not only on all aspects of physical, psychological, social and spiritual of participants' life, but also they have negative effects on doing self-care activities by the Iranian patients who suffer from chronic hepatitis. Chronic hepatitis causes the Iranian patients to straggle for doing self-care activities in order to improve their quality of life .Self-care activities support participants to improve and to obtain an overall balance and equilibrium in their life (Chenard Chris, 2007).

However self-care activities in many Iranian patients with chronic hepatitis were poor because of there were some hindrances which avoid them to do appropriate self-care measures. Lack of information and inaccurate information about self-care measures was one of the most hindrances for doing self-care measures by Iranian patients who suffer chronic hepatitis. Although Iranian patients with chronic hepatitis were seeking form a wide range of information in regards to physical, psychological and social aspects of their life, inaccurate information hinder them to do self-care activities appropriately. Providing accurate and proper information is essential to do self-care measures and health care professionals should spend enough time for teaching patients with chronic hepatitis. If health professionals do not spend enough time to teach patients with chronic hepatitis, patients will receive inappropriate or unsuitable information from others source (Chenard Chris, 2007).

Almost all of the participants believed that people in the Iranian society have negative perspective on patients with hepatitis. Mohammadpour states that Iranian known hepatitis as a dangerous problem and escape from people with



hepatitis (Mohammadpour, 2010). Negative perspective of Iranian was one the hindrance for doing self-care activities when there are involved with others in the society. Iranian patients with chronic hepatitis not only avoid to consider self-care measures when they are socialised, but also they are reluctant to talk to others about their problem because they were frightened to be rejected. Negative perspective of hepatitis among Iranians had not only crucial influences on doing self-care activities by the participants in this study, but also some of the participants discuss the experiences of discrimination, isolation, stigma, insult and depression due to the negative perspective of Iranians to hepatitis. Therefore they hide their problem and did not adhere self-care consideration in their social life.

Insufficient health care settings, limited primary health care facilities and poor follow up system was another challenge for Iranian patients with hepatitis to support and educate the patients for adhering self-care measures. Chronic hepatitis patients in Iran discussed that there is limited facilities to provide and support education for patients. Lack of health care facilities caused that the Iranian patients with hepatitis have difficulty to receive formal support and education. Some of the participants in this study believed that Iranian health system needs a reform in order to support patients with chronic hepatitis and provide appropriate and sufficient information to them in order to prevent the patients to obtain their inaccurate information from informal resources.

## 5. Conclusion

Suffering chronic hepatitis presents major challenges for patients in all aspects. Chronic hepatitis is not a disease which influence on physical health status of patients. In fact, it vanish patients' life in physical, psychological, social and spiritual aspects. Therefore they have to struggle to do self-care measure and maintain their health. Although the research has provided evidence of self-care as a significant issue for patients with chronic hepatitis, it revealed that Iranian health system do not provide enough support for patients with chronic hepatitis. Provision of self-care education to patients who suffer from chronic hepatitis needs to be considered in health care system reformation.

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