Re-designing Orem's Self-care Theory for Patients with Chronic Hepatitis

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ABSTRACT

Background: Hepatitis is an inflammatory disease which has many adverse effects on patients' life because of its chronic nature. Since Orem's theory of self-care is a grounded theory, the concepts and applications of this theory in patients with chronic hepatitis who have special needs may lead to some challenges. The purpose of this study was to explore self-care in patients with chronic hepatitis.

Methods/Design: A directed content analysis was used in this qualitative study. Participants were recruited from a metropolitan area. Data were collected through semi-structured interviews. The verbatim transcripts of the participants' interviews were analyzed according to directed content analysis.

Results: In this study, four themes, suggested by Orem, were drawn from the data according to directed content analysis. The codes generated from the data were classified into concepts and then the concepts were assigned into these four themes. These themes were "needs in the matrix of time and place," "self-care agency," "need for change in self-care" and "consequences of hepatitis."

Conclusion: The use of Orem's self-care theory cannot meet the need for self-care in hepatitis patients because these patients have vital sexual, respect and belonging, physical, economical, and psychological-behavioral needs, and lack adequate knowledge about self-care. Consequently, the specific self-care model developed in this study helps health professionals identify self-care activities in patients with chronic hepatitis.

Key words: Chronic hepatitis, Directed content analysis, Orem's self-care theory

INTRODUCTION

Self-care was introduced by Orem as one of the components of self-care nursing theory.[1] Orem recognizes human and environment as a single unit and believes that human and environment, and also humans themselves, influence each other reciprocally in this unit.[2] Beliefs, social and cultural background, personal characteristics, and relationship between health care providers and clients are some of the factors which influence self-care behaviors.[3] In addition, ethnicity, socioeconomic background, educational level, employment status, environmental factors such as pollution, sociopolitical variables, and

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lack of knowledge are other factors affecting self-care behaviors.[4]

The importance of self-care concept is related to human's need for maintaining and promoting health and recovery, lack of healthcare services, inadequate access to health services for the whole community, and increased expenditure of healthcare services.[5] Self-care activities alleviate symptoms and complications of diseases, shorten recovery, and reduce hospital stay and rehospitalization rate.[6] It has been reported that lack of self-care knowledge in patients with chronic disease, such as hepatitis, is the main reason for frequent referring to healthcare centers and rehospitalization.[2,7]

Chronic disease,[8] especially hepatitis, can have a significant impact on the quality of life of the patients.[9] Patients with chronic hepatitis face many physical and mental problems such as fatigue, weakness, sleep disorders, and anxiety.[10] Patients with chronic hepatitis become predisposed to depression, loss of family and community support and social isolation due to fear, complications of diseases, social and economic problems, and use of certain drugs.[11] The chronic course of disease and its economic impacts on patients and their families may cause daily life challenges for these patients.[12]

Therefore, it is necessary to provide patients with further information on the status of disease and their care plans, and to encourage them to take responsibility for their own health. The association between self-care and the outcomes has been investigated in hepatitis patients. A study has indicated that self-care was a complex process in patients with hepatitis and had numerous influences including individual, familial, and healthcare system-related.[2] Self-care behaviors facilitated participants' acceptance and changed the participants' perspectives regarding emotional and social support. In addition, care providers' behavior, negative attitudes toward self, and fear of disclosing the disease have been reported to be the barriers to self-care activities.[11] However, hepatitis can be prevented through self-care activities and behaviors due to mental problems. Mental problems and poor socioeconomic status are known as the two main factors which influence self-care.[13]

Therefore, patients living with chronic hepatitis can enhance the quality of life, functional capacity, and personal and social welfare through self-care activities.[2] One of the gaps in the care of chronic patients, especially in patients with hepatitis, is the lack of a suitable framework to investigate the patients' special needs.[14] The purpose of this study is to explore how patients living with chronic hepatitis can practice self-care and to redesign a specific version of Orem's self-care theory for patients with chronic hepatitis.

METHODS

Study design

A qualitative directed content analysis approach was used to conduct this study from May 2012 to May 2013. Sometimes, there is an available theory about a phenomenon that is incomplete or may benefit from further description. In this case, qualitative research practitioners might choose to use a directed approach to content analysis.[15]

Ethical considerations

The Research Ethics Committee of the Tehran University of Medical Sciences approved the protocol of this study (approval no. 92-5-18).

Setting and recruitment

The potential participants were recruited from a referral center, the Shahrekord Hepatitis Services Organization. A purposive sampling method was adopted, and the sampling continued until data saturation was achieved throughout the process of data collection. Saturation of data was obtained with recruitment of 18 participants. The inclusion criteria were diagnosis of chronic hepatitis by a specialist, referral of patients aged 18 years and over to behavioral counseling, and being consent to participate in the study. The participants were excluded from the study if they withdrew from the study. Informed consent to participate in the study was provided by the participants prior to data collection.

Data collection

The data were collected from 22 semi-structured interviews with 18 participants and direct observation of their behaviors in the process of data collection by the researchers. The participants were interviewed individually in the local hepatitis services organization by the first author. This location was chosen to protect confidentiality. However, the participants could freely choose to be interviewed either in their own place of choice or the local hepatitis services organization.

To access reliable and rich information, the researchers created a close and direct relationship with the participants. The data were collected through semi-structured, in-depth interviews and fieldnotes that the researchers took as

they observed the participants. To familiarize with the participants and gain their trust before the formal interview, the researchers met the participants individually in an informal session and then interviewed them in a formal session. Prior to the interview, the researchers obtained the informed consent from the participants to record the interviews.

Throughout the process of interview, initially, the Orem's pattern-based general questions were asked. Then, the self-care activities as the main subject were focused. If the interview was diverted from the purpose of the study, the researchers redirected the interview toward the research purposes using illustrative questions. The number and duration of each interview session varied according to the content and conditions of the participants and depended on various factors including time, desire, the participants' patience and strength, and physical and mental condition, the information level of participants, and environmental conditions. The shortest interview lasted for 30 min and the longest one for 80 min. In addition, the mean interview duration was 55 min. All interviews were tape-recorded and then transcripted verbatim.

The researchers took fieldnotes on their observations throughout the interview, if necessary. The patients were asked questions during interviews, such as "What does hepatitis mean to you?," "Did you face difficulty in relation to your illness?," "What should the attitude toward hepatitis management be?," "How has hepatitis affected your life?," "How do you do self-care activities?," and "What education have you had in relation to the disease and how does it affects social life?" Before completion of each interview, the researchers offered all the participants 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 like to add?"

Data analysis

Immediately after each interview, the researchers transcripted the recorded interviews word by word and then checked the interview transcripts against the recorded audio tapes to ensure their accuracy. In this study, directed content analysis was used for data analysis. The researchers initially specified Orem's main concepts using content analysis. Then, the whole transcript was read by the researchers several times to achieve a general sense of the text. Then, the researchers read the text and fieldnotes carefully until the sentences turned into meaning units or units of analysis. Afterward, using the words similar to the participants' statements, the researchers derived primary codes. The primary codes were read several times and classified according to the differences and similarities.[16]

The classified codes were merged, by directed content analysis, into the larger themes derived from Orem's self-care concepts and subthemes. The researchers categorized the classified codes that were inappropriate for being classified as subthemes of Orem's concepts into independent subthemes. These classifications were eventually merged into one of the four themes of the study so that the fitness and inconsistency of the subthemes with the existing data could be examined by the original concepts.

Throughout gathering and analysis of the data, the ideas were written down. The researchers repeatedly moved back and forth among the questions, checked previous questions and refined them, developed hypotheses, and paid attention to the strengths and weaknesses. The data were examined in depth through extending the existing codes till all the levels of codes were completed and no new conceptual data were available to represent the new codes. To ensure the validity of the data in this study, the researchers used prolonged engagement, check member, peer review, searching for disconfirming evidence, research credibility, and audit.[17] The process of the study and the consistency of the data were examined by the researchers. Data analysis was conducted by MAXQDA software (VERBI GmbH, Berlin, Germany).

RESULTS

Table 1 presents the demographic characteristics of the participants. Most (83%) of the participants were male. Using Orem's ontological concepts in this study, the researchers derived four themes of "needs in matrix of time and space," "self-care agency," "need for change in self-care activities" and "consequences of hepatitis."[18] Table 2 presents the themes and subthemes.

Needs in matrix of time and space

Hepatitis in the matrix of time and space, based on the theory of self-care, consists of three subthemes: "general needs," "developmental needs," and "health diversion needs." For the participants in the present study, vital needs such as water, food, and defecation were less influenced by the disease although hepatitis affected certain dimensions of their vital needs. One of the participants said:

"*Hepatitis has made me lethargic. My blood pressure often comes down.*"

Table 1: Demographic characteristics of the participants

Demographic characteristics	*n* (%)
Gender	
Male	15 (83)
Female	3 (17)
Mean±SD (year)	37±4.25
Education	
Failing to complete high school	11 (60.9)
Completed high school	6 (33.3)
Tertiary education	1 (5.8)
Source of infection	
Needle-stick or work exposure	1 (5.8)
Drug abuse	10 (55.5)
Blood transfusion	2 (11.2)
Unknown	5 (27.4)
Economic status ($)	
<200/month	10 (55.5)
200-500/month	6 (33.3)
>500	2 (11.2)

SD: Standard deviation

Table 2: Themes and subthemes

Themes	Subthemes
Needs in matrix of time and space	General needs
	Developmental needs
	Health diversion needs
Self-care agency	Ability to practice self-care
	Deficit in self-care
Need for change in self-care activities	Changes in the healthcare system and changes in the society and people
Consequences of hepatitis	Aura of fear
	Adaptation

The balance between work and recreation was one of the basic needs affected by hepatitis. A participant said:

"*I feel dizzy, fall to the ground, and can't maintain my balance. I can't work properly. How I would do sports?*"

Social interactions were one of the basic needs influenced by hepatitis. Concerning this, a participant said:

My spirit was so emotionally damaged. It was pretty bad especially when I was told that I shouldn't kiss anybody, communicate with anybody. It had a very bad effect on my spirit. I got depressed. I got physically too thin. I got very destroyed.

Self-care agency

The theme of self-care agency reflects the ability and limitations that participants encounter with regard to self-care activities. This theme consists of two subthemes, "ability to practice self-care" and "deficit in self-care." In this theme, there was a variety of factors contributing to the participants' ability to practice self-care. Some participants trusted the healthcare personnel to avoid transmitting the infection to others and said the personnel that they had hepatitis, but they had less confidence in other people in this regard. A participant said:

If I go to hospital or dentistry, I tell the physician or nurse I have hepatitis to take care of myself and other persons. Well, the doctors are educated and understand us. We tell the doctors to use preventive tools, but as soon as common people who have no knowledge about hepatitis discover that we have hepatitis, they avoid us.

One of the obstacles reported by the patients was the fact that despite the great efforts made by them, there were still no centers of self-care education for the patients. In this regard, another participant said:

"*Quitting addiction, hepatitis treatment, and education can facilitate self-care. But I did a lot of work but there was nowhere to go to be trained for self-care.*"

Need for change in self-care activities

Change in self-care activities was one of the themes derived in this study. This theme refers to the need for change in self-care practices perceived by participants. The participants faced many challenges in practicing self-care activities, which prevented them from doing these activities satisfactorily. This theme consists of two subthemes: "changes in the healthcare system" and "changes in the society and people." The participants reported that a major problem in the healthcare system was lack of accountability in dealing with hepatitis patients by healthcare team. A participant said:

"*When I went to dentist and he was going to take out my tooth, I said to him hepatitis. The dentist took me out of the office.*"

In this regard, another participant reported:

I referred for surgery and told I have hepatitis B. I saw the personnel chattering with each other regularly, I asked them why you didn't operate me. After few hours, I saw that they took me to the ward and didn't operate me. I asked them why you didn't operate me and they replied that as soon as the doctor found that you have hepatitis, he refused to do surgery.

Consequences of hepatitis

The consequences of hepatitis represents the effects of disease on the participants' daily life and activities that result from hepatitis acquisition. For the participants

in the present study, the disease outcomes comprised a continuum, which developed compatibility on one extreme and fear on the other in the patients. Accordingly, the consequences of hepatitis comprised two subthemes, aura of fear and adaptation. Family behavior was one of the important points, of which some of the participants complained strongly. Family's inappropriate behaviors led to exacerbation of the disease conditions in some of the participants. In this regard, one of the participants reported:

My daughter, son, husband, sisters, and brothers also know that I have hepatitis and that's why they don't like to have relationship with me. When someone finds out, he blames the person and says he has hepatitis, and he is afraid of transmitting hepatitis to himself.

Another participant said:

The day my wife discovered that I have hepatitis, when she brought me a cup of tea, threw the cup in the trash. So I just reacted and asked why she did it?! Well, I got well. She always told me you are AIDS patient. You are hepatitic.

A participant said:

"*People consider opium so bad, but consider hepatitis much worse than opium and look at it as a vampire…. They have a very bad attitude toward hepatitis patients. They do not accept hepatitis patients.*"

Another subtheme was related to psychological and spiritual orientation. The participants reported that they used various defense mechanisms to justify their problem. A participant said:

"*I do not know of any illness from God to me. I do not care who trusts in God, just get whatever he wants.*"

Others believed that prayer and meditation led to relaxation. In this regard, one of the participants said:

"*I always pray that I would be happy. I just read the prayer and have faith in God, and God always tells me the truth.*"

DISCUSSION

From the subtheme of general self-care needs, two categories were derived, essential needs and basic needs. The participants expressed that hepatitis affected the satisfaction of food needs greatly, in terms of defecation, the balance between work and recreation, and between loneliness and social interaction as well as prevention of life-threatening risks so that they were faced with certain challenges to satisfy their basic needs. Most of the participants complained of some problems such as insomnia, malnutrition, constipation, and depression. A study conducted on chronic hepatitis patients demonstrated fear, anxiety, depression, mental problems, insomnia, and weakness in the majority of participants.[19] In a study on patients with chronic hepatitis, 31% of the patients experienced mental disorders and substance abuse that had negative impact on the patients' quality of life.[16]

A study by Cotler *et al.* on patients with chronic hepatitis and AIDS found that sleep disorders were the most common problems reported by the patients.[20] The data obtained from the participants in this study showed that hepatitis negatively affected individual, familial, occupational, and psychological function in the patients and made some of them frustrated and isolated. The results of another study have indicated that chronic hepatitis heavily influences physical, psychological, and familial function, and generally the whole person so that it causes many challenges for the patients.[21]

Another theme generated from the participants' data was self-care consisting of two subthemes, ability to practice self-care and deficit in self-care. The participants in the present study made great efforts to take care of themselves, but they faced many obstacles. In a study on patients with chronic hepatitis, stigmatization and discrimination by the public and healthcare personnel were derived to be one of the factors resulting in the disturbance of self-care so that these patients were not motivated to do self-care and/or suffered from isolation, mental disorders, impatience, and community avoidance.[19] Study findings have indicated that patients with chronic hepatitis, in practicing self-care activities, encounter numerous problems because they have difficulty prioritizing their care plans and making various care programs similar.[22]

The data derived from transcripts of the interviews with patients living with chronic hepatitis in this study showed that several factors, including individual, family, community, and healthcare system, contributed to doing self-care activities. In addition, socioeconomic status, family support, public and private organizations, and health conditions affected self-care activities in the present study. Because self-care includes diet, sleep, exercise, weight control, smoking, alcohol, drugs, personal hygiene, eating habits and healthy lifestyle promotion, prevention and periodical medical examination, the patients may face disturbances in self-care process if one of them is delayed.

Another theme was change in self-care such that the healthcare team not only disregarded the treatment of

patients with hepatitis but also frustrated them with annoying, discriminatory, and irresponsible behaviors; therefore, the patients did not trust the healthcare team and were not hopeful about their help and support. The findings of Groessl *et al*.'s study indicated that healthcare team did not behaved hepatitis patients appropriately, evaded the patients, did not deliver appropriate healthcare services to the patients, and labeled and dealt with them discriminatorily.[3] Staff's behavior toward hepatitis patients differed from their behavior toward patients with other diseases such as cancer so that healthcare team delivered acceptable medical services to hepatitis patients less frequently.

The findings of the present study indicated that the participants complained of lack of delivering medical and dental services by physicians and dentists and/or reported that they refused to do these services when they were informed of the disease. A study indicated that physicians and dentists did not deliver suitable services to patients with hepatitis.[11] Another study of patients living with chronic hepatitis indicated that lack of suitable communication between treatment personnel and chronic hepatitis patients led to a decline in and/or no trust among the patients, and eventually isolation and failure to adhere to therapeutic and health regimen.[2,19] In this study, the disease outcomes consisted of two subthemes, aura of fear and compatibility. The theme of consequences of hepatitis covers all conditions of the participants well, and gives the reader a new insight toward hepatitis. Being informed of hepatitis acquisition caused numerous mental, familial, economic, and social difficulties for the participants so that an aura of fear and apprehension was developed in the participants and very hard, excruciating circumstances governed their life.

A study reported that being afraid of acquiring hepatitis was the most important stressor in the lifetime of hepatitis patients.[22] Patients with hepatitis were afraid of their disease influencing their families' behaviors. Being informed of hepatitis acquisition can cause numerous negative effects on family and friends which make patients experience certain variations in family life. The adverse effects of acquiring hepatitis can destroy the patients' family and their spouses may attempt to get a divorce and

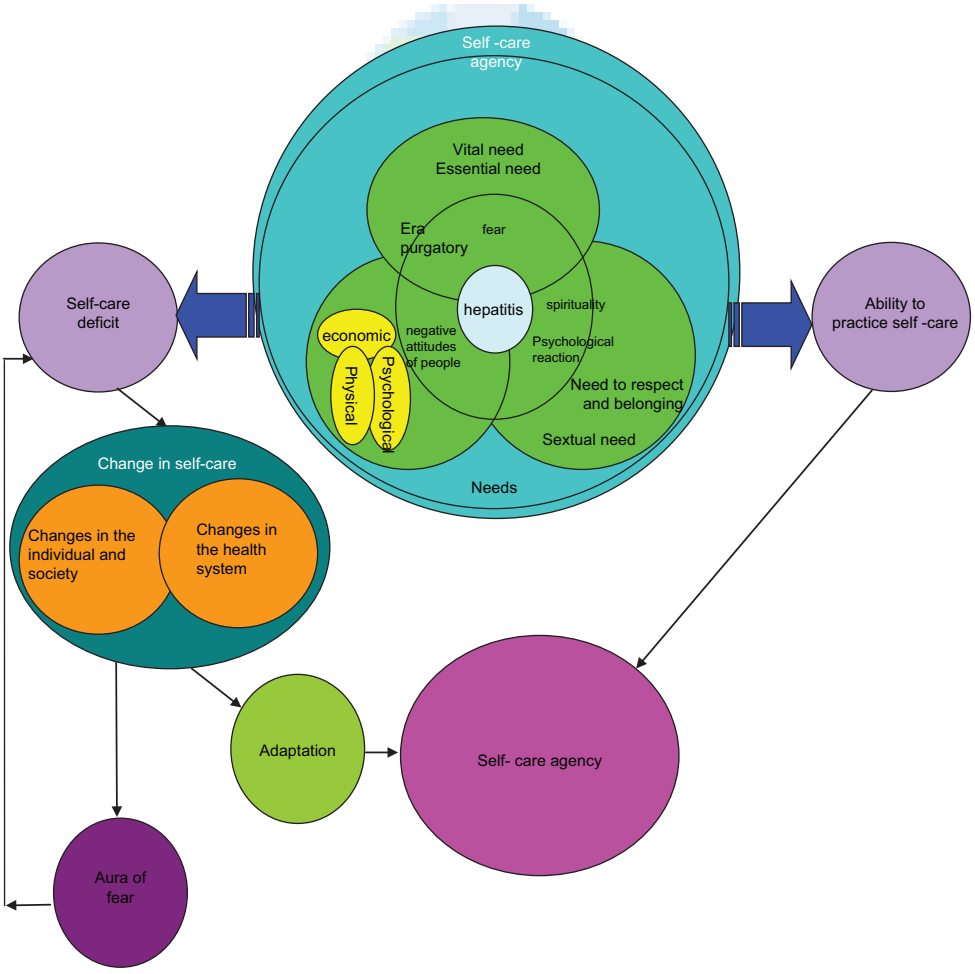

Figure 1: Dehkordi's self-care model for patients with hepatitis

abandon them. According to the findings of a study, 78% of the spouses of patients with hepatitis left their spouses as they became informed of their disease.[16]

Fear of family's behavior causes the patients to hide their disease even from their spouse and children, which, may influence the self-care behaviors in patients with hepatitis. A study in China indicated that hepatitis patients were reluctant to let their family members be informed of their disease and attempted to hide their disease even from their spouses.[20] Fear of stigmatization negatively affects patients with hepatitis such that the patients in this study were severely afraid of being stigmatized and isolated by the community. As a result, they made efforts to hide their disease. A study showed that people did not have a positive attitude toward hepatitis and blamed patients with hepatitis.[20]

The self-care model, developed in this study [Figure 1], is a specific self-care model for chronic hepatitis. Although hepatitis is a chronic health problem, the developed self-care model is not appropriate and applicable for other chronic conditions. The purpose of this study was not to generalize the research findings. However, the model can be tested and examined before its application in different cultural backgrounds.

CONCLUSION

Use of Orem's self-care theory cannot meet the need for self-care in hepatitis patients because these patients have vital sexual, respect and belonging, physical, economical, and psychological-behavioral needs, and lack adequate knowledge about self-care. The model suggested by the present study was developed specifically for patients with hepatitis.

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Conflicts of interest

There are no conflicts of interest.

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