

Limitations of self-care behaviour in heart failure patients—a qualitative research with approach Orem’s theory.

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Abstract

The purpose of this research was to defining the limitations of self-care behaviours in heart failure patients. The participants of the study were 24 patients with heart failure and 3 members of their family using purposive sampling. Using content analysis, 99 basic codes, 13 categories and 4 themes were obtained including economical-sociocultural limitations, medical regimes and disease limitations, individual and family limitations and environmental limitations. In the first steps of heart failure, knowledge limitation, judgment and decision cause the most self-care limitations, and in the advance steps of the disease, physical and psychological limitations lead to the self-care limitations of the patients. In the current study, self-care limitations in the patients with heart failure were economical sociocultural limitations, disease and medical regimes limitations, individual and family limitations and environmental limitations. The limitations of self-care behaviour provide a framework to test the patients for learning and changing the self-care behaviour. There are evidences of self-care behaviour that help the nurses to determine the required range and type of nursing care for patients.

Keywords: Limitations, Self-care behaviour, Heart failure (HF), Orem’s theory.

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Introduction

Heart failure is a chronic progressive [1] and debilitating disorder [2] characterized by impaired cardiac pump function in metabolic needs of the body [3]. The disease prevalence is between 2-3% of the population [4], 6.5 million of people hospitalized as the result of heart failure yearly [5] and 1-2% of the health care budget spent on this disease [6]. Thus, the heart failure is one of the challenges of the health care team [7]. Heart failure effects on physical, psychological, social functions and daily living activities [8]. The treatment of heart failure mainly focuses on self-care activities [9]. Self-care behaviour has the major role in the disease management [10], reducing re-hospitalize [11], and improving the patients’ life quality [12]. Despite the advantages of self-care in management of the heart failure disease, the patients face with some limitations to achieve the optimum self-care behaviour [13] that cause many changes in patient’s lifestyle [14]. Accordingly, the limitations of self-care behaviour should be determined in order to improve the self-care ability of the patients and increase the efficiency of those who care the patients [15]. The limitation of self-care behaviour defined as effective factors that limited people to take the necessary measures to achieve health. Self-care barriers are known as limited knowledge, lack of social supports, complexity of regimes, and lack of access to treatment or high costs. There

are other limits including features of heart failure, environmental factors, individual characteristics, and the factors relevant to self-care systems [16]. “Orem” is one of the nursing theorists who explain the limitations of self-care behaviour in her self-care deficit theory [17]. She defines the limits of self-care behaviour as the man’s limited capacity in self-care activities. She also mentions that as the self-care agent people are able to identify and explain their self-care needs, judge and make decision about what to do and practice the purposeful activities. Self-care deficit occurs when people are unable to meet the mentioned capabilities. Thus, as the result of the current limitations (limited knowledge, limited judgment and decision making and limited result full practice), people are unable to meet self-care requisites. Orem, moreover, believes that man’s self-care capability is affected by internal and external factors as “basic conditional factors” that effect on the range and type of self-care needs and people’s capability in involving self-care practice (age, sex, evolution, health, socio-cultural orientation, health-care system, family system, lifestyle, environmental factors and access to resources). Regarding the effects of socio-cultural factors on self-care or the limits of self-care, also limited attention to this issue in the heart failure patients in Iran, the researcher aimed at explaining the limitations of self-care behaviour in heart failure patients on the basis of socio-cultural factor. To this end, Orem’s theory

was applied to describe the limitations of self-care behaviour in HF patients.

Materials and Methods

The current investigation is a qualitative research using Conventional content analysis approved by Research Ethics Committee of Tarbiat Modarres University. 24 chronic heart failure patients and 3 members of their family participated in the study for 6 months using purposive sampling in Shahid Rajaei Heart Research Medical Centre of Tehran. They were interviewed and they were clarified with the purpose of the study, the right of individuals to participate in the study and confidentiality of data, then informed consent were obtained. The individual deep interviews were conducted for two-way conversation (about 50 minutes for patients and 20 minutes for their family). All interviews were recorded and analysed-conventional content analysis- simultaneously by "Graneheim" and "Lundman" methods (2014). Each interview was typed verbatim, each text were read several times, meaning units were determined, basic codes were extracted according the patients' experiences, the codes were classified in terms of relevance and similarity, then categories and sub-categories were created. Furthermore, comparing the categories and analysing the data, the major themes were extracted. Interviews continued until data saturation was achieved; in that, the data was sutured after interview of 24 participants and no new data were obtained in 3 last interviews. "Lincoln" and "Guba" methods were used to check the validity of data. To validate the data, sampling was conducted with a maximum variance (the samples were selected in Shahid Rajaei Heart Research Medical Centre of Tehran where there are many patients across the country with different ages, sexes, education, residential places, heart failure classes, jobs, disease histories), also the researcher involved continuously in the subject of the study and samples for 6 months. Member check methods were also used in order to check the authenticity of the work; that, after the first analysis the codes of each interview were given to the participants to verify the accuracy. Furthermore, the interview transcript, the codes and classification of the codes were reviewed by other observers in order to enhance the accuracy of the codes.

Results

A total of 27 interviews, using content analysis, 99 basic codes, 13 categories and 4 themes were obtained including economical-sociocultural limitations, disease and food regimes limitations, individual and family limitations and environmental ones.

Economical-sociocultural limitations

This theme is composed of three sub-categories no affordability, sociocultural habits and limited work activities. 7 men and 2 women acknowledged that they are not able to afford medical costs, so they cannot leave their job and rest (52-year-old man: "a few weeks ago my doctor prescribed a

capsule about 10\$, but I could not afford it" 47-year-old man: "the doctor says, I have to rest, but I can").

In this study, sociocultural habits including conservatism in social relations are the limitations of self-care behaviour. 7 men acknowledged that they are embarrassed to say we are stick to the diet. For instance, a 72-year-old man says, "When I have a guest, if I do not eat food on the table they say I am a snob. Some patients embarrass, so they hide their disease or they do not report some of their problems to the doctor. 42-year-old man says, "I am sexually weak, but I'm ashamed to talk about it with my female doctor". 2 women and 3 men said that they just like to use Iranian toilet. (37-year-old woman says, "One of our problems is that, my mam only use Iranian toilet that causes dyspnoea). Avoid taking help from others is another cultural habit that 3 women and 6 men mentioned it (63-year-old man: "I do not like to apply other's experiences, I'd prefer to do whatever I recognize it profitable").

Disease and medical regimes limitations

Disease and medical regimes limitations: Physical limitation and complexity of medical regimes are the sub-categories of this theme. 2 women and 15 men acknowledged that as the disease progress, physical limitation has negative effects on their self-care behaviour and cause to be dependent on others (23-year-old woman: "as my disease progressed, I became so weak and I could not care myself, so my mother and sister did all my work"). 5 men participants said that another chronic disease also limit self-care behaviour (62 year-old man: "I am suffering from enlarged prostate, so the doctors do not accept the surgery because of my heart problem, I take Lasix pill that causes urine increasing, but I cannot urinate and suffer from that"). Complexity of food and medicine regimes is one of another factor that limits self-care behaviour. 2 women and 8 men acknowledged that long term complexity of diet, large number of drugs and the side effects of drugs caused bewilderment and tiredness of self-care (35-year-old man: "I am tired, how long I cannot eat salt or other things, it is better to die"), (52 year-old man: I take 14 pills daily that is really suffering. I would like my doctor discontinue the drug).

Individual and family limitations

The sub-categories of this theme are limited knowledge about the disease and treatment, lack of self-care responsibility, depression and unresponsive family. 1 woman and 15 men confirmed limited knowledge about the disease and medical regimes as the limitation of self-care behaviour Judgment and decision making due to limited knowledge especially at the first steps of the disease leads to actions by patients in order to decrease the symptoms of the disease that make the situation worse (37 year-old woman, patient's daughter says, "My mother was not instructed and she does not know what to do" 52 year- old man: "I wake up and drink water when I feel dyspnoea" 35-year-old man: "my doctor prescribed some pills that makes me better, I even went mountain climbing").

In this study, lack of self-care responsibility is one of the most important limitations of self-care behaviour. 3 women and 10 men acknowledged that they do not follow their medical regimes deliberately (75 year-old man: "I eat whatever I would like, I take my six pills all together). Lack of self-care responsibility causes ignorance of medical regimes due to holidays, parties, trips or partial recovery. (24-year-old woman, patient's daughter: "unfortunately, my mother does not care herself continuously" 54-year-old woman, patient's mother: "My daughter quit her diet in holidays").

3 women and 6 men said that they do not go to hospital at the first steps of the disease and they wait for symptoms subside (26 year-old man: "I do not like to go to the doctor immediately, I am tired of going to hospital").

Depression is another limitation of self-care behaviour that patients confront with this limitation in advanced stage of the disease. 5 women and 14 men expressed that as the disease progresses and the symptoms exacerbates they imagine that the health care is not effective that leads to be disappointed and depressed (35 year-old man: "At the first steps of my illness I eagerly follow the medical regimes to have a normal life, but when the situation became worse I was disappointed, 57-year-old woman: "my illness makes me so sad and depressed).

Unresponsive family is another limitation of self-care behaviour. 1 woman and 3 men expressed that loneliness due to divorce or spouse death leads to the limitation of self-care behaviour. For instance, 33 year-old woman says, "My husband left me after the disease and he said that I cannot take care of you anymore, so I was disappointed to care myself. 4 men also said that the family illness causes mental stress that leads to symptom exacerbation. 50-year-old man, for example, says: "my mother suffers from diabetes, I go to the hospital because I became sad and stressful for my mother's disease".

Environmental limitations

Lack of access to self-care essentials, inefficient health care system, adverse environment and social stressful environment are defined as the sub-categories of environmental limitations theme. 1 female and 3 male participant expressed that, they did not have access to self-care essentials due to environmental limitations, so they did not care themselves appropriately (57-year-old woman says: "we are living in the village, so we do not have access to a clinic, its faraway" 60-year-old man: you have to eat any food in prison").

Inefficient health care system is another limitation of self-care behaviour including unavailability of some drugs, lack of full insurance coverage and inefficiency of patients' instruction. 2 female and 8 male patients mentioned that the insurance companies do not cover the foreign drug that causes the treatment disorder (23-year-old woman said that "I took "Lisinopril", it was an appropriate medicine, I have not found it for several months; instead three drugs were prescribed that is difficult").

5 male participants expressed that some of their problems are not considered when they are examined, also they did not

satisfied with instruction quality (49-year-old man: "I am suffering from sexual inability, unfortunately, none of the doctors did not pay attention to it and do not advice" 42-year-old man: "we should be clarified about the disease and what should we do, they only say do not eat salt, how should I know the salty foods, or I do not know about the side effects of drugs").

Adverse environment is another limitation of self-care behaviour. 2 female and 10 male participants acknowledged that adverse environmental conditions such as heat, air pollution or physical location cause symptoms exacerbation (41 year-old- man: "I am living at the 2nd floor without elevator and I feel dyspnoea when I am climbing stairs" 23-year-old woman: "The climate of our area is hot, dry and very dusty, which causes dyspnoea"). 1 female and 5 male participant also mentioned that social stressful environment including pitiful behaviour causes demoralization and depression and self-care disorder (23-year-old woman: "everyone came to me was crying and said: why at this age have heart disease, I was thinking about what they would say and becoming worse").

Discussion

In the current research, the limitations of the self-care behaviour were determined on the basis of the experiences of participants including economical-sociocultural limitations, disease and medical regimes limitations, environmental limitations and individual and family limitations. In respect of Orem's theory, the mentioned limits were classified into three following aspects: limited knowledge, limited judgment and decision making and limited result full practice.

The results indicated that lack of affordability for self-care costs causes limited result full practices. In USA, decreasing salary as the result of after illness disability and high treatment costs lead to the lack of affordability of the patients for their health care costs [15]. In Iran, also the participants expressed severe economic difficulties and lack of supportive resources [18]. According to Orem's theory lack of access to resources that effect on providing self-care requisites leads to the limitations of self-care behaviour. In this study, after illness disability that leads to low salary was one of the reasons of lack of affordability of the patients, so they were not able to afford health care costs. Moreover, some participants had to work to afford the costs that lead to ignoring the self-care behaviour and illness exacerbation.

Sociocultural habits were another limitation of self-care behaviour in this study that impairs judgment and decision making led to unrecognizing the appropriate self-care behaviours. Orem believes that, cultural norms effect on self-care responsibilities and individual, family and society behaviour. In this research, conservatism in social relations is one of the self-care behaviour limitations that stems from Iranian cultural norms. Iranians are the people of compliments and they try to speak indirectly in their inter-personal relationships and behave so pleasant to others. Thus, the

patients do not manifest their disease when they are at the party that leads to the violation of their medical regimes. Avoid taking help, also stems from Iranian culture. In general, Iran is an individualism society with little interest to group works. Accordingly, some patients did not ask for help-even in critical situations. Orem; moreover, says that sometimes people reject the self-care requisites due to sociocultural point of view. This may justify the participants' behaviour when they used mostly Iranian toilet. In respect of cultural view, most Iranians have negative feeling to normal toilet and they think it is not hygienic and it is difficult for them to clean themselves. Thus, in spite of the care team recommendations, they prefer to use Iranian toilet.

The results showed that the disease factors and medical regimes cause limitations of self-care behaviour. Physical limitations due to the illness are one of self-care limitations. The second factor of such limitations fatigue from the illness or disability caused by aging [15]. Limitations of heart failure patients effect on their ability and limit daily living activities and self-care behaviour [16]. Orem also explains that low energy, disability or limited ability of physical movements limit the self-care behaviour. In this research, fatigue and dyspnoea were the most physical limitations in advanced HF participants (class 3 & 4) and patients with milder HF do not have physical limitations, so they are able to care themselves.

Simultaneous chronic diseases were another limitation of self-care behaviour. Simultaneous chronic disease misleads the heart failure patients due to recognize the symptoms [16]. In respect of Orem's theory, people experience new self-care needs due to their illness that may conflict with the self-care needs of another disease. The researcher believes that simultaneous chronic disease causes the complexity of treatment and conflicts of self-care needs. A patient, for example, had to drink water while taking medicines to prevent stomach ache; however, it caused water retention in the body and disease exacerbation. Simultaneous chronic disease did not effect on the self-care of male patients with heart failure because of their mastery in symptoms diagnosis [19]. In this study, also the participants who planed how to take their daily medicines faced with little problems.

The results of the study revealed that individual and family factors caused the limitations of self-care behaviour in HF patients. One of the individual limiting factors was limited knowledge about the disease and treatment of the disease that the results were in consistence with the study of Desai, 2013 [20]. Saibai says that limited knowledge about medical regimes and misconceptions about the nature of disease lead to misunderstanding the relationship between the symptoms [16]. According to Orem's theory, patients confront with unknown self-care needs that limited knowledge causes self-care limitation. In this study, the majority of participants had limited knowledge about the disease and medical regimes that caused exacerbation of the illness, for example drinking water while dyspnoea appears.

In the current research, lack of self-care responsibility, non-compliance with medical regimes, and self-care carelessness

are the limitations due to recovery of the patients. In USA the reason the patients do not comply with medical regimes are as follows: unpleasant tasting (free salt foods), thirst, impotence and frequent urination due to taking Diuretics. Holden; moreover, reports that forgetfulness and miscomprehension of the self-care benefits are the signs of lack of accountability to treatment. Non-compliance with regimes is related to patients' negative attitude to medicines and the effects of drugs [18].

Orem believes that self-care behaviour needs both knowledge and motivation, and instability of the patients is due to lack of purposefulness and respect for self-care. In this study, lack of accountability in patients newly diagnosed with the disease was due to limited knowledge about the disease and misperception of the conditions. These patients neglected the regime immediately after resolution of symptoms. However, lack of self-care responsibility in the patients with advanced degree of disease was due to lack of motivation; that, although they complied with their regime, the disease exacerbated. In this respect, the participants with higher knowledge, motivation, and supportive sources adhered to their medical regime. Another sign of lack of self-care responsibility was due to postpone going to clinics or hospitals. The patients usually go to clinics after three-day delay [21]. In the current research, the reason why the patient's postpone going to hospital or clinic was due to limited self-care motivation; in that the patients did not pay attention to their illness due to fatigue, hopelessness and incurable beliefs.

Unresponsive family including unsupportive family and illness of family members was another self-care limitation. Riegel Family supports effect on self-care behaviour and social isolation due to loneliness has negative effects on self-care behaviour [19]. Supportive environment increases the patient's self-esteem, coping with illness, compliance with regime and motivation [16]. In respect of Orem's theory, the family can help the patients to manage their self-care needs and family crisis limits the patients' self-care ability. In this research, divorce due to the disease or spouse death caused critical situations in patient's life. Moreover, the patients frustrated due to losing emotional supports that effect on self-care behaviour. However, the patients who had supports of family faced little self-care limitations. The illness of other members of family was another critical situation that caused the limitations of self-care behaviour. The patients have to care other family members due to their illness, so they do not have enough time for self-care behaviour [15]. In the current research, limitations of self-care behaviour due to illness of family members had multiple reasons. Some of the participants involved in taking care of family members, so they did not have enough time to take care of themselves. Sometimes emotional feelings and stress due to illness of family members caused disease exacerbation and impair judgment and decision making. Furthermore, sometimes the illness of spouse led to loose physical and emotional supports that affected on self-care behaviour.

According to the results, depression caused the limitations of self-care behaviour. In women, the grief due to disease caused

that they do not pay attention to disease symptoms and waiting for spontaneous resolution of symptoms [19]. Depression and hopelessness due to disease treatment led to non-compliance with self-care behaviour [18]. Complexity of long term medical regimes causes the patients think about the treatment process and they feel depressed because they are not able to see the signs of recovery [20]. Orem believes that lack of social supports to reassure the patients in complex treatment situations leads to limitations of self-care behaviour. In this study, also the depression of some patients stemmed from treatment complexity, lack of social supports to motivate and advise the patients. However, the patient who had supportive and motivational resources felt less depression and actively participated in self-care practices.

In this study, environmental limitations such as lack of self-care essentials and adverse physical environment defined as the limitations of self-care behaviour. Environmental factors including lack of resources, unavailability of tools and technology, distance medical centres, weather conditions and physical place of living effects on self-care behaviour [15]. According to Orem's theory, environmental factors effect on the onset and maintenance of self-care practice. In this study, adverse weather conditions such as heat and air pollution (dyspnoea exacerbation) caused the limitations of self-care practices. Moreover, some patients live in the villages and they did not have access to health care centres, so they were not able to go to hospitals or clinics immediately. However some participants changed their living environment such as movement to good weather or near the health centres in order to overcome the current limitations and manage threatening conditions. In respect of Orem's theory, drug availability is one of the resources in order to onset and continues self-care behaviour. Unavailability of some drugs especially foreign ones with multiple spectrum caused taking more drugs that led to complexity of medical regime. Another limitation of self-care behaviour was impairing instruction of the patients. Orem believes, due to the illness, new self-care needs are essential that require both knowledge and professional help by medical team guides. The participants were not satisfied with their instructions, because they were instructed only by pamphlet that illiterate and limited literate patients faced with problems. Moreover, since the time of periodical physician's office visit was too short, doctor's instructions were inefficient. However, literate patients or those who were in touch with the doctor continuously, had sufficient knowledge to care themselves.

Conclusion

In this study, the limitations of self-care behaviour in heart failure patients were as follows: economical-sociocultural limitations (no affordability, disability to work and sociocultural habits), disease and medical regime limitations (physical limitation due to the disease and complexity of medical regime), individual and family limitations (limited knowledge about the disease and regime, lack of self-care responsibility, depression and unsupportive family) and environmental limitations (unavailability to self-care essentials,

inefficient health care system, adverse physical environment and social stressful environment). On the basis of Orem's theory, moreover, the type of self-care limitation was related to severity of disease; that, in the stages of disease, patients confronted with knowledge, judgment and decision making limitations, and in advanced stages of disease, they faced physical limitations due to the disease and psychological limitations. The results of the research emphasized on the complexity of self-care limitations. Since the nursing intervention emphasizes on instruction of heart failure patients in order to increase the self-care ability, the instructions should be purposeful, and patients' self-care abilities and the limitations should be evaluated. To this end, the results provide a framework to evaluate the ability of the patients for learning; also, the evidences of the self-care behaviour limitations determine the type and the degree of essential nursing care for the patients.

Implications for practice

In the current study, self-care limitations in the patients with heart failure were economical sociocultural limitations, disease and medical regimes limitations, individual and family limitations and environmental limitations. The limitations of self-care behaviour provide a framework to test the patients for learning and changing the self-care behaviour. There are evidences of self-care behaviour that help the nurses to determine the required range and type of nursing care for patients.

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