ORIGINAL ARTICLE

Antecedents of Coping with the Disease in Patients with Multiple Sclerosis: A Qualitative Content Analysis

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Received: 25 April 2016 Revised: 18 July 2016 Accepted: 26 July 2016

ABSTRACT

Background: Due to many physical and mental disorders that occur in multiple sclerosis patients, identifying the factors affecting coping based on the experiences of patients using qualitative study is essential to improve their quality of life. This study was conducted to explore the antecedents of coping with the disease in patients with multiple sclerosis.

Methods: This is a qualitative study conducted on 11 patients with multiple sclerosis in 2015 in Tehran, Iran. These patients were selected based on purposive sampling. Data were collected using semi-structured and in-depth interviews and coded. These data were analyzed using the conventional content analysis. The rigor of qualitative data using the criteria proposed by Guba and Lincoln were assessed.

Results: Five main categories were revealed: (1) social support, (2) lenience, (3) reliance on faith, (4) knowledge of multiple sclerosis and modeling, and (5) economic and environmental situation. Each category had several distinct sub-categories.

Conclusions: The results of this study showed that coping with multiple sclerosis is a complex, multidimensional and contextual concept that is affected by various factors in relation to the context of Iran. The findings of the study can provide the healthcare professionals with deeper recognition and understanding of these antecedents to improve successful coping in Iranian patients suffering from multiple sclerosis.

KEYWORDS: Qualitative research, Multiple sclerosis, Iran, Coping

Please cite this article as: Dehghani A, Dehghan Nayeri N, Ebadi A. Antecedents of Coping with the Disease in Patients with Multiple Sclerosis: A Qualitative Content Analysis. IJCBNM. 2017;5(1):49-60.

INTRODUCTION

Multiple sclerosis (MS) is a chronic progressive disease that destroys the central nervous system myelin, thereby affecting the sensory and motor function and can be determined in 85 to 90% of patients with periods of worsening (exacerbation of symptoms) and recovery. This disease is one of the most common neurological diseases in humans and the most common cause of disability in young people² and one of the most important life-changing diseases, because it damages the best time of the individuals' life and leads them gradually to inability.3 The most common age affected by this disease is from 20 to 40 years and the prevalence is 1.1 million people in the world.³ The number of people with this disease in Iran is about 40,000 people.⁴ The prognosis of this disease is uncertain and the patients experience various physical and mental disorders that strongly influence their daily performance, social and family life, functional independence, and individual planning for the future,5 and in relation to a high level of uncertainty associated with negative emotional consequences, such as depression and emotional distress that needs to be coped with.6 On the other hand, the cost of treatment for any patient with multiple sclerosis in Iran is estimated to be \$1,000 monthly, and much of the costs is imposed on patients, together with physical and mental disabilities caused by the disease which require more coping with the disease.⁷

Since multiple sclerosis has a wide range of debilitating effects, patients encounter confusion in assessment of its impacts on their lives, which requires coping with the disease to improve the quality of life. In addition, Iranians are faced with some problems that are specific to the Iranian context. Therefore, these issues attract the attention of the patients in the country to cope with the increasing challenges of the disease and investigate the affecting antecedents. Moreover, investigating the antecedents affecting coping, based on the experiences of the patients, can be effective in the transfer from mere medical focus to using individual

experiences for improving coping and the quality of life.⁹

Antecedents coping with the disease are the underlying factors that help the patients with multiple sclerosis to cope with the disease, achieve better quality of life, and also positive outcomes. On the other hand, since patients with multiple sclerosis, compared with other diseases, experience a higher prevalence of affective disorders and are faced with various physical and psychological coping needs,10 investigating the affecting antecedents based on the participants' experiences can help to improve and reduce the need for drug therapies. Although Quantitative studies can well explain causal relationships, in rich data creation which is the result of deep understanding of the phenomenon, they are powerless. Being present in natural environment, qualitative research tried to interpret the phenomena and is the best method to describe experiences; 11 therefore, studying and explaining the antecedents of coping based on the experiences of patients who live with the disease is a major help for the promotion of coping with the disease. Based on the conducted surveys, a study with this subject was not found, and also qualitative studies conducted mostly the emphasis is on coping process and how the patients cope. To the best of our knowledge, no study has examined the factors affecting coping based on the experiences of multiple sclerosis patients. Thus, a deep understanding of the antecedents of coping in patients who experience this crisis is essential. Therefore, this study was conducted to investigate the experiences of patients with multiple sclerosis in the context of antecedents affecting coping with the disease using a qualitative approach.

MATERIALS AND METHODS

Study Design and Participants

This study is a qualitative research with conventional content analysis approach which was performed from April to December 2015, (about nine months) in Iran MS Society in

Tehran, Iran. 11 patients with multiple sclerosis participated in the study. Five of them were male and six were female. Their age ranged from 24 to 46 years and their disease experience varied from 1 to 20 years. Their education level was from diplomas to doctoral degree. Patients were selected using purposive sampling based on the willingness and ability to provide experience with an attempt to observe maximum variations in terms of demographic characteristics. Also, primary participants were selected from multiple sclerosis patients whom the researcher knew. Inclusion criteria for the participants were (a) definite diagnosis of multiple sclerosis disease, (b) willingness to participate in the study, and (c) ability to express experiences. Exclusion criteria for participation were mental illness confirmed by a physician or the individual patient and lack of willingness to participate in the study.

Data Collection and Analysis

Data collection was continued until saturation which occurred when a new category did not appear and until the existing categories were enriched. The data were collected through deep and semi-structured face to face interviews. Each interview lasted on average 60 and 110 min. All interviews were conducted in a peaceful environment and with prior agreement of the participants. Interviews began with the general and main questions "Explain briefly about the nature of the illness and its problems", "What did you do when you were diagnosed with this disease?", "What factors help you to better cope with your illness?", "How did you come along with this disease?", and "What problems have you been confronted with during this disease? All interviews were audio-recorded with the permission of the participants.

In analyzing the data, qualitative content analysis by conventional method and Graneheim and Lundman model¹² were used, with the following steps: (a) implementing the interview conducted immediately after it was done, (b) reading the entire

text to understand its general content, (c) determining the units of meaning and initial codes, and (d) classifying the initial codes in more comprehensive categories. In this approach, codes classification was directly extracted from the interviews.¹³ In the present study, categories were extracted irrespective of preconceived categories of data. Thus, after each interview, the text was transcribed and typed verbatim in Microsoft Word and the initial codes were extracted after several times of listening. Then, the sub-categories and categories were formed based on the similarities of the extracted codes. In the beginning, initial codes were analyzed by AD; then, the list of categories and subcategories was reviewed and re-categorized by the study team. Cases of disagreement were discussed with the research team to reach a final consensus.

To provide rigor and reliable data concerning credibility, the researcher had a long and close acquaintance with the participants and spent a long time in the field searching for data and enough time to gather and analyze the data. Furthermore, peer check and constant comparison were used. Dependability was established by using the experts' comments, and revision was done by the participants and co-workers. Sampling mode, questions development, the method of coding and category extraction and modification were recorded to obtain sufficient conformability. Transferability was obtained by description of data-rich.

Ethical Considerations

The present study was approved by the ethics committee of Tehran University of Medical Sciences in Iran (Code of Ethics IR.Tums.Rec.1394.1171). Before data collection, the researchers obtained the oral and written informed consent to ensure the confidentiality of the names of people, privacy and an emphasis on voluntary participation. At the beginning of the interviews, research goals and method were explained to the participants and they were assured of confidentiality of information.

RESULTS

The mean age of the participants was 33.2 years and the mean duration of the disease was 10.5 years. Based on content analysis, five main categories were revealed: (1) social support, (2) lenience, (3) reliance on faith, (4) knowledge of multiple sclerosis and modeling, and (5) economic and environmental situation. Each category had several different sub-categories, as shown in Table 1.

Social Support

Many participants believed that social support including support from family, spouse, peer friends with multiple sclerosis and also professional organizations and the multiple sclerosis society are the factors affecting coping with the disease. Participants expressed that financial, emotional, mental, and spiritual support can alleviate their symptoms and improve their adherence to treatment and life expectancy. The participants also believed that social support decreased their level of stress, enabled them to tolerate and manage their problems more easily, and improved their physical and psychological well-being. The following examples highlight this point:

"Having the support of my family at all times helped me a lot; my father says that they are always ready to help me" (Participant #7, Female).

Another one commented: "Having my husband supports really helped me for coping with disease. He pays for my drugs although I know that he doesn't have a high income, but tells me not to worry about the cost of drugs" (Participant #5, Female).

A participant told about the support of friends: "The whole time that I was hospitalized, my friends were there for me, from morning to night, they were in hospital so that hospital nurses said your friends eat breakfast and dinner at hospital" (Participant #6, Female).

The participants believed that organizational support like Ministry of Health or multiple sclerosis society decreased their level of stress, made them feel relaxed and able to bear their problems more easily, limited the symptoms of the disease, and improved their physical and psychological condition. A participant said: "the Ministry of Health or multiple sclerosis society and or other authorities can help us to cope with the disease; for example, they can cover our medicines by insurance or provide regular programs for the control and treatment of such patients" (Participant #8, Female).

Lenience

This category includes the following

Table 1: Categories and subcategories of antecedents of coping with the disease among Iranian multiple sclerosis patients

Categories	Sub-categories
Social support	Social support
Lenience	Underestimation of multiple sclerosis compared to other diseases
	Acceptance of disease symptom
	Distracting one's attention
	Positive attitude
	Self-confidence and high morale
	Hope for recovery
Reliance on faith	Religious beliefs
	Acceptance of disease as a divine test
Knowledge of multiple sclerosis and modeling	Gathering information about disease
	Community awareness about disease
	Observing and considering the behavior of peers
Environmental - economic Situation	Suitable living environment
	Stressful and stress-free environment
	Loss of employment
	Exorbitant cost of drugs

sub-categories of the underestimation of multiple sclerosis compared to other diseases, acceptance of disease symptom, distraction from one's attention, positive attitude, self-confidence and high morale, and hope for recovery.

Patients were trying to take the disease easy. They believed that in this way they were more easily able to cope with the disease. The majority of the participants underestimated multiple sclerosis when compared with other diseases, such as cancer, and they were satisfied they were not afflicted with a worse disease. Indeed, the participants often compared themselves with worse situations. Most of them thought that their situation was much better than that of other patients like cancer or incurable diseases. A participant said:

"If I was healthy, I might get caught in a worse situation such as cancer or a crippling disease, so thanks God that I have multiple sclerosis" (Participant #11, Male).

Another said:

"I always compare myself with a cancer patient or a worse condition and then I have much better feeling" (Participant #8, Female).

The participants also try accepting the current situation and symptoms of the disease and are indifferent to its complications. They believed that the disease has happened and they should live with it. They mentioned if we do not accept the disease, we will suffer more. For example:

One said: "The fact is that I have to cope with it; disease has happened and nothing can be done about it. For this reason, I accepted the existence of this symptom with me and don't take it hard" (Participant #7, Female).

Patients were also trying through different ways, forget their illness and symptoms and free their mind from negative and destructive thoughts. In this regard, a participant said: "I try to spend my time in going to park and mountaineering, shopping, and going out with friends to free myself from loneliness and think less about it. I'd better cope with the disease". (Participant #8, Female).

The participants believed that one's attitude

to disease is very important in coping with it; they also expressed that their own attitudes about MS and how they deal with them are effective in coping. The participants tried to have a positive attitude toward their problems and disease.

In this regard, a participant said: "Everything depends on one's attitude; many tell me that my disease will be cured, God's willing. I say it is not important to me. They ask why? I say in this case, neurology doctors will have nothing to do" (Participant #4, Male).

Participants commented one of the factors that help them cope with disease, indicating that self-confidence and high morale were among such factors. A participant said: "Positive morale can be a great help to cope with the disease; for example, Mr. ... is always laughing. He says we have multiple sclerosis and we should cope with it." (Participant #2, Female).

Another stated: "Accepting my disease was not that difficult because I have high morale. I was a little depressed in the beginning, but I did not become demoralized" (Participant #11, Male).

For coping with disease, the participants also believed one should always keep hopeful and that hopelessness equals death. They believed that human is alive with hope. The hope of recovery was of the affecting antecedent, for instance: "I always say that the definitive treatment of multiple sclerosis will be found one day, because medical science will have much progress, so why lose hope?" (Participant #5, Female).

Reliance on Faith

This category includes the following subcategories: religious beliefs and acceptance of disease as a divine test. A reliance on faith was an important coping antecedent among the participants. Most participants believed that their disease was their fate, chosen by God and thought that changing the condition was impossible. They believed that affliction with multiple sclerosis had increased their closeness to Allah. A male participant stated: "This was my destiny. God had decided so". (Participant #11, Male).

A female participant said: "All these things are God's will. I believe God would restore my health" (Participant #3, Female).

The majority of the participants believed that their disease was a kind of divine test, which they had to accomplish with pride. Indeed, belief in God's help and acceptance of the disease as a divine test were the affecting antecedents in coping. For instance, a participant said: "Every problem in life is a divine test. I did not want to have this disease, but this is a divine test and I need to come along with it." (Participant #10, Male).

Most patients used religious beliefs to support them in coping and living with multiple sclerosis.

Knowledge of Multiple Sclerosis and Modeling

This category includes the sub-categories of gathering information about the disease, community awareness about it, and observing and considering the behavior of peers. Most participants believed that the patient's and community members' proper knowledge about the symptoms, problems and disease treatment is effective in coping. Awareness and information about the disease could have a good effect. It decreased the participants' fear, anxiety, and stress, which allowed them to feel relaxed. Having information about the causes of the disease created a greater sense of confidence and greater independence in them. One said:

"I always get information about my disease from different sources, such as physicians, books, etc.. This information showed me how I should behave with the disease; this reduces my stress." (Participant #3, Male).

Another patient stated:

"If I knew more about the disease and my information was more complete, I would more conveniently cope and live with multiple sclerosis" (Participant #4, Male).

People's information about the disease was effective in their degree of coping. The participants believed that providing

appropriate information for members of the community provides the opportunity to cope better with multiple sclerosis and its challenges in patients; most of the participants suffered from community low information about the disease. People are really uneducated. When they see us in the streets, they do not deal properly with us and don't understand our conditions. A participant said: "There are families that leave their patients at sanitarium. The people in the community do not have information about multiple sclerosis. If members of the community know the disease, then it can help us." (Participant #6, Female). Another said: "The most important problem of multiple sclerosis is that nobody knows anything about it." (Participant #9, Male).

Patients also tried to model the behavior of other people with multiple sclerosis in order to model the positive and negative behaviors for better coping. They tried to be a model of patients who are successful in management and coping with the disease. The interaction with successful multiple sclerosis patients leads to better coping with disease. A participant said:

"I model some of the things I see in my friends; for example, I observe some of the patients who mope and have stress, or I model some positive things I see in them, such as being happy, speaking and laughing." (Participant #9, Male).

Environmental-Economic Situation

This category includes the sub-categories of suitable living environment, stressful and stress-free environment, loss of employment and exorbitant cost of drugs. Most of the participants said that having access to supplies, elevators and toilets, and also a quiet environment free from the stress can be effective in coping. From the participant's perspective, appropriate environmental situation leads to improvement of psychological state, relaxation and more coping of patients. For instance:

"I must rent a house that has elevator and a western toilet, because I feel more

comfortable." (Participant #1, Female).

A female participant said: "I have designed my house so that everything is available" (Participant #5, Female).

Participants commented that stress and stressful environment made their symptoms worse and the believed that it might lead to an exacerbation. One said: "once, I took part in a ceremony and got immediately sick and was needed to be hospitalized for corticosteroid therapy. I go out in quiet environments weekly to be away from stress and home concerns." (Participant #5, Female).

Economic and financial state was also another antecedent identified effective in coping with multiple sclerosis. Most patients mentioned that loss of employment and exorbitant cost of drugs due to degenerative nature of the disease are dramatically effective in coping. The participants also mentioned that inadequate financial resources, income reduction and disability prevented them from using rehabilitation services and assistive devices such as more effective drugs or regular physiotherapy and caused a lot of stress, anxiety and problem. Several participants indicated that they left work because of the potential adverse consequences of stress.

As to loss of employment, a participant said: "It is about 4 years that I cannot go to work for my severe dizziness; I am unemployed and financially in crisis; I don't know what to do." (Participant #9, Male).

Another one stated: "I get Betaferon early in the disease, but because of rising prices, lack of insurance coverage and financial budget drop, I had to get Ziferon; it is not as effective as Betaferon, but I have to." (Participant #8, Female).

DISCUSSION

According to the results of this study, antecedents that lead to better coping or failure to cope with multiple sclerosis are identified in five categories of social support, lenience, reliance on faith, knowledge of multiple sclerosis and modeling, economic and environmental situation. Social

support was the first category obtained from the data, and the participants believe that it is a crucial factor in maintaining and restoring mental peace and coping with the disease. They used the social network including family, spouse, friends, peer patients, employees, and relevant professional organizations as a source of support so that their appropriate support can reduce negative effects caused by chronic disease and help the patients to better cope with their disease. The results of a study also showed that emotional support helps the patients to rely on family support and feel that they support them at this difficult and critical situation; thus, it is easier to cope with the disease.¹⁴ One study also found out that better emotional, mental, and psychosocial support from family and friends is directly associated with improved mental health and patients' coping with multiple sclerosis. This study emphasized the power of the family in patients' emotional support, which should not be ignored.¹⁵ On the other hand, patients who have less social support are more prone to mental health problems, especially stress, and the severity of the disease is higher; this can have effects on the patients' coping and quality of life.16 In addition to support from family, support from peers is an effective source in coping with stressful experiences and obtaining information.¹⁷ Preliminary studies show that the impact of peer support groups on people with chronic diseases creates an opportunity to share experiential knowledge, helps the members explore their approaches that help them cope effectively with the stress caused by the disease.¹⁸ Moreover, support groups help the patients validate personal experiences, increase awareness of therapeutic areas and cope with the chronic diseases.¹⁹ In addition, various studies have shown the impact of positive experiences of peer patients on coping with chronic diseases 19,20

Lenience is the second classification and antecedent in coping with the disease. Most participants thought that their condition was better than some other diseases such as cancer and were trying to underestimate their disease, so they felt relaxed and coped

with the disease easier. Some participants in another study said: If I was not afflicted with multiple sclerosis, I would have been involved in a worse threatening condition and disease such as cancer; why should I think that I will be a wheelchair user or paralyzed; none of this will happen to me. 21 In another study, this antecedent and its impact on coping were mentioned.²² On the other hand, patients who show that their disease is greater than what it is, always mope, and constantly look for the cause of the disease are experiencing social isolation and depression, their symptoms increase, and the process of control and recovery can be impaired.²³ Another antecedent of coping was acceptance of the symptoms of the disease. Acceptance of the situation and disease symptom are frequently reported in relation to other threatening illnesses.²⁴ By distracting one's attention, participants tried to decrease the importance of the event. Studies have shown that patients who are experiencing lifethreatening illnesses frequently distract their attention from the situation.²⁴ Positive attitude of patients toward the disease was the subcategory obtained from the data which can also influence the patients' coping, so positive and negative attitudes lead to coping and lack of coping, respectively. The results of a study showed that patients with relapsing forms of the disease have a more positive attitude toward their duties and disease control as compared to patients with a progressive form of the disease.²⁵ Researchers also expressed that the individual's attitude to multiple sclerosis had a significant role in coping with it.⁶ The present study revealed that having self-confidence and high morale played an important role in helping the patients to re-engage with life and cope with the disease. These results are in the same line with the data reported by Dalvandi et al., who revealed the importance of selfconfidence in re-connecting with life for those surviving after a stroke.²⁶ The patients' hope is the factor that can help maintain optimism and coping with multiple sclerosis; the hope that their disease will be treated in the future and medicines will be discovered to control

the disease can help them cope with the disease.²¹ The results of this study were based on optimism. They believed that optimism facilitates their coping with the disease.²⁷

Reliance on faith was the most frequently used antecedent in this study. The participants viewed that reliance on their faith helped them to cope with multiple sclerosis and overcome limitations. The participants also viewed the disease as a God's test. Therefore, in several studies, the positive role of religion and hope on eternal power of God in coping has been mentioned.^{28,29} How people are coping with disease and stress is influenced by religion. A lot of patients get more religious than in the past during the illness, when adjustment mechanisms do not have the necessary performance to cope with the disease' and at this time, prayer is an effective adjustment mechanism that creates the feeling of worth and hope in the individual by reducing feelings of loneliness and pain.²⁹ The results of a study in Iran on chronic diseases showed that spiritual beliefs not only are effective in coping with the disease, but also play an important role in patients' lifestyle, and create a sense of purposefulness, increase the patients' motivation to the treatment regimen and are used as a sedative agent by patients.³⁰ About patients with heart failure, the results of a study also showed that relationship with God, religious values, and communicating with others are essential components of the participants who survived from heart attacks and spirituality helped patients cope with their stress and fears.31

Knowledge of multiple sclerosis and modeling are the fourth category obtained from the data that was identified as an antecedent affecting the coping. Sufficient knowledge (of individual and community) about multiple sclerosis, including facts such as treatment and symptoms of the disease and how these symptoms affect their lives, as well as the quality of information and how this information was presented at the time of disease diagnosis, can enable people to understand more and use active coping and

assessment processes. The participants in this study tried to cope with their disease by gathering information about the disease and its treatment and outcomes. Learning about the disease and its treatment modalities gradually reduces the patients' fear and enables them to cope with the conditions. Therefore, cognitive impairment in early stages of the disease can prevent multiple sclerosis patients from using the coping resources.³² Another study also showed that individual and community knowledge of the disease was effective in coping.33 However, some participants in the study conducted by Farsi et al. believed that although overall information was often helpful, information about the mortality rates and treatment side-effects increased their stress and worries.²⁴ Modeling the positive and negative behaviors of peer patients is of the antecedents effective in coping with the disease from the perspective of the participants, who were in the above category. Patients believed that observing and modeling the emotions and behaviors of multiple sclerosis patients who were successful in managing their disease can be effective in coping with the disease. Patients tend to learn through social interaction and observing the behavior of others.34 The study results also showed that observing others' emotional status and behavior is effective in arousing feelings for modeling; thus, both positive and negative behaviors can be emulated to be effectively used by patients.³⁵

The fifth category obtained from the data was the environmental-economic situation that participants frequently mentioned. In this regard, patients expressed that they chose a place to live where their access to daily supplies, elevators and toilets were provided. Several studies have emphasized the relationship between environmental conditions and physical health, since environmental characteristics and factors associated with it were effective on fatigue, severity of the illness, physical activity, recreation and commuting; they can also affect the patients' quality of life and ultimately

coping with the disease.³⁶ Previous studies have provided evidence showing that proper environmental conditions are important factors in the physical and mental health of patients with chronic diseases.³⁷ A meta-analysis study findings also showed that the living environment and environmental conditions contributed to the development of many gastrointestinal and neurological disorders, such as multiple sclerosis, Parkinson, etc., and have unfavorable effects on physical and mental health and adjustment of individuals.³⁸ In another meta-analysis study, an ongoing relationship between stressors and worsening of multiple sclerosis was observed. Also, stressors are related to the sense of health and lower self-efficacy. On the other hand, using relaxation techniques and providing a stress-free environment can help the patients to cope with the disease.³⁹

Economic problems resulting from the disease including loss of employment and exorbitant cost of drugs were the other antecedents causing discomfort. Due to the progressive nature of the disease, many patients lose their employment leading to lower productivity and incomes of life and have effects on the patient's coping. In addition, income reduction resulting from disability as well as the high cost of treatment and medication are associated with reduced quality of life for these patients. Therefore, the largest portion of direct costs in multiple sclerosis is related to the cost of the drug, consultation, and nursing, respectively. In Iran, only interferon therapy for multiple sclerosis patients costs 300,000 Tomans monthly. These costly drugs with other relevant problems, including loss of employment, seriously affect the patients' coping. Therefore, the economic problem in Iranian patients with multiple sclerosis is very important and requires serious attention due to the lack of easy access to drugs, lack of support in terms of rehabilitation and treatment costs, and incomplete insurance coverage of the drugs.⁷

The results of this study are limited to

the antecedents affecting coping with the disease in the culture and context of Iran; thus, further studies in different cultures have to be done for further use of the findings. Restricting the field of study to members of the MS Society was another limitation; thus, it is recommended that, in future studies, experiences of patients who aren't a member of the MS Society should be considered.

CONCLUSION

The findings of this study showed that coping with multiple sclerosis is a complex, multidimensional and contextual concept that is affected by various factors such as social support, lenience, reliance on faith, knowledge of multiple sclerosis and modeling, and economic and environmental situation. Hence, identification of these factors increases our knowledge and help the nurses and other health-care professionals as well as patients and families to improve coping with the disease.

ACKNOWLEDGMENTS

This study was part of a PhD dissertation in nursing with an ethical approval number (IR. Tums.Rec.1394.1171). Authors extend their appreciation to all the study participants for their contributions. The present article was extracted from the thesis written by Ali Dehghani and financially supported by Tehran University of Medical Sciences with thesis code 9121199016.

Conflict of Interest: None declared.

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