Original Article

Exploring the self-management strategies in people with multiple sclerosis

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ARTICLE INFO	ABSTRACT
	Background & Aim: People with multiple sclerosis (MS) face numerous physical and psychological problems and use multiple strategies to manage these problems to reduce its impact on their own lives. The aim of this study is to explore the self-management strategies in people with MS. **Methods & Materials:** This study is a qualitative research with content analysis approach. Data were collected through semi-structured interviews with seven people with MS recruited from a rehabilitation clinic and the MS Support Community. Participants were selected through purposive sampling method. Data collection continued until data saturation. Trustworthiness criteria were considered to ensure the quality of findings. Data were analyzed using qualitative content analysis with conventional approach. **Results:** Analysis of the data ultimately led to the emergence of "attempt to maintain independence" as the main theme referring to the self-management strategies in people with MS. Self-management strategies the participants used in this study were grouped into seven categories: disease acceptance, information enhancement, change of lifestyle, developing psycho-emotional balance, environmental modifications, improving financial credits, and promoting capabilities. **Conclusion:** People with MS use various self-management strategies for reducing their problems. Due to the nature of the disease, the use of self-management strategies can improve their control over illness. Understanding these needs and strategies helps health providers to provide better services to people with MS.

Introduction

Multiple sclerosis (MS) is a disease of the central nervous system (1). About 2.5 million people are affected by MS around the world. MS is one of the most common neurological diseases and causes of disability in young people (2). Neurological defects caused by the disease are various and include visual impairment, sensory and motor loss, tremor, ataxia, movement disorders and balance, and coordination problems (3).

The unpredictable pattern of relapse and remission of the disease and the emergence of various symptoms decreases one's control over the life. This is one of the most obvious characteristics of MS resulting in depression, hopelessness, decline of quality of life, and weakness in psychosocial participation (4).

Living with a chronic disease like MS needs

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to control the disease and limit its progression. In most chronic disease, patients and their caregivers play an important role in self-management (5). People with MS must manage the daily effects of the disease on their lives. This management style is called self-management (2).

A disease self-management program was developed in the US, in 1990, in response to an increase in medical care costs and a need to improve the quality of treatment (6). Prior to the development of specific self-management approaches for a disease, the chronic disease self-management programs were more general and developed for people with any chronic conditions (6). The first chronic disease self-management programs were started by Lorig et al., (7) at the Stanford University, with specific programs for people with rheumatoid arthritis.

In general, the three primary tasks of self-management include managing medication, roles and emotion. Medical management includes taking medication, adhering to a special diet, using medical services, changing the lifestyle (sleep, hygiene and exercise). Role management covers maintaining changing and creating new meaningful behaviors in life roles such as changing responsibilities within the family. Emotional management is related to how to deal with the feelings resulting from a chronic disease such as anger, fear, disappointment, and depression which are commonly experienced as a result of a chronic disease.

Some of the self-management skills are problem-solving, decision making, resource utilization, communicating with health care providers, taking action, and self-tailoring. One of the most important objectives of the chronic diseases self-management programs is to increase self-efficacy to solve problems and make daily decisions in response to changes in disease conditions. Self-management interventions enhance the clients' self-efficacy and increase their confidence in performing the favorite activities. Furthermore, these skills help patients to form a partnership with their health care providers to improve the management of chronic conditions (8).

Considering the mentioned definitions, these interventions are especially appropriate for people with MS, because they face a series of symptoms that vary from day to day and over time.

Therefore, it is necessary to pay more attention to self-management programs which is exactly designed for the care of patients with MS (9). Although it is known that patients with MS and people with other special conditions apply coping techniques to self-manage their disease, little is known about the experiences of people with MS of self-management (10). Furthermore, knowing about self-management strategies used by people with MS is required to design appropriate intervention programs. Thus, this study using a qualitative method, aimed to explore self-management strategies used by people with MS in Iran.

Methods

The conventional content analysis was used in this study. Qualitative content analysis is a research approach which its objective is to provide new knowledge, enhance the researcher's understanding of phenomena (11). The conventional approach is usually used in designing the studies whose objective is to explain a phenomenon, if existing literature and theories about that phenomenon is limited (12). In qualitative content analysis from a conventional point of view, there are three steps including open coding, creating categories, and abstraction (13).

Participants of the present study were people with MS who referred to specialized rehabilitation clinic related to patients with MS and a MS Community Support Center. Seven MS patients were selected purposely to participate to the study (Table 1). The inclusion criteria of the research were: being age above 18, the disease being under control, obtaining score of 27 or more on mini-mental status examination. Sampling continued until data saturation was reached.

Data were collected through a semi-structured interview. First, the participants were interviewed by semi-structured interview about the self-management strategies used by them. The interviews were carried out in an appropriate physical and psychological space. All interviews were recorded by an audio recorder and transcribed verbatim. The duration of interview varied from 40 to 75 minutes. Collecting the data continued until they reached a point of data saturation, data saturation was reached when the last two interviews, did not add any new categories or concepts.

Table 1. Demographic data table

Number of participant	Age	Sex	Education	Marital status	History of disease	Mini mental status
First	37	Female	A.D	Married	18	30
Second	40	Male	Diploma	Single	16	30
Third	49	Male	Diploma	Married	18	29
Fourth	29	Female	B.S	Single	8	30
Fifth	45	Female	Diploma	Married	8	29
Sixth	30	Female	B.S	Single	10	30
Seventh	39	Female	B.S	Married	14	28

Interviews were conducted using interview guide. After analysis of initial interviews and based on emerged concepts, subsequent interviews were more focused with more leading questions. Some examples of interview guide questions includ:

1. Could you talk about yourself and your disease?

2. What problems did you face following your disease?

3. What strategies did you use to solve the problems resulting from your disease?

4. What factors do you think were helpful in coping with the problems resulting from disease?

For data analysis, first, each transcribed text from interview was read several times to get a proper understanding. Then, one code was allocated to each part of the text, and the code was written in the margin of each part. Next the codes were put in categories, the similar categories were placed together, and this process continued until the categories representing the studied phenomenon were formed. In the present study, the analysis of data started after the first interview and continued until the end of data collection. Finally, one main theme was extracted. Researchers increased credibility of the data by prolonged engagement with data, using member check and peer debriefing. Member checking was achieved by asking the participants to verify the preliminary findings from the earlier interviews. In peer debriefing, the categories emerged from data analysis were reviewed by peers and in the case of disagreement, they were revised by the research team members to resolve any contradictions.

The external audit technique enhanced dependability and conformability. During the external audit, texts of the interviews and the codes and categories extracted from them were examined by two experienced researchers in qualitative research who were selected outside the research team. They confirmed the correctness of the analysis, as well. Transferability was ensured by comparing the similarity of findings with the experiences of non-participants and describing the research context and the assumptions that were central to the research (14).

The objectives of the study were explained to participants, and verbal and written consent from the participants was obtained. Maintaining the confidentiality of the participants' information and giving the participants the right to withdraw from the research at any time were other ethical considerations that were observed in the present study.

Results

The result of the initial data analysis in open coding step was 137 codes. In this step, after selecting meaning units from the text of interview, coding was performed. In the following part, an example of a selected meaning unit and coding of the text of interview related to the first participant has been illustrated.

Meaning unit

The selected code was "getting consultation from other patients." For this meaning unit: "He gave me the phone number of the boy who had MS. He said call him, he can help you. Hence, I called him. We talked on the phone just once but for just that 1 time he gave me lots of energy, he talk to me about his experiences with his disease and he gave me such a spirit that made me think of how trivial MS is."

In this way, the codes were obtained from the analysis of seven interviews. Through data analysis, after finding the meaning unit and related codes, subsets of the sub-categories, sub-categories, and main categories were identified based on the judgment of the research team members. In this step, seven main categories

including "disease acceptance," "information enhancement," "change of lifestyle," "developing psycho-emotional balance," "environmental modifications," "improving financial credits," "promoting capabilities" and also thirty sub-categories were created. Some of the sub-categories such as "informational resources" had sub sub-categories. In table 2, an example of the ways creating the main categories and sub-categories has been present. In the final step of data analysis, the main concept latent in the texts of all interviews emerged. The main concept formed in this study was "attempt to maintain independence," because the general content of all interviews, and all attempts and also the strategies applied by participants in the study were somehow related to "keeping independence."

In this case, one of the study participants explained: "everybody in this world does his best to do his work himself and be independent from others (the second participant." Table 3 shows the final result of data analysis. In the first main category "disease acceptance," lack of acceptance of disease by the patients, prevents them to apply their available potential capabilities. As an example, participant number 4 declared in this regard that: "first, when I learned that I have this disease, I cried a lot. I did not want to accept that I am sick. I went to doctor many times, it seemed I was waiting for somebody to tell me that there is a mistake and I did not have this problem. It was very difficult for me to accept my condition."

One of the other extracted main categories was "information development." Having enough and accurate information about the disease and problems resulting from that, the ways of confronting the problems and preventing the complications of disease are very effective in the management of disease. In this regard, the participant number 4 said: "having enough information and that the patient knows what to do are very helpful in the control of disease."

The third main category was "change of lifestyle." Changing the lifestyle refers to changing daily habits and routines in the manner appropriate to one's current conditions. This category included sub-categories of planning and setting the goals, having proper nutrition, getting regular sleep, asking other people for help, simplifying activities, wearing suitable clothes, dividing tasks, and energy conservation. For instance, participant 2 had found planning and having a purpose to be very effective in the successful management of disease and keeping a normal routine of life. He said: "I had a lot of problems but I planned to set my goal. I knew what I wanted to do; now I'm satisfied for that."

Another one of main categories was "developing psycho-emotional balance." The participants of this study, to alleviate psychological problems (including depression and anxiety) used the methods such as a tendency toward religious factors, avoiding stressful factors, anger control, improvement of personal communications, evacuation of negative excitements, and doing favorite activities. For example, participant 1 mentioned that her beliefs and tendency toward religious factors were effective in reducing depression. In this regard, she said: "first I just thought that why I should be sick, I was sad so that I got depressed but then I told myself that it has been God' will." The fifth extracted main category was environmental modifications.

Table 2. Determination of major and minor categories

Main categories	Sub categories	Codes
Acceptance	Accepted abilities and disabilities	Accepting physical changes caused by disease
		Accepting change of walking quantity
		Believing abilities
	Hope	Hope for the future
		Awareness of the future of disease
		The positive effects of hope
	Coping with illness	Continue to life
		Trivialize the disease
		Changing attitude about the disease
		Not seeing disease problems
		Coping with illness
		Adaptation to illness

The participants of the study found that modifying their surrounding environment was an effective way to manage their problems. Among methods included in this category we can refer to informing other people, using assistive devices and changing decoration. With regard to informing other people, participant 2, said, : people around me did not have any knowledge about the disease. Sometimes they behaved me badly. So, I asked my doctor to explain that for them."

Improving financial credits is one of the other main categories extracted from the data. Most participants of this study had economic problems resulted from their unemployment and their disabilities in performing occupational related tasks, inappropriate workplace environment, and also high treatment expenses.

Table 3. Final analysis of data

The main concept	Main categories	Sub-categories	Sub-sub-categories
Independence	Disease acceptance	Accepted abilities and disabilities	
		Hope	
		Coping with illness	
	Information enhancement	Experience	Individual
			Other patient
		Informational resources	Use of mass media
			Consultation with health care team
			Written references
	Changing life style	Setting goal and planning	
		Suitable nutrition	
		Regular sleep	
		Ask for help and get help	
		Simplification of activities	
		Wearing suitable clothes	
		Dividing tasks	Dividing duties between family member
			Dividing tasks into necessary and unnecessary
			Dividing tasks into light and heavy
		Energy conservation	Increase the rest time
			Using massage
			Touching foot ground touch
	Developing psycoemotional balance	Beliefs and attitudes to religious factors	
		Avoidance of stress	
		Anger management	Identify the threshold of anger
			Leave place in anger
			deep breath
			Drinking water
			Walking
			Enhance problem-solving skills
		Development of personal communication	Development of friendly relation
		Discharge negative emotion	Wit
			Positive thinking
			Inner speech
			Extroversion
		Doing favorite activities	
		Controlling depression	Deep breath
			Exercising
	Environmental modification	Notifying people	
		Use of assistive device	
		Changes at home	
	Improving financial credits	Occupation	Choosing second job
			Changing gob
			Seeking for job
		Investing in bank	
		The use of supplemental insurance	
		Use of inexpensive medicine	
	Promoting capabilities	Motor exercises	
		Mental training	

To solve this problem, the participants used different ways such as career change, investment in bank, using supplementary insurance, and inexpensive medications. participant 2, with regard to career change said: "I changed my career, now it is more comfortable for me because I do my activities while sitting at the desk and I do not need to walk."

The last main extracted category was "promoting capabilities." The participant found that it was useful to improve their mental and physical abilities for reducing their problems. Regarding the effect of doing physical exercises on the improvement of mental and physical conditions, participant 5 said: "I do some exercise every day and now both my movements and spirit are improving."

Discussion

This study is a qualitative study aimed to explore the self-management strategies in people with MS. The literature review showed that there have not been any qualitative studies in this field to date. Hence, in this study, a deep insight was gained into the self-management strategies applied by people with MS to control and manage their problems. Paying attention to these strategies can help healthcare providers and patients to take care of patients and their health. Many definitions of self-management have been presented in the literature. In some studies, those of self-management aspects have been referred to, which confirm the aspects found in this study. As an example, Nakagawa-Kogan et al. (15) has stated that main goal of self-management is to maximize the one's functioning of a regulatory process. Clark et al. (16) have mentioned to a continuous, dynamic and flexible process of self-management and pre-requisites of successful self-management methods. Clark believes that self-management includes the day to day tasks people must undertake to cope with psychosocial problems and manage daily life based on their own social and economic conditions. a successful self-management method for people with chronic disease is requires an adequate knowledge of the condition and its treatment, the condition man-

agement activities and applying necessary skills to maintain appropriate psychosocial functioning. According to Knaster et al., (9) it is important to pay more attention to self-management interventions exactly designed for people with MS, because there is little information about self-management experiences of people with MS.

Based on the findings of the present study, accepting the disease is an important factor in performing the activities. Acceptance means to make decision to change painful feelings (17). The results from Research indicate the effect of disease acceptance on person's physical, emotional and social functioning such as the use of health care services and occupational status (17). With regard to the other main category, "information development," it was mentioned that having adequate information is effective in management and control of the disease. Knaster et al. (9) suggest that acquiring information about MS and strategies related to the disease control is one of the components of self-management. The third main category, that is a change of lifestyle, refers to changing life habits and routines. In Stuifbergen et al.'s study (18), changing lifestyle led to an increase in participants' quality of life and health promoting behaviors planning to do activities including change of lifestyle leads to successful performance of self-management tasks. Having proper nutrition and diet was one of the other contents of lifestyle change in the present study. One of the results of self-management programs is to change diets and dietary habits (19). Wassem and Dudley (20) found that the change of nutritional conditions was effective in improvement of symptoms management in people with MS. Stuifbergen and Rogers (21), suggested the self-care strategies as an effective way in enhancing resistance to fatigue. Getting enough and regular sleep asking other people for help, simplifying activities, wearing suitable clothes, dividing tasks and getting massage and energy conservation were other contents of lifestyle change. Getting enough sleep has significant effect on fatigue in people with MS and is one of the most common health promoting behaviors (22). Furthermore, regular sleep affects the immune system function and

maintains the function of this system. To simplify doing the activities can be an effective factor in one's ability to do them. Therefore, those strategies which help to decrease the fatigue in people with MS, considering the wide prevalence of this problem, are more likely to be considered than other strategies. Vanage et al., (23) identified the energy conservation techniques as a very useful and effective intervention for people with MS. Fatigue management programs can be beneficial in decreasing fatigue and improving self-efficacy and quality of life. Massage which is one of the other content of lifestyle change causes a decrease in anxiety and depression and an increase in one's self-confidence and physical and social functioning. The forth main category that is developing psycho-emotional balance refers to different methods applied by people with MS to solve their psycho-emotional problems including tendency toward religious factors, avoiding stressful factors, anger control, improvement of friendly communications, evacuation of negative excitement, doing favorite activities and depression control. It is necessary to take into account the social and psychological factors. The result of Mitchell et al. study (24) indicated that many psychosocial factors including coping skills, creation, self-efficacy and available supports affect the quality of life in people with MS, even more than biological factors such as weakness or the extent of injury area. Tendency toward religious factors and spirituality were the most applicable method used by the participants to decrease their psycho-emotional problems. In Harvey and Silverman study (25), spirituality has been considered as a component of self-management process and an important factor influencing individual health and well-being. The fifth main category was "environmental modifications" that included changing the arrangement of furniture to match it with physical condition and using the assistive devices. In Mathiowetz et al. study (26), changing the place of furniture and their arrangement mentioned as the methods to save energy. People with MS can use the aid tools like stick, wheelchair and scooter. Using the aid tools can increase the person's independence (27). The sixth main category was "improving financial

credits." In one hand, high treatment expenses and on the other hand losing the job and lack of financial support can cause many economic problems for people. Most people with chronic conditions may give up their treatments due to lack of support for the treatment, and imposed economic pressures (28). The care received by people with chronic conditions is financed by various sources including government programs such as Medicare and Medicaid, and Insurance Services (29). Participants of Schoen et al. study (30), mentioned advantages of complex insurance policies and the primary care system in different countries such as Australia, Canada, France, Germany, New Zealand and the U.S. Considering the importance of insurance, this case has been resolved in developed countries and in the literature has not been considered as an influencing factor as a result a certain management method was not found in the studies to resolve the economic problems. The last main category that is "promoting capabilities" implies the use of self-management methods to promote mental and physical capabilities. Regular exercise, keeping the independence in doing personal affairs, and doing mental practices were the exercises used to improve person's capabilities. In Lorig study (31), exercise was suggested to be as a component of self- management programs leading to an increase in health promoting behaviors. Exercise programs lead to an improvement in the level of physical activity functional outcome and the conditions of women with MS (32). Exercise programs are introduced as interventions which have many advantages for people with MS. In general, it can be said that successful self-management of people with MS requires making some changes in health care system, as well as healthcare providers should pay more attention in teaching the different aspects of this disease. It seems that poor communication skills with healthcare providers are a main factor in the lack of use of efficacious self-management strategies in patients, because healthcare providers are the main sources to obtain required information and knowledge about different aspects of this disease. Providing the self-management programs, including all three assumed tasks, is necessary for patients with

more emphasis on medication and emotion management. This study had several limitations including the lack of cooperation of some people due to the long duration of interviews, as well as limitation of time and not being expressed some strategies by the participants because of being taboo.

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Conflict of interest

The authors declare no conflict of interest.

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