

Exploring Self-management Needs of Persons With Multiple Sclerosis: A Qualitative Study for Mobile Application Development

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Background: Multiple sclerosis (MS) is a common cause of neurologic disability in young adults. Individuals with MS deal with the day-to-day effects of the disease on their lives. Self-management can help with these challenges. This study aimed to explore MS self-management needs according to experiences of persons with MS and was conducted as part of a research project to develop an MS self-management mobile application.

Methods: We used a qualitative method to elicit self-management needs among 12 individuals with MS and conducted semistructured interviews with them. The participants were chosen based on snowball sampling. The interviews were recorded and transcribed verbatim. Finally, qualitative data were analyzed using a content analysis method (inductive way) to identify the underlying themes and subthemes.

Results: The analysis resulted in the emergence of 7 themes: the source of information, basic needs, understanding MS, physical exercises in MS, useful nutrition in MS, MS monitoring, and communication. Within these 7 themes we identified 23 subthemes.

Conclusions: The themes that emerged in this study show what needs are essential to help persons with MS improve their self-management capacity. These findings can help in the development of self-management mobile applications for supporting individuals in managing MS. *Int J MS Care. 2022;24:1-7. doi:10.7224/1537-2073.2019-129*

Multiple sclerosis (MS) is a common cause of nontraumatic neurologic disability in young adults that affects approximately 2.5 million people worldwide.^{1,2} It is a chronic autoimmune disorder of the central nervous system that causes progressive demyelination and axonal loss.^{1,4} This disorder occurs early in life, between 20 and 50 years of age, and causes many physical, psychological, and social problems for patients.^{3,4} MS is characterized by a variety of symptoms, such as balance problems, chronic pain, fatigue, vision disorders, bladder and bowel disorders, loss of cognitive function, emotional changes, sleep disturbances, and depression. The emergence of MS at a young age, the wide range of MS symptoms, and the presence of MS symptoms in the lifetime of the patients have made

self-management the most important option for empowering patients with MS.⁵⁻⁹

Self-management in chronic illness is an approach through which patients can gain empowerment to manage their health status. At the core of self-management is daily monitoring of the chronic condition, assuming that self-management will improve symptom control and quality of life for the patient.⁸ In general, the 3 primary self-management tasks are medical management, role management, and emotion management. Medical management includes taking medication, adhering to a special diet, using medical services, and changing one's lifestyle. Role management covers changing behaviors and creating and maintaining new meaningful roles and responsibilities within the family.

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Emotion management deals with the feelings of anger, fear, disappointment, and depression experienced during chronic disease.¹⁰ Six self-management skills include problem-solving, decision making, resource utilization, the formation of a patient-provider partnership, action planning, and self-tailoring.¹⁰ For those with MS, self-management is considered a dimension of health care, and the self-management tasks and skills are of great importance.¹¹

Persons with MS practice self-management to maximize their physical, social, and psychological performance. The complex and multifaceted nature of MS makes self-management critically important, polymorphic, and highly individualized.^{8,12,13} Persons with MS use a range of self-management strategies for MS management and adaptation: adjusting outlook, managing stress, managing symptoms, living a healthy lifestyle, communicating effectively, and setting priorities and planning.¹¹ Given the variety of ways that MS can affect physical, cognitive, and psychological functioning, self-management in MS requires a wide range of knowledge about this disorder, identification of self-management needs, and use of strategies to improve the performance of people with MS.^{12,14} Therefore, it is essential to characterize the experience of people with MS and explore patients' needs for managing their condition, in particular in the early stages of their disease. Studies have reported that digital self-monitoring of health in individuals with MS with smartphone applications (apps) could support self-management as well as personalized health care.¹⁵ The development of successful digital tools requires the consideration of patients' self-management needs.^{15,16} This study aimed to identify MS self-management needs based on experiences of persons with MS as an initial phase of a project to develop a mobile app for MS self-management.

Methods

Design

The researchers used semistructured interviews for a qualitative collection of experiences of individuals with MS. Then a qualitative content analysis method was applied for developing themes. Qualitative study approaches have an exploratory nature. They are used to understand the complexity of people's experiences.¹⁷ Content analysis is a method for analyzing written, verbal, or visual communication messages expressed by humans.¹⁸

Participants and Settings

Individuals were included in the study if they were older than 18 years, had been diagnosed as having MS at least 2 years before entering the study, and had no hearing, speaking, or cognitive problems. The snowball sampling method was

used for recruiting participants in this research and continued until data saturation. Snowball sampling is a nonprobabilistic method of gathering information to access specific groups of individuals. In this method, the researcher first identifies individuals, obtains information from them, and finally asks them to introduce him or her to another person.¹⁹ Participants were selected from the East Azerbaijan and West Azerbaijan provinces in northwest Iran. The neurologist (S.S.) on the research team performed a cognitive evaluation to confirm a lack of cognitive impairment in the participants for inclusion in the study.

Data Collection

Semistructured face-to-face interviews were used for data collection. The semistructured interview provides the opportunity to discuss the details of the topic at hand. In the present study, interviews were conducted individually and face-to-face. The interviews were based on an interview guide through an open-ended approach. The interview guide focused on the following areas: (1) unmet information needs of the participants for MS self-management; (2) information sources used by the participants for meeting their information needs; (3) necessary parameters for monitoring and controlling their daily life; and (4) needs for different types of online communications between the participants and others.

All members of the research team participated in preparing the interview guide. To test validity, the interview guide was given to 5 domain experts, and their opinion was taken and applied. However, due to the nature of qualitative studies, questions were changed during data collection when required. Interviews begun with demographic questions such as sex, age, level of education, work status, and history of MS diagnosis and continued with open-ended questions about the aforementioned areas.

Each interview lasted approximately 40 minutes, and all interviews were digitally recorded through a voice recorder and transcribed verbatim. All interviews were conducted by one researcher (Z.S.) in the Persian or Azeri Turkish language according to the interviewee's preference. The dominant language of people in northwest Iran is Azeri Turkish. The interview place was determined according to the interviewee's availability and convenience. During the interview, extra questions about unexpected but relevant aspects were added and then merged. Data saturation was reached after 10 interviews.

Data Analysis

Morse and Field's²⁰ qualitative content analysis approach was used for data analysis. In this approach, the researcher reads the entire interview and identifies several important topics in the interview. These topics then become the primary categories or category labels. Eventually, categories will have to be combined.²⁰ Content analysis is a research method for the subjective interpretation of the content of text data that is conducted through the systematic classification process of coding and identifying themes or patterns. This method uses a descriptive approach in the coding of the data and in its interpretation of quantitative counts of

Table 1. Basic Characteristics of the 12 Participants With MS

| Characteristic | Value |
|--|------------|
| Sex, female/male | 10/2 |
| Age, years (y) | 34 [20-50] |
| Educational level | |
| High school diploma/certificate or lower | 5 |
| Some college/college graduate | 5 |
| Master's degree or higher | 2 |
| Employment status | |
| Full-time | 2 |
| Part-time | 2 |
| Retired/housekeeper | 7 |
| Student | 1 |
| Duration of MS | |
| 2-5 y | 4 |
| 6-10 y | 4 |
| 11-15 y | 2 |
| 16-20 y | 2 |

MS, multiple sclerosis.

Note: Values are given as number or mean [range].

the codes.^{21,22} To analyze the data, the interviews were transcribed and then read. In the second step, data were reread word by word several times to derive codes and meaning units. Next, thoughts and initial analyses were noted. Then the extracted codes were inductively analyzed to produce subthemes and themes based on a comparison between similarities and differences. MAXQDA 12 software (VERBI GmbH) was used for content analysis in this study.

Ethical Considerations

The research ethics committee of Tabriz University of Medical Sciences approved the research proposal. Before starting the interview, all the participants were informed about the research and completed the informed consent form. All the participants also provided consent to record their voices. Participation in this study was voluntary; therefore, participants could withdraw from the study at any time. The researchers assured the participants of the confidentiality and anonymity of the provided data.

Results

Participants' General Characteristics

Twelve people with MS participated in this study: 10 women and 2 men (mean age, 34 years). They had lived with MS for 8.5 years on average. **Table 1** provides demographic information about the participants.

Themes on Needs of Persons With MS for Self-management

The present findings are shown as themes and subthemes. Seven main themes and 23 subthemes emerged

from the thematic analysis of the interviews regarding the needs of persons with MS for self-management (**Table 2**). The direct quotations of participants were elucidated for this purpose.

Source of Information

The source of information was 1 of the main themes for MS self-management. The participants chose different sources, such as MS associations, other individuals with MS, MS specialists, related books, the internet, and websites, for obtaining information about MS. Most interviewees mentioned their reliance on the MS association to meet their information needs as the first source of information. The participants referred to other people with MS and the MS specialists as their second source of information about MS. Most of the interviewees mentioned that they obtained information from their physician whenever new symptoms or problems occurred. However, 2 participants indicated that they did not ask physicians their questions. One of the interviewees mentioned the doctor's inappropriate behavior at the time of questioning as an obstacle: "I do not ask the doctor my questions, because when I ask the doctor a question, he treats me badly and does not answer my questions."

Most participants mentioned a lack of trust in the internet regarding information needs. The reasons behind this distrust were the presentation of incorrect information, the frustrating nature of the information, and, in some cases, the provision of information by unskilled and uninformed individuals: "I don't use the internet to search for information about MS at all, because it's frustrating." "I used MS association brochures to search for information when I was first diagnosed with MS, but now 16 years after the diagnosis that I can differentiate between right and wrong information, I use the internet and books for obtaining the information."

Basic Needs

The participants believed that the primary needs of a person who has recently been diagnosed as having MS include maintaining hope, accepting MS, being supported by the family, and communicating with other people with MS. All interviewees pointed to maintaining hope as the first and most basic need of an individual newly diagnosed as having MS. As 2 interviewees stated: "I advise the newly diagnosed person to maintain his or her hope. Family support is also important." "I tell a newly diagnosed person that MS is not a terrible situation and the sooner he/she accepts MS, the better he/she can control it."

Table 2. Themes and Subthemes of Self-management Needs of Participants With MS

| Theme | Subthemes |
|-------------------------|--|
| Source of information | MS associations People with MS Physicians Books Internet and websites |
| Basic needs | Maintaining hope Accepting MS Family support Communication with other people with MS |
| Knowing about MS | Information for acceptance of MS Information about MS Information about experiences of people with MS MS-aggravating factors Factors slowing MS progress |
| Physical exercise in MS | Useful physical exercises in MS Exercise advice (do's and don'ts) |
| Useful nutrition in MS | Nutritional recommendations in MS Useful foods in MS |
| MS monitoring | Monitoring symptoms Monitoring rest status Monitoring stress |
| Communication | Optimistic people with MS MS specialists |

MS, multiple sclerosis.

Understanding MS

From the participants' perspectives for understanding MS, the information should first be offered to the person to maintain his or her hope: "I tell the newly diagnosed person that MS is not a disability, MS is a special way of living."

Interviewees highlighted the necessity of providing patients with information about MS. They mentioned that they need to gain some insight on MS itself, nutrition and physical exercise in MS, experiences of other people with MS, factors exacerbating MS, causes behind the disease, factors that slow the disease progression and prevent its relapse, and the impact of stress on feelings in

people with MS and progression of the disease. One said, "Information about MS and its exacerbating factors. As you know, MS is a disease that is directly related to stress, it has many causes, but its main causes are stresses, negative emotions, and pressures. The information must be provided in these aspects." Another: "First, persons with MS should understand MS and know the various symptoms of MS that they experience and know about the aggravating factors in MS, then they can control MS."

Physical Exercise in MS

The participants emphasized the importance of exercise in MS self-management. The subthemes of "useful physical exercises in MS" and "exercise advice in MS" were elucidated from the participants' direct quotations. Interviewees mentioned that they need to be provided with information in these areas. The participants noted the usefulness of yoga, swimming, aerobic exercise, and walking for MS. As stated by 3 participants: "People with MS should not do exercises that cause great excitement, increased body temperature, and sweat. They should do calming exercises such as swimming and yoga." "I don't exercise myself but I recommend sports such as walking." "Exercises like swimming and aerobic exercise are useful, which I think MS patients should be aware of these exercises."

Useful Nutrition in MS

The participants mentioned that complying with a nutritional regimen helped them prevent the occurrence of MS symptoms. This theme emerged from the interviewees' direct quotations with 2 subtopics: "nutritional recommendations in MS" and "useful foods in MS."

Five participants who reported on nutrition in MS stated that awareness of the beneficial foods for MS and knowledge of nutritional recommendations and regimens could be helpful for people with MS. One of the participants stated: "MS patients should be aware of dietary advice, I follow nutritional recommendations, and regimens, for example, I have been eating honey consistently for 6 years."

Participants also highlighted the need for awareness of harmful foods in MS. For example, another participant said: "People with MS should eat less fatty foods, they should not eat fast foods at all."

MS Monitoring

Interviewees reported this topic with 3 subcategories: monitoring MS symptoms, monitoring resting status, and monitoring stress condition. Some participants underscored the importance of MS symptom monitoring as a useful component in MS self-management. For example, 1 of the participants gave the following statement: "To monitor MS status, for example, I currently record the

number of times that I go to the WC during the night. Because I had urinary problems a few years ago. Some people may be embarrassed to report such symptoms, they can record these problems in a notebook and thereby inform the physician of their symptoms.”

Another participant referred to the monitoring of rest and stress status as an important component in the daily control of MS: “Things that matter during the day are the rest and a happy and stress-free environment. Getting enough rest is the number one priority in self-management of MS.”

Communication

Most participants stated that they prefer to communicate with optimistic people with MS about their condition. Some interviewees noted that they prefer not to communicate with pessimistic ones. Four participants reported the usefulness of communicating with physicians using the following statements: “I prefer communicating about my condition with optimistic MS people.” “We should not communicate with MS people who have negative moods and have not willing to change their mood. I prefer communicating with doctors or positive MS people.” “I prefer to have communication with my physician because people with MS have different problems and symptoms.” “Communicating with your physician and positive MS people can be helpful in a variety of problems.”

Discussion

Generally, the identified needs in this study can be classified into four general categories: (1) accepting MS and getting support; (2) obtaining knowledge (knowing and understanding MS, healthy lifestyle in MS); (3) MS monitoring; and (4) communicating. These 4 categories do not cover the full range of self-management dimensions for MS. They emphasize more the primary needs of a newly diagnosed person in the path of self-management. Of course, as time goes on and at each stage of the disease or with experiencing new symptoms, different needs might emerge to be considered for the self-management.

As findings in the first category revealed, the primary needs of a newly diagnosed person with MS include accepting MS, maintaining hope, and getting support from the family. Similarly, other studies reported the patients’ demands for recovering their optimism and getting emotional and physical support from family, friends, and health care professionals.^{11,23} The recommended model for MS self-management by Ghahari et al¹¹ considered support by family, friends, other people with MS and colleagues as a

personal social network and one of the self-management dimensions.

Obtaining information about MS was found to be one of the main items in self-management toward getting adapted to MS. As evidence has highlighted, getting information about MS is very important in adapting to the disease and accepting it. Lack of knowledge about MS has been listed as one of the barriers to its self-management.^{11,23,24} Note that this knowledge must be obtained from reliable sources. Participants mentioned that they seek information from various sources, such as MS associations, other people with MS, MS specialists, related books, the internet, and websites. Multiple sclerosis associations were the most trusted source of information from the perspective of the participants. Specialists in MS and other people with MS were cited as the next reliable sources. The participants expressed their preference to obtain information from physicians and neurologists when experiencing new symptoms and problems. This finding is consistent with patients’ statements in other qualitative studies in which they had reported that physicians are the main source of information about the symptoms of MS and its related medical and therapeutic aspects.^{25,26} This preference to obtain medical information from specialists can be promising to follow the right path to know the disease and its management by the patients. However, some interviewees in this research pointed to the inappropriate behavior of some physicians while asking questions. For example, they expressed that physicians ignore their questions and do not answer them. These behaviors cause patients to be reluctant to communicate all their problems with physicians. The consequence of this may be a lack of adherence to the physician’s recommendations.²³ This finding is consistent with the results of one study from Iran that reported the dissatisfaction of patients with MS with some health care professionals (particularly physicians) in this regard. Patients had also perceived that there was no sympathy and no empathy by their physicians about their condition. As mentioned in the literature, this contributes to a lack of adherence to physician orders. Stress due to lack of compliance with recommendations and treatments can have irreversible consequences for the patient.²³

Lack of trust in the internet and websites was another issue stated by the participants. They believed that the information provided on the internet is not only untrustworthy but also upsetting. This result is in line with a qualitative study that reported that

information provided on the internet is inaccurate and disappointing and hinders the practice of effective self-management for those attempting to manage their MS.⁷ The volume of information available on the internet makes it difficult for patients to assess credibility. Provision of reliable information sources on the internet by the related authorities and introducing them to the patients can decrease their confusion resulting from information overload.

Acquiring knowledge about lifestyle in MS, especially nutrition and exercise in MS, was among the identified needs in this study. The interviewees emphasized the importance of awareness of useful physical exercises and their role in MS self-management. They noted that information about useful exercises should be provided to persons with MS, as well as their “shoulds” and “should nots.” This is in line with findings from a study conducted in Canada that revealed that patients with MS want to get information about physical activities, their importance, and types.²⁷ Participants also emphasized that doing exercise is very helpful, not only physically but also mentally if the exercise type is chosen correctly depending on disease severity. Physical exercise is considered a beneficial strategy for people with MS to manage symptoms, restore function, optimize quality of life, promote wellness, and boost participation in daily life activities.²⁸ Given that physical activity is of great importance for patients with MS, consultation with a physician or a physical therapist, and careful consideration of patients’ capabilities, are considered necessary for patients before starting exercises.²⁹ Starting exercises

without awareness about beneficial exercises can cause many problems in persons with MS.

The awareness of appropriate nutrition was identified as one of the dimensions for MS self-management. According to the present results, complying with the nutritional regimen had helped prevent the occurrence of MS symptoms based on the participant’s experiences. The participants believed that information about nutrition recommendations and useful and harmful foods in MS should be offered for people with MS. A similar study reported that healthy lifestyles, such as diet, exercise, supplemental therapies, and the balance between activities and appropriate rest, are important factors affecting the health of people with MS from the participant’s perspective.³⁰ A healthy lifestyle (defined as “eating well, having quality sleep, not smoking or drinking, and participating in active pursuits”) has been considered one of the main dimensions in the MS self-management model recommended by Ghahari et al.¹¹

Monitoring MS status was the third theme that emerged from the study. Monitoring MS status can be very important in understanding MS and its individual aspects. The nature of MS has made its self-management of paramount importance, multifaceted, and highly individual. Self-management of MS includes elements of the general self-management framework, with special attention to MS in each person with the unique experience of living with MS.^{8,12} Therefore, monitoring MS status can cover the individual aspects of MS management and help the person listen to their body. The participants emphasized the importance of monitoring MS symptoms, rest status, and stress status for the daily monitoring of MS status. Pursuing each of these items and recognizing the impact of each can clarify the self-management path individually for each person with MS.

The development of communications was classified in the fourth category of these findings. For creating a sense of empathy and motivation, most interviewees preferred to communicate with other optimistic people with MS. These are in line with other studies’ findings.^{24,26} Some participants pointed out that communication with physicians acts as a support system for patients with MS. Note that providing the possibility of communicating with physicians through online channels can be an effective solution to answer patients’ questions about their new symptoms and problems.

Strengths and Limitations

The present study was conducted as the first phase of a research project to develop an MS self-management

PRACTICE POINTS

- Maintaining hope, accepting MS, getting support from the family, and communicating with other optimistic individuals with MS are the primary needs of a newly diagnosed person with MS from the perspective of patients.
- Understanding MS from reliable sources, adaptation to MS, awareness of useful physical exercise in MS and doing the exercise, eating beneficial foods, and adherence to nutritional recommendations for patients with MS were the main components that participants pointed to as necessary for MS self-management.
- Monitoring of MS symptoms, rest status, and stress status is essential for the daily management of MS.

app and to prepare the content of this app. The researchers believe that to develop successful self-management apps it is not enough to rely on self-management guides and articles and that the needs of the apps' beneficiaries must be extracted and considered as well. Despite the potential benefits, this study has several limitations that should be addressed in future research. Access to people with MS who have more awareness about self-management was limited. Interviews with those individuals could have gained in-depth insight into the MS self-management needs. Most of the participants were women, which means that the perspective of men with MS is still unexplored. In this study, only 2 participants were men, which can be attributed to MS being more common in women than in men. The interviews were conducted only with those with MS. Caregivers, families, or partners of people with MS have important roles in patient self-management practice, and their perspectives could help in exploring self-management needs.

Conclusions

The present qualitative study was conducted as part of a research project to develop an app for MS self-management toward using the potential capacity of health apps to meet the patient's self-management needs. Extracting patients' needs and getting insights into their experiences of living with MS is an integral part of developing successful self-management programs, and the same is true for designing a self-management mobile app for individuals with MS. Credible sources of information for persons with MS, basic needs of newly diagnosed individuals, information priorities for knowing and understanding MS, awareness of useful exercises and nutrition in MS, how to monitor MS, and the need to enable online communication in the MS community were the main components that participants pointed to as necessary for MS self-management. □

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