

ORIGINAL ARTICLE

Challenges in the Daily Living Activities of Patients with Multiple Sclerosis: A Qualitative Content Analysis

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ABSTRACT

Background: Multiple sclerosis (MS) is a chronic nervous system disease with a wide range of symptoms that affect the self-care ability of patients in daily activities of life; the patients afflicted with this disease face with many challenges. This study was conducted to explore the activities of daily living (ADL) challenges of these patients.

Methods: In this conventional content analysis study, fourteen MS patients who were selected purposively from Iran MS Society in Jahrom (Iran) participated in 2018. Data were gathered using semi-structured and in-depth interviews. A total of 14 interviews were conducted. These data were analyzed using MAXQDA 10 Software and the Graneheim and Lundman method.

Results: Analysis of data led to extraction of the main theme “fear of ambiguous future of diseases” as the most important daily living challenge in MS patients. This challenges were categorized in four main categories: 1) confrontation to physical, emotional, psychological and behavioral changes, 2) fear of becoming crippled, 3) tolerance of financial burden of the disease, and 4) confrontation to cultural-social wrong beliefs.

Conclusion: The results of this study showed that people with MS face a number of ADL challenges. Fear of an ambiguous future leads to problems in ADL of patients. Therefore, considering the ADL challenges, health care personnel especially nurses, family members and social organizations can improve ADL and compromise patients with the disease as much as possible by providing conditions for application of the self-care activities and their implementation by patients.

KEYWORDS: Activities of daily living, Iran, Multiple sclerosis, Qualitative research

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INTRODUCTION

Multiple sclerosis (MS) is a chronic progressive disease that destroys the central nervous system myelin, thereby affecting the sensory and motor function.¹ This disease is determined with periods of worsening and recovery.² It is one of the most common neurological disorder and cause disability in young people.³ It is also one of the most important life-changing diseases because it damages the best periods of the people's life and leads to inability.⁴ MS has afflicted about 1 in 1000 people and the prevalence is 1.1 million people in the world.⁴ The number of patients in Iran has been announced 40,000 people, which is on the rise.⁵

The disease is not curable and the goal of the treatment is to accelerate the patient's recovery from attacks and prevent further progression of the disease.⁶ 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; it destroys the feeling of being good in a person.⁷ In addition, chronic diseases affect the identity, psychosocial dimensions, emotional balance, self-satisfaction, sense of competence and efficacy, and social interactions. There is a need to identify these problems and concerns and take effective measures to manage challenges and concerns.⁸ Problems caused by symptoms of the disease restrict the person from engaging in daily activities. Even those who are mildly affected by MS suffer from reduced level of physical activity and daily basic activities than healthy people. Such effects certainly reduce the level of daily activity and increase the sense of fatigue and activity-related fatigability.¹

This disease, due to the chronicity and causing many problems, imposes a lot of costs on patients and government.⁹ It should be noted that much of the costs is imposed on patients, despite physical and mental disabilities caused by the disease and it doubles the concerns and problems of them.¹⁰ As a

result, patients with MS may be confronted with activity limitations (i.e. difficulties in task performance), leading to a loss of functional independence and community participation. The ability to perform activities of daily living (ADL) is, therefore, often compromised by disease progression, often reducing the quality of life. Also, efforts to understand diminished independence in ADL in MS typically point to the physical impairments found in MS including decreased ambulation, coordination, balance, and visual difficulties.¹¹ The results of a qualitative study in Iran showed that patients with chronic disease faced with many challenges in life and personal activity.¹² Previous quantitative studies have indicated that levels of ADL in MS patients are low; therefore, it is necessary to identify the causes and improve the ability of patients in this area to improve their quality of life.^{13, 14} The results of the study also showed that physical changes and complications caused by MS have a devastating effect on the daily routine functioning of the patients which requires serious intervention.¹⁴ Therefore, patients with MS, due to the numerous physical, motor and psychological problems caused by disease progression, are faced with challenges and concerns in their daily activities and care that these challenges also affect other functional activities.¹¹

MS disease has a chronic and progressive nature. The disorders caused by this disease are very different from other chronic diseases. For example, MS disease affects people's movements and causes movement disorders. Motor problems such as tremors, slow motion, disturbances in walking and imbalance in these patients are common. Therefore, these patients face a lot of ADL challenges due to motor problems, etc.¹¹ Assessment of the ADL challenges based on the participants' experiences can help to improve and reduce the need for drug therapies.¹² 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.¹³ Being

present in natural environment, qualitative research tried to interpret the phenomena, as the best approach to describe experiences;¹⁵ therefore, studying and explaining the ADL challenges based on the experiences of patients who live with the disease is a major help for the promotion of ADL of patients. Also, qualitative studies with context-based understanding of the phenomenon can produce priceless information about in-depth experiences of patients.¹⁵ Based on the surveys conducted, a study on this subject was not found. Hence, a deep understanding of the ADL challenges in patients who experience this crisis is essential.^{12, 15} Thus, through qualitative research, some effective steps can be taken to identify ADL challenges and help these patients to improve, manage the symptoms, and improve the quality of their lives. Therefore, this study was carried out to find out the ADL challenges in Iranian patients with MS.

MATERIALS AND METHODS

This study is a qualitative research with conventional content analysis approach which was performed from January to October 2018 (about ten months) in MS Society in Jahrom, Iran. In this approach, the codes and their classification were directly extracted from the interviews. In

content analysis, the researcher interpreted the results by presenting data in words and themes which involved understanding, interpreting and conceptualizing of the underlying meanings of the qualitative data.¹⁶ 14 patients with MS were selected through purposive sampling, with an attempt to observe the maximum variations in terms of demographic characteristics including age, sex, education level, etc. Table 1 displays the characteristics of the participants. Inclusion criteria for the participants were (a) definite diagnosis of MS disease by a neurologist, (b) willingness to participate in the study, (c) ability to express experiences, (d) at least one years passed from MS disease, and (e) membership in MS Society. Patients who were at the stage of experiencing acute and critical attacks of the disease were excluded.

The data were collected through semi-structured and face to face precise interviews. Data collection was continued until data saturation was reached a new category, concepts and ideas did not appear. Each interview lasted on average 30 to 45 min based on the participant's conditions. All patients were interviewed only once. A total of 14 interviews were conducted according to the participant's prior agreement and at the time and place they were comfortable. All interviews were conducted in MS Society in Jahrom. Interviews began with more general

Table 1: Characteristics of the study participants

Participant	Sex	Age (years)	Education	Disease duration (years)	Interview location
P1	Female	28	Associate Degree	6	MS Society
P2	Female	45	Associate Degree	23	MS Society
P3	Female	34	Associate Degree	11	MS Society
P4	Female	34	Diploma	1	MS Society
P5	Female	32	Diploma	4	MS Society
P6	Male	25	Associate Degree	3	MS Society
P7	Female	28	High school	3	MS Society
P8	Female	39	Associate Degree	7	MS Society
P9	Female	38	High school	9	MS Society
P10	Female	33	High school	7	MS Society
P11	Female	24	Diploma	9	MS Society
P12	Female	35	Associate Degree	12	MS Society
P13	Female	40	High school	8	MS Society
P14	Female	37	High school	4	MS Society

questions. Then after the interviews and simultaneous analysis of data, more detailed questions were asked, as follows:

1) Could you briefly explain about the nature of your illness and how it has affected your life?

2) Could you talk about the cares taken throughout a day?

3) What difficulties do you face in your ADL?

All interviews were audio-recorded after obtaining informed consent and with the permission of the participants. In analyzing the data, the Graneheim and Lundman's approach were used.¹⁷ In the present study, the analysis of data started after the first interview. After each interview, the text was transcribed on a Microsoft Word file. The trial version of the MAXQDA 10 Software was used to manage the coding process. In this stage, 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. Finally, one main theme was extracted. The interviews were conducted by the first and third authors. Coding and data analysis were done by all the three researchers.

Researchers increased the credibility of the data by prolonged engagement with data, spent quite a long time in the field, collecting and analyzing the data and using member check and peer check. In the member check, coded interviews were returned to five participants to reach an agreement between the researchers and participants. In the peer check, recommendations and comments of the four professors were used to determine the codes and categories. Also, we tried to use more appropriate questions which were in line with the main question of study. For enhanced dependability and conformability, the external audit technique was used. In the section, texts of the interviews, codes and categories extracted from them were examined and confirmed by two independent experienced researchers. Therefore, for dependability, the participants were asked questions from

all of the same areas. Transferability was enhanced through purposive and maximum variation in sampling in terms of demographic characteristics. Also, a detailed description of the data collection and analysis processes was presented. All interviews were conducted with similar conditions in the MS Society.

This study was approved by the ethics committee of Jahrom University of Medical Sciences in Iran (Code of Ethics IR.Jums. Rec.1396.079). Before data collection, the researchers obtained oral and written informed consent to ensure the confidentiality of the names of people, considering privacy and emphasizing voluntary participation. Participants were informed about the purposes of the research and allowed to record the interviews.

RESULTS

The result of the initial data analysis in the primary coding step was 148 codes. The codes were put in similar categories based on similarity and differences between them. Overall, four main categories as the ADL challenges in MS patients were obtained (Table 2).

1. Confrontation to Physical, Emotional, Psychological and Behavioral Changes

This category includes subcategories of tiredness and lethargy, numbness and imbalance, isolation and introversion after suffering illness, anxiety and depression, sensation of despair and frustration, impatience and early anger, and excessive sensitivity. Participants believed that MS disease causes multiple physical, emotional, psychological and behavioral changes that affect their daily life activities, and self-care confronts them with many challenges. As to the tiredness and impatience, one of the participants said: "*Some days, I get up and feel bored, generally weak and fatigued so that I cannot do anything else; excessive fatigue does not allow my daily activities to be done as I like*" (P11). Regarding the isolation and introversion after suffering from illness,

Table 2: The theme, categories and sub-categories of the study

Theme	Categories	Sub-categories
Fear of ambiguous future of diseases	1. Confrontation to physical, emotional, psychological and behavioral changes	1. Tiredness and lethargy 2. Numbness and imbalance 3. Isolation and introversion after suffering illness 4. Anxiety and depression 5. Sensation of despair and frustration 6. Impatience and early anger 7. Excessive sensitivity
	2. Fear of becoming crippled	1. Fear of dependence on others 2. Fear of disease progression 3. Fear of disability 4. Fear of wheelchairs
	3. Tolerance of financial burden of disease	1. Impose costs of illness and treatment on the family 2. Lack of financial support from insurance organizations
	4. Confrontation to cultural-social wrong beliefs	1. The negative attitude of the community towards MS 2. The compassion of others towards the patient with MS 3. The wrong belief that the MS is contagious 4. The wrong belief towards early death of MS patients 5. The refusal to participate in the community and ceremonies due to wrong opinion

another participant stated: *“Since I have suffered from MS disease, I’ve communicated very little with others, even with my family. Psychological changes have affected my living conditions and decreased my activities”* (P3).

With respect to the feeling of despair and frustration, another participant stated: *“With the passage of time, I get more frustrated. Before I was ill, I always used to think positively, but now I have no hope to live”*(P3).

2. Fear of Becoming Crippled

This category includes subcategories of fear of dependence on others, fear of disease progression, fear of disability and fear of wheelchairs. One of the main concerns and challenges of the majority of participants was fear of becoming crippled. The participants feared that they would be disabled with disease progression and need wheelchairs, so they would depend on others including family members in their daily activities. About the fear of dependence on others, one of the participants said: *“Sometimes, I tell the kids that if I get bedridden, do not let me die hard or anyone else get in trouble. Have a needle of air in my blood vessel....”* (P3).

One of the participants in this regard said: *“Nearly 15 years ago, when I saw a patient with*

MS, he was a piece of meat on a wheelchair so that in his son’s wedding he could not do anything. I’m so afraid if my illness progresses and I get crippled. The fear of becoming crippled and dependence on others has been one of my daily challenges” (P3).

3. Tolerance of Financial Burden of the Disease

This category includes subcategories of imposing costs of illness and treatment on the family and lack of financial support from insurance organizations. The participants mentioned MS disease brought a lot of costs for the patient and his family members. Some of the costs include diagnostic procedures, frequent tests, nerve and muscle strain, physician visits, medications, etc. As to the treatment and medication costs, one of the participants said: *“The doctor told me to change the drug; the new foreign medicine is very expensive. I’m very worried about how to afford it. Providing the drugs caused the family to get into trouble”*(P3).

The other participant, regarding the lack of financial support from insurance organizations, stated: *“In Iran, there is not good insurance coverage for patients with MS; for example, taking medicine, doing physiotherapy or visiting a doctor; many of*

them say they are not under the coverage of an insurance company”(P9).

4. Confrontation to Cultural-Social Wrong Beliefs

This category includes subcategories of the negative attitude of the community towards MS, compassion of others toward the patients with MS, the wrong belief that MS is contagious, the wrong belief towards early death of MS patients, and the refusal to participate in the community activities and ceremonies due to wrong opinion. The majority of participants argued that one of the challenges of the MS patients is that people in the community do not have the right knowledge and information about MS. Some people think our disease is contagious, so they stay away from us; also, some think we have cancer that must make us feel compassionate.

A participant said *“When I found out that I have MS, I went to the hospital. When I went to a woman and said, “I have MS.”, “she surprisingly answered, “you have MS!” “And then she pointed me out to her colleague; these behaviors are worrying and make us stay home rather than go out”* (P10).

Another participant stated: *“We had a swimming class in the pool; we did not have anyone in the pool because they said” “there’s an MS patient, and the disease is transmitted to you.” “These misconceptions regarding MS hinder our social activities outside our home”* (P5).

Another participant, regarding the refusal to participate in the community activities and ceremonies due to wrong opinion, stated: *“Our community does not have enough knowledge of MS. In this case, we have to hide our illness from others and not go out as much as possible in the communities. This has affected all our activities inside and outside of our house”* (P13).

In the final step of data analysis, the main concept in the texts of all interviews emerged as the main theme. The main concept formed in this study was “Fear of ambiguous future of diseases” because the general content of all

interviews and all concerns of the participants were related to “Fear of future.”

In this case, one participant described *“I’m always worried about what my future is, whether my illness will be good or not. Can I get married? Will a definite treatment be found for the disease? and ... The fear of the unpredictable future and the main challenges in our daily lives are the MS patients’ concern”* (P8).

DISCUSSION

This is the first study to report ADL challenges in adults with MS. The first ADL challenge for MS patients, which led to problems and concerns in daily activities, was a change in the dimensions of physical, mental, emotional, and behavioral that arose from the disease. From the perspective of participants, MS disease causes many problems, including fatigue, imbalance, weakness, anxiety, frustration, boredom, excessive sensitivity, etc. In this regard, when the participants in the study were asked to indicate which of their needs for the disease were not provided, the majority of patients indicated that they did not meet their psychological needs.¹⁸ In some studies, suffering from chronic disease was associated with progressive physical disability, psychological disturbance, emotional exhaustion, stress, and depression. These problems and concerns cause the patient to suffer disturbance during the disease in daily living activities; as a consequence, these challenges affect the patients, their family and caregivers.¹² ¹⁹ Results of the study showed physical and psychological changes, especially fatigue and depression, associated with MS, affect daily living activities in these patients and lead to a decrease in quality of life.²⁰ Also, results of a study conducted in Stockholm showed that following disease ADL, social activities were affected in two-thirds of people with MS.¹³ The results of the studies show that creating opportunities for patients and their families to discuss their experiences, challenges and ADL can be effective in identifying the patients’ daily living needs and improving their quality

of life.²¹⁻²³

One of the problems and challenges of ADL in MS patients was fear of becoming crippled that was shown in various ways such as fear of dependence on others, fear of disease progression, and fear of disability and wheelchairs. Various factors such as physical and psychological problems, observation of patients with disabilities and wheelchairs, lack of definitive treatment of the disease, dependence on others in daily activities, etc caused such concerns in patients. In Finlayson 's study, one of the main concerns of patients with MS was fear of decreased ADL and dependence on others.²⁴ This finding was consistent with the results of another study indicating that fear of becoming crippled was identified as the most important concern for Parkinson's patients.¹² Comparison of these findings shows that the shared challenges of patients with chronic illness such as MS, and Parkinson's included fear of becoming crippled and dependent on others in daily living activities. For this reason, MS patients express their fear of becoming crippled as their most important concern; they are mainly young and are in the productivity period of their lives.

Another challenge for MS patients in ADL is the financial burden caused by the disease that affects the patient and their families. Performing frequent medical tests for effective treatment, using high-cost combination drugs, and the severity of disease disability over time double the financial burden of the illness for patients and their families. In this regard, results of a study showed that in most cases the financial pressures from chronic illnesses are underestimated.²⁵ Results of another study showed that patients without adequate socioeconomic support could not follow the prescribed medical regimen; therefore, they may leave the treatment at any moment.²⁶ Also, one of the challenges in Parkinson's patients was the illness financial burden that affected their self-care activities.¹² Another study showed that economic problems, inability to earn money and financial support also affect

the individuals' ability in doing daily living activities and coping.²⁷ Another study revealed that the patients were affected not only because of physical changes, but also due to the intense economic pressures of all their daily activities and they could not continue to live in normal process.²⁸ Similar results obtained in various studies in this regard suggest that imposing high costs on patients leads to changes in ADL and affects self-care in patients. Also, the results of a study confirmed that MS imposed a severe burden on Australian society, particularly on its productivity. The burden increases with worsening disability associated with the disease.²⁹ On the other hand, inadequate insurance coverage by insurance organizations for patient drugs, physiotherapy and rehabilitation, medical tests and examinations, etc. in Iran confront these patients with more severe financial problems. Thus, it seems that the development of chronic diseases such as MS through imposing heavy costs can reduce the comfort of life of the patients and limit their daily living activities. These findings highlight the need for professionals to consider the financial problems associated with this disease and the impact of this strain on the ADL of individuals with MS and their families.

Another major challenge in patients with MS is the socio-cultural wrong beliefs about MS disease in the society. Patients participating in the study have been worried about the wrong beliefs and views such as MS as a contagious disease, MS as an incurable disease, a negative attitude to the illness, and a sense of commiseration among people in the community and they express the people's misconception as self-care challenges. MS patients participating in another study stated community awareness of the disease could be effective on the way the patients cope with it.³⁰ The results of a study also showed that community knowledge and attitude of the disease was effective in coping.³¹

Results of the study showed that the knowledge and attitude of the community about the nature of MS disease are the

influencing factors on the patients' self-esteem.³² Another study also show that wrong beliefs are one of the obstacles for searching of health information and self-care.³³ The results of a qualitative study showed that the participants almost unanimously identified societal attitudes, such as ignorance and misconceptions about MS, as a barrier their job.³⁴ Therefore, culture-building, proper informing and awareness raising of the community about the facts of MS can reduce the patients' concern and play an effective role in increasing self-esteem and active participation of patients in self-care activities.

In the present study, fear of ambiguous future of diseases was identified as the most important challenge and concern for MS patients; in that way, fear was the dominant sign and concern in these patients. This fear, physical and psychological changes, progression of the disease, observation of patients with disabilities, additional financial burdens, and the negative attitude of the community towards the disease would be more. Also, in the Finlayson's study, the fear of future was a predominant concern among the participants.²⁴ Hence, these fears with different origins can severely affect life-long activities such as marriage, childhood, self-care, socioeconomic functions, etc. Thus imposing financial burden on families, caregiver and the community over a long period of time.

The fact that only the viewpoints of the patients in Jahrom have been used in this study could be considered as a limitation. 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 are not a member of the MS Society should be considered. Also, the use of the perspective of patients regardless of family member's viewpoints is one of the other limitations.

CONCLUSION

The results of this study showed that people

with MS face a number of challenges to ADL. These challenges are manifested in various dimensions of physical, psychological, etc. Confrontation with physical and emotional changes, fear of becoming crippled, financial burden, and social-cultural wrong beliefs were identified as the most importance concerns of daily living activities of this group of patients. The findings of the study can provide the nurses and other health-care professionals with deeper recognition and understanding of these patients in order to identify their daily and life-long needs.

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