

## Informal Caregivers' Experiences of Caring of Multiple Sclerosis Patients: A Qualitative Study

### Abstract

**Background:** Approximately one-third of people suffering from multiple sclerosis (MS) need long-term care by their families, however, we know little of their experiences. Exploring these experiences can be a guideline to improve the quality of care for MS patients. The goal of this study is to explore informal caregivers' experiences regarding care of MS patients. **Materials and Methods:** A qualitative content analysis method was used to conduct this study in 2014. The study participants were 23 informal caregivers of MS patients who were chosen by purposeful sampling from the MS association of Iran. Data was analyzed by content analysis. **Results:** The analysis resulted in the emergence of six themes and seventeen subthemes. The main themes were being plagued, mental health damage, being captive among obstacles, perception of the affected family, being an emotional supporter, and need to maintain the functional independence of the patient. **Conclusions:** The findings represent the mean of long-term care by informal caregivers of MS patients, as well as the needs and challenges of this relationship. The findings can serve to create a framework for developing nursing care processes and planning educational sessions and support programs for MS patients and their informal caregivers.

**Keywords:** *Informal caregiver, multiple sclerosis, nursing*

### Introduction

Over 2.5 million people worldwide are affected by multiple sclerosis (MS),<sup>[1]</sup> and approximately 60000 people in Iran currently live with the disease. According to the Iran Neurology Society, number of people suffering from MS have increased from 51.9 in 2009 to 73 in 100000 people in 2011; moreover, prevalence rates of MS in Iran are twenty times more than other countries in the region.<sup>[2]</sup> MS may lead to the manifestation of a range of symptoms, including spasticity, movement disorders, fatigue, bladder and bowel dysfunctions, pain, depression, visual disorders, numbness, cognitive difficulties, speech disorders, and dysphasia.<sup>[3]</sup> Because of the debilitating symptoms of multiple sclerosis, approximately one-third of the people suffering from MS will need comprehensive long-term care during the course of their disease.<sup>[4]</sup> This is clearly indicative of the growing importance of the role of related careers as the disease progresses. Substantial and accumulating evidence consistently indicates that caregivers—family members—provide the vast majority

of direct care to MS patients. In the process of care giving, informal caregivers have live experience of caring.<sup>[5]</sup> Exploring these experiences can be a guideline to improve the quality of care for patients and reduce problems in this area. On the other hand, it is also becoming clear that the emphasis on MS treatment needs to shift from a patient-focused approach to a combined patient- and caregiver-focused approach because these subjects are vital in the long-term well-being of MS patients.<sup>[6]</sup> All descriptive and qualitative studies showed a significant amount of burden on the care giver's shoulders in Iran. We had three interventional study and all of them were on care givers of mental patients. Although effective, the narrow spectrum of caregivers require additional research on chronic diseases such as MS and acquired immunodeficiency virus (AIDS).<sup>[7]</sup>

Caring science research has an important role in understanding and responding to the changing pattern of diseases with an unpredictable course such as MS.<sup>[8]</sup> The secret of patient care is in caring for the patient.<sup>[9]</sup> We know little regarding

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the experiences of caregivers, whether in terms of the care process or the care burden of patients with multiple sclerosis.<sup>[10]</sup> However, there has been little attempt to explore the perceptions of caregivers surrounding the caring of MS patients.<sup>[11]</sup> In this study, a qualitative approach was adopted using interviews with caregivers of MS patients with different experiences to examine this issue in Iran.

## Materials and Methods

A qualitative method with conventional content analysis approach was used to collect and analyze data regarding the experiences of informal caregivers of MS patients.<sup>[12]</sup> The participants in this study were 23 caregivers of MS patients (7 mothers, 11 spouses, 2 father, 1 sister, and 2 children of patients) who were selected with a purposeful sampling method from MS associations and neurologists' clinics. General inclusion criteria were awareness of the phenomenon under study, willingness and ability to communicate experience, and some more specific criteria including, having a history of caring for MS patient's  $\geq 2$  years and no problem in hearing and speaking.

## Data collection

Data were collected from September 2013 to August 2014 through unstructured interviews by the researcher. Each interview lasted 50–90 minutes. The place of the interview was selected according to participants' wishes (department of MS Society, neurologists' clinics, rehabilitation centers, patients' home, and hospitals). Each participant was interviewed one or two times (after transcription of some interviews, if the researcher did not understand the meaning of participants, another interview was conducted). In total, 25 face-to-face interviews with 23 participants were conducted. The interviews began with general questions, such as "would you please explain a typical day for me? Or how do you care for the patient?" Then, it was continued with exploratory questions such as "Can you give an example to clarify how you felt exactly, so that I can understand your feeling?. Then what happened?" The interviews were continued to obtain deep and more complete data and was stopped when no new information emerged. In this study, a saturation point was reached at the 22<sup>nd</sup> interview.

## Data analysis

Qualitative content analysis was used for analyzing the data. The following steps were taken to analyze the data.<sup>[13]</sup> Transcribing the interviews verbatim and reading through several times to obtain the sense of the whole; dividing the text into meaning units that were condensed; abstracting the condensed meaning units and labeling with codes; sorting codes into subcategories and categories, based on comparisons regarding their similarities and differences; and formulating themes as the expression of the latent content of the text.

## Rigor

The conformability and credibility of the findings underwent verification through member checking, peer checking, and maximum sampling variation in terms of age, sex, education, and duration of care. To create intertranscript reliability, two experts conducted the second review process. Approximately 70% of the transcripts underwent revision to the point at which the studying team expressed strong agreement. To reach a conclusive decision, disagreements underwent modification through discussion.

## Ethical considerations

Approval to conduct the study was granted by the Ethics Committee, University of Social Welfare and Rehabilitation Science in Iran. Potential participants were informed that participation in the study was voluntary and they could withdraw at any time, their confidentiality would be maintained, and that no individual would be identified in any publications arising from the study; the registration number of this project is 500-234.

## Results

Participants in this study were 23 caregivers of patients (7 mothers, 11 spouses, 2 father, 1 sister, and 2 children of patients) with MS, with the mean age of 39 years and mean 4 years of experience of caring of patient; 3 caregivers had Master's degree, 4 had Bachelor's degree, 2 had associate degree, 3 had Diploma, and 6 had under diploma education.

During the data analysis, 1379 open coding, 384 units, 16 subthemes, and 6 main themes emerged from the caregiver experiences of caring for patients with MS. The main themes were being plagued, mental health damage, being captive among the obstacles, perception of the affected family, being an emotional supporter, and need to maintain the functional independence of patient.

## Being plagued

Hard and prolonged care for a loved one in bed caused enervation and fatigued depression for some participants

### *Feeling of tiredness*

Long-term physical care and sometimes the lack of improvement in the situation of the patients exhausted caregivers in this study.

"Long-term care of my brother made me extremely tired. How long will this situation continue?" (Sister of a 39-year-old patient, participant 14).

### *Feeling of helplessness*

A number of caregivers reached a deadlock in the care of patients, and experienced helplessness and misery.

"It's almost 8 years that my young daughter has become worse day after day in front of my eyes. No one can help

me. I feel so helpless. This situation bothers me.” (Mother of a 28-year-old girl, participant 2).

### **Mental health damage**

All participants experienced mental symptoms such as anxiety, depression, and stress. They recognized tough and long-term care as being the cause of these symptoms.

“I feel deeply depressed and anxious after becoming a caregiver.” (Wife of a 46-year-old patient, participant 1).

“I take more drugs than I should to help relieve stress or anxiety associated with care giving.” (Mother of a 35-year-old boy) “I lose my temper with family and friends due to involvement in the difficulties of caring. I feel depressed.” (Husband of a 48-year-old patient, participant 3).

### **Being held captive by the obstacles**

Many participants faced several obstacles during patient care. When the informal caregivers needed help and support from family and community, when they were asked to provide medication and other health care facilities, when patients needed rehabilitation therapy, and when they wanted to provide patients with proper care, they faced several obstacles. Long-term care forces all participants to seek support from various sources.

### **Lack of social and governmental support**

All participants complained about the high cost of treatment and lack of insurance coverage for the majority of them.

“After 2 years trying, recently the Welfare Organization has given us a meager monthly budget which does not even cover my son’s monthly medical requirements. Taking care of a paralyzed youth costs a lot. Government support and insurance coverage are too negligible.” (Mother of a 31-year-old boy, participant 6).

Most participants were discontent about the lack of physiotherapy or rehabilitation centers for MS patients across the city.

“There is just one MS specialist Physiotherapy Center in this city, which is too far from our home. Going there is too hard and costs a lot. My daughter becomes so tired and fatigued on the way. Authorities should provide facilities in this field.” (Mother of a 28-year-old girl, participant 2).

Most participants sought opportunities and facilities in the community to get the patient out of the house in order to improve his/her psychoemotional situation.

“Unfortunately there are no facilities to take my wife out with a wheelchair. Sidewalks are not safe, and most stores do not have ramps. Authorities are required to address these kinds of issues.” (Husband of a 27-year-old woman, participant 5).

### **Lack of information**

Most participants were dissatisfied with the lack of adequate training about medications and care of patients by healthcare providers.

“I did not even know what kind of foods I should give to my daughter! I did not know what kind of side effects her medications had!” (Mother of a 27-year-old girl, participant 7).

### **Lack of support from friends and relatives**

Taking care of those who were completely paralyzed or dependent on a wheelchair was more difficult for caregivers. In the absence of family members, they always look for help from relatives and friends.

“In the absence of his father, I had to ask for help from neighbors for showering my son, but unfortunately they refused. I was so embarrassed, but it’s hard to take care of a young boy!” (Mother of a 31-year-old boy, participant 6).

### **Perception of the affected family**

MS is not just a disease of the patient it is a disease of the family. Chronic diseases usually bring economic problems, relational, emotional, and physical harm to the patient’s family members.<sup>[9]</sup>

### **Affected family roles**

These study experiences of caregivers show that care of patients affects not only their role but those of other members in the family.

“My mother’s illness has caused me to have to do all house-hold chores besides going to college. Sometimes my father cooks. However, I never have enough time to do my homework or be with my friends.” (Daughter of a 40-year-old patient, participant 16).

### **Loss of family tranquility**

Disorders in comfort and tranquility were more prevalent in families in which care was for a patient with progressive type of MS.

“My family life is messed up; we do not have any comfort at all. His mother and I are awake at night and move him regularly. In the mornings I’m often late for work.” (Father of a 34-year-old son, participant 13).

### **Emotional harm of family members**

Some participants said that the patients’ situation and constant care had negative impact on family members’ emotional status.

“My little girl has become so depressed from seeing her sick father that she never comes out with us, she does not play with her friends anymore. She is always concerned about her father.” (Wife of a 33-year-old man, participant 11).

### Being an emotional supporter

All participants mentioned empathy and sympathy as the main components of care. The participants experienced an unfavorable relationship with patients due to their neglect of emotional support of patients.

“My wife expects me to be more empathetic and sympathize with her sometimes she tells me, I don't want you to wash the dishes or cook, you make me calmer by just listening to me and empathizing with me.” (Husband of a 41-year-old woman, participant 12).

### Need to maintain the functional independence of patient

Some participants tried as much as possible to maintain and promote the patient's functional independency, using multiple methods to achieve this.

#### *Avoid using excessive restrictions*

Participants tried to keep the patient's functional independence by avoiding limiting patients from carrying out their activities and providing the necessary facilities.

“I tried to reduce my concerns and the constraints that I had taken for my daughter. I let her bathe alone, cook, and go out with her friends. Despite all the difficulties, she was so satisfied.” (Father of a 26-year-old girl, participant 9).

#### *Encourage maintaining the existing abilities*

Encouraging and motivating the patients to keep their remaining abilities was another approach that participants had adopted in the care of patients and to maintain their functional independence.

“I told my wife that your hand and right foot are numb, but you still have lots of abilities. You should try to do your work not be tied to me or your mother.” (Husband of a 30-year-old woman, participant 15).

#### *Make changes in physical structure of house*

A number of participants, for better care of the patient tried to change the physical environment of the house, according to the patient's conditions and disabilities.

“I bought a chair with brakes for my wife to shower alone. I installed an outside the basin shower and some knobs in the house and in the bathroom.” (Husband of a 50-year-old woman, participant 17).

### Discussion

With an overview and comparison of results with other studies within and outside the country, the following cases can be cited: Several studies outside the country on MS,<sup>[14,15]</sup> and other chronic diseases;<sup>[16]</sup> Ghanati *et al.*<sup>[17]</sup> entitled economic costs of MS drugs and feasibility of economic agents to provide health insurance for the disease. All these studies point to the obstacles related to the cost of care and treatment of MS and other chronic diseases.

### Being plagued and mental health damage

In the present study, a number of participants experienced tiredness, helplessness, depression, anxiety, and stress caused by hard and prolonged care of patients. Buchanan *et al.*<sup>[4]</sup> and Forbes *et al.*<sup>[10]</sup> showed in their studies that physical and mental damage of informal caregivers are barriers to care for patients with MS. Strategies to reduce the feeling of depression, frustration, and helplessness are necessary to improve the health and quality of life among informal caregivers and people with MS receiving assistance.<sup>[18]</sup> Hence, health professionals should be aware of the caregiving effects on the mental health of caregivers.<sup>[18]</sup>

### Being held captive by the obstacles

Many participants faced many obstacles during patient care. Long-term care forces all participants to seek support from various sources. A number of participants did not have sufficient information about the amount and type of patient care and how to provide it. Based on their experiences, education of healthcare professionals was general or inadequate; hence, when faced with various problems and questions regarding the care of patients, they began to search for a source of educational support. Governmental support was insufficient according to participants' experiences. However lack of governmental support in caring of patients are found less in studies abroad.<sup>[19]</sup> Findings of Hosseini's study showed a lack of social facilities for patients with epilepsy.<sup>[20]</sup> This issue was notable for participants as to how in a country, with a large number of veterans, adequate social facilities for disabled persons are not considered?! It seems that this is a question for future research to improve the current situation and provide assistance to people with physical disabilities, such as MS patients and their caregivers. Family and friends can be crucial members in a network of assistance, however, caregivers often reported that it was hard to actually get their help, which was another obstacle for them.<sup>[21]</sup>

### Being an emotional supporter

All participants believed that emotional support of patients was more effective than their physical help and support in coping with the disease. Kleiboer<sup>[22]</sup> in her study noted that MS patients need emotional support from family, especially their informal caregivers, more than physical support.

### Need to maintain the functional independence of patient

One of the steps that caregivers in this study did in order to maintain functional independence of patients was avoiding excessive restrictions on patient care. In their opinion, this limitation was due to their worry; patients were dissatisfied with these limitations and considered it as their weakness. Findings of Nordgren *et al.*<sup>[23]</sup> showed that patients with heart failure were unhappy with the care limitations of their caregivers at home.

Participants believed that patients with progressive type of MS and their caregivers have been forgotten by the society and healthcare professionals. This could be due to the lesser presence of these patients in society, they were usually at home under care. Therefore, designing a caring model for patients with MS, especially progressive MS is necessary; moreover, home visits and support of informal caregivers should be considered in the care model of MS patients. According to the abovementioned, it seems that making changes in support programs of informal caregivers by the society, government, and healthcare professionals is essential. There was no limitation in this study. Further studies in other cultures and contexts are suggested to improve the transferability of findings and to draw a more complete picture of care of patients with MS for future planning regarding care.

### Conclusion

The findings of this study highlight several critical issues regarding inpatient MS care that need improvement such as support of informal caregivers by healthcare professionals and government (financial, emotional, instrumental and informational support), attention to functional independency, and emotional needs of patients during care. Therefore, an increase in awareness of these findings can help health administrators and healthcare professionals, such as nurses, to plan and design a comprehensive care model for MS patients and develop a support program for their caregivers. In the present study, there was no limitation.

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### Conflicts of interest

There are no conflicts of interest.

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