

# Iranian family caregivers' challenges and issues in caring of multiple sclerosis patients: A descriptive explorative qualitative study

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## ABSTRACT

**Background:** The broad spectrum of problems caused by multiple sclerosis (MS) imposes heavy responsibility to caregivers in caring of their patients. Therefore, they encounter many issues and challenges in this situation. The purpose of this study was to explore the experiences and challenges of MS family caregivers.

**Materials and Methods:** A qualitative design, based on a thematic analysis approach, was used to reach the study aim. Data were collected and analyzed concurrently through in-depth unstructured interviews, field notes, and observations that were held with 23 participants (14 family caregivers and 9 MS patients) at two referral centers in Ahvaz, Iran.

**Findings:** Three major themes were extracted from the analysis of the transcripts: "emotional exhaustion of caregivers," "uncertain atmosphere of caring," and "insularity care." The first theme consisted of three subthemes: "stressful atmosphere of caring," "conflict and animism," and "continuing distress affecting the caregiver." The second theme consisted of three subthemes: "unstable and complicity of disease," "caring with trial and error," and "frequent hospitalization of patients," and the third theme consisted of two subthemes: "caring gap and disintegration" and "lack of sufficient support."

**Conclusions:** This study will be useful to healthcare system for managing the challenges of MS patients' family caregivers. Improving the conditions and performance of family caregivers is crucial in order to provide high-quality care to people with MS.

**Key words:** Challenges and issues, family caregivers, Iran, multiple sclerosis, nursing, qualitative research

## INTRODUCTION

Multiple sclerosis (MS) disease is one of the most common chronic, degenerative, and severe neurological disorders among young adults and the most common cause of non-trauma-related disability in this age group. The prevalence rate of the disease varies from 60 to 200 per 100,000 people in the United States.<sup>[1]</sup> Iran is considered to be located in a medium prevalence zone for MS<sup>[2]</sup> and its rates have dramatically increased in the past 20 years. Although no epidemiological studies have been published on the prevalence and incidence of

the disease in Ahvaz, according to statistics information from the MS society of Ahvaz, more than 1300 cases have been registered.<sup>[3]</sup> As the disease progresses, patients cannot manage by themselves and family caregivers are required to perform time-consuming care on their behalf. Many family caregivers report that they have no knowledge and skills required for the care of their patients, and a model of knowledge and skills for the care of these patients has not been developed. So, many aspects of caring for these patients are still unknown. Therefore, they do not have enough confidence and preparedness for caring of their patients. As Given *et al.*, Saunders, and Benito *et al.* have mentioned in their studies, the caregivers do not get adequate healthcare guidelines from health providers, so they do not know how to play their caring role and the nature and quality of care needed. Also, they do not even know how and what resources are used to support; therefore, they are faced with several difficulties in the caring process of these patients.<sup>[4-7]</sup> So, it is important to support family caregivers and identify their needs and challenges in order to provide quality care to patients with chronic diseases.<sup>[8,9]</sup> Although the caring and support for caregivers is important, studies have shown that in many situations, there is not enough interaction between hospital care team and family

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caregivers, and providing the necessary information to maintain their health and welfare is ignored. Meeting these needs and supporting caregivers is the duty of the healthcare system. Studies have also shown that in critical situations, caring knowledge only allocate to the patient care, while the emphasis is on family needs too. Several studies have reported a lack of support for caregivers and their needs.<sup>[10-12]</sup> In Iranian healthcare context, family members are a valuable resource for incapable patients and they have essential roles in patients' support.<sup>[13]</sup> In this regard, open dialog with family caregivers about the caring situation and their challenges could promote caring knowledge.<sup>[5,14]</sup> Healthcare providers should be responsible for providing proper care to patients with MS and their families.<sup>[13]</sup> Due to exhausting nature of MS and the biological, social, and psychological demands of these patients, caregivers endure high level of tension and distress.<sup>[10,13]</sup> Therefore, failure to identify and explore caring challenges could lead to excessive burnout and frustration for family caregivers.

Some studies have been conducted in Iran on the quality of life and self-efficacy of MS family caregivers,<sup>[15]</sup> and their knowledge, skill, and attitude.<sup>[13]</sup> In addition, researchers have studied the epidemiologic aspects of diseases<sup>[2,3]</sup> and self-concepts<sup>[10]</sup> of family caregivers. Thus far, all of these studies have employed a quantitative approach. There is no published research on the experiences of MS family caregivers in Iran. As most of the studies focus on patients under care and do not consider family caregivers, lack of studies exploring MS caregivers' experiences about their caring issues is felt.<sup>[10]</sup> It is becoming clear that the emphasis in MS caring challenges has to shift from a patient-focused approach to a combined patient- and caregiver-focused approach because these subjects are vital in the long-term caring of MS patient.<sup>[6]</sup> With regard to this research gap, this study was conducted to explore the challenges of family caregivers in the caring of Iranian MS patients.

## MATERIALS AND METHODS

This study is part of the lead researcher's doctoral dissertation that was approved by the Jundishapur University of Medical Sciences in Ahvaz. This study was done with a qualitative approach and descriptive explorative method, which aimed to explore the challenges of caring for Iranian MS Patients. A thematic analysis approach was used. It was conducted between February 2012 and March 2013. The participants belonged to two medical and educational centers of Ahvaz Jundishapur University of Medical Sciences and the MS society in Ahvaz, Iran. Twenty-three subjects selected by purposeful sampling participated in the research (14 family caregivers and 9 MS patients).

Data gathering techniques in this study were in-depth unstructured interviews and observations (care behaviors of participants in clinical settings such as internal neurology part and the MS society). In the purposeful sampling method, the interviews were in Persian and were started by asking the core question, "Please tell me about the caring problem and difficulties about your patients." Probing questions such as "Could you say more about that?," "What did you think then?," and "Could you please give an example?" were asked based upon the participants' response, to enrich the information. All interviews were conducted in a calm and private environment. They were digitally recorded via an MP3 and their length varied from 45 to 100 min based on the mental and physical conditions of the participants and their tolerance. In order to gather the data precisely, besides recording the interviews, field note taking was also followed.

The data were thematically analyzed to identify patterns within the text.<sup>[16]</sup> Data collection and analysis were done concurrently and began after the first interview. The interviews were transcribed in Persian language and were analyzed by the first author. By means of data collection and constant comparative analysis, the researcher would be able to ask more probing questions in the next interview.<sup>[17,18]</sup> In the first instance, the transcriptions were read and compared with the recorded interviews in order to ensure that the participants' words had been captured correctly. Braun and Clarke's guide to the six phases of thematic analysis method was followed for identifying, analyzing, and reporting patterns (themes) within the data.<sup>[19]</sup> The analysis process in this study started when we began to familiarize with the data and notice and look for patterns of unit meaning and issues of potential interest in the data. This was followed by generating the initial codes and searching, reviewing, defining, and naming themes. Reporting of the content and meaning of patterns (themes) in the data was the ending stage. Analysis involved a constant moving back and forward between the data set, the coded extracts of information that we were analyzing and the analysis of the data that we were producing. Eventually, data collection continued until each category was saturated. It ended when no new exploratory finding related to the created analyzed themes was observed.<sup>[18]</sup> Finally, after conducting 23 interviews, the code lists were merged and the study's themes were saturated [Tables 1 and 2].

In this study, in order to ensure trustworthiness, credibility was established through peer checking, member checking, and prolonged engagement. The second and third authors (expert supervisors) and two other PhD students of nursing conducted peer checking. After the constant comparative analysis, member checking was done almost 2 months

**Table 1: Example of analysis process**

Subtheme	Code	Story
Caring by trial and error	Inadequate caregiver information Performance based on personal experiences Wavering function	<i>“Over time, my patient’s condition is much cluttered and I could not do anything for problems. I do not have enough information. I do a lot of things for her according to own experience, If my action was effective, I am continue it. So many things to do with doubts because I am not familiar with lesson, all in my mind is that, my God what if you”</i>

**Table 2: Continuation of analysis process (example)**

Theme	Subthemes
Uncertainty caring atmosphere	Unstable and complicity of disease Caring with trial and error Frequent hospitalization as a result of excessive caution

after the start of the interviews to provide necessary time for the in-depth analysis of the transcripts, by asking the respondents to verify the preliminary findings from the earlier interviews. Maximum variation of the sampling enhanced the confirmability of research. Besides, reflective memos were used to enhance the Audit Trial. The researchers independently analyzed the data in order to identify and categorize the initial codes, and then the codes and themes were compared. In areas where the two did not agree, definitions were clarified and discussion continued until a consensus was reached.<sup>[20-22]</sup> In addition, a summary of the interviews was returned to the interviewees as a member check, and confirmations were received certifying that the researchers were representing the interviewees' perspectives and experiences. Prolonged engagement in the field to collect data (a time length of more than 13 months) attracted the participants' trust and helped gather in-depth data. In this study, reflective memos were used to enhance the Audit Trial of decision making during the research process.

After obtaining approval from the university's ethics committee (ethics code: ETH-553), participants were informed about the purpose of the research, as well as the data collecting procedures in order to ensure privacy. Participants were assured that taking part in the study was voluntary and that they could cancel proceeding at any time. The interviews were recorded with the consent of participants, and the location of the interviews was a quiet place with privacy and comfort. Before the interview, participants declared their approval by signing a written consent.

**FINDINGS**

Interviews were conducted for 23 participants: 14 family caregivers and 9 MS patients (average age 34 years, range 20–50 years). In the first stage, over 1374 first-level

codes extracted. After the classification and integration, eight subthemes were acquired. Finally, three themes were extracted. The resulting themes included: emotional exhaustion of caregiver, uncertain atmosphere of caring, and insularity care.

Emotional exhaustion of caregivers is one of the major challenges that affected optimal caring of the caregivers. This theme consisted of the three subthemes including stressful atmosphere of caring, conflict and animism, and continuing distress affecting the caregiver.

**Stressful atmosphere of caring**

One of the challenges was the stressful atmosphere of caring that had a negative impact on the efficiency of caregivers and led to internal tensions. As one of the participants expressed:

*“Condition when I’m taking care of my patient is so stressful and a high-tension moment. Because of his problem that is emotional disorder and not physical and when his mood is imbalanced, everything gets affected.”* (Participant with 8 years of experience in caring)

Caring combined with stress affected all functions of caregivers and it exacerbates their psychological symptoms and problems. One of the participants reported:

*“Stress was part of me in this period, and I cannot do anything without stress: when taking the medication, eating, sleeping, and, ....”* (Participant with 2 years of experience in caring)

**Conflict and animism**

One of the special challenges of caregivers was conflict with their patients. The nature of disease directed home care condition of patients in the atmosphere of double-faced mental and psychological disorders for patients and their caregivers. Related to this conflict that led to the loss of efficiency of caring process, one of the participants said:

*“About their diet condition and physician order, any food that he takes, he’ll grouch too much and does not eat food and throws mess. At a young age, he encountered with this*

condition, therefore he couldn't tolerate it and grouch with anything." (Participant with 5 years of experience in caring)

In the experiences of patients' caregivers emerged a particular phenomenon, i.e. animism (the belief that natural objects, natural phenomena, and the universe itself pose as souls) because of the severe psychological problems suffered by the patients. As an example, a participant declared:

"Recently I observed that he was speaking and confabulating with objects such as dolls or pot and does not tell us his confabulates and problems. I feel he is tired because of extremely whining and somehow decreases our patience and tolerance, therefore he has taken refuge to things." (Participant with 11 years of experience in caring)

### Continuing distress affecting the caregiver

Continuous suffering from distress and torture of MS patients affected their caregivers. One of them declared:

"Each day when I see his condition gets worse and I don't see him with the least improvement, it hurts me very much and sometimes shakes my hands and feet. I would tell myself that I would even miss him...." (Participant with 3 years of experience in caring)

Caring in progressive distressing situations affected the quality of patients' care that was delivered by their caregiver. A participant said:

"When you cared him perfectly and don't see him better, it disturbs your concentration and your performance comes down; recently my appetite and quality of sleep was affected and I cannot take care of him like before...." (Participant with 9 years of experience in caring)

Another theme that was inhibiting effective and beneficial caring delivery among caregivers was uncertain caring atmosphere. This theme was extracted from three subthemes that included unstable and complicity of disease, caring with trial and error, and frequent hospitalization of patients.

### Unstable and complicity of disease

Caring in uncertain condition leads to dubiety in the caregivers during patient care and prevents them from delivering effective care. Unstable nature and complex conditions of the disease were important challenges that affected caregivers' activities. One of the participants declared:

"My patient's disease is such that everything breaks down and sometimes I don't know with which one to get ahead; when I'm controlling his scar to not get infected,

he suddenly develops a urinary tract infection. I'd just it; other problem emerged such as respiratory infection and fail to act." (Participant with 7 years of experience in caring)

Frequent recurrence of the disease had spread a heavy shadow cast upon caregivers of these patients. One of the interviewees declared:

"Recently his disease has relapsed quickly and bothered us as a part of his body suffered impairment and failed. Once his right eyes, then his left legs and now half of his body is paralyzed...." (Participant with 11 years of experience in caring)

### Caring with trial and error

Caregivers implemented their activities without having strong academic background and practical guidelines. Some caregivers mentioned that they did a lot of caring actions by trial and error, which suggests that this condition was not a safe condition:

"I taught a lot of things myself and didn't learn anything from anybody. For example, I gave her food, if she tolerated I continued, and if not, I did not give." (Participant with 4 years of experiences in caring)

Another caregiver believed that difficulty to access scientific resources and systematic guidelines is a factor related to prepared caring in unsafe situation:

"Nowhere can we tell our problems and get strategy and advice. In hospital, staffs do not give enough attention to us because of crowded situation. So, we are trying to ask our doubts in an unscientific way or we ourselves practice and learn it." (Participant with less than 1 year of experience in caring)

### Frequent hospitalization of patients

Caregivers are too cautious due to absence of scientific information and caring in unstable and uncertainty situation. Therefore, they hospitalized their patients when the slightest problem occurred. One of the participants reported:

"We don't trust caring by ourselves because we aren't experts and we haven't received necessary training; therefore, we have to hospitalize our patients." (Participant with 6 months of experience in caring)

Frequently hospitalizations of patients indicate lack of caring experiences with complex medical problems.

"Sometimes we feel that his condition is too bad, so we can't take care, we ourselves feel that we admitted him to hospital too many times." (Participant with 3 years of experience in caring)

Another factor mentioned by the participants which was introduced as a challenge in caring was insularity care. This theme is composed of two different subthemes which include caring gap and disintegration and lack of sufficient support.

### Caring gap and disintegration

Caring gaps existed in the caring process of MS patients and was evident in the experiences of caregivers. Where they knew care dedicated exclusively only to the hospitals and had complained from insufficient follow-up of caring process and guidance in home.

They believed that when patients are discharged from the hospital, caring of these patients is stopped and the burden of caring is on the caregivers who do not have enough ability to professional empowerment of care. One of the interviewees said thus:

"In hospital, he received high-quality care, but when he was discharged, all the supervision and consulting of health care system got interrupted." (Participant with 4 years of experience in caring)

Caring by family caregivers was done separately and according to personal experiences and styles. So many caring activities may sometimes result in duplication or some of them are omitted.

"The patient is a wanderer in her house, and anyone, for example, brother, sister, or... does something separately for him. What we do for him is scrappy and disintegrated." (Participant with 8 years of experience in caring)

### Lack of sufficient support

The nature of MS care is to blend support from multidisciplinary healthcare team. Inadequate support to caregivers leads to their failed performance:

"In home care, we need support and to be followed, but we don't receive enough support from MS society and welfare association." (Participant with 6 years of experience in caregiving)

Lack of support by the healthcare systems and failing to understand their needs were obvious gaps in caregivers' experience.. Poor accesses to organizational support are suppress caregivers motivation's for prepare effective care and attention. In this regard, one of the participants said:

"It is not like family alone could solve all problems of the disease, and we are feeling that we are alone and without support." (Participant with 9 years of experience in caring)

## DISCUSSION

This is the first time that the Iranian family caregivers' challenges and issues in caring of MS patients have been articulated and, thus, contribute to the literature. It was found in this study that caring for MS patients created some issues for caregivers that affected their caring process. These challenges were several factors related to emotional disturbances of caregiver, uncertain atmosphere of caring, and insularity care.

Caring in stressful situation due to the unstable conditions of MS disease was the issue that eclipsed the performance of caregivers. Our findings are consistent with a previous study on stressful situation. Benito *et al.* have highlighted that the factors affecting the performance of caregivers were stress and anxiety related to the current situation and the future of the disease. Caregivers in this situation had volatile performance and were feeling sad and lonely related to the patient's condition.<sup>[6]</sup> In the present study, stressful and exhausting caring condition affected the caregivers' performance, which would have negative impact on the efficiency of their caring.

Experiences of caregivers indicate that emotional and spiritual support for the patient care management was essential. The lack of this support led to strain and excessive emotional exhaustion in them. Koopman *et al.* in a qualitative study confirmed our findings and highlighted the personal, psychological, educational, and financial needs of MS patients' caregivers.<sup>[23]</sup> We know that complex neurological conditions such as MS, similar to other long-term illnesses, affect the relationship between the patients and family caregivers. In this regard, Baker *et al.* mentioned that family caregivers are an important member of the interdisciplinary team, having a unique position of care. When a patient has limited or non-existent communication skills due to the nature of the disease or progressive deterioration, it is important that there is a clear and effective communication between the patients and family caregivers.<sup>[24]</sup> Experiences of participants in the present study showed that eventuality of conflict between the caregiver and the MS patient is inevitable. The current investigation revealed that negligence and inattention to this fact gave rise to a phenomenon known as animism. However, failure to understand patient's feelings and their psychological and physical problems could lead to the patient's isolation. This condition causes the patients to use animism mechanism in order to confabulate their feelings. In this regard, Baker *et*

*al.* suggested that due to the patient and his/her caregivers being lay people without educational delivery expert, conflicts emerged.<sup>[24]</sup> Nevertheless, one notable finding from this study is that the special atmosphere of caring situation with continuous emotional disturbances leads to conflict and inconsistency in patient–caregiver relationship, which is deterrent to provide optimal care.

It is important to know that psychological distress related to care for patients with chronic conditions affected their family caregivers. The severity of these problems depends on the nature and consequences of the disease, and its complications impose high burden and emotional disorders on the caregivers. Keigher *et al.* pointed out that young carers felt more need of support to overcome stigma, anxiety, and loneliness challenges.<sup>[25]</sup>

Another point in this regard is the influence that the patients' continuous suffering of disease has on the caregivers. They may feel angry and frustrated about the interference of their patient's condition with their performance and personal control.<sup>[24]</sup> Boeijc *et al.* pointed out that MS is a physically exhausting disease that has extensive far-reaching psychosocial consequences, so it overshadowed both individual and family caregivers.<sup>[26]</sup> Experiences of participants of the present study showed that continuous distress of patients affected the function of the caregivers, and ultimately would have negative impact on the quality and effectiveness of caring. In the same way, Buchman *et al.* claimed that a mental and psychological disorder like MS is associated intimately with caregiver distress. Therefore, the need of employing effective strategies to improve the quality of life and health of the patient and his/her caregivers is felt. They also showed that burden of care in carers is relevant to their mental condition.<sup>[27]</sup> Consistent with prior research, the findings of this study confirmed this fact. In this study, it was observed that tough and volatile condition of MS care influenced the caregivers to meet the difficulties in delivering comprehensive care. On the other hand, Forbes *et al.*, in their study evaluating MS nursing specialized programs, showed that negative experiences of the disease create the feeling of need for a specialist nurse to improve communication between patients and family caregivers.<sup>[28]</sup> Therefore, caregivers' interventions should be designed based on this need to prevent the occurrence of mutual conflict.

Another challenge for caregivers of MS patients is uncertain caring atmosphere. In the experiences of caregivers, unstable nature of the disease and the presence of complex diseases resulted in caring in uncertain environment. In this regard, Halper believed

that uncertainty about the nature of the disease has been likened to unpredictable conditions. Considering the uncertain situation, family caregivers should understand the effects of these conditions on patients; therefore, they should be more responsible for patients. Also, the author pointed out that the nature of acute exacerbation condition of the disease as a red flag that every moment's making notice that MS still exists..<sup>[29]</sup> Also, uncertainty is a dominant indicator of diseases associated with each relapse that affects caregiver's partnership: challenges such as guilt, anxiety, and negative emotions such as stigma. Therefore, caregivers in such areas seek stable performance of care.<sup>[29]</sup> Results of this study revealed that uncertainty led to ambiguity in caregiver's performance. They had to use trial and error strategies in this unstable situation for responding to the complex caring needs. Hebert *et al.* claimed that caregivers in the care of patients with end stage face medical, practical, psychosocial, and religious/spiritual uncertainty issues. They believed that uncertainty is a universal experience with different degrees in individuals, and the lowest uncertainty is in medical and the highest in psychosocial domain as it may lead to conflict.<sup>[30]</sup> Corresponding to the results of the present study, other studies like that of Hebert *et al.* have reported uncertainty in medical and functional fields of caregivers.

The unstable nature of the disease and getting inadequate support from the healthcare team have made the caregivers function with trial and error challenges. Atmosphere of uncertainty had caused negative consequences to patients and their caregivers, such as frequent admission to hospital due to clumsy precautions. Thus, frequent hospitalization imposes more psychological tension to family caregivers and the concerned healthcare system. Here, the role of supporting and empowering caregivers to provide more reliable care in a confident atmosphere is invaluable. Regardless of Halper's report that the MS perspective became more positive during the 20th century,<sup>[29]</sup> in Iranian caring context, problems and issues related to MS caring process are concerned with family caregivers and healthcare providers. The creation of such issues causes turbulent situation for caregivers and also leads to frequent mandatory hospitalization of their patients. Buchman *et al.* demonstrated that 80% of MS patients in the United States are cared by family caregivers. It, therefore, caused caregiver burnout related to visiting of specialist nurse at home. They showed that if caregivers have access to specialist care, visiting specialist nurses is reduced and decreases the rate of hospitalization consequently.<sup>[11]</sup> The results of the above-mentioned studies and that of the current study confirmed that uncertainty is an important factor of patients' hospitalization.

Other major issue that was obtained from the experiences of caregivers was insularity care. Our findings are inconsistent with those of previous work on integrated care and revealed gap fragmentation in delivery care system and weakness in the overall support of caring process, which made the caregivers fail to provide integrated care. In this regard, Baker *et al.* suggested that caregivers of patients with neurological problems are deprived of support from healthcare profession.<sup>[24]</sup> Therefore, the need for mental health support and rehabilitation services to patients and caregivers is the most important. Baker *et al.* showed that the burden of MS disease has been associated with insufficient access to community health nurses.<sup>[24]</sup> So, the Iranian caring context causes heavy burden on family caregivers due to fragmentation of health services of caring. It is important to know that caregivers of MS patients need specialized training and systemic support and Perfect attention. Our analysis of experience of caregivers in the Iranian context of caring showed that they are encountered with splitting and fragmentation of caring services. Despite its importance, however, caregivers often have so much information about the disease, all of which is public information rather than specialized information, and this makes them more confused.<sup>[24]</sup> This finding was different from that of Hung *et al.* who reported that caregivers are provided continuous training at every stage of care, from the hospital to the community, with regard to patients' emotional and physical needs. They concluded that healthcare system developed a close personal relationship with the family caregivers and the patients.<sup>[31]</sup> Therefore, in the Iranian context of caring, the necessity for greater consistency to support family caregivers is sensed. Like in the Iranian caring context, Forbes *et al.*, in their evaluation of England context, showed that many patients received healthcare services at a suboptimal level in disease management and availability of facilities, faced difficulty in access to quality care and were weak in applying practical strategies to prevent complications, and received little emotional and spiritual support. These patients have poor information and their institutions are also weak.<sup>[28]</sup> Findings of the present study are consistent with those of other studies reporting that patients' needs are constantly changing through the disease trajectory and MS is different from other chronic debilitating diseases such as diabetes, epilepsy, and Parkinson's.<sup>[28]</sup> Therefore, caregivers must be able to evaluate psychological, social, and physical coordination to manage specialized interventions, such as training and support, research, and audit. So, caring in MS disease is important and disintegrated care cannot meet the needs of patients and their caregivers. It seems that there is a need for integrated and specialized care for MS patients in each caring context.

## CONCLUSION

Family caregivers are invaluable to the care of patients with serious illnesses such as MS. We believe that improving the main concern of medical, practical, and psychosocial issues of caregivers that surround care and caring will lead them to prepare themselves better for delivery of efficient care and, as a result, improve their quality of caring.

Based on the characteristics of this qualitative study, its findings should be interpreted with caution. Generalization of the results of this study is limited to specific environment of Ahvaz nursing home care. However, this is the first study of its kind exploring MS family caregivers' challenges about caring. Therefore, more studies are recommended to identify the challenges faced in effective and efficient care giving for people with MS.

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