



## Experiences of Iranian family caregivers supporting individuals with multiple sclerosis: A qualitative study

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### ABSTRACT

Family members of patients are often considered informal primary caregivers, particularly for those living with chronic diseases including multiple sclerosis (MS). Caregivers often report increased burden and stress when caring for individuals with chronic care needs. It is important to explore the caregiver experience in the context of MS. The aim of this study is to describe the experiences of family caregivers caring for individuals with Multiple Sclerosis. A purposive sampling method was utilized. A total of eighteen family member caregivers of patients with multiple sclerosis participated in this study. Data were collected through semi-structured and in-depth interviews conducted in the multiple sclerosis society and hospitals of Tabriz in Iran. Data were analyzed using qualitative content analysis assisted by MAXQDA 10 software. Three main categories emerged from interviews about their caregiving experiences. These include 1) emotional reactions; 2) caregiver needs; and 3) caregiver expectations. Results of this study demonstrate that family caregivers of individuals with MS show different emotional reactions and have complex needs and expectations from other 'non-caregiver relatives and society. This study highlights the psychosocial, physical and economic needs of caregivers of individuals with MS and enhances social understanding of this impact of the condition. This may improve the support clinicians provide to family caregivers. There is need to develop targeted interventions that reduce caregiver burden for those caring for individuals with MS.

**Keywords:** Multiple Sclerosis; Family Caregivers; Emotional Reactions; Caregiving Burden; Qualitative Research

### INTRODUCTION

Coping and adjusting to living with chronic disease is often challenging and stressful. Chronic conditions impacts individuals, families, communities and the broader society in many ways. The burden of chronic disease can be challenging and stressful for family and relationships[1, 2]. When a family member is diagnosed with a chronic condition, the families may experience alterations in quality of life, regardless of their culture or religion. A family's overall performance, flexibility and ability to manage daily life dramatically change. As a consequence, all family members would experience the psychosocial and physical effects of caregiving responsibility[1]. Family caregivers are often described as 'hidden patients' as they maintain silence and conceal their burden through facing the challenges often at their own physical and psychological expense[3].

Having a chronically ill family member may make life stressful for family. High responsibility of patient's caregiving may become a focus of frustration to the family unit as a whole. Families who care for the chronically ill have greater rates of stress and emotional burnout, when compared to non-caregiving families[1, 4, 5]. Caring for a chronically ill family member may have a destructive effect on all family members. Family members, particularly parents, may experience emotional reactions including: shock, confusion, numbness, ignorance, anger, anxiety, self-regret, fear, helplessness, depression and inner anger toward ill family member, spouse and other children[6]. Additionally, the quality of life in those living with chronic conditions may be low due to lack of social interaction with friends and relatives, lack of family support and family dissociation. These families are at risk of psychological disorders such as depression and marital divorce with feelings of loneliness, hopelessness and rejection by other families are common[1, 7, 8].

Every aspect of a chronic disease brings role changes within the family by assuming responsibilities to care for the individual. Whilst individuals with chronic conditions may experience decreased mood and low levels of self-confidence, in turn creating uncertainty for an unpredictable future associated with feelings of distress, anxiety, stress, hate, and helplessness. There are many factors that influence the way a family reacts to a chronic disease. These may differ based on age, growth and developmental stage of patient, power and strength of family adaptation skills, and life cycle stage of the family[9].

The progressive nature of Multiple Sclerosis (MS) presents as a key challenge for family caregivers [10]. MS is an autoimmune disease of central nervous system (CNS) with neural inflammation, demyelization and loosing axon of neurons features, often diagnosed in 20 to 40 years old and 2-3 times more prevalent in women[11]. Reports show that there are nearly 400,000 patients with MS in United States[12]. Within the United Kingdom (UK) MS affects more than 100,000 people, with Scotland having the highest incidence of MS worldwide[13]. To date, there is a paucity of MS prevalence data available in Iran, although in Iran's 12<sup>th</sup> International Congress of MS it was estimated to be around 60,000 to 70,000 cases[14].

MS is an unpredictable condition which varies from person to person and in a person at different times and its prognosis and trajectory are unpredictable[15]. People with MS may need long-term support from informal family caregivers, particularly as MS is more common in younger people and progresses over many years[12].

MS affects not only the individual, but also impacts their family members. In early stages of the disease, the prognosis of a patient is unclear and feelings of helplessness and loss of control are common, and may potentially contribute to social isolation[16, 17]. The severity of MS, its unpredictable course, and the unpredictable or slow effect of pharmacological therapies make adapting to live with MS challenging for many. Feelings of confusion and disappointment are common during the stages between first symptom presentations to diagnosis. Such feelings may lead to a sense of loss of control and upset with both the individual and their family members[17-19].

Previous research highlights that emotional burden placed on caregivers of individuals with chronic conditions such as MS. Having caregiving responsibilities can be time consuming for family members and this may impact on time available for leisure activities, loss of self-confidence and ultimately impact on lifestyle and relationships with others[18, 20]. Caregiver stress is common and may also place additional burden on marital life with divorce not uncommon[21, 22]. Additionally, financial burden may result as a shift in role modifications within the family unit and alternations in ability to undertake full time paid employment due to caregiving responsibilities. Caregiving responsibilities may lead to less job options and opportunities and be a factor in job performance and career progression. Caregivers may feel caregiving takes priority over career, whereby loyalty to spouse is expressed with greater importance than job opportunities[20, 23]. Moreover, taking care of MS patients may lead to losing job opportunities and play a negative role in job success. Losing hiring opportunities, changing full time to part time employment and having to leave paid employment are among MS patient's caregiving complications[17, 20].

This inability for caregivers to undertake paid employment at the same time as informal caregiving activities may result in financial burden and economic poverty. Families may be required to adapt due to lower income, and additional expenses incurred through caregiving activities such as through adaptation to living environments and purchase of equipment for manual handling such as hoists or in-house railing[24, 25]. Other expense may include assistance with in-house cleaning, cost of hospitalization, rehabilitation, or direct expenses on purchase of medications or other non-pharmacological therapies[26, 27].

Families are therefore required to adapt to respond to the changes and challenges of caregiving and family life with supporting a family member with MS. As MS progresses the patient's ability for self-care decreases as caregiver involvement to achieve activities of daily living increases. Providing daily care for the chronically ill may result in physical, psychosocial and economic burden to caregivers. This places caregivers at higher risk of depression and reduced quality of life[12]. Understanding family caregivers' complex needs requires frequent assessment and evaluation by clinicians. Common concerns of caregivers include worrying about the future outlook, and unknown or frequent change in prognostication of patient outcome[28].

MS is a relatively rare condition in Iran. Thus, many people are not aware or well educated about this condition or its complications or the implications for caregivers. Further, the care needs of people with MS remain relatively unknown and not addressed[29]. Qualitative studies may provide a comprehensive understanding and rich insight into living with MS and better supporting caregiver of individuals with MS[30]. To date, there is a paucity of qualitative research that has explored MS from a family caregiving perspective. Therefore, this study aims to address this research gap. This study aims to describe the experiences of family caregivers of individuals living with MS in Iran.

### MATERIALS AND METHODS

This study used purposive sampling methods. Data were analyzed using qualitative content analysis informed by Graneheim & Lundman (2004)[31]. Primary codes and theoretical sampling were used for coding and developing categories. Sampling continued until obtain data saturation occurred. This was achieved through interviewing a total of fifteen family caregivers of individuals with MS (15 females and 3 males). Participants were all close relatives of the MS patients, and included husbands, wives and parents.

Participants were considered eligible for inclusion in this study if they; 1) had a minimum of six months caregiving experience; 2) were a close relative of the family member with MS. Participants were recruited over an eight month period at the Multiple Sclerosis Society, Internal Medicine and Neurology hospital wards in Tabriz, Iran during May to December, 2015.

Data were first collected through unstructured in-depth interviews with family caregivers using broad questions about their experiences whilst living with person with MS and continued toward semi-structured questions including; 1)“*What were your experiences about the awareness of catching the family member with illness?*” and 2)“*What changes have lately occurred in your life?*” Interviews lasted between 45 and 60 minutes in duration.

#### Data Analysis

A six-step conventional content analysis method was used to analyze data. This process involved:

1. Transcribing data by reading and re-reading documents to find the perceived initial ideas
2. Creating the original codes, verbatim and line by line
3. Searching for themes by compiling codes into potential themes
4. Reviewing themes, and relating themes with each other, with extracted codes and with the entire data set
5. Defining and naming themes after ongoing analysis, refining themes, creating apparent definitions and naming each theme
6. Producing a report after final analysis, moving between transcripts and themes, selecting vivid stories for each theme, and generating the final report[31].

The MAXQDA software 10.0 (2010) was used to store, organize and analyze data[32]. To ensure rigor, researchers discussed and debated the findings as a group to reach consensus. The primary analysis and results were presented to the participants to verify accuracy and validate congruency of the codes with their experiences. Credibility of data was improved through long term engagement with the subject. To increase dependability, at beginning of study researchers had partial review of literature to reduce researchers' bias in data gathering and analysis processes. Confirmability was achieved by careful data recording, reporting steps, and decision making to provide a path for further research. Selection of a diverse group of participants helped amplify transferability[33].

This study was approved by the Regional Ethics Committee for Medical Research at Tabriz University of Medical Sciences, in addition to an official agreement was provided by the Multiple Sclerosis Society and hospital managers to approach and recruit family caregivers of MS patients. Written and informed consent was obtained by all

participants. Participation was voluntary and participants were free to withdraw at any stage of the study. Confidentiality was ensured, and all information collected was anonymous and de-identified.

## RESULTS

Table (1) outlines baseline demographic information. The mean duration of caregiving history was 3.6 years, with an age range of 27-54 years (Mean age=41.5 years).

**Table 1: Demographic characteristics of the study participants**

Participant no.	Age(year)	Gender	Type of Relation	Caregiving history(year)
P1	27	Female	Wife	3
P2	44	Male	Husband	4
P3	32	Female	Wife	2
P4	54	Male	Husband	7
P5	35	Female	Wife	4
P6	29	Female	Wife	3
P7	48	Female	Mother	4
P8	36	Female	Wife	3
P9	48	Female	Mother	2
P10	50	Male	Husband	6
P11	30	Female	Wife	2
P12	47	Female	Mother	4
P13	49	Female	Mother	3
P14	38	Female	Wife	2
P15	25	Female	daughter	4
P16	46	Male	Husband	3
P17	38	Female	Wife	4
P18	48	Female	Mother	3

Based on the analysis of interview contents, 654 primary codes were extracted. These primary codes were then classified into 12 subgroups and 3 groups. These were then named according to their concept; which included three main themes 1) 'Emotional Reactions' 2) 'Caregiver Needs', and 3) 'Caregiver Expectations'.

### Emotional Reactions

Experiences of participants suggested that when a diagnosis was ascertained and they processed this, they felt confused and helpless due to the chronicity of the disease and showed mixed emotional reactions. Emotional reactions included that of disbelief, anger, hopelessness, fear and anxiety, and isolation and depression.

**Amazement and disbelief:** On first learning of a family member's diagnosis, caregivers expressed severe reactions, most expressing shock at the severity of this. Many were shocked when they first became aware of the diagnosis and would not accept this, thus they often referred to secondary physician (for a second opinion) hoping that the initial diagnosis was not correct. *'When the doctor told me that your daughter is suffering MS, I cried and sat on the ground and could not stand up. I could not believe that my daughter is suffering MS and I may miss her one day. I begged him to say that it is not true, but he didn't say anything. I cried again'* (P8).

**Anger:** Many caregivers expressed that once their family member was diagnosed, they looked for solutions, however this resulted in anger. *'When I found that my wife is suffering MS, I was confused and did not know what to do. When doctor told me that this disease is incurable and I should take care her life-long, I felt really angry.'* (P2).

**Hopelessness:** Feelings of hopelessness were common in this group of individuals. The expressed hopelessness when they became aware of the progressive nature of the condition, and the lack of a cure. This was expressed by one participant:

*'When I understood that my daughter is suffering MS, I got anxious. When I found that it is incurable and there is no way for her recovery, hopelessness filled me ... I felt I could do nothing. I felt really hopeless'* (P5).

**Fear and Anxiety:** The progressive nature of MS and the lack of available treatments was a cause of stress for many of the family caregivers. This fear and anxiety focused around the unknown recovery, indefinite future, early death and fear of not being able to take care of their family members.

*'As I found that my mother is suffering MS, I felt really upset and cried all the time. I was anxious and worried. There were many questions in my mind: what will happen to my mother? Is this disease curable? May I worsen so that she could not move? May it happen that I could not take care of my mother? I was very worried that something happens to my mother and I become alone' (P1).*

**Isolation and Depression:** Participants expressed that due to alterations in appearance of their family member such as changes in facial expression and movement / immobility, were factors that influenced their willingness to socialize, due to fears of being judged or criticized. This was a source of isolation. In some cases, relatives did not express willingness to communicate with patients and their families' maybe because seeing their awful situation made them upset and they preferred not to encounter this situation. This was a key contributor to feelings of isolation for the patient and their caregivers. To some extent, the complexity of MS and these moral and social pressures were factors contributing to depression amongst individuals with MS and their caregivers. Complicated issues of the disease on the one hand and moral pressure of disease on the other hand, caused depression in patients' and their families to some extent.

*'When we go out with my mother, I would hold her hand so that she does not fall, I noticed that everybody would look at us, some looking sharply, and some feeling unfortunate. I am afraid that relatives and friends may see us and ask us what has happened? Why your mother is walking this way? I am really tired of this situation and I don't want to go out. I want to be alone. This way, I may feel relaxed. I don't feel like being with anyone. I feel I am depressed.'* (P11).

#### **Caregiver Needs**

The experiences of caregivers revealed that caring for a family member with MS may contribute to low morale and social pressures affecting all family members. Families expressed that there were many needs when caring for individuals with MS. These needs may be due to losing hope due to a lack of knowledge of the condition, high cost burden associated with medications and treatments, poverty and lack of relative support. .

**Monetary needs:** Patients' families stated that high costs of medications and treatment caused monetary pressure on the family. This often resulted in financial problems to the extent of not being able to pay therapeutics expenses or not being able to purchase required medications. Further, losing or reducing paid employment contributed to the severity of this economic burden.

*'When my husband [was diagnosed with MS] 'became diseased', he couldn't work and lost his job. From then on, we experienced monetary problems and we could not even buy his medications. We had to borrow from friends and relatives and sometimes I worked in others houses to make some money... we had a difficult situation.'* (P7).

**Needing Support:** Participants stated that most families required support from governmental organizations and relatives due to the difficult situation they were experiencing and it was not possible for them to continue without support. Most of them found themselves helpless and felt upset, thus needed comprehensive support including monetary, social, emotional, and morale support.

*'Unfortunately when problem occurs, or you experience monetary issues, everybody leaves you with various excuses. We need help and support in this situation both from government and society, friends and relatives. Without their help we cannot continue. Since we are having several problems and could not manage it. When we see that others are with us, it gives us hope and confident'* (P4).

**Therapeutic needs:** Caregivers revealed many unmet therapeutic needs of individuals with MS. These ranged from medication purchasing, a lack of diagnostic and therapeutic equipment, a lack of hospitalization and treatment of the patient, problems with equipment used for caring for patients such as wheelchairs and walkers. The most common problem was the expense of the MS related medications; their price simply made it difficult for the families to provide them.

*'It's been five months we are using " Betaferon ", but [our] doctor told us it is not effective now and we should use a stronger medication. But it is very expensive-more than 2.000.000 Tomans (about 600 US dollars). They say it may be due to sanctions and we should buy MS medications from the black market'* (P13).

Another participant said that:

*'Patient must be hospitalized since it is not possible to take care [for them] at home. It is a difficult situation. Patient cannot walk and it may cause bed sore. Moreover, patient loses bowel control and families do not know what to do... there is no one to guide them'* (P5).

**Information needs:** Most of the participants expressed that they did not know enough about MS and its chronic and progressive nature. Some of them had never heard of this condition and believed was a communicable disease. Following MS diagnosis of family members, caregivers often expressed that they felt confused in how to take care of their relatives and contributed this to a lack of availability and provision of information. Providing information and education about MS and how to take care of patients was usually undertaken by the MS Association and through mainstream media. Participants sometimes sought information by personal trial and error or from physicians, other clinicians, the internet and through networking with other families of MS patients.

*'First, it was really difficult for me; I didn't know what to do, since I did not have any information about [MS] the disease. Few people knew about it and we did not know what kind of disease it is and it made us more and more concerned. Seeing leg stiffness, limb, and blurred vision I were thinking my husband will die soon. I asked someone and they thought it is a contagious disease. People have negative attitude about this disease and try to stay apart from patient. Families need governments to give them information through the media to learn this disease.'* (P9).

### **Caregiver Expectations**

Participants expressed many concerns in relation to expectations and outlook. Fears focused around an indefinite future with worries about ongoing security. Caregivers sought coping strategies to reduce fear and increase feelings of hope. These expectations were a perspective of their wishes so that they can be hopeful about future and achieve relative morale relaxation and welfare.

**Free treatment:** Participants expressed huge financial burden in caring for individuals with MS. Factors contributing this financial burden included the high cost of medications and treatments, including hospitalization, equipment for caregiving at home, and diagnostic testing and imaging. Many participants stated that they were unable to cover the costs of routine medications. Therefore, they expected that government and related organizations to provide free treatment so that these financial pressures could be reduced.

*'Families expect that the government provide free hospitalization and treatment for them so that they don't be concerned about repetitive hospitalization. Families also expect that healthcare authorities provide free medications and home-care equipment since most of them have monetary problems and cannot buy them. Wheelchair and wavy mats are necessary for taking care of MS patients at home.'* (P7).

**Monetary help and insurance coverage:** Caregivers expressed concerns around loss of paid employment and this in combination with the high cost of medications resulted in a fear of monetary crisis and poverty which could endanger the whole family. This was a major contributor of fear and anxiety, with caregivers often not having a clear picture of the future. Caregivers expressed the need for government support and provision of disability insurance as an approach to reduce this fear and anxiety.

*'Since my husband [was diagnosed with MS] became diseased, he does not go to work, actually he cannot. His salary is not paid; we are not insured. Our future is indefinite and it is not clear that what will happen. We expect government to provide monthly salary and disability insurance to reduce our fear of future to live hopefully.'* (P4).

**No commiseration and pity:** Caregivers indicated that they were annoyed by the way friends and relatives behaved and commiserated and displayed pity, so that they avoided them. Consequently, families were not willing to socialize and preferred to stay at home. This form of social isolation was thought to be a contributor to mental health disorders including depression. Participants wanted that their friends and relatives to be aware to their relatives diagnosis and wished that they would support them emotionally and socially. Families preferred relatives to maintain positive and supportive relationships and help them solve problems instead of portraying feelings of commiseration and pity.

*'The issue that makes us (families) very upset is relatives' commiseration. Artificial behaviors and commiserations do no good to us and make us more annoyed. Families want their relatives help them solve problems instead of staying away and showing artificial commiseration.'* (P2).

## **DISCUSSION**

Our findings demonstrate that, following a diagnosis of MS, family caregivers experienced shock and disbelief. Caregivers felt helpless due to progressive, chronic and incurable nature of MS. Consequently, fear and anxiety about future were common. Similar studies reveal that families, when faced with chronic disease, often experience tension and show emotional reactions such as anger, depression, family problems and hopelessness [9, 34-38].

Seeing a pitiable situation and poor care trajectory of MS contributed to the feelings of helplessness expressed by caregivers. Other factors including caregiver exhaustion due to long term caregiving, ineffectiveness of drugs and lack of patient recovery, disease recurrence and worsening also confounded this feeling of helplessness and depression. Depression, loneliness, anger, frustration, anxiety and sadness are common responses in caregivers who provide long-term care to people with chronic illness [39].

The diagnosis of MS is a stressor and risk factor for a family's morale. Based on Selye theory (1960), tension is result of any demand out of body's capacity which affects mental and physical status. In fact, tension takes place when a person's ability is not adequate to solve issues[40]. According to stress theory of Lazarus Folkman (1984), tension is a complex procedure resulting from person's response to stress and leads to emotional responses[41]. Based on this theory, family when facing the stress of having a diseased person in the family, consequences of this stress will be fear, anxiety, hopelessness, and depression.

This study highlights the profound disabling nature of MS its physical complications, high cost of treatment, and lack of government support, families faced issues and needs including monetary, therapeutic, support, and educational needs. Not being aware, or adequately educated about MS and lack of information on how to care for relatives may further impact feelings of helplessness for caregivers. Caregivers were required to gain information about disease from other families and other sources. It is clear that there are monetary needs for caregivers of individuals with MS. Previous studies have demonstrated that families of individuals with MS face many problems and need the social support of others to overcome their problems[28, 42, 43]. Economic poverty has a significant effect on welfare and mental wellbeing of caregivers. Extra expenses of life may be considered a stressor especially in families who depend on disability pension[25, 44, 45]. Some studies also show that the need for awareness and information about MS has been main demands of patients and their families[29, 46, 47].

Results of current studies showed that patient's families, when understood that they are facing lots of problems and did not see any supporter besides them, they expected government, society and relatives, so that their needs be heard seeking their help and support. These least expectations include government monetary support in form of monthly salary and disability insurance. Patients' families had a vague imagination and fear of unknown future due to problems and needs resulting from the disease; an endless and grinder expectation with high mental effect. Thus, it was clear that they expected secure and permanent sources to lessen their worry and stress to some extent and achieve relative relaxation and welfare. Results of several studies showed that MS patients families suffer from monetary problems and asking monetary support from government[29, 46]. Study results suggest that nearly one third of MS patients' caregivers suffered stress and anxiety and need help and support[48]. Other study results show that availability of social support is the main source for caregivers' adaptability when stressed[27]. Also, O'Brien et al. study (1995) showed that receiving social support was linked to general health and moral and familial satisfaction in MS patients' caregivers[49].

Showing no commiseration from relatives are of other expectations of patient's families. Their experience indicates that adventitious and exaggerated commiseration of relatives always caused resentment. Human naturally want others to face him with honesty and dislikes artificial reactions. Patient and their family members hated fake commiseration which had destructive effects on their morale and caused them to stay away from relatives. This issue is probably related to cultural and ethical values of Iranian society and this may be the reason why this is not stated in studies in other countries.

### **Study limitations**

We recognize that there are some limitations to our study. Our sampling was purposive, however some potential participants declined to be involved within this study, due to spiritual reasons. Therefore we did not capture these views. However, our study provides rich insight into the experiences of caregivers in supporting individuals with MS in Iran.

### **CONCLUSION**

Caregivers expressed a range of emotional reactions in type and severity which is affected by cultural, religious and personal factors. It is natural for caregivers to display emotions such as disbelief, fear and anxiety, given the progressive and chronic nature of MS. Our study reveals there are many unmet needs of caregivers of individuals with MS, particularly in addressing therapeutic needs and financial support. Disability insurance and government support would be a method of reducing fear and anxiety for caregivers. Targeted public health messaging and

positive media campaigns to increase community knowledge of MS is an important strategy to reduce stigma of and has potential to increase community support and understanding for family caregivers. Finally, results of our study may help to increase understanding of the psychosocial, physical and economic burden of caregivers of individuals with MS. There is need for future studies that target interventions to reduce caregiver burden. Healthcare organizations, policy makers, clinicians and researchers should tailor support programs that support caregivers of individuals living with MS.

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