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How primary caregivers of individuals with multiple sclerosis cope with social isolation: a grounded theory study in an Iranian context

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Abstract

Background/Aims Multiple sclerosis is a progressive neurological disease that can significantly impact the psychosocial aspects of primary caregivers of individuals with multiple sclerosis. This study explored the process of social isolation among primary caregivers of individuals with multiple sclerosis in Kerman, Iran.

Methods A grounded theory approach was employed to explore the various aspects of social isolation. Data were collected through unstructured and semi-structured interviews with 15 primary caregivers of individuals with multiple sclerosis, 13 individuals with multiple sclerosis and five health care providers who were selected based on purposeful and theoretical sampling. The data were analysed via constant comparative analysis.

Results The core variable identified from the interviews was social isolation. Other concepts that were connected with this were: insufficient knowledge and awareness, escaping stigma, occupational difficulties, marital challenges and management of restrictions.

Conclusions Social isolation can affect the wellbeing of primary caregivers of individuals with multiple sclerosis. Recognition and awareness of the process of social isolation and factors influencing it can be beneficial in designing theory-driven evaluation and intervention methods. It is recommended that rehabilitation specialists pay close attention to the common needs and interests of both individuals with multiple sclerosis and their primary caregivers.

Key words: Grounded theory; Multiple sclerosis; Primary caregivers; Social isolation

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Introduction

Multiple sclerosis is one of the most common chronic, debilitating and progressive neurological diseases in adults (Cheung and Hocking, 2004). Over half of individuals with multiple sclerosis are in need of some degree of assistance from their primary caregivers to perform routine tasks (Buchanan et al, 2010). Primary caregivers are mainly close relatives who assume responsibility for taking care of the patient on a voluntary basis (Vasileiou et al, 2017).

The special characteristics of multiple sclerosis, such as the unpredictability of its course, its progressive nature and lack of definitive treatment can increase the burden on caregivers (Corry and While, 2009) and create social difficulties for them (McKeown et al, 2003; Corry and While, 2009). Studies of caregivers of adult patients with chronic illnesses have indicated that taking care of these individuals can be a burden. The social isolation and disruption to social interactions resulting from caregiving have been identified as risk factors that can contribute to this burden (Rodakowski et al, 2012; Adelman et al, 2014). In their qualitative study, Öhman and Söderberg (2004) found that the primary caregivers of individuals with chronic and neurological diseases experience social isolation. Being socially connected can be a positive influence on the psychological and physical wellbeing of adults and older adults (Uchino, 2006), but social isolation has a negative effect on their wellbeing (Cornwell and Waite, 2009). Some studies have revealed that social isolation increases the risk of coronary heart disease, stroke (Valtorta et al, 2016) and premature death (Holt-Lunstad et al, 2015).

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Various studies relating to the experiences of primary caregivers of individuals with multiple sclerosis have identified social isolation and a reduction in social interactions as having an impact on carers' wellbeing (DesRosier et al, 1992; Heward et al, 2006; Bogosian et al, 2009; Mutch, 2010). For example, Bogosian et al (2009) found that spousal caregivers of individuals in the early stages of multiple sclerosis felt socially isolated and experienced a reduction in social connection. Bogosian et al (2009) emphasised the need for deeper investigation of this phenomenon in future studies, but no studies to date have investigated this phenomenon in detail.

The present study intended to investigate the social isolation experienced by primary caregivers of individuals with multiple sclerosis in an Iranian context. Iran is an Islamic country in which the family is considered an important social institution. Iranian families are highly committed to providing care for family members who are unwell (Navab et al, 2013). Kerman is the largest province in southeast Iran. It has a population of nearly 3 million, and Kerman City contains around 723 000 people (Shahesmaeili et al, 2018). Ebrahimi and Sedighi (2013) reported the prevalence of multiple sclerosis to be 31.5 per 100 000 individuals in Kerman Province and 57.3 per 100 000 people in Kerman City. The Ministry of Health and other governmental organisations in Iran have provided individuals with multiple sclerosis with access to medical and rehabilitation services, including occupational therapy, physical therapy and psychology. Although government subsidies cover the cost of medical and rehabilitation services for individuals with multiple sclerosis in public hospitals, these measures do not cover all their needs and patients still suffer from lack of medical and rehabilitation centres and have difficulty accessing comprehensive services (Yazdannik et al, 2015). Social isolation is complex, multifactorial and subjective in nature (Freeman et al, 2019), therefore it was hoped that exploring this phenomenon in detail would assist rehabilitation specialists in the development of further studies and the application of theoretically based interventions.

Methods

Design

This study was designed based on grounded theory, as recommended by Corbin and Strauss (2014). This method is appropriate for the exploration of a phenomenon that has not been well described and to investigate the perceptions and experiences of individuals in their natural context (Corbin and Strauss, 2014).

Participants

Three distinct groups were recruited, caregivers, people with MS and healthcare professionals, each with their own inclusion and exclusion criteria. Primary caregivers of individuals with multiple sclerosis were recruited via the Multiple Sclerosis Association in Kerman, Iran, between February 2017 and April 2018. The inclusion criteria were being a primary caregiver of an individual with multiple sclerosis with first-hand experience of social isolation, a willingness to participate in the study, and being a monolingual Persian speaker.

Because of the qualitative nature of the study, the authors did not consider any exclusion criteria for the primary caregivers of individuals with multiple sclerosis to make the experience as diverse and rich as possible. Primary caregivers were selected using a purposive sampling method to develop and expand concepts. To better understand the concepts and discover the relationships between the concepts that were extracted, theoretical sampling was carried out.

Following this sampling, a number of individuals with multiple sclerosis and health care providers were invited to participate in interviews to study the challenges faced by primary caregivers. The inclusion criteria for people with multiple sclerosis were willingness to participate in the study and being a monolingual Persian speaker. The exclusion criteria for them were if they were in the relapsing phase.

The inclusion criteria for health care providers were the willingness to participate in the study, being experienced in the field of multiple sclerosis care, and having at least a bachelor's degree. In total, this study included 33 participants ([Table 1](#)):

Table 1. Participants' demographics (n=33)	
Primary caregivers of an individual with multiple sclerosis (n=15)	
Sex, F/M	10/5
Age, years	
Mean	40
Range	24–59
Standard deviation	9.73
Occupation	
Employed	7
Unemployed	3
Housekeeper	5
Marital status	
Married	12
Single	2
Divorced	1
Education level	
Primary	3
Diploma	6
Bachelor	5
Masters	1
Length of caregiving, years	
Mean	9
Range	3–30
Standard deviation	6.53
Relationship of caregivers to care-recipients	
Husband	5
Wife	5
Mother	3
Daughter	2
Individuals with multiple sclerosis (n=13)	
Sex, F/M	9/4
Age, years	
Mean	34
Range	21–61
Standard deviation	14.52
Occupation	
Employed	7
Unemployed	1
Student	1
Housekeeper	4

Table 1 Participants' demographics (continued)

Marital status	
Married	10
Single	2
Divorced	1
Education level	
Primary	1
Diploma	6
Batchelor student	1
Batchelor	5
Type of multiple sclerosis	Relapsing–remitting
Length of time since diagnosis, years	
Mean	9.5
Range	2–30
Standard deviation	8.30
Relationship to their caregivers	
Husband	4
Wife	5
Daughter	2
Mother	2
Health care providers (n=5)	
Occupation	
Neurologist	1
Psychologist	1
Nurse	3
Work experience, years	
Mean	8
Range	2–15
Standard deviation	4.3

- 15 primary caregivers: 10 women and five men with a mean age 40 years
- 13 individuals with multiple sclerosis: nine women and four men with a mean age of 34 years
- Five health care providers with an average of 8 years of experience.

Ethical approval

This study was part of a PhD thesis and was approved by the Research Ethics of Committee of University of Social Welfare and Rehabilitation Sciences (USWR.REC.1395.398). Before the interviews, all potential participants were informed that participating in the study was voluntary and that they were entitled to withdraw without any conditions at any stage. The study goals, importance and protocol were explained, and written informed consent was obtained. All participants were assured of confidentiality and anonymity.

Data collection

Data were collected by the principle investigator via interviews. Participants chose the time and place of the interview to feel more comfortable. For example, some interviews

were conducted at their home and the rest were performed at the Multiple Sclerosis Association. Initially, the interviews were conducted in an unstructured format and broad questions were asked. For example, primary caregivers were asked, 'How do you find living with an individual with multiple sclerosis?' Based on the findings, gradually the questions were narrowed to clarify the concepts. For each participant, a broad to narrow strategy was conducted in one interview session. In cases where there was a need for other people to further clarify and understand the concepts and their relationships to each other, theoretical sampling was performed.

Based on the theoretical sampling, individuals with multiple sclerosis and health care providers were interviewed to explore the challenges faced by primary caregivers. For example, individuals with multiple sclerosis were asked: 'What challenges has your caregiver faced?' Health care providers were asked: 'Based on your experiences and expertise, what challenges are these primary caregivers facing?' The time and place of the interviews were selected by the participants. Each interview took between 30 and 90 minutes.

Data analysis

Data collection and analysis happened simultaneously. All the interviews were audio-recorded and transcribed verbatim. In the open coding, concepts were formed by data fragmentation. Concepts were grouped based on their similarities and differences into separate categories.

In the axial coding, analysis focused on the paradigmatic model and the relationship between categories and subcategories were determined. Categories were integrated, refined and the core variable determined through selective coding. Memoing and diagramming were used to complete the analysis. Constant comparative analysis was performed to chart the relationship between theoretical concepts and theoretical saturation.

Rigour

Prolonged engagement with the data and emerging codes and categories was used in addition to triangulation to increase the credibility of the findings. To check the accuracy of the codes based on participants' perceptions/beliefs, the transcripts and extracted codes were given to participants. Next, the supplementary comments were collected and essential changes made. All stages of the research, including coding and categorisation, were checked by supervisors for dependability and confirmability. To ensure transferability, the process of data collection and analysis was comprehensively described (Schwandt et al, 2007).

Results

The use of grounded theory enabled the experiences of primary caregivers to be explored in detail. Social isolation was recognised as the main theme and core variable and all other categories that were identified were related to it. These categories included insufficient knowledge and awareness, escaping stigma, occupational difficulties (including rest/sleep, leisure, and work), marital challenges and managing restrictions. **Table 2** presents the themes, categories and subcategories, and gives examples of the inductive process used to explore concepts based on the raw data.

Insufficient knowledge and awareness

The majority of participants in this study complained of insufficient knowledge and information about the disease. Poor knowledge about the nature of the disease and a lack of valid sources of information, along with non-scientific beliefs about multiple sclerosis, negatively influenced primary caregivers' social interactions. This was the result of the subsequent increase in severity of disability or intensification of symptoms in the individuals with multiple sclerosis. For example:

'I had no idea that multiple sclerosis is a long-lasting disease and it is not expected to be cured soon! In fact, one of the reasons that my husband's leg got numb and made us housebound was that I had no information about the disease and I couldn't help in time.' (P22)

Table 2. Theme, categories and subcategories of data

Theme	Categories	Subcategories	Examples of codes	Examples of quotes
Social isolation	Insufficient knowledge and awareness	Insufficient knowledge about the nature of the disease	Having no prior knowledge of multiple sclerosis	'The first time [the] doctor told me that my daughter had multiple sclerosis, I hadn't even heard of this disease.' (P17)
			Caregivers' insufficient awareness of multiple sclerosis symptoms	'Most of the time when we want to go out, my wife says she is tired. Is it possible that someone feels tired every day?' (P1)
		Insufficient knowledge of valid sources of information	Caregivers' confusion about how to obtain valid information	'If I had known how to obtain info about this disease, my husband's disease wouldn't have advanced so much, and I wouldn't have been limited so much.' (P4)
			Referring to internet searches	'I search for all my wife's needs on the internet. Through this, I found out that such patients should never consume yogurt and milk.' (P18)
		Non-scientific beliefs	Metaphysical beliefs about multiple sclerosis	'Jinn possession is the cause of multiple sclerosis. Patients' physical abilities fluctuate because of this.' (P14)
			Metaphysical treatment beliefs	'As soon as I found out my son had multiple sclerosis, I immediately took him to a mullah to prescribe him a magic verse.' (P16)
	Escaping stigma	Concealing the condition (patient)	Patient trying to keep their dignity	'I am held in high esteem by my relatives and don't want to lose their respect by revealing this disease.' (P19)
		Concealing the condition (caregiver)	Caregiver being ashamed of a patient's multiple sclerosis	'I try not to let anybody know that my wife has multiple sclerosis. I am ashamed of it.' (P1)
	Occupational difficulties	Sleep and rest disturbances	Having constant preoccupations	'Every night when preparing for sleep, a thousand worrying thoughts come to my mind regarding my daughter's [care-recipient's] future and I can't sleep.' (P17)
		Work disturbances	Patient in need of full-time care	'A patient with multiple sclerosis may feel sick at any moment and needs full-time care. Most of the time, I have to leave work to go back home to take care of my wife [care-recipient].' (P6)
		Obstacles to participation in leisure activities	Care-induced physical burnout	'I got a severe low back pain from repeatedly carrying my son [care-recipient] alone and I can't go even to a park for relaxation.' (P16)
Marital challenges	Inappropriate fulfilment of gender roles	Inappropriate fulfilment of gender roles	Insufficient fulfilment of the caregiver's emotional needs	'Me [caregiver] and my wife [care-recipient] are just two roommates. [Since her] multiple sclerosis diagnosis she doesn't care about my emotional needs.' (P20)
		Patient's marital insecurity	Patient's distrust toward the caregiver	'Many of my quarrels with my wife [care-recipient] are due to her distrust toward me and she thinks that since she is sick, I will leave her someday.' (P2)
Managing restrictions	Maladaptive strategies	Maladaptive strategies	Suppressing the feeling of loneliness	'Whenever I have to stay home for a long period for the sake of my mother [care-recipient], I try to decrease my feeling of loneliness by taking sleeping pills.' (P12)
		Attempts at cooperation	Involving the patient in joint activities	'Since the first time I took my daughter to my workplace [my store], she has felt much better and helped me with sales. I also feel less lonely and fatigued.' (P10)

Some of the participants believed that multiple sclerosis is caused by jinn possession. Therefore, they had turned to people with no medical or rehabilitation expertise to cure the disease. This had affected both individuals with multiple sclerosis and primary caregivers, and further limited their social interaction and communication. One primary caregiver said:

‘The spiritualist prescribed my mother a meat-free diet to expel the jinn from her body, and forced us to stop communicating with all families who have lost a member or [have a child that is] 3 years of age. Such prescriptions have really limited our communication. We just couldn’t go anywhere and we had to disband from our friends.’ (P14)

The participating health care providers believed that the shortage of treatment centres, especially rehabilitation centres, for individuals with multiple sclerosis was the root cause of insufficient awareness of patients and their families regarding the disease and its scientific treatments. A health care provider said:

‘There are only two service provision [treatment] centres across Kerman Province that provide occupational therapy, physical therapy and psychological services to individuals with multiple sclerosis, and many towns in this province are deprived of such services. That’s why they have insufficient awareness and knowledge about multiple sclerosis.’ (P30)

Some of the health care providers also believed that having insufficient knowledge and awareness about multiple sclerosis-led patients and their families to seek non-scientific treatments. For example, one of the health care providers said:

‘Superstitious beliefs and use of non-scientific treatments in individuals with multiple sclerosis who are referred to these centres from other towns with no centres is far more frequent, as people in these underprivileged towns have little knowledge and awareness about the disease.’ (P32)

Escaping stigma

Some participants complained of people’s inappropriate behaviour and attitude resulting from insufficient awareness of and information about multiple sclerosis, causing them to unfairly judge individuals with multiple sclerosis and primary caregivers. For example:

‘When we enter a ceremony such as a wedding reception, people treat us in a strange way as if we have committed some crime or other. Or as if my daughter has the plague. They try to avoid us. Such behaviours have isolated us.’ (P10)

As a result, they tended to hide the disease from others so as to avoid the stigma connected with the disease. Participants stated that:

‘My mother does not like anyone to know about her disease. So, we have had to reduce interactions with others [so as] not to let them know about her disease. This has prevented us from being able to seek assistance or advice.’ (P12)

‘I don’t like my colleagues to know about my wife’s disease. You know, it does not have a good social image. For example, the disease causes the patient to have urinary incontinence. If my colleagues [get to] know about this, I will be embarrassed. Despite my efforts, we have fewer social and family interactions.’ (P2)

Occupational difficulties

Participating primary caregivers stressed the impact of caregiving on rest, sleep, leisure and work. They believed that these difficulties had limited their social interactions. For example, some of the primary caregivers considered the disturbance to their sleep

while caring for individuals with multiple sclerosis at night as having a negative impact on their social function. One primary caregiver stated that:

'My wife has an injection every other night. After the injection, she always has a fever. I have to stay up until morning to keep checking her fever and temperature. Because of this sleeplessness, I have to cancel some of the items scheduled for the next day.' (P2)

Another primary caregiver described work problems and social isolation because of the excessive dependence of the care-recipient:

'My absence upsets my husband. He likes me to stay next to him round the clock. This has caused damage to [my lifestyle]. I can't regularly go to work and I am housebound.' (P24)

Most of the primary caregivers believed that after their care-recipients had received a diagnosis, their leisure activities had been limited. This had caused them to feel socially isolated and lonely. For example:

'After my daughter was diagnosed with multiple sclerosis, I could not interact with my friends and have fun. I feel desperately lonely. I have to work round the clock to handle the costs of this disease.' (P10)

Marital challenges

Some spousal caregivers stated that insufficient fulfilment of gender and sexual roles by their partners with multiple sclerosis, and consequently the rise of sexual/marital insecurity, had caused quarrels and marital challenges. Several felt that their partners with multiple sclerosis tried to reduce their social interactions to better control them. The following quotes highlight how multiple sclerosis had impacted the marriages of some caregivers:

'When I come back home from work and see that my wife has not prepared lunch and the house is a mess, despite understanding her bad condition, I can't stand it and I get angry.' (P20)

'Since I was afflicted with multiple sclerosis, my sex drive has severely declined, and this has caused my husband to be edgy and he keeps arguing with me over things.' (P21)

'My wife has lost confidence in me since she was diagnosed with multiple sclerosis. She thinks that since she has multiple sclerosis, I'm having some sort of affair with another person. She keeps trying to check up on me or limit interactions with my friends.' (P6)

Managing restrictions

Primary caregivers talked about strategies they had used to reduce the limitations caused by multiple sclerosis, such as reducing and limiting their social interactions. Some of these strategies were maladaptive and had eventually caused adverse results. For example, instead of trying to improve their social relationships, some of the primary caregivers tried not to think about the limitations caused by multiple sclerosis.

The result of such behaviour did not reduce the limitations experienced but, according to their statements, gradually led to feelings of depression and further limitations in primary caregivers. For example, one caregiver said:

' Since I [was] spending loads of time in this prison [home] doing chores to avoid thinking about my problems and limitations, I got depressed.' (P16)

Some primary caregivers believed that in order to reduce the restrictions they were experiencing, they had to focus on the individual with multiple sclerosis and their needs. They believed that performing collaborative activities favoured by the care recipients would

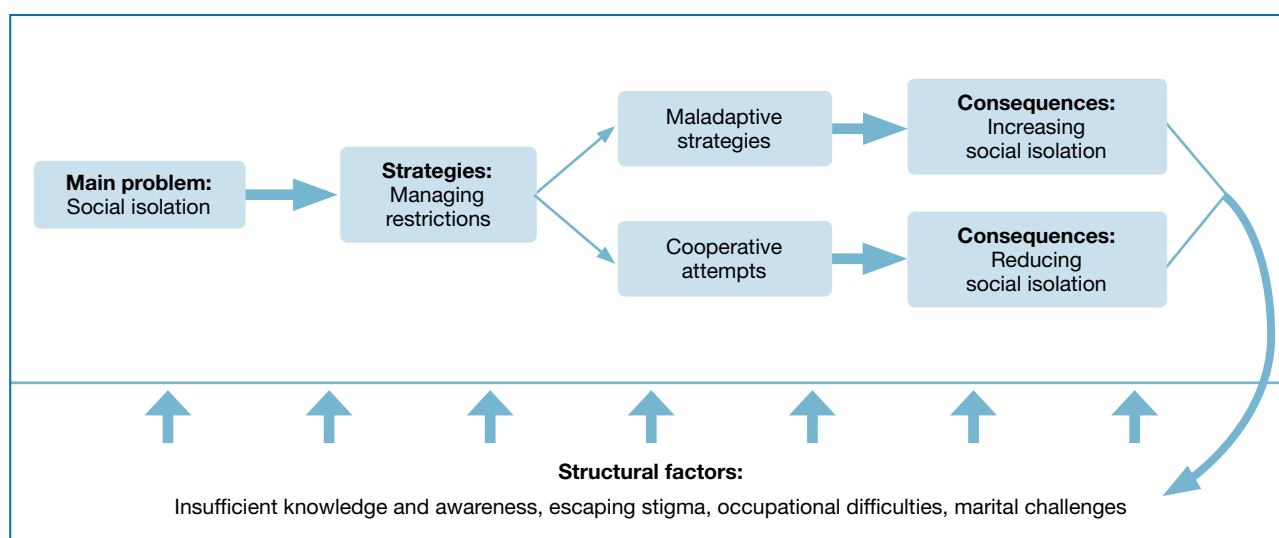


Figure 1. Conceptual model of social isolation among primary caregivers of individuals with multiple sclerosis

earn their trust and reduce caregiving pressure, and hence enable primary caregivers to better perform their social roles. Some caregivers noted that:

‘I learned to cooperate with my wife in her favourite activities. For example, she likes me to help her in cooking. We cook together and set the table, and even do the dishes. This way, I help her not to get too tired, and earn her trust so that I can handle my other businesses outside home better.’ (P18)

‘My husband would not allow us to go anywhere because of his poor emotional stability. He stopped going to work too. As I knew he loved agriculture, I decided to take a loan from Keshavarzi Bank [an agriculture bank] and run a saffron field. He did not disagree with this; he started working alongside me with passion. This caused our financial condition and our interaction with others to significantly improve.’ (P8)

The categories identified in this study made up the structural factors and strategies in the conceptual model (Figure 1). The structural factors included insufficient knowledge and awareness, escaping stigma, occupational difficulties and marital challenges. The strategies applied by primary caregivers to deal with social isolation consisted of managing restrictions.

Discussion

The present study was carried out to enhance understanding of the psychosocial problems experienced by primary caregivers. The categories identified (the structural factors and processes in Figure 1) were either directly or indirectly connected to social isolation, which was the core concept.

Core variable

Social isolation was considered to be the main problem by participants. It included the negative effects multiple sclerosis had on caregivers’ occupations (eg sleep, work and leisure activities), marital relationships and others’ views of the caregivers, which ended up reducing their social relationships.

In a study by Heward et al (2006), primary caregivers reported that motor disorders and constant fatigue prevented individuals with multiple sclerosis from joining them in religious and social activities. Over time, fear of the possible negative consequences of leaving individuals with multiple sclerosis alone in the house forced primary caregivers to stay at home with the individuals with multiple sclerosis and become socially isolated

too. Bogosian et al (2009) considered lack of understanding and support from others as the main factor leading to primary caregivers' social isolation. In a qualitative study, caregivers of chronic and neurological patients considered continual fulfilment of their caregiving role and prioritising the patient's needs over their own needs as the main causes of reduced interactions with friends and acquaintances (Öhman and Söderberg, 2004).

Structural factors

Structural factors resulted in restrictions and social isolation for primary caregivers. Two strongly associated factors were 'insufficient knowledge and awareness about multiple sclerosis' and 'escaping stigma'. The former isolated primary caregivers in two ways: first, by increasing the incapacities of individuals with multiple sclerosis and therefore the caregiving burden; and second, stigmatisation of individuals with multiple sclerosis and their primary caregivers. Multiple sclerosis-related stigma tempted both primary caregivers and individuals with multiple sclerosis to hide the disease. These findings are in line with qualitative studies carried out by Masoudi et al (2017) and Abolhassani et al (2015).

The health care providers participating in this study considered the shortage of treatment centres in Kerman Province as an important factor in poor awareness about multiple sclerosis and felt this contributed to the use of non-scientific treatments by and superstitious beliefs of individuals with multiple sclerosis and their carers. In line with this finding, a study carried out in Kerman concluded that there is a negative relationship between level of education and awareness about mental illness and the likelihood of performing superstitious practices such as visiting the mullah to receive a magic verse (Ghaffari-Nejad et al, 2003). Bukhari et al (2002) reported that in some areas of Pakistan, which neighbours Iran, superstitious beliefs about health problems prevail mainly a result of inadequate access to medical education and health services. Thus, it is suggested that the Ministry of Health and other health policymakers increase the number of comprehensive service centres available to individuals with multiple sclerosis and their families in order to educate them about multiple sclerosis and decrease the physical, mental and social problems associated with the condition.

Multiple sclerosis had caused primary caregivers to experience sleeplessness as well as difficulties at work and with participation in community-based leisure activities, reducing their social interaction. Vasileiou et al (2017) indicated that feelings of loneliness and isolation experienced by primary caregivers were linked to limitations in their leisure activities. In their qualitative study, Heward et al (2006) found that the work and leisure activities primary caregivers are able to participate in are impacted by caregiving. Finally, a systematic review indicated that multiple sclerosis has a substantial influence on the social and work life of primary caregivers (McKeown et al, 2003).

Marital challenges were found to have an influence on the social interactions of primary caregivers. Navidian et al (2017) and Rollero (2016) also believed that multiple sclerosis has a profound impact on a couple's relationship and causes marital disharmony.

Process factors

Primary caregivers had developed various strategies to overcome the restrictions and social problems resulting from structural factors associated with multiple sclerosis. Cheung and Hocking (2004) believed that primary caregivers would eventually be capable of positively adapting to the caregiving challenges. This was not the case with all participants in the present study, as some adopted maladaptive strategies that further increased their difficulties with social interactions. Abolhassani et al (2015) believed that social problems can exert a severe psychological burden on individuals with multiple sclerosis and their primary caregivers and increase the likelihood they will adopt maladaptive coping strategies.

A qualitative study recommended that primary caregivers be assessed separately from their partners with multiple sclerosis, as better assessment of primary caregivers' personal issues will provide the opportunity to reduce their social isolation (Mutch, 2010). However, some caregivers participating in the current study found that they needed to take part in collaborative activities focused on the needs and interests of the individual with multiple sclerosis if they were to have greater scope to pursue their own social interests. Given these findings, assessment of both partners at the same time – considering their common

Key points

- Insufficient knowledge and awareness of multiple sclerosis may result in individuals with the condition and their primary caregivers being stigmatised.
- Stigma may cause the condition to be hidden by individuals with multiple sclerosis and their primary caregivers, and hence socially isolate them.
- Social isolation may cause the primary caregivers of individuals with multiple sclerosis to use maladaptive coping strategies, including suppressing their social needs.
- Common interests and needs of primary caregivers and individuals with multiple sclerosis can be used to design collaborative activities to reduce the caregiving burden and improve the level of social interaction experienced by primary caregivers of individuals with multiple sclerosis.

interests and needs in planning interventions – may better address primary caregivers' situations and improve their levels of social interaction.

Limitations

Since all of the primary caregivers in this qualitative study cared for someone with relapsing-remitting multiple sclerosis, it is unlikely that this study included a comprehensive spectrum of primary caregivers' experiences. To broaden the findings, it is recommended that researchers carry out similar studies on the primary caregivers of individuals with other types of multiple sclerosis.

Conclusions

This study investigating the psychosocial problems faced by primary caregivers found social isolation to be their main concern. This complex phenomenon was influenced by a number of factors, such as insufficient knowledge and awareness of multiple sclerosis, disease-related stigma and occupational and marital difficulties that often developed as a result of mismanagement of the negative effects of multiple sclerosis by the primary caregivers. Given these results, it is recommended that rehabilitation specialists consider the common interests and needs of primary caregivers and individuals with multiple sclerosis in order to provide more appropriate management of the social limitations experienced by primary caregivers. Quantitative studies should be performed to investigate the association between the various categories of concepts identified in this study.

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Conflicts of interest

The authors declare that there are no conflicts of interest.

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