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The Impact of Cognitive Impairment in Adults with Multiple Sclerosis and Their Family Caregivers

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Practice Points

- The impact of cognitive impairments that affect both the person with MS and their partner, including their health-related quality of life, communication, relationship quality, and performance of daily activities, can be improved by promoting positive coping strategies.
- The partner plays a major role in helping the person with MS adjust to cognitive impairments, and it is important for practitioners to provide information and resources to the family at the time of diagnosis along with signposting for further support.
- Participants expressed a desire for more support, such as education about strategies to overcome regularly occurring challenges in communication and activities of daily living.

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Abstract

Background: Cognitive impairment is a prominent feature of multiple sclerosis. However, the impact that cognitive symptoms have on daily life, and the effect this has on persons with multiple sclerosis and their relationship with spouses/ partners, remains unclear. This qualitative study sought information on the nature of cognitive impairments experienced, and the impact of cognitive impairments on the daily lives of both adults with multiple sclerosis and their partners, to gain further insights into how healthcare professionals can best support families.

Methods: Fifteen persons with multiple sclerosis and their spouses/partners participated in separate telephone semi-structured interviews.

Results: Six themes were identified from the data, along with several subthemes. These were: the social impact of cognitive impairments in MS, changes to daily living, relationship quality, communication, ways of coping with MS, and the desire for help in managing MS.

Conclusions: Our results identified types of support that couples needed and wanted; ways that multiple sclerosis affects couples' social lives; that there are difficulties negotiating changes in roles due to cognitive challenges; that there are difficulties coping with the impact of cognitive challenges on daily living; that couples often have difficulty communicating about the impact of cognitive changes on daily living and related issues, which also contributes to relationship strain; and finally, that most participants felt that they did not understand enough about the cognitive symptoms of multiple sclerosis. We outline key areas to address these needs identified.

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Introduction

Cognitive impairment is common in people with multiple sclerosis (MS), with prevalence estimates ranging between 40% and 75%.¹ Common cognitive problems include slowed processing speed, difficulty learning new information, and deficits in memory retrieval.¹ A study of 45 adults with MS found the frequency of cognitive impairment increased from 26% at initial assessment to 56% ten years later.² There is little association between cognitive and physical symptoms; thus, individuals with mild physical symptoms can present with more severe cognitive impairment.³

Research suggests cognitive impairment in MS is significantly associated with low health-related quality of life (HRQoL), including difficulties in activities of daily living, social and vocational participation, and family relationships.⁴ Reduced cognitive function has a greater impact on employment than physical disability¹ such as job loss due to poor performance. Despite the importance of cognitive impairment to daily functioning in MS, and the estimated 80% of individuals with MS who live with family members⁵, limited research has examined the impact of cognitive changes on close relationships with family caregivers.

Several studies have explored the impact of a partner's diagnosis of MS on the couple's relationship, including mutual coping strategies used.^{6,7} Communication problems have been a particular focus of attention. A survey of couples in which a member has MS found that better communication was significantly positively correlated with higher marital satisfaction, whereas caregiver burden was significantly negatively related to marital satisfaction.⁸ One study found

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family caregivers of persons with MS reported relationship problems such as loss of intimacy and reduced communication due to the partner's reduced cognitive abilities.⁹ The wider impact of cognitive impairment in MS on close family relationships is still under study. The aim of this study is to study the impact MS has on close relationships, with a focus on challenges related to cognitive impairment. We also asked family members about supports they currently receive to manage the impact of MS on their relationship and help they would like to receive. Despite cognitive difficulties and associated functional impairments in MS, and burden on caregiving, there is no standardized, empirically supported approach for working with patients and caregivers to learn how to manage these difficulties, and improve their coping with the disorder. To achieve this, it is important to combine patient and caregiver reported needs alongside knowledge from the literature and clinical experience.

Methods

Overview

Semi-structured one-to-one telephone interviews were conducted with 30 participants (15 adults with MS and their 15 spouses/partners). Participants received a \$20 gift voucher in appreciation for their time. The institutional review board Schulman approved the research protocol. Informed consent was obtained for each participant. Additional care was given to participants with MS to ensure they fully understood the informed consent form and study procedures. All participants were given time to read, sign and return the completed consent form.

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Participants

Participants were invited to participate in our research via North American Research Committee on Multiple Sclerosis (NARCOMS) patient registry. NARCOMS mailed invitations to adults with MS who: (1) lived in the Eastern Time Zone of the US, (2) had a score of 3 or above (scores ranged from 1 [mild] to 5 [severe]) on the Performance Scale (PS) ©¹⁰ domain of cognitive functioning taken within the last year, (3) were living at home, and (4) were married or had a domestic partnership (referred to as a partner hereafter). Upon contacting the research team potential participants were further screened for: a) willingness of their spouse or partner living at home who is their primary caregiver to participate, and b) access to a telephone and internet (computer, laptop, tablet, or smartphone) in a private setting. Participants had not received any treatment for their cognitive symptoms or rehabilitation. Participants were asked to self-report any medical or psychological conditions in screening and were excluded if they reported learning disability, dementia (or related diagnosis that may impair cognitive functioning) or severe mental illness.

Participants with MS included 13 females and two males, aged between 38 and 73 years ($M = 60.2$). Fourteen participants were diagnosed with relapsing-remitting MS and one was diagnosed with secondary progressive MS. Time since diagnosis ranged from 6 to 37 years ($M = 19.4$). Spouses/partners included three females and 12 males aged between 44 and 73 years ($M = 62.0$). The number of years the couples reported being together ranged from 8 to 50 years ($M = 27.6$). One couple was a same-sex couple. *Table 1* provides further demographic details.

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Spouses/partners reported no mental health conditions or physical disabilities. Participants with MS reported additional medical conditions as listed in *Table 2*. All participants with MS were able to walk without assistance, while 4 participants reported using a cane sometimes. We refer to spouses/partners as “partners” throughout the results.

One-to-One Interviews

The interviewer asked each participant questions, with optional follow-up questions established in advance, based on an interview guide. Topics included the impact of cognitive difficulties on themselves and their partner, on their social relationships, and their perceived need and desire for help and support, and the desired outcomes related to such help.

Constant Comparative Analysis

All interviews were audio-recorded and transcribed verbatim. As there was not enough information in previous literature to generate specific hypotheses, a grounded theory approach was selected to identify emergent themes.¹¹ The constant comparative method, a reliable approach to generating themes in qualitative data¹², was used to identify and code categories.^{13,14}

Using NVivo Qualitative data analysis software,¹⁵ the first (E.H.) and second authors (J.S.) independently read and coded the interviews to identify concepts in the text. These authors reviewed and agreed on their initial coding and categorization, then organized codes into overarching themes. Any discrepancies found in interpreting and coding the data were discussed

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and resolved with the fourth author (K.M.). Final themes and subthemes were agreed upon by all authors.

Results

Theme 1: Social Impact of Cognitive Impairments in MS

Concerns About Disclosure

Some participants, both participants with MS and their partners, felt the “invisibility” of many MS symptoms (including cognitive symptoms) contributed to not being understood by others. Several participants with MS felt they did not want to disclose their cognitive symptoms to friends and family for fear of being treated differently and experiencing a lack of empathy. Participants with MS also expressed fear about disclosing their cognitive symptoms to co-workers due to concerns about potential job loss.

Caregiving partners also felt they had difficulty disclosing the cognitive symptoms of their partners' MS to others. Of the MS symptoms, participants reported the cognitive symptoms were the least understood and accepted, despite how they impact the couple. One partner wanted help communicating these symptoms to others and said “A lot of times I’m not sure what to say. I think I’m going say the wrong thing... but maybe I can learn ways to try and... inform people a little bit more, uh, about her individual difficulties and challenges.”

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Support of Family and Friends

Many participants, both individuals with MS and their partners, described appreciating the support of family and friends when coping with the impact of MS. Examples provided by participants with MS that were specific to cognitive symptoms included appreciating how their friends reacted with humor about word finding difficulties, or how friends and family showed patience and "... don't get mad when I forget things."

Feelings of Isolation

Partners described feeling isolated from family and friends. Sometimes this was due to family living far away and travel becoming difficult for the couple. Several participants with MS encouraged their partner to socialize independently as they were concerned about them becoming socially isolated (e.g., "I think it is a good thing she still goes out and does things, she needs time to herself.") Sometimes this was successful, but other times participants indicated their partner would not go out without them because they felt they needed to stay with them.

Managing Social Events

Several couples reported needing to carefully plan social opportunities (e.g., 'We can't be spontaneous anymore, we have to schedule everything.'). Many couples reported having to reschedule or cancel social events due to increases in fatigue. Fatigue was reported by

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participants with MS as exacerbating their cognitive symptoms, which then impacted their ability to make arrangements to attend social events. In addition, several participants with MS reported leaving social events because the need to concentrate and focus during communicating with others, caused too much fatigue.

Theme 2: Changes to Daily Living

Loss of Previous Abilities and Changes in Couples' Roles

Participants with MS identified a range of daily activities they had previously been able to do that were now affected by cognitive impairments such as: forgetting appointments, names, and dates; having difficulty concentrating when conversing, watching TV, using the computer, or reading; being unable to cook or having difficulty managing household bills; and having difficulty completing tasks such as tidying and cleaning e.g., tasks taking longer than usual, or being unable able to identify steps to finish a task.

Because of these difficulties, partners had usually taken on additional responsibilities, such as driving, cooking, managing household bills and supporting them with memory retrieval and daily tasks. For example, one participant with MS described her partner as follows: "He's like my external hard drive. He has to remember a lot of things for me... and I have trouble completing tasks, either because of exhaustion, because of pain, or because of my memory. So this combinations [sic] of things have put a burden on him."

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Emotional Responses of Person with MS and Their Partner

Participants with MS expressed frustration with how cognitive difficulties interfered with their daily functioning (e.g., “I find it annoying when I forget something,” “I’m frustrated by the loss of my ability to read like I used to.”) Participants found it difficult to accept their reduced independence. One participant described how she had to let her husband take over the cooking as “a hard thing to do, to let things go.” One caregiving partner said that as a result of his wife’s insistence on continuing to shop, despite memory problems, that he had to buy an additional fridge to hold the excess groceries. Caregiving partners spoke about their concerns when their partner with MS continued activities such as driving or cooking despite their symptoms.

Many participants with MS described ways their partner supported them and said they appreciated their partner’s patience. However, some participants with MS said their partner had become obviously frustrated about the impact of cognitive symptoms, such as becoming upset about having to repeat themselves frequently due to the person with MS experiencing memory loss.

Some caregiving partners said they found it challenging to stay patient about their partner’s cognitive impairments. They described feeling frustrated and impatient about the effects of these impairments on their functioning in areas such as using the computer, shopping, and managing bills.

Loss of Work

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Nearly half of the participants with MS reported losing their job or having to leave work due to their cognitive symptoms. Their partners expressed concern regarding the impact of these changes on their partner's well-being (e.g. "When she lost her job, she lost some of herself").

Theme 3: Relationship Quality

Some couples had viewed their relationship positively, but others felt MS had a negative impact on their relationship. When one participant described positive changes, the other tended to agree (e.g., "MS has brought us closer together," "I believe the MS diagnosis has strengthened our relationship"). Conversely, two partners confided they believed that if they'd known about the impact of MS earlier on in their relationship, they may have ended the relationship. Further details of communication and coping in relationships are discussed in Theme 4 and 5.

Some partners said their relationship had not changed due to MS symptoms, although they had made practical adjustments (e.g., "MS hasn't changed our emotional connection, we are the same as when we were married, but I do more household things now" and "I love her as much as I always did" "The main thing is, that if you love the person, you accept and deal with their condition").

Theme 4: Communication

Impact of Communication Difficulties

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Several participants with MS described how cognitive difficulties, such as memory loss, had affected their relationships with friends and past partners. The greatest social impact of these difficulties were reported to be in communication (e.g., “I keep digressing in conversation and it must be annoying to others,” “I feel embarrassed when I cannot find the word”) and forgetting people’s names. These occurred both in personal relationships and at work.

Impact of Communication Difficulties on Relationships

Several participants with MS said they felt the key to their success as a couple in managing MS was effective and positive communication. Conversely, several participants described difficulties communicating with their partner when the interactions were negative and blaming. For example, one participant with MS said, “He notices things and brings them to my attention but... he hammers me... he doesn’t bring up a problem and say ‘here it is’ in a mutual way.”

Theme 5: Coping with MS

Emotion-Focused Coping

Participants with MS described using a variety of emotion-focused strategies to cope with cognitive changes. Some described minimizing the extent of the changes (e.g., “We don’t want

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to make things seem worse than they are,” “We minimize the [cognitive] changes as we think that is the healthiest way to deal with things”). Several participants also tried to maintain a balanced perspective by comparing their situation to others whom they felt had it worse. Several participants felt it was important to take cognitive changes ‘as they happen’ and not ruminate about the future (e.g., “The cognitive changes are stressful but I take it one day at a time”). However, many participants described that they used to worry a great deal about the future, and only more recently adopted a more positive attitude in coping with the MS.

Some partners minimized the impact of taking on additional responsibilities, e.g., “I have always helped around the house, so it’s no big deal to help more now,” “I have had to make adjustments but I don’t feel I have had to change my life too much.” Some partners described a positive attitude towards their additional responsibilities, e.g., “I believe I am handling everything I need to do pretty well.” However, some participants with MS expressed concern about how their partners were dealing with the MS, describing a “lack of acceptance,” and “denying changes”. Many partners spoke about using humor to cope with challenges related to MS: “The humor in our relationship keeps me from getting frustrated or impatient,” “Humor gets us through a lot,” and, “Humor should be in the coping toolbox.” Several partners said if they’d failed to develop ways to cope with the impact of MS on their relationship, they would have considered ending the relationship.

Problem-Focused Coping

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Participants described a range of different strategies they developed to cope with the cognitive symptoms of MS. For example, one participant with MS described how she and her partner go through the alphabet together if she forgot a name, “Does it start with A... Alec Baldwin?” and that they frequently find humor (as well as the word) in the process.

Some participants felt they could manage their memory problems effectively. Many participants used multiple methods to address memory losses, e.g., using e-calendars or day planners as compensatory aids. Several participants with MS described extensive note-taking to help remember things. A few participants also described their frustration with strategies such as memos to self, and lists and that they do not always work for them, e.g., “I lose my lists and spend hours looking for them”. Many participants felt help would be beneficial if it enables them to successfully manage their cognitive symptoms.

Theme 6: Desire for Help Managing MS

This theme reflects the types of help participants described as wanting or needing during their interviews. The first two subthemes are communication and coping, as related to themes 4 and 5.

Communication

Using Positive Language. Several participants said that they wanted to improve their communication as a couple, so they could discuss challenges in a way that would be more

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supportive and understanding, and less blaming. One participant said he felt things would improve if his partner stopped repeating “I told you so” to him, which makes him feel embarrassed about his memory problems.

Talking About Cognitive Challenges. Some partners wanted to learn how to discuss cognitive symptoms with their partner, describing the symptoms as “The elephant in the room that we’re not talking about.”

Acknowledgment of Cognitive Changes. Some caregiving partners also said they didn’t talk about cognitive changes and challenges with their partner out of fear it might upset them. These caregiving partners identified that being able to acknowledge the impact of cognitive impairments would help them discuss these openly and non-judgmentally together as a couple.

Help Coping with MS

Strategies to Manage Cognitive Difficulties. Participants wanted practical strategies to deal with common cognitive challenges, such as ways to manage forgetting things and work through processing problems. Participants wanted to learn about online programs or mobile applications that could help.

Strategies for Reducing Impact of Problems on Either Partner. Several participants with MS wanted their partner to be more balanced in their approach to cognitive symptoms, e.g., managing their frustration, listening more, and being patient. These participants felt strategies and support to help partners deal with the impact of MS would help. Partners also wanted support in these areas, in particular, learning to manage their frustration of the situation.

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Information About MS

Both participants with MS and their partners wanted more information about MS and the possible progression of symptoms. Several participants were frustrated they had not received sufficient information from doctors. Many said they had received no information about the cognitive problems associated with MS. The timing of education about MS was also important to some participants. Many participants noted that help with emotional support and the provision of information about MS would have been very beneficial early after diagnosis. However, one participant said she felt too upset after her diagnosis to make use of the information provided to her, suggesting that some partners may need access to information about MS that is available over the longer-term course of the disorder.

Support Groups

Many participants had attended support groups provided by the National MS Society and found them to be beneficial. However, some participants had negative attitudes about support groups or described negative experiences attending them. For example, one partner said “I don’t want to speak with other caregivers because I don’t want to get depressed over it.” Another said, “We went to one group and found the discussion really depressing.” These participants felt other types of support would be more helpful, such as one to one counseling or smaller group sessions.

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Delivery of Support

Fourteen of the 15 couples said that it would be helpful to learn about strategies or more information together as a couple. All the participants with MS said they were happy to participate in any type of support with their partner. However, some partners said they would like additional support individually so they could privately discuss sensitive experiences, such as coping with increased caregiving roles. Due to time and travel restrictions, participants said that supportive services should be delivered flexibly, such as providing sessions at home or online.

Discussion

Our results identified a number of ways in which the cognitive symptoms of MS impacted couples' lives. Additionally, our results suggest several potential areas of need that couples articulated.

The first theme explored the social impact of cognitive impairments in MS. Previous research has shown that better social support predicts better health related quality of life in people with MS¹⁶ and several of the participants described appreciating the support they received. Studies have also found a relationship between lower social support and higher caregiver burden.¹⁷

The second theme concerned changes to daily living. Our findings are consistent with previous research exploring the impact of MS symptoms on daily life.¹⁸ However, our study points to the importance of cognitive changes in leading to problems in daily living, and its

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effects on the partner and the couple's relationship. Persons with MS expressed negative feelings about lost independence and role changes caused by cognitive symptoms. They described difficulty 'letting go' of previous valued roles and activities. There was also a clear impact of these daily living changes on partners. Our findings build on a significant literature exploring caregiver burden in MS¹⁹ by showing how partners cope with the impact of role changes and additional responsibilities, i.e., minimizing those responsibilities, or managing emotions such as frustration.

The third theme addressed the quality of the relationship between the couple. Some couples described their relationship more positively than others; however, in all cases, good communication was described as being vital to relationship quality, consistent with previous research.^{6,7,9}

The fourth theme addressed the challenges of communication changes for couples. Many participants described how difficulties talking about the cognitive symptoms of MS led to conflict. Some partners found it difficult to discuss role changes when their partner denied or minimized the impact of MS on their ability to perform daily activities. Previous literature has found that differing perceptions about the impact of MS contributes to communication problems²⁰ and that these differences contribute to communication problems and reduced psychological well-being in the person with MS and the partner.²¹

The fifth theme concerned the coping strategies used by participants. We focused on participants' description of strain related to coping; our findings provide examples of daily interactions and the emotional consequences of these interactions and expand on previous literature suggesting that the severity of cognitive impairment can have a significant negative

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impact on partners' physical and psychological well-being.^{22,23} Additionally, we provided examples of positive, mutually shared coping, particularly the use of humor when dealing with sensitive issues such as memory loss. Humor has been found to be a positive way of coping.²⁴

The sixth theme addressed the perceived needs for support of both persons with MS and their partners. As the average age of participants in our study is 61 years old, their negative impressions about support groups may reflect the fact many participants had been living with MS for some time, and the groups may have outlived their usefulness. However, participants may have found support groups useful in the past. Considering these areas identified by participants and the wider literature on family support related to cognitive changes in chronic illness, we present the following key areas for consideration for providing help and assistance to couples in which one partner has MS.

Education About MS

Most participants felt that they did not understand enough about the symptoms of MS, in particular during early stages of diagnosis. Over time, the cognitive symptoms of MS were the least understood by the couple. Education about MS symptoms would help in long-term planning about disease progression. It is also important to present the information in a way that is manageable for the couple; one partner said, "I wish there was a TV show about MS we could watch together."

The timing of education also requires consideration. Couples who initially face mild impairments may need very limited information about more severe impairments until later in the

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course of the MS. Even when severe cognitive impairments are present early in the course of MS, sensitivity must be used to determine the timing and content of related education. Better education may increase mutual understanding and communication about cognitive changes. Although most participants with MS had relapsing-remitting MS, their changes and perceptions of the trajectory of their changes may have been influenced by their type and presentation of MS.

Teaching Self-Management Strategies

Many couples were interested in learning more about how to better manage their cognitive difficulties. Management and self-management strategies could be used by both the person with MS and their partner, and participants suggested that this knowledge could help them provide better support to their partner. The results underscore the need for couples to have practical approaches to cognitive difficulties that can minimize tension experienced by the couple. This need could partly be addressed by teaching cognitive self-management strategies (e.g., removing distractions to facilitate attention and concentration), including developing routines, implemented with the help of the partner. Teaching such strategies could help preserve relationship quality. There is significant evidence demonstrating the effectiveness of cognitive self-management components for families and individuals with illnesses such as schizophrenia.^{25,26}

Improving Communication Skills

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Previous research has shown individuals with MS have difficulties in communication.²⁹ Improving communication can increase relationship quality⁸ and make it easier for couples to address cognitive challenges by working together to cope with cognitive challenges.^{21,22} As shown in family interventions for schizophrenia, effective communication that minimizes blame and provide opportunities for mutual problem-solving can reduce family tension regardless of the individual client's insight into their illness. For example, information about good communication practices (e.g., use of "I" statements, clear expression of emotions, avoiding blaming "You" statements), and separating the consequences of MS from the person's intentions and personality. Unawareness or minimization of cognitive difficulties in persons with MS, combined with feelings of guilt and shame, may be more effectively approached through a combination of teaching strategies for managing cognitive limitations and improving communication than efforts focusing solely on education and increasing awareness.

Helping the Supportive Partner Maintain Independent Social Connections and Activities

One key finding was that participants with MS were concerned about their partner maintaining independent social connections and activities. Many partners chose not to do this as they felt responsible for staying with their partner with MS. However, participants stressed the importance of their partners' maintaining their other social connections. Reduced social contact outside of the family is a common consequence identified across several chronic illnesses, such as schizophrenia.²⁸ This increases strain as more social needs must be met within that primary

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relationship. Therefore facilitating social connections may help the couple, but also the caregiving partner in particular.

Limitations

The results of this study should be interpreted bearing in mind several considerations. The average age of participants was 61 years old, and therefore many participants were reflecting back on changes that took place over several decades. Some cognitive impairments described may overlap with age-related changes or other diagnoses, although the study attempted to screen out diagnoses other than MS that could cause cognitive impairments. However, this was based on self-report only. Finally, recruitment was completed through a patient registry, NARCOMS. It is likely that the people recruited from this registry are more open to participating in research as this is the goal of the registry, and this could limit generalizability to the wider population of individuals with MS and their partners. For example, there was little variability in ethnicity and socio-economic status in this group.

Conclusion

Overall, addressing the effects of cognitive impairment through education, skill, and support could help persons with MS and their partners deal more effectively a variety of challenges, both in daily functioning and their relationship. Our findings provide clear examples of positive and negative daily experiences and interactions of couples living with MS, and

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provide information for healthcare professionals who work with families. Meeting these unmet needs may be especially important in early stages of MS as research suggests partners do not often seek help at this stage.²⁸

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Table 1. Race, employment status and education level of participants

	Participant with MS (N)	Partner (N)
<u>Race</u>		
White or Caucasian	9	10
Asian	0	1
Unknown/Not Reported	6	4
<u>Employment Status</u>		
Full Time	3	7
Part Time	0	1
Homemaker	0	2
Retired	6	5
Retired on Disability	3	0
Unemployed	1	0
Unemployed on Disability	2	0
<u>Highest Education Level</u>		
Post Graduate Degree (Masters or Doctoral)	4	5
Bachelor's Degree	7	1
High School or Equivalent	0	7
Some College	4	1
Vocational/Technical	0	1

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Table 2. Current medical or psychological conditions reported by the participants with MS

	<i>N</i>
<u>Head, Eye, Ear, Nose, Throat</u>	9
Gastrointestinal	7
<u>Musculoskeletal</u>	6
Allergy	6
<u>Genitourinary</u>	4
Dermatologic	3
<u>Anxiety (self-reported)</u>	3
Cardiovascular	2
Endocrine-Metabolic	2
Depression (Diagnosed)	2
Depression (self-reported)	2
Respiratory	1
Blood/Lymphatic	1
Anxiety (Diagnosed)	1