Perceptions of Cognitive Symptoms Among People Aging With Multiple Sclerosis and Their Caregivers

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Objective. We sought to examine the nature and extent of agreement on cognitive symptoms reported by people aging with multiple sclerosis (MS) and their primary caregivers and the factors associated with disagreement.

Method. Data were generated from telephone interviews with 279 dyads of people with MS and their caregivers.

Results. Eighty dyads (28.7%) disagreed about the presence of cognitive symptoms in the person with MS. Disagreeing dyads were of two types: a dyad in which the person with MS indicated no cognitive symptoms, but the caregiver did (41 dyads; 14.7%), and a dyad in which the person with MS indicated cognitive symptoms, but the caregiver did not (39 dyads, 14%). Multinomial regression showed that gender and the number of years the person with MS has experienced symptoms were associated with type of disagreement.

Conclusion. The results point to the importance of discussing cognitive symptoms with people with MS and their caregivers.

Multiple sclerosis (MS) is a chronic, progressive neurological disease that is characterized by physical, sensory, emotional, and cognitive symptoms (Brassington & Marsh, 1998). People who have MS experience a wide range of occupational performance limitations (Finlayson, Impey, Nicolle, & Edwards, 1998; Lexell, Iwarsson, & Lexell, 2006; Mosley, Lee, Hughes, & Chatto, 2003). To address those limitations, occupational therapists use intervention approaches that include adapting occupations and environments, training clients in the use of compensatory techniques, and educating clients in the implementation of self-management strategies (Finlayson, 2006).

Because of the progressive nature of MS, educating caregivers is also an important role for occupational therapists on the MS care team (Finlayson, 2006). Caregiver support is critical to enabling people with MS to remain living in the community (Khan, Pallant, & Brand, 2007). Working with both clients and caregivers can be challenging. Research has highlighted the importance of consistent perceptions between caregivers and care recipients with respect to symptoms, levels of functioning, and decisions about care (Edwards & Forster, 1999; Fried, Bradley, O’Leary, & Byers, 2005; Hadjistavropoulos, Taylor, Tukko, & Beattie, 1994; Horowitz, Goodman, & Reinhardt, 2004; Knapp & Hewison, 1999). Discrepant perceptions can increase the stress and conflict within an already physically and emotionally demanding relationship (Edwards & Forster, 1999; Fried et al., 2005). For occupational therapists, the presence of discrepant perceptions has the potential to threaten the therapeutic process and the achievement of the desired outcomes, particularly if...
the recommendations being made influence the occupations and environments of both the client and the caregiver.

Factors that contribute to discrepant perceptions between people with MS and their caregivers have not previously received attention in the occupational therapy literature and have only just begun to be investigated by other disciplines (Chipchase & Lincoln, 2001; Figved, Myhr, Larsen, & Aarsland, 2007; King & Arnett, 2005). Caregiver distress has been shown to be higher when the person with MS experiences cognitive symptoms (Chipchase & Lincoln, 2001; Figved et al., 2007). In addition, caregivers have reported lower dyadic adjustment to the disease when the person with MS has problems with executive functioning (King & Arnett, 2005). These findings are important to occupational therapists, particularly because cognitive symptoms occur in at least 40% of persons with MS, with some estimates as high as 70% (Bobholz & Rao, 2003; Brassington & Marsh, 1998).

Cognitive symptoms can range from mild to severe and affect memory, attention, information-processing speed, and executive functioning (e.g., problem solving, multitasking; Brassington & Marsh, 1998). Once a person with MS begins to experience cognitive symptoms, these symptoms are not likely to remit (Achiron et al., 2004; Amato, Ponziani, Siracusa, & Sorbi, 2001) and may become more severe with disease progression (Amato et al., 2001; LaRocca & Kalb, 2006; Rao, Leo, Bernardin, & Unverzagt, 1991). People with MS who experience cognitive symptoms have greater difficulty engaging in daily activities such as working, maintaining a household, engaging in social and leisure activities, and driving (Rao et al., 1991; Schultheis, Garay, & DeLuca, 2001; Shevil & Finlayson, 2006b; Stenger, Knudsen, & Jensen, 1991). Unlike many of the other symptoms of MS, cognitive ones are invisible and often require that the person with MS actively disclose them to family, friends, and coworkers, which can be very difficult (Shevil & Finlayson, 2006b; Yorkston, Klasner, & Swanson, 2001). Even if an individual is prepared to disclose, the cognitive symptoms often compromise the communication process and threaten the person’s ability to use other self-management strategies to maintain participation in everyday life (Yorkston et al., 2001). To complicate the picture further, one of the potential results of cognitive symptoms in MS is reduced awareness (Goverover, Chiaravalloti, & DeLuca, 2005). In a situation in which a person with MS has reduced awareness, the caregiver may notice cognitive difficulties, whereas the person with MS may be unaware of any problems or of the impact of cognitive symptoms on his or her ability to engage in daily activities.

The complexity of the client–caregiver relationship, the invisibility of cognitive symptoms, and the potential for compromised communication and reduced awareness may lead to variability in how people with MS and their caregivers perceive cognitive symptoms. Knowledge about the nature and extent of and factors associated with discrepant perceptions may enhance occupational therapy practice with people with MS in several ways.

First, knowing about the nature and extent of the discrepancy would enable occupational therapists to think critically about their assessment procedures and determine whether changes or refinements are needed to uncover potential discrepancies and their impact. These more targeted assessments could facilitate intervention planning and delivery, particularly if the intervention is dependent on caregiver participation (e.g., environmental modification). Second, knowing what factors might increase the likelihood of discrepant perceptions would facilitate the ability to evaluate occupational therapy interventions for people with MS. Knowing about these factors would enable researchers to control or adjust for them in the design and analysis of intervention evaluations. Finally, appreciating the nature and extent of factors associated with discrepancies might enable occupational therapists to promote communication between people with MS and their caregivers about the implications of cognitive symptoms on occupational performance. Therefore, the specific research questions posed for this study were as follows:

- What are the characteristics of people aging with MS who report experiencing cognitive symptoms?
- What are the characteristics of primary caregivers who state that the people with MS for whom they care experience cognitive symptoms?
- Are there discrepancies between people with MS and their caregivers with respect to the presence of cognitive symptoms in the people with MS?
- What characteristics of people with MS and their caregivers are related to discrepancies in perceptions regarding cognitive symptoms?

Method

Participants

We combined data from 302 people with MS and their primary caregivers to form dyads for this study. All of the participants in these dyads were part of a larger study focused on examining the unmet health-related needs of people aging with MS in the Great Lakes region of the United States (i.e., Minnesota, Wisconsin, Illinois, Indiana, Michigan), which was reviewed and approved by the human subjects committee of the University of Illinois at Chicago.

First, we recruited the people with MS using five methods to identify potential participants: direct mailing to...
registrants of the National Multiple Sclerosis Society chapter in five states, direct mailing to members of the NARCOMS database (an international volunteer MS patient registry), advertising in the MS Connections newsletter, distributing flyers at MS society events, and advertising in nursing homes and assisted living facilities known by staff at the local MS societies to have multiple residents with MS. People interested in volunteering for the study contacted the study office and were provided with additional details about the project. To participate, people with MS had to be age 45 or older, live in one of the five target states, and be willing to complete a telephone interview. There were no participation restrictions on the basis of location of residence (e.g., community vs. institution). Although a total of 1,282 people with MS completed an interview, only the data from the 302 participants whose primary caregiver also participated in the study were available for the current analyses.

As part of the interview process, people with MS were asked whether they had a primary caregiver. If they did, the interviewer asked for permission to contact the caregiver for an interview. A total of 1,003 people with MS provided permission to contact their primary caregiver. Caregivers were stratified according to the age of the people with MS for whom they provided care (45–64 or ≥65). Individual caregivers were randomly selected from each strata. Invitations were sent to 343 caregivers selected through this process; 174 provided care to a person with MS between the ages of 45 and 64, and the remaining 169 provided care to people with MS ages 65 or older. In total, 41 caregivers refused to participate in the study when contacted. Consequently, 302 caregivers completed an interview, 150 of whom provided care to a person age 65 or older.

Procedure

Four trained project staff members completed the interviews with people with MS by telephone several months before the interviews with the primary caregivers were initiated. Both interview guides used a structured set of questions addressing a variety of demographic, social, and health-related information. The same staff completed both sets of interviews. Because of the time between interviews, any potential interviewer bias that may have occurred by interviewing both members of the dyad was minimized.

All of the interview questions for the people with MS were closed-ended, survey-type questions and produced numerical data. The average length of the interviews was approximately 41 min. During this time, the people with MS were asked about their disease course and symptoms, activity limitations, use of mobility devices, availability of social support, and use of and need for a wide range of health and ancillary services. One of the symptom questions addressed cognition, specifically poor concentration and forgetfulness, which is one of the most common cognitive symptoms in MS. The response options were “not a problem,” “interferes a little bit,” or “interferes a great deal” with daily activities. We used participants’ response to this question to identify those experiencing cognitive symptoms. Three participants chose not to answer this question.

Caregivers were asked about their own health and activity limitations, the symptoms experienced by the person with MS for whom they cared, the nature of the assistance that they provided to that individual, the amount of time spent caregiving, and the challenges they experienced during the course of their caregiving responsibilities. As part of the symptom questions, caregivers were asked whether the person with MS experienced problems with poor concentration or forgetfulness. Response options were “yes,” “no,” or “don’t know.” Eighteen caregivers responded “don’t know” to this question, and two others refused to answer. The majority of the questions for the caregivers were closed-ended, survey-type questions. The average length of the caregiver interviews was 40 min.

Analysis

We entered numerical data from the interviews into two separate files in SPSS DataBuilder (SPSS, Inc., 2002): one for the people with MS and one for their caregivers. To prepare for the current analysis, we exported all data to SPSS 12.0 and then merged the two data files to create dyads of people with MS and their caregiver. We then imported these data into SAS 9.1 for analysis (SAS Institute, Inc., 2006). Because of missing data on the key variables regarding the presence of cognitive symptoms, the final sample size was 279 dyads with complete data.

To identify people with MS who reported cognitive symptoms, we used the question addressing poor concentration and forgetfulness. Inadequate cell size necessitated collapsing two of the response options to ensure stable statistical estimates. We collapsed the two categories “interferes a little bit” and “interferes a great deal” and labeled them “has cognitive symptoms.” Collapsing these categories acknowledges that cognitive symptoms require a person with MS to develop and use strategies to manage them, regardless of their level of severity (Shevil & Finlayson, 2006a, 2006b; Yorkston et al., 2001).

We compared participants who reported cognitive symptoms with those who did not on the following characteristics: gender, age, years of symptoms, years since diagnosis, status of MS over the past year (stable, improving, deteriorating, or variable), course of MS since diagnosis (mild and intermittent, steady and progressive, or unpredictable), and extent to which depression interfered with
daily activities (not a problem, interferes a little bit, or interferes a great deal).

To identify caregivers who reported that the person with MS for whom they cared experienced cognitive symptoms, we used the question addressing poor concentration and forgetfulness. To examine the characteristics of these caregivers and compare them to caregivers who did not report cognitive symptoms in their care recipient, we used the following variables: caregiver gender, age, relationship to care recipient (spouse or nonspouse), employment status (employed or not employed), number of years of caregiving, and average number of hours per day of caregiving.

We used McNemar’s test, kappa statistics, and intraclass correlation coefficients (ICCs) to examine whether there were discrepancies in the perception of cognitive symptoms between the people with MS and their caregivers. McNemar’s test evaluated whether the responses to the cognitive symptoms question differed between the people with MS and their caregiver. Kappa statistics measured the amount of agreement between the people with MS and their caregivers and whether this agreement was significantly different from chance. The ICC measured the amount of variability between people with MS and their caregivers, and it was obtained from a mixed-effect logistic regression model.

From the contingency table used to examine the discrepancies, we grouped dyads that were independently consistent in their perception of cognitive symptoms in one of three ways: (1) a dyad that “agreed,” regardless of direction of agreement; (2) a dyad in which the person with MS indicated no cognitive symptoms, but the caregiver did (person with MS [PwMS] = no symptom, caregiver [C] = symptom); and (3) a dyad in which the person with MS indicated cognitive symptoms, but the caregiver did not (PwMS = symptom, C = no symptom). We used this three-category variable to represent our outcome of interest to address the final research question regarding the factors associated with discrepancies in perceptions between people with MS and their caregivers. Given the nominal nature of this three-category outcome variable, we used multinomial logit models. Multinomial regression is a natural extension of the logistic regression for outcome with three or more unordered categories (Agresti, 2002).

The variables considered in the modeling process included the variables used to address the first two research questions and the extent of limitations in activities of daily living (ADLs) and instrumental activities of daily living (IADLs) of the people with MS. In total, 15 potential covariates were involved in the modeling process in which we used the stepwise, backward, and forward selection methods with a criterion of \( p = .05 \) to determine potential significant effects. We compared the results from the three selection methods and found that two different models were obtained. The stepwise and forward selection methods found only the years of symptoms experienced by the people with MS to be a significant factor, whereas the backward selection method found the gender of the people with MS to be significant. To determine the best model, we compared the Akaike information criterion from these two models, along with a third model including both the years of symptoms and gender as covariates. The model with both of these variables was found to be the best model of the three. We assessed this model’s fit using the Pearson and deviance residuals test, which did not indicate any lack of fit.

Results

Characteristics of People With MS

The 302 people with MS included in this study ranged in age from 45 to 88 years (\( M = 62.8, SD = 9.4 \)), and 72.2% were female. They had been diagnosed with MS for an average of 18.3 years (\( SD = 11.8, \) range = 2 months to 53 years). Almost 61% reported cognitive symptoms interfered to some degree with their ability to engage in everyday activities.

Differences Between People With MS Who Reported Cognitive Symptoms and Those Who Did Not

From the simple analyses performed, we found that the age of the people with MS and whether they reported feeling depressed were significantly associated with whether they reported cognitive symptoms. People with MS who reported experiencing these symptoms were significantly younger (61.9 years [\( SD = 9.4 \)] vs. 64.2 years [\( SD = 9.1 \)], \( p = .0403 \)) and were likely to also report problems with depression (53% vs. 25%, \( p < .0001 \)). There were no significant differences between the two groups with respect to gender, years with symptoms, years since diagnosis, MS status over the past year, and MS course since diagnosis.

Characteristics of Caregivers of People With MS

Almost 72% of the 302 primary caregivers were the spouses of the people with MS, and on average they had been providing care for 17.1 years (\( SD = 11.9 \)). Of the caregivers in this study, 54% were male, and their average age was 59.6 years (\( SD = 13.1 \)). On average, these caregivers provided 2.75 hr of care per day. Fifty-three percent of caregivers worked outside of the home. Of the 282 caregivers who responded to the question about the presence of cognitive symptoms, 62.7% reported that their care recipients experienced these symptoms.
Differences Between Caregivers Reporting That the People With MS Had Cognitive Symptoms and Those Who Did Not

The results from the logistic regression found that only the amount of caregiving time was significantly associated with whether the caregiver perceived the care recipient to be experiencing cognitive symptoms ($p = .0264$). On average, caregivers who reported that their care recipient was experiencing cognitive symptoms spent 3.2 hr per day ($SD = 4.5$) providing care compared with the 1.9 hr ($SD = 3.2$) spent by caregivers who did not feel that their care recipient was having cognitive symptoms. Overall, hours of caregiving were greater for those people with MS who had greater limitations in ADLs ($p < .0001$), greater limitations in IADLs ($p < .0001$), and experienced a more progressive MS course ($p < .0001$).

There were no significant differences between caregivers who reported that their care recipients were experiencing cognitive symptoms and caregivers who did not in terms of gender, age, relationship to the care recipient, employment status, and the number of years providing care.

Extent of Agreement About Cognitive Symptoms Between People With MS and Their Caregivers

Table 1 presents a cross-tabulation of the responses of the people with MS and their caregivers regarding perceptions of cognitive symptoms in the people with MS. The kappa test of agreement resulted in a kappa score of $.392$ ($p < .0001$), which indicates that the amount of agreement observed between the people with MS and their caregivers was significantly greater than chance. Similarly, we obtained an ICC of $.20$, which indicates that only $20\%$ of the total variation in the responses of the dyads can be attributed to within-pair difference. Put another way, the ICC indicates that there was substantial agreement among the dyads with respect to their perceptions of the cognitive symptoms of the people with MS. McNemar’s test of marginal homogeneity resulted in a chi-square value of $0.05$ ($p = .8321$), which indicates that the odds of having either type of disagreement (i.e., people with MS reported symptoms and caregiver did not, or vice versa) were not significantly different from each other.

Examination of the Dyads and the Presence of Discrepancies in Perceptions of Cognitive Symptoms

Table 1 identifies 199 pairs of agreement dyads; 41 PwMS = no symptom, $C =$ symptom dyads and 39 PwMS = symptom, $C =$ no symptom dyads. Table 2 provides a descriptive profile of the characteristics of these dyads. Although we found some variability across the three dyad groups, only the years of symptoms of the people with MS was statistically different across the three dyad groups.

Results From the Multinomial Logistic Regression Model

Table 3 shows the final multinomial regression model obtained, with the parameter estimates and odds ratios. The regression analysis found the gender of the people with MS ($p = .0497$) and their years of symptoms ($p = .0364$) to be significantly associated with the type of discrepancy found within the dyad. More specifically, findings showed that the greater the years of MS symptoms (in general) were, the greater the likelihood was of having a disagreement about the presence of cognitive symptoms. This finding was especially true for the type of disagreement in which the people with MS reported no cognitive symptoms, but the caregiver did ($p = .0104$). In addition, women with MS were more likely to report a disagreement with their caregiver regarding the presence of cognitive symptoms. In these situations, the person with MS was more likely to report having cognitive symptoms and the caregiver to report that the person did not ($p = .0451$).

Discussion

This study is the first in the occupational therapy literature to examine the nature and extent of and factors associated with discrepant perceptions between people with MS and their caregivers regarding the presence of MS cognitive symptoms. Literature from other disciplines has indicated that discrepant perceptions can increase caregiver distress and compromise dyadic adjustment to the disease. Because caregiver support is critical to enabling people with MS to remain living in the community (Khan et al., 2007), occupational therapists working with this population must consider the possibility of discrepant perceptions and their potential implications for the therapeutic process and its outcomes. If the occupational therapist fails to acknowledge and address the potential for discrepant perceptions between the person with MS and his or her caregiver, interventions that target

<table>
<thead>
<tr>
<th>Perception of Person With MS</th>
<th>Perception of Caregiver, n (%)</th>
<th>Person With MS Has Symptoms</th>
<th>Person With MS Does Not Have Symptoms</th>
<th>Total (n [%])</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has symptoms</td>
<td></td>
<td>134 (48.0)</td>
<td>39 (14.0)</td>
<td>173 (62.0)</td>
</tr>
<tr>
<td>Does not have symptoms</td>
<td></td>
<td>41 (14.7)</td>
<td>65 (23.3)</td>
<td>106 (38.0)</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>175 (62.7)</td>
<td>104 (37.3)</td>
<td>279 (100.0)</td>
</tr>
</tbody>
</table>

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continued independent living may be compromised. Fortunately, the study’s findings offer several insights for clinical practice and future research.

First, findings indicate that people with MS who report cognitive symptoms are more likely than those who do not to be younger and to report problems with depression. This finding is consistent with current MS research showing a complex relationship between cognition and depression in this population (Arnett, Higginson, Voss, Randolph, & Grandey, 2002). From a clinical perspective, this information points to the need for careful multidisciplinary evaluation of people with MS to ensure appropriate and comprehensive intervention. Recent research has suggested that two simple screening questions can reliably identify almost all people with MS meeting the criteria for major mood disorder (Mohr, Hart, Julian, & Tasch, 2007): “During the past 2 weeks, have you been bothered by feeling down, depressed, or hopeless?” and “During the past 2 weeks, have you been bothered by little interest or pleasure in doing things?” Occupational therapists could easily use these questions in their practice to identify people with MS who should be referred for a more comprehensive assessment for depression.

The finding that younger people were more likely to report cognitive symptoms reinforces the need to inquire

Table 2. Characteristics of People With Multiple Sclerosis (MS) and Caregivers on the Basis of Agreement About the Presence of Cognitive Symptoms in the Person With MS (N = 279)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Agreement (n = 199)</th>
<th>Disagreement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td></td>
</tr>
<tr>
<td>Gender of person with MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>62</td>
<td>81.6</td>
</tr>
<tr>
<td>Female</td>
<td>137</td>
<td>67.5</td>
</tr>
<tr>
<td>Caregiver’s gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>104</td>
<td>67.5</td>
</tr>
<tr>
<td>Female</td>
<td>95</td>
<td>76.0</td>
</tr>
<tr>
<td>Caregiver’s work status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Currently working</td>
<td>115</td>
<td>75.7</td>
</tr>
<tr>
<td>Not currently working</td>
<td>84</td>
<td>66.1</td>
</tr>
<tr>
<td>Relationship of caregiver to person with MS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>146</td>
<td>72.2</td>
</tr>
<tr>
<td>Nonspouse</td>
<td>53</td>
<td>68.8</td>
</tr>
<tr>
<td>MS status of person with MS in the past year a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stable or improving</td>
<td>92</td>
<td>73.0</td>
</tr>
<tr>
<td>Deteriorating</td>
<td>68</td>
<td>71.6</td>
</tr>
<tr>
<td>Variable</td>
<td>38</td>
<td>66.7</td>
</tr>
<tr>
<td>MS course of person with MS within the past year a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unpredictable</td>
<td>22</td>
<td>62.9</td>
</tr>
<tr>
<td>Mild and intermittent</td>
<td>86</td>
<td>68.8</td>
</tr>
<tr>
<td>Steady and progressive</td>
<td>88</td>
<td>77.2</td>
</tr>
<tr>
<td>Person with MS’s symptoms of depression a</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is a problem</td>
<td>89</td>
<td>74.2</td>
</tr>
<tr>
<td>Not a problem</td>
<td>109</td>
<td>69.0</td>
</tr>
<tr>
<td>Age of person with MS</td>
<td>62.1</td>
<td>9.3</td>
</tr>
<tr>
<td>Age of caregiver</td>
<td>59.1</td>
<td>12.8</td>
</tr>
<tr>
<td>Person with MS’s years of symptoms</td>
<td>24.8</td>
<td>13.6</td>
</tr>
<tr>
<td>Person with MS’s years since diagnosis</td>
<td>17.3</td>
<td>11.4</td>
</tr>
<tr>
<td>Caregiver’s years of providing care to person with MS</td>
<td>16.2</td>
<td>11.2</td>
</tr>
<tr>
<td>Person with MS’s hours of care per day</td>
<td>2.9</td>
<td>4.1</td>
</tr>
</tbody>
</table>

Note. Bold p value indicates significance.

*Counts may not match column totals because of missing data.
Table 3. Parameter Estimates From Multinomial Logistic Regression

<table>
<thead>
<tr>
<th>Effects (Reference: Agreement)</th>
<th>df</th>
<th>β Estimate</th>
<th>SE</th>
<th>OR</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>2</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Person with MS = NS, caregiver = S</td>
<td>1</td>
<td>-2.3763</td>
<td>0.4461</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Person with MS = S, caregiver = NS</td>
<td>1</td>
<td>-1.6406</td>
<td>0.4016</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Years of symptoms</td>
<td>2</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Person with MS = NS, caregiver = S</td>
<td>1</td>
<td>0.0341</td>
<td>0.0133</td>
<td>1.04</td>
<td>1.01 - 1.06</td>
</tr>
<tr>
<td>Person with MS = S, caregiver = NS</td>
<td>1</td>
<td>0.0098</td>
<td>0.0133</td>
<td>1.01</td>
<td>0.98 - 1.04</td>
</tr>
<tr>
<td>Person with MS’s gender (Reference: Female)</td>
<td>2</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Person with MS = NS, caregiver = S</td>
<td>1</td>
<td>0.7351</td>
<td>0.4493</td>
<td>2.09</td>
<td>0.87 - 5.03</td>
</tr>
<tr>
<td>Person with MS = S, caregiver = NS</td>
<td>1</td>
<td>0.9419</td>
<td>0.4702</td>
<td>2.57</td>
<td>1.02 - 6.45</td>
</tr>
</tbody>
</table>

*p value indicates significance. OR = odds ratio; CI = confidence interval; MS = multiple sclerosis; NS = no symptoms; S = symptoms.

Note. Bold p value indicates significance. OR = odds ratio; CI = confidence interval; MS = multiple sclerosis; NS = no symptoms; S = symptoms.

about the impact of cognitive issues on occupational performance, regardless of age. In the future, qualitative research to examine the occupational factors (e.g., roles, habits, activities) that contribute to how people with MS perceive cognitive symptoms and whether perceptions are influenced by a misfit among person, environment, and occupation would be useful, both clinically and theoretically.

A second important finding was that caregivers who spend more time providing care to a person with MS were more likely to report that the care recipient experienced cognitive symptoms. Caregivers providing greater amounts of care may simply have more opportunities to observe the person with MS perform or attempt to perform everyday tasks and therefore may be more aware of cognitive symptoms. In addition, concealing cognitive symptoms may be easier for the person with MS when the caregiver is not providing frequent care. Overall, this finding is not particularly surprising, but it does highlight the importance of knowing who the primary caregiver is and how much time he or she is spending in the provision of care. Occupational therapists may need to spend more time educating less frequent caregivers about the potential for cognitive symptoms and what signs could indicate that additional supervision may be warranted. Examples of such signs might include evidence that medications are not being taken correctly or are being forgotten, increased household accidents, or missed appointments.

A third major finding of this study was that although there were high levels of agreement noted in the sample, there was disagreement among 30% of the dyads about the presence of cognitive symptoms. Several possible reasons for the various discrepancies exist, depending on the type of disagreement. In the PwMS = no symptom, C = symptom dyad, the number of years of MS symptoms was greater. Most MS-related symptoms, including cognitive ones, progress with disease duration (Amato et al., 2001). In addition, the longer cognitive symptoms have been present, the greater the likelihood of reduced awareness of them is (Goverover et al., 2005). Therefore, it may be that people who have been experiencing symptoms longer are not able to recognize their cognitive symptoms or the extent to which they have progressed. Caregivers, however, may become more aware as the need for caregiving increases.

In the PwMS = symptom, C = no symptom dyads, disagreement may be a result of poor communication. People with MS may not be able to adequately communicate cognitive symptoms to their caregivers or may avoid disclosure because of embarrassment, fear, or uncertainty about how the caregiver may respond. Previous research has documented the difficulties experienced by people with MS with respect to communicating about cognitive symptoms (Shevil & Finlayson, 2006a, 2006b; Yorkston et al., 2001). If difficulty communicating is contributing to discrepant perceptions of the presence of cognitive symptoms, occupational therapists may want to alert other members of the MS care team (e.g., social worker, psychologist) to initiate discussions and develop strategies so that the person with MS and the caregiver can begin to address this issue.

Another potential explanation for why there is disagreement in the PwMS = symptom, C = no symptom dyad is that these caregivers may not know that people with MS can experience cognitive symptoms as part of the disease. Alternatively, they may attribute functional difficulties to symptoms other than cognitive ones or may be unable to accept cognitive symptoms as a legitimate reason for the difficulties experienced by the person with MS. Questions about the legitimacy of cognitive symptoms have been documented among caregivers of people with dementia (Savundranayagam, Hummert, & Montgomery, 2005). Once again, these potential explanations point to the need to ensure that caregivers understand MS, the potential for cognitive symptoms, and how these symptoms may present themselves in the day-to-day lives of people with MS.

Gender was the final factor contributing to discrepant perceptions about the presence of cognitive symptoms.
between people with MS and their caregivers. Findings indicated differences in how men and women interpret their observations of cognitive symptoms. Women with MS tended to report cognitive difficulties, whereas their male caregivers were less likely to report them. Social sciences researchers have hypothesized that men and women may perceive, evaluate, and report illness differently (e.g., Verbrugge, 1985). The social construction of gender roles and psychological characteristics have been identified as potential explanations for gender differences in health perceptions (Anson, Paran, Neumann, & Chernichovsky, 1993). The few studies that have investigated gender differences in caregiving have identified important differences between men and women (for a review, see Houde, 2001). Future research needs to examine these differences, explore why they exist, and offer suggestions on ways to address them during the therapy process.

Discrepant opinions between people and their caregivers can lead to increased stress for members of the dyad (Fried et al., 2005; Horowitz et al., 2004). Caregivers may experience increased frustration when the people with MS do not acknowledge their cognitive symptoms and do not provide the type and level of assistance they need to support their occupational performance. Because cognitive difficulties may be less visible, it is important for both members of the dyad to recognize that they may exist and that they may be related to other MS symptoms producing similar challenges (e.g., depression, fatigue). Occupational therapists have an important role to play in educating both members of the dyad about this possibility so that their clients can be maintained in community settings with their families.

Limitations of This Study

This study had several limitations. First, the topic of this analysis was not the focus of the original study. The questions posed to the people with MS and their caregivers were not worded identically. Furthermore, the questions focused on poor concentration and forgetfulness, not the full range of cognitive symptoms or how these symptoms presented for the participants with MS. Future research expanding on the types of symptoms examined and how these symptoms influence the daily lives of people with MS and their caregivers would be useful.

Second, it is possible that other factors beyond those measured in this study influence the potential for discrepant perceptions between people with MS and their caregivers. Such factors may include quality of marital relationships, nature of tasks the caregivers are providing help with, acceptance of the disease, and availability of other helpers who can validate opinions about cognitive symptoms. Third, the study incorporated a relatively small sample (compared with the larger original study); as a result, it was not possible to look at whether the nature of agreement was dependent on the specific tasks. This issue is worth examining in future research. Fourth, we addressed the presence of cognitive symptoms through self-report and therefore can make no statement about the objective levels of cognitive impairment in the people with MS. Fifth, the caregiver group was not homogeneous, and differences may be identified depending on the type of caregiver (e.g., spouse vs. child). Examining discrepancies across types of caregivers was not possible because of sample size issues. Finally, there was a gap in time between the two interviews, so it is possible that the rate of discrepancies may have been different had the interviews been conducted concurrently.

Conclusion

Discrepant perceptions about the presence of cognitive symptoms can influence the relationship between the person with MS and his or her caregiver and, in turn, influence efforts made by the occupational therapist during the therapeutic process. Occupational therapists must acknowledge and address the potential for these discrepancies and be aware of factors that may contribute to them. In this way, occupational therapists will be able to engage people with MS and their caregivers about cognitive symptoms and their potential effects on occupational performance and participation and find ways to minimize these effects.

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References


