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## The Impact of Cognitive Functioning on Daily Occupations for People with Multiple Sclerosis: A Qualitative Study

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# The Impact of Cognitive Functioning on Daily Occupations for People with Multiple Sclerosis: A Qualitative Study

## Abstract

*Background:* Cognitive rehabilitation research in multiple sclerosis is ever-developing, but the impact of cognitive difficulties, seen in 40% to 80% of people, on daily occupations is not well known. The aim of this study is to explore the needs of people with MS who have self-reported cognitive deficits.

*Methods:* An exploratory qualitative descriptive research design was used. Data was collected through semi-structured telephone interviews with the participants. Recordings were transcribed and analyzed thematically.

*Results:* Seven participants were recruited (mean age 47). Three themes were developed through associations found in the data. "Neglected symptom" reported the participants' frustrations around the importance afforded to cognition by health care providers. "Impact on participation in daily occupations" described the everyday impacts of cognitive difficulties. "Adaptations and adjustments to continued participation" reported how the participants manage, despite their difficulties.

*Conclusion:* The findings describe how cognitive difficulties affect individuals with multiple sclerosis and their occupations, as well as the dissatisfaction felt with the progress in and access to cognitive treatment and research. The results indicate the need for occupation-focused interventions in cognition for people with multiple sclerosis that address daily challenges.

## Comments

The authors report that they have no conflicts of interest to disclose.

## Keywords

multiple sclerosis, cognition, activities of daily living, occupational therapy

## Credentials Display

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Multiple sclerosis (MS) is a chronic autoimmune disorder of the central nervous system (Hakim et al., 2000). It impacts approximately two million people worldwide (Connick, Chandran, & Bak, 2013), and the severity of the condition and the persistence of symptoms vary. Individuals with MS can experience many symptoms, such as mobility issues, speech difficulties, fatigue, visual impairment, spasticity, sensory issues, and cognitive impairment (Schiavolin et al., 2013). An online survey carried out on 4,639 people by the Multiple Sclerosis International Federation (Multiple Sclerosis International Federation [MSIF], 2013) found 80% of participants experienced cognitive difficulties. Concentration and difficulty remembering were found to be the problems that had the greatest impact on life for 70% of the people surveyed (MSIF, 2013).

Cognitive difficulties and fatigue with MS are associated with an increased likelihood of being unemployed (Glanz et al., 2012). Honan, Brown, and Batchelor (2015) found that a decreased speed of information processing was a significant predictor of unemployment and decreased work hours for people with MS. They reported that impaired or delayed recall was the most significant predictor of decreased working hours. The results of the study also found that an individual's perceived cognitive deficits can predict poor work outcomes, regardless of the individual's objective performance on cognitive assessments (Honan, Brown, & Batchelor, 2015).

Slowed information processing in people with MS was also found to be a determinant of vocational problems or unemployment in a review by Raggi et al. (2015). Roessler, Rumrill, and Fitzgerald (2004), in a sample of 1,310 participants with MS, found that participants who reported the presence of cognitive impairments were 49% more likely to be unemployed than those who did not have cognitive issues. A study by Benito-León (2003) also reported that individuals with cognitive impairments due to MS were less likely to be employed. Shevil and Finlayson (2006) reported on the impact on educational performance in a study with four participants. They found that participants reported difficulty in succeeding in higher level education because of being unable to focus in lectures and being easily distracted. It is important to note, however, that participants with MS who are still working often score higher on cognitive assessments (Beatty, Blanco, Wilbanks, Paul, & Hames, 1995) than those who are not working.

The number of studies in the area of cognitive rehabilitation has grown significantly since 2007 (Goverover, Chiaravalloti, O'Brien, & DeLuca, 2017). There have been studies targeting cognitive training with people with MS, particularly computerized training, but a systematic review by Yu and Mathiowetz (2014a) only found moderate evidence of effectiveness and very focused benefits (e.g., improvements in one cognitive area with little transfer to daily life). The long-term benefits of cognitive rehabilitation in MS are not yet evident (Yu & Mathiowetz, 2014a) and may be shown with the passing of time. Existing evidence-based strategies include the modified Story Memory Technique (Chiaravalloti, Moore, Nikelshpur, & DeLuca, 2013) and self-generation techniques (Chiaravalloti & De Luca, 2002), which have been proven effective for people with MS.

It is essential that the effect of cognitive difficulties from the perspective of people with MS are demonstrated, given the impact they have (Glanz et al., 2012). Although we are aware that impaired cognition can be a significant cause of disability in individuals with MS (Baumstarck-Barrau et al., 2011), and there is emerging evidence on effective rehabilitation techniques (Yu & Mathiowetz, 2014a), it is essential to understand the full effect cognitive difficulties can have on the everyday lives of people with MS. Shevil and Finlayson (2006) began this process but a new exploration of the topic is required, as the treatments, technologies, and life demands have changed in the past 10 years (Goverover et al., 2017). There is a need to understand the current experiences of people with MS so that interventions can be targeted to the needs of the population in order to address the challenges experienced by this group of people. There has been a recent call by a group

of clinicians, researchers, and people with MS for remedial interventions and accommodations to allow for improved functioning at home, work, or school for people with MS (Kalb et al., 2018). In order to target the right interventions, we need to identify the needs of this group. The aim of this study is, therefore, to explore the needs of people with MS who have self-reported cognitive deficits.

### **Method**

This qualitative study uses an exploratory descriptive research design to allow better understanding without providing a solution (Sandelowski, 2000).

#### **Participant Selection**

Inclusion criteria were: (a) diagnosis of MS, (b) have self-reported cognitive difficulties, (c) aged 18 years or older, and (d) fluent in English. The term cognitive difficulties was explained in the participant information sheet. The participants identified themselves (self-reported) with guidance from the participant information sheet and discussions with the researcher, if they were experiencing difficulty with cognition, including memory, attention, learning new information, and/or organization.

Following ethical approval from the National University of Ireland in Galway on April 3, 2016, a link to the study information was made available on the MS Ireland website and also on the MS Ireland Facebook page. The participants contacted the research team through email or by phone if they were interested in participating. The participants were asked to self-rate the level of cognitive difficulty they were experiencing. They were asked whether they consider their cognitive difficulties as having a mild, moderate, or severe effect on their daily activities. The Multiple Sclerosis Neuropsychology Questionnaire (MSNQ) (Benedict et al., 2004) was then administered over the phone, and the participants were included if they scored > 23, as recommended by Benedict et al. (2004). Benedict et al. reported that self-report on the MSNQ is correlated with scores on neuropsychological tests that validated the inclusion/exclusion of the participants in the study.

#### **Data Collection**

We used a semi-structured telephone interview consisting of 14 questions (see Appendix). The interview guide was developed based on previous research in the area (Shevil & Finlayson, 2006) and clinical experience, and was guided by the research aims. Interviews began with an explanation and clarification of the term cognition. Questions addressed the effects of cognitive difficulties on occupations.

The interview was piloted with three separate participants to check for timing, ease of use, and understanding. Changes were suggested during piloting to the way in which questions were phrased to improve clarity of the questions. There were no changes made to the content of the questions. The interview guide was also approved by the ethics committee prior to piloting and use in the study. The pilot participants' data was not included in the study or in the reported data.

Telephone interviews were used in an effort to decrease overall expenses and also to access the participants in wider, dispersed areas (Novick, 2008). As individuals with MS sometimes have difficulty with driving (Pakenham, Tilling, & Cretchley, 2012), fatigue (Finlayson, Preissner, & Cho, 2012), and using public transportation (Kobelt, Berg, Lindgren, Fredrikson, & Jönsson, 2006), it was hoped that telephone interviews would eliminate these issues and encourage a larger number of individuals to participate. Interviewing through the medium of telephone can also increase the quality of the data as the interviewee may be more forthcoming with information as a result of the anonymity provided by the telephone (Drabble, Trocki, Salcedo, Walker, & Korcha, 2016).

The telephone interviews took, on average, 30 min and were recorded using a Dictaphone®. Recording the telephone interviews allowed for an authentic and precise record of the interviews and

allowed the interviewer to focus completely on the discussion (Witzel, 2000). Recordings were transcribed verbatim immediately following each interview. Member checking was not possible due to time constraints, but coding samples were checked by both authors to ensure the essence of the transcript could be detected in the sampling of coding provided.

### Data Analysis

The open-ended interview questions were analyzed using inductive thematic analysis. Thematic analysis was chosen, as recommended by Boyatzis (1998), to identify, analyze, and report themes related to the data. This approach enabled the participants' perceptions of how cognitive difficulties impact their occupations to be examined in detail and then interpreted (Polgar & Thomas, 2013). Analysis was completed by the first author, who carried out the interviews in consultation with the second author. QDA Miner Lite version 1.3.4. (Provalis Research, 2014) software was used for analysis of the interview data. The demographic data gathered were entered into Microsoft Excel and analyzed descriptively. The researcher used QDA Miner Lite version 1.3.4 software to organize the data (Provalis Research, 2014). The researcher followed guidelines set out by Braun and Clarke (2006) to carry out the analysis.

- Phase 1: The researchers familiarized themselves with the collected data through reading and rereading the transcribed interviews.
- Phase 2: The production of initial codes took place by the researcher (AMcA) immersing themselves in the data.
- Phase 3: The researcher (AMcA) analyzed the identified codes and grouped them into candidate overarching main themes and sub-themes.
- Phase 4: During this phase, the researcher (AMcA) reread the transcripts and reviewed the identified themes. Some themes were merged, some were dropped, and some remained the same. This was done in consultation with supervisor (SH).
- Phase 5: Sub themes were defined and refined by the researchers during this phase. The essence of each theme was identified by the researcher and named. A thematic map was produced during this phase. An example of the thematic map is shown in Table 1.
- Phase 6: This stage involved the researcher's analysis (AMcA in consultation with SH) and write up. This involved coherent, concise analysis of the themes, supported by evidence; in this case, quotes from the transcribed interviews with the participants. A concise summary was produced.

**Table 1**

*Data Analysis: Thematic Map Example*

| Quote   | Code                       | Sub-theme            | Theme  |
|---|----------------------------|----------------------|--|
| "He was calling me and I said '(child's name) sit down and go to sleep' instead of saying 'just have your shower'. But he just laughed when I was trying to enforce some little bit of discipline." | Difficulty with discipline | Impact on parenting  | Impact on participation in daily occupations |
| "I have loads of books to read but it takes me an awful lot longer to read a book because I keep having to go back over to remember the plot."  | Difficulty reading         | Hobbies/Interests    | Impact on participation in daily occupations |
| "Trying to sift through things and put them in any sort of constructive order is extremely difficult."  | Unable to organize oneself | Impact on employment | Impact on participation in daily occupations |
| "It's very hard to sit down and concentrate. I could read the same sentence 20 times and I still couldn't tell you what the sentence said."   | Difficulty concentrating   | Impact on education  | Impact on participation in daily occupations |

The data analysis included the following checks to increase its trustworthiness:

- Credibility was demonstrated in this study through external checks of the inquiry process. This was achieved by reviewing and piloting the interview schedule, as recommended by Chwalisz, Shah, and Hand (2008).
- Bracketing was also used (Chwalisz, Shah, & Hand, 2008). Here, the researcher (AMcA) took time before beginning the research process to reflect on any ideas or beliefs she may have had. A reflective diary was kept by the researcher AMcA for the duration of the study.
- Transferability was demonstrated by providing sufficient description of the study so that it can be replicated (Krefting, 1991) in future studies, including the provision of the interview guide.
- All data in the study were recorded and transcribed verbatim as each experience is considered important (Krefting, 1991).
- The process and content of the study was audited by the second author (SH) to reduce potential inquirer bias (Chwalisz et al., 2008).

### Results

Seven individuals (five female, two male) with clinically diagnosed MS and self-reported cognitive difficulties were recruited to the study. All of the participants who contacted the researcher fit the eligibility criteria. Only one recruitment announcement was sent through MS Ireland due to time constraints as this research project was done as part of a final year thesis. The participants had a mean age of 47 with a range from 23 to 59 years. Three of the participants described their difficulties with cognition as mild, while four reported moderate difficulties. Demographic data are shown in Table 2.

**Table 2**

*Demographic Data*

| Participant | Age | Gender | Type of MS               | Employment Status    | MSNQ |
|-------------|-----|--------|--------------------------|----------------------|------|
| PA          | 59  | Male   | Relapsing-remitting (RR) | Retired              | 24   |
| PB          | 58  | Female | RR                       | Retired              | 30   |
| PC          | 52  | Female | RR                       | Retired              | 28   |
| PD          | 53  | Female | RR                       | Retired              | 23   |
| PE          | 28  | Female | RR                       | Employed (full-time) | 24   |
| PF          | 56  | Male   | RR                       | Retired              | 26   |
| PG          | 23  | Female | RR                       | Student              | 28   |

Three themes emerged following analysis:

1. Neglected symptom
2. Impact on participation in daily occupations
3. Adaptations and adjustments to continued participation

#### **Neglected Symptom**

None of the participants in the study reported receiving treatment for their cognitive difficulties. They stated that they had not been offered any treatment in this symptom area, despite it having an impact on their lives. The participants also felt that it was a neglected area and that it deserved “more recognition and awareness, really. It is a big problem” (PC).

The participants reported being dissatisfied with research, knowledge, treatments, and progress made with regard to cognition and MS. There was a feeling that cognition was not addressed adequately by health care providers and that it was not taken “seriously enough.” “It is been long-neglected and is finally out of the MS closet” (PF). The participants detailed that physical symptoms were treated routinely but that this was not the case for cognitive difficulties, despite the need and the emerging evidence to suggest that more research has been done in the area.

PE explained that due to the lack of neuropsychologists, assessment and treatment are delayed until cognition is severely affected. “It’s not until you are in a very severe state with your cognition that you actually get attention and by then it is too late anyway.”

All of the participants emphasized the importance of recruiting more health professionals who are trained to work with people with MS who have cognitive difficulties.

### **Impact on Participation in Daily Occupations**

The participants spoke about how their cognitive difficulties impacted negatively on their employment, education, parenting, and meaningful hobbies. Five out of the seven participants interviewed were not working, despite being of working age. All of the participants who described themselves as being “retired” took early retirement due to difficulty keeping up with the demands of the job. Three of the participants stated fatigue as their reason for their early retirement. Two of the participants stated that increasing cognitive difficulties led them to retire early, such as PB, who retired due to decreasing organizational skills and difficulty concentrating on tasks. Another participant found multi-tasking an issue. His memory was affecting his ability to do his job competently. He found his information processing speed was impacting his work.

I have lost the ability to multi-task, losing the details as I move from one thought/task to another. It began to take me much longer to accomplish much less work. I couldn’t recall names of clients, points of conversation...I could not be interrupted during a telephone call, typing or in a conversation, without losing my train of thought. (PF)

One participant detailed her difficulties while enrolled in a university. She found that her concentration and attention problems were negatively impacting her ability to complete assignments and be attentive during lectures.

I’m listening but I am not hearing or I am hearing but I am not listening you know that kind of way. Like I can hear the lecturer talk but nothing is going through . . . my processing of information is very slow. (PG)

Six of the participants in this study had children, and half of these participants stated that their cognition impacted parenting. The experiences ranged from taking the wrong route to school to disciplining a child while experiencing word finding problems. One participant reports how her cognitive difficulties have impacted negatively on her relationship with her daughter, who is frustrated with her due to her poor memory.

She is totally frustrated with me. Asking her to repeat things, and trying to write them down all the time. I keep having to double-check with her . . . and with my husband. They are both totally frustrated that I forget things. (PB)

One participant reported how assisting his children with their homework has become increasing difficulty because of his cognitive challenges.

I had to give up on helping with their homework, studying for tests, and other school assignments. Not because I didn’t understand it, but I was having difficulties explaining processes and concepts that I had taken for granted. (PF)

For this participant it became necessary to stop helping with homework and have his wife take on the task instead.

Six-of the seven participants reported that cognitive difficulties were impacting their ability to participate in meaningful hobbies and activities. Reading was the most common hobby mentioned that was difficult for participants. There was a frustration because of forgotten plotlines or losing concentration, which had not been an issue before.

One participant also stated that she was having difficulty with playing golf and bridge because of her memory difficulties: remembering cards and golf scores. Another participant admitted that he can no longer participate in board games with his family because of his cognitive difficulties: “Since I absorb details much slower than before, it is very difficult for me to recall the rules and manage the strategy and game pieces effectively” (PF). The participants spoke about how social activities and interests are sometimes avoided because of embarrassing situations. Memory for other people’s names was an issue that was raised by the participants. They spoke about becoming embarrassed when this happened. There was also discussion around communication difficulties in social situations.

Trying to communicate with others. I find that very difficult. I just get stuck for words. I just find it very hard sometimes just to communicate. I have it in my head but then when I try to put it into words nothing happens. (PG)

### **Adaptations and Adjustments to Continued Participation**

As well as reporting on the difficulties that they experienced in daily life, the participants also spoke about how they adapted their occupations to ensure continued participation. As the participants in the study reported that they had not received any cognitive treatments to date, they instead introduced different adjustments into their lives. Some of the participants adjusted their work environments to deal with the difficulties with cognition. Another participant said he would receive reminders from his secretary about meetings and deadlines. Another cut down her hours and also used a notepad as a memory aid.

I would keep notes, keep a jotter or a notepad for writing things down. I would go back to it then and tick things off that I had done trying to keep some sort of structure on it like that. (PB)

Another participant began to organize and use her time and mental energy more while enrolled at a university: “I have to pick and choose my lectures. Every second week I would have to miss one and go to the other. I try to read up beforehand” (PG). A number of the participants reported no longer helping their children with their homework. One participant, who still helps with homework, explained how he adapted his family life so that he was still able to help his daughters.

Our children learned to ask me one question at a time and to be patient with receiving the answer. I quite often had to break up the questions, to make them more manageable. It is important to have no distractions, such as phones, television, e-mails, etc. I sometimes would ask my wife to help the children when I was unable to help. (PF)

The participants spoke about strategies that they use to try and maintain their interest in reading. One participant had difficulty remembering what books she had read. She reported that she would give books away to remove them from the house after she has read them. This was the only way that she could be sure that she had not previously read that book. Other participants adapted this meaningful occupation by taking notes that would be reviewed whenever necessary: “I have to take notes during the reading of the book or I will forget the plot. It's just so that I can look back to refresh my mind” (PD).

Meeting people socially posed difficulties for the participants. Remembering names, details of conversations, etc., were listed as difficult. One participant detailed strategies she uses to remember conversations when meeting with friends.

If I meet somebody that I haven't met for a while, when I come home I write down the important things they have said so that when I go back and meet them the next time I will remember. I have a special little book in my bag for that." (PB)

### **Discussion**

The participants in this study had similar, and also varying, experiences on how memory, concentration, attention, and information processing difficulties impact their lives. The majority of the participants were also not satisfied with the research carried out in the area of cognition in MS. Chiaravalloti and DeLuca (2008) also acknowledge that cognitive impairments have only been recognized as an important symptom of MS over the past few decades and effective treatments have not yet been identified (Chiaravalloti & DeLuca, 2008). One participant highlighted the importance of early treatment in an attempt to prevent or slow the course of cognitive deterioration. There was a level of frustration surrounding the discussions of treatment availability which was reflected in the participants' language (e.g., "neglected"). It is important to note that the reports in relation to treatments obtained may be affected by recall bias. As we had no objective method of ensuring that the participants were giving accurate information, this needs to be considered when interpreting this. Having available routine cognitive tests as part of patient reviews would ensure early detection and enable early treatment. Early baseline screening using the Symbol Digit Modalities Test along with annual reviews has been recommended (Kalb et al., 2018). This would in turn prevent further decline and lessen the effect cognitive impairments have on an individual's life (Patti, 2009). Participants in this study may not have been offered treatment, as they did not present with any obvious cognitive impairment.

All of the participants spoke about how cognitive difficulties impacted their occupations. Two participants lost their roles as employees due to cognitive difficulties. This finding is not unique to the participants in this study as Kobelt et al. (2006), in a study of 13,286 participants with MS, showed that employment rates for the participants were only 25% to 40%. This was markedly lower than the European employment rate of that time, which was 64.3% (Kobelt et al., 2006). Honan et al. (2015) found that cognitive change was a predictor of job loss and unemployment. Short-term memory and delayed recall are two of five variables that explained variance in unemployment in a sample of individuals with MS (Beatty et al., 1995). Raggi et al. (2015) also found that problems in working memory contributed to difficulties carrying out vocational tasks. Occupational therapists often work in the area of vocational rehabilitation, work hardening, and maintaining work roles for their clients. Given the large number of people with MS who are of working age but not employed (Honan et al., 2015), there needs to be more awareness of the specific needs of this population in terms of work rehabilitation.

Parenting was also shown to be more of a challenge for this group of participants because of difficulties with cognition. Helping with homework and disciplining their children were the main issues reported. Pakenham et al. (2012) also reported that people with MS relied on their partners for extra support: the parent with MS would have problems with tasks, such as remembering daily schedules and assisting children with their homework. They found that support from the parent without MS was needed to assist children with homework. This was also the case for the participants in this study, some of whom had passed over the task completely to their spouses or partners.

Reading for leisure was identified as a hobby that was now difficult for some of the participants. Retaining the plot was the main issue highlighted. This is supported by Shevil and

Finlayson (2006), whose participants had difficulty reading because of concentration, attention, and memory issues. The participants in this study said that they often avoided social situations to prevent embarrassment that they attributed to poor memory and concentration. A study by Hoogs, Kaur, Smerbeck, Weinstock-Guttman, and Benedict (2011) echoed this finding, as they found reduced speed of mental processing may have a negative impact on an individual's level of social interaction.

Occupational therapists have a key part to play in prioritizing, assessing, and addressing the issues identified by people with MS. Occupational therapists are well-placed to help people with MS maintain meaningful participation. This requires greater emphasis and awareness being placed on cognitive symptoms for patients with MS and training provided to therapists on cognitive assessment and intervention. Research has found that occupational therapists are a key part of goal-directed multidisciplinary rehabilitation programs (Yu & Mathiowetz, 2014b) for people with MS. Participating in meaningful, challenging activities in different environments, as suggested by research, in the area of occupational adaptation with other populations (Johansson & Björklund, 2016) could be an effective option for people with MS and warrants further investigation.

Awareness of and intervention for cognitive difficulties that impact participation should be a priority for healthcare practitioners. Medical professional's awareness of cognitive difficulties as a symptom of MS is improving and enhanced research tools and imaging are also generating optimism in this area (Rahn, Slusher, & Kaplin, 2012). Occupational therapists are increasingly involved in neuropsychological assessment and treatment and awareness of the needs of this population is essential. In fact, a recent paper aiming to promote understanding of cognitive impairment in MS recommended "increased professional and patient awareness around the prevalence, impact, and appropriate management of cognitive symptoms" for people with MS (Kalb et al., 2018, p. 1665).

A number of limitations exist in this study. The MSNQ was used to determine the cognitive status of the participants in the study. Previous research has found correlational analyses to indicate the MSNQ is significantly correlated with mood and self-reports of functioning but not with objective measures of daily functioning and only to a few neuropsychological tests (O'Brien et al., 2007). This is a limitation given its use in screening participants for the study. We also did not assess depression here, which may have had a potential impact on the MSNQ scores or confounded some of the results, as there may be overlap in the symptoms (e.g., confusion and disorganization).

Recruitment of the participants was carried out through the Irish national association's website and Facebook page, which may have limited the audience. This meant that potential participants who did not use the Internet and who may not be connected with the association were not likely aware of the study. An unstandardized interview schedule was developed, as a suitable, existing schedule was not available. Interviews were also carried out over the phone, which has reported limitations, including a lower response rate, an absence of visual or nonverbal cues, and also a necessity for short interviews, compared to face-to-face interviews (Novick, 2008). This format may have also been more challenging for people with a cognitive impairment and may have been off-putting to potential participants.

This study had a small sample and a low representation of male participants. This is common for studies with individuals with MS since MS affects a greater percentage of females; however, males may perceive difficulties in cognition differently than females and so further examination of gender-specific issues would be important. Finally, all of the participants were diagnosed with relapsing remitting MS. Different experiences may exist for people with other types of MS, and this is worth exploring in future studies as it was not possible to address here.

## Conclusion

The main finding of this study is the frustration the participants with MS describe with the health system and health providers who do not take cognitive complaints seriously. The results of this study also show that for people with MS, the employee role can be lost, parenting can be increasingly difficult, education can be a struggle, and hobbies and interests can be impacted negatively.

Although we acknowledge that this is the experience of a small group of participants, we aim to highlight the need to include cognitive assessments when working with people with MS to (a) identify deficits and (b) provide evidence-based interventions. Making cognitive testing a routine part of assessment would allow health care professionals working with people with MS to first identify issues and then address the needs of this population. Future research in this area should aim to develop meaningful interventions for people living with these challenges. Occupational therapists are experts in daily life and the art of doing, and so they should be the driving force behind implementing change and developing the research agenda for people with cognitive difficulty due to MS.

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## Appendix

### Indicative Interview Guide

#### *Note to facilitator:*

- ✓ Begin with introductions and information about the purpose of the interview.
- ✓ Following this, give description of the study and its purpose.
- ✓ Ask for any questions on the study or anything that needs to be clarified.
- ✓ Ensure that the participant is still happy to participate.
- ✓ Explain again what you mean by “cognition.”
- ✓ Follow the questions listed below to elicit views of the participant. Some questions may require more prompting; prompt as necessary.
- ✓ Leave some time at the end for any further questions and to thank the participant.

#### *Interview questions:*

1. *“I am going to start by gathering some information about you.”* Ask the following questions:
  - a. What age are you today?
  - b. What type of MS do you have?
  - c. What is your employment status at present?
2. Have you noticed any cognitive changes/difficulties as a result of your MS?
3. How would you rate these difficulties? e.g., mild, moderate, severe.
4. Do these cognitive difficulties affect your ability to succeed in college/work/volunteering?  
Please give some details. (Provide examples if required.)
  - a. How have you been managing this?
  - b. Has this been effective?
5. Do you feel that these cognitive difficulties affect your ability to childmind/parent effectively?  
Give details.
  - a. How have you been managing this?
  - b. Has this been effective?
6. Do these cognitive impairments affect your ability to partake in hobbies/interests? Give details.
  - a. How have you been managing this?
  - b. Has this been effective?
7. Do these cognitive difficulties affect your ability to carry out household chores? Give details.
  - a. How have you been managing this?
  - b. Has this been effective?
8. What are the three things in your daily life that you find most difficult due to your difficulties with cognition?
9. Have you any other strategies in place already to deal with these issues? Give details.
10. Do you use any aids or devices to help you with your cognition? (Examples would include a diary, phone, noticeboard, Smartphone Apps.)
11. Do you ever experience cognitive fatigue or extreme mental tiredness?
  - a. If yes, please give some detail as to when this is most likely to happen and how you usually deal with it, if at all.
12. Have you ever been to an occupational therapist as a result of these cognitive issues?
  - a. Give details of any interventions carried out.
13. Have you received or are you presently receiving any other treatment or intervention? (*For example, medication/psychology/mindfulness*)
14. Any other comment?