Assessment and Management of Cognitive Problems in People with Multiple Sclerosis: A National Survey of Clinical Practice

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Assessment and Management of Cognitive Problems in People with Multiple Sclerosis: A National Survey of Clinical Practice

Background: People diagnosed with Multiple Sclerosis often have cognitive problems. However, it is unclear how cognitive impairment is currently assessed and managed in the UK.

Aims: To understand current clinical practice of assessment and management of cognitive impairment in people with MS and to highlight any national variation.

Methods: A survey was posted to 150 MS centres and large hospitals and an online version was shared via e-mail and on social media.

Results: Responses were analysed from 109 healthcare professionals. Approximately 59% (n=64) reported they used cognitive assessment tools: the Montreal Cognitive Assessment (MoCA) was the most widely used. Assessments were usually done by Occupational Therapists (55%; n=60) or Clinical Neuropsychologists and Psychologists (38%; n=41); 49% (n=53) of respondents developed and implemented a cognitive rehabilitation plan when the assessment indicated that patients had cognitive problems; 16% (n=17) indicated they would refer patients to specialist cognitive rehabilitation for symptom management; 3% (n=3) followed a manual when providing a cognitive rehabilitation programme.

Conclusion: Clinical pathways for assessing and managing cognitive problems vary and are dependent on the individual expertise of health professionals, available resources and access to specialist services. Although healthcare professionals highlight the importance of assessment and management, cognitive rehabilitation programmes are not routinely offered in the UK.

Keywords: multiple sclerosis; cognitive dysfunction; rehabilitation; clinical practice; survey

**What's known?**

It is estimated that between 40-65% of people with MS experience mild to moderate cognitive deficits in attention, memory, information processing speed and executive functioning.

Recent clinical guidelines are vague regarding assessment and management of cognitive impairment in MS.

**What's new?**

This research presents current clinical practice of the assessment and management of cognitive impairment in people with MS.

Assessment measures and management techniques vary widely and are dependent on clinical expertise and available resources, such as time and training.

Healthcare professionals rate the importance of assessing and managing cognitive impairment in people with MS higher than they rate their confidence in providing these.

# Introduction

Multiple Sclerosis (MS) affects around 100,000 people in the UK (1). It is estimated that up to two-thirds of those diagnosed experience cognitive impairment (2, 3). Common cognitive problems include deficits in memory, attention and executive function, often making it difficult for people to engage in rehabilitation, uphold social roles and maintain employment (4). These difficulties limit the individual’s independence and can have a negative impact on overall quality of life (5).

Currently it is unclear how cognitive impairment is assessed and managed in people with MS. Recommendations for routine cognitive screenings have been documented in detail while recommendations for remedial interventions remain imprecise (6, 7). Internationally, there is growing consensus on which assessment tools should be used, however, the management of cognitive problems in MS remains less clear. Screening tools that have been recommended include the Brief International Cognitive Assessment for MS (BICAMS) (8), or longer measures such as the Brief Repeatable Battery of Neuropsychological tests (BRB-N) (9) or the Minimal Assessment of Cognitive Function in Multiple Sclerosis (MACFIMS) (10). The BICAMS has been translated into a number of languages (11), but the extent to which this has been implemented in clinical practice remains unknown. The Symbol Digit Modalities Test (SDMT) (12), which features in the BICAMS, the BRB-N and the MACFIMS, has also been recommended as a single screening test (6, 13). Health centres and MS charities in different countries offer online resources for people with MS, their families and health service providers with information regarding the management of cognitive problems (14, 15), but documentation of clinical management practices is lacking.

The National Service Framework for long-term neurological conditions (16) is not specific about care pathways for cognitive problems for people with MS. The framework simply suggests that there may be benefit in delivering “community rehabilitation” for cognitive problems (p.35). Additionally, the most recent National Institute for Health and Care Excellence (NICE) guidelines (17) are vague regarding cognitive rehabilitation in MS. They recommend that healthcare professionals should “consider referring people with MS and persisting memory or cognitive problems to both an Occupational Therapist and a Neuropsychologist to assess and manage these symptoms” (Guideline 1.5.33). This reference to consider and manage symptoms is open to interpretation by individual healthcare professionals. As evidence suggests that cognitive impairment in MS is often overlooked or attributed to other problems (18), it is important to understand how cognition is currently assessed and managed in clinical practice and whether screening for cognitive impairment is conducted routinely.

The MS Trust has highlighted the need for improved understanding of service delivery in MS (19). Collecting such data is also necessary to inform ‘usual care’ provided in randomised controlled trials to assess the efficacy of new rehabilitation interventions.

# Aims and objectives

The aim was to understand cognitive assessment and management for people with MS who experience cognitive impairment from the perspectives of a variety of healthcare professionals working with people with MS, and to highlight any national variation. Specifically, the objectives were to describe the following areas:

* Current cognitive assessment and management practices in services for people with MS
* Healthcare professionals’ expertise in assessing and managing cognitive problems
* Healthcare professionals’ confidence in assessing and managing cognitive problems in people with MS
* Healthcare professionals’ perceptions on the importance of assessing and managing cognitive problems in people with MS

# Methods

The study received ethical approval from the University of Nottingham Medical School Ethics Committee (Ethics Reference No: I11082015).

The authors developed a questionnaire with input from current and former healthcare professionals, researchers and with patient and public involvement. The questionnaire covered the following:

* General information of symptoms assessed or treated within the service
* Assessment practices of cognitive impairment in people with MS
* Management practices of cognitive problems in people with MS
* Participants’ professional background, training and role within a service
* Formal clinical pathways and referral methods
* Healthcare professionals’ confidence in assessing and managing cognitive problems in people with MS
* Healthcare professionals’ perceptions on the importance of assessing and managing cognitive problems in people with MS

## Participants

We wanted to recruit qualified healthcare professionals who worked clinically with people with MS in the UK. This included Occupational Therapists (OTs), Neuropsychologists, Clinical Psychologists, Physiotherapists, MS Nurses and Neurologists (although other healthcare professionals were invited to participate).

## Recruitment

Three strands of recruitment were implemented; postal mail, e-mail and social media.

A database of 150 large hospitals in the country likely to have MS centres was created based on the MS Trust’s ‘heat map’ which was published with the MS Specialist Nursing in the UK 2016 report (20). In total, 150 envelopes containing the survey questionnaire were addressed to a named Occupational Therapist, Clinical psychologist/Neuropsychologist or, if neither was available, to a named Neurologist or the whole team of a Rehabilitation Service. To obtain individual names of healthcare professionals, relevant hospital departments were contacted by telephone. Postal reminder letters were sent out to those who did not respond by three weeks. Each questionnaire had an identifiable code in order to ascertain the geographical representativeness of the sample of returned questionnaires.

Special interest groups for Allied Health Professionals and Psychologists (such as the Royal College of Occupational Therapists Specialist Section in Neurological Practice and the Association of Chartered Physiotherapists in Neurology) were asked to share the information about the study with their membership, and they agreed. In addition, MS-related organisations such as the MS Society and the MS Trust were asked to share information about the study and the link to the online questionnaire version. A version of the questionnaire in Microsoft Word format was attached as an alternative option for healthcare professionals to complete, if preferred.

A description of the study and a link for completion was shared twice a week on social media.

## Analysis

Data was analysed using descriptive statistics.

# Results

## Participant characteristics

Responses were received from 112 participants, 42 responses were received from hospitals by post, 6 were received by e-mail and 64 were submitted online. Of these, 3 were excluded: 2 were completed from outside the UK and 1 was submitted blank. Thus, 109 questionnaires were included in the analysis. Responses were received from a geographical spread across the UK; the largest response was from the South East of England, followed by the West and East Midlands (Fig. 1).

**[Figure 1]**

The background of healthcare professionals was mixed, with Occupational Therapists in the majority (41.3%, n=45; Table 1).

**[Table 1]**

The experience of healthcare professionals varied from less than 1 year to 38 years, with an average of 13.67 years (SD= 8.99).

Healthcare professionals worked in a variety of clinical settings. Almost 67% (n=73) worked in neurological rehabilitation services, of which 9% (n=10) worked in an outpatient neurological rehabilitation service and 8% (n=9) worked in an inpatient neurological rehabilitation service. Almost 21% (n=23) worked in MS clinics, 9% worked in a non-neurology specific community rehabilitation team and the remaining worked in a general neurology clinic. One participant did not specify the clinical setting they worked in.

## Providing information to patients about cognitive problems in MS

The majority of respondents (92.7%, n=101) reported that they provide information to patients about cognitive problems, of these, 71.3% (n=72) stated they provided leaflets to patients and 70.3% (n=71) sign-posted patients to relevant websites.

## Assessment of cognitive impairment practice

Approximately a third of respondents (32.1%, n=35) reported that the services within which they worked routinely screened for cognitive impairment. This would happen at the first assessment and at every review appointment. Respondents named one or multiple healthcare professionals within a service who would do this; 53 responses were given of professionals who routinely screened for cognitive impairment in people with MS (Table 2).

**[Table 2]**

Generally, at the first assessment, the majority took a history from the patient or family/carer (95.4%, n=104) and consulted medical notes or referral letters (73.4%, n=80). In addition, 58.7% (n=64) reported they used screening and assessment measures. The 16 most used assessment measures are shown in Figure 2. Respondents named either one or multiple measures that they used within their service. In total, respondents reported 50 different cognitive screening and assessment measures that they used to assess cognitive impairment in MS. Measures that were ticked by less than 5 respondents were not included in Figure 2.

**[Figure 2]**

Of those who reported that their service routinely screened for cognitive problems (32.1%, n=35), about a third (34.3%; n=12) further commented that cognitive assessments were “general assessments” imbedded within the initial assessment and done informally by asking the patient a question related to their cognition. Formal assessments were only done when concerning issues were noticed by the healthcare professional or when the patients specifically brought up cognition as a problem:

 “OT screens through general assessment, may do functional and/or standardised cognitive assessment as required” (OT, ID 5).

 “MS nurse would ask about cognitive impairment, no formal screening process” (MS Specialist Nurse, ID 49).

Respondents stated that cognitive assessments were usually performed by Occupational Therapists (55%, n=60), Clinical Neuropsychologists or Clinical Psychologists (38%, n=41) and/or MS Specialist Nurses (29%, n=32). Some respondents ticked more than one professional who would do the assessment depending on availability. The majority reported that the cognitive assessments were done by Occupational Therapists, which is also supported by respondents’ comments that they did not have access to Clinical Neuropsychologists or Clinical Psychologists. One respondents commented that the assessment was done by an “Occupational therapist due to no psychology locally” (OT, ID4).

## Management of cognitive impairment practice

When the cognitive assessment indicated that the patient had cognitive problems, the following steps were followed by healthcare professionals (Table 3).

**[Table 3]**

Outcomes for the strategies healthcare professionals advised and/or taught to people with MS to improve their memory and attention are shown in Figure 3.

**[Figure 3]**

When asked about what the advised strategies were based on, the majority replied that the strategies were based on the professional’s clinical judgment (87.2%, n=95) and less than a third 28.4% (n=31) stated that they were based on specific training they had received, such as a course on external memory aids. Almost 13% (n=14) reported that they based their strategies on a plan devised by another healthcare professional and about 7% (n=8) stated that they followed a treatment protocol in their service. Almost 4% (n=4) stated that their based their strategies on a manualised rehabilitation programme in their service. Some healthcare professionals ticked more than one answer.

With regard to manuals, about 3% reported that they followed manuals when providing cognitive rehabilitation strategies (Table 4) and about 4% stated that they based their strategies on a manualised rehabilitation programme in their service. One respondent stated that they would like to find out more about current manuals in use:

 “Would like to know about manuals in use, […]” (OT, ID 17)

Another respondent highlighted that following manuals may not be helpful to patients as any treatment strategy needs to be tailored to the individual:

“In my clinical experience using manualised cognitive strategy programmes are ineffective. Every individual has different priorities, goals and needs and these need to be taken into account along with the formulation in order to devise an effective cognitive rehab programme” (Clinical Neuropsychologist, ID 32).

With regard to the methods used to advise on and/or teach strategies to people with MS, three respondents (2.8%) ticked the ‘Follow manual’ box. More details on other methods are shown in Table 4.

**[Table 4]**

## Confidence and importance scales of assessing and managing cognitive problems in people with MS

Healthcare professionals were asked to rate their confidence of assessing and managing cognitive problems in people with MS as well as how important they rated assessing and managing these on a 10-point Likert scale. The results are shown in Figure 4.

**[Figure 4]**

When respondents’ additional post-registration courses were considered, findings showed that healthcare professionals, who received additional training to asses and manage cognitive impairment, were more confident than healthcare professionals who did not receive additional training. This discrepancy in confidence was especially relevant for healthcare professionals whose main specialisation was not in the field of assessing and managing cognitive impairment.

In addition, when respondents’ reported team sizes were considered, outcomes showed that those in medium (4-6 team members) and large teams (7 or more team members) felt more confident in assessing and managing cognitive problems compared to those based in small teams (1-3 team members).

# Discussion

## Survey study

To our knowledge this is the first UK study to examine how cognitive problems are assessed and managed from the perspective of healthcare professionals. The sample covered a good geographical spread across the UK although there were more responses from England and Scotland than from Northern Ireland and Wales. There was a wide variety of healthcare professionals who assessed cognitive impairment and who provided cognitive rehabilitation strategies for people with MS and there was considerable variation of the provision of services.

## Assessment of Cognitive Problems in MS

Despite the growing international consensus to use batteries such as the BICAMS, BRB-N or the MACFIMS, or single tests such as the SDMT, our findings show that this recommendation has not been translated into clinical practice in the UK. The Montreal Cognitive Assessment (MoCA) and the Addenbrooke’s Cognitive Examination Revised (ACE-R) were the most widely screening measures used. The MoCA, a one page-test, is easy and fast to administer and is a widely used screening tool for mild cognitive impairment and early Alzheimer’s disease (21, 22). The MoCA was the most frequently used test to assess cognitive functioning in people with MS although MS specific screening measures are available (8, 23, 24). The preference of using the MoCA may be due to the fact that it is easy and fast to complete while MS specific and comprehensive screening may take more time and resources to complete. While the MoCA may be equally useful for initial screening (22), healthcare professionals need to make sure that this is followed up by further specialist neuropsychological evaluation if required (25).

In total, respondents named 50 different screening measures which indicates a high national variation in how cognition is assessed in people with MS. Of the three recommended batteries, only the BRB-N is in the top 16 assessment measures with 11% (see Figure 2) while the BICAMS and the MACFIMS batteries were named by fewer than five respondents. The individual tests of the BICAMS (i.e., SDMT, California Verbal Learning Test-II and the Brief Verbal Memory Test-R), were used by fewer than 8% of healthcare professionals. The large number of screening measures used in clinical practice makes it difficult to compare cases and renders referrals for further assessments or for symptom management dependent on the healthcare professional’s individual judgement. Clear guidelines and documented pathways could help to improve how these services are provided to ensure that people with MS receive adequate support.

## Management of Cognitive Problems in MS

Clinical pathways varied greatly depending on the access to local specialist and cognitive rehabilitation services.

With regard to strategies, the majority of respondents reported they advised on “usual” external memory aids such as a calendar, diary, and/or mobile phone rather than internal memory strategies such as the chunking of numbers to remember telephone numbers and repetition or rehearsal of information. Hence, most advice focused on compensation strategies rather than retraining of cognitive abilities. This could be due to individual needs and preferences or due to the lack of cognitive rehabilitation programmes that cover a wider set of strategies, which is also a factor of time, resources and knowledge of such programmes. In addition, the effects of neuropsychological rehabilitation for people with MS have not been studied as extensively as in stroke patients, for instance (26). Regarding methods used to teach strategies, only 3% (n=3) reported that they followed a manual. Evidence suggests however, that manuals are being increasingly used in randomised controlled trials (RCTs) and descriptions thereof have been made available online (27, 28). Barriers to optimal cognitive management, such as a reluctance by healthcare professionals to discuss memory problems, may play an additional role contributing to the lack of service provision (6). Overall, the reported lack of referral options and lack of expertise of healthcare professionals may act as a barrier to discuss cognitive impairment in patients.

## Confidence and importance ratings to assess and manage cognitive problems in MS

There was a discrepancy between respondents’ reporting of the importance of assessment and management of cognitive problems and their confidence to undertake this. Respondents consistently rated the importance to assess and manage cognitive problems higher than their confidence to provide these services. Team size within a service as well as received post-registration training seemed to be associated with greater confidence in assessing and managing cognitive problems in MS. Moreover, with respect to the team size, larger teams consisted of a variety of trained health professionals, such as Neuropsychologists, Occupational Therapists, Physiotherapists and MS nurses, for instance and this facilitated learning from colleagues. Confidence appears to play a crucial role as behaviour models indicate that a person’s psychological or physical ability to enact a behaviour is a crucial determinant whether the behaviour will be performed (29). Therefore, increased training opportunities for healthcare professionals may remove this barrier to address symptom management for cognitive impairment in MS.

## Limitations

Although researchers can reach out to larger populations, the survey sample may be limited to those who are particularly interested in the research and therefore, the sample may not be representative of the whole population of interest. In addition, surveys may be biased to people with internet access (30, 31), resulting in coverage error. To avoid coverage error, part of this survey study involved sending out postal surveys to large hospitals throughout the UK who had MS centres as listed in the MS Trust website’s ‘heat map’ for MS services (20). By employing several strands of recruitment and three options for survey completion, we were able to collect data from MS services across the UK.

The advantages of the survey method such as having time- and cost-effective access to a large sample are well documented (32) and are facilitated with the use of the internet where the speed of the response is in general faster and the generated data more complete and detailed (33, 34).

Conclusion

Currently, while there is growing international consensus emerging in the research literature around taking a systematic approach to the assessment and management of cognitive problems in people with MS, there is no evidence of this knowledge being translated into clinical practice in the UK. Clinical pathways seem to be dependent on the expertise of individual healthcare professionals, available resources such as time and funding for training and access to specialist services for onward referral. Cognitive rehabilitation programmes are not routinely offered to people with MS in the UK although healthcare professionals highlight the importance of providing these services. Given the number of people with MS who have cognitive impairment, the lack of recognised clinical pathways and specialist symptom management must be a concern.

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Author contributions:

Olga A. Klein: Concept/ Design; Data collection; Data analysis/interpretation; Drafting article; Statistics; Critical revision of article; Approval of article

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Joanne Ablewhite: Data collection; Drafting article; Critical revision of article; Approval of article

Avril Drummond: Concept/ Design; Data interpretation; Drafting article; Critical revision of article; Approval of article

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# Tables

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| --- |
| Table 1 |
| *Role of Participating Healthcare Professionals* |
| Role of healthcare professional | n | Percentage |
| Occupational Therapist (OT) | 45 | 41.3% |
| MS Specialist Nurse | 19 | 17.4% |
| Physiotherapist | 16 | 14.7% |
| Clinical Neuropsychologist |  8 |  7.3% |
| Nurse |  6 |  5.5% |
| Neurologist |  6 |  5.5% |
| Clinical Psychologist |  5 |  4.6% |
| OT MS Specialist |  2 |  1.8% |
| Other |  1 |  0.9% |
| Not known |  1 |  0.9% |
| Note. *n*=number of participants. |

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| Table 2 |
| *Role of Healthcare Professionals Who Routinely Screened for Cognitive Impairment (out of 53 responses)* |
| Healthcare professional | n | Percentage |
| Occupational Therapist | 17 | 32.1% |
| Clinical Neuropscyhologist/Clinical Psychologist | 13 | 25.5% |
| Any member in the team |  7 | 13.2% |
| MS Specialist Nurse |  7 | 13.2% |
| Physiotherapist |  3 |  5.7% |
| Neurologist |  3 |  5.7% |
| Assistant Psychologist |  2 |  3.8% |
| Speech and Language Therapist |  1 |  1.9% |
| Note. *n*=number of participants. |

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| Table 3 |
| *Steps Healthcare Professionals Followed When the Assessment Indicated that the Patient Had Cognitive Problems* |
| Steps healthcare professionals follow | n | Percentage |
| Discuss findings with the individual | 103 | 94.5% |
| Offer some cognitive strategies as secondary to other rehabilitation | 95 | 87.2% |
| Discuss findings with the family and/or carer | 92 | 84.4% |
| Report findings to other therapists involved with the individual | 88  | 80.7% |
| Adapt how they deliver other kinds of rehabilitation with that individual | 83 | 76.1% |
| Inform the individual’s GP | 81 | 74.3% |
| Develop and implement a cognitive rehabilitation plan | 53 | 48.7% |
| Refer on for more specialist cognitive assessment | 40 | 36.7% |
| Develop a cognitive rehabilitation plan for other healthcare professionals to implement | 23 | 21.2% |
| Refer on for specialist cognitive rehabilitation | 17 | 15.6% |
| Notes. *n*=number of participants. |

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| Table 4 |
| *Methods Used to Advise on and/or Teach Strategies to People With MS* |
| Method | n | Percentage |
| Verbally encourage the individual to use the strategy | 92 | 84.4% |
| Write out a plan for how to use the strategy | 64 | 58.7% |
| Use functional activities to practice strategy | 55 | 50.5% |
| Practice strategy in rehabilitation sessions | 52 | 47.7% |
| Give ‘homework’ based on the strategy | 52 | 47.7% |
| Develop a game around the strategy |  7 |  6.4% |
| Follow manual |  3 |  2.8% |
| Note. *n*=number of participants. |

# Figure legend

|  |  |
| --- | --- |
| Number | Figure description |
| 1.) | Responses received per geographical location (UK). |
| 2.) | Top 16 (out of 50) assessment measures used by healthcare professionals to assess cognition in people with MS. |
| 3.) | Strategies healthcare professionals advised and/or taught people with MS to improve their memory and attention. |
| 4.) | Healthcare professionals' confidence and importance ratings of assessing and managing cognitive problems in people with MS on a 10-Likert scale. |

# Figure 1



# Figure 2



# Figure 3



# Figure 4

