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What would improve MS clinic services for cognition? – a stakeholder panel and survey exploration

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Abstract

Cognitive difficulties in MS are widely acknowledged to have a major negative impact on the lives of people with MS (PwMS). However they are viewed as “invisible” symptoms, sometimes overlooked or ignored by health professionals. DL and CAY are in the process of writing a cognition handbook for MS clinics, summarising practical information to help the MS multidisciplinary team improve care for PwMS who have cognitive difficulties. We convened a stakeholder panel and offered a survey at a major MS professional education conference, to understand what content would be most helpful for our clinic handbook. The survey showed that health professionals think that cognition is not generally addressed well by clinics and that infrastructure and resources, education and information for both PwMS and professionals, and technologies to assess and treat cognition are all required to deliver better cognition services in MS clinics.

MS cognition

Multiple sclerosis (MS) is an autoimmune-mediated neurodegenerative disease of the central nervous system characterized by inflammatory demyelination with axonal transection. MS affects approximately 2.3 million people worldwide. It typically presents in young adults (mean age of onset, 20-30 years) and can lead to cognitive impairment, physical disability, and decreased quality of life (McGinley et al., 2021). Cognitive impairment is most prevalent in the domains of information processing speed and memory function (Benedict et al., 2020). It has a marked effect on the instrumental activities of daily living, additional to the impact of physical impairments. This is reflected in the finding that impairments in several cognitive domains each relate to the economic burden of care, independent from physical disability (Maltby et al., 2022).

Cognition is also related to a number of health outcomes, including medication adherence (Washington and Langdon, 2022). For example, cognition predicts attendance and success in physiotherapy (Gomes et al., 2022). Difficulty learning new verbal information was associated with a greater likelihood of "no showing" at one or more physical therapy sessions. Reductions in working memory and processing speed have been associated with PwMS meeting fewer rehabilitation goals in out-patient physiotherapy and verbal intelligence affected multidisciplinary in-patient rehabilitation outcomes (Langdon and Thompson, 1999).

All MS clinic health professionals need to address cognition as part of their professional practice, including occupational therapists (e.g. Krasniuk et al., 2021) and physiotherapists (e.g. Mardaniyan et al., 2022). It is important to know how to manage cognitive impairment from a nursing perspective (Slough and Brownlee, 2021). Jarrett (2020) argues that MS Nurses have the opportunity to play a vital role in supporting people with MS to manage cognitive changes throughout the disease trajectory.

Despite the marked impact on PwMS' lives, confidence and knowledge gaps persist in understanding and management of cognition, sometimes designated an “invisible symptom” (Lakin et al., 2021). In an effort to address this, a medical publishing company named Karger have commissioned an MS clinic cognition handbook, to be written autonomously by DL and CAY (Langdon and Young, 2022). In order to understand stakeholder perspectives and find out what content would be useful, a stakeholder panel and health professional survey were arranged.

Stakeholder panel

A stakeholder panel was convened across two meetings. The first comprised MC (MS Nurse), CM (Consultant Neurologist), BM (PwMS' care partner). The second comprised GP (Applied Psychologist, PwMS). DL (Neuropsychologist) and CAY (Consultant Neurologist) attended both groups. All areas of the British Isles were represented. The discussions were transcribed and group discussion lead to consensus on four emergent themes, which were then cited in the literature.

(i) Information

It was noted that PwMS and care partners would like to know about cognitive issues right from the start. One clinic provides a cognition talk from an outside expert for PwMS early on in the disease. It was acknowledged that there is now significant demand from PwMS for information about cognition and it can be their main concern at diagnosis. There can be miscommunications regarding the type of cognitive loss that can occur in MS. Some PwMS are concerned that they will experience a dementia. The sources of information that currently exist for PwMS may not adequately address cognition in an accessible way. Qualitative studies have also demonstrated that PwMS want cognition information at diagnosis and feel that documentation of their cognitive difficulties would facilitate communication about their situation with others (Mortensen et al., 2020). PwMS increasingly expect to be fully involved in shared decision making and to be given comprehensive, current information (Yeandle et al., 2018).

(ii) Communication

There was a feeling that health care professionals (HCP's) do not always organise their interactions optimally for PwMS with cognitive difficulties. For example, asking a PwMS when was their last relapse, when the PwMS is unable to remember. There is often a significant wait for an appointment to start which does not convey respect and collaboration, but instead emphasises the limited time available, making it harder for the PwMS to discuss difficult issues such as cognition. Repeating and summarising what has been said in a conversation and a written summary were felt to be useful. It was mentioned that the PwMS might be facing life circumstances that make managing difficult (e.g. young family, children, unsympathetic employer). The HCP should interview comprehensively to ensure that they are fully aware of the current personal context and offer tailored guidance and management advice. Self-efficacy has been shown to vary over time and to follow different trajectories for different groups of PwMS (Young et al., 2022). Information about symptom management can be structured to overcome cognitive disability, for example when managing intermittent self-catheterisation (Vahter et al., 2009; Wyndaele 2014). MS medication information can also be presented in a way to protect understanding in the context of cognitive deficits (Reen et al., 2021).

HCP's should be aware that some PwMS dispute or downplay their cognitive difficulties, either due to lack of insight or because of concern about the consequences of acknowledging their problems. PwMS may be reluctant to disclose cognitive difficulties because of fears about losing their driving license, which is key to independence in the context of physical disability. Similarly single parents may fear that disclosing cognitive challenges may lead to safeguarding concerns regarding their children and possibly loss of custody. PwMS also have concerns about disclosing their diagnosis and disease management needs, including for cognition (e.g. to employers, Kirk-Brown et al., 2014; and dating partners, Tabassum et al., 2021) and support for these situations would be helpful. Invisible symptoms can create barriers to communication (Campbell et al., 2022).

Cognitive issues may be raised in a consultation by family or friends who have noticed changes in the behaviour or cognitive abilities of the PwMS; if these are disputed by the PwMS, sensitivity is needed to allow the concerns to be disclosed while supporting the PwMS. The HCP should consider that care partners have the advantage of observing the PMS over extended periods and comparing current and past behaviour (Fenu et al., 2018).

(iii) Employment

Inability to work was recognised as a very significant issue for PwMS and a major influence ona person's self-esteem. Cognition is an independent predictor of income (Kavaliunas et al., 2019) and employment status (Kavaliunas et al., 2022). Employment significantly influences quality of life for PwMS; vocational rehabilitation should be initiated early (Momsen et al., 2022).

(iv) Clinic services

A clear definition of "cognition" would be helpful. Education about how MS cognitive difficulties relate to dementia and the cognitive trajectory of normal ageing would be useful. Information about how other factors affect cognition is lacking (menopause, pain, depression, medication). Sleep is important for optimal cognition and referral to a sleep clinic should be possible. Clinic staff face challenges regarding which cognitive test(s) to use and how to interpret them. They would like clear guidance on how an MS Nurse can help with cognitive difficulties and when a PwMS should be referred to a neuropsychologist. Information for HCP's about suitable tools, the Brain Health Agenda, social cognition and cognitive relapses is lacking. There is a mistaken but persistent perception that "nothing can be done about cognition", This is outdated and does not align with the evidence. We consider how a clinic can address and manage cognition in a separate paper (Langdon and Young, in prep). It has been demonstrated that rates of identification of cognitive concerns in standard clinical practice are significantly lower than the identified prevalence in epidemiologic studies. This has been attributed to overreliance on self-disclosure by PwMS and HCP's concerns about broaching cognition when they feel that inadequate resources are available to address these issues (Walker et al., 2019).

Specific recommendations for the book

It was felt that highlighting the voices of PwMS and care partners would be key and a section written by experts by experience would be important. Practical advice for care partners would be welcomed (e.g. need to repeat does not denote PwMS' lack of interest, it is the result of cognitive impairment). Cognition is a symptom that is not tabled the same way as other (physical) symptoms. PwMS can be defensive or refuse to discuss it. This kind of issue requires sensitivity, especially when the concern has been disclosed in confidence by a concerned relative. Including guidance about how to address feared scenarios and "solutions" e.g. anticipating (advanced) care planning, considering major transitions caused by MS in advance, Power of Attorney. strategies and skills for having difficult conversations should be covered. The wider MS community recognises the importance of providing clear, accurate information to PwMS (Vermersch et al., 2020). These conversations may sometimes be difficult, but are essential. It is acknowledged to be a challenging, stressful and emotionally demanding task, especially when engaging with PwMS with cognitive difficulties (Anestis et al., 2021).

Health professional survey

An anonymous survey was offered with a poster explanation at the MS Trust annual conference in 2022. A convenience sample of 27 health professionals completed the survey (18 MS Nurses, 8 physiotherapists and 1 OT). 16 worked in an NHS MS clinic, 7 in NHS community services, 3 in charity MS centres and the rest in a range of other MS services. 2 of the professionals saw less than 50 people with MS per year, 1 saw 50-99, 1 saw 100-199, 7 saw 200-299, 4 saw 300-399 and 11 saw more than 400. Visual inspection of survey forms suggested that the service gaps identified were similar across caseloads. The caseloads are in line with those previously reported (mean MSSN caseload 472, Naik, 2022). It is of note that likely half of our respondents had caseloads in excess of the currently recommended 315 per year for MS Nurses (Punshon et al., 2021). With such a burden of work, the significant time required to engage cognitively impaired patients is understandably hard to find.

How important do you think that cognitive difficulties are to PwMS?	N=27
Not at all important	0%
Quite important	7%
Very important	82%
Most important aspect of MS	7%
How well do you think your service addresses cognitive assessment?	N=26
Hardly	8%
Somewhat	85%
Well	12%
Very well	0%

How well do you think your service addresses management of cognitive difficulties?	N=26
Hardly	19%
Somewhat	73%
Well	8%
Very well	0%
What do you think about the information on MS cognition that you currently have easily accessible in clinic?	N=27
Almost nothing that is easily available	20%
Some information but not comprehensive	73%
Information is readily available but it is poor at addressing some aspects	8%
Excellent and comprehensive information is already available	0%

Table 1. Survey responses about current practise (% rounded to nearest whole figure)

There was a strong feeling that cognition was an important issue for PwMS, with 82% of respondents rating it "very important" (Table 1). The most frequent response regarding how well clinics assess and manage cognition was "somewhat". There was a majority view that information about cognition for MS clinics was lacking. 20% said that there was "almost nothing". There was a majority view that access to cognition specialists (59%) and information for PwMS and care partners (48%) would improve services (Table 2). Need for knowledge and training for clinic staff (33%) and assessment tools (26%) were also identified. Regarding the MS clinic cognition handbook, cognition management advice and tips for PwMS was thought to be the most useful content (63%), followed by clinic assessments (44%) and patient/care partner information about cognition (30%) (Table 2). Information about (local) specialist services was again frequently mentioned (26%). Aside from the survey, conference delegates mentioned informally to one author that understanding how MS cognitive difficulties relate to normal ageing, and how MS cognitive difficulties differ from typical dementia, would be helpful for PwMS and clinic staff to understand. Another delegate commented that reports and communications from specialist cognitive services were not always useful.

What three things would improve how your service addresses cognition?	
Access to cognition specialists	59%
Information/education resources for PwMS (and care partners)	48%
Clinic staff knowledge/training	33%
Assessment/screening technology for clinic staff	26%
How to manage cognition/strategies	22%
More time to devote to cognition	11%
Support for PwMS (and care partners)	7%
Increased awareness of cognition	7%
Importance of cognition recognised/priority over physical impairments	7%
Other/unclear	11%
What should our MS clinic handbook contain that you would find helpful?	
Management advice/tips for PwMS	63%
Assessments for clinics or PwMS to complete	44%
Patient/care partner info about cognition	30%
Local services available	26%
Information about pattern of MS cognitive difficulties for staff	15%
Brain Health information for PwMS	11%
Coping strategies for PwMS	11%
Usefulness of strategies such as brain training	11%
Case studies	7%
Information about interrelation of cognition, fatigue, mood, Brain Health for staff	4%
PwMS experience of living with cognitive difficulties	4%

MS or menopause causing cognitive challenges	4%
Medication influence	4%
How to approach a clinic assessment	4%
PwMS experience of cognitive treatment	4%
Activities examples	4%
Consider benefit of cognitive assessment – what will it add to patient's care?	4%
Other/unclear	15%

Table 2. Survey responses regarding what is required (free text responses grouped according to themes, % reflects how many HCP's mentioned the theme as one of their three possible responses, % rounded to nearest whole number). When identifying themes, we have taken "coping" to mean emotional support and reported it separately to rehabilitation strategies.

Services/infrastructure

Our survey highlighted the need for access to cognition specialists and this sits in a context of consensus opinion and detailed work developing a clinical pathway to identify and manage cognitive problems in MS (Smith et al., 2021). Only 20% of MS Nurses reported good access to psychology in a nationwide UK survey (Naik, 2022). Allocating time during clinic appointments and within staff workloads were stated to be essential resources for implementation (Smith et al., 2021). Cognitive specialists tend to be Occupational Therapists or Neuropsychologists (Quinn and Hynes, 2021; Foley and Portnoy, 2018). It is not possible to determine how many OT's or neuropsychologists are currently working in MS services in the UK.

Health Education England is making significant increases in clinical psychology training numbers over five years, year on year and this, along with the identified NHS priority area of dementia and memory problems, will hopefully increase numbers of cognition specialists working with MS clinics (https://www.longtermplan.nhs.uk/online-version/overview-and-summary/). It is likely that specialist cognitive rehabilitation services will become more accessible to PwMS now that software rehabilitation packages can be effectively and feasibly delivered at home (Campbell et al., 2016). The COVID pandemic has accelerated this trend to remote delivery of treatments (Ghadiri et al., 2022). Cognitive rehabilitation studies are now fully engaging with PwMS with progressive disease, which should also increase reach and accessibility (Feinstein et al., 2020; Prouskas et al., 2021).

Clinic staff requirements – information, education, training

The need for HCP information, education and training to engage with cognitive difficulties in MS was frequently mentioned. The majority of training for HCP's is provided by charities in the UK (Naik, 2022). There has been a call for Europe-wide standards and education for multi-disciplinary teams (MDT's) providing MS services (Feys et al., 2016).

Technology

A range of cognitive assessments are available for adults with MS (Elwick et al., 2021), but few are feasible for routine MS clinic use, including being designed for most health professionals to use. The Brief Cognitive Assessment for MS (BICAMS) is an exception to this, taking only 15 minutes and requiring only paper, pencils and a stopwatch (Langdon et al., 2012). BICAMS has been embraced by the international MS community, with 29 published national validations, and has been endorsed by the American Academy of Neurology. Digital assessments show promise but need further refinement, especially regarding validity (Galioto et al., 2021).

PwMS information requirements

PwMS are avid consumers of information about MS. 90% reportedly use information technology daily and those with cognitive difficulties would like cognitive rehabilitation options via their mobile phone (Haase et al., 2021). However, the text of our survey responses included requests for paper and online materials. It is recognised that younger PwMS are more receptive to online technology, perhaps side lining older PwMS, and physical disabilities in the domains of vision and hand function may also restrict use of smartphone and other materials (Haase et al., 2021). Also, PwMS with lower SDMT scores do not use the internet (Higueras et al., 2022). Education interventions for PwMS may also have limited usefulness (Arienti, 2020). The text of our survey responses often acknowledged this with qualifications like “accessible”, “easy to understand”,

Some of the information needs identified by the survey could arguably be filled by existing materials, suggesting there may be a requirement for dissemination and awareness. For example, the UK MS charities provide useful, free materials about cognition and the MS Trust has a free online cognition tool for PwMS (https://mstrust.org.uk/resources/staying-smart). There are also excellent Brain Health materials for both health professionals and PwMS freely available online (https://www.msbrainhealth.org/people-with-ms/brain-health-a-guide-for-people-with-ms/). There is a free co-produced consultation planner available online, to enable PwMS to record the issues they wish to discuss and signal this clearly and comprehensively to their health professional at consultation, hence mitigating cognitive restrictions (My MS Priorities https://www.mymspriorities.com, Oreja-Guevara et al., 2019). Writing down in advance what they wish to discuss is a popular strategy for PwMS (Campbell et al., 2022).

Limitations

We have sought the experiences and advice of people representing key stakeholder groups, but they were a convenience sample and not strictly representative or chosen by random sampling. The stakeholder group did not include an OT or a PT. OT’s, psychologists and physicians were under-represented in the survey. We cannot therefore exclude response bias. We have not conducted a stakeholder panel or survey among PwMS; this may be the subject of further work.

Conclusions

We have convened a stakeholder panel and collected information from a convenience sample of 27 HCP’s working in MS services, to explore what would help MS clinics to provide better cognition services and what would be useful content for our MS clinic cognition handbook. There was significant concordance in some of the needs identified, ranging from information for PwMS and HCP’s, to technology for assessing and treating cognitive difficulties. In addition, the focus group discussions emphasised the need for thoughtful and appropriate communication and the HCP survey highlighted infrastructure and access to cognitive specialist services.

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