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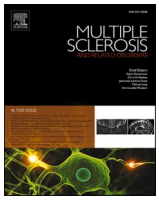

Cognitive impairment and its impact on employment: A qualitative interview-based study involving healthcare professionals and people living with multiple sclerosis

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ABSTRACT

Background: Cognitive impairment can considerably impact the work life of people who have multiple sclerosis (MS). Cognitive symptoms are associated with an increased likelihood of unemployment, changes in employment and decreased working hours. This qualitative interview-based study aims to gather real-word experiences and perspectives from both people living with MS and healthcare professionals, to explore how cognitive symptoms are experienced in the workplace, how their impact is addressed, and what can be done to support people in managing and minimizing this impact on employment.

Methods: Semi-structured, one-to-one interviews were conducted with people living with MS who experience cognitive symptoms, and with healthcare professionals working in MS care. Participants were recruited from a healthcare market research agency based in the United States. The data obtained from the interviews were subsequently analysed using a Grounded Theory method, in order to identify the core themes that form the basis of this paper.

Results: A total of 20 participants ($n = 10$ people living with MS; $n = 10$ healthcare professionals) from the United States were interviewed. Overall, 9 themes were identified from the raw data, which were grouped into three core themes describing the perspectives and experiences reported by both people living with MS and healthcare professionals: (1) The implications of cognitive symptoms on work; (2) Challenges in addressing cognitive impairment and its impact on work in MS care; (3) Strategies and support for managing the impact of cognitive symptoms.

Conclusion: The real-world insights of PwMS and HCPs gained from this qualitative study show that a multi-faceted approach to addressing cognitive impairment and its impact on the employment of PwMS is required. Workplace adjustments can range from self-implemented changes to changes put in place by employers to accommodate the various ways in which cognitive symptoms may impact a person's work. This study provides valuable information on how people living with MS can be affected by cognitive symptoms in the context of their employment; furthermore, that preparing early when possible and maintaining a proactive approach to managing their impacts on work are important for maintaining a good quality of life.

1. Introduction

Cognitive symptoms in multiple sclerosis (MS) are estimated to affect 40–70 % of all people living with MS (PwMS), (Rao et al., 1991; DiGiuseppe et al., 2018; Vanotti and Caceres, 2017) and include reduced information processing speed, memory difficulties, lower social cognition (the process which drives interpersonal skills such as social perception), mental fatigue and a decline in verbal fluency. (Leone et al.,

Abbreviations: HCP, healthcare professional; MS, multiple sclerosis; MS21, MS in the 21st Century; PwMS, people living with multiple sclerosis.

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Table 1
Demographic data for the PwMS and HCP participant groups.

Characteristic	Interview respondent: People living with MS (n=10)	Interview respondent: Healthcare professionals (n=10)
Median age (standard deviation)	41 (SD= 9.77)	Not collected
Gender	90% female	Not collected
Time since diagnosis (years): Median, mean (standard deviation)	6,11 (SD ± 9.30)	Not applicable
Current employment status		Not applicable
• Full-time	5	
• Part-time	3ǂ	
• Self-employed	1	
• Volunteering	2*ǂ	
• Unemployed	0	
• Retired	1*	
Changed from full-time to part-time employment since MS diagnosis	2ǂ	Not applicable
Years practicing in MS care, Median and mean (standard deviation)	Not applicable	23.5, 23.4 (SD= 6.5)
Location of practice:	Not applicable	
• Urban		4
• Suburban		6
Mean % of time in practice spent on MS care (standard deviation)	Not applicable	17.6 (SD= 6.62)
Monthly total of MS patients attended to (standard deviation)	Not applicable	31 (SD= 16.1)

SD, standard deviation

*Respondent was retired and engaged in volunteering

ǂOne respondent worked part-time after having switched from full-time employment, and was also engaged in volunteering

2015; Jongen et al., 2012; Pérez-Martín et al., 2016; Giazkoulidou et al., 2019) Similar to non-cognitive symptoms of MS, these vary between different PwMS and can vary throughout the day depending on other factors such as poor sleep or fatigue and/or other stressors. (Ghasemi et al., 2017; MÁ and Ciampi, 2019) Cognitive impairment can considerably impact employment, which is considered to be one of the key factors affecting quality of life (QoL). (Cadden and Arnett, 2015; Clemens and Langdon, 2018; Ruet et al., 2013; Amato et al., 2001) Since the focus of care for chronic conditions like MS is to manage symptoms and maintain good QoL, it is important to understand how the impact of cognitive impairment on employment is experienced by PwMS, approached by and currently addressed in MS care.

The MS in the 21st Century (MS21) initiative is led by an international steering group of MS specialists and MS patient advocates. MS21 aims to improve communication between PwMS and HCPs, to promote better patient-directed care. The initiative recently identified cognitive impairment and its impact on employment as an area of considerable unmet patient need through a series of open-forum workshops involving both PwMS and HCPs specialising in MS. (Rieckmann et al., 2018)

In this research, a series of interviews with PwMS and HCPs specialising in MS were conducted to investigate cognitive impairment and its impact on employment. To the authors' knowledge, this is the first qualitative study investigating the topic of employment in the context of the cognitive symptoms of MS, considering both PwMS and HCP perspectives. The aim was to gather detailed insights into their real-world experiences and perceptions around this topic: the authors hope that the insights gained from these interviews will highlight the challenges around managing cognitive MS symptoms in relation to employment and help overcome challenges related to the impact of cognitive symptoms on employment.

2. Methodology

2.1. Participants

All participants were based in the United States and were invited to take part in this research through a healthcare market research recruiting agency, receiving appropriate remuneration for their participation. Participants were then asked to complete several screening questions (Appendix A) to confirm their eligibility for the study, including questions about self-reported cognitive symptoms. Eligible PwMS participants had a diagnosis of relapsing/remitting or active secondary progressive MS, had experienced self-reported cognitive symptoms, and had been in full- or part-time employment in the 6 months prior to the interview. Eligible HCP participants were board-certified neurologists or MS specialists, heads of department or consultants, and had been practicing for 2—30 years. They must have been spending ≥60 % of their clinical time in direct patient care, treating ≥10 PwMS per month, and been personally responsible for prescribing treatments for these patients.

Informed consent was obtained from all respondents and care was taken to ensure that they fully understood the informed consent form and interview procedure. All participants had read, signed and completed a consent form.

Table 2
Process for establishing core themes.

Conceptual headings identified from raw data	Refined into 9 subcategories	Grouped under 3 core themes:
The difficulties which patients experience at work due to cognitive symptoms		
Misunderstandings in the workplace due to cognitive symptoms		
People with MS feeling worried about their work performance		
Perceptions of HCPs about how cognitive symptoms affect employment		
Perceptions of HCPs about the cognitive impairment of their patients		
Methods which people use to cope with the effect of cognitive symptoms at work		
Uncertainty about cognitive symptoms and their impact at work		
Discomfort for HCPs to discuss cognitive symptoms with their patients		
How HCPs clinically address cognitive impairment		
Shifts in mindset to adapt to changes in work in response to cognitive symptoms		
Perceived support received from the healthcare team		
Communication about cognitive symptoms between patients and their HCP		
Supportive resources which extend beyond the healthcare team		
		Theme 1: The implications of cognitive symptoms on work
		Theme 2: Challenges in addressing cognitive impairment and its impact on work in MS care
		Theme 3: Strategies and support for managing the impact of cognitive symptoms

2.2. Semi-structured one-to-one interviews

Semi-structured, web-assisted, one-to-one interviews were conducted with 10 PwMS and 10 HCPs, using the communication platform Zoom. The interviews were conducted between the 10th and 26th August 2022 by 3 different moderators: all HCP respondents were interviewed by Moderators 1 and 2, whereas respondents who were PwMS were interviewed by Moderators 1 and 3.

The questions in the interviews with PwMS and HCP participants differed according to the participant type. Overall, the topics covered the communication between PwMS and HCPs, as well as any discussions with employers about cognitive impairment and its impact on employment, its perceived or experienced impact on work life, and how symptoms and their implications on employment are addressed both by the person living with MS and by their MS care team.

2.3. Grounded theory analysis of the interviews

All interviews were recorded, transcribed and subsequently analysed using the Grounded Theory method. The qualitative data captured from the interviews were coded for concepts, and relationships across these concepts were identified. (Foley and Timonen, 2015) The Grounded Theory analysis consists of three steps following data collection, which are open coding, axial coding and selective coding (these are described in more detail in Appendix B). (Foley and Timonen, 2015) After the core themes identified in the selective coding phase had been discussed by all the independent reviewers, they were refined and a consensus on the final set of core themes and associated subcategories was reached. The reflexive role of the independent reviewers is described in Appendix B.

3. Results

3.1. Participants (N = 20)

The overall median age of the participants who were PwMS ($n = 10$) was 41 years (SD = 9.77); the mean time since MS diagnosis was 11 years (SD = 9.30). Employment status varied, and none of the participants reported themselves to be unemployed. The mean and median number of years which the HCP participants ($n = 10$) practiced in MS care were 23.4 and 23.5, respectively (SD = 6.5 years). Table 1 provides further data about both the patient and HCP participant demographics.

3.2. Identification of conceptual headings and collation into core themes

Conceptual headings were identified from the raw data from the interviews with both HCP and PwMS participants (open coding, see Appendix B). These were refined into nine subcategories and grouped into 3 core themes (Table 2).

The quotes from the interviews which are presented throughout the Results section are not exhaustive and do not encapsulate all the relevant quotes from the interviews.

Theme 1: The implications of cognitive symptoms on work

The practical experience of cognitive symptoms on work life

Respondents with MS described having difficulties in concentration and memory which created difficulty in maintaining focus on work tasks:

"On a bad day I can still function (…) but this would not be a day when I'd schedule a strategic brainstorming session, or that kind of focus time that's necessary on a larger project."

"I have to remember stuff at work and be on top of things: that's why I teach Elementary now, so that I don't have remember things like Pythagorean theorem. I stick with what I know or am most comfortable with."

One respondent who was self-employed stated that they had lost several clients because of their forgetfulness. Several respondents also shared that they felt noticeably slower than, and needing to "catch up" with, their colleagues. This was associated with emotions of overwhelm and stress:

"I end up feeling overwhelmed with trying to remember things, and getting behind because I'm looking at notes and trying to figure something out that should be fairly easy for anyone to stay on task."

"I feel like I'm always trying to catch up to everybody else."

HCP respondents highlighted stress, the risk of losing a job, fatigue in the workplace and difficulty in keeping up with work tasks as being the impact of cognitive impairment on their employment: their insights aligned with the experiences that respondents with MS described.

PwMS concerns about being misjudged at work and disclosing cognitive symptoms

A recurring theme among the respondents with MS was the worry about being misunderstood by colleagues and employers. Several respondents highlighted that employers may assume that cognitive symptoms entirely prevent employees from being capable at work:

"I don't want them to jump to conclusions that I'm not able to get my work done, and I don't want to *not* be put on projects that the team might need me on, because they think I can't handle it from a cognitive standpoint."

"Only if it were to benefit [the clients] I might share it, but I'm hesitant to because they might think 'oh they have MS, they can't do work with me', they might think that."

Some respondents also felt that they sometimes had to clarify certain actions which had been influenced by their cognitive symptoms to ensure that clients, colleagues or employers did not misunderstand them. For example, one respondent described how they once had to explain to colleagues that they had not returned their missed calls due to MS-related forgetfulness, rather than intentionally ignoring the calls.

The decision taken by several respondents with MS to not disclose their cognitive symptoms at work to employers, colleagues and/or to clients was related to their fear of being seen as "not capable" of working. For example, one of the respondents with MS explained that they chose to not disclose these symptoms to their clients in case the latter would assume that they were unable to do the job:

"My employer knows I have it [MS], but not about cognitive symptoms. I feel like they might just start to question if I'm a valid employee, so I don't want to raise any flags, and have them think they need to find somebody else."

Another reason shared by some respondents for not disclosing their cognitive symptoms at work was the fear of being subsequently fired or of not getting hired in a new job:

PwMS face uncertainty about career future and development

Several respondents expressed uncertainty about how cognitive symptoms might change in the future and how their employment might subsequently change. Some respondents with MS who described themselves as professionally ambitious highlighted how this uncertainty affected how they felt about their career future:

"Experiencing cognitive symptoms like the ones I've described are disheartening for me, because I want to continue delivering quality work on the projects I'm undertaking […] and really get the results that I'm aiming for professionally, and I want to continue advancing in my career. […] I worry that [cognitive symptoms] could affect my future ability to keep advancing professionally."

"It's just the uncertainty: you don't know what's going to happen, you just don't know with MS what the future is going to be like, so I'm just trying to do the work that I'm doing now."

"I haven't looked for advanced positions in other companies where I might have to disclose more about disease and symptoms, I've barely explored the possibility of other positions […] I don't want to have to disclose more about my personal health information, particularly jobs […] where I might be managing more complex projects, more overall strategy, managing more staff."

Theme 2: Challenges in addressing cognitive impairment and its impact on work in MS care

Difficulties faced by HCPs in discussing cognitive impairment with their patients with MS

Several HCP respondents shared that they didn't routinely initiate discussions about cognitive symptoms with their patients who have MS.

"It [the cognition assessment tool] is not sensitive enough, especially in the early stages."

Various reasons were given for this: the limited time available for consultations and concerns about adding further stress to patients who already have other aspects of their disease to manage:

"I don't talk about it; they already have enough concerns."

Some respondents also believed that patients with MS may prefer not to think about the cognitive aspect of their MS, especially during the initial stages of their disease journey. Another reason was that there isn't a treatment specifically targeted for cognition which HCPs can prescribe, resulting in them feeling like there isn't much they can offer to support their patients:

[In response to being asked why they do not routinely assess cognition in their MS clinic]
"Because there is nothing I have, medication wise."

"If there was a medication available, then I'd address cognition specifically."

Several HCP respondents shared that they would discuss cognitive symptoms only when their patients brought up the topic or when their patients had questions about symptoms which they could potentially have in the future.

Difficulties faced by HCPs and PwMS around addressing cognition in MS

Although most HCPs described how they typically measure cognitive impairment in their practice, such as psychological screening, small "mental tests", neurological examination and the Montreal Cognitive Assessment scoring system,[1] there was dissatisfaction with cognition assessment tools among some of these respondents. They highlighted the high cost of these tools, particularly as these are not always covered by medical insurance, as well as the extensive time taken for booking an assessment and the fact that some tests are very time-consuming to complete:

"It is costly and takes 2 months to get an appointment."
"It is time consuming and very expensive [cognition assessments]."

Accuracy was also seen as a problem by several HCP respondents:

One respondent also stated that there is no standardised way to measure the decline of cognition. Some HCPs described how they preferred to gain information about a patient's cognitive symptoms directly through conversation with them or their family, feeling this to be more accurate than cognition assessment tools.

A difficulty expressed by both HCP and PwMS respondents was the fact that cognitive symptoms can resemble other aspects of life, such as ageing, or other morbidities or psychological traits (such as depression and emotional lability) which are unrelated to MS: this can add to the challenge of recognising cognitive symptoms.

The "priority hierarchy" regarding physical and cognitive impairment in MS

[1] Montreal Cognitive Assessment scoring system: A screening tool for the assessment of cognitive impairment[1]

The notion that there is a "priority hierarchy" whereby physical symptoms take precedence over cognitive symptoms, was expressed by some of the respondents with MS. These respondents stated that their physical symptoms were a more important focus of their MS care than their cognitive symptoms, despite having discussed at length during the interviews the ways in which they experience cognitive symptoms and how these significantly impact their work life:

> "When I talk with my neurologist, we're going to talk about the main things that's making my life hard, the cognitive aspect is not that bad, this is the problem [physical fatigue]: this is what's interfering with my everyday life, so I prioritise what's more important."

> "Physical symptoms are the primary issue to deal with."

Several respondents with MS reported dissatisfaction with the ways that their MS care approaches physical and cognitive symptoms; these respondents reported that they would like to see cognitive impairment be more proactively addressed in MS care.

> "I see a lot of focus from the neurologist on physical symptoms and how to address those, and I think the healthcare team takes a fairly holistic approach to that (…). I don't really see that same approach when it comes to cognitive symptoms, and maybe not the same level of curiosity from the healthcare team, asking about those kinds of symptoms, or digging a bit deeper with the patient as to how they're affecting their work life, or home or family life."

> "I mean, they do the MRIs every year or two, like clockwork, so they should do the cognition assessments too."

The fact that cognitive impairment is excluded from the Expanded Disability Status Scale was highlighted by one respondent:

> "The scale for disability [Expanded Disability Status Scale] is based on physical things […] but it doesn't have anything to do with the cognitive aspect, which is the number one reason people stop working; it's cognitive, not their physical [symptoms]"

The notion that cognitive symptoms are prioritised according to their level of severity was also brought up in the interviews with some of the respondents with MS. For example, one of the respondents shared that they would only discuss their cognitive symptoms with their HCP if these started to have a more severe adverse impact on their life. Another respondent perceived cognitive symptoms to be mostly downplayed in MS care unless they were severe.

Theme 3: Strategies and support for managing the impact of cognitive symptoms

PwMS and HCP perspectives about self-implemented strategies to manage cognitive symptoms at work

Most of the respondents with MS described practical strategies which they implemented in their work life to adapt and manage the impact of their cognitive symptoms. For example, several respondents mentioned the use of notes and detailed planning in calendars to cope with their memory difficulties:

> "I have to write things down all the time, into a calendar and keep notes, because someone might have told me something maybe two weeks ago, like 'oh I need you to do this on this day': if I don't write it down, I'm not going to remember."

Another recurring theme was time management and the prioritisation of work tasks around the occurrence of cognitive symptoms:

"I needed to think more critically about what tasks had to be completed or put on schedule for what time of the day: mid-afternoon would be a time I'd experience more fatigue, and I wouldn't want to take on tasks that would include a higher level of cognitive analysis."

"I have to plan out the day, as I know that I can't do multitasking or a lot of activities all at once. I have to prioritise, every day."

As a response to cognitive symptoms, some respondents with MS shifted to remote working from home, whilst others reported changing their full-time employment to part-time to make their work more manageable.

HCP respondents shared several suggestions on practical strategies which PwMS could implement themselves to better cope with their cognitive symptoms at work: these included the use of to-do lists, staying organised, and breaking up large work tasks into smaller segments to make them more manageable. Some HCP respondents also highlighted the value of engaging in physical exercise as well as staying mentally active by using brain-training exercises, such as memory enhancing games.

HCP perceptions of employer-implemented workplace adjustments for accommodating cognitive symptoms

Several HCP respondents described workplace adjustments that they felt would help to accommodate employees who have cognitive symptoms. These included more frequent breaks, changing the type of tasks done at work, the option to work from home when possible, and more time given to employees for the completion of tasks. Some HCP respondents highlighted that the possibility of making such adjustments not only depended on employers having a flexible approach to work, but also depended on the type and industry of the job. One respondent also highlighted the importance of PwMS knowing how to communicate about their cognitive symptoms and to make requests for workplace adjustments to be made. A few HCP respondents were not confident that employers would accommodate for cognitive symptoms: for example, one respondent stated that:

"Employers can't support workers with cognitive issues and stay competitive."

Support systems for helping PwMS to manage their cognitive impairment and its impact on work

Several HCP respondents described support services which may help PwMS to manage their cognitive symptoms, such as referral to physical and cognitive therapy and counselling for managing the stress resulting from the impact of these symptoms. The value of accessing educational materials about cognitive impairment and gaining support and advice from the wider MS community was also highlighted. Several respondents with MS stated that having a good support system was very important to help with managing their cognitive symptoms. Support networks were described in terms of family, colleagues and/or employers who are understanding and accommodating, for example:

"Luckily, when I'm in a classroom I have 3 assistants because of my students, so I'm not in a classroom alone (…) especially the one who really kept an eye on me over the last 2 years and pays a lot of attention to it [cognitive symptoms]: it's just having a good support system."

Peer support via MS patient organisations was reported as helpful in learning about ways to effectively cope with cognitive symptoms. For example, one respondent with MS described how PwMS in a support group that he attended actively discussed cognitive symptoms in the workplace and offered a positive outlook on the topic:

"The good thing about the support group is we know so many resources and ways to get help, and I don't know of anybody who's been improperly fired because of what they couldn't do."

Respondents with MS also discussed how they felt HCPs could provide more support, by asking about cognitive symptoms and engaging in conversation about how these symptoms affect their life, providing advice on ways to practically deal with certain effects, suggesting practices which help to maintain cognition and reduce stress, and carrying out routine cognition assessments. For example, one respondent stated:

"A support group hearing about how others deal with cognitive symptoms would be helpful."

4. Discussion and conclusions

This qualitative study aimed to identify how cognitive impairment impacts the employment of PwMS, how this is perceived and addressed by both PwMS and HCPs, and to identify obstacles as well as areas of improvement in addressing this topic in MS care. In reviewing the interview responses, three key themes were identified: the implications of cognitive impairment on employment, the barriers to addressing cognitive impairment in the workplace, and strategies and support for managing this aspect of MS.

The negative impact of cognitive MS symptoms on employment has previously been established in the literature, with quantitative research finding significant associations between cognitive symptoms and reduced work hours as well as difficulties in employment. (Clemens and Langdon, 2018; Ruet et al., 2013; Amato et al., 2001) However, current qualitative analyses of patient-reported experiences of employment do not specifically address this in terms of the impact of cognitive impairment, nor do they include HCP perceptions on this topic. (Railton et al., 2022; Yorkston et al., 2003) Furthermore, quantitative studies can miss out on valuable details gained through the methodology of semi-structured interviews. Several insights gained from this study highlight actionable steps that can be taken by PwMS, HCPs and the wider MS community to support PwMS in managing their cognitive symptoms at work. For instance, the concerns that PwMS have in relation to how their cognitive symptoms may be misunderstood in the workplace and may affect some aspects of their work highlight the importance of communication in the workplace, with or without disclosure of cognitive symptoms. MS care teams can help by equipping people affected by MS with the right knowledge and guidance to navigate these sensitive conversations in the workplace. The uncertainty that many PwMS reported having about the future of their career is another important concern to engage with. There is to the authors' knowledge little research or ongoing efforts to address this issue, who suggest that more needs to be done to: (1) raise awareness about how cognitive impairment can affect the long-term career future of PwMS and (2) engage with PwMS on this issue and develop support strategies to help them adapt and plan for their future career.

It is well established that there are a number of obstacles that must be overcome in order to develop clinically meaningful interventions and diagnoses for cognitive impairment in MS. (Sumowski et al., 2018) The time requirement for carrying out cognition assessments in clinics can prove to be a practical challenge: this has been previously suggested as a reason for why routine cognition assessment is not always a standard procedure in MS clinics. (Sumowski et al., 2018) Furthermore, previous research has highlighted the difficulties in extracting clinically meaningful data from cognition test scores, (Sumowski et al., 2018; Elwick et al., 2022) as well as discrepancies between self-reported cognitive deficits and scores from cognitive test performance. (Akbar and Finlayson, 2021) HCP respondents in our study echoed these findings, linking a perceived lack of availability for practical, affordable and accurate cognition assessments to not incorporating routine cognition assessment as standard procedure in their clinical MS practice. Furthermore, no effective symptomatic treatment has been developed for addressing cognitive impairment in MS; (Niccolai et al., 2017) the benefit of existing disease-modifying therapies for the cognitive aspect of the disease is unclear and clinical studies investigating it are sorely limited. (Niccolai et al., 2017; DeLuca et al., 2020) This unmet treatment need was echoed by HCP respondents in our study.

Although personal proactivity plays a key role in successful MS management, (Vijayasingham and Mairami, 2018) the authors argue that it is the joint responsibility of PwMS to adopt behavioural responses and habits to better cope with the impact of cognitive symptoms on employment, and for HCPs to encourage and advise them on how to do so. As was reported by respondents in our study, there are diverse ways in which PwMS can proactively address the effects of their cognitive symptoms on work and help to maintain their employment. They can also have a degree of control over how their cognitive symptoms can be accommodated in the workplace by requesting specific adjustments. The authors wish to emphasise that employees who have cognitive MS symptoms do not necessarily need to disclose their cognitive symptoms to request workplace adjustments from their workplace. The authors also propose that a key role for HCPs and patient advocacy groups would be to provide guidance for PwMS on how to have a "safe" conversation with employers about the impact of their MS in the workplace, without necessarily needing to disclose their cognitive symptoms.

Although the perspectives of employers were not included in this study, they have an important role in this matter. As pointed out by several respondents with MS, employers may assume that cognitive symptoms completely prevent employees performing in their job, although this may not always be the case as simple workplace adjustments could help employees to maintain their productivity. The provision of guidance about supportive workplace adjustments for employers to whom disclosure of MS has been made would be a useful resource to help them make decisions about supportive workplace adjustments.

It is important to note the distinction between *coping* with cognitive symptoms and their impact on employment and *maintaining* cognition to protect against future cognitive deficits and their impact on future employment. Several forms of non-pharmaceutical treatment can help PwMS to protect their cognition, as highlighted by HCP and PwMS respondents in this study. Research in recent years has provided evidence for the protective effect of cognitive rehabilitation, the benefits of having a "brain-healthy" lifestyle involving physical exercise, an active social life, and hobbies to build cognitive reserve. (Brandstadter et al., 2019; Katz Sand, 2018; Mische and Mowry, 2018; Motl et al., 2017; Chen et al., 2021; Lincoln et al., 2020; Brochet, 2021; Stern, 2002; Schwartz et al., 2015; Schwartz et al., 2013) Conversations about addressing cognitive impairment and its impact on employment should therefore extend to service-level practices, rather than only self-implemented strategies.

To summarise, the authors suggest that future clinical research should be conducted to investigate the cognitive benefit of existing and in-development disease-modifying therapies to offer a pharmaceutical answer to cognitive impairment in MS. The authors also advocate for the development of resources for PwMS to (1) inform about the possible impact of cognitive symptoms on employment, (2) to educate on strategies to adapt and plan their future employment, (3) and to educate on ways to manage the impact of cognitive symptoms in the workplace on a practical, day-to-day basis. Finally, training for PwMS on how to hold a "safe" conversation with employers and ask for workplace adjustments to support them, should be developed with the input from PwMS and people who work as employers and/or Human Resources departments.

The authors hope that the findings from this study will encourage efforts to raise awareness about how the impact of cognitive impairment on work can be proactively managed and encourage MS care teams to proactively approach the topic of cognitive impairment and employment.

5. Limitations

The generalisability of these findings was limited due to a few factors. The insights from this study are based on self-report only and, therefore, should be interpreted with caution. Furthermore, data on participant socioeconomic status were not collected, which means that any potential influence that socioeconomic status may have on participant perceptions and experiences was not accounted for.

Only one participant living with MS who was male was recruited, which is a limiting factor as it means the study design does not adequately represent the male population of people living with MS. Experience with cognitive symptoms was self-reported rather than defined by a clinical screening measure. Additionally, the location of participants recruited was limited to the US and, therefore, only reflects the impact of US legislation about workplace adjustments for PwMS.

The study was also limited to a total of 20 interview participants: in view of the small sample size, data saturation (the point at which additional data would not result in further insights into the topic and serves only to confirm what has been observed and concluded) was not ensured.

It is important to note that using a web-assisted communication platform such as Zoom to conduct the interviews may limit the level of rapport which can be built with respondents compared with face-to-face communication: this may possibly limit the depth of detail shared during the interviews.

Author contributions

All named authors had full access to all of the content within this manuscript and take complete responsibility for the integrity and accuracy of the content. All named authors take responsibility for the integrity of the work as a whole and have given their approval for this version to be published.

Compliance with ethical guidelines

This study did not involve human subjects and/or animals or the use of identifiable patient data; therefore, ethical approval and informed consent were not required.

CRediT authorship contribution statement

David Yeandle: Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Sarah A. Morrow:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Maija Pontaga:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Marja-Liisa Sumelahti:** Writing – review & editing, Writing – original draft, Methodology, Conceptualization. **Nektaria Alexandri:** Conceptualization, Methodology, Visualization, Writing – original draft, Writing – review & editing.

Declaration of competing interest

Sarah A Morrow has served as an advisory board member or received consulting fees from Biogen Idec, Bristol Myers Squibb/Celgene, EMD Serono, Inc., Rockland, MA, USA, an affiliate of Merck KGaA, Darmstadt, Germany, Novartis, Roche, Sanofi Genzyme and Teva Neurosciences; has participated in a speaker's bureau for Biogen Idec, Bristol Myers Squibb/Celgene, EMD Serono, Inc., Rockland, MA, USA, an affiliate of Merck KGaA, Darmstadt, Germany, Novartis, Roche and Sanofi Genzyme; has received research support from Biogen Idec, EMD Serono, Inc., Rockland, MA, USA, an affiliate of Merck KGaA, Darmstadt, Germany, Novartis, Roche and Sanofi Genzyme; and has participated as a site investigator in clinical trials sponsored by Bristol Myers Squibb/Celgene, EMD Serono, Inc., Rockland, MA, USA, an affiliate of Merck KGaA, Darmstadt, Germany, Novartis, Roche and Sanofi Genzyme. Nektaria Alexandri is an employee of Merck Healthcare KGaA, Darmstadt, Germany. David Yeandle is a member of the MS in the 21st Century Steering Group, Southampton, UK. Maija Pontāga has received honoraria or personal fees from Merck KGaA, Darmstadt, Germany. Marja-Liisa Sumelahti has received honoria or personal fees from Merck KGaA, Darmstadt, Germany, Novartis, Pfizer, Teva, Novartis, Lundbeck, Abbvie and Eli Lilly for lecturing or participating in advisory boards. She is also principal investigator for trials sponsored by Roche, Lundbeck, Novartis and Teva.

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Appendix A

Screening questions for HCP participants

S1a Do you, or does any member of your household, work for or **have any affiliation with** any of the following?

An advertising agency, market research, or competitive intelligence company	01	**THANK AND CLOSE**
A manufacturer or distributor of pharmaceutical/biotech products	02	**THANK AND CLOSE**
A pharmacy or drug store	03	**THANK AND CLOSE**
The FDA	04	**THANK AND CLOSE**
None of these **[exclusive]**	05	**GO TO S1b**

S1b Do you work for any of the following healthcare providers? [SELECT ALL THAT APPLY]

Humana	01	**GO TO S2**
Kaiser Permanente	02	**THANK AND CLOSE**
Wellpoint	03	**GO TO S2**
Other (specify) **[anchor]**	04	**GO TO S2**
None of the above **[anchor; exclusive]**	05	**GO TO S2**

S2 Please can you confirm your primary medical specialty?

Neurologist	01	**GO TO S3**
MSologist	02	**GO TO S3**
Other	03	**THANK AND CLOSE**

S3 What is your level/grade?

Head of Department / Clinical Lead (or equivalent)	01	**GO TO S4a**
Consultant	02	**GO TO S4a**
Specialist Registrar (or equivalent)	03	**THANK AND CLOSE**
Registrar/ Junior grade (or equivalent)	04	**THANK AND CLOSE**
Other	05	**THANK AND CLOSE**

S4a Which state do you currently practice in? If you practice in more than one state, please select the state where you consider your primary practice to be located.

State

THANK AND CLOSE IF PRACTICING IN IF VERMONT, MINNESOTA, MAINE, WEST VIRGINIA OR US TERRITORIES
S4b In your primary specialty, are you board-certified, board eligible, or neither?

Board-certified	01	**CONTINUE**
Board-eligible	02	**THANK & CLOSE**
Neither	03	**THANK & CLOSE**

S5a How would you characterize your practice type?

Single specialty	01	**CONTINUE TO S5b**
Multi-specialty	02	**CONTINUE TO S5b**

S5b How would you characterize your practice location?

Urban	01	**CONTINUE TO S5c**
Suburban	02	**CONTINUE TO S5c**
Rural	03	**CONTINUE TO S5c**

S5c How would you characterize your practice setting?

Academic/Research	01	**CONTINUE TO S5d**
Large Practice/ Center (Infusion Focused)	02	**CONTINUE TO S5d**
Large Practice/ Center (Focused on Broad DMT use)	03	**CONTINUE TO S5d**
Community Clinic/Center	04	**CONTINUE TO S5d**
Other, please specify: _____ [Anchor]	05	**CONTINUE TO S5d**

S5d How would you characterize your practice ownership?

Owner of practice or medical group	01	**CONTINUE TO S6**
Employee of practice or medical group	02	**CONTINUE TO S6**

S6 Excluding residency, how many years have you been practicing?

Number of years

IF <2 YEARS OR >30 YEARS THANK & CLOSE, OTHERWISE GO TO S6

S7a Approximately what percentage of your time is spent on direct patient care (as opposed to non-clinical activities such as teaching or administrative tasks)?

% of time in direct patient care

IF <60 % THANK & CLOSE, OTHERWISE GO TO S7b

S7b Overall, what percentage of your practice time was focused on treating patients with multiple sclerosis (MS)?

% of time devoted to treating MS

S8 In an average month, how many individual patients have you treated personally for Multiple Sclerosis?

IF <10 THANK & CLOSE, OTHERWISE GO TO S9

S9 Thinking about all your patients with MS, what percentage have each of the following types of MS? *Your answers must sum to 100 percent. Enter "0" if there were no patients in a particular type.*

		% of MS patients
Clinically isolated syndrome (CIS) or patients who have experienced a first clinical episode and have MRI features consistent with MS	01	___%
Relapsing Remitting MS (RRMS)	02	___%
Primary Progressive MS (PPMS)	03	___%
Non-Active Secondary Progressive MS (SPMS)	04	___%
Active Secondary Progressive MS (SPMS)	05	___%

S10 Are you personally responsible for prescribing treatments for your Multiple Sclerosis patients?

Yes	01	**CONTINUE TO S11**
No	02	**THANK AND CLOSE**

S11 Have you participated in any market research regarding Multiple Sclerosis within the last 3 months?

Yes	01	**THANK AND CLOSE**
No	02	**CONTINUE TO S12**

S12 Could you please confirm that if selected for an interview, you will have access to a computer/ laptop/ desktop with good internet for the entire length of the interview? **Please note tablets/ iPads or other electronic devices will not be suitable**

SINGLE CODE

Yes	01	**CONTINUE TO S13**
No	02	**THANK AND CLOSE**

S13 Would you be willing to be contacted in the future with regards to this research, should there be any follow-up questions based on the research conducted?

SINGLE CODE

Yes	01	**RECORD**
No	02	**RECORD**

Screening questions for participants living with MS

S1 Are you and/or the person you live with who has a health condition, or any member of your household, employed by the pharmaceutical industry on a full-time or consultancy basis, or is any member of your household employed by a communication or advertising industry related to pharmaceutical products?

Yes	01	**THANK AND CLOSE**
No	02	**GO TO S2**

S2 Please indicate your gender / the gender of the person you live with/gender of the person you have close contact with who has a health condition

Male	01	**GO TO S3**
Female	02	**GO TO S3**
Other	03	**GO TO S3**

S3 Please can you tell me which of the following age brackets you / the person you live with/ the person you have close contact with who has a health condition fall(s) into?

Under 18 years	01	**THANK AND CLOSE**
18 – 30 years	02	**GO TO S4**
31 – 44 years	03	**GO TO S4**
45 – 50 years	04	**GO TO S4**
51 – 60 years	05	**GO TO S4**
61 – 75 years	06	**GO TO S4**
Over 75 years	07	**THANK AND CLOSE**

S4 What is your 5 digit zip code? [NUMERICAL RESPONSE; ALLOW ONLY 5 DIGITS]

East [107,120,122,130,140,146,121,131,133,139,109,149,108]	01	**GO TO S5**
Midwest [114,115,123,136,150,116,117,124,126,128,135,142]	02	**GO TO S5**
South [101,110,111,118,125,134,141,143,147,104,119,137,144]	03	**GO TO S5**
West [103,106,113,127,129,132,145,151,105,138,148,102,112]	04	**GO TO S5**
Non-U.S. State [153–160]	05	**THANK & CLOSE**
Unknown [ALL OTHERS]	06	**THANK & CLOSE**

S5 Have you / the person you live with who has a health condition/ the person you have close contact with who has a health condition received a confirmed diagnosis from a doctor for any of the following conditions?

Epilepsy	01	**THANK & CLOSE**
Arthritis	02	**THANK & CLOSE**
Psoriasis	03	**THANK & CLOSE**
Diabetes	04	**THANK & CLOSE**
Multiple Sclerosis	05	**GO TO S6**

S6a When were you / the person you live with/ the person you have close contact with first diagnosed with Multiple Sclerosis (MS)? [NUMERICAL ANSWER, RANGE 0 TO 99; RECRUIT MIX OF RESPONSES]

[_____] – **GO TO S6b**

S6b What type of MS are you / the person you live with/ the person you have close contact with currently diagnosed with?

Relapsing/Remitting MS	01	**GO TO S6c**
Active Secondary Progressive MS	02	**THANK & CLOSE**
Non-Active Secondary Progressive MS	03	**THANK & CLOSE**
Primary/Progressive MS	04	**THANK & CLOSE**
Clinically Isolated Syndrome (CIS)	05	**THANK & CLOSE**
Other	06	**THANK & CLOSE**
Not sure	07	**THANK & CLOSE**

S6c Which of the following symptoms do you / the person you live with/ the person you have close contact with experience due to MS?

Memory loss	01	**GO TO S6d if at least 1 response selected**
Concentration	02	
Remembering new things	03	
Planning	04	
Multi-tasking	05	
None of the above	06	**THANK & CLOSE**

S6d How often do you / the person you live with/ the person who you have close contact with experience the symptoms you selected?

SHOW SYMPTOMS SELECTED AT S5b		**SELECT ONE OPTION**	
Memory loss	01	Once a month or less	**RECORD & GO TO S6e**
	02	A few times a month	
	03	Once a week or more	
Concentration	01	Once a month or less	
	02	A few times a month	
	03	Once a week or more	
Remembering new things	01	Once a month or less	
	02	A few times a month	
	03	Once a week or more	
Planning	01	Once a month or less	
	02	A few times a month	
	03	Once a week or more	
Multi-tasking	01	Once a month or less	
	02	A few times a month	
	03	Once a week or more	
None of the above	01	Once a month or less	
	02	A few times a month	
	03	Once a week or more	

S6e Which of the following options best describes the physical impairments (if any) you/ the person you live with/ the person you have close contact with currently experience due to your multiple sclerosis?

No physical impairment	01 – code mild	**CONTINUE TO S7a**
Some physical impairment, but able to walk freely with minimal assistance (cane or crutch)	02 – code moderate	**CONTINUE TO S7a**
Physical impairment enough to require occasional walking assistance (<50 % of time requiring a cane or crutch or <25 % of time, occasional use, of wheel chair) for typical walking activities	03 – code moderate to high	**CONTINUE TO S7a**
Physical impairment enough to require >50 % of time use of wheel chair assistance for typical walking activities	04 – code very high	**THANK & CLOSE**

S7a Which of the following prescription drug treatments are you aware of for the treatment of MS?

Aubagio (teriflunomide)	01	**CONTINUE TO S7b**
Gilenya (fingolimod)	06	**CONTINUE TO S7b**
Mavenclad (cladribine) tablets	19	**CONTINUE TO S7b**
Mayzent (siponimod)	20	**CONTINUE TO S7b**
Ocrevus (ocrelizumab)	16	**CONTINUE TO S7b**
Rebif (interferon beta-1a)	07	**CONTINUE TO S7b**
Tecfidera (dimethyl fumarate)	08	**CONTINUE TO S7b**
[ALWAYS SHOW UNDER CODE 8] Generic dimethyl fumarate (i.e. generic Tecfidera)	28	**CONTINUE TO S7b**
Tysabri (natalizumab)	09	**CONTINUE TO S7b**
Copaxone, Glatopa / Generic (glatiramer acetate injection)	21	**CONTINUE TO S7b**
Vumerity (diroximel fumarate)	22	**CONTINUE TO S7b**
Avonex (interferon beta-1a) / Plegridy (peginterferon beta-1a)	24	**CONTINUE TO S7b**
Zeposia (ozanimod)	25	**CONTINUE TO S7b**
Kesimpta (ofatumumab)	26	**CONTINUE TO S7b**
None of these **[ANCHOR]**	10	**CONTINUE TO S7b**

S7b Please indicate which of the following treatments you/the person you live with who has MS/ the person you have close contact with have ever taken, including the treatment you/they are currently taking, for the management of your/their MS

Aubagio (teriflunomide)	01	**CONTINUE TO S7c**
Gilenya (fingolimod)	06	**CONTINUE TO S7c**
Mavenclad (cladribine) tablets	19	**CONTINUE TO S7c**
Mayzent (siponimod)	20	**CONTINUE TO S7c**
Ocrevus (ocrelizumab)	16	**CONTINUE TO S7c**
Rebif (interferon beta-1a)	07	**CONTINUE TO S7c**
Tecfidera (dimethyl fumarate)	08	**CONTINUE TO S7c**
[ALWAYS SHOW UNDER CODE 8] Generic dimethyl fumarate (i.e. generic Tecfidera)	28	**CONTINUE TO S7c**
Tysabri (natalizumab)	09	**CONTINUE TO S7c**
Copaxone, Glatopa / Generic (glatiramer acetate injection)	21	**CONTINUE TO S7c**
Vumerity (diroximel fumarate)	22	**CONTINUE TO S7c**
Avonex (interferon beta-1a) / Plegridy (peginterferon beta-1a)	24	**CONTINUE TO S7c**
Zeposia (ozanimod)	25	**CONTINUE TO S7c**
Kesimpta (ofatumumab)	26	**CONTINUE TO S7c**
Never taken a prescription drug for MS	10	**CONTINUE TO S7c**
None of these	99	**THANK AND CLOSE**

S7c Please specify which of the following prescription treatments you/the person you live with/ the person you have close contact with are **currently taking** to treat your/their MS

[PIPE IN BRANDS SELECTED AT S6b	01	**CONTINUE TO S8a**
Not currently taking a prescription drug for MS	10	**THANK AND CLOSE**

S8a Which of the following best describes your current employment status / the current employment status of the person you live with/ the current employment status of the person you have close contact with?

Working full time	01	**GO TO S9**
Working part time	02	**GO TO S9**
Full time student	03	**GO TO S8b**
Unemployed	04	**GO TO S8b**
Other (please specify)	05	**GO TO S8b**

S8b Have you / the person you live with or have close contact with been in full time or part time employment since you were diagnosed with MS?

Yes, in the last 6 months	01	**GO TO S9**
Yes, but more than 6 months ago	02	**THANK AND CLOSE**
No	03	**THANK AND CLOSE**

S9 In which industry do you work / does the person you live with or have close contact with work in? Or previously worked in the last 6 months? **SINGLE CODE**

Accounting	01	**GO TO S10**
Advertising	02	**GO TO S10**
Aerospace	03	**GO TO S10**
Agriculture	04	**GO TO S10**
Biotechnology	05	**GO TO S10**
Business services	06	**GO TO S10**
Computers	07	**GO TO S10**
Construction	08	**GO TO S10**
Consulting	09	**GO TO S10**
Education	10	**GO TO S10**
Engineering	11	**GO TO S10**
Entertainment	12	**GO TO S10**
Finance	13	**GO TO S10**
Food Service	14	**GO TO S10**
Government / Military	15	**GO TO S10**
Healthcare	16	**GO TO S10**
Internet	17	**GO TO S10**
Legal	18	**GO TO S10**
Manufacturing	19	**GO TO S10**
Marketing	20	**GO TO S10**
Media	21	**GO TO S10**
Mining	22	**GO TO S10**
Non-profit	23	**GO TO S10**
Pharmaceutical	24	**GO TO S10**
Research	25	**GO TO S10**

(*continued on next page*)

(*continued*)

Real estate	26	**GO TO S10**
Retail	27	**GO TO S10**
Telecommunications	28	**GO TO S10**
Transportation	29	**GO TO S10**
Utilities	30	**GO TO S10**
Wholesale	31	**GO TO S10**
Professional services – other	32	**GO TO S10**
Other	33	**GO TO S9b**

S9b In which industry do you work/ does the person you live with or have close contact with work in?
OPEN END [only show if code 33 selected in S5]
– **GO TO S10**
S10 Have you participated in any market research regarding Multiple Sclerosis within the last 3 months?

Yes	01	**THANK AND CLOSE**
No	02	**CONTINUE**

S11 Could you please confirm that if selected for an interview, you will have access to a computer/ laptop/ desktop with good internet for the entire length of the interview? **Please note tablets/ iPads or other electronic devices will not be suitable**
SINGLE CODE

Yes	01	**CONTINUE**
No	02	**THANK AND CLOSE**

S12 Would you be willing to be contacted in the future with regards to this research, should there be any follow-up questions based on the research conducted?
SINGLE CODE

Yes	01	**RECORD**
No	02	**RECORD**

Appendix B

Grounded Theory

Open coding: The first independent reviewer processed the raw data from the interview transcripts into discrete sections, under conceptual headings. These were framed in terms of how participants described their experiences.

Axial coding: Two independent reviewers examined the proposed conceptual headings and assessed possible relationships emerging between these.

Selective coding: A fourth independent reviewer identified core themes which would contain the conceptual headings proposed by the previous two reviewers.

Reflexive role of the reviewers:

In this research, two of the independent reviewers involved in the axial coding of the data had worked on projects relating to various unmet needs of PwMS in MS care. Their background therefore may have imparted some preconceived expectations around themes which could emerge from the data. To mitigate for any possible bias, the reviewers annotated any preconceived ideas about what they expected would emerge from the data, before beginning axial coding to reduce unconscious bias. The independent reviewers then shared these pre-conceived notions with one another during discussions after selective coding before a final consensus on core themes was reached.

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