

“There’s No Magic Pill”: A Multimethods Qualitative Study Exploring Routine Fatigue Care in People With Multiple Sclerosis

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TARGET AUDIENCE: The target audience for this activity is physicians, advanced practice clinicians, nursing professionals, social workers, and other health care providers involved in the management of patients with multiple sclerosis (MS).

LEARNING OBJECTIVES:

1. Examine current methods for assessing fatigue in clinical settings and the utility of incorporating available standardized tools for fatigue assessment to improve recognition of multiple sclerosis-related fatigue and its manifestation within a person’s daily life.
2. Recognize the value of evidence-based fatigue interventions and strategies for implementation of these techniques in clinical settings including referrals to other members of the care team.

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ABSTRACT

BACKGROUND: Fatigue is a common and debilitating symptom for people with multiple sclerosis (MS). Evidence suggests that behavioral treatments, particularly cognitive behavioral therapy and some exercise therapies, are effective in reducing MS fatigue. However, few people are offered these treatments in routine care, and little is known about the reasons for this research-to-practice gap. The aim of this study was to explore how routine care is currently delivered for MS fatigue.

METHODS: Health care professionals (n = 28) took part in 6 focus groups and 6 one-to-one interviews exploring experiences with assessing, managing, and treating fatigue. How health care professionals (n = 10) delivered MS fatigue management was observed across 19 patient-clinician consultations in 4 National Health Service clinics in London, the North East, and the South West of England. All data were analyzed using reflexive thematic analysis.

RESULTS: Three key themes with subthemes were generated: (1) MS fatigue is not formally screened, (2) promoting self-management for MS fatigue, and (3) MS fatigue cannot be treated in isolation. Key findings included relying on people who have MS to recognize and report their experience of fatigue, the use of the multidisciplinary team to trickle fatigue management through their practice, and the tendency for professionals to sometimes differ in their interpretations of fatigue management advice.

CONCLUSIONS: The findings indicate that introducing a formal screening measure and developing a standardized, evidence-based behavioral treatment that can be implemented into routine care may allow for improved treatment of MS fatigue.

Int J MS Care. 2025;27:346-359. doi:10.7224/1537-2073.2024-097

Fatigue is a fact of life for many people with chronic health conditions. This is particularly true for people with multiple sclerosis (MS), a lifelong, demyelinating disease of the central nervous system; 90% of people with MS report experiencing fatigue.¹ Fatigue can be one of the most debilitating symptoms of MS, is the biggest predictor of poor quality of life,² and is a key reason people with MS leave the workforce before standard retirement age.³

Behavioral treatments, particularly those grounded in cognitive behavioral therapy (CBT), and some exercise therapies are effective treatments for reducing fatigue in people with MS.⁴ However, a large United Kingdom survey showed that these behavioral fatigue treatments were rarely offered in routine care.¹ In one study, of the 31% of participants with MS who were offered treatment for fatigue, 6% were offered behavioral therapy, 3% were offered exercise therapy, and 22% were offered drug-based therapies,

which have shown no to minimal significant effectiveness in randomized controlled trials.^{5,6} Further, of the offered behavioral treatments, only 13% were purely CBT-based treatments, with more than half combining CBT with less effective treatments, such as those based on the principles of energy conservation.⁴

We currently know little about why people with MS are infrequently offered evidence-based treatments for fatigue, although there are some preliminary indicators from qualitative studies. In a study exploring beliefs about exercise and fatigue in MS, health care professionals (HCPs) expressed how difficult it can be to conceptualize, verbalize, and measure fatigue, despite it being a common symptom.⁷ Professionals spoke of having to do “detective work” to unpack how fatigue manifests in each person they treat, which, coupled with service barriers like time-restricted appointments, makes it difficult to detect and treat MS fatigue.

Researchers in another study reported that people with MS expressed some confusion over which fatigue treatments they believed were effective, specifically regarding whether exercise helps or exacerbates MS fatigue.⁸ Some of this uncertainty may be linked to different professionals giving different fatigue management advice; physiotherapists were more likely to mention encouraging people to increase their activity levels, whereas occupational therapists (OTs) tended to speak about promoting energy conservation to prioritize activities of daily living.⁷ Some HCPs noted that they sometimes felt as though they were “tinkering” with MS fatigue in the absence of an established evidence base for treating and supporting people with MS fatigue.⁷ Taken together, it seems that uncertainty and inconsistency in the fatigue care pathway may contribute to the fatigue treatment gap.

Regardless, we still know very little about how fatigue treatments are actually delivered in routine care, including how fatigue is detected and who delivers these treatments. Identifying what is working well and where there might be gaps will help inform more evidence-based treatment pathways for MS fatigue. Therefore, in this study we aimed to investigate how fatigue care is routinely delivered for people with MS.

METHODS

Design

We conducted a multimethod qualitative study⁹ using semistructured focus groups and one-to-one interviews with HCPs working in MS services, alongside clinical observations of patient-clinician consultations in National Health Service (NHS) clinics in distinct regions of England. Adopting a critical realist stance,¹⁰ we explored the delivery of routine MS fatigue care through HCP insights interpreted by

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the researchers. We adhered to the consolidated criteria for reporting qualitative research in reporting our methodology.¹¹

We estimated a sample size of 20 to 30 a priori using general standards of qualitative analysis.¹² Researchers experienced in qualitative methods conducted analyses alongside data collection to determine when fewer new codes were generated, thereby guiding sample size and purposive recruitment.

Ethical approval was obtained through the King's College London Health Faculties Research Ethics Subcommittee (HR/DP-22/23-34826), and Health Research Authority approval was gained through the Research Ethics Committee, West Midlands, Coventry, Warwickshire (23/WM/0165).

Participants

Participants were eligible if they were 18 years or older, lived and worked in the United Kingdom, and had experience working as an HCP with people with MS. Those invited to focus groups or interviews worked in the NHS, private practice, or nonprofit therapy centers. Observations took place in 4 NHS clinics in London, the South West, and the North East of England.

Participants were recruited through convenience and snowball sampling via community networks and 4 NHS services. We also approached participants through neurology or MS-specific conferences, charities, professional organizations, and social media. As data collection progressed, we used purposive sampling to ensure participants represented a range of disciplines. Five participants who consented dropped out of scheduled focus groups due to time commitments, even when offered a shorter one-to-one interview at a time of their convenience. Recruitment occurred between April 2023 and January 2024.

Procedures

Online Focus Groups and Interviews

All HCPs gave informed consent and completed a questionnaire about their age, sex, professional experience, current role, and service through an online survey. Focus groups lasted between 103 and 120 minutes, whereas interviews ranged from 54 to 63 minutes, all conducted and recorded via Microsoft Teams. Audio files were transcribed by a third-party transcription company and manually checked by the research team. Transcripts were pseudonymized. Focus groups and interviews followed a topic guide developed with input from nonparticipant HCPs experienced in MS (TABLE S1) to explore fatigue assessment, management, and treatment experiences.

Clinical Observations

All HCPs and people with MS received an information sheet and provided informed consent. Three researchers (E.O'C., H.W., O.T.) independently observed various clinical consultation formats: one-to-one or group, delivered in-person or online. Consultations focused on general MS checkups and MS fatigue-specific issues, and 1 group session focused on general neurological fatigue. Field notes were taken during

TABLE. Demographics and Professional Characteristics of Participants

	Focus group or interview aggregate n = 28	Observations aggregate n = 10
Age in years, M (SD), range	42.7 (9.1), 26-60	N/A
Sex		N/A
Female	27	
Male	1	
Roles (n)		
Physiotherapist	6	2
Occupational therapist	14	4
Nurse	5	1
Service manager	1	0
Neurologist	0	3
MS Pilates instructor	1	0
Research therapist	1	0
Service type		
NHS	22	10
Therapy center	4	0
Private practice	1	0
University	1	0
Years working with people with MS,* M (SD) min-max	11.1 (7.6) 1-25	N/A
Service region		
North East	0	1
North West	2	0
Yorkshire and the Humber	3	0
West Midlands	0	0
East Midlands	1	0
East of England	1	0
London	5	0
South East	2	2
South West	11	1
Wales	3	0

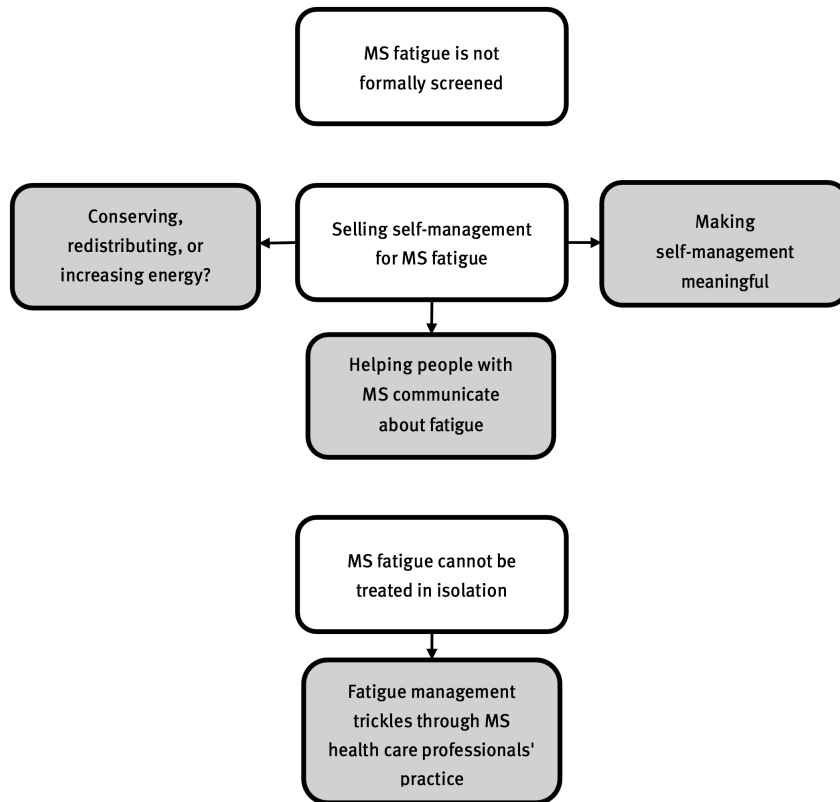
M, mean; max, maximum; min, minimum; MS, multiple sclerosis; N/A, data not collected; NHS, National Health Service.

*n = 26

consultations; researchers noted spoken content, verbal expression, tone, and body language, recording verbatim quotations where appropriate. One person with MS requested withdrawal of their observation data after the consultation, which was granted.

Analysis

Inductive reflexive thematic analysis was used to analyze all data.¹³ Researchers (E.O'C., T.F., T.S.) familiarized themselves with the transcripts and field notes. The primary coder (E.O'C.) generated semantic and latent codes relevant to understanding routine care in MS fatigue. Data extracts were

FIGURE. Thematic Map of Themes and Subthemes

MS, multiple sclerosis.

Note: Themes are in white; subthemes are in gray.

coded into multiple codes where necessary. The coding process was data-driven and iterative, with frequent referral to the full dataset to ensure ideas had not been missed or misinterpreted. Initial themes were generated and later reviewed, redefined, and renamed. NVivo 14 was used to organize the data.

Predefined criteria and processes¹⁴ were followed to enhance the trustworthiness of the analysis. Regular data clinics facilitated discussions about coding and theme generation. A workshop with observers and the wider multidisciplinary research team helped contextualize the data regarding MS fatigue alongside qualitative insights from people with MS and their caregivers. Six MS HCPs, including 2 participants from focus groups/interviews, provided feedback on the analysis during a separate online workshop. The primary coder also consulted with a practicing occupational therapist in MS care. For a detailed reflexivity statement, see [TABLE S2](#).

RESULTS

Thirty-five HCPs participated in the study; 28 professionals took part in 6 focus groups and 6 interviews, while 10 professionals were involved in observations of 19 clinician-patient consultations. Three participants from a focus group were also observed during a consultation. The [TABLE](#) outlines the professional roles and demographics of the participants

and the types of health care services that participated, including geographic locations.

Three themes with subthemes were generated to describe how participants delivered routine care for MS fatigue (see [FIGURE](#)). All themes and subthemes were generated from professional views expressed in the focus groups and interviews and the observations of professionals in routine clinical practice (see [TABLE S3](#) for supporting quotations for each theme and subtheme). Participant quotations have been lightly edited for clarity while maintaining the original meaning.

Theme 1: MS Fatigue Is Not Formally Screened

To initially screen for MS fatigue, HCPs discussed using 2 informal methods: asking the person with MS whether fatigue is a problem for them or waiting for them to raise it as a priority symptom. Professionals noticed that both methods depended on the individual's ability to recognize and articulate their experience of fatigue, which can be complex and difficult to unpack.

"I worked in the NHS until fairly recently... We would perhaps have an assessment session, and I always asked people to bring their top 3 things they wanted to discuss. So, often people would bring fatigue as an issue, and then that would be, in a sense, easier because that was their priority...but it's the people who don't necessarily report fatigue. Again, going back to the cognitive [fatigue], the issues that people often don't necessarily know that's what perhaps underlying some of the problems that they're having" (Focus group with physiotherapist 1, MS therapy center).

Professionals noted that these informal screening methods depended on people with MS acknowledging that fatigue is disrupting their lives. At times, it was evident that the normalization of fatigue as an accepted part of living with MS made this difficult. They reported that, even if MS fatigue is bothersome, some individuals may not report it or seek intervention, believing fatigue is something they "can't do anything about" (observation of video consultation with MS nurse 4). Further, those who recognized the impact of fatigue but have "a lot going on in their lives" may overlook the benefit of fatigue intervention because "giving them loads of information is just another thing that makes them exhausted" (focus group with OTs 11). Professionals highlighted the limitations of detection methods, expressing concern that some people with MS may experience fatigue for a long time before receiving an opportunity for intervention. They also

highlighted limited patient contact time, which makes it difficult to assess fatigue more formally, especially in the context of treating other MS symptoms.

Theme 2: Selling Self-Management for MS Fatigue

Once it was acknowledged as a problem, clinical management of MS fatigue focused on self-management. HCPs described using a “coaching approach” (OT10, NHS) to support people with MS taking an active role in management. Although some characterized reliance on self-management as enabling greater treatment “ownership” (OT10, NHS), it was also regarded as the inevitable therapeutic option in the absence of a “magic pill” (interview with nurse 2, NHS). Part of the professional role involved managing treatment expectations and reinforcing the importance of active participation in fatigue self-management.

“At the end of day, you have to be the one to know where your limits are. We can’t be with you, you need to understand your own routine, so you’re not wiped out all day tomorrow” (observation of online group fatigue management session with OTs 14 and 15).

Professionals noted that encouraging people to engage in self-management was one of the most challenging parts of delivering fatigue therapy, especially with people who were more passive in their illness self-management, expecting the professional “to do something for them” (focus group with OT 6, NHS). Professionals acknowledged that encouraging self-management was often a gradual, nonlinear process that could be bolstered using tools like peer support. Although there was general agreement that information-giving was a foundational part of the professional role, professionals claimed that the coaching component was far more important in actively engaging people with MS in the self-management of their fatigue. Pharmacological treatments for MS fatigue were rarely mentioned and were branded as a sideline treatment to be used alongside self-management.

Subtheme 2.1: Conserving, Redistributing, or Increasing Energy?

One of the key self-management strategies identified from the data was energy conservation. Three key pillars of energy conservation were frequently mentioned: planning, pacing, and prioritizing. There were some inconsistent opinions among the professionals across the groups about whether energy levels were limited or whether they could be increased. Some professionals encouraged the introduction of rest to conserve energy, while others focused on the redistribution of energy expenditure, alluding to people having a limited amount of energy that they could reallocate to their most important tasks.

“I quite often talk about it in monetary values, in that across a month I’ve only got X amount to spend and there may be some months or some weeks that I really might want to prioritize doing something a bit special, and that might put me in deficit, but that’s OK.... So we’re not going to give them more

energy, they’re just going to have to reprioritize how they’re going to spend it” (focus group with OT 2, NHS).

Conversely, professionals noted that people with MS could slowly increase activity levels over time, with the potential for gentle exercise to “reward you with more energy” (interview with nurse 3, NHS). While sometimes contradictory, professionals found these nuances useful in tailoring their advice to suit the patient. For example, they might encourage a person with a busy schedule to conserve their energy but ask a person with a sedentary lifestyle to steadily increase their activity levels. Although HCPs mentioned using CBT-based techniques, such as thought reframing, these were secondary to more “practical” strategies grounded predominantly in energy conservation (OT9, NHS). Interestingly, there was no distinct pattern in which professions favored a particular type of fatigue management.

Subtheme 2.2: Helping People With MS Communicate About Fatigue

Another key self-management strategy championed by professionals was coaching people with MS to become more confident in communicating about their fatigue, explaining how it manifested, and what impacts it had. Professionals emphasized the importance of giving people the “language” (focus group with physiotherapist 1, MS therapy center) to comfortably explain their experience of MS fatigue, set boundaries, and recruit help to support self-management.

“I had a patient who worked in engineering, and they got a flag system, so every job that they did they had a red, amber, and green flag system, so she adopted that for herself. So, in the morning when she first got to work, she’d have a green flag on her desk and people knew that they could give her work...and then by the end of the day when she was a red flag, they knew that they couldn’t give her any more work to do and that she just had to finish what she got with no disturbance and she’d kind of utilized that system to set out very clearly how her fatigue impacted her” (focus group with nurse 2, NHS).

Professionals noted the negative impact of others not adequately understanding fatigue and perceiving the person with MS as lazy (focus group with OT 10, NHS), which professionals linked to a decreased likelihood in the person engaging with fatigue treatment.

Subtheme 2.3: Making Self-Management Meaningful

To increase engagement with fatigue self-management, professionals spoke of making management strategies feel more meaningful. One way they achieved this was to encourage the person with MS to work toward functional goals, grounded in things that mattered to them.

“When talking about adaptations to his routine, the occupational therapist suggested he get dressed later in the day, as he seemed to be more tired if he got dressed very early, or suggested he do some activities, such as a puzzle, that would ‘prompt him to rest’ in between other activities. The person with MS seemed quite resistant to this and said he just didn’t



Fatigue in multiple sclerosis (MS) was acknowledged as an important clinical problem by health care professionals (HCPs), but there is no current standardized assessment.

By introducing a formal screening for MS fatigue that is quick to use and can be implemented in current care pathways, recognition of fatigue as a symptom that needs treatment may be improved.

Fatigue treatments varied, sometimes including approaches that were ineffective, and HCPs from different disciplines tended to trickle this information through their respective areas of practice. Using a standardized, evidence-based behavioral treatment for MS fatigue, alongside training for HCPs in evidenced-based cognitive behavioral therapy and exercise treatments, could improve the consistency of fatigue care that people with MS receive in routine practice. ■

think he would change certain behaviors. The occupational therapist brought up his grandchild, who stayed with them once a fortnight and visited often. Having this motivating factor seemed to really help the person with MS focus on making these small changes. He agreed to start showering in the evening before a long day so that it wouldn't be an extra tiring activity" (observation of home visit consultation with OT 17).

Some professionals also mentioned that they used a variety of outcome measures to evaluate fatigue therapy, focusing on function as well as severity. For example, focusing on the person's satisfaction with their ability to do activities allowed people with MS to identify improvements that may have otherwise remained invisible, enabling them to act in ways that might improve their fatigue. HCPs said that shifting the focus to person-centered measures could allow fatigue management to feel more meaningful, and subsequently, more engaging. They also used metaphors to make fatigue self-management strategies feel more meaningful, relevant, and accessible, such as financial references like "budgeting energy" (interview with occupational therapist 9, NHS) to encourage people with MS to spend their energy more wisely.

HCPs used a similar redefinition approach to get people with MS to engage in exercise. While they acknowledged that exercise can be walking on a treadmill, "parking a few roads away from your kid's school and walking" (interview with service manager 1, NHS) could be a more functional and meaningful way to incorporate exercise into everyday life.

Theme 3: MS Fatigue Cannot Be Treated in Isolation

HCPs explained that the multifaceted nature of MS fatigue makes it difficult to treat as an isolated symptom. The close relation of fatigue to other symptoms, including bladder and cognitive dysfunction, spasticity, pain, and adverse medication effects, can worsen fatigue or make it harder to engage with fatigue management strategies.

"The neurologist asked her about sleep, to which she said she gets approximately 5 hours in 'fits and starts' across the night due to her pain or needing the toilet" (observation of in-clinic consultation with neurologist 2).

Sometimes these secondary causes of fatigue could be addressed within fatigue management (eg, poor sleep), but some overlapped with other aspects of symptom management. This overlap could involve referrals for bladder or psychological symptoms, or reviewing medications that cause drowsiness, which may draw on the expertise of others. As a result, HCPs spoke of the need to treat MS fatigue holistically, noting that they often see people with various complex needs that interact and require care coordination.

"[P]eople are broken down into areas, fatigue over there, so refer back to physio for the physical needs. And something that we tried to bridge that gap is [the multidisciplinary team] approach and actually, 'Let's do some joint work; we'll do a joint assessment'" (focus group with OT 6, NHS).

While HCPs were often in favor of a holistic approach as a more effective way of treating MS fatigue, services were not always configured to allow for this. The reality of long waiting lists, large caseloads, and staff shortages made it difficult to promote a truly multidisciplinary team approach; accessing psychological input was particularly difficult.

Subtheme 3.1: Fatigue Management Trickles Through MS HCPs' Practices

While referrals for more intensive fatigue management were usually made to occupational therapy, fatigue management also trickled in from all members of the multidisciplinary team. All professionals spoke of giving fatigue management advice, often "planting some seeds" (interview with nurse 3, NHS) to encourage people with MS to think about changing their lifestyle and finding ways to conserve their energy. Even though it was perceived that OTs must deal with fatigue as one of their main professional priorities—"the OTs do fatigue, cognition, and work" (interview with nurse 5, NHS)—nurses and physiotherapists could also deliver fatigue management, depending on how their practice was staffed, resourced, and configured. Neurologists, while involved in making fatigue referrals and signposting to other care, were far less involved in fatigue care. During neurology consultations, fatigue could be more easily overlooked due to the nature of neurologists' priorities, which were focused on checking for symptoms that might indicate disease relapse or progression.

The nature of professionals' roles and their respective priorities contributed to how much input they had in fatigue management. This was particularly the case for nurses who act as a "screening point" (focus group with nurse 1, NHS) to detect and

intervene for all MS symptoms, meaning that they may naturally have less time to dedicate to fatigue management.

"...[T]he MS nurses know all about this; it's the fact that they don't have time to concentrate on many specifics with each patient if they are catching up with them and they're dealing with what the patient is worried about at the time, which is, let's face it, there's a lot. They're going to be contacting about relapses and drugs..." (focus group with physiotherapist 4, private).

For some services, there were doubts about how successful the trickle-down approach to fatigue management was. For example, an OT noted that some physiotherapists who focus more on the motor side of fatigue "might start a bit of education and they might do a bit of pacing, but they just feel like they're playing at it" until occupational therapy can step in (focus group with OT 10, NHS). As a result, professionals acknowledged that people with MS may receive varying levels of fatigue treatment depending on the professional they see. For example, some community services can only deliver "basic advice" when there is no one to accept fatigue referrals (interview with service manager 1).

DISCUSSION

To our knowledge, this study is the first to explore routine care for MS fatigue using multiple qualitative methods. Our findings show that MS fatigue is not formally screened in standard practice, and individuals with MS are expected to recognize and report their fatigue. Much of fatigue care relies on HCPs encouraging self-management and the adoption of energy conservation principles, though interpretations of some of these interventions varied. Our findings show that MS fatigue is not treated as a standalone symptom, as its management is intertwined with other MS symptoms. Professionals described fatigue management trickling in from all members of the multidisciplinary team, rather than a specific focus always being administered to treat fatigue.

The absence of routine formal screening for MS fatigue contributes to the gap in our understanding of why so few people with MS fatigue receive treatment.¹ Our finding is perhaps unsurprising given that the current National Institute for Health and Care Excellence guidelines recommend that HCPs simply ask about fatigue rather than implement formal screening measures.¹⁵ A recent study examining the electronic health records of an MS center in the US found similar problems with screening, noting that none of the 260 patients had completed a fatigue assessment scale.¹⁶ Although we found that professionals sometimes asked about fatigue, they also reported waiting for people to raise it as a priority, which is concerning given the challenges of identifying MS fatigue,⁷ especially without professional guidance.¹⁷ Implementing formal screening for MS fatigue may enhance treatment provision. There are several validated fatigue scales in MS¹⁸⁻²⁰ that can be completed quickly and could be routinely administered electronically or in waiting rooms before appointments. The Chalder Fatigue Scale¹⁸ has a recognized clinical cutoff and could be used to start conversations. However, further research may be required

to understand how fatigue screening might be best integrated into existing work structures.

We also gained insight into the content of MS fatigue treatments that are currently being used in routine care. A quantitative patient survey suggested that more patients were offered pharmacological rather than behavioral treatment.¹ Despite this, we found that behavioral strategies, notably self-management based on energy conservation principles, were perceived as the first-line treatment by HCPs, with pharmacological treatments seen as supplementary. Research also suggests that CBT-based and some exercise-based treatments are more effective than energy conservation.⁴ Although the professionals interviewed in our study were consistent in citing the benefits of exercise for MS fatigue (even though previous findings suggest that the need for exercise has not always been clear to people with MS⁸), they mentioned CBT techniques much less frequently. Further research is needed to explore this evidence-to-practice gap, although poor access to CBT training has been suggested as a systemic barrier to the delivery of CBT in real-world practice.²¹ Ensuring that CBT training is accessible to professionals who are nonspecialists in psychological therapies, such as OTs and physiotherapists, will be crucial for delivering the most effective behavioral treatments for MS fatigue.

We also identified inconsistencies in how professionals interpreted behavioral and exercise treatments for MS fatigue. Although not an aim of the study, in contrast to previous findings,⁷ we did not observe differences in the tendency of OTs and physiotherapists to favor either energy conservation or exercise therapy in their discussions with people with MS. Differences were apparent regarding whether energy levels are fixed or can increase, particularly when exercise therapy and energy conservation were used in conjunction. While variations in fatigue treatment are important to suit the needs of different people, the basic principles of these treatments should be delivered consistently. The lack of specification in current professional guidelines for managing MS fatigue may perpetuate inconsistent delivery,^{7,25} although the trickle-down approach may also contribute. While this approach allows professionals to collaborate on a multifaceted symptom like MS fatigue, there should be enough standardization in fatigue care to ensure people with MS receive similar opportunities for intervention, regardless of which HCP they consult.

CONCLUSIONS

This study has several clinical implications and directions for future research. Our findings underscore the need for standardized screening to improve the detection of MS fatigue in routine care. Future research should explore alternative screening methods to assess the effectiveness and feasibility of implementing formal screening measures across diverse MS services. Clearer HCP guidance is also needed to ensure consistent delivery of fatigue management advice, while still allowing for individualization. Our findings emphasize the importance of HCP training to support the delivery of evidence-based treatments for MS fatigue, making it accessible and relevant to their roles. In addition, existing education

and training for HCPs should be explored to understand whether improvements could be incorporated early on. Future research should provide clearly documented treatments for MS fatigue and develop clinical training competencies for treatments that show clinically significant effects. There are some existing evidence-based protocols available that have demonstrated small effects in clinical trials.²² Training professionals in these methods could address some of the issues raised in this paper, but this will require the availability of staff to implement them. Digital interventions offer a way to scale interventions with reduced or no support, but there is still some economic cost to widespread implementation. Health care systems need to view behavioral treatments as priorities to make these investments. Our findings also highlight important aspects of fatigue care endorsed by professionals, such as helping people with MS communicate their boundaries and making self-management meaningful, which should be considered in the development of future behavioral fatigue treatments.

The strengths of this study reside in its novelty in using in-depth qualitative methods to provide a broader understanding of routine care for MS fatigue, drawing on the experiences of HCPs and observations of clinical consultations across various parts of the UK. Yet, this study also has limitations. Professionals who volunteer to discuss MS fatigue may have a heightened interest in the topic or work in services where fatigue is prioritized. In addition, participants were aware of the researchers' interest in fatigue, which may have altered their behavior during consultations. Although we aimed to recruit professionals and services from diverse regions and roles, the variability in MS services across the UK may limit the relevance of our findings and prohibit generalizations to all services. Further, we failed to recruit neurologists to our focus groups or interviews due to scheduling conflicts; thus, their perspectives are not represented in this study. This introduces an area for future research.

Overall, our findings enrich our present understanding of routine care for people with MS fatigue and provide context for the development and implementation of future evidence-based behavioral treatments.

Acknowledgments: We would like to thank the participants of this study for their valuable insights, the wider project collaborators for their support, and the funders for making this work possible.

Prior Presentation: A conference abstract of an earlier version of this study was submitted to the 81st Annual Meeting of the American Psychosomatic Society (now the Society for Biopsychosocial Science and Medicine), March 20-23, 2024, Brighton, UK.

Financial Disclosures: The authors declare no relevant conflicts.

Funding/Support: This work was cofunded by a National Institute for Health and Care Research (NIHR) and MS Society Programme for Applied Research grant. The study was delivered through the NIHR Maudsley Biomedical Research Centre. The views expressed are those of the author(s) and not necessarily those of the MS Society, the NIHR, or the Department of Health and Social Care.

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TABLE S1. Main Questions and Follow-Up Prompts From the Topic Guide

Section 1: Understanding fatigue
Broadly, what do you understand about fatigue in multiple sclerosis (MS)?
<i>Additional prompts to use flexibly, if necessary:</i>
<ul style="list-style-type: none"> • How would you describe the fatigue that is experienced by people with MS? • What would you say are the causes of fatigue in MS?
Section 2: Addressing fatigue
What have been your experiences while assessing fatigue in people with MS?
What have been your experiences with treating or managing fatigue in people with MS?
<i>Additional prompts to use flexibly, if necessary:</i>
<ul style="list-style-type: none"> • How much time do you have to talk with patients about fatigue? • What challenges do you face in helping patients manage their fatigue? • Is there anything you think would help you, or your service, to address fatigue? • Who do you consider responsible for fatigue management in your service? • What do you think are helpful treatments or management strategies for fatigue in MS? • Are these treatments being offered to patients? [If not] What are the reasons they are not offered? • Which treatments are well received or less well received by patients? • Do you find that people's support networks impact fatigue management? If so, how?

TABLE S2. Reflexivity Statement From the Primary Coder (Emma O'Connor)

<p>As someone working in academic multiple sclerosis (MS) research, I could not personally relate to the experiences of health care professionals during data analysis. I had some prior contextual understanding that likely contributed to my interpretation of the data, including theoretical knowledge of MS fatigue, the evidence base for fatigue treatments, and interactions with relatives who work as physiotherapists in the National Health Service. We attempted to develop a topic guide with open-ended questions, although these questions may have been influenced by prior academic knowledge. Before focus groups and interviews began, experienced, nonparticipant health care professionals were consulted to give feedback on the topic guide to ground the questions in real professional experiences.</p> <p>As a young White woman from a British background, I was both an insider and an outsider to the health care professionals participating in this study, who were often White and female but spanned a large age range. Before conducting any focus groups or interviews, I underwent extensive training and completed several mock interviews and focus groups to increase my confidence in my role as the facilitator. I initially felt like more of an outsider during focus groups and interviews, but I grew more comfortable with this role as data collection progressed, building rapport and understanding the differences in my role as facilitator of a focus group versus an interview. I conducted all focus groups and interviews, except for 1 interview, which was facilitated by a King's College London psychology undergraduate assigned to the research team. Introducing an additional interviewer may have changed how the questions were asked, or how the participant was probed in that interview, although the secondary interviewer had similar prior knowledge of MS in an academic context.</p> <p>As a researcher whose primary interest is MS-related fatigue, I may have been extra sensitive to information relating to MS fatigue during observations, and my presence may have also made the health care professional more conscious of fatigue, and subsequently altered their behavior from their usual practice. Two additional observers also watched patient-clinician observations. While these observers also had similar prior academic knowledge of MS, we may have been more or less aware of different aspects of the consultations and subsequently highlighted these in our respective field notes. Two additional researchers (T.S., T.F.) with extensive expertise in qualitative methods contributed to the analysis of all data. Working with them meant that their academic backgrounds in sociology and implementation, respectively, introduced 2 different lenses with which to interpret the data. They had less knowledge of MS-related fatigue, although they had previously conducted similar academic work exploring care in other long-term conditions.</p>
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TABLE S3. Additional Supporting Quotations From the Sessions

Theme/ subtheme	From the transcripts	From the field notes
(1) MS fatigue is not formally screened	<p>Focus group with physiotherapist 4, private: “Having those engaged MS nurses and people that are knowledgeable on fatigue, it means that the patient journey is probably a lot smoother because they can get referred into a specialist service relatively early rather than grappling with fatigue for many years before anyone thinks to do something about it. It’s kind of potluck of who you see as a patient and what they know, I suppose, and who they might refer on to.”</p> <p>Interview with service manager 1, NHS: “...and not just physical impairment and cognitive impairment and fatigue, but talking about sexual dysfunction and bladder problems and spasticity and pain and roles and relationships and tissue viability and end-of-life stuff. Can you do all of that? And we can just about probably ask all those things, but then can you do outcome measures for tissue viability and cognition and fatigue and walking and balance? No. So, you’ve kind of got to pick the priority area in those clinics to either focus on 1 thing but knowing that that review may be the only review that they get in a year, maybe 6 months if we’re lucky, so making sure that you’re reviewing everything and checking on everything proactively so that people can manage it, referring to the right place, giving self-management advice at that same time.”</p>	<p>In-clinic consultation with neurologist 1: [Explaining the study preappointment] “The person living with MS said that his partner always says he has ‘borderline narcolepsy’ and that he can ‘go really quickly’ when he gets fatigue. He mentioned that sometimes he could be reading a bedtime story for his kids and then suddenly fall asleep and not realize. He mentioned getting the train home and starting to feel fatigued so he would stand up so as not to ‘miss a stop’.” [After neurology appointment] “MS fatigue was quite a big problem but not raised during the appointment with the neurologist.”</p> <p>Online consultation with nurse 4: MS nurse: “Any background symptoms, pain, muscles spasms, bladder, fatigue?” Person with MS: Fatigue is the top one. “Is that down to the MS? Down to me getting older?”</p>
(2) Promoting self-management for MS fatigue	<p>Focus group with occupational therapist (OT) 3, NHS: “I think it [fatigue] is just put down to the bottom of the pile because it’s seemed that nothing can be done to help you manage it. And often they always come into the clinic thinking ‘I need a pill, I need something.’ Whereas if we said, ‘Here’s a pill: It’s called rest; take it 4 times a day,’ they’d do it, but because it’s not fun, it’s not exciting, it’s exhausting trying to plan and pace your activity and prioritize things.”</p> <p>Focus group with OT 10, NHS: “And I know when we’ve looked at the diaries and things and people themselves, encouraging rather than us again analyzing and telling them what we think, you know, a lot of the homework we’ll give them is like, ‘Do that and then have a look. Have you noticed anything about this? What are your thoughts?’ And actually, they come prepared, and it’s again about setting that expectation. Is that what we want? We’re not going to tell you the answers.”</p> <p>Interview with physiotherapist 2, MS therapy center: “He and I sat down and we talked about his fatigue, and he just said, ‘I know, I know what I’ve got to do. I know what I’ve got to do, I just can’t do it,’” and trying to get him to make that shift from knowing what to do to actually doing it is, that for me is the tricky thing.”</p> <p>Interview with nurse 3, NHS: “I think I was saying some of the challenges that you don’t always feel like you’ve got the tools to help them. So despite the fatigue management, I can send out a booklet, but that’s not going to be a magic wand that waves, that takes away their fatigue anyway, so that’s a challenge in itself, isn’t it? There’s nothing that’s going to totally cure it and, I suppose people need to have realistic expectations that what we’re doing is helping them manage their fatigue, not really taking it away, maybe improving it slightly, maybe making them feel they’re more in control of things.”</p>	<p>Online consultation with nurse 4: MS nurse: “Can you have a good rest in the day/throughout the day? Do something that’s not overstimulating, having a cup of tea to take time out.” Person with MS: Can often go to the van or whatever. MS nurse: “Do you do that to manage or do you push yourself through?” Person with MS: <i>Nods.</i> MS nurse: “Do your colleagues know about your diagnosis?” Person with MS: <i>Nods.</i> MS nurse: “Might be worth explaining to your senior site manager... oh, is that you?” Person with MS: “Yes.” <i>Laughs.</i> MS nurse: “Telling yourself!” <i>Laughs.</i></p> <p>Home visit consultation with OT 17: “The OT asked the person with MS if he ‘were to do the day again, what would you do differently?’ which allowed the person with MS to lead on what they thought could be reasonable adjustments. The person with MS said they could ‘get a taxi instead’ and they discussed spreading out high energy activities so they weren’t all in 1 day. For example, that day he had been to the shop and back, but he was also out in the evening so he was extra tired.”</p>

EDSS, Expanded Disability Status Scale; FACETS, Fatigue: Applying Cognitive Behavioural and Energy Effectiveness Techniques to Lifestyle; HCP, health care professional; MS, multiple sclerosis; NHS, National Health Service.

(continued)

TABLE S3. (continued) Additional Supporting Quotations From the Sessions

<p>(2.1) Conserving, redistributing, or increasing energy</p>	<p>Interview with nurse 3, NHS: “I do say gentle exercise can reward you with energy. I tell them that they need to pace themselves and I think of them as having, like, a bucket of energy and they need to sort of divide it up throughout the day doing things that give them pleasure and not always just things that drain them from energy. So, for example, some people enjoy housework but if it’s something that just drains you, then you’re going to waste a lot of that bucket on energy that’s even more depleting, but if you go out for a gentle walk then it may be that it rewards you with more energy.”</p> <p>Focus group with Pilates instructor 1, MS therapy center: “To give an example, there is a member here who goes downstairs and gives a small group core class. This member is probably around or over an EDSS 6.5, so they don’t walk very well and they only walk with a rollator.... You would think that, to a degree, they’re tired, but actually, when they come in to see me only half an hour later, they actually move better. Now, that being said, I could think of numerous other examples where actually, you know, I had another member the other day who had done too much in their week, not necessarily exercise, but potentially exercise, and then they came in to see me and they just couldn’t do anything. So there is a conflict of knowing what is exercise, again, that’s going into that boom or bust cycle, or what is exercise that is actually helping you inch, what is that envelope that you can push before it becomes problematic, and what is the envelope that you can manage and start progressing in?”</p> <p>Interview with service manager 1, NHS: “I think there’s such a fine balance because often what we might find on an initial interview when we’re talking to someone about fatigue is that their main, neurological fatigue impairment is that they’re so sedentary and that they’re not engaging in any activity, and then I suppose there’s 2 arms, really. The opposite of that is someone who’s really busy and is constantly on the go and doesn’t rest, which then we would be talking about rest breaks. But for those patients who have more of a sedentary lifestyle and are less active, our focus would be on returning to activity and exercise. So we’d be talking about moderate to light resistance exercise to support with fatigue levels.”</p> <p>Interview with OT 9, NHS: “What we talk about is thinking about how we might reframe thoughts and how our automatic thoughts really influence our behaviors and influence our routines and our thought patterns, but we spend a lot of time thinking about how they can be quite deep-rooted into current routines, and then, therefore, how can we challenge them. And we would spend time, maybe using thought diaries to analyze what this might look like, thinking about the emotions that they feel, the evidence that’s for and against.”</p>	<p>Home visit consultation with OT 17: “He had been asked to fill out a fatigue diary between 5 AM and 10 PM every day for a week and HCP went through this to note down what was taking a low, medium, or high amount of energy. She noted, ‘What takes all your energy and what wipes you out?’ She explained about noticing patterns and said the reason was to help him try things differently, plan or organize his time better, prepare for a high-energy task or how to ‘recharge his batteries.’ It was clear going through this what was tiring for him and it seemed to be a really helpful way to demonstrate to him what areas could be adapted to help him with his fatigue. They had obviously discussed previously about his daily activities tiring him out as he mentioned that he had just hired a cleaner to help him keep on top of things.... When talking about adaptations to his routine, the HCP suggested he get dressed later in the day, as he seemed to be more tired if he got dressed very early or suggested he do some activities, such as a puzzle, that would ‘prompt him to rest’ in between other activities.”</p> <p>Online group fatigue management session with OTs 14 & 15: “Negative thinking styles can be really easy to fall into, can’t manage what you used to manage before, can creep in.... Rest a bit before you’re getting frustrated, trying to learn your body, learn when you’re getting fatigue, before getting to that point of frustration that you can’t do something.... Reminder of their fatigue management toolbox—delegation, pacing, prioritization, grading, organization, sleep hygiene, energy conservation, relaxation, exercise, and diet.”</p>
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EDSS, Expanded Disability Status Scale; FACETS, Fatigue: Applying Cognitive Behavioural and Energy Effectiveness Techniques to Lifestyle; HCP, health care professional; MS, multiple sclerosis; NHS, National Health Service.

(continued)

TABLE S3. (continued) Additional Supporting Quotations From the Sessions

(2.2) Helping people with MS communicate about fatigue	<p>Focus group with physiotherapist 1, MS therapy center: “It’s giving people a language or some way of communicating how fatigue is relevant for them or how it impacts them. Sometimes it’s an analogy. One of the favorites that people tell me about is the phone charger, you know, if you plug it in before it runs out of battery completely, it’s quicker to charge. People generally really like that analogy and tend to use it quite a lot with friends and family.... I think it opens up conversations for people with their support networks about what people can do to help, whether that’s encouraging the rest breaks, or for other people, it might be about encouraging the activity.”</p>	<p>Online group fatigue management session with OTs 14 and 15: “‘You can’t sometimes see what’s going on on the inside with fatigue, not like a cast on your leg.’ Occupational therapists talked about people living with MS understanding more about their own fatigue so they can hopefully be more confident to talk about it.”</p>
	<p>Focus group with occupational therapist 4, NHS: “We always say to individuals, ‘Be aware of what triggers you,’ but actually, you might be displaying some symptoms prior to your sheer exhaustion, where you can identify where your battery is running down, and somebody outside can actually identify that to you. For instance, we had an individual patient who, when she was sheerly exhausted, had really bad headaches and migraines, her eyes became much worse, but she wasn’t aware, probably a while before that occurred, she actually started to adjust her glasses, so almost her brain was telling her, ‘You can’t see properly’ so she started to adjust her glasses, but actually her husband noticed that and actually said, ‘That is a preexisting symptom. If I tell her that, look, you know, you’re starting to adjust your glasses now, just take a break.’ So, actually allowing them to give permission to their carers to actually enable them to pace and prioritize as well.”</p>	<p>In-clinic consultation with neurologist 2: “The neurologist asked the person with MS about who supports her. It seems her partner lives 25 miles away and her 4 children are adults and don’t live at home. The person with MS mentioned that she had spoken to her children about supporting her more but they didn’t seem keen so she didn’t push it.”</p>
	<p>Focus group with OT 10, NHS: “A relative saying, ‘You’re just not doing enough; you’re lazy,’ it just feeds into that negative experience for that person, and they’re less likely to take on strategies because they’re just perceived to be lazy.”</p>	<p>Online consultation with nurse 4: MS nurse: “Is there anyone else that can walk the dog?” Person with MS: Partner walks dog in the morning and evening, “unless I feel up to it.” MS nurse: “Great, so you don’t feel the pressure, you’ve got that backup there.”</p>

EDSS, Expanded Disability Status Scale; FACETS, Fatigue: Applying Cognitive Behavioural and Energy Effectiveness Techniques to Lifestyle; HCP, health care professional; MS, multiple sclerosis; NHS, National Health Service.

(continued)

TABLE S3. (continued) Additional Supporting Quotations From the Sessions

<p>(2.3) Making self-management meaningful</p>	<p>Focus group with physiotherapist 4, private: “When you get to know people better, you can often delve a bit deeper into, well, ‘You’ve got grandchildren, what do you like doing with them? Do you like to play with them?’ I suppose reframing it, so maybe not talking about it in a fatigue management way, but in a ‘What are we trying to achieve?’ What do we need to be able to get there? I suppose fatigue management as a concept to your average Joe doesn’t mean much, maybe.”</p> <p>Focus group with physiotherapist 2, MS therapy center: “No, I definitely agree with that, with the goal setting, because it’s like you say, we can improve the fatigue levels, but what does that actually mean? It means that you’ve got a different number on a bit of paper. It needs to actually relate to everyday life. ‘I want to improve this because it means I can take the kids to school 3 days out 5’ or whatever or I can do and actually then you’ve got something objective to measure.”</p> <p>Interview with service manager 1, NHS: “I think people are quite reluctant with exercise when they’re that tired, and it’s quite a hard sell. I guess as a physio, I’m quite used to having a hard sell on people doing exercises and activity, but I guess in the physio world, there was a big push a couple of years ago that actually telling people to do exercises isn’t particularly useful and, actually, if you frame it as activity and that different things can be done as exercise, things like maybe parking a few roads away from your kid’s school and walking to and from and those kinds of things and the housework and the gardening and it’s those things that aren’t, you know, running on a treadmill or doing weights or whatever in the gym. So it’s for people who aren’t naturally people who like exercising, framing it differently, but it is a hard sell with fatigue because when you’re that tired, they say ‘Oh, I haven’t got, I haven’t got the energy for anything else let alone exercise,’ but we talk about the research a little bit and we talk about, actually, ‘I know it sounds strange, but just trust us with this, give it a go and see how it goes and some do and some don’t, but some do.’”</p> <p>Focus group with occupational therapist 10, NHS: “It’s the Canadian Occupational Performance Measure.... So, for example, a lady who has MS was saying that she really wanted to be able to play with her grandchildren more, and that was something that was really important to her and she said that her level of satisfaction at the moment is only a 2, it was really bad, she wanted it to be much better, so we did a piece of work with her on fatigue and giving her ideas and grading her activities, etc, and then you repeat it at the end and she rescored and anything above an increase in 2 is deemed clinically significant.”</p>	<p>Home visit consultation with OT 17: “He said he would ‘walk a bit, rest a bit’ and that the rollator helped him with pacing, so he could just sit whenever and ‘watch the traffic,’ but it was also very tiring. The HCP asked if he ‘were to do the day again, what would you do differently?’ which allowed the [person with MS] to lead on what they thought could be reasonable adjustments. The [person with MS] said they could ‘get a taxi instead’ and they discussed spreading out high energy activities so they weren’t all in 1 day. For example, that day he had been to the shop and back, he was also out in the evening so was extra tired.”</p>
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(continued)

TABLE S3. (continued) Additional Supporting Quotations From the Sessions

<p>(3) MS fatigue cannot be treated in isolation</p>	<p>Focus group with OT 5, NHS: “For quite a while, I’ve felt like a counselor. So, someone would be referred for fatigue, but actually, there’s a lot more going on than just the fatigue. It impacts on their relationships; there’s the whole adjustment process, a grieving process. So, yeah, a lot of what I was doing, particularly on a one-to-one is, was around counseling, and other members of the team as well, before we even got to the strategies, the pacing, the planning, and all, and all that kind of thing. It’s massive. Like you said, specialist input is rare, isn’t it? Even though it’s such a big part of...of living with MS.”</p>	<p>In-clinic consultation with OT 16 (patient 1): “When discussing secondary fatigue, the OT said ‘medication might cause tiredness’ or infections. The therapist asked the person with MS about her sleep, ‘not very good’ but ‘a bit better recently.’ ‘Listens to the radio’ and has ‘bad sleep hygiene.’ She wakes up a couple of times a night to go to the loo, and the therapist picked up on this, ‘sleep is a really big one’ and asked if the neurologist had referred the person with MS about her bladder urgency and suggested this. The person with MS said that she ‘feels like I need to go now, which I don’t’ and this was discussed a little more.”</p> <p>In-clinic consultation with OT 16 (patient 2): “When discussing medication, the person with MS gave a long list of medications, which caused the OT clear concern. These medications can cause drowsiness, and the therapist spoke about these side effects and suggested that the person with MS spoke with their MS nurse or neurologist about whether all the medications were needed. They discussed what times of the day these medicines were being taken, and they discussed a medication review.”</p>
<p>(3.1) MS health care professionals trickle-down fatigue management</p>	<p>Focus group with OT 1, NHS: “I think it’s a little bit different in occupational therapy than it is probably with the nursing and elsewhere, so if that’s the goal that they [person with MS] want to work with, I can spend as much or as little time. If they’re willing, obviously, I give more time, isn’t it? I will make sure that I rebook them more often. There are limitations because the caseload is big and you have to be mindful of it, but you make it work.”</p> <p>Interview with physiotherapist 2, MS therapy center: “I mean, I say if they have identified that [fatigue] in that as one of their key problems, then, you know, after my initial assessment, we would always have a discussion about, right, this is what.... These are your priorities, this is what we can help you with, where shall we start? So, it’s always a discussion.”</p> <p>Interview with service manager 1, NHS: “And everyone’s area is a priority area, and fatigue is a huge area, don’t get me wrong, but the physios will think that balance and spasticity are, and, obviously, mental health services think that we ought to be doing that on everybody, and you can see the importance of everything. But how much can you actually do?”</p> <p>Interview with service manager 1, NHS: “I think it’s all very different. So, some nurses will offer basic advice or more thorough advice. In some areas, the nurses have been doing the FACETS courses themselves, so you know, this is just from my knowledge from networking and may not be wholly accurate, but to get a general feeling.... Some people I know, they’ll maybe ask about it [fatigue], but haven’t got that much knowledge on it and so it will be basic advice only and referral on if there’s someone to refer to, but we know that in community services, in terms of fatigue and OT advice or other professionals who do it, there aren’t any. So it’s basic advice only. It varies quite a lot, I think.”</p>	<p>In-clinic consultation with physiotherapist 8: “They talked about the effort required to push yourself in a wheelchair and how it was much better with the motorized version. The physiotherapist asked about how adjustable the wheelchair was and whether the arms could be moved out of the way to get in and out of the chair.”</p> <p>Video consultation with nurse 4: MS nurse: “Yes, do something you’re looking forward to,” following a routine. MS nurse followed up with: “Are you finding that you’re getting tired by the end of the day?” Person with MS: “Still struggling to sleep if getting up...” MS nurse: “Are you on antidepressants at the moment with your mood being low?” Person with MS: “Yes, been on citalopram for quite a long time.” Takes duloxetine as well, not as an antidepressant but for pain. MS nurse: “Citalopram can sometimes help with fatigue. Do you find benefit with that drug?”</p> <p>In-clinic consultation with neurologist 2: “The person with MS mentioned fatigue multiple times, but this was not picked up on by the neurologist.”</p> <p>In-clinic consultation with neurologist 3: “The neurologist discusses topics including family, work, the patient’s culture, and background. He also asks about their interests or profession, which he uses to spur conversation, relax the patient, assess patient lifestyle choices regarding their conditions, and often to make analogies from, to explain medical terms in their area of expertise. He is interested in the patient’s career, life events, or general lifestyle, while accessing medical information on the computer, often leaving pause for silence where a patient may interject, but mainly, the conversation flows, and things are addressed as they come up. His initial topics regarding function are bowel, bladder, mobility, spasticity, speech and swallowing. Neurologist: ‘How’s life, apart from the bloody MS?’”</p>

EDSS, Expanded Disability Status Scale; FACETS, Fatigue: Applying Cognitive Behavioural and Energy Effectiveness Techniques to Lifestyle; HCP, health care professional; MS, multiple sclerosis; NHS, National Health Service.