The Canadian Journal of Neurological Sciences (2026), 1–10
doi:10.1017/cjn.2026.10531

Canadian Journal of Neurological Sciences
Journal Canadien des Sciences Neurologiques

Original Article

Perceived Cognitive Fatigability in Multiple Sclerosis: Input from People with Lived Experience on Unmet Needs

Tamanna Islam[1,2], Jason A. Berard[1,2,3] and Lisa A.S. Walker[1,2,3]

[1]School of Psychology, Faculty of Social Sciences, University of Ottawa, Ottawa, ON, Canada, [2]Neuroscience, The Ottawa Hospital Research Institute, Ottawa, ON, Canada and [3]University of Ottawa Brain and Mind Research Institute, Ottawa, ON, Canada

ABSTRACT: ***Purpose:*** Cognitive fatigability (CF), which refers to a decline in performance during sustained cognitive effort, can significantly impact people with multiple sclerosis (PwMS). This study examined the unmet needs related to perceived CF in PwMS. ***Methods:*** One hundred PwMS completed a survey assessing factors known to contribute to CF. Participants indicated whether each factor, including CF itself, was disruptive and whether adequate support was available to address these concerns. A factor identified as disruptive and insufficiently addressed was considered an unmet need (Need Index [NI] ≥50%). ***Results:*** Group-level analysis revealed no significant unmet needs, although fatigue (NI = 30.23), CF (NI = 22.96) and physical activity (NI = 19.55) were more frequently reported. Individual-level analyses revealed that unmet needs varied by community setting (rural vs urban) and socioeconomic status (SES) (lower vs higher SES), with rural participants and those with lower SES reporting higher rates of unmet needs. In addition, PwMS who indicated CF was an unmet need reported more difficulties across most contributory factors, including *sleep quality*, *fatigue*, *cognitive impairment*, *depression* and *contextual factors*. The presence of fatigue and CF combined contributed to greater unmet needs across various domains, especially *fatigue*, *CF* and *cognitive impairment*, compared to fatigue alone. ***Conclusions:*** Participants from rural and low socioeconomic backgrounds were more likely to have unmet needs. Notably, 36% of participants ($N = 33$) reported unmet needs related to perceived CF. The findings highlight the importance of tailoring future interventions to address identified needs more adequately.

RÉSUMÉ : La fatigue cognitive perçue dans le cas de la sclérose en plaques : des témoignages de personnes ayant vécu l'expérience de besoins non satisfaits ***Objectif :*** La fatigue cognitive (FC), qui désigne une baisse des performances lors d'un effort cognitif soutenu, peut avoir un impact significatif sur les personnes atteintes de sclérose en plaques (PASP). Cette étude a donc cherché à examiner les besoins non satisfaits liés à la FC perçue chez les PASP. ***Méthodes :*** Une centaine de PASP ont répondu à une enquête évaluant les facteurs connus pour contribuer à la FC. Les participants ont ainsi indiqué si chaque facteur, y compris la FC elle-même, était perturbateur et si un soutien adéquat était disponible pour répondre à ces préoccupations. Un facteur identifié comme perturbateur et insuffisamment pris en compte a été considéré comme un besoin non satisfait (indice de besoin [IB] ≥ 50%). ***Résultats :*** Une analyse de groupe n'a révélé aucun besoin non satisfait notable, et ce, bien que la fatigue (IB = 30,23), la FC (IB = 22,96) et l'activité physique (IB = 19,55) aient été plus fréquemment signalées. Des analyses individuelles ont révélé que les besoins non satisfaits variaient selon le milieu (rural ou urbain) et le statut socio-économique (SSE) (faible ou élevé), les participants issus d'un milieu rural et ceux ayant un SSE faible signalant des taux plus élevés de besoins non satisfaits. En outre, les PASP qui ont indiqué que la FC était un besoin non satisfait ont signalé davantage de difficultés en lien avec la plupart des autres facteurs contributifs, notamment la qualité du sommeil, la fatigue, les troubles cognitifs, la dépression et les facteurs contextuels. La présence combinée de la fatigue et de la FC a du coup contribué à accroître les besoins non satisfaits dans divers domaines, en particulier la fatigue, la FC et les troubles cognitifs, par rapport à la seule fatigue. ***Conclusion :*** Les participants issus de milieux ruraux et défavorisés sur le plan socio-économique étaient plus susceptibles d'avoir des besoins non satisfaits. Il est à noter que 36 % des participants (n = 33) ont signalé des besoins non satisfaits liés à la FC perçue. Ces résultats soulignent donc l'importance d'adapter les interventions futures afin de répondre de manière plus adéquate aux besoins identifiés.

Keywords: Cognitive fatigability; fatigue; multiple sclerosis; needs assessment; survey

(Received 13 November 2025; final revisions submitted 16 December 2025; date of acceptance 5 January 2026)

Corresponding author: Tamanna Islam; Email: tisla028@uottawa.ca

Cite this article: Islam T, Berard JA, and Walker LAS. (2026) Perceived Cognitive Fatigability in Multiple Sclerosis: Input from People with Lived Experience on Unmet Needs. *The Canadian Journal of Neurological Sciences*, https://doi.org/10.1017/cjn.2026.10531

© The Author(s), 2026. Published by Cambridge University Press on behalf of Canadian Neurological Sciences Federation.

Highlights

- Rural people with multiple sclerosis (PwMS) and those with lower socioeconomic status (SES) reported more unmet needs than urban or higher SES PwMS.
- Cognitive fatigability (CF) combined with fatigue contributed to greater unmet needs across various domains.
- PwMS identifying CF as an unmet need reported more difficulties across contributing factors.

Introduction

Multiple sclerosis (MS)-related fatigue is a persistent feeling of a lack of physical and/or mental energy.[1] Cognitive fatigability (CF) is a related but distinct concept that pertains specifically to task performance.[2] CF is reflected by declines or increased variability in performance during sustained cognitive tasks. CF can be assessed both objectively through cognitive testing[3] and, as in the current study, subjectively through patient-reported outcomes.[4] In MS, fatigue and fatigability can occur independently or together, both of which impact therapeutic outcomes.[5] Distinguishing between them remains a challenge as perceived fatigue is often, but not always, associated with CF.[6] MS-related fatigue is linked to depression,[7] sleep disorders[8] and physical inactivity,[9] and objective CF is similarly predicted by depression, anxiety and sleep disturbances.[10] Perceived CF may be predicted by levels of physical activity and self-reported cognitive function.[11] These shared predictors suggest that fatigue and CF may arise from common underlying factors. Thus, addressing CF requires a comprehensive approach that considers the interrelatedness of these factors.

A needs assessment (NA) can be used to determine whether the needs of people with MS (PwMS) who experience CF are being met by evaluating unmet healthcare needs, including health education, treatment and rehabilitation, as well as broader social and environmental factors. It incorporates patient feedback and professional expertise to prioritize care needs before interventions are implemented.[12] Past NAs have identified the top needs of PwMS and their significant others,[13] assessed support arrangements, provided information about service usage and compared perspectives between PwMS and their care partners.[14] Despite the presence[15] and detrimental impact[16] of CF in MS, no NA has been conducted to evaluate the disruptiveness of CF or its contributory factors. In addition, no NA has evaluated how PwMS feel that current healthcare and community support systems address these concerns. An NA should also consider how these needs may vary on the basis of social determinants of health (SDOH) such as socioeconomic status (SES)[17] and community type.[18]

We aimed to (1) obtain information directly from the PwMS about factors known to contribute to CF, (2) identify which factors that the PwMS felt were disruptive and insufficiently addressed at present (i.e., their needs), (3) consider the influence of the SDOH on these needs, (4) investigate whether PwMS who identify CF as an unmet need report greater difficulties related to CF contributing factors than those who do not, (5) assess whether unmet needs vary based on the type of fatigue experienced and (6) inform future interventions designed to target CF.

Methods

Participants

A total of 100 PwMS from the Ottawa Hospital MS Clinic were enrolled. Sample size was determined based on previous NAs involving PwMS,[19,20] considering both the effect sizes observed in earlier studies and practical constraints on recruitment. The eligibility criteria included a confirmed diagnosis of MS, age of at least 18 years and English fluency.

Procedure

This study was approved by the Ottawa Health Science Network (20230572-01H) and the University of Ottawa, Research Ethics Boards (H-11-23-9890). Participants who consented to the research study were identified via electronic health records and were invited to complete an online NA survey following informed consent. Demographic and clinical characteristics were collected, and individuals completed self-report questionnaires as outlined below. The survey included items examining CF itself, as well as other factors known to contribute to CF: *fatigue*, *cognitive impairment*, *mood symptoms*, *physical activities*, *sleep disturbances* and *contextual factors*. The choice of these items was informed by our team's clinical expertise and existing literature,[10,11,21,22] and these items were then used to calculate the Need Index (NI) for each factor.

Survey details

Demographic characteristics

Sociodemographic information included age, sex, gender identity, marital status, ethnicity, education level, employment status, annual household income, living situation and community type as defined by Statistics Canada.

Clinical characteristics

The respondents indicated their MS diagnosis date, disability level using the Patient Determined Disease Steps (PDDS), the date of their most recent MS relapse, any previous cognitive assessments, comorbid health conditions, substance use and types of fatigue experienced.

Patient Determined Disease Steps (PDDS)

A valid patient-reported outcome of MS disability whereby individuals indicate their level of mobility impairment and symptom burden[23,24] on a scale of 0 (normal) to 8 (bedridden).

Modified Fatigue Impact Scale (MFIS)

A 21-item multidimensional questionnaire adapted from the Fatigue Impact Scale.[25] The MS Council for Clinical Practice Guidelines recommended the use of the MFIS to assess MS-related fatigue.[26] A 5-point Likert scale assesses the perceived impact of fatigue on daily activities over the past four weeks, compiled into three subscales: physical, cognitive and psychosocial fatigue. Scores range from 0 to 84, with 38 commonly used as the cut-off to discriminate between fatigued and non-fatigued individuals.[27]

Pittsburgh Fatigability Scale (PFS)

Ten items designed to evaluate performance fatigability[28] and validated in PwMS.[29] The PFS contains two subscales: physical fatigability (PF) and mental fatigability (equivalent to CF). Respondents rate the level of both PF and CF they imagine they would feel after completing activities of varying intensity and duration using a 5-point Likert scale. Scores for both subscales range from 0 to 50. PF was excluded from the current analysis, as prior research links perceived fatigue with CF but not with PF.[30] A PFS-mental score of ≥13 indicates greater CF in older adults.[31,32]

https://doi.org/10.1017/cjn.2026.10531 Published online by Cambridge University Press

Perceived Deficits Questionnaire – 5-Item Version (PDQ-5)

The PDQ is part of the MS Quality of Life inventory[33] and was designed exclusively for PwMS to measure self-reported cognitive impairment.[34] It consists of five questions about perceived cognitive deficits over the past month. Each item is scored on a 4-point Likert scale. A total score can vary from 0 to 20, with higher scores indicating a greater perceived deficit. Due to the absence of an established cut-off score for the PDQ-5, we applied a threshold of ≥10, which may be indicative of the presence of cognitive impairment.

Hospital Anxiety and Depression Scale (HADS)

Developed to assess depression and anxiety in adults receiving general medical care in an outpatient clinic[35] and validated in PwMS.[36] It includes 14 items measured via a Likert scale, with 7 each for anxiety and depression. The cumulative scores range from 0 to 21. A score of 0–7 on either subscale suggests a lack of anxiety or depression, a score of 8–10 suggests borderline anxiety or depression and a score of 11–21 suggests clinical anxiety or depression.[35]

Pittsburgh Sleep Quality Index (PSQI)

Evaluates sleep disruptions and sleep quality over the previous month[37] and has been validated in PwMS.[38] It includes 19 items rated on a 0–3 scale, forming seven component scores. Total scores range from 0 to 21, with higher scores suggesting poorer sleep quality. A total score of >5 indicates poor sleep.[39]

Godin Leisure-Time Exercise Questionnaire (GLTEQ)

Developed to assess leisure-time physical activity in healthy adults[40] and is a reliable physical activity measure in ambulatory PwMS.[41] It examines weekly frequencies of strenuous, moderate and mild activities. Scores of ≥24 suggest an active lifestyle, scores of 14–23 suggest moderate activity and scores of <14 indicate insufficient activity.[42]

Contextual Burden Scale

Context refers to external elements, such as our social obligations (e.g., caregiving), our physical surroundings (e.g., noise and light) and our activity demands (i.e., workload). Ten items were used to assess the impact of context on fatigue, via a 5-point Likert scale, with scores from 0 to 40. Scores of ≥21 indicate the presence of contextual factors impacting functioning. This scale was developed by our team for the purpose of this study and has not been previously validated.

Assessment of unmet needs

The scale consisted of 21 items, with three each representing the seven factors identified as contributing to unmet needs: fatigue, CF, cognitive impairment, mood symptoms, physical activities, sleep disturbances and contextual factors. Respondents rated how disruptive these factors were to their everyday lives on a 5-point Likert scale and then rated the same items to indicate how well these issues were addressed by existing community support and healthcare systems. An NI was calculated following the Concerns Report Method to measure the extent to which a need was met.[43] Ratings for disruptiveness and how well they were addressed were converted into percentages using the following formula[44]:

$$\frac{4n(4)+3n(3)+2n(2)+1n(1)+0n(0)}{N(4)}\times 100 = \%Disruptiveness\ OR\%\ Well\text{-}Addressed$$

where $4n$ = the number of participants who rated the item as 4, $3n$ = the number of participants who rated the item as 3, and so on, and N = the total number of responses to the survey that were completed.[43] This formula produced % disruptiveness and % well-addressed scores, with 100% being the maximum and 0% being the minimum. The NI for each item was then calculated by subtracting the percentage of how well an issue was addressed from its perceived disruptiveness (i.e., NI = % Disruptiveness – % Well-Addressed). An NI of ≥ 50% indicates an unmet need[19].

Data analysis

The survey data were imported into IBM SPSS (version 29). Sociodemographic and clinical characteristics were summarized with frequency and descriptive statistics. Chi-square analyses assessed relationships between community settings and unmet needs, as well as between SES and unmet needs. Fisher's exact test was used when expected frequencies were <5. Chi-square analyses assessed whether having CF as an unmet need was associated with difficulties (i.e., met cut-offs) in self-reported sleep, fatigue, cognitive impairment, mood, physical activity and contextual factors. One-way multivariate analysis of variance (MANOVA) compared the impact of different MS-related fatigue profiles (i.e., fatigue only and both fatigue and CF) on various NIs.

Results

Participant characteristics

The recruitment flowchart is illustrated in Figure S1. Table 1 provides a summary of the participants' sociodemographic and clinical characteristics. The sample indicated significant levels of fatigue, with a mean MFIS score of 41.44 (SD = 17.75), and perceived CF, with a mean PFS-mental score of 16.76 (SD = 12.95).

Group-based Need Index findings

Table 2 presents group-based NIs across the seven factors. None of the factors met the threshold (NI ≥ 50) to be considered unmet needs. At the group level, the top three areas of concern were fatigue, CF and physical activity. Conversely, mood was identified as the only fulfilled need.

Individual-based Need Index findings

Group-level results may not accurately reflect the opinions of all individuals. As such, a finer-grained analysis was performed to look at individual NIs using this formula:

$$\left(\frac{\text{Rating on each item by each participant}}{4}\right)\times 100 = \%\ Disruptiveness\ OR\%\ Well\text{-}Addressed.$$

Individual-level findings revealed a broader array of needs, showing that a substantial number of participants identified unmet needs within each domain, with more than a third of the sample identifying *fatigue* and *CF* as unmet needs (Figure 1).

https://doi.org/10.1017/cjn.2026.10531 Published online by Cambridge University Press

Table 1. Characteristics of the participants

Variable	Mean (SD) or *N* (valid %)
Sociodemographic characteristics	
Age indicated	48.56 (12.60)
Sex assigned at birth	
Female	73/100 (73%)
Male	27/100 (27%)
Gender identity	
Woman	72/100 (72%)
Man	27/100 (27%)
Non-binary	1/100 (1%)
Ethnicity	
Indigenous Canadian	1/100 (1%)
Caucasian–North American origins	45/100 (45.5%)
Caucasian–European origins	44/100 (44.4%)
Latin, Central and South American origins	2/100 (2%)
African origins	2/100 (2%)
Other	5/100 (5.1%)
Marital status	
Single/never married	13/100 (13.4%)
Married/common law partner	71/100 (73.2%)
Divorced/separated	12/100 (12.4%)
Widowed	1/100 (1%)
Current employment status	
Full-time	52/100 (52.5%)
Part-time	7/100 (7.1%)
Student	1/100 (1%)
Unemployed	2/100 (2%)
Retired	15/100 (15.2%)
Unable to work due to illness or disability	22/100 (22.2%)
Socioeconomic status based on annual household income	
Lower (<$15,000–$50,000)	17/100 (19.8%)
Middle and Higher ($50,001–>$200,000)	69/100 (80.2%)
Highest level of education attained	
University–PhD or equivalent	3/100 (3%)
University–master's degree	14/100 (14.1%)
University–bachelor's degree	30/100 (30.3%)
College or other non-university diploma	37/100 (37.4%)
Completed secondary school/high school diploma	14/100 (14.1%)
Partial secondary school/high school or less	1/100 (1%)
Use of assistive equipment for mobility	
None	56/100 (56%)
Cane/crutch	20/100 (20%)
Walker	9/100 (9%)
Wheelchair	7/100 (7%)
Walker and wheelchair	8/100 (8%)
Current living situation	
Alone	15/100 (15.2%)
With roommate	2/100 (2%)
With partner	52/100 (52.5%)
With family members	30/100 (30.3%)
Community setting	
Urban and suburban	77/100 (77%)
Rural	23/100 (23%)
Type of fatigue experienced	
No fatigue	8/100 (8%)
Physical	18/100 (18%)
Cognitive	2/100 (2%)
Both physical and cognitive	67/100 (67%)
Experience fatigue, but not sure which type	5/100 (5%)
Outside personal experience, received information about MS-related fatigue from another source	
No	63/100 (63%)
Yes	37/100 (37%)
External sources from which information about MS-related fatigue was obtained	
Internet or social media	28/100 (28%)
MS neurologist	24/100 (24%)
Other people with MS	24/100 (24%)
Family [hysician/general physician	10/100 (11%)
MS clinic nurse	11/100 (11%)
Word of mouth	3/100 (3%)
Other	7/100 (7%)
Completed survey without technical assistance	
No	4/100 (4%)
Yes	95/100 (96%)
Clinical characteristics	
Disease duration (years)	13.61 (10.75)
Types of MS	
RRMS	65/100 (65%)
PPMS	12/100 (12%)
SPMS	13/100 (13%)
Other/unknown	10/100 (10%)
PDDS indicated as median (range)	3 (0–8)

Note: RRMS = relapsing-remitting MS; PPMS = primary progressive MS; SPMS = secondary progressive MS; PDDS = Patient Determined Disease Steps.

Impact of social determinants of health on needs

Figure 2 displays the percentages of rural and urban respondents identifying unmet needs. Significant differences in unmet needs were found between community settings for *fatigue*, *CF*, *cognitive impairment*, *physical activity* and *sleep* (Table S1). Odds ratios indicated rural PwMS were more likely to report *fatigue* (2.86

https://doi.org/10.1017/cjn.2026.10531 Published online by Cambridge University Press

Table 2. Need indices for corresponding factors and survey items

Factors	Items	Disruptiveness (%)	Well-addressed (%)	Need Index (%)	Mean Need Index for factors (%)	Rank
Fatigue	I feel more tired than my peers.	71.88	35.99	35.89	**30.23**	1
	I become tired more quickly than I did previously when performing physically demanding activities.	71.25	38.02	33.23		
	I need to take breaks more frequently and for longer periods of time than I did before.	63.75	42.19	21.56		
Cognitive fatigability	It takes me longer to complete tasks when I am tired.	71.25	39.18	32.07	**22.96**	2
	At the end of the day, I am mentally exhausted and have no energy to engage in tasks requiring thinking.	60.61	37.37	23.24		
	I make more mental errors at the end of the day.	46.21	32.63	13.58		
Physical activity	It is harder for me to engage in physically demanding tasks than it was before.	70	41.15	28.85	**19.55**	3
	My movements are slower than they used to be.	56.63	40.96	15.67		
	It is difficult for me to exercise.	57.5	43.37	14.13		
Sleep disruption	Even when I get a full night's sleep, I do not feel well-rested when I wake up.	63.52	33.06	30.46	13.44	4
	I wake up several times throughout the night.	54.89	41.95	12.94		
	I have difficulty falling asleep at night.	34.54	38.59	−4.05		
Cognitive impairment	I have a difficult time remembering things.	45.15	35.11	10.04	5.6	5
	I find it hard to multitask or do more than one thing at a time.	42.5	36.7	5.8		
	I have a hard time doing things that require me to concentrate.	37.63	36.68	0.95		
Contextual factors	I get easily overwhelmed by noise, light and busy environments.	45.88	35.05	10.83	4.03	6
	I find it hard to say no to others when asked to do things.	48.5	41.15	7.35		
	My family does not understand my struggles.	42.35	48.42	−6.07		
Mood symptoms	I am no longer interested in activities that I used to enjoy.	41.07	36.29	4.78	−2.55	7
	I am frequently anxious or find myself distracted by worrying thoughts.	39.03	41.22	−2.19		
	I am sad much of the time.	33	43.23	−10.23		

Note: The bolded values in the "mean Need Index for factors" column represent factors that were reported more frequently; however, these factors did not meet the ≥50 threshold required to be classified as unmet needs.

times), *CF* (3.75 times), *cognitive impairment* (4.56 times), *physical activity* (5 times) and *sleep* (3.10 times) as unmet needs compared to urban PwMS.

Figure 3 shows the percentages of respondents from lower and higher SES identifying unmet needs. Significant differences were found between SES groups in unmet needs for *mood symptoms* and *contextual factors* (Table S2). PwMS with lower SES were more likely to report unmet needs for *mood symptoms* (5.6 times) and *contextual factors* (5.5 times) than those with higher SES.

Group differences between those who do and those who do not identify CF as an unmet need

Significant differences were found for *sleep quality*, *fatigue*, *cognitive impairment*, *CF*, *depression* and *contextual factors* between those who identified CF as an unmet need versus those who did not (Table S3). Odds ratios indicated that those with *poor sleep* (6.25 times), *fatigue* (6.25 times), *cognitive impairment* (5.87 times), *moderate to severe depression* (6.07 times) and *issues with contextual factors* (12.91 times) were more likely to report CF as an unmet need.

Group differences in NIs between fatigue profiles

Most respondents (42%) ($N = 42$) met cut-offs for fatigue and CF on both MFIS and PFS Mental Subscales, respectively, while 23% ($N = 23$) met the MFIS cut-off for fatigue alone, and 4% ($N = 4$) met the PFS Mental Subscale cut-off for CF alone. Although 46.5% ($N = 46$) of participants experienced CF, the CF-only group was considerably smaller, as most with CF also reported fatigue. Given the small size of the CF-only group, comparisons of NI scores were limited to the fatigue-only group and the group with both fatigue and CF.

A MANOVA using Pilla's trace revealed no significant overall difference in NIs between groups, $V = 0.20$, $F\ (7,\ 47) = 1.56$, $p = 0.16$ (>.05). However, separate univariate ANOVAs (Table S4) revealed significant group differences in NIs for *fatigue* ($F\ (1,\ 53) = 5.19$; $p = .027$ (<.05); partial $\eta^2 = .089$), *CF*, ($F\ (1,\ 53) = 4.48$; $p = .039$ (<.05); partial $\eta^2 = .078$) and *cognitive impairment* ($F\ (1, 53) = 5.41$; $p = .024$ (<.05); partial $\eta^2 = 0.93$). No significant group differences were found for *mood, physical activity, sleep* and *contextual factors.* Those with both fatigue and CF had higher NIs than those with fatigue alone (Table S5).

https://doi.org/10.1017/cjn.2026.10531 Published online by Cambridge University Press

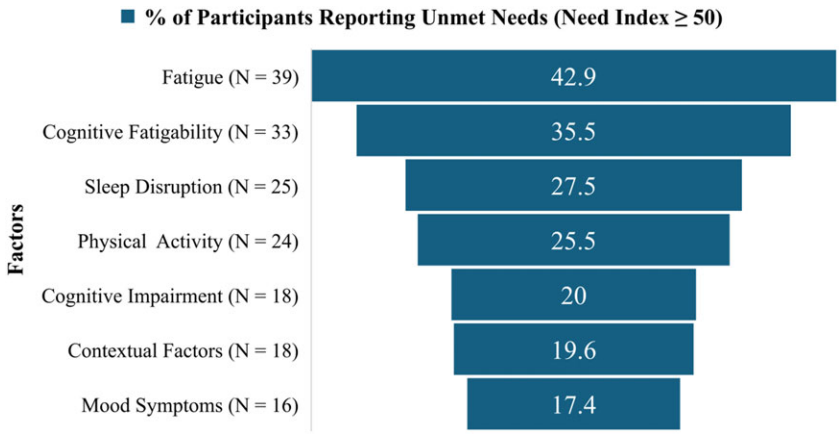


Figure 1. Percentage of individuals with unmet needs in each factor.

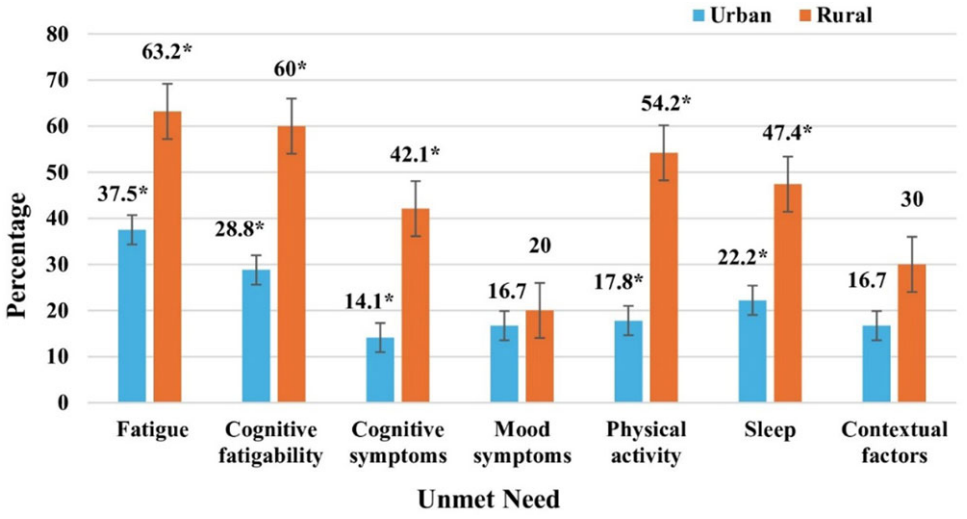


Figure 2. Percentage of rural and urban respondents identifying unmet need.

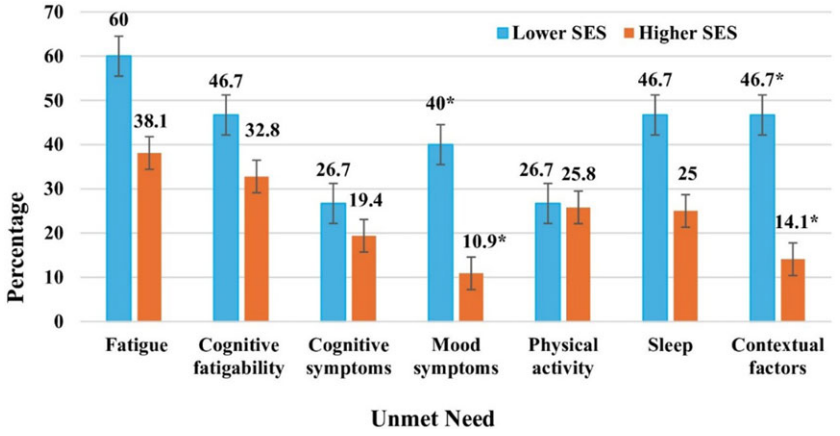


Figure 3. Percentage of respondents from lower and higher socioeconomic statuses (SES) identifying unmet needs.

Discussion

An online NA survey was administered to PwMS to obtain information directly from these individuals about factors known to contribute to CF. This study sought to identify the most disruptive and insufficiently addressed needs for PwMS, while considering factors that may have impacted these unmet needs. Overall, the sample closely reflected a typical Canadian MS population,[45] in terms of sex distribution (female: male = 2.70:1), disease subtype (65% relapsing-remitting MS [RRMS]) and age (mean = 48.56, SD = 12.60), supporting generalizability.

Group- and individual-based Need Index findings

At the group level, no unmet needs were identified, possibly due in part to the use of a stringent cut-off (e.g., an NI of ≥ 50%) for

https://doi.org/10.1017/cjn.2026.10531 Published online by Cambridge University Press

defining unmet needs. Recent research has adopted lower thresholds (e.g., an NI of ~ 30%), suggesting that the higher the NI, the higher the concern in relation to the item.[46] This more lenient threshold aligns more closely with the NI scores from our sample for the top three prioritized concerns: fatigue (NI = 30.23), CF (NI = 22.96) and physical activity (NI = 19.55).

Although group-level analysis did not reveal unmet needs under the more conservative definition, individual-level analyses suggested that rural PwMS and those with lower SES reported more unmet needs. The predominance of urban and suburban participants (77%) with middle or higher SES (80.2%) in our sample may explain, at least in part, the absence of unmet needs at the group level, given greater potential to access services as needed. Additionally, all participants were served by an urban tertiary care center in a country with universal healthcare access, likely because needs were largely perceived as being met in the group as a whole. Although there continue to be gaps in the system[47] and room for improvement, if this survey were conducted in a context with greater disparity in healthcare access, the findings may have identified greater group-level needs.

Individual-level analyses uncovered a broader spectrum of unmet needs, with *fatigue* being the most reported unmet need (42.9%), followed by *CF* (35.5%), *sleep disruption* (27.5%), *physical activity* (25.5%), *cognitive impairment* (20%) and *contextual factors* (19.6%). Despite *mood* being a fulfilled need at the group level, 17.4% of individuals identified *mood* as an unmet need. The clinical presentation of MS varies widely,[48] with each individual having unique needs.[49] When these needs are unmet, patients are left to manage their illness on their own.[49] MS care must be personalized[49] to ensure appropriate intervention specific to the individual, as seen in precision medicine. The complex interplay of multiple contributing factors likely exacerbates the burden of unmet needs on individuals when left unaddressed. Personalized interventions should be developed on the basis of individual-level assessments to target specific needs.[50] This approach helps identify those at highest risk of unmet needs, leading to better resource allocation and more effective outcomes.

Impact of social determinants of health on needs

Rural PwMS and those with lower SES reported more unmet needs. This aligns with the findings of previous NAs, which reported that a high proportion of people with progressive MS living in rural areas reported more non-pharmacological unmet needs.[51] PwMS in rural areas may have limited healthcare access, fewer specialists, long travel distances for care and a lack of specialized rehabilitation centers.[18] For example, sleep issues often require sleep specialists, therapy programs or support groups, which may be inaccessible in rural settings. Additionally, lower health literacy may contribute to rural residents' unmet needs, as individuals may lack awareness of symptom management strategies, particularly for fatigue and cognitive impairment, where self-management is key.[52] No significant rural/urban group differences were found in unmet needs related to *mood* and *contextual factors*, possibly because our sample had relatively low levels of depression (89% with no or mild depression) and anxiety (77% with no or mild anxiety), which may account for the smaller proportion of individuals identifying this as an unmet need (17.4%). Additionally, 65% of participants had RRMS, whereas depression is more prevalent in progressive forms of MS.[53] Notwithstanding the absence of significant differences between rural and urban participants in mood-related unmet needs, access to evidence-based therapy (e.g., cognitive-behavioral therapy) remains limited more generally.[54] Moreover, those in rural Canada often have limited access to mental health specialists and reduced availability of evidence-based psychotherapy services,[55] which may result in underdiagnosis and undertreatment of mood disorders. While mood disorders can sometimes be managed by general practitioners who are able to prescribe antidepressants, undertreatment of depression and anxiety in MS remain common.[54] Therefore, future research should examine mental health support needs more thoroughly in rural MS populations.

PwMS with lower SES reported more unmet needs related to *mood symptoms* and *contextual factors*. In MS, higher SES is associated with a lower burden of psychiatric symptoms and better recovery from mental health treatment.[17] Lower SES is connected to financial stressors that exacerbate mood disorders[56] and restrict access to mental health services. Without adequate support, individuals may struggle to manage mood symptoms. Additionally, lower SES is tied to housing instability, poor living conditions, unsafe neighborhoods or frequent relocations, creating insecurity and stress that exacerbates contextual challenges. They may face added pressures related to work and family, such as managing multiple low-paying jobs or caregiving responsibilities.

Group differences between those identifying CF as an unmet need and those who do not

PwMS who indicated that CF was an unmet need reported more difficulties across factors known to contribute to CF, demonstrating that CF may not be an isolated issue but is closely linked to other challenges.[21] This highlights the need for interventions targeting both CF and its related factors. However, contrary to prior findings linking CF to anxiety[10] and improved cognition in less fatigued PwMS with moderate physical activity,[57] we found no significant differences in the likelihood of meeting the cut-off values for *anxiety* and *physical activity* between those reporting CF as an unmet need and those who did not. This discrepancy may be due to the limitations of a survey study in which patient-reported outcomes were used, which allowed for only subjective rather than objective measurements of CF.

Group differences in need indices between fatigue profiles

PwMS with both fatigue and CF combined reported higher NIs in all areas than those with fatigue alone, suggesting distinct fatigue profiles. Notably, 42% of the participants experienced both fatigue and CF, suggesting that they are often experienced together. This overlap may reflect a compounding effect, whereby fatigue (subjective feelings of exhaustion) and CF (performance decline with sustained mental effort) mutually exacerbate each other, resulting in more unmet needs across various domains and hindering the capacity to problem-solve ways to meet needs using available resources. This further suggests the need for interventions that address both CF and fatigue together in PwMS.

Implications for rehabilitation

These findings highlight the importance of conducting comprehensive NA prior to the development and implementation of interventions for PwMS. NA surveys gather direct input from PwMS, enabling clinicians and researchers to better understand patient-reported priorities and to design and deliver targeted interventions that reflect lived experiences and promote patient-centered care. Given that MS-related CF is multifactorial,

https://doi.org/10.1017/cjn.2026.10531 Published online by Cambridge University Press

intervention targeting CF should address the broad range of contributing factors to improve the efficiency and impact of rehabilitation.

Future directions

Given that the top needs were fatigue, CF and physical activity, it is essential that future interventions explicitly target these factors. Existing, easy-to-access programs can be leveraged, such as the MS Society UK's online MS-Fatigue Management Course[58] and NeuroSask, a virtual program supporting movement, wellness and social connection for people with neurological conditions.[59] As PwMS in rural areas and those with lower SES report greater unmet needs, a more targeted approach for these individuals is warranted. This may include conducting interviews with PwMS from rural and lower SES backgrounds, as well as clinicians working with these groups, to better understand relevant barriers and facilitators.

Limitations

Our sample was not restricted to PwMS with CF only; it included PwMS with varying fatigue profiles. This should be considered when interpreting findings. Future research would benefit from samples specifically selected based on CF criteria to better isolate its effects. Additionally, our sample was from one tertiary care MS Clinic in a country with universal health care, which may have introduced bias. Results might differ with a broader sample from various MS communities/regions with less equitable healthcare access. The online survey method may have introduced selection bias, as individuals with less technological proficiency may not have participated. However, only 4% reported requiring technical assistance when completing the survey. The self-reported data also have limitations, as clinical outcome variables (e.g., disability level) were not verified through medical records, potentially leading to recall bias. The study also relied on subjective experiences rather than objective measurements. Future research should also employ longitudinal designs to assess how unmet needs evolve over time, particularly following targeted interventions.

Conclusions

This was the first study to administer an NA survey examining the unmet needs associated with MS-related CF. Our findings reveal potential gaps in care and highlight the influence of community type and SES on unmet needs, underscoring the need for personalized, tailored interventions to effectively address CF. Addressing these SDOH may help clinicians reduce the barriers faced by PwMS and improve outcomes. The results will help inform a CF intervention planned by our group in the future.[60] By actively incorporating direct input from PwMS, targeting all contributing factors to CF and delivering the intervention in a way that is accessible to all participants across SES levels and community settings, we are ensuring that the planned intervention will be responsive to real-world challenges.

Supplementary material. The supplementary material for this article can be found at https://doi.org/10.1017/cjn.2026.10531.

Data availability statement. The data that support the findings of this study are available from the corresponding author upon reasonable request.

Acknowledgments. The authors express their sincere gratitude to the PwMS who participated in this study; their time and effort were invaluable.

Author contributions. **Tamanna Islam:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Visualization, Writing – original draft. **Jason A. Berard:** Conceptualization, Formal analysis, Investigation, Methodology, Project administration, Supervision, Writing – review & editing. **Lisa A.S. Walker:** Writing – review & editing, Supervision, Resources, Project administration, Conceptualization, Formal analysis, Methodology.

Funding statement. This work was supported in part by scholarships to T. Islam from the University of Ottawa Brain and Mind Research Institute and the Canadian Psychological Association. There were no other funding sources.

Competing interests. The authors have no competing interests to declare.

Prior presentation. This work was presented as a poster titled "*Needs Assessment for Those with Multiple Sclerosis: Examining Needs Related to Cognitive Fatigability*" by T. Islam on February 28, 2025, at the Americas Committee for Treatment and Research in Multiple Sclerosis (ACTRIMS) Forum 2025, in West Palm Beach, Florida, USA.

References

1. Braley TJ, Chervin RD. Fatigue in multiple sclerosis: mechanisms, evaluation, and treatment. *Sleep*. 2010;33(8):1061–7.
2. Kluger BM, Krupp LB, Enoka RM. Fatigue and fatigability in neurologic illnesses: proposal for a unified taxonomy. *Neurology*. 2013;80(4):409–16. https://doi.org/10.1212/WNL.0b013e31827f07be.
3. Bryant D, Chiaravalloti ND, DeLuca J. Objective measurement of cognitive fatigue in multiple sclerosis. *Rehabil Psychol*. 2004;49(2):114–22. https://doi.org/10.1037/0090-5550.49.2.114.
4. Luo DH, Holtzer R. Perceived physical and mental fatigability in older adults with and without multiple sclerosis. *Mult Scler Relat Disord*. 2024;90:105807. https://doi.org/10.1016/j.msard.2024.105807.
5. Bertoli M, Tecchio F. Fatigue in multiple sclerosis: does the functional or structural damage prevail? *Mult Scler J*. 2020;26(14):1809–15. https://doi.org/10.1177/1352458520912175.
6. Loy BD, Taylor RL, Fling BW, Horak FB. Relationship between perceived fatigue and performance fatigability in people with multiple sclerosis: a systematic review and meta-analysis. *J Psychosom Res*. 2017;100:1–7. https://doi.org/10.1016/j.jpsychores.2017.06.017
7. Kroencke DC, Lynch SG, Denney DR. Fatigue in multiple sclerosis: relationship to depression, disability, and disease pattern. *Mult Scler J*. 2000;6(2):131–6. https://doi.org/10.1177/135245850000600213.
8. Strober L, Arnett P. An examination of four models predicting fatigue in multiple sclerosis. *Arch Clin Neuropsychol*. 2005;20(5):631–46. https://doi.org/10.1016/j.acn.2005.04.002.
9. Gervasoni E, Anastasi D, Di Giovanni R, et al. Physical activity in non-disabled people with early multiple sclerosis: a multicenter cross-sectional study. *Mult Scler Relat Disord*. 2022;64:103941. https://doi.org/10.1016/j.msard.2022.103941.
10. Mackay L, Johnson AM, Moodie ST, Rosehart H, Morrow SA. Predictors of cognitive fatigue and fatigability in multiple sclerosis. *Mult Scler Relat Disord*. 2021;56:103316. https://doi.org/10.1016/j.msard.2021.103316.
11. Feinstein A, Amato MP, Brichetto G, et al. Cognitive rehabilitation and aerobic exercise for cognitive impairment in people with progressive multiple sclerosis (CogEx): a randomised, blinded, sham-controlled trial. *Lancet Neurol*. 2023;22(10):912–24. https://doi.org/10.1016/S1474-4422(23)00280-6.
12. Maneotis S, Krauss AD. A proper needs assessment is key to starting a wellbeing intervention off right. In *Derailed Organizational Interventions for Stress and Well-being: Confessions of Failure and Solutions for Success*. Dordrecht: Springer Netherlands; 2015. pp. 229–236, https://doi.org/10.1007/978-94-017-9867-9_26.
13. Koopman WJ, Benbow CL, Vandervoort M. Top 10 needs of people with multiple sclerosis and their significant others. *J Neurosci Nurs*. 2006;38(5):369–74.
14. Aronson KJ, Cleghorn G, Goldenberg E. Assistance arrangements and use of services among persons with multiple sclerosis and their caregivers. *Disabil Rehabil*. 1996;18(7):354–61. https://doi.org/10.3109/09638289609165894.

15. Berard JA, Fang Z, Walker LAS, et al. Imaging cognitive fatigability in multiple sclerosis: objective quantification of cerebral blood flow during a task of sustained attention using ASL perfusion fMRI. *Brain Imaging Behav*. 2019;14(6):2417–28. https://doi.org/10.1007/s11682-019-00192-7.
16. Sievertsen HH, Gino F, Piovesan M. Cognitive fatigue influences students' performance on standardized tests. *Proc Natl Acad Sci U S A*. 2016;113(10):2621–4.
17. Wang Y, Tian F, Fitzgerald KC, et al. Socioeconomic status and race are correlated with affective symptoms in multiple sclerosis. *Mult Scler Relat Disord*. 2020;41:102010. https://doi.org/10.1016/j.msard.2020.102010.
18. Buchanan RJ, Stuifbergen A, Chakravorty BJ, Wang S, et al. Urban/Rural differences in access and barriers to health care for people with multiple sclerosis. *J Health Hum Serv Adm*. 2006;29(3):360–75.
19. Fakolade A, Latimer-Cheung A, Parsons T, Finlayson M. A concerns report survey of physical activity support needs of people with moderate-to-severe MS disability and family caregivers. *Disabil Rehabil*. 2019;41(24):2888–99. https://doi.org/10.1080/09638288.2018.1479781.
20. Edwards T, Fakolade AO, Lindale K, Pilutti LA. *Exercise In Nonambulatory People with Multiple Sclerosis*. PhD thesis, University of Ottawa; 2021, https://doi.org/10.20381/ruor-27167
21. Berard JA, Smith AM, Walker LAS. Predictive models of cognitive fatigue in multiple sclerosis. *Arch Clin Neuropsychol*. 2019;34(1):31–8. https://doi.org/10.1093/arclin/acy014.
22. Abou L, Fritz NE, Kratz AL. Predictors of performance and perceived fatigability in people with multiple sclerosis. *Neurol Res*. 2023;45(11):994–1002. https://doi.org/10.1080/01616412.2023.2252283.
23. Learmonth YC, Motl RW, Sandroff BM, Pula JH, Cadavid D. Validation of patient determined disease steps (PDDS) scale scores in persons with multiple sclerosis. *BMC Neurol*. 2013;13(1):37. https://doi.org/10.1186/1471-2377-13-37.
24. Hohol MJ, Orav EJ, Weiner HL. Disease steps in multiple sclerosis: a simple approach to evaluate disease progression. *Neurology*. 1995;45(2):251–5. https://doi.org/10.1212/wnl.45.2.251.
25. Fisk JD, Pontefract A, Ritvo PG, Archibald CJ, Murray TJ. The impact of fatigue on patients with multiple sclerosis. *Can J Neurol Sci*. 1994;21(1):9–14. https://doi.org/10.1017/S0317167100048691.
26. Multiple Sclerosis Council for Clinical Practice Guidelines. *Fatigue and multiple sclerosis: evidence-based management strategies for fatigue in multiple sclerosis: clinical practice guidelines*. The Council; 1998.
27. Kos D, Kerckhofs E, Carrea I, Verza R, Ramos M, Jansa J. Evaluation of the modified fatigue impact scale in four different European countries. *Mult Scler J*. 2005;11(1):76–80. https://doi.org/10.1191/1352458505ms1117oa.
28. Glynn NW, Santanasto AJ, Simonsick EM, et al. The Pittsburgh fatigability scale for older adults: development and validation. *J Am Geriatr Soc*. 2015;63(1):130–5. https://doi.org/10.1111/jgs.13191.
29. Carlozzi NE, Boileau NR, Murphy SL, Braley TJ, Kratz AL. Validation of the pittsburgh fatigability scale in a mixed sample of adults with and without chronic conditions. *J Health Psychol*. 2021;26(9):1455–67. https://doi.org/10.1177/1359105319877448.
30. Aldughmi M, Huisinga J, Lynch SG, Siengsukon CF. The relationship between fatigability and sleep quality in people with multiple sclerosis. *Mult Scler J - Exp Transl Clin*. 2016;2:205521731668277. https://doi.org/10.1177/2055217316682774.
31. Cohen RW, Meinhardt AJ, Gmelin T, et al. Prevalence and severity of perceived mental fatigability in older adults: the long life family study. *J Am Geriatr Soc*. 2021;69(5):1401–3. https://doi.org/10.1111/jgs.17075.
32. Simonsick EM, Schrack JA, Santanasto AJ, Studenski SA, Ferrucci L, Glynn NW. Pittsburgh fatigability scale: one-page predictor of mobility decline in mobility-intact older adults. *J Am Geriatr Soc*. 2018;66(11):2092–6. https://doi.org/10.1111/jgs.15531.
33. Fischer JS, Rudick RA, Cutter GR, Reingold SC. The multiple sclerosis functional composite measure (MSFC): an integrated approach to MS clinical outcome assessment. *Mult Scler J*. 1999;5(4):244–50. https://doi.org/10.1177/135245859900500409.
34. Sullivan MJ, Edgley K, Dehoux E. A survey of multiple sclerosis: I. Perceived cognitive problems and compensatory strategy use. *Can J Rehabil*. 1990;4(2):99–105.
35. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand*. 1983;67(6):361–70. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x.
36. Honarmand K, Feinstein A. Validation of the hospital anxiety and depression scale for use with multiple sclerosis patients. *Mult Scler J*. 2009;15(12):1518–24. https://doi.org/10.1177/1352458509347150.
37. Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ. The pittsburgh sleep quality index: a new instrument for psychiatric practice and research. *Psychiatry Res*. 1989;28(2):193–213. https://doi.org/10.1016/0165-1781(89)90047-4.
38. Jerković A, Mikac U, Matijaca M, et al. Psychometric properties of the pittsburgh sleep quality index (PSQI) in patients with multiple sclerosis: factor structure, reliability, correlates, and discrimination. *J Clin Med*. 2022;11(7):2037. https://doi.org/10.3390/jcm11072037.
39. Park BK. The Pittsburgh sleep quality index (PSQI) and associated factors in middle-school students: a cross-sectional study. *Child Health Nurs Res*. 2020;26(1):55–63. https://doi.org/10.4094/chnr.2020.26.1.55.
40. Godin G, Shephard RJ. A simple method to assess exercise behavior in the community. *Can J Appl Sport Sci*. 1985;10(3):141–6.
41. Motl RW, McAuley E, Snook EM, Scott JA. Validity of physical activity measures in ambulatory individuals with multiple sclerosis. *Disabil Rehabil*. 2006;28(18):1151–6. https://doi.org/10.1080/09638280600551476.
42. Godin G. The Godin-Shephard leisure-time physical activity questionnaire. *Health & Fitness Journal of Canada*. 2011;4(1):18–22. https://doi.org/10.14288/hfjc.v4i1.82.
43. Schriner KF, Fawcett SB. Development and validation of a community concerns report method. *J Community Psychol*. 1988;16(3):306–16. https://doi.org/3-1002/1520-6629(198807)16.
44. Fawcett SB. *Concerns report handbook: planning for community health*. 1980.
45. Atlas of MS. September. (2020). *Available at:* https://www.atlasofms.org/fact-sheet/canada.
46. Pétrin J, McColl MA, Donnelly C, French S, Finlayson M. Prioritizing the healthcare access concerns of Canadians with MS. *Mult Scler J - Exp Transl Clin*. 2021;7(3):20552173211029672. https://doi.org/10.1177/20552173211029672.
47. Walker LAS, Gardner C, Freedman MS, MacLean H, Rush C, Bowman M. Research-to-practice gaps in multiple sclerosis care for patients with subjective cognitive, mental health, and psychosocial concerns in a Canadian center. *Int J MS Care*. 2019;21(6):243–8. https://doi.org/10.7224/1537-2073.2017-090.
48. Silveira C, Guedes R, Maia D, Curral R, Coelho R. Neuropsychiatric symptoms of multiple sclerosis: state of the art. *Psychiatry Investig*. 2019;16(12):877–88. https://doi.org/10.30773/pi.2019.0106.
49. Maida E, Abbadessa G, Cocco E, et al. Identifying definite patterns of unmet needs in patients with multiple sclerosis using unsupervised machine learning. *Neurol Sci*. 2024;45(7):3333–45. https://doi.org/10.1007/s10072-024-07416-9.
50. Henschke A, Desborough J, Parkinson A, et al. Personalizing medicine and technologies to address the experiences and needs of people with multiple sclerosis. *J Pers Med*. 2021;11(8):791. https://doi.org/10.3390/jpm11080791.
51. Lonergan R, Kinsella K, Fitzpatrick P, et al. Unmet needs of multiple sclerosis patients in the community. *Mult Scler Relat Disord*. 2015;4(2):144–50. https://doi.org/10.1016/j.msard.2015.01.003.
52. Gillis D, Sears S. Health literacy in rural communities: challenges and champions. In: Kulig JC, Williams AM, editors. *Health in rural Canada*. University of British Columbia Press; 2011, pp. 258–79.
53. Young CA, Langdon D, Rog D, et al. Prevalence, treatment and correlates of depression in multiple sclerosis. *Mult Scler Relat Disord*. 2024;87:105648. https://doi.org/10.1016/j.msard.2024.105648.
54. Freedman DE, Oh J, Feinstein A. Not for everyone: factors influencing who receives psychotherapy in people with multiple sclerosis. *Mult Scler Relat Disord*. 2025;94:106245. https://doi.org/10.1016/j.msard.2024.106245.
55. Friesen E. The landscape of mental health services in rural Canada. *Univ Tor Med J*. 2019;96:47–52.
56. Brannen C, Dyck K, Hardy C, Mushquash C. Rural mental health services in Canada: a model for research and practice, *Health in rural Canada*. University of British Columbia Press; 2012, pp. 239–57, 10.59962/9780774821742-016

https://doi.org/10.1017/cjn.2026.10531 Published online by Cambridge University Press

57. Redlicka J, Zielińska-Nowak E, Lipert A, Miller E. Impact of moderate individually tailored physical activity in multiple sclerosis patients with fatigue on functional, cognitive, emotional state, and postural stability. *Brain Sci*. 2021;11(9):1214. https://doi.org/10.3390/brainsci11091214.
58. Online MS Fatigue Management Course | Multiple Sclerosis Society UK. *Available at:* https://www.mssociety.org.uk/about-ms/signs-and-symptoms/fatigue/managing-fatigue/online-fatigue-management-course.
59. NeuroSask. School of Rehabilitation Science - College of Medicine. rehabscience January 22, 2025. *Available at:* https://rehabscience.usask.ca/neurosask/index.php.
60. Walker LAS, Berard JA, Islam T, Pilutti LA, Morrow SA, Finlayson M. Development of a behavioural intervention for cognitive fatigability in multiple sclerosis: protocol for a pilot and feasibility study. *Front Rehabil Sci*. 2022;3:999266. https://www.frontiersin.org/articles/10.3389/fresc.2022.999266

https://doi.org/10.1017/cjn.2026.10531 Published online by Cambridge University Press