

Prioritizing the healthcare access concerns of Canadians with MS

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Abstract

Background: Canadians with MS are high users of healthcare services, yet they report multiple unmet needs, high disease burden, and low satisfaction with care. Engaging patients in healthcare planning can lead to improvements in access and care. There is currently limited evidence that has harnessed the perspectives of Canadians with MS.

Objective: To identify and prioritize the healthcare access concerns of Canadians with MS.

Methods: A cross-sectional online survey informed by the Concerns Report Methodology was used to address the objective. Participants were recruited through multiple methods. Descriptive statistics were used to identify the main barriers to healthcare providers, and concerns report methods were used to calculate needs indexes to prioritize concerns of participants.

Results: 324 Canadians with MS participated in the study between November 18, 2019 and March 27, 2020. The most pressing healthcare access concerns of Canadians with MS were related to availability of healthcare providers with MS knowledge and affordability of services that aim to improve wellness.

Conclusion: These findings provide healthcare planners with prioritized access concerns of Canadians with MS, which can be used to guide strategic planning to improve the quality of life of these individuals.

Keywords: Multiple sclerosis, access to healthcare, Canada, healthcare priorities, concerns report method

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Introduction

Efforts to improve the Canadian healthcare system target safety, timeliness, effectiveness, efficiency, equity and patient-centred care.¹ Multiple stakeholders must be involved in efforts to support these outcomes, including patients themselves. Engaging patients in healthcare design and delivery reforms leads to improvements in care, including better access to appointments, and improved patient safety and satisfaction.² Current documents guiding healthcare for people with multiple sclerosis (PwMS) have been developed primarily by expert providers and researchers.^{3,4} The expertise of Canadians with MS has not been fully realized.

PwMS are high users of the Canadian healthcare system; however, they also report multiple unmet needs, high disease burden, low satisfaction with care, and multiple access barriers to care.⁵ By directly engaging PwMS in healthcare planning, we may be able to understand and address these issues. Therefore, we sought to identify and prioritize the healthcare access concerns of Canadians with MS, by asking these research questions:

1. What are the main barriers PwMS experience when accessing specific health care providers to manage their disease?

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2. What are the most pressing concerns that PwMS have in accessing the Canadian healthcare system to manage their condition?
3. Who is most at risk of experiencing those concerns?

Methods

Study design

We conducted a cross-sectional online survey informed by Concerns Report Methodology (CRM),⁶ which actively engages citizens in the identification and prioritization of their healthcare concerns and strengths.

Survey content and design

The survey development was an iterative process informed by the findings of a previously published qualitative study,⁷ the Candidacy Access Framework,⁸ past MS healthcare surveys,^{9,10} a working group of five PwMS, and the study authors. The survey was divided into five main sections: (1) general health and MS-related information; (2) healthcare seeking behaviour and confidence levels; (3) healthcare service use and barriers to health care providers; (4) Concerns Report Items (described below); and (5) sociodemographic information. After several rounds of review and revision, the survey was uploaded in Qualtrics, an online survey system, and piloted with three people with MS for clarity and flow.

Concerns report items. The first author generated the concerns report items based on healthcare access experiences of PwMS⁷. Each concerns report item requires that participants rate a single statement on two dimensions, importance and satisfaction, using a scale of 0 (not at all important/satisfied) to 4 (very important/satisfied). The working group reviewed, revised, and selected the final items for inclusion in the survey.

The items were grouped into four main categories: Healthcare provider interactions, affordability, physical accessibility, and availability and accommodation. Ratings were used to calculate a needs index (NI), which measured the gap between how important an item is to the community and how satisfied they are with this item.

Participant recruitment and survey dissemination

Recruitment occurred by distributing the survey link nationally through multiple avenues (e.g., MS Society of Canada's research portal, local MS chapters, social media). We aimed to enroll a minimum of 220 PwMS, based on the rule of ten, since 22 predictor

variables were initially considered¹¹ for analysis (see below). We were unable to calculate a response rate due to the nature of the recruitment methods.

Individuals who clicked the survey link were directed to the survey webpage, provided with study information, and asked for consent. If consent was provided, eligibility was determined: (1) ≥ 18 years old; (2) Diagnosed with MS by a neurologist; (3) Canadian citizen or permanent resident; and (4) Able to complete survey in English. See Figure 1.

Data analysis

Descriptive analyses were conducted to summarize the sample's socio-demographic, general health, MS-related health information, and basic health service use, using mean (SD) and frequency distributions (n (%)) as appropriate.

Needs index and identifying concerns. The calculation of the needs index involved two main steps, consistent with the instructions in the CRM handbook.¹² Step one uses the formula $\frac{4n(4) + 3n(3) + 2n(2) + 1n(1) + 0n(0)}{N(4)} \times 100$ - to calculate the weighted mean importance percent and weighted mean satisfaction percent for each item in the concerns report section of the survey. Step two uses the needs index calculation: Weighted Mean of Item Importance Rating - Weighted Mean of Item Satisfaction Rating. Higher NIs represent items where participants rated high levels of importance but low levels of satisfaction, the NIs run from 0 to 100. The higher the NI the higher the concerns of the community in relation to the item.

Factors affecting concerns. We identified the top three NIs (Concerns). For each index, the outcome variable was *Needs Gap Reported*. This dichotomous outcome was derived using each participant's raw results of Importance-Satisfaction (described in section *Concerns report items*). All respondents who rated the item with an Importance - Satisfaction Score ≥ 2 were grouped into *Needs Gap Reported*, whereas all scores < 2 were consider *Needs Gap Not Reported*. Using these dichotomous outcomes, we estimated three separate backwards conditional logistic regression models to determine the profile of participants reporting the specific need. Independent variables included variables capturing social determinants of health, demographics, and MS-related characteristics (see Table 1 for details). Prior to modelling, variables were assessed for multicollinearity using Variance Inflation Factor.¹¹

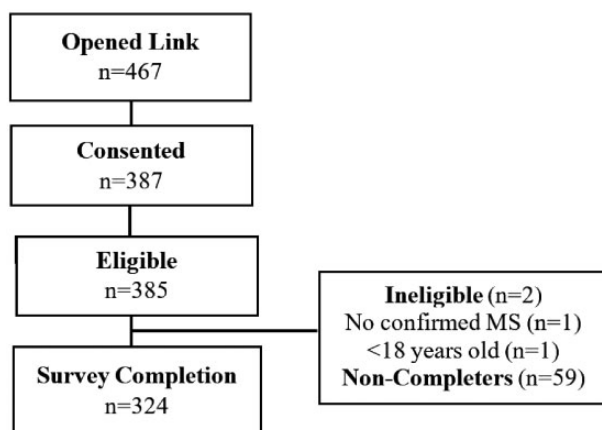


Figure 1. Flow of survey participants.

Table 1. Independent variables selected for each model.

Model 1 – Availability of healthcare providers with MS Knowledge (Concern 1)	Model 2- Affordability of complementary care (Concern 2)	Model 3 – Affordability of physiotherapy and occupational therapy (Concern 3)
Social determinants of health and demographic		
Age	Age	Age
Sex	Sex	Sex
Confidence in care seeking	Income	Income
Rurality	Private health insurance (yes/no)	Private health insurance (yes/no)
MS-related characteristics		
Level of disability - patient determined disease steps (PDDS)	Number of comorbidities ^a	Number of comorbidities
MS stability in last year	Number of MS symptoms ^b	Number of MS symptoms
MS relapse in past 2 years	Number of medications	Number of medications
Time living with MS	Taking a disease-modifying therapy (DMTs)(yes/no)	Taking a disease-modifying therapy (DMTs)(yes/no)
MS: Multiple Sclerosis; PDDS: Patient Determined Disease Steps; DMTs: Disease Modifying Therapies. Note: Variables included in initial analysis that were non-significant – Disease Type, Regions, Rurality, Living arrangement, type of DMT. ^a Comorbidities reported by participants and included in this variable: hypertension, heart disease, hyperlipidemia, chronic lung disease, diabetes, cancer, anxiety, depression, hearing loss, and vision loss. ^b Symptoms reported by participants and included in this variable: fatigue, mobility and balance issues, numbness and tingling, pain, spasticity, coordination, tremors, visual impairments, speech impairments, swallowing issues, concentration and attention impairments, bladder dysfunction, bowel dysfunction, and sleep issues.		

The model fit was assessed using the Hosmer and Lemeshow goodness-of-fit test.¹¹

Results

Participant characteristics and use of healthcare provider services

Table 2 provides the details of the participant characteristics, as well as details about their use of healthcare providers. Most participants were

female (84%) living with relapsing remitting MS (73.5%) for an average of 11 years (SD = 8.9). Just over half (53%) were employed full or part-time. Most of the sample (77%) had supplementary health insurance coverage, not funded through Medicare. Just over half (51%) lived in a large urban area. The Patient Determined Disease Steps (PDDS)¹³ scores spanned from 0 to 7 with a median of 2. Most (62%) were taking disease modifying therapy (DMTs). These characteristics are generally representative of the Canadian MS

Table 2. Participant characteristics and health service use (N = 324).

Variable	n	(%)	Variable	n	(%)
Type of MS			Education level		
Relapsing-remitting MS	238	(73.5)	High school	40	(12.3)
Secondary progressive MS	36	(11.1)	College/vocational	116	(35.8)
Primary progressive MS	28	(8.6)	Undergraduate	103	(31.8)
Not sure	15	(4.6)	Graduate	50	(15.4)
Missing	7	(2.1)	Rather not disclose	5	(1.5)
PDDS			Missing	10	(3.1)
0–2 (Mild disability)	158	(48.7)	Employment		
3–5 (Moderate disability)	105	(32.5)	Employed full time	122	(37.7)
6–8 (Severe disability)	41	(12.6)	Employed part time	49	(15.1)
Missing	20	(6.2)	Unable to work/disability	68	(20.9)
Main source of MS care			Retired	59	(18.2)
Neurologist	218	(67.3)	Other	14	(4.3)
Family physician	48	(14.8)	Rather not disclose	2	(0.6)
Nurse	20	(6.2)	Missing	10	(3.1)
Physical therapist	8	(2.5)	Rurality		
Specialist	7	(2.2)	Rural area (less than 1000)	34	(10.5)
CAM therapist	6	(1.9)	Small pop. centre (1,000 to 29,999)	44	(13.6)
Other	9	(2.8)	Medium pop. centre (30,000 to 99,999)	71	(21.9)
Missing	8	(2.5)	Large urban centre (100,000 or more)	166	(51.2)
Setting of most MS Care			Missing	9	(2.8)
MS clinic	183	(56.5)	Household income (CDN)		
General neurologist clinic	63	(19.4)	Less than \$20,000	20	(6.2)
Family physician practice	40	(12.3)	\$20,000 – \$49,999	53	(16.4)
I Do Not receive MS care	13	(4)	\$50,000 – \$99,999	99	(30.6)
Interdisciplinary practice	10	(3.1)	\$100, 000 – \$149, 999	53	(16.4)
walk In/afterhours/emergency	8	(2.6)	\$150,000 or more	52	(16)
Missing	8	(2.5)	Rather not disclose	40	(12.3)
Province of residence			Missing	7	(2.2)
Alberta	63	(19.4)			
British Columbia	23	(7.1)			
Manitoba	15	(4.6)			
New Brunswick	11	(3.4)			
Newfoundland	9	(2.8)			
Nova Scotia	13	(4.0)			
Ontario	100	(30.9)			
Prince Edward Island	2	(0.6)			
Quebec	8	(2.5)			
Saskatchewan	47	(14.5)			
Missing	33	(10.2)			

PDDS: Patient Determined Disease Steps.

population,¹⁴ with 9% more females and 14% more respondents being employed than the general Canadian MS population.

Almost all participants had a regular family physician (n = 304, 93%) and a regular neurologist (n = 304, 93%). Participants visited their family

physician an average of 4.8 times/year (SD:3.8), where 32% of the visits were MS-related. Neurologists were visited 1.5 times/year (SD:0.9). Participants primarily identified neurologists as their main source of MS care (67%), followed by family physicians (15%). Just over half received most of their MS care from an MS clinic (57%),

followed by general neurology clinics (15%), and family physician offices (12%).

Healthcare providers access barriers

The top three healthcare providers that participants needed to see but did not have access to were occupational therapists (19%), mental health providers (17%), and physiotherapists (18%). Participants also reported wanting to see physiotherapists (15%) and complementary and alternative medical practitioners (18%), specifically massage therapists, naturopaths, and acupuncturists, more often. The most common barriers to seeing these providers were cost, due to lack of insurance, and difficulties getting appointments, due to availability and lack of referrals. Of note, almost a quarter of participants who reported not having access to an occupational therapist reported not knowing how to make an appointment with them (n = 17, 21%). The healthcare provider that participants reported wanting to see more often but having difficulties accessing was a neurologist (35%). The main barrier to seeing a neurologist was difficulty getting appointments (n = 84, 70%). See Tables 3 and 4 for more details.

Most important healthcare access items

Participants placed a high degree of importance across all 25 concerns report items and categories,

where no item received less than a 70% rating. These items were then ranked into the top ten, where six of the ten items were related to healthcare provider interactions, three involved aspects of availability and accommodation and one involved affordability. See supplementary materials table 1 for details.

Items related to healthcare access satisfaction

Participants were generally satisfied with all concerns report items, where they rated 15 items above 70%. The items that received the highest satisfaction ratings were considered healthcare access strengths. Of the top ten items, eight were related to healthcare provider interactions, while two were related to physical accessibility. See supplementary materials table 2 for more details.

Needs indexes – Concerns

Table 5 presents the top ten calculated NIs. Concerns regarding availability, accommodation and affordability were the most reported. Availability and accommodation items included being able to get an MS specialist or neurologist appointment and having healthcare providers who communicate and coordinate care. Affordability items included cost of DMTs, prescription medications, adaptive aids, and therapy aimed at improving wellness. The top three prioritized concerns were: (1) Having healthcare

Table 3. Healthcare providers (N = 314).

Provider	I need, but do not have access n (%)	I see, but would like to see more often n (%)	I see as much as needed n (%)	Not needed n (%)	Missing n (%)
Neurologist	7 (2.2)	113 (34.9)	187 (57.7)	7 (2.2)	10 (3.1)
GP	10 (3.1)	34 (10.5)	264 (81.5)	5 (1.5)	11 (3.4)
Nurse practitioner	37 (11.4)	19 (5.9)	75 (23.1)	180 (55.6)	13 (4.0)
Nurse	29 (9.0)	34 (10.5)	90 (27.8)	156 (48.1)	15 (4.6)
Physiotherapist	57 (17.6)	49 (15.1)	69 (21.3)	134 (41.4)	14 (4.6)
Occupational therapist	60 (18.5)	22 (6.8)	41 (12.7)	187 (57.7)	14 (4.3)
Personal support worker	38 (11.7)	9 (2.8)	17 (5.2)	245 (75.6)	15 (4.6)
Pharmacist	2 (0.6)	10 (3.1)	252 (77.8)	48 (14.8)	12 (3.7)
Mental health Provider (counsellor, psychologist, social worker)	56 (17.3)	37 (11.4)	55 (17.0)	159 (49.1)	12 (3.7)
Allied health providers (chiropractor, nutritionist)	53 (16.4)	20 (6.2)	96 (29.6)	139 (42.9)	16 (4.9)
Complementary care providers (acupuncture, naturopath, massage)	29 (15.1)	59 (18.2)	93 (28.7)	107 (33.0)	16 (4.9)
Specialists (urologist, gynecologist, ophthalmologist)	30 (9.3)	27 (8.3)	129 (39.8)	117 (36.1)	21 (6.5)

Table 4. Barriers to accessing healthcare providers.

Provider/barrier	Neurologist (n = 120)	PT (n = 105)	OT (n = 81)	MHP* (n = 92)	CAMP** (n = 107)
n (%)					
Difficulty getting an appointment	84 (70.0)	22 (21.0)	29 (36.3)	22 (23.9)	6 (5.6)
Costs – lack of insurance coverage	1 (0.8)	55 (52.4)	21 (25.9)	38 (41.3)	78 (73.0)
Distance to provider	12 (10.0)	7 (6.7)	4 (4.9)	2 (2.2)	4 (3.7)
Lack of services in community	9 (7.5)	3 (2.9)	6 (7.4)	9 (9.8)	3 (2.8)
Do not know how to book an appointment	3 (2.5)	8 (7.6)	16 (19.8)	10 (11.0)	5 (4.7)
Other	11 (9.2)	10 (9.5)	5 (6.2)	11 (12.0)	13 (12.1)

providers with sufficient MS-related knowledge in their communities; (2) Being able to afford to maintain their wellness through use of complementary care, and (3) Being able to afford physiotherapy and occupational therapy to maintain their wellbeing and prevent worsening of their condition.

Profile of PwMS who reported the top 3 healthcare access items as concerns

The logistic regression is provided in in Table 6. Variables included in analysis had independent effects within the models, as Variance Inflation Factors were all below 5. Each model showed good fit with the data, as Hosmer and Lemeshow Goodness-of-Fit Test produced p-values of 0.9, 1.0, 0.9, respectively.

Availability of healthcare providers with MS-related knowledge located in their community. Participants who experienced a relapse within the past 2 years were more likely to report a concern for healthcare providers with MS-related knowledge in their community (OR = 1.99 [1.15-3.47], compared to those who had not experienced a relapse. Individuals with MS reporting higher PDDS scores were also more likely to report this concern (OR = 1.22 [1.06-1.41]). Finally, people who reported high levels of confidence in seeking healthcare, were less likely to report this concern (OR = 0.76 [0.62-0.93]). Participants were also less likely to report this concern as age increased (OR = -0.97 [0.95-1.00]).

Affordability of complementary care aimed at maintaining wellness. Three variables remained significant in the model. Females were twice as likely than males to report a concern for affordable access to complementary care for wellness (OR = 2.33 [1.02–5.36]). As the number of MS symptoms that participants reported as interfering greatly in their daily life increased, so did their odds of reporting

this item as a concern. (OR = 1.18 [1.06–1.32]). Similar to the model above, participants were less likely to report this concern as age increased (OR = -0.97 [0.95–0.99]).

Affordability of PT and OT to improve wellbeing through preventative and maintenance care. Three variables remained significant in this model. PwMS who have supplemental health insurance are less likely to report a need for affordable physiotherapy and occupational therapy to improve their wellbeing (OR = 0.49 [0.25-0.96]). PwMS taking DMTs were also less likely than individuals who were not are taking DMTs to report this item as a need (OR = 0.48 [0.23-0.90]). Participants reporting higher numbers of comorbidities, were more likely to report this item as a concern (OR = 1.24 [1.03–1.50]).

Discussion

This is the first Canadian study that provides a ranking of healthcare access concerns by persons living with MS. The findings provide insight into aspects of healthcare that are perceived by this population to be functioning well and which aspects require improvements to meet their needs.

PwMS placed highest importance on healthcare provider interactions, including active communication, respect and shared decision making. This focus is in accordance with findings internationally^{15,16} and previous work by our group⁷. Interestingly, participants indicated the highest level of satisfaction with these items, suggesting that patient-centered care^{17,18} reforms may be taking hold. Continuing to build on these aspects of the current system will be important as healthcare reforms continue to evolve.

Table 5. Ranked needs indexes – Access concerns.

Concerns report items	Access category	Needs index	Rank order
There are multiple healthcare providers in my community that have sufficient MS-related knowledge to guide my care planning and referrals	Availability/ Accommodation	33.6	1
I can afford to maintain my wellness through complementary care such as massage therapy, yoga, naturopathic and/or chiropractic care	Affordability	33.3	2
I can afford physical or occupational therapy to improve my well-being through preventative and maintenance care	Affordability	31.4	3
My healthcare providers communicate to ensure that my care is coordinated	Availability/ Accommodation	29.1	4
I can get an appointment with my neurologist if I am experiencing new symptoms or a relapse	Availability/ Accommodation	25.8	5
I can get an appointment with my primary MS healthcare provider when I need one	Availability/ Accommodation	24.2	6
Many of the healthcare providers that are part of my healthcare team work together as a unit within one location to ensure my best possible care	Availability/ Accommodation	24.0	7
I can afford the costs of my disease modifying therapies and my prescription medications for my MS-related symptoms	Affordability	23.5	8
There is an MS clinic or MS specialist within or near my community	Availability/ Accommodation	22.3	9
I can afford the adaptive aids and/or medical equipment that I need	Affordability	20.5	10

Consistent with previous Canadian research⁵ and other countries with universal access to care,¹⁹ nearly all survey respondents had a regular family physician and neurologist. Just under three quarters of participants reported that their regular neurologist worked in an MS clinic, which is slightly higher than previous work.²⁰ In Canada, there are 33 MS specialized clinics located in urban areas in most provinces, making up the Canadian Network of MS Clinics. These clinics are not standardized, therefore healthcare providers present within each clinic vary, from an MS trained neurologist and nurse to larger teams with interprofessional healthcare providers, including occupational therapists, physical therapist and social workers.

Although these MS-trained neurologists are best suited to manage MS²⁰ and some clinics are interdisciplinary,²¹ meeting best care guidelines,²² only

about half of participants received most of their MS care from an MS clinic. This finding may explain why over one third of participants reported wanting to see their neurologist more often but had difficulty booking appointments, further Canadian MS clinics follow practice of one annual visit per person.²¹ Limited access to MS neurological care has been described internationally⁹ which led many to seek care from non-specialist providers including general neurologists and family physicians,¹⁶ which is synonymous to our findings. These findings may explain why the highest concern of participants was the availability of healthcare providers with MS-related knowledge in their community.

Across the top ten healthcare access concerns of PwMS, items related to availability and affordability were the most common. These included timely access to MS specialists, coordination of care, and

Table 6. Profile of persons with MS who report the top three healthcare access concerns.

	df	Estimates (β)	SE	OR	95 % CI		<i>p</i>
					Lower	Upper	
<i>Availability of Healthcare Providers in the Community with MS-Knowledge (n = 269)</i>							
Constant	1	1.051	0.650	2.860			0.160
Age	1	-0.030	0.013	0.970	0.946	0.995	0.018
PDDS	1	0.199	0.073	1.220	1.058	1.407	0.006
Having a relapse in Past 2 years	1	0.691	0.282	1.996	1.149	3.467	0.014
Confidence in care seeking	1	-0.270	0.106	0.763	0.620	0.939	0.011
<i>Affordability of complementary care to maintain wellness (n = 280)</i>							
Constant	1	-0.619	0.950	0.425			0.515
Age	1	-0.029	0.011	0.972	0.950	0.994	0.010
Sex	1	0.847	0.424	2.332	1.015	5.355	0.046
Number of MS symptoms	1	0.169	0.057	1.184	1.060	1.324	0.003
<i>Affordability of PT and OT to improve wellbeing (n = 275)</i>							
Constant	1	0.976	0.841	2.654	0.246		0.632
Having supplemental insurance	1	-0.707	0.342	0.493	0.252	0.964	0.039
Taking disease modifying therapy	1	-0.736	0.321	0.479	0.225	0.899	0.022
Number of comorbidities	1	0.216	0.0981	1.241	1.025	1.503	0.027

PDDS: Patient Determined Disease Steps.

affordability of adaptive aids and DMTs. These findings are consistent with a recent Canadian microsimulation study showing the rising costs associated with MS,²³ studies highlighting the low availability of neurologists in Canada,²⁴ and the importance of coordination of care due to the complex needs of PwMS.⁷ What our study contributes is a ranking of these needs from the perspective of Canadians with MS.

Prioritized healthcare access concerns

The top concern of participants was access to healthcare providers with MS-related knowledge in their community to guide care planning and referrals. PwMS wanting generalists to possess more MS-related knowledge has been reported both internationally,^{15,16} and in Canada.⁷ Further, a Canadian study investigating family physician' knowledge of MS diagnosis and treatment demonstrated low levels of basic MS knowledge, even though respondents managed patients with MS.²⁵ Another Canadian study reported that many family physicians do not feel comfortable managing PwMS.²⁶ Several strategies could address these challenges: offering additional continued medical education for these practitioners regarding the features and management of MS; strengthening communication and coordination between MS neurologists and family physicians to foster the adoption of MS knowledge;²⁴

improving access to MS expertise through telehealth appointments and consultations,²⁷ as well as implementing interdisciplinary teams, including patient medical homes.²⁸

Although the Canadian healthcare system is publicly funded through Medicare,²⁹ the next two prioritized concerns of PwMS were related to affordability. More specifically, affordability of healthcare services outside of the hospital setting that help maintain independence and promote wellness. These needs align with participants reporting lack of affordability as a main barrier to seeing occupational therapists, physiotherapists, and complementary and alternative medical providers. Medicare does not cover these healthcare services, and while a majority of respondents have supplemental private insurance, coverage for physiotherapists and occupational therapists is often only partial, and limited by eligibility criteria,^{29,30} whereas complementary and alternative medical providers are often not covered. A recent MS Society of Canada survey showed that PwMS placed maintenance of independence as a crucial component of quality of life.¹⁴ Together these findings suggest that improving the quality of life of PwMS will require broader coverages including community-based healthcare services aimed to improve function, participation and independence. An additional measure that may help improve

access to occupational therapists and other interdisciplinary health providers would be an education initiative aimed to improve the knowledge about other professions and how to navigate access to these providers.

Profile of PwMS who reported the top 3 healthcare access items as concerns

There were multiple MS-related characteristics, social determinants of health and demographics that were associated with PwMS reporting these healthcare access concerns. Many of these characteristics help gain a clearer understanding of the profile of PwMS reporting these needs, however, they did not offer new insight that could help tailor approaches to healthcare reform. In general, the profile of those reporting these needs were of PwMS that reported higher symptoms interfering with daily life and higher reported comorbidities. As both symptom severity and comorbidities lead to higher disease burden and increased levels of disability spanning different functional systems,³¹ care seeking from individuals with MS-knowledge and healthcare providers promoting function and participation³² is warranted. The findings suggest that the barriers of affordability and availability of these warranted and required services need to be addressed to meet the ongoing needs of this group of PwMS.

A single modifiable factor was identified, that could be used to help improve a concern of PwMS. PwMS with higher confidence in their care seeking ability were less likely to report a need for healthcare providers in their community with MS-knowledge than those with lower levels of confidence, suggesting that an intervention helping PwMS develop care seeking skills and confidence may help address this concern. As PwMS age, they were also less likely to perceive this item as a concern, which may be due to gained knowledge and confidence in care seeking over the years.

Limitations

There are limitations to the current work. The sample size within individual provinces was not conducive to examining provincial and territorial differences, which is unfortunate since the Canadian healthcare system is managed at a provincial level, and therefore variations exist in care provision, drug coverage, and reimbursement models, and level of income. Access priorities may shift across Canada, based on specific community needs, as smaller villages in Newfoundland and Labrador may require more infrastructure support and access to DMTs, as compared to larger cities like Vancouver. Future work is required

to investigate these provincial and regional variation to help priority setting for their MS communities. The methods of recruitment, used to increase reach, made it impossible to measure response rates. Again, to improve reach and ease of survey delivery we used an online format, which may have limited our sample to people who can access the internet and know how to use it and persons with higher education and income that could afford access to a computer. Our sample did not reflect the diversity of ethnic and racial backgrounds of people with MS in Canada. Although we had a reasonable representation of people with progressive and relapsing types of MS, further work needs to be completed to ascertain if there are any major differences in terms of healthcare access priorities between these groups. As this study highlights the importance of access to healthcare that improves participation, we recommend that future studies on this topic include a measure of MS impact or participation, to expand understanding beyond typical measures like the PDDS, symptoms, and comorbidities.

Conclusion

The most pressing healthcare access concerns of Canadians with MS are related to lack of available healthcare providers with MS specific knowledge in their communities, as well as lack of affordability of complementary care, physiotherapy, and occupational therapy services that aim to maintain wellness and improve independence. These findings provide healthcare planners prioritized concerns and a profile of PwMS that have these concerns, which can be used to guide strategic planning to improve the quality of life of Canadians living with MS.

Conflict of Interests


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