



“How come you sent me the Canadian one?” Application and uptake of the Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis in the United States

Journal:	<i>Adapted Physical Activity Quarterly</i>
Manuscript ID	APAQ.2020-0136.R1
Manuscript Type:	Original Research
Keywords:	physical activity, qualitative inquiry, health promotion, neuroscience, exercise

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UPTAKE OF PHYSICAL ACTIVITY GUIDELINES FOR MS

16 **“How come you sent me the Canadian one?” Application and uptake of the Canadian**
17 **Physical Activity Guidelines for Adults with Multiple Sclerosis in the United States**

18 **Introduction**

19 Multiple sclerosis (MS) is a chronic, often progressive, immune-mediated disease of the
20 central nervous system (CNS) with a prevalence of nearly 1 million adults in the United States
21 (Wallin et al., 2019) and 2.5 million adults worldwide (Browne et al., 2014). This disease
22 typically involves intermittent episodes of inflammation in the CNS that result in the
23 demyelination and transection of axons in the brain, optic nerves, and spinal cord (Hemmer et
24 al., 2006; Trapp & Nave, 2008), and later progresses into a neurodegenerative process involving
25 the lack of neurotrophic support in the CNS. The damage of CNS tissue, depending on its degree
26 and location, can manifest in a myriad of symptoms such as walking and cognitive dysfunction,
27 imbalance, fatigue, depression, and pain, and reduced quality of life and participation (Motl &
28 Pilutti, 2012).

29 There has been increased interest in the application of physical activity, particularly
30 exercise training, for restoration of function, management of symptoms, and improvements of
31 overall health and quality of life among people with MS (Dalgas et al., 2019; Motl et al., 2017).
32 Physical activity is defined as any bodily movement produced by contraction of skeletal muscles
33 and resulting in substantial increase in energy expenditure over resting levels (Caspersen et al.,
34 1985). Exercise training can be described as a type of physical activity that is planned,
35 structured, and repetitive with an objective of improving or maintaining fitness and other health
36 outcomes (Caspersen et al., 1985). The benefits of exercise training among persons with MS
37 include improvements in walking performance, cognition, balance, fatigue, depression, and
38 quality of life (Motl & Pilutti, 2012; Motl et al., 2017). Nevertheless, the majority of adults with

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39 MS do not engage in sufficient amounts of exercise training, often quantified as moderate-to-
40 vigorous physical activity, necessary for experiencing those benefits, particularly when
41 compared with healthy adults from the general population (Kinnett-Hopkins et al., 2019; Motl et
42 al., 2005). This conundrum of substantial benefit, yet lack of participation, has motivated interest
43 in creating approaches for broad-scale promotion of exercise training in MS.

44 There are many barriers for engagement in exercise among persons with MS, particularly
45 the lack of knowledge regarding the safety, benefits, and prescription of exercise training
46 (Learmonth & Motl, 2016). To that end, one likely explanation for the lack of broad-scale
47 participation in exercise among people with MS may involve uncertainty regarding a guideline
48 for a safe and effective dose of this behavior for health benefits. Such an observation motivated
49 the development of a guideline for prescribing the appropriate dose of exercise for people with
50 MS based on existing evidence for improvements of fitness, function, symptom, and quality of
51 life outcomes (Latimer-Cheung, Pilutti, et al., 2013). The scientific evidence informed the
52 development of the Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis
53 (PAGs) for adults aged between 18 and 64 years who have mild-to-moderate MS disability
54 (Latimer-Cheung, Pilutti, et al., 2013). The PAGs recommend engaging in 30+ minutes of
55 moderate-intensity aerobic exercise twice weekly and strength training exercises for major
56 muscle groups twice weekly, and meeting these guidelines should yield improvements in fatigue,
57 mobility, and health-related quality of life (Latimer-Cheung, Martin Ginis, et al., 2013).

58 We are aware of two studies reported in three papers that have examined the feasibility
59 and outcomes of delivering the PAGs in MS (Adamson et al., 2016; Canning & Hicks, 2020;
60 Learmonth, Adamson, Kinnett-Hopkins, et al., 2017). The first study examined the feasibility of
61 delivering a home-based exercise program supported by telerehabilitation for meeting the PAGs

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62 in MS (Adamson et al., 2016; Learmonth, Adamson, Kinnett-Hopkins, et al., 2017). The results
63 supported the feasibility of delivering a home-based exercise intervention for meeting the PAGs
64 among adults with mild-to-moderate MS based on the feasibility metrics of process (e.g.,
65 recruitment and eligibility rate), resource (e.g., monetary costs of research and adherence,
66 retention, and attrition rates), management (e.g., IRB approval procedures and staff time
67 requirements), and scientific (e.g., adverse events, participant demographic information, and
68 treatment effects) outcomes. The results further indicated that the home-based exercise
69 intervention based on the PAGs significantly increased exercise behavior based on scores from
70 the Godin Leisure-Time Exercise Questionnaire (GLTEQ) and patterns of change in aerobic and
71 resistance exercise training recorded in participants logs. All participants in the intervention
72 condition progressively increased the volume of aerobic and resistance activity over the 4-
73 months of the program. For example, the mean volume (i.e., time duration and number of steps)
74 of the aerobic component of the intervention was 15.5 ± 18 min and 1568 ± 1356 steps per
75 session in Week 1 of the program, and this increased progressively wherein the mean volume
76 was 39.1 ± 11.1 min and 3966 ± 1076 steps per session in Week 16 of the program. The second
77 study examined the benefits of meeting the PAGs in persons with MS (Canning & Hicks, 2020).
78 The researchers reported significant improvements in fitness, mobility, fatigue, and quality of
79 life and confirmed that meeting the PAGs can yield benefits for people with MS. The PAGs
80 further serve as the basis of the exercise prescription in a large, multi-site, and ongoing
81 comparative effectiveness study of center versus home-based exercise for improving mobility in
82 MS (Motl et al., 2019).

83 The aforementioned research seemingly supports the applicability and perhaps efficacy of
84 the PAGs in MS, yet exercise levels (based on rates of physical activity) have remained

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85 markedly low in people with MS even after the publication of the PAGs. This may suggest a
86 problem with the dissemination and uptake of the PAGs in MS and this is a target of focal
87 research (Richardson, Fifolt, et al., 2020). For example, one recent review paper suggested that
88 establishing a conceptual framework and toolkit for translating the evidence-based guidelines
89 into practice could be instrumental in changing exercise patterns in MS (Motl et al., 2017). This
90 is consistent with research indicating that many persons with MS receive minimal or conflicting
91 advice on exercise from healthcare professionals (Learmonth, Adamson, Balto, et al., 2017), yet
92 would prefer exercise information from healthcare professionals or professional with both MS
93 and exercise knowledge (Learmonth & Motl, 2016). This collectively indicates that further
94 understanding of the knowledge, needs, and preferences for approaches of implementing the
95 PAGs could provide a major step-forward in the promotion of exercise in MS.

96 To date, there is limited information and understanding regarding the knowledge, needs
97 (e.g., resources) and preferences (e.g., settings) of people with MS for implementing the PAGs.
98 Such information is important for developing strategies for broad-scale dissemination and
99 implementation of the PAGs in MS. The current study adopted a qualitative research design and
100 sought information on awareness of the PAGs, and potential approaches for increasing the
101 uptake of the PAGs by people with MS from across the United States. We addressed three focal
102 questions, namely (1) ‘What are your first impressions of the PAGs?’ (2) ‘What would you add,
103 remove, or clarify regarding the PAGs?’, and (3) ‘How would you personally use the PAGs?’.

104 **Methods**

105 **Philosophical assumptions**

106 This research was informed by an interpretivist paradigm (i.e., ontological relativism and
107 epistemological constructionism). Ontological relativism asserts that reality is malleable, socially

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108 constructed, and subjective (Papathomas, 2016). Epistemological constructionism perceives
109 knowledge as something constructed through interactions between individuals in respective
110 social and cultural environments, and that researchers are intimately a part of this knowledge
111 construction (Burr, 2015). The researchers further use experiences in the construction and
112 interpretation process. Reflecting the assumptions of this research, an inductive, thematic design
113 was implemented with the objective of creating a rich, in-depth, and cohesive account of
114 approaches for increasing the uptake of the PAGs in MS.

115 Sampling procedure and participants

116 Overall, 40 persons with MS were recruited for this study. To recruit participants, we
117 used purposeful sampling strategies involving convenience, criterion-based, and quota-based
118 maximum variation techniques. We adopted these particular sampling strategies for the inclusion
119 of different geographical, cultural, and MS experiences regarding exercise (Sparkes & Smith,
120 2013). Quota-based sampling seeks an equal representation of participants (Robinson, 2014). We
121 targeted recruitment of 7+ persons per geographical region of the U.S. for a broad cross-section
122 of feedback on the PAGs. Our recruitment of 7+ participants per geographic region provides
123 rigorous heterogeneity in a cross-sectional sample, and a total sample size of 40 is consistent
124 with recommendations on qualitative research sample size (Bernard, 2017; Berteaux, 1981;
125 Creswell & Poth, 2018; Kuzel, 1992; Morse, 1994) that recommend 6-8 participants be recruited
126 per heterogeneity (e.g., Southeast, Southwest, Midwest, West, and Northeast). The final sample
127 of 40 participants represented 27 of the states in the United States. To use quota sampling, we
128 utilized an extensive list of persons who contacted us and requested information about studies
129 from our lab, and divided the list into Northeast, Midwest, Southeast, Southwest, and West. To
130 apply maximum variation sampling, the first author mailed flyers containing study information

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131 among 202 potential participants who were wide ranging regarding geographic region of the
132 United States, gender, and age, yet who seemingly matched the inclusion criteria. Of these 202
133 persons, 40 expressed interest and were screened for inclusion criteria: (i) age over 18 years, (ii)
134 confirmed diagnosis of MS, (iii) and Multiple Sclerosis Neuropsychological Screening
135 Questionnaire (MSNQ) score ≤ 27 (Benedict et al., 2004). There were no individuals who did not
136 meet the eligibility criteria, and no participants were lost to follow up. Age ranged between 39
137 and 80 years with a mean age of 58.6 (SD = 9.3) years. The majority of participants were
138 Caucasian (n = 36; 90%) and female (n = 30; 75%), and this is reflective of the U.S. MS
139 demographics (Wallin et al., 2019). Seven participants reported being diagnosed with primary-
140 progressive MS, 10 participants were diagnosed with secondary-progressive MS, and most
141 reported being diagnosed with relapsing-remitting MS (n = 23; 58%). The disease duration
142 ranged between 2 and 45 years, with a mean disease duration of 18.0 (SD = 10.1) years.

143 Data collection

144 Data were collected through online, one-on-one, semi-structured interviews; the
145 interview guide is provided in the appendix. Although the interview itself covered a range of
146 topics, for the purpose of this research we are focusing only on data pertaining to the PAGs. We
147 intend to explore other areas at a later date. Interviews were conducted using online virtual
148 meeting software (i.e., video conferencing) that allowed for face-to-face interviews via computer
149 or tablet. Video conferencing methods of data collection are emerging as a common method
150 utilized by qualitative researchers because of reduced barriers for participation (Hanna, 2012).
151 This method has been highlighted as the preferred method among persons with MS (Synnot et
152 al., 2014). This method of interviewing allowed for longer, more in-depth interviews with
153 individuals from across the U.S., as there was little effort committed to travel (Janghorban et al.,

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154 2014) and did not exacerbate fatigue of persons with MS (Synnot et al., 2014). Additionally,
155 online interviewing moderates the researcher-participant power differential as it gives the
156 participant the option to terminate the conversation at any time if they begin to feel
157 uncomfortable, just by clicking a button (Bertrand & Bourdeau, 2010). Video conferencing
158 further facilitated a richer data set of diverse experiences as geographic location is no longer a
159 barrier (i.e., 27 states represented across all 5 geographic regions of United States). We thereby
160 collected data from a broader geographic area regarding opinions on the PAGs. In an effort to
161 obtain a representative sample, if a participant was unable to connect to the videoconferencing
162 system, the interview was completed via phone. The semi-structured interview design allowed
163 participants freedom when discussing experiences important to them, but gave the interviewer
164 the opportunity for focusing on areas of interest. The interview guide was created through
165 engagement with the literature and discussion with the second and third authors, who acted as
166 ‘critical friends’ (Sparkes & Smith, 2013) and provided support, advice and feedback throughout
167 the research process.

168 Participants provided verbal consent for taking part in the interview with audio recording,
169 and participant names were removed from any written transcripts in line with the Institutional
170 Review Board approval process. Over 42 hours of raw data were collected (2510 min) and
171 interviews ranged between 30 and 90 minutes. Interviews lasted an average of 64.0 minutes (SD
172 = 12.2 minutes).

173 **Data analysis and rigor**

174 To understand the meaning in the data, we applied thematic analysis (TA), a qualitative
175 research method for identifying, analyzing, and interpreting common themes in collected data.
176 We applied inductive, semantic TA when analyzing the data whereby themes were constructed

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177 from participant testimonies rather than a pre-existing framework, and opinions and evaluations
178 of participants were identified explicitly in the data without applying a further layer of
179 interpretation (Clarke et al., 2016). To ensure rigor, we followed the six-stage guide on
180 conducting inductive TA (Clarke et al., 2016).

181 The first author took the lead throughout the research process including analysis. In phase
182 1, the first author became immersed in the data by conducting all interviews and (re)reading all
183 transcripts after completion. In phase 2, codes were applied to the data to generate a list of initial
184 ideas for each participant. Codes were segments of data that appeared interesting to the
185 researcher and that had the potential to become themes. These were highlighted using a
186 traditional method of writing notes in margins (Burnard, 1991, 1996). In phase 3, the first author
187 searched for themes. After codes were applied throughout all transcripts, a list was created for
188 each participant. The list of codes was then sorted and collated into potential themes. Similar
189 codes were placed in the same group. Phase 4 involved reviewing the themes to determine if
190 these were too diverse, insufficiently supported, could be consolidated into one theme, or needed
191 to be broken down into more specific themes. In phase 5, the themes were named in a way that
192 explained data content and any subthemes that existed within another theme were identified
193 (provided in Table 1). In phase 6 of the analysis, a report was produced, which will be presented
194 in the results and discussion section.

195 We utilized a relativist approach for ensuring scientific rigor in our research. This
196 stipulates that evaluative criteria must be specific for the purpose and design of the research
197 (Burke, 2016). We chose the evaluative markers of substantive contribution, coherence, and
198 transparency from the ongoing list proposed by Smith and Caddick (2012). We strived for our
199 work to make a substantive contribution by identifying a gap in knowledge within the field of

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200 MS, which if answered well, could meaningfully contribute to our understanding of exercise and
201 MS. We sought to be coherent by recruiting participants who represented various perspectives of
202 exercise in MS and could create a rich, meaningful picture of approaches for increasing the
203 uptake of the PAGs. We chose to maintain transparency by completing an audit trail whereby the
204 first author used the second and third authors as critical friends throughout the analytical process.

205 **Results**

206 Through thematic analysis, three main themes regarding the uptake of the PAGs were
207 identified; (i) PAGs are ‘a good introduction’ of structured exercise, (ii) PAGs should be
208 modified for inclusivity, and (iii) PAGs should be disseminated and implemented through a
209 multifaceted approach. We provide quotes below, and participants were assigned pseudonyms
210 for anonymity.

211 **PAGs are ‘a good introduction’ of structured exercise.**

212 This theme embodies perceptions of the PAGs regarding applicability for MS. Participants
213 viewed them as a solid foundation of information on structured exercise for MS; “... I feel like
214 it’s something concrete, and I’m very much, I’ve always been somebody that I need it laid out for
215 me. I need to have something in writing and laid out in front [of] me to follow it” (Lisa, F, 50).
216 Participants believed that the PAGs served as a memory aid and suggested different formats that
217 would be helpful for implementation, and these included written and illustrated information.

218 Well that would be beneficial for me to have the little picture-type things, you know? Or
219 else I find myself doing the same thing over and over, the little arm curls and forgetting
220 the back of the arms. I don’t know if it would be beneficial for everybody, but it would be
221 for me. (Sybil, F, 60)

222 Another participant compared the PAGs with the current guidelines for the general population:

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223 The guidelines already kinda help you get started. They tell you to look for the
224 professional, look for the qualifications and all that kinda stuff. And then, of course, the
225 what's recommended, the second page, where it says how often, how much, how hard.
226 You look up the ACSM [American College of Sports Medicine], they don't break it down
227 like that, because it's for the apparently healthy. I like how all of this is kind of spelled
228 out for you, in regards to helping somebody get started. It kinda gives them a little, well
229 guideline as to what to do. (Michelle, F, 45)

230 Regarding that extract, Michelle provided a personal overview of the information in the
231 PAGs. When comparing the PAGs for MS and those for the general population, Michelle pointed
232 out that the PAGs provide more recommendations on how to be physically active. The PAGs
233 provided options for aerobic activities (for both upper and lower body), strength training
234 activities (i.e., weight machines, free weights, cable pulleys), and other types of exercise that are
235 safe for adults with MS (i.e., elastic resistance bands, aquatic exercise, calisthenics). By
236 comparison, the recently updated PAGs for Americans, including adults with chronic health
237 conditions and disabilities, do not offer examples of aerobic or strength training activities
238 (Stamatakis et al., 2019).

239 **“Well this must not be for me”: PAGs should be modified for inclusivity.**

240 The previous theme highlighted first impressions of the PAGs and how participants
241 would use them for guiding/modifying current exercise routines; however, many deemed further
242 refinement of the PAGs as necessary for increasing uptake in MS. Participants specifically
243 expressed concern over the inclusion of ‘Canadian’ in the title and the exclusion of adults with
244 MS over age 64. This theme is comprised of two subthemes: “it doesn’t need to say Canadian”
245 and “increase the age limit”.

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246 ***“It doesn’t need to say Canadian”.***

247 Participants viewed the inclusion of ‘Canadian’ in the guidelines as a possible deterrent
248 for uptake by individuals with MS in the U.S.

249 Interviewer: Was there anything else that stood out to you when you kind of first looked
250 over them?

251 Participant: I was just curious. How come you sent me the Canadian one? (Erica, F, 63)

252 Well, the first thing I thought was I didn't realize that we were following the
253 Canadian Physical Activity Guidelines. Okay. Because I was gonna say, I was like is this
254 not implemented here? (Michelle, F, 45)

255 The question I had for you actually these say Canadian physical guidelines, does
256 that mean we don't have any? (Quinn, F, 42)

257 The initial labeling of the PAGs as ‘Canadian’ may infer that these are only for
258 Canadians with MS, and leave Americans with MS reasoning, "Well, this must not be for me
259 because I'm not from Canada" (Brenda, F, 67), or that the PAGs are only for “the country above
260 us” (Quinn, F, 42). Participants suggested a simple solution; “It doesn't need to say Canadian,
261 just physical activity guidelines for people with MS is probably sufficient” (David, M, 59).

262 ***Increase the age limit.***

263 The fact that the PAGs only offer recommendations for adults with MS up to 64 years of
264 age was a source of considerable consternation among participants:

265 Interviewer: ...When you looked over the guidelines, do you feel like there's anything
266 that we could improve on? Anything we could change?

267 May: What happens after age 64?

268 Interviewer: Excellent question.

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269 May: I mean, next year I'm 64, then what? I don't follow this or?

270 Interviewer: Right, right. So, clarifying that you don't have to stop exercising at the age
271 of 64. [crosstalk 00:36:47] Okay.

272 May: What's the point of the age range? (May, F, 63)

273 Participants further noted that limiting the PAGs to adults under 65 implies that older
274 adults with MS do not need to be active; “Well, see, the fact that I'm 67 and it says that these
275 guidelines are appropriate for adults 18 to 64, it's like, “Oh okay. Well, this isn't for me then”
276 (Brenda, F, 67). This is in direct contrast with the belief that “[at] any age, if you’ve got MS, you
277 need to be moving” (June, F, 73). Participants believed the PAGs do not prescribe exercise that
278 is too strenuous for older adults with MS; therefore, the age range should be extended:

279 I think you should extend it to older than 64. Because it's not that strenuous. Really. Two
280 times per week for... I mean, my dad's 93, and up until this year, he's slowed down a little
281 bit, but he still was walking, and he'd get up in the morning and he'd exercise. He has a
282 treadmill. He'd walk on his treadmill and he'd do some leg lifts. (Erica, F, 63)

283 Participants further reasoned that limiting the age up to 64 years makes people with MS
284 feel like they’re being let down by the medical profession: “But I just think if you tell someone
285 that... Put a cap on it, then they're going to mentally think, "Oh, well, the medical profession
286 doesn't think that I at this age should be doing this." But I think you should push people. That's
287 my attitude” (Erica, F, 63).

288 **PAGs should be disseminated and implemented through a multifaceted approach.**

289 This theme focused on attitudes towards dissemination strategies for the current PAGs
290 and suggestions toward increasing the implementation of the PAGs. Many participants were
291 concerned that someone unfamiliar with exercise might find “having this handout is close to not

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292 useful” (Joe, M, 59). Participants believed that utilizing a combination of dissemination
293 strategies would increase the awareness and implementation of the PAGs. These strategies
294 comprise the three subthemes and include improving the reach of the PAGs, increasing people’s
295 motivation for using and applying the PAGs, and increasing people’s ability for using and
296 applying the PAGs.

297 ***‘I wish I had known these existed’: Improve the reach of the PAGs.***

298 When questioned about prior knowledge of the guidelines, almost all participants
299 acknowledged having never seeing the PAGs before engaging in the research study.

300 But I never knew, I've had MS for 20 years, and I know exercise is important, and I know
301 all the talk of exercise, but I never knew there were actual guidelines.

302 I mean I really... I've gone to a lot of different... I'm having a word finding problem now.

303 Different presentations through our local neuro resource center on MS and MS and
304 exercise and different topics with MS. They've never once over all these years have
305 talked about physical activity guidelines. (Lisa, F, 50)

306 The lack of awareness of the PAGs echoed across participants and may illustrate the
307 ineffectiveness of passive dissemination strategies. Participants frequently cited electronic media
308 sources when questioned about current sources of exercise information: “I subscribe to many
309 online things, like multiple... MS Society, National MS Society, different MS-related groups.
310 They talk about different exercises and clinical studies, and different things, just to keep myself
311 educated” (Veronica, F, 47). Others referred to print media as a primary source of exercise
312 information; “[The MS Momentum magazine] comes in the mail. They have the online version,
313 but I don't do that. I prefer paper in my hands kind of thing” (Quinn, F, 42).

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314 Participants were interested in receiving PAG information via both print (brochures,
315 leaflets, and instruction booklets) and electronic (email, DVDs, websites, webinars, social media)
316 media sources; “Postal mail wouldn't be bad. Email wouldn't be bad. I hate blogs. In my old age
317 I'm becoming very ... I think social networks are going to be the death of this country” (Sam, M,
318 58). These preferences were in line with participants current experience and may reflect that
319 people with MS will seek out familiar information sources unless told otherwise.

320 Occasionally, some participants indicated that receiving information in print format may
321 not be ideal. This was either because participants perceived that people with MS would not take
322 the time to read printed information, or because printed information is harder to disseminate.

323 ***Increase motivation to use and apply the PAGs.***

324 Many participants discussed a preference for receiving exercise promotion information in
325 person and expressed that the ideal source for PAG dissemination would have professional
326 understanding of both MS and exercise. This was because participants deemed that such a source
327 would have a good understanding of MS symptoms and disease progression and prioritize these
328 areas when promoting the PAGs.

329 Interviewer: Do you feel like if your neurologist provided you information about exercise, or
330 provided you with these guidelines, do you feel like it's something that would matter, or
331 change your [inaudible 00:47:07]?

332 Heidi: Oh, I think, yeah, definitely. Especially if he was knowledgeable about 30 minutes of
333 aerobic exercise. Oh well, if you can't do 30 minutes, you can do 10 minutes, six times a
334 week. If he knew the guidelines, and not just, "Here you go, do this." If he could discuss it
335 with you, I think that would definitely hit home, for me anyway, to hear my doctor say, "If

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336 you try this, or..." Yeah. I don't think any of my neurologists has ever said anything about
337 exercise. (Heidi, F, 52)

338 There were participants who portrayed a lack of confidence in a neurologist's ability to
339 promote exercise. This was typically based on a previous negative experience with a neurologist.
340 Other participants reported that neurologists sometimes recommended exercise options that were
341 deemed personally inappropriate, and this resulted in the participant being less receptive to
342 exercise promotion from those healthcare providers.

343 Well, they sent me to a general neurologist first and he was ... I'm going to put him probably
344 late 50s, early 60s. Like on the verge of retirement. And his advice to me was, "You may
345 have MS, you need to rest. Don't do extra things. Figure out how to get by with the minimum
346 level of activity possible because that's going to preserve your energy." Because more
347 research has been done. He would have finished up residency what, 30 years ago? Maybe
348 that was what they did. But along the way there's been more time to study everything. There's
349 new guidelines that unless they're really up to date on all the latest research, the doctors that
350 completed residency 30 years ago aren't necessarily going to know. (Alexa, F, 39)

351 Participants want physicians to promote the PAGs and be educated about MS and
352 exercise; "I think doctors, some sort of... you can't just say "Okay doctors, you need to encourage
353 your patients to exercise." Because most of them don't know" (Kathryn, F, 60). Participants
354 sought discussions about exercise with physicians that were more than simply encouraging, but
355 instead offered productive exercise guidance. Participants further acknowledged the importance
356 of being motivated to exercise by the commitment of a clinical appointment. This aspect of
357 external accountability was wanted by all participants to a lesser or greater degree. Some of the
358 participants wanted the promotion of the PAGs to be part of coordinated healthcare involving

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359 neurologists and allied healthcare professionals (i.e., nurse practitioners, physical therapists,
360 exercise professionals). These participants wanted referrals for professions who were experts in
361 both exercise and MS.

362 When you're first diagnosed, it'd be hard to get them [the PAGs] from your doctor and
363 actually pay attention to them. Because when you're first diagnosed it's like A, you're trying
364 to learn as much as you can about what your diagnosis is. And so just being handed a sheet of
365 paper from your doctor that says hey, here's our guidelines. Or like I said, you go in for your
366 doctor's appointments to make sure that your medication's still working and all that, but that
367 they're going to refer you over to someone else maybe that works with the hospital or the
368 physical therapy department or something, where they say, "You know what, I'm going to
369 recommend that you go to six months with a wellness coach." And they're going to address
370 these various items and they'll have 15 minutes or a half our every other week to check in
371 with you. And that way you can have more time to digest the information. (Alexa, F, 39)

372 Participants who lacked confidence in the healthcare provider's ability to promote
373 exercise frequently deemed MS role models and peer support a useful strategy for increasing the
374 uptake of the PAGs. MS role models and peers can share PAG information in a way that is more
375 applicable, practical, and appealing to others with MS, making it more likely to result in a
376 behavior change. Participants frequently discussed the importance of peer support, "People with
377 MS need to be able to talk to one another to find out how they're doing, what's going on, what's
378 changed with them, what their doctors are telling them about what's new and everything else"
379 (Alfred, M, 71). One participant actually reported dispersing the PAGs among a support group
380 after receiving a copy of them; "I even presented, I made copies of the guidelines, and I had an
381 MS mom support group here, there were only two other women that showed up, and I gave them

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382 a copy of the guidelines” (Lisa, F, 50). Several participants further re-counted engaging others
383 with MS to become exercisers.

384 Any time I meet somebody with MS and occasionally I run across them you can usually
385 immediately tell what their attitude is whether they're a fighter or whether they just kind of,
386 "This is the way it is and I'm not going to do anything about it." People are fighters or at least
387 [inaudible 00:42:35]. I always tell them, "Look, I found bicycle riding to be very, very
388 beneficial. I highly suggest it but you got to find something." (Brian, M, 61)

389 ***Increase ability to use and apply the PAGs.***

390 This subtheme characterizes the wants and needs of people with MS regarding resources
391 for using and applying the PAGs. Participants felt that the PAGs provided a good introduction to
392 structured exercise, but many believed the PAGs lacked the details necessary to plan an exercise
393 program.

394 I think you pretty much covered the waterfront, because you talk about what the
395 guidelines are, what they're for, getting started, all that, and then you break it down into
396 frequency, how much, how hard to work, and how to do it. Beyond just as guidelines, it's
397 a good introduction. I'm sure there are people who are totally unfamiliar with this kind of
398 activity, would appreciate more detail. There's people out there, have no idea what free
399 weights are. (Bill, M, 66)

400 This sentiment was more common in participants who were either moderately active or
401 insufficiently active, and suggested that the inclusion of additional materials and resources may
402 be most useful for this subgroup and increase motivation for exercise. Participants want and need
403 materials that make exercise more feasible within the context of physical mobility, as well as
404 materials that facilitate goal setting and accountability.

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405 There was a strong preference for individualized exercise programs among participants,
406 and participants desired information on specific exercises for safely managing MS symptoms
407 that are appropriate for mobility level. One participant described an exercise ‘toolbox’ that
408 individuals with MS can access for exercises based on physical mobility.

409 And it could be a toolbox, and you can choose, these are aerobic exercises for people
410 with MS, with maybe moderate impairment. So choose from here, choose from here, and
411 you can kind of design your own and you'll benefit from some exercise that'll help
412 maintain your MS. (Beth, F, 70)

413 Participants were further clear about wanting an individualized exercise plan, particularly
414 for strength training; “It [the exercise plan] might have examples of strength training that would
415 be feasible for me to do, and what equipment I need to have in order to do that strength training
416 ... But, yeah, for me it would really just be getting examples ... of aerobic activity and strength
417 training” (Summer, F, 45). Participants sought an exercise program that allowed gradual
418 progression toward meeting the PAGs, no matter current exercise level and described the specific
419 exercise equipment which could be offered as part of the exercise program (resistance bands,
420 treadmills, and free weights). Some participants suggested providing alternatives to traditional
421 aerobic exercise, such as dancing.

422 Another thing, which they don't mention in here, if you go cable, we got one TV in the
423 house, and the last time it was on was months ago. We just don't watch TV. But there are
424 exercise programs, there are DVDs, I know for a fact there is stuff on YouTube. One of
425 the things I do with YouTube, I found a ... and I forget what they call it, grooving to the
426 60s or rock and roll, let me see if, I don't remember it right now. But it's a riot, it's Oldies
427 music, it's classic rock and roll, stuff from 50s, 60s. And they just play all this really cool

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428 rhythmic music. Well find some music that you really like and stand there and move. I
429 think they could have expanded the other types of exercise that could bring benefit
430 because some of that is just stuff you can do right at home. (Kathryn, F, 60)

431 Participants further wanted materials to facilitate planning, goal setting, and
432 accountability. Participants wanted and needed assistance in clearly identifying facilitators for
433 exercising as well as methods to self-monitor exercise behaviors (i.e., written exercise diaries or
434 mobile phone applications with exercise diaries, fitness tracker). Participants discussed methods
435 to increase accountability to exercise and the importance of social support. One participant felt
436 that having someone review a personal exercise diary would increase motivation and adherence
437 for exercise; “Someplace where I can log my activity that it's actually reviewed by someone or...
438 because I can log it myself, but if I'm the only one reviewing it, the motivation isn't there” (May,
439 F, 63).

440 Social support in the form of MS-specific exercise classes was another example strategy
441 for uptake of the PAGs. Participants frequently expressed a desire for MS-specific exercise
442 classes; “So I just wish they had programs at the gyms and stuff for people that look like they're
443 normal or whatever, but not so hard on. Where I'd be more encouraged to go, and want to go to
444 somewhere like that and work out” (Donna, F, 55). Difficulty keeping pace in a “normal”
445 exercise class and consequently falling was a commonly cited fear among participants.

446 Or maybe my leg gives out and I'm on the floor and everybody's like, "Oh my God, are
447 you okay?" That's one of my biggest fears, being somewhere ... I mean I would love to go
448 to a gym and be able to do that but the fear of not being able to do it and disrupting the
449 class or causing a disruption or whatever. That's why I don't do it. (Tamara, F, 51)

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450 Providing MS-specific exercise classes structured around the PAGs offers a source of social
451 accountability, and participants suggested offering these classes both online and in-person. One
452 participant referenced an existing online exercise class specific for those with MS; “I will tell
453 you that, and again, this speaks to my motivation, I have signed up for something referred to as
454 MS Challenge. It's a series of online classes, Donald Burr and the MS workouts team” (Bill, M,
455 66). Many felt that classes offered in-person should be done so through existing organizations
456 such as the YMCA or National MS Society (NMSS).

457 That's a good way. A good thing would be like, that I haven't been able to fit in my
458 schedule, but like a group activity with people with MS or through the ... Shoot. The
459 YMCA. They've offered workout things too, but I don't have a YMCA in my area,
460 though I've seen some of their advertising stuff. But and I've seen how the MS Society
461 has offered exercise once in a while, like once a week or so. So, that's something that's
462 cool, that's offered for people with MS ... (Asher, M, 60)

Discussion

464 The PAGs recommend adults with MS between 18 – 64 years of age engage in 30+
465 minutes of moderate-intensity aerobic exercise twice weekly and strength training exercises for
466 major muscle groups twice weekly, and research suggests that meeting these guidelines is
467 achievable (Adamson et al., 2016; Canning & Hicks, 2020; Learmonth, Adamson, Kinnett-
468 Hopkins, et al., 2017) and can yield significant improvements in fitness, mobility, fatigue, and
469 quality of life (Canning & Hicks, 2020; Latimer-Cheung, Martin Ginis, et al., 2013).
470 Nevertheless, engagement in exercise training, based on rates of overall physical activity levels,
471 is still remarkably low, and this may be explained by the many barriers for engagement in
472 exercise among persons with MS, particularly the lack of knowledge regarding the safety,

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473 benefits, and prescription of exercise training (Learmonth & Motl, 2016). To that end, this
474 underscored our interest in research regarding perceptions, understanding, and awareness of
475 PAGs for exercise engagement in people with MS. This study adopted a qualitative research
476 design and gathered information regarding the knowledge, needs (e.g., resources) and
477 preferences (e.g., settings) of people with MS for implementing the PAGs outside of clinical
478 research. The PAGs were perceived as an essential step toward removing existing informational
479 barriers regarding exercising with MS, but participants expressed a strong desire for more tips
480 and strategies on how to implement and meet the PAGs. Participants further underscored the
481 importance of modifying the PAGs for inclusivity and applying a multifaceted approach for
482 dissemination and implementation that may increase uptake of exercise behavior.

483 The participants generally agreed that the PAGs provided a solid foundation for structured
484 exercise, yet were concerned that the PAGs were more informative than instructional,
485 particularly for those who were physically inactive or new exercisers. Indeed, the PAGs
486 recommend an appropriate dose of aerobic and strength training exercise for people with MS, yet
487 only general guidance is provided on gradually increasing duration, frequency, and intensity as a
488 progression towards the guidelines. People with MS who are non-exercisers will likely be
489 required to seek this information elsewhere (Lavis et al., 2003), and this additional step in the
490 information seeking process may pose a barrier to uptake. Indeed, previous research indicates
491 that people with MS desire exercise training information that conveys not only the importance
492 of being active, but further offers a wide array of suggestions for symptom-specific exercises
493 (Sweet et al., 2013). Therefore, it is crucial to construct and deliver PAGs that target inactive
494 individuals with little or no past experience with exercise training as these people might be more
495 likely to seek exercise training information than persons who are regularly active. The PAGs

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496 should convey the benefits of exercise, address misconceptions about exercise training, and offer
497 symptom-specific suggestions on engaging in exercise.

498 Another overarching issue was that participants believed the PAGs were focused too
499 narrow on a group of individuals with MS. One area of big concern was related to the title
500 “Canadian Physical Activity Guidelines for Adults with Multiple Sclerosis”; there was a strong
501 consensus that the title infers that the PAGs are only for individuals with MS who live in
502 Canada. Indeed, this lack of applicability is a common barrier to guideline implementation
503 (Fischer et al., 2016), and this highlights the importance of inclusiveness in the dissemination
504 and implementation planning process. For example, amending the title to the “Physical Activity
505 Guidelines for Adults with MS” would highlight that the PAGs are for all people with MS. The
506 PAGs further prescribe exercise for adults with MS aged between 18 and 64 years who have
507 mild-to-moderate MS disability (Latimer-Cheung, Martin Ginis, et al., 2013), and this excludes
508 individuals over the age of 65 as well as those who are non-ambulatory (i.e., wheelchair users).
509 This is of utmost concern since there are increasing numbers of adults with MS who are now
510 aging into older adulthood (Marrie et al., 2010; Minden et al., 2004), and these individuals are at
511 an elevated risk of future disability. The existing research indicates that reducing sedentary
512 behavior and/or increasing exercise reduces this risk and improves physical function among the
513 general population of older adults (McAuley et al., 2013), and we are aware of a few studies
514 suggesting the same is true for older adults with MS (McAuley et al., 2015; Sebastião et al.,
515 2018).

516 Participants were dissatisfied with the current passive dissemination strategies and
517 believed that utilizing a combination of different, mutually reinforcing dissemination strategies
518 would increase the awareness and implementation of the PAGs. These strategies included

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519 increasing the awareness of the PAGs through the use of print and electronic media sources,
520 training doctors and MS peers to disseminate the PAGs, and providing additional materials and
521 resources to increase uptake, and is in line with other research (Learmonth, Adamson, Balto, et
522 al., 2017; Sweet et al., 2013). One approach for increasing the uptake of the PAGs addresses a
523 more general problem: the ineffective translation between a health behavior and putting that
524 behavior into practice (Schüler et al., 2019). In order for people with MS to successfully meet the
525 PAGs, it is important to tailor information that addresses not only MS limitations, but further
526 self-management capabilities and motivational preparedness for implementing the PAGs. Social
527 cognitive theory (SCT) is derived from social-learning theory and posits that individuals learn
528 behaviors through dynamic, reciprocal interactions between the person, the environment, and the
529 behavior (Bandura, 2004). There are four core determinants of SCT, namely self-efficacy,
530 outcome expectations, goal setting, and facilitators/impediments (Bandura, 2004). Bandura
531 (2004) further highlighted that the extent to which an individual acts upon these core
532 determinants is influenced by knowledge (or lack of knowledge) of health risks and benefits, and
533 posited that this informs a threefold stepwise implementation model that can help healthcare
534 providers tailor support and guidance based on an individual's motivation for change. Table 2
535 includes the brief descriptions of these levels, and research supports an association between
536 changeability readiness and exercise behavior (Fifolt et al., 2018; Silveira et al., 2020). The
537 stepwise implementation model could prove useful in planning the dissemination and
538 implementation of the PAGs by ensuring materials and strategies are appropriate for people with
539 MS no matter what level of change they're in. For example, providing more practical evidence
540 and personal experience of the beneficial effects of exercise may increase the self-efficacy of
541 level 2 individuals with MS (those who require additional support and guidance through

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542 interactive means) and help tilt them towards exercise. As noted in the results, participants who
543 were either moderately active or insufficiently active (level 3) wanted not only tips and strategies
544 on how to reach the PAGs, but an exercise ‘toolbox’ with informational resources providing tips
545 on how to reach the PAGs based on their physical mobility. Future research should evaluate the
546 relevance of the stepwise implementation model for increasing the uptake of the PAGs in people
547 with MS.

548 **Limitations**

549 This study is not without limitations. All interviews were conducted online, reducing the
550 interviewer’s ability to perceive bodily, non-verbal cues that can provide rich information in
551 qualitative research. Participants in the study were primarily middle-aged Caucasian females
552 with RRMS, highlighting the need for research among different subgroups within the MS
553 population such as those who experience health disparities (e.g., African Americans). We further
554 acknowledge that we only recruited persons from 27 states, and as participant experiences across
555 regions and states may differ, it is important that future investigations occur on a wider scale.
556 Future research should look through a more cultural/geographical lens and identify differences in
557 barriers and facilitators to physical activity among different regions in the U.S., particularly those
558 sharing a border with Canada. We do note that some research suggests that there might not be
559 noteworthy or substantial differences in perceptions of exercise across regions of the United
560 States (Richardson, Barstow, et al., 2020). There further is limited information on the
561 knowledge, needs, and preferences of Canadians with MS for implementing the PAGs outside of
562 clinical research, and future research might address this possibility of similarities/differences
563 between countries in North America and worldwide. Overall, we minimized limitations by

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564 following an interview guide, conducting ongoing qualitative methodology training among
565 authors, and approaching data analysis using an inductive thematic approach.

566 **Conclusions**

567 This study represents preliminary work of understanding the knowledge, needs (e.g.,
568 resources) and preferences (e.g., settings) of people with MS regarding implementing the PAGs
569 outside of clinical research. We established that the PAGs provide a good introduction to
570 exercise, yet there is a strong desire for further details on the appropriate frequency, duration,
571 intensity, and exercise modality that persons with MS ought to follow in order to receive health
572 benefits. Overall, the current data underscores the importance of applying a multidisciplinary
573 approach to dissemination to increase the overall uptake and implementation of the PAGs across
574 geographic settings among people with MS. The primary focus of research on exercise training
575 in MS should include both analyzing the effects of exercise in this population *and* the specific
576 challenges faced by persons with MS in putting the PAGs into practice.

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For Peer Review

UPTAKE OF PHYSICAL ACTIVITY GUIDELINES FOR MS

734 **Table 1.** Themes and subthemes.

Theme	Subtheme	Codes
PAGs are a 'good introduction' for structured exercise		<ul style="list-style-type: none"> • Outline for exercise program • PAGs provide centralized physical activity information • Use PAGs to evaluate current exercise routine • Generalizable to all settings
PAGs should be modified for inclusivity	<ul style="list-style-type: none"> • "It doesn't need to say Canadian" 	<ul style="list-style-type: none"> • Aerobic activity suggestion daunting to inactive people with MS • PAGs are for Canadians • Rebrand guidelines • Age limit unnecessary
	<ul style="list-style-type: none"> • Increase the age limit 	
PAGs should be disseminated and implemented through a multifaceted approach	<ul style="list-style-type: none"> • "I wish I had known these existed": Increase the reach of the PAGs 	<ul style="list-style-type: none"> • No prior knowledge of PAGs • PAGs must come from reputable source • Disseminate PAGs via digital/social media • Disseminate PAGs via print media/mailing/email
	<ul style="list-style-type: none"> • Increase motivation to use and apply PAGs 	<ul style="list-style-type: none"> • Healthcare professionals should encourage PAGs • Low confidence in neurologist for exercise information • People with MS inform people with MS
	<ul style="list-style-type: none"> • Increase ability to use and apply PAGs 	<ul style="list-style-type: none"> • Not enough information to implement • Exercise program based on mobility • Guidance on appropriate equipment • Information on types of exercises • Include behavior change strategies

735 Note: PAGs = Physical Activity Guidelines for Adults with Multiple Sclerosis; MS = multiple
 736 sclerosis

UPTAKE OF PHYSICAL ACTIVITY GUIDELINES FOR MS

737 **Table 2.** Three levels of the stepwise implementation model.

LEVEL	DESCRIPTIONS
1	The first level includes people with a high sense of self-efficacy and positive outcome expectations for behavior change. These persons can typically succeed with behavior change with minimal guidance, and only require minor prompts.
2	The second level includes people who have self-doubts about self-efficacy and the likely benefits of behavior change. These persons require additional support and guidance by interactive means for behavior change, and this could be provided through tailored print or telephone consultations.
3	The third level includes people who believe that current health habits are beyond personal control and see little benefit for behavior change. These persons require a great deal of personal guidance in a structured mastery program for behavior change. Progressive successes build belief in the ability to control and bolster the staying power for behavior change in the face of difficulties and setbacks.

738 Based on Bandura (2004).

739 Health promotion by social cognitive means. (p. 146, 148)

UPTAKE OF PHYSICAL ACTIVITY GUIDELINES FOR MS

740 **Appendix A. Implementing the Physical Activity Guidelines for MS Interviewing Protocol**741 **Grand Tour Questions**

- 742 1. First, can you tell me about yourself?
- 743 a. Years since diagnosis of MS
- 744 b. Type of MS
- 745 c. Work/family/hobbies
- 746 d. Living situation/location
- 747 2. Can you tell me about your experiences exercising?
- 748 a. What has helped you exercise?
- 749 b. What has made it difficult for you to exercise?
- 750 c. Does where you live effect your participation in exercise?
- 751 d. How has exercise impacted you and your MS?

752 **Guideline-Specific Questions**

- 753 1. What were your first impressions of the guidelines?
- 754 2. Could you see yourself following these guidelines?
- 755 a. Why/Why not?
- 756 3. How would you use these guidelines in your setting?
- 757 4. What resources would you need in order to successfully implement these guidelines?
- 758 a. Why would you need those resources?
- 759 5. What do you think are the strengths of these guidelines?
- 760 6. What do you think could be improved?
- 761 7. In your opinion, how easy do you think it would be for people with MS living in different
- 762 areas across the country to follow these guidelines? Why?
- 763 8. What would you add, remove, or clarify regarding the guidelines?
- 764 9. Is there anything else you would like to say about the physical activity guidelines for
- 765 people with MS that has not been covered?
- 766 10. How do you get your information about exercise? Or how would you like it to be
- 767 delivered to you?