

# Perceptions of physical activity guidelines among wheelchair users with multiple sclerosis

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## Abstract

**Background:** Physical activity guidelines provide prescriptive resources for population-level promotion of behavior change to improve health outcomes. The National Multiple Sclerosis Society (NMSS) recently created and disseminated physical activity guidelines for persons with multiple sclerosis (MS) across the disease spectrum.

**Objective:** This study aimed to assess perceptions of the updated NMSS Physical Activity Guidelines among wheelchair users with MS.

**Methods:** One hundred thirty-four wheelchair users with MS participated in a cross-sectional study examining health behaviors. Outcomes were measured using an online questionnaire that included items related to demographic and clinical characteristics and a battery of questions regarding perceptions of the NMSS Physical Activity Guidelines based on Expanded Disability Status Scale groups 7.0–7.5 & 8.0–8.5.

**Results:** Among the 134 participants, 77 participants (58%) did not meet the general recommendations, 43 participants sometimes meet the general recommendations (32%), and 14 participants (10%) reported meeting the general recommendations. Participants reported positive perceptions across modalities (i.e. Breathing, Flexibility, Upper Extremity, Lower Extremity, and Core Exercises); however Upper and Lower Extremity Exercises were rated as the most challenging based on inability to complete independently.

**Conclusion:** Wheelchair users with MS in this study generally rated the NMSS Guidelines for Physical Activity as appropriate.

**Keywords:** Multiple sclerosis, exercise, physical activity, wheelchairs, guideline adherence, health promotion

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## Introduction

Physical activity guidelines provide healthcare providers and policymakers with prescriptive resources for promoting behavior change and improving health outcomes among target populations. The Physical Activity Guidelines for Americans were first released in 2008 and focused on improving health outcomes among adults, children and adolescents, older adults, women during pregnancy and postpartum, adults with disabilities, and people with chronic medical conditions.<sup>1</sup> The updated second edition, released in 2018, added specific benefits regarding outcomes such as brain health, cancer, and sleep, and highlighted the risks of sedentary behavior.<sup>2</sup>

There have been additional physical activity guidelines for spinal cord injury, Parkinson's Disease, stroke and multiple sclerosis (MS).<sup>3–8</sup> The Canadian Physical Activity Guidelines for Adults with MS, in particular, were developed in 2013 through a rigorous scientific literature review and focused on a guidelines for improving health and disease outcomes among adults of 18–64 years with mild-moderate disability resulting from relapsing remitting or progressive clinical courses.<sup>4</sup> The guidelines included recommendations for aerobic and strength training exercises, and target 30 + minutes of moderate-intensity aerobic activity twice per week (60 min total) and strength training with an emphasis on training all major

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muscle groups on 2 or more days a week. There were obvious limitations of those guidelines with the most significant being the lack of recommendations for those with advanced disease characterized by wheelchair use; this was based on the lack of scientific evidence for benefits of physical activity in this segment of MS.

The National MS Society (NMSS) later addressed significant gaps in the Canadian Physical Activity Guidelines for Adults with MS, specifically the lack of guidelines for adults with severe MS and omission of additional modalities that might benefit persons with MS.<sup>9</sup> The expert panel included physicians, nurses, physical therapists, occupational therapists, exercise scientists, community health professionals and created the NMSS Physical Activity Guidelines that focused on both lifestyle physical activity and exercise for major subgroups of differing disability status based on Expanded Disability Status Scale (EDSS) ranges.<sup>10</sup> This resulted in guidelines for those with mild impairment (i.e. EDSS 0–4.5), increased mobility impairment (i.e. EDSS 5.0–6.5), diminished ability to perform activities of daily living (ADLs)—non-ambulatory (i.e. EDSS 7.0–7.5), increasing difficulty performing ADLs—confined to a wheelchair (i.e. EDSS 8.0–8.5), and inability to perform most ADLs—confined to a bed or chair (i.e. EDSS 9.0). Of note, the guidelines for those with advanced MS disability were largely based on expert opinion, whereas those for persons with mild or moderate MS disability were evidence-based and supplemented by expert opinion. Such guidelines provide a roadmap for healthcare providers and researchers for prescribing exercise for all persons with MS; however, substantial inquiry is needed to understand the appropriateness of the guidelines from the perspective of persons with MS, particularly those with more severe disease who were excluded from the original Canadian guidelines.

This study assessed perceptions of the NMSS Physical Activity Guidelines among wheelchair users with MS (i.e. EDSS 7.0–8.5). This research was timely, as there are currently no evidence-based physical activity programs for wheelchair users with MS.<sup>11</sup> This report provides a foundation for current physical activity behavior within the exercise modalities prescribed within the guidelines (i.e. breathing, flexibility, upper extremity, lower extremity, and core exercises) and participant opinions regarding benefits, harms, and challenges of engaging in physical activity that can guide future research and practice.

## Materials and methods

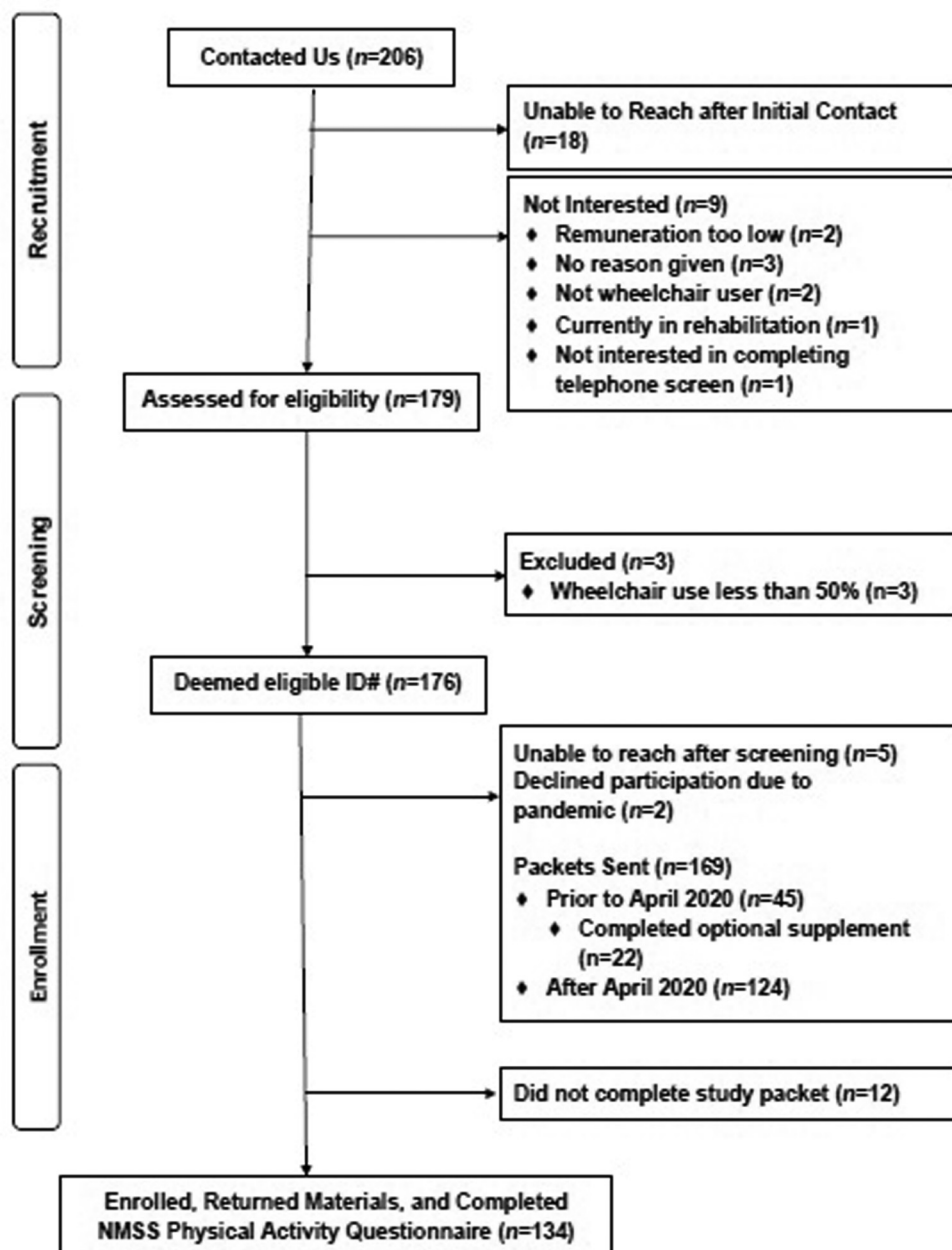
### Participants

Participants for this study were recruited from a larger cross-sectional study examining diet, physical activity, and wellness outcomes in wheelchair users with MS.<sup>12</sup> The larger study included a one-week data collection period wherein participants completed a large battery of questionnaires regarding diet, physical activity, and wellness outcomes as well as device-measurement of physical activity that are beyond the scope of the current study.<sup>12</sup> Participants were recruited from February 2020–July 2021 through e-mail and postal mail advertisements via the NMSS, iConquerMS, and North American Research Committee on MS. Interested participants contacted the research team and were screened for the following inclusion criteria: (a) age 18 years or older, (b) diagnosis of MS, (c) use of a wheelchair for mobility  $\geq 50\%$  of the day, (d) Internet access, and (e) willingness to complete the study protocol.

Two hundred six individuals expressed interest, and 179 were formally screened for eligibility (Figure 1). One hundred seventy-six individuals were deemed eligible. We followed up with participants prior to mailing packets to ensure it was appropriate timing and seven participants were lost to follow-up (i.e. 169 packets were mailed). Twelve participants dropped out or did not complete the protocol. The NMSS Physical Activity Guidelines were released in April 2020 after the study had begun, and we submitted an Institutional Review Board (IRB) amendment to (i) contact participants who completed the study to invite them to complete an optional supplement providing feedback on the NMSS Physical Activity Guidelines ( $n = 45$ ) and (ii) add the supplemental questions providing feedback on the NMSS Physical Activity Guidelines to the survey for all participants enrolled moving forward. Twenty-two participants who completed the study prior to April 2020 completed the NMSS Physical Activity Guidelines questionnaires as an optional supplement, and 112 participants completed the questionnaires as part of the full study protocol (i.e. packet sent after April 2020). The final sample for this study included 134 participants who enrolled, returned materials, and completed the Demographics and NMSS Physical Activity Guidelines Questionnaires described further in *Measures*.

### Procedures

All study procedures were approved by the University of Alabama at Birmingham IRB (IRB-300004359).



**Figure 1.** CONSORT diagram depicting participant recruitment, screening, and enrollment.

Participants who were deemed eligible during telephone screening were invited to enroll in the study, which was completed in their home. The research team contacted enrolled participants prior to sending packets to ensure that it was an appropriate time for the one-week data collection. Study packets were sent in batches and included two copies of the informed consent document, instructions for completing questionnaires online, and a pre-paid envelope for returning materials. Upon receipt of the study packet, participants were prompted to complete

questionnaires online using Qualtrics survey software. Participants were only considered enrolled and compensated if they returned a signed informed consent document via pre-paid postage provided.

### Measures

#### *Demographics and MS clinical characteristics.*

Participants self-reported demographic characteristics including biological sex, marital status, age, employment status, race, and level of education. Participants

self-reported MS clinical characteristics including MS clinical course, year of MS diagnosis, and the type of wheelchair used for mobility.

*NMSS physical activity guidelines questions.*

Participants were prompted to choose the EDSS category that aligned with current disability status based on the options:

EDSS 7.0- Unable to walk beyond approximately 5m even with aid. Essentially restricted to wheelchair; though wheels self in standard wheelchair and transfers alone. Up and about in wheelchair some 12 h a day.

EDSS 7.5- Unable to take more than a few steps. Restricted to wheelchair and may need aid in transferring. Can wheel self but cannot carry on in standard wheelchair for a full day and may require a motorized wheelchair.

EDSS 8.0- Essentially restricted to bed or chair or pushed in wheelchair. May be out of bed itself much of the day. Retains many self-care functions. Generally has effective use of arms.

EDSS 8.5- Essentially restricted to bed much of day. Has some effective use of arms retains some self-care functions.

Participants were then taken to the questions specific to the NMSS EDSS 7.0–7.5 or EDSS 8.0–8.5 Physical Activity Guidelines. The table of EDSS-specific Guidelines from Kalb *et al.* 2020 were presented on the screen for participants to refer when responding to the same list of questions (Figures 2 & 3).<sup>9</sup> The first question asked, “Do you currently meet the General Recommendation?” with response options of “Yes, Sometimes, or No.” Specific questions were then asked regarding Breathing, Flexibility, Upper Extremity, Lower Extremity, and Core Exercises. These questions included: Do you currently engage in this type of physical activity?; Do you think this type of activity is beneficial?; Do you think this type of activity is harmful?; Could you engage in this type of exercise independently?; Do you think the guidelines for (Insert Modality) Exercises are: Overly Challenging, Appropriate, Not Challenging Enough. Participants were provided open-ended questions that were coded for common themes between EDSS groups: What are your first impressions of the guidelines?; What resources would you need to implement these guidelines?; What are the strengths of the guidelines?;

What do you think could be improved about the guidelines?; What concerns, if any, do you have about the guidelines?.

*Data analyses*

Quantitative data analyses were conducted using IBM SPSS Statistics for Windows, version 27 (IBM Corp., Armonk, NY, USA). Descriptive statistics [mean  $\pm$  standard deviation; n(%)] were utilized for summarizing the sample demographic and MS clinical characteristics as well as responses to the NMSS Physical Activity Guidelines questions. All questions were voluntary, yielding some missing data for specific items; however, this occurred in less than 5% of cases.

Qualitative data were analyzed using thematic analysis with an inductive, semantic approach to identify recurrent themes among responses to each open-ended question.<sup>13</sup> We used the standard six-stage, iterative protocol wherein the first author began by creating open-ended questions, reviewing responses multiple times, and making initial notes. The first author then generated initial codes in the second stage. The third stage was a comprehensive review of codes to generate common themes. The themes were then reviewed with the team in stage four and refined in stage five to ensure key points were addressed. The final stage is the reporting of results in this manuscript.

**Results**

*Participants*

Demographic and clinical characteristics of the 134 participants are presented in Table 1. The mean age of participants was  $61 \pm 10$  years, and years since MS diagnosis was  $24 \pm 11$  years. Seventy-eight participants (58%) reported using a power wheelchair/scooter as the primary mobility device, and 111 participants (83%) reported a progressive clinical course. The majority of participants identified as female (n = 99, 74%), married (n = 79, 59%), White (n = 117, 88%), not currently employed (n = 117, 88%), and having a college degree or more (n = 97, 72%). Eighty-nine participants identified as EDSS 7.0–7.5 and 45 participants as EDSS 8.0–8.5.

*Attainment of general recommendations*

Participants were prompted to read the table of recommendations for the EDSS level from Kalb *et al.* 2020 (Figures 2 & 3) and rated meeting, sometimes meeting or not meeting the general recommendations. Among the 89 participants with the EDSS 7.0–7.5

Recommended exercise strategies EDSS 7.0–7.5 (diminished ability to perform ADLs—non-ambulatory)
<b>General Recommendation</b>
Up to 20 min/day, 3–7 days/week (with each person working to her or his own maximum in order to make gains)—can be accumulated across several shorter sessions, with rest breaks between repetitions and gradual progression in small increments toward the goal
<b>Breathing</b>
• Every second day, 3 sets, 10 repetitions/set; resistive breathing apparatus (e.g. spirometer)
<b>Flexibility</b>
• 1x/day, ≥30–60 seconds, hold/stretch all affected upper and lower extremity joints—combining stretches when possible
<b>Upper extremities</b>
• Six 3-minute intervals at 70% target HR, active range of motion with resistance as able (e.g. arm cycling)
• 3x/week, 3 sets, 10 repetitions/set or 10 sets, 3 repetitions/set, as able, with rests as needed; weights or resistance bands
<b>Lower extremities</b>
• Overground walking with walker as able (approximately 10 ft)
• 3 sets, 10 repetitions/set of sit-to-stand, reducing assistance and support when possible
• 3–5x/week, 30 minutes, power assist cycling
• 3x/week, 30 minutes, standing
• 2–5x/week, 30–60 minutes, body weight supported treadmill training
<b>Core</b>
• 2x/day, 4–5 repetitions of seated isometric abdominal muscle strengthening, holding each repetition 10–15 seconds
• 3–5 min/day of moving or stationary seated balance, unsupported or supported
• Every 1–2 hours, posture exercises (pull shoulder blades back/head up/straighten back), hold for 10–15 seconds

**Figure 2.** National multiple sclerosis society physical activity guidelines table for persons with multiple sclerosis expanded disability status scale 7.0–7.5.

group, 52 participants (58%) did not meet the general recommendations, 27 participants sometimes meet the general recommendations (30%), and 10 participants (11%) reported meeting the general recommendations. Among the 45 participants within the EDSS 8.0–8.5 group, 25 participants (56%) did not meet the general recommendations, 16 participants sometimes meet the general recommendations (36%), and 4 participants (9%) reported meeting the general recommendations.

#### *Perceptions by modality*

The descriptive statistics for each question by Modality (i.e. Breathing, Flexibility, Upper Extremity, Lower Extremity, and Core Exercises) are reported for the full sample in Table 2 and reported by EDSS group in Supplemental File 1 for EDSS 7.0–7.5 and Supplemental File 2 for EDSS 8.0–8.5.

**Breathing exercises.** Among the 134 participants, 51% (n=68) did not currently engage in Breathing Exercises. Seven participants reported that Breathing Exercises were not beneficial and only one participant

reported that they may be harmful. Sixteen participants reported that they could not complete Breathing Exercises independently. The majority of participants reported that the guidelines were appropriate (n=110), with nine participants reporting they are overly challenging and thirteen participants reporting they are not challenging enough.

**Flexibility exercises.** Among the 134 participants, 35% (n=47) did not currently engage in Flexibility Exercises. Zero participants reported that Flexibility Exercises were not beneficial and zero participants reported that they may be harmful. Thirty participants reported that they could not complete Flexibility Exercises independently. The majority of participants reported that the guidelines were appropriate (n=112), with eleven participants reporting they are overly challenging and eleven participants reporting they are not challenging enough.

**Upper extremity exercises.** Among the 134 participants, 35% (n=47) did not currently engage in Upper Extremity Exercises. Zero participants reported that Upper Extremity Exercises were not beneficial

Recommended exercise strategies	
EDSS 8.0–8.5 (increasing difficulty performing ADLs—confined to wheelchair)	
General Recommendation	
Up to 10–15 min/day, 3–7 days/week with rests between repetitions	
<b>Breathing</b>	<ul style="list-style-type: none"> <li>• Every second day, 3 sets, 10 repetitions/set; resistive breathing apparatus (e.g. spirometer)</li> </ul>
<b>Flexibility</b>	<ul style="list-style-type: none"> <li>• 1x/day, ≥30–60 seconds, hold/stretch all affected upper and lower extremity joints, with assistance as needed</li> </ul>
<b>Upper extremities</b>	<ul style="list-style-type: none"> <li>• Six 3-minute intervals at a target HR (or 70% effort), active range of motion with resistance as able (e.g. arm cycling)</li> <li>• 3x/week, 3 sets of 10 repetitions/set or 10 sets of 3 repetitions/set; weights or resistance bands appropriate to ability level</li> </ul>
<b>Lower extremities</b>	<ul style="list-style-type: none"> <li>• 2–3x/day, 1–2 minutes of standing with assistance</li> <li>• 3x/week; 30 minutes; standing frame</li> </ul>
<b>Core</b>	<ul style="list-style-type: none"> <li>• 2x/day, 3–5 repetitions of seated isometric abdominal muscle strengthening, holding each repetition 5–6 seconds</li> <li>• 1–2 min/day of moving or stationary seated balance, unsupported and supported</li> <li>• Every 1–2 hours, posture exercises (pull shoulder blades back/head up/straighten back), hold for 10–15 seconds</li> </ul>

**Figure 3.** National multiple sclerosis society physical activity guidelines table for persons with multiple sclerosis expanded disability status scale 8.0–8.5.

and zero participants reported that they may be harmful. Twenty-three participants reported that they could not complete Upper Extremity Exercises independently. The majority of participants reported that the guidelines were appropriate ( $n=108$ ), with twenty-two participants reporting they are overly challenging and four participants reporting they are not challenging enough.

**Lower extremity exercises.** Among the 134 participants, 51% ( $n=68$ ) did not currently engage in Lower Extremity Exercises. Seven participants reported that Lower Extremity Exercises were not beneficial and four participants reported that they may be harmful. Seventy-three participants reported that they could not complete Lower Extremity Exercises independently. Sixty-four participants reported that the guidelines were appropriate, while sixty-six participants reporting they are overly challenging and four participants reporting they are not challenging enough. This is the only modality wherein a large proportion of participants rated the guidelines as overly challenging and that they were not able to execute them independently across EDSS groups.

**Core exercises.** Among the 134 participants, 36% ( $n=48$ ) did not currently engage in Core Exercises. Two participants reported that Core Exercises were not

beneficial and zero participants reported that they may be harmful. Seventeen participants reported that they could not complete Core Exercises independently. The majority of participants reported that the guidelines were appropriate ( $n=113$ ), with fifteen participants reporting they are overly challenging and six participants reporting they are not challenging enough.

**Between group comparison.** Figures 4a-e provide bar graphs depict group differences between participants who identified in the EDSS 7.0–7.5 group versus EDSS 8.0–8.5. The primary difference noted was in ratings of ability to engage in exercise independently (Figure 4(d)), wherein it appears a greater proportion of participants in EDSS 8.0–8.5 group reported inability to complete Flexibility, Upper Extremity, Lower Extremity, and Core Exercises independently (Supplemental Files 1 & 2).

#### *Open-Ended questions*

Results from thematic analysis of open-ended questions are presented in Table 3 by EDSS group. First impressions of the guidelines among participants were mostly positive ( $n=49$ ) with a portion of negative ( $n=30$ ) and mixed responses ( $n=28$ ). The three most common resources needed to implement the guidelines were equipment ( $n=47$ ), person/assistance ( $n=40$ ), and instructions ( $n=21$ ). The most

**Table 1.** Participant demographic and clinical characteristics among full sample and by expanded disability status scale groups.

Variable	Full Sample N = 134	EDSS 7.0-7.5 N = 89	EDSS 8.0-8.5 N = 45
<b>Age, years <math>\pm</math> SD</b>	61.0 $\pm$ 9.8	60.6 $\pm$ 10.3	61.8 $\pm$ 8.9
<b>Sex, n(%)</b>			
Female	99(74)	64(72)	35(78)
Male	35(26)	25(28)	10(22)
<b>Marital Status, n(%)</b>			
Married	79(59)	50(56)	29(64)
Single/Divorced/Separated/Widower	55(41)	39(44)	16(36)
<b>Employment, n(%)</b>			
Yes	17(13)	15(17)	2(4)
No	117(87)	74(83)	43(96)
<b>Race, n(%)</b>			
White	117(87)	75(85)	42(93)
Other	17(13)	14(15)	3(7)
<b>Education, n(%)</b>			
Less than college degree	37(28)	24(27)	13(29)
College degree or more	97(72)	65(73)	32(71)
<b>MS Duration, years <math>\pm</math> SD</b>	23.6 $\pm$ 10.5	24.0 $\pm$ 10.9	22.7 $\pm$ 9.7
<b>Type MS, n(%)</b>			
Relapsing Remitting	23(17.1)	18(20)	5(11)
Progressive	111(82.8)	71(80)	40(89)
<b>Wheelchair Type, n(%)</b>			
Power Wheelchair/Scooter	78(58)	50(56)	28(62)
Manual Wheelchair	56(42)	39(44)	17(38)

*Note.* MS = multiple sclerosis; EDSS = Expanded Disability Status Scale.

commonly noted strengths of the guidelines were general information (n = 21), specificity (n = 21), and comprehensiveness (n = 16). Common suggestions for improvement were need for individualization (n = 18) and instructions (n = 17). Participants reported attainability (n = 18) and safety (n = 11) as the two most common concerns about the guidelines.

### Discussion

Overall, the updated NMSS Guidelines for Physical Activity were rated as appropriate among wheelchair users with MS. Lower Extremity and Flexibility Exercises were rated as the most challenging, based on the ability to execute the exercises independently. Flexibility and Upper Extremity Exercises were rated as at least somewhat beneficial, and not harmful, among most participants in this sample, and Core Exercises were rated as not harmful by all participants. Importantly, only 11% of participants in the EDSS 7.0–7.5 group, and 9% of participants in the EDSS 8.0–8.5 group reported meeting the general

physical activity recommendations. This study can guide researchers and practitioners promoting physical activity among wheelchair users with MS given the comprehensive nature of data provided about each individual exercise modality.

This study examined perceptions of Breathing, Flexibility, Upper Extremity, Lower Extremity, and Core Exercises among wheelchair users with MS. Other physical activity guidelines have focused primarily on either aerobic or resistance training as the primary modalities of physical activity;<sup>6,7</sup> however, the updated guidelines acknowledged the supplemental rehabilitative needs of wheelchair users with MS. One recent qualitative study informing exercise programs for wheelchair users with MS further highlighted Rehabilitative Therapies as an additional adjunct therapy that this population rates as critical for overall functioning and independence.<sup>11</sup> Importantly, fewer than 20% of participants reported engagement in the prescribed Lower Extremity and Breathing Exercises,

**Table 2.** National multiple sclerosis society physical activity guidelines question responses among 134 wheelchair users with multiple sclerosis.

Question <i>Response Options</i>	Modality				
	Breathing n(%)	Flexibility n(%)	Upper Extremity n(%)	Lower Extremity n(%)	Core n(%)
<b>Do you currently engage in this type of physical activity?</b>					
<i>Yes</i>	25(19)	38(28)	42(31)	24(18)	34(25)
<i>Somewhat</i>	41(30)	49(37)	45(34)	42(31)	52(39)
<i>No</i>	68(51)	47(35)	47(35)	68(51)	48(36)
<b>Do you think this type of activity is beneficial?</b>					
<i>Yes</i>	90(68)	113(84)	112(84)	105(78)	114(85)
<i>Somewhat</i>	34(25)	21(16)	22(16)	22(17)	18(13)
<i>No</i>	9(7)	–	–	7(5)	2(1)
<b>Do you think this type of activity is harmful?</b>					
<i>Yes</i>	1(1)	–	–	4(3)	–
<i>Somewhat</i>	3(2)	5(4)	4(3)	10(8)	6(4)
<i>No</i>	129(97)	128(96)	130(97)	120(89)	128(96)
<b>Could you engage in this type of exercise independently?</b>					
<i>Yes</i>	84(63)	65(49)	74(55)	30(22)	78(59)
<i>Somewhat</i>	34(25)	39(29)	37(28)	31(23)	38(29)
<i>No</i>	16(12)	30(22)	23(17)	73(55)	17(12)
<b>Do you think the guidelines for (Insert Modality) Exercises are:</b>					
<i>Overly challenging</i>	9(7)	11(8)	22(16)	66(49)	15(11)
<i>Appropriate</i>	110(83)	112(84)	108(81)	64(48)	113(85)
<i>Not challenging enough</i>	13(10)	11(8)	4(3)	4(3)	6(4)

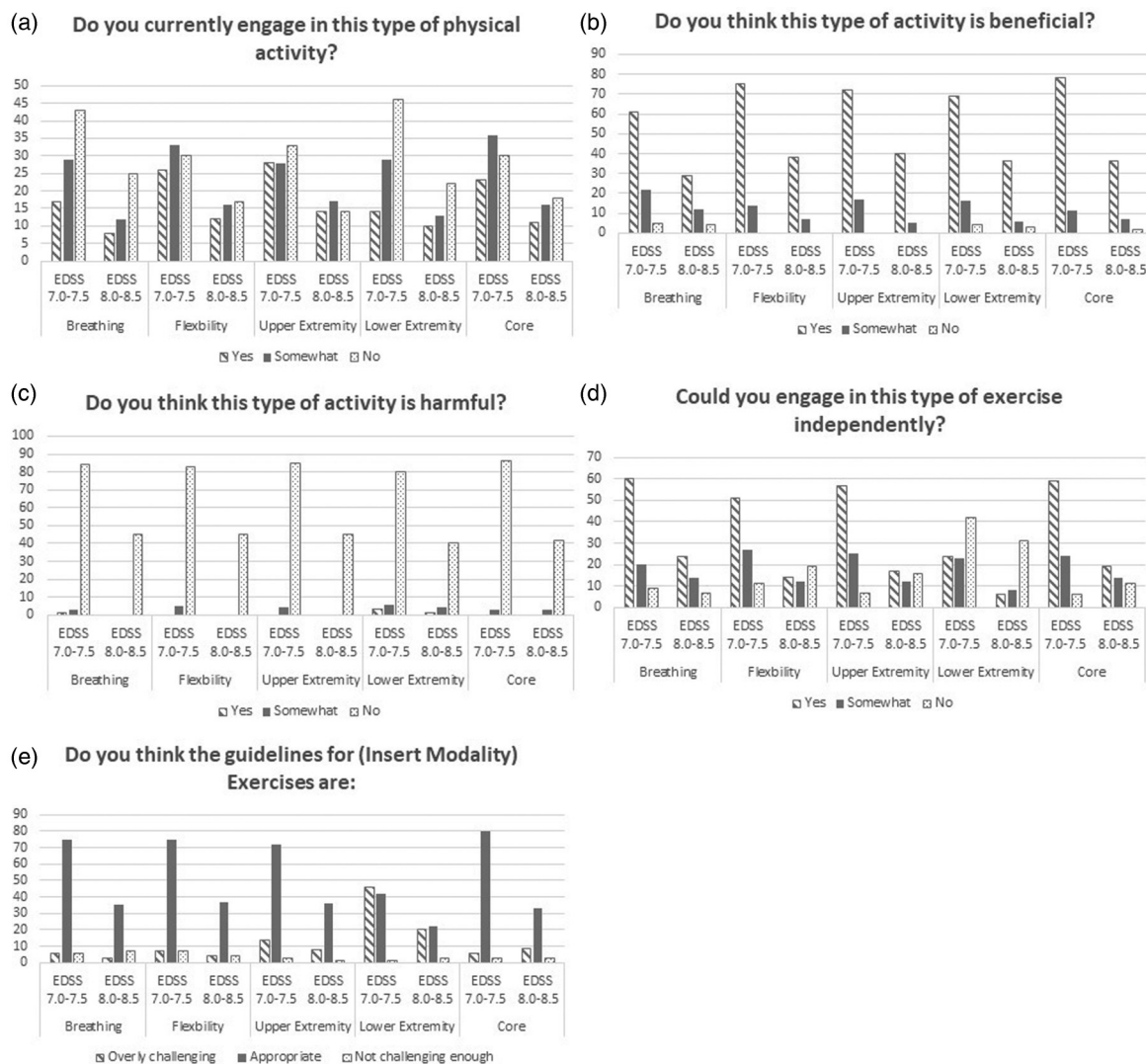
followed by only 25% engaging in sufficient Core Exercises, 28% for Flexibility Exercises and 31% for Upper Extremity Exercises. There is significant need for improvement in engagement within all modalities; however, innovative technologies are needed for Lower Extremity exercises in particular. The current recommendations and resources for Lower Extremity exercises among wheelchair users lack sufficient independent and pragmatic options and a significant portion of participants across EDSS groups noted them as overly challenging. Further, among participants with EDSS 8.0–8.5, less than 50% of participants reported that they could execute exercises independently for all modalities except Breathing Exercises, which is a crucial consideration for guideline creators, researchers, practitioners and patients.

Open-ended questions in the current study provided an opportunity for rich feedback regarding the novel guidelines. Initial perceptions of the guidelines were mixed, but largely positive across EDSS groups. Participants highlighted that the guidelines were a good starting point and provided clear targets;

however, areas for improvement included the need for clear instructions and individualization that is often not possible in general community settings. Additionally, one important consideration for wheelchair users with MS is the need for assistance and specialized equipment that contribute to commonly noted barriers to engagement in exercise in this population.<sup>11,14</sup> Consistent with the quantitative ratings, safety and attainability of the guidelines were common concerns that may be addressed through comprehensive programming created by professionals in kinesiology and disability. Collectively, the qualitative findings provided depth to the study that should be utilized when providing suggestions for exercise among wheelchair users with MS in community and clinical settings.

This study focused on physical activity guidelines, as guidelines are utilized as a public health tool for providing guiding practitioners. Persons with MS are interested in exercise as a second-line approach for managing MS symptoms and disease progression and often search for information online.<sup>15</sup> One





**Figure 4.** a,b,c,d,e. Bar graphs indicating frequency of questionnaire responses among participants in expanded disability status scale 7.0–7.5 and 8.0–8.5 Groups.

recent study evaluated the quality and consistency of information on webpages for physical activity against physical activity guidelines for MS, and results indicated that most resources were either inconsistent with the established physical activity guidelines or did not mention the guidelines.<sup>16</sup> Of note, one other recent study highlighted some confusion among persons with MS with the original physical activity guidelines for persons with MS published in 2013 because of the term “Canadian.”<sup>17</sup> We suggest comprehensive dissemination of physical activity guidelines among persons with MS, caregivers, and healthcare providers through trusted internet resources (e.g. NMSS or Consortium of Multiple Sclerosis Centers) as an avenue to promote knowledge of the guidelines as an initial step that can

guide identification of MS-appropriate programs and resources.

This study is not without limitations. The Physical Activity Guidelines questions were completed by some participants as an optional supplement to the study after completion as opposed to inclusion in the primary questionnaire battery, which led to some missing data. The nature of data collected in this study is descriptive, which limits our ability to examine potential causal mechanisms related to engagement in physical activity among participants. One strength of the current study is the guidance provided for creating physical activity programs for wheelchair users with MS that may align with their preferences and perceptions within each exercise

**Table 3.** National multiple sclerosis society physical activity guidelines open-ended question responses by expanded disability status scale levels.

Question	Codes	EDSS 7.0-7.5	EDSS 8.0-8.5
<b>What are your first impressions of the guidelines?</b>	Positive	n = 38	n = 21
	Negative	n = 25	n = 5
	Mixed (i.e. Positive and Negative)	n = 16	n = 12
	Neutral	n = 8	n = 7
<b>What resources would you need to implement these guidelines?</b>	Person/Assistance	n = 17	n = 23
	Equipment (e.g. exercise, assistive devices)	n = 32	n = 15
	Greater Functional Abilities	n = 6	n = 1
	Instructions (e.g. videos, pictures)	n = 17	n = 4
	Motivation	n = 8	n = 6
	Facility	n = 4	n = 3
	Reminders	n = 1	n = 1
	Individualization	n = 0	n = 1
	N/A*	n = 10	n = 3
<b>What are the strengths of the guidelines?</b>	General Information (e.g. starting point)	n = 18	n = 3
	Comprehensive (e.g. full body included)	n = 13	n = 3
	Specific (e.g. clear and measurable)	n = 13	n = 8
	Cover Multiple Modalities	n = 2	n = 1
	Attainable	n = 8	n = 6
	Transferability to Activities of Daily Living	n = 4	n = 1
	Motivating	n = 1	n = 3
	Benefits for Health and Mobility	n = 12	n = 9
	Independent/Home-Based	n = 4	n = 3
	N/A*	n = 10	n = 9
<b>What do you think could be improved about the guidelines?</b>	Need Instructions	n = 11	n = 6
	Individualization	n = 14	n = 4
	Safety Considerations	n = 3	n = 1
	Increased Challenge	n = 2	n = 1
	Focus on Upper Body/Seated Only	n = 4	n = 0
	Small Increases (i.e. incremental change)	n = 3	n = 1
	Overwhelming	n = 3	n = 1
	Applications to Activities of Daily Living	n = 3	n = 0
	Improved Presentation of Materials	n = 4	n = 0
	Reminders/Schedule	n = 1	n = 1
	Include Help/Assistance from Person	n = 2	n = 0
	Need Motivator	n = 1	n = 1
	Remove Specific Components (i.e. breathing, equipment)	n = 5	n = 2
	Peer Support	n = 1	n = 0
	Include Neck Exercises	n = 0	n = 1
N/A*	n = 22	n = 21	

(continued)

**Table 3.** Continued.

Question	Codes	EDSS 7.0-7.5	EDSS 8.0-8.5
<b>What concerns, if any, do you have about the guidelines?</b>	Not Attainable	n = 14	n = 4
	Safety	n = 9	n = 2
	Individualization	n = 2	n = 6
	Need Instructions	n = 8	n = 2
	Need Equipment	n = 5	n = 2
	Need Assistance	n = 2	n = 3
	Rest/Fatigue	n = 6	n = 1
	Broad	n = 1	n = 0
	Lower Extremity Function	n = 1	n = 0
	Motivation	n = 1	n = 2
	Not Challenging	n = 1	n = 0
N/A*	n = 26	n = 16	

*Note.* Participant responses that included multiple codes were counted separately. \*N/A = Not applicable or nothing; EDSS = Expanded Disability Status Scale.

modality outlined in the updated physical activity guidelines.

Wheelchair users with MS have been excluded from the majority of research on physical activity among persons with MS; however, the recent NMSS Physical Activity Guidelines provide clear recommendations for promoting physical activity in this population. The guidelines provided for wheelchair users with MS are therefore based primarily on expert opinion as opposed to a strong body of evidence. The current study provides perceptions and feedback directly from the target population that can be used as an additional tool for the creation of physical activity programs among wheelchair users.



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### Supplemental material

Supplemental material for this article is available online.

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