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Pilot study exploring quality of life and barriers to leisure-time physical activity in persons with moderate to severe multiple sclerosis

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Abstract

Background: We sought to assess how impairment (physiological/psychological) and disability (social/environmental) are associated with physical and leisure/recreation activity levels and quality of life (QOL) in people with moderate/severe multiple sclerosis (MS). We conducted a cross-sectional survey at the MS Comprehensive Care Center, Stony Brook University Hospital, Stony Brook, NY, of a convenience sample of 43 people (50 eligible) with MS and Expanded Disability Status Scale scores of 6.0 to 8.0. The main outcome measures were QOL measured by MSQOL-54, physical activity measured by Physical Activity Disability Scale, and leisure/recreation activity measured by Nottingham Leisure Questionnaire. We analyzed the canonical correlations among physical and leisure/recreation activity levels and (1) impairment and (2) QOL.

Results: Higher levels of physical and leisure/recreation activity were associated with lower levels of apathy and depression and higher levels of cognition, self-efficacy, and QOL (physical and mental). Major barriers reported included fatigue, lack of motivation, and cost.

Conclusion: Impairments and social/environmental disabilities create barriers to physical and leisure/recreation activity. Additional research is needed to determine, for people with MS, what supports might increase participation in physical and leisure/recreation activities and whether this increase yields improved QOL.

Keywords: Multiple sclerosis; Social problems; Recreation; Exercise; Quality of life

People with moderate to severe multiple sclerosis (MS) face numerous challenges in daily life including physiological and psychological *impairments* (e.g., reduced mobility, self-efficacy, and cognition, and increased depression, fatigue, and apathy) [1-5] and significant *disabilities* (social/environmental barriers such as inaccessible locations, financial limitations, and lack of transportation) [6-9]. Throughout this paper, a distinction, central to disability studies [10-13], is made between impairment (physiological/psychological) and disability (social/environmental), the combination of which may mutually reinforce barriers and compromise quality of life (QOL) [14-17].

MS is an immune-mediated, demyelinating chronic condition of the central nervous system with an average onset age of 30 years and an estimated U.S. prevalence of 400,000 to 500,000 [18,19]. The incidence of depression and related diagnoses in people with MS is 40% to 50% higher than that in the general population [20-23]. Crayton et al. [24] suggest that depression leads to decreased exercise and consequent aggravation of physical symptoms. MS symptoms are interrelated and can have a compounding effect, influencing motivation and engagement in leisure/recreation activity [4,5]. For example, cognitive impairment affects the ability to cope with stressors such as global fatigue [25,26]. Global fatigue increases the risk of depression, which may lead to additional physical fatigue [5,20,21,26]. Severe physical fatigue predicts reduced physical activity, which in turn may exacerbate physical impairment [5,27].

Research in disabled and nondisabled populations suggests that exercise can help reduce depression [28-30]. Research has also shown that health-promoting activities (e.g., exercise, rehabilitation, and recreation) can reduce fatigue and secondary health conditions, and enhance QOL, cognition, fitness, community participation, and integration of people with physiological/neurological impairments

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(including MS) [14-17,31-34] if these are made accessible and tailored to participants' needs [14,25,35-44]. Limited research exists showing that rehabilitation and leisure/recreation activity positively influence QOL for people with MS [33,38,39,45,46].

However, in most cases, research does not document the barriers to physical and leisure/recreation activity or indicate how they might be overcome. Research suggests that the presence or absence of a safe and supportive environment greatly influences the levels of sustainable, community-based leisure/recreation activity for people with MS and other neurological disabilities [42,47,48]. Despite general recognition that the health and well-being of people with impairments can be improved through physical and leisure/recreation activities [25,48], people with MS face many barriers to participating in such activities [20,21,26,32,33] such as lack of accessible facilities, lack of knowledge of proper exercise techniques, cost, and limited accessible transportation [7-9,42,49-51].

The researchers designed a cross-sectional pilot study to explore these issues in people with moderate to severe MS: (1) What is the relationship between impairment-related barriers, collectively, and levels of physical and leisure/recreation activity? (2) What is the relationship between levels of physical and leisure/recreation activity and QOL (physical and mental)? (3) Which impairment- and disability-related barriers to physical activity do participants report, what issues do they have with fitness centers, and what are their opinions about participation in exercise programs?

Table 1
Demographic and Medical Characteristics of Study Participants (N = 43)

Characteristic	n	%
EDSS score (physician report)		
6.0	20	46.5
6.5	10	23.3
7.0	5	11.6
7.5	6	14.0
8.0	2	4.7
8.5	0	0.0
Age		
Mean	53.74	
SD	10.28	
Gender		
Women	31	72.1
Men	12	27.9
Race		
White	39	90.7
Black	2	4.7
Other	1	2.3
Data absent	1	2.3
Hispanic		
No	41	95.3
Yes	2	4.7
Type of MS (physician report)		
Secondary-progressive	37	86.0
Relapsing-remitting	5	11.6
Progressive-relapsing	1	2.3
Highest level education		
High school or GED	11	25.6
Some college	11	25.6
2 Years college	3	7.0
4 Years college	5	11.6
Some graduate school	1	2.3
Graduate/medical/law	11	25.6
Other	1	2.3

All data were self-reported, except as noted.

Methods

Study participants

Researchers sequentially (February-August 2004) recruited a convenience sample of 43 participants from among 50 eligible people at the MS Comprehensive Care Center, Stony Brook University Hospital, Stony Brook, NY, USA. The study was approved by the university's Committee on Research Involving Human Subjects. Inclusion criteria were a diagnosis of MS and an Expanded Disability Status Scale (EDSS) score of 6.0 (unilateral assistance required to walk 100 m), 6.5 (bilateral assistance required to walk 20 m), 7.0 (bilateral assistance required to walk 5 m), 7.5 (bilateral assistance required to walk a few steps), 8.0 (restricted to bed or chair), or 8.5 (restricted to bed) [52]. Exclusion criteria were incomplete data (n = 4), inability to read/understand English (n = 0), or unwillingness to participate (n = 3). Table 1 provides a summary of participants' demographic and medical information.

Instruments

Impairments

The Rey Auditory-Verbal Learning Test (RAVLT) [53] and the Symbol Digit Modalities Test (SDMT) [54] assess aspects of cognitive functioning that are frequently impaired in persons with MS [55]. The RAVLT assesses verbal learning and memory [56] and was scored by summing the total number of words recalled (immediate free recall across 5 learning trials). The SDMT assesses sustained attention and speed of information processing [57] and was scored by counting the number of correct symbol/digit associations. The General Perceived Self-Efficacy Scale (GPSS) is a 10-item self-report Likert scale (range, 1-4) assessing perceived sense of resourcefulness and ability to deal with unexpected events and find solutions to problems [58]. The researchers used this general self-efficacy scale, rather than one specific to physical activity, to assess participants' ability to overcome both the impairment (physiological/psychological) and disabling (social/environmental) barriers to physical and leisure/recreation activities. The GPSS is scored by summing the ratings for all items, as are the CMDI, AES, FSS, and NLQ (described next). The Chicago Multiscale Depression Inventory (CMDI) is a 50-item self-report Likert scale (range, 1-5) assessing depression. It contains 42 items that are symptoms of depression (and 8 positive ''distracters'') that describe

feelings the participant may have had [59]. The Apathy Evaluation Scale (AES) is an 18-item self-report Likert scale (range, 1-4) that assesses apathy in adults. *Apathy* refers to a lack of motivation that is not caused by decreased consciousness, cognitive impairment, or depression [60]. The Fatigue Severity Scale (FSS) is a reliable 9-item self-report Likert scale (range, 1-7) that assesses fatigue in individuals with MS and other disabilities [61-63].

Physical and leisure/recreation activity

The Nottingham Leisure Questionnaire (Short Version) (NLQ) is a 30-item self-report Likert scale (range, 0-2) that assesses participation in leisure/recreation activities in individuals with disabilities [64]. These include active (e.g., walking, gardening, and shopping) and nonactive (e.g., reading, watching TV, and listening to the radio) activities. The NLQ assesses only pursuits that are undertaken primarily for an individual's enjoyment. The researchers added a 31st item to inquire if participants went to casinos or engaged in gambling. The Physical Activity Disability Scale (PADS) is a 31-item self-report questionnaire developed to provide a measure of the day-to-day, low-level physical activities of people with disabilities [65], because many existing instruments that measure physical activity include types of activities in which people with disabilities seldom participate [66]. Questions relate to types and frequency of physical activity, including exercise, sports, therapy, and household- and work-related physical activity. The PADS assesses only active pursuits, some of which are and some of which are not undertaken for an individual's enjoyment. Evaluation provides an overall score for physical activity level (with a higher score indicating greater physical activity) [66] and was done in summer 2004 using an online algorithm available at http://www.ncpad.org/myncpad/ [67].

Barriers to activity

The Barriers to Physical Activity Disability Scale (BPADS) is a 17-item self-report questionnaire assessing social/environmental, physical, and emotional issues that are faced by individuals with disabilities and that limit physical activity, with an emphasis on exercise programs outside the home [68]. The BPADS includes questions about desire to exercise and opinions of fitness centers. Most items were answered "yes" or "no." Because there is no formal scoring system for the BPADS, these data were interpreted descriptively.

QOL, demographic and clinical

The Multiple Sclerosis Quality of Life-54 (MSQOL-54) is a 54-item self-report instrument assessing QOL using both generic and MS-specific items [69,70]. The MSQOL-54, scored according to the MSQOL User's Manual [71], produces both a physical health QOL score (MSQOL-P) and a mental health QOL score (MSQOL-M). The Expanded Disability Status Scale (EDSS) indicates progression of MS by assessing neurological impairment and level of disability. EDSS is measured in half-step increments, from 0.0 (normal) to 10.0 (death) [72]. Researcher-designed forms collected participants' age, gender, race/ethnicity, and education (from participants) and EDSS score and type of MS (from clinicians).

Procedure

An experienced clinician determined each patient's EDSS score. Those with EDSS scores between 6.0 and 8.5 were recruited and given a consent form. Completion of the research assessments indicated consent to participate. A research assistant administered the 2 cognitive tests (RAVLT and SDMT). Participants were given the option of completing the remaining assessments in the clinic or taking them home with a stamped, self-addressed return envelope.

Data analysis

The data were analyzed using SPSS version 14.0 [73]. An α level of .05 was used for all statistical tests. Descriptive statistics for the instruments may be found in Table 2. Only a few other studies (on people with MS who had a similar EDSS range) were located that used these measures. Our means on the SDMT [74], FSS [4,75], and MSQOL-M [76] were similar to those in other studies, while our mean for the MSQOL-P [76] was lower.

A 1-sample Kolmogorov-Smirnov test determined that all the quantitative instruments' data were normally distributed except for MS progression (EDSS). An initial analysis was performed to determine bivariate correlations among the impairment-related barriers, physical and leisure/recreation activity, and QOL (physical and mental) (Table 3).

The researchers performed 2 canonical correlations with the normally distributed variables. The first canonical correlation assessed the relationship between impairment-related barriers, collectively, and levels of physical and leisure/recreation activity. The second canonical correlation assessed the relationship between levels of physical and leisure/recreation activity and QOL (physical and mental).

Table 2
Descriptive Statistics of Quantitative Instruments (N = 43)

Evaluation tool	Mean	SD	Minimum	Maximum
NLQ	21.19	6.94	11.00	37.00
PADS*	10.66	57.90	−162.91	99.70
MSQOL-P	41.79	16.10	13.80	86.74
MSQOL-M	60.44	20.92	20.83	98.84
AES	30.82	9.34	18.00	57.00
GPSS	30.70	5.14	19.00	39.50
CMDI	120.63	23.45	85.74	187.06
FSS	5.08	1.59	1.00	7.00
RAVLT	39.23	12.92	0.00	69.00
SDMT	32.05	14.58	0.00	63.00
EDSS	6.53	0.63	6.00	8.00

* PADS version 1 raw score.

Table 3
Correlations (p Values) of Quantitative Instruments (Pearson Correlation Coefficients Except as Noted) (N=43)

	Activity participation measures				Quality of life measures			
Evaluation tools	NLQ	p value	PADS	p value	MSQOL-P	p value	MSQOL-M	p value
NLQ	NA	NA	0.311	(.042)*	0.416	(.005)**	0.433	(.004)**
PADS†	0.311	(.042)*	NA	NA	0.188	(.228)	0.266	(.085)
MSQOL-P	0.416	(.005)**	0.188	(.228)	NA	NA	0.673	(.000)***
MSQOL-M	0.433	(.004)**	0.266	(.085)	0.673	(.000)***	NA	NA
AES	−0.464	(.002)**	−0.278	(.071)	−0.261	(.090)	−0.332	(.030)*
GPSS	0.321	(.036)*	0.225	(.146)	0.252	(.103)	0.315	(.039)
CMDI	−0.486	(.001)**	−0.304	(.048)*	−0.582	(.000)***	−0.586	(.000)***
FSS	0.061	(.697)	0.070	(.658)	−0.446	(.003)**	0.218	(.160)
RAVLT	0.230	(.137)	0.349	(.022)*	0.273	(.076)	0.289	(.060)
SDMT	0.249	(.108)	0.524	(.000)***	0.061	(.700)	0.210	(.176)
EDSS‡	−0.258	(.095)	−0.334	(.028)*	−0.287	(.062)	−0.236	(.127)

* $p < .05$.
** $p < .01$.
*** $p < .001$.
† PADS version 1 raw score.
‡ Spearman correlation coefficients.

Results

Table 3 shows that the bivariate correlations of the impairment variables with the PADS and NLQ are quite different. The PADS' relationship was statistically significant with the NLQ and the 2 cognition measures (positively correlated) and depression (negatively correlated). The NLQ's relationship was statistically significant with apathy and depression (negatively correlated), self-efficacy, and physical and mental QOL (positively correlated). Neither the PADS nor the NLQ had a statistically significant correlation with the fatigue measure, which had a statistically significant relationship only with mental QOL (negatively correlated).

In the first canonical correlation, the 6 normally distributed impairment-related barriers (depression, cognitive impairment [both RAVLT and SDMT], fatigue, apathy, and reduced self-efficacy) comprised one set of variables and physical and leisure/recreation activity levels comprised the second set of variables. This canonical correlation produced 1 statistically significant (cc = 0.741, $p = .001$) canonical variate, which explained 54.9% of the variance. All variables (except fatigue) loaded onto this canonical variate with canonical loadings greater than (an absolute value of) 0.30, which are considered meaningful [77] (Table 4). This canonical correlation indicated that higher levels of physical and leisure/recreation activity are associated with lower levels of apathy and depression and higher levels of cognition and self-efficacy.

In the second canonical correlation, activity (physical and leisure/recreation) levels comprised 1 set of variables and QOL (physical and mental) comprised the second set of variables. This canonical correlation produced 1 statistically significant (cc = 0.479, $p = .032$) canonical variate

Table 4
Canonical Correlation Analysis Summary Table Between Apathy, Perceived Self-Efficacy, Depression, Fatigue, and Cognitive Impairment and Physical and Leisure/Recreation Activity

	Six independent variables		Three independent variables	
	Standardized canonical coefficients	Canonical loadings	Standardized canonical coefficients	Canonical loadings
	First variate*		First variate*	
Set 1				
Apathy	0.357	0.622	0.4	0.626
Self-efficacy	−0.043	−0.457	NA	NA
Depression	0.569	0.662	0.508	0.667
Fatigue	−0.179	−0.109	NA	NA
Cognitive: RAVLT	0.052	−0.481	NA	NA
Cognitive: SDMT	−0.606	−0.64	−0.627	−0.655
Set 2				
Leisure/recreation	−0.629	−0.818	−0.612	−0.806
Physical activity	−0.606	−0.801	−0.623	−0.813
Canonical correlations		0.741		0.731
		$p = .001$		$p < .000$
Variance explained		54.90%		53.40%

* Only the first canonical variate was statistically significant.

that explained 22.9% of the variance. All variables loaded onto this canonical variate with canonical loadings greater than (an absolute value of) 0.30 (Table 5). This canonical correlation indicates that higher levels of QOL (physical and mental) are associated with higher levels of physical and leisure/recreation activity. Of particular note are the high canonical loadings of QOL-mental (−0.947) and leisure/recreation (−0.969) activity. Although statistically significant, the lower percent of variance explained (22.9%) indicates, as would be expected, that there are factors, other than physical and leisure/recreation activity levels, that affect QOL.

Because of the low number of participants in this study (N = 43) and the large number of variables in these analyses, these results must be considered only a preliminary indication of associations [78]. Table 6 contains the barriers to physical activity that participants reported, the issues they had concerning fitness centers, and their opinions about participation in exercise programs.

Discussion

The results suggest that lower levels of impairment-related barriers (depression, cognitive impairment, apathy, and reduced self-efficacy but not fatigue) are associated with higher physical and leisure/recreation activity levels. This is consistent with existing research on MS which indicates that higher self-efficacy is associated with higher levels of physical activity while depression and apathy are associated with lower activity levels [1-5]. The results also suggest that higher physical and leisure/recreation activity is associated with better QOL. Recent research has shown that exercise may improve functional impairment but not QOL [15], but perhaps physical activity undertaken in the context of leisure/recreation is more enjoyable than exercise, and thus more likely to improve QOL.

Lack of energy (interpreted as fatigue) was the most frequently mentioned barrier to physical activity, indicated (on the BPADS) by over half (n = 23) of the participants as a reason for not exercising, which is consistent with the fact that fatigue is a common and debilitating symptom of MS [1,5,27]. However, fatigue did not load meaningfully onto the canonical variate with physical and leisure/recreation activity, making these results consistent with other research findings that subjective fatigue is not correlated with objective measures of behavior [79] and that exercise can actually reduce symptoms of fatigue in persons with MS [25].

Lack of motivation (interpreted as apathy) was also mentioned frequently as a barrier (n = 17) to physical activity. Lack of motivation is often a consequence or a warning sign of depression. Depressive symptoms are commonly seen in persons with MS, contributing to decreased QOL and activity participation [21,22,80]. Both apathy and depression loaded onto the canonical variate with physical and leisure/recreation activity. Increasing physical activity of people with MS may help alleviate depressive symptoms, because research in nondisabled and disabled populations has suggested that exercise can help reduce, prevent, and/or manage depression and increase motivation [28-30,80].

It is encouraging that over three-fourths (n = 34) of the participants thought that exercise would be beneficial and over half (n = 26) were interested in beginning an exercise

Table 5
Canonical Correlation Analysis Summary Table Between Physical and Leisure/Recreation Activity and Quality of Life (Physical and Mental)

	First variate*	
	Standardized canonical coefficients	Canonical loadings
Set 1		
Leisure/recreation	−0.889	−0.969
Physical activity	−0.258	−0.535
Set 2		
Physical QOL	−0.433	−0.875
Mental QOL	−0.656	−0.947
Canonical correlations		0.479
		p = .032
Variance explained		22.9%

* Only the first canonical variate was statistically significant.

Table 6
Barriers to Physical Activity Results

	n	%
Person-centered barriers to physical activity		
Lack of energy	23	53.5
Cost	18	41.9
Lack of motivation	17	39.5
Lack of support, lack of an accessible facility, fear of leaving the home	8	18.6
Pain, health concerns	7	16.3
Difficulty exercising	6	14.0
Lack of interest, personal and community mobility issues	5	11.6
Not knowing where, lack of time	4	9.3
Fear of exacerbating symptoms, boredom during exercise	3	7.0
Not knowing how, thinking that exercise will not improve condition	2	4.7
Thinking of self as too old	1	2.3
Participant's fitness center issues		
Knew of a fitness center that they could get to	22	51.2
Would like to go to that fitness center	17	39.5
Had transportation to that fitness center	18	41.9
Could afford to pay for that transportation	5	11.6
Would willing to pay for that transportation	9	20.9
Fitness center staff lacked knowledge of how people with MS should exercise	16	37.2
Sensitivity to how they appear to others, based on visible physical impairments	6	14.0
Participants' opinions about participation in exercise		
Felt that exercise would be beneficial to their health	34	79.1
Interested in beginning an exercise program	26	60.5
Were already in an exercise program	8	18.6
Thought that exercise would improve their quality of life	6	14.0

program. This finding is consistent with existing studies showing that persons with disabilities can engage in and benefit from aerobic, strengthening, rehabilitation, and health promotion activities, if these are made accessible and tailored to their needs [25,37-41]. However, in addition to the impairment-related barriers, discussed above, participants cited significant social/environmental barriers including lack of accessible facilities (n = 8), lack of assistance from exercise center personnel for proper exercise techniques (n = 16), and cost (n = 18), and only about half of the participants (n = 22) knew of a health center that they could get to. In addition, 6 participants noted sensitivity to how they appear to others, based on visible physical impairments. Other factors limiting exercise were pain, lack of interest, difficulty exercising, lack of time, fear of exacerbating symptoms, boredom during exercise, lack of support, thinking of self as too old, and thinking that exercise will not improve condition. Work and family responsibilities did not negatively influence physical activity participation. Our data agree with research suggesting that the presence or absence of social supports and a safe, supportive environment greatly influence the level of sustainable community-based physical and leisure/recreation activity for people with MS [42,47,48].

Study limitations

The low number of participants in this study (n=43) and the large number of variables in the canonical correlations mean that these results must be considered only preliminary indications of associations. Also, this study was done using a convenience sample from only 1 hospital, so generalizability is limited.

Suggestions for future research

This study should be replicated with a larger, random sample to verify these associations. A long-term, randomized, controlled trial, addressing both impairment and disability, would be needed to determine if activity levels and QOL improved. Additional research would then be needed to determine effective ways to address impairment- and disability-related barriers to enhance QOL by increasing physical and leisure/recreation activity.

Conclusion

There is preliminary evidence that impairments (physiological/psychological barriers) combined with disabilities (social/environmental barriers) might reduce participation in physical and leisure/recreation activities to the detriment of QOL for people with moderate/severe MS. Results indicate that higher levels of physical and leisure/recreation activity are associated with lower levels of apathy and depression and higher levels of cognition, self-efficacy, QOL-physical, and QOL-mental. To simultaneously overcome impairments and disabilities, a holistic, coordinated rehabilitation approach may be necessary. Implementation of such a rehabilitation plan is beyond the scope of most MS practitioners. As is the case with many chronic diseases, a collaborative effort combining the resources of health care delivery systems and community organizations may be needed [81].

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