



Associations between activity and participation in adults with multiple sclerosis: a cross sectional study

Jennifer M. Ryan^{a,b,*}, Andrea M. Stennett^a, Sarah Peacock^a, Gayle Baker^a,
Meriel Norris^a

^a Department of Clinical Sciences, Brunel University London, United Kingdom

^b Department of Epidemiology and Public Health Medicine, Royal College of Surgeons in Ireland, Dublin, Ireland

Abstract

Objectives The aim of this study was to determine the association between walking ability in a clinical setting (activity capacity), walking ability in a person's daily environment (activity capability) and walking performance in daily life (activity performance), and the contribution of each activity construct to participation among people with multiple sclerosis (MS).

Design Cross-sectional study.

Setting Five MS therapy centres in England.

Participants Fifty-two adults (13 males) with MS who were independently ambulatory with or without a walking aid (mean (SD) age 55.4 (9.1) year).

Interventions No intervention.

Main outcome measures Activity capacity, capability, and performance were assessed using the Six Minute Walk Test (6MWT), Twelve Item MS Walking Scale (MSWS-12), and steps/day measured using a pedometer worn for 6 days, respectively. Participation was assessed using the Impact on Participation and Autonomy questionnaire (IPA).

Results Distance walked on the 6MWT was associated with MSWS-12 score ($\beta = -0.56$, 95% CI -0.87 to -0.22) and steps/day ($\beta = 129.49$, 95% CI 48.48 to 207.57). MSWS-12 score was also associated with step count ($\beta = -87.35$, 95% CI -172.29 to -15.71). 6MWT distance was associated with the autonomy indoors subscale of the IPA ($\beta = -0.02$, 95% CI -0.04 to -0.01). No other activity measure was associated with participation.

Conclusions Findings suggest that while activity capacity, capability and performance are related, activity is a poor predictor of participation. The strength of associations between constructs of activity, and activity and participation, however, are often small with wide confidence intervals, indicating that there is considerable uncertainty associated with effect estimates.

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Keywords: Multiple sclerosis; Activity; Participation; Walking; Mobility

Introduction

Multiple sclerosis (MS) is an inflammatory disorder of the brain and spinal cord that may result in motor, cognitive, and visual impairment, fatigue and pain [1]. It is a degenerative disease that is commonly diagnosed in young or middle

age [1]. The impact of disability due to MS on a person's functioning can be described in terms of the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) [2]. According to the ICF framework, a person functions on three levels: body functions/structures, activity and participation. In this framework, activity is defined as "the execution of a task or action by an individual" and participation is defined as "involvement in a life situation" [2]. Disability as a result of MS impacts at activity [3–5] and participation levels [6]. Walking is an activ-

* Corresponding author at: Department of Epidemiology and Public Health Medicine, Royal College of Surgeons in Ireland, Dublin, Beaux Lane House, Lower Mercer Street, Dublin 2, Ireland.

E-mail address: Jenniferryan@rcsi.com (J.M. Ryan).

ity that is commonly impacted by MS [7] and reported to be a key priority for people with MS [8]. Furthermore, declines in walking speed coincide with declines in participation among people with MS who have moderate-to-severe disability [7].

Since the ICF was developed it has been proposed that activity may be further divided into activity capacity, capability and performance [9]. This acknowledges the role of context when evaluating activity [10]. Helsebeeke proposed the following definitions for each: “capacity describes what a person can do in a standardised, controlled environment”; “capability describes what a person can do in his/her daily environment”; “performance describes what a person actually does in his/her daily environment” [9]. The important distinction between each construct is the environment in which activity is assessed. While activity capacity, capability, performance and participation are known to be reduced in people with MS in comparison to people without MS [5,11–14] there is limited understanding of how each construct of activity relates to the other and to participation, respectively. For example, if walking ability improves in the clinical setting (activity capacity), does walking performance in daily life also improve (activity performance), and do they predict improvement in participation?

Activity performance and participation are important indicators of perceived health among people with MS [15] and priorities for rehabilitation [16]. However, mobility interventions for people with MS primarily focus on activity capacity, often with the aim of achieving concurrent improvements in activity performance and participation [17]. A better understanding of the relationship between activity capacity, capability, performance and participation will provide a stronger theoretical underpinning for mobility interventions designed to optimise participation in everyday life [18]. The aim of this study was to examine the association between walking ability in a clinical setting (activity capacity), walking ability in a person’s daily environment (activity capability) and walking performance in daily life (activity performance), and the relative contribution of each activity construct to participation among people with MS.

Methods

Participants were recruited for this cross-sectional study through five MS therapy centres in England between January 2015 and August 2016. Inclusion criteria were: a self-reported diagnosis of MS; over 18 years of age; ability to walk independently indoors with or without a walking aid. Exclusion criteria were: contraindication to exercise identified by the Physical Activity Readiness Questionnaire (PAR-Q) [19]; a cognitive or visual impairment that prevented them from completing the questionnaires; or experiencing a self-reported exacerbation of MS symptoms. Information about the study was displayed at MS centres and in newsletters. Gatekeepers at each respective centre also provided potential participants with information sheets via email or in per-

son. All people who expressed an interest in participating to the research team were provided with an information sheet, screened for eligibility and given the opportunity to ask any questions regarding their participation in the study, before providing written informed consent. Participants were informed at each assessment that participation was completely voluntary and that they had the right to withdraw at any point.

Data were collected by researchers during two sessions at MS centres approximately one week apart. Four researchers, who were independent to the MS centres, conducted assessments. All researchers were trained in the assessments and followed a standardised protocol. At the first session participants completed a demographic questionnaire, the Fatigue Severity Scale [20], the Six Minute Walk Test (6MWT) [21], the Twelve Item MS Walking Scale (MSWS-12) [22], and the Impact on Participation and Autonomy (IPA) questionnaire [23]. The order of completion of these assessments was randomised for each participant in order to minimise the potential impact of physical and cognitive fatigue on outcomes. Participants were informed that they could rest at any time during the assessments. Following the completion of these assessments participants were provided with a pedometer, instructions on how to use it, and a diary to record steps/day. Participants were instructed to wear the pedometer for the following 6 days. Participants returned the pedometer and step count diary to the research team at the second session. The Expanded Disability Status Scale (EDSS) was used to determine disease severity [24]. Participants with an EDSS score of 1 to 4.0 were categorised as mild and 4.5 to 6.5 were categorised as moderate.

Six Minute Walk Test

The 6MWT was used to assess participants’ activity capacity. The test was conducted in accordance with the guidance outlined by the American Thoracic Society [21]. Participants were instructed to walk as far as possible for 6 minutes along a 10 m walkway marked with two cones at either end. Participants were permitted to slow down, stop or rest as necessary. The total distance completed was recorded. The 6MWT is a valid and reliable measure of walking capacity among people with MS [25,26].

Twelve Item MS Walking Scale

The Twelve Item MS Walking Scale (MSWS-12) was used to assess participants’ activity capability. The MSWS-12 asks respondents to report how much their ability to mobilise, for example walking, running, climbing stairs, has been limited over the past two weeks, on a scale of 1 to 5 (not at all to extremely) [22]. The MSWS-12 captures different aspects of walking capability including balance, use of support, speed, distance and automaticity. The MSWS-12 has demonstrated excellent validity and test-retest reliability, and high internal consistency among people with MS across a range of dis-

ability severities [22]. Scores range from 12 to 60 on the MSWS-12 with a higher score indicating poorer walking capability.

Pedometer

The Yamax SW200 Digi-Walker pedometer was used in the current study to assess activity performance. This pedometer is a valid and reliable measure of physical activity in people with MS [27,28]. Participants were instructed to wear the pedometer on the waistband of their clothing or belt directly over the right hipbone, facing forwards and in line with their knee. They were told to put it on first thing in the morning and wear it during waking hours, removing it only for showering or swimming. Participants were instructed to reset the pedometer each morning, so that the step count on the monitor read zero, and to record the number of steps displayed on the monitor in the step count diary at the end of each day. Participants with a minimum of three days of at least 8 hours of data were included in the analysis as three days of monitoring results in good reliability (intra-class correlation of 0.80) [28]. Data were averaged over the number of days on which participants wore the pedometer.

Impact on Participation and Autonomy questionnaire

The IPA was used to assess participants' participation. The IPA assesses the perceived personal impact of disability on participation and autonomy on a five-point scale (0 to 4; very poor to very good) across five subscales (autonomy indoors, family role, autonomy outdoors, social life and relationships, work and education). A score for each subscale was calculated, if at least 75% of the subscale was completed, according to the manual for the IPA. The median score was obtained for each subscale with a median score of 0 indicating no limitation in participation and autonomy and a median score of 4 indicating very poor participation and autonomy. The IPA is a valid, reliable and acceptable measure of participation and autonomy among people with MS [23].

Data analysis

A complete case analysis was conducted. Data were examined using histograms, Q-Q plots, cross-tabulations and box-plots. Descriptive statistics were reported for all variables using mean (standard deviation [SD]), median (interquartile range [IQR]), or frequencies, where appropriate.

Separate linear regression models were fitted to examine the unadjusted associations between distance on the 6MWT, MSWS-12 score and mean steps/day, and the subscales of the IPA, respectively. Exploratory analyses were conducted to identify potential confounders. To be considered a true confounder a variable must be associated with the outcome variable, be associated with the predictor variable, and not be on the causal pathway between the predictor and outcome

variable. Firstly, we explored the relationship between participant characteristics (age, sex, type of MS, disease severity based on EDSS score, disease duration, fatigue based on Fatigue Severity Scale score), and each activity construct and participation, respectively, using linear regression. Each potential confounder was then added separately to the regression models to assess its impact on the associations between 6MWT, MSWS-12 score, mean steps/day, and the subscales of the IPA, respectively. Variables that altered the coefficient for 6MWT, MSWS-12 score, or mean steps/day (depending on the model) by more than 10% were included in the final model. To improve ease of interpretation steps/day and 6MWT distance were scaled in all analyses so that the regression coefficient for steps/day and 6MWT, respectively, related to the change in the outcome for an increase in 500 steps/day and 10 m.

Assumptions of homoscedasticity, normally distributed residuals, and linearity were assessed by examining plots of residuals against fitted values, and histograms and Q-Q plots of residuals. As there was some evidence from all linear regression models that residuals did not follow a normal distribution, and given the relatively small sample size, a bootstrapping procedure was used. The bootstrap is a computationally intensive method that can be used to provide valid confidence intervals in the presence of non-normally distributed residuals and/or a small sample size. The method involves sampling "bootstrap samples" with replacement from the original sample and calculating the statistic (in this case β) from each bootstrap sample [29]. For the purpose of this analysis bias-corrected and accelerated bootstrap confidence intervals (CIs) were calculated from 2000 replicates [29]. As exact p-values are not calculated when a bootstrapping procedure is used the p-value associated with each effect estimate was inferred from the confidence interval (CI) (95% or 99% CI).

Results

Fifty-four participants were recruited to the study. One participant did not have valid pedometer data and one participant did not have data for the MSWS-12. Fifty-two participants were included in the final analysis. Of these, only 29 people completed the work and education subscale of the IPA and therefore this subscale was not included in the analysis. Participant characteristics are presented in Table 1. Participants were aged 29 to 71 years (mean [SD] 55 [9.1] years) with a median time since diagnosis of 10 year (range 0 year to 42 years). Twenty-five percent of participants were male. The majority of participants (58%) had an EDSS score of 5 to 7. Participants wore the pedometer for a median of 6 days (range 4 d to 7 days) and mean (SD) wear time per day was 14 (1) hour (range 11 hours to 17 hours). Mean (SD) MSWS-12 score was 39 (13), mean (SD) distance on the 6MWT was 271 (116) m, and mean steps/day were 4211 (3231) steps. Median score on the autonomy indoors, auton-

Table 1

Participant characteristics and scores obtained on measures of activity and participation (n = 52).

		Range
Mean (SD) Age, year	55.4 (10)	29 to 71
Males, n(%)	13 (25)	
Type of MS		
Relapsing remitting	24 (46)	
Primary progressive	10 (19)	
Secondary progressive	18 (35)	
Time since diagnosis, year	10.2 (16) ^a	0.3 to 42.0
Employed, n(%)	28 (54)	
Mobility aid		
No aid	16 (31)	
1 stick, n(%)	26 (50)	
2 sticks, n(%)	3 (6)	
Rollator, n(%)	7 (13)	
EDSS score		
1 to 4.0	22 (42)	
4.5 to 6.5	30 (58)	
Fatigue severity scale	43 (20) ^a	12 to 61
MSWS-12	38.9 (13)	12 to 60
6MWT distance, m	270.9 (116)	33.5 to 544.0
Mean steps per day	4211 (3231)	256 to 16,065
Participation		
Autonomy indoors	0 (1) ^a	0 to 2
Autonomy outdoors	1 (1) ^a	0 to 4
Family role	1 (1)	0 to 4
Social life and relationships	0 (1)	0 to 3

^a Presented as median (interquartile range).

omy outdoors, family role, and social life and relationships subscales of the IPA were 0, 1, 1, and 0, respectively (Table 1).

Association between activity capacity, capability and performance

Associations between 6MWT distance, MSWS-12 score, and mean steps/day are presented in Table 2. 6MWT distance explained 32% of the variation in MSWS-12 score. 6MWT distance explained 45%, and MSWS-12 score explained 30% of the variation in mean steps/day, respectively. After adjusting for confounders there was evidence of a negative association between 6MWT distance and MSWS-12 score

($p < 0.01$). An increase of 10 m on the 6MWT was associated with an improvement of 0.56 (95% CI 0 to 1) on the MSWS-12. There was also evidence of a positive association between 6MWT distance and steps/day ($p < 0.01$), and a negative association between MSWS-12 score and steps/day ($p < 0.05$), after adjusting for confounding factors. An increase of 10 m on the 6MWT was associated with an increase of 130 (95% CI 49 to 208) steps/day. An improvement of 1 point on the MSWS-12 was associated with an increase of 87 (16 to 172) steps/day.

Association between activity and participation

Associations between activity and each subscale of participation are presented in Tables 3, Supplementary Tables S1, S2 and S3. Prior to adjusting for confounding factors there was evidence that 6MWT distance and MSWS-12 score were associated with the autonomy indoors, autonomy outdoors, and family role subscales, respectively ($p < 0.05$). There was also evidence that mean steps/day was associated with autonomy outdoors ($p < 0.05$). However, after adjusting for confounders, only 6MWT distance remained associated with participation, specifically the autonomy indoors subscale ($p < 0.01$). A 10 m increase in 6MWT was associated with an improvement in the score for autonomy indoors of 0.02 (95% CI 0 to 0).

Discussion

In summary, all constructs of activity were interrelated; walking capacity (6MWT) was associated with both walking capability (MSWS-12) and walking performance (mean steps/day), and walking capability was associated with performance. Walking capability and performance were not associated with any participation subscale. Walking capacity was associated with the autonomy indoors subscale of the IPA only, i.e. the ability to look after oneself (washing, dressing, going to bed, eating and drinking), and get around the house as wanted. However, the association between walking

Table 2

Unadjusted and adjusted regression coefficients, with 95% confidence intervals, for associations between Six Minute Walk Test, Twelve Item MS Walking Scale and steps per day, respectively.

	Unadjusted analyses			Adjusted analyses ^a		
	Coefficient (95% CI)	p value	R ²	Coefficient (95% CI)	p value	R ²
Dependent variable: Twelve Item MS Walking Scale						
Model 1	−0.64 (−0.87 to −0.39)	<0.01	0.3244	−0.56 (−0.87 to −0.22)	<0.01	0.4319
Six Minute Walk Test (10 m)						
Dependent variable: mean steps per day						
Model 2	186.66 (122.74 to 251.29)	<0.01	0.4479	129.49 (48.48 to 207.57)	<0.01	0.4864
Six Minute Walk Test (10 m)						
Model 3	−135.62 (−216.38 to −64.12)	<0.01	0.2968	−87.35 (−172.29 to −15.71)	<0.05	0.4693
Twelve Item MS Walking Scale (1 unit)						

CI: confidence interval.

^a Model 1 and 3 adjusted for disease duration and disease severity according to EDSS; Model 2 adjusted for disease severity according to EDSS.

Table 3

Unadjusted and adjusted regression coefficients, with 95% confidence intervals, for associations between Six Minute Walk Test, Twelve Item MS Walking Scale, steps per day, and autonomy indoors subscale, respectively.

Dependent variable: autonomy indoors	Coefficient (95% CI)	p value	R ²
Unadjusted analysis			
Six Minute Walk Test (10 m)	−0.02 (−0.03 to −0.01)	<0.01	0.1749
Covariate: type of MS			
Six Minute Walk Test (10 m)	−0.02 (−0.04 to −0.01)	<0.01	0.1805
Unadjusted analysis			
MSWS-12 (1 unit)	0.01 (0.001 to 0.02)	<0.05	0.0882
Covariates: EDSS score ^a and FSS score			
MSWS-12 (1 unit)	0.01 (−0.01 to 0.02)	>0.05	0.1324
Unadjusted analysis			
Steps per day (500/day)	−0.03 (−0.06 to 0.001)	>0.05	0.1261
Covariate: EDSS score ^a			
Steps per day (500/day)	−0.02 (−0.06 to 0.02)	>0.05	0.1508

CI: Confidence interval; MS: multiple sclerosis; EDSS: Expanded Disability Status Scale; FSS: Fatigue Severity Scale.

^a EDSS score dichotomised as 1 to 4.0 and 4.5 to 6.5.

capacity and participation was weak, with a 10 m increase in walking distance associated with only a 0.02 (95% CI 0.01 to 0.04) improvement in score for autonomy indoors (scale 0 to 4). The clinical implication of these findings is that standardised measures of activity completed in the clinical setting may not predict a person with MS's ability to participate in everyday life.

Previous studies have similarly found associations between 6MWT distance and step-count [30], and MSWS-12 score and step-count [26,30–32], respectively. Gijbels *et al.* [33] found a very similar correlation between steps/day and 6MWT ($R^2=0.46$) to the current study, despite having a younger sample and a larger proportion of participants with mild disability. However, Cavanaugh *et al.* [30] reported that the associations between MSWS-12 score and step-count ($\rho=-0.83$), and between 6MWT distance and MSWS-12 score ($\rho=-0.80$), respectively, were stronger than that between 6MWT distance and step-count ($\rho=0.67$). The results may not be comparable as the sample size was considerably smaller than that in the current study ($n=21$), although the distribution of age and EDSS score was similar. Further, findings should however be interpreted with caution as potential confounders, such as disease severity, which may be driving the relationship between activity measures, were not adjusted for [30]. The current analysis strengthens the evidence base by indicating that associations between 6MWT, MSWS-12 and step-count remain after adjusting for potential confounders.

Authors of previous studies have suggested that MSWS-12 score and 6MWT distance may be useful outcomes for evaluating physical therapy interventions when objective assessment of walking performance is not possible, given the strong association between these measures and step-count [30,33]. However, this conclusion was based on the strength of the association rather than interpretation of effect estimates. While we found similarly strong associations between measures of activity, our findings suggest that the 6MWT and MSWS-12 respectively, may have little clinical utility as predictors of habitual walking performance, given the

relatively small effect estimates. Motl *et al.* [31] identified that approximately 800 steps/day is a clinically meaningful increase in step-count. Our findings suggest an increase of approximately 61 m in 6MWT distance and a decrease of approximately 9 points on the MSWS-12 is associated with an increase of 800 steps/day. This represents a 22% and 23% improvement in 6MWT distance and MSWS-12 score relative to the mean values observed in our sample, and thus may be unrealistic.

The current evidence regarding the association between activity and participation is equivocal. While associations have been found between activity, measured using walk tests and the MSWS-12, and participation [34,35], a comprehensive analysis of the correlates of participation found that cognitive problems and environmental barriers have the largest direct effect on participation [35]. Similarly, Conradsen reported that even though people with MS with mild disability experienced decline in walking speed over a 10-year period they did not experience concurrent decline in participation in social and lifestyle activities [7]. The association between walking performance and participation has not been examined to date, even though it may be expected that the walking a person actually completes in their daily life better predicts their participation compared to a walk test in a clinical environment. However, our findings did not support this hypothesis. The results of this study suggest that walking capacity is the only predictor of participation, although the association is weak. While meaningful change on the IPA has not been established for people with MS, minimal detectable change on the autonomy indoors subscale among people with spinal conditions was 0.70 [36]. Extrapolating our findings indicate that an increase of 350 m in 6MWT distance would be required to obtain an associated increase of 0.70 on the autonomy indoors subscale. As the mean distance on the 6MWT in our sample was 270.9 m, this result clearly has no clinical relevance. Additionally, 6MWT distance only explained 17% of the variation in participation, indicating that the majority of variation in participation is not explained by walking capacity. As identified by the ICF framework, participation

is a complex construct that is impacted by the interaction between environmental factors, personal factors, and a person's impairments and activity limitations [2]. Self-efficacy, accessibility, personality, assistive devices, and social supports have been identified as factors influencing participation among people with mobility impairments [14,35,37,38] and may explain some of the variation in participation that was not captured by the variables assessed in this study.

The findings of this study suggest that it cannot be assumed that improvements in activity coincide with improvements in participation. Rehabilitation interventions often target impairments and activity limitations, which may result in improvements in activity [17]. The impact of rehabilitation on participation is assessed less frequently [17]. As such, it cannot be assumed that interventions targeting specific constructs of activity such as activity capacity result in meaningful improvements in other activity constructs or participation. Prior to developing a treatment plan, activity and participation should be individually assessed in order to determine the impact of MS on all levels of a person's functioning. Further, if improvements in participation among people with MS are of interest, interventions that specifically target participation may be required.

Study limitations

There are several limitations to this study that should be considered when interpreting the results. The study included a relatively small number of participants so the results may not be representative of the larger population of people with MS and the analysis is likely underpowered to detect associations. While we excluded people with a self-reported exacerbation of MS symptoms to reduce bias, this likely reduced the representativeness of the sample further. Additionally, it may have been more appropriate to exclude people based on a standardised questionnaire such as the Assessing Relapse in MS (ARMS) questionnaire. The ratio of females to males was however similar to that reported in the MS population [39] and the mean age was approximately 50 years, which is known to be the age at which the prevalence of MS peaks [39]. The study was limited to people with MS who could walk independently and therefore the results cannot be extrapolated to people with MS with more severe disability. The small sample size also resulted in large confidence intervals for some regression coefficients, and so regression coefficients should be interpreted with consideration of the degree of imprecision associated with them. Further, since the development of the ICF framework there have been inconsistencies in how participation is defined, and consequently there exists a range of measures that purport to measure participation from different perspectives. Although the IPA is a valid measure of participation [40,41], different results may have been observed if a different measure of participation was used. Finally, as with all observational studies residual confounding may be present. We did not assess general health status or examine the potential impact of weather

conditions or temperature on associations. As participants were recruited for this study over a period of 19 months, participants' activity and participation may have varied across this time because of weather conditions and temperature. As assessments were conducted on each participant during a period of a week, it is possible that although absolute values of activity and participation may have differed between certain months, associations between each construct remained consistent. However, it is also possible that while temperature affected a participants' activity performance for example, it did not affect capacity, capability or participation to the same extent.

Conclusions

In conclusion, this study highlights the importance of considering the impact of MS on both activity and participation when developing and evaluating a rehabilitation programme. Walking ability in the clinical environment is associated with walking ability in a person's daily environment and of actual walking performance in daily life. However, large improvements in both walking capacity and walking capability may be required to observe any clinically relevant improvement in walking performance. Walking capacity, capability or performance are not strongly associated with participation. Therefore, if participation is of interest it should not be assumed that improving activity will result in concomitant improvements in participation or that measures of activity may be used as surrogate measures of participation.

Key messages

- Among people with MS, walking ability in a clinical setting is associated with walking ability in a person's daily environment and walking performance in daily life.
- Our findings suggest that an increase of 61 m in 6MWT distance and a decrease of approximately 9 points on the MSWS-12 (score 12 to 60) is associated with clinically meaningful increase in daily step-count.
- Only walking ability in a clinical setting is associated with participation.
- The strength of the association between activity and participation is too weak for measures of activity to be considered surrogate indicators of participation.

Ethical approval: Ethical approval for this study was provided by Brunel University London's College of Health and Life Sciences Research Ethics Committee (Ref: 14/12/PHY/05).

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Conflicts of interest: None declared.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at <https://doi.org/10.1016/j.physio.2018.11.002>.

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