Relationships between Patient Determined Disease Steps and Neuro-QoL Lower Extremity and Upper Extremity Functional Domains for Different MS Subtypes

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Background

Physical disability is a common experience of people with multiple sclerosis (MS). For example, mobility impairment is a key complaint for people with MS (PwMS).

The clinician-assessed Kurtzke Expanded Disability Status Scale (EDSS)[1] is routinely used to measure disability in PwMS in care settings, clinical trials and research studies. The patient-reported Patient Determined Disease Steps (PDDS)[2], which correlates highly with EDSS, has also been used frequently to measure physical disability in PwMS. Both assessment tools are heavily weighted toward mobility.

Although mobility restriction is an important aspect of physical disability, there are many activities of daily living, distinct from mobility, that matter greatly to PwMS and affect their quality of life. Patient Reported Outcomes (PROs) can provide information on a wide range of symptoms, disabilities and quality of life issues that affect PwMS. For example, PROs can provide insights into lower extremity (LE) and upper extremity (UE) functional disabilities experienced by a person living with MS that cannot be assessed by EDSS or PDDS.

With an increased interest in research on MS disease progression and in clinical trials for interventions designed to stop, reduce or reverse disability in MS, there is a clear need for tools to assess MS disability more comprehensively. As disability outcome measures, both EDSS and PDDS fail to capture the wide range of physical abilities and disabilities experienced by PwMS. This need for new tools for assessing disability progression, particularly PRO measures, was recently highlighted in the European Medicine Agency's Draft Qualification Opinion of Multiple Sclerosis Clinical Outcome Assessment[3].

To explore the benefits of using PRO measures to assess physical disability in MS, we evaluated the relationships between PDDS and the LE and UE function domains of the Neuro-QoL Adult Short Form (Neuro-QoL)[4] responses contributed by members of the iConquerMS™ People-Powered Research Network (PPRN).

Objectives

1. **To evaluate relationships between PDDS and Neuro-QoL LE and UE function domains for different MS subtypes.**
2. **To understand how well PDDS reflects physical function disability in people living with MS for both lower and upper extremities.**
3. **To explore the value of PROs for assessing physical function abilities in people living with MS**

The iConquerMS PPRN

iConquerMS™ is an online MS PPRN established in 2014. To date, over 5,000 PwMS have joined iConquerMS. Participants are invited to provide their data for research purposes under informed consent. Baseline surveys on the iConquerMS.org portal include Demographics, MS History, Neuro-QoL and PDDS.

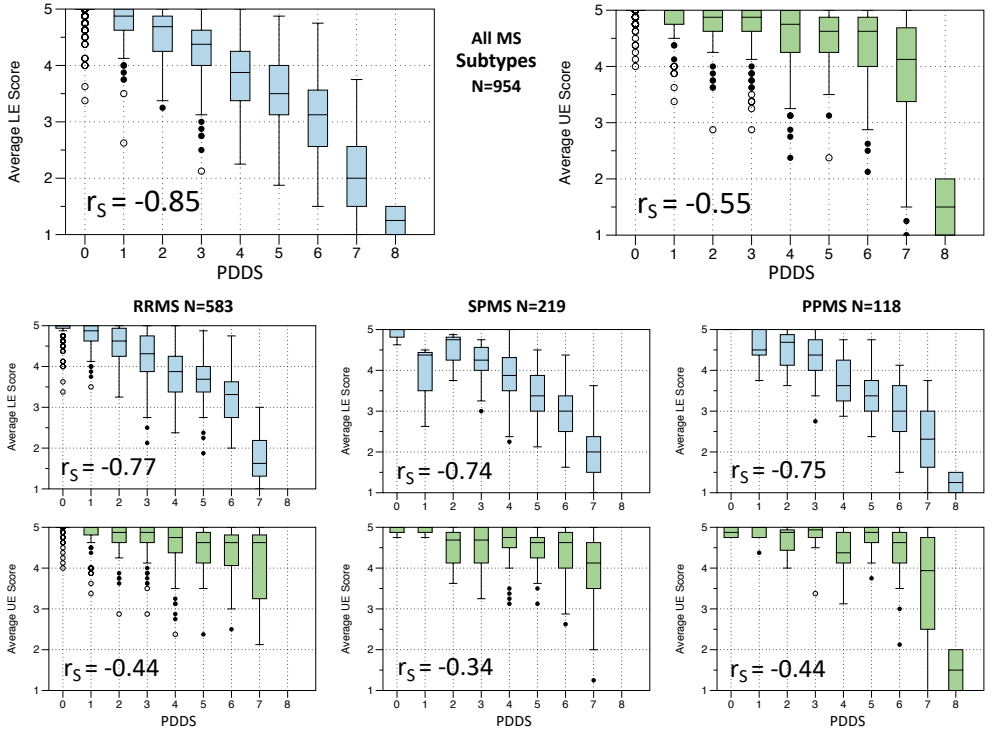
Methods

A dataset comprising baseline data provided by 954 iConquerMS participants for PDDS, Demographics, MS History and the LE and UE function domains of Neuro-QoL was downloaded. The dataset included the following MS subtypes: clinically-isolated syndrome (CIS, N=34); relapsing-remitting MS (RRMS, N=583); secondary progressive MS (SPMS, N=219); and, primary progressive MS (PPMS, N=118).

Likert Scale Neuro-QoL LE and UE answers were converted to 5-point integer raw scores (5=best outcome to 1=worst outcome). Raw scores for the 8 questions in each domain were averaged and plotted (box & whisker) for all MS subtypes combined and, individually, for RRMS, SPMS and PPMS against PDDS values*. Spearman correlation coefficients (r_s) were generated for relationships between PDDS values and average LE and UE scores for all MS subtypes, combined and individually. CIS results not shown below due to low N and data bunching.

To further explore the relationships between specific activities of daily living, correlation coefficients were calculated for individual questions in the LE and UE Neuro-QoL domains.

Results: Graphs of LE or UE Domain Average Scores vs PDDS Values



*PDDS: 0=Normal, 1=Mild Disability, 2=Moderate Disability, 3=Gait Disability, 4=Early Cane, 5=Late Cane, 6=Bilateral Support, 7=Wheelchair/Scooter, 8=Bedridden

Results: Single Question Correlation Coefficients

Selected Question	r_s
Lower Extremity	
Are you able to go for a walk of at least 15 minutes?	-0.72
Are you able to get out of bed into a chair?	-0.46
Are able to get on and off a toilet?	-0.51
Upper Extremity	
Are you able wash and dry your body?	-0.40
Are you able to make a phone call using a touch tone keypad?	-0.20
Are able to brush your teeth?	-0.28

Discussion and Conclusions

The graphs of average LE scores versus PDDS values and the associated Spearman correlation coefficients (r_s) reveal that, although there is a strong correlation between the two measurements of lower extremity function, the average LE scores can vary widely for any PDDS level in PwMS self reporting any MS subtype. Some individual questions in the LE item bank that do not strictly assess mobility have lower r_s values than questions that do assess mobility.

The graphs of average UE scores versus PDDS values for any MS subtypes reveal a moderate correlation between the two measurements of physical function. Some individual questions in the UE item bank have low r_s values for their correlations with PDDS. PDDS is a poor measure for assessing UE functional ability in PwMS.

These results highlight the limitations of a single measure focused heavily on mobility, such as PDDS or EDSS, for assessing physical disability in PwMS. The results also highlight the preservation of UE functional abilities in PwMS who have high levels of disability assessed by their PDDS level. PROs can provide an important level of granularity in the assessment of a wide range of physical abilities associated with activities of daily living that matter greatly to people living with MS.

References

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