Language and communication in MS - patient-reported outcome measures (PROMs) and cross-sectional studies

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**Speech pathologist:**
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Research methodologies

1. Patient-reported outcome measures (PROMS)

2. Cross-sectional clinical study
Rationale:
Why should we investigate language impairment in MS?
Image: https://radiopaedia.org/cases/brocas-and-wernickes-areas-illustration
Subcortical structures (deep grey matter)

White matter pathways

https://imgbin.com/png/hdR1n7Rz/coronal-plane-human-brain-neuroanatomy.png
• **Clinical studies**: people with MS can have impaired performance on language tasks e.g. difficulty with non-literal language tasks, verbal reasoning tasks, spontaneous speech (e.g. shorter sentences, less content), and word finding tasks.

(Carotenuto et al., 2018; Laakso et al. 2000; Lethlean & Murdoch, 1994, 1997; Mackenzie & Green, 2009; Renauld et al., 2016).

• **Limitations of previous studies:**
  
  – Do not provide explanatory information as to why people with MS experience difficulty with language tasks.
  
  – No information on the prevalence of language impairment in MS or its association with health-related quality of life (HRQoL).
  
  – Do not consider other factors, such as general cognition and motor speech skills as potential confounding variables.
Research gaps

• No information on the prevalence of language impairment in MS and its association with HRQoL in an international population.

• No validated PROM specifically designed to measure language and communication in MS.

• The underlying cause/s of language impairment in MS remains unknown. Is it due to:

  - Damage to language-specific areas of the brain?
  - And/or impaired general cognitive skills (e.g. memory, attention)?
  - And/or (conflated by) motor speech impairment?
Rationale: Why should we investigate this symptom in MS?

- **Further research is needed:** this will help to better understand why people with MS experience language impairment to determine the best treatment options e.g. mixed intervention approach vs. domain specific approach.

- **Impact of language impairment:** social isolation, loss of vocational standing, frustration, loss of autonomy, and reduced participation in everyday activities.

  (Klugman & Ross, 2002; Yorkston et al. 2014).
Study 1 and Study 2: PROMS
Study 1: Prevalence of self-reported language impairment in MS and the association with HRQoL
Aims

1. To determine the prevalence and nature of self-reported language impairment in MS using a validated MS-specific PROM.

2. To identify the demographic and clinical variables associated with PwMS with self-reported language impairment.

3. To determine the association between self-reported language impairment and self-reported HRQoL.
Method

• **Questionnaire:** Participants completed an online questionnaire, which comprised of:
  
  – 4 language items of the *Speech pathology-specific questionnaire for persons with MS (SMS)* to assess language. 5-point Likert scale with anchors ‘never’ to ‘almost always’.
  
  – 12-Item Short Form Survey (SF-12) to assess HRQoL.

• **Participants:**
  
  – **Respondents:** 160 PwMS responded to the questionnaire.
  
  – **Recruitment:** internationally through professional MS bodies, neurology clinics, and MS support groups.
  
  – **Inclusion criteria:** (1) over 18 years, (2) have MS, and (3) be English-speaking.
Results

• 75% (120 out of 160) PwMS self-reported a language impairment.
• 65.7% reported difficulty with word retrieval
  “I find myself searching for the right word to express my thoughts”
• 53.8% reported difficulty with expressive language
  “When talking, I have difficulty conveying precisely what I mean”
• 49.4% reported difficulty with confrontational naming
  “I find myself calling a familiar object by the wrong name”
• 40.6% reported difficulty with receptive language in spoken discourse.
  “I find it difficult to make sense out of what people say to me”

Results

• Statistical analyses revealed that age, sex, educational status, country of residence, disease duration, age at time of diagnosis, MS subtype, and medication management, were NOT associated with the prevalence of self-reported language impairment.

• Participants with self-reported language impairment had lower HRQoL than those without language impairment, scoring lower on both the SF-12 mental \( (t(158) = 4.0; p < 0.001) \) and physical \( (t(158) = 4.9; p < 0.001) \) summary scores, with medium to large effect sizes (Cohen's \( d = 0.66 - 0.83 \)).

• Participants with self-reported language impairment had higher rates of unemployment than those without language impairment \( (\chi^2 = 18.2; p < 0.001) \).

• Of the 120 participants reporting a language impairment, only 1 participant was receiving speech pathology intervention.
Limitations

• Language ability was assessed using 4 questionnaire items only.

• This may be considered a brief measure of language ability.

• The study findings underline the need to further investigate language impairment in MS given its high prevalence and association with lower HRQoL.
Conclusions

• Language can be compromised in PwMS regardless of clinical and demographic characteristics.

• Language impairment in MS is associated with lower HRQoL.

• Language impairment in MS is associated with lower employment rates.

Recommendations

• Frontline healthcare providers need to be aware of language impairment in MS and should ask their patients about this symptom.

• PwMS with self-reported language impairment should be referred to a speech pathologist for further evaluation.
Study 2:
Development and validation of a self-report questionnaire to measure communication and language impairment in MS
Aim

1. To develop and validate a self-report tool to measure language and communication ability in PwMS.
Method

• **Questionnaire:** initial questionnaire item pool includes 40 items generated from the:
  – La Trobe Communication Questionnaire (LCQ)
  – Speech pathology-specific questionnaire for persons with Multiple Sclerosis (SMS)
  – The literature describing communication and language in MS

• **Participants:**
  – **Recruitment:** internationally through professional MS bodies, neurology clinics, and MS support groups.
  – **Inclusion criteria:** (1) over 18 years, (2) have MS, and (3) be English-speaking.
  – **Respondents:** 215 PwMS responded to the questionnaire.

https://redcap.sydney.edu.au/surveys/?s=PCR8ND4T9D
Analysis

1. **Principal component analysis**: to explore variability in the 40-items and to cluster related items into homogenous subscales.

2. **Internal consistency**: to evaluate how correlated items are in each subscale.

3. **Test-retest reliability**: to determine if scores are consistent over time.

4. **Criterion validity**: to correlate the tool with an established PROM: the communication participation item bank (CPIB).

5. **Floor and ceiling effects**
Implications

Clinical trials

Research

Longitudinal studies

Service provision studies

Clinical practice
Results

Communication and Language Assessment questionnaire for persons with Multiple Sclerosis (CLAMS)
Study 3: Solving the puzzle: language impairment in MS and the complex interplay of factors (A multi-pronged cross-sectional study)
Aims

1. To determine whether language impairment in MS is due to impaired general cognitive skills (e.g. attention, working memory) and/or impaired language-specific skills (e.g. word meaning, speech sounds).

2. To identify how language symptoms in MS are associated with neuropathology (e.g. lesion size, lesion location, whole brain volume).

3. To investigate the association between language tasks and self-reported questionnaires: HRQoL, depression, communication-related participation, social support networks, and employment status.

4. To (a) identify characteristics of spoken discourse in MS different from healthy matched controls and (b) whether linguistic deficits in spoken discourse are related to specific brain neuropathology patterns.
Methods

Clinical behavioral tasks

Experimental tasks

Formal language and cognitive assessment tasks

Control tasks

Self-report questionnaires

Lesion location and volume

Functional connectivity

MRI brain scans

Patient-reported measures

White matter organisation

Whole brain, grey matter, white matter, and subcortical volume

Methods

Clinical behavioral tasks

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Participants

Patients with MS:

- Westmead Hospital
- MS clinic run by Prof. Steve Vucic

Controls:

- Family members of patients with MS
- Community volunteers
## Analysis

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Method of analysis</th>
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</thead>
<tbody>
<tr>
<td>To analyse neuropathology on <strong>MRI brain scans</strong></td>
<td>Voxel based morphometry (VBM) using Functional MRI of the Brain Software library (FSL)</td>
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<tr>
<td>To explore <strong>differences between groups</strong> (i.e. participants with MS and controls) (e.g., demographic, clinical, and MRI variables)</td>
<td>Parametric and non-parametric statistical tests</td>
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<tr>
<td>To determine the relative contribution of different <strong>predictor variables</strong> on the prevalence and severity of language impairment</td>
<td>Multivariate analysis (logistic regression)</td>
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<tr>
<td>• Demographic variables (e.g., age, sex)</td>
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<tr>
<td>• Clinical variables (e.g., disease duration, age at time of diagnosis, MS subtype)</td>
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<tr>
<td>• MRI neuropathology variables (e.g., brain atrophy, lesion volume)</td>
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</table>
Results

To come...
References


Questions