

Fear of progression in multiple sclerosis

Evaluation of existing patient-reported outcomes (PRO) Instruments

Naomi Suminski, MS

Parexel International

Background and objective

- Multiple sclerosis (MS) is a chronic, progressive disease characterized by debilitating symptoms and causes great psychological and emotional distress.
- Fear of disease progression (FoP) has been widely assessed in oncology and other chronic conditions, but has been less studied in MS.
- The prevalence of suitable, content valid patient reported outcomes (PROs) to measure FoP, and related concepts like health anxiety and fear of relapse (FoR), in MS is unclear.
- This study aimed to identify existing PROs that have been used to measure FoP, and related concepts, in people with MS (PwMS).

Methods

- A literature review was conducted in Embase and Medline (December 2022).
- Search criteria were developed to identify MS studies utilizing PROs measuring FoP, worry, health anxiety, etc. (Figure 1).
- A supplementary search using Google Scholar identified additional records.
- Abstracts were screened via the screening tool Abstrackr and full articles selected for review; PROs were extracted from articles and evaluated for conceptual relevance.

REFERENCES



Results

- 212 records were identified in the primary search and five records in the supplemental.
- 58 records were reviewed in full, from which 38 PROs were identified; 11 PROs were further identified as most relevant.
- The most frequently used PROs were the Hospital Anxiety and Depression Scale (HADS), a generic instrument, followed by two MS-PROs (MS Impact Scale [MSIS-29] and MS Quality of Life [MSQoL-54]) (Table 1).
- The Fear of Relapse Scale (FoR) and Functional Assessment of MS (FAMS) were the most relevant disease-specific measures containing FoP- and health anxiety-related items.
- The Fear of Progression Questionnaire (FOP-Q) was the most relevant generic measure, though utilized less frequently.

Conclusions

- Many PRO instruments have been used to measure emotional wellbeing, like depression and anxiety, in MS yet few specifically assess worry or fear of disease progression or relapse.
- PROs which focus on FoP-related concepts (e.g., FoP-Q) have been utilized, but lack MS-specific items.
- New MS-specific FoP-related PROs have been developed (e.g., FoR) but are not yet widely implemented.
- The development and implementation of MS-specific instruments, which evaluate the nuanced emotional and psychological experiences of PwMS, is supported.

Figure 1. Literature review search strategy

Primary search items	Sources and limits	Screening criteria
<ul style="list-style-type: none">Disease terms: Multiple SclerosisInstrument terms: Patient reported outcome OR clinical outcome assessment OR instrument OR questionnaireConcept terms: Fear of progression OR Fear of relapse OR Concern about OR Worry about OR health anxiety	<ul style="list-style-type: none">Search conducted with Medline and EmbaseLimit to published form 2000-PresentLimit to English languageSupplementary search via Google Scholar	<ul style="list-style-type: none">Abstracts included if they reported PROs that assess fear of progression, or related concepts, in MS.Abstracts excluded if they primarily focused on: (1) pathogenesis, genetics, or molecular biology of disease, or (2) treatment or non-human research.

Table 1. Conceptual gap analysis of the most relevant PROs identified

PRO	# of sources reporting (n)	FoP/FoR	Anxiety	Depression	Worry/ concern	Nervous	Expectation disease will get worse	Positive affect/ wellbeing	Other relevant emotional impacts
Generic									
HADs	23		✓	✓		✓		✓	✓
EQ-5D-5L	5		✓	✓					✓
SF-12/SF-36	5			✓		✓	✓	✓	✓
BDI/BDI-II	5		✓	✓	✓				✓
Neuro-QoL	4		✓	✓		✓		✓	✓
DASS-21	3		✓	✓	✓	✓			✓
FOP-Q-SF	1	✓	✓		✓	✓			
MS-Specific									
MSIS-29	13		✓	✓	✓				✓
MSQoL-54	6			✓	✓	✓	✓	✓	✓
FoR	2	✓					✓		✓
FAMS	1	✓		✓	✓	✓	✓	✓	✓

HADs: Hospital Anxiety and Depression Scales; EQ-5D-5L: EuroQol 5-dimension-5-level; NeuroQoL: Neuro-Quality of Life Scales/Short Forms (Emotional, Cognitive, Anxiety); BDI: Beck Depression Inventory; SF-12: 12-item Short Form Survey; SF-36: 36-item Short Form Survey; BDI-II: Beck Depression Inventory Second Version; DASS-21: Depression Anxiety Stress Scales Short Form; FoP-Q-SF: Fear of Progression Questionnaire Short Form; MSIS-29: Multiple Sclerosis Impact Scale; MSQoL-54: Multiple Sclerosis Quality of Life-54 Questionnaire; FoR: Fear of Relapse Scale; FAMS: Functional Assessment of Multiple Sclerosis

Parexel International
2520 Meridian Pkwy
Durham, NC 27713, USA
+1 919 544-3170
www.parexel.com

