

Instruments measuring (health-related) quality of life in people with multiple sclerosis: a systematic review following COSMIN guidelines

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Background. There are many patient-reported outcome measures (PROMs) of quality of life (QoL) and health-related QoL (HRQoL) in MS. However, a comprehensive assessment of the most suitable (HR)QoL PROMs for use in an evaluative application is lacking. This systematic review aimed to assess the psychometric properties of (HR)QoL PROMs for people with MS.

Methods. We conducted a systematic review following the Consensus-based Standards for the selection of health Measurement Instruments (COSMIN) methodology (PROSPERO 2024; CRD42024507743). We searched MEDLINE, EMBASE, CINAHL, and PsycINFO databases. We included studies if their aim was to evaluate at least one psychometric property of a generic/MS-specific (HR)QoL PROM. Instruments with evidence for sufficient content validity and internal consistency were recommended, while those with high quality evidence for any insufficient measurement property were unrecommended.

Results. We screened 3628 abstracts, reviewed 267 full-text articles, and included 144 studies. 35 PROMs were identified including 16 generic (HR)QoL and 19 MS-specific (HR)QoL instruments. Overall, hypotheses testing for construct validity (convergent and known-groups validity), internal consistency, test-retest reliability, and structural validity were the most investigated measurement properties. Criterion validity, measurement error and cross-cultural validity/measurement invariance were the least studied.

Seven instruments were recommended for use: LMSQoL, MSQoL-54, MSIS-29, MusiQoL, Neuro-QoL, MSQoL-29, and SQoL.

Conclusions. This review identified evidence in support of (HR)QoL MS instruments. Our findings will guide clinicians to select the most suitable (HR)QoL instruments and provide researchers with insight into gaps in the literature. Measurement error and cross-cultural validity/measurement invariance should be further investigated.

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