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TITLE

**Measuring informal carer health-related quality of life in motor neuron disease:
A systematic review of the content validity of self-report instruments using COSMIN**

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Aim(s)

Motor Neuron Disease (MND) is a rare neurodegenerative condition characterised by frequently swift progression and devastating functional impact. Current treatment is offered to prolong life without curative intent. The rapid physical disease progression, incurability and prevalence of cognitive and behavioural change place unique demands on informal carers of people living with MND (plwMND), impacting upon their own health-related quality of life (HRQoL). Several patient-reported outcome measures (PROMs) have been employed to assess the HRQoL (or an aspect thereof) of informal carers of plwMND, yet their validity for this cohort remains unclear. This review has two aims. Firstly, to identify PROMs that have been used to assess the HRQoL of informal carers of plwMND. Secondly, to appraise the content validity of the identified PROMs using COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) methodology.

Method(s)

The protocol is published on PROSPERO (ID: CRD42023484037). Systematic searches were conducted in six electronic databases (MEDLINE, EMBASE, PsycINFO, CINAHL, Cochrane database of systematic reviews, Cochrane Central Register of Controlled Trials) with no restriction to publication date. Study identification followed published guidance, with sifting undertaken by two reviewers independently, and where discrepancies occurred, ratification through a third review. Data extraction from PROMs will be conducted by two independent reviewers, with consensus from a third reviewer. Extracted evidence will be qualitatively synthesised and evaluated, including risk of bias, against COSMIN methodology.

Results

Database searches yielded 3618 papers following deduplication, with 260 remaining for full-text review. Data extraction is ongoing, with 107 PROMs currently identified for assessment via COSMIN methodology. Full results will be available by October 2024.

Conclusions

Informal caring in MND has an undeniable impact upon the HRQoL of carers. Various different PROMs could be used to assess informal carer HRQoL. This review will provide a recommendation for the most suitable identified PROM(s) to assess HRQoL of informal carers in terms of their content validity. Should the review identify instrument(s) with good content validity, further assessment of psychometric performance would be warranted.

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