A global survey of linguistic validations of the NMSQuest and NMSS: implications for non-motor studies in Parkinson’s disease

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BACKGROUND

- The patient completed Parkinson’s disease (PD) non-motor symptoms questionnaire (NMSQuest) and the health-professional completed non-motor symptoms scale (NMSS) were validated since 2006 and recommended by the International Parkinson’s and Movement Disorders Society (IPMDS) and other learned societies for holistic assessment of non-motor symptoms (NMS) and their burden.
- The range and nature of the use of these tools across the world has not been properly evaluated.

METHODS

- An initiative and global survey of the IPMDS Non-motor- Parkinson’s disease- Junior Subgroup.
- Involvement of members from representative areas where the tools are used.
- Review of the literature and face to face interviews.
- Consultation with Mapi institute in relation to available translations.

RESULTS

- Table 1 summarize the linguistic validations for NMSQuest and NMSS captured as part of this survey.
- NMSS has been used as an outcome measure in several industry-sponsored clinical trials globally in a multi racial population (e.g. Abbvie, Britannia, Lundbeck, Pfizer, Cynapsus, UCB among others).


• The value of the use of the NMSQuest and NMSS in clinical practice and clinical trials is now reasonably established, but in spite of this, our work shows that the tools are often not used in a validated fashion.

• It is possible that there are local translations in several countries which have not been captured by our methodology.

• Our survey could not capture the numerous locally translated versions of NMSQuest or NMSS which are in use worldwide as we have purely relied on English language pubmed publications.

• This survey indicates that using linguistic validation using standard methodology needs to be adopted where these tools are currently used.