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Towards end-user centered outcome measurement: An example from Parkinson's disease

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Clinical trial rating scale based outcome measures have been criticized of lacking relevance and meaning to end-users, particularly patients. This is concerning since inferences regarding the usefulness of therapies are based on rating scale derived numbers. In order to be meaningful and in accord with their purpose in clinical trials, rating scale based outcome measures should not only be rigorous measures of the variables they intend to quantify, but they also need to represent variables that are important to end-users such as patients and health care professionals. This requires an understanding of what to measure, and state-of-the-art psychometric methods to ensure that rating scale derived data represent meaningful quantitative measures. However, relatively little is known about what variables that people with, e.g. Parkinson's disease (PD) prioritize for outcome measurement and how this compares to the views of health care professionals. These issues will be discussed and illustrated in view of recent mixed-methods (Group Concept Mapping) studies in PD. Results illustrate similarities in patient's and health care professional's views in that both considered quality of life as the most important outcome variable and both ranked walking/mobility and sleeping problems among the top five outcome variables. This may serve as guidance in designing future clinical trials. However, data also illustrate important differences in conceptual perspectives. Considerations such as those revealed in these studies should be taken into account in order to render clinical trial outcomes more meaningful and interpretable from an end-user perspective.

Biography

Peter Hagell has a clinical background in neuroscience nursing subspecializing in movement disorders, and completed his PhD at the age of 35 years from Lund University. He is Professor of neurological caring science at Kristianstad University (Sweden). His research focuses on measuring and understanding outcomes and disease impact in neurological and other long-term conditions. He has published more than 80 papers in reputed international scientific journals and has served on several editorial, organizing and scientific boards and committees as well as in leadership positions of professional organizations.

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