Too broad to be sensitive? An exploration of the responsiveness of the ICECAP-O capability wellbeing measure and the EQ-5D-3L in people with Parkinson’s

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Methods

Data source The ICECAP-O questionnaire, along with the EQ-5D-3L, PDQ-39 (a Parkinson’s specific QoL measure), demographics and clinical characteristics were collected from 1,023 participants with varied severity of Parkinson’s at intervals two years apart in the PD MED trials.

Ten criteria for grouping The Hoehn and Yahr (H&Y) motor symptom clinical measure (used for measuring clinical severity of Parkinson’s), PDQ-39 summary index (PDQ-39-SI) and its eight dimension scores were used independently as external indicators to classify participants to five change groups: largely/slightly improved/deteriorated, and no change.

Statistical analyses:

Correlation coefficients of the change in ICECAP-O / EQ-5D-3L index value against the change in PDQ-39-SI for each participant were examined.

Effect size (ES) and the standardised response mean (SRM) were calculated for each of the groups classified by the ten criteria. The standard error and confidence intervals for SRM and ES were generated through bootstrap with 1000 replicates.

Missing data were imputed using multiple imputation with chained equations (MICE) method.

Objective

To explore the responsiveness of the ICECAP-O measure to the change in health and QoL aspects in people with Parkinson’s and compare this with the responsiveness of the EQ-5D-3L instrument in a large-scale RCT in people with Parkinson’s.

Results

Sample characteristics The mean age of participants was approximately 74 years, with the mean duration since Parkinson’s diagnosis of 6.54 years.

An overall trend of deterioration in clinical scores (median H&Y change from 2.5 to 3), health related QoL and capability wellbeing over the two years was observed (Figure 1 on the right).

Correlation results: The point estimates of the correlation coefficients indicated stronger correlation between ICECAP-O and PDQ-39 change scores than between EQ-5D-3L and PDQ-39 change scores, although differences were small (Figure 2).

Responsiveness to the change in H&Y (motor symptoms): ICECAP-O was shown to be slightly less responsive to the change in H&Y than EQ-5D-3L.

Responsiveness to the change in PDQ-39 SI (overall QoL and wellbeing): the ICECAP-O was associated with a larger magnitude (not statistically significant) of SRM in all of the four change groups than EQ-5D-3L (Figure 3). The ICECAP-O was shown to be marginally more responsive to mobility, stigma and social support dimensions than the EQ-5D-3L, but less responsive to activities of daily living, emotional wellbeing, and bodily discomfort.

Summary of results

In a trial population with Parkinson’s, there is evidence that the ICECAP-O was slightly more responsive to the change of overall QoL and wellbeing, while the EQ-5D-3L was slightly more responsive to the change of motor symptoms. The differences in the estimates were small and not statistically significant.

Conclusion

The results demonstrate that the ICECAP-O is responsive to the change of health, QoL, and wellbeing in people with Parkinson’s. In addition, sensitivity of the broad scoped ICECAP-O measure to the specific health change was not inferior compared to a health-related QoL measure.

This study shows that the broad scope of ICECAP-O instrument could provide rich information on the capability wellbeing in the Parkinson’s population without compromising its sensitivity to the clinical and specific QoL change in this patient group.