Clinic versus patient association sampling of people with Parkinson's disease

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Objective:

To explore the influence on common outcome variables when sampling people with Parkinson's disease (PD) from a neurology clinic versus a patient association (PA).

Background:

Since study results relate to the sample and its characteristics, a central issue is whether sampling sources affect generalizability of study results. It has, e.g. been suggested that PA members may not be representative, and that using PA-samples in research may induce a bias.

Methods

Data from two postal surveys were analyzed: one from a university neurology clinic consisting of people with diagnosed PD and one from patient members of a regional branch of PD patient association (PA).

Clinical sample, n=191 (response rate: 68%)
•Dementia or severe cognitive impairment constituted exclusion criteria
•Mean (min-max) age and PD duration was 70 (42-91) and 6 (0.9-28) years, respectively.

PA-sample, n=150 (response rate: 63%)
•Mean (min-max) age and PD duration was 70 (43-88) and 8 (1-25) years, respectively.

Included rating scales targeted:
•Fatigue (FACIT-F)
•Physical functioning (PF, SF-36)
•Mental health (MH, SF-36)
•Distress (NHPD)
•Walking difficulties (Walk-12G)
•A question concerning memory problems during the past month (rated as: never, seldom, sometimes, often or always).

Analyses

Regression analyses with age, PD duration and the respective rating scales as dependent variables and sampling source as independent variable (controlling for memory problems) were conducted.

Results

Sampling source (clinic or PA) was not significantly associated (P-values, 0.090 to 0.977) with the variations in age, PD duration or any of the rating scale total scores, see Table.

Table. Regression analyses with sample (clinic/patient association) as independent variable among people with Parkinson's disease [a]

Dependent variables [a]	B	95% CI	P-value
- Age, years	0.136	-1.834, 2.105	0.892
- PD-duration, years	1.049	-0.165, 2.262	0.090
- Walking difficulties (Walk 12-G)	0.036	-2.353, 2.424	0.977
- Fatigue (FACIT-F)	-0.582	-2.710, 1.546	0.591
- Physical Functioning (PF)	-1.604	-7.427, 4.220	0.588
- Mental Health (MH)	-3.017	-7.354, 1.319	0.172
- Distress (NHPD)	3.366	-1.279, 8.011	0.155

[a] All dependent variables were corrected for self-reported memory problems during the past month.
B: regression coefficient, CI: confidence interval, PD: Parkinson's disease, Walk-12G: the generic version of the Walk-12, FACIT-F: Functional Assessment of Chronic Illness Therapy - Fatigue scale, PF: Physical Functioning scale (from the SF-36), MH: Mental Health scale (from the SF-36),NHPD: Nottingham Health Profile index of Distress.

Conclusions:

This study suggests that clinic- or PA-based sampling do not influence key outcome variables in PD. Further studies using identical inclusion criteria between samples, and assessing additional dependent variables, are needed.

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