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.

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.

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

<table>
<thead>
<tr>
<th>Dependent variables</th>
<th>B</th>
<th>95% CI</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, years</td>
<td>0.136</td>
<td>-1.834, 2.105</td>
<td>0.892</td>
</tr>
<tr>
<td>- PD-duration, years</td>
<td>1.049</td>
<td>-0.165, 2.262</td>
<td>0.090</td>
</tr>
<tr>
<td>- Walking difficulties (Walk-12G)</td>
<td>0.036</td>
<td>-2.303, 2.424</td>
<td>0.977</td>
</tr>
<tr>
<td>- Fatigue (FACIT-F)</td>
<td>-0.582</td>
<td>-2.710, 1.546</td>
<td>0.591</td>
</tr>
<tr>
<td>- Physical Functioning (PF)</td>
<td>0.036</td>
<td>-7.427, 4.220</td>
<td>0.568</td>
</tr>
<tr>
<td>- Mental Health (MH)</td>
<td>3.017</td>
<td>-7.394, 1.319</td>
<td>0.172</td>
</tr>
<tr>
<td>- Distress (NHPD)</td>
<td>3.366</td>
<td>-1.279, 8.011</td>
<td>0.155</td>
</tr>
</tbody>
</table>

a All dependent variables were corrected for self-reported memory problems during the past month.

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