Clinimetrics, clinical profile and prognosis in early Parkinson’s disease
Post, B.

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
Chapter 3

Part 2

Comparing the AMC linear disability score item bank with the ‘gold standard’ UPDRS ADL

B. Post
N. Weisscher

Submitted
Introduction

The most widely used scale to assess disability in patients with Parkinson disease (PD) is the Activities of Daily Living part of the Unified Parkinson’s Disease Rating Scale (UPDRS-ADL). In a recent study we examined the clinimetric properties of the AMC Linear Disability Score (ALDS), a new generic disability measure based on Item Response Theory (IRT), in newly diagnosed Parkinson’s disease (PD) patients.(1) Unfortunately, no comparison with the “gold standard” UPDRS-ADL was made. Although, measures constructed using modern psychometric methods, such as IRT, are superior to traditional sum score based measures, it is important to demonstrate this advantage and its implications in practice. Therefore, we now examined construct and know-group validity for both scales.

Methods

The study sample was recently described in depth.(1) In short, the sample comprised 70 patients with newly diagnosed PD who were participants in a longitudinal research project investigating the course of functional status and its determinants in PD. The clinical diagnosis of PD was based on internationally accepted diagnostic criteria.(2) The data presented here were obtained at three year follow-up. Subsequently to the disability status assessed by the UPDRS-ADL (range 0-52, lower scores indicating less disability) and ALDS (range 0-100, lower scores indicating more disability), the severity of extrapyramidal symptoms was rated using the motor examination part of the UPDRS (UPDRS-ME).(3) Disease stage was determined with the Hoehn and Yahr staging scale (HY; range 1-5).(4)

Results

Thirty eight (54%) patients were male, mean age of onset of symptoms was 65 (SD ± 10.5 years) and the patients’ mean age at examination was 69 (SD ± 10.5 years). Mean disease duration at examination was 56 (SD ± 10.3) months. The disease started with bradykinesia or rigidity symptoms in 35 (50%) of the patients, with tremor in 27 (39%) patients and in 8 (11%) patients with all three symptoms. The total sample mean UPDRS-ME score was 25.1 (SD ± 10), mean UPDRS-ADL score 10.8 (SD ± 6.9) and mean ALDS score was 75.2 (SD ± 19.9).

The UPDRS-ADL and ALDS showed a moderate correlation (r = 0.63). With regard to known-group validity (Table 1), UPDRS-ADL and ALDS scores registered an association between the severity of PD as determined by HY classification and impaired disability.
status. Both disability scores were not different between HY stage 1 and stage 2 (Tukey HSD; UPDRS-ADL, $p = 0.14$; ALDS, $p = 0.84$). Patients with HY stage 3 had lower ALDS scores compared to HY stage 2 (Tukey HSD; $p < 0.0001$). However, UPDRS-ADL score were not significantly different (Tukey HSD; $p = 0.59$). Score distributions of the UPDRS-ADL and ALDS reflect that patients with more severe extrapyramidal symptoms were more disabled than patients with less severe extrapyramidal symptoms. Additionally, both scales showed an association between postural (in) stability and disability level.

### Discussion

Recently we showed the ALDS has promising clinimetric properties in terms of internal consistency reliability, construct and clinical validity, and absence of ceiling effects. Now we expanded these clinimetric evaluations to a comparison with the most often used UPDRS-ADL.

The association between both disability scales was moderate, indicating they both measure the same concept to some extent. However, the authors expected a somewhat higher correlation because both scale intend to measure ADL. This could be explained by the allocation of items to specific sections of the UPDRS, which is not consistent, leading to ambiguity of interpretation. Some items of the UPDRS-ADL are directly related

---

**Table 1.** Score distributions of the ALDS between groups of patients with known differences in clinical status.

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>ALDS (± SD)</th>
<th>p-value</th>
<th>UPDRS-ADL (± SD)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>HY</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 1</td>
<td>3</td>
<td>89 (± 0.5)</td>
<td>&lt;0.001</td>
<td>2 (± 2.6)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Stage 2</td>
<td>32</td>
<td>85.6 (± 6.1)</td>
<td></td>
<td>8.4 (± 5.3)</td>
<td></td>
</tr>
<tr>
<td>Stage 3</td>
<td>17</td>
<td>69 (± 19)</td>
<td></td>
<td>10.2 (± 4.5)</td>
<td></td>
</tr>
<tr>
<td>Stage 4</td>
<td>6</td>
<td>41.2 (± 19.2)</td>
<td></td>
<td>19.2 (± 3.7)</td>
<td></td>
</tr>
<tr>
<td>Stage 5</td>
<td>1</td>
<td>12</td>
<td></td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>UPDRS-ME a</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 25.1</td>
<td>30</td>
<td>84.7 (± 6.6)</td>
<td>&lt;0.001</td>
<td>7 (± 4.2)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>≥ 25.1</td>
<td>31</td>
<td>70.1 (± 20.6)</td>
<td></td>
<td>12.8 (± 6.4)</td>
<td></td>
</tr>
<tr>
<td>Posture (item 30) b</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Score 0</td>
<td>18</td>
<td>87.5 (± 3.1)</td>
<td>&lt;0.001</td>
<td>5.9 (± 4.2)</td>
<td>0.001</td>
</tr>
<tr>
<td>Score ≥ 1</td>
<td>46</td>
<td>70.7 (± 22.1)</td>
<td></td>
<td>12.3 (± 6.9)</td>
<td></td>
</tr>
</tbody>
</table>

Score distributions are presented in mean (± SD); differences in mean logit scores are calculated using one-way ANOVA (H&Y) and an independent t-test (UPDRS-ME, posture item 30). aUPDRS-ME was dichotomized on base of the mean value of the scores. bScore range of item 30 was 0 – 4; 0 = Normal; 1 = Retropulsion; 2 = Absence of postural response; 3 = Very unstable; 4 = Unable to stand without assistance.
to daily activities (e.g. dressing, eating), but some also examine patient perceptions of primary disease manifestations (e.g. tremor, salivation) or gait items that assess primary parkinsonian symptoms (freezing, falls).(5) When validating this instrument in a PD population we were well aware that a new instrument would only be interesting if it was able to rise above the qualities of the "gold standard" UPDRS-ADL. Probably due to its linearity, the ALDS was able to discriminate between HY stage 2 and stage 3 in contrast to the UPDRS-ADL. The ALDS is a new, generic, non-disease-specific item bank consisting of 77 ADL items. By administering the ALDS, only those items relevant to a person's disability status are used, thereby reducing patient burden in time and effort. Combined with attractive new and relevant features, for example improving the clinical interpretation of scores and the possibility to use computer adaptive testing, the ALDS is a promising new instrument to assess the level of disability in patients with PD.
Reference list


