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### The AMC Linear Disability Score (ALDS) : measuring disability in clinical studies

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# Chapter part 2

Comparing the AMC  
Linear Disability Score  
item bank with the 'gold  
standard' UPDRS-ADL

Nadine Weisscher, Bart Post

## 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).<sup>1</sup> Recently we examined the clinimetric properties of the AMC Linear Disability Score (ALDS), a generic disability measure based on item response theory (IRT), in newly diagnosed PD patients. We showed the ALDS has promising clinimetric properties in terms of internal consistency reliability, construct and clinical validity, and absence of ceiling effects.<sup>2</sup> At that time no data was available to compare the item bank with the 'gold standard' UPDRS-ADL. Here we present current results regarding the construct and clinical (known-group) validity for both scales.

## Methods

The study sample has been described in depth.<sup>2</sup> 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<sup>3</sup> 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).<sup>1</sup> Disease stage was determined with the Hoehn and Yahr staging scale (H&Y; range 1-5).<sup>4</sup>

## Results

Thirty eight (54%) patients were male, mean age at onset of symptoms was 65 (SD  $\pm$  10.5 years), mean age at examination was 69 (SD  $\pm$  10.5 years), and mean disease duration at examination was 56 (SD  $\pm$  10.3 months). The disease started with bradykinesia / rigidity symptoms in 35 of the patients, with tremor in 27 patients and in 8 patients with all three symptoms. Median H&Y score was 2.5 (range 1-5) and the mean UPDRS-ME score was 25.1 (SD  $\pm$  10). The mean disability scores on the UPDRS-ADL score was 10.8 (SD  $\pm$  6.9) and on the ALDS 75.2 (SD  $\pm$  19.9).

The UPDRS-ADL and ALDS showed moderate construct validity ( $r = -0.62$ ). With regard to the clinical validity, the disability scales significantly discriminate between the severity levels of PD as measured with the H&Y (Table). Both disability scores were not different between H&Y stage 1 and stage 2 (Tukey HSD; UPDRS-ADL,  $p = 0.14$ ; ALDS,  $p = 0.84$ ). Patients with H&Y stage 3 had lower

ALDS scores compared to H&Y stage 2 (Tukey HSD;  $p < 0.0001$ ). However, UPDRS-ADL scores were not significantly different (Tukey HSD;  $p = 0.59$ ). Score distributions of the UPDRS-ADL and ALDS reflect that patients with severe extrapyramidal symptoms and patients with postural instability were more disabled than patients with opposite characteristics.

**Table**

**Score distributions of the ALDS between groups of patients with known differences in clinical status: Clinical validity.**

	n	ALDS	p-value	UPDRS-ADL	p-value
H&Y					
Stage 1	3	89 ( $\pm$ 0.5)*		2 ( $\pm$ 2.6)*	
Stage 2	32	85.6 ( $\pm$ 6.1)	<0.001	8.4 ( $\pm$ 5.3)*	<0.001
Stage 3	17	69 ( $\pm$ 19)		10.2 ( $\pm$ 4.5)	
Stage 4	6	41.2 ( $\pm$ 19.2)		19.2 ( $\pm$ 3.7)	
Stage 5	1	12		36	
UPDRS-ME †					
< 25.1	30	84.7 ( $\pm$ 6.6)	<0.001	7 ( $\pm$ 4.2)	<0.001
$\geq$ 25.1	31	70.1 ( $\pm$ 20.6)		12.8 ( $\pm$ 6.4)	
Posture (item 30) ‡					
Score 0	18	87.5 ( $\pm$ 3.1)	<0.001	5.9 ( $\pm$ 4.2)	0.001
Score $\geq$ 1	46	70.7 ( $\pm$ 22.1)		12.3 ( $\pm$ 6.9)	

Score distributions are presented in mean ( $\pm$  SD); differences in mean disability scores were calculated using One-Way ANOVA (H&Y) and an independent t-test (UPDRS-ME, posture item 30).

\*All post-hoc Tukey HSD tests for the ALDS and UPDRS-ADL score between the H&Y stages were significantly different ( $p < 0.05$ ), except between stage 1 and 2 for the ALDS ( $p = 0.84$ ) and UPDRS-ADL ( $p = 0.14$ ), and between stage 2 and 3 for the UPDRS-ADL ( $p = 0.59$ ).

†UPDRS-ME was dichotomized on base of the mean value of the scores.

‡Score 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.

## Discussion

In this analysis we compared the ALDS item bank with the 'gold standard' UPDRS-ADL. The correlation between the disability scale scores was relatively lower than one might expect, since the two scales intend to measure the same concept: ADL. This moderate association can be explained by the item content of the UPDRS-ADL which reflects aspects of both ADL and neurological impairments (tremor, salivation, and freezing).<sup>5</sup> In general, the ALDS and the UPDRS-ADL were able to detect differences in disease severities. Probably due to insufficient statistical power both scales

could not discriminate between H&Y grading 1 and 2. In contrast to the UPDRS-ADL, the ALDS turned out to be sufficiently sensitive to discriminate between H&Y stages 2 and 3.

The ALDS item bank is constructed using the modern psychometric technique of IRT. An important advantage of this approach is that when assessing the ability to perform ADL, it is possible to present more difficult items to less disabled patients and easy items to more severely disabled patients, while the scores obtained remain comparable across the whole patient group.<sup>6</sup> Combined with other attractive 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.

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# Chapter 6

The AMC Linear Disability  
Score item bank:  
a new generic disability  
measure in stroke

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*Submitted*