The AMC Linear Disability Score (ALDS) : measuring disability in clinical studies
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Tenslotte worden in hoofdstuk 9 de belangrijkste bevinden samengevat, enkele voor- en nadelen van het gebruik van de item response theorie in het algemeen en de ALDS in het bijzonder in patiënt-gebonden onderzoek worden besproken en worden suggesties gedaan aangaande de gewenste koers van de ALDS in toekomstig klinisch onderzoek.

Appendix 1

A practical guideline to the ALDS item bank
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Background

The disability status of patients is often described in terms of their ability to carry out basic activities of daily life (ADL) in terms of mobility and self-care or instrumental ADL such as housekeeping and shopping. Over the years numerous generic and disease-specific disability instruments have been developed, for example the Barthel Index, the Sickness Impact Profile or the Stanford Health Outcome Questionnaire.

Most of these instruments are multi-item questionnaires, adding up individual item scores to a sum score. A disadvantage of this summated approach is that all items have to be presented to all patients to calculate a total score. Moreover, since sum scores are dependent on the items included in the instrument, it is difficult to compare scores obtained on different instruments, even if they measure the same health concept.

Recently, interest in item response theory (IRT) techniques has grown as an alternative method to the sum score approach. IRT measures at the item level, in contrast to sum score methods, which are based on the whole instrument. There are a number of advantages to the use of IRT in clinical measurement. One of the most exciting is the implementation of an adaptive testing procedure; in which more difficult ADL items (e.g., ‘walk for more than 15 minutes’) are presented to less disabled patients and easier items (e.g., ‘get out of bed’) to more severely impaired patients. Hence, the estimates of disability level will be detailed and completely comparable, even if patients are offered different selections of items.

Adaptive testing can only be applied if an items bank, in this case the AMC Linear Disability Score (ALDS) item bank, is available. This is a collection of items which have been calibrated by obtaining psychometric information on the measurement properties of the items from large groups of patients.

Content of the AMC Linear Disability Score item bank

The ALDS project constructed an item bank to measure the disability status of patients with a broad range of diseases. Disability was defined as the ability to perform the activities of daily life required to live independently or in an appropriate care setting. Because of the generic nature of the ADL construct, one would expect overlap in item content and range even between scales for different diseases. Therefore, items for inclusion in the ALDS item bank were obtained from a systematic review of generic and disease-specific ADL scales and supplemented by diaries of activities performed by healthy adults. A total of 190 items were selected from over 110 existing functional status scales. In the current item bank, 77 items fitted the IRT model, the ADL items are hierarchically ordered from simple to complex activities. These items cover a wide range of activities, ranging from eating, bed to chair transfer, self-care, to light household task, running and travelling. In general, the ALDS is a generic, non-disease specific, item bank.

Assessment and scoring

The ALDS can be self-administered, but can also be give face-to-face in a clinical setting or in a telephone interview format by trained clinical assessors (nurses or different paramedic disciplines). Patients find the ALDS items entirely self-explanatory and clarifications are seldom required. Approximately 20 items from the 77 item bank are needed to estimate the underlying ability level. The respondents are asked whether they are able to carry out a given activity at the present time. Three scoring categories are used:

- ‘I cannot carry out the activity’
- ‘I can carry out the activity’ (with or without difficulty)
- ‘not applicable’

Patients are asked to rate if they are able to carry out the activities at this moment as they would at home or in their own area. When the patient is able to perform the activity independent, without any help from anybody else, the response ‘I can’ is recorded. Aids or devices are allowed. A ‘cannot’ score is given if the activity is physically or cognitively not possible irrespective of the underlying cause, when the performance of the activity results in unacceptable symptoms for the respondent (e.g., pain, shortness of breath) or when help of others is needed to carry out the activity. If patients had never had the opportunity to experience a activity a ‘not applicable’ response is recorded.

Responses in the category ‘not applicable’ are treated in the statistical phase as if the individual items had not been presented to the individual respondent. If subjects are unable to respond due to cognitive problems, a significant other or caregiver can be interviewed on there behalf.

Interpretation of the ALDS scores

Administering all 77 ADL items to all subjects would be highly inefficient. Since IRT centers on the measurement properties of individual items, rather than the instrument as a whole, it is not essential for all respondents to be examined using all items. Hence, the essence of an IRT item bank is that the included items have met the assumptions of an IRT measurement model, and that allows its users to compare disability outcomes measured by different item sets selected from the item bank. Evidently, for each patient the probability to be able to perform all 77 items from the item bank can also be estimated using IRT analysis.
The original units of the ALDS scale are (logistic) regression coefficients, expressed in logits (see Appendix 3). Both the item difficulty and the patient’s ability are arranged on a single hierarchical linear scale. To make the results easier to interpret, the logit scores are linearly transformed into values between 0 (dead) and 100. The value 1 represents the lowest level and the value 100 the highest level of functional status possible. To allow for gradations of disability status below the level of the easiest item (‘putting a T-shirt on’) and above the level of the most difficult item (‘cycling for 2 hours’) in the current version of the item bank the linear transformed score ranges from 0 to 90.

Clinimetric properties

Although measures constructed with modern psychometric methods theoretically are superior to traditional measures, it is essential to demonstrate this advantage in practice. The paper by Holman et al. describe the construction of the ALDS item bank in a population with a broad range of conditions including stroke, Parkinson’s disease and chronic pain. Also residents of supported housing, residential care or nursing homes were interviewed. Those geriatric patients had (co)morbid conditions such as movement and skeletal disorders and urologic, endocrine, gastrointestinal, pulmonary, cardiovascular and neurological diseases. The results show that the ALDS can be used as a reliable indicator of disability status in this mixed population. Additional papers examined the psychometric properties of the ALDS items in patients with rheumatoid arthritis, patients with newly diagnosed Parkinson’s disease, and acute and post stroke patients [article submitted for publication].

What translations are available?

The ALDS item bank was originally developed by a systematic review of English literature. Dutch items were constructed using the forward and backward translation method. At present psychometrically sound versions in English and Dutch are available. French, Italian and Spanish versions are in the process of validation.

User permission

The ALDS is considered to be in the public domain, consequently there is no charge for the permission to use the ALDS. However, we request the users to register with the ALDS project team and cite relevant ALDS articles in their publications (see key journal references).

References