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ACTIVLIM - Neuromuscular
For children and adults with neuromuscular disorders

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ACTIVLIM: A Rasch-built measure of activity limitations in children and adults with neuromuscular disorders
Laure Vandervelde, Peter Y.K. Van den Bergh, Nathalie Goemans, Jean-Louis Thonnard

Contents:
- ACTIVLIM sample version of the clinical analasis and results.
- Included in Appendix is sample version questionnaire/Test of the ACTIVLIM for children and adults with neuromuscular disorders.
Please goto page 1 to purchase the full complete version of ACTIVLIM Clinical analasis and questionnaire/Test.

Abstract

A common measure of activity limitations for both children and adults with neuromuscular disorders was developed using the Rasch model. A self-reported questionnaire containing daily activities was submitted to 245 adult patients and to the parents of 124 affected children from the two major Belgian communities. They were asked to provide their perceived difficulty in performing daily activities on a three-level scale. The 22 items of the final scale define a unidimensional and linear measure of activity limitations and show a continuous progression in their difficulty. The item difficulty hierarchy is invariant with regard to the diagnosis, community, gender and age. The scale exhibits a good precision, since the 22 items are well targeted on our sample ($r = 0.96$); furthermore, it is reproducible over time ($ICC = 0.93$). The patients’ measures are related to the Functional Independence Measure motor score ($r = 0.85$), to the Brooke ($r = -0.63$) grade and to the Vignos ($r = -0.83$) grade.

1. Introduction

Most neuromuscular disorders (NMD) have a progressive clinical course that is characterized by a decrease of muscle strength [1] leading to an impaired motor function. Some consequences are fatigue, problems with locomotion and loss of functionality in activities of daily living. The International Classification of Functioning, Disability and Health (ICF) describes an individual’s functioning in three domains taking into account his health condition [2]. These domains are (1) body functions and anatomical structures, (2) activity, and (3) participation. Problems in each domain are, respectively, impairments, activity limitations, and participation restrictions. In NMD patients, impairments such as muscle weakness are frequently assessed using quantitative or manual testing [3,4]. However, the evaluation of the functional abilities of patients can be also considered as a priority. These could be assessed from the level of activity limitations defined as the difficulties a patient may have in executing daily activities [2]. The achievement of daily activities depends on the muscle strength, but the relationship between the two is not straightforward [5]. It is a combination of motor function, compensatory behaviour of the patient, and personal (e.g. age, lifestyle, motivation) and
environmental (e.g. architectural characteristics, ground type) factors. For these reasons, the activity level should be evaluated separately and not simply inferred from the patients’ impairments.

Instruments specifically applicable to the population being studied are essential for clinical evaluation [6], and a common scale for both children and adults makes it possible to follow patient status across time. The existing scales measure the functional status of NMD patients, either in a restrictive and general way, with a description of patients’ limb function on a single grade (e.g., Vignos or Brooke grades [3]) or they do not measure the activity limitations themselves. The Functional Independence Measure [7] takes into account technical or human assistance and gives a measure of the patients’ autonomy. A motor function measure was recently developed and validated for NMD paediatric and adult patients [8]. This scale proposes a motor measure focused on the observation of analytical tasks achieved by the patients. The time wasted for observation could be reduced by self-reported measures, especially since observed functional abilities are not psychometrically superior or easier to administer than reported measures [9]. Self-reported measures in adult patients are usually considered the gold standard [10]. In child functional assessment, parents are valid proxies since they report a finer perception of their children’s abilities than the children themselves do [11,12]. The purpose of the study is to develop ACTIVLIM, a self-reported questionnaire of activity limitations in children and adults with any NMD by submitting it to the adult patients and to the parents of the affected children.

2. Patients and methods

2.1. Patients

This multicentric study was approved by the Medical Ethics Committees of the Université catholique de Louvain and of the Katholieke Universiteit Leuven. The patients were recruited through the neuromuscular reference centres of two university hospitals, each in a different Belgian language community (Dutch and French). Moreover, 10% of the children came from three centres specializing in NMD. Adult patients and parents of affected children gave written informed consent before the evaluation.

Age, gender, language community, type of NMD, Functional Independence Measure motor score [7], and Vignos and Brooke Grades [3] were included as independent demographic and clinical indices in the validation analysis. Three hundred and sixty-nine patients (124 children and 245 adults) with a diagnosis of neuromuscular disorder were assessed by the same examiner. Sample description is given in Table 1.

2.2. Questionnaire development

The ACTIVLIM questionnaire was designed to cover the widest range of daily activities and it included activities for children and for adults. The preliminary questionnaire included 138 items selected from various existing scales: ABILHAND [13,14], ABILHAND-Kids [11], Physical Functioning Subscale of SF-36 [15], Sickness Impact Profile [16], Amyotrophic Lateral Sclerosis Functional Rating Scale [17], ADL Self-Report [18], Paediatric Quality of Life Inventory [19], Lower Extremity Functional Scale [20], EK Scale [21] and Level of Rehabilitation Scale III [22]. These items were submitted to 32 experts on patients with NMD (neurologists, physicians, physical therapists, occupational therapists, nurses and a psychologist) and to 23 NMD adult patients. The experts were asked to determine the relevance of the activities for a NMD child and for a NMD adult. The adult patients were asked to evaluate the perceived difficulty in performing each activity. Both experts and adult patients were asked to propose other relevant items not included in the original item set.

The questionnaire for adult patients was achieved by removing 52 items, either because experts considered them irrelevant (44 items), or because the analysis of the 23 adults’ responses through the Rasch model showed that they did not contribute to the definition of a unidimensional variable (8 items) [23]. Five items were added to the set following experts’ and patients’ suggestions. The adult patients were therefore assessed with a 91-item experimental questionnaire.

The experimental questionnaire for children included 99 items, since 39 items from the original set of 138 items were eliminated because experts considered them to be irrelevant.

2.3. Instrument

The ACTIVLIM questionnaire explored difficulties of performing daily activities that required the use of upper limbs or/and the use of lower limbs. The adult patients and the parents of affected children filled in either the adult form or the child form of the questionnaire. They were asked to provide their perceived difficulty in performing each activity using a three-level scale: impossible (0), difficult (1), easy (2). Each activity must be completed without technical or human assistance. Activities unfamiliar to individual patients were recorded as missing responses (2.2% of the data).
4. Discussion

The purpose of this study was to develop a common measure of activity limitations using the Rasch model and to validate it in both adults and children with NMD. The ACTIVLIM questionnaire was constructed from the adults' and the parents' perception of the difficulty in performing activities of daily living. The 22 items selected for the final version of the ACTIVLIM scale share the same ordered rating scale structure, fit a unidimensional scale and present no differential item functioning across age, gender, speech community and type of NMD.

The few items removed because of reversed thresholds indicate that both adults and the parents of affected children correctly discriminate the three proposed response categories. Moreover, a common scale model for children and adults could be applied since the response categories were equally discriminated by the adults and the parents of the affected children [29]. The perception of the parents was indeed preferred to that of the children's because children have a more dichotomous perception of their abilities [12]. They perceived the activities either as “impossible” or “easy” with rare intermediate responses [11]. Therefore, the use of the children's responses could lead to a narrower range of measurement, with more patients with extreme measures, leading to a less appropriate scale for the NMD sample.

Despite the temptation to construct a scale measuring different facets of NMD patient (e.g. activity limitations, fine hand motor skills, cognition, . . .), ACTIVLIM is a unidimensional scale that only measures activity limitations without other characteristics potentially leading to biased results of the evaluation [23]. The large number of items that did not contribute to the definition of the unidimensional variable may indicate that the experimental questionnaire measures more than one variable [27]. Seventy percent of such deleted items mainly require hand and finger strength in order to be achieved (e.g., cutting meat, fastening the snaps of a jacket, unscrewing a bottle cap) and they appear to assess the manual ability of the patients. The reasons for the unsuitability of these items to the model can be explained after data examination [40]. The patients with a distal NMD have more difficulties in performing the manual activities than do patients with a proximal NMD; whereas the former have a higher level of activity. For this reason, the scores observed for the manual items do not correspond to the scores predicted by the model. The final ACTIVLIM scale does not include exclusively digital and manual activities, but it is suitable for all types of NMD and is reliable enough to be clinically useful. A scale of manual ability is however being developed for NMD patients.

The differential item functioning tests allowed to select items with no significantly different hierarchy between the compared person-related factors. For example, the hierarchy of the 22 selected items is invariant if the item difficulty is estimated by patients with a proximal NMD or by patients with a distal NMD. The same invariance was also observed between males and females and between Dutch and French speakers for the 22 final items, and between adults and children for the 14 common items.

The hierarchy of the 22 items retained for the scale is consistent with the psychomotor qualities and with the energy expenditure necessary to perform the activities. The activities requiring more balance, force or endurance, and therefore higher energy expenditure [41], tend to be more difficult for NMD patients. The easiest activities can be often managed in a sitting position, using adaptive strategies. The most difficult activities usually involve lower limbs, and wheelchair-bound patients would answer “impossible” for these activities. As “impossible” correspond to “0”, total raw score of wheel-chair bound patients will be lower than the one of walking patients, as well as their activity level expressed in logits (Fig. 2, third panel). In addition, the hierarchy of the 22 selected items was consistently estimated by both samples of patients (Fig. 1) and the psychometric properties of the sample-2 scale are equivalent to the calibration of sample-1. This indicates that the selected items correspond to pertinent and appropriate activities to assess activity limitations in any NMD patients.
The analyses of the relationships between the patients’ measures with other widely used scales, such as the Vignos and Brooke grades and the motor score of the FIM, highlighted the good construct validity of the scale, with correlation coefficients of −0.83, −0.63 and 0.85, respectively. A higher activity level relates to lower Vignos and Brooke grades and to a higher level of independence. The Vignos and the Brooke grades respectively class the function of the lower and the upper limbs into a single category. Nevertheless, each category represents a rather wide range of ACTIVLIM measures in logits (Fig. 3). ACTIVLIM is therefore more complete and precise than both of these grades since it allows to differentiate groups of patients within a same category of Vignos and Brooke grades. Concerning the FIM, few studies have validated it in a NMD population [44,45]; although it is one of the most commonly used questionnaires in the evaluation of NMD patients [4]. Moreover, the motor score of the FIM seems not to be precise enough to distinguish groups of patients in the high levels of the motor score (Fig. 3). Indeed, half of patients have a motor score above 80, indicating a high level of independence; while their activity measures range from −0.55 to 5.9 logits, representing a wide range of activity levels. These results confirm the observations in patients with poliomyelitis sequelae [46], among which a large number were independent in the activities of daily living, even if they reported difficulties in these activities. However, the FIM motor score and ACTIVLIM measure different aspects of the patient’s health condition. ACTIVLIM evaluates activity limitations in terms of difficulties in performing daily activities without technical or human assistance, and the FIM measures the independence of the patient taking into account the environmental factors [2]. For example, patients who can propel their wheelchair themselves are considered independent for the locomotion item “walk/wheelchair”; yet following the ACTIVLIM questionnaire, it is “impossible” for them to walk more than one kilometre (item d), since a wheelchair is considered to be a form of technical assistance. ACTIVLIM could however determine the technical assistance necessary to achieve some items. Furthermore, this scale is more precise and detailed than the FIM and it can remedy to the lack of sensitivity of the FIM.

The relationships between the patients’ measures and demographic and clinical indices appear as clinical information. The significant relationship between the patients’ measures and the type of NMD confirms previous reports [46,8] that patients with distal NMD and with myotonic dystrophy are less disabled in their functional status than are patients with proximal NMD and in particular those with Duchenne muscular dystrophy. The measures of the patients were not related to age, gender or speech community.

The Rasch model was used to construct and validate the ACTIVLIM scale. This particular methodology provided a measurement scale with fundamental psychometric qualities known as linearity and unidimensionality. This questionnaire has also good reliability, precision, construct validity and reproducibility. Moreover, ACTIVLIM can be used for evaluation of both adults and children with NMD making possible to follow the disease course from childhood to adulthood using a single scale. The hierarchy of the items is invariant across age, gender, language community or type of NMD indicating that ACTIVLIM can be used for any patients with NMD. Finally, the questionnaire is extremely easy to administer, since it can be completed in 5 minutes in the waiting room by the patient himself or a child’s parent. Nevertheless, ACTIVLIM does not claim to replace clinical evaluation methods that principally measure the impairments (manual muscle testing, range of motion, timed tasks test, etc.) [2]; it is rather complementary to these.

Further applications of the ACTIVLIM scale include the study of its responsiveness. The high precision of the scale ensures to statistically predict a good sensitivity to change in activity limitations induced, for instance, by the progressive course of the disease or by treatment. Nevertheless it must be clinically verified. Moreover, its relationships with impairment measures and its similarity between the self-reported version and the achievement of daily activities observed by a therapist will also be investigated.

For clinical use of ACTIVLIM, a website (www.rehab-scales.org) including downloadable scoring sheets and instructions will be available soon. Moreover, on-line analyses taking into account the missing values would directly convert raw scores into linear measures of activity limitations.

Acknowledgements

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INSTRUCTIONS FOR THE ACTIVLIM QUESTIONNAIRE

The ACTIVLIM questionnaire

The ACTIVLIM questionnaire was developed as a measure of activity limitations in children and adults with neuromuscular disorders (Vandervelde et al, Neuromuscul Disord, 2007). Activity limitations are defined as difficulties a patient may have in executing activities of daily living. The questionnaire includes 22 items that are daily activities. Among these 22 items, 4 are specifically designed for child evaluation, 4 for adult evaluation, and the remaining 14 items are common to all patients. ACTIVLIM was built either on the perception of the parents of the affected children or on the perception of the adult patients themselves. This perception concerns the difficulty in performing each activity of the questionnaire. The 22 items of ACTIVLIM defined a valid, reliable and reproducible scale. ACTIVLIM was originally developed using the Rasch measurement model. It allows to convert ordinal scores into linear measures located on a unidimensional scale.

Evaluation

For a child evaluation (between 6 and 15 years-old):
The parents fill in the questionnaire by estimating their child’s difficulty or ease in performing each activity.

For an adult evaluation (more than 16 years-old):
The patient fills in himself the questionnaire by estimating their own difficulty or ease in performing each activity.

The activities should be done:
  • Without technical or human help (even if the patient actually uses help in daily life)
  • Irrespective the limb(s) actually used to achieve the activity
  • Whatever the strategy used (any compensation is allowed)

Three responses are presented. These assess the perception of the difficulty/ease depending on whether the activity is “impossible”, “difficult” or “easy”. Activities not attempted in the last 3 months are not scored and entered as missing responses (to tick the question mark).
So, for any activity, the four potential answers are:

- **Impossible**: The patient is unable to perform the activity without using any other help.
- **Difficult**: The patient is able to perform the activity without any help but experiences some difficulty.
- **Easy**: The patient is able to perform the activity without any help and experiences no difficulty.
- **Question mark**: The patient cannot estimate the difficulty of the activity because he has never done the activity.

**Watch out!!** If the activity was never attempted because it is impossible, then it must be scored “impossible” rather than “question mark”.

### Activities order

The activities of the ACTIVLIM questionnaire are presented in a random order to avoid any systematic effect. Ten different random orders of presentation are used. The rater must select the next one of the 10 orders for each new assessment, no matter which patient is tested.

### Package content

- 1 instruction sheet.
- Testing forms of ACTIVLIM in 10 random orders (1 sheet for each)
### ACTIVLIM - Activity Limitations Measure

#### English version

Name: ___________________________  Date: ___________________________

<table>
<thead>
<tr>
<th>How difficult are the following activities?</th>
<th>Impossible</th>
<th>Difficult</th>
<th>Easy</th>
<th>?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Putting on a T-shirt</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Washing one's upper body</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Dressing one's lower body</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Taking a shower</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Sitting on the toilet</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Taking a bath</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Walking downstairs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Stepping out of a bath tub</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Opening a door</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Walking outdoors on level ground</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Washing one's face</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Hanging up a jacket on a hatstand</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Wiping one's upper body</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 Walking upstairs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

To evaluate an adult patient (age 16-80), please answer to the following questions.

To evaluate a child patient (age 6 -15), please mark the following questions with the "?"

<table>
<thead>
<tr>
<th>15 Carrying a heavy load</th>
<th>A</th>
</tr>
</thead>
<tbody>
<tr>
<td>16 Getting into a car</td>
<td>A</td>
</tr>
<tr>
<td>17 Standing for a long time (± 10 min)</td>
<td>A</td>
</tr>
<tr>
<td>18 Walking more than 1 kilometre</td>
<td>A</td>
</tr>
</tbody>
</table>

To evaluate a child patient (age 6-15), please answer to the following questions.

To evaluate an adult patient (age 16-80), please mark the following questions with the "?"

<table>
<thead>
<tr>
<th>19 Closing a door</th>
<th>C</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 Hopping on one foot</td>
<td>C</td>
</tr>
<tr>
<td>21 Putting on a backpack</td>
<td>C</td>
</tr>
<tr>
<td>22 Running</td>
<td>C</td>
</tr>
</tbody>
</table>

Order 1