Dependence and Perceived Difficulty in Daily Activities in Community-Living Stroke Survivors 2 Years After Stroke
A Study of Instrumental Structures

Gunnar Grimby, MD, PhD; Eva Andrén, BSc, OT; Yvonne Daving, MSc, OT; Benjamin Wright, PhD

Background and Purpose—There is a need for better understanding of the structure of instruments for functional outcome assessment after discharge from rehabilitation. One purpose of the study was to contribute to the analysis of instrumental dimensionality. Another purpose was to compare disability in stroke patients within the younger age range 2 years after onset of stroke with that at discharge with respect to both dependence and patients’ perceived difficulty and to extend the assessments with instrumental activities.

Methods—We studied 68 stroke survivors aged 18 to 71 years at onset (59% aged <55 years) by means of interviews in their home, using activities from the Functional Independence Measure (FIM) and Instrumental Activity Measure (IAM) for ratings of dependence and perceived difficulty. Rasch analysis was used to construct calibrated linear measures and to evaluate the level of fit.

Results—Acceptable models for comparison of dependence between discharge and follow-up were found for the physical and the social-cognitive items in FIM. However, personal care and social-cognitive items showed an increased level of dependence at follow-up compared with at discharge. A combination of physical activities from FIM and IAM also gave acceptable models for both dependence and perceived difficulty, and the hierarchical orders of activities are presented. In general, there was agreement between the ratings of dependence and perceived difficulty, but with some discrepancies. Men found it harder to be independent in such instrumental activities as cooking and cleaning than women; the opposite was true for small-scale shopping and locomotion outdoors. Subjects aged ≥55 years had slightly higher level of dependence and perceived difficulty in IAM activities than those below that age.

Conclusions—Changes in the hierarchical order of activities should be taken into account in follow-up studies. Differences in the environment between hospital and home, as well as differences in support and motivation, might explain the relatively larger degree of dependence at follow-up compared with at discharge and indicate the need for further rehabilitation efforts. Instrumental activities could be combined with FIM activities in a model. For individual items, ratings of both dependence and perceived difficulty may provide further insight into the disablement process. (Stroke. 1998;29:1843-1849.)

Key Words: activities of daily living ■ disability evaluation ■ rehabilitation ■ stroke outcome

Several functional outcome studies on stroke survivors have been published; most are limited to the first 6 months,1-3 but some also refer to longer periods, up to 3 years4 or 5 years.5 Nearly all those studies consider stroke survivors of all ages, but the elderly are the dominant age group. Age and gender differences are seldom analyzed. There is a need to analyze the structure and dimensionality of the instruments to enable comparison of repeated assessments. This is particularly true because sum scores from ordinal scale data are often misused for such comparisons. Differences in the changes in level of disability between individual items may provide further insight into the disablement process and the need for rehabilitation interventions. Disability can be assessed as perceived difficulty in different activities or as level of dependence on personal help. As Jette6 pointed out, rating of perceived difficulty in performing various activities can be considered the primary assessment of disability, whereas rating of actual dependence on assistance is an assessment of the consequence of disability. Both types of assessment are useful in increasing our understanding of the disablement process and are included in the follow-up in the present study. A similar set of ratings, including instrumental activities of daily living (ADL) items, was also used in a study of community-living adults with cerebral palsy and spina bifida.7

In a previous study in which the same instruments were used, data were treated with the Rasch model.8 The Rasch model, which was also used in the present study, estimates...
the subject’s perception of difficulty or dependence and the hardness of the activities. A linear scale is constructed with the activities placed hierarchically from easy to hard and with fit statistics indicating how well individual activities and subjects fit on the linear scale.

There is definitely a need to obtain further insight into the level of disability of stroke patients after discharge from the hospital and their need for further rehabilitation interventions. Our follow-up study, which concentrated on “younger” stroke patients who needed inpatient rehabilitation after acute care, aims at defining such needs. This report particularly emphasizes the methodological aspects of this type of follow-up study, including the fit of the suggested models. The results may also provide a basis for comparison of the structure of the instruments used be-

TABLE 1. IAM Items

<table>
<thead>
<tr>
<th>Activity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Locomotion outdoors</td>
<td>Walk or use a wheelchair ~300 m (900 ft) in the subject’s residential area, eg, to bus stops and parking places.</td>
</tr>
<tr>
<td>Simple meal</td>
<td>Arrange a hot drink, eg, coffee or tea, cut bread, and make sandwiches with butter and meat.</td>
</tr>
<tr>
<td>Cooking</td>
<td>Arrange a dinner meal: peel potatoes, cut vegetables for a salad, fry meat, set the table, and put the hot meal on the table.</td>
</tr>
<tr>
<td>Public transportation</td>
<td>Use public vehicles, eg, trams, buses, local trains, and ferries in the subject’s residential area. Includes transfer to and from stops, transfer in and out and transfer inside, paying, sitting during the trip, and changing vehicles.</td>
</tr>
<tr>
<td>Small-scale shopping</td>
<td>Shop for single articles from local shop, eg, buy newspaper, milk, or bread. Includes locomotion to, from, and inside the shop, choosing, paying, and bringing articles home from the shop.</td>
</tr>
<tr>
<td>Large-scale shopping</td>
<td>Includes buying foodstuffs and articles of consumption for weekly use and all tasks related to shopping: locomotion to, from, and inside the shop, choosing, paying, and bringing articles home from the shop.</td>
</tr>
<tr>
<td>Cleaning</td>
<td>Includes all weekly cleaning tasks: making bed, daily tidying, floor mopping, vacuuming, changing sheets, and removal of refuse.</td>
</tr>
<tr>
<td>Washing</td>
<td>Includes all laundry management tasks: washing sheets and clothes in apartment house laundry or with own washing equipment, locomotion and transfer of goods to and from the washing machine, sorting laundry goods, choosing washing program, using controls and equipment, taking laundry in and out of machines, hanging up wet clothes, and folding and managing dry and clean laundry.</td>
</tr>
</tbody>
</table>

TABLE 2. Fit Statistics for Poorly Fitting Items for Rating of Dependence Using 13 Physical Items From FIM at Discharge and at 2-year Follow-Up

<table>
<thead>
<tr>
<th>Item</th>
<th>Measure</th>
<th>Infit</th>
<th>Outfit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Logit</td>
<td>MNSQ</td>
<td>STD</td>
</tr>
<tr>
<td>Bladder</td>
<td>-1.25</td>
<td>4.94</td>
<td>7.1</td>
</tr>
<tr>
<td>Bowel</td>
<td>-1.38</td>
<td>2.54</td>
<td>3.7</td>
</tr>
<tr>
<td>Eating</td>
<td>0.61</td>
<td>1.44</td>
<td>1.7</td>
</tr>
<tr>
<td>Bladder</td>
<td>0.02</td>
<td>1.93</td>
<td>2.9</td>
</tr>
<tr>
<td>Bowel</td>
<td>-0.88</td>
<td>3.33</td>
<td>5.3</td>
</tr>
</tbody>
</table>

Figure 1. Joint calibration for dependence at discharge from rehabilitation ward and at 2-year follow-up for physical FIM activities (A through M). The hardness of the item is expressed in logits, with the center of the scale set at 0. The identity line is also shown as arbitrarily drawn lines for personal care and transfer-locomotion items.

Figure 2. Joint calibration for dependence at discharge from rehabilitation ward and at 2-year follow-up for social and cognitive FIM items (N through R) for nonaphasic (top) and aphasic (bottom) patients separately. The hardness of the item is expressed in logits, with the center of the scale set at 0. The identity line is also shown as an arbitrarily drawn line for all items except social interaction.
Subjects and Methods

Subjects

Sixty-eight patients (44 men, 24 women) who had been treated in our Department of Rehabilitation Medicine in the period 1992–1994 and had been discharged to their homes participated in the study. Informed consent was obtained by Grimby et al.7 The Ethical Committee of the Faculty of Medicine. The age range at onset was 18 to 71 years, with a mean and median age of 53 years. Forty (59%) of the patients were aged <55 years. According to the organization of rehabilitation at the hospital, patients aged <65 (or 70) years of age will usually be treated at the Department of Rehabilitation Medicine, whereas older patients will be treated within the Department of Geriatric Medicine. The present follow-up study was performed ~2 years after onset (median, 2 years and 32 days; interquartile range, 61 days). The median time from onset of stroke to admission to the rehabilitation ward was 30 days (mean, 46 [SD 46]), and the median length of stay at the rehabilitation ward was 62 days (mean, 74 [SD 44]); range, 8 to 210 days). Length of stay did not differ between patients aged ≥55 and <55 years. Sixty-one percent had cerebral infarction, 14% intracerebral hemorrhage, and 25% subarachnoid hemorrhage. At discharge 32% had right hemiplegia, 57% left hemiplegia, and the remaining patients either a mixed paresis or no persistent paresis. Sixteen of the patients received new clinical diagnoses between discharge and follow-up, with epilepsy in 7 patients and depression in 6 patients being the most common diagnoses. Only 1 of those patients (with a hip fracture) had been admitted to the hospital during the follow-up period. In the treatment of the data at follow-up, patients with and without a new diagnosis were compared, but no overall impact of other diagnoses and impairments not related to the actual stroke could be considered in this material with a limited number of patients.

Instruments and Procedures

The Functional Independence Measure (FIM) consists of 13 physical (or motor) and 5 social-cognitive items, assessing self-care, sphincter management, transfer, locomotion, communication, social interaction, and cognition. It uses a 7-level scale anchored by extreme ratings of total dependence as 1 and complete independence as 7; the intermediate levels are as follows: 6, modified independence; 5, supervision or setup; 4, minimal contact assistance or the subject expends ≥75% of the effort; 3, moderate contact assistance or the subject expends 50% to 75% of the effort; and 2, maximal assistance or the subject expends 25% to 50% of the effort. Its reliability and validity have been well studied, and its dimensional characteristics have been analyzed according to the Rasch model (for review, see Deutsch et al10). A Swedish translation of the manual11 was used. Instrumental activity items were developed for a new instrument termed Instrumental Activity Measure (IAM), which assesses dependence and perceived difficulty. It was introduced by Grimby et al12 and was used in adult subjects with cerebral palsy and spina bifida. Its structure was analyzed in those patient groups, and good reliability was demonstrated. The activities assessed in the present study were as follows: Locomotion outdoors, Simple Meal, Cooking, Public Transportation, Small-Scale Shopping, Large-Scale Shopping, Cleaning, and Washing (Table 1). Compared with the previous study,12 Shopping was divided into Small-Scale Shopping and Large-Scale Shopping, since they were found to be of different difficulty and content. Reliability (0.88) for the new version was demonstrated in the present study.

For both FIM and IAM, dependence was rated according to the rating scale for FIM. In addition, at the follow-up the subject’s perceived difficulty was rated for both FIM and IAM items with a 4-level scale with the levels categorized as none, little, great, and impossible.
and the IAM item could be combined in a model, and this was also done in the analysis in the present study.

The ordinary \( t \) test was used for calculation of individual differences of measurement values (logits) as they are placed on a linear scale. Differences between men and women, single and cohabitant, were tested with the Mann-Whitney nonparametric test because of the distribution of measurement values. A value of \( P<.05 \) was considered statistically significant.

## Results

FIM activities showed the same order of dependence at admission and discharge with improvements in all items, as demonstrated in earlier reports from our department (not illustrated in the present article). It was possible to obtain an acceptable model for a joint calibration of FIM activities, for physical and social-cognitive items separately, for discharge and follow-up with a reliability of 0.94. The poorly fitting physical items were Bowel, Bladder, and (at follow-up) Eating, but only in a few subjects (in outfit) (Table 2). There were no poorly fitting social-cognitive activities. Patients with and without aphasia were calibrated separately (reliability 0.88 and 0.86, respectively). It should also be observed that most patients were relatively independent, but a minority of the patients had a high level of dependence. There were changes in the order of dependence for the different activities, with significantly increased dependence for personal care activities at follow-up compared with at discharge, although not for the other physical FIM activities Bowel, Transfer to
Toilet, Walk/Wheelchair, and Stairs (Figure 1). The increase in dependence was \( \approx 2 \)-fold larger for the personal care activities as for the transfer and locomotion activities. There was a significant increase in dependence for all social-cognitive items at the 2-year follow-up, particularly for social interaction, for which the increase was \( \approx 2 \)- and \( 3 \)-fold larger than the other items for nonaphasic (Figure 2, top) and aphasic (Figure 2, bottom) patients, respectively. There was a significant increase in dependence in terms of physical activities (Figure 3) in 51% of the individuals and a significant reduction in 10%. For social-cognitive items (Figure 4), there was an increase in 53% and 64% of the nonaphasic and aphasic patients, respectively, and a reduction in 5% and 4%. When the patients with new diagnoses between discharge and follow-up (n = 16) were excluded from the analysis, the same results were found, and these patients were evenly distributed in the total material concerning increase in dependence at follow-up. There was no significant difference in dependence for patients aged <55 years and \( \geq 55 \) years at either discharge or follow-up for physical and social-cognitive activities in FIM.

At follow-up, IAM and physical FIM items for rating of dependence could be combined in a joint Rasch model (reliability, 0.94) with a higher level of dependence in the instrumental ADL (IAM) activities, except for Locomotion Outdoors and Simple Meals, which were as difficult as the most difficult FIM items, Bathing and Dressing (upper and lower body) (Figure 5). Bowel and Bladder were excluded from the model, as in the previous study by Grimby et al' on community-living subjects with cerebral palsy and spina bifida, because they showed a high degree of misfit. With the remaining items in the model, Large-Scale Shopping and Washing showed systematic misfit, as shown by the infit values, whereas Eating and Public Transportation showed misfit for only a few subjects, as shown by the outfit values (Table 3). Items with ratings of perceived difficulty could also be arranged in a combined model (Figure 6); the poorly fitting items were Eating, Grooming, and Small- and Large-Scale Shopping (Table 4). When only the 8 IAM activities were used for the calibration, only Large-Scale Shopping was a misfit, both for dependence (infit MNSQ 1.74, STD 2.8; outfit MNSQ 1.87, STD 2.1) and perceived difficulty (infit MNSQ 1.64, STD 2.7; outfit MNSQ 1.93, STD 2.7). The reliability for the 8 IAM activities was 0.88. The validity for the IAM activities is seen in the hierarchy of the activities, which extend in a clinically correct way from easy to hard.

Assessments of dependence and perceived difficulty gave essentially the same results as illustrated for the IAM activities in Figure 7, but Public Transportation and Locomotion Outdoors were perceived as more difficult than the other activities in comparison with the level of dependence. Cooking might be an activity with a relatively higher level of dependence than according to the perceived difficulty.

The ratings for men and women were analyzed separately for the IAM items in a joint model, allowing comparison of dependence on the same linear scale (Figure 8). Men found it harder to be independent in such activities as Washing, Cooking, and Cleaning than women, whereas the opposite was true of Large- and Small-Scale Shopping and Locomotion Outdoors. An analysis of the gender difference for perceived difficulty gave similar results. A similar analysis with respect to subjects being cohabitant (n = 42) and single (n = 25) was done, but no evident differences in the hierarchical order of activities were found (not shown in figure).

<table>
<thead>
<tr>
<th>Item</th>
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<th>Infit</th>
<th>Outfit</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Logit</td>
<td>Error</td>
<td>MNSQ</td>
</tr>
<tr>
<td>Eating</td>
<td>0.55</td>
<td>0.21</td>
<td>2.11</td>
</tr>
<tr>
<td>Grooming</td>
<td>0.55</td>
<td>0.21</td>
<td>2.28</td>
</tr>
<tr>
<td>Small-scale shopping</td>
<td>0.26</td>
<td>0.18</td>
<td>1.27</td>
</tr>
<tr>
<td>Large-scale shopping</td>
<td>-1.66</td>
<td>0.17</td>
<td>1.83</td>
</tr>
</tbody>
</table>
The analysis of measurement values for men and women and cohabitant and single subjects (data from 1 subject were missing) concerning IAM activities showed a significantly higher overall level of dependence ($P<0.05$) at follow-up for men than for women, but with no significant difference when cohabitant and single persons were compared (Figure 9). Patients aged $\geq 55$ years had a slightly higher level of dependence and perceived difficulty in IAM activities than those below that age ($P<0.05$), with correlation coefficients with age of 0.25 and 0.31 ($P<0.05$), respectively. The younger group of patients found Locomotor Outdoors more difficult than the older group but without difference in dependence between the 2 age groups.

As a validation of the assessment of disability from the physical FIM and the IAM items, respectively, the measurement values from these 2 instruments at follow-up have been compared with regression analysis ($r=0.71$, $P<0.001$). Close agreement would indicate that measures from both instruments reflect similar characteristics of the subjects. A similar conclusion can also be reached from the acceptable fitness of the joint model of FIM and IAM items in the Rasch analysis, indicating that these 2 groups of items can be treated together in a unidimensional model.

**Discussion**

As shown in a number of previous studies, Rasch analysis can produce useful models for disability scales using assessments with ordinal scales. The poor fit of Bladder and Bowel in FIM is well known from previous studies,11,12 and in the joint model of FIM and IAM activities, these items were also excluded. The increase in dependence recorded at 2-year follow-up may have several explanations: the demands of some tasks may be higher for subjects living in the community compared with in the hospital (eg, difference in clothing or hygiene rooms), help from other persons for different social reasons (overprotection or a rational task performance), lack of motivation, or decline of functional status. There are, however, no evident medical explanations for this finding, since similar changes were found in the subgroup without any new medical diagnosis between discharge and the 2-year follow-up. The impact of the different assessment methods (team assessment by observation during hospital stay and interview by trained raters at follow-up) should be studied further. The present results should lead to further consideration of rehabilitation efforts in the patients’ own homes, where training and adaptation can be more directly oriented toward the individual needs of the patients than in the hospital setting. There is also an increasing interest in home-based rehabilitation programs with some positive effects in the short term,13,14 but these were not demonstrated in another study.15

In a recent study of domiciliary occupational therapy after discharge from the hospital, better ability in extended (instrumental) ADL was demonstrated compared with a control group receiving the “usual” service.16 There might also be unmet needs in stroke patients for qualified follow-up in the years after discharge. This seems to be most obvious in the social and cognitive areas. A slower recovery of cognitive than of physical functions has been noted by Desmond et al.17 The impact of any mild or moderate depression and of reduced motivation was not further studied in our group but should be taken into account in future studies. The social isolation and lack of leisure activities for stroke survivors have been reported by several authors, eg, Viitanen et al.18 Our results also indicate the need for increased social support and activities with leisure therapy, involving the stroke survivor as well as family members.

It is of methodological interest that the physical items in FIM (excluding Bowel and Bladder) and the newly developed instrumental activity items (IAM) could be combined in 1 model, as in the subjects with cerebral palsy and spina bifida.7 However, the item Large-Scale Shopping is a misfit for both dependence and perceived difficulty, even when only IAM items are used for the model, and it should be either further refined or excluded from the model.

The studies demonstrate that the level of dependence and perceived difficulty are, as expected, higher in most instrumental activity items than in the personal care and indoor mobility activities. For dependence, Simple Meal, Locomotion Outdoors, and, for perceived difficulty, Small-Scale Shopping were, however, ordered in a manner similar to the harder FIM activities (see Figures 4 and 5). There were some misfits, but in the present group they were in activities other than those in the group of persons with cerebral palsy and spina bifida,7 which could be the result of the impact of different impairments as well as different age distribution and social situations. The item difficulty agreed in general with that in the group previously studied,7 which could be related to locomotion being a basic limitation for most activities. Further studies on the relationship between impairments (and functional limitations) and disability are indicated. It is also necessary to develop more task-specific items, particularly for cognition and orientation, since the contributions of such factors to the more “global” instrumental activities used in the present study are difficult to evaluate.

The unidimensional model used in the present and previous reports7 allows an overall measurement value for disability to be ascertained in each individual on the basis of many different activity areas. These values can then be treated with ordinary statistical methods. On the other hand, we would
argue that single-item analysis has its value for specific clinical and follow-up study questions. The Rasch analysis is also of value here, and unusual behavior in terms of a particular item in an individual will be indicated by its misfit and can give a diagnostic indication of specific problems for that individual.

The slight differences in item order between dependence and perceived difficulty may have several explanations, one being that subjects try to maintain independence in certain activities despite the perceived difficulty, as in Public Transportation and Locomotion Outdoors among IAM activities and Stairs among FIM activities (not shown in the figure), whereas in an activity such as Cooking, subjects may appear to be more dependent than indicated by their perceived difficulty. This also leads to the question of different characteristics of instrumental activities depending on factors such as gender and social circumstances. The size of the present group of subjects does not allow detailed analysis, other than with respect to gender and living single or as a cohabitant. Earlier reports have indicated that certain home activities might lead to a relatively higher degree of dependence in men than in women; this would, however, also be dependent on cultural factors and the time period for the study, since gender roles may change. In the present study men found it harder to be independent in some instrumental activities such as Washing and Cooking than women; the opposite was true of Small-Scale Shopping and Locomotion Outdoors. The Rasch model with a joint calibration of both sexes allows a comparison of the relative difficulties of the activities despite any overall differences in the ability between the two sexes. As shown in Figure 8, with the mean measurement values for the subjects, men were overall more dependent than women. Differences in the degree of neurological impairments between the men and women studied, however, cannot be ruled out. In another report women were found to be more dependent than men, but that study included patients older than those in the present study and with a higher mean age in women. A higher level of dependence might be expected with increasing age, but this has not previously been analyzed with the use of linear measurements, as in the present study. Within the age range at <70 years and with ~60% of the patients aged <55 years, we could not demonstrate any difference between the young group and the older group for FIM activities, but a small difference for instrumental activities was observed.

The present study reveals several important aspects concerning follow-up studies of individuals living in the community, such as further knowledge of the effect of differences in methods of data collection in the hospital and at home, a problem often overlooked in follow-up studies, and the need to include task-relevant activities in community-living subjects. Assessments of dependence and perceived difficulty provided rather similar information, but further insight into these two aspects of disability could be achieved by additional studies.

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References
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