Professor: A TOOL FOR REAL-LIFE ASSESSMENT OF ACTIVITIES OF DAILY LIVING IN PATIENTS WITH COGNITIVE IMPAIRMENT

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Although there are many instruments for assessing activities of daily living (IADL) in brain injured patients, few instruments specifically target cognitive impairment and its impact on IADL. The present study presents the development of the Profinteg instrument, a tool for real-life assessment as well as rehabilitation of IADL in patients with cognitive impairment. This two-stage instrument covers over 90 activities. Psychometric properties of the different Profinteg measures were explored in twenty-five patients with mild to severe cognitive difficulties and twenty-five caregivers. The feasibility of the Profinteg rehabilitation procedure was explored in three patients. Excellent inter-rater reliability ($r > 0.90, p < 0.01$) was observed for all measures. Good sensitivity to changes in IADL disability over time was also observed ($T = 2.37, p < 0.02$). Significant improvement of IADL functioning was found after rehabilitation guided by Profinteg assessment. The Profinteg instrument detects with precision the difficulties patients encounter in their real-life setting via (1) assessment of a large number of activities and (2) detailed decomposition of activities into sub-activities. The Profinteg tool also provides promising results for guidance of IADL rehabilitation in the patient’s real-life environment.

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The cognitive deficits associated with brain injury often result in a severe degradation of the patient’s quality of life and autonomy. When developing rehabilitation programs for these patients, clinicians not only have to consider underlying cognitive deficits, but critically they also have to consider their impact on everyday functioning. This study presents a preliminary validation study of the Profinteg tool, which has been specifically designed to assess instrumental activities of daily living (IADL) in patients with cognitive deficits, and this in the patients’ real-life setting, in contrast to most of existing IADL assessment tools.

A large number of assessment scales have been developed to assess IADL (Burns, Lawlor, & Craig, 2004; Keith, Granger, Hamilton, & Sherwin, 1987; Lindeboom, Vermeulen, Math, & De Haan, 2003; Moore, Palmer, Patterson, & Jeste, 2007; Sikkes, de Lange-de Klerk, Pijnenburg, Scheltens, & Uitdehaag, 2009; Teunisse & Derix, 1997; Voigt-Radloff, Leonhart, Schützwohl, Jurianz, Reuster, Gerner et al., 2012). The typical purposes of these scales are to screen a population in terms of general levels of functional independence and to assess the severity of symptoms for a small number of activities (Athlin, Norberg, Axelsson, Moller, & Nordstrom, 1989; Beck, 1988; Galasko, Bennett, Sano, Ernesto, Thomas, Grundman et al., 1997; Kuriansky & Gurland, 1976; Lawton & Brody, 1969; Loewenstein, Amigo, Duara, Guterman, Hurwitz, Wilkie et al., 1989; Lucas-Blaustein, Filipp, Dungan, & Tune, 1988; Oakley, Sunderland, Hill, Phillips, Makohon, & Ebner, 1991; Teunisse & Derix, 1997). This restriction does not offer the clinician the opportunity to establish a complete profile of the patient’s difficulties, while s/he is still attempting to carry out many daily activities. Secondly, a number of scales rate each activity as a function of global autonomy scores, but they do not consider the sub-activities of an entire activity (Bucks, Ashworth, Wilcock, & Siegdried, 1996; Galasko et al., 1997; Hindmarch, Leinfelder, De Jongh, & Erzigkeit, 1998; Lawton & Brody, 1969; Linn & Linn, 1982; Mahurin, DeBettignies, & Pirozzolo, 1991; Teunisse & Derix, 1997). Only a few consider sub-activities (Gélinas, Gauthier, McIntyre, & Gauthier, 1999; Loewenstein et al., 1989; Patterson, Mack, Neundorfer, Martin, Smyth, & Whitehouse, 1992; Skurla, Rogers, & Sunderland, 1988; Tappen, 1994). This lack of precision makes a patient’s deficits within complex activities, such as food preparation, rather hard to identify. Furthermore, many scales do not specifically highlight difficulties in IADL that are caused by cognitive deficits, but rather they merge cognitive and physical problems, such as the Lawton and Brody scale (Lawton & Brody, 1969), preventing the clinician from clearly identifying the origin of the encountered difficulties. Importantly, most scales provide no observation method for assessing the patient’s difficulties in his/her real-life setting; the occurrence of difficulties in IADL is merely inferred from the patient’s self-
report or the caregiver’s report. In order to be useful for rehabilitation, IADL scales should allow the experimenter to identify the actual activities and sub-activities the patient has difficulties with, and the precise circumstances under which these difficulties arise, as for example proposed by the AMPS observational method (Fisher & Jones, 2010). This information is fundamental for implementing efficient rehabilitation procedures of IADL. For example, patients can be trained to use a toaster or another device in a rehabilitation centre, but they may yet not be able to use this device in their everyday environment.

We present here a validation study of the Profinteg tool that has been specifically developed to assess IADL in the patients’ everyday life environmental settings. Furthermore, this tool focuses specifically on impairment in IADL that is due to cognitive deficits, in order to efficiently guide cognitive rehabilitation of IADL. Also, contrary to existing ADL scales, the Profinteg tool covers a wide range of IADL (currently 98) while allowing for time-efficient assessment. The Profinteg tool is composed of two parts (see Figure 1). The first part is an IADL questionnaire quickly screening over the 98 activities, and allows to identify those activities the patient has difficulties in due to non-physical impairment, as well as the severity of these difficulties according to the patient and the caregiver. The second part is an activity decomposition grid and focuses on a subset of these activities in order to gain more precise information about the nature of the difficulties and the circumstances under which they arise, in order to guide further rehabilitation of these activities; this part is similar to the AMPS observational method developed by Fisher and Jones (2010) while focusing again specifically on difficulties related to cognitive impairment. This assessment is limited to those activities for which the patient and his carer decide that they need to be rehabilitated, based on their importance for the patient’s quality of life and functional independence. This is achieved by an observational grid that allows for a detailed and reliable identification of the successful and deficient steps of a given activity, while the patient carries out this activity in his typical everyday environment.

The aim of this study is to provide preliminary data for the reliability and sensitivity of the Profinteg tool as well as to explore its validity and usefulness in the clinical setting. Patients with cognitive impairment as well as their carer were administered the Profinteg tool, and inter-rater reliability, sensitivity to deficit, sensitivity to change and test duration were established. The scores obtained by the Profinteg tool were also compared to those obtained by the Lawton and Brody (1969) IADL scale which is the most widely used scale and for a wide spectrum of neurological conditions. Although elementary, this scale is still commonly used in cognitive rehabilitation settings and is one of the most cited instruments of ADL assessment.
PROFINTEG: A TOOL FOR REAL-LIFE ASSESSMENT OF ACTIVITIES

(Burns et al., 2004; Kane, Ouslander, & Abrass, 2004). A subset of patients further underwent rehabilitation of IADL in order to explore the potential of the Profinteg tool for IADL rehabilitation.

**Figure 1**

*Structure and measures of the Profinteg tool*

- **Profinteg IADL questionnaire**
  - 98 activities
  - Approximate duration: 30 minutes

- **Activity decomposition grids**
  - One for each of the 98 activities
  - A subset of grids are selected, based on the difficulty, importance and burden scores identified at the previous step
  - Approximate duration of grid administration and scoring: 10 minutes
  - For each activity:
    - Determination of the number of subactivities used by the patient to carry out an activity, based on a template provided by the grid
    - Determination of the subactivities carried out incorrectly
    - Determination of the dependency score

- **Rehabilitation of the activity**
  - Direct training of those subactivities that have been identified to be carried out incorrectly during assessment with the activity decomposition grid

No further assessment if:
- Physical disability preventing the execution of a given activity
- Activity never carried out before

If difficulties reported since onset of cognitive impairment:
- Determination of the difficulty score
- Determination of the importance of the activity to the patient
- Determination of the burden for the caregiver
Method

Participants

Twenty-five patients with cognitive impairment and their caregivers were selected for this study. The patients (33% female) had a mean age of 62.5 years ($SD = 17.0$). The presence of cognitive impairment in the patients was established via the administration of standardised neuropsychological tests covering language, attention, episodic memory, working memory, and executive functions (see Table 1, p. 8). As shown in Table 1, all patients showed scores significantly outside control range (Z score $< -2$ or Percentile $< 2$) in at least one of the above mentioned cognitive domains. Patients presented cognitive deficits due to various neurological conditions: Alzheimer’s disease ($n = 11$), cerebrovascular accident ($n = 7$), head injury and anoxia ($n = 5$), and brain tumour ($n = 2$) (see Table 1 for further details).

Procedure

The first part of the Profinteg tool, the IADL screening questionnaire, was administered in the experimenter’s office, to the patient and the caregiver independently by one examiner; the assessment was tape recorded for additional independent scoring by a second rater; the raters were professionals trained either in psychology or occupational therapy and who had been trained in the use of the scale. These assessments were used to establish interrater reliability. The following measures were obtained via questions asked using a structured interview (see Figure 1 for overall structure; see Appendix 1 for a list of all activities; full details are available at www.dpb.be/Profinteg.html): number of applicable activities (activities which the patient carried out before cognitive impairment and of which execution at the time of assessment is not hindered by physical impairment); the fact that an activity is problematic due to physical impairment or not is determined by an analysis of patient neurological history, i.e., presence of motor disturbance at the time of study or not, and by patient/caregiver interview; in case of doubt, the activity is scored as applicable and cognitive/motor origin is further determined on the basis of performance and associated physical effort/difficulty on the Profinteg decomposition grid, if the activity is passed on to this level – see below); number of problematic activities (activities for which difficulties are reported since onset of cognitive impairment); total difficulty score (the severity of reported difficulties, with 0 point if no difficulties, 1 point for each of the following difficulties: lack of activity initiation, omission of one or several steps, wrong execution of one or several steps, 4 points for perseveration errors and 5 points if the activity cannot be carried out at all, and summed over the reported problematic activities); total importance score for the patient (the
# Table 1

Patient background information

<table>
<thead>
<tr>
<th>Patient</th>
<th>Neurological condition</th>
<th>Age</th>
<th>Cognitive deficits</th>
<th>Activities targeted for rehabilitation</th>
</tr>
</thead>
<tbody>
<tr>
<td>BH</td>
<td>Brain tumour</td>
<td>40</td>
<td>EM, A, EF</td>
<td>setting the table; dialling a mobile phone number;</td>
</tr>
<tr>
<td>GI</td>
<td>CVA</td>
<td>50</td>
<td>EF,</td>
<td>receiving a mobile phone call; carrying out a payment via a bank transfer; watching a DVD</td>
</tr>
<tr>
<td>HC</td>
<td>CVA</td>
<td>56</td>
<td>EM, A, EF, L</td>
<td></td>
</tr>
<tr>
<td>HS</td>
<td>Head Injury</td>
<td>20</td>
<td>EM, A, EF</td>
<td></td>
</tr>
<tr>
<td>LV</td>
<td>Anoxia</td>
<td>35</td>
<td>WM, EM, A, EF</td>
<td></td>
</tr>
<tr>
<td>MO</td>
<td>CVA</td>
<td>65</td>
<td>WM, L</td>
<td></td>
</tr>
<tr>
<td>PR</td>
<td>Anoxia</td>
<td>34</td>
<td>WM, EM, A, EF</td>
<td></td>
</tr>
<tr>
<td>HH</td>
<td>CVA</td>
<td>82</td>
<td>WM, EM, EF, L</td>
<td></td>
</tr>
<tr>
<td>JP</td>
<td>Anoxia</td>
<td>65</td>
<td>EF, L</td>
<td></td>
</tr>
<tr>
<td>1011</td>
<td>CVA</td>
<td>67</td>
<td>EM, A</td>
<td></td>
</tr>
<tr>
<td>1024</td>
<td>CVA</td>
<td>52</td>
<td>EM, A, EF</td>
<td></td>
</tr>
<tr>
<td>2016</td>
<td>Head Injury</td>
<td>60</td>
<td>A, EF</td>
<td></td>
</tr>
<tr>
<td>2019</td>
<td>Brain tumour</td>
<td>58</td>
<td>EM</td>
<td></td>
</tr>
<tr>
<td>2028</td>
<td>CVA</td>
<td>48</td>
<td>EM, A, EF</td>
<td></td>
</tr>
<tr>
<td>GL</td>
<td>ND</td>
<td>72</td>
<td>WM, A, EF</td>
<td></td>
</tr>
<tr>
<td>DDE</td>
<td>ND</td>
<td>87</td>
<td>WM, EM, A, EF, L</td>
<td></td>
</tr>
<tr>
<td>MK</td>
<td>ND</td>
<td>75</td>
<td>EM, EF</td>
<td>dialling a mobile phone call; receiving a mobile phone call</td>
</tr>
<tr>
<td>FG</td>
<td>ND</td>
<td>74</td>
<td>WM, EM, A, EF, L</td>
<td></td>
</tr>
<tr>
<td>JD</td>
<td>ND</td>
<td>77</td>
<td>EM</td>
<td></td>
</tr>
<tr>
<td>AP</td>
<td>ND</td>
<td>71</td>
<td>EM, A, EF</td>
<td></td>
</tr>
<tr>
<td>DDI</td>
<td>ND</td>
<td>73</td>
<td>EM, EF</td>
<td></td>
</tr>
<tr>
<td>JR</td>
<td>ND</td>
<td>67</td>
<td>EM, EF</td>
<td></td>
</tr>
<tr>
<td>ML</td>
<td>ND</td>
<td>77</td>
<td>EM, EF, L</td>
<td></td>
</tr>
<tr>
<td>CD</td>
<td>ND</td>
<td>76</td>
<td>WM, EM, EF</td>
<td></td>
</tr>
<tr>
<td>LD</td>
<td>ND</td>
<td>81</td>
<td>EM</td>
<td></td>
</tr>
</tbody>
</table>

Note: CVA: cerebro-vascular accident; ND: neurodegenerative disease; WM: working memory deficit, as assessed by performance at least 2 standard deviations below norms of the WAIS-R forward and backward digit span tests (Wechsler, 1989); EM: episodic memory deficit, as assessed by performance at least 2 standard deviations below norms of the California Verbal Learning Test (Delis, Kramer, Kaplan, & Ober, 1987) or the Buschke selective reminding test (Grober & Buschke, 1987); A: attention deficit, as assessed by performance at least 2 standard deviations below norms of selective attention tests (Brinkenkamp & Zillmer, 1988; Soukup, Ingram, Grady, & Schiess, 1998); EF: executive function deficit, as assessed by performance at least 2 standard deviations below norms of the Behavioural Assessment of Dysexecutive Syndrome battery (Wilson, Alderman, Burgess, Emslie, & Evans, 1996) and at the part B (flexibility) of the Trail Making Test (Soukup et al., 1998); L: language deficit, as assessed by performance at least 2 standard deviations below norms of the naming subtask of the Aachener Aphasie Test (Huber, Poeck, Weniger, & Willmes, 1983) or the Bachy naming task (Bachy, 1987)
importance to the patients’ well-being of an activity reported to be problematic, on a scale ranging from 0 to 3, and summed over the reported problematic activities; total burden score for the caregiver (the time devoted to provide assistance or to supervise the patient in an activity on a scale ranging from 0 to 3, and summed over the reported problematic activities). Sensitivity to disability was explored via an examination of the variability of the number of problematic activities and difficulty scores overall, as well as via a comparison of patient and caregiver versions of the IADL questionnaire. The Lawton and Brody (1969) scale was also administered at the same time.

The second part of the Profinteg tool, the activity decomposition grid, was administered to the patients at home while carrying out a subset of activities. These activities were chosen in the light of the results of their Profinteg IADL assessment, and more precisely as a function of the reported level of difficulty (i.e., high), the activities’ importance to the patient (i.e., high) and the resulting burden for the caregiver (i.e., high) (the activities considered were preparing a meal, reheating/defrosting food, using a coffee machine, setting the table, calling using a mobile phone, receiving a phone call, managing a phone call, leaving a voicemail on a phone, checking a voicemail on a phone, dialing a mobile phone number, receiving a mobile phone call, carrying out a payment via a bank transfer, doing crosswords, watching a DVD, using a computer: displaying digital photos). The administration of the decomposition grid was filmed for later blind scoring by two independent raters, for the establishment of inter-rater reliability. The following scores were obtained via the templates provided by the decomposition grids (see appendix 2 for a sample grid): the number of subactivities used by the patient and the total dependency scores (number of wrongly executed subactivities weighted by the respective severity of impairment for each substep, on a scale ranging from 1 to 4; the severity of impairment is expressed in terms of the help needed to carry out the subactivity and provided by the experimenter: 1 = general cue (‘No’, ‘Incorrect’), 2 = specific cue (‘You should not do this in this way’), 3 = total indication (‘You should do it this way’), 4 = physical intervention (the examiner must carry out the subactivity in order to further proceed with the activity). The usefulness of the Profinteg decomposition scales for rehabilitation of IADL was further explored in three patients. The rehabilitation procedure involved directly training those subactivities that were identified as being wrongly executed by the decomposition grid for a given activity. The patients were reassessed by the decomposition grid three months later.
Results

Profinteg-IADL questionnaire

Inter-rater reliability

As shown in Table 2, robust intra-class correlation coefficients between the assessment of two independent raters were observed for all measures of the Profinteg IADL questionnaire (number of applicable activities, number of problematic activities, activity difficulty scores, patient activity importance scores, caregiver burden scores). These values were nearly identical for patient and caregiver versions of the questionnaire, showing that the Profinteg IADL questionnaire yields reliable assessment of the patient’s difficulties and their severity when carrying out IADL.

Table 2

Interrater reliability and descriptive statistics of the Profinteg IADL questionnaire

<table>
<thead>
<tr>
<th>Profinteg variables</th>
<th>Interrater Reliability*</th>
<th>Score range</th>
<th>Mean (SD)</th>
<th>Correlation with Lawton &amp; Brody IADL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of applicable activities (max = 98)</td>
<td>.96</td>
<td>8 – 50</td>
<td>34.36 (11.11)</td>
<td>.63</td>
</tr>
<tr>
<td>Patient</td>
<td>.95</td>
<td>8 – 56</td>
<td>35.21 (18.17)</td>
<td>.56</td>
</tr>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of problematic activities (max = 98)</td>
<td>.93</td>
<td>0 – 30</td>
<td>10.12 (7.35)</td>
<td>– .27</td>
</tr>
<tr>
<td>Patient</td>
<td>.91</td>
<td>5 – 28</td>
<td>18.25 (18.65)</td>
<td>– .04</td>
</tr>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Difficulty score (max = 490)</td>
<td>.95</td>
<td>0 – 74</td>
<td>25.32 (22.58)</td>
<td>– .38</td>
</tr>
<tr>
<td>Patient</td>
<td>.91</td>
<td>8 – 111</td>
<td>42.87 (27.77)</td>
<td>– .08</td>
</tr>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Importance score (max = 294)</td>
<td>.92</td>
<td>0 – 66</td>
<td>11.04 (19.98)</td>
<td>—</td>
</tr>
<tr>
<td>Burden score (max = 294)</td>
<td>.93</td>
<td>0 – 19</td>
<td>13.17 (21.66)</td>
<td>—</td>
</tr>
</tbody>
</table>

* intra-class correlation coefficients

Note: For all correlations, values in bold are significant at p < .01

Sensitivity to impairment

For the same set of measures, an extensive range of scores was observed, indicating that the PROFINTEG tool is sensitive to a wide range of difficulties in IADL activities (see Table 2). Difficulties in IADL were identified in all patients, although for some patients this was only the case for the caregiver version of the questionnaire. When further comparing the patient and caregiver versions, the mean number of applicable activities led to similar means in patients and caregivers (t(22) = 1.55, p = .13), but their reports significantly
differed in magnitude when they had to assess the number of problematic activities \((t(22) = -2.82, p < .01)\), which were consistently more frequently reported to be problematic by caregivers than by patients, with also higher difficulty scores in caregivers than in patients \((t(22) = -2.86, p < .01)\). In other words, the IADL questionnaire is not only sensitive to differences in IADL impairment between patients, but also to differences in the perception of impairment between patients and caregivers. This was further explored by performing item-based intra-class correlations between patient and caregiver ratings: the mean intra-class correlation coefficient between the patient and caregiver ratings of the number of applicable activities was high (ICC = .80, \(p < .01\)) but decreased for problematic activities (ICC = .59, \(p < .01\)) as well as for the level of difficulties in these activities (ICC = .51, \(p < .01\)); these lower correlations were essentially driven by a greater discordance between patient and caregiver versions for patients with neurodegenerative disease which typically show lower levels of deficit awareness (ICC = .49 and ICC = .47 for patients with Alzheimer’s disease; ICC = .76 and ICC = .64 for patients with other neurological conditions); given the small subsample sizes, these results nevertheless need to be treated cautiously.

**Time-efficiency**

The IADL Profinteg questionnaire, despite of its covering of a very large range of activities, is a time-efficient assessment tool given that only a portion of the activities listed in the scale are considered for a given patient. As shown in Table 3, only about 30 out of the 98 activities are considered for further questioning in each patient. In some patients, only 8 activities were applicable. Be reminded that this does not mean that the patient is able to carry out perfectly all the other 90 activities: activities which are difficult to carry out due to physical disability or which had never been carried out before the onset of cognitive impairment are not eligible for Profinteg IADL assessment. Overall, the duration of assessment by the Profinteg IADL questionnaire ranged between 20 and 60 minutes.

**Relation with the Lawton and Brody IADL scale**

We investigated the relationship between the different Profinteg IADL measures and the total autonomy score of the Lawton and Brody IADL scale. As shown in Table 2, the only significant correlations that were observed concerned the number of applicable activities measure of the Profinteg IADL questionnaire: a patient showing a high score of autonomy on the Lawton and Brody IADL scale was likely to engage in a larger number of activities assessed by the PROFINTEG IADL questionnaire. However, given that the Lawton and Brody scale does not distinguish between physical and cognitive
disability, and given the restricted range of activities considered, the autonomy score of the Lawton and Brody scale should not be very informative with respect to the number of activities that lead to difficulties due to cognitive impairment, and even less to the severity of these difficulties: as expected, the correlations with the number of problematic activities and difficulty scores of the Profinteg IADL scale were all non-significant. This was also confirmed by performing ROC analyses, by dividing our patient group in high and low performers on the Lawton and Brody scale, and by assessing the classification accuracy of the Profinteg IADL measure: while the Profinteg number of applicable activities measure distinguished between high and low performers on the Lawton and Brody scale (patient version: area under the curve = .95, \( p < .001 \), sensitivity = .85 and specificity = .91 for a cut-off score of 36; caregiver version: area under the curve = .88, \( p < .001 \), sensitivity = .67 and specificity = .91 for a cut-off score of 36), this was not the case for the number of problematic activities measure (patient version: area under the curve = .63, \( p = .28 \); caregiver version: area under the curve = .61, \( p = .37 \)) or for the difficulty scores (patient version: area under the curve = .66, \( p = .17 \); caregiver version: area under the curve = .61, \( p = .39 \)).

**Profinteg decomposition grid**

**Inter-rater reliability**

For the Profinteg decomposition grids, Table 3 shows a high inter-rater agreement (intra-class correlation) (\( r > .90 \), \( p < .01 \)) as concerns both the number of subactivities identified for a given activity and the total dependency score for carrying out these subactivities in a patient. This indicates that the two independent raters assessed sub-activities and the difficulties in carrying-out these subactivities in a similar way for a given patient. The duration of assessment ranged between 3 and 20 minutes.

**Table 3**

<table>
<thead>
<tr>
<th>Profinteg variables</th>
<th>Interrater Reliability</th>
<th>Score range</th>
<th>Mean (SD)</th>
<th>Correlation with Profinteg IADL difficulty score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of steps assessed (max = 21)</td>
<td>.97</td>
<td>5-21</td>
<td>10.08 (4.42)</td>
<td>-</td>
</tr>
<tr>
<td>Dependency score (max = 66)</td>
<td>.91</td>
<td>0-66</td>
<td>11.17 (18.27)</td>
<td>.54</td>
</tr>
</tbody>
</table>

1. intra-class correlation coefficients.

Note: For all correlations, values in bold are significant at \( p < .01 \)
Correlation with Profinteg IADL questionnaire

A significant positive Pearson correlation was observed between the total dependency score for the decomposition grids that were administered and the total difficulty score of the Profinteg IADL questionnaire as assessed by patients’ reports (see Table 3). This indicates that the more severe and/or numerous the deficits within an activity (high total dependency score), the more the patient reports difficulties in IADL activities as assessed by the total difficulty score of the Profinteg IADL scale.

Sensitivity to rehabilitation effects

A subsample of the patient group (one patient with Alzheimer’s disease, one patient with anoxia, one patient with CVA) was subjected to rehabilitation of selected IADL activities ($n = 7$ activities, see Table 1), and was assessed before and after rehabilitation with the decomposition scale corresponding to each activity being rehabilitated. The rehabilitation procedures consisted in directly training those subactivities that had been identified by the decomposition grids to be deficient, by either providing the patient with verbal cues during the execution of the problematic activity or by providing the patient with a graphical guide describing the deficient subactivity/step and/or its structure/sequence (see also below for a concrete illustration). A significant decrease in the total dependency score was observed when comparing the dependency scores for the targeted activities before and three months after rehabilitation (dependency score pre-rehabilitation: mean = 20.71, range = 6-66; dependency score post-rehabilitation: mean = 2.57; range = 0-13; Wilcoxon non-parametric test: $T(6) = 2.37, p < .02$).

We furthermore examined the specificity of the rehabilitation effects via a single case study where the full Profinteg instrument was administered before and after rehabilitation. This patient (patient HH; see Table 1) had difficulties in 18 activities; among these difficulties, setting the table and dialling a mobile phone number were chosen for rehabilitation given their importance for the patient’s quality of life and autonomy (see Table 4). The decomposition grids revealed that for table setting, the patient did not know anymore what subactivities to carry out (i.e., the fork and knife were wrongly placed or omitted), indicating loss of knowledge about the script “table setting”. Therefore the rehabilitation consisted of providing the patient with the script, by showing a photograph of a table set correctly during the execution of the table setting task. For giving a phone call, the decomposition grid revealed that the patient did not manage anymore retrieving phone numbers stored in the memory of her mobile phone; here, the rehabilitation consisted of directly training the retrieval of phone numbers using the memory of the mobile phone. No other problematic activity was trained during the rehabilitation
phase which lasted less than 3 months, with 2 rehabilitation sessions per week. As shown in Table 4, after rehabilitation, the patient’s dependency scores on the respective decomposition grids fell to zero, indicating that she was able again to carry out again the given activities with no external help. On the other hand, assessment by the Profinteg IADL questionnaire revealed that the number of problematic activities only diminished slightly, from 18 to 16, showing that only those two activities that had been targeted for rehabilitation did actually improve. This is also reflected by the difficulty scores, which fell about 6 points, corresponding to the total pre-rehabilitation difficulty score for the two activities that were targeted by the rehabilitation. This case study shows that the rehabilitation procedures that are guided by Profinteg assessment are specific to the actual activities under consideration.

### General discussion

The novel contribution of the Profinteg tool, relative to existing IADL scales, can be summarised as follows. First, the Profinteg tool allows the reliable assessment of patients in their real-life environment, directly reflecting the patient’s difficulties for carrying out a number of activities. This allows the clinician to target more efficiently the patient’s difficulties and to design rehabilitation procedures that can be directly implemented in the patient’s daily-life setting. Second, the tool provides a large yet relatively time-efficient inventory of IADL assessment, leading to a rich and informative profile of the problems a patient may encounter. Third, the nature and the intensity of the deficits observed within a given activity are specified, allowing the clinician to target the specific steps of an activity that are deficient for rehabilitation while avoiding wasting time on training still functional sub-activities. Four, the point of view of both the patient and his/her caregiver are taken into account.
account with respect to the patient’s difficulties, a strategy that increases the accuracy of collected data.

The preliminary exploration of the Profinteg tool’s reliability and sensitivity parameters showed that this tool identifies and characterises in a reliable and sensitive manner the difficulties brain-injured patients encounter in carrying out IADL. The Profinteg tool presents reliability estimates similar to a number of other ADL scales (Burns et al., 2004; Keith et al., 1987; Lindeboom et al., 2003; Moore et al., 2007). However, as we have already noted, the purpose of most of these scales is a descriptive rather than a therapeutic one. On the other hand, existing therapy-oriented scales are limited in scope, assessing a much smaller number of activities and sub-activities than the Profinteg tool (Gélinas et al., 1999; Loewenstein et al., 1989; Patterson et al., 1992; Skurla et al., 1988; Tappen, 1994). Currently, this tool exists in three different languages: French, German, and Dutch and is freely available via the following website: http://www.dpb.be/Profinteg.html.

Other naturalistic assessment procedures proposed for brain-injured patients have been shown to be effective for rehabilitation (Lindeboom et al., 2003; Manchester, Priestley, & Jackson, 2004). For instance, Adam, Van der Linden, Juillerat, and Salmon (2000) succeeded in restoring knitting as a leisure activity in their patient. The assessment procedure consisted of asking the patient to verbally report her knowledge about knitting and to record her performance on videotape. Once her difficulties identified, the authors simplified the knitting activity so that the patient could perform the activity. The empirical assessment method described in that study led to significant rehabilitation results for a given activity, and was limited to the activity that was targeted. Another assessment method has been developed by Chevignard, Taillefer, Picq, Poncet, Noulhiane, and Pradat-Diehl (2008) who assessed disability of brain-injured patients with a dysexecutive syndrome during a cooking task. The authors took into account different error types and attempted to associate them with the patient’s neuropsychological deficits. This promising approach however only focused on executive problems, so that the resulting classification of errors – i.e., control errors, context neglect, environmental adherence, purposeless actions, dependency, and behavioural disorders – was specific to the behavioural deficits associated with this type of problems. In contrast, the Profinteg tool is not limited to a given activity or to a target patient group, but is characterised by a general, a priori method allowing for the assessment of any IADL activity in patients suffering from cognitive deficits. One may argue that one of the advantages of the Profinteg tool, its completeness of assessment, is tempered by the amount of time needed to administer the scale. Full administration of the two parts of the Profinteg tool can amount up to 90 minutes. However, the richness and completeness of information provided by the Profinteg tool is likely to enhance the efficiency of
rehabilitation procedures, as we have shown above, and hence speed up the overall rehabilitation process. Furthermore, we should note that the data presented in this study were collected in standard clinical settings (neuropsychological rehabilitation units), and not in laboratory settings specifically designed for this study. Administration duration could however be a problem for clinical settings with a high time pressure.

We should note that the present study should be considered as being preliminary since it is limited by a relatively small sample size (50 data points, including patient and caregiver scores). At the same time, the results obtained with respect to inter-rater reliability, sensitivity and specificity for the Profinteg IADL questionnaire and decomposition grids were very robust despite this limited number of data points, and despite the inclusion of a rather heterogeneous patient group in terms of age and lesion type and extent. Although the present results are encouraging, future validation studies will need to assess in a more extended sample the usefulness of the Profinteg tool for IADL rehabilitation, especially as a function of patient subgroup; responses to rehabilitation, especially over the longer term, are likely to be different in patients with progressive, neurodegenerative disease relative to patients with head trauma or cardiovascular accident. The positive results obtained for IADL rehabilitation in three patients in the present study indicate that the Profinteg can guide IADL rehabilitation; at the same time, and in the absence of a golden standard for rehabilitation procedures and measurement of rehabilitation effects, future studies will need to provide a more complete assessment of the usefulness for rehabilitation of all the 98 activities proposed by the Profinteg instrument.

References


Appendix 1: List of activities considered by the Profinteg IADL questionnaire

Food-related activities
1. Preparing a meal (habitual)
2. Preparing a meal (new)
3. Reheating/Defrosting food
4. Cooking pastry
5. Using a coffee machine
6. Using a Senseo® machine
7. Using a coffee maker
8. Using a pressure-based coffee maker
9. Preparing filter coffee
10. Preparing soluble coffee
11. Preparing packaged tea
12. Preparing unpackaged tea
13. Setting the table
14. Clearing the table
15. Doing the dishes
16. Using a dishwasher

Medication-related activities
17. Preparing a pillbox
18. Using a pillbox
19. Taking medicine without a pillbox

Homework (in a broad sense)
20. Removing dust
21. Vacuum cleaning
22. Sweeping up
23. Cleaning the soil
24. Cleaning the toilets
25. Cleaning the windows
26. Sorting the rubbish
27. Getting out the rubbish
28. Washing clothes
29. Ironing

Shopping activities
30. Compiling a shopping list
31. Purchasing
Looking after domestic animals, plants, and the garden
32. Taking care of animals
33. Watering plants
34. Mowing the grass
35. Working in one’s kitchen garden
36. Working in one’s ornamental garden

Knitting and sewing
37. Knitting
38. Sewing: repairs and hems
39. Sewing: ready-to-wear clothes

Using the phone
40. Dialling a phone number
41. Receiving a phone call
42. Managing a phone call
43. Leaving a voicemail on a phone
44. Checking a voicemail on a phone
45. Dialling a mobile phone number
46. Receiving a mobile phone call
47. Managing a mobile phone call
48. Leaving a voicemail on a mobile phone
49. Checking a voicemail on a mobile phone
50. Sending a SMS
51. Reading a SMS

Moving
52. Using public transportation (habitual trip)
53. Using public transportation (new trip)
54. Travelling using a bike (habitual trip)
55. Travelling using a bike (new trip)
56. Having a walk (habitual trip)
57. Having a walk (new trip)

Management activities
58. Scheduling an appointment
59. Going to an appointment
60. Managing (postal) mails
61. Sending (postal) mails
62. Filling in a form
63. Going to an administrative counter
64. Carrying out a payment via a bank transfer
65. Using a cash dispenser
66. Carrying out an electronic bank transfer
67. Carrying out a payment using the internet (credit card)
68. Carrying out a payment using a phone (phone banking)
69. Transferring money between one’s own bank accounts
70. Using cash
71. Using a debit card
72. Managing energy

Leisure activities
73. Doing crosswords
74. Doing a jigsaw puzzle
75. Playing manual solitaire
76. Doing a Sudoku
77. Playing Scrabble
78. Drawing/Painting
79. Taking silver photos (automatic camera)
80. Taking silver photos (manual camera)
81. Taking digital photos
82. Using a radio
83. Using a CD player
84. Using a record-player
85. Using an audio-cassette player
86. Watching television
87. Recording a television program on a videotape
88. Watching a videotape
89. Watching a DVD
90. Using a computer: general functions
91. Using a computer: word processing (MS Word®)
92. Using a computer: tables and graphs (MS Excel®)
93. Using a computer: displaying digital photos
94. Playing computerized solitaire
95. Surfing the internet
96. Sending and receiving electronic mails
97. Reading

Organisation
98. Storing objects (keys, etc.)
Appendix 2: Sample of a decomposition grid
(activity: “watering plants”)

<table>
<thead>
<tr>
<th>WATERING PLANTS</th>
<th>Dependency score</th>
<th>OBSERVATIONS (errors, assistance provided, other comments)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Prepare the required material</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>a) Take the watering can</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>b) Take the fertiliser (approximately once a month)</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>(2) Provide plants with water</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>a) Put some water in the watering can</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>b) Add the recommended quantity of fertiliser (if necessary)</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>c) Choose the plant to water and slowly pour water onto the soil</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>d) Stop pouring water before overflow</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>e) Proceed in a similar way for the other plants</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>f) Avoid watering the same plant more than once</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>g) Refill the watering can when empty</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>h) Add the recommended quantity of fertiliser each time the watering can is refilled (if necessary)</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>i) Empty the watering can before putting away (if necessary)</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
<tr>
<td>j) Put away the material (watering can and fertiliser)</td>
<td>0 1 2 3 4</td>
<td></td>
</tr>
</tbody>
</table>