CHAPTER 5

A new informant-based questionnaire for instrumental activities of daily living in dementia

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ABSTRACT

Background: Interference in everyday functioning is part of the diagnostic criteria for dementia. Questionnaires measuring 'instrumental activities of daily living' (IADL) are used to measure this interference but their psychometric quality is often questioned. In addition, these questionnaires are less suited for early-onset patients. This is problematic given the high frequency of relative young patients in memory clinics. In this article we describe the development and psychometric properties of a new informant-based IADL questionnaire aimed at detecting incipient dementia and appropriate for a broad age range. **Methods:** We defined IADL in consensus with experts and constructed items based on existing items and suggestions from experts and informants. Informants of subjects (n=206) who visited the Alzheimer Center of the VU University Medical Center completed the questionnaire. Factor structure was investigated using classical exploratory factor analysis and item response theory (IRT). We assessed test-retest reliability in 73 informants using weighted kappa's. **Results:** The questionnaire consisted of 75 items and was computerized to enhance ease of administration. Exploratory factor analysis supported a single factor model, with 48.3% of the variance being explained by the first factor. We removed five items as they did not fit the model. High internal consistency was demonstrated. Test-retest reliability showed that the majority of items (87.9%) had substantial to almost perfect kappa values. **Conclusion:** The Amsterdam IADL Questionnaire®, [a] is a 70 item informant-based computerized questionnaire aimed at detecting early dementia and early-onset dementia. First results show that this questionnaire is a promising new tool.

[a] Amsterdam IADL questionnaire is a registered trademark of Alzheimer Center VU University Medical Center, Amsterdam, the Netherlands

BACKGROUND

Dementia is one of the most common syndromes in later life. It is characterized by multiple cognitive deficits and problems in everyday functioning.[1] Everyday functioning is generally measured using tools measuring 'instrumental activities of daily living' (IADL). IADL can be described as the activities necessary to function independently in society.[2] These activities include, but are not limited to, cooking, doing finances and shopping.[2,3] They can be distinguished from basic activities of daily living (BADL), which include basic self-care skills.

Since IADL involve higher order activities, they are vulnerable to the early effects of cognitive decline and therefore useful for diagnosing dementia.[2,4-7] It has been suggested that problems in complex everyday activities might even be among the first indications of the disease for the patient or family members.[8] In addition to the guidance for a clinical diagnosis, the ability to perform IADL provides an estimation of a patient's ability to live independently and is one of the main factors affecting a patient's quality of life.[9] Moreover, IADL is an important outcome measure for therapeutic drug studies.[8] In consequence, the assessment of IADL is of great relevance.

There are three established methods to assess IADL: self-report by the individual, performance-based assessment and informant report.[3,8,10] Each method of assessment has its own strengths and weaknesses. Self-report is the easiest method. In demented patients however, an impaired insight can make the reports invalid.[11-13] Performance-based assessment provides an objective behavioral evaluation of functional skills by a trained rater.[3] Nevertheless, it is a time-consuming and costly assessment and only a restricted number of activities can be evaluated.[8,14] Another limitation is the difference in patients' performance between artificial (clinical) settings and their performance at home.[15] The third assessment method is the informant report. An informant or proxy can be a spouse, partner, relative or a close friend. Possible disadvantages are that informant characteristics such as anxiety, depression, caregiver burden and general perceived health might influence informant ratings.[16,17] Advantages, on the other hand, include the ease of administration, ratings based on real-world functional performance of IADLs and that the patient is not burdened by an assessment. These advantages make the informant report the most used IADL assessment method in dementia evaluation.[3]

A large number of informant-based IADL questionnaires is available.[8,18,19] However, reviews showed that the quality of these questionnaires needs more attention.[20-22] In a recent systematic review of dementia-specific informant questionnaires, twelve IADL questionnaires were rated on eight psychometric properties. Information was lacking for many important measurement properties, such as the content validity, internal consistency and reproducibility.[23]

Another drawback of these questionnaires is that they were mostly developed in the late 1960s, with more recent developments in the early 1990s.[2,24-28] In the meantime however, advances in technology have changed our daily environment dramatically. For example, the use of mobile phones, computers and household appliances is part of our everyday live now. This is of particular importance for patients under the age of 65, a substantial proportion of patients visiting a memory clinic.[29] Revisions to more up-to-date items are therefore considered necessary.[30]

In view of the above, we developed a new dementia-specific informant-based IADL questionnaire. The aims were to assess complex everyday activities, to be helpful in diagnosing early and early-onset dementia, to be psychometrically sound and suitable for computerized administration.

Definition of IADL

Lawton and Brody described IADL as the activities sensitive for cognitive decline in the elderly.[2] The limits of IADL are difficult to establish though, as the relation between cognition and daily functioning is not straightforward. Instrumental activities cannot be linked to single cognitive domains, but seem induced by multiple cognitive domains.[3,7,31-33] Their degree of difficulty varies from person to person and the extent to which activities rely on controlled processing.[34] Controlled processing tasks require attention, are not entirely familiar or predictable and cannot be carried out well in conjunction with other tasks. Automatic processing tasks on the other hand, demand little attentional capacity and are little affected by other processing demands.[34] Practice can influence the extent to which activities rely on automatic or controlled processing. Controlled processing tasks have been shown to decline early in dementia.[35] As a definition of IADL was lacking, we also aimed to develop a definition of the construct IADL.

METHODS

Definition of IADL

Incorporating the relevant aspects of theories on IADL, we composed the following definition of IADL to guide the developmental process of the questionnaire:

– IADL are complex activities with little automated skills for which multiple cognitive processes are necessary.

The proposed definition was presented to a team of experts, consisting of four neurologists, a neuropsychologist, a geriatrician, two occupational therapists, two nurse specialists and two epidemiologists. The experts were consulted individually and all agreed on the definition of IADL.

Item selection and generation

We started with the collection of items from existing IADL questionnaires, as these items have usually gone through repeated processes of testing.[36] We did not want to adopt the existing items uncritically, as they might use quaint or ambiguous terms. To select relevant and useful items, we individually consulted informants of dementia patients and the experts mentioned above. Experts answered the following three questions: i. was the activity considered as IADL using the proposed definition, ii. was the activity likely to be affected in early dementia and iii. was the item clearly defined and formulated? Twenty informants of early stage and early onset dementia patients and patients with mild cognitive impairment (MCI) answered two questions: i. was the activity affected early in the disease course and ii was the activity clearly formulated? Items rated by a majority of experts or informants as not affected in early stages, not clearly formulated or not seen as IADL were removed from the questionnaire.

Experts and another group of ten informants of dementia patients were also consulted to generate new items for the questionnaire. We interviewed informants individually using in-depth interviews using the 'sampling to redundancy' criterion, that is, interviewing persons until no new themes emerge.[36] We asked both experts and informants to list activities affected in the early stages of the disease which were not mentioned in the existing questionnaire items.

Item wording and response options

We aimed to capture several important aspects of daily functioning in the item response options. First of all, the inability to perform an IADL activity needed to be the results of cognitive problems, and not for example secondary to physical limitations. Second, the patients' current level of functioning needed to be compared to his or her ability to carry out the task in the past. If a patient never did the activity before, items concerning that activity would provide no information. To ensure this, informants were first asked if the patient had recently performed the activity. A time period of 4 weeks was chosen, because there is a limited ability of persons to recall past events.[36] Subsequently we asked whether the patient had difficulty performing this task (see Figure 1). A five point response option was chosen to maximize the measurement of variability in impairment. Responses ranged from 'no difficulty', 'slightly more difficulty', 'more difficulty', 'much more difficulty' to 'no longer able to perform this task', with each item scored as 0,1,2,3 and 4 respectively. As some items consisted of detailed questions about an activity, items were skipped when the main activity was not performed, ensuring an individually tailored approach. For example, detailed questions about work were skipped if the patient was retired or not working due to other reasons. A minimum number of 47 activities were presented.

Did he/she carry out household duties in the past 4 weeks?

Yes → Did he/she find it more difficult to perform household duties than he/she had in the past?

- ○ No
- ○ Yes, slightly more difficult
- ○ Yes, more difficult
- ○ Yes, much more difficult
- ○ Yes, he/she is no longer able to perform this task

No → He/she did not carry out any household duties for the following reason:

- ○ He/she was unable to do so due to his/her cognitive problems
- ○ He/she was unable to do so due to his/her physical problems
- ○ He/she has never done that before
- ○ Other, please state ……

Don't know

Figure 1. Example of a questionnaire item

Pilot testing and further item refinement

To ensure all items were clear and unambiguous, the questionnaire was tested in a pilot study. A third group, consisting of seventeen informants of dementia and MCI patients were asked to complete the questionnaire while thinking out loud. This technique ensured questions were being interpreted as intended. Remaining ambiguous or incomprehensible items were either reframed or removed from the questionnaire.

Quality testing

Subjects

Informants of patients who visited the Alzheimer Center of the VU University Medical Center for dementia screening between October 2009 and May 2010 completed the questionnaire. All patients underwent a standardized dementia screening. Informants completed the questionnaire while the patient was tested. Informants who completed the questionnaire between February and June 2010 were additionally asked to complete the questionnaire again at home after an interval of approximately two weeks time. The Medical Ethical Committee of the VU University Medical Center approved the study and all patients provided written informed consent.

Statistical analyses were performed using SPSS version 15.0 for Windows (SPSS Inc., Chicago, IL, USA), Mplus version 6.1 [37], Stata version 11 [38] and SAS version 9.2 (SAS Institute inc., Cary, NC, USA).

Factor Structure

To investigate the factor structure of the Amsterdam IADL Questionnaire® we performed a classical exploratory factor analysis (EFA). The number of factors was based on the inspection of the items, the factor content and the (rotated) factor loadings. Factor loadings of at least 0.40 were considered to be satisfactory.

Subsequently, a factor analysis for ordered categorical data was performed, which is equivalent to a commonly used item response theory (IRT) model for polytomous items, the graded response model (GRM).[39,40] In IRT, the latent trait is assumed to underlie and directly influence responses to items on a scale designed to measure that trait.[41] This analysis was performed using Mplus and the estimation method used was maximum likelihood (ML), a method suitable for handling missing data. Reliability of summed items was calculated using a nonlinear structural equation modeling (SEM) method for ordered categorical items.[42]

Test-retest reliability

Test-retest reliability was investigated by quadratic weighted kappa values for the individual items. Weighted kappa takes the probability of agreement due to chance into account and weights the disagreement according to the magnitude of the difference in the scores. Weighted kappa considers partial agreement, and is therefore suitable for scaled responses.[43] Disagreement weights are based on the square of the amount of discrepancy. With this weighing scheme, the weighted kappa is identical to the intraclass correlation coefficient.[36] We calculated kappa values using Stata and we considered a kappa value of >.60 as sufficient, according to the criteria of Landis & Koch.[44]

RESULTS

Item selection and generation

The flowchart in Figure 2 shows the item selection and generation. The majority of experts rated 82 items as not being IADL and these were subsequently excluded. Interviews with the experts and informants of dementia patients resulted in the suggestion of 92 new IADL items. Many of these newly suggested items were related to everyday technology use, such as household appliances and computer use.

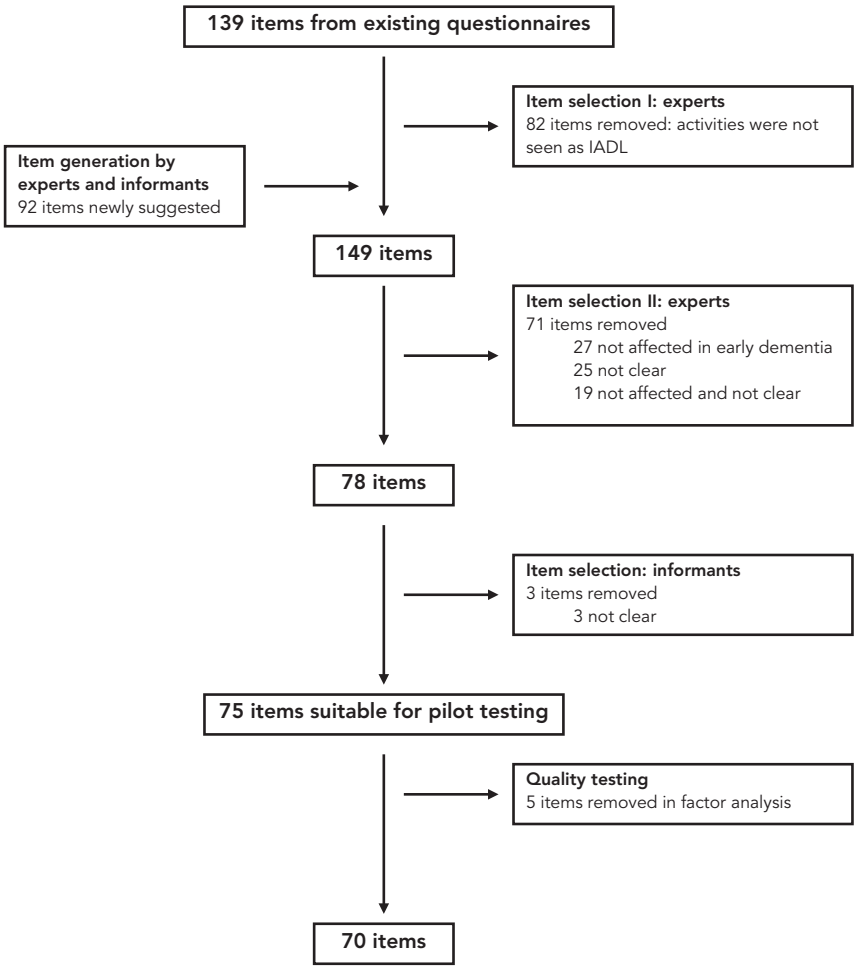

Figure 2. Flowchart item selection and generation.

The items were formulated and we presented a total of 149 items to the experts. Items were retained if the majority indicated that the item was affected in early dementia, well-formulated and comprehensible. We presented the remaining 78 items to the informants and another three items were removed because of unclear wording, resulting in a total of 75 items suitable for pilot testing.

Pilot testing and further item refinement

In the pilot test, informants completed the 75 item questionnaire while thinking out loud. Most items were understood as intended by the researchers. Several adjustments were made to the wording and answer options to improve clarity. In general, the questionnaire was being perceived as important and relevant.

Computerization of the questionnaire

However, informants also indicated that the questionnaire was complex due to the tailored answer options and the possibility of skipping non applicable items. We therefore decided to computerize the questionnaire using eXamine 2.0, a web survey and internet research tool.[45] Using an algorithm, no irrelevant item response options or items were presented, which greatly reduced the complexity of the questionnaire. For example, if a patient never used a computer, detailed items on computer use were not shown. The feedback of the informants improved after the introduction of the computerized questionnaire and they perceived the questionnaire as easy to complete.

Quality testing

The computerized questionnaire was completed by 206 informants. Table 1 shows the patient and informant characteristics. The majority of the informants consisted of spouses (77%). Other informants were children (13%), siblings (2%) or otherwise (8%). Most informants (75%) lived together with the patient.

The median time to complete the questionnaire was 23 minutes (interquartile range 17-29). The median number of activities presented was 59 (interquartile range 50-64). The mean number of items scored, excluding items not performed due to other reasons than cognitive problems and 'don't know' responses was 37 (SD=10).

Factor structure

To investigate the factor structure, we removed item 59 (difficulty using a smartphone), which had a low number of respondents and therefore a small

Table 1. Patient and informant characteristics.

	Patients n=206	Informants n=206
Age	64 (10)	59 (12)
Female gender	95 (46.1%)	132 (64.1%)
Level of Education*	5 (4-6) †	5 (5-6) ‡
Diagnosis of dementia	93 (49.2%) §	
MMSE	25 (20-28) ¶	
Relationship (spouse)		159 (77.2%)
Duration of relationship > 10 years		191 (92.7%)
Living together with patient		153 (74.6%)

Data are presented as mean (SD), median (interquartile range) or n (%). *Education according to Verhage's classification, ranging from 1 (low) to 7 (high).[46] † n=203, ‡ n=205, § n=189, ¶ n=171. MMSE = mini mental state examination.

coverage. Two, three and four factor solutions were investigated, but did not show consistent content results. The first factor explained 48.3% of the variance and a scree plot inspection also supported a single factor solution. Five items were removed from the questionnaire due to high residuals of correlations. These items were 'major repairs', 'dealing with changes at work', 'volunteer work', 'functioning at voluntary work' and 'remembering names'. Factor loadings of the remaining 70 items are presented in Table 2. Estimates of the item thresholds are available upon request. The nonlinear SEM reliability coefficient was .97, suggesting a high internal consistency.

Test-retest reliability

A total of 73 informants completed the questionnaire for the test-retest study within a median time interval of 19 days. In four cases, a different informant completed the second questionnaire and these data were therefore excluded from further analyses. For four items, it was not possible to calculate kappa values, as there was low variation in answers on the items. The kappa values and the percentages of agreement are shown in Table 2. The majority of the items (87.9%) had kappa values >.60, indicating substantial to almost perfect kappa's [44]. A few items had low kappa values, indicating low test-retest reliability. However, upon inspection, these items had a high percentage agreement. Figure 3 shows the total range of kappa values.

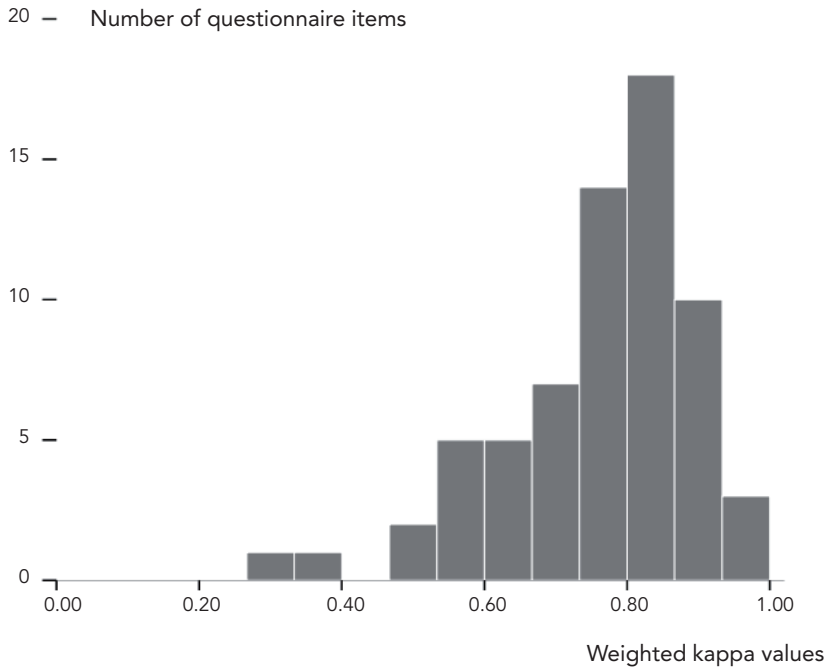

Figure 3. Weighted kappa values for 66 of the 70 items, n = 69.

Table 2. Item characteristics: Number of respondents per item, factor loadings, mean scores, weighted kappa's and percentage of agreement.

					Test-retest		
Item	Content	N	Factor loading	Mean score (range 0-4)	N	Weighted kappa	Percentage agreement
1	Household duties	189	0.770	1.15	63	0.62	94.2%
2	Shop 1	184	0.761	1.27	58	0.78	96.9%
3	Shop 2	145	0.688	1.21	38	0.84	95.0%
4	Shop 3	145	0.691	1.16	40	0.80	93.6%
5	Shop 4	163	0.795	0.63	52	0.84	96.6%
6	Cook 1	138	0.819	1.30	43	0.82	95.9%
7	Cook 2	63	0.758	0.94	16	0.56 †	93.1%
8	Cook 3	139	0.847	1.25	42	0.73	94.6%
9	Cook 4	183	0.755	0.38	59	0.75	97.2%
10	Repairs	102	0.828	1.64	36	0.88	97.2%
11	Domestic appliances 1	196	0.796	0.83	64	0.66	96.1%
12	Domestic appliances 2	151	0.798	0.99	51	0.74	95.7%
13	Domestic appliances 3	65	0.877	1.42	9	0.69	87.6%
14	Domestic appliances 4	105	0.883	1.19	31	0.78	94.6%
15	Domestic appliances 5	110	0.782	0.60	41	0.77	96.5%
16	Domestic appliances 6	182	0.778	0.46	61	0.86	98.8%
17	Domestic appliances 7	127	0.741	0.74	34	0.60	94.3%
18	Paying 1	142	0.786	2.00	43	0.75	93.3%
19	Paying 2	130	0.821	1.57	43	0.84	95.5%
20	Paying 3	87	0.658	0.70	25	0.74	96.0%
21	Telephone 1	141	0.782	1.19	38	0.76	94.6%
22	Telephone 2	155	0.704	1.26	48	0.80	95.4%
23	Finances 1	126	0.836	1.98	35	0.86	95.0%
24	Finances 2	158	0.801	1.30	56	0.83	94.5%
25	Finances 3	75	0.857	1.56	31	0.90	97.1%
26	Finances 4	53	0.884	0.55	23	0.37 †	94.2%
27	Finances 5	54	0.905	0.81	21	0.54 †	91.7%
28	Finances 6	176	0.746	0.85	63	0.72	95.1%
29	Finances 7	134	0.832	0.56	41	0.69	95.7%
30	Finances 8	187	0.782	0.60	59	0.83	97.8%
31	Appointments	178	0.696	1.46	56	0.81	95.9%
32	Forms	139	0.886	1.86	28	0.84	94.4%
33	Work 1	85	0.684	2.19	28	0.81	92.9%
34	Work 2	48	0.610	1.15	14	0.67	93.6%
35	Computer 1	139	0.817	1.38	52	0.74	95.5%
36	Computer 2	95	0.843	1.03	35	0.92	98.4%
37	Computer 3	87	0.866	0.80	35	0.86	97.3%
38	Computer 4	55	0.936	0.84	16	0.86	96.5%
39	Computer 5	68	0.742	0.40	26	0.89	98.7%
40	Computer 6	64	0.900	0.78	20	0.95	98.9%

Table 2. Continued.

Item	Content	N	Factor loading	Mean score (range 0-4)	Test-retest		
					N	Weighted kappa	Percentage agreement
41	Computer 7	19	0.811	1.26	6	1.00	100%
42	Computer 8	23	0.927	1.09	9	0.47 †	92.6%
43	Computer 9	13	0.953	2.00	2	-	100.0%
44	Computer 10	40	0.878	2.33	5	0.93	97.8%
45	Computer 11	16	0.800	1.56	3	-	100.0%
46	Operate devices 1	192	0.795	0.86	59	0.61	94.8%
47	Operate devices 2	200	0.747	0.68	69	0.70	97.1%
48	Operate devices 3	71	0.911	1.63	16	0.93	97.2%
49	Operate devices 4	29	0.912	1.07	4	-	50.0%
50	Operate devices 5	110	0.798	1.35	33	0.84	95.3%
51	Operate devices 6	44	0.889	0.75	10	0.74	92.5%
52	Operate devices 7	64	0.775	1.36	18	0.73	95.1%
53	Instruction manual 1	82	0.895	2.01	21	0.86	94.6%
54	Instruction manual 2	54	0.892	1.30	10	0.29 †	87.5%
55	Smartphone	9	0.927	1.89	5	0.58 †	90.0%
56	New devices	87	0.833	2.32	17	0.89	96.1%
57	Play games	108	0.655	1.20	29	0.66	92.3%
58	Booking	67	0.908	2.24	15	0.98	99.3%
59	Driving 1	80	0.749	1.50	17	0.76	91.9%
60	Driving 2	109	0.718	0.96	27	0.53 †	93.7%
61	Driving 3	111	0.700	0.82	36	0.77	96.3%
62	Driving 4	68	0.908	2.04	19	0.93	97.7%
63	Driving 5	28	0.886	0.86	4	-	75.0%
64	Driving 6	27	0.935	0.96	5	0.85	95.0%
65	Driving 7	69	0.794	1.20	21	0.91	97.9%
66	Public transport	111	0.843	1.12	27	0.91	97.9%
67	Look for things 1	136	0.663	1.90	39	0.64	94.5%
68	Look for things 2	124	0.590	1.60	42	0.58 †	90.7%
69	Deal with the unexpected	102	0.634	1.69	15	0.80	97.1%
70	Medication	156	0.742	0.96	51	0.82	96.7%

† kappa value ≤.60. Several kappa values could not be calculated due to low variance in item responses.

DISCUSSION

In this study, we described the development of the Amsterdam IADL Questionnaire® and its psychometric properties. The aim of this informant-based questionnaire was to measure IADL in the earliest stages of dementia, for both clinical and research purposes. We defined IADL as complex everyday tasks, determined by

multiple cognitive processes and controlled processing. Factor analysis supported unidimensionality of IADL and a high internal consistency. Test-retest reliability was substantial to perfect for the majority of items.

Previous studies have shown that the psychometric quality of many existing IADL questionnaires is lacking.[23] For the Amsterdam IADL Questionnaire®, we investigated the content validity, internal consistency and reliability.

One of the most important psychometric properties is the content validity. It is based of the judgment of experts regarding the content of items.[36] Experts and informants agreed on the importance and relevance of the items and we therefore provided an appropriate justification for the items included in the questionnaire.

Another relevant quality aspect of the newly developed questionnaire includes the factor structure. Whereas other recently developed questionnaires such as the E-cog have tried to include daily activities linked to specific neuropsychological domains [47], we aimed to include those activities dependent on multiple cognitive domains. The finding of a single factor confirms that we have succeeded in our attempt. This finding is in accordance with the finding that IADL tasks have multiple cognitive determinants, any one of which can diversely affect functional performance.[3,31]

Another quality aspect investigated in the current study is the test-retest reliability. For the vast majority of items, test-retest reliability was good, despite the difference in administration setting. Some items had high agreement, but low kappa values, a well-know phenomenon caused by skewed marginal totals and originating from the method kappa is calculated.[48] These low kappa values should therefore not be regarded as an indication of insufficient quality.

Several general difficult issues remain in measuring IADL as a number of factors beside cognitive problems may influence one's daily activities. Ethnicity and gender have been found to affect everyday functioning scores.[49,50] In addition, the prior level of functioning strongly influences the current level of functioning. For example, a patient who has been functioning as an accountant may perform better on tasks related to finances relative to someone who has never done financial tasks before. This prior level of functioning can be considered as 'functional reserve'.[3] This 'functional reserve' is very important in determining one's IADL impairment. We therefore included a range of activities suitable for men, women, younger and older patients, whereas existing questionnaires were mainly aimed at household activities.

Other differences with existing questionnaires include the involvement of experts and informants in the developmental process, the integration of new devices into the questionnaire items, the tailored approach and that the non-informative non-applicable answer option is avoided.

An important advantage of an informant questionnaire is that the informant is likely to interact with the patient over long periods of time and in many different situations. The informant report may therefore serve as an overall estimate of the individual's functional status.[3] However, it is unknown whether the type of informant influences the reliability of the results. One can imagine a spouse being able to give more reliable information than a relative who sees the patient only twice a year. In addition, caregiver burden, depression and anxiety might influence responses.[16] Further research into these informant characteristics on IADL scores is necessary.

A possible limitation of the questionnaire is the high number of items. However, due to the computerized tailored approach, the questionnaire was not received as burdensome. Because of the previously mentioned individual differences in IADL, we believe that the high number of activities is in fact one of the strengths of the questionnaire.

Another limitation is that due to the tailored questioning, not all patients will complete the same items. As a consequence, IADL disability ratings are based on variable numbers of activities. This makes the interpretation of the results challenging. IRT modeling might be a suitable method of scoring and we will explore this in future studies. IRT may even enable the use of computerized adaptive testing, a form of computer testing which adapts to the patient's ability level. Another advantage of computerized adaptive testing is that it will reduce the number of items and the time of administration, which is currently still relatively long.

Future studies are necessary to further validate this questionnaire in other populations with different patient groups, age categories or ethnicity. We will continue the validation of the Amsterdam IADL Questionnaire® by investigating the construct validity and discriminant validity, with the most important aspect differentiating between demented and non-demented patients.

The Amsterdam IADL Questionnaire® is free for use in all Public Health and not-for-profit agencies, and can be obtained from the authors following a simple registration.

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