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ORIGINAL REPORT

ASSESSMENT OF DEPENDENCE IN DAILY ACTIVITIES COMBINED WITH A SELF-RATING OF DIFFICULTY

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Objective: **To study the information gained by extending a well-established instrument of dependence/independence in activities of daily living with a self-rating of difficulty, and to illustrate the relevance and usefulness of this combined approach with cross-national data.**

Design and subjects: **Cross-sectional survey study data collected with 1918 very old persons in 5 European countries.**

Methods: **The "ADL staircase assessment" of dependence/independence, extended with a self-rating of difficulty, was administered at home visits. Data distribution in the 5 national samples and analyses with or without use of the self-rating data were carried out.**

Results: **High proportions of the subjects were independent in most of the activities assessed, while substantial proportions reported difficulties. Considerable differences were identified among the national samples. In personal activities of daily living, those assessed as independent varied from 87% to 100%, while the proportion of those who rated themselves as "independent without difficulty" ranged from 53% to 98%. In instrumental activities, 33–91% were assessed as independent, while the proportions of "independent without difficulty" ranged from 24% to 77%. Analysis results differed as to whether or not self-ratings of difficulty were used.**

Conclusion: **The combined approach to data collection gave a diversified, information-rich picture. The assessment used is easy to administer and can be used in practice contexts in different countries.**

Key words: activities of daily living, aged, 80 and over, geriatric assessment, rehabilitation.

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INTRODUCTION

The most widely used indicator of disability is the ability to perform activities of daily living (ADL) (1). Whilst many different approaches to assessment of ADL ability exist, dependence on assistance from another person is one of the most common dimensions targeted (1–4). Such assessments are informative, but since today's community-living ageing population is, to a considerable extent, independent in personal (P-) as well as instrumental (I-) ADL (5–8), data collected based on this sole dimension show low variance.

Extensive research has demonstrated that the large group of old and very old community-living individuals assessed as ADL independent is not homogeneous, while other aspects of ADL ability than dependence/independence have potential to help us grasp this heterogeneity. In 1994, Jette (9) published a paper showing that a difficulty scale produced higher estimates of disability than estimates of "human assistance". Later studies display similar results, also in terms of differences among sub-groups of older people, e.g. age and sex (2, 7, 10, 11). Gill et al. (11) showed in a general population of community-living older Americans that P-ADL disability was most common in bathing and dressing, in terms of difficulty as well as dependence. They concluded that difficulty and dependence in self-care provide complementary information that together portrays the continuum of disability more fully than either question alone (11). Still, only a few surveys include ratings of independence/dependence as well as difficulty, and there are problems with reaching valid conclusions even with the best possible data on the subject (12). To date, our knowledge in this respect still is limited, and studies including data on P-ADL as well as I-ADL are called for. Moreover, healthcare providers and practitioners need access to valid and reliable, easily administered instruments, generating useful data for planning and evaluation purposes. In order to understand differences in need and demands in the ageing population and in specific client groups, it is valuable to have access to methodology for ADL assessments including objective aspects (e.g. independence/dependence) as well as subjective indicators of performance problems (e.g. tiredness, insecurity, difficulty). This links to the issue of identifying early indicators of disability in terms of ADL ability, and the fact that since the proportions of persons assessed as independent in population studies generally are high, assessment of dependence/independence has low potential in this respect. Instead, other and additional assessment dimensions might have more potential. For example, Avlund and co-workers (13) demonstrated that tiredness and/or reduced speed in activity performance of P-ADL added important information when studying the onset and trajectory of disability.

Turning to the complexity of the construct of ADL, actual ADL ability is the result of dynamic transactions between the person, the environment and the tasks people need and want

to perform. Thus, change in any component of these transactions will affect the performance (14). For instance, Iwarsson and co-workers (5, 15) problematized and studied the fact that more complex ADL seem to be considerably influenced by traditional gender roles as well as environmental factors. With the increasing need and interest for cross-national research on ageing (2), such aspects are becoming increasingly important. Thus, cross-national comparability is another important issue in research involving assessments of ADL ability.

Starting out from the P-ADL items originally developed by Katz et al. (1), in the early 1990s Swedish researchers presented the ADL Staircase (6, 16, 17). This instrument was an extension to Katz' ADL Index, comprising 4 I-ADL items in addition to the original P-ADL items. The ADL Staircase targets independence/dependence and rests on solid methodological ground (6, 16, 17). Recently, it has been successfully applied in cross-national, European research (18). Most important, the instrument has gained much recognition and is in widespread use in clinical contexts, e.g. for estimation of burden of care and evaluation of rehabilitation efforts. Thus, it would be valuable to investigate whether it would be possible to combine the assessment of independence/dependence with a self-rating of difficulty. Therefore, our aim was to study the information gained by such a combined approach to data collection on ADL ability, and to illustrate the relevance and usefulness of this combined approach with cross-national data.

METHODS

Project context

This study was based on data from the European project "Enabling Autonomy, Participation, and Well-Being in Old Age: The Home Environment as a Determinant for Healthy Ageing" (ENABLE-AGE) (19). The main objective of the project was to examine the home environment and its importance for major components of healthy ageing, while much data is at hand for, for example, methodological sub-studies. The project design was explicitly explorative and did not aim for national representativity. The target group was community-residing, very old, single-living inhabitants in Sweden, Germany, the United Kingdom (UK), Hungary, and Latvia.

Sample

The current study is based on data collected with the 1918 participants of the ENABLE-AGE Survey Study. For each country, the target sample was 400 very old single-living persons in geographically defined urban areas, stratified for gender (75% women, 25% men). Due to longer life expectancy, the samples in Sweden, Germany, and the UK consisted of persons aged 80–89 years, while in Latvia and Hungary they consisted of persons aged 75–84 years (20). The national sample sizes and gender proportions were as follows: Sweden, $n = 397$ (75% women), Germany, $n = 450$ (78% women), the UK, $n = 376$ (70% women), Hungary, $n = 392$ (81% women), and Latvia, $n = 303$ (86% women). Background characteristics, such as health, income, and years of schooling varied among the national samples (for details, see (18)).

Procedure

In all countries, the data collection was performed by project assistants; the majority were experienced occupational therapists. Before the data collection started, all project assistants underwent a 3-day course, followed by cross-national, iterative pilot and inter-rater reliability testing of relevant parts of the survey instrumentation (21). Thereafter, data collection was accomplished at home visits.

Instruments

The ENABLE-AGE Survey Study Questionnaire was very comprehensive, incorporating a wide range of well-proven self-report scales and observational formats along with project-specific questions. In all, the data collection generated 1600 variables (see http//:www.enableage.arb.lu.se). Besides basic demographic data, for the current study only a limited portion of the ENABLE-AGE Survey Study database was utilized, i.e. data on ADL independence/dependence and difficulty. Consequently, only the instruments used for collecting these data are described below.

Independence/dependence in ADL. ADL independence/dependence was assessed using the ADL Staircase (6, 16). This instrument comprises 5 P-ADL items (i.e. feeding, transferring, going to the toilet, dressing, and bathing) as defined by Katz et al. (1), extended with 4 I-ADL items (i.e. cooking, shopping, cleaning, and transportation) (6, 16). The ADL Staircase is administered using a combination of interview and observation. With dependence defined in terms of assistance from another person, the assessment is recorded on a 3-graded scale: independent, partly dependent, and dependent.

Perceived difficulty in ADL. In order to capture self-perceived difficulty in ADL, for the ENABLE-AGE Survey Study Questionnaire an additional question about self-perceived difficulty was developed. That is, for each of the ADL Staircase items (6, 16) where the participant was rated as independent, in direct sequence after the assessment of independence/dependence he/she was asked to state whether the current activity (item) was performed "with" or "without difficulty".

Data analyses

In each of the 5 national samples we studied the distribution of the ADL Staircase assessments into the categories independent/partly dependent/dependent, combined with the distribution of the self-rated responses on difficulty for those participants assessed as independent in ADL Staircase items. For each item, excluding individuals with missing data on the ADL Staircase assessments, the results were presented separately for the 5 national samples.

Next, in order to illustrate the relevance and usefulness of our data collection approach, we investigated whether assessment of independence/dependence vs assessment of independence/dependence combined with a self-rating of difficulty in ADL influenced statistical analysis of results, analysing the Swedish data twice. That is, first we performed the analyses using the original scale with the 3 categories (independent/partly dependent/dependent). Secondly, we performed the analyses extending the category independent into 2 (without/with difficulty). Here we included only individuals with all assessments on all 9 items. Analyses were performed by testing sex differences for each item separately, but also for all P-ADL and I-ADL treated as 2 separate groups of items. In order to analyse data on several items simultaneously, a ranking method described elsewhere was used (22). This method is a generalization of the ideas behind the Mann-Whitney U test. In the current study, it was performed by ranking the individuals according to the assessments in all relevant ADL items.

RESULTS

Relative distribution of responses

Overall, the results show that considerable proportions of the national samples were independent in the majority of activities included in the assessment (Tables I and II). The proportions of independent participants were very high and similar among the P-ADL assessed, while somewhat lower for I-ADL. At the opposite endpoint of the 3-graded ADL Staircase scale, likewise the proportions of dependent participants were similar among the activities assessed. When it comes to the data

Table I. *Relative distribution (%) of responses to personal activities of daily living (P-ADL) items in 5 national samples*

	Independent					Partly	
ADL item	Total	Missing	Without difficulty	With difficulty	(Difficulty/ independent)*	dependent Total	Dependent Total
Feeding							
Germany	99.7	0.0	98.0	1.7	(1.7)	0.0	0.3
Hungary	98.6	0.5	92.9	5.2	(5.3)	1.4	0.0
Latvia	100.0	0.0	97.4	2.6	(2.6)	0.0	0.0
Sweden	100.0	2.8	92.4	4.8	(4.8)	0.0	0.0
UK	99.2	8.9	85.4	4.9	(4.9)	0.3	0.5
Transfer							
Germany	99.8	0.0	71.6	28.1	(28.2)	0.2	0.0
Hungary	99.0	0.3	75.1	23.6	(23.8)	1.0	0.0
Latvia	97.4	0.3	65.9	31.1	(32.0)	2.6	0.0
Sweden	98.9	1.3	69.7	28.0	(28.3)	0.8	0.3
UK	99.2	6.5	65.8	27.0	(27.2)	0.3	0.5
Toileting							
Germany	99.8	0.0	84.1	15.7	(15.7)	0.2	0.0
Hungary	99.7	0.5	90.6	8.6	(8.7)	0.3	0.0
Latvia	98.4	0.0	76.5	21.9	(22.2)	1.0	0.6
Sweden	98.6	1.0	85.9	11.6	(11.8)	1.3	0.3
UK	99.2	9.4	80.1	9.7	(9.8)	0.5	0.3
Dressing							
Germany	96.0	0.0	75.4	20.6	(21.5)	2.7	1.3
Hungary	97.0	1.0	78.5	17.5	(18.1)	1.4	1.6
Latvia	98.1	0.0	71.9	26.2	(26.7)	1.2	0.7
Sweden	96.0	1.5	72.2	22.2	(23.2)	2.5	1.4
UK	97.3	7.8	70.9	18.6	(19.1)	1.3	1.4
Bathing							
Germany	90.6	0.0	62.7	27.9	(30.8)	5.0	4.4
Hungary	88.8	0.3	66.8	21.7	(24.5)	4.7	6.5
Latvia	87.1	0.0	53.0	34.1	(39.2)	8.6	4.3
Sweden	89.4	1.0	71.7	16.7	(18.6)	3.8	6.8
UK	93.0	5.4	55.5	32.1	(34.5)	4.0	3.0

*Individuals answering "With difficulty" out of those assessed as "Independent", expressed in %.
Germany, $n=402$; Hungary, $n=382$; Latvia, $n=302$; Sweden, $n=396$; UK, $n=371$.

distributions demonstrated for the self-ratings of difficulty, the picture is more diverse. The degree of difficulty pattern shows that the lowest proportions of difficulty were identified for the most basic P-ADL, i.e. feeding, transferring and toileting, while higher proportions of participants perceived difficulty in performing more complex I-ADL. For example, in cooking, 78–90% of the participants were independent, while 6–19% of those reported difficulty in this activity. In transportation, with independence defined as using public transportation including going to and from the bus/train stop without assistance, the differences displayed are even more striking; while 56–83% were independent, 10–29% of those reported difficulty. That is, these results show that adding a self-rating of difficulty in ADL performance generates considerably more information.

Furthermore, cross-national differences were displayed, in particular in the information based on self-ratings of difficulty (Table I and II). For the 5 P-ADL items the proportions assessed as independent in the 5 national samples varied from 87% to 100%, with the lowest percentages for bathing. Among those who were assessed independent without difficulty the range was much wider (from 53% to 98%), with the largest percentages for feeding and the smallest for bathing and transferring. For the 4 I-ADL items, the proportion assessed as independent varied from 33% to 91%. The proportions independent without difficulty ranged from 24% to 78%, with the higher percentages for cooking, but fairly low percentages for the 3 other items. Again, there were considerable differences between the 5 national samples with regard to the proportion of participants assessed as independent as well as with regard to the added information based on the self-rating of difficulty. For example, in transportation, 83% of the German participants were assessed as independent, while only 56% of the Swedish participants used public transportation without assistance. On the other hand, in Germany 27% of the independent participants perceived difficulty in transportation, while in Sweden only 10% responded that they perceived such difficulty. In cleaning, including dusting furniture, vacuuming and wiping floors in the dwelling, only 33% of the German participants were assessed as independent, while 70% of the Latvian participants managed on their own. In contrast, 37% of those Latvian participants perceived difficulties in this activity, while only 9% of the German participants who were independent in cleaning stated that they had difficulties in this area. It is worth noting that among those assessed as independent there is a proportion that did not respond to the self-rating of difficulty that followed. This is particularly true for the UK, where this proportion

Table II. *Relative distribution (%) of responses to as instrumental activities of daily living (I-ADL) items in 5 national samples*

	Independent					Partly	
ADL item	Total	Missing	Without difficulty	With difficulty	(Difficulty/ independent)*	dependent Total	Dependent Total
Cooking							
Germany	81.8	0.0	75.4	6.5	(7.9)	9.5	8.7
Hungary	84.6	0.5	76.7	7.3	(8.7)	8.1	7.3
Latvia	90.8	0.3	70.9	19.5	(21.5)	7.9	1.3
Sweden	78.1	2.0	65.2	10.9	(13.9)	14.1	7.8
UK	90.3	8.1	70.9	11.3	(12.5)	6.7	3.0
Transportation							
Germany	83.1	0.0	55.7	27.4	(32.9)	4.0	12.9
Hungary	68.3	0.3	49.0	19.1	(28.0)	12.3	19.4
Latvia	76.5	0.0	44.7	31.8	(41.6)	8.3	15.2
Sweden	55.8	1.0	44.9	9.8	(17.6)	6.1	38.1
UK	74.1	6.5	55.8	11.9	(16.0)	10.5	15.4
Shopping							
Germany	61.9	0.0	44.3	17.7	(28.5)	23.4	14.7
Hungary	65.4	0.0	48.2	17.3	(26.4)	12.6	22.0
Latvia	72.9	0.0	43.4	29.5	(40.5)	7.9	19.2
Sweden	75.0	1.0	57.3	16.7	(22.2)	10.9	14.1
UK	64.1	5.4	42.6	16.2	(25.2)	19.7	16.2
Cleaning							
Germany	33.1	0.0	24.1	9.0	(27.1)	22.9	44.0
Hungary	59.7	0.0	39.0	20.7	(34.6)	22.0	18.3
Latvia	69.8	0.0	33.1	36.8	(52.6)	16.6	13.6
Sweden	56.4	0.8	36.4	19.2	(34.1)	9.8	33.8
UK	58.8	2.4	36.9	19.4	(33.0)	18.3	22.9

*Individuals answering ”With difficulty” out of those assessed as ”Independent”, expressed in %.
Germany, $n=402$; Hungary, $n=382$; Latvia, $n=302$; Sweden, $n=396$; UK, $n=371$.

varied between 2% and 9%. In contrast, in the German sample every participant assessed as independent responded to the self-rating question.

Influences on analysis results

The descriptive results (Tables I and II) show that the group of independent participants was not homogenous as regards ADL ability. The information gained by extending the data collection with a self-rating of difficulty was used to illustrate the usefulness of this approach.

When testing the difference between the sexes in the Swedish sample ($n=376$), for some items the difference was accentuated when the self-ratings of difficult were included (the p-value decreased), while for other items the difference was weakened (the p-value increased) (Table III). For instance, for transferring, defined as transfer from bed to chair or between 2 chairs, the p-value decreased from 0.236 to 0.022. Based on the ADL Staircase assessment almost 100% were assessed as independent in transferring (97/97 for men, 275/279 for women), but the inclusion of the difficulty rating revealed that 80% of the men rated themselves as independent without difficulty vs only 68% of the women (78/97 vs 191/279). For transportation the p-value increased from 0.081 to 0.402; a seemingly large difference in proportion of independent of 48% for men and 59% for women (46/97 and 164/279, respectively) diminished to a small difference between 46% and 47% independent without difficulty (45/97 and 130/279, respectively).

DISCUSSION

The results of the current study confirm the well-known heterogeneity in ADL ability among older, community-living people. However, most previous studies did not combine assessment of ADL dependence with self-ratings of difficulty, while our study demonstrates that such an approach gives a more diversified picture. As expected, the results show that in using dependence/independence to capture ADL ability there are marked ceiling effects, reducing the variance of the data, while among individuals assessed as independent in ADL, varying proportions of the samples perceived difficulty. Compared with previous studies (11, 13), the results add to the knowledge on the distribution of dependence and difficulty across a wider range of ADL, i.e. not only in P-ADL. That is, we were able to present how this pattern looks for I-ADL. In addition, the cross-national differences demonstrated will nurture new research questions for comparisons of ADL ability across national and cultural contexts.

Since the data collection approach was based on the principles of the widespread Katz' ADL Index (1) extended with I-ADL (6, 16), in combination with a straightforward self-rating of difficulty, the combined data collection approach is easily applied in practice contexts, as is the descriptive analysis approach. Thus, besides the scientific contribution this study is practically and clinically relevant and important. The dichotomous self-rated question on difficulty in activity performance was developed specifically for the ENABLE-AGE

Table III. *Frequencies exemplifying how assessment of independence vs assessment of independence and self-rating of difficulty in personal and instrumental activities of daily living (P-ADL, I-ADL) influence results; sex comparisons[a] in the Swedish national sample, n = 376*

ADL item Sex, *n*	Independent	Independent without difficulty	Independent with difficulty	Partly dependent	Dependent	Independence[b] *p*-value	Independence and difficulty[c] *p*-value
P-ADL							
Feeding						1.000	0.365
Male	97	94	3	0	0		
Female	279	264	15	0	0		
Transfer						0.236	0.022
Male	97	78	19	0	0		
Female	275	191	84	3	1		
Toileting						0.146	0.245
Male	97	88	9	0	0		
Female	273	241	32	5	1		
Dressing						0.253	0.136
Male	95	77	18	2	0		
Female	266	201	65	7	6		
Bathing						0.054	0.023
Male	92	79	13	3	2		
Female	246	196	50	10	23		
Total[d]						0.039	0.009
I-ADL							
Cooking						0.000	0.002
Male	60	55	5	24	13		
Female	233	197	36	29	17		
Transportation						0.081	0.402
Male	46	45	1	8	43		
Female	164	130	34	13	102		
Shopping						0.051	0.001
Male	81	73	8	6	10		
Female	205	151	54	30	44		
Cleaning						0.579	0.897
Male	53	40	13	10	34		
Female	162	101	61	26	91		
Total[a]						0.012	0.424

[a]Based on the Mann-Whitney *U* test.
[b]Sex differences based on ADL Staircase assessments (independent/partly dependent/dependent)
[c]Sex differences based on ADL Staircase assessments and self-ratings of difficulty (independent without difficulty/independent with difficulty/partly dependent/dependent)
[d]Based on Iwarsson & Lanke's ranking method (2004).

Survey Study (19), and worked well with the very old people interviewed. In particular, it should be noted that the combined assessment format used in the current study is available in 5 European languages (see www.enableage.arb.lu.se), laying the ground for further cross-national studies. Whether our approach is valid, including data on 2 dimensions of ADL ability in the same variable could of course be debated. Another way would be to analyse the dimensions independence/dependence and difficulty separately (23), while the lack of combined approaches to ADL assessments recently has been brought to the fore (12). Since the resulting variable still has ordered categories allowing analyses with statistical methods for ordinal variables (22, 24, 25), data was treated without violating sound conceptual or scale propriety principles (25–28).

An important contribution is the exemplification of how the assessment dimensions chosen influence data analysis results. On an overall level, our results confirm that there are subgroup differences in ADL ability among older people (9–11), while the new insight gained is that the assessment dimension chosen also influences the results of basic inferential analyses. A limitation deserving comment is the fact that our assessment approach did not capture perceived difficulty occurring together with dependence. This leads us to reflect upon the important issue of considering objective as well as perceived, subjective aspects of ADL ability. Having stated this, even if a lot of ADL instruments do exist, the instrument arsenal at hand is not sufficient for use with the heterogeneous older population of today. Nearby reflections concern the pathway to disability in old age, characterized either by traumatic accidents (e.g. hip fracture) or sudden illness (e.g. stroke) that might result in temporal or permanent dependence, or the progressive functional decline and loss of reserve capacity occurring along the ageing process. That is, ADL disability probably develops differently depending on the underlying causes of loss of functional capacity. One consequence of the "natural ageing" pathway might be perceived difficulty in ADL. It has been demonstrated that P-ADL and I-ADL can be combined to a single hierarchical scale with discriminative and predictive validity (6, 16, 17, 29). Thus, serving as an early indicator of disability, assessments of dependence/independence in combi-

nation with self-reported difficulty can be used for even earlier intervention in clinical contexts. Furthermore, here is potential for development of more discriminative instrument for use in general population studies. However, as exemplified by Gill et al. (11), longitudinal studies are required to take this development further, as well as studies on item response bias among women and men in different countries and cultures.

Keeping in mind the explorative nature of the ENABLE-AGE Project (18–20), cross-national comparisons based on our results should be made with caution. Still, it is noteworthy that compared with the other national samples, higher rates of German respondents were dependent in, for example, cleaning. While descriptive ENABLE-AGE data show (18) that there were no significant differences among the samples in terms of functional limitations, in particular Latvian very old persons were more independent in cleaning. This finding might indicate that other reasons than intrinsic disability influenced our results. For example, the German sample had considerably higher income and one possible explanation is that they hired cleaning services, while the Latvian participants perhaps did not have this opportunity. As shown in Table II, one-third of the Latvian participants who were independent in cleaning perceived difficulties in this activity. Overall in former Eastern Europe, home services for older people are under-developed (30), suggesting that results from ADL assessments are influenced by societal and cultural differences. As yet, this type of environmental impact on ADL ability has scarcely been studied, but given the increasing importance of cross-national ageing research, this aspect of our results generate new research questions. This is another example of environmental influences on ADL performance, and of the importance of being aware of the person-environment-occupation transactions (14). However, in healthcare and social service contexts, practitioners are not often aware of environmental influences induced by social policies and welfare systems. In line with other studies (31, 32) our results clearly show the importance of raised awareness of such influences, not least in today's multi-cultural Europe.

In conclusion, there is substantial additional information to be gained by asking community-living older people assessed as independent in ADL to rate themselves according to difficulty. That is, with such a combined approach to data collection the variance in data increases considerably. These results have generated several new research questions, concerning, for example, how ADL ability is influenced by cultural, social and infrastructural factors. Another research question concerns whether the kind of results we present can be used for identification of indicators for how disability develops along the ageing process. Finally, the assessment used has practical and clinical relevance and potential to be developed further to an instrument that can be used for comparisons of ADL ability across national and cultural contexts.

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