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Functional ability, social support and quality of life

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2 The Groningen Activity Restriction Scale for measuring disability: Its utility in international comparisons

(Theo Suurmeijer, Dirk Doeglas, Torbjørn Moum, Serge Briançon, Boudien Krol, Robbert Sanderman, Francis Guillemin, Anders Bjelle, and Wim van den Heuvel)

2.1 Introduction

Rheumatoid Arthritis (RA) is a chronic disease with a varying clinical course. Therefore, measures of the 'objective' severity of the disease are always time-dependent. The paroxysmal character of the disease makes it fairly unpredictable for patients themselves and for their significant others. Part of the burden of RA is caused by this varying and unpredictable course (Wiener 1975).

Sooner or later, patients with rheumatoid arthritis experience impairments and 'social disability', that is, 'the dysfunctioning in a social role or in some aspect of social behavior' (Wiersma 1986). The relevance of the behavioral consequences of a disease has often been stressed because these consequences are of crucial importance for the daily functioning of the individuals involved (CBS/NIMAWO 1990). In this article we will confine ourselves to restrictions regarding certain activities and tasks, that is, Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL), sometimes referred to as 'Housekeeping activities of Daily Living' (HDL; Van den Bos 1991).

ADL functions are essential for an individual's self-care (e.g. washing or dressing oneself), whereas IADL functions are more concerned with self-reliant functioning in a given environment (e.g. shopping, preparing meals; Spector et al. 1987). The distinction between these two groups of activities is mainly a consequence of 'institutional thinking'. In many countries, the delivery of care with respect to these two groups of activities is provided by different professions or agencies (sometimes combined with different types of financing); therefore, these two groups of activities have been distinguished and measured separately (Kempen and Suurmeijer 1990, Kempen 1990). From the perspective of the patient, however, ADL functions are no less 'instrumental' than IADL functions.

Partly on the basis of existing instruments, Suurmeijer and Kempen (1990) developed the Groningen Activity Restriction Scale (GARS). The instrument was developed to measure both ADL and IADL disability in community-based studies with respect to the aid and services provided by professional home help and district nursing

agencies. The patient's physical condition, of course, plays an important role in this respect, but the patient's personality and contextual and interactional variables may be important as well in the 'appraisal of one's abilities' (Blaxter 1980, Locker 1983).

The GARS has been applied in several studies in the Netherlands (Kempen et al. 1993). It has proven to be a very useful instrument: it makes it possible to (1) more precisely describe the severity of the disablement caused by several chronic conditions, (2) establish changes in disablement over time, (3) differentiate more accurately between degrees of disability, and (4) improve the assessment of the need for professional care.

In this article we use data from an international longitudinal study of patients recently diagnosed with RA (EUropean Research on Incapacitating Diseases and Social Support; EURIDISS 1990) to analyze the overall psychometric properties of the GARS across countries. More specifically, we test the unidimensionality and hierarchical order of the scale items and explore the scale's construct validity.

2.2 Methods

2.2.1 *Sampling procedures*

The criteria for inclusion in the EURIDISS study (1990) have been published elsewhere. By the end of November 1992, data had been collected on a total of 630 patients with RA: 116 French, 292 Dutch, 124 Norwegian and 98 Swedish patients. The non-response rate varied from 12% (the Netherlands) till 30% (France). The patients' mean age was 52 years; the mean disease duration was 2.6 years. Thirty-one percent of the patients were men and 69% were women. Because of incomplete data, 7 of these respondents were omitted from the analysis.

2.2.2 *Description of the GARS*

The 18 GARS items and 5 response categories are presented in appendix 1. The items refer to what respondents are able to do and not to their actual performance, which is a very important distinction (Myers 1992). When an item refers to more than one activity (e.g. item 5), the activity causing the greatest problems to the patient determines the response.

2.2.3 *Statistical analysis*

In the analyses, the two most extreme response categories (score 4 and 5) were combined, partly because response 5 was chosen by only a few patients. Consequently, sumscores could vary from 18 (not disabled) through 72 (severely disabled).

A principal component analysis was carried out on the scale items, both for the countries separately and for all countries together. Next,

reliability figures (Cronbach's α (1951) or ρ (Molenaar 1982)) were calculated.

The hierarchical order of the ADL and IADL items was tested with the Mokken Scale Analysis for Polychotomous items (MSP; Molenaar 1982, Debets and Brouwer 1989). MSP is a probabilistic (nonparametric) extension of Guttman scale analysis (Niemöller and Van Schuur 1983) that can handle three or more rank-ordered response categories per item. The program calculates three different scalability coefficients: H_i for individual items, H_{ij} for item pairs and H for a set of items as a whole. For a set of items to be accepted as a scale, it is required that all H_{ij} 's be greater than .00 and all H_i be greater than or equal to .30. In that case H will be greater than or equal to .30. The H coefficient refers to the strength of the scale as a whole: if H is from .30 up to .40, the scale is 'weak'; if H is from .40 up to .50, the scale is 'moderately strong'; if H is equal to or greater than .50, the scale is 'strong'.

Analyses of variance were carried out to test for differences in GARS scores across countries, age and sex, and the construct validity of the GARS and its component parts was explored.

2.3 Results

2.3.1 *Results of factor analyses*

From the principal component analysis on the GARS items, both for the countries separately and for all countries together, it appeared that the first factor was a very strong and reliable one. The sumscore of the GARS was directly derived from the raw (i.e., unweighed) scores. The correlation between this sumscore and the factorscores (i.e., weighed item scores) was .9938. Therefore, the raw scores can be used when calculating the GARS score. A scree plot of the eigenvalues of the extracted components confirmed the assumption of one underlying dimension: after the first general component (eigenvalue = 8.71), there was a clear 'elbow' in the curve of the consecutive eigenvalues.

As mentioned before, the ADL and IADL items are often considered to indicate two specific types of disability. Therefore, we repeated the same analyses as before for the 11 ADL and 7 IADL items separately, for the countries separately and all countries together. It appeared that both the ADL and IADL items form one strong and reliable general factor; no other factors with an eigenvalue of 1.00 or more could be extracted.

The mean GARS score (range = 29.2-32.6), as well as the mean ADL and IADL score (range = 15.8-17.4 and 13.2-15.2, respectively), differed somewhat between countries. These differences may be due to environmental and cultural differences in the appraisal of activities included in the GARS. Probably because of sex role-specific socialization patterns, women scored significantly higher than men

on the IADL scale, although the mean difference was very small (means = 14.8 and 13.6, respectively). On average, older people scored significantly higher on the GARS as a whole and on the ADL and IADL scales; these higher scores support the fact that, in general, older people are more disabled than younger ones (CBS/NIMAWO 1990) (range = 32.5-27.6, 17.5-14.8 and 15.0-12.8, respectively). There were no interaction effects between age, sex, and country. The validity of the GARS and the ADL and IADL scales was explored by assessing the scale's association with several other instruments measuring physical problems and subjective health. Specifically, we used the Physical Mobility subscale from the Nottingham Health Profile (Hunt et al. 1981, Kind and Carr-Hill 1987), the Karnofsky Performance Status Scale (Karnofsky and Burchenal 1948), the Somatic Symptoms subscale from the General Health Questionnaire (Goldberg and Williams 1988), and an overall evaluation of health item using a ruler as a visual analogue scale. In the latter case, the patient was asked, 'How would you rate your health at the moment. Would you say that it is very poor, that it is excellent or that it is somewhere in between?' (Goldstein et al. 1984). The ruler ran from 'very poor' (a score of 1) to 'excellent' (a score of 100). The GARS and the ADL and IADL scales were expected to correlate highest with those measures most comparable with the GARS (the Physical Mobility subscale from the Nottingham Health Profile and the Karnofsky Performance Status Scale) and to correlate lowest with those instruments less comparable to the GARS (the overall evaluation of health and the Somatic Symptoms subscale from the General Health Questionnaire) (Table 2.1).

Table 2.1 Correlations of the GARS, the ADL and IADL scales with the Physical Mobility subscale from the Nottingham Health Profile (NHP-PM), the Karnofsky Physical Status Scale (KPSS), the Overall Evaluation of Health (OEH) and the Somatic Symptoms subscale from the General Health Questionnaire (GHQ-SS).

	NHP-PM	KPSS	OEH	GHQ-SS
GARS	.78	.68	-.40	.25
ADL	.77	.64	-.39	.26
IADL	.71	.66	-.37	.21

The pattern of correlations encountered yielded additional support for the utility of the GARS. Moreover, from the pattern and size of the correlation coefficients, it appears that there was no difference between the GARS and the ADL and IADL scales, which may be an

additional reason to treat the ADL and IADL as one scale. (It also appears legitimate to use the ADL and IADL scales separately if necessary.)

2.3.2 Results of MSP

Finally, the hierarchical ordering of the items (in the data sets of the four European countries together) was tested with MSP (Table 2.2).

Table 2.2 Mokken Scale Analysis for Polychotomous items on the GARS, for the combined European data set.

Ordered GARS Items		Item Mean Scores	Scalability Coefficient for the Individual Items (H _i)
1 Wash face/hands	(ADL)	1.22	.49
2 Feed yourself	(ADL)	1.24	.40
3 Get around inside house	(ADL)	1.26	.50
4 Get on/off toilet	(ADL)	1.32	.48
5 Prepare breakfast/lunch	(IADL)	1.35	.47
6 Get in/out bed	(ADL)	1.43	.47
7 Stand up from chair	(ADL)	1.45	.49
8 Light cleaning	(IADL)	1.54	.46
9 Dress yourself	(ADL)	1.59	.53
10 Walk outdoors	(ADL)	1.60	.50
11 Wash/dry body	(ADL)	1.76	.51
12 Prepare dinner	(IADL)	1.79	.47
13 Go up/down stairs	(ADL)	1.81	.48
14 Wash/iron clothes	(IADL)	2.07	.47
15 Take care feet/toenails	(ADL)	2.10	.42
16 Makes beds	(IADL)	2.35	.47
17 Do shopping	(IADL)	2.49	.43
18 Heavy cleaning	(IADL)	2.79	.49
Scalability coefficient H of the GARS			.47
Reliability coefficient ρ			.94
Scalability coefficient H of the ADL-items			.52
Reliability coefficient ρ			.90
Scalability coefficient H of the IADL-items			.51
Reliability coefficient ρ			.89
n			623

The items are ordered according to their difficulty as expressed by the item mean scores. All the H_i 's were greater than or equal to .40; the reliability coefficient ρ was .94. The H coefficient of .47 nearly met the criterion for a strong scale.

2.4 Conclusions

The results of the analyses were highly satisfactory. They showed a strong and reliable general first factor, indicating one underlying dimension of disability for ADL, IADL, or both. For institutional reasons, or to differentiate between sex or age groups, the ADL and IADL scales can be used separately.

The GARS turned out to be a rather strong unidimensional, hierarchical scale. The same was even more true for the separate ADL and IADL scales. The fact that the GARS-items were hierarchically ordered means that respondents with the same score had the same problems with ADL and IADL. However, Kempen et al. (1995) warn against the use of cutpoints or single questions to categorize patients: 'Hierarchical evidence should not be used to justify minimal patient questioning'. This has partly to do with the fact that the Mokken model is not sample independent. Differences between samples may be due to language, education, motivation, opportunity or environmental factors (living arrangements, availability and proximity of services, means of transportation, and so on) (Locker 1983, Myers 1992, Kempen et al. 1995, Guralnik et al. 1989, Linn et al. 1980). However, when the Mokken analysis is applied to a maximally large group, its sample dependence gradually diminishes.

One of the advantages of the MSP over the Guttman analysis is that more than two response categories can be used. As a consequence, more accurate distinctions can be made, which are not only more realistic about the daily functioning of patients but also necessary to target support services (Kempen and Suurmeijer 1990, Suurmeijer and Kempen 1990, Myers 1992, Kempen et al. 1995).

Of course, other instruments have been developed to measure disability in ADL or IADL (Bowling 1991, Spilker 1990), but the GARS measures both simultaneously, and it is a very reliable and valid scale with hierarchically ordered, polychotomous items. In addition, it is community based and not disease-specific. These characteristics make the GARS very useful for international, comparative and longitudinal research both across countries and across diseases.