

Development of an activities of daily living scale to screen for dementia in an illiterate rural older population in India

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Abstract

Objective: to develop a measure of activities of daily living appropriate for use in assessing the presence of dementia in illiterate rural elderly people in India.

Design: identification of relevant items, pre-testing of items and refinement of administrative procedures and scoring in four successive groups of 30 subjects each, pilot testing in a group of 100 subjects comparable to those for whom the measure is intended, administration to a representative sample of 387 people aged 55 and older, and assessment of the reliability of the final measure.

Setting and subjects: age-stratified random sample of older men and women in rural areas of Ballabgarh, Northern India

Results: the original pool of 35 items covering mobility, instrumental and personal care activities was reduced to an 11-item unidimensional scale (to which an additional item on mobility was added) with internal consistency (Cronbach's α) = 0.82, perfect inter- and intra-rater reliability, test-retest reliability (intraclass correlation) = 0.82 (any disability) and 0.92 (unable to perform for 'mental' reasons). Women, older subjects, the totally illiterate and subjects with poorer cognitive function performed significantly more poorly ($P \leq 0.02$ for all).

Product: a brief, reliable and valid activities of daily living measure, with norms, which is appropriate for use in assessing dementia in illiterate rural elderly people in India.

Keywords: activities of daily living, cognitive, dementia, developing country, elderly, Everyday Abilities Scale for India, illiterate, India, rural

Introduction

Measures of activities of daily living (ADL) appropriate for use in developing countries are notable for their absence. Over the last 10 years only two measures, the Chula ADL index [1], and the Old Age Disability Scale [2], have been standardized for use in such a setting. The Chula ADL index, evaluated in Thailand, clearly indicates that even when the activity examined (e.g. climbing stairs) appears to involve the same physical capabilities, it may represent a more complex intellectual activity. The Old Age Disability Scale views

disability in a broad manner, using a diverse approach to assessment.

Our task was the development of a valid and reliable measure of ADL for use in an epidemiological study of dementia in rural India, where the older residents have little, if any, education.

In developing this measure we were guided by certain factors: (i) standard diagnostic criteria for dementia and Alzheimer's disease that state for dementia to be present there must be disturbance in social or occupational activities or in ADL [3–6]; (ii) the theoretical framework for classifying ADL into mobility,

instrumental and basic proposed by Katz [7]; and (iii) the recommendations of Sainsbury that relevant, culturally appropriate items—commonly performed activities which are usual and expected tasks—be selected [8]. Items also had to meet accepted criteria for reliability and validity. They had to concern behaviours for which informants could give accurate information, since the responses of the severely cognitively impaired cannot necessarily be accepted as accurate. Items had to be easy to administer and to score, and understood unambiguously by those to whom they were addressed. As brief a measure as possible was desired, since informants might be involved in additional testing. The scale had to include, but not be limited to, ADL which were likely to be affected by cognitive impairment, as we wished the measure to be useful in providing information relevant to assessment of dementia.

Methods

Study population

The ADL measure was intended for assessment of the older residents of Ballabgarh, a community of 28 villages 22 miles from New Delhi. This community is the intensive field practice site for the Centre for Community Medicine of the All-India Institute of Medical Sciences. The age, sex, level of education and location of residents are recorded. Most older people in this community are illiterate.

Data from four groups each of 30 volunteers and one randomly sampled group of 100 subjects, comparable in terms of age, sex, education and geographic area to those for whom the final ADL scale was intended, provided successive pretest information basic to reviewing, rewording and culling items for the scale, and refining the administration and scoring procedures.

For final scale development, all subjects 55 years of age and over in the census database as of 1 January 1994 were classified into three age groups: 55–64, 65–74 and 75 and over. Within each age group 160 subjects were chosen at random. Ninety-three of these 480 subjects did not participate: one was found to be a duplicate case, eight were found to be younger than 55, 53 had died and 22 had moved out of the study area. Eight who refused a cognitive evaluation and one who was cognitively untestable were excluded, as we wished to examine performance of ADL in relation to cognitive functioning. Information on the remaining 387 subjects was used to develop the final scale, determine its psychometric characteristics and develop norms.

Informed consent was obtained from these subjects following procedures approved by both the Human Volunteers Protection Committee of the Centre for

Ageing Research in India (New Delhi) and the Institutional Review Board for Psychosocial Research of the University of Pittsburgh.

Selection of items

As in other developing regions, few, if any, formal activities are expected of the older members of this community [9]. The first challenge was therefore to identify ADL which these elderly people could be expected to perform, and which would be relevant regardless of sex, socio-economic status, caste and special characteristics of certain villages.

An initial set of items was developed after discussion with professional experts, field workers familiar with the community and village leaders. They were asked such matters as: at what age (or stage) are adults no longer expected to do anything? Who cooks, cleans, tends the fire, fetches water, makes decisions, looks after sick family members? When the older person no longer does the work is he or she still expected to issue instructions? Do older people still sew, discuss village affairs, arrange marriages? Do they participate in planting, harvesting or arranging for the sale or barter of farm produce? What is their involvement in weddings, festivals and other rituals?

These discussions resulted in the development of a lengthy set of activities, including necessary seasonal tasks, in which most elderly people in the community might be expected to engage and which were unaffected by social status (e.g. taking interest in grandchildren). The items selected focused on basic ADL—roughly subdivided into eating-related behaviour (four items), personal hygiene (four items), dressing/grooming (seven items) and attention to health needs (two items)—and instrumental activities, the performance of which is required to remain a participating member of society. The latter included mobility within the local area and further afield (six items); social interaction within the family and in the larger community (six items); and activities related to cognitive function (six items)—e.g. able to go alone by bus to New Delhi, interact appropriately with visitors, deliver a message as promised.

Development of a coding system

We found that both respondents and interviewers could consistently understand only a 2-point scale. Respondents were therefore asked whether the subject could (coded as 0) or could not (coded as 1) generally perform the activity. Thus, a higher total score reflected greater overall disability. If the subject could not generally perform the activity, the reason for non-performance was ascertained. Responses clearly indicative of physical or mental problems or both, were so coded. Ambiguous responses (e.g. 'old age') were probed and only when it was obvious that no further clarification was forthcoming were they left as such.

With the exception of mobility items, in analysis we have assumed that a response of 'old age' reflected a mental rather than a physical problem.

The procedures used to obtain information (e.g. repetition, alternative phrasing, probes) were recorded. This permitted rapid identification of problem items for further refinement of the instrument.

Item administration

By design, administration and data gathering were carried out by field workers—trained people from the area who had partial high-school education. In consequence, the items not only had to be phrased simply and clearly in the local dialect, but response had to be noted on forms which permitted recording in a simple but accurate manner. Field workers were trained to deliver instructions and clarifications to subjects according to a script and to record responses verbatim. All data gathering through the first four groups was audiotaped. This permitted review by people not present at the interview, facilitated training of field workers and provided data necessary for studies of inter- and intra-rater reliability.

Since the ADL measure was intended for assessment of the potentially demented, who could not necessarily respond accurately, information on ADL performance was obtained not from the subject, but from a close family member who was younger than 55 and in daily contact with the subject (typically the daughter-in-law). These people were expected to provide an accurate view of the older person's performance. The husband or wife of the subject, a sibling or a sibling's spouse were ineligible as it was felt that they might be less willing to report on the subject's deficits.

Reliability assessment

Thirty subjects with a range of ADL disabilities were selected. To assess intra-rater reliability the original coder was asked to recode the raw data from this group. Inter-rater reliability was determined by asking a second rater to listen to the audiotapes of the 30 informants and to code the recorded responses.

To ascertain test-retest reliability, the ADL items were readministered after 8–36 days (mean 16.4 ± 5.2 days) to 34 informants who had previously provided data on sample members.

Statistical analysis

Descriptive statistics were used to summarize information on the sample, while κ , percent agreement and intraclass correlation coefficient were used to assess reliability.

After initial item elimination, information was available on 26 dichotomously scored items for each of 387 respondents. Because items were scored

dichotomously, data reduction by the more common factor analytic techniques was inappropriate, while procedures available through PRELIS for analysing dichotomously scored variables could not be used because the ratio of items to respondents was too high [10]. A matrix of ϕ coefficients (which measure the degree of association between dichotomously scored items) was therefore calculated. This matrix was used for two purposes: to examine item inter-relationships, paying particular attention to convergent and discriminant validity, and to identify items which could be eliminated, thus reducing the length of the scale. For convergent and discriminant validity to be present items designed to measure the same concept should share higher ϕ coefficients with each other (convergent) than with items intended to measure a different concept (discriminant). For scale reduction, we defined as superfluous any item which had a very high correlation with another item, or whose pattern of correlations with a set of items was comparable to that of another variable. We defined as inappropriate any item which had a very low correlation with all other variables, and so may not have been assessing ADL. The reliability of the resulting abbreviated scale was assessed by means of Cronbach's α .

Two summary scores were developed for the abbreviated scale: one which reflected performance inability for any reason and one which reflected inability for mental reasons. Because scores were highly skewed (approximately three-quarters of the sample could perform all activities and only 7.5% had problems with three or more items), exact nonparametric statistical tests were employed to examine the relationships between the score on the ADL scale and age group, sex, literacy (defined as being able to read a newspaper and write a sentence) and score on the Hindi Mental State Examination (HMSE) [11].

Ordinal logistic regression was used to determine the significance of interactions among age, sex and literacy with ADL score. Analyses were run separately for scores based on performance problems for any reason (overall ADL score) and performance problem attributed to mental reasons. For analyses focused on performance problems for any reason, overall ADL scores of 3 or greater were recoded to 3 to satisfy goodness-of-fit criteria; scores of 2 or greater on the mental ADL score were recoded to 2. Continuous age values were used in the regression models.

Results

The 387 subjects ranged in age from 55 to 93; their overall mean age was 69.5 (SD=8.9) years. One hundred and twenty-three (31.8%) were aged between 55 and 64, 145 (37.5%) were aged 65–74 and 119 (30.7%) were 75 years of age or older. Most were male (207, 53.5%). Only 84 individuals (21.7%), of whom 74

(88.1%) were male, were minimally literate, i.e. had previously or were now able to read a newspaper and write a sentence; the rest were illiterate. All but one person completed the HMSE, a measure of cognitive functioning designed to be comparable to the Mini-Mental State Examination [11, 12]. The majority (195, 50.5%) obtained scores of 27–30, 108 (28.0%) obtained scores of 23–26 and the remainder (83, 21.5%) had scores of 22 or less, the range most suggestive of cognitive impairment.

Of the original group of 35 ADL items, nine were eliminated because they appeared to be irrelevant, assessed only physical condition, were gender-specific or were not well understood. The remaining 26 items were grouped into four categories comparable to the categories of Western ADL/instrumental ADL measures. These categories were personal self-maintenance tasks (13 items), social interaction (five items) and cognitive functioning (six items), which were comparable to instrumental or advanced ADL, and mobility (two items).

Examination of the ϕ coefficient matrix to determine whether inter-relationships among items within a given named area were stronger than associations across areas, indicated values of 0.30 or greater only within the area of cognitive function where, of the 15 possible pairs of associations among the six constituent items, eight reached this value. Items in the other named areas did not appear to be uniformly measuring

the relevant concept. Indeed, some items bore a closer relationship to items in other areas than to those in their own. The areas of personal hygiene, dressing and care of clothing and cognitive functioning included items which correlated notably with items in all other areas, while items in the social interaction area correlated with all but eating-related items. This suggested that the named areas were not discrete, and that items could be pooled and culled to produce a unidimensional measure. To facilitate the creation of a brief, unidimensional measure we selected those items which had ϕ coefficients of 0.30 or greater with at least seven other items.

Further examination of the patterns of correlations among pairs of items indicated that two pairs had almost identical patterns, suggesting that one member of each pair was superfluous. Examination of items not selected indicated that no additional scale, e.g. representing a second dimension, could be developed. The focus of the nonselected items typically overlapped that of included items, although some appeared to measure alternative, nonassociated, activities. The resulting 11-item scale, the Everyday Abilities Scale for India (see Tables 1 and 2), included items concerned with eating, personal hygiene, dressing, social interaction and cognitive functioning. While most areas are represented by two items, eating is represented by only one, and cognitive functioning by four items. In the interests of content validity and because of its relevance to assessment of severity of dementia, a twelfth item, on mobility, was added. Since this item did not meet the same selection criteria as the 11 items mentioned above it was excluded from determination of the psychometric characteristics of the scale. Mobility is also indirectly represented through association with personal hygiene, social interaction and cognitive activities.

Table 1. The items of the Everyday Abilities Scale for India

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1. Does he/she ever forget that he/she has just eaten and ask for food again after he/she has just eaten?
 2. Does he/she urinate in an appropriate place?
 3. Do his/her clothes ever get dirty from urine or stools?
- Tell me the following about his clothes:
4. Is his/her shirt buttoned properly?
 5. Is his/her dhoti/petticoat tied properly?
 6. Is he/she able to work as a member of a team i.e., in a group activity which requires different roles from people will he/she be able to participate?
 7. Does he/she express his/her opinion on important family matters, e.g., marriage?
 8. If he/she is assigned or himself/herself decides to undertake an important task can he/she follow it through to completion?
 9. Is he/she able to remember important festivals such as Holi, Diwali?
 10. If he/she is asked to deliver a message does he/she remember to do so?
 11. Does he/she discuss local/regional events such as marriages, disasters, politics appropriately?
 12. Does he/she ever lose his/her way in the village?
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Reliability assessment

The internal consistency of the 11-item scale, assessed using Cronbach's α , is 0.82.

Examination of intra- and inter-rater reliability indicated perfect agreement for each individual item with the original score. Test-retest reliability based on 34 subjects, the same informants providing information on each occasion, showed substantial agreement ranging from 82 to 100% for individual items across the two testing occasions (Table 3). The κ values are low because the marginal values were severely skewed since most subjects could perform the tasks [13, 14]. On the three items with the highest percentage disagreement (items 6, 8 and 10), the informant did not always seem to be clear as to whether the response should reflect mental or physical behaviour. These questions have since been clarified by adding specific examples for the interviewer to use. For the 11-item scale as a whole, the intraclass

Table 2. ϕ coefficient matrix of the items of the Everyday Abilities Scale for India

		Coefficient, by item										
		Eating related		Personal hygiene		Dressing, clothes		Social interaction		Cognitive function		
		1	2	3	4	5	6	7	8	9	10	11
1.	Forgot to eat		0.49	0.54					0.30	0.41		
2.	Toilet location			0.54		0.39	0.33	0.32	0.35	0.30		0.30
3.	Soil clothes				0.31		0.33	0.35		0.37	0.33	0.34
4.	Shirt buttoned					0.58		0.48	0.37	0.45	0.47	
5.	Dress properly								0.33	0.33	0.31	0.34
6.	Team work								0.46		0.31	
7.	Family opinion									0.57	0.35	0.37
8.	Complete tasks										0.38	0.36
9.	Remember festivals										0.40	0.48
10.	Deliver message											0.38
11.	Understand events											
12.	Lose way in village ^a						0.39		0.42			

Information only provided for ϕ coefficients of 0.30 or greater.

^aAdditional item on mobility.

correlation coefficient was 0.83 for disability for any reason and 0.92 for disability attributed to mental reasons.

Validity assessment

Content validity is present. Care was taken to select

Table 3. Test-retest reliability on 34 subjects

Item	No. unable ^a	% agreement	κ
1. Forgot to eat	2.0	94	0.47
2. Toilet location	2.5	91	0.35
3. Soil clothes	1.5	91	0.00
4. Shirt buttoned	3.5	91	0.52
5. Dress properly	1.5	92	0.65
6. Team work	7.0	82	0.40
7. Family opinion	1.0	100	1.00
8. Complete tasks	12.5	85	0.68
9. Remember festivals	2.0	94	0.47
10. Deliver message	5.5	85	0.47
11. Understand events	1.5	97	0.65
12. Lose way in village	4.0	100	1.00

^aAveraged over both testing sessions.

items that assessed ADL, and in particular activities with a substantial cognitive component. In developing this measure we were guided by a basic practical [8] and theoretical [7] approach, and selected items accordingly.

Assessment of Western ADL scales indicates that older people and those with less education and poorer cognitive functioning tend to have a lower level of ADL performance [15-20]; relationship to gender is ambiguous [21]. We examined our 11-item measure to determine whether it exhibited comparable relationships.

As with Western measures, bivariate analyses indicate that problems performing these ADL activities increased significantly with age, and were greater among those who were illiterate and with poorer scores on the HMSE. Overall, problems were more common in women, who were also more likely to be illiterate. Differences were stronger for 'any inability' than for inability attributed to 'mental' reasons.

Multiple regression modelling reveals that age and sex are independently associated with both overall ADL score and 'mental' ADL score ($P=0.0045$ and 0.046 respectively). Literacy was not significantly associated with either score when adjusted for the two main effects ($P>0.4$). None of the interaction terms reached statistical significance ($P>0.2$). The distribution of scores on the 11-item ADL measure, separately for any reason for non-performance and for mental reason for non-performance, is given in

Table 4. Distribution of activities of Everyday Abilities Scale for India summary scores

Score	Number and % of subjects, by reason for non-performance			
	Any		Mental	
	<i>n</i>	%	<i>n</i>	%
0	285	73.6	338	87.3
1	52	13.4	29	7.5
2	22	5.7	6	1.6
3	10	2.6	4	1.0
4	6	1.6	3	0.8
5	3	0.8	3	0.8
6	2	0.5	2	0.5
7	2	0.5	1	0.3
8	2	0.5	0	-
9	1	0.3	0	-
10	1	0.3	0	-
11	1	0.3	1	0.3

Table 4. Mean, median and tenth percentile cut-points of the ADL score (the group with poorest functioning, in which those with dementia are most likely to be found) for each age, sex, literacy and HMSE

category are given in Table 5. The interquartile range is not presented, since 74% of the sample had a score of 0 (able to perform all activities).

Discussion

While ADL measures have been developed to characterize the performance of demented people [22–25], some are not sufficiently structured for use in epidemiological surveys or by non-professional staff, and others include activities inappropriate outside the type of setting in which they were developed. Their administration time may also limit consideration as a screen.

In addition, ADL and in particular instrumental ADL measures, are culture-sensitive [26]. Even within a country there may be culturally determined differences, most notably reflecting gender roles [27, 28]. Beyond the cultural differences that may be expected, major differences between developed and developing countries in infrastructure and resources require even universal tasks, such as cooking, cleaning and personal care, to be performed in different ways. In consequence, a scale developed in one setting may not measure ostensibly common activities in the same way in another setting. To date, no ADL measures specific to non-industrialized countries have been developed and published, although some common western ADL measures have been adapted and used in surveys of

Table 5. Everyday Abilities Scale for India scores by age category, sex, literacy, and Hindi Mini Mental State Examination Score

	Everyday Abilities Scale for India score										
	Overall						Mental				
	<i>n</i>	Range	Median	10th %	mean (SD)	<i>P</i>	Range	Median	10th %	Mean (SD)	<i>P</i>
Age (years)											
55–64	123	0–7	0	1	0.28 (0.99)	0.001	0–6	0	1	0.12 (0.61)	0.003
65–74	145	0–8	0	2	0.52 (1.2)		0–4	0	2	0.30 (0.68)	
75+	119	0–11	0	4	1.10 (2.0)		0–4	0	3	0.57 (0.97)	
Sex											
Female	180	0–10	0	3	0.77 (1.6)	0.004	0–6	0	2	0.43 (0.90)	0.02
Male	207	0–11	0	2	0.48 (1.4)		0–4	0	2	0.24 (0.65)	
Literacy											
No	303	0–10	0	3	0.68 (1.5)	0.02	0–6	0	2	0.39 (0.88)	0.0035
Yes	84	0–11	0	2	0.38 (1.4)		0–2	0	1	0.11 (0.35)	
Hindi Mental State Exam score (1 missing)											
0–22	83	0–11	1	5	1.50 (2.5)	<0.001	0–4	0	3	0.72 (1.1)	<0.0001
23–26	108	0–8	0	2	0.54 (1.3)		0–6	0	2	0.30 (0.80)	
27–30	195	0–4	0	2	0.28 (0.72)		0–3	0	1	0.18 (0.52)	
All	387	0–11	0	3	0.61 (1.5)		0–6	0	2	0.33 (0.78)	

the elderly in such regions—e.g. Kaniyambadi study, India (S. Bhattacharji, personal communication); disabled and nondisabled elderly in India [2]; Western Pacific area [29]—and in other cultural settings [30]. Further work in this area is ongoing at several sites in India and in the UK (K. Sen, personal communication).

We have tried to develop a measure of ADL functioning that is modelled on the experience of Western measures and is helpful in identifying functional disability related to dementia, in a largely illiterate elderly rural population in India. In doing so we have recognized the substantial cultural and socio-economic differences between rural Indian and Western society.

Limitations of this study include restriction in the types of statistical analysis that can be used because item response is dichotomized. A further limitation underlies the development of nearly all ADL measures. Most individuals of the age selected can generally carry out all the activities of concern. Thus, usual injunctions in scale development to delete items assented to by less than 20% or more than 80% of the group for which the measure is intended do not hold in this area. Western ADL measures, for instance, typically include inquiry into feeding self, although fewer than 2% of community residents 65 years of age or older have problems with this activity. Indeed bathing, the personal self-maintenance activity with which the largest percentage of those 65 years of age and over report difficulty [15, 16], can still be performed by 90% of them.

Probably because of the care taken in selecting items and making sure that they were appropriately understood, and the careful training of interviewers, all forms of reliability examined were high. Although data are not yet available to examine all forms of validity (e.g., predictive validity), there is evidence of content validity and the scale is related in the expected manner to demographic and cognitive characteristics.

Messick [31], in his unified concept of validity, suggests that attention should be paid to six aspects: content, substantive, structural, generalizability, external and consequential. If we recast our information in this format, the content and substantive aspects appear to be well met. Using as a guide Western ADL/instrumental ADL assessments, relevant items and domains were selected for examination. Further, all items are relevant to and actually engaged in by the respondents for whom they are intended.

The structural aspect of validity requires that scoring should be relevant. Scoring of the scale has been made as accurate and appropriate as feasible. It can be handled by interviewers with little education and, uniquely, allows determination of the perceived reasons for non-performance, so that it is potentially feasible to identify accurately individuals with cognitive problems. External validity focuses on expected relationships. We expected the scale to have the same relationship with selected demographic characteristics

as Western ADL measures and, indeed, found this to be the case. Two aspects of validity await confirmation: we do not yet know the extent to which this measure is generalizable, i.e. the extent to which the measure generalizes to or can be used with other populations and in other settings. Finally, the consequential aspect of validity—the consequence of testing—remains to be determined. Ideally, together with information on the HMSE and other neuropsychological tests, this measure will help to identify accurately those with dementia.

If this can be done with high sensitivity (accurate identification of cases) and high specificity (accurate identification of non-cases), it will improve the feasibility of determining the prevalence and incidence of dementia in this population, provide a measure of severity of impairment, help to identify risk factors for dementia, which may be of world-wide value and aid in long-term planning for care of elderly people.

The present scale is brief. It is easily administered, readily understood and can be scored rapidly. Since information on age category, sex and literacy level can usually be obtained with ease, identifying whether a respondent has an unusual number of problems and so merits further evaluation, can be done quickly. Additional work is in progress, which will indicate the extent to which this measure is valuable in identifying dementia in older illiterate rural residents of India.

Acknowledgements

This work was partly supported by research grant AG09202 from the National Institute on Aging, US Government Department of Health and Human Services. The authors acknowledge with gratitude the following individuals in New Delhi and Ballabgarh whose efforts and support made this work possible: Sujatha Sharma, Arun Mehta, B. S. Nair, R. K. Kaushik, Roshan Lal, Gajraj Singh, Desh Raj and Vijay Ram. We acknowledge the co-operation extended by Suresh Kapoor, Guresh Kumar and other staff of the Comprehensive Rural Health Services Project, Ballabgarh, of the All India Institute of Medical Sciences, New Delhi, India.

Key points

- Measures of activities of daily living (ADL) developed in Western industrialized societies may not be appropriate for use in developing countries with different cultural expectations.
- Deterioration in ADL performance because of cognitive decline is a key marker of dementia. Therefore, as an aid in assessing the presence of dementia in rural minimally educated elderly in India, we developed an ADL scale for this population.

- This brief, informant-based ADL scale is valid and reliable, and can be administered and scored by individuals with partial high-school education.
- Information on the procedures used to develop this measure may be helpful to investigators in other cultural settings.

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Received 2 March 1998; accepted 10 March 1998