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Evaluation of the Validity and Reliability of the Alzheimer's Disease-Related Quality of Life (ADRQL) Assessment Instrument

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Abstract

The Alzheimer's Disease-Related Quality of Life (ADRQL) instrument was developed to assess health-related quality of life in people with Alzheimer's disease (AD) using assessments from family caregivers or professional staff. Validity and reliability of the ADRQL in its original form and a revised version are assessed in a sample consisting of persons in three residential settings (community, assisted living, nursing home). The ADRQL exhibits good item internal consistency (67.5% of items met .40 standard); high correlation of items to hypothesized scales (85% of items met criteria for 4 of 5 subscales and the overall instrument); a good range of scores (21.6 to 100 for total sample revised instrument); very low missing data; and internal-consistency reliability coefficients exceeding the minimum reliability standard for group comparisons (.86 for total scores; range of .56 to .83 for subscales). In a community sample, the ADRQL discriminates between groups and is responsive over time in hypothesized directions. Characteristics of caregiver raters (community sample) including demographics and self-rated health were largely unrelated to scores. The results support the use of the ADRQL to evaluate health-related quality of life in persons with Alzheimer's disease across various care settings and various stages of the disease. Modest correlations with cognitive and functional disability levels suggest that the ADRQL provides insight into other important dimensions of life experience in persons with dementia. The revised version has improved measurement properties and is recommended for use over the original.

Keywords

dementia; Alzheimer's; health-related QOL; ADRQL

INTRODUCTION

The Alzheimer's Disease-Related Quality of Life (ADRQL) instrument was developed to assess health-related quality of life in people with Alzheimer's Disease. Although quality of life (QOL) assessment usually draws on self-report of subjective phenomena, dementia inhibits reliable introspection and reporting of self evaluation.1 Despite these challenges,

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Conflict of Interest Declaration

Drs. Kasper, Rabins and Black are entitled to a share of fees received on sales of the ADRQL questionnaire. The terms of this agreement are being managed by the Johns Hopkins University in accordance with its conflict of interest policies.

assessing QOL in persons with dementia is important given the need to evaluate emerging treatment modalities from drugs to environmental design.2

The ADRQL was designed to evaluate QOL in persons with Alzheimer's Disease using assessments by family caregivers or professional staff in residential care facilities. The instrument evaluates five QOL domains -- social interaction, awareness of self, feelings and mood, enjoyment of activities, response to surroundings -- and incorporates preferences that reflect caregiver judgments about the contribution of individual items to health-related QOL. The ADRQL was intended to discriminate differences in QOL among persons with AD, as well as to be responsive to change in QOL over time.3 The development and conceptual framework of the ADRQL are described in detail elsewhere 4, 5 and an abbreviated description is provided below.

The objectives of this paper are: 1) to examine various psychometric properties of the ADRQL, including scaling assumptions and internal-consistency reliability; 2) to evaluate the validity and responsiveness of the instrument; and 3) to assess validity of proxy respondent assessments by examining whether characteristics of proxy respondents influence their evaluation of subject QOL. Two versions of the ADRQL are assessed -- the original instrument, and a revised version with several items eliminated and some assigned to different domains. We evaluate the original instrument because it is in use in several studies. However, we recommend the revised version to future users, based on the results presented in this paper.

METHODS

The ADRQL

Instrument Development—The objective of all health-related quality of life instruments is to quantify day-to-day living experiences as they are affected by health and illness. The development of the ADRQL drew on concepts from health-related quality of life research6 with important modifications for application to persons with Alzheimer's disease and other dementias.

Development of the domains and items for the ADRQL proceeded through several steps. Initially an item pool was developed based on objectives for the instrument, knowledge of other health-related quality of life measures, and clinical and research experience with Alzheimer's disease. A local expert panel of health care professionals was convened, asked to review and add to existing items, and develop a list of major life domains. A draft instrument based on these recommendations was mailed to 12 experts with national reputations in research or treatment of AD. These individuals were asked to review the instrument and make recommendations regarding inclusion or deletion of both items and domains. A revised version of the instrument was then presented to a focus group of 12 family caregivers of patients with Alzheimer's and further modifications followed. Finally, to verify placement of items within domains, five researchers in gerontology and health services research without prior knowledge of the instrument were asked to sort items into domains.

In designing the ADRQL, we chose to use proxies – close family members or professional caregivers – as raters of health-related quality of life for persons with dementia. This approach allows assessment of individuals at all stages of disease severity, including late-stage dementia, and facilitates inclusion of individuals in care settings, such as nursing homes, where many are severely impaired. Sloane et al.7, for example, in a comparison of several dementia QOL instruments in a population of persons in residential care and assisted

living was unable to administer a self-report quality of life instrument to three-quarters of study subjects because they were too severely cognitively impaired.

Domains, Items and Weights—The ADRQL consists of items that assess 5 domains:

- social interaction – relates to family members, friends, neighbors or professional caregivers in some observable way through gestures, talking or facial expression
- awareness of self – awareness of his/her own special personal identity and major relationships in the family, in friendships or in work or community
- feelings and mood – signs that can be seen or heard by others of how a person often feels. These may be spoken statements, expressions or physical gestures.
- enjoyment of activities – participation and enjoyment in daily life, such as in leisure and recreational activities or hobbies.
- response to surroundings – how a person responds to his/her living environment and other places in some observable way through physical gestures, talking or facial expressions.

Each item, its subscale assignment, and an abbreviated description are shown in Table 1 for both the original and revised version of the ADRQL. Caregiver respondents are asked to "agree" or "disagree" whether items describe the subject in the last 2 weeks. The revised ADRQL represents a first step in refining the instrument. We examined correlations of items with all subscales and eliminated 7 items that did not correlate above .40 with any of the 5 domain subscales and reassigned 12 items to other subscales (based on item to scale correlations).

The ADRQL incorporates caregiver preferences into scores through weights for each item, using an established methodology for developing preference-based assessment tools.8 These weights (mean scores for each item) were developed through scaling exercises conducted with sixty-one caregivers who ranked each item within each subscale on the importance to good/poor health-related quality of life in persons with Alzheimer's disease.5,9 Weighting has several advantages over a categorical Likert-type scaling: it provides better representation of infrequent but important items rather than treating all scores as equivalent in importance and it increases sensitivity to differences among individuals by providing a continuous measure for each item. In addition, both total and subscale scores can be calculated for each person by summing the weighted items overall or within subscales.

Study Populations

Data on individuals diagnosed with Alzheimer's disease were used for this evaluation. These individuals resided in 3 types of settings:

- a community sample of individuals with AD (n = 87 diagnosed at baseline; 146 including baseline and those diagnosed over the course of the study) who were drawn from a community-based study of older individuals with dementia.10 Diagnosis was based on ICD-9 codes from Medicare claims, a primary physician's medical record, or the report of diagnosis by a family member.
- a sample of 89 individuals from two nursing homes who were diagnosed with AD based on medical records;
- a sample of 134 individuals diagnosed with AD drawn from of a study of persons in assisted living facilities.11

In each sample, 60% or more were age 80 or older and 80% or more were female. Overall, 80% were white (vs. Black or other race). In the community sample, 75.9% had Mini-Mental State Examination (MMSE)12 scores below 18, indicating severe cognitive impairment13,14; 61.9% of those in the assisted living sample, and 91.1% of the nursing home sample had scores in the severely impaired range. One third of the community sample (34.5%) had been diagnosed within 2 years, whereas 45.5% of the nursing home sample had been diagnosed 5 or more years ago (data not available for assisted living group).

Analyses

Several psychometric properties of the total ADRQL and its subscales are examined for the total sample and for subgroups residing in the community, in assisted living facilities, and in nursing homes. Analyses report both total and subscale scores that are based on summing weighted items.

Both item to total correlation (item-internal consistency) and scaling success (% of items within a scale that correlate significantly higher with the hypothesized scale than with other scales) are used to assess scale structure. Cronbach's alpha coefficients (reliability) provide estimates of the internal consistency of items in each scale, and overall.15 Score distributions also are examined including observed range, means and standard deviations, and floor and ceiling effects.

Construct validity is assessed in terms of both discriminant validity (hypothesized differences between groups) and responsiveness (hypothesized detection of changes over time). These analyses are restricted to the community-residing individuals in the sample, for whom information on personal characteristics and longitudinal data were available.

Measures of cognitive and physical functioning were purposefully not included in the ADRQL because many well-validated measures of these domains exist and their inclusion would likely dominate the assessment of QOL in patients with AD, given the impact of the disease on both. That said, we expect individuals with lower MMSE scores and severe ADL difficulty to have poorer ADRQL scores than others. Sloane et al.7 found cognition and ADL function to be the strongest predictors of QOL scores across several instruments tested in assisted living facility residents, including the ADRQL. Other characteristics expected to be associated with poorer scores are behavioral and psychological symptoms (psychosis, agitation or depression), more years since diagnosis, death within 3 years, and nursing home entry within 3 years.

The responsiveness of the ADRQL is examined in persons who over a one-year period experienced declines in ADL functioning (from 0 to 1 or more ADL difficulties, or from 1 or 2 to 3 or more) and those who did not change. We expect individuals who experienced decline in functioning to show changes in ADRQL scores in response.

Finally, we examine the relationships of rater characteristics to QOL scores. Although the items in the ADRQL were designed to reflect behaviors that proxy raters could observe and accurately report, the use of proxies to assess QOL raises questions concerning whether characteristics of the raters might influence their assessments. We hypothesize that caregiver characteristics – age, gender, education, relationship to subject, self-rated health, mental health, vitality and social functioning -- will not be associated with ADRQL scores. These characteristics were obtained in interviews with the caregivers who completed the ADRQL ratings for community-resident persons diagnosed with AD. Mental health, vitality and social functioning are SF-36 scales that assess these domains.16, 17

RESULTS

Scale Structure

Item internal consistency coefficients reflecting the correlation of each item to its hypothesized scale (corrected for overlap) are shown in Table 2 for all subscales in the original ADRQL and in the revised version. Item internal consistency coefficients for the revised scales ranged from .23 to .68. Overall, 67.5% of items (27/40) met the .40 standard for supporting item-internal consistency18 in the revised ADRQL (in contrast to 36.2% in the original). The Social Interaction, Awareness of Self, and Feelings and Mood subscales ranked highest with 75.0%, 87.5%, and 66.7% of items meeting this standard, respectively. Among the 3 population subgroups, the percentage of items meeting the .40 standard for supporting item-internal consistency ranged between 57.5% (assisted living) and 65.0% (community). Item internal consistency was higher across all subscales for community and nursing home residents than for those in assisted living, with the exception of Response to Surroundings. For example, 91.7% of items in the Social Interaction Scale for diagnosed community residents, and 75.0% of items for diagnosed nursing home residents, correlated at .40 or higher with the hypothesized scale, compared to only 58.3% for persons in assisted living.

Scaling success indicates the percentage of items where the correlation between an item and its hypothesized scale exceeded that between the item and all other scales. In the total sample, scaling success rates for the revised ADRQL were above 90% for Social Interaction, Awareness of Self, and Feelings and Mood, and at 87.5 % for Response to Surroundings. Enjoyment of Activities was lower, at 56.3%. Scaling success rates were above 60% for most scales in each of the subgroups (smaller samples generally exhibit lower scaling success rates since these tests are based on the standard error of the correlation coefficient which grows larger as sample size decreases). The exceptions were Enjoyment of Activities and Response to Surroundings in the community sample, Enjoyment of Activities in the assisted living group, and Response to Surroundings in the nursing home group.

The last column in Table 2 shows the correlation of each scale to the total ADRQL (corrected for overlap). Multiple domains are typically assessed in quality of life instruments, but each domain taps into the underlying construct of “quality of life” and is expected to correlate with other domains that comprise the instrument. Results indicate correlations for the revised instrument range from .53 (Response to Surroundings) to .82 (Social Interaction). The two scales that vary the most across subgroups are Awareness of Self – correlated at .71 for the community sample, but .56 and .55 respectively for those in assisted living and nursing homes – and Response to Surroundings – ranging from .38 in the nursing home group to .61 and .55 respectively for the assisted living and community subgroups. Between scale correlations are not shown for reasons of space, but for the total sample the range was .23 to .53. Of the 10 comparisons 5 were below .40 and 4 were between .40 and .50.

Score Distribution and Completeness of Data

The observed range, mean and standard deviation, floor (% minimum) and ceiling (% maximum) effects, and internal-consistency reliability of each scale score (based on Cronbach’s alpha) are shown in Table 3 for the total ADRQL and each subscale. The range of the revised ADRQL is somewhat broader (21.6 – 100.0) than for the original (30.3 – 100.0). For 4 subscales of the revised instrument, the full range of scale scores from 0 to 100.0 was observed in the total sample. Mean scores indicate that responses are skewed toward the higher end for the total ADRQL and for each subscale (higher scores indicating better quality of life), which is typical of scales that measure health18 or health-related

quality of life. The overall mean for the revised ADRQL was 73.5, with means for Social Interaction and Response to Surroundings being somewhat more skewed (>80%) than other scale means. Scale means were lower in the nursing home group than for persons in the community or assisted living (Response to Surroundings being the exception).

Floor effects were minimal across scales in the revised ADRQL, for the total sample and for each of the subgroups. Ceiling effects were observed, however, for the subscales --although not for the total ADRQL. Modest ceiling effects were observed for Awareness of Self (15.5%), Feelings and Mood (25.5%), and Enjoyment of Activities (22.9%); greater ceiling effects were seen for Social Interaction (34.5%) and Response to Surroundings (57.7%).

Response to Surroundings was the subscale with the highest ceiling effects in all three subpopulations (41.4% in the community group; 61.9% in the assisted living group; 67.4% in nursing home residents). The revised subscale has fewer items than the original which may contribute to higher ceiling effects although item internal consistency and scaling success were improved. For Social Interaction, ceiling effects were at 36.8% in community residents and 40.3% for assisted living residents, but the percentage of nursing home residents at the highest possible response was only 23.6%. With the exception of Response to Surroundings, ceiling effects were lower in the nursing home group than among community or assisted living residents.

Information on completeness of data is not shown due to space constraints. Missing values were quite low, however, for each scale and across all subsamples by setting. Individuals responding to the ADRQL questions were “knowledgeable informants” in the community – persons identified by the subject as someone knowledgeable about his/her health and health care (often someone who lived with the subject). For persons in assisted living and nursing home settings, the respondent was a staff aide who cared for the subject. Among all community respondents, the percentage of items completed ranged from 98.4% for Enjoyment of Activities to 99.6% for Feelings and Mood. In the assisted living sample, 100.0% of items were completed for every scale. In the nursing home sample, 100.0% of items were completed for Feelings and Mood, Enjoyment of Activities, and Response to Surroundings, 99.1% for Social Interaction, and 90.4% for Awareness of Self. Two items – no response to his/her name and no beliefs or attitudes expressed – accounted for the missing responses in the Awareness of Self scale in the nursing home sample. The item regarding beliefs or attitudes expressed was the most problematic. Knowing whether subjects were expressing beliefs or attitudes may be difficult for nursing home aides who have not known subjects for extended periods.

Item Internal Consistency

Table 3 also shows internal-consistency reliability coefficients for the total ADRQL and each subscale. For the total diagnosed sample, all reliability coefficients (for total ADRQL and subscales) exceeded the minimum reliability standard of 0.50 to 0.70 for group comparisons. The coefficient for the total revised ADRQL was .86 (.87 for the original ADRQL); subscales ranged from .56 for Response to Surroundings to .83 for Social Interaction. Reliability coefficients varied somewhat across subsamples, but only dropped below the .50 level for the Response to Surroundings subscale in the community and nursing home samples. Coefficients were above .70 for the total ADRQL and the Social Interaction, Awareness of Self, and Feelings and Mood subscales in each subgroup, but dropped below that level for the Enjoyment of Activities and Response to Surroundings scales.

Indicators of Measurement Validity and Responsiveness

Several indicators of validity can be assessed for the ADRQL among individuals in the community-resident sample using information from baseline and subsequent annual interviews with the study subjects and a knowledgeable informant.10 As noted earlier, indicators of both cognitive and physical functioning were excluded from the ADRQL during its development because of their close alignment with disease severity and progression. The ADRQL is intended to allow evaluation of health-related quality of life more broadly, not merely reflect cognitive and physical functioning (and changes in these). Sloane et al.7 found in an assisted living population, that ADL limitations, cognitive functioning, depressive symptoms and agitated behavior accounted for about 25% of the variance in the ADRQL. The authors concluded that the ADRQL (and other quality-of-life measures they examined) were "capturing far more than can be inferred from basic information on resident characteristics."

Table 4 indicates that in the community-resident subsample diagnosed with Alzheimer's, the ADRQL discriminates between individuals with severely impaired cognitive functioning (MMSE <18) and others, and persons with no versus any ADL difficulties. Persons with and without behavioral and psychological symptoms (psychosis, depression, or agitation) also had significantly different ADRQL scores, overall and for each subscale. The overall score also discriminated between individuals who were recently diagnosed and others, although few subscales did so, and the difference in scores primarily reflected differences between persons diagnosed 3 years or longer (lower mean score) in contrast to recently diagnosed persons.

Indicators of predictive validity for the ADRQL also were assessed. Persons who died within 3 years of baseline had significantly lower overall mean scores than those who survived. ADRQL scores were only marginally different, however, for persons who entered a nursing home within 3 years versus those who remained community-resident.

In order to gauge responsiveness of the ADRQL, we examined scores one-year apart for persons who had meaningful one-year increases in number of ADL difficulties and those who experienced no change. Persons experiencing an increase in ADL difficulties from one year to the next had significant changes (decline) in overall ADRQL scores between the base and follow-up years. Those experiencing no change in ADL difficulties over that period exhibited no difference in scores at baseline and one year later.

Applying a Bonferroni adjustment for multiple comparisons, most of the construct validity comparisons met significance criteria. The changes in response to ADL decline/no change do not reach significance using this adjustment, perhaps due to small samples in each of the 4 categories.

Relationship of Rater Characteristics to ADRQL scores

In Table 5, we examine whether characteristics of caregivers bias their ratings of QOL, under the hypothesis that characteristics of raters will not be related to ADRQL scores. Caregiver characteristics were not available for the nursing home or assisted living samples, so the analysis is restricted to the community sample.

Caregiver characteristics were not associated with overall ADRQL scores (with one exception). A few significant differences by caregiver characteristics were observed for subscales. Social Interaction scores varied by age; Feelings and Mood varied by gender. Spouses gave more positive assessments to the Feelings and Mood subscale but were no different from non-spouse raters on other subscales. No differences emerged between

caregiver raters who lived with the subject and those who did not. Only Awareness of Self differed by caregiver's self-rated health.

Caregiver social functioning (based on the SF-36 Social Functioning scale) was the only characteristic associated with differences in several subscales (Social Interaction, Awareness of Self, and Enjoyment of Activities) as well as the overall ADRQL. Higher (better) social functioning for a caregiver was associated with a higher rating for subjects. None of these differences, or those noted above for specific subscales, reaches significance if the Bonferroni adjustment for multiple comparisons is applied, however.

DISCUSSION

The study reports on the validity and reliability of the ADRQL as a tool for assessing health-related quality of life in persons with dementia. Data on diagnosed persons were drawn from three settings – the community, assisted living, and nursing homes. Measurement properties assessed here suggest the instrument has good item internal consistency, score distribution and scaling success, and exceeds minimum reliability standards for group comparisons (Cronbach's alpha of .86 for the total score; range from .56 to .83 for subscales). The revised ADRQL has somewhat fewer items and exhibits better measurement properties than the original on all dimensions, with the exception of higher ceiling effects for some subscales (likely as a result of reducing the number of items and heterogeneity of items within a scale). Importantly, no ceiling effects were observed for the total score. For these reasons, the revised version is preferred over the original.

A strength of this assessment of the ADRQL is examining its performance in persons with Alzheimer's disease across three residential settings. Although the ADRQL performed in a consistent fashion across these subsamples, there were differences. These variations support the importance of a multi-dimensional approach to evaluating quality of life. Mean scores tended to be lower, overall and for subscales, in the nursing home population than for persons in community and assisted living settings. For example the mean for the Awareness of Self subscale was .64 in community residents, .72 in assisted living residents, and .32 in nursing home residents. These differences may reflect, in part, greater disease severity in nursing home residents. Similarly, Social Interaction scale means were above .80 for community and assisted living individuals, but at .74 for nursing home residents. Although the instrument is meant to be scored as a whole, subscales may convey information about specific areas of potential intervention. Use of the instrument as people change settings (e.g. move from community to assisted living) also has the potential to help evaluate the impact on well-being of changes in environment.

The construct validity and responsiveness of the ADRQL was supported by its ability to discriminate among individuals based on cognitive and physical functioning, and behavior. Persons with low scores at baseline were also more likely to die within 3 years, and those who experienced a decline in ADL functioning over a one-year period also experienced a decline in ADRQL scores. Scores were no different at baseline, however, between persons who entered a nursing home within 3 years and those who remained community resident. Many factors influence nursing home entry among persons with dementia including living arrangements, marital status, and availability of community services.[19–21] Our results suggest that prior to nursing home entry, health-related quality of life does not differ between those who remain community resident and those who subsequently enter nursing homes. As noted earlier, scores among nursing home residents are generally lower than for community residents and persons in assisted living. Analyses of changes in scores over time, and among persons before and after nursing home entry, are beyond the scope of this paper,

but would be needed to understand whether changes are associated with risk of nursing home entry and whether nursing home placement affects health-related quality of life.

Few differences were observed in ratings by caregiver characteristics, although only community caregivers could be evaluated. This is important given the potential for a caregiver's own health or mental health to affect his/her evaluation of the subject's quality of life. Studies support the use of proxy or caregiver respondents across a wide range of health-related assessments including physical health and functioning and cognition 22, depressive symptoms in persons with Alzheimer's disease23 and health-related quality of life in people with aphasia after stroke.24 At the same time, there is evidence that caregiver stress may affect assessments of subject health and well-being.22, 25, 26 The ADRQL relies on proxy raters to assess subjects and the instrument was developed with attention to items that could be observed by others.5 Evidence suggests that agreement between proxy and self-respondents is higher for observable domains.27

Of the caregiver characteristics examined here, only Social Functioning of caregivers was associated (positively) with the total ADRQL score. It is possible that higher sociability in community caregivers affects the social functioning of subjects as well, accounting for the higher scores observed for Social Interaction, Awareness of Self and Enjoyment of Activities, as well as the total score. Our focus in this paper is on potential bias in QOL ratings associated with caregiver characteristics, but whether some caregiver characteristics influence (improving or diminishing) subject QOL needs further investigation.

The primary objective of this paper was to assess several important measurement properties of the ADRQL, which is already in use in several research studies.3, 28 With broader use, additional assessments of the strengths and shortcomings of the ADRQL for evaluating quality of life in individuals with Alzheimer's disease and dementia will be possible.

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Table 1

ADRQL Original and Revised Item Groupings and Abbreviated Item Content by Subscale

ADRQL Subscale	*Original* Item Groupings & Abbreviated Content	*Revised* Item Groups & Abbreviated Content
Social Interaction	1 smiles around people	1 smiles around people
	2 no attention to others	2 no attention to others
	3 stays around people	3 stays around people
	4 seeks contact	4 seeks contact
	5 talks with people	5 talks with people
	6 touches/allows touching	6 touches/allows touching
	7 comforted or reassured by others	7 comforted or reassured by others
	8 not comfortable around strangers *	--
	9 pleasure from pets/children	8 pleasure from pets/children
	10 talks on telephone *(b)*	--
	11 upset when approached *(c)*	--
	12 pushes, grabs, hits *(c)*	--
	--	9 is cheerful
	--	10 shows delight
	--	11 shows humor
	--	12 enjoys other's activities
Awareness of Self	1 activities related to previous work	1 activities related to previous work
	2 aware of place in family	2 aware of place in family
	3 makes choices in routine activities	3 makes choices in routine activities
	4 upset by personal limitations *	--
	5 shows interest in events, places from past	4 shows interest in events, places from past
	6 no response to his/her name	5 no response to his/her name
	7 no beliefs or attitudes expressed	6 no beliefs or attitudes expressed
	8 indicates "yes" or "no" *	--
	--	7 talks on telephone
	--	8 enjoyment from possessions
Feelings and Mood	1 is cheerful *(a)*	--
	2 wrings hands	1 wrings hands
	3 hits, kicks objects	2 hits, kicks objects
	4 yells, curses	3 yells, curses
	5 locks self in	4 locks self in
	6 easily angered	5 easily angered
	7 says wants to die *(d)*	--
	8 cries	6 cries
	9 shows delight *(a)*	--
	10 restless and wound-up	7 restless and wound-up
	11 resists help	8 resists help

ADRQL Subscale	*Original* Item Groupings & Abbreviated Content	*Revised* Item Groups & Abbreviated Content
	12 clings*	--
	13 content	9 content
	14 says feels sick, has pain*	--
	15 shows humor *(a)*	--
	--	10 upset when approached
	--	11 pushes, grabs, hits
	--	12 upset when in home
Enjoyment of Activities	1 enjoys activities alone	1 enjoys activities alone
	2 no participation in former activities	2 no participation in former activities
	3 enjoys other's activities *(a)*	--
	4 no pleasure from activities	3 no pleasure from activities
	5 does nothing	4 does nothing
Response to Surroundings	1 enjoyment from possessions *(b)*	--
	2 says feels unsafe	1 says feels unsafe
	3 upset outside home	2 upset outside home
	4 tries to leave*	--
	5 upset when in home *(c)*	--
	6 comfortable moving around*	--
	7 talks about leaving	3 talks about leaving
	--	4 says wants to die

*Dropped from revised ADRQL

*(a)*Item moved to Social Interaction

*(b)*Item moved to Awareness of Self

*(c)*Item moved to Feelings and Mood

*(d)*Item moved to Response to Surroundings

Table 2

Item-Scaling Tests and Scale to Total Correlations

Scales by Sample Type	Item Internal Consistency[a]	% ≥ 0.4[b]	% Scaling Success[c]	Scale to Total Correlations[d]
Total Sample of Diagnosed Persons				
Original ADRQL				
Social Interaction (12)[e]	.15, .54	33.3 (4/12)	64.6 (31/48)	.77
Awareness of Self (8)	−.33, .53	62.5 (5/8)	75.0 (24/32)	.68
Feelings and Mood (15)	.11, .60	40.0 (6/15)	71.7 (43/60)	.65
Enjoyment of Activities (5)	.31, .52	40.0 (2/5)	55.0 (11/20)	.70
Response to Surroundings (7)	−.06, .30	0	46.4 (13/28)	.27
Revised ADRQL				
Social Interaction (12)[e]	.37, .68	75.0 (9/12)	95.8 (46/48)	.82
Awareness of Self (8)	.32, .64	87.5 (7/8)	96.9 (31/32)	.67
Feelings and Mood (12)	.23, .66	66.7 (8/12)	91.7 (44/48)	.78
Enjoyment of Activities (4)	.34, .49	50.0 (2/4)	56.3 (9/16)	.73
Response to Surroundings(4)	.29, .40	25.0 (1/4)	87.5 (14/16)	.53
Subsample s of Diagnosed Persons by Setting (Revised ADRQL)				
Community				
Social Interaction	.35, .75	91.7 (11/12)	75.0 (36/48)	.82
Awareness of Self	.24, .59	75.0 (6/8)	59.4 (19/32)	.71
Feelings and Mood	.12, .78	58.3 (7/12)	72.9 (35/48)	.75
Enjoyment of Activities	.23, .45	50.0 (2/4)	18.8 (3/16)	.71
Response to Surroundings	.14, .33	0	25.0 (4/16)	.55
Assisted Living				
Social Interaction	.26, .62	58.3 (7/12)	79.2 (38/48)	.76
Awareness of Self	.30, .54	50.0 (4/8)	75.0 (24/32)	.56
Feelings and Mood	.24, .61	66.7 (8/12)	81.3 (39/48)	.79
Enjoyment of Activities	.29, .40	25.0 (1/4)	50.0 (8/16)	.71
Response to Surroundings	.37, .53	75.0 (3/4)	87.5 (14/16)	.61
Nursing Home				
Social Interaction	.32, .71	75.0 (9/12)	79.2 (38/48)	.81
Awareness of Self	.15, .58	75.0 (6/8)	75.0 (24/32)	.55
Feelings and Mood	.19, .75	50.0 (6/12)	79.2 (38/48)	.79
Enjoyment of Activities	.34, .54	75.0 (3/4)	62.5 (10/16)	.71
Response to Surroundings	.15, .34	0	50.0 (8/16)	.38

[a] Range for correlations(min., max.) to the hypothesized scale corrected for overlap.

[b] Items correlated at .4 or higher with hypothesized scale corrected for overlap. For example, 33.3% (4 of 12 items) in the original ADRQL Social Interaction Scale were correlated at .40 or above with the Social Interaction scale minus the item being tested.

[c] % of items with item to scale correlation > 2 SE than item correlation to other scales.

[d] Correlations of subscale to total corrected for overlap.

[e] Number of items in each scale shown in parentheses.

Sample sizes: total = 310; community = 87; assisted living = 134; nursing home = 89.

Table 3

Score Distribution and Internal Consistency for the ADRQL

Scales by Sample Type	Observed Range		Mean (SD)		% Min[a]	% Max[b]	Reliability (Cronbach's alpha)
Total Sample of Diagnosed Persons							
Original ADRQL							
Total Score	30.3	100.0	73.8	(15.5)	<1.0	<1.0	.87
Social Interaction	8.5	100.0	77.2	(20.2)	<1.0	19.0	.83
Awareness of Self	0	100.0	62.7	(25.3)	<1.0	7.1	.79
Feelings and Mood	18.7	100.0	76.9	(19.2)	<1.0	12.9	.81
Enjoyment of Activities	0	100.0	65.3	(28.7	5.8	21.6	.58
Response to Surroundings	13.2	100.0	79.8	(17.6)	<1.0	25.8	.56
Revised ADRQL							
Total Score	21.6	100.0	73.5	(17.1)	<1.0	1.0	.86
Social Interaction	0	100.0	80.9	(23.2)	<1.0	34.5	.83
Awareness of Self	0	100.0	58.6	(31.4)	5.8	15.5	.79
Feelings and Mood	15.2	100.0	76.6	(23.3)	<1.0	25.5	.81
Enjoyment of Activities	0	100.0	60.1	(32.0)	10.6	22.9	.61
Response to Surroundings	0	100.0	83.6	(23.9)	1.6	57.7	.56
Subsamples of Diagnosed Persons by Setting (Revised ADRQL)							
Community							
Total Score	21.6	100.0	77.0	(16.5)	1.1	1.1	.87
Social Interaction	7.9	100.0	84.3	(22.5)	1.1	36.8	.84
Awareness of Self	0	100.0	64.3	(27.7)	4.6	14.9	.76
Feelings and Mood	25.4	100.0	83.8	(20.7)	1.1	36.8	.81
Enjoyment of Activities	0	100.0	57.8	(29.8)	10.3	16.1	.52
Response to Surroundings	0	100.0	77.4	(24.9)	2.3	41.4	.44
Assisted Living							
Total Score	33.2	100.0	78.2	(14.9)	<1.0	1.1	.84
Social Interaction	8.0	100.0	83.1	(21.0)	<1.0	40.3	.81
Awareness of Self	0	100.0	72.3	(25.2)	<1.0	23.1	.71
Feelings and Mood	18.3	100.0	78.0	(21.7)	<1.0	26.9	.78

Scales by Sample Type	Observed Range		Mean (SD)		% Min[a]	% Max[b]	Reliability (Cronbach's alpha)
Enjoyment of Activities	0	100.0	69.9	(29.3)	6.0	32.8	.56
Response to Surroundings	0	100.0	83.8	(25.7)	2.2	61.9	.66
Nursing Home							
Total Score	29.1	97.7	63.2	(16.5)	1.1	1.1	.79
Social Interaction	0	100.0	74.2	(25.8)	2.2	23.6	.84
Awareness of Self	0	100.0	32.5	(27.5)	14.6	4.5	.80
Feelings and Mood	15.2	100.0	67.6	(25.2)	1.1	12.4	.81
Enjoyment of Activities	0	100.0	47.7	(33.6)	18.0	14.6	.66
Response to Surroundings	23.3	100.0	89.4	(18.1)	1.1	67.4	.41

[a] % with lowest possible score (floor)

[b] % with highest possible score (ceiling)

Sample sizes: total = 310; community = 87; assisted living = 134; nursing home = 89.

Table 4

Construct Validity and Responsiveness of the Revised ADRQL in Community-resident Persons Diagnosed with Alzheimer's Disease[a]

	ADRQL Total	Social Interaction	Awareness of Self	Feelings & Mood	Enjoyment of Activities	Response to Surroundings
			Mean Scores			
MMSE score[b]						
<18	78.3**†	85.0**	64.6**†	85.0	61.3**	81.4
18+	88.7	94.4	86.5	89.3	75.0	85.5
ADL difficulties (0 to 5)[b]						
None	91.0**†	94.5**†	87.4**†	93.3**	80.6**†	89.9*
1–2	83.3	90.4	77.8	85.9	65.5	80.8
3–5	72.2	80.6	53.3	80.6	52.9	77.9
Behavioral & psychological symptoms[b,c]						
No	93.6**†	98.1**†	84.3**	97.3**†	83.3**†	96.7**†
Yes	78.8	85.7	69.2	83.5	61.4	79.2
Years since diagnosis[b]						
< 1	80.7**	84.1	69.6**†	89.3	60.1	86.8
1–3	81.8	88.8	76.5	86.3	59.4	76.8
3+	72.2	80.5	52.3	81.6	54.0	76.7
Survival						
Died within 3 years	75.5**†	81.2**†	60.4**†	83.4	61.3	78.8
Survived	86.0	92.7	79.9	88.4	69.3	85.3
Nursing home entry						
No	83.3	88.7	77.1	86.0	66.4	86.9*
Within 3 years	84.7	92.3	75.5	90.5	65.3	78.9
ADL difficulties[d]						
Increase						
Baseline	84.0**	90.5	74.4	89.5	65.4**	83.6*
1 yr follow-up	73.8	82.2	64.0	81.3	41.1	75.0
No change						

	ADRQL Total	Social Interaction	Awareness of Self	Feelings & Mood	Enjoyment of Activities	Response to Surroundings
Baseline	80.7	89.1	70.5	84.5	62.8**	79.9
1 yr follow-up	76.0	86.2	63.3	81.9	47.7	77.2

[a] N = 146 community-resident persons diagnosed over 3 years.

[b] At baseline.

[c] Psychosis, depression, or agitation.

[d] 1 year increase from 0 to 1 or more ADLs; 1 or 2 to 3 or more ADLs.

** p< .05 for difference in means

* p< .10 for differences in means

† p< .001 Bonferroni adjustment for multiple comparisons.

Table 5

Relationship of Characteristics of Community Caregiver Raters[a] to Revised ADRQL Scores

	%	ADRQL Total	Social Interaction	Awareness of Self	Feelings & Mood	Enjoyment of Activities	Response to Surroundings
Community Caregiver Characteristics		**Mean Scores**					
Age[b]							
<65 years	56.8	82.3	89.5**	74.1	85.4	67.1	80.4
65 to 74 years	18.5	83.3	91.5	69.1	88.3	67.4	86.7
75 years or older	16.4	77.7	77.5	66.5	90.3	57.5	84.9
Gender[b]							
Male	25.3	84.0	89.8	71.6	91.4*	67.7	86.7
Female	68.5	80.8	87.2	72.1	84.7	64.6	80.8
Education[b]							
< HS	27.6	82.4	87.5	74.0	87.8	64.5	84.3
HS	37.3	81.6	86.8	73.2	86.8	65.8	81.6
More than HS	35.1	80.7	88.9	68.0	85.5	64.8	82.1
Relationship to Subject							
Spouse	15.1	84.4	88.6	70.3	94.3**	65.2	88.9
Other	84.9	81.7	88.4	73.0	85.2	66.5	81.8
Lives with subject							
Yes	72.4	82.7	88.8	72.4	87.3	67.7	84.8
No	21.2	80.5	87.2	73.0	85.3	62.7	77.0
Self-rated health[b]							
Excellent/Very good	41.1	82.0	88.8	74.4*	85.7	64.5	80.6
Good	31.5	82.2	86.4	68.5	90.3	68.2	86.7
Fair/Poor	21.2	80.7	88.5	72.0	83.7	63.2	81.5
SF36 scales:		Pearson Correlation Coefficients					
Mental Health	---	.02	−.01	.08	.00	.01	−.06

	%	ADRQL Total	Social Interaction	Awareness of Self	Feelings & Mood	Enjoyment of Activities	Response to Surroundings
Vitality	---	.05	−.07	.05	.10	.06	.12
Social Functioning	---	.15*	.19**	.16*	.02	.14*	−.03

[a] N = 146 Community caregivers who completed the ADRQL in the Memory and Medical Care Study for persons diagnosed with Alzheimer's (at year 1, 2 or 3 of the study).

[b] % do not add to 100 due to missing cases

** p<.05 for difference in means;

* p<.10 for difference in means;

† p< .001 Bonferroni adjustment for multiple comparisons.

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