Development of the Knowledge about Memory Loss and Care (KAML-C) test

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Abstract

The purpose of this study was to develop a test to assess the knowledge of family caregivers concerning memory loss, the early stages of Alzheimer's disease (AD), and related care issues. A total of 31 multiple-choice items were generated in three domains: medical information, caregiving, and legal/financial planning. The test was administered to experts in the field of dementia research and care, medical students, and family caregivers. Item analysis procedures were then used to reduce the test to 15 items. Results suggest that the Knowledge about Memory Loss and Care (KAML-C) test is a reliable and valid test for examining the knowledge level of family caregivers with a relative in the early stages of dementia.

Key words: memory loss, Alzheimer's disease, dementia, knowledge, test, caregivers

Introduction

Relatives provide the majority of care to persons with memory loss due to Alzheimer's disease (AD) and related dementias. Family members who assume this responsibility need information concerning these medical conditions and related issues to cope adequately as caregivers. A study of a large clinic population by Murphy and colleagues[1] attests that persons with AD are diagnosed earlier in the disease than they were a decade ago. In addition, mild cognitive impairment (MCI) has emerged as an identifiable condition and, in many cases, is a transitional state preceding diagnosable AD. In light of the trend toward earlier detection and treatment of persons with memory loss over the past decade, there is a growing need for information and educational programs specifically suited for families caring for relatives in the early stages of AD.

Support groups for individuals diagnosed with AD in its early stages have become commonplace in large urban areas. Participation by diagnosed individuals is typically tied to participation by their relatives who meet in parallel groups. Although the focus of such groups is primarily emotional support, education also occurs formally or informally in order to address the issues confronting participants. Relatives of persons in the early stages of AD have different educational needs than relatives caring for persons in later stages of AD. In the early stages, for example, learning to accommodate a relative's memory loss is a key challenge for families, whereas providing that individual with full-time supervision may be critical as the disease progresses. Families typically report a need for education rather than emotional support and respite services. Based on their extensive study of caregiving, Montgomery and Kosloski[2] note: "In the earliest phases of caregiving, caregivers are most likely to seek information about the disease process, the availability of community services, and legal and financial information." Thus far, little research has been conducted regarding the benefits of participation in these groups. No valid, reliable test has been developed that assesses the level of knowledge gained by family caregivers participating in such groups or educational programs focusing on the early stages of AD.

George[3] was the first to develop a test of family caregivers' knowledge about AD using 10 true-false items;

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however, internal consistency reliability was rather low (α =.41). Dieckmann and colleagues[4] developed the Alzheimer's Disease Knowledge (ADK) test mainly for use by professionals, and many of the 20 multiple-choice items pertain to advanced stages of the disease. The authors of the ADK rightly predicted that expansion of knowledge in the field would necessitate periodic updates. Subsequent research by Edwards and colleagues[5] challenged the psychometric properties of the ADK. The ADK has been used mainly among professionals and students.[6-8] In addition, Werner[9] modified the ADK for use among family caregivers and found poor knowledge correlated with low education and status as a spousal caregiver.

Graham, Ballard, and Sham[10] developed a knowledge survey that was administered to family caregivers, but details regarding the instrument's development and psychometric properties were not reported. Likewise, Roberts and colleagues[11] administered a 13-item knowledge test about AD to professionals and lay volunteers to understand differences between African-Americans and Caucasians, but no details were reported about its development and psychometric properties. Ayalon and Arean[12] developed a knowledge of AD test consisting of 17 true-false items administered to older adults to differentiate knowledge among four ethnic groups, but, again, critical details about the test are not reported. A few other tests of knowledge have been developed for professional education.[13-15] In summary, a psychometrically sound test specifically targeting family caregivers of persons with AD has not been developed.

The purpose of the present study was to develop a valid, reliable test to assess the knowledge of family caregivers concerning memory loss and related care issues, particularly in the early stages of AD. The development of the Knowledge about Memory Loss and Care (KAML-C) test is described and its utility in assessing the effectiveness of education programs for families caring for someone in the early stages of dementia is examined.

Methods

Sample

Caregivers. Researchers recruited family members in the metropolitan Chicago area who agreed to participate in a five-week educational program about caring for a relative in the early stages of AD.[16,17] Caregivers were recruited from two memory disorder clinics, a continuing care retirement community, a senior center, and the local chapter of the Alzheimer's Association. Criteria for eligibility required that participants have a relative in the early stages of AD as determined in one of two ways. First, there must have been a diagnosis of probable AD and a score of 20 points or above on the Mini-Mental State Exam[18] (MMSE) within the past six months. A score of 20 on the MMSE is often cited by experts as the cutoff point for the early/mild stage of AD. Second, in the absence of an MMSE score, another set of criteria was used to define the early stages of AD: 1) according to family caregivers, their relative with AD did not require help with any personal activities of daily living such as bathing; and 2) the relative with AD reportedly did not exhibit significant behavioral challenges such as agitation and hallucinations. These two criteria encapsulate the definition of early AD by Reisberg and colleagues.[19] Persons not meeting the above criteria were referred to support groups or educational seminars sponsored by the local chapter of the Alzheimer's Association.

A total of 51 eligible persons agreed to participate (Table 1), of whom 45 (88 percent) completed at least four sessions of the five-part education program. These 45 persons form the basis of the present report. Participants ranged in age from 25 to 83 years, were primarily female (73.3 percent), Caucasian (95.5 percent), and married (73.3 percent). Caregivers were typically either the child of the relative with AD (57.8 percent) or a spouse (28.9 percent). All participants had graduated from high school, but most had attended some college (35.6 percent) or graduated from college (28.9 percent).

Relatives with AD ranged in age from 51 to 85 years (Table 2) and were primarily female (66.7 percent) and Caucasian (97.8 percent). Caregivers reported that AD symptoms had been evident among their relatives for a mean of 17.1 months (SD = 16.9), and the diagnosis of AD had been made a mean of 11.9 months (SD = 11.1) prior to participation in the educational intervention. MMSE scores were available for 33 of 45 persons with AD, and their mean score was 22 points (SD = 2.5).

Experts. Experts (n = 37) in the fields of medicine (16.2 percent), nursing (29.7 percent), social work (37.8 percent), health services research (5.4 percent), psychology (5.4 percent), gerontology (2.7 percent), and working at federally funded AD centers were recruited to complete the 31-item test (Table 3). These experts were 49.4 years of age on average (SD = 8.2), were primarily female (86.5 percent), were highly educated (M = 18.7 years, SD = 2.1), and had an average of 13.1 years of clinical experience in the field of AD (SD = 6.2).

Medical students. Fourth year medical students from Oregon Health & Science University (N = 39) were also recruited to complete the 31-item test (Table 3). These students were 28.2 years of age on average (SD = 2.9), primarily male (61.5 percent), highly educated (M = 19.9 years, SD = 0.6), and had an average of 0.5 years of clinical experience in the field of AD (SD=1.9).

Table 1. Demographics of caregivers (N = 45)

Characteristic	Mean (SD) or percent of total
Age, mean (SD)	54.3 (15.3) (range, 25 to 83 years)
Female	73.3
Caucasian	95.5
Marital status	
Married	73.3
Single, never married	15.6
Divorced	8.9
Widowed	2.2
Relationship	
Adult child	57.8
Spouse	28.9
Other relationship	13.3
Education level	
High school graduate	13.3
Some college	35.6
College graduate	28.9
Advanced degree	22.2
Employment status	
Employed full-time	52.3
Employed part-time	18.2
Retired	29.5

Procedure

Construction of the KAML-C consisted of several steps: 1) articulation of the knowledge domains, 2) choice of test format and item generation by experts, 3) administration to external experts coupled with their commentary, 4) administration to sample populations, and 5) item analysis.

In the first phase, knowledge domains were identified from a survey completed by persons caring for relatives in the early stages of AD.[20] Three key domains were identified: medical information, caregiving, and legal/financial planning. A panel of seven professionals including two physicians, two nurses, two social workers, and a psychologist from a state and federally funded AD center in Chicago served as consultants in writing items relevant to these three domains. A total of 31 multiple-choice items were generated including 10 medical items, 15 caregiving items, and six legal/financial items. Each item was assigned five possible responses.

The 31-item test was then administered to three different pools: experts, family caregivers, and medical students. First, the test was completed by 37 experts, independent of the seven experts who consulted in writing items, who were also instructed to make comments regarding the validity, accuracy, and readability of each item. Second, 45 caregivers completed the 31-item test both before and after participating in a five-week education program aimed at improving knowledge about memory loss and related care issues.[16,17] Third, 39 medical students completed the test. This final sample was included as a comparison to the experts and the caregivers, with the hypothesis that medical students would not score as high as experts but would score higher than the caregivers with respect to total scores and the three domain scores.

Analysis

Two item analysis procedures—item difficulty and item discrimination—were used to validate the test using responses by the experts and the caregivers. Item difficulty indices for each item were calculated by determining the percentage of participants who answered the item correctly. Item difficulty indices between .3 and .7 (i.e., between 30 percent and 70 percent of participants answered the item correctly) are desirable for maximum discriminability.[21]

Item discrimination indices for each item were calculated by subtracting the percentage of low-scoring respondents (approximately, the lower third of the sample) who incorrectly answered the item from the percentage of high-scoring respondents (approximately, the upper third of the sample) who correctly answered the item. With possible item discrimination indices ranging between -1.0 and +1.0, positive indices larger in magnitude are desired. Positive scores indicate that high-scoring participants answered an item more accurately than low-scoring participants, whereas negative scores show that low-scoring participants outperformed high-scoring participants on that item.

Similar to the development of the ADK,[4] the KAML-C was validated via a pre- and post-test difference index (PPDI), which is the difference in an item's difficulty prior to and following instruction or an intervention. With an appropriate intervention, PPDI scores should be positive, signifying that participants' knowledge increased in the topic the intervention addressed.

Retention of items in the KAML-C was based on three steps: first, examination of item difficulty and discrimination indices from caregivers' pre-intervention responses;

Table 2. Demographics of relatives with AD (N = 45)

Characteristic	Mean (SD) or percent of total
Age, mean (SD)	74.3 (7.4) (range, 51 to 85 years)
Female	66.7
Caucasian	97.8
Months since symptoms evident	17.1 (16.9)
Months since diagnosis	11.9 (11.1)
Marital status	
Married	55.6
Widowed	26.7
Divorced	11.1
Single, never married	6.7
Living situation	
Lives with family	70.5
Lives alone	29.5

second, examination of item PPDI scores from caregivers' postintervention responses; and third, examination of item difficulty indices based on experts' responses.

Data from the retained items were analyzed using the Statistical Package for the Social Sciences (SPSS Version 12.0). An overall score for the knowledge test was computed as the total number of correct responses. Scores were also computed as the total number of correct items within the three domains (medical, caregiving, and legal/financial). The items comprising these domains were established a priori.

The items comprising the test, although utilizing multiple response options, are considered dichotomous (i.e., correct response versus incorrect response). For this reason, the internal consistency of the overall test as well as the three domains was examined using the Kuder-Richardson formula 20 (KR-20) for dichotomously scored items.[22] Test scores from caregivers prior to their participation on the education program were used.

Due to non-normal data for experts and medical students, the nonparametric Kruskal-Wallis one-way analysis of variance by ranks test was used to examine differences in pretest scores. Post hoc comparisons for this statistic were also conducted, as described by Siegel and Castellan.[23]

Results

Item analysis led to a reduced number of items in the KAML-C. Caregivers' pretest scores were used to calculate item difficulty and discrimination indices for the initial 31 items. Items with difficulty indices between .30 and .70 and discrimination indices greater than .30 were retained. This analysis reduced the number of items to 18. It is worth noting that an item about drug treatment for AD was eliminated in this analysis as it proved to be too easy for caregivers.

Items with item difficulty indices nearing the lower (.30) and upper (.70) bounds of acceptability were subjected to scrutiny following caregivers' completion of the post-test. Namely, if the item's PPDI score was less than .10, meaning caregivers did not show notable improvement on that item after having participated in an educational program, it was eliminated. This analysis reduced the number of items from 31 to 17.

Items having met acceptability for the above two criteria were then examined using their difficulty indices from experts' responses. If less than 75 percent of experts answered an item correctly, that item was deemed too difficult and removed. This process reduced

Table 3. Demographics of experts and medical students

	Experts (n = 37)	Medical students (n = 39)
	Mean (SD) or percent of total	
Age	49.4 (8.2)	28.2 (2.9)
Female	86.5	39.5
Education (years)	18.7 (2.1)	19.9 (0.6)
Clinical experience (years)	13.1 (6.2)	0.5 (1.9)
Profession		
Medicine	16.2	100
Nursing	29.7	0
Social work	37.8	0
Health services research	5.4	0
Psychology	5.4	0
Gerontology	2.7	0
Other	2.7	0

the number of items by two, resulting in the final 15-item test (Appendix A). Caregiver pretest difficulty and discrimination indices, PPDI scores, and expert difficulty indices are listed for each retained item (Table 4).

Cronbach's coefficient alpha suggests that the retained 15 items are internally consistent ($\alpha = .76$). However, items comprising the medical (#1-4), caregiving (#5-8, 12, 13, and 15) and legal/financial (#9-11 and 14) domains were not internally consistent ($\alpha = .46, .61$, and $.53$, respectively). These domains were not analyzed further.

A Kruskal-Wallis test identified significant differences between the mean rank of experts' (95.31), medical students' (54.85), and caregivers' (38.12) pretest scores ($\chi^2(2)=56.61$, $p<.0005$). Post hoc analyses show that experts scored significantly higher than both medical students and caregivers ($p < .05$), and that medical students scored significantly higher than caregivers ($p < .05$).

Discussion

Item analysis identified 15 items with acceptable properties for inclusion in the revised KAML-C. Reliability analyses demonstrated the internal consistency of this test. Further analyses demonstrated that the KAML-C is useful in distinguishing among experts, medical students, and caregivers. Although domains of knowledge were unreliable as subscales, the 15-item KAML-C captures a breadth of knowledge by incorporating items from three domains: medical, caregiving, and legal/financial. Thus, findings suggest that the KAML-C is a reliable and valid test for examining the knowledge level of family caregivers with a relative in the early stages of AD. However, because test validation is a multistep process, future research should address alternate forms of validity, such as convergent and divergent validity.

Although two of the original 31 items concerned drug treatment of AD, it is worth noting that these items were ultimately deemed too easy by all three groups and thus were eliminated from the final test. It is particularly interesting, but not surprising, that family caregivers whose relative had been diagnosed with AD were knowledgeable about the names of the few available drug treatments as well as their limited benefits. Likewise, two items related to diagnostic evaluation of AD were also deemed too easy and were thus eliminated from the final test. On the other hand, items deemed too difficult by family caregivers were, in most cases, also

Table 4. Difficulty, discrimination, and prepost difference indices for caregivers and difficulty index for experts

Item	Caregivers			Experts
	Difficulty index	Discrimination index	PPDI	Difficulty index
1	.38	.31	.46	.89
2	.56	.62	.08	.97
3	.69	.62	.22	.95
4	.67	.46	.13	1.00
5	.69	.31	.18	.76
6	.67	.38	.11	.92
7	.69	.54	.20	.92
8	.69	.54	.29	.92
9	.56	.54	.10	.84
10	.62	.62	.17	.89
11	.53	.54	.24	.95
12	.42	.46	.33	.95
13	.31	.62	.24	.76
14	.56	.54	.06	.84
15	.62	.62	.13	1.00

deemed problematic by experts in terms of the accuracy and readability of such items.

Limitations

The present study has several limitations. The sample size was relatively small, and the study population was predominantly white and well-educated. All caregivers reportedly had relatives in the early stages of AD, whereas other forms of dementia and MCI were not represented. It is not known if the test is applicable to caregivers of relatives in later stages of AD or other forms of dementia. Replication of this study among a large and diverse population is necessary before findings can be generalized. Another limitation is that the test was devised with an American population in mind, with a few items pertaining to US laws and customs. Slight modifications could be easily made so that the test would be useful among other populations.

Changes in medical knowledge, care practices, and legal/financial policies may ultimately occur that could render some questions or responses outdated. Thus, modification may be required in the future. For example, item #11 will soon need modification due to recent changes in US law that guarantees government coverage for prescription drugs beginning in 2006. As a result, the correct response (A: outpatient doctor's visits) will have to be combined with a previously incorrect response (D: prescription drugs), and a new incorrect response should be substituted: (e.g., respite care).

Conclusion

Because families typically seek information and education in the early stages of AD, it is essential that programs that address these needs be assessed. Despite the above limitations, the KAML-C can be useful in determining the effectiveness of such programs. It is worth noting that increased knowledge is not necessarily predictive of changes in behavior or attitudes that are necessary for successful caregiving. In a review of interventions targeting dementia family caregivers, Kennet, Burgio, and

Schulz[24] conclude: "Once informational needs have been met, the caregiver may additionally benefit from interventions that train the caregiver in general problem-solving skills as well as more specific skills in areas such as managing patient behaviors or their own affect." Thus, increasing caregivers' knowledge about dementia, caregiving, and resources must be viewed as an initial step. Just as a care recipient's dementia progresses, so too do the needs of the caregiver over time. Education and support programs geared to the early stages of AD or related dementias are important starting points along a continuum of services for families who provide the majority of care.

In light of the growing number of persons with AD and related dementias, coupled with the trend toward earlier diagnosis, stage-specific education and support programs for family caregivers will become increasingly important. This test can be useful in determining the effectiveness of such programs.

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Appendix A: Knowledge about Memory Loss and Care (KAML-C) test

Correct responses are marked with an asterisk (*)

1. Which of the following is the most common cause of memory loss in people over age 65?

_____ 1. Alzheimer's disease*
_____ 2. Senility
_____ 3. Normal aging
_____ 4. Hardening of the arteries
_____ 5. Benign senescent forgetfulness

2. Which of the following conditions may resemble Alzheimer's disease?

_____ 1. Major depression
_____ 2. Pernicious anemia
_____ 3. Thyroid disorder
_____ 4. Parkinson's disease
_____ 5. All of the above*

3. Genetic testing for Alzheimer's disease is currently

_____ 1. A reliable way of predicting if symptoms will develop later in life
_____ 2. Useful only as a research tool*
_____ 3. A definitive means of diagnosis after the onset of symptoms
_____ 4. An accurate means of diagnosis in most cases
_____ 5. Approved for home use by the government

4. A symptom of Alzheimer's disease usually NOT seen in the early stage is

_____ 1. Disorientation to time and place
_____ 2. Word finding difficulty
_____ 3. Aggressive behavior*
_____ 4. Recent memory loss
_____ 5. Difficulty with calculations

5. Giving reminders such as the date and place to persons with memory loss disease will

_____ 1. Improve memory for a time
_____ 2. Improve orientation for a time
_____ 3. Not change memory or orientation
_____ 4. Increase confusion
_____ 5. Be useful temporarily but will have no lasting effect on memory or orientation*

6. The BEST way to enable someone with memory loss to understand you is to

_____ 1. Logically explain your reasoning
_____ 2. Write out a detailed note
_____ 3. Repeat yourself until the point is made
_____ 4. Give brief and simple instructions*
_____ 5. Speak in a quiet tone

7. Which of the following is NOT likely to be a problem for a person in the early stage of memory loss who is living alone?

_____ 1. Forgetting to turn off the stove
_____ 2. Making travel plans
_____ 3. Managing money
_____ 4. Remembering to take medications
_____ 5. Getting dressed in the morning*

8. Which of the following approaches is NOT HELPFUL for persons with memory loss in completing tasks?

_____ 1. Breaking tasks down into small steps
_____ 2. Encouragement to try harder*
_____ 3. Repeating old, familiar skills
_____ 4. Having others assist them as needed
_____ 5. Companionship

9. The BEST way for persons in the early stages of memory loss to ensure that their rights and personal preferences will be protected in the future is to

_____ 1. Sign a living will for health and financial decisions*
_____ 2. Complete Durable Powers of Attorney for Property and Health Care
_____ 3. Have a legal guardian appointed
_____ 4. Have a loved one speak up in their behalf as needed
_____ 5. Transfer their assets into the name of a loved one

10. In regard to financial affairs, persons with memory loss can

_____ 1. Be persuaded of the need for a legal guardian
_____ 2. Usually be trusted to manage their income and assets
_____ 3. Be exploited if safeguards are not put in place*
_____ 4. Be responsible for paying their bills if in the early stage of the disease
_____ 5. Make transactions after thorough consultation

11. Medicare covers which one of the following for persons with Alzheimer's disease?

_____ 1. Doctor's visits on an out-patient basis*
_____ 2. Nursing home care on a long-term basis
_____ 3. Adult day care
_____ 4. Companion services at home
_____ 5. Medications

12. Most persons with Alzheimer's disease live

_____ 1. In nursing homes
_____ 2. In retirement communities
_____ 3. In their own homes*
_____ 4. With their adult children
_____ 5. In assisted living facilities

13. Primary caregivers of persons with Alzheimer's disease suffer from major depression

_____ 1. At about the same rate as the general population
_____ 2. At a lower rate than the general population
_____ 3. At a much higher rate than the general population*
_____ 4. At a slightly higher rate than the general population
_____ 5. At a much lower rate than the general population

14. For a married person with Alzheimer's disease to qualify for Medicaid in order to pay the cost of nursing home care,

_____1. The spouse is required to spend down their liquid assets to $2000
_____2. The spouse must sell their residence and exhaust all assets
_____3. The spouse is entitled to keep a protected level of income and assets*
_____4. The spouse may transfer most of their assets to their children
_____5. The spouse must file for bankruptcy or divorce

15. Those LEAST likely to be primary caregivers of persons with Alzheimer's disease are

_____ 1. Their sons*
_____ 2. Their daughters
_____ 3. Their daughters-in law
_____ 4. Their husbands
_____ 5. Their wives