

Adaptation and Reliability of the Arabic Version of Alzheimer's Disease Knowledge Scale (ADKS) among Sample of Middle aged and Elderly Egyptians Attending Outpatient Clinics in Mansoura University Hospital

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Abstract

Background: As Egypt is expected to maintain the highest rank of old populations in the region; the increased understanding of public views to Alzheimer's disease (AD) becomes a priority. **Objective:** To assess the reliability of Alzheimer's disease Knowledge Scale (ADKS) and the level of knowledge about the disease among a sample of middle aged and elderly people in Mansoura, Egypt. **Methods:** A cross-sectional survey conducted in two stages. The first stage was the adaptation of the Arabic Alzheimer's disease Knowledge Scale (ADKS-A) from the original English form by the translation process followed by a pilot testing. The second stage was to test the reliability of the ADKS-A among a sample of 442 apparently healthy middle aged and elderly in Mansoura, Egypt. **Results:** reliability statistics for the overall scale were accepted: Cronbach's alpha = 0.710 and the interclass correlation for the test-retest statistic was statistically significant ($p=0.01$). The corrected inter-item correlation for the test-retest scores ranged from 0.31-0.77. Item analysis didn't necessitate any omissions. The overall mean score of knowledge among the studied elderly was 11.7 ± 3.02 ranging from 3-28 with 38.9% accuracy on the scale. Younger age, urban residence, higher education and living with family were significant predictors for better knowledge on ADKS in Linear regression model ($F=12.2$, $R^2=0.406$, $P<0.001$). **Conclusions:** The ADKS-A was found to be reliable and acceptable tool. Further study to complete validation of this scale was needed. Also, poor general knowledge about AD among Egyptian middle aged and elderly points to an urgent need for educational outreach programs and campaigns to improve AD knowledge.

Keywords: *Knowledge; Socio-demographic characteristics, Healthy older Egyptians; Alzheimer Disease.*

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Introduction

Alzheimer's disease (AD) is a disease of permanent degeneration in the brain that frequently starts bit by bit to destroy memory, thinking skills, and eventually the ability to carry out the simple tasks of daily living and worsens by time. As it is responsible for 60% to 70% of dementia cases^{1,2}, AD is considered on the top among the several causes of dementia.³

The problem that its early symptoms are often mistaken for normal ageing¹ and there is no treatments to stop or reverse its progression.² In addition, it has a shocking impacts on the lives of patients and caregivers whereas the affected people progressively more rely on others for assistance, placing a burden on the caregiver in addition to the social,

psychological, physical, and economic pressures.⁴ Although there is currently no medical cure, early detection and management can improve the quality of life for both patients and caregivers.⁵

Prevalence of dementia/AD continues to rise worldwide until it has become a global health concern. Currently, it was reported that there were approximately 29.8 million people worldwide with AD.^{2,5,6} In Egypt, although there are only few reports which provide prevalence rates of dementia in general and AD in particular⁷, it was mentioned that the estimated number of Egyptian persons suffering dementia in 2013 is about 350000 persons; most of them are elderly.⁸ Unfortunately, Egypt is expected to maintain the highest rank of both old and oldest populations in the region to the extent that 20 million Egyptians will be categorized as elderly by the year 2050. So, aging is considered a great challenge for healthcare system and threat to the preservation of society welfare.⁹ The experience of AD in Egypt is surrounded by many misconceptions; Alzheimer patients are suffering because they, their caregivers and their families don't fully understand the disease experience.¹⁰ In the case of AD, illness perceptions and misconceptions may hamper efforts in the areas of risk reduction and early diagnosis, making an increased understanding of public views about the disease a priority.¹¹ Due to this lack of awareness, Alzheimer patients go through a long journey of challenge, dependency and weakness.¹⁰

Although many studies reporting dementia/AD prevalence in Egypt¹²⁻¹⁷, few conducted studies on dementia/AD literacy both in Egypt¹⁸ and also in other countries showed that public knowledge was generally low.¹⁹⁻²² It was mentioned that public's literacy is crucial to public acceptance of evidence-based mental health care and encourages patients and their families to come forwards and not

be hindered by the stigma and myths of the disease.²³

With the rapid ageing of the Egyptian population and the increasing risk for AD together with inadequate representation of AD knowledge among Egyptian olds who are the most vulnerable group commonly viewing the disease symptoms as normal part of aging and frequently exposed to abuse due to dementia furthermore, because the knowledge gaps in AD may occur in underserved communities and among elderly populations thus, we decided to conduct this study aiming to assess the reliability of ADKS and to evaluate the AD knowledge levels and its associated socio-demographic factors among a sample of middle aged and elderly in Mansoura, Egypt. We also assessed the participants' opinion about the main source of knowledge which could be used for increasing awareness and recognition about AD.

Methods

Study design: This is a cross-sectional survey study that was conducted in two stages from October to December, 2017 in different outpatient clinics of Mansoura University Hospital (MUH), Mansoura, Egypt.

Target group: The aged visitors of both patients and their accompanying persons, who attended the different outpatient clinics of various departments in MUH, were recruited as a reflection of the general population. Eligibility criteria were being aged 50 years or more, whose native language was Arabic, and apparently healthy, i.e. free from severe chronic diseases, physical disabilities, mental, hearing and speech impairments as well as who accepted to participate in the study.

Study instrument: The present study collected data using 2 parts interviewing questionnaire. Part I included socio-demographic information of participants. Part II assessed the knowledge level

about AD and the participants' opinion about the main source of knowledge which could be used for increasing their awareness and recognition about AD.

Knowledge level about AD was assessed by using the Alzheimer's disease knowledge scale (ADKS). The ADKS was believed to likely reflect the current general knowledge about AD. It is a simple, short, adequately valid and reliable scale with adequate psychometric properties that was designed for use in both applied and research contexts, capable of assessing knowledge about AD among the general public, patients, caregivers, and professionals.^{24,25} The scale comprises 30-items having true or false answers taking around 5-10 minutes to complete with the resulting score being the number answered correctly, giving a total score with a range of 0-30. Although, the ADKS is conceptually split into seven subscales: life impact, risk factors, symptoms, treatment & management, assessment & diagnosis, care giving and course of the disease; it is best expressed by the overall knowledge score rather than separately scored subscales. Thus, the ADKS is not a complete assessment tool, but rather contains representative items indicating the level of general knowledge about AD.²⁴ We also decided to use this scale with true/false response format as an assessment tool for AD knowledge due to its relative ease in use for interviewing than multiple choices format as well as its simplicity in scoring. Kline, 2005 reported that multiple choices format is no better than a true/false format in deciding the incorrect answers from actual misinformation.²⁶

First stage of the study: The first stage of the study was the adaptation of the ADKS-A from the original English form by the translation process. The translation process was based on forward-backward method via two independent bilingual translators for

whom Arabic was a mother language. We compare between the first English copy and the back translation form. Two professional medical translators who were unaware with the original wording of the questions were concerned with evaluation of the back translation form. Then, the ADKS-A and the back translated version were presented to a panel of experts who decided on the cultural equivalence of each of the items in the scale. On arriving at an agreement, the final ADKS-A was formed.

Then, the ADKS-A was pilot tested on a group of target population (20 persons) who were not included in the final analysis in order to check the clarity, comprehension, length, ease of running and cultural acceptability in addition to improve the quality of the translated final version of the tool. Subsequent to piloting, slight modifications were only done.

Second stage of the study: The second stage of the study was to test for the internal consistency and reliability of the finally prepared ADKS-A among a sample of healthy aged population in Mansoura, Egypt, whereas their Knowledge about AD was measured on the scale and some associated socio-demographic factors were also investigated to assess their respective contribution to variation in knowledge and understanding of Alzheimer's disease. Every questionnaire was doubly distributed to all participants with two hours interval from the first time for the purpose of the study. A well trained interviewer was concerned with data collection.

Sample size: It was estimated by assuming that the prevalence of having accurate knowledge about different aspects of AD was 50% at 95% confidence interval and 0.05 margin of error to be at least 384 old using Daniel formula.²⁷ In order to overcome the non-responders, we added 15% to the estimated sample size to be finally 442

Table (1): Socio-demographic characteristics of the studied group

Characteristics	n = 442	%
<u>Age</u>		
-60	260	58.8
-70	172	38.9
70+	10	2.3
Mean age ±SD	58.17±5.66	
Range	50-71	
<u>Gender:</u>		
- Male:	286	64.7
- Female	156	35.3
<u>Residence:</u>		
- Urban	136	30.8
- Rural	306	69.2
<u>Marital status:</u>		
- Single	4	0.9
- Married	240	54.3
- Divorced/Widowed	198	44.8
<u>Education:</u>		
- Illiterate/Read and write	79	17.9
- <Secondary	266	60.2
- ≥Secondary	97	21.9
<u>Working status:</u>		
- Working	261	59
- Not working	181	41
<u>Income:</u>		
- Satisfactory	197	44.6
- Unsatisfactory	245	55.4
<u>Living status:</u>		
- Living alone	114	25.8
- Living with family.	328	74.2
<u>Personal experience of having Alzheimer's patients:</u>		
- Yes	106	24.0
- No	336	76.0

old. Fortunately, all old who were recruited accepted to join our study, so that the response rate was 100%.

Data management: Data were coded, processed and analyzed using SPSS for windows (version 23). A descriptive statistics of the collected data was done in the form of frequencies, mean ± SD and range.

Each of the 30 items of the ADKS-A was recoded into either “correct = 1” or “incorrect = 0”, then the relative frequency distributions of all items were

carefully reviewed to better understand the percentage of the correctly respondents to each item. The percents correct out of total possible (accuracy) were also calculated for the overall scale and subscales.

The Cronbach's alpha was used to assess the internal consistency and the interclass correlation coefficient for test-retest reliability. In addition to the overall internal consistency, we estimated item-total correlations and scale reliability coefficient if an item was deleted. A Cronbach's alpha equal to 0.7 was considered accepted. If exclusion of any item was significantly increased the Cronbach's alpha, removing this item was recommended for improving the homogeneity of the scale.²⁸ To recognize the non-consistent items, McNemar's test was used to compare between the test and re-test for each items of the ADKS.

After deciding on the final number of items to be retained, the overall score of the ADKS was generated using the mean ± SD. Referred to the scoring mentioned in the original study of Carpenter et al²⁴ on older adult subsample, we considered participants with mean score below 24.1±2.95 as not well knowledgeable. Independent sample t-tests was done using MEDCALC software calculator to compare mean score in the present study with mean score of Carpenter et al. A multiple linear regression analysis was performed to detect which socio-demographic characteristic best predicted the total score of correct knowledge on the ADKS. The change in variance (R²) was calculated to quantify the amount of variance in the knowledge score that each predictor explained. We also tested for the normality in the variables incorporated in the regression model. P≤ 0.05 was considered statistically significant.

Ethical considerations:

Approvals were obtained from the Institutional Research Board (IRB) of Mansoura Faculty of Medicine, and from

Table (2): Reliability analysis with test-retest of correct answers percentage on ADKS among the studied group.

Overall Knowledge Score: Mean±SD= 11.7±3.02 Range= 3-28 Cronbach's α= 0.710				
Knowledge item with answer key	%	Inter-item correlation	Cronbach's α if Item deleted	α if
1. People with AD are particularly prone to depression (T).	40.5	0.43		0.512
2. It has been scientifically proven that mental exercise can prevent a person from getting AD (F).	25.1	0.34		0.652
3. After symptoms of AD appear, the average life expectancy is 6 to 12 years (T).	24.9	0.33		0.630
4. When a person with AD becomes agitated, a medical examination might reveal other health problems that caused the agitation (T).	22.4	0.35		0.654
5. People with AD do best with simple, instructions giving one step at a time (T).	37.3	0.40		0.652
6. When people with AD begin to have difficulty taking care of themselves, caregivers should take over right away (F).	44.6	0.52	0.546	
7. If a person with AD becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day (T).	27.1	0.45		0.600
8. In rare cases, people have recovered from AD (F).	17	0.31		0.672
9. People whose AD is not yet severe can benefit from psychotherapy for depression and anxiety (T).	48.9	0.64		0.491
10. If trouble with memory and confused thinking appears suddenly, it is likely due to AD (F).	56.1	0.70		0.497
11. Most people with AD live in nursing homes (F).	51.1	0.66		0.559
12. Poor nutrition can make the symptoms of AD worse (T).	41.4	0.64		0.588
13. People in their 30s can have AD (T).	18.6		0.32	0.611
14. A person with AD becomes increasingly likely to fall down as the disease gets worse (T).	48.4		0.73	0.531
15. When people with AD repeat the same question or story several times, it is helpful to remind them that they are repeating themselves (F).	38		0.63	0.664
16. Once people have AD, they are no longer capable of making informed decisions about their own care (F).	21.3	0.49		0.652
17. Eventually, a person with AD will need 24 hours supervision (T).	69.7	0.72		0.458
18. Having high cholesterol may increase a person's risk of developing AD (T).	35.5	0.59		0.652
19. Tremor or shaking of the hands or arms is a common symptom in people with AD (F).	31.9	0.42		0.622
20. Symptoms of severe depression can be mistaken for symptoms of AD (T).	30.5	0.71		0.670
21. AD is one type of dementia (T).	18.8	0.36		0.652
22. Trouble handling money or paying bills is a common early symptom of AD (T).	34.8	0.45		0.652
23. One symptom that can occur with AD is the believing that other people are stealing one's things (T).	49.5	0.68		0.571
24. When a person has AD, using reminder notes is a crutch that can contribute to decline (F).	26.9	0.41		0.662
25. Prescription drugs that prevent AD are available (T).	44.8	0.57	0.593	
26. Having high blood pressure may increase a person's risk of developing AD (T).	77.4	0.75		0.481
27. Genes can only partially account for the development of AD (T).	69.9	0.72	0.471	
28. It is safe for people with AD to drive, as long as they have a companion in the car at all times (F).	71.7	0.77		0.450
29. AD cannot be cured (T).	39.1	0.35		0.662
30. Most people with AD remember recent events better than things that happened in the past (F).	32.1	0.46		0.654

F: false **T:** true **Correlation** is significant at the 0.05 level (2-tailed).

the authority of MUH. The interviewers introduced themselves to the participants and informed them about the study aims

and the guarantees of anonymity and confidentiality. The response to the study was on voluntary base. Every participant

Table (3): Reliability analysis with test-retest of correct answers on subscales of ADKS among the studied group.

Subscales	No. of items	Correct answers		Cronbach's α	Inter-class correlation
		%	Mean \pm SD		
Life impact (Q _{1, 11, 28})	3	24.4 ^a	1.6 \pm 0.79	0.610	0.610
Risk factors (Q _{2, 13, 18, 25, 26, 27})	6	45.2 ^b	2.7 \pm 1.12	0.664	0.664
Symptoms (Q _{19, 22, 23, 30})	4	29.6 ^c	1.0 \pm 0.84	0.622	0.622
Treatment (Q _{9, 12, 24, 29})	4	39.1 ^d	1.6 \pm 0.89	0.633	0.633
Diagnosis (Q _{4, 10, 20, 21})	4	31.9 ^e	1.3 \pm 0.90	0.618	0.618
Care giving (Q _{5, 6, 7, 15, 16})	5	42.7 ^f	1.7 \pm 1.14	0.660	0.660
Course of the disease (Q _{3, 8, 14, 17})	4	40.0 ^g	1.6 \pm 0.85	0.645	0.645
Overall Scale (Q₁₋₃₀)		30	11.7 \pm3.02	0.710	0.710
38.9^h					
The % correct out of total possible: a= 324/1326		b=1199/2652	c= 523/1768	d= 691/1768	
e= 565/1768		f= 944/2210	g= 707/1768	h= 5158/13260	

was asked to give a verbal informed consent.

Results

Table 1 shows that the 442 participants in our study had age ranged from 50-71 years with the average of 58.2 \pm 5.7 years and more likely belonged to age category below 60 years (58.8%). Out of those participants, 64.7% were male, 54.3% were married, 59% were working, 74.2% were living in family and the majority held low level of education (<Secondary). They were more likely belonging to rural residence (69.2%) with unsatisfactory income (55.4) and 84.6% had no personal experience of having Alzheimer's patients.

Table 2 shows that the Cronbach's alpha for the overall scale was 0.710. The corrected inter-item correlation (ITC) for the test-retest scores ranged from 0.31 to 0.77 with the lowest for question 8 and 13, and highest for question 28. Item analysis did not necessitate any omissions. The table shows that the overall mean score of knowledge among the studied old on the ADKS was

11.7 \pm 3.02 ranging from 3-28 out of 30 compared to the older adult in Carpenter et al original study (average score = 24.10 \pm 2.95 ranging from 15-30). The most correct knowledge our participants had was that having high blood pressure may increase a person's risk of developing AD (77.4 %) while the most incorrect one was that in rare cases, people have recovered from AD (83 %). Compared to the older adult in Carpenter et al, our participants scored significantly lower on the ADKS: P <0.0001 (This comparison data is not displayed in table).

Table 3 shows that the percents correct out of total possible on the seven domains of ADKS were also poor as the total scale with overall equivalent to 38.9% accuracy. The interclass correlation coefficient (ICC) of the test-retest scores of the subscales ranged from 0.610 to 0.664 with the lowest for Life impact subscale and highest for Risk factors subscale. However, reliability statistics for the overall translated 30-items ADKS was accepted (Cronbach's alpha = 0.710), and the interclass

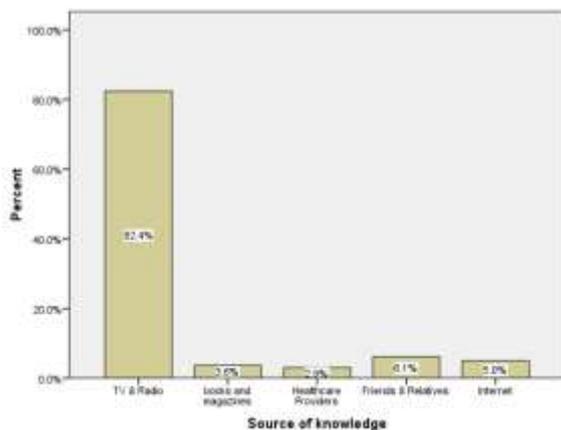


Figure (1): Main Source of Knowledge for Increasing AD Awareness according to Studied Group Opinion

general olds population. In comparison to our result, the original ADKS by Carpenter et al¹⁸ reported that test-retest reliability coefficient was adequate (0.81) while internal consistency of the English version was comparable with our degree of consistency (the average inter-item correlation). However, the present study showed that the ADKS-A in general met the statistical requirement for the reliability issue.³⁰ Even Though the present study revealed that the internal consistency reliability coefficients of the subscales were low, they were comparable with the original ADKS by Carpenter et al who mentioned that the ADKS is best thought of as a scale of overall knowledge in order to examine what people know about AD and not as a set of separately scored subscales.²⁴

In comparison to the original study of Carpenter et al, the present work revealed that our studied subjects were in general, poorly knowledgeable about AD with big variability in their knowledge level whereas their average score on ADKS was 11.7 ± 3.02 ranging from 3-28 with statistically significant difference ($P < 0.0001$). The current overall knowledge was equivalent to 38.9% accuracy. This difference in knowledge level from the original validation study could be explained by different sample characteristics specially those related to

culture, age and level of education. Carpenter et al²⁴ mentioned that the relatively high knowledge level in his general older adult group was consequently related to some people who actually were caregivers and have been included among this older adult group in addition to their high overall intellectual ability compared to our studied old. Also, we didn't believe that translation inaccuracy was blamed for this poor knowledge score as expert medical translators were assigned to assess the back translation, in addition to the interviewing nature of the used questionnaires which were directed by a well trained interviewer to exclude any misunderstanding. The current study revealed that the most correct knowledge was that having high blood pressure may increase a person's risk of developing AD while the most incorrect one was that people have recovered from AD in rare cases. In contrary to our study, a previous Egyptian study conducted in Ain Shams University Hospitals and El Abbassia Hospital for mental health by using multiple choice questionnaire to explore knowledge about Dementia and AD, reported 43.3% as a mean knowledge percentage among participants whereas genetic nature of the disease was the most correct knowledge versus the false believe that patient interview, neurological examination and CT brain give 100% diagnostic accuracy as the most incorrect ones.¹⁸ In accordance to the current finding, previous studies on older adults using another tool: Alzheimer's disease Awareness Test (ADAT) revealed also deficient knowledge about AD in Vietnamese Americans (average score of 6.4 out of 19 with 34% accuracy)³¹, in South Africa (average score of 8.55 out of 19 with 53.44% accuracy).³² Also, Hispanic study found that there was lack of knowledge about Alzheimer's among Hispanic older adults; they have misperceptions about the reasons why a

person develops the disease.³³ Another study, that evaluated AD knowledge in 4 ethnic groups of older adults (Anglo, Latino, Asian and African American) in San Francisco, USA using a constructed 17 true–false questions on AD found Low levels of knowledge across all four ethnic groups with significant misperceptions about the prevalence, the etiology, the diagnosis, the financial coverage of treatments, and the course of AD.³⁴

Our studied olds mentioned media (TV/Radio) as the main source in their opinion for increasing their awareness and recognition towards AD (82.4%). The current finding was comparable to that of another Egyptian study on Dementia and AD which reported 96% of the studied population mentioned TV as the best method to offer public awareness about AD.¹⁸

Several associated factors were previously addressed as common correlates of higher levels of AD knowledge. Our study revealed that younger age, urban residence, higher education and living with family were significant predictors for improving AD knowledge level among the studied olds. These predictors could point to certain groups that AD educational efforts should be targeted. It was not surprising to detect greater knowledge among those of younger age, urban residence, higher education and living with family because these characteristics would provide them an opportunity to see, hear and read more about AD, thus looking for more information about the illness in addition to that exposure to urban culture give more chance to have some concepts and information about AD while mental health is not a priority health concern for rural Egyptians. Supporting some of our predictors, another Egyptian study found that the educational level was the only factor that significantly improving AD knowledge level.¹⁸ Reporting educational level as significant predictors for

improving AD knowledge was very important issue among Egyptian society in which the illiteracy affects 26 % of it.³⁵ We would agree that educational level as well as public exposure to awareness campaigns and health education programs about AD specially through media (TV/Radio) deservedly appears in the top spot as a plausible determinant of AD knowledge. A systematic review of 40 international studies identified older age, female gender and higher education as common correlates of greater levels of AD knowledge³⁶ while education partially explained differences in knowledge of AD between Latino and Anglo older adults and longer years of speaking English was reported among older Asian Americans³⁴ versus younger age, knowing someone with AD, and more acculturation among Korean and Chinese Americans.^{37,38,39} These associated factors with AD knowledge were largely absent among Vietnamese Americans.³¹

Limitations: A major limitation of this study is the relatively low internal consistency reliability of ADKS-A. This may be due to its true/false response format however; in general, the reliability statistics of this scale were accepted. Another limitation that discriminate analysis was not carried out in this work and the studied olds who recruited from outpatients and their accompanying persons may not truly represent the Egyptian general population as most of them may have low education and socioeconomic level. Thus, further testing of the scale among another cohort with different characteristics with the possibility for self-administered application rather than interview may have to be used. Also application of this scale amongst other populations speaking Arabic with real evaluation of AD-related knowledge is needed.

Conclusions

The Arabic version of the ADKS was shown to be a reliable tool for assessing general knowledge of the public regarding AD and its associated factors in the Egyptian setting. But we have to mention that this work was just a reliability study that calls for further study to validate this scale and to implement it on different cohorts.

Also the study concluded poor general knowledge about AD among Egyptian middle aged and elderly which point to an urgent need for educational outreach programs and campaigns to improve knowledge about the disease with special emphasis on social media to increase AD awareness which will ultimately reflect on the quality of life of Egyptian seniors to get better.

Conflict of interests: None

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