

Original Article

Assessment of Dementia Knowledge Among Family Members/Care givers in Egypt.

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Abstract:

Introduction: Despite numerous studies reporting dementia/Alzheimer's disease (AD) prevalence in Egypt, few have explored dementia/AD literacy in the country, revealing generally low public knowledge. Thus, there is a pressing need to enhance understanding of public perceptions regarding dementia/AD literacy.

Objective: This study aimed to evaluate the level of knowledge about dementia among family members and caregivers within a sample of the Egyptian population.

Methods: A cross-sectional study was conducted. The study involved 150 adult family members and/or caregivers of elderly patients, 60 years and above, either experiencing dementia or not. The participants were assessed, for their dementia knowledge, by using the Dementia Knowledge Assessment Scale (DKAS).

Results: The DKAS total scores ranged from 14 to 46, with an average score of 31.013 that indicates a moderate level of dementia knowledge. The level of dementia knowledge was found significantly higher among females, individuals with higher education, and those participants who were exposed before to dementia cases.

Conclusion: This study identified a notable gap in dementia knowledge, as the participants demonstrating a moderate level of understanding. The findings underscore the importance of targeted educational interventions to address this knowledge gap.

Keywords: Dementia knowledge, assessment, care givers

INTRODUCTION

Dementia is a condition marked by a deterioration in memory and other cognitive functions, impacting an individual's capacity to carry out routine tasks [1]. Dementia is common among the elderly. It is estimated that 42.3 million people were living with dementia in 2020, which is going to increase to 81.1 million in 2040. It is projected that across the world every 20 years, the number of people living with dementia will double [2].

Dementia is a condition primarily observed in the elderly population, where it stands as a major factor contributing to dependency and disability [3]. Projected data suggests a significant rise in the elderly demographic, with an estimated increase of 1.25 billion individuals aged ≥ 60 years by 2050, constituting 22% of the global population. Notably, 79% of this elderly population is anticipated to reside in less developed regions across the world [4].

The majority of individuals dealing with dementia rely heavily on the support of a family member, thereby influencing not just those directly affected by dementia but also placing a significant burden on the informal primary caregiver [5]. The family caregiver assumes responsibility starting from the initial phase of the condition, characterized by mild memory impairment, and continues through the advanced stages when the person with dementia necessitates assistance with every aspect of daily living—including bathing, household tasks, and cooking—resulting in the need for continuous, full-time care [6].

While extensive literature exists on the factors contributing to caregiver burden in dementia, there is limited understanding of the elements that can positively or negatively impact a caregiver's knowledge and attitude towards dementia [7].

The Dementia Knowledge Assessment Scale (DKAS) was developed in response to the limitations of existing measures [8]. This scale, conceived as a questionnaire, specifically targets family caregivers, nurses, and professional caregivers engaged in the provision of care for individuals affected by dementia [9].

Therefore, Annear and colleagues developed the DKAS to address these shortcomings. The test-retest reliability exhibited high values, and the internal consistency, along with the initial construct, concurrent, and factor validity, proved to be satisfactory [10].

MATERIALS AND METHODS

Aim of the study

The aim of this study was to assess the level of knowledge about dementia in family members/ care givers; among a sample of Egyptians.

Study design and participants

- **Design:** This was a cross sectional study that was conducted in a sample of Egyptian population.
- **Study Setting:** The Geriatric outpatients' clinic and inpatient wards at Ahmed Shawki-Geriatric medicine Hospital, Ain Shams University Hospitals, Cairo, Egypt.
- **Sample size:** A total of 150 participants.
- **Inclusion criteria:** Adult family members and /or caregivers for elderly patients (60 years and above, either demented or not), who attended Geriatrics outpatients' clinic and/or inpatient wards, at Ahmed Shawki-Geriatric medicine Hospital, Ain Shams University Hospitals
- **Exclusion criteria:** No specific exclusion criteria apart from those who refused to participant in the research.

Methods

For the evaluation of the caregivers, the following instruments were administered: sociodemographic questionnaire, the DKAS, the Patient Health Questionnaire-2 (PHQ-2) (to screen the caregiver for depression) and asking them about any history of caring for patients with dementia or being in close contact to a dementia patient. **Prior to the interview, informed consent was obtained from all participants.**

A demographic questionnaire, encompassing details such as age, gender, place of residence, occupation, marital status, educational background, and smoking history, was employed to gather pertinent information from the participants. It took approximately 15–20 minutes for

the participants to fill out the questionnaires.

1. Screening for depression: by using PHQ-2 (11). The PHQ-2 score spans from 0 to 6, with the authors determining a score of 3 as the optimal threshold for indicating depression when utilizing the PHQ.
2. Application of the DKAS: this was done by interviewing each participant individually, asking them verbally about each item of the DKAS then reporting their response for each item.

▪ **Assessment of dementia knowledge:**

The evaluation of dementia knowledge utilized the Dementia Knowledge Assessment Scale (DKAS) developed by **Annear et al, 2015** [8]. The DKAS scale, comprising 25 items, assesses knowledge related to dementia across four subscales: (I) causes and characteristics (7 items), (II) communication and behavior (6 items), (III) care considerations (6 items), and (IV) risks and health promotion (6 items). Each item presented five response options: false, probably false, probably true, true, and I don't know. Scoring on the DKAS involves assigning two points for a 'true' response to a truthful statement or a 'false' response to an untrue statement, one point for a 'probably true' response to a truthful statement or a 'probably false' response to an untrue item, and zero points for a 'true' or 'probably true' response to

an untrue statement, or a 'false' or 'probably false' response to a truthful item, or an 'I don't know' response. The total achievable score is 50.

The reliability of the 25-item DKAS was demonstrated to be strong, with a Cronbach's alpha of .85, and the subscale internal consistency was deemed acceptable, ranging from Cronbach's alpha values of .65 to .76 [8].

▪ **Data analysis:**

Statistical presentation and analysis of the current study was conducted, using the mean, standard deviation, student t-test, and Analysis of variance [ANOVA] tests by SPSS V25. Unpaired Student T-test was used to compare between two groups in quantitative data.

Analysis of variance (ANOVA) tests was used to compare quantitative variables between more than two groups. P-value > 0.05 Non-significant, P-value ≤ 0.05 Significant, P-value < 0.01 Highly Significant

RESULTS

This was a cross-sectional study that included a total number of 150 caregivers and/or family members for elderly people 60 years and older. The study was conducted in the Outpatients' clinic and inpatient ward, at at Ahmed Shawki-Geriatric medicine Hospital, Ain Shams University Hospitals

Table (1): Socio-demographic data of the studied population.

Socio demographic data & contact with dementia cases				
Age		Mean \pm SD (Range)	40.66 \pm 12.9 (20 – 72)	
Gender	Male	n (%)	56 (37.3%)	
	Female	n (%)	94 (62.7%)	
Address	Rural	n (%)	51 (33.9%)	
	Urban	n (%)	99 (66.1%)	
Educational Level	Illiterate	n (%)	10 (6.67%)	
	<6 yrs education	n (%)	9 (6%)	
	6-12 yrs education	n (%)	51 (34%)	
	Higher education	n (%)	80 (53.33%)	
Smoking	Yes	n (%)	35 (23.3%)	
	No	n (%)	115 (76.67%)	
Caregiver role	Professional caregiver	n (%)	28 (18.67%)	
	Family member	n (%)	122 (81.33%)	
Contact with dementia cases	Yes	107 (71.33%)	Family members	79(73.83%)
			Professional caregivers	28 (26.17%)
n (%)	No	43 (28.67%)		

The mean age of the study population was 40.66 \pm 12.9 years, spanning from 20 to 72 years. The predominant demographic features comprised a majority of female participants (62.7%), highly educated (53.33%), family members of elderly patients (81.33%), non-smokers (76.67%) and living in urban areas (66.1%). (Table 1)

Regarding contact with dementia cases, the table shows that majority of the participants had contact with dementia cases as a family member (73.83%) and to a lesser extent as a professional caregiver (26.17%). The average DKAS score among the study participants was 31.013.

Table (3): DKAS score in relation to socio demographic data, exposure to dementia cases, and depression among the study participants.

		DKAS total score				
		N	Mean	± SD	T-Test	P-value
Gender	Male	56	29.107	± 6.254	-2.481	0.014*
	Female	94	33.149	± 7.800		
Address	Rural	51	29.412	± 7.624	-2.425	0.056
	Urban	99	31.838	± 7.518		
Exposure to dementia	Yes	107	32.355	± 7.417	4.831	<0.001*
	No	43	27.206	± 6.232		
PHQ2	Depressed	30	33.00	± 8.738	2.606	0.100
	Not depressed	120	30.517	± 6.964		
ANOVA					F	P-value
Education Level of education	Illiterate	10	21.000	± 5.676	24.455	<0.001*
	<6 Years	9	23.556	± 4.447		
	6-12 Years	51	28.824	± 6.276		
	Higher education	94	34.500	± 6.158		

T: Student t-test was used, ANOVA: Analysis of variance. P-value < 0.05 is considered statistically significant.

The DKAS total score was significantly higher in female participants; and participants who were exposed to dementia cases, and those with higher level of education. (table 3)

DISCUSSION

The global prevalence of dementia is on the rise, posing a substantial economic, social, and health challenge in the coming years. Consequently, health policies should prioritize research not only into effective pharmacological interventions but also preventive strategies and initiatives to enhance the well-being of both patients and caregivers [1].

Therefore, it is necessary to examine whether healthcare professionals, families, and society have sufficient knowledge of the dementia [12].

Enhancing understanding of dementia care through health education facilitated by healthcare professionals has the potential to improve clinical and community support in both home and specialized environments [13].

Conversely, insufficient knowledge within populations and healthcare practitioners may result in delayed diagnoses or confusion regarding symptoms, potentially leading to improper identification and management [14].

Therefore, the aim of the current study was to assess the level of knowledge about the dementia among family members/ care givers among sample of Egyptian population.

This study involved a sample of 150 participants with ages spanning from 20 to 72 years. The average age of the participants was 40.67 years, with a standard deviation of ±12.902. The gender distribution in the sample indicated a higher representation of females at 62.67%, while males accounted for 37.33%. Smoking habits were reported

by 39 (23.33%) participants, while 115 (76.67%) were non-smokers.

The study revealed that there is statistically significant difference in dementia knowledge regarding sex difference (P value: 0.023), as women participants had higher DKAS score compared to men. Similarly, **Erol et al's, (2015)** has identified that dementia care is a heavily gendered issue and found that, “across all regions and settings, females bear the brunt of the incidence of dementia and the responsibility for caring for people with dementia” [15].

Similar to that finding, **Tan et al's, (2021)** in their study that was conducted among primary informal caregivers of dementia patients with mean age 55.6 years, showed that being a male caregiver was associated with low dementia knowledge [16].

In addition, many studies examining gender distinctions in caregiving have documented an increased burden among women, although the findings exhibit variability [17].

In our study, most of the participants were living in urban settings (66.1%) compared to only 33.9% in rural areas. The majority were highly educated (53.33%). We found higher educational level was significantly associated with higher dementia knowledge as assessed by DKAS. This was similar to **Zheng et al's, (2020)** study that was conducted on 3338 participants and showed that a high level of education was associated with a comprehensive understanding of the alterable factors that pose risks and offer protection against dementia [18].

Moreover, we found that the majority of the participants had previous exposure to dementia (71.33%), and most of them were family members (68.37%) to cases of dementia, with a significant association

between dementia knowledge and exposure to dementia (P value 0.001).

This finding was similar to **Zheng et al's, (2020)** study that was showed that exposure to dementia significantly associated with an extensive understanding of the modifiable risk and protective factors for dementia [18].

On the other hand, **Wezel et al's, (2022)** study revealed no differences were found between those with a low level of education versus those with a higher level; those who frequently provided care versus those who did so less frequently; and those who lived together with a person with dementia versus those who did not [19].

In this study the mean score of the DKAS was 31.01 out of total score 50 point, indicating moderate level of dementia knowledge among participants. This is similar to **Sung et al's, (2021)** study that was conducted on home care workers and showed the average score for the DKAS-TC (Taiwan Chinese) was 27.7 out of 50, signifying a moderate level of dementia knowledge [20]. Additionally, **Annear et al's, (2017)** discovered in their research that the mean DKAS scores within the global health professional cohort ranged from 32.5 to 37.1 out of 50, indicating levels above the moderate range [21]. Our study showed that the mean score for all participants on the scale was 31.01 points out of 50. DKAS score for the professional caregivers and family members who had exposed to dementia cases was 32.58 ± 7.12 , that was significantly higher in comparison to those family members without exposure to dementia scored low (27.26 ± 6.5). This was similar to **Carnes et al's, (2021)** who showed that The average score for all participants on the scale was 27 points out of a maximum score of 50. Among the groups, professional caregivers had the highest scores (31.28 ± 7.12), followed by students

(29.52±7.65), with non-professional caregivers scoring the lowest (23.06±8.73) [22].

Knowledge gaps were evident, encompassing challenges in recognizing symptoms, holding inaccurate perceptions, and misunderstanding the terminal nature of dementia. Being a syndrome with various causative factors and a spectrum of symptoms, dementia poses difficulties in diagnosis [23].

Dementia-related health issues, such as difficulty in swallowing, respiratory problems, intricate behaviors, and concurrent delirium or depression, further complicate the diagnostic process for healthcare professionals, potentially leading to delays in appropriate care [24]. Additionally, a notable portion of participants failed to acknowledge the limitations of existing pharmacological (psychotropic) interventions for effectively addressing behavioral symptoms of dementia. This lack of recognition stems from the potential harms associated with medications, including an elevated risk of mortality, which often outweighs the benefits [25].

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CONCLUSION

This study sheds light on the crucial issue of dementia knowledge among family members and caregivers in Egypt. The findings underscore the increasing global prevalence of dementia, emphasizing the urgent need for comprehensive health policies that address both pharmacological treatments and preventive measures. The study reveals a significant gap in dementia knowledge, with participants exhibiting a moderate level of understanding, emphasizing the necessity for targeted educational interventions.

Ethical Considerations:

- 1- The study was reviewed and approved by research ethical committee, Faculty of Medicine, Ain Shams University (Number: FMASU MS 542/2022).
- 2- Confidentiality and privacy of data was ensured.

Conflict of interest: On behalf of all authors, the corresponding author states that there are no conflict of interest.

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