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Dementia awareness in Egypt: what do people really know?

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Abstract

Background Dementia is a pressing problem for families and society. In 2019, a total of 57.4 million people worldwide were estimated to be living with dementia, and this number will almost double every 20 years, especially in Africa and the Middle East. This study aimed to investigate knowledge about dementia among the Egyptian population. A cross-sectional online survey was conducted among a sample of adult Egyptians using a socio-demographics data sheet and a designed dementia knowledge questionnaire.

Results Nearly one-third (33.4%) had a poor knowledge score. The items most often answered incorrectly were the sudden onset of cognitive problems as characteristic of dementia (59.3%). The highest percentage of good knowledge was in the manifestations and prevention domains (62.20% and 67.18%, respectively). On the other hand, the lowest rate of good knowledge was in the treatment and life impact domains (35.23% and 25.70%, respectively). Not working in the medical field (OR 2.656, 95% CI: 1.504–4.688, p < 0.001), had no contact with dementia patients (OR 1.910, 95% CI: 1.229–2.970, p = 0.004), no previous knowledge on dementia (OR 3.184, 95% CI: 1.797–5.642, p < 0.001), or never heard about dementia "Marad Alkharaf" (OR 6.385, 95% CI: 4.127–9.878, p < 0.001) were significantly associated with poorer dementia knowledge.

Conclusion The findings of our study indicated variable levels of knowledge of dementia among Egyptians. Our recommendation is to encourage conducting campaigns for raising public awareness about dementia and through media that has an important and widespread effect in reaching the Egyptian population.

Keywords Public, Knowledge, Dementia, Alzheimer's disease, Egypt

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Background

Dementia is a collective term including a significant decline in at least one of the cognitive domains such as memory, executive function, language, perceptual-motor, complex attention, learning, or social cognition. The decline is characterized by being progressive and persistent in time and shows a change in the person's prior level of cognitive functioning. This must also be associated with a decline in the person's ability to function and perform his/her daily activities [1]. Being one of the leading causes of disability and dependence, it has a profound impact on the patient's quality of life, as well as their acquaintances who often later become their caregivers [2].

The number of people with dementia is expected to increase from 57.4 million cases in 2019 to 152.8 million cases in 2050. The projected increases are geographically heterogeneous around the globe with the largest in North Africa and the Middle East and eastern sub-Saharan Africa [3]. The global prevalence of dementia has been estimated to range from 43.8–46.8 million individuals in 2015–2016 with an expected higher rise in lower- and middle-income countries (LMIC) where the life expectancy is increasing at a higher rate than in high-income countries [4, 5]. Dementia prevalence in Egypt varied among studies ranging from 2.01 to 5.07% [6].

The World Health Organization called for greater dementia awareness and education in response to increasing global prevalence [7]. In LMIC, dementia is often seen as part of the aging process and is subjected to stigma issues and inadequate resources for the care of people with dementia (PWD) [8].

The general public usually lacks the awareness that the risk for dementia can be modified by the management of existing health conditions and healthy lifestyle modifications [9]. It was also found that the insufficiency in dementia knowledge was not only among the general public, but also among healthcare professionals in the Middle East [10].

On the other hand, the estimation of the basic level of knowledge among the Egyptian population will help in the construction of national dementia policies. As a growing population, national policies are usually directed towards non-communicable diseases. Awareness campaigns and educational programs can be designed according to the level of public knowledge. Raising awareness can help in dementia risk reduction, early diagnosis and ultimately enhancing the quality of life of patients and their caregivers. Moreover, increasing awareness among different age groups and different professional levels can eventually create a more "dementia-friendly" community [11].

The emphasis on public knowledge reflects the interest of medical and nursing professionals in both clinical and research points of view in leading to a clearer and more understanding way of people's knowledge towards the condition. Inappropriate identification and rehabilitation of people with dementia in health services, stigmatization of patients, and lack of family support are the consequences of poor public knowledge [12].

Hence, our aim in this research is to address the following questions: (1) What does the Egyptian public know about dementia? (2) What are the associated factors with Egyptian public knowledge about dementia?

Methods

A cross-sectional online survey was conducted among a sample of adult Egyptians over a period of three months. The survey was distributed via social media; Facebook, Twitter, and WhatsApp using electronic form. All adults aged 18 years or older who can read and write and have internet access were eligible to share in the study. Study participants were allowed to fill out the questionnaire after reading and approving the online informed consent. The study population included 782 adults, sample size was calculated using Epi Info version 7.2 based on the following data: an expected level of knowledge of 50%, a margin of error of 5%, and a design effect of 2. The minimum calculated sample size was 768.

The questionnaire package completed by the participants consisted of 9 questions on socio-demographic characteristics, and 30 questions on their knowledge about dementia. Respondents were also asked if they heard about dementia before, had contact with someone with dementia, or received specific training on dementia. The first phase of questionnaire development included item generation, by a group of experts in the geriatric field, based on an extensive literature review [2, 13-18]. The initial item pool contained 60 items that addressed different aspects of dementia-related knowledge. Those 60 items covered seven areas (dementia general characteristics, risk factors, clinical presentation, diagnosis, preventive factors, treatment, and life impact). To eliminate redundancy, the expert panel reduced the measure to 30 items that represented the seven areas. The panel agreed that the 30-item scale had adequate content validity to address the public knowledge regarding dementia. The questions were translated to Arabic using a forward/ backward translation process and administered to 20 individuals for pilot testing to assess item wording, comprehensibility, scale layout, and content coverage. Participants received one point for correctly answering and they received Zero points for incorrectly answering or "I do not know". The total score was calculated by adding scores of all questions and it ranged from 0-30 with a

higher score indicating a higher level of knowledge. Reliability was tested using internal consistency and a reliability coefficient (Cronbach alpha) of 0.896 was found for the 30 items of the questionnaire. Total knowledge score was categorized into three levels: poor (<50%), average (50–70%), and high knowledge (>70%) [19].

The collected data were analyzed using the Statistical Package of Social Science (SPSS) (version 21) by IBM, Chicago, IL, USA. Qualitative data were described using the number and percent while numerical data were presented as mean and standard deviation (SD). Chi-squared test (\times 2) was used to test the association between categorical variables. Bivariate and multivariate logistic regressions were conducted to assess the factors affecting the level of dementia knowledge. P-values \leq 0.05 were considered statistically significant. All statistical analysis was done using two-tailed tests.

Results

Our study included 782 adult Egyptians from the public. No participants were excluded from the study based on their responses or characteristics. The ages ranged from 18–80 years old. Most of the respondents were females (75.1%), and more than half of the participants were married (53.7%) and university graduates (59.1%). Most of the study sample was living in urban areas (84.1%). About two-thirds (66.1%) of the participants did not work in the medical field, and more than half of them did not have

any previous contact with dementia patients (59.6%) or previous knowledge about dementia (64.9%).

Approximately one-third of the sample demonstrated poor knowledge about dementia (33.4%). Less than half of the participants (45.3%) obtained an average knowledge score, while only 21.4% achieved a high knowledge score (>70%). The mean percentage of knowledge about dementia in each domain of the study questionnaire illustrated in Fig. 1 shows the domains with the highest mean percentage of knowledge were manifestations and prevention, with scores of 62.20% and 67.18%, respectively. Conversely, the domains with the lowest mean percentage of knowledge were treatment and life impact, with scores of 35.23% and 25.70%, respectively.

Assessment of the level of knowledge about dementia using the designed questionnaire revealed that the items most often answered incorrectly were the sudden onset of cognitive problems as characteristic of dementia (59.3%), once people have dementia, they are no longer capable of making informed decisions about their care (52.6%) and dementia is a normal part of aging (37.1%) (Table 1). Regarding the symptoms of dementia, we found that most participants had a good idea about them; however, about half of them (50.5%) did not recognize the fact that the ability of dementia patients to recall events from a long time ago is better than their ability to recall recent events. In the same line, about 57.6% of them did not know that depression is one of the most important

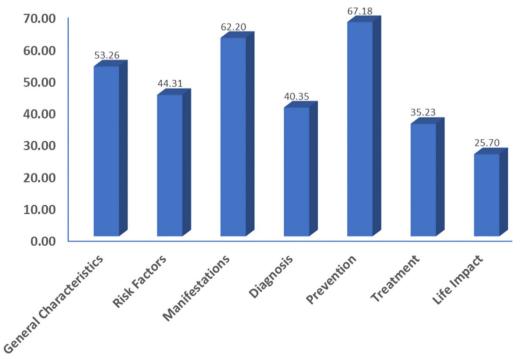


Fig. 1 Mean percentage of dementia knowledge questionnaire dimensions (n = 782)

Table 1 Knowledge about dementia and Alzheimer's disease (n = 782)

	Total (n = 782)						
	Correct answer		Incorrect answer		Do not know		
	n	%	n	%	n	%	
General characteristics							
1. Alzheimer's disease (AD) is the most common form of dementia. (T)	515	65.9	35	4.5	232	29.7	
2. Dementia is a normal part of the aging process. (F)	318	40.7	290	37.1	174	22.3	
Risk factors/cause							
3. The chance of developing dementia decreases as you get older. (F)	581	74.3	44	5.6	157	20.1	
4. Dementia is more common in males than females. (F)	138	17.6	199	25.4	445	56.9	
5. Some types of dementia have a genetic risk. (T)	434	55.5	37	4.7	311	39.8	
6. Hardening of the arteries is a common cause of dementia. (T)	295	37.7	80	10.2	407	52.0	
7. Significant or repeated Brain trauma linked to AD. (T)	378	48.3	68	8.7	336	43.0	
8. Some organic diseases can cause dementia (for example, thyroid diseases). (T)	253	32.4	73	9.3	456	58.3	
Manifestations (clinical presentation)							
9. The primary symptom of AD is memory loss. (T)	610	78.0	44	5.6	128	16.4	
10. Able to recall events from long ago less accurately than events that occurred recently (as an example; remembering changes in government 20 years ago compared to present times). (F)	395	50.5	247	31.6	140	17.9	
11. Sometimes has difficulty naming objects by their actual names. (T)	615	78.6	23	2.9	144	18.4	
12. Misplaces objects because they have put them in unusual places (for example, keys in the bathroom cabinet). (T)	548	70.1	36	4.6	198	25.3	
13. Difficulty completing tasks that were previously undertaken with ease (for example, completing a government form, shopping, preparing meals). (T)	603	77.1	21	2.7	158	20.2	
14. Loses track of the month or the season (as an example, thinking it's Summer when it's late Autumn). (T)	545	69.7	37	4.7	200	25.6	
15. Aware of difficulties they have with driving that places them at risk (F)	407	52.0	135	17.3	240	30.7	
16. If a person develops dementia, he or she may experience changes in his or her personality. (T)	616	78.8	20	2.6	146	18.7	
17. People with dementia may get aggressive, agitated, or disinhibited. (T)	591	75.6	26	3.3	165	21.1	
18. Some people with dementia can have psychotic symptoms (for example, hallucinations and delusions). (T)	507	64.8	49	6.3	226	28.9	
19. Symptoms of severe depression can be mistaken for symptoms of AD.(T)	331	42.3	138	17.6	313	40.0	
20. The sudden onset of cognitive problems is characteristic of common forms of dementia. (F)	69	8.8	464	59.3	249	31.8	
Diagnosis							
21. Early diagnosis of dementia can help in slowing the deterioration of the condition. (T)	581	74.3	39	5.0	162	20.7	
22. Advanced brain imaging can help differentiate different types of dementia. (T)	472	60.4	13	1.7	297	38.0	
Preventive factors							
23. People who follow a healthy lifestyle are more likely to get dementia. (F)	494	63.2	127	16.2	161	20.6	
24. Intellectual activities such as reading books or newspaper and playing chess or card games are helpful for people with AD. (T)	527	67.4	21	2.7	234	29.9	
25. Active participation in various social activities may protect the cognitive function of AD patients. (T)	555	71.0	25	3.2	202	25.8	
Treatment							
26. Drugs are available to treat the symptoms of AD. (T)	286	36.6	180	23.0	316	40.4	
27. Some types of dementia are reversible and can be cured. (T)	265	33.9	120		397		
Life impact							
28. Researchers reported that after symptoms of AD appear, the average life expectancy is 6–12 years. (T)	118	15.1	86	11.0	578	73.9	
29. Once people have AD, they are no longer capable of making informed decisions about their care. (F)	118	15.1	411	52.6	253	32.4	
30. Most people with AD should live in nursing homes. (F)	367		181		234		
Total mean score (mean ± SD)	-0,	16.03	±	6.78			

AD Alzheimer's disease, SD standard deviation, T correct answer is true, F correct answer is false

differentials of dementia. More than half of the respondents correctly answered the items concerning diagnosis and preventive factors of dementia such as a healthy lifestyle, intellectual activities, and social activities (63.2%, 67.4%, and 71.0%, respectively). The items concerning treatment and life impact were the most difficult ones.

There was a significant association between age and dementia knowledge. Individuals aged 25–44 had the highest proportion of high knowledge (25.8%), followed by those aged 45–80 (18.7%) and 18–24 (11.8%).

Education level showed a significant association with poor dementia knowledge as those who completed up to year 12 had the highest proportion of poor knowledge (51.5%, p<0.001). Individuals residing in urban areas exhibited a significantly higher proportion of high knowledge (22.9%) compared to those in rural areas (12.9%). Working in the medical field, contact with people living with dementia, previous knowledge about dementia, or hearing about dementia all were significantly associated with higher levels of knowledge (p<0.001) (Table 2).

Table 2 Exploring determinants of dementia knowledge levels: an analysis of associated factors (n = 782)

	Poor knowledge (n = 261)		Average knowledge (n = 354)		High knowledge (n=167)		<i>P</i> -value
	n	%	n	%	n	%	
Age (years)							0.003*
18–24	69	37.1	95	51.1	22	11.8	
25-44	149	31.5	202	42.7	122	25.8	
45-80	43	35.0	57	46.3	23	18.7	
Gender							0.399
Male	69	35.4	91	46.7	35	17.9	
Female	192	32.7	263	44.8	132	22.5	
Marital status							0.453
Married	137	32.6	186	44.3	97	23.1	
Single	114	34.9	153	46.8	60	18.3	
Widowed/divorced	10	28.6	15	42.9	10	28.6	
Education							< 0.001*
Up to year 12	17	51.5	13	39.4	3	9.1	
University graduate	177	38.3	221	47.8	64	13.9	
Postgraduate	67	23.3	120	41.8	100	34.8	
Place of residence							0.024*
Urban	220	33.4	287	43.6	151	22.9	
Rural	41	33.1	67	54.0	16	12.9	
Working status							< 0.001*
Working	134	28.5	206	43.8	130	27.7	
Not working/housewife	55	45.1	54	44.3	13	10.7	
Retired	17	50.0	11	32.4	6	17.6	
Student	55	35.3	83	53.2	18	11.5	
Working in the medical field							< 0.001*
No	229	44.3	235	45.5	53	10.3	
Yes	32	12.1	119	44.9	114	43.0	
Contact with people living with	dementia						< 0.001*
No	199	42.7	192	41.2	75	16.1	
Yes	62	19.6	162	51.3	92	29.1	
Previous knowledge on dement	ia (workshops, tra	ining)					< 0.001*
No	241	47.7	213	42.2	51	10.1	
Yes	20	7.2	141	50.9	116	41.9	
Hear about dementia "Marad A	lkharaf"						< 0.001*
No	196	68.3	86	30.0	5	1.7	
Yes	65	13.1	268	54.1	162	32.7	

^{*}Statistically significant at $p \le 0.05$

Based on the multivariate logistic regression findings, results showed that those who do not work in the medical field, had no contact with dementia patients, no previous knowledge on dementia, or never heard about dementia "Marad Alkharaf" were significantly associated with poorer dementia knowledge (Table 3).

Discussion

The current study provides valuable insights into the knowledge of dementia among the Egyptian population, shedding light on prevalent misconceptions and areas of concern.

Almost half of the participants had an average knowledge score. It was observed that the highest dementia knowledge was among middle-aged people (25–44 years). Previous studies targeted different ranges of age groups consequently it was difficult to compare them, but it was observed that in general middle-aged people start to pay attention to chronic diseases and illnesses affecting old age. This is consistent with a large study conducted on the Chinese population that showed that the sandwich generation (20–60 years) had the highest knowledge score [20].

Higher education was associated with higher levels of dementia knowledge, as postgraduates had average dementia knowledge, these results were congruent with the study conducted by Joo and colleagues [21].

Though there was no statistically significant difference between males and females regarding dementia knowledge, females showed more knowledge than males and this was consistent with previous studies by Seo and colleagues [22].

People living in urban areas were found to have more dementia knowledge, this was in line with the study of Panghal and team [23]. This result highlights the need to bridge the knowledge gap between urban and rural areas

via targeted awareness campaigns and patient and public involvement events.

The discrepancy in the answers given to the seven domains the questionnaire involved (General characteristics, risk factors, clinical presentation, diagnosis, preventive factors, treatment, and life impact) was in favor of poorer knowledge in the "life impact and treatment domains". On the contrary, better knowledge was noticed in the "dementia manifestations and prevention" domains. Most of the correct answers were in the category of dementia prevention which corresponds to the results in the study by Low and Anstey [24]. However, this was not the case in the national survey in Ireland carried out in 2017 which showed that most of the population did not know there was something that could be done to prevent dementia [15].

The "I do not know" option in the questionnaire answers provided extra certainty about the "yes" answers. This is like the methodology used in the national survey in Germany by Lüdecke and colleagues [16].

Our study showed that more than half of the participants believed that once a person was diagnosed with dementia, he was incapable of making informed consent about their care. This is like the results found in the Northern Ireland study that explored the public perception of living with dementia [25].

Also considering dementia as a normal part of aging among part of our participants is like the results of the World Alzheimer Report in 2019 on the global attitudes to dementia which showed that 2 out of 3 people think that dementia is a part of normal aging [26].

Several studies worldwide have shown the relationship between having previous information about dementia as well as contact with dementia patients and better knowledge of Dementia [16, 27, 28]. This resonates with our results showing poorer knowledge in those with

Table 3 Predictors of poor dementia knowledge according to the results of multiple regression analysis (n = 782)

		В	B SE	<i>p</i> -value	OR	95% CI for aOR	
						LL	UL
Working in medical field	Yes (Ref.)						
	No	0.977	0.290	< 0.001*	2.656	1.504	4.688
Contact with people living with dementia	Yes (Ref.)						
	No	0.647	0.225	0.004*	1.910	1.229	2.970
Previous knowledge on dementia (workshops, training)	Yes (Ref.)						
	No	1.158	0.292	< 0.001*	3.184	1.797	5.642
Hear about dementia "Marad Alkharaf"	Yes (Ref.)						
	No	1.854	0.223	< 0.001*	6.385	4.127	9.878

^{*}Statistically significant at $p \le 0.05$

B regression coefficient, SE standard error, OR adjusted odds ratio, CI confidence interval, LL lower limit, UL upper limit

no previous knowledge or contact with persons with dementia.

Our study's strengths lie in the inclusive design of the used questionnaire. The questionnaire targeted all the required aspects of dementia knowledge respecting the distinctive cultural and religious background of the Egyptian population. The questionnaire was also designed in Modern Standard Arabic which is the literary standard among the Arabic-speaking populations and thus can be used in further surveys to assess Dementia knowledge across the Arab world and Middle East. The online format of the questionnaire also allowed more inclusion of participants during the time of the pandemic in which public gatherings were limited.

Limitations of this study include the small sample size based on the electronic distribution of the questionnaire by the researchers. Also, the online form of the questionnaire owed to the relatively homogenous age range of the participants, who are familiar with the use of social media platforms. The previous two factors also probably led to the availability of the questionnaire to participants of more fortunate socioeconomic status and central cities. These limitations can be overcome if national surveys were made with in-person interviews and designs that allow illiterate people to participate. Also, since the study was conducted using an online survey, this did not allow for randomization of the collected sample. This limitation should be considered when interpreting the generalizability of our findings.

Moreover, while our research focused on dementia awareness, it is important to note the potential over-estimation of AD among participants. Future studies should incorporate questions that address the negative aspects of AD over-estimation to provide a more balanced understanding of public knowledge and perceptions. Additionally, some of the questions in our questionnaire may have been leading, potentially influencing responses and reducing the sensitivity of our results. This potential bias should be considered when interpreting our findings. Future research should aim to design more neutral questions to mitigate this issue.

Conclusions

To our knowledge, this study is one of the first studies in the Middle East that explored the knowledge about dementia. The results of the study found that good public knowledge was in the domains of manifestations and prevention of dementia. Significant factors associated with dementia knowledge were working in the medical field, contact with dementia patients, previous knowledge of dementia, and hearing about dementia "Marad Alkharaf". We recommend the need for public awareness campaigns that could address dementia knowledge

among the Egyptian population, especially among lower education levels, younger populations, and those living in rural areas. Nationwide surveys are recommended to build a representative image of the public dementia knowledge that can be used by policymakers to construct and implement a national dementia plan in Egypt.

Abbreviations

AD Alzheimer's disease
B Regression coefficient
CI Confidence interval
LL Lower limit

LMIC Lower- and middle-income countries

OR Adjusted odds ratio
PWD People with dementia
SD Standard deviation
SE Standard error
UL Upper limit

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Author contributions

A.A.A., H.K., M.N., and O.K. shared in the conception, design of the work, and writing the main manuscript. N.S. shared in writing and revising the manuscript. A.D.A. shared with statistical analysis and prepared the figures. S.A. acquired IRB approval and shared in the results writing. All authors reviewed the manuscript and approved the final version.

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Availability of data and materials

The data are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was approved by the ethics committee of National Cancer Institute, Cairo University, Egypt (IRB approval number: 2103-502–003). The study was performed in accordance with the declaration of Helsinki standards. The purpose of the study was explained to the participants at the beginning of the online form. Also, all participants were informed that their participation was voluntary, and their informed consent was taken prior to answering the study questions. Confidentiality and anonymity were thoroughly ensured, and no names or email addresses were obtained. The gathered data were used only for the purposes of the study.

Consent for publication

Not applicable.

Competing interests

The authors have no relevant financial or non-financial interests to disclose.

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