

Knowledge about Alzheimer's disease in the Brazilian population

Conhecimento sobre a doença de Alzheimer na população brasileira)

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ABSTRACT

Dementia is a very common disease, but the general population's knowledge about its main etiology, Alzheimer's disease (AD), is still poor, leading to delayed seeking of healthcare services, less prevention of disease by lifestyle changes and more difficulty in managing the care of the demented. **Objective:** To measure knowledge about AD in a Brazilian sample, taking into account some demographic variables. **Methods:** A link to a self-administered online questionnaire was sent by email and via other social media to anyone older than 18 years old. Our questionnaire contained sociodemographic questions and the Alzheimer's Disease Knowledge Scale (ADKS), a well-established scale comprising 30 "true or false" questions about AD. **Results:** 1,414 people (1,076 females), with a mean age of 42.3 years (SD \pm 14.1), and 87.4% having more than 11 years of schooling, answered the online questionnaire. The mean total score for the ADKS was 21.6 out of 30 points (SD \pm 3.73); however when we excluded health professionals (36.4% of the sample), it dropped to 20.5/30 (SD \pm 3.51). The scores were positively influenced by educational level, professional skills (better for health professionals, mainly physicians) and by age (younger than 65 years). Being a caregiver or family member did not influence the knowledge about disease. **Discussion:** Despite the high prevalence of AD, few studies have been conducted in Brazil regarding the population's knowledge about the disease. Our study revealed a lack of information about AD in our country, even in relatives and caregivers of demented patients.

Keywords: Alzheimer's disease; knowledge; dementia.

RESUMO

Apesar da alta e crescente prevalência de demência em nosso meio, o conhecimento da população sobre sua principal causa - a Doença de Alzheimer (DA) - é insuficiente, levando à menor procura por serviços de saúde, menor prevenção da doença por meio de mudanças no estilo de vida e maior dificuldade no cuidado aos pacientes com demência. **Objetivo:** Mensurar o conhecimento sobre DA em uma amostra da população brasileira, levando em conta algumas variáveis demográficas. **Métodos:** Um link para um questionário online auto-aplicável foi enviado por email e por meio de outras mídias sociais para pessoas com mais de 18 anos de idade. O questionário era composto por itens sociodemográficos e pela "Alzheimer's Disease Knowledge Scale" (ADKS), uma escala bem estabelecida composta por 30 questões relacionadas à DA, no formato "verdadeiro ou falso". **Resultados:** 1414 pessoas (1076 mulheres), com idade média de 42,3 anos (DP \pm 14,1) e mais de onze anos de escolaridade em 87,4%, responderam o questionário online. A pontuação média na escala ADKS foi de 21,6 em 30 pontos possíveis (DP \pm 3,73). Contudo, excluindo profissionais de saúde (36,4% da amostra), a pontuação média caiu para 20,5 (DP \pm 3,51). Os resultados foram influenciados positivamente pela escolaridade, profissão (profissionais de saúde, principalmente médicos, tiveram melhor desempenho) e idade inferior a 65 anos. Cuidadores e familiares de pessoas com demência não tiveram melhor desempenho que os demais. **Discussão:** Apesar da alta prevalência da DA, poucos estudos brasileiros avaliaram o conhecimento da população sobre esta doença. O nosso estudo revelou falta de informação da população brasileira em relação a este tema, mesmo entre familiares e cuidadores de pessoas com demência.

Palavras-chave: Doença de Alzheimer; conhecimento; demência.

Dementia is a common condition and a public health concern, especially in developing countries, with studies in Brazil having shown a prevalence around 12% in the population over 65 years of age^{1,2,3,4,5,6,7}. In Latin America, Alzheimer's disease (AD) is considered the etiology of dementia in 49.9% to 84.5% of patients, followed by vascular dementia⁸. Moreover, dementia

creates considerable costs for the Brazilian government, reaching US\$13,468.80, US\$18,106.80 and US\$19,736.40 annually for mild, moderate and severe forms of AD, respectively⁹.

Many studies have shown the relationship between AD and cerebrovascular disease, hypertension, diabetes mellitus, metabolic syndrome, smoking and others¹⁰. Consequently, it is likely

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that controlling these risk factors could reduce the incidence of cognitive impairment in the general population. Forreter et al.¹¹ compared the incidence of dementia in patients treated for isolated systolic hypertension with a control group in a randomized double-blind study, finding a relative risk reduction of 0.62% in the treated group. Bernick et al.¹², observing over an average of seven years, compared the elderly treated with statins with a control group and found that the use of statins was associated with a slight reduction in cognitive decline, but the relationship was probably not sufficiently explained by the lowering of serum cholesterol¹². Another study that included 1,382 non-demented elderly, found that a high serum total cholesterol in midlife is associated with a greater chance of cognitive decline in late-life; however, lowering the total cholesterol after midlife may be related to poorer cognitive status¹³.

Despite the evident impact of some lifestyle changes in human health, the general population appears to be unaware of this and, consequently, does not adhere to healthier habits that could reduce the risk of dementia and other diseases. In an Australian study, only 41% of 1,003 participants who were interviewed by telephone believed that the dementia risk could be reduced by lifestyle changes, but only 26.9% of them were confident that they could act to diminish their own risk. Most responders (57.1%) affirmed that mental activity can reduce the risk of dementia, but fewer believed that physical exercise, healthy diet and social activities help to prevent it (31.3%, 23.3% and 12.1% respectively)¹⁴.

Specific symptomatic treatment must be introduced early in AD, to have less institutionalization, better survival and a lower long-term economic burden¹⁵; but in those patients diagnosed with AD, the prevalence of cholinesterase inhibitors use is only 12% in Brazil, and ranges from 3% to 20% in Europe (in the Netherlands and France, respectively)^{16,17}. It is necessary that information regarding risk factors, symptoms, causes, prognosis and the course of AD is widely available, not only to health professionals and caregivers, but also to the general public, so that interventions could be applied to reduce risk factors, get an earlier diagnosis and a better follow-up of AD patients, reducing the burden on the public health system. Furthermore, better popular knowledge would bring less stigmatization, more social inclusion and facilitate access to adequate healthcare.

A systematic review of the literature included 40 studies from different countries that assessed the knowledge about dementia in the population, most of them from developed countries (60% from USA, UK or Australia), and three studies from developing countries (Brazil, Pakistan and Turkey). Almost half of these studies found a limited knowledge about AD and dementia in the general population, and a common concept was that dementia is part of aging. The lack of information was more prevalent in individuals with an advanced age, low educational level and in racial and ethnic minorities. In total, 10 studies found that participants with a better knowledge about dementia were more educated¹⁸.

Regarding the tools for measuring dementia knowledge, Spector et al.¹⁹ reviewed five of them, the majority of which were directed at health professionals or caregivers. The Alzheimer's Disease Knowledge Scale (ADKS) was the only one that was designed and tested for different samples, including the general population and laypeople; however it seems to have a ceiling effect, probably due to the relatively easy items for those with some knowledge on the topic. It has an adequate validity and reliability, with a variable internal consistency reliability, ranging from 0.32-0.98 and good test-retest correlation (0.81)¹⁹. A more recently-developed tool, the Dementia Knowledge Assessment Scale, has been shown to have more internal consistency, probably due to the use of a 4-point Likert scale (strongly disagree to strongly agree) with an auxiliary "I don't know" option, while the ADKS is a dichotomous scale, restraining the evaluation of uncertainties of the responders and being more focused on AD^{20,21}. The Dementia Knowledge Assessment Scale was recently tested in an international cohort of 3,649 individuals, and was shown to be a reliable and valid measure of dementia knowledge for different populations (general public, students, health professionals)²². The Alzheimer's Disease Knowledge Test is another test, created in 1988 by Dieckmann et al.,²⁰ comprising 20 multiple-choice item with five options, including an "I don't know" option, with a moderate test retest reliability.

Studies on the knowledge about dementia and AD in Brazil are scarce and include a small number of participants. Information about the public's self-knowledge is one of the first steps to developing public health strategies to cope with a disease. Considering the paucity of studies among the Brazilian population regarding the knowledge about AD, and the fact that there is a wide range of educational levels and a vast geographic variable in our country, the objective of this study was to investigate the knowledge about this disease, taking into account demographic data, being a caregiver, or a health professional.

METHODS

We provided a link to a self-administered online questionnaire at Google Forms, which was sent by email to patients and their relatives of a tertiary memory clinic, as well as made available on its social media pages for anyone older than 18 years old. Our questionnaire contained some sociodemographic questions (age, sex, level of education, profession and the presence of a family member with dementia or being a caregiver) and the ADKS.

The ADKS is a well-established scale comprising 30 "true or false" questions regarding AD, with scores varying from 0 (worst) to 30 (best), which can be divided into seven subscales, assessing life impact, risk factors (questions 2, 13, 18, 25, 26 and 27), course, assessment and diagnosis, caregiving, treatment and management and symptoms.

There is no cut-off score²³. There was no validated version of the ADKS adapted to Portuguese, so the questions were translated into Portuguese, maintaining the same structure and meaning of the original questions.

Participants were divided into four groups based on years of education: group 1: 1-4 years; group 2: 5-8 years; group 3: 9-11 years; and group 4: 12 or more years of education.

In order to compare individuals based on their occupation, four groups were used: group 1 included general services (e.g. working as a salesperson, making repairs, cleaning, cooking); group 2 included technical-level professionals (e.g. metallurgy, computer and chemical technicians); group 3 were university-level professionals (e.g. lawyers, economists, architects); group 4 were those who were not working (e.g. retired, unemployed, student).

The study was approved by the Ethics Committee of Hospital Santa Marcelina, and the participants signed consent electronically, before completing the questionnaire.

Statistical analyses

Data were analyzed descriptively using means, standard deviation (SD) and frequency (absolute and relative). For analyses of means among groups nonparametric tests were

performed (Kruskal-Wallis and Mann-Whitney tests). To investigate the association between scores on the ADKS and demographic and social variables, multivariate linear regression analysis was performed with age, education, and profession as potential confounders. The Chi-square test was performed to compare health and non-health professionals, and individuals with 12 or less years of education and those with more than 12 years in each question. The Epi Info, version 7 was used. The significance level was set at $p < 0.05$.

RESULTS

Between November 2016 and March 2017, 1,414 people (76.1% women) from 26 federative units of Brazil, answered the online questionnaire. Most of the participants lived in the State of São Paulo (65.7%) (Figure 1), were women (76.1%), highly educated (87.27% with 12 years or more) and university-level professionals (69.6%). Relatives of individuals with dementia accounted for 41%, while caregivers represented 13.86% of responders. A significant proportion of participants were health professionals (36.42%), of whom almost 40% were physicians. The mean age of responders was 42.3%, and 66.27% were younger than 50 years of age.

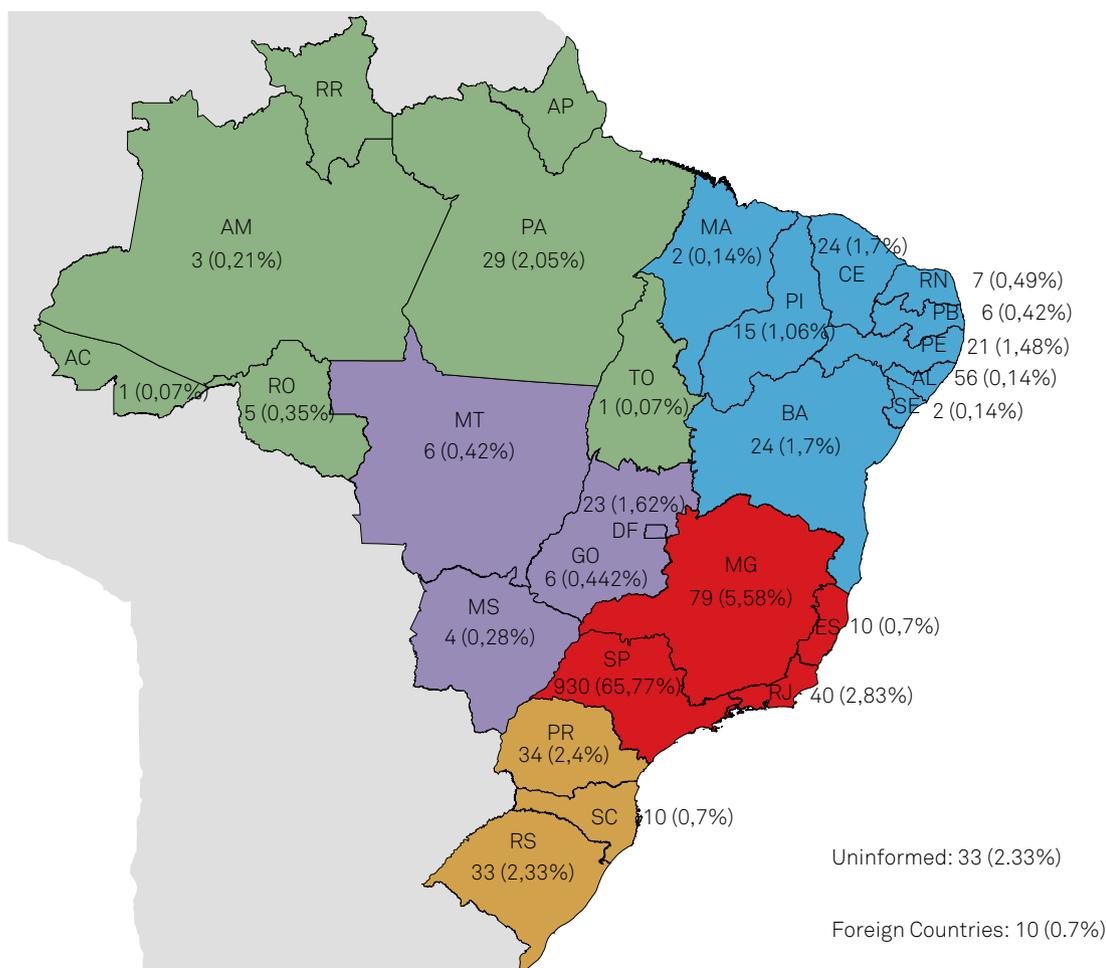


Figure 1. Number of participants for each Brazilian state.

The mean total score for the ADKS was 21.59 (SD ± 3.73); however, when excluding health professionals, it dropped to 20.5 (SD ± 3.51). As shown in Table 1, better educated individuals, health professionals (especially physicians), those below 65 years of age, and university-level professionals had better scores on the ADKS. There was no statistical significance in the total score when analyzing sex, caregivers and relatives of demented patients.

Analyzing each question individually, 11 out of 30 had more than 25% wrong answers. Questions 2, 18 and 26 had the highest rate of errors (78.50%, 65.91%, 67.82% respectively), all of them belonging to the subgroup of risk factors, while questions 5, 29 and 30 had the lowest rate of errors about care-giving (question 5: 10.28%), treatment and management (question 29: 8.27%) and symptoms (question 30: 10.18%). Table 2 shows the proportion of correct answers for each question for all participants, comparing groups by years of education; and Figure 2 compares the

performance of health and non-health professionals for each item. There were 19 questions in which individuals with more than 12 years of education performed significantly better ($p < 0.05$) than those with 12 or less years of education, while health professionals did better than non-health professionals in 22 questions.

DISCUSSION

Our findings showed a better knowledge about issues concerning diagnosis, management and treatment of AD among the younger, better educated, health and university professionals. Interestingly, caregivers did not differ from other people, despite more contact and demanding status during the care of demented relatives.

A Malaysian study applied the ADKS to 445 pharmacists in public hospitals and health clinics, and found a mean score

Table 1. Mean and median scores by sociodemographic variables.

Variable	n	Mean score (SD)	Median	p-value
Sex				
Male	338	21.77 (3.61)	22	0.245
Female	1,076	21.53 (4.08)	22	
Educational level				
1-4 years	26	17.15 (2.86)	17	< 0.001*
5-8 years	47	18.97 (3.60)	19	
9-12 years	107	19.71 (3.43)	19	
> 12 years	1,234	21.95 (3.62)	22	
Age				
18-49 years	937	21.95 (3.70)	22	< 0.001*
50-64 years	373	21.32 (3.24)	21	
≥ 65 years	194	19.30 (3.24)	20	
Profession				
General services	76	19.17 (3.81)	19	< 0.001*
Technical-level professionals	37	19.78 (2.61)	20	
University-level professionals	988	22.20 (3.67)	22	
Not working	313	20.49 (3.43)	20	
Relatives with dementia				
Yes	579	21.90 (3.84)	22	0.016**
No	835	21.38 (3.53)	22	
Caregiver				
Yes	196	21.80 (3.76)	22	0.489**
No	1,218	21.56 (3.48)	22	
Health professional				
Yes	515	23.46 (3.51)	24	< 0.001*
No	899	20.50 (3.33)	21	
Physician				
Yes	202	25.14 (3.55)	26	< 0.001**
No	1,212	20.99 (2.63)	21	

*Kruskal-Wallis Test; **Mann-Whitney Test.

Table 2. Percentage of correct answers for each item.

Question	Subscale	% of correct answers	Years of education: % of correct answers	p-value
1. People with AD are particularly prone to depression.	Life impact	81.57%	0–12 years: 75.98% > 12 years: 82.39%	< 0.05
2. It has been scientifically proven that mental exercise can prevent a person from getting AD.	Risk factors	21.50%	0–12 years: 21.11% > 12 years: 21.52%	0.89
3. After symptoms of AD appear, the average life expectancy is 6 to 12 years.	Course	52.98%	0–12 years: 39.44% > 12 years: 54.94%	< 0.05
4. When a person with AD becomes agitated, a medical examination might reveal other health problems that caused the agitation.	Assessment and diagnosis	68.95%	0–12 years: 65.55% > 12 years: 69.45%	0.29
5. People with AD do best with simple instructions, given one step at a time.	Caregiving	89.92%	0–12 years: 79.44% > 12 years: 91.33%	< 0.05
6. When people with AD begin to have difficulty taking care of themselves, caregivers should take over right away.	Caregiving	53.89%	0–12 years: 32.78% > 12 years: 56.97%	< 0.05
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.	Caregiving	64.57%	0–12 years: 65.00% > 12 years: 64.51%	0.89
8. In rare cases, people have recovered from AD.	Course	83.31%	0–12 years: 83.33% > 12 years: 83.31%	0.99
9. People whose AD is not yet severe can benefit from psychotherapy for depression and anxiety.	Treatment and management	78.29%	0–12 years: 77.22% > 12 years: 78.44%	0.71
10. If trouble with memory and confused thinking appears suddenly, it is likely due to AD.	Assessment and diagnosis	81.11%	0–12 years: 58.88% > 12 years: 84.36%	< 0.05
11. Most people with AD live in nursing homes.	Life impact	84.16%	0–12 years: 74.44% > 12 years: 85.57%	< 0.05
12. Poor nutrition can make the symptoms of AD worse.	Treatment and management	81.26%	0–12 years: 77.44% > 12 years: 88.34%	< 0.05
13. People in their 30s can have AD.	Risk factors	55.80%	0–12 years: 42.78% > 12 years: 57.70%	< 0.05
14. A person with AD becomes increasingly likely to fall down as the disease gets worse.	Course	84.79%	0–12 years: 81.67% > 12 years: 85.25%	0.21
15. When people with AD repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.	Caregiving	79.00%	0–12 years: 64.44% > 12 years: 81.12%	< 0.05
16. Once people have AD, they are no longer capable of making informed decisions about their own care.	Caregiving	60.74%	0–12 years: 33.88% > 12 years: 64.67%	< 0.05
17. Eventually, a person with AD will need 24-hours supervision.	Course	84.79%	0–12 years: 87.22% > 12 years: 84.44%	0.33
18. Having high cholesterol may increase a person's risk of developing AD.	Risk factors	34.09%	0–12 years: 21.11% > 12 years: 35.98%	< 0.05
19. Tremor or shaking of the hands or arms is a common symptom in people with AD.	Symptoms	86.07%	0–12 years: 73.89% > 12 years: 87.84%	< 0.05
20. Symptoms of severe depression can be mistaken for symptoms of AD.	Assessment and diagnosis	71.00%	0–12 years: 60.00% > 12 years: 72.61%	< 0.05
21. AD is one type of dementia.	Assessment and diagnosis	90.31%	0–12 years: 83.33% > 12 years: 91.33%	< 0.05
22. Trouble handling money or paying bills is a common early symptom of AD.	Symptoms	76.03%	0–12 years: 71.67% > 12 years: 76.66%	0.14
23. One symptom that can occur with AD is believing that other people are stealing one's things.	Symptoms	81.54%	0–12 years: 80.56% > 12 years: 81.69%	0.71
24. When a person has AD, using reminder notes is a crutch that can contribute to decline.	Treatment and management	58.98%	0–12 years: 46.11% > 12 years: 60.94%	< 0.05
25. Prescription drugs that prevent AD are available.	Risk factors	77.30%	0–12 years: 67.78% > 12 years: 78.69%	< 0.05
26. Having high blood pressure may increase a person's risk of developing AD.	Risk factors	32.18%	0–12 years: 19.44% > 12 years: 34.03%	< 0.05
27. Genes can only partially account for the development of AD.	Risk factors	86.21%	0–12 years: 75.56% > 12 years: 88.84%	< 0.05
28. It is safe for people with AD to drive, as long as they have a companion in the car at all times.	Life impact	79.84%	0–12 years: 79.44% > 12 years: 79.90%	0.88
29. AD cannot be cured.	Treatment and management	91.73%	0–12 years: 89.44% > 12 years: 92.06%	0.23
30. Most people with AD remember recent events better than things that happened in the past.	Symptoms	89.82%	0–12 years: 84.44% > 12 years: 90.60%	< 0.05

AD: Alzheimer's disease

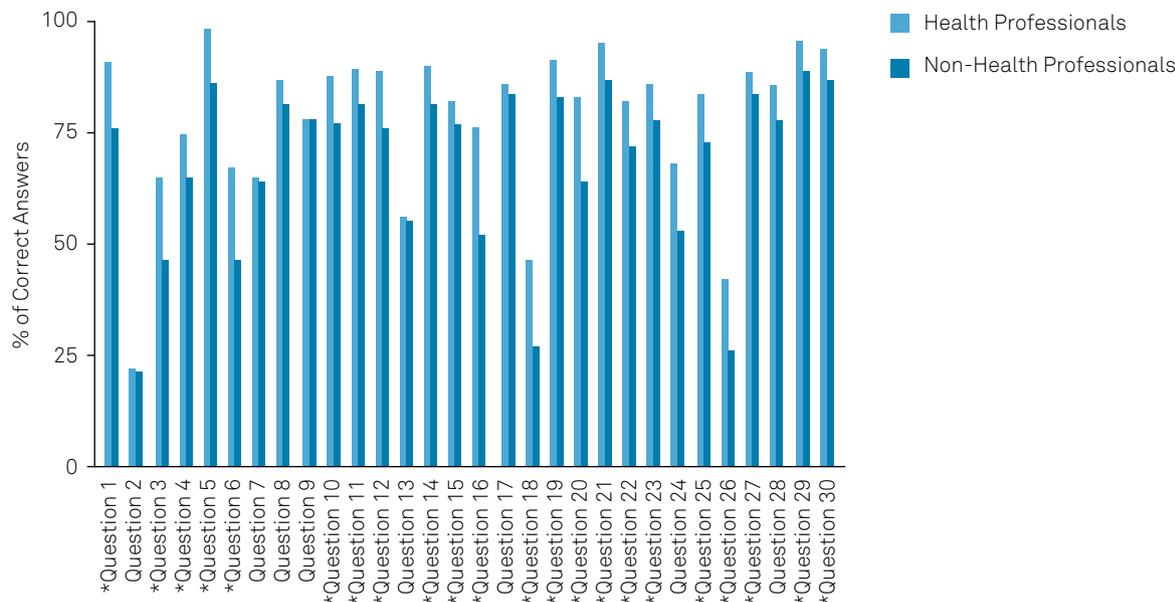


Figure 2. Comparison between health and non-health professionals in each item.

of 18.47 and 19.05 out of 30, respectively²⁴. A study conducted in Australia evaluated 360 health professionals (nursing, medicine, allied health, support staff), who had a mean score of 23.6 out of 30. Medical professionals had a better score (mean score of 26.0); risk factors and course of the disease were the subdomains with the lowest scores²⁵. Norwegian psychologists tested on the ADKS demonstrated a good knowledge about AD, with a mean score of 24.10 out of 30 among 956 participants²⁶. Taking into account these results, Brazilian health professionals had a similar performance in our study, with a mean score of 23.46 points (SD ± 3.33), while physicians (202 participants) had an even better performance (mean score 25.12 – SD ± 2.63). These results show that health professional have a more accurate understanding of AD than the general population, confirming the expectations. A possible explanation for these results is that health professionals, especially physicians, are constantly dealing with people with dementia and generally have more access to detailed scientific information, while laypeople lack open access and high quality information.

A British study assessed the knowledge of 312 adults using the ADKS. By using *post-hoc* analysis, they found that the domains “risk factors” and “course” had fewer correct answers compared with the other domains. There were 10 questions with a high rate of wrong answers, considered by this study as having more than 40% of mistakes. In our study, risk factors and course of disease were also the domains with the highest proportion of errors; eight questions had more than 40% wrong answers, four of them belonging to the risk factor domain. Despite growing evidence that cardiovascular risk factors, such as hypertension, diabetes, hyperlipidemia and metabolic syndrome, increase the risk of AD by different mechanisms, in our study only 34.09% and 32.18% of responders believed

in the association between high cholesterol levels and high blood pressure and AD, respectively. Meanwhile, 21.5% had the erroneous belief that mental exercise is a scientifically-proven prevention of AD. On the other hand, the studied population demonstrated a good knowledge about “assessment and diagnosis”, “symptoms” and “life impact”, domains in which none of the items had scores less than 60%²⁷.

A South Korean study, in which 2,189 participants older than 10 years of age answered a questionnaire of 12 true or false statements regarding dementia, showed a high rate of correct answers (nine or more in 75% of participants). After analyzing subgroups based on educational level, those with 13 or more years of education (54.5% of participants) had a mean of 9.6 correct answers while those with less than six years of study had a mean of 7.3, showing a discrepancy based on educational level²⁸. Yang et al.²⁹ applied a questionnaire about AD to 140 individuals in Tianjin, China and only 11.4% and 12.9% gave correct answers about the main clinical features and risk factors of AD, respectively. Those with a higher educational level and with a lower age had a better performance.

Our study also demonstrated better results among those more educated, with a mean score of 21.95 (SD ± 3.62) and 17.15 (SD ± 2.86) for those with more than 12 years, and 1–4 years of study, respectively (p < 0.05). Similarly, university-level professionals had a better performance when compared with those working in general services, technical-level professionals and those who were not working.

Despite the importance of the general population and caregivers knowing basic information about AD and its consequences and implications, few studies have been conducted in Brazil regarding this issue. Schelp et al.³⁰ conducted a study in which 73 people from a mid-size city in southeast Brazil (Botucatu) answered a questionnaire comprising seven

questions (one multiple choice and the rest open questions) about this topic. When asked to define dementia, 41% cited memory impairment, 32.9% behavioral changes and 8.2% movement disorders. Only 23.3% of responders cited memory impairment as a finding associated with dementia, whereas 56% cited behavioral manifestations³⁰. Matioli et al.³¹ interviewed the population of Santos, São Paulo, Brazil and found that the majority (95%) of the elderly had heard of AD, but only 69.5% of the responders actually knew what AD was, despite the high percentage of individuals who affirmed that they knew of it³¹. Five hundred inhabitants of São Paulo had their knowledge about AD measured, in which only 39.4% recognized dementia as a mental disease, and 22% believed that those symptoms were part of natural aging. A study conducted with 40 relatives of AD patients in São Paulo (equally divided between a private care clinic and a specialized public center) used a specific questionnaire created by the authors, and found that 42.5% of participants believed that patients should be told about the diagnosis in the early stages of AD; 35% of the public service's caregivers versus 30% of the private clinic, were in favor of necropsy for confirming the diagnosis³².

In a systematic review about the public's knowledge of AD, only 16 out of 40 studies used samples of more than 900 people¹⁸. To enlarge our sample, we opted to mail an online questionnaire via email or social networks, reaching thousands of people from different regions of Brazil. Although the majority of responders lived in the state of São Paulo, individuals of almost all of the federative units of Brazil engaged in the research, totaling 1,414 people. As São Paulo is the most developed state in Brazil and the participants had a high educational level, it is possible that the real knowledge of the general population of the country is worse than that which we obtained. The low mean age of responders may also have contributed to the better results, because of the open access to information in the last years, and may have occurred due to the great accessibility that youngsters have to online content, compared with the elderly.

Unlike the logical presumption that caregivers and relatives of affected people would perform better in the questionnaire, there was no statistically significant difference

between relatives and non-caregivers or non-relatives of the demented, demonstrating that even those who deal with AD patients have a poor understanding about the disease. Therefore, it is important to educate the entire population, especially caregivers and relatives of patients, by disseminating high quality information via the internet, social media, support groups and awareness campaigns.

Items 2, 18 and 26 had fewer than 50% correct answers (Table 2), all of which belonged to the risk factors subscale, revealing an important lack of knowledge in this important area, even among health professionals. Furthermore, when analyzing non-health professionals separately, items 3 (subscale "course") and 6 (subscale "caregiving") also showed more than 50% wrong answers. When taking education into account, there were five questions in which less educated individuals (12 years of education or less) had a lower than 50% rate of correct answers, compared with more than 50% among participants with more than 12 years of education. However, as a large part of the studied population had a high level of education, the results tended to represent those participants.

A limitation of this study was the high educational level of the participants, of whom 87.27% had studied for 12 or more years, while 43.7% of the Brazilian population has 11 or more years of schooling. This bias probably occurred due to the higher education of São Paulo citizens (largest part of the responders) compared with other regions, as well as the fact that an online questionnaire reaches those who have more access to technology and social networks. Moreover, true or false questions lead to higher rate of correct answers without being sure, considering that the probability of guessing the answer is 50%. Therefore, the addition of a third option ("I don't know") should be considered in further studies.

In conclusion, despite the increasing prevalence of AD, our study proved that there is still a lack of knowledge regarding this disease in the Brazilian population, especially concerning risk factors, which creates a barrier to preventing dementia. Also, we found that despite the constant contact with people with dementia, caregivers did not perform better than the general population. Thus, interventions should aim to improve the availability and quality of information about dementia.

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