






# Who are the people with Alzheimer's disease in Brazil? Findings from the Brazilian Longitudinal Study of Aging

## *Quem são as pessoas com Doença de Alzheimer no Brasil? Resultados do Estudo Longitudinal da Saúde dos Idosos Brasileiros (ELSI-Brasil)*

Natan Feter<sup>II</sup> , Jayne Santos Leite<sup>III</sup> , Eduardo Lucia Caputo<sup>I</sup> , Rodrigo Kohn Cardoso<sup>IV</sup> ,  
Airtón José Rombaldi<sup>I</sup> 

**ABSTRACT:** *Objective:* To describe the socioeconomic, behavioral, clinical, and health-related characteristics of Brazilian older adults with Alzheimer's disease (AD). *Methods:* Baseline data from the Brazilian Longitudinal Study of Aging were analyzed. This nationwide survey interviewed 9,412 adults aged at least 50 years. Self-reported medical diagnosis of AD and exposure variables (sociodemographic, clinical, behavioral, and health-related) were assessed by face-to-face questionnaire-based interview. Multivariate analyses accounted for possible confounding factors, and values were reported in prevalence ratio (PR) and 95% confidence interval (95%CI). *Results:* Participants with AD have important demographic differences compared with older non-AD participants such as low education level and retirement. Clinically, these patients reported more medical appointments, falls, and higher frequency and duration of hospitalizations compared with non-AD participants. These characteristics may be related to worse physical and mental health observed in this population. Indeed, two out of five older adults with AD in Brazil reported always feeling lonely, while two out of three said they felt depressed or sad much of the time. Adjusted analyses showed that patients with AD were 95% (95%CI 1.08 – 3.50) more likely to be hospitalized in a year compared with non-AD older adults. People with AD in Brazil were more likely to be diagnosed with diabetes (PR = 1.83 [95%CI 1.08 – 3.12]), depression (PR = 3.07% [95%CI 1.63 – 5.79]), Parkinson's disease (PR = 17.63 [95%CI 6.99 – 44.51]), and stroke (PR = 3.55 [95%CI 1.90 – 6.67]) compared with non-AD participants. *Conclusion:* Older adults with AD in Brazil reported impaired physical and mental health compared with the non-AD population.

**Keywords:** Alzheimer disease. Aged. Cohort studies. Brazil.

<sup>I</sup>Superior School of Physical Education, Universidade Federal de Pelotas – Pelotas (RS), Brazil.

<sup>II</sup>School of Human Movement and Nutrition Sciences, University of Queensland – Brisbane (Qld), Australia.

<sup>III</sup>Graduate Program in Cardiology, Medicine School, Universidade Federal do Rio Grande do Sul – Porto Alegre (RS), Brazil.

<sup>IV</sup>Colégio Militar de Porto Alegre – Porto Alegre (RS), Brazil.

**Corresponding author:** Natan Feter. Centre for Research on Exercise, Physical Activity and Health, School of Human Movement and Nutrition Sciences, University of Queensland, 4072, Brisbane, Australia. E-mail: natanfeter@hotmail.com

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**RESUMO:** *Objetivo:* Descrever as características socioeconômicas, comportamentais, clínicas e aquelas relacionadas à saúde de idosos brasileiros com Doença de Alzheimer (DA). *Métodos:* Foram analisados dados de linha de base do Estudo Longitudinal da Saúde dos Idosos Brasileiros (ELSI-Brasil). Essa pesquisa nacional entrevistou 9.412 adultos com pelo menos 50 anos. O diagnóstico de DA e as variáveis de exposição (sociodemográficas, clínicas, comportamentais e aquelas relacionadas à saúde) foram avaliados por meio de entrevista face a face baseada em questionário. As análises multivariadas foram ajustadas por possíveis fatores de confusão, e os valores foram relatados na razão de prevalência (RP) e intervalo de confiança de 95% (IC95%). *Resultados:* Participantes com DA apresentam diferenças demográficas significativas em comparação com idosos sem DA, como aposentadoria e baixa escolaridade. Os respondentes relataram mais consultas médicas, quedas, e maior frequência e duração de hospitalizações quando comparado a participantes sem DA. Essas características podem estar relacionadas à pior saúde física e mental observada nessa população. Dois em cada três idosos com DA no Brasil relataram que se sentiam deprimidos ou tristes na maior parte do tempo. As análises ajustadas revelaram que os pacientes com DA tinham maior probabilidade de serem diagnosticados com diabetes [PR = 1,83 (IC95% 1,08 – 3,12)], depressão [PR = 3,07% (IC95% 1,63 – 5,79)], doença de Parkinson [PR = 17,63 (IC95% 6,99 – 44,51)], e acidente vascular cerebral [PR = 3,55 (IC95% 1,90 – 6,67)] em comparação com adultos mais velhos sem diagnóstico de DA. *Conclusão:* Idosos com DA no Brasil relataram problemas de saúde física e mental em comparação com a população idosa sem DA. *Palavras-chave:* Doença de Alzheimer. Idoso. Estudos de coortes. Brasil.

## INTRODUCTION

In 2016 Brazil presented the second-highest age-standardized prevalence of dementia in the world<sup>1</sup>, with Alzheimer's disease (AD) accounting for about 70% of cases<sup>2</sup>. From 2007 to 2017, the number of deaths due to dementia in the country increased in 55.5%, which is more than breast, prostate, and liver cancer deaths combined<sup>3</sup>. High prevalence and mortality rate have led to an increased burden of AD in the Brazilian hospital system. According to the Brazilian Ministry of Health<sup>4</sup>, the number of hospitalizations due to AD and their total economic cost increased 88 and 44%, respectively, from 2010 to 2019. For comparison purposes, hospitalizations from cerebrovascular and ischemic heart disease increased 36.3 and 29.3%, respectively, during the same period.

In addition to cognitive and behavioral symptoms and loss of functional capacity, other factors may be associated with the increased burden of AD for patients and their families such as high presence of comorbidities<sup>5-7</sup>, impaired access to healthcare facilities<sup>8</sup>, and unhealthy lifestyle<sup>9</sup>. In this sense, Brazil has made important advances in the development and implementation of healthcare programs and policies focusing on mental and physical health of the older adult population to reduce the social and economic burden of AD<sup>10</sup>. In 2020, the first step to create the National Policy on AD and other dementias was completed in the Federal Senate of Brazil<sup>11</sup>. Similar to what is observed in other countries, this document aims to improve the prevention and care of people with AD as well as to raise awareness of this disease.

However, the lack of national perspective on social, economic, and clinical factors among people with AD in Brazil lead to disparities in access, coverage, and treatment<sup>12</sup>. For example, a recent systematic review showed that, from seven studies that identified the prevalence of clinically-assessed dementia among older adults in Brazil, six were conducted in the Southeast (states of São Paulo and Minas Gerais) and one in the Northeast (state of Bahia) regions<sup>13</sup>. Then, the objective of this study was to describe the socioeconomic, behavioral, clinical, and health-related characteristics of people with AD in Brazil.

## **METHODS**

### **STUDY DESIGN**

This descriptive study analyzed baseline data from the Brazilian Longitudinal Study of Aging (ELSI-Brazil). This longitudinal home-based survey was conducted in 2015 and 2016 with a nationally representative sample of adults aged 50 years or older in Brazil<sup>14</sup>. Data were collected by face-to-face questionnaire-based interviews and physical measurements (e.g., weight, height). Interviewers were trained and certificated according to the study protocol<sup>14</sup>. Further, as a quality assurance and control strategy, interviews were recorded, if authorized by the respondent, to be reviewed by trained supervisors.

A series of pilot studies were performed to identify and correct potential problems in the data collection instruments and procedures. The standardized study procedures are detailed in the ELSI-Brazil operations manual (available at the ELSI-Brazil homepage: <http://elsi.cpqrr.fiocruz.br/>). The ELSI-Brazil was approved by the Ethics Committee of the René Rachou Research Center of Oswald Cruz Foundation. More details on survey methods, data collection, and study design can be found elsewhere<sup>14</sup>. The full household and individual questionnaires are available from the ELSI-Brazil homepage (<http://elsi.cpqrr.fiocruz.br/>).

### **SAMPLE**

The sample size was estimated in 10,000 older adults (9,412 participated in the study). Sampling design was conducted with selection stages in order to obtain a representative sample of the noninstitutionalized population within the eligible age range (i.e., 50 years or older) and also from municipalities of different population size. Primary sampling units consisted in municipalities that were allocated to four strata based on population size. Then, eight census tracts were selected in each municipality in the second stage. In the third and last selection stage, households were selected from each census tracts. Then, sample weight was obtained to account for nonresponses and geographic stratification, in such a way population-based inference was possible<sup>14</sup>. All residents aged 50 or older were eligible for individual interview.

## OUTCOME VARIABLE

To measure the number of diagnosed cases of AD among older adults in Brazil, the following question was used: “*Has a doctor ever told you that you have Alzheimer’s disease?*”. If the participant was not able to take part of the interview for any reason (i.e., cognitive impairment), a family member or caregiver answered it.

## DEMOGRAPHIC VARIABLES

The authors used information about age (years), sex (men/women), education (no formal education, elementary, high school, or higher), ethnicity (white, mixed-race, other), marital status (married, singled, separated or divorced, widowed), total annual income (quintile), occupation (employed, unemployed, retired) and, if applicable, reason for being retired (age, time of service, disability, other).

## CLINICAL VARIABLES

Information related to health insurance, frequency of appointments with general physician (GP) or dentist, incidence and duration (none, one week or less, more than one week) of hospitalization, screening services (mammography and eye examination), and incidence of falls were also assessed.

## BEHAVIORAL, NUTRITIONAL, AND HEALTH-RELATED VARIABLES

Interviewers also accessed self-perception of general health (very good or good, fair, poor or very poor), hearing, and vision (excellent to good, regular, bad to very bad). Functional capacity was examined by interviewers at the respondent’s home. The 3-meter walking test<sup>15</sup> (tertile) and questionnaire about functional impairment (impairment in none, one or two, or three or more activities of daily living – ADL) were performed. Further, the survey also examined social interaction (participation in social events), quality of life based on the Quality of Life Scale (CASP-19<sup>16</sup>) score, frequency of sadness and happiness based on 8-item Center for Epidemiologic Studies–Depression Scale (CES-D-8<sup>17</sup>), and sleep quality (very good to good, regular, bad to very bad). Use of drugs to sleep was assessed. More information about each test can be found in the article concerning the ELSI protocol<sup>14</sup>.

Physical measurements were performed in duplicate at the participants’ residences. Weight and height were assessed to obtain body mass index (BMI [normal, overweight, obese]). Waist circumference was reported based on the cutoff proposed by the World Health Organization (102 cm or higher for men and 88 cm or higher for women<sup>18</sup>). In addition,

leisure-time physical activity (measured by the International Physical Activity Questionnaire<sup>19</sup>), awareness of public program to practice physical activity, smoking habit (never, former smoker, current smoker), presence of diagnosed hypertension, diabetes, depression, stroke, and Parkinson's disease were investigated.

Leisure-time physical activity was further categorized in active, insufficiently active, and inactive, based on the World Health Organization guideline<sup>20</sup> (active: at least 150 minutes of moderate-to-vigorous physical activity per week; insufficiently active: between 149 and 1 minute per week; inactive: 0 minute per week).

## STATISTICAL ANALYSIS

Data were imported into STATA 13.1 (StataCorp, College Station, Texas). All analyses were carried out using the “svy” command in order to consider the sample weights and expand the results for the Brazilian population aged 50 years or older. Descriptive data are presented as relative frequencies and 95% confidence interval (95%CI). In order to compare proportions between groups, Chi-squared and Fisher's exact tests were used, as appropriate. When applicable, linear trend test was performed to identify linear associations between variables. Moreover, independent T-test was used to identify differences between groups in continuous variables (i.e., age in years).

In multivariable analysis, Poisson regression was performed to identify the probability of AD participants present the exposure variables compared with non-AD participants. A p-value  $\leq 0.20$  in bivariate analyses was assumed to include a variable on multivariable analyses. Then, a three-level hierarchical model was used<sup>21</sup>. In the first level, sex, age, ethnicity, marital status, education level, and occupation were included. The second level was composed of health insurance and falls. The third level included health status, walking test, quality of life, depression scale, body mass index, leisure-time physical activity, smoking habit, diabetes, and hypertension. The adopted level of significance was  $p < 0.05$ .

## RESULTS

### SOCIODEMOGRAPHIC CHARACTERISTICS

From a total of 9,412 individuals, 82 (0.75%; 95%CI 0.58 – 0.98) participants reported medical diagnosis of AD, as shown in Supplementary Table S1. The prevalence was higher among participants aged between 70 and 79 years (1.67% [95%CI 1.11 – 2.50]), 80 years or older (4.56% [95%CI 3.12 – 6.63]), and widowed (1.88% [95%CI 1.26 – 2.80%]). Self-or proxy-reported medical diagnosis of AD was more prevalent among older individuals, women (67.9%), married (47.2%), participants with elementary school only (70.3%), and

retired (84.8%), as shown in Supplementary Table S2. Proxy interviews were conducted in 61% (n=50) of the participants. Table 1 illustrates the findings from the multivariable analysis. Participants with AD were more likely to be older, unemployed or retired, and less likely to be black. In addition, participants who completed elementary school or had lower educational attainment were more likely to report medical diagnosis of AD.

## HEALTH SYSTEM COVERAGE

As shown in Supplementary Table S3, older adults with AD in Brazil have more appointments per year with GP compared with non-AD participants. On the other hand, people with AD have fewer visits to specialists (i.e., dentist and eye examination) and lower frequency of mammography among women than non-AD participants. Furthermore, people with AD have higher frequency of falls and hospitalizations, and longer hospital stays when compared with non-AD participants.

After adjusting for covariates, participants with AD were more likely to have 10 or more GP appointments in the last 12 months, and to have more hospital admissions and longer hospital stays in the same period compared with non-AD participants (Table 1). Furthermore, AD participants were more likely to have the latest eye examination and dentist appointment over 2 years before the survey.

## CLINICAL AND BEHAVIORAL CHARACTERISTICS

Supplementary Table S4 reported that older adults with AD perceived their health, hearing, and long-distance vision worse than non-AD participants. In addition, about 70% of all AD participants were in the lowest tertile of walking test and 64.8% reported some impairment in at least one instrumental activity of daily living. There was no difference between groups in short-distance vision, social activity, quality of life, CESD-8 score, sleep quality, BMI, knowledge of public program of physical activity promotion, and smoking habit.

A total of 41% of AD participants reported always feeling lonely (Supplementary Table S3). Similarly, 65 and 68.2% said they felt depressed and sad most of the time, respectively. Moreover, the proportion of AD participants who reported feeling happy much of the time was lower than non-AD participants. The proportion of older adults with AD using drug for sleep, high waist circumference, physically inactive, diagnosed hypertension, diabetes, and depression was higher than the non-AD group.

Table 2 describes the multivariable analysis among clinical characteristics according to self- or proxy-reported medical diagnosis of AD in Brazil. As expected, people with AD were more likely to report impairment in three or more activities of daily living (PR [prevalence ratio] = 10.59 [95%CI 4.43 – 25.25]). Furthermore, these patients were 2.75 (95%CI 1.13 – 6.67) times more likely to feel sad much of the time, and hence they were less likely

Table 1. Analyses of sociodemographic characteristics from adults diagnosed with Alzheimer's disease in Brazil, 2015 (n = 9,412).

	Crude			Adjusted*		
	PR	95%CI	p-value	PR	95%CI	p-value
Women (ref: men)	1.80	1.05 – 3.08	0.031 <sup>a</sup>	1.02	0.54 – 1.94	0.956 <sup>a</sup>
Age, years	1.12	1.10 – 1.14	< 0.001 <sup>b</sup>	1.11	1.08 – 1.15	< 0.001 <sup>b</sup>
Ethnicity (ref: white)						
Mixed-race	1.07	0.62 – 1.84	0.117 <sup>a</sup>	1.70	0.93 – 3.02	0.007 <sup>a</sup>
Black	0.30	0.08 – 1.14		0.08	0.01 – 0.64	
Asian	0.21	0.03 – 1.54		0.41	0.06 – 3.56	
Marital status (ref: single)						
Married	0.86	0.36 – 2.08	0.002 <sup>a</sup>	1.00	0.32 – 3.13	0.809 <sup>a</sup>
Divorced/separated	0.71	0.22 – 2.26		1.52	0.49 – 4.71	
Widowed	2.88	1.25 – 6.63		1.21	0.40 – 3.64	
Education level (ref: high school or higher)						
Elementary school or lower	0.72	0.38 – 1.35	< 0.001 <sup>b</sup>	2.61	1.00 – 6.83	0.531 <sup>b</sup>
Occupation (ref: employed)						
Unemployed	27.09	4.00 – 183.61	< 0.001 <sup>a</sup>	16.77	1.99 – 141.51	0.016 <sup>a</sup>
Retired	91.81	12.89 – 654.03		21.44	2.95 – 155.72	
Health insurance (ref: no)	1.50	0.90 – 1.53	0.121 <sup>a</sup>	1.02	0.60 – 1.72	0.954 <sup>a</sup>
≥ 10 medical visits in the last 12 months (ref: < 10 visits)	4.21	2.69 – 6.58	< 0.001 <sup>b</sup>	3.19	1.76 – 5.79	< 0.001 <sup>a</sup>
Hospitalized in the last 12 months (ref: no)	3.39	2.19 – 5.23	< 0.001 <sup>b</sup>	1.95	1.08 – 3.50	0.026 <sup>b</sup>
Fall in the last 12 months (ref: no)	2.16	1.28 – 3.65	0.004 <sup>b</sup>	1.34	0.68 – 2.64	0.399 <sup>b</sup>
Hospitalization longer than one week (ref: one week or less)	5.42	2.23 – 13.19	< 0.001 <sup>b</sup>	2.27	0.87 – 5.92	0.046 <sup>b</sup>
Last dentist visit (ref: < 2 years ago)	1.80	1.44 – 2.26	< 0.001 <sup>a</sup>	1.90	1.06 – 3.42	0.031 <sup>a</sup>
Looked for any medical service in the last 2 weeks (ref: no)	4.21	2.69 – 6.58	< 0.001 <sup>b</sup>	1.44	0.75 – 2.79	0.272 <sup>a</sup>
Last mammography exam (ref: < 3 years ago)	2.68	1.49 – 4.83	0.001 <sup>a</sup>	0.98	0.47 – 2.05	0.963 <sup>a</sup>
Last eye exam (ref: < 2 years ago)	1.28	1.07 – 1.53	0.007 <sup>a</sup>	1.24	1.05 – 1.46	0.012 <sup>a</sup>

PR: prevalence ratio; 95%CI: 95% confidence interval; ref: reference; <sup>a</sup>heterogeneity test; <sup>b</sup>linear trend test; \*adjusted for sex, age, ethnicity, marital status, education level, occupation, health insurance, and fall.

Table 2. Crude and adjusted analyses among clinical characteristics according to self-reported medical diagnosis of Alzheimer's disease in Brazil, 2015 (n = 9,412).

	Crude			Adjusted*		
	PR	95%CI	p-value	PR	95%CI	p-value
Health status (ref: Very good/good)						
Fair	1.03	0.54 – 1.98	0.056 <sup>b</sup>	1.20	0.55 – 2.63	0.117 <sup>b</sup>
Poor/very poor	3.00	1.52 – 5.94		2.61	1.21 – 5.64	
Self-rated hearing (ref: excellent/good)						
Regular	1.39	0.77 – 2.54	< 0.001 <sup>b</sup>	0.72	0.32 – 1.64	0.200 <sup>b</sup>
Bad – very bad	7.31	3.75 – 14.25		2.45	0.95 – 6.30	
Self-rated long-distance vision (ref: excellent/good)						
Regular	1.93	1.0 – 3.76	< 0.001 <sup>b</sup>	1.06	0.49 – 2.33	0.153 <sup>b</sup>
Bad – very bad	3.64	2.05 – 6.46		1.87	0.87 – 4.02	
Walking test, tertile (ref: 1 <sup>st</sup> and 2 <sup>nd</sup> tertile) <sup>d</sup>						
3 <sup>rd</sup> (slowest)	3.97	1.67 – 9.44	0.002 <sup>b</sup>	0.86	0.28 – 2.65	0.875 <sup>b</sup>
Impaired ADL (ref: less than 3)						
3 or more	23.75	13.22 – 42.67	< 0.001 <sup>b</sup>	10.59	4.43 – 25.25	< 0.001 <sup>b</sup>
Quality of life (ref: 1 <sup>st</sup> [lowest])						
2 <sup>nd</sup>	0.42	0.14 – 1.19	0.103 <sup>b</sup>	0.50	0.14 – 1.72	0.438 <sup>b</sup>
3 <sup>rd</sup> (highest)	0.34	0.08 – 1.43		0.60	0.15 – 2.68	
Elevated depression symptoms (ref: no) <sup>e</sup>	2.01	0.69 – 5.91	0.202 <sup>b</sup>	2.61	0.88 – 7.79	0.085 <sup>a</sup>
Happy most of the time (ref: no)	0.46	0.22 – 0.95	0.036 <sup>a</sup>	0.41	0.15 – 1.09	0.073 <sup>a</sup>
Sad most of the time (ref: no)	3.66	1.76 – 7.61	0.001 <sup>a</sup>	2.75	1.13 – 6.67	0.026 <sup>a</sup>
Feel lonely (ref: sometimes or never)						
Always	4.77	1.74 – 13.07	0.005 <sup>b</sup>	2.52	0.73 – 8.67	0.158 <sup>b</sup>
Central obesity <sup>b</sup> (ref: no)	1.86	1.15 – 3.00	0.012 <sup>a</sup>	1.23	0.67 – 2.23	0.505 <sup>a</sup>
Physical activity (ref: inactive)						
Insufficiently active	0.33	0.17 – 0.64	< 0.001 <sup>b</sup>	0.41	0.14 – 1.21	0.242 <sup>b</sup>
Active	0.29	0.14 – 0.59		0.59	0.23 – 1.53	
Smoking habit (ref: never)						
Former smoker	0.78	0.44 – 1.37	0.120 <sup>a</sup>	0.75	0.38 – 1.49	0.348 <sup>a</sup>
Smoker	0.39	0.16 – 0.98		0.81	0.27 – 2.39	
Sleep quality (ref: very good/good)						
Regular	1.19	0.64 – 2.18	0.363 <sup>b</sup>	1.16	0.57 – 2.36	0.675 <sup>b</sup>
Bad/very bad	1.57	0.84 – 2.96		1.17	0.47 – 2.96	
Drugs for sleep (ref: no)	3.78	2.19 – 6.55	< 0.001 <sup>a</sup>	2.54	1.29 – 5.01	0.007 <sup>a</sup>
Hypertension (ref: no)	1.91	1.08 – 3.38	0.026 <sup>a</sup>	1.30	0.71 – 2.39	0.390 <sup>a</sup>
Diabetes (ref: no)	2.41	1.38 – 4.22	0.002 <sup>a</sup>	1.83	1.08 – 3.12	0.040 <sup>a</sup>
Diagnosed depression (ref: no)	3.57	2.18 – 5.86	< 0.001 <sup>a</sup>	3.07	1.63 – 5.79	0.001 <sup>a</sup>
Parkinson's disease (ref: no)	21.41	11.20 – 40.92	< 0.001 <sup>a</sup>	17.63	6.99 – 44.51	< 0.001 <sup>a</sup>
Stroke (ref: no)	6.37	3.94 – 10.29	< 0.001 <sup>a</sup>	3.55	1.90 – 6.67	< 0.001 <sup>a</sup>

PR: prevalence ratio; 95%CI: 95% confidence interval; ADL: Activities of daily living; ref: reference; <sup>a</sup>heterogeneity test; <sup>b</sup>linear trend test; <sup>c</sup>only among women; <sup>d</sup>lower score indicates high functional impairment; <sup>e</sup>score higher than 4 in the 8-item CES-D; \*adjusted for sex, age, ethnicity, marital status, education level, occupation, health insurance, and fall.



to feel happy most of the time, although this association did not reach statistical significance (PR=0.41 [95%CI 0.15 – 1.09];  $p = 0.075$ ). Participants with AD had no increased likelihood to worse sleep quality although they were more likely to use drugs for sleep (PR = 2.54 [95%CI 1.29 – 5.01]). In addition, these participants were more likely to be diagnosed with diabetes (PR = 1.83 [95%CI 1.08 – 3.12]), depression (PR = 3.07 [95%CI 1.63 – 5.79]), Parkinson's disease (PR=17.63 [95%CI 6.99 – 44.51]), and stroke (PR = 3.55 [95%CI 1.90 – 6.67]) compared with non-AD participants.

## DISCUSSION

This is the first study that described the socioeconomic, clinical, behavioral, and health-related characteristics of people with AD in Brazil. The authors highlighted that older adults with AD are less likely to be black and more likely to be retired or unemployed. Moreover, these participants are more likely to have more GP visits and hospitalizations during a one-year period. On the other hand, they are less likely to do regular eye examination and visit a dentist. These findings showed that older adults with AD in Brazil reported poor mental health with higher likelihood of feeling sad and being diagnosed with other chronic condition such as depression and Parkinson's disease.

The observed prevalence of AD in the present study (0.75% [95%CI 0.58 – 0.98]) was similar to the prevalence reported by the Institute for Health Metrics and Evaluation (0.75% [0.65 – 0.85]) in Brazil in 2015<sup>3</sup>. Furthermore, the proportion of people with AD in Brazil increased 127% since 1990 (0.33 [95%CI 0.28 – 0.38]). Other studies have explained that ageing is the most important risk factor for AD<sup>22</sup>. According to the Brazilian Institute of Geography and Statistics (IBGE)<sup>23</sup>, the population aged 60 years or older will increase in 284.2% from 2000 to 2050. In this study, the likelihood of medical diagnosis of AD among the sample increases 11% (95%CI 8 – 15) for each year increased in ageing.

On the other hand, black participants have lower likelihood of reporting medical diagnosis of AD than whites. Racial inequalities in life expectancy<sup>24</sup> and healthcare system access<sup>25,26</sup> in Brazil may partly explain the lower likelihood for AD among black participants. Also, some authors explained that the word used for "Black" in Brazil — "*preto*" — might be used as a racial slur. This factor might lead some black people not to declare other individuals or even themselves as black<sup>27</sup>. However, the proportion of individuals self- or proxy-declared as black was similar to the observed in the latest national survey (continuum PNAD 2019)<sup>28</sup>. The 2020 report of the Lancet Commission showed that racial disparity is still one factor to be tackling in the management of AD and other dementias. Providing equal access to healthcare facilities is one way to reduce racial inequality in the burden of AD and other dementias.

The lack of regular screening, such as eye examination and dentist visits, must be highlighted. The reduced physical function and impaired activities of daily living with the disease progression may diminish the ability to adequate oral hygiene care<sup>29</sup>. Consequently, adequate access for maintenance of good oral health must be provided for patients with AD

in Brazil. In an extended literature review, Kocaelli et al.<sup>30</sup> reinforced that dental treatment, especially for patients with AD, represents less pain, more dignity, and a better quality of life. Besides, lower frequency of eye examinations seems to be associated with an increased prevalence of vision problems in this population<sup>31</sup>. Similar to oral health, adequate access to visual treatment means not only an optimal visual function, but also a better quality of life.

AD is characterized by a decline in cognitive and physical capacity leading to fragility and inability to independently perform daily activities. Previous findings have proposed gait speed, an index of functional capacity, as an independent predictor of mortality in older adults<sup>32,33</sup>. As expected, people with AD were more likely to report impairment in three or more activities of daily living<sup>34</sup>. Strictly associated with independence and functional capacity, vision and hearing impairments were also highly prevalent in this population. However, there is no consistent positive effect of interventions, such as provision of hearing aids, prism lens, and cataract surgery, in cognitive decline and caregivers' burden of people with AD<sup>35</sup>. Therefore, patients must be stimulated to perform physical and social activity in a daily basis as a non-pharmacological approach to preserve or even improve functional capacity and quality of life. Reducing the degree of dependence from caregivers is a reachable goal that results in a reduced burden of AD for the patient, caregivers, and the family.

Furthermore, presence of comorbidities, such as cardiovascular and metabolic diseases<sup>5</sup>, might be associated with the high rate of hospital admissions in older adults with AD. The 2020 report of the Lancet Commission<sup>36</sup> highlighted the need for holistic post-diagnostic care, as most people with AD and other dementias have other illnesses and might struggle to correctly manage them. The correct management of chronic diseases might reduce the occurrence of potentially preventable hospitalizations. For example, diabetes-related complications increase in 2.25 and 1.61 the likelihood for potentially avoidable hospitalization in individuals with AD<sup>7</sup>. Likewise, in the United States of America, falls and ischemic heart disease are the main causes of hospitalizations among AD patients<sup>6</sup>. Impaired physical capacity has been described as risk factor for mortality<sup>37</sup>, poor quality of life<sup>38</sup>, and increased economic cost<sup>39</sup>. Although its cause has not been completely understood, decline in physical capacity have been linked to low level of physical activity and increased sitting time<sup>9</sup>. Thus, it is worth highlighting the importance of increased awareness on these diseases not only as independent chronic diseases, but also in the biological and social relationship between them.

Some limitations of the present study must be acknowledged. First, its cross-sectional design does not allow the authors to propose any causal relationship between the assessed variables and medical diagnosis of AD. For example, the low likelihood of sleep problems in people with AD might be associated with the high proportion of participants who reported using drugs to sleep. However, this type of study design is essential to provide information for policymakers about the current needs of people with AD in Brazil.

Second, AD was assessed based on self- or proxy-report of physician diagnosis. In order to mitigate the effect of memory failures that could lead to misclassification bias, proxy interviews (61% [n = 50]) were conducted with a family member or caregivers if the participant was physically or cognitively impaired. ELSI-Brazil is part of the Health and Retirement

Study (HRS) — Family Studies, covering around 150,000 older adults worldwide<sup>40</sup>. In all HRS-Family Studies, Alzheimer's disease was assessed with the same strategy (self- or proxy-reported medical diagnosis) in order to preserve comparability.

Third, 82 individuals reported medical diagnosis of AD in this survey. This low prevalence may be related to the under-detection rate of 77% in Brazil<sup>41</sup>. Nevertheless, the Brazilian National Survey of Health (*Pesquisa Nacional de Saúde* — PNS), conducted in 2013, was the largest survey in Brazil to monitor the health conditions and behaviors that included a question about dementia diagnosis. According to PNS, a prevalence of 0.60% (95%CI 0.48 – 0.73) of dementia was found, which is similar to that reported in the present study (0.75%; 95%CI 0.58 – 0.98). Indeed, the Institute for Health Metrics and Evaluation<sup>3</sup> estimated a prevalence of AD and other dementia in Brazil in 0.75% (0.65 – 0.85), which is close to the values reported in both ELSI and PNS. However, since PNS conducted in 2013 and ELSI, in 2015, no national-based survey with questions about dementia (i.e., AD) prevalence was conducted in the country with the second-highest age-standardized-prevalence of this syndrome. Prevalence data are mostly gathered from studies conducted in high-income countries<sup>1</sup> that may not have the best picture of how dementia impacts the public health system of a middle-income country such as Brazil.

The present study provides the first evidence, based on national survey, that people with AD in Brazil are more likely to have worse mental and physical health. People with AD in Brazil are underdiagnosed and undertreated, which may lead to higher frequency of medical visits, hospital admission, and comorbidities. The development of a universal and evidence-based agenda to preserve and improve the health of people with AD in Brazil is necessary to reduce the social and economic burden of this disease for the patients, their families, and society.

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