## Announcements

# The 27th World Alzheimer's Day — September 21, 2020

Alzheimer's disease (AD) is a common chronic progressive neurodegenerative disorder among the elderly. It was first described by Alois Alzheimer in 1906 for a patient he first encountered in 1901 (*1*). As the most common form of dementia, it affects 3.21% of the population over the age of 65 years old in China (*2*). The number of people affected by the disease is expected to increase dramatically as it devastates families and communities and is one of the costliest chronic conditions to manage (*3*).

World Alzheimer's Day was launched by Alzheimer's Disease International (ADI) on September 21, 1994, and then September was designated as World Alzheimer's Month in 2012 (*4*). World Alzheimer's Day and Month have become global efforts to raise awareness and challenge the stigma that surrounds dementia.

The theme of this year's campaign — "Let's talk about dementia" — is especially important as the coronavirus disease 2019 (COVID-19) pandemic has led to extremely high death rates amongst people with dementia globally (*5*).

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## Preplanned Studies

# Undetected Dementia in Community-Dwelling Older People — 6 Provincial-Level Administrative Divisions, China, 2015–2016

Shige Qi[1]; Han Zhang[1]; Haoyan Guo[1]; Jing Wu[1]; Zhihui Wang[1,#]

**Summary**

**What is already known about this topic?**

Dementia affects approximately 5.3% of the population aged over 60 years in China — an estimated more than 10 million elderly people. Many older adults living with dementia have not been formally diagnosed, and a previous study found a peak of 93.1% of dementia patients during 2007–2011 remained undetected.

**What is added by this report?**

The latest undetected dementia rate and differences between urban and rural areas were estimated in this study based on a large nationwide study carried out in China in 2015–2016. The overall proportion of undetected dementia was 85.8%, 75.0% in males, 90.4% in females, 77.5% in urban residents, and 93.5% in rural residents.

**What are the implications for public health practice?**

Efforts should be made to increase the awareness of dementia in the public, to improve the capacity of early recognition of dementia by primary care physicians in community settings, and also to improve the local diagnostic capability of dementia.

Dementia is a leading cause of disability in people older than 65 years old worldwide, and dementia patients in China account for approximately 25% of all patients with dementia worldwide (*1*). According to a previous study, 93.1% of dementia was undetected (*2*). In order to understand the latest proportion of undetected dementia in China, data from the Prevention and Intervention on Neurodegenerative Disease for Elderly in China (PINDEC) study was analyzed, and the proportion of undetected dementia was estimated using questionnaire-based interviews and a standard procedure of dementia screening and

diagnosis. The differences of undetected dementia between demographic and geographic subgroups were analyzed via chi-squared test. This study reported that the proportion of undetected dementia declined from the past but remained at a high level among the elderly in China, especially among those whom were female (compared to male), resided in rural areas (compared to urban), were aged <75 years (compared to other age groups), and were illiterate (compared to literate). Awareness of dementia should be increased in the general public to improve the capacity of early recognition of dementia by primary medical doctors in the community setting and also to improve the local diagnostic capability of dementia.

Dementia is a chronic disease with progressive deterioration in activities of daily living (ADLs), cognition, and behavior leading to severe disability and ultimately death (*3*). Globally, dementia is one of the most prevalent neurological disorders and accounts for the fourth largest loss of disability-adjusted life years (DALYs) and the second largest proportion of deaths among all neurological disorders (*4*). A recent meta-analysis reported an overall prevalence of dementia of 5.30% for the Chinese population aged 60 years and above in 2018 (*5*); this would be an estimated 10 million elderly people affected by dementia in 2019 based on the number of elderly people in China. In recent years, measures including policy initiatives, health education, and training programs were conducted to improve dementia screening and diagnosis, but little is known about the latest proportion of undetected dementia, especially differences between residents of urban and rural areas.

All patients were from the PINDEC study that was initiated in 2015 aiming to understand the epidemiology of neurodegenerative diseases and associated risk factors among the population aged 60 years and above in China. We used multistage clustered sampling to select the study sample based on geographic location, population size, and level of economic development. The selected provincial-level administrative divisions (PLADs) included Beijing, Shanghai, Hubei, Sichuan, Guangxi, and Yunnan. Within each PLAD, one urban district and one rural county were randomly selected as study sites (counties/districts). Within each site, one subdistrict in urban areas and one township in rural areas were selected with probability proportional to size. Within each subdistrict or township, four to eight neighborhood communities or administrative villages were selected with probability proportional to size. Within each neighborhood community or administrative village, 100 to 200 households with people aged 60 years and above were randomly selected as study households. In the final stage, all family members aged 60 years and above who have a registered Hukou (household registration) and lived in the household for more than one year were selected as study participants. A total of 26,164 people were selected and 24,117 participated in the survey. In 2015–2016, 24,117 community residents participated in questionnaire-based interviews and a procedure of dementia screening and diagnosis. The study was approved by the Ethical Committee of the National Center for Chronic and Non-Communicable Disease Control and Prevention, China CDC. All participants provided written informed consent.

Dementia was assessed using a three-stage approach. All participants were first screened with a Chinese version of the Ascertain Dementia 8 (AD8) (*6*). Participants with AD8 score ≥2 were then assessed with the Mini-Mental State Examination (MMSE) and cognitive impairment was defined as MMSE ≤17 for illiterate participants, ≤20 for those with primary school education and below, and ≤24 for those with junior high school education and above (*7*–*8*). In the final stage, all participants with cognitive impairment underwent a thorough clinical examination by neurologists. Dementia was diagnosed based on the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (*9*).

Descriptive statistical analyses of different undetected dementia were performed for gender, age, and area type (urban/rural) by using software SAS (version 9.4; SAS Institute, Inc. Cary, NC, USA). Chi-squared tests were adopted to analyze the differences of undetected dementia between subgroups, with a *p*-value of <0.05 considered statistically significant. Patients with undetected dementia were defined as those who were diagnosed in the survey but did not have doctor-diagnosed dementia before.

The characteristics of study participants were presented in Table 1. Among the 24,117 participants in the survey aged 60 years and above, 44.5% were men, 53.7% resided in urban areas, 22.8% were widowed, and 11.7% were living alone. Among 24,117 participants, we diagnosed 740 (3.1%) as having dementia. Among those detected, there were 105 (14.2%) patients who had doctor-diagnosed dementia before. The overall proportion of undetected dementia was 85.8% (95% CI: 83.3%–88.3%), 75.0% (95% CI: 69.2%–80.8%) in men, and 90.4% (95% CI:

TABLE 1. General characteristics of the study sample from the Prevention and Intervention on Neurodegenerative Disease for Elderly in China (PINDEC) conducted in 6 provincial-level administrative divisions, 2015–2016.

| Characteristics | Number of participants (n=24,117) | Proportion (%) |
|---|---|---|
| Location | | |
| Urban | 12,950 | 53.7 |
| Rural | 11,167 | 46.3 |
| Sex | | |
| Men | 10,722 | 44.5 |
| Women | 13,395 | 55.5 |
| Age group (years old) | | |
| 60–64 | 5,346 | 22.2 |
| 65–69 | 7,033 | 29.2 |
| 70–74 | 5,076 | 21.0 |
| 75–79 | 3,639 | 15.1 |
| ≥80 | 3,023 | 12.5 |
| Marital status | | |
| Non-widowed | 18,613 | 77.2 |
| Widowed | 5,504 | 22.8 |
| Education | | |
| Illiterate | 9,376 | 38.9 |
| Primary school | 7,652 | 31.7 |
| Junior high school and above | 7,089 | 29.4 |
| Living status | | |
| Alone | 2,824 | 11.7 |
| With family | 21,293 | 88.3 |

Abbreviation: n=number.

87.8%–92.9%) in women. The proportion of undetected dementia was higher in the group aged 70–74 years than the other age groups, higher in widowed participants than non-widowed, higher in people living alone than living with families (Table 2).

The proportion of undetected dementia in rural populations was significantly higher than that in urban populations (93.5% *vs.* 77.5%, $p<0.001$). In urban areas, the proportion of undetected dementia increased with age before 75 years but decreased with age after 75 years ($p=0.011$) and was higher in widowed participants than non-widowed ($p<0.001$). However, no age group and marital status differences were found among rural residents ($p=0.332$ and $p=0.068$, respectively). In addition, both in rural and urban areas, the proportion of undetected dementia was higher in illiterate groups than literate groups. (Table 2).

## DISCUSSION

This study showed that older adults in China had a high level of undetected dementia, especially among females (compared to males), rural residents (compared to urban), age <75 years (compared to other age groups), and illiterate people (compared to literate). The overall proportion of undetected dementia was 85.8%, which was much higher than the world average and some developed countries. Systematic research was conducted until October 2016 for studies reporting the proportion of undetected dementia in either the community or in residential care settings worldwide and found that the pooled rate of undetected dementia was 61.7% (*10*). Amjad et al. estimated that about 58.7% of older adults with probable dementia were undetected in the US (*11*). The World Health Organization's (WHO) *Global action plan on the public health response to dementia 2017–2025* set out a target for countries: "in at least 50% of countries, as a minimum, 50% of the estimated number of people with dementia are diagnosed by 2025" (*12*).

This study showed progress in China toward this goal. According to a previous study with a sample of 7,072 participants aged ≥60 years in 6 PLADs during 2007–2011, a peak of 93.1% of dementia patients were undetected (*2*). An explanation for the recent decline to 85.8% found in this study may be due to general improvements of socioeconomic conditions and health services, such as medical insurance coverage, the establishment of memory clinics, and the increased education level of the public.

This study found that an increased risk of having undetected dementia was strongly associated with low socioeconomic factors such as residing in rural areas, having lower levels of education, and being windowed, which was consistent with previous studies (*2,11*) and may be due to the lack of healthcare, poor health awareness, and health insurance coverage. This study also found that women had a higher proportion of undetected dementia than men, which is consistent with a previous study in China but was different from the US (*11*). Gaps still existed in dementia diagnosis in rural and urban areas with 93.5% of patients being undetected in rural areas and 77.5% being undetected in urban. This might be due to rural elderly residents having lower awareness and worse medical conditions when compared to urban residents or due to the higher prevalence of dementia in rural areas than in urban areas (*13*). This study also found that in urban areas, the proportion of undetected dementia increased with

TABLE 2. Numbers and proportions of undetected dementia by basic characteristics among the elderly (aged ≥60 years) from the Prevention and Intervention on Neurodegenerative Disease for the Elderly in China (PINDEC) conducted in 6 provincial-level administrative divisions, 2015–2016.

| Characteristics | n (%) | Overall | | | Urban | | | Rural | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | | Number | Proportion (%) (95% CI) | *p*-value | Number | Proportion (%) (95% CI) | *p*-value | Number | Proportion (%) (95% CI) | *p*-value |
| Sex | | | | <0.001 | | | 0.004 | | | <0.001 |
| Men | 220(29.7) | 165 | 75.0(69.2−80.8) | | 93 | 69.4(61.5−77.3) | | 72 | 83.7(75.8−91.7) | |
| Women | 520(70.3) | 470 | 90.4(87.8−92.9) | | 183 | 82.4(77.4−87.5) | | 287 | 96.3(94.2−98.5) | |
| Age group (years old) | | | | 0.030 | | | 0.011 | | | 0.332 |
| 60–64 | 73(9.9) | 61 | 83.6(74.9−92.3) | | 22 | 78.6(62.4−94.8) | | 39 | 86.7(76.3−97.0) | |
| 65–69 | 129(17.4) | 115 | 89.1(83.7−94.6) | | 56 | 84.8(76−93.7) | | 59 | 93.7(87.5−99.8) | |
| 70–74 | 130(17.6) | 122 | 93.8(89.7−98.0) | | 53 | 91.4(83.9−98.8) | | 69 | 95.8(91.1−100.6) | |
| 75–79 | 188(25.4) | 158 | 84.0(78.8−89.3) | | 66 | 71.7(62.4−81.1) | | 92 | 95.8(91.8−99.9) | |
| ≥80 | 220(29.7) | 179 | 81.4(76.2−86.5) | | 79 | 70.5(62.0−79.1) | | 100 | 92.6(87.6−97.6) | |
| Marital status | | | | <0.001 | | | <0.001 | | | 0.068 |
| Non-widowed | 485(65.5) | 393 | 81.0(77.5−84.5) | | 187 | 71.9(66.4−77.4) | | 206 | 91.6(87.9−95.2) | |
| Widowed | 255(34.5) | 242 | 94.9(92.2−97.6) | | 89 | 92.7(87.4−98.0) | | 153 | 96.2(93.2−99.2) | |
| Education | | | | <0.001 | | | <0.001 | | | 0.001 |
| Illiterate | 454(61.4) | 430 | 94.7(92.6−96.8) | | 138 | 92.0(87.6−96.4) | | 292 | 96.1(93.9−98.3) | |
| Primary school | 157(21.2) | 115 | 73.2(66.2−80.2) | | 66 | 68.0(58.6−77.5) | | 49 | 81.7(71.6−91.7) | |
| Junior high school and above | 129(17.4) | 90 | 69.8(61.7−77.8) | | 72 | 66.1(57.0−75.1) | | 18 | 90.0(75.6−104.4) | |
| Living status | | | | 0.043 | | | 0.116 | | | 0.815 |
| Alone | 129(17.4) | 118 | 91.5(86.6−96.4) | | 39 | 86.7(76.3−97.0) | | 79 | 94.0(88.9−99.2) | |
| With family | 611(82.6) | 517 | 84.6(81.7−87.5) | | 237 | 76.2(71.4−81.0) | | 280 | 93.3(90.5−96.2) | |
| Overall | 740(100.0) | 635 | 85.8(83.3−88.3) | | 276 | 77.5(73.2−81.9) | | 359 | 93.5(91.0−96.0) | |

Abbreviation: CI=confidence interval.

age before 75 years but decreased with age after 75 years. People with dementia before the age of 75 may have mild symptoms, which is considered normal aging, or, because of stigma, they might not want a dementia diagnosis while they can live without help.

Detecting people living with dementia is crucial for necessary care and treatment. Early diagnosis allows for advanced-care planning and improves prognosis (*2*). However, there are many factors that affected the accurate diagnosis of dementia such as the following: a shortage of dementia specialists; the stigma associated with dementia; inconsistent versions or cutoff scores for neuropsychological tests; the costs of certain advanced techniques to assist with the diagnosis, such as positron emission tomography (PET), which are not fully covered by health insurance; the refusal by patients and their families of invasive diagnostic examinations such as lumbar puncture and brain pathological examinations; lack of regular screening programs in community settings; and an low awareness of dementia (*1*,*14*–*15*).

This study was subject to some limitations. First, the proportion of undetected dementia among community-dwelling older people might be overestimated because patients with dementia living in hospitals or private nursing institutions were not included in this study. Second, the data for undiagnosed dementia for each type cannot be distinguished in this study, because the types of dementia were not subdivided in the diagnostic stage. Furthermore, this study was conducted not for the purpose of identifying the knowledge, attitudes, and practice of screening and early diagnosis of dementia in primary care and cannot offer information for the examination of factors affecting accessibility to diagnosis.

In conclusion, this study represents the most up-to-date data with a relatively large sample size and standard diagnostic criteria to estimate the proportion of undetected dementia (85.8%) in China. Despite

improved access to health services, inadequate diagnosis and management for dementia is still common, particularly in rural areas. Efforts should be made to increase the awareness of dementia in the public, to improve the capacity of early recognition of dementia by primary care physicians in community settings, and also to improve the local diagnostic capability of dementia.

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[#] Corresponding author: Zhihui Wang, wangzhihui@ncncd.chinacdc.cn.

[1] National Center for Chronic and Non-Communicable Disease Control and Prevention, Chinese Center for Disease Control and Prevention, Beijing, China.

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