

# Factors associated with caregiving status and caregiver burden for patients with Alzheimer's disease in China

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## Research

**Keywords:** Alzheimer's disease, Caregiving status, Caregiver burden

**Posted Date:** April 20th, 2021

**DOI:** <https://doi.org/10.21203/rs.3.rs-435565/v1>

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## Abstract

## Background

The prevalence of Alzheimer's disease (AD) is rapidly increasing in China, which puts a great deal of pressure on the patient's family and society. The way of patient care deserves social attention. This study focused on the caregiving status and the relationship between caregivers' burden and patient factors based on the Chinese pension system.

## Methods

This is a large-scale, multicenter cross-sectional study aimed to investigate the two types of caregiving (family care and nursing care), and the caregiver burden of patients with AD. A total of 1675 patients with a definite diagnosis of probable AD from 30 provincial, municipal, and autonomous regions of mainland China were enrolled from August 2019 to December 2019. Caregivers of AD patients completed the questionnaire under the guidance of trained investigators. The characteristics of patients and caregivers were summarized by descriptive statistics.

## Results

Among the 1675 AD patients, 1522 (90.87%) patients adopted family care. There was a significant correlation between the housing condition, annual income, self-care ability, and the choice of caregiving ( $P < 0.05$ ). According to the caregiver burden inventory score, 28.90% of the caregivers had a low burden, 57.01% had a medium burden and 14.09% had a heavy burden, concerning the patient's age, caring style, self-care ability, etc. The burden of the caregivers in the nursing facilities is relatively high than that of family care ( $P < 0.05$ ).

## Conclusion

Family care is the main way of care for AD patients in China. Caregiving status is affected by living place, patient income and severity of the disease. The burden of family caregivers of AD is generally high, especially patients with disabilities.

## Background

China is the most populous country in the world and the increasing age of the population is becoming more and more serious every year. With the larger number of older adults, the prevalence of dementia is also rapidly rising [1]. According to a large, multiregional study, Alzheimer's disease (AD) is the most common form of dementia. It has been estimated that the prevalence of AD among older adults aged 65 years and above is 3.21% and increases substantially with age [2]. At the same time, the increasing prevalence of AD places a large burden on Chinese society [3]. In China, the average socioeconomic cost of AD per patient per year is US \$19,144.36 (RMB 122,523). In 2015, the total cost was estimated to be US \$167.74 billion [4], a 5.95-fold increase over the previous estimate of US \$28.18 billion according to the World Alzheimer Report in 2015. Overall, the AD-related cost in China is huge and rapidly growing.

The questions that remain involve how these patients can receive appropriate care and how to reduce the disease burden on families. It has been found that family care is the best method of care for patients with AD as it provides emotional and psychological comfort [5]. However, studies measuring the functional health of patients under family care show different outcomes [6, 7]. Also, the demands of caring responsibilities change at different stages of the disease, which can be a great challenge for the family. AD can cause emotional and psychological distress to family caregivers, urging them to seek professionals to help care for the patients [8]. Therefore, the relationship between family care and nursing care has recently become very close.

In western society, the family and nursing care of patients depend on personal needs, financial situations, and the availability of care [9]. However, in traditional Chinese culture, the family should be responsible for their sick and elderly. To date, few studies have been conducted on the caregiving status and the relationship between caregiver burden and patient factors in China. Therefore, in this study, we focused on the choice of care giving and the burden of caregivers. We aimed to investigate the current caregiving status and burden as well as to analyze the relationship between caregiver burden and patient factors to suggest ideas for policy and research programs on chronic diseases.

## Methods

### Design and samples

This study was approved by the Ethics Committee of Peking University First Hospital and conducted after obtaining informed consent from all patients and their caregivers.

This is a large-sample, multi-center, cross-sectional study performed between August 2019 and December 2019. We collected data from 30 provincial, municipal, and autonomous regions of mainland China. Among them, the eastern provinces, such as Zhejiang, Beijing, and Hebei contributed the most participants (Fig. 1).

The patients were diagnosed as probable AD by cognitive experts from comprehensive psychiatric hospitals. The diagnosis of probable AD dementia was based on the diagnostic criteria established by the National Institute of Aging and Alzheimer's Association (NIA-AA) in 2011 [3, 4]. Patients who visited the hospital recently and those who were compliant with the diagnostic criteria, inclusion criteria, and exclusion criteria took part in the survey.

After the questionnaire was designed, the diagnostic doctors were given a comprehensive training about filling in the questionnaire. Caregivers of the patients completed the questionnaire under the guidance of doctors.

## Measures and data collection

We designed a comprehensive questionnaire, which includes essential information, regional distribution, demographic characteristics, household income, diagnostic and treatment history, care situation, and burden of participants. The caregiving status of the patients was divided into two categories, including family care and nursing care. Family care was defined as situations in which family members, including spouses, children, grandchildren, and other relatives, take care of AD patients with or without the help of a nurse. Nursing care indicates that the patients are taken care of by nurses in nursing facilities. Similarly, self-care ability was divided into two classes: basic self-care and partially or wholly dependent. The type of caregiving was assessed by caregivers based on whether the patients could take care of themselves in their daily lives.

The caregiver burden inventory (CBI) (Chinese version) was used to describe the multidimensional burden of the caregivers and to distinguish related factors of different burden dimensions [10]. The scale was translated into Chinese by Yue et al and passed the reliability and validity test. The inventory consists of 24 questions that refer to five dimensions: time-dependence burden (questions 1–5), developmental burden (questions 6–10), physical burden (questions 11–14), social burden (questions 15–18), and emotional burden (questions 19–24). Each item was graded on a 4-point Likert scale according to the degree of each situation. A high score represented a high burden and the total score is 96. After calculating the total score and each dimensional score, we divided the caregivers into three categories according to the burden score. The point range from 0–32 was considered as a low burden, from 33–64 as a medium burden, and from 65–96 as a high burden.

A total of 1694 people participated in the survey. After eliminating the erroneous and invalid questionnaires, 1675 valid questionnaires were left, resulting in an effectiveness of 98.88%.

## Statistical analyses

We used descriptive statistics to represent patient and caregiver characteristics, gender, age, housing condition, level of education, and annual income. Quantitative variables were described as the mean  $\pm$  standard deviation. For the analysis of different types of caregivers and caregiver burden, we used an independent-samples *t*-test and one-way ANOVA to compare the characteristics of patients and caregivers. The same tests were used to find factors of caregiver burden level related to different patient characteristics. We considered other factors ( $P < 0.2$ ) in the logistic regression analysis with 95% confidence intervals (CI) to determine the possible influence of other factors in the choice of caregiving of AD patients. All data analyses were performed using SPSS 26.0 (SPSS Inc., Chicago, IL, USA). Differences were considered statistically significant when the *P*-value was less than 0.05.

## Results

### Patient Characteristics

The patients characteristics are presented in Table 1. This study included 1675 AD patients from 30 provincial, municipal, and autonomous regions of mainland China, including 650 (38.81%) men and 1025 (61.19%) women. Most of the patients were above 60 years of age with features of AD. The participation of patients in urban areas was higher than that in rural areas (79.76% vs. 20.24%). The geographical distribution of the patients is shown in Fig. 1.

Table 1  
 Characteristics of caregivers and patients with AD (N = 1675).

Variable	N	%
<b>Patients</b>	650	38.81%
Sex	1025	61.19%
Male		
Female		
Age	580	34.63%
≤70	546	32.60%
71–80	549	32.78%
≥80		
Living area	1336	79.76%
Urban	339	20.24%
Rural		
Education level, years	492	29.37%
≤6	776	46.33%
7–12	407	24.30%
≥12		
Self-care ability		
Basic self-care	424	25.31%
Partially or wholly dependent	1251	74.69%
Annual patient's income (10,000yuan)	767	45.79%
≤3	522	31.16%
3–5	386	23.04%
≥5		
Annual household income (10,000yuan)	611	36.48%
≤5	802	47.88%
5–15	262	15.64%
≥15		
<b>Caregivers&amp; Treatment</b>		
Caregiving status	1522	90.87%
Family care	153	9.13%
Nursing facility		
Dementia drug application	1278	75.30%
On medication	259	15.46%
Used and withdrawal	138	8.24%
Unmediated		
Annual medical cost (10,000 yuan)	821	49.01%
≤1	585	34.93%
1-2.4	269	16.06%
≥2.4		

Variable	N	%
Annual care cost (10,000 yuan)	542	32.36%
≤2	573	34.21%
2–6	266	15.88%
≥6	294	17.55%
Unclear		
Caregiver burden	484	28.90%
Low	955	57.01%
Medium	236	14.09%
High		

## Care-giving status of AD patients

Of the 1675 AD patients sampled, 1522 (90.87%) patient families cared and 153 (9.13%) patients cared at nursing facilities. To identify the factors associated with the choice of caregivers, we analyzed the characteristics of the patients' caregiving status (Table 2). We found no statistically significant difference between family care and nursing care based on the gender or education level of patients. Living in a nursing facility is common among patients who are above 80 years ( $P=0.003$ ) and who are living in urban areas ( $P=0.001$ ). Concerning economic status, the choice of patient care is related to the annual income of the patient ( $P=0.001$ ). A greater proportion of patients living in nursing homes belong to a higher income group; however, no significant difference was found between annual household income groups ( $P=0.122$ ). According to self-care ability and CBI score, patients who are less capable of taking care of themselves and who impose a large burden to family caregivers choose nursing facilities ( $P=0.001$ ).

Table 2  
The caregiving status of the familial caregiver of patients with AD in relation to patient and caregiver characteristics (N = 1675).

	Family care N = 1522 (%)	Nursing care N = 153 (%)	P-value
Sex	591(38.83)	59 (38.56)	0.948
Male	931 (61.17)	94 (61.44)	
Female			
Age	538(35.35)	42(27.45)	0.003
≤70	506(33.25)	40(26.14)	
71–80	478(31.41)	71(46.41)	
≥80			
Living area	1194 (78.45)	142 (92.81)	0.001
Urban	328 (21.55)	11 (7.19)	
Rural			
Education level, years	457 (30.03)	35 (22.88)	0.052
≤6	706 (46.39)	70 (45.75)	
6–12	359 (23.59)	48 (31.37)	
≥12			
Annual patient's income (1,0000 yuan)	724 (47.57)	43 (28.10)	0.001
≤3	798 (52.43)	110 (71.90)	
>3			
Annual household income (1,0000 yuan)	564(37.06)	47(30.72)	0.122
≤5	728(47.83)	74(29.25)	
5–15	230(15.11)	32(20.92)	
≥15			
Self-care ability	408(26.81)	16(10.46)	0.001
Basic self-care	1114(73.19)	137(89.54)	
Partially or wholly dependent			
Caregiver burden	450(29.57)	34(22.22)	0.001
Low	872(57.29)	83(54.25)	
Medium	200(13.14)	36(23.53)	
High			

We used logistic regression analysis to identify the relevant factors for choosing nursing facilities for patients with AD (Table 3). We found that housing condition is a fixed influential factor in the choice of caregiving. Urban patients are more likely to choose nursing homes than rural patients (OR 2.374; 95% CI, 1.228–4.588). Self-care ability was also a significant risk factor choosing nursing homes. Older patients who cannot take care of themselves choose a nursing home; however, independent patients would choose family care (OR 0.329; 95% CI, 0.183–0.588). The caregiver burden is also a related factor as caregivers with the highest burden score were more inclined to seek nursing homes for aged patients (OR 0.574; 95% CI, 0.373–0.884).

Table 3  
Logistic regression models for the caregiving status of AD patients (N = 1675).

	OR	(95% CI)		P-value
Age	Ref.	0.489	1.131	0.167
≤70	0.744	0.427	0.983	0.041
71–80	0.648			
≥80				
Living area	Ref.	1.228	4.588	0.010
Urban	2.374			
Rural				
Annual patient's income (10,000 yuan)	Ref.	0.330	0.789	0.003
≤3	0.511			
≥3				
Annual household income (10,000 yuan)	Ref.	0.512	1.500	0.631
≤5	0.877	0.462	1.141	0.165
5–15	0.726			
≥15				
Self-care ability	Ref.	0.183	0.588	≤0.001
Basic self-care	0.329			
Partially or wholly dependent				
Caregiver burden	Ref.	0.411	1.235	0.227
Low	0.713	0.373	0.884	0.012
Medium	0.574			
High				

## Burden on caregivers of AD patients

In this study, 25.31% of the patients could take care of themselves. The other 74.69% of patients were partially or wholly dependent on others for care. About 36.48% of patients were completely dependent, which indicates that a large proportion of AD patients have severe disabilities. According to the CBI score of the caregivers, 28.90% of caregivers had a relatively low level of burden, 14.09% of caregivers had a high level of burden, and the other 57.01% of caregivers had a medium level of burden. From the perspective of burden classification, our study separately calculated all five dimensions of burden in different characteristics of caregivers (Table 4). According to the results of the correlation analysis, the self-care ability of patients reduced the burden of caregivers. All aspects of caregiver burden significantly increased when patients were not able to take care of themselves ( $P \leq 0.001$ ). Caregiving status was also associated with burden grade. Caregivers at nursing facilities had a higher total burden of care compared to the caregivers at home ( $P \leq 0.001$ ). In the five burden aspects mentioned above, there was no difference between family care and nursing care on the emotional side of caregivers ( $P = 0.510$ ). In addition, in other aspects such as time-dependence, development limitation, health, and social contact, families bear a higher burden when the patients are sent to a nursing home than those who got care at home.

Table 4  
CBI scores of the familial caregiver of patients with AD based on the caregiving status.

Burden Classification	n	Time-Dependence (x ± s, score)	P-value	Developmental (x ± s, score)	P-value	Physical (x ± s, score)	P-value	Social (x ± s, score)	P-value	Emotional (x ± s, score)	P-value	Total (x ± s, score)
Self-care ability			0.001		0.001		0.001		0.001		0.001	
Basic self-care	424	6.53 ± 4.65		7.62 ± 5.62		4.56 ± 4.16		3.30 ± 3.36		3.02 ± 3.63		25.04 ± 18.02
Partially or wholly dependent	1251	15.45 ± 4.20		14.09 ± 4.87		9.60 ± 4.42		5.90 ± 4.07		4.82 ± 4.65		49.87 ± 16.81
Care-giving status			0.001		0.001		0.001		0.008		0.510	
Family care	1522	12.98 ± 5.81		12.30 ± 5.74		8.17 ± 4.83		5.16 ± 4.02		4.34 ± 4.41		42.95 ± 20.05
Nursing facility	153	15.29 ± 5.34		13.96 ± 6.14		9.90 ± 5.07		6.14 ± 4.41		4.62 ± 5.17		49.92 ± 21.03

The burden of caregivers was affected by both the self-care ability and caregiving status of the patients at the same time. To exclude confounding factors, we used stratified correlation analysis to determine the impact of self-care ability and caregiving status on the burden of caregivers (Table 5). There was no significant caregiver burden, either family care or nursing facility ( $P = 0.520$ ), if the patients could take care of themselves. However, if the patients were unable to care for themselves, the overall burden was higher for partially or wholly dependent AD patients ( $P = 0.015$ ), and the differences mainly manifested in the burden of time-dependence ( $P = 0.002$ ) and the health of caregivers ( $P = 0.008$ ).

Table 5  
CBI scores of caregivers with different care status after classification according to patient self-care ability.

Self-care ability	n	Time-Dependence (x ± s, score)	P-value	Developmental (x ± s, score)	P-value	Physical (x ± s, score)	P-value	Social (x ± s, score)	P-value	Emotional (x ± s, score)	P-value	Total (x ± s, score)	P-value
Basic self-care			0.163		0.557		0.902		0.873		0.561		0.520
Family care	408	6.59 ± 4.69		7.65 ± 5.61		4.57 ± 4.14		3.30 ± 3.29		3.04 ± 3.64		25.15 ± 17.95	
Nursing facility	16	4.94 ± 3.21		6.81 ± 5.79		4.44 ± 4.84		3.50 ± 4.97		2.50 ± 3.63		22.19 ± 20.26	
Partially or wholly dependent			0.002		0.118		0.008		0.094		0.901		0.015
Family care	1114	15.32 ± 4.20		14.01 ± 4.76		9.48 ± 4.38		5.84 ± 4.05		4.81 ± 4.57		49.46 ± 16.53	
Nursing facility	137	16.50 ± 4.08		14.80 ± 5.63		10.54 ± 4.72		6.45 ± 4.26		4.87 ± 5.28		53.15 ± 18.66	

## Discussion

AD is a progressive neurodegenerative disorder, which causes the cognitive decline of memory, judgment, orientation, and reasoning abilities [11]. Behavioral and psychological symptoms gradually occur in AD patients, resulting in disability [12] and most patients require complete care in the middle and later stages of the disease. According to previous studies, either from the perspective of public health or disease care, family care has certain advantages compared to nursing facilities [13]. Nevertheless, in the current situation, family care has undoubtedly brought a huge burden to caregivers.

Our results suggest that family care is the most common choice for families of AD patients in China. The majority of patients and their families are not willing to choose nursing homes. Although many nursing facilities have been set up, the nursing facilities have a low acceptance rate among families with older patients (Table 6). Aside from the patient's health condition, other problems can include an insufficient number of nursing homes, inadequate facilities and care, high cost, and so on. Many people view that nursing homes cannot provide individual care to patients. It is noteworthy that some family caregivers

mention that the patients who earlier chose to live in a nursing home, for various reasons, often decide to leave the nursing home and choose family care. This shows that the construction of China's nursing homes and the corresponding support system is still not perfect. In addition to the above factors, the reasons for this phenomenon include Chinese traditional cultural heritage. Chinese people attach great importance to filial piety. In traditional Chinese culture, when parents fall ill, children should care for their parents; those who do not may face various social difficulties both at home and in the community. Some older adults who enter a nursing home are also seen as being abandoned by their children and incentivized them to choose family care rather than to live in nursing homes.

Table 6  
Reasons for patients not choosing to live in nursing facilities.

Item	N	%
λ Subjective factors		
Disagreement of the patient's family members.	614	36.7
Disagreement of the patient him/herself.	558	33.3
λ Objective factors		
No local nursing facilities.	108	6.4
Too long of the queuing time.	137	8.2
Insufficient service level of nursing facilities.	578	34.5
Too much expense of the nursing facilities.	584	34.9
Unable to move in due to physical condition (illness, disability, etc.).	199	11.9
λ Once lived, and the patient/family felt not suitable to live in the nursing facility.	74	4.4

AD patients often need long-term care as many patients cannot take care of themselves in the later stage of the disease. Therefore, caregivers have to bear a great burden. On the economic front, AD also brings a huge burden to both the patients' families and society [14]. According to International multilateral cost-of-illness (COI) studies, the socioeconomic cost of AD includes direct medical, direct non-medical and indirect costs [15]. A study in 2015 showed that the annual cost of an AD patient in the US was \$19,144.36 [16]. The burden of AD on families is not just financial, but also affects other aspects of life that cannot be neglected. For example, the symptoms of dementia often cause physical, emotional, and mental stress [17]. Many studies have explored the influence factors of caregiver burden, indicating that the burden on caregivers is higher in families with lower income and disease severity [18, 19]. At the same time, the burden of patients increases with time [20]. After taking care of patients, the health of caregivers can be affected, increasing anxiety and depression, and decreasing satisfaction with life [21]. Most families experience mental tension due to this disease and create a negative flow of energy between caregivers and patients [22]. However, there are few large-scale studies on caregiver burden of Chinese AD patients, and most studies have focused on patients receiving family care [23–25]. Hence, there is a lack of research on the impact of care style on family care burden.

According to this study, the self-care ability and care status of AD patients has a significant impact on the burden of caregivers. The families who choose a nursing home for their elderly who lost self-care abilities suffered a higher burden in general. The reasons for this phenomenon, however, are diverse and caregivers are often more concerned about whether the nursing facilities are careful with older patients. Underdeveloped social nursing facilities in China also bring many concerns to caregivers of AD patients, the care of who is different from ordinary older adults. Questions therefore remain as to how patients can receive personalized care, if they fall sick again because of improper care and if they feel lonely or sad. On the other hand, the improper pension security system also results in a higher cost of living in a nursing home for the patients' families. Other aspects also affect these results and most families willing to send their elderly to nursing homes have a higher awareness of diseases and try their best to treat and change the patient's condition. Comparatively, some families care less about the symptoms of patients and spend less time and energy on the treatment and care of patients [26], which gives them a lower burden.

Currently, China's social welfare and pension security system can partly satisfy social needs, but it still needs to improve in some aspects. There is still a lack of nursing assistance and policy help for patients with AD [27]. For patients with AD, there are restricted alternatives and only a few ensured ways to live their lives when considering economic limitations. According to a study in 2015, most patients have two children or more (80.56%), while 19.44% of participants have only one child or no child [16]. The one-child situation is going to be more distinct in the coming decades as families with one child may face serious problems in caring for AD patients. Therefore, the social support system needs to be corrected and long-term strategies and effective measures should be made and implemented by the government.

Our study has some limitations that should be noted. First, the sample size of this work is small and did not fully represent the AD patient population in China. Second, the questionnaire used here was only available to patients who were diagnosed as probable AD dementia and most of them need an electronic platform to complete the questionnaire. Therefore, the study mainly included patients from urban and suburban areas, leading to a demographic bias. Therefore, the results obtained may not represent all AD patients in China. Third, the severity of AD could not be quantified with our study design and functional health outcomes could not be measured. We did not focus much on the economic burden and mental stress of the patients' family, which further affects the analysis and conclusions. All these problems warrant further investigation in a larger and more widespread patient cohort. Although the investigation described in this work is imperfect, we can gain a basic understanding of the caregiving status and burden on Chinese families of AD patients.

## Conclusions

The economic costs of AD come from all directions. Family care is the primary method of care for AD patients in China. The method of patient care is influenced by the housing condition, patient income, and disease severity. Furthermore, the burden of family caregivers for patients with AD is generally high, especially for disabled patients cared for in nursing facilities. Overall, this study reveals the present situation of AD patients and their families and provides insights to help public health policymaking.

## Declarations

### Ethics approval and consent to participate

This study was approved by the Ethics Committee of Peking University First Hospital and conducted after obtaining informed consent from all patients and their caregivers.

### Consent for publication

Not applicable.

### Availability of data and materials

The datasets generated and/or analysed during the current study are not publicly available due the study is still in progress but are available from the corresponding author on reasonable request.

### Competing interests

The authors declare that they have no competing interests.

### Funding

The study was supported by National Key R&D Program of China (2018YFC1314200) and Group-Style Medical Aid Project for Tibet (XZ2017ZR-ZY13).

### Authors' contributions

H-LW, H-GX, and Y-AS conceptualized and designed the study. Y-XL, H-QJ, J Z, J X, J-YT, S-WC, X-TL, A-LD, F-QZ, W S, X-WK, L-ZC and J-XQ conducted the study. Y-XL and H-QJ analyzed and extracted data. Y-XL wrote the first draft of the manuscript. All authors reviewed the manuscript. All authors read and approved the final manuscript.

### Acknowledgments

We sincerely thank all members of the Alzheimer's Disease Chinese for their contributions to recruiting patients and data collection, and thank Health Times for questionnaire design and data analysis.

## Abbreviations

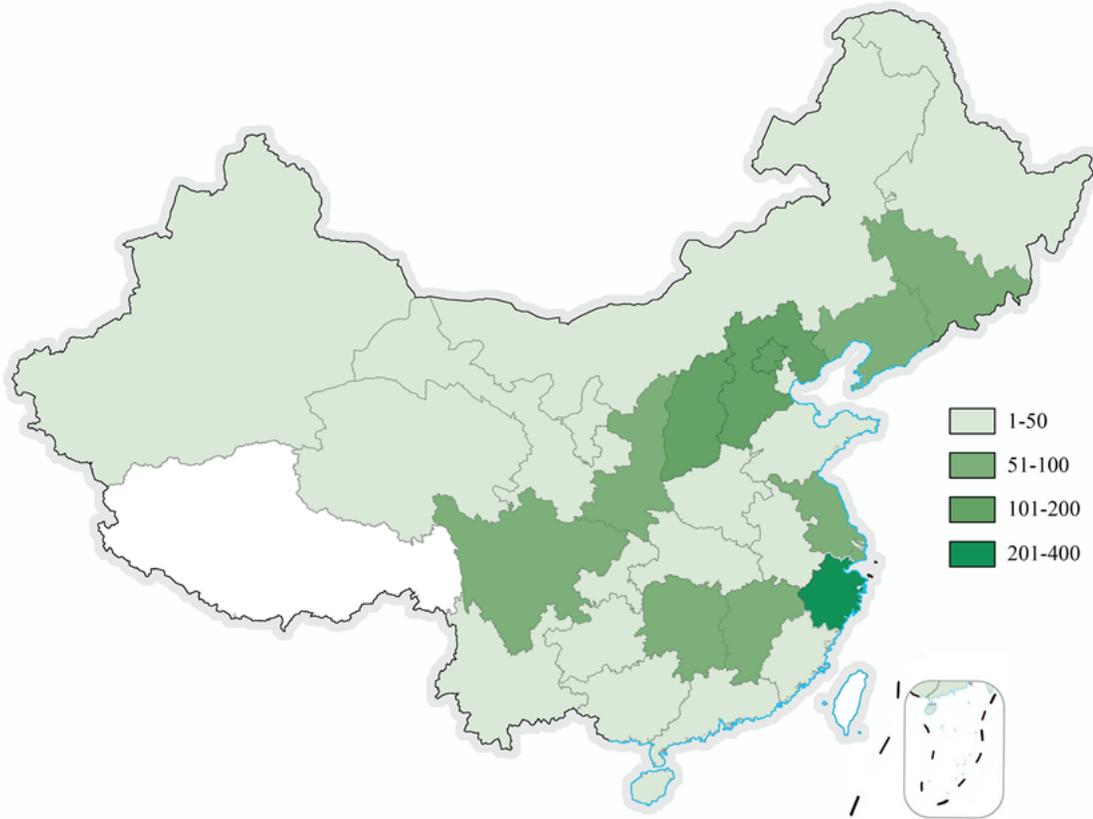
AD: Alzheimer's disease; NIA-AA: Aging and Alzheimer's Association; CBI: caregiver burden inventory; CI: confidence intervals; COI: cost of illness

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## Figures



**Figure 1**  
Geographical distribution of patients with AD in this study. The designations employed and the presentation of the material on this map do not imply the expression of any opinion whatsoever on the part of Research Square concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. This map has been provided by the authors.