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## Clinical Characterization and the Caregiver Burden of Dementia in China

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### ABSTRACT

**Objectives:** The prevalence of dementia in China is among the highest in the world, but systematic estimates of the rate of dementia subtypes and characterization of associated deficits are lacking. The primary aim of this study was to determine the clinical presentation of dementia and describe the caregiver burden in mainland China. **Methods:** A 3-month, open-enrollment, multicenter, cross-sectional study was conducted at 48 tier-3 hospitals. Caregivers who qualified for study entry (provided amount and duration of care information), had intimate knowledge of patient status, and accompanied enrolled patients to study sites were asked to participate in an interview about patient care and caregiver burden. Caregiver burden was assessed via the Chinese version of the validated Zarit Burden Interview. **Results:** A total of 1425 caregivers completed the survey. Patients had mild to moderate dementia (mean Clinical Dementia Rating score of  $1.67 \pm 0.79$ ), and the most common dementia subtypes were Alzheimer

disease (46.7%) and vascular dementia (28.7%). Among caregivers, 57% were females, 52% were patients' spouses, and 67.3% had been caring for patients for 1 year or more. Most patients required family help and lived at home or with a family member. Caregiver awareness of dementia was limited. The mean total caregiver Zarit Burden Interview score was 26.6. Observations were similar across age, gender, education, dementia type, Clinical Dementia Rating score, and duration of care. **Conclusions:** China faces multiple obstacles in preparing to care for its fast-growing dementia population. Better understanding of patients and caregivers may mitigate these challenges by improving awareness and education.

**Keywords:** caregiver burden, China, cross-sectional studies, dementia.

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### Introduction

Dementia is a typically progressive disease characterized by cognitive, functional, and/or behavioral deficits. The most well-known and common subtype of dementia is Alzheimer disease (AD); other subtypes include vascular dementia (VaD), Lewy body dementia, and frontotemporal dementia. In 2010, it was estimated that 35.6 million people worldwide suffer from dementia [1]. By 2030, approximately 65.7 million people will be living with dementia; and by 2050, the number is expected to increase to 115.4 million [1].

One country most likely to be impacted by the growing burden of dementia is China. In addition to having the largest population in the world, China has the fastest growing elderly population [2]. It is established that dementia primarily affects older patients, and the risk of developing dementia approximately doubles every 5 years after the age of 65 years [1]. By 2040, the number of individuals living with dementia in China will equal the combined total of patients with dementia from high-income countries [3].

Given the current and projected prevalence of dementia in China, the country must be prepared to address the impact of the disease on affected patients, their caregivers, and the health care system. Informal care costs (i.e., unpaid care provided by families and others) account for more than half of the overall costs

associated with dementia care in rapidly developing countries such as China (58% and 65% in lower- and middle-income countries, respectively, vs. 40% in high-income countries) [1]. To develop and implement effective strategies to reduce informal care costs and alleviate associated burdens, policymakers and governmental institutions must have an understanding of the caregiver experience.

Studies investigating the caregiver experience in Chinese culture have been reported. Most of these reports, however, have focused on populations from Hong Kong or Taiwan while data from mainland China are limited. To address this gap in data, a multicenter, cross-sectional, hospital-based study that surveyed caregivers of patients with dementia was carried out across all seven regions of mainland China. Results reported here are the first to characterize the diagnosis and awareness of dementia, as well as the burden of dementia care as perceived by a cohort of caregivers from mainland China.

### Patients and Methods

#### Study Design

This was a cross-sectional study. The study was approved by local hospital ethics committees and completed in accordance with

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the Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects, adopted by the General Assembly of the World Medical Association (1996). In addition, the study was in accordance with the International Conference on Harmonisation guidelines on Good Clinical Practice and applicable local regulatory requirements and laws. All enrolled patients and caregivers provided informed consent following Chinese regulations. Patients were under supervision of their legal guardian if necessary.

The study characterized demographics, cognitive clinical status, and caregiver burden in patients with dementia who presented at neurology clinics in China. The study had a 3-month open enrollment that started in September 2009 and was completed in December 2009. To ensure coverage of all regions and provinces, 48 tier-3 hospitals from all seven regions of mainland China (Northern, Northeast, Northwest, Southwest, Central, Eastern, and Southern) were selected. The number of sites per province was proportional to the population of the region, and hospitals were chosen by size, treatment tier, university affiliation, and the presence of a neurology/dementia center. Each participating neurology/dementia center had a designated principal investigator who underwent a 2-day centralized training session that included standard diagnosis of dementia and its subtypes, the dementia scales, patient/caregiver interviews, and standard processes of data capture and transfer in the study protocol. The principal investigators were then responsible for delivering training to their staff.

### Patient Selection, Screening, and Diagnosis

Patients were selected by systematic screening of more than 500,000 male and female patients visiting participating neurology/dementia clinics. Potential subjects were initially screened by a health care professional for any cognitive complaints. Suspected patients with dementia were referred to the lead neurologist at the study site, and then assessed for dementia by using the validated and authorized Chinese version of the Mini-Mental State Examination where low to very low scores correlate closely with the presence of dementia [4]. The raw score was corrected for educational attainment; the criterion for dementia diagnosis was a Mini-Mental State Examination score of less than 19 for patients who were illiterate or had no education, 22 or less for patients with primary school education (education  $\leq 6$  years), and 26 or less for those with middle school education or above (education  $> 6$  years). The study used a cut-point sensitivity of 93.2% for detecting dementia. Patients diagnosed with dementia and their caregivers were then informed about the study and given the option to participate.

All enrolled patients received a full evaluation of cognitive, functional, and behavioral status using standard and validated clinical measurements. Medical data collected included demographics, living habits and history, medical history, physical exam, assessment of comorbidities, and laboratory tests that included serum lipids and fasting glucose levels. Cognitive evaluation included dementia severity, cognitive function, functional status, assessment of symptoms, brain imaging by computed tomography and magnetic resonance imaging for dementia subtype diagnosis, and neuropsychological behavioral disturbance assessment. Dementia was diagnosed on the basis of The National Institute of Neurological and Communicative Disorders and Stroke and Alzheimer's Disease and Related Disorders Association criteria and the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* criteria. Dementia subtypes were also diagnosed according to accepted published criteria for VaD, Lewy body dementia, Parkinson's disease dementia, and mixed dementia.

### Caregiver Assessment Interview

Caregivers who qualified for the study design (provided amount and duration of care information), had intimate knowledge of patient status, and accompanied enrolled patients with dementia to the study site provided their consent to participate in the Caregiver Assessment Interview on the patient and caregiver profile, patient care, and caregiver experience. The Caregiver Assessment Interview consisted of a series of questions about the patient and a Clinical Dementia Rating (CDR) scale assessment for the caregiver, both of which were completed by the study physicians (investigators) with the information provided by caregivers as informants. The patient questionnaire was designed to obtain information on basic demographics, reasons for current clinic presentation, pattern of symptoms, length of time since symptom onset, current or previous treatment history, treatment satisfaction and compliance, and costs related to treatment and care. The CDR is a global measure of dementia severity composed of six domains that assess cognition and function: memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care. Impairment in each category is rated on a five-point scale (none = 0, questionable = 0.5, mild = 1, moderate = 2, and severe = 3). A physician with detailed knowledge of the patient completes the scale. A structured interview is also part of the rating scale. The CDR is given to both the patient and the caregiver [4].

### Caregiver Burden Assessment

Caregiver burden was measured by using the Chinese version of the validated Zarit Burden Interview (ZBI) [5] questionnaire. The ZBI consists of 22 questions about the impact of the patient's disabilities on the caregivers' life. For each item, caregivers indicate how often they felt that way and responses are rated from 0 to 4 (0 = never, 1 = rarely, 2 = sometimes, 3 = quite frequently, and 4 = nearly always). The ZBI was scored by adding the numbered responses from individual items. Total score ranged from 0 to 88, with higher scores indicating greater caregiver distress [6]. Norms for the ZBI have not been computed, but estimates of the degree of burden can be divided into four categories: 0 to 20 (little or no burden), 21 to 40 (mild to moderate burden), 41 to 60 (moderate to severe burden), and 61 to 88 (severe burden) [6]. In this analysis, only questionnaires with responses to 18 or more out of 22 questions ( $\geq 80\%$  valid responses) were used. For missing data ( $< 4$  missing questions), the average scores from valid responses were rounded to the next integer and used to fill in any missing fields.

### Data Collection

Data were collected through digital or pen and paper report forms in Chinese. All electronic and pen/paper data were sent to the principal investigator of each study site for entry into the study database by the research team.

### Statistical Analysis

Data were summarized by using descriptive statistics using statistical software SAS, version 9.0.

## Results

### Demographics of Patients with Dementia

A total of 1425 caregivers who met the study qualifications completed the study procedures with assistance from the site investigator. About 50% of the study caregiver participants (719 of 1425) were from the eastern and northern regions (the former

included three hospitals in Shanghai while the latter included four hospitals in Beijing). More than 80% of the patients were aged between 51 and 80 years, with a mean age of  $67.6 \pm 12.8$ , and 51.5% ( $n = 734$ ) were men (Table 1). Patients were roughly evenly divided between three reported occupations: white-collar worker (36.5%,  $n = 520$ ), laborer (29.5%,  $n = 420$ ), and farmer (26.2%,  $n = 373$ ), with a minority reporting self-employment (2.7%,  $n = 39$ ) or other (5.1%,  $n = 73$ ) as their profession. More than three quarters of the patients had achieved some level of education, with 28.1% ( $n = 400$ ) completing elementary school, 22.4% ( $n = 319$ ) completing junior high school, 14.9% ( $n = 213$ ) completing high school or vocational school, and 13.2% ( $n = 188$ ) completing college. Twenty-one percent were illiterate ( $n = 299$ ). The majority of the patients resided in urban areas (62.9%), while 28.8% of the patients resided in rural areas. The remaining 8.3% consisted of suburban dwellers (8.0%) and other (0.3%).

The overall severity of dementia among patients in this cohort was mild to moderate (mean CDR of 1.67). Most patients with dementia were diagnosed with AD (46.7%), followed by VaD (28.7%), other dementia (11.6%), and mixed dementia (9.1%).

**Table 1 – Demographics and clinical characteristics of patients among the study cohort.**

Characteristic	N = 1425
Age (y), mean $\pm$ SD	67.6 $\pm$ 12.8
Gender, n (%)	
Female	690 (48.4)
Male	734 (51.5)
Missing	1 (0.1)
Occupation, n (%)	
White-collar	520 (36.5)
Laborer	420 (29.5)
Farmer	373 (26.2)
Other*	73 (5.1)
Self-employed	39 (2.7)
Level of education, n (%)	
Elementary school	400 (28.1)
Junior high	319 (22.4)
High school/vocational school	213 (14.9)
College/university	188 (13.2)
Illiterate	299 (21.0)
Other*	6 (0.4)
Permanent residence, n (%)	
Urban	896 (62.9)
Rural	411 (28.8)
Suburb	114 (8.0)
Other*	4 (0.3)
CDR score, mean $\pm$ SD	1.671 $\pm$ 0.791
CDR score, n (%)	
0.5	106 (7.4)
1	557 (39.1)
2	512 (35.9)
3	248 (17.4)
Type of dementia diagnosed, n (%)	
AD	665 (46.7)
VaD	409 (28.7)
Mixed dementia	129 (9.1)
LBD	17 (1.2)
Parkinson's disease dementia	28 (2.0)
Other types of dementia	166 (11.6)
Temporal lobe dementia	11 (0.8)

AD, Alzheimer disease; CDR, clinical dementia rating; LBD, Lewy body dementia; VaD, vascular dementia.

\* Unknown, missing, or incomplete data.

The remaining cases of dementia ( $\leq 2\%$  each) consisted of Parkinson's disease dementia, Lewy body dementia, and temporal lobe dementia. Disease onset was slow for a majority of patients (56.3%), followed by sudden (26.4%), insidious (14.5%), and unknown (2.9%).

### Demographics of Caregivers of Patients with Dementia

Most caregivers were female (56.9%), and 47.3% had an educational level of high school or above (Table 2). The most common caregiver relationship to the dementia patient was spouse (51.9%), followed by son (33.2%) and daughter (9.2%). The majority of family caregivers (57.4%) provided full-time care to the patient.

### Characterization of Dementia as Reported by Caregivers

The remainder of this report focuses on responses from 1387 caregivers (either family members or hired individuals who provided care for patients with dementia). Results were also divided into two categories: caregivers of patients who were previously diagnosed with dementia ( $n = 404$ ) and caregivers of patients who were newly diagnosed with dementia at the study site ( $n = 983$ ). Table 3 shows the characteristics of the patient's dementia diagnosis as recalled by the caregiver. Among caregivers of patients previously diagnosed with dementia, decline in memory was the most often cited reason for prompting a visit to the doctor (84.2%). The latency between the appearance of dementia symptoms and seeing a neurologist was greater than 3 years (28.2%), less than 6 months (21.0%), 1 to 2 years (20.0%), 6 to 12 months (16.6%), and 2 to 3 years (13.6%). In the majority of the cases (72%), the latency between the patient's first doctor visit and a confirmed diagnosis of dementia was less than 6 months.

Among caregivers of patients who were diagnosed with dementia at the time of screening, 31.4% responded that the latency between the appearance of dementia symptoms and seeing a neurologist was less than 6 months followed by more than 3 years (22.9%), 1 to 2 years (17.4%), 6 to 12 months (13.7%), and 2 to 3 years (12.6%). Only 15.3% of the caregivers indicated that the patient was completely aware of dementia symptoms at the first doctor visit.

**Table 2 – Demographics of caregivers among the study cohort.**

Characteristic	n (%)
Gender	
Female	811 (56.9)
Male	603 (42.3)
Missing or unknown	11 (0.8)
Level of education	
Elementary school	228 (16.0)
Junior high	427 (30.0)
High school/vocational school	380 (26.7)
College/university	293 (20.6)
Illiterate	84 (5.9)
Missing or unknown	13 (0.9)
Is the family member the full-time* caregiver to the patient?	
Yes	818 (57.4)
No	592 (41.5)
Missing or unknown	15 (1.1)

\* Temporary caregiver defined as a part-time worker, neighbor, or volunteer.

**Table 3 – Caregiver’s characterization of dementia diagnosis.**

Characteristic	n (%)	
	Previous diagnosis of dementia (n = 404)	First diagnosis of dementia (n = 983)
Which dementia symptoms prompted you to see the doctor? (multiple answers allowed)		
Decline in memory	340 (84.2)	733 (74.6)
Change in temperament	140 (34.7)	283 (28.8)
Psychological symptoms	92 (22.8)	188 (19.1)
Other symptoms or illness	78 (19.3)	375 (38.1)
No details/do not remember	15 (3.7)	33 (3.4)
Latency between appearance of dementia symptoms and seeing a neurologist		
> 3 y	114 (28.2)	225 (22.9)
2–3 y	55 (13.6)	124 (12.6)
1–2 y	81 (20.0)	171 (17.4)
6–12 mo	67 (16.6)	135 (13.7)
< 6 mo	85 (21.0)	309 (31.4)
Other*	2 (0.5)	19 (1.9)
Latency between patient’s first doctor visit and confirmed diagnosis of dementia		
> 3 y	10 (2.5)	NA
2–3 y	22 (5.4)	NA
1–2 y	30 (7.4)	NA
6–12 mo	46 (11.4)	NA
< 6 mo	291 (72.0)	NA
Other*	5 (1.2)	NA
At the first doctor visit, was the patient aware of his or her dementia symptoms?		
Completely aware	57 (14.1)	150 (15.3)
Somewhat aware	162 (40.1)	467 (47.5)
Completely unaware/denied dementia	174 (43.1)	349 (35.5)
Other*	11 (2.7)	17 (1.7)

\* Unknown, missing, or incomplete data.

### Caregiver Awareness of Dementia

Investigators also evaluated caregiver awareness of dementia. Most caregivers of patients with previously diagnosed dementia (62.9%) responded that they had a limited understanding of dementia. More than half (54.7%) of the caregivers indicated that the patient was taken to the doctor immediately following the first signs or symptoms. The most common reasons for not taking the patient immediately to the doctor were unawareness

of symptom severity (25.5%), unawareness of signs/symptoms of dementia (24.5%), belief that the symptoms were part of the aging process (18.8%), and being in denial of dementia (14.9%).

Among caregivers of patients who were diagnosed with dementia at the time of screening, 42.8% reported taking the patient to the doctor immediately after the first signs or symptoms. Compared with caregivers of patients with previously diagnosed dementia, more caregivers reported being unaware of the symptom severity (40.9%), unaware of the signs/symptoms of dementia (36.9%), believing the symptoms were part of the aging process (30.5%), and being in denial of dementia (24.4%). Not enough data were collected regarding the caregivers’ personal understanding of dementia to draw a conclusion.

With regard to the patient’s awareness of his or her dementia symptoms, only 14.1% of the caregivers reported that the patient was completely aware of dementia symptoms at the first doctor visit.

### Characterization of Dementia Care

More than three quarters (78.7%) of the caregivers had been caring for the subjects with dementia for a year or more, while 10.8% had been caring for them for 3 months or less. Among previously diagnosed patients with dementia, the most common caring arrangements were patients living in their own home with help from their family (51.7%) and living in a family member’s home with help from a family member (24.0%). The most common caring arrangements among patients diagnosed with dementia at the time of this study were patients living in their own home with help from their family (57.6%) and living in a family member’s home with help from a family member (27.7%). As expected, more previously diagnosed patients lived in hospital/nursing home/convalescent hospitals (10.9%) versus 1.5% of those diagnosed with dementia at the time of the study. This may reflect the longer disease course and progression of dementia in the previously diagnosed patients. The mean total ZBI score was higher for caregivers of patients who had previously been diagnosed with dementia (28.34) compared with caregivers of patients who were diagnosed with dementia at the time of the screening (24.98).

### Analysis of Caregiver Burden

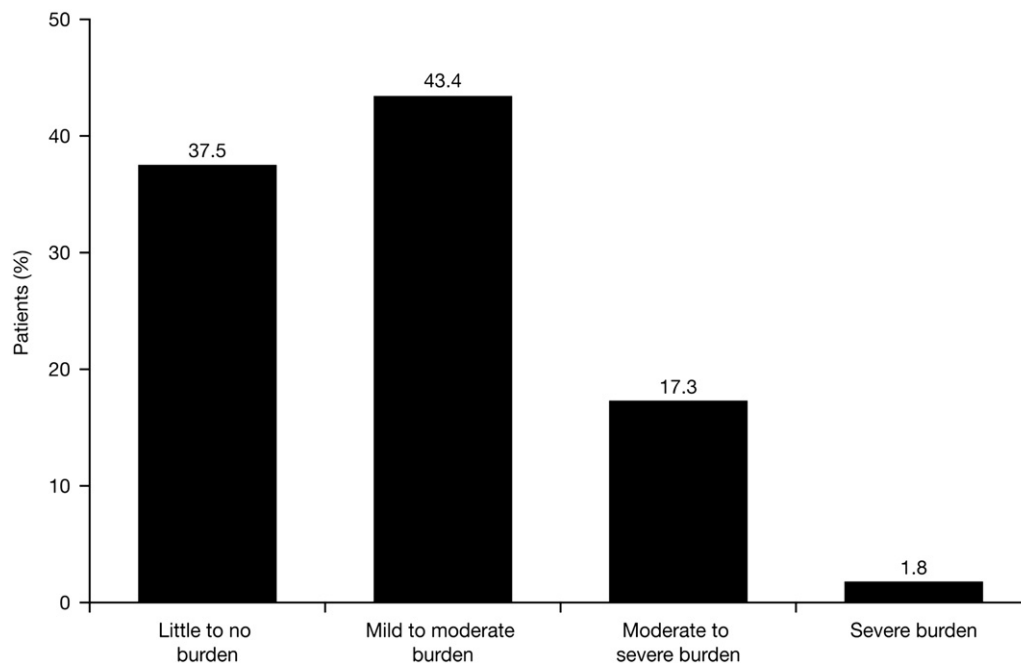
Valid ZBI responses were obtained from 1381 caregivers and used for analysis. Overall, 62% of the caregivers reported experiencing a burden associated with dementia care (67% in caregivers of previously diagnosed dementia vs. 60% in caregivers of patients diagnosed with dementia at study screening). Most caregivers reported mild to moderate burden (43%) or little to no burden (38%) (Fig. 1). The total mean caregiver burden ZBI score was 26.6. When caregiver burden was analyzed by age of caregiver (Fig. 2A), gender of caregiver (Fig. 2B), level of education of caregiver, dementia type (Fig. 3A), CDR (Fig. 3B), and duration of care, a similar pattern was observed.

### Discussion

To date, this study represents the largest comprehensive screening of patients with dementia and their caregivers across mainland China. Results were obtained from both urban and rural patients/caregivers from all seven regions of China. In addition, the study collected data from patients previously diagnosed with dementia and those who were diagnosed at the time of enrollment, allowing for a comparison of caregiver burden between these groups.

AD and VaD account for a majority of dementia cases worldwide, with AD being the more prevalent of the two. In 2005, Zhang et al. [7] surveyed families of patients with dementia in





**Fig. 1 – Overall caregiver burden questionnaire scores.**

Beijing. The survey identified 732 cases of AD and 295 cases of VaD (yielding an AD to VaD ratio of 2.48:1). In two independent population-based studies from China, the ratio of AD to VaD was 2.2:1 ( $n = 87,761$ ) and 3.2:1 ( $n = 34,807$ ) [8]. In other developing countries such as China, the AD to VaD ratio can range from 1.2:1 up to 3.4:1 [8]. Among the cohort of patients with dementia reported here, 46.7% were diagnosed with AD while 28.7% were diagnosed with VaD, yielding an AD to VaD ratio of 1.63:1, which is within the range of developing countries [8].

### Diagnosis of Dementia

Although there is currently no consensus regarding the potential benefits of early diagnosis and pharmacologic intervention in dementia [9], some studies report a positive correlation. A French study among 970 patients with VaD or AD reported that survival was associated with the latency between first symptoms and first visit: the shorter the latency, the longer the patients survived [10]. Although there is no evidence of a relationship between caregiver burden and early diagnosis or treatment, early pharmacologic intervention has been shown to improve cognitive and functional outcomes in patients with mild and moderate AD [11]. Persistent treatment with antidementia drugs has also been shown to have a positive impact on disease progression across multiple cognitive, functional, and global outcome measures in patients with Alzheimer-type dementia [12].

In the current study, caregivers appeared to be proactive with patient care. More than half (54.7%) of the caregivers of previously diagnosed patients with dementia and 42.8% of the caregivers of patients diagnosed with dementia at screening reportedly took the patient to the doctor immediately following the first signs and symptoms. In addition, the diagnosis of dementia was confirmed within 6 months of the first doctor visit for the majority of patients with previously diagnosed dementia (72%). In both groups, however, more than half of the caregivers reported that the latency between the appearance of dementia symptoms and seeing a neurologist was greater than 1 year. This delay likely reflects the lack of specialists available to treat and care for the overwhelming number of dementia (and elderly) patients in China [2]. Inadequate access to specialists may delay

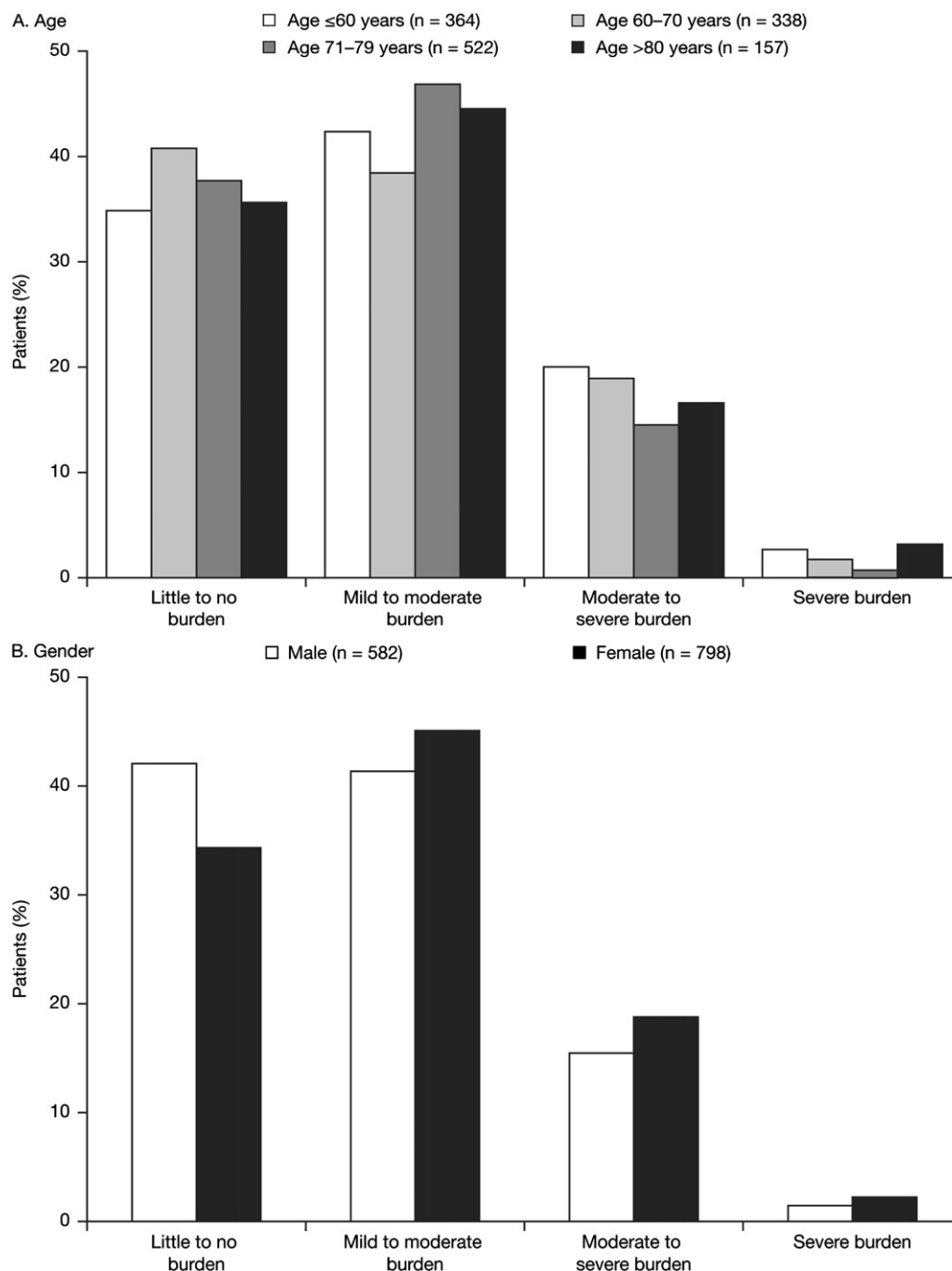
diagnosis and initiation of treatment interventions (pharmacologic and/or behavioral).

### Caregiver Awareness of Dementia

This study has a number of parallels with the Facing Dementia Survey (FDS), one of the largest research surveys done on dementia involving more than 2500 persons from six European countries (France, Germany, Italy, Poland, Spain, and the United Kingdom) [13]. The FDS included interviews with approximately 1200 members of the general public, 600 persons who served as primary caregivers for a person with AD, and 96 persons with AD. Caregiver interviews were either conducted face to face or via telephone, and persons with dementia responded to a qualitative interview that was designed to develop insight and direction rather than quantitatively projectable measures [13].

A number of key messages from the FDS are similar to findings in this study of Chinese dementia. First, AD and dementia are difficult to recognize and diagnose. Both this study and the FDS cited decline in memory as the most prevalent reason for them to consult medical professionals. Caregivers were slow to realize that the memory loss, confusion, and personality changes were different from signs of normal aging. In the present study, at least 45.3% of the caregivers did not take the patient immediately to the doctor following the first symptoms. A prolonged period of inaction following the appearance of symptoms was also evident in the FDS study, in which more than 1.5 years passed between the time symptoms were noticed and the diagnosis of AD [13].

The lack of knowledge of dementia is one of the primary reasons for the delay in diagnosis. Physicians from the FDS responded that most members of the general population do not know the difference between the early stages of AD and the signs of normal aging and that most do not recognize the early signs of the disease [13]. Other reasons cited for the diagnostic delay were the belief that memory loss is a normal part of aging, the lack of physician awareness of and experience with AD, and the observation that patients and families usually avoid unpleasant issues or consciously ignore symptoms [13]. In this study, the majority of caregivers said that they knew nothing about or had a limited



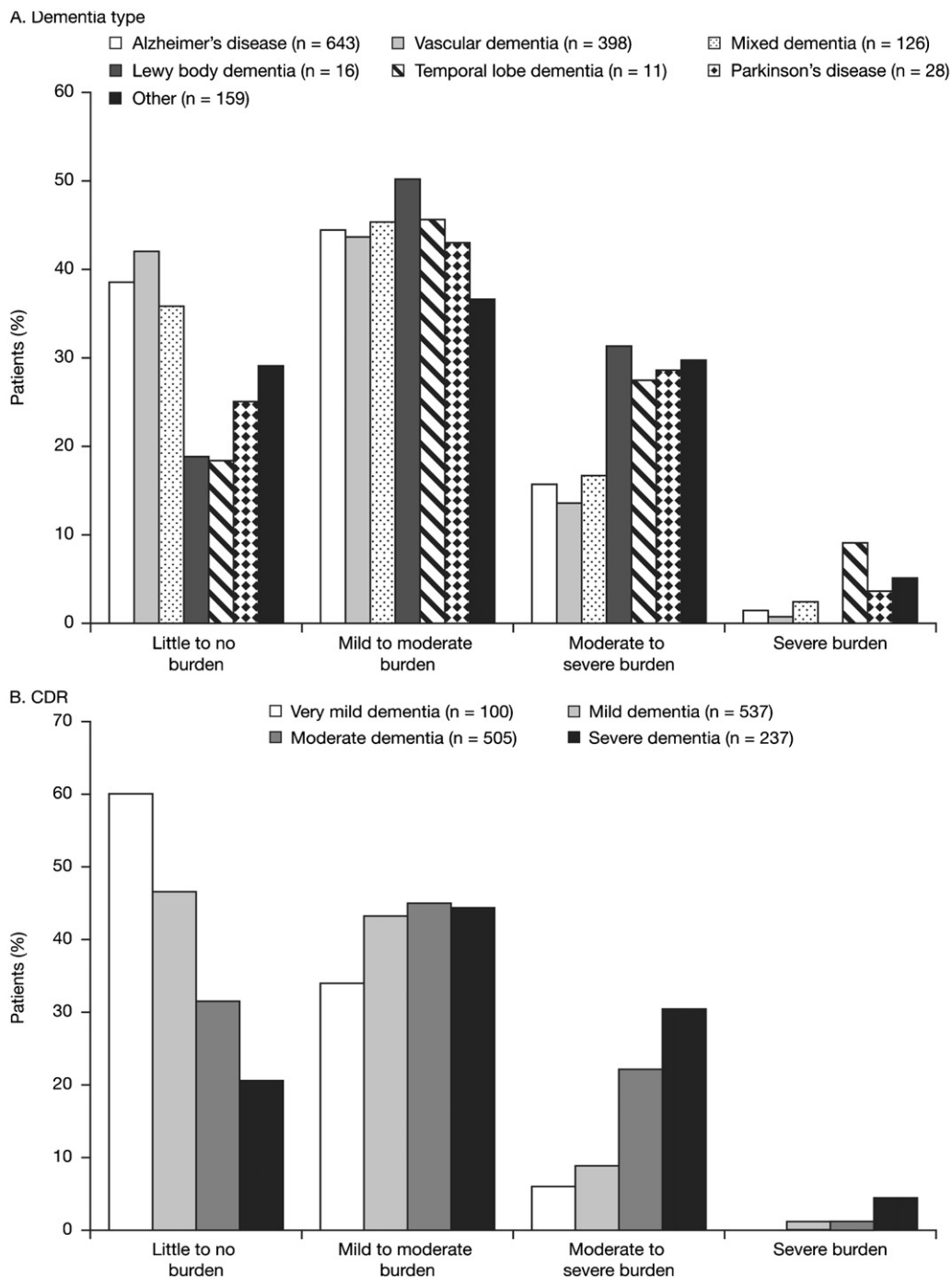
**Fig. 2 – Caregiver burden questionnaire scores by (A) age and (B) gender.**

understanding of dementia. Both studies demonstrate that most caregivers and members of the general public do not have sufficient information about dementia and the benefits of treatment and care.

Results reported here underscore the need for dementia awareness, education, and support initiatives across mainland China. According to the China Alzheimer's Project, a voluntary health organization in China, existing social support programs (both nongovernmental and nonprofit) are small scale and offer limited support for patients with dementia and their families [2]. Studies investigating the benefits of disease management programs that provide education and support to caregivers in developing countries have been promising. The impact of such

programs on caregiver burden has been demonstrated in neighboring countries. The 10/66 Dementia Research Group has published results from two studies that provided caregiver interventions to families of patients with dementia in Russia [14] and India [15]. In Russia, families in the caregiver intervention group showed significant improvement in caregiver burden compared with usual care, though there were no significant differences in caregiver/patient quality of life or caregiver psychological distress [14]. In India, caregiver intervention significantly improved patient behavioral disturbances and caregiver mental health [15].

More recently, a randomized controlled trial in families of patients with dementia compared the effects of a dementia care



**Fig. 3 – Caregiver burden questionnaire scores by (A) dementia type and (B) CDR score. CDR, Clinical Dementia Rating.**

program against standard care in Hong Kong [16]. At the 18-month follow-up, the program produced significantly greater improvements in patient symptoms and institutionalization rates, as well as improvements in caregiver quality of life and caregiver burden, compared with standard care [16].

Given the lack of dementia awareness in the present study, it would behoove policymakers in China to invest in disease management programs. From an economic standpoint, the costs associated with such programs may be offset by the savings they produce in patient hospitalization and caregiver burden. As reported by the China Alzheimer's Project, there is minimal governmental and political support for dementia care as

evidenced by low levels of support for public health education and clinical research, or providing access to therapeutics. In addition, there is currently a shortage of facilities and experienced physicians specializing in treating patients with dementia and elderly patients in general [2].

**Caregiver Burden**

The total mean score on the ZBI questionnaire in the caregivers of patients previously diagnosed with dementia was 28.34 compared with 24.98 for the caregivers of patients who had been recently diagnosed in this study. The difference between the

groups suggests that caregiver burden increases over time with the progression of the disease.

The ZBI scores of both groups were lower than the mean score of 31.0 established in a non-Asian study by Zarit et al. [6] but in line with two validation studies of the Chinese version of the ZBI that had mean ZBI scores of 24.6 and 24.4 [5,17]; these scores were most comparable to the ZBI scores of caregivers of the patients who were diagnosed with dementia at the study screening. Indeed, Chan and Chiu [17] noted that the patients with dementia in their study were at a relatively early stage in the course of their illness similar to the patients diagnosed with dementia at study screening. In a Japanese study [18], the mean total ZBI score for caregivers of patients with dementia was 28.6, somewhat higher than in the present study, but lower than in Zarit's study of non-Asians [6].

A number of factors in addition to the ZBI should be considered when comparing caregiver burden in different populations. It is important to consider caregiver characteristics such as age, gender, educational level, ethnicity, and cultural values [17]. Studies have previously shown differences in caregiver burden among different age groups and gender according to the relationship with the patient [19,20]. Higher caregiver burdens have been associated with younger age [21,22] and female gender [20]. In addition, lower caregiver educational levels have been associated with higher caregiver burdens [22,23]. In the present study, however, no correlation was found between caregiver burden and caregiver age, gender, or level of education.

Previous reports suggest that caregiver burden differs by type of dementia and disease progression. In a study by Vetter et al. [24], patients with early stage VaD imposed a greater burden on caregivers than did patients with AD. As time progresses, this relationship reverses, and caregivers of patients with AD report experiencing greater burden than do caregivers of patients with VaD [24]. Moreover, Vetter et al. [24] and Fuh et al. [23] reported that caregiver burden scores increased with disease progression. This was confirmed in a recent literature review on AD, in which the factors most strongly correlated with caregiver burden were the patient's level of behavioral disturbance and psychiatric/cognitive dysfunction, and the duration of dementia [25]. Interestingly, the present study showed no correlation between the type of dementia and the degree of burden, as all types seem to impact most caregivers in a mild or moderate manner. Because caregivers from both previously and newly diagnosed patients cohorts were reported here, a possible explanation could be that most patients were newly diagnosed with dementia. As a consequence, the degree of burden reported in our study for dementia showed a higher "mild to moderate" score rather than a severe burden score.

### Study Limitations

The present study has some limitations. First, subjects were recruited from neurology clinics in tier-3 hospitals, who may not be representative of patients and caregivers in the community. While this was a large sample, the findings should not be generalized to the whole Chinese population as the patients were from either large urban or regional rural hospitals and may not be representative of the population on the whole. While it would be of interest, identifying regional differences in caregiver burden are beyond the scope of this report. Second, the study had a cross-sectional design, meaning that cause-and-effect relationships cannot be established. Third, 277 (19.4%) caregiver responses were categorized as "unknown" or "missing." Last, because the study was based on self-reporting by caregivers, objective validation of reporting (e.g., level of awareness of dementia and different dementia characteristics) was not possible. However, because of the sample size of the study, the

responses were valid for showing trends but should not be used as strict quantitative measures of the Chinese population. Even with these limitations, important information on the state of dementia and caregiver distress was obtained.

### Conclusions

Dementia has significant emotional, social, and financial impact on patients and their caregivers, regardless of demographics and geography. This study highlights the growing issues of dementia and the burdens caregivers experience across mainland China. Dementia was found more often in patients living in urban areas and affected both genders equally. The majority of patients in the study had mild to moderate dementia, with AD as the diagnosis in slightly less than half the patients followed by VaD in a quarter of the patients. Dementia care was provided primarily by family members, with more than half being spouses and one third of caregivers being sons. Dementia caregiver burden assessed by the ZBI was mild to moderate.

This study highlights the fact that caregivers of patients with dementia face barriers to effective care that may be improved by public education and public awareness campaigns that include descriptions of dementia and normal aging. Further research is needed on programs aimed at improving the psychosocial support of both persons with dementia and their family caregivers across the many diverse Chinese populations.

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