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Family Caregiver’s Perception of Alzheimer’s Disease and Caregiving in Chinese Culture

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This study examined the perception of Alzheimer’s disease (AD) and caregiving among family caregivers of individuals with mild cognitive impairment (MCI) and AD in China. In-depth semistructured interviews were conducted with 46 family caregivers of individuals with cognitive impairment in 2009 in Wuhan and Beijing, China. Participants included 38 spouses, 7 adult children, and 1 sibling, aged between 41 and 85 years old. The findings showed that all family caregivers thought the Chinese terminology of AD laonian chidai, brought discrimination to individuals with cognitive impairment. Caregivers of individuals with AD experienced burden and desired an increase of formal services. Traditional beliefs of respecting elders and caring for extended family members were held among family caregivers of individuals with cognitive impairment, and there was nearly no difference found between caregivers of AD and those of MCI. It implied that traditional culture provided positive influences on caring for elders with cognitive impairment. An alternative term for MCI may contribute to further reducing the discrimination brought by the old Chinese terminology of AD laonian chidai. Development of formal services for elders with cognitive impairment may contribute to reducing caregivers’ worries about future caregiving.

Keywords: Cognitive impairment, culture, China, dementia, elderly, family caregiver

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INTRODUCTION

It is estimated that about five million people in China suffer from dementia (Z. X. Zhang et al., 2004), of which Alzheimer’s disease (AD) is the most common type. As in the United States (Alzheimer’s Association, 2009, 2010), the large majority of persons with AD (96%) in China are cared for at home by family members (Z. X. Zhang et al., 2004). Although not all individuals with mild cognitive impairment (MCI) actually progress to AD, it is unknown which factors predict whether MCI will worsen over time, and family members of individuals with MCI are major potential informal caregivers of AD (Alzheimer’s Association, 2009, 2010). Early detection and intervention of cognitive impairment may hold promise in determining the cause of the syndrome and delaying the onset of AD. It has been suggested that appropriate and effective ways to help family caregivers of individuals with cognitive impairment is essential to address the public health impact of AD (Austrom & Lu, 2009; Bruce, McQuiggen, Williams, Westervelt, & Tremont, 2008; Garand, Dew, Eazor, DeKosky, & Reynolds, 2005).

It is well known that such action as family caregiving is tightly bound to family caregivers’ perception of that action (Wong, Manson, Tremblay, & Welsh, 2013), and a better understanding of family caregivers’ perception of AD and caregiving will contribute to developing appropriate and effective interventions and services to address this public health issue. Culture has been found to exert influence on family caregivers’ perception of dementia and family caregiving (Eloniemi-Sulkava et al., 2009; Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007), and differences were reported between ethnic groups in perception of dementia and family caregiving (Foster, 1990; Mahoney, Clutterbuck, Neary, & Zhan, 2005), leading to different caregiving experiences (Boutoleau-Bretonnière & Vercelletto, 2009; Shaji, George, Prince, & Jacob, 2009; Wilson, Houtven, Stearns, & Clipp, 2007). For example, African Americans, who represent southern culture in the United States, have been found to interpret the meanings and significance associated with AD symptoms in a way not described in terms of biomedical models (Gaines, 1988/1989). Black and Hispanic American caregivers reported more strongly held original cultural beliefs and more filial (child or offspring to parent) support than White counterparts (Connell & Gibson, 1997), and White caregivers reported more stress than African American caregivers (Janevic & Connell, 2001; Sleath, Thorpe, Landerman, Doyle, & Clipp, 2005). Studies showed that Chinese family caregivers of individuals with AD experienced negative (e.g., burden) and positive feelings (e.g., satisfaction), through which traditional culture were supposed to be the main influencing factors (R. Zhang, Yang, Wang, & Li, 2008). Developing culturally appropriate interventions to help family caregivers of individuals with cognitive impairment cope with the long-term-care challenge has been a major public health issue (Belle et al., 2006; Wang, Yu, & Levkoff, 2005).

Appropriate support designed to help Chinese family caregivers of individuals with cognitive impairment is indispensable in AD home care (Gavrilova et al., 2009; Guerra, Ferri, Fonseca, Banerjee, & Prince, 2010; Schoenmakers, Buntinx, & DeLepeleire, 2010). However, family caregiver’s perception of AD and caregiving in Chinese culture were poorly understood (Sosa, Albanese, & Prince, 2009), and there are very few empirical studies conducted to examine it. This study examines Chinese family caregivers’ perception of AD and caregiving with the purpose of identifying information for developing a follow-up culturally appropriate intervention for family members of elderly individuals with cognitive impairment in China. The study result will provide information that is necessary to assist policy makers, researchers, and health care providers in creating culturally appropriate interventions for family caregivers of individuals with cognitive impairment.

METHOD

We relied on in-depth semistructured interviews with surveys of family caregivers of individuals with cognitive impairment, and grounded theory was used to reveal common themes derived from
the data itself (Glaser & Strauss, 1967; Strauss & Corbin, 1997). Grounded theory operates almost in a reverse fashion from traditional social science research. The first step for grounded theory is to collect data by a variety of methods. The key points are marked with a series of codes extracted from the data collected. Then, the codes are grouped into similar concepts and categories are formed from these concepts. Grounded theory, which has been a classic and still standard technique for analyzing health data and aims to conceptualize what is going on by using empirical research, is useful to describe the similarities among persons with specific experiences. In-depth qualitative interviews were conducted with 46 family caregivers of individual with cognitive impairment.

Sampling

Purposive sample was used in this study. We recruited participants from an epidemiological study on AD titled Cognitive Impairment Survey in Chinese Hospitals that lasted from October to December, 2009, among 42 major hospitals in China, including Zhongnan Hospital, Wuhan. The physicians in the memory clinics at Zhongnan Hospital at Wuhan University in Wuhan and Dementia Care & Research Center at Peking University, Institute of Mental Health, China, referred the patients with MCI/ mild AD and their family members to the study team. The diagnosis of MCI was adopted from Petersen et al. (1999). Clinical criteria and diagnosis procedure for AD were adopted from Diagnostic and Statistical Manual of Mental Disorders, 4th ed. (DSM-IV; American Psychiatric Association, 1994) and National Institute of Neurologic and Communicative Disorders and Stroke-Alzheimer’s Disease and Related Disorders Association (NINCDS-ADRDA) criteria (McKhan, et al., 1984). Inclusion criteria for family members were (1) primary family caregiver now or most likely to become the primary family caregiver of individuals with cognitive impairment in the near future and (2) age 18 years or older and able to describe their perception of AD and caregiving. One caregiver per family was recruited in the study.

The protocol of the study was approved by the Institutional Review Board at Wuhan University Health Sciences Center and Peking University Institute of Mental Health. Verbal informed consent was obtained prior to each interview. Appointments for the face-to-face, in-depth semistructured interviews were made by telephone in a week after the individual with cognitive impairment and their family members were referred to the study team. Interviews were conducted according to the interviewee’s preference, mainly at home.

We recruited 21 participants (14 family members of individuals with MCI and seven of individuals with mild AD) from a memory clinic at the Zhongnan Hospital at Wuhan University in Wuhan, China, and 25 participants (eight family members of individuals with MCI and 17 of individuals with mild AD) from the Dementia Care & Research Center at Peking University, Institute of Mental Health, China.

Data Collection

Each interview was recorded with a digital voice recorder after the interviewee agreed. A survey questionnaire was completed to collect the demographic data before the interview began. The in-depth interviews lasted between 60 to 180 minutes and were conducted by two trained researchers who understood the local dialect. The research questions were shaped by the explanatory model (Kleinman, 1980, 1986). Each interview began with a broad data-generating question: “Please tell me about your perception of Alzheimer’s disease and caregiving.” After that, additional questions were asked to further understand their perception of AD and caregiving. Example probes were “What are the causes of memory loss in your opinion?” “Can you describe what you do for him/her on a typical day?” and so on.

Efforts were made to ensure the validity and credibility of the results. The interviewers were given systematic training about how to conduct interviews to ensure a consistent approach in the
interview process. Each interview was conducted by two trained researchers who understood the local dialect with one responsible for taking the notes and one responsible for the interviewing. Supervision of the interview was done by the one who was responsible for taking the notes by checking the topical outline throughout the interview process to ensure that interview was semistructured and the interviewer followed the topical outline with an adequate coverage of topics. Prior to the interviews, study investigators had conducted a pilot study obtaining process data from family caregivers to ensure the suitability of the open-ended questions.

Data Analysis

Data were analyzed by a research team. Two research members independently transcribed recorded tapes into Mandarin Chinese and compared results. For accuracy, the transcriptions were compared

<table>
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<tr>
<th>Characteristic</th>
<th>Spouse</th>
<th>Child</th>
<th>Sibling</th>
<th>Total (N = 46)</th>
<th>n</th>
<th>%</th>
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<td></td>
<td></td>
<td></td>
<td></td>
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<td>55–64</td>
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<td></td>
<td></td>
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<tr>
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<td>1</td>
<td>2.2</td>
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<td>1</td>
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<td>1</td>
<td>2.2</td>
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<tr>
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<td>1</td>
<td>38</td>
<td>82.6</td>
<td></td>
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<tr>
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<td>0</td>
<td>2</td>
<td>4.3</td>
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<td>0</td>
<td>2</td>
<td>4.4</td>
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<td>≤ RMB15000</td>
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<td>5</td>
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<td></td>
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<td>RMB15001–30000</td>
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<td>16</td>
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<td></td>
</tr>
<tr>
<td>&gt; RMB30000</td>
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<td>3</td>
<td>1</td>
<td>20</td>
<td>43.5</td>
<td></td>
</tr>
<tr>
<td>Missing</td>
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<td>1</td>
<td>0</td>
<td>5</td>
<td>10.9</td>
<td></td>
</tr>
<tr>
<td>Diagnosis of recipient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild cognitive impairment</td>
<td>19</td>
<td>2</td>
<td>1</td>
<td>22</td>
<td>47.8</td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>19</td>
<td>5</td>
<td>0</td>
<td>24</td>
<td>52.2</td>
<td></td>
</tr>
</tbody>
</table>

RMB = Ren min bi.
again with the recorded tapes by two research team members who understood the local dialect. Another two research members independently translated the transcription into English, and compared results with each other. Discrepancies in the translation were resolved by seeking input from senior bilingual researchers and conducting back-translation of transcripts from English to Chinese.

Three coders who had been trained for grounded theory and opening coding independently coded the translations for themes, subthemes, and categories. Open coding that is conceptualizing on the first level of abstraction (Strauss & Corbin, 1997) was conducted by three coders with line-by-line coding. The codes were checked by the first author to ensure the validity of the interview coding. Discrepancies in coding were resolved by discussion among the coders. After the consensus of the codes was obtained, the codes were put into categories, from which the themes and subthemes were extracted. Themes were consolidated to figure out “core variables” present in the majority (i.e., more than 60%) of interviews until saturation was attained and no new themes emerged. The codebook was created only after the coauthors obtained consensus of the thematic results. Descriptive analysis was conducted, using SPSS 15.0.

RESULTS

Participant Characteristics

Table 1 summarizes the 46 participants’ characteristics by group based on relationship with the care recipients. The demographic characteristics for family caregivers of individuals with MCI and AD were very similar (results not shown).

Thematic Analysis Findings

Two main themes emerged, which were (1) laonian chidai is natural, and (2) family caregiving is a Chinese tradition. Two subthemes were identified regarding laonian chidai is natural, which were (1) laonian chidai involves discrimination, and (2) it is simply this way. Three subthemes were identified regarding family caregiving is a Chinese tradition, which were (1) respecting him or her as before, (2) caring for my family member, and (3) experience of burden (see Table 2).

<table>
<thead>
<tr>
<th>Response Category</th>
<th>Specific Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Laonian chidai” is natural</td>
<td></td>
</tr>
<tr>
<td>“Laonian chidai” involves discrimination</td>
<td>“Laonian chidai,” bad, discrimination, couldn’t accept, what will happen in the future</td>
</tr>
<tr>
<td>It is simply this way</td>
<td>Normal, the law of nature, natural process, common</td>
</tr>
<tr>
<td>Family caregiving is a Chinese tradition</td>
<td></td>
</tr>
<tr>
<td>Respecting him/her as before</td>
<td>Treat her like before, care more about, social norm</td>
</tr>
<tr>
<td>Caring for my family member</td>
<td>Family member, set an example, the Chinese tradition</td>
</tr>
<tr>
<td>Experience of burden</td>
<td>Basically no burden (mild cognitive impairment), everyday stay with, care for, elderly home (Alzheimer’s disease)</td>
</tr>
</tbody>
</table>
Laonian Chidai Is Natural

*Laonian chidai involves discrimination.* All participants described the diseases as “mild cognitive impairment,” “Alzheimer’s disease.” In Chinese, they were well-known as *laonian chidai*. One caregiver and spouse of an individual with AD said, “The doctor directly told us the diagnosis of Alzheimer’s disease called “laonian chidai” in Chinese and explained the symptoms of AD to us.” One caregiver and spouse of an individual with MCI commented:

The doctor told us the diagnosis of mild cognitive impairment, “laonian chidai” [which means AD in Chinese], without hesitation. Also, he told us how this disease will go on and what will happen in the final stage in the future.

Most caregivers dislike the Chinese terminology *laonian chidai*. One caregiver and daughter of an individual with MCI said, “I feel that the terminology *laonian chidai* is bad, and to some extent it involves discrimination.” Another caregiver and daughter of an individual with MCI specifically stated:

When the doctor told us that she will develop *laonian chidai* [which means AD in Chinese], my family and I couldn’t accept the diagnosis of *laonian chidai*. Why do doctors call it *laonian chidai*? During this interview, please call it *jijili zhang'ai* [the transliteration of MCI].

Similarly, a caregiver and spouse of individuals with MCI stated:

Generally, I describe the disease as “Alzheimer’s disease” rather than *laonian chidai* [which means AD in Chinese]. I tell others he has Alzheimer’s disease, and I tell him [the individual with MCI] that his problem is just memory decline or he will be unhappy.

*It is simply this way.* When describing the causes of cognitive impairment, most caregivers agreed that it was the law of nature for old age to be accompanied by cognitive function decline, including memory loss. Frequently, they mentioned that “When one gets old, it is simply this way,” “It is normal for elders to lose memory gradually.” One caregiver and daughter of an individual with MCI commented, “It is not a shame for elders to fall ill . . . . She just has some problems with memory. However, for elders, it is the law of nature to be like this.” Similarly, one caregiver and spouse of an individual with MCI stated, “I think it is normal for her to be like this. Sometimes, she behaves just like a little child and I can understand her.”

Not only caregivers of individuals with MCI, but also most caregivers of individuals with AD, believed that elders with memory loss behaving like a little child was a part of normal aging. For example, a caregiver and son of an individual with AD commented:

It is normal for elders to fall ill and show symptoms (like this). Sometimes, his behaviors look funny . . . . However, when this happens, we don’t go to see a doctor. We think it will be okay once it passes. There is no need to seek health care or other kinds of help, for it is a natural process and nobody can help.

A caregiver and spouse of an individual with AD stated:

Memory loss is common among common people. When I get older, I couldn’t memorize anything too . . . . I think it is normal (for her to be like this). . . . Though we may take measures to delay the process of memory loss, there is one day that it will come.

Family Caregiving Is a Chinese Tradition

*Respecting him/her as before.* Based on the common responses to the causes of cognitive impairment, all caregivers felt that individuals with cognitive impairment “were respected as before.” A caregiver and daughter of individuals with MCI stated, “She is respected by people as before . . . . Son, daughter and grandchildren all respect her. When outsiders see her, they will greet...
her politely rather than talking back or dodging her.” A caregiver and spouse of individuals with MCI stated, “She is respected by others as before. Outsiders are happy to chat with her . . . . Family members treat her like before as well. She has fallen ill and we should care more about her.” A caregiver and son of individuals with AD stated, “Of course, he is respected by others as before. In our country, respecting elders is the social norm.”

A majority of caregivers believed that traditional belief of extended family influences them most during the caregiving. They stressed that family members should care for each other, and that elders with cognitive impairment shouldn’t be abandoned due to the fact that they were family members. A caregiver and son of individuals with MCI said, “She is a very important family member. She is my mother.” A caregiver and spouse of individuals with MCI said, “We have lived together for so many years. As long as he is alive, he is my family member.” A caregiver and sibling of individuals with MCI said, “I have only one sister . . . we need to care for each other. Surely, she is my family member.” A caregiver and spouse of an individual with AD said, “Of course, she is my family member, we can’t abandon her because of illness.”

Most caregivers of individuals with AD experienced burden though they didn’t mention it explicitly. For example, a caregiver and spouse of individuals with AD stated:

I spend almost 8 hours caring for my mother everyday. She has not only Alzheimer’s disease but also other diseases, such as diabetes. She is 82 years old. She has disabilities in walking and daily activities. So, she needs me to do everything for her . . . . When she watched TV, I can do some housework and something I want to do. At night, I can watch TV or take a rest after she gets to sleep.

Caregivers of individuals with AD significantly worried about the future caregiving, and a majority expressed an increasing desire for formal services. For example, a caregiver and spouse of individuals with AD stated:
Every day I stay with her and care for her... There will be some day in the future when she completely depends on others' caregiving. When that day comes, perhaps my body also has some problems. What can we do then? I wish we can find an appropriate elderly home where we can live in together

**DISCUSSION**

It is well known that old people will suffer from functional decline as the age increases, and no treatment can prevent this natural process. As shown in previous studies among African, Latino, and Chinese American caregivers, in this study, family caregivers of individuals with cognitive impairment showed the same perception of cognitive impairment and associated it with normal aging process (Hinton & Levkoff, 1999; Mahoney et al., 2005; Zhan, 2004). Similar to other functional decline among elders, cognitive decline has no treatment offered to prevent its progression until now—either West medicine or traditional Chinese medicine (Birks & Flicker, 2006; Feldman et al., 2007). That can partly explain why most participants perceived their family members’ symptoms as part of normal aging process even after their family member was given a medical diagnosis of cognitive impairment.

This perception of AD may contribute to the delay in seeking out a physician. As shown in a study conducted in Beijing, Xi’an, Shanghai, and Chengdu, China, only about one half of family caregivers of individuals with AD who recognized the problems brought their family members with AD to the memory clinics, 72% of those who did not bring the individuals with AD to the memory clinics did not do so because they believed it was part of normal aging process, and remaining 20% believed that there was no effective treatment (Z. X. Zhang et al., 2004).

Traditionally, caring for family members who are old or unable to take care of themselves was understood as part of family member’s responsibilities, which were regarded as the essentials of extended family in China (Chan et al., 2009). That is, the offspring has responsibilities to care for elders (filial piety) and the same generation (e.g., spouse and sibling) should care for each other in the extended family (Dai, Zhou, & Mei, 2013; Dai, Zhou, Mei, Wu, & Mao, 2011). By implementing these family responsibilities, Chinese set an example to the offspring and get positive feelings (e.g., satisfaction) from family caregiving. Similar to the previous studies (Miller, 2007), findings in this study showed that traditional beliefs persist in China.

Additionally, elders were respected because they were believed to be wiser than other age groups traditionally. In this study, family members maintained their respect to the cognitively impaired elderly. However, similar to other studies conducted in China (Guo, Levy, Hinton, Weitzman, & Levkoff, 2000; Hinton, Guo, Hillygus, & Levkoff, 2000; Hinton & Levkoff, 1999; Wu, Emerson, & Chang, 2010; Wu, Yu, et al., 2010), this study found that the Chinese term for AD *laonian chidai*, was stigmatizing. *Chidai*, which is an unfriendly adjective, means dull witted and demented, and the Mandarin terminology for AD and dementia, *laonian chidai*, which comes from a translation of an imported English biomedical term, literally translates to “stupid, demented elderly.” It has been reported that the terminology *laonian chidai* brings about discrimination to individuals with cognitive impairment, which significantly increases family caregivers’ depression (Bi & Wang, 2010; Dai et al., 2013; Wu et al., 2010) and may cause delays in diagnosis and treatment for the patient (Zhan, 2004). In this study, a majority of family caregivers, especially those who were children, understood the terminology of the disease more from its literal than biomedical meaning: they associate the term with its cultural incongruity rather than with its neurological symptomatology or etiology. These findings are similar to a study conducted in Beijing, Xi’an, Shanghai, Chengdu (Z. X. Zhang et al., 2004). Additionally, the Chinese terminology for AD *laonian chidai* resulted in discrimination of individuals with MCI, which is stigmatized as the early stage of AD (Bi & Wang, 2010; Wu, Emerson, et al., 2010; Wu, Yu, et al., 2010). To eliminate the discrimination for AD, in October 2012, the Ministry of Health of China launched a rectification to change *laonian chidai* into *aercihaimeibing* that is the
transliteration name of “Alzheimer’s disease.” As the new term for AD is relative professional, popularizing it may need a long period. Also, an alternative term is needed for MCI. Some terms, such as “age-related cognitive impairment” or the transliteration name of “mild cognitive impairment,” needs further discussion.

Petersen et al. (1999) focused on MCI as a prodromal condition for AD and emphasized memory impairment. Individuals with MCI referred to the study team were mainly amnestic MCI (aMCI). Therefore, in this study, caregivers of individuals with MCI talked more about how they coped with memory loss, and those who were family caregivers of individuals with AD reported experience of burden. Taking the progressive nature of AD into account, family caregivers who played the central role in home care for elders began to worry about the future caregiving due to few options available for elders. Since the birth control policy launched in China in the late 1970s, the estimated increases in the number of elderly who will need dementia care coincides with a dramatic decrease in the number of family members who will be available to take on that care (Bartlett & Phillips, 1997; Peng, 1998; Wu, Carter, Goins, & Cheng, 2005). Although it is widely acknowledged that there is a need for additional formal services such as adult day care, respite care and institutional care services, the formal long-term care system remains in the preliminary stages of development in urban China and most institutional care facilities are not prepared to provide care for elders with cognitive impairment (Chu & Chi, 2008; Wu, Mao, & Xu, 2008; Wu, Mao, & Zhong, 2009).

CONCLUSIONS

As shown in this study, all family caregivers of cognitive impairment had similar views with regards to the Chinese terminology of AD and causes of cognitive impairment. Traditional beliefs of respecting elders and caring for extended family members were held among family caregivers of individuals with cognitive impairment. Caregivers of individuals with AD experienced burden of caregiving and desired for an increasing need of formal services. It is implied that traditional culture provides positive influences on caring for elders with cognitive impairment. An alternative term for MCI may contribute to further reducing the discrimination brought by the old Chinese terminology of AD laonian chidai. Development of formal services for elders with cognitive impairment may contribute to reducing caregivers’ worries about future caregiving.

LIMITATIONS

This study was conducted with a small sample size of fewer than 50 family caregivers of individuals with cognitive impairment. Given the small sample size, it was not possible for this study to do any subgroup analyses (by age, gender, or relationship). The study sample consisted of family caregivers of individual with aMCI and mild AD, and their perceptions may not reflect the perceptions of those who are caring for individuals with other forms of MCI and moderate/severe AD. Meanwhile, the fact that individuals with cognitive impairment were recruited only from memory clinics at Wuhan and Beijing may influence the sample representativeness, and the study results may be different because family caregivers may have different experiences in a longer period of time.

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