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Cultural Differences in Caring for People with Dementia: A Pilot Study of Concern about Losing Face and Loneliness in Chinese American and European American Caregivers

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Abstract

Objectives: Heavy demands upon dementia caregivers can lead to a number of poor health outcomes including declines in physical, mental, and brain health. Although dementia affects people from all backgrounds, research in the US has largely focused on European American caregivers. This has made providing culturally-competent care more difficult. This study begins to address this issue by empirically examining how culturally-shaped beliefs can influence loneliness in family caregivers of people with dementia.

Methods: We conducted a preliminary questionnaire study with Chinese American and European American family caregivers of people with dementia (N=72).

Results: Chinese American caregivers were more concerned than European American caregivers about losing face, which in turn, was associated with greater loneliness. This pattern remained when accounting for caregiver gender, age, and relationship to the person with dementia.

Conclusions: These preliminary findings highlight the role that cultural beliefs can play in adverse caregiver outcomes, and suggest that addressing concerns about losing face may be an important way for healthcare providers to help reduce loneliness among Chinese American caregivers.

Clinical Implications: Understanding how cultural beliefs influence caregiver outcomes is critical as healthcare professionals work to provide culturally-competent care and design culturally-sensitive interventions.

Keywords

Chinese Culture; Chinese Americans; Dementia; Caregiving; Loneliness; Losing Face; Aging

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Caregiving for a loved one with dementia can be a challenging experience that is often associated with a greater vulnerability to adverse mental and physical health outcomes, such as depression and loneliness (Brodaty & Donkin, 2022; C. Chen et al., 2020; Joling et al., 2010; Kolanowski et al., 2004; Richardson et al., 2013; Stall et al., 2019). These poor health outcomes, in addition to the chronic stress and burden commonly associated with dementia caregiving, also have a bidirectional and often accelerative effect on worsening caregivers' brain health and cognitive functioning (Dassel et al., 2017; Richardson et al., 2013; Vitaliano et al., 2011). With over 50 million people worldwide diagnosed with dementia (World Health Organization, 2019) and the vast majority of care being provided by family members (over 80% of care is provided by familial caregivers in the US alone; Friedman et al., 2015), identifying caregivers who may be at heightened risk for adverse health outcomes represents an important public health goal.

Thus far, research on caregivers of people with dementia has largely focused on European American caregivers, despite the fact that dementia prevalence is similar or higher across different ethnic groups (S. Lim et al., 2020; Mayeda et al., 2016; Shah et al., 2016). As the world's population becomes older and more diverse, it is critical to examine cultural differences that may play a role in adverse caregiver outcomes. In particular, Asia has the largest population of people with dementia (Wimo et al., 2003), and the East-Asian region is projected to see prevalence rates increase by 200% over the next two decades (Prince, 2015). Understanding dementia caregiver outcomes among the Asian community may thus be especially helpful in providing researchers and clinicians with findings that generalize to a wider population and enable more culturally-competent care. East Asian caregivers may also hold culturally-shaped beliefs that, while beneficial in many contexts, make them more vulnerable in the context of caregiving. The present study examines how caregivers' cultural background may play a role in their health outcomes by examining a mental health concern commonly experienced among dementia caregivers: Loneliness.

Loneliness in Dementia Caregivers

Loneliness is a common adverse effect of caregiving (Bramboeck et al., 2020; Victor et al., 2021). Because caregiving requires substantial time and energy (Lima-Silva et al., 2015; Zhang et al., 2018), there may be fewer opportunities and resources for maintaining social relationships (Brodaty & Donkin, 2022). Further, loneliness is often exacerbated in many familial dementia caregivers because of the perceived loss of a spouse or parent who in the past provided a supportive social connection (Beeson, 2003; Bergman-Evans, 1994; Brodaty & Hadzi-Pavlovic, 1990; Chang, Chiou, & Chen, 2010). Dementia caregivers tend to be older adults themselves, which can pose an additional risk for loneliness. Although younger age has been associated with greater loneliness (Barreto et al., 2021; although see Hawkey, 2022), older adults may be more vulnerable to poor health, shrinking social networks, widowhood, and lower socioeconomic status, all risk factors for loneliness (Dong et al., 2012; Hawkey et al., 2022; Luhmann & Hawkey, 2016; Simon et al., 2014).

Understanding loneliness in caregivers is crucial given that loneliness has been consistently linked to numerous downstream adverse health outcomes such as depression, high blood pressure, stress across the lifespan, functional declines, and higher mortality risk (Cacioppo

et al., 2006; Dahlberg et al., 2022; Hawkey, 2022; Hawkey & Cacioppo, 2010; M. H. Lim et al., 2020; National Academies of Sciences & Medicine, 2020; Perissinotto et al., 2012). Furthermore, extant literature suggests that loneliness in both caregiving and non-caregiving populations has been associated with worse brain health, such as an increased risk of dementia and poor cognitive functioning (Corrêa et al., 2019; Fonareva & Oken, 2014; Richardson et al., 2013; Salinas et al., 2022). While these consequences are concerning regardless of caregiving status, it is especially problematic for caregivers of people with dementia, because worse caregiver health in these domains can also jeopardize the clinical care and well-being of the people in their care (Cooney et al., 2006; Guterman et al., 2019; Quinn et al., 2020; Wiglesworth et al., 2010). Indeed, worse caregiver mental health (Lwi et al., 2017) and greater caregiver burden (Schulz et al., 2020) have been associated with greater risk for mortality in people with dementia even after adjusting for a number of other known risk factors. Thus, examining the factors that contribute to caregiver loneliness may help identify an early intervention target that could protect multiple health domains (i.e., medical, mental, and brain) of caregivers and the people with dementia in their care.

For Chinese and Chinese American dementia caregivers, research has begun to study the impact of cultural factors in areas such as caregiving burden and coping (Guo et al., 2019; Huang et al., 2015; Lai, 2007; Liu et al., 2021; Miyawaki, 2020) and dementia literacy (Sun et al., 2015), but very little empirical research has considered cultural factors that may contribute to loneliness in dementia caregivers. This represents a significant gap in the literature. In the current paper, we propose that dementia caregivers from a Chinese cultural background may be at heightened risk for loneliness due to commonly held cultural beliefs concerning “losing face.”

Chinese Culture and Concern about Losing Face

Bridging the literatures on caregiving and culture, we propose that Chinese caregivers are particularly likely to be concerned about losing face – a cultural belief that centers around maintaining one’s good reputation in the eyes of others. For members of Chinese culture, avoiding losing face requires understanding Chinese social norms regarding social cohesion and harmony (Oyserman et al., 2002), and having the ability to monitor and adjust behaviors that help maintain that harmony (Matsumoto, 1993; Singelis & Sharkey, 1995). Behaviors that demonstrate a lack of this social understanding are judged to be negative or unacceptable (Ho et al., 2004), leading to the loss of one’s good reputation and consequent feelings of shame and embarrassment (Hu, 1944). Losing face can lead to personal suffering and suffering within the family (Hinton et al., 2000; Liu et al., 2008; Yang, 2007) and plays an important role in defining a Chinese individual’s social status or self-worth (Hu, 1944; Ting-Toomey, 2005). Although concerns with losing face are found in many cultures, they are more profound in Asian and Chinese Americans compared to their European American counterparts (Lau et al., 2009; Mak et al., 2009; Zane & Yeh, 2002).

The desire to avoid losing face within Chinese culture may be especially salient for caregivers of people with dementia. Given the strong norms to maintain social harmony in Chinese culture, caregivers may become increasingly concerned about losing face as their family member with dementia experiences progressive impairments in cognitive

and emotional functioning that lead to increased amounts of socially inappropriate and potentially embarrassing behaviors (Levenson & Miller, 2007; McKhann et al., 1984; Rascovsky et al., 2011). Indeed, a recent study examining stigmatizing beliefs around Alzheimer's disease across Asian Americans reported that Chinese Americans had the highest rate of endorsing feeling embarrassed if a family member had dementia (Liang et al., 2021). Chinese culture has also been found to view dementia in relatively stigmatizing ways, including folk models that view dementia as karmic or moral punishment (S. Lim et al., 2020; Liu et al., 2008; Miyawaki, 2015; Woo & Chung, 2013), or as a form of insanity (Ayalon et al., 2004). Thus, caring for someone with dementia may be particularly challenging and socially isolating for Chinese American caregivers who are concerned about losing face.

Concern about Losing Face and Loneliness

For dementia caregivers across all cultural backgrounds, being concerned about losing face may increase risk for loneliness. Even in cultures that are thought to be lower in their concern about losing face (e.g., mainstream United States culture), reputational concerns still influence people's social behaviors (Hu, 1944). Particular social behaviors – such as social withdrawal – may be especially damaging for caregivers of people with dementia. Although no empirical research to our knowledge has examined concern about losing face in dementia caregivers, we propose that caregivers who are concerned about losing face may be more likely to withdraw socially to avoid public embarrassment regarding their loved one's socially-inappropriate behaviors, or to reduce the discomfort or fear of those in the community who do not understand these behaviors (Liang et al., 2021; Zhang et al., 2020). This social withdrawal provides a fertile breeding ground for loneliness. It can also create a vicious cycle, with dementia caregivers receiving less social support when they need it the most (Bressan et al., 2020; de Vugt & Verhey, 2013; Newman et al., 2019; Xu et al., 2021), which further exacerbates their burden and vulnerability to negative medical and mental health outcomes (Hsiao et al., 2016; Sneed & Schulz, 2017).

The Present Research

Loneliness is a common experience in dementia caregivers (Victor et al., 2021) and is associated with worse mental and physical health (Cacioppo et al., 2002; M. H. Lim et al., 2020; National Academies of Sciences & Medicine, 2020). Although prior qualitative research suggests that caregivers from specific cultures may be at heightened risk for loneliness (Hinton & Levkoff, 1999), no empirical studies to our knowledge have examined how cultural beliefs influence loneliness in Chinese American dementia caregivers. This gap in the caregiving literature is consistent with the general under-representation of diversity in psychology research (Roberts et al., 2020) and the general marginalization of Asian Americans more broadly in scientific fields (Yip et al., 2021). Unfortunately, one of the consequences of this under-representation is that few studies are available to help inform decisions about how best to provide culturally informed support to dementia caregivers (Dilworth-Anderson et al., 2020).

In our study, we focus on Chinese Americans because they are both one of the largest aging populations in the United States (Lim et al., 2020) and the fastest-growing population with dementia (Prince, 2015), which in turn creates a parallel rise in familial Chinese American dementia caregivers. Further, Chinese American dementia caregivers may hold particularly salient cultural beliefs that affect their behaviors and perceptions of dementia, which may make them more vulnerable to adverse outcomes. Specifically, factors such as stigma and cultural differences in how dementia and aging behaviors are understood and normalized (Dai et al., 2015; Guo et al., 2000; Hinton et al., 2000; Sun et al., 2015; Yang et al., 2020), often causes Chinese Americans to delay seeking healthcare services (Cipriani & Borin, 2015; Sun et al., 2012; Werner et al., 2014). This can make it more difficult for them to receive care that is preventative or optimal for managing a neurodegenerative disease. It is thus critical to examine the experience of Chinese American dementia caregivers in order to better understand how to address their healthcare needs and the barriers they encounter.

The present research begins to address this important issue by studying 40 Chinese American caregivers of people with dementia (and a comparison group of 32 European American caregivers). European American caregivers were included as a comparison group to examine whether certain differences in caregiver experience (i.e., losing face) were culturally-based or constituted a common feature associated with being a caregiver for a person with dementia across cultures. This study provides a preliminary test of the importance of considering the role of culture in caregivers' mental health. Specifically, we examined whether: (a) Chinese American dementia caregivers are more concerned about losing face than European American caregivers, and (b) being more concerned about losing face is linked with greater loneliness. To evaluate the robustness of our findings, we repeated all analyses while accounting for several important caregiver demographic factors (i.e., gender, relationship to the person with dementia, and age).

Methods

Participants

Participants were 40 Chinese American caregivers and 32 European American caregivers (total $N=72$, see power analyses below). We recruited 21 Chinese American and 32 European American caregivers through the University of California, San Francisco's Memory and Aging Center (UCSF) and its Alzheimer's Disease Research Center (ADRC). To increase outreach to Chinese American caregivers, we recruited an additional 19 Chinese American caregivers through phone calls, emails, and flyers posted at Chinese hospitals, adult day care centers, and Alzheimer's Association caregiver support groups in San Francisco and Seattle.

Within our sample, 66% of caregivers were spouses, 25% were adult children, 5% were friends or other relatives, and 4% declined to provide identifying information. For all participants, caregiver culture matched the culture of the person with dementia. Regarding the person with dementia, 61% of caregivers were caring for a person who had Alzheimer's disease (AD; $n=44$), 28% had frontotemporal dementia (FTD; $n=20$), and 11% had either vascular dementia, corticobasal syndrome, Parkinson's disease, progressive supranuclear palsy, or dementia with Lewy bodies ($n=8$). See Table 1 for additional demographic data

by culture. Missing demographic data were handled using listwise deletion. For cultural comparisons of dementia type, see Supplementary Table 1.

Measures

Demographics.—Caregivers self-reported their ethnicity, age, and gender. Their relationship to the person with dementia was reported by selecting one of the following categories: spouse, child, friend, or other (with space provided for additional elaboration).

Caregiver loneliness.—Loneliness was measured using the UCLA Loneliness scale (Russell et al., 1980), a 20-item questionnaire that consists of questions such as “*How often do you feel that you lack companionship?*”, “*How often do you feel close to people?*”, and “*How often do you feel left out?*” Caregivers provided ratings using a 4-point Likert scale ranging from “*never*” (1) to “*often*” (4). The Chinese version of this scale was translated and developed by Wang and colleagues and found to have an internal consistency of 0.82 (Wang et al., 2001). A sum of the item ratings was used to calculate loneliness, with higher scores indicating greater loneliness. The average level of loneliness reported by the overall group was 31.9 ($SD=10.2$). This scale is widely used (e.g., Cacioppo et al., 2006; Hawkey & Cacioppo, 2010; Nguyen et al., 2020) and reliability in our sample was high (overall $\alpha=.91$, Chinese American $\alpha=.89$, European American $\alpha=.93$).

Caregiver concern about losing face.—Concern about losing face was measured using the Assessment of Loss of Face scale (Zane & Yeh, 2002) a 21-item questionnaire that consists of statements such as, “*I maintain a low profile because I do not want to make mistakes in front of other people,*” “*I hesitate asking for help because I think my request will be an inconvenience for others,*” and “*I try to act like others to be consistent with social norms.*” Caregivers rated how much they agreed with these statements using a 7-point Likert scale ranging from “*strongly disagree*” (1) to “*strongly agree*” (7). Both the English and Chinese versions of this scale were provided by Dr. Zane. An average item rating was computed such that higher scores indicate greater concern about losing face. The average level of concern about losing face reported by the overall group was 4.2 ($SD=0.78$). This scale is widely used (S. X. Chen et al., 2020; Leung & Cohen, 2011), and reliability in our sample was high (overall $\alpha=.87$, Chinese American $\alpha=.85$, European American $\alpha=.85$).

Diagnosis of person with dementia.—For participants recruited through UCSF, the person with dementia underwent standard neurological and psychological testing and assessment of cognitive and behavioral symptoms. This information was used to provide a diagnosis based on criteria for Alzheimer’s disease (McKhann et al., 1984), frontotemporal dementia (Gorno-Tempini et al., 2011; Rascovsky et al., 2011), corticobasal syndrome (Armstrong et al., 2013), progressive supranuclear palsy (Litvan et al. 1996), dementia with Lewy bodies (McKeith et al., 1996), and vascular dementia (Román et al., 1993). Because of UCSF’s Memory and Aging Center’s expertise in neurodegenerative disease and ongoing research programs, referrals typically include less common neurodegenerative diseases (e.g., frontotemporal dementia). Thus, the distribution of dementia types recruited from UCSF was somewhat different than that seen in typical memory clinics.

For participants recruited via our additional outreach efforts, caregivers reported the diagnosis the person with dementia had received. Caregivers recruited through these two methods did not significantly differ in demographic variables (See “Preliminary Analyses” below for comparisons).

Procedure

Caregivers were contacted via phone or e-mail and invited to participate in a 20–30 minute questionnaire study. Caregivers who agreed to participate were given the choice of completing the questionnaires online or using paper forms (which were mailed back to the UC Berkeley Psychophysiology Lab using a self-addressed stamped envelope that was provided). Both the paper and online versions of the questionnaire package contained a consent form (approved by the UC Berkeley Committee for the Protection of Human Subjects) and the questionnaires for assessing caregivers’ current experience of loneliness and concern about losing face. All participants were given the option to complete the questionnaire in English. Chinese American participants were also given the option to complete the questionnaire in Chinese (with traditional characters). All participants were given the option to decline to respond to any specific question. All caregivers who consented to participate received a payment of \$25.

Results

Analytic Approach

Preliminary analyses examined potential cultural differences in caregiver demographics (i.e., gender, relationship to the person with dementia, age) and patient demographics (gender, diagnosis, age). Variables that differed across cultural groups were then included as covariates when appropriate. For primary analyses, we examined the associations between cultural group and both concern about losing face and loneliness using univariate MANOVAs. We examined the association between concern about losing face and loneliness using a regression analysis. To compare effect sizes across MANOVAs and regressions, we used standardized regression coefficients for the cultural group analyses (with culture entered as a dummy-coded predictor: Chinese American = 1, European American = 0). To examine the robustness of these effects, each analysis was repeated including the covariates of caregiver age, relationship to the person with dementia, and gender.

Power Analyses

Post-hoc power analyses for each of the analyses indicated that the present sample size was adequately powered (i.e., power > 80%) to detect whether cultural background is associated with concern about losing face ($d=.93$; 97% power), and whether concern with losing face is associated with loneliness ($f^2=.11$; 87% power). Power was lower for our analyses examining the effect of culture on loneliness ($d=.54$; 61% power) and whether concerns about losing face mediate the association between culture and loneliness ($\beta=.15$, 69% power). All power analyses were conducted with G*Power (Faul et al., 2009) and MedPower (Kenny, 2017).

Preliminary Analyses

Cultural differences in caregiver demographics.—Preliminary analyses were conducted to examine whether Chinese American and European American caregivers differed in their gender, relationship to the person with dementia, and age. Compared to European American caregivers, Chinese American caregivers were more likely to be female, less likely to be a spouse, and marginally younger (see Table 1 for statistical comparisons). Given these differences, all three of these variables were included as covariates in the primary analyses.

Cultural differences in patient demographics.—Analyses were also conducted to examine whether Chinese American and European American caregivers were caring for people with dementia who differed in gender, diagnosis, and age. As summarized in Table 1, results indicated there were no cultural differences in gender. However, there were significant differences in dementia diagnosis with nearly all of the Chinese American caregivers caring for a person with Alzheimer's disease and the majority of European American caregivers caring for a person with frontotemporal dementia. Using the data provided by the Chinese American caregivers who were willing to report the age of the person with dementia, results indicated that Chinese American caregivers were caring for people with dementia who were older than those being cared for by European American caregivers. This is consistent with the fact that most Chinese American caregivers were caring for people with AD, which typically has a later age of onset compared to frontotemporal dementia (Alzheimer's Association, 2019).

Although we observed cultural differences in the age of the person with dementia and dementia type, we did not control for these variables as covariates for two key reasons. First, adjusting for age would result in a significant amount of missing data in the analysis given that one third of the Chinese American sample declined to report the age of the person with dementia. Second, adjusting for dementia type would lead to issues of multicollinearity when examining cultural differences in loneliness or concern about losing face (as noted above, most Chinese American caregivers were caring for a person with AD and most European American caregivers were caring for a person with frontotemporal dementia). However, descriptive analyses provide evidence for cultural differences even when holding dementia subtype constant. For example, when focusing only on caregivers of people with AD, Chinese American AD caregivers reported greater concern about losing face by nearly a full scale point ($M=4.5$, $SD=0.7$, $n=38$) compared to European American AD caregivers ($M=3.7$, $SD=1.0$, $n=6$). These means are also virtually identical to the means for the cultural groups that collapse across dementia subtype (Chinese American caregivers: $M=4.5$, $SD=0.7$, $n=40$; European American caregivers: $M=3.8$, $SD=0.8$, $n=32$). While certainly not definitive, these analyses suggest that differences in dementia subtype do not wholly account for the observed cultural differences.

Demographic differences across recruitment groups.—Caregiver demographic variables were also examined in terms of the different recruitment approaches used for Chinese American caregivers (i.e., through UCSF versus through the community more widely). Chinese American caregivers recruited through UCSF were similar in age

($n=21$, $M=56.2$, $SD=14.6$) to community-recruited Chinese American caregivers ($n=19$, $M=60.1$, $SD=11.6$). The proportion of female Chinese American caregivers was similar across the two groups (88% vs. 80% female). UCSF Chinese American caregivers reported similar levels of loneliness ($M=42.3$, $SD=9.9$) and loss of face ($M=4.5$, $SD=0.7$) to community-recruited Chinese American caregivers ($M=41.9$, $SD=10.9$) and ($M=4.5$, $SD=0.7$), respectively. All independent t-tests and χ^2 results comparing these recruitment groups were not significant ($ps >.389$).

Primary Analyses

Culture and concern about losing face.—Chinese American caregivers reported greater concern about losing face ($M=4.5$, $SD=0.7$) than European American caregivers ($M=3.8$, $SD=0.8$), $F(1, 70)=17.29$, $\beta=0.45$, $p < .001$. This group difference remained significant when caregiver covariates were entered into the model, $F(1, 64)=13.67$, $\beta=.47$, $p < .001$.

Concern about losing face and loneliness.—Greater concern about losing face was associated with feeling more loneliness, $B=4.08$ ($SE=1.48$), $\beta=.31$, $p=.007$. This association remained significant when caregiver covariates were entered into the model, $B=4.64$, ($SE=1.58$), $\beta=.35$, $p=.005$.¹

Culture and loneliness.—Chinese American caregivers reported greater loneliness ($M=42.3$, $SD=10.1$) than European American caregivers ($M=37.0$, $SD=9.6$), $F(1,70)=5.02$, $\beta=0.26$, $p = .028$. This group difference remained significant when caregiver covariates were entered into the model, $F(1,64)=6.80$, $\beta=0.36$, $p=.011$. Finally, an exploratory mediation analysis conducted using the PROCESS macro with 50,000 bias-corrected bootstrapped samples provided evidence for a significant indirect effect such that Chinese American (vs. European American) caregivers were more likely to have greater concern about losing face, which in turn accounted for their greater loneliness, *indirect effect* $B=2.23$ ($SE=1.30$), $CI_{95}=[0.10, 5.33]$. The indirect effect was also significant when caregiver covariates were entered into the model, $B=2.58$ ($SE=1.43$), $CI_{95}=[0.31, 6.08]$.²

Discussion

Millions of dementia caregivers worldwide are relied upon to help loved ones with their daily activities and medical care (Wolff et al., 2016). Although the adverse mental health outcomes that can result from managing the stressors and burdens of caregiving (Schulz & Sherwood, 2008; Sneed & Schulz, 2017) have been well studied, less research has focused on cultural factors that influence these outcomes. This is a critical gap, because without additional research, information on whether dementia caregivers of different ethnic groups vary in their risk for adverse health outcomes remains limited or mixed (Apesoa-Varano

¹We note that the association between concern about losing face and greater loneliness was *not* moderated by culture, *interaction* $B=0.50$ ($SE=3.32$), $CI_{95}=[-6.15, 7.14]$, $p=.882$. Post-hoc power analysis indicated that this sample size was well-powered for this analysis ($f^2=.11$, 87% power). This finding indicates that concern about losing face was associated with greater loneliness to comparable degrees in both Chinese American and European American caregivers.

²Because 19 (of the 72) of the caregivers completed questionnaires in Chinese, we also examined the results with questionnaire language included as a dummy variable (0=English, 1=Chinese). All results remained consistent.

et al., 2015; Liu et al., 2021). Further, this scarcity of research can also lead to healthcare decisions that lack the cultural considerations that may be particularly relevant for this large and growing group of Chinese American dementia caregivers. This pilot study conducted in a sample of Chinese American and European American caregivers of people with dementia begins to address this gap by using multiple approaches to recruitment when conducting outreach to Chinese American communities, and by providing preliminary evidence that culturally-shaped beliefs, such as concern about losing face, influences caregiver mental health outcomes such as loneliness.

Specifically, the present results revealed that relative to European American caregivers, Chinese American caregivers were more concerned about losing face which, in turn, was associated with more loneliness. These results remained robust even after adjusting for several socio-demographic variables that could also influence loneliness, namely, caregivers' age, relationship to the person with dementia, and gender. These findings align with prior research findings that concern about losing face accounts for cultural differences in outcomes such as depression or anxiety in non-caregiver samples (Kalibatseva et al., 2017; Kong et al., 2020; Lau et al., 2009).

Concern About Losing Face and Loneliness in Dementia Caregivers

Concern about losing face is a salient concept in many cultures that shapes social interactions by linking one's personal reputation to the behaviors expressed by oneself or one's family. Thus, to maintain their public reputation, people are motivated to behave in ways that are socially accepted, and actively consider how others may feel in order to allow for harmonious social interactions. Concern about losing face has notable social benefits (e.g., promoting social harmony and collective responsibility; Hu, 1944). However, our findings suggest that this concern can also have drawbacks. Specifically, when people who are concerned about losing face are in situations where opportunities to lose face are high (e.g., caring for a person with dementia), they may withdraw socially and thus increase their loneliness. In the context of dementia caregiving, behaviors of loved ones that could lead to public embarrassment or negative evaluation can motivate social withdrawal and foster greater loneliness. While social withdrawal is understandable and may ameliorate the issue in the short term, chronic social withdrawal is quite damaging for most people in the long term (Hawkley & Cacioppo, 2010). Our findings thus highlight the importance of having healthcare professionals intervene early by considering caregivers' concern about losing face, given that their subsequent decision to either isolate or seek social support can have quite different downstream effects on their medical health (Beutel et al., 2017; Cacioppo et al., 2006; Hawkley et al., 2006; National Academies of Sciences & Medicine, 2020; Perissinotto et al., 2012; Uchino et al., 1992), mental health (Beutel et al., 2017; Cacioppo et al., 2006), and brain health (Corrêa et al., 2019; Salinas et al., 2022).

Broader Implications for a Culturally Sensitive Approach to Dementia Caregiving

This study highlights important cultural facets to consider when providing care and support to dementia caregivers. Specifically, we believe these results indicate that concern about losing face may account for greater loneliness among Chinese American caregivers compared to European American caregivers, which in turn suggests several promising

intervention targets. First, interventions could help caregivers manage their concern about losing face. For example, dementia caregivers who are sensitive to losing face could benefit from interventions focused on adaptive emotion regulation skills to help manage distressing emotions (e.g., shame). CBT approaches incorporating psychoeducation and emotion regulation skills have been found to be effective in improving a number of outcomes in Chinese caregivers (Ma & Saw, 2020), and may thus also be effective in reducing concern about loss of face specifically. Teaching caregivers skills to help their loved ones with dementia minimize their disruptive behaviors (Cheung et al., 2015; Nichols et al., 2011) could also help reduce opportunities for loss of face and embarrassment.

For Chinese American caregivers, providing coping skills for the responses and social losses of their community may be particularly valuable. Adaptive caregiver coping strategies have been linked to reduced dementia caregiver burden (Etters et al., 2008; Iavarone et al., 2014; Khalaila & Cohen, 2016) and may even help slow cognitive and functional declines in people with dementia (Tschanz et al., 2013). For Chinese dementia caregivers, teaching coping strategies may also have the added benefit of helping them manage the internalized stigma that may undergird concerns about losing face and motivate social withdrawal (Gallagher-Thompson et al., 2007). Chinese American dementia caregivers may also benefit from interventions that help educate friends, family, and peers about dementia, which in turn could reduce the stigma and negative evaluations associated with the disease (An et al., 2020). Such interventions could also indirectly reduce caregivers' concerns about losing face, because viewing dementia through a medical lens may reduce perceptions of dementia behaviors as being purposefully disruptive. In other domains (e.g., mental illness), interventions focused on altering stigmatizing beliefs and enhancing coping skills related to stigma have been found to be quite effective (Mittal et al., 2012; Thornicroft et al., 2016).

Given the associations between loneliness and its many consequences on caregivers' medical, mental, and brain health outcomes, interventions that target caregiver loneliness directly may also be helpful. For example, studies have found that older adults who engage in social support groups and increased their levels of social engagement were able to maintain or even improve their cognitive functioning (Evans et al., 2019; Myhre et al., 2017; Pitkala et al., 2011). In dementia caregivers, such outcomes would be critical not only for maintaining the health of the dementia caregivers themselves, but also for their ability to manage the complex medical care that their loved one with dementia may need in order to support their brain health and functioning. Additionally, caregivers who lack social support often experience increased burden and stress (Coen et al., 1997; Ruisoto et al., 2020; van der Lee et al., 2014), which in turn may negatively impact the health, well-being, and prognosis of their loved one with dementia (Quinn et al., 2020; Ruisoto et al., 2020). It thus follows that interventions that address social isolation and increase social engagement through peer support, support groups, or psychoeducation groups have been found to reduce symptoms of depression and burden in dementia caregivers (Dam et al., 2016; Mittelman et al., 2004; Roth et al., 2005) and may contribute to reducing mortality in dementia care recipients (Brodaty et al., 1993). Such support groups may be particularly critical for Chinese caregivers, who often wait until burdens become overwhelming and personal resources have been depleted before seeking support (Sun et al., 2012), thus, further increasing their vulnerability to adverse health outcomes. Developing and evaluating interventions that target

loneliness in Chinese American and other dementia caregivers is an important avenue for future research.

Strengths, Limitations, and Future Directions

We believe that this study had several strengths. First, we addressed gaps in the literature on loneliness in Chinese American dementia caregivers. This is an area that has important implications for adverse health consequences (M. H. Lim et al., 2020; National Academies of Sciences & Medicine, 2020) and could serve as a critical target for early intervention or prevention measures in Chinese American dementia caregivers. Second, we considered how cultural beliefs can impact the experience and outcomes of dementia caregivers, and more specifically, determined how a culturally-shaped belief (i.e., concern about losing face) is related to dementia caregivers' loneliness. We believe these strengths have important implications for planning clinical care for caregivers and mounting future efforts to educate the public about dementia and caregiving in different cultural groups.

This study also has several limitations that suggest important avenues for future research. First, while demonstrating that understudied Chinese American dementia caregivers can be successfully recruited for empirical research using multiple approaches, we still met significant challenges recruiting sufficient numbers of Chinese American research participants. These challenges may have stemmed from cultural beliefs and stigma associated with dementia as we stated in our discussion, and which have been well-documented by others (e.g., Guo et al., 2000; Hinton et al., 2000). Second, although our analyses suggest that differences in recruitment strategies or dementia subtype did not account for the present results, future research will benefit from larger samples that allow more definitive assessment of how different recruitment strategies and dementia subtypes influence caregiver outcomes in different cultural groups. Third, although the literature supports our hypothesis that concern about losing face may play an important mediational role between caregiver culture and loneliness, our exploratory mediational analyses were conducted using cross-sectional data. Future research will greatly benefit from using longitudinal methodologies that can replicate and extend these findings. Finally, future studies would also benefit from examining additional caregiver variables that may also impact caregiver loneliness and concern about loss of face, such as immigration and socioeconomic status, education levels, and acculturation (Ma & Saw, 2020; Miyawaki, 2020).

Conclusion

The present study found that, compared to European American dementia caregivers, Chinese American dementia caregivers were more concerned about losing face, and that losing face was associated with experience greater loneliness. Although we consider this to be a pilot study, it has provided preliminary empirical findings concerning important cultural differences that may be highly relevant when planning care, support, and interventions for Chinese American dementia caregivers. Increasing the effectiveness and relevance of caregiver interventions, in turn, may play an important role in prolonging the brain health and functioning of the dementia family member under their care. We hope

these initial findings will encourage others to conduct additional research examining cultural influences in dementia caregivers and other vulnerable populations. However, it is important to acknowledge that this kind of research will hinge upon successful recruitment of caregivers from underrepresented populations, which will require building strong community partnerships. Greater community engagement can be facilitated by having culturally-representative and culturally-competent researchers involved in participant recruitment and in administering research procedures. Such community engagement can increase the likelihood that in-depth, well-powered, and ecologically-valid research can be conducted on important issues related to culture, caregiving, and mental health. Importantly, community engagement can also provide additional opportunities for psychoeducation, a necessity for helping people recognize symptoms of concern in family members, reducing stigma associated with dementia, and increasing willingness to seek out needed support and professional services in Chinese Americans caregivers and other underrepresented cultural groups.

Overall, these findings underscore the importance of increasing the diversity of the populations we study and of understanding how cultural beliefs and stigma impact psychosocial outcomes. In a world with increasingly diverse aging populations and rising dementia prevalence, examining how culture and culturally-shaped beliefs can impact caregivers' mental health is essential for providing culturally-competent care and designing culturally-sensitive interventions that will benefit caregivers and the loved ones under their care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Data Availability Statement

The data that support the findings of this study are available from the corresponding author, SL, upon reasonable request

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Clinical Implications

- Concern about losing face may account for greater loneliness among Chinese American dementia caregivers compared to European American caregivers. Thus, early assessment of concern about losing face may be important for preventing loneliness and isolation among Chinese American caregivers, which can contribute to maximizing physical, mental, and brain health in dementia caregivers and their care recipients.
- Engaging in community outreach and overcoming common recruitment challenges (e.g., stigma, retention, trust) is critical for including greater diversity in the dementia caregiving literature and increasing cultural competence in health care.

Table 1

Demographic Comparisons of Chinese American and European American caregivers and people with dementia.

Demographics	Chinese American	European American	Statistical Comparison
Caregiver			
Gender (% female)	80%	50%	$\chi^2(1) = 8.25, p=.004$
Relationship (% spouse)	43%	94%	$\chi^2(3) = 18.89, p<.001$
Children	43%	3%	
Friend/Other	13%	3%	
Age	58.5 (13.0)	63.6 (9.1)	$t(68) = 1.87, p=.066$
Person with Dementia			
Gender (% female)	33%	50%	$\chi^2(1) = .41, p=0.52$
Diagnosis (% Alzheimer's)	95%	19%	$\chi^2(1) = 43.49, p<.001$
FTD	2.5%	59%	
Other	2.5%	22%	
Age	80.2 (10.9)	68.5 (5.6)	$t(58) = 5.29, p<.001$

Note. Mean (SD). FTD = Frontotemporal Dementia. Nine Chinese American caregivers declined to report the gender of their family member with dementia, 13 people declined to report their family member's age, one declined to report their own gender, two declined to report their own age, and three declined to report their relationship to the person with dementia. Missing data were managed with listwise deletion.