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A scoping review of dementia caregiving for Korean Americans and recommendations for future research

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Abstract

Objectives: This scoping review aims to examine the caregiving experiences of Korean American caregivers of persons with dementia.

Methods: A comprehensive electronic search was conducted within 5 databases (PubMed, CINAHL, Web of Science, Embase, PsycINFO-ProQuest) for papers published from 01/01/00–01/24/22. Seventeen articles met the inclusion criteria. Thematic analysis was used to summarize key findings from these papers.

Results: Most Korean American dementia caregivers were immigrants and wives/daughters/daughters-in-law. Two themes emerged: 1) how Korean American caregivers perceived their caregiving experiences, and 2) how Korean American caregivers perceived their caregiving support services. Korean American caregivers often experience poor mental health and burden.

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Social support and familism were found to be two of the most important factors that determine their attitudes toward caregiving. Most reported barriers to utilizing public services. Challenges in finding culturally relevant resources were common.

Conclusions: Dementia caregiving is a significant public health problem facing Korean Americans. Recommendations for future research are provided.

Keywords

Korean; Korean American; dementia caregiving; health disparities; Alzheimer's disease; dementia; scoping review

Introduction

Dementia and dementia caregiving pose significant public health concerns in the United States (US). One-third of older US adults die from dementia – a range of conditions associated with cognitive decline that can interfere with daily function and independence (Alzheimer's Association, 2022). The most prevalent form of dementia among older adults aged 65 and older is Alzheimer's disease (AD) (60–80%) (Alzheimer's Association, 2021).

Older adults living with Alzheimer's disease and related dementias (ADRD) tend to receive assistance from family or informal caregivers (92%) (Kasper, Freedman, Spillman, & Wolff, 2015). In 2019, more than 16 million Americans provided unpaid care for persons with dementia (PWD): these hours of unpaid care amount to 18 billion hours (valued at \$44 billion) (Alzheimer's Association, 2020). Of importance, informal caregivers of people with dementia report poorer physical and mental health than those of other chronic conditions (Jones et al., 2017).

Despite the public health significance of dementia caregiving, there is limited research in this area on Asian Americans, who are the fastest growing racial group and projected to become the largest group of immigrants in the US in the coming decades (Pew Research Center, 2017). Korean Americans in particular are one of the largest Asian American populations, with an estimated 1,908,000 residing in the US as of 2019, 59% of whom are foreign-born, and 12% are 65 years old and older (with a higher proportion of 20% among those who are foreign-born) (Budiman, 2021). A higher proportion of older Korean Americans are living in poverty compared to Asian Americans overall (19% vs. 12%, respectively) (Budiman, 2021), and half of foreign-born Korean Americans have limited English proficiency (Migration Policy Institute, 2017). In 2019, the median annual household income for Koreans in the US (\$72,200) was lower compared to the median for all Asian Americans (\$85,800) (Budiman, 2021). These unique characteristics of Korean Americans including the high proportion of limited English proficiency may pose as a challenge for Korean American caregivers of persons with dementia.

Moreover, caregiving for Korean Americans is greatly influenced by cultural beliefs, customs, and values. The majority of older Korean Americans tend to retain traditional Korean cultural values (Jang, Kim, Chiriboga, & Kallimanis, 2007). Korean culture is heavily shaped by collectivism and Confucianism (Oak & Martin, 2000) contrary to the

Western emphasis on individualism and autonomy. Collectivism is a significant element of Korean culture and Koreans identify strongly with their in-group (e.g., family), thus, Koreans place greater value on interpersonal relationships and interdependence. Confucian values – built upon principles of social order and clear hierarchy – are ingrained into Korean family structures and customs: these practices include filial piety (showing care and respect to one’s elders), authority of fathers/husbands, submission of individual to family, etc. (Lehrer, 1996).

Another factor that may potentially affect the caregiving experiences of Korean Americans is related to the US health and social services systems. For example, although Asian American caregivers including Korean Americans, are more likely than other racial/ethnic populations to want doctors and other health care professionals to ask them about what their care recipient’s needs are (AARP Public Policy Institute, 2020), Korean Americans with limited English proficiency are at increased odds of not having a usual source of care or regular health checkups (Jang & Kim, 2019). Compared to other older Asian Americans, fewer Korean American older adults have reported accessing healthcare systems on a regular basis (Nguyen, 2012). Moreover, more Asian American caregivers, including Korean Americans, find their role to be emotionally stressful compared to African American or Hispanic caregivers, and most Asian American caregivers report feeling that they do not have a choice in taking on their caregiving responsibility (AARP Public Policy Institute, 2020).

Given the rapidly growing Korean American population and dementia caregiving needs that will also increase significantly, it is important to understand what we know and what has been done in dementia caregiving for Korean Americans. We therefore used a scoping review methodology to examine the knowledge, attitudes, and experiences about dementia caregiving among Korean Americans. Findings from this review will provide directions for future research and inform the development of culturally and linguistically appropriate caregiving programs for Korean American dementia caregivers.

Methods

A scoping review was conducted to identify the knowledge gaps and scope the body of literature about Korean American dementia caregiving (Munn et al., 2018). Covidence, a web-based software platform that streamlines the production of systematic reviews (Covidence systematic review software, No date) and is effective in identifying duplicate references (McKeown & Mir, 2021), was used to organize this scoping review search. The review was conducted by two primary reviewers (QL & JVL) and a secondary reviewer (VP). This review was developed using the scoping review methodological framework proposed by Arkley and O’Malley (Arksey & O’Malley, 2005) which consists of five steps:

Step 1: identifying the research question

Our research question is: What are Korean American dementia caregivers’ experiences including with dementia caregiving programs/interventions?

Step 2: identifying relevant studies

The search period was from 01/01/2000 to 01/24/2022 on five databases: Embase, PsycINFO ProQuest, PubMed, CINAHL, and Web of Science. Three primary terms within the research question were identified and used to develop the search strategy and identify relevant papers: Korean American, dementia, and caregiver.

To broaden the number of potentially relevant papers, similar search terms were subsequently developed for each concept. To capture articles relevant to Korean Americans, the following search terms were included: Korean Americans, Asian Americans, and Koreans. Search terms related to dementia, such as Alzheimer's, mild cognitive impairment, and memory loss were identified and included in the second part of the search. For the third set of search terms, to capture articles relevant to caregivers' experience and the use of resources, the search was expanded to include terms such as caregiver attitude, caregiver burden, caregiver burnout, caregiver health, caregiver network, caregiver support, and caregiver self-help.

Other information sources included reference lists in published papers, and consultation with field experts for other known published articles that were not found from the other sources.

Step 3: study selection

The studies were selected using a two-stage screening process. For the initial phase of the article identification process, the title and abstract of citations were screened independently by two members of the research team (QL & JVL). Studies that did not meet the minimum criteria were eliminated. The articles that did not have abstracts available were included for review of the full article. During the subsequent phase of the review, the full texts of articles that met the minimum inclusion criteria were further reviewed. Discrepancies related to study selection during these two phases were discussed and resolved by a third reviewer (VP) if they could not be addressed by the two initial reviewers alone.

Studies were eligible for inclusion if they broadly appeared to reference the target demographic and topic (Table 1). Both quantitative and qualitative studies were eligible for inclusion. Studies were included if they involved Korean American caregivers of people who had dementia (and/or other dementia-related conditions), and how caregivers perceived caregiving experiences and/or caregiving support services. Papers that "lumped" Korean Americans under "Asian" or "Asian American" were also retrieved and reviewed. Only original research papers that study Koreans who live in the US were included. Only English language papers were reviewed. Exclusion criteria was used to eliminate ineligible studies.

Citations were imported from each database the web-based systematic review software Covidence for title and abstract relevance screening and data characterization of full articles. The citations were imported and reviewed one database at time, and duplicates were removed after we reviewed the duplicate list that Covidence captured.

Of the 1,042 papers that were identified through the database screening, 17 papers met the inclusion and exclusion criteria for this literature review paper. Data were reported in

accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMAScR) (Tricco et al., 2018) (Figure 1).

Step 4: charting the data

The data extracted from eligible studies were general study characteristics, such as location and year of publication; design; study aims; outcomes; participant information including ethnicity, age, gender, sample size, place of birth, years in the US, and type of caregiving relationship.

Step 5: collating, summarizing, and reporting results

The results section describes the bibliometric and other pertinent study information as well as the thematic analyses. The bibliometric metrics included authors, publication year, study aims, study sample size, study location, sample description, and main findings, which were presented by type of study (quantitative and qualitative).

Thematic analysis was conducted by analyzing the main objective and findings of the selected articles according to this paper's research question. Two primary reviewers independently conducted thematic coding of the qualitative data using Luborsky's thematic analysis approach (Luborsky, 1994) which is widely used in qualitative studies. Thematic analysis entails two approaches that are identifying repetition and analyzing central meaning; both complement each other through introducing emergent themes and reinforcing recurrent ones via systematic comparison. After the initial thematic analysis, the reviewers discussed discrepancies about the major themes until agreement was achieved. The combined analysis was then reviewed by two secondary reviewers to ensure accuracy and clarity of the themes. Data saturation, defined as no additional data were found, was reached for the prevalent themes (Glaser & Strauss, 1967).

Results

Of the 1,042 papers that were identified through the database screening, 17 papers met the inclusion and exclusion criteria for this review. There were 8 quantitative papers and 9 qualitative papers. Data were reported in accordance with the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMAScR) (Tricco et al., 2018).

The results were summarized by type of methodological approach in Table 2 (quantitative studies) and Table 3 (qualitative studies). All the quantitative studies utilized cross-sectional surveys and the qualitative studies included focus groups or interviews. Half of the quantitative studies (Chun, Knight, & Youn, 2007; Jang, Yoon, Park, Rhee, & Chiriboga, 2018; Lee & Farran, 2004; Lee et al., 2017) while only one qualitative study (Richardson et al., 2019) had study samples that included Korean Americans along with other populations (e.g., Koreans from South Korea; other US subgroups). Common aims found in both qualitative and quantitative studies included exploring the knowledge about ADRD among caregivers, examining experiences and concerns related to ADRD caregiving, and identifying cultural factors that influence decisions to seek support from community services.

Regarding sample characteristics across studies, the average age range for Korean American caregivers was 54–72 years old. Majority of Korean American caregivers were married, wives/daughters/daughters-in-law of the care recipients, and first-generation immigrants from Korea. There was one study that included Korean American non-family caregivers who were professional personal care aids (Lee, Casado, & Hong, 2018). The average number of years that caregivers reported living in the US ranged between 12 and 33.

Of the 8 quantitative studies, the majority focused on factors influencing the attitudes and experiences of Korean American dementia caregivers. Two studies compared mental health outcomes between Korean American, South Korean, and Caucasian American caregivers (Chun et al., 2007; Lee & Farran, 2004). Three studies compared outcomes between child and spouse caregivers (Chun et al., 2007; Lee & Farran, 2004; Lee & Bronstein, 2010), and five studies examined how cultural factors influence the caregiving experience (Casado, Hong, & Lee, 2018; Chun et al., 2007; Lee & Farran, 2004; Lee & Bronstein, 2010; Lee & Choi, 2013). Five studies discussed community services, care-seeking behaviors and other resources related to ADRD (Casado et al., 2018; Jang et al., 2018; Lee et al., 2017; Lee & Casado, 2011; Lee & Choi, 2013).

Out of 9 qualitative studies, there were 2 studies that focused on experiences among former caregivers (Kim, 2009; Kong, Deatrack, & Evans, 2010) and the remaining 7 studies focused on experiences among current caregivers (Kim, Kehoe, Gibbs, & Lee, 2019; Lee Casado, Lee, Hong, & Hong, 2015; Lee et al., 2018; Lee & Smith, 2012; Lee & Yim, 2013; Richardson et al., 2019; Yong & McCallion, 2003).

Two key themes emerged from the review: 1) How Korean American caregivers perceived their caregiving experiences, and 2) How Korean American caregivers perceived their caregiving support services.

Theme 1: how Korean American dementia caregivers perceived their caregiving experiences

Knowledge and beliefs about ADRD among Korean American caregivers—

Several of the studies reported on stigmatizing beliefs and the availability and impact of ADRD knowledge and resources. Three of these studies measured cultural stigma and beliefs about ADRD (Casado et al., 2018; Jang et al., 2018; Lee & Casado, 2011), and three measured prior exposure to people with dementia and current knowledge of the disease (Casado et al., 2018; Jang et al., 2018; Lee & Bronstein, 2010).

Some studies found that limited English proficiency played a role in how Korean American dementia caregivers generally had limited knowledge and/or held misconceptions regarding ADRD and how to take care of people with ADRD (Kim et al., 2019). One study found that when Korean American caregivers searched online for dementia-related information, they often did not do so in English (Lee et al., 2017).

Korean American caregivers expressed strong beliefs about the stigma of pity toward and public avoidance of persons with ADRD and their family members (Casado et al., 2018). Another study reported a misconception held among the majority of participants

that dementia is a form of insanity (Lee & Casado, 2011). The belief that dementia is an inevitable part of aging was mentioned in four studies (Jang et al., 2018; Lee Casado et al., 2015; Lee & Casado, 2011; Richardson et al., 2019).

Many Korean American caregivers expressed their desire to learn more about how to take care of PWD (Lee et al., 2018; Lee & Yim, 2013). Those with greater knowledge of ADRD typically responded more favorably to care-seeking (Casado et al., 2018).

The impact of cultural factors in Korean American caregivers' perceptions regarding caregiving—Cultural factors appeared to be important in Korean American caregivers' perceptions about caregiving. For example, while Korean American caregivers in one study reported lower levels of familism than South Korean caregivers (Chun et al., 2007), participants in another study (Kong et al., 2010) mentioned “the Korean way of thinking” to describe their perceptions on caregiving such as the obligations to take care of their family member with dementia to keep their cultural roles and responsibilities. Similarly, Korean American caregivers from other studies expressed the need to uphold transgenerational continuity of filial piety and familism (Kim et al., 2019; Kim, 2009; Lee Casado et al., 2015). In addition, gender roles, family hierarchy (Richardson et al., 2019), marital commitment (of spouse caregivers) and cultural expectations (of child caregivers) (Youjung Lee & Smith, 2012) explained the high number of female caregivers in the articles for this review.

Mental and emotional outcomes associated with dementia caregiving—A wide range of psychological and emotional responses was shared by Korean American dementia caregivers including depression, anxiety, uncertainty, isolation, guilt, regret, grief, and loss (Kim et al., 2019). In some extreme cases, caregivers thought of suicide and death. Participants felt they were struggling and overwhelmed in caregiving responsibilities (Lee Casado et al., 2015). Caregiver burden and emotional distress were correlated with the care recipient's disruptive behavior, memory problems and depression (Chun et al., 2007). Caregivers' experience with confusion and hopelessness were also commonly reported (Richardson et al., 2019). Family stress due to strained relationships among family members when appointing and dividing caregiving responsibilities were also found (Kim et al., 2019; Lee Casado et al., 2015).

One study examined a culture bound syndrome called, Hwabyung, the most prevalent somatization among Koreans which arises when they are unable to confront their anger as a result of conditions which they perceive to be unfair such as caregiving stress among female Korean American dementia caregivers (Yong & McCallion, 2003). The participants of this study, who were daughters-in-law of the care recipients, also expressed the feeling of “being trapped” with their duties and experienced anger toward the fact that being a primary caregiver took away their freedom and joy.

Demographic characteristics and caregiving outcomes—The degree to which Korean American dementia caregivers experienced negative psychological outcomes varied based on the type of relationship they had with the care recipients as well as their socioeconomics. Of the eight quantitative studies, most caregivers were female and related

to the care recipients as wives, daughters, or daughters-in-law (Casado et al., 2018; Chun et al., 2007; Jang et al., 2018; Lee & Farran, 2004; Lee et al., 2017; Lee & Casado, 2011; Lee & Bronstein, 2010; Lee & Choi, 2013). In one of the two studies that compared mental health outcomes among Korean American caregivers with those of Caucasian American and South Korean caregivers, spouse caregivers experienced higher levels of depression compared to child caregivers across all groups, and South Korean wives and daughters-in-law were more depressed than Korean American wives and daughters-in-law (Lee & Farran, 2004). Similarly, another study found that child caregivers reported more meaning in caregiving than spouse caregivers (Lee & Bronstein, 2010).

One study indicated that Korean American spouse caregivers found less meaning in dementia caregiving when compared to the child caregivers, and income showed a significantly positive correlation with the caregivers' finding meaning in caregiving (Lee & Bronstein, 2010). Korean American child caregivers were generally more acculturated and had higher incomes than spouse caregivers (Chun et al., 2007; Lee & Bronstein, 2010). Korean American caregivers reported higher incomes and educational levels than South Korean caregivers (Chun et al., 2007). Among Korean American caregivers, those who had higher educational levels also had lower caregiver anxiety (Chun et al., 2007), and college education was associated with a more positive attitude toward care-seeking with AD specialists (Casado et al., 2018).

Theme 2: how Korean American caregivers perceived their caregiving support services

Needs and challenges to find support services—Many articles discussed the needs and challenges in finding support services by Korean American dementia caregivers. In one study, Korean American caregivers shared that they felt guilty when sending their family members with ADRD to nursing homes because that went against their beliefs about familial piety (Kong et al., 2010). Other Korean American caregivers expressed their needs for culturally responsive community services, and are often concerned over the differences in language, foods, bathing habits, and sleeping behaviors that may prevent their family members from receiving appropriate care (Lee Casado et al., 2015; Richardson et al., 2019). Korean American caregivers perceived that staff from community services may not be trained adequately to provide culturally sensitive care (Kim, 2009).

In addition, the lack of knowledge about available community-based services was also a barrier for Korean American caregivers to find additional supports (Richardson et al., 2019). Only one study found their participants were aware of several community services and had generally favorable attitudes toward people from community services (Lee & Casado, 2011). Two studies reported that most Korean American caregivers were not aware of any local organization or resources (Jang et al., 2018; Lee et al., 2017), and that when they searched online for dementia-related information, they often did not do so in English (Lee et al., 2017).

Self-care strategies and social support—Acceptance of dementia varied for caregivers given the various stages of the care recipients' health (Kim et al., 2019; Kim, 2009) and some Korean American caregivers turned to self-defining (e.g., "caregiving was

a continuation of the marital relationship”) and self-appraising (e.g., “It is God who rules how long we live on the earth. However, it was me ... who provided care to him”) of their caregiving experiences (Kim, 2009). Korean American caregivers also valued familial support and found comfort in spiritual and religious beliefs (Kim et al., 2019; Lee & Smith, 2012; Yong & McCallion, 2003). Korean American caregivers reported fewer emotional and instrumental support helpers than Caucasian American caregivers but more than South Korean caregivers (Chun et al., 2007). Two studies found that caregivers with higher levels of social support found more meaning in caregiving (Lee & Bronstein, 2010; Lee & Choi, 2013). Greater emotional support was associated with reduced anxiety (Chun et al., 2007). Satisfaction with available social support significantly influenced attitudes toward caregiving while the size of the support network did not (Yong & McCallion, 2003).

Three studies mentioned the use of support groups among ADRD caregivers who found sharing caregiving experiences with groups helped them gain essential knowledge and emotional support (Kim et al., 2019; Lee & Smith, 2012; Lee & Yim, 2013). Moreover, one study examined post-caregivers’ experiences and their perceptions of making meaning in caregiving (Kim, 2009). The participants provided emotional support and shared caregiving experiences with fellow caregivers to find meaning in the hardships they had faced while being an ADRD caregiver (Kim, 2009).

Discussion

This scoping review provides a unique overview of the knowledge, attitudes, and experiences of Korean American caregivers by examining 17 quantitative and qualitative studies about dementia caregiving. We also sought to identify clinical, research, and policy implications such as developing and improving culturally/linguistically appropriate caregiving programs for Korean American dementia caregivers. The caregivers in the selected studies were mostly immigrants and wives/daughters/daughters-in-law.

Two major themes were identified among the studies included in this review. The first theme that emerged from our scoping review was how Korean American dementia caregivers perceived their caregiving experiences. Korean American caregivers reported poor mental health and burden. Social support and familism were found to be two of the most important factors that determine Korean American caregivers’ attitudes toward caregiving. The other major theme was related to how Korean American caregivers perceived their caregiving support services. Various factors shape Korean Americans’ underutilization of ADRD and related services: those most reported include the lack of culturally and linguistically appropriate services and the desire to care for their care recipients at home. For instance, discrepancies in foods, bathing tendencies, sleeping behaviors, and language or negative perceptions about nursing homes in Korean culture could hinder patients from utilizing available domestic services.

Strategies to combat caregiving burden were identified as having a strong social network and social support. Similar to Korean American counterparts, spouse dementia caregivers in South Korea have also reported the notable influence that social network and support play in reducing the mental burden (symptoms of depression) associated with dementia

caregiving (Kim, De Bellis, & Xiao, 2018). In South Korea, the absence of informal support for daughters-in-law were associated with the highest rates of caregiving burden when caring for a PWD (Kim, Lee, Shin, & Park, 2017). Lack of social networking has also been found to have a significant association with negative mental health effects of spouse cognitive impairment (Kim et al., 2017). The protective effects of social networking should be stressed early on to more vulnerable caregivers (e.g., daughters-in-law) and earlier in adulthood. When considering caregiving-related education or resource allocation, it is especially important to consider differences in family structure and the impact of gender in South Korean vs. Western Korean American families.

Other resources that may provide relief for caregivers include linking clinical practice and community-based service for Korean American dementia family caregivers. Korean American dementia family caregivers' unique needs and well-being are often ignored and are not routinely assessed. An assessment of any disparities in dementia care will improve engagement between clinical practices (i.e., primary care clinics, dementia, and memory clinics, etc.) and Korean American serving community organizations to meet the unmet needs. Unmet needs may include referrals to receive culturally and linguistically tailored resources/support/programs; to improve delivery of dementia care; and, to support informed decisions made by Korean American dementia family caregivers.

Future research implications

All of the papers were cross-sectional surveys or qualitative studies; hence, none of the papers included intervention research. We recommend that such future intervention research involve collaborations with community partners and consider incorporating "best practices" and new technologies from programs in South Korea. As a part of implementation research, dementia case management should be offered to Korean American dementia family caregivers. Although this service is the most frequently performed intervention for dementia family caregivers, it is far less frequently offered to or utilized by Korean American dementia family caregivers due to cultural and linguistic barriers (Chu, Edwards, Levin, & Thomson, 2000; Corvol et al., 2017; Francke et al., 2017; Khanassov & Vedel, 2016; Pimouguet, Lavaud, Dartigues, & Helmer, 2010; Somme et al., 2012). In addition, developing, testing, and implementing specific types of interventions for specific groups of Korean American family caregivers would be beneficial (e.g., new to dementia family caregiving, late-stage care interventions, respite care, etc.).

Research has indicated the appropriateness and effectiveness of cognitive-behavioral therapies (CBT) and principles for Asian Americans (Iwamasa & Sorocco, 2007), but dementia caregiving intervention research with Korean American dementia caregivers are limited. A potential approach to help address this research gap is to culturally tailor an evidence-based CBT dementia caregiving intervention by Gallagher-Thompson et al.'s which have been culturally tailored for Chinese Americans (Gallagher-Thompson et al., 2007) and Vietnamese Americans (Ta Park et al., 2018; 2019; 2019). These studies reported improvement in caregiver outcomes and acceptability of the programs.

Policy implications

These findings emphasize the urgent need to develop culturally responsive care for Korean American families. This would include implementing policy changes to mandate the recruitment and training of more bilingual and bicultural Korean health and social service providers. The Healthy People 2030, which establishes the national objectives to improve health and well-being over the next decade, recognizes that language-concordant care improves a variety of health outcomes (Diamond, Izquierdo, Canfield, Matsoukas, & Gany, 2019). Hence, a Healthy People 2030 objective (in development) is to “increase the proportion of limited English proficient (LEP) adults who report that their doctors or other health providers always explained things in a way that was easy to understand” (US Department of Health and Human Services, 2022).

Potential policy implications may target the needs of Korean American female dementia caregivers since this review found that caregivers tend to be female family members which is similar in South Korea (Jang & Baik, 2019; Jang, Avendano, & Kawachi, 2012; Jang & Kawachi, 2019). In addition, currently, several government programs are available for family members to get paid but such policies are not available across states and may not be available to family members who live with the care recipients (USAGov, 2021). In contrast, in South Korea, in 2008, the government subsidized familycare workers, which allowed older patients to be cared for at home by family members (Kim et al., 2018). Kim et al. examined the paid family care workers of PWD, and found that although physical, emotional, and financial burdens that come along with caregiving were reported, factors such as financial subsidies, social support, filial piety, and religion encouraged the caregivers to find relief. Potential policy changes could include the implementation of a similar financially subsidized system in the US beyond the existing programs which are very limited.

Strengths and limitations

To the best of our knowledge, this scoping review paper is the first to provide a comprehensive synthesis of the existing literature about Korean American dementia caregiving. Asian American subgroups are frequently combined into a single Asian category in national health data thus conceal the distinct heterogeneity and characteristics among the subgroups (Holland & Palaniappan, 2012; Kanaya et al., 2022). A major strength of our study was providing a focused review on a single Asian subgroup that allowed us to provide a meaningful review of this topic as cultural values are critical to consider in the Korean American population. Another major strength of our paper was evaluating both quantitative and qualitative papers related to this topic.

A potential limitation may be that our search did not yield all the potential studies, however, we had two reviewers independently search five different databases to identify potential articles, then eligible articles were agreed upon. While the methodology of a scoping review is relatively recent, future research may use the findings of this scoping review paper to conduct a systematic review as a next step and potentially “confirm the relevance of inclusion criteria and potential questions” (pp. 1) (Munn et al., 2018).

Conclusions

Given the dementia caregivers' important roles for PWD, the development and provision of dementia caregiving programs and interventions are necessary. Research has shown that interventions that have the family caregivers' active involvement, are flexible and adjustable during the disease progression, and the dual engagement of both caregivers and PWD have shown beneficial effects in relieving the caregiving-related physical and emotional stress (Gitlin, Marx, Stanley, & Hodgson, 2015). To ensure the successful implementation of an intervention program, including clinical programs, in diverse communities, culturally appropriate approaches are needed (Fauth et al., 2019; Gitlin et al., 2015; Zarit, Lee, Barrineau, Whitlatch, & Femia, 2013).

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Clinical implications

- Health care providers should more carefully assess caregiver burden and emotional distress of Korean American dementia caregivers in considering their culture of filial piety and familism.
- Routine family meetings with Korean American dementia caregivers and health care providers may be needed to discuss progression of dementia, care of PWD, and culturally relevant resources.
- Culturally and linguistically appropriate support groups and community services should be referred for Korean American dementia caregivers. Home care services may benefit Korean American caregivers who desire to take care of their PWD at home.

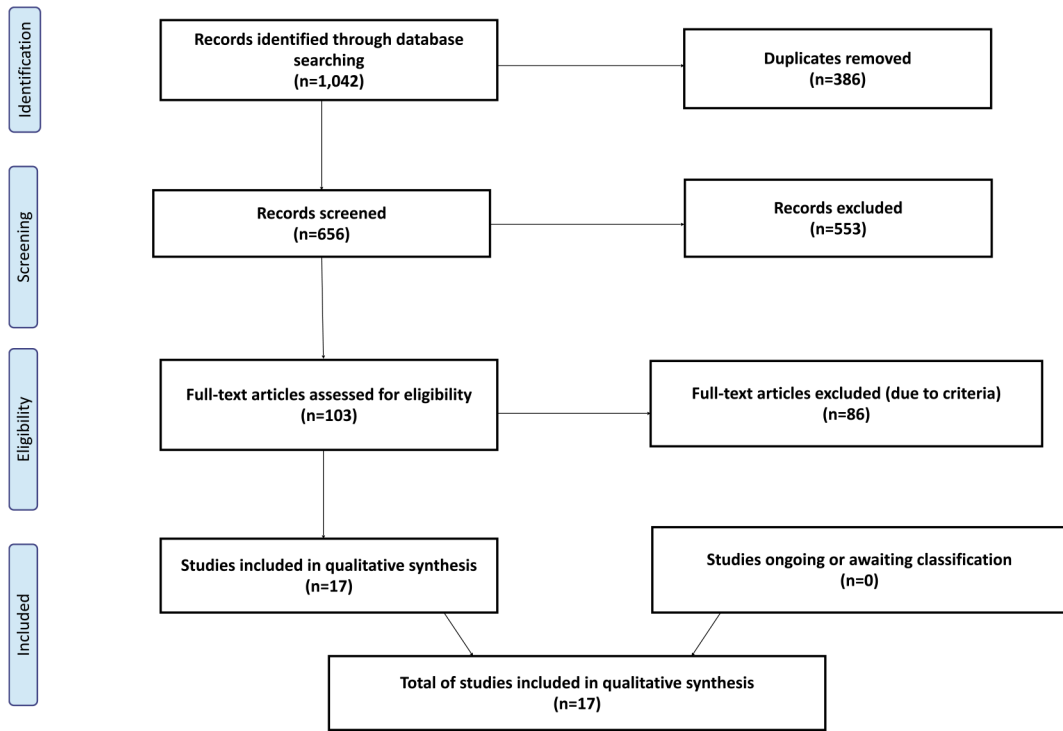


Figure 1.
PRISMA flowchart of the studies selection process

Table 1.

Inclusion and exclusion criteria.

	Inclusion	Exclusion
Populations	Korean American dementia CGs	Korean CGs outside the U.S.
Diseases/Disorders	Dementia; AD; mild cognitive impairment; memory loss	Other cognitive/mental disorders that are not related to ADRD
Interventions*	Dementia CG interventions, supports, programs, networks, trainings, and/or self-help	Diagnosis, treatment, assessment, medication of the disease/disorder
Outcomes**	CGs' burden, role strain, health (e.g., mental, or physical health), use of services	Outcomes that do not relate to CGs
Types of paper	Original research papers (quantitative; qualitative), review papers	Papers that only briefly mention this population; secondary papers
Language	English	Non-English

Abbreviations: Alzheimer's disease (AD); Alzheimer's disease and related dementias (ADRD); caregiver (CG); caregivers (CGs)

* Relevant to quantitative papers only

** Relevant to intervention studies only

Table 2.

Summary of quantitative papers on dementia caregiving among Korean Americans.

Authors	PY	Study Aims	Sample Size	Study Location	Study Sample	Main Findings
Casado BL, Hong M, Lee SE	2018	Examined KAs' attitudes toward AD care-seeking from PCPs and AD specialists, and factors influencing their attitudes	N = 234	Mid-Atlantic region	Primary caregivers 40 years old, mean age of 54 years. Majority were female (60%) and married (81%)	Participants correctly answered about 59% of the questions on the AD knowledge scale. KAs indicated strong beliefs about the stigma of pity (associated with the concept of dishonor) toward and public avoidance of persons with AD and their family members. KAs with greater AD knowledge had more positive attitudes toward seeking care from PCPs. However, the study showed quite favorable attitudes among KAs toward seeking care from both PCPs and AD specialists. Normative beliefs shared within the group, not cultural orientation, may influence KAs' attitudes toward AD care-seeking.
Chun M, Knight BG, Yoon G	2007	Compared path models of emotional distress among three groups of caregivers for elderly patients with dementia: KKs, KAs, and CAs	N = 171 KA = 53	South Korea (Kwangju area), Los Angeles, Orange County	In KAs, majority were female (76%), married (85%) Majority were first generation immigrants. Average duration stay in America 17.8 years. Average age 58.9 Spouse (42%), children (43%), children-in-law (15%)	KKs had highest proportion of female caregivers, followed by KAs. KKs were the least educated and had the lowest annual income, followed by KAs. CAs were the most educated with the highest annual income. Majority of KK caregivers were children-in-law, while KA caregivers showed an approximately equal distribution between spouses and children. KK caregivers reported highest scores on depression, anxiety, and burden outcomes, followed by KAs. CAs reported the lowest across all measures. Three kinds of patient's problems (patient's disruptive behavior, patient's memory problem, and patient's depression) positively affected caregiver burden, which consequently plays a role in caregiver's depression and anxiety.
Jang Y, Yoon H, Park NS, Rhee M-K, Chiriboga DA	2018	Examined Asian Americans' concerns about AD (both concerns about one's own development of AD and about becoming an AD caregiver) and plans for AD	N = 2,609 KA = 471	Austin, Texas	KAs aged from 18 to 60yo and older. KAs 61% were female, 74.3% married. 37% lived in U.S for < 10 years	AD exposure and literacy were common predictors of all three outcomes. KAs were the most concerned regarding both developing AD and becoming an AD caregiver. Beliefs that associate AD as a normal part of the aging process (i.e., normalization) and a matter of fate increased the odds of having AD concerns. The odds of having AD plans were found to be higher among those with such concerns.
Lee EE, Farran CJ	2004	Compared depressive symptoms among KKs, KAs, and Caucasian Americans (CAs) female family caregivers of older persons with dementia. Examined background variables, such as demographic characteristics and cultural context; primary stressors, such as care receiver cognition, activities of daily living (ADL), and behaviors; and the outcome variable, depression.	N = 237 KA = 59	Seoul, Chicago and Los Angeles	46/59 KAs placed their relatives in long-term care institutions. Average age 57.8. Males 28.8%, females 71.2%. Spouse 23.7%, adult children 71.2% KA caregivers were first-generation Koreans born in Korea, lived in the US at the time of the data collection, and were able to speak and read Korean.	With regards to relationship with the older person with dementia, KK caregivers were more likely to be daughters-in-law. KA caregivers were more likely to be daughters, whereas CA caregivers were more likely to be wives or daughters. Relative to daughters and daughters-in-law, spousal caregivers were found to be more depressed. Of the three cultural groups examined, KK caregivers exhibited the most depressive symptoms. When caregiver relationship was additionally examined, KK and KA wives were found to be most depressed, and KA daughters-in-law the were least depressed group.
Lee JA, Nguyen H, Park J,	2017	Identified smartphone and computer usage among family caregivers of dementia patients	N = 35 KA = 15	Southern California	Female 86.7% Average age 66.3	Dementia caregivers use smartphones more often than computers (86.7% vs 60.0% daily use). Almost all KA participants reported that they used social media apps for sending messages, pictures, or short

Authors	PY	Study Aims	Sample Size	Study Location	Study Sample	Main Findings
Nguyen T, Huynh Y		(i.e., Korean and Vietnamese Americans) to develop dementia-care education programs for them			Spouse 60%, adult child 40% Mean years living in US 32.5	video files. Furthermore, many of the participants reported barriers to participation due to caregiving responsibilities and transportation challenges.
Lee SE, Casado, BL	2011	Examined attitudes toward community services use among KAs to understand the future demand for community services use in dementia care.	N = 209	Los Angeles County	Female 50.2%, married 79.3%, average age 59.5, mean year living in US 20.3	Participants had favorable attitudes toward using community services in dementia care. Higher self-rated health, greater social network, and greater awareness toward community services were significantly related to attitudes toward community services use.
Lee Y, Choi S	2013	Explored how KA family caregivers view the services they offer to patients with dementia. Also examined social network, satisfaction with social support, demographic characteristics, caregiving-related stress factors, and cultural factors	N = 85		KAs responsible for a community-dwelling spouse, parent, or other family member diagnosed with dementia. Caregivers' mean age 62.5. Female 77.6%, male 22.4%. Spouses 38.8%, daughters 25.9%, daughters-in-law 10.6%, sons 9.4%	Social network did not have a statistically significant association with KA caregivers' attitudes toward working with patients with dementia. On the other hand, satisfaction levels with social support did contribute significantly to KA dementia caregivers' attitudes on caregiving. The second most important factor that influences attitudes regarding caregiving among KA caregivers was familism. Satisfaction with social support was positively associated with caregiving attitudes among KA caregivers.
Lee Y, Bronstein LR	2010	Examined the role of culture in KA dementia caregivers' finding meaning in caregiving and compares a group of spouse caregivers with a group of child (including in-law) caregivers	N = 65	Chicago, Los Angeles, Houston	KA spouse caregivers, daughters and daughters-in-law Mean age 63.85 years. Females 77.8%, spouse 45.8%, daughters 30.6%, daughters-in-law 12.5%. Mean year in US: 15.63 (spouses) and 18.94 (children)	Greater social support was significantly associated with finding meaning in caregiving among KA dementia caregivers. Among KA spousal caregivers, both social support and income were the best predictors of spouses finding meaning in caregiving. Relative to KA spousal caregivers, KA child caregivers found more meaning in dementia caregiving.

Abbreviations: KA = Korean American, AD = Alzheimer's disease, PCP = primary care provider, PWD = person with dementia, NES = non-English speaking, KK = Koreans from Korea, CA = Caucasian American, PCAs = personal care aides, PY = publication year

Table 3.

Summary of Qualitative Papers on Dementia Caregiving among Korean Americans.

Authors	PY	Study Aims	Sample Size	Study Location	Study Sample	Main Findings
Casado BL, Lee SE, Hong M, Hong S	2015	Examined the experiences and concerns among family caregivers of KAs with dementia in their own words	N = 23	Mid-Atlantic region	Age range 43–76, mean age 67.3. Female 82.6% Mean year living in US 28.6 year (range 3–40 years). Caregivers were spouses (4 husbands and 12 wives), daughters (5), and daughters-in-law (2).	Eight themes were identified from four focus groups with family caregivers of older KAs with dementia symptoms: struggling and overwhelmed; keeping the cultural roles and responsibility; doing it by themselves; family as a source of stress; limited knowledge and misconceptions; learning as they go; undiagnosed dementia and misunderstandings about medical care; and barriers to use of services and need for culturally responsive services.
Kim HJ, Kehoe P, Gibbs LM, Lee J-A	2019	Explored the caregiving experience of KA families of PWD	N = 18	Southern California	KAs, 15 females (83.3%) Mean age 65.3 years old, age range 29–85 years old. Spouses 61.1% (9 wives and 2 husbands), adult child 38.9% (5 out of 7 were daughters) Mean year of living in US 32.8 (range 17–46 years)	Four themes were identified: challenges in finding resources; struggling with mental health issues; traveling the path of acceptance; and finding ways to survive. Due to language and health care access barriers, KA caregivers reported seeking out dementia-related information online in the Korean language and traveling to South Korea to see dementia specialists. Some KA caregivers expressed suicidal thoughts and depression. Familism prevented help seeking and possible relief from their difficulties.
Kim Y	2009	Applied a transcendental phenomenological approach to understand experiences and meaning among KA family postcaregivers	N = 8	Midwestern region	First-generation KAs that had previously provided in-home care to a PWD and were in a postcaregiving trajectory. Included three wives (37.5%), one husband (12.5%), three daughters (37.5%) and one daughter-in-law (12.5%). Caregivers age range 48–84 years old, mean age 66.6.	Five core themes were identified from in-depth interviews: understanding elderly patients with Alzheimer's by accepting it as a disease; self-defining and self-appraising of caregivers; caregiving as a family affair while examining transgenerational continuity of filial piety; returning caregiving to caregivers in turn as a mode of mourning; reviewing dissatisfying experiences with the formal care system.
Kong E-H, Deatrick JA, Evans LK	2010	Described Korean immigrant caregivers' experiences, needs and challenges regarding American nursing home placement of their non-English-speaking older relatives with dementia	N = 10	Northeastern region	Mean age 54 (range 40–70), all were married. 5 daughters-in-law (50%), 4 daughters (40%), and 1 wife (10%) 6 rated their English "well" or "fair," 4 rated "not well" or "not at all." Caregivers took care of PWD at home 1–5 years before nursing home placement.	Six major themes were identified via semi-structured interviews to gain insights related to communication and cultural issues of KA immigrant caregivers' experiences regarding nursing home placement for their non-English-speaking older relatives with dementia. The "Korean way of thinking" was the underlying theme, which included respect, repayment, taking care of parents at home, and not sending parents to nursing homes. Nursing home placement meant "not fulfilling filial piety", which resulted in: taking care of parents with dementia at home for several years before a nursing home placement, experiencing strong feelings of guilt, making frequent visits to nursing homes, and labeling themselves as "unfilial" or "bad." For non-English-speaking family caregivers, acculturation, English proficiency, and assessing for caregiving-related difficulties and needs are important factors for developing interventions.
Lee SE, Casado BL, Hong M	2018	Explored experiences and perspectives of KA personal care aides (PCA) concerning dementia	N = 10	Mid-Atlantic region	KA PCAs of older KAs with dementia symptoms. Majority were in the middle-age range, female and born in Korea, working as a	Findings from focus groups with PCAs caring for older KAs with dementia symptoms found the following: (1) considered dementia caregiving as challenging, demanding and stressful, yet they cared for their clients with Jeong (a Korean cultural concept of love,

Authors	PY	Study Aims	Sample Size	Study Location	Study Sample	Main Findings
Lee Y, Smith L	2012	Explored KA dementia caregivers' attitudes toward caregiving.	N = 8	Flushing, New York	PCA for approximately two and a half years on average. 100% female. Mean year in US 12 (range 4-27 years).	<p>affection, sympathy, and bondage);(2) They learned about dementia mostly "on the job" and expressed their need and strong desire to learn more about dementia and dementia care; (3)They observed many family struggles and conflicts as it relates to filial obligation; and (4) PCAs advocated for a more integral and visible role and involvement of PCAs in dementia care.</p> <p>Results from the interviews disclosed five major themes related to KA dementia caregivers' perception of caregiving and the factors that contribute to their experience: the importance of marital commitment for spouse caregivers; cultural expectations of adult child caregivers; the mediating role of social support in dementia caregiving; the role of spirituality in dementia caregiving; negative perceptions of nursing homes.</p>
Lee Y, Yim N- Y	2013	Tested the effectiveness of the psycho-educational group in Korean American dementia caregivers and to investigate the cultural factors relating to the success/failure of the intervention model in the group.	N = 7	Queens, New York	5 spouse caregivers (62.5%), 3 adult child caregivers (37.5%), 1 male (12.5%), 7 females (87.5%) Mean age 69 years old. All were immigrants from Korea.	<p>Four major themes emerged from the focus groups to gain insight into what contributes to the success of a psychoeducational program for KA dementia family caregivers: importance of education about dementia; social support from other Korean caregivers; role of language and Korean culture; heterogeneity of caregivers' needs regarding the stages of disease and relationship with caregivers. Findings show the importance of (1) educating family caregivers on dementia and dementia caregiving; and (2) providing individualized services based on the severity of the care recipients.</p>
Richardson VE, Fields N, Won S, Bradley E, Gibson A, Rivera G, Holmes SD	2019	Explored how cultural factors influenced ethnically diverse dementia caregivers' experiences and use of services.	N = 15 KA = 5	Midwestern area in Ohio, Los Angeles	Three minority groups: African American, Hispanic, and South Korean. Average age for South Koreans was 66, all were females (three daughters and two spouses).	<p>Several themes emerged from the in-depth interviews: limited knowledge about dementia, gender roles (daughters and daughters-in-law are supposed to do caregiving), negative feelings about nursing home (cultural insensitivity), lacks of knowledge about community-based services, and language problems prevent caregivers from finding support.</p> <p>The authors suggest that interventions should not only address generic mechanisms to alleviate caregiver burden but also incorporate culturally tailored components (e.g., taking into account language, gender norms, food preferences, etc.).</p>
Yong F, McCallion P	2003	Explored how KA caregivers with a relative with dementia give meaning to their caregiving experiences. Hwabyung as caregiving stress was described in the context of Korean culture.	N = 2	New York, NY	Caregivers born in Korea, living in the US. Both were daughters-in-law in their 50s taking care of mothers-in-law with dementia. One reported having hwabyung while the other did not.	<p>Four themes emerged from the telephone interviews: perception of dementia; caregiving situation; the expression of stress; coping skills. Uncertainties were found as it relates to knowledge regarding dementia. This may have resulted in a delay to seek appropriate treatment for their relative with dementia, which concurrently escalated stress levels. The authors suggested that caregiving stress and service needs for KAs are similar to other groups, but the expression of stress is unique among KAs.</p>

Abbreviations: KA = Korean American, AD = Alzheimer's disease, PCP = primary care provider, PWD = person with dementia, NES = non-English speaking, KK = Koreans from Korea, CA = Caucasian American, PCA = personal care aide, AA = Asian American, PY = publication year