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Caregiving Experience of Dementia Among Korean American Family Caregivers

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Abstract

Dementia is a major public health problem affecting 5.5 million people in the United States. This qualitative study explored the caregiving experience of Korean American (KA) families of persons with dementia (PWD). Adult KA caregivers of PWD ($n = 18$) were recruited for semi-structured interviews. Thematic analysis yielded four themes: challenges in finding resources, struggling with mental health issues, traveling the path of acceptance, and finding ways to survive. Due to the language barrier, most KA caregivers reported using Korean Internet for information on dementia and caregiving. Some traveled to South Korea seeking medical assistance for dementia (medical tourism). Importantly, some KA caregivers expressed suicidal thoughts and depression. Unexpectedly, familism prevented help seeking and possible relief from their difficulties. There is an urgent need to improve access to dementia care services and education for the KA community. Building a trusting relationship with healthcare providers is even more important for KA caregivers to address their mental health concerns.

Keywords

Alzheimer's disease; dementia; family caregiver; Korean Americans; qualitative research

Introduction

Alzheimer's disease (AD) is a major public health problem affecting roughly 5.5 million people in the United States (Alzheimer's Association, 2017). One in 10 Americans older than 65 has AD and the number of people with AD is expected triple to a projected 13.8 million by 2050 (Alzheimer's Association, 2017). AD is the sixth leading cause of death for all Americans, Asian Americans (AAs) included (National Center for Health Statistics, 2017). Because AAs are a rapidly growing population and projected to double in size by 2050—with those 65 and older increasing five times faster, the issue of dementia appears to

be a significant and troubling factor (Nguyen, 2012). The prevalence of AD in the AA population is difficult to ascertain due to their reluctance to seek diagnosis and treatment of AD for reasons including cultural beliefs associated with aging, language barriers, financial and health insurance status, and stigma related to mental illness in general. These factors contribute to delayed diagnosis of AD and overall dementia care service utilization in the community (Chow, Ross, Fox, Cummings, & Lin, 2000; Ross, Brennan, Nazareno, & Fox, 2009; Yoo, Musselman, Lee, & Yee-Melichar, 2015).

More specifically, the Korean American (KA) community is ranked fourth in size among AAs with a rapid increase in its own older population (H. B. Lee, Han, Huh, Kim, & Kim, 2014; Yoo et al., 2015). With the growing KA population in the U.S., AD and related dementias will continue to be a significant health concern among KA elders and their families, especially in states like California and New York where large groups of Korean immigrants reside (East-West Center, n.d.; Pew Research Center, 2017). Knowledge deficits related to AD in many KAs have been reported including their belief that dementia is a part of the normal aging process (S. E. Lee, Lee, & Diwan, 2010). Prior research shows that KA families with elders with dementia are less likely to seek help, especially for memory decline alone. Rather, seeking help is triggered by the presence of other behavioral or health issues (Watari & Gatz, 2004). In addition, health insurance is important for older KAs to utilize healthcare services. Older KAs with lower English proficiency and less trust in Western medical care showed less satisfaction in healthcare services and negative perception of health (Y. Jang, Kim, & Chiriboga, 2005). Furthermore, fewer KA elders reported having a regular place to receive health care than other AA elders (Nguyen, 2012). Underutilization of mental health services for depression and dementia among older KAs was also noted (H. B. Lee et al., 2014).

Family caregivers fill in the gaps that exist from the lack of support from the healthcare systems. Caring for the elderly with chronic conditions impacts caregivers physically, emotionally, socially, financially, and spiritually (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014) and this is even more true for caregivers of persons with dementia (PWD) (Ross et al., 2009). KA caregivers of PWD reported having more burden and psychological distress due to patients' symptoms and had less coping strategies and more need of emotional support compared to other American caregivers (Chun, Knight, & Youn, 2007; Janevic, Connell, & M Connell, 2001). In light of the overall pattern of underutilization of services among KAs due to factors such as health insurance, income, English proficiency, stigma, and cultural values (Watari & Gatz, 2004), outreach and engagement efforts should be made to utilize strategies that meet KA needs in terms of dementia caregiving.

Therefore, the purpose of this study was to explore the caregiving experience of KA families of PWD and to understand how KA caregivers of PWD try to fulfill the gaps between their needs and available healthcare services for dementia care in the U.S. Additionally, we aim to utilize this needs assessment for developing a community-based, caregiver-centered, and culturally appropriate dementia care education series for the KA community.

Methods

Setting and Participants

Upon the approval of the University of California Irvine, Institute of Review Board (IRB) for Human Subjects Research, multiple recruitment strategies were employed. We posted flyers in a local community center for KAs in Southern California and send out the flyers via a community listserv. Administrative personnel in the community center referred potential participants for KA caregivers' needs assessment interviews. We also distributed our flyers in two local non-profit Alzheimer's service organizations to recruit KA dementia family caregivers. A few participants were obtained via snowball recruitment. Potential eligible caregivers either directly contacted the study team or gave our study participants permission to release their contact information to the study team.

Eligibility criteria for participation were (a) adults aged 18 years or older and (b) informal KA caregivers who provided care for PWD. KA family members who were involved in the care of PWD on a daily basis were included in this study regardless of place of birth, primary language, severity of dementia symptoms, or living status of PWD. Once caregivers participated in the individual interviews, we asked them whether we could also interview other family members to understand how family members support each other (parent and adult children or among adult children). Prior to interview, participants received an IRB approved study information sheet that included the purpose and procedure of the interviews. Written consent forms were waived by the IRB due to the minimal risk of the study. Participants received \$50 cash as appreciation for their time and commitment.

Data Collection

A gerontology expert nursing faculty conducted semi-structured interviews in Korean or English as preferred by the participant. Interviews started with a broad opening question asking them to recall their memories at the time of diagnosis and subsequent questions were followed when needed: knowledge about dementia and caregiving, barriers in seeking help, caregiver health status, self-care strategies, and thoughts on future education for KA dementia caregivers. Although interviews were mostly face-to-face in participants' homes, a few interviews were conducted by phone per participants' request. Each interview lasted approximately one hour and was audio-recorded.

Data Analysis

Data were analyzed following the six-step procedure for thematic analysis by Braun and Clarke (2006). Interviews were transcribed verbatim in Korean and translated into English by a bilingual transcriber. One of the authors listened to all audio-recordings and verified translated transcripts for accuracy. Interviews obtained in English were directly transcribed into written text. Transcripts were read multiple times and coded by two independent raters using a qualitative and mixed data analysis tool, Dedoose (Dedoose, 2018). After comparing similarities and differences among preliminary codes, initial themes were identified. Raters reviewed and refined the initial themes representing KA caregivers' experience of caring for PWD and their needs in caregiving. With the third member's input, themes were finalized with definitions and labeling.

Results

Participants

Table 1 presents the characteristics of family caregiver participants and their PWD. A total of 18 KA dementia family caregivers of 15 PWD participated in the needs assessment interviews. Caregivers' mean age was 65.3 years with 15 of 18 being female. Nine of the women were wives and the other 6 were adult children (5 daughters and 1 daughter-in-law). Of the three men, two were husbands and one was a son. With the exception of two daughters born in the U. S., the other participants were born outside the U.S. and immigrated to the country. These participants had lived in the U.S. on average more than 30 years, but rated their English proficiency as low or moderate. KA caregivers perceived severity of dementia symptoms mostly moderate. Most caregivers ($n = 14$), lived at home with PWD while others lived close by providing daily care for their PWD. Two adult children, although they did not reside with PWD, identified themselves as primary caregivers heavily involved in daily operations and reported spending most of their time caring for PWD each day. Two spouse caregivers had recently placed the PWD in skilled nursing homes for acute care. None of the families interviewed sent their PWD to a long-term institution for dementia.

Themes

Four themes were identified describing the experience of KA family caregivers and their needs: (a) challenges in finding resources, (b) struggling with mental health issues, (c) traveling the path of acceptance, and (d) finding ways to survive.

Challenges in Finding Resources

The first theme described KA caregivers' efforts to search for helpful resources, which were affected by multiple factors such as English proficiency, health insurance, financial status, knowledge of dementia, and attitude towards the illness. English proficiency was particularly important for KA caregivers from the time of diagnosis. Finding Korean-speaking physicians was an arduous task requiring multiple visits to different providers. Moreover, seeing Korean-speaking providers was not necessarily satisfying. When faced with the new reality of dementia, most KA caregivers shared that they did not receive any education about how to care for PWD nor information on support groups or any other available services either in English or in Korean from medical providers. Pharmacological treatment was the most common intervention by medical providers. One wife said, "We mostly depended on the doctor and his recommendations.... I would come to each doctor's visit hoping to get answers for all the questions I had, but I was always unsuccessful."

Therefore, most KA caregivers talked about self-initiated efforts to improve their knowledge on dementia and caregiving after getting the diagnosis. Online searches in Korean, particularly using Korean search engines (i.e., NAVER www.naver.com or DAUM www.daum.net) was frequently mentioned. These search engines provided not only written information on dementia in Korean but also live-streaming videos, documentary films, and television shows on dementia in Korean. One caregiver said, "I searched mostly in Korean [on the Internet]. Everything comes out in Korean." Some caregivers received information on resources from family, friends, and acquaintances at church.

Some KA caregivers affirmed that support groups for caregivers were extremely helpful in learning how to better interact with PWD. KA caregivers who attended support group meetings acquired practical knowledge of day-to-day care from participants who themselves were caregivers and learned about other resources including in-home services, daycare information, and therapeutic activity programs. However, these resources often required dealing with several barriers that prevented KA caregivers from utilizing them to the fullest extent as early as possible. KA caregivers specifically expressed their concerns over the lack or absence of appropriate and affordable services run by professional and compassionate care providers for KAs. A few adult day centers provided Korean foods or had Korean speaking staff. Most adult day centers with Korean staff only accepted the elders with Medicaid. What KA caregivers often found was overflowing, overcrowded, and short-staffed dementia services and programs.

I did expect there to be an Alzheimer's center in the U.S ... unless they had resources in Korean, I wouldn't be able to understand any of them. My English skills aren't good enough to receive education or training in English.... I get very anxious whenever I have to leave him alone. (wife, age 57)

There's no facility, or at least I don't know yet, that has large Korean-speaking programs ... that also all the staff is well-trained. I didn't find a place like that.... [I] actually went to visit two facilities. It's all Korean daycare centers run by Korean staff. They speak Korean language and provide Korean food, which is a lot of comfort. But both of them are really crowded.... [Without Medicaid] you have to pay privately.... I wasn't sure about the quality of their real program. (daughter, age 61)

Interestingly, three caregivers even reported seeking professional help in Korea. These KA caregivers discussed seeing dementia specialists (e.g., neurologist) to do full check-ups including neuro-psychological tests, psychiatric assessment, and brain imaging tests in South Korea.

I found out about a doctor [on the Internet] ... in Seoul. He's a renowned specialist in dementia care.... For this doctor, it takes anywhere from six months to a year to see.... Thankfully there was a cancellation so we suddenly had to go to Korea... The doctor ordered a full set of tests and imaging for him... you get diagnosed faster in Korea since they test for everything. So they performed an MRI on him, as well as the amyloid peptide test and blood test.... We found out through the National Health Insurance Service that his [husband's] resident registration number in South Korea was still valid, making him eligible for coverage. He received his insurance card immediately the day after and had full coverage for most things, with only a copayment for procedures such as the MRI. The only service not covered by insurance was the amyloid peptide testing which we had to pay out of pocket. (wife, age 67)

Two caregivers were planning to move out of country for affordable long-term care. One of them said, "I think it's most practical to stay in Seoul. It's inconvenient to stay here. Our children will struggle, and there are far better care facilities in Seoul. I think for now we'll have to return to Seoul and see how he [husband] does."

Struggling with Mental Health Issues

The second theme evolved around KA family caregivers' struggle with several challenges related to dementia symptoms, their own emotions, health management, and family dynamics. All KA caregivers shared difficult moments of dealing with progressing symptoms of dementia. Examples were: decreased social awareness and subsequently inappropriate behaviors in public; personality changes; anger and agitation; refusal to cooperate, especially with hygiene and appetite; wandering; disrupted communication; and poor judgment leading to safety concerns. KA caregivers reported feeling the need for physical proximity to constantly observe, monitor, and supervise PWD. Eventually, their life had to be adjusted to focus on caregiving and many KA caregivers quit working, moved, suffered from lack of social interaction, and had less leisure time.

At this point, he doesn't meet many people.... It gives him a headache to have people come over. So I had to request that even our relatives not visit our home.... He is always home ... and stays in one designated area of the room. Because of that I am able to briefly leave the house, but I get very nervous with him out of sight so I do not go out. (wife, age 57)

In the midst of changes and adjustments when dealing with PWD's symptoms on their own, several KA caregivers revealed experiencing intense, mostly negative emotions. Getting upset, angry, and frustrated was frequently mentioned when caregivers had to deal with similar challenging situations repeatedly. Other commonly reported negative emotions included depression, anxiety, uncertainty, loneliness, grief and loss, guilt, or regrets. KA caregivers also talked about feeling scared, exhausted, and overwhelmed. Even after acquiring adequate intellectual knowledge on dementia, they struggled with intense emotional responses ignited by specific daily triggers.

The most concerning response associated with this negative emotional experience was the ideas of suicide and death reported by four KA caregivers. When dealing with patient's symptoms and caregiving became too much with no one to help or rely on, these caregivers thought about ending their lives along with PWD's as a solution or wishing for death before the burden of dementia became too unbearable for them and other family members, specifically their children.

About two years ago ... I did occasionally have those thoughts.... I imagined hanging myself, but then again didn't know what to do about my husband. I even imagined going on a cruise and jumping off together.... The idea of disappearing off the face of the Earth didn't seem so bad. (wife, age 75)

My children are all busy with their own lives. All of my daughter-in-law's.... I just hope to live long and be able to continue caring for her [my wife].... Occasionally I get radical thoughts. It may be better if the both of us just end our life together, you know? (husband, age 79)

Several KA caregivers discussed developing physical and emotional health issues while caring for PWD. Balancing their health with caregiving responsibilities was difficult, even more so for those with their own aging process to deal with.

It was after I received surgery for gastric cancer when I realized that I needed to change. As was my father and sister, I was diagnosed with gastric cancer.... I think the situation with my mother did affect my health a bit, especially because I struggled a lot in the beginning. (daughter, age 67)

I noticed myself being more depressed.... After some time, I thought I should do something about it and told the doctor about my depression and he suggested I try taking some medication. I thought being around my husband all the time might negatively impact my emotional health....The morning after I took the medication, I had the weirdest experience looking at myself in the mirror. It was definitely my face, but it wasn't my usual face. Even my daughter told me that day that my facial expression and affect was not of my usual self. (wife, age 61)

Lastly, dealing with family dynamics and conflicts with other family members were brought up as another set of challenges that many KA caregivers encountered along with dementia caregiving. A few caregivers even talked about having to step up to take over the caregiving responsibility after losing former primary caregivers. They reported that one of the detrimental consequences of being a primary caregiver for PWD is early or unexpected death that causes even greater anxiety for the following family caregiver.

My father had always been very healthy throughout all of this, but maybe it's because of the stressful year he spent looking after my mother, he suddenly passed away.... I couldn't believe that he would just pass away like that.... My older sister and younger sibling used to be around, but earlier on they broke all ties. I'm the only one there to take care of my mother. (daughter, age 66)

Traveling the Path of Acceptance.

KA caregivers described their journey of acceptance which varies greatly among caregivers. Several caregivers discussed coming to terms with a new reality and putting efforts into providing the best possible care in the areas like nutrition and diet, exercise and activities, as well as communication strategies with compassion and love.

Everything about dementia patients seems bizarre and unusual. However, that's normal for their disease. And it's all about fully accepting them as they are.... He would go into the bathroom by himself and start laughing.... I would just laugh with him.... I thought to myself it might actually be healthier for my husband to go into a bathroom and laugh meaninglessly since he never laughs. (wife, age 61)

While these caregivers tried to be understanding of the patient's behaviors by viewing them from the patient's perspectives, there were other KA caregivers who talked about not wanting to create awkward social situations and burden others including family members and relatives by revealing the diagnosis publicly. One caregiver recalled, "I was so hurt, so upset. I couldn't accept that he [husband] had dementia. I didn't want to. I was worried that people would know. I was embarrassed, ashamed, and wanted to hide it."

Despite difficulties they dealt with on a daily basis, many KA caregivers expressed a desire to take care of PWD at home, using care facilities as the very last option. Some had negative views on care facilities and nursing homes. This was mostly out of familism or familial

piety, love, and appreciation for the patients. Spouses and children of PWD stated they would regret not trying every available option before placement. They said that dealing with caregiving at home would be easier than living with guilt and what-ifs later. One caregiver said, "I'd rather endure living with her [mother] now than to regret admitting her into a facility.... I really think it requires a family member to be a caregiver." Some KA caregivers talked about not fully disclosing information about the illness or treatments to the patient, believing that it was for the patient's best interest.

I was told to give one pill per day, but gave her [wife] two instead, one in the morning and one in the evening. I lied to doctors, lied to pharmacists. I got more meds and gave them to her.... I don't have enough meds now, so I can't give two pills anymore. But I think her symptoms progressed much slower than others because I gave her more meds. (husband, age 72)

Finding Ways to Survive.

The last theme was about specific strategies KA caregivers used to deal with caring for PWD. Most caregivers reported self-care strategies such as walking, healthy eating, rest and sleep, medical check-ups, and hobbies. Caregivers felt obligated to take care of their own health because PWD did not have anyone to rely on if something happened to them. A few KA caregivers mentioned that they coordinated schedules with other family members and arranged for PWD to spend a few hours a day in daycare centers. Taking a break from caregiving helped them cope better with the primary caregiver role.

All my siblings are very cooperative. I'm very grateful for them.... We pulled together and with that, my youngest sister is coming more often. (daughter, age 61)

The duration of when he goes to daycare is my only time to rest.... I felt that I could fly away when I walked out after dropping him off. (wife, age 75)

KA caregivers found comfort in familial and social support as well as spiritual and religious beliefs. Maintaining a positive mindset and keeping busy were additionally identified as useful strategies.

Discussion

This study examined KA family caregivers' experience of caring for PWD and identified how they tried to fulfill their needs to know more about the illness and provide better care with their limited English proficiency and limited resources that they wish to have in Korean language. Similar to many other caregivers of all ethnicities, KA caregivers in this study reported how they were physically, emotionally, psychologically, and socially impacted by caregiving. Familism or familial piety is a cultural value that is extremely important for KA caregivers and the participants in this study described how it affected their caregiving experience of dementia. This is consistent with previous findings on the dementia caregiving experience of Korean or KA caregivers (Kim, 2009; Kong, Deatrck, & Evans, 2010; Park, Butcher, & Maas, 2004) or other AA caregivers (Gallagher-Thompson et al., 2007; Meyer et al., 2015; Sun, Ong, & Burnette, 2012). However, in this study, the familism seemed to negatively affect spouse caregivers not to actively seek help from their adult children. These

caregivers did not want to be a burden and tried to protect their adult children from the caregiving responsibilities.

KA caregivers of PWD reported that they were exhausted and drained in all aspects of their lives, overwhelmed with lack of support from others, and crushed under the weight of multi-layered issues including stigma, finance, overall family relationships, and uncertainty related to the future (Kim, 2009; Meyer et al., 2015; Park et al., 2004; Tatangelo, McCabe, Macleod, & You, 2018). Along with this, a most notable finding in the present study was four caregivers' reports of suicide- or death-related thoughts. In this study, suicide-related thoughts were reported by caregivers who lived with PWD expressing perceived lack of resources regardless of financial, social, or emotional status. They verbalized views that taking their own lives along with PWD's was one of the problem-solving options. One expressed it would be a good death as their disappearance would no longer inflict any further damage, suffering, or burden on the rest of the family.

Although unmet needs for mental health among caregivers of PWD have been reported in previous studies (Tatangelo et al., 2018), those reporting suicidal thoughts and ideations and prevention strategies for the caregivers of PWD are difficult to find. Occurrences of suicidal ideation were reported for as low as one in eight dementia caregivers in other countries including Netherlands (Joling, O'Dwyer, Hertogh, & van Hout, 2018), Australia, England, Canada, and U.S. (O'Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2016).

However, few studies report suicide-related thoughts and behaviors for KA caregivers of PWD. In fact, suicide rate in South Korea is the highest among the industrialized countries (Noah, Acciai, & Firebaugh, 2016) and suicide among the elderly below poverty line is a public health problem in South Korea (Evans, 2015). It has been reported that suicide rate in South Korea spiked to 33.6 per 100,000 in 2010 when that of the U. S. was 12.5 per 100,000. KAs are also reported to have the highest suicide rate than other AAs in the U.S. (Kuroki, 2018). Together with the underutilization of mental health care services among KAs (H. B. Lee et al., 2014), mental health literacy, and attitudes towards mental illness among older KAs (Y. Jang, Chiriboga, & Okazaki, 2009; Y. Jang, Gum, & Chiriboga, 2011), suicide is a concern for KA caregivers. Therefore, healthcare providers need to attend to KA caregivers of PWD to strengthen their resilience and affect their overall attitudes toward caregiving. Further studies on suicide and culturally relevant interventions will be required for this population.

KA caregivers in this study mentioned that the U.S. healthcare system was complex. It was difficult for them to obtain available services and resources in community for dementia care. In facing these challenges, KA caregivers utilized Korean online information as a way to overcome the limited access to information and resources related to dementia and caregiving. Several KA caregivers reported searching the Internet for dementia-related information in Korean that was not offered by their healthcare providers in the U.S. Internet searches were convenient and affordable with easy access without a need to travel leaving the PWD alone. They believe that self-taught information from Internet searches (e.g., YouTube videos related to dementia) provided further knowledge on dementia and caregiving. These self-initiated efforts to locate health-related information and resources

among KA caregivers can be empowering for the caregivers. However, there are potential issues that can arise from the Internet-based information such as the credibility of the sources of information and incorporating the obtained knowledge into actual caregiving and decision-making via discussions with healthcare providers (Tan & Goonawardene, 2017).

Interestingly, a few KA caregivers in the study reported that they traveled to South Korea to see dementia specialists to overcome the language or health care access barriers they encountered. Medical tourism, a combination of medical care and tourism, is advertised on- and off-line media in KA communities in the U.S. (Jun & Oh, 2015). Medical transnational ties with the home country among KAs is not an uncommon phenomenon for reasons such as costs, quality healthcare services with short waiting time and simple steps, easy communication, familiar culture, and emotional comfort of being in the home country (S. H. Jang, 2017; Oh, Jun, Zhou, & Kreps, 2014). Depending on the reports, rates of medical tourism among KAs ranged from 8% to 29%, particularly for comprehensive health assessments (De Gagne, Oh, So, & Kim, 2014; S. H. Jang, 2017; Oh et al., 2014). In this study we found that KA caregivers specifically utilized medical tourism during the time of dementia diagnosis.

One of the concerns for healthcare providers to consider when KA caregivers of PWD seek health care via medical tourism is the potential disruption in continuity of care (Turner, 2007). Therefore, it will be important for U.S. healthcare providers to make purposeful efforts to build more trust with KA caregivers and their PWD providing them with local resources that KA caregivers can utilize on a daily basis.

There are some considerations in understanding the findings of this study. First, participants of the study resided in Southern California. Despite the high density of KA population, their presentation is geographically limited. Second, it is important to note that participants voluntarily reached out for interviews. Despite differences in stages of caregiving, participants in this study were at a point where they re-established new routines evolved around caregiving for PWD instead of an immediate crisis phase. They were ready to talk about their caregiving experience and trials and errors with a goal to help other KAs in similar situations. Third, the characteristics of most KA caregivers in the study were similar - married, Christians, older than 55 years in age, college-educated, and insured. Therefore, transferring the findings of the study to other conditions (e.g., uninsured or low education) requires caution. Lastly, as the study was based on the needs assessment interviews among KA caregivers of PWD, the interview questions focused on the overall caregiving experience among KA caregivers and what they identified as lacking and needed to improve the quality of dementia caregiving experience. Therefore, the study did not intend to ask participants to delineate the differences of caregiving experiences in depth based on participant characteristics such as caregiver and care-recipient relationships, residing with PWD, severity of symptoms, or years of caregiving.

This study calls for healthcare providers including psychiatric nurses to be mindful of individual efforts made by KA caregivers with PWD to compensate for lack of support and resources from the formal healthcare system. Healthcare providers should put more effort to understand cultural aspects affecting care for PWD and their families (e.g., familism,

depression and suicidal thoughts, and medical tourism). In addition, healthcare providers should evaluate KA caregivers' knowledge as well as how applicable their knowledge gained from online resources in Korean is in local settings where daily operations of care occur. Lastly, suicide assessment and prevention interventions need to be implemented by healthcare providers, especially geropsychiatric nurses when working with KA caregivers with PWD with an understanding of high suicide rates in this population and views on suicide and death in Korean culture.

Conclusions

This study explored KA informal caregivers' experiences of caring for family members with dementia and presented how they overcome challenges to fulfill the needs for dementia care. Reports by KA caregivers indicate that caregiving for PWD presents many challenges. KA caregivers in this study reported an emotional roller-coaster with confusion followed by intense negative emotions including frustration, depression, anxiety, and denial. They expressed language, cultural, and systematic barriers prevented KA caregivers from asking for assistance they needed, which caused high levels of burden and distress to the point where thoughts of suicide and death sometimes occurred. Thus, this study brings attention to the urgent need to educate the KA community about dementia, to improve quality and quantity of culturally appropriate care services, and to provide practical help for day-to-day caregiving.

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Table 1.

Characteristics of family caregivers and their loved ones with dementia

	Korean-American Family Caregivers (N=18) Frequency (percent)
Gender (female)	15 (83.3%)
Mean age (range), year	65.3 (29-85)
60	5 (27.8%)
61-70	5 (27.8%)
71	8 (44.4%)
Caregiver relationship with the patient	
Spouse (wife or husband)	11 (61.1%)
- wife	9 of 11 (82%)
Adult child (daughter, son, or daughter-in-law)	7 (38.9%)
- daughter	5 of 7 (71.4%)
Age by spouse vs. non-spouse	
Mean/median age of spouse participants (n=11)	73.3/74 (range: 57-85)
Mean/median age of non-spouse participants (n=7)	52.9/59 (range: 29-67)
Marital status	
- married	14 (77.8%)
- widowed/divorced	2 (11.1%)
- single	2 (11.1%)
Living status with persons with dementia (PWD)	
Living together in the same house	14 (77.8%)
Not living with PWD	4 (22.2%)
Having a religion (Yes)	17 (94.4%)
Mean year of living in the United States (range)	32.8 (17-46) ^a
English proficiency, ^b mean (SD):	2.8 (±1.4)
High school completion or above	17 (94.4%)
Currently employed	3 (16.7%)
Recruitment methods	
A Korean American community center	6 (33.3%)
Alzheimer's Korean support group	5 (27.8%)
A dementia care class	3 (16.7%)
Snowballing	4 (22.2%)
Persons with dementia (N=15)^c	
Age (mean, median, range)	80.7, 83, 57-91
Gender (Female)	8 (53.3%)
Types of dementia (reported by caregiver)	
Alzheimer's dementia	9 (50%)
Vascular dementia	1 (6.6%)
Lewy body dementia	1 (6.6%)

Korean-American Family Caregivers (N=18) Frequency (percent)	
Fronto-temporal dementia	1 (6.6%)
Don't know	3 (20%)
Severity of dementia status (reported by caregiver)	
Mild	3 (20%)
Moderate	11 (73.35%)
Severe	1 (6.6%)
Taking dementia related medications (yes)	10 (66.7%)
Insured	
Only Medicare	9 (60%)
Medicaid + Medicare	6 (40%)
Utilization of social services	
Adult day center	2(13.3%)
In-home supportive care	1 (6.6%)

^aTwo caregiver participants who were born in the United States (U.S.) were excluded.

^bEnglish proficiency measured with 5-likert scale (5=Excellent, 1=Cannot speak English): Two caregiver participants who were born in U.S. were excluded in this mean calculation.

^cFive caregivers interviewed were from two families (mother and two daughters, mother and son)