Dementia Care Decisions, Caregiving Situations, and Formal Service Use in Korean Immigrant Families: A Qualitative Application of a Sociocultural Model

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Abstract: Given the significant role of culture and place in dementia caregiving, we conducted a qualitative study with Korean American family caregivers of persons with dementia. Guided by the sociocultural model of dementia caregivers’ service use, we explored the categories of care decisions, caregiving situations, and formal service use within the context of culture and place. Data from in-depth interviews with 16 Korean American dementia caregivers living in the greater Los Angeles area were analyzed using the constant comparison method. Across the three conceptual categories, we derived eight themes: (1) personal motivation; (2) family context; (3) attitude toward formal care; (4) strains; (5) rewards; (6) language and geographic region; (7) knowledge and awareness; and (8) social support and cultural stigma. Our findings demonstrate not only varied experiences in care decisions, caregiving situations, and formal service use but also their interconnectedness. Supporting the influential role of culture and place in dementia caregiving, the findings include positive and negative elements within each domain and provide implications for programs and services to respond to identified needs and barriers.

Keywords: dementia caregiving; culture; place; sociocultural model; Korean Americans; qualitative methods

1. Introduction

The growing fear of getting Alzheimer’s disease and related dementias (ADRDs) or having to provide care for a loved one with ADRD is becoming a reality for many. ADRD is a major public health concern, affecting 6 million Americans in 2020, with an estimated increase to 12 million by 2050 (Alzheimer’s Association 2022). The progressive and degenerative nature of ADRD takes physical, emotional, and financial tolls on informal caregivers (Alzheimer’s Association 2022). Over the past few decades, a sizable body of literature on stress and well-being among dementia caregivers has accumulated, some of which has focused on caregivers with racial and ethnic minority backgrounds (Dilworth-Anderson et al. 2020; Liu et al. 2021). Demonstrating both strains and strengths among minority caregivers, studies have underscored the importance of considering the cultural context in which caregiving is embedded (Dilworth-Anderson et al. 2020; Knight and Sayegh 2010).

Despite the fact that caregivers in immigrant families are more prone to caregiving stress due to various immigration and culture-related challenges (e.g., limited English profi-
ciency, cultural barriers, racism, discrimination, and health inequity), these caregivers have been understudied and underserved (Rote and Moon 2018; Yellow Horse and Patterson 2022). Among Asian immigrants, dementia caregiving can be shaped by factors such as caregivers’ adherence to traditional cultural values of familism and filial piety (E. Lee and Mock 2005; Sung and Song 2001) as well as stigmatizing beliefs about dementia and institutionalization (Chan 2010; Jang et al. 2019; Liang et al. 2021). Barriers to the language and culture of the host society, social exclusion, and limited resources and services commonly experienced by immigrants present particular risks for dementia caregiving (Morhardt et al. 2010). An individual’s location also offers an important context; the availability and accessibility of ADRD-related services vary with geographic location owing to differing ethnic population densities (MacLeod et al. 2017; Phillipson et al. 2014).

This study is guided by the sociocultural model of dementia caregivers’ service use (Roberto et al. 2022), which emphasizes the role of both culture and place in the use of formal services for dementia care. Following the sociocultural stress and coping model (Knight and Sayegh 2010) and the domains of the behavioral model of health services use (Andersen 1968), the sociocultural model of dementia caregivers’ service use posits that caregivers’ use of formal services is associated with predisposing factors (e.g., reasons for caregiving and previous experience), needs (e.g., dementia patients’ behavioral problems), and enabling factors (e.g., service knowledge and social support), which are dynamically interrelated and ultimately influenced by the beliefs and cultural norms within a broader context of culture and place. The model offers a useful framework for assessing the complexity of dementia caregiving in diverse groups of caregivers, taking their culture and place into account. Applying the model to dementia caregivers in immigrant families, we conducted qualitative assessments of care decisions, caregiving situations, and formal service use.

We focused on Korean American family caregivers of persons with dementia living in the greater Los Angeles area. Korean Americans are the fifth largest Asian American subgroup (Budiman 2021). Owing to their relatively recent immigration to the U.S., a high proportion of Korean American adults comprises first-generation foreign-born immigrants with cultural and linguistic barriers (Budiman 2021). About one-third of all Korean immigrants in the U.S. reside in California, and 67% of the Korean immigrants in California are concentrated in the greater Los Angeles area (O’Connor and Batalova 2019). The high Korean population density in this area makes Korean-oriented resources and services available, including home and community-based services and nursing homes with Korean-speaking staff. Given traditional Korean culture’s valuation of familism and filial piety, adaptation through immigration and acculturation, and access to ethnically oriented community resources, Korean American caregivers of family members with dementia living in the greater Los Angeles area offer a unique opportunity to explore diverse experiences of dementia caregiving and the contextualizing role of culture and place. Building upon prior qualitative research with Korean American dementia caregivers that has demonstrated diverse experiences and attitudes toward caregiving shaped by cultural norms and family dynamics (e.g., Lee Casado et al. 2015; Kim et al. 2019; Y. Lee and Choi 2013), our study extends its focus through a qualitative application of Roberto et al.’s (2022) model of culture and place. By investigating dementia care decisions, caregiving situations, and formal service use among Korean American caregivers, our approach seeks to deepen our understanding of how cultural and geographical contexts influence caregiving practices within this community, thereby advancing current knowledge on caregiving experiences among Korean Americans.

2. Methods

We conducted in-depth interviews with caregivers of family members with dementia between 15 December 2021 and 12 March 2022. Using purposive sampling, we recruited 16 participants. Sources for recruitment included established community networks, referrals, and public advertisement. One exemplary source was the Asian American Resource Database (AARD), which our research team had developed, listing health and social ser-
services available in Asian communities in the greater Los Angeles area. We established strong partnerships with key leaders and organizations in Korean communities identified in the AARD, and they were actively engaged in the recruitment and referral efforts. It should also be noted that there were two participants who were referred by other participants.

Self-identified Korean Americans aged 18 or above who currently resided in the greater Los Angeles area and provided care to a family member with dementia were eligible for participation. Interviews were conducted by the first and second authors in Korean. In compliance with the research activity restriction imposed due to COVID-19, all interviews were conducted remotely. Fifteen of the interviews took place online via Zoom; one interview was conducted via phone with an 82-year-old female who was not a user of computers and the Internet. We ensured that participants were in a setting that could ensure their privacy. Study protocols and procedures were approved by the Institutional Review Board at [name of the University blinded]. All participants were informed of the study's goals, and their verbal informed consent was recorded. Interviews consisted of a short survey of background information (e.g., demographic characteristics and caregiving contexts) and semi-structured interview questions. Major interview questions were as follows: “Would you tell us how you became a caregiver for the person with dementia?” “How would you describe your overall caregiving experience?” “What are the challenges or difficulties you face as a caregiver?” “Do you have any positive experiences with caregiving?” “How familiar are you with dementia-related resources and services in your community?” “Do you use such resources and services?” and “What helps or hinders your use of such resources and services?” The interviewers asked questions and prompted follow-up explanations for further elaboration. When relevant, prompts addressed culture and place. Each interview lasted about 90 min, and the sessions were recorded.

Analytic Strategy

Following guidelines for cross-language qualitative research (Suh et al. 2009), audio recordings of the interviews were transcribed verbatim in Korean. All interviewers and coders were bilingual in English and Korean; all had expertise in aging, dementia caregiving, and health services and had worked with Korean immigrants and their families. Coding and data analysis were guided by the constant comparison method (Glaser and Strauss [1967] 2017). All authors read all transcripts and immersed themselves in the data. The first three authors coded transcripts line by line and developed a preliminary code list independently; they then compared their codes, discussed discrepancies, and refined the codes for the first two transcripts. Using these consensus codes, the coders again independently coded two additional interview transcripts and then compared the codes and discussed any discrepancies. Through this iterative comparison and consensus (i.e., independent coding followed by discussion of all areas of disagreement), a consensus code list was developed. With this list, all transcripts were reviewed, with each transcript reviewed by at least two coders to reduce bias. The refined codes were clustered into categories to yield themes and theoretical concepts. For an additional reliability check, the last two authors independently reviewed the coded transcripts, codes, and categories and checked their accuracy; they also provided holistic feedback on themes. To enhance rigor and trustworthiness, we employed several strategies, including intensive engagement, cross-coding, regular debriefings, record-keeping, and a feedback loop for consensus (Shibusawa and Lukens 2004). A qualitative data analysis program, Atlas.ti 23 (Scientific Software Development, Berlin, Germany), was used to organize and analyze codes. The translation of the selected quotes into English was conducted as a final step to minimize the loss of content and meaning in the original language (Suh et al. 2009).

3. Results

The sample included 16 caregivers; their descriptive characteristics are summarized in Table 1. Their mean age was 54.5 years (SD = 12.2; range, 30 to 82); 13 (81%) were women, and 13 were married (81%, including one who was separated). All were born in Korea, and
Korean was their primary language. The caregivers’ years of living in the U.S. ranged from 3 to 44 (M = 24.7; SD = 11.2). Nine were providing care for their own parent, four were caring for a parent-in-law, one for a spouse, one for a grandparent, and one for a relative. The mean age of care recipients was 85.4 (SD = 8.02; range, 66 to 99). Years of caregiving averaged 4.81 (SD = 3.97).

Table 1. Descriptive summary of participating caregivers.

<table>
<thead>
<tr>
<th>ID</th>
<th>Age</th>
<th>Gender</th>
<th>Marital Status</th>
<th>Years in U.S.</th>
<th>Relation to Patient</th>
<th>Age of Patient</th>
<th>Years of Caregiving</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>58</td>
<td>Female</td>
<td>Married</td>
<td>14</td>
<td>Daughter</td>
<td>84</td>
<td>4</td>
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<tr>
<td>2</td>
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<td>Married</td>
<td>17</td>
<td>Daughter-in-law</td>
<td>99</td>
<td>3</td>
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<tr>
<td>3</td>
<td>52</td>
<td>Female</td>
<td>Separated</td>
<td>30</td>
<td>Daughter-in-law</td>
<td>84</td>
<td>1</td>
</tr>
<tr>
<td>4</td>
<td>60</td>
<td>Female</td>
<td>Married</td>
<td>32</td>
<td>Daughter</td>
<td>87</td>
<td>7</td>
</tr>
<tr>
<td>5</td>
<td>58</td>
<td>Female</td>
<td>Married</td>
<td>29</td>
<td>Daughter</td>
<td>95</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>63</td>
<td>Male</td>
<td>Married</td>
<td>44</td>
<td>Son</td>
<td>90</td>
<td>2</td>
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<tr>
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<tr>
<td>8</td>
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<td>Married</td>
<td>25</td>
<td>Daughter</td>
<td>86</td>
<td>6</td>
</tr>
<tr>
<td>9</td>
<td>52</td>
<td>Female</td>
<td>Married</td>
<td>30</td>
<td>Daughter-in-law</td>
<td>86</td>
<td>5</td>
</tr>
<tr>
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<td>42</td>
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<td>Single</td>
<td>40</td>
<td>Grandson</td>
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<td>2</td>
</tr>
<tr>
<td>11</td>
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<td>Male</td>
<td>Married</td>
<td>26</td>
<td>Son</td>
<td>87</td>
<td>12</td>
</tr>
<tr>
<td>12</td>
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<td>Female</td>
<td>Married</td>
<td>24</td>
<td>Daughter-in-law</td>
<td>66</td>
<td>3</td>
</tr>
<tr>
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<td>Married</td>
<td>36</td>
<td>Daughter</td>
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<tr>
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<td>Daughter</td>
<td>85</td>
<td>3</td>
</tr>
<tr>
<td>15</td>
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<td>Married</td>
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<td>Relative</td>
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<tr>
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<td>Female</td>
<td>Married</td>
<td>18</td>
<td>Spouse</td>
<td>84</td>
<td>16</td>
</tr>
</tbody>
</table>

From the interview data, we identified eight themes and 21 subthemes, which we grouped into the three conceptual categories of care decisions, caregiving situations, and formal service use (see Table 2). The findings are also depicted in Figure 1.

Table 2. Categories, themes, and subthemes that emerged from interviews.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care decisions</td>
<td>Personal motivation</td>
<td>Emotional bonding</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cultural beliefs</td>
</tr>
<tr>
<td></td>
<td>Family context</td>
<td>Unavailability of other family members</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gender role and family expectation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sacrifice for family harmony</td>
</tr>
<tr>
<td></td>
<td>Attitude toward formal care</td>
<td>Reluctance to formal care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Recognized needs for formal care</td>
</tr>
<tr>
<td>Caregiving situations</td>
<td>Strains</td>
<td>Physical health issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Emotional burden</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social isolation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Relational conflict</td>
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<tr>
<td></td>
<td>Rewards</td>
<td>Sense of fulfillment</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Improved quality of relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Personal growth</td>
</tr>
<tr>
<td>Formal service use</td>
<td>Language and geographic region</td>
<td>Language barriers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Regional differences</td>
</tr>
<tr>
<td>Knowledge and awareness</td>
<td></td>
<td>Dementia literacy</td>
</tr>
<tr>
<td>Social support and cultural stigma</td>
<td></td>
<td>Service awareness</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Social support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Cultural stigma</td>
</tr>
</tbody>
</table>
3.1. Care Decisions

3.1.1. Personal Motivation

Many caregivers, particularly those who were caring for their own parent or grandparent, reported special bonding and affection with their care recipients over the life course. Many noted the reciprocity of love and support that they had received from their care recipients earlier in life. As one female 58-year-old caregiver who was taking care of her 84-year-old mother said: “When my family immigrated to the U.S., my mom helped me raise my kids. While I was working, she was fully in charge of them. Now I am paying back what I owe to my mom.” The caregiver described feeling indebted to her mother and described caregiving as returning the love and kindness that she received from her mother.

The sense of feeling indebted or obligated to one’s parents appeared to resonate with other caregivers, which may be rooted in culture and tradition. Several participants described caregiving as a filial responsibility: “As the eldest daughter, I am taking it as my responsibility. I had seen my eldest aunt being a caregiver of my grandfather when I was young, and the role of caregiving is quite familiar to me” (female, age 41). The caregiver described how being the first-born came with additional responsibilities and that caregiving was evident in her family across generations.

The norms and expectations of caregiving in Korean culture are often passed down from generation to generation. As one 55-year-old female caregiver said, “In a way, I am setting an example for my kids. Not that I want my kids to do the same thing for me as I would never want to burden them, I hope my kids get some life lessons by observing what I am doing”. This respondent highlighted an important way that culture is transmitted, which is by modeling how to give care so that her children will adopt a similar view toward caregiving.

Intertwined with culture and tradition is religiousness. Some participants attributed their reason for assuming the caregiver’s role to religion, for example, by following God’s instruction to respect one’s parents and help others. A spousal caregiver of a retired pastor stated, “It is the Lord’s blessing that I can take care of him and his symptoms do not get worse. Every day I give God thanks” (female, age 82). Religious beliefs were not only motivations for care but also sources for coping.
3.1.2. Family Context

The unavailability of other family members was a key subtheme under family context. Various reasons were given, such as geographic distance, employment, personal health issues, and responsibilities for other family members. Some caregivers embraced their role positively: “I have been living with my mom for many years, and it is natural for me to continue. There is no one else that knows mom better than me” (female, age 60). Others, however, expressed resentment and discontent with their situation and with other family members: “Because I live close, I became the one that should do everything. My siblings who live far seem to take it for granted. This seems to be unfair” (female, age 55). Caregivers held varying attitudes toward their responsibilities.

Many participants mentioned gender roles in caregiving. Traditionally, Korean culture prioritizes sons, particularly the eldest son, in family decisions, but daily caregiving tasks fall mostly on women. One female caregiver (age 58) gave the following opinion:

I don’t think it is a good idea that the eldest son should be in charge. Men are just a placeholder, and all those tasks are mostly done by their wives. Frankly speaking, being a caregiver for those who are not your own parents is very hard. Since I know my mom is not an easy person to work with, I don’t expect my sister-in-law to be involved. I am trying to protect my brother and his married life.

Several participants pointed out that such traditional expectations make daughters-in-law distressed and cause family conflict. One caregiver who was taking care of her 66-year-old mother-in-law expressed her hardship with tears. Along these lines, many caregivers made personal sacrifices to optimize care situations and preserve family harmony, making accommodations in their employment and living arrangements. One caregiver (age 58) moved into a small apartment with her mother who had severe behavioral symptoms of dementia, leaving her husband and adult son at home.

3.1.3. Attitude Toward Formal Care

In general, unfavorable perceptions and attitudes related to formal care were common among the caregivers: “Nursing homes are like prison cells. I would feel guilty if I send my mom there” (female, age 41). Another caregiver who had considered nursing home placement stated, “I actually toured several places, but none of them gave me a good impression. Those places were so depressing, and everyone there seemed to be heavily medicated” (female, age 55). Caregivers expressed that nursing homes were unacceptable for their family members.

An emerging subtheme, however, was the recognition that, sometimes, formal care was necessary. Caregivers stated that placement might be inevitable when patients’ safety was jeopardized, when family caregivers were unavailable or overburdened, or when professional medical care was needed: “The good thing about nursing homes is that nurses and doctors are there to take care of emergency situations” (male, age 63). Another caregiver (age 60) said that having nursing homes as an option made her feel relieved: “Neither myself nor my mom likes the idea [nursing home placement], but the fact that I do have an option helps me breathe”. Nonetheless, she ended her remarks by indicating her preference for caregiving at home: “If my mom’s condition gets worse, I may let her stay there temporarily, but I’d like to keep her at home as long as possible”. The caregivers generally felt that while the home was the ideal place for the patient, sometimes formal care could help alleviate some of the burden.

3.2. Caregiving Situations
3.2.1. Strains

Caregiving eventually took a physical toll on many caregivers in our study. Many caregivers spoke of physical health issues resulting from caregiving stress, such as fatigue, headaches, indigestion, and sleep disturbances. Participants who were taking care of patients with intense personal care needs (e.g., bathing, diaper change, and bedsore care)
reported physical challenges associated with these tasks. A female caregiver who was 8 months pregnant said that she could not bathe her mother-in-law any longer. While providing care, one caregiver had a finger fracture, and another developed a herniated disk. Neither were able to pay full attention to their own treatment because they were occupied with caregiving responsibilities. The caregiver with the fractured finger said that she had to cease physical therapy because she could not leave her mother alone. An 82-year-old caregiver of her 84-year-old husband had her own health issues with diabetes and impaired vision; she had recently undergone back surgery but could not fully attend to her recovery because no one else could take care of her husband. These examples show that caregivers are sometimes faced with difficult decisions to care for their loved ones at the expense of their own health.

The toll of caregiving was not only physical but also mental and emotional. Caregivers reported an array of emotions, including feelings of helplessness, frustration, denial, distress, anger, and sadness. It is worth noting that the specific symptoms of dementia can be especially psychologically distressing. For example, a 55-year-old caregiver who provided around-the-clock care for her 86-year-old mother said that, “hearing the same questions over and over makes me insane. It feels true that I could die earlier than my mom”. Another caregiver reported that she kept hearing her mom screaming in her mind all the time and could not relax. Two female caregivers explicitly stated that being a dementia caregiver made them depressed.

Relatedly, caregiving can have a dramatic impact on one’s social functioning. In our study, social isolation was noticeable among many caregivers: “My social life has been cut off since I started taking care of my grandmother. Many of my friends are now disconnected from me” (male, age 42). For many, the responsibilities of caregiving can be time-consuming and exhausting, making it difficult to stay socially connected. Further, caregiving can also directly create family conflicts about care decisions and involvement, which strains one’s social support system. One female caregiver (age 41) caring for her mother said, “I wish my brothers and sisters could simply acknowledge that I am suffering here. I don’t think I am asking too much from them. It would be comforting to me if they could just appreciate”. Caregiving can produce feelings of resentment when responsibilities are not equitably distributed or when the caregiver’s efforts and sacrifices are not recognized and appreciated.

3.2.2. Rewards

While caregivers undoubtedly expressed the challenges of caregiving, several of the caregivers described their caregiving experiences positively. Some reported a sense of fulfillment to the expectations of their family and religion. One female caregiver (age 58) stated that, “God gave me this opportunity to make me not regret when my mom passes away. I am following the path God has built for me”. Participants also said that they experienced a sense of achievement and happiness when their care recipients’ conditions improved with care.

The caregivers also reported positive changes in relationships. A male caregiver (age 63) caring for his own mother stated that, “I feel much closer to my mom. As I spend a lot of time with her, I get to say that I love her and touch her face. When I was young, I was one of those sons who rarely talk to their moms, and this is a huge change for me”. Spending time with his mother granted him more opportunities to express love and cultivate a relationship with his mother that was markedly different than the relationship he had with her as a child. Others also described relational improvements. A daughter-in-law (age 52) described one such change:

My mother-in-law used to give me a very hard time, and our relationship was never good. I honestly had resentment toward her, but those feelings are totally gone. She is now a person whom I need to protect and take care of. I feel like I am building a new relationship with her. The other day when her clear mind was back, she held my hands and thanked me. That was a memorable moment of my life.
She also said that the quality of her relationship with her husband had improved and that he deeply appreciated her for her hard work and sacrifice. Beyond relational improvements, other rewards associated with caregiving included personal growth, including a greater appreciation of life, health, family, stronger religious faith, and family bonding. Caring for someone who was unhealthy prompted some to reflect on their own health and to exercise more. These benefits may not always readily come to mind when thinking about caregiving but are important to acknowledge and build upon.

3.3. Formal Service Use

3.3.1. Language and Geographic Region

Several caregivers mentioned the challenges of language barriers and noted the advantage of living in a region with many Koreans where services and resources were available in the Korean language. One female caregiver (age 55) said, “I don’t speak English well, but that is not a big issue here in LA. If I lived elsewhere, I could have not handled many things on my own”. One of the services that she relied upon consisted of weekly home visits by a Korean home health worker: “My mom enjoys her visit very much because she can talk in Korean. A home health worker’s visit is a special treat for my mom”. As such, having a home health worker who spoke Korean also allowed the patient to have a social connection and to enjoy the home visit.

However, caregivers reported some difficulties when services were not available in Korean. One female caregiver (age 52), who lived outside of a Korean-concentrated neighborhood, described the challenges of location: “I desperately needed help and tried home health services. But there were no Korean providers in my neighborhood. The ladies sent by the agency spoke Spanish, and my mother-in-law did not want the service because she could not communicate with them”. In areas with dense populations of Koreans, nursing homes with Korean-speaking staff and Korean foods were available. But parts of LA did not have these services available: “My aunt lives in a very luxurious facility, but she has no one to talk to in Korean and of course no Kimchi there”. Thus, the cultural responsiveness of the local services depends largely on the geographic and sociocultural location, and the quality of the service depends on linguistic and cultural compatibility.

Although many referred to the benefit of receiving services in Korean, some did mention concerns. As one female caregiver (age 55) stated, “My information sources are only limited to Korean, and I often wonder if I am missing out on any important things”. Another (age 58), who expressed a high level of dissatisfaction and distrust with her mother’s Korean doctor, said that she was “stuck” with him because she had nowhere else to go: “As I don’t speak English and my mom’s insurance is Medi-Cal, I only have to use a Korean doctor who accepts Medical patients”. Another female caregiver (age 82) stated that, “The [Korean] community is so small, and I don’t report any bad experiences with Korean home health workers. I just let it go when they came late, didn’t do a good job, or even stole money from my purse”. In these examples, caregivers were constrained by their geographic and sociocultural location and could not pursue options due to language and cultural barriers.

3.3.2. Knowledge and Awareness

The caregivers’ knowledge of dementia varied. Two female caregivers who had some educational background or work experience in the medical field reported that they knew about dementia before they became caregivers. However, most said that they had no knowledge of dementia and had missed early signs of dementia in their care recipients. As one female caregiver (age 60) recalled, “I had no idea, and I just thought my mom was growing old and becoming forgetful. I wish I knew about the disease and had taken her to a doctor earlier”. For this caregiver, knowing about dementia may have resulted in earlier action and potentially could have saved her some distress.
Several participants also referred to a lack of information about dementia in the context of social and instrumental support, suggesting that people learn about dementia and caregiving from other dementia caregivers. As one male caregiver (age 63) noted,

*I had to figure out everything on my own. Now I think I know a bit about what dementia is and how to handle my mom, but I had to learn it the hard way. I wish someone had told me. I had to spend so much of my time and emotion figuring things out. I often wonder how other people do their caregiving.*

This caregiver expressed that having social and informational support early in the stages of caregiving would have been helpful. Along these lines, many caregivers spoke of a lack of information on dementia-related resources and services:

*When my mother-in-law was diagnosed with Alzheimer’s disease, I didn’t know where to turn to. It was totally different from when she had cancer. There were a lot of information and services for cancer patients and caregivers. I tried to find dementia-related services, but I didn’t get much. It seems like the Alzheimer’s Association offers programs and services, but none in Korean.* (female, age 39)

The caregiver appeared to be alluding to a structural and systemic barrier, where there were notable gaps in outreach, engagement, and culturally responsive services for Koreans in her area at the time when she first needed help.

3.3.3. Social Support and Cultural Stigma

A few of the caregivers noted that family members, friends, church, and community networks provided service-related information and helped them use services. The caregivers learned about hospice and home health services, for example, through their social networks. After connecting with formal services, the formal service providers could make additional connections. For example, one caregiver who had sleep problems and symptoms of depression was referred to a mental health specialist by a hospice social worker who had a regular home visit for her mom.

But caregivers also noted not only a lack of social support, but also negative impacts caused by members of their social networks. Caregivers sometimes faced mixed messages and conflicting opinions from their social contacts (e.g., decisions about nursing home placement and treatment options). Other times, social networks were not reliable, as some in the absence of family support or in the presence of conflicting opinions.

Stigmatizing beliefs about dementia were also noted. Several caregivers indicated an unwillingness to disclose their care recipient’s disease. One female caregiver (age 58) said, “I just don’t want to share negative things about my family with other people. I don’t want other people to feel pity for my mom or me”. Another caregiver (male, age 63) noted, “This is not like having cancer. Dementia is a mental problem that people don’t want to talk about. Besides, it has to do with a family heritage”. These stigmatizing beliefs suggest that there may be some embarrassment or shame associated with the diagnosis, making it difficult for caregivers to seek outside help and utilize formal services. One caregiver stated:

*I am doing my best to keep my mother at home, and, in a way, this is to save her face and avoid shame. My mother used to care so much about what other people thought about her and believe that nursing homes are where people abandoned by their own families would go. Knowing this, how could I even consider it?* (female, 60)

This caregiver’s response reveals a cultural stigma surrounding brain diseases and the isolation that can result from avoiding social settings to avoid shame. Further, this response also shows the shame associated with placing a loved one in a care facility.

4. Discussion

Our study applied the sociocultural model of dementia caregivers’ service use (Roberto et al. 2022) to the experiences of Korean American families. Roberto et al.’s (2022) model posited that care decisions, caregiving situations, and service use are interconnected and
situated within cultural and geographic contexts. Using a qualitative lens, we applied this model to describe the culturally specific examples of the model’s constructs and generated additional themes that emerged when exploring Korean American caregiver experiences. While our findings largely coincided with the model, our findings also added cultural nuances and themes that may pertain to Korean Americans and potentially Asian Americans more broadly.

4.1. Care Decisions

We found that care decisions were based on a variety of cultural and geographic factors. In many ways, our findings comported with Roberto’s sociocultural model. For instance, affection for the care recipient, reciprocity of love, and care obligations were significant motivators for care, and this finding is consistent with a recent systematic review on motivations for informal care (Zarzycki et al. 2022). Further, decisions were also influenced by contexts, such as geographic distance, caregivers’ employment or personal health, and other caring responsibilities. However, our findings also revealed cultural aspects of care decisions among Korean Americans. One theme that emerged for Korean Americans was the obligation to make a personal sacrifice and assume caregiving responsibilities to maintain family harmony. Filial piety, a traditional Asian value deeply ingrained in Korean culture, emphasizes love, reciprocity, family harmony, respect, responsibility, and sacrifice for parents (Sung and Song 2001). This traditional emphasis on filial obligation for elder care embedded in the family and culture presents a challenge for Korean American family caregivers, most of whom have been born and educated in Korea. Accepting the use of formal care services can mean losing face by not fulfilling one’s filial obligation. Many of the caregivers in this study were reluctant to consider formal care as a viable option unless family caregivers were unavailable or care recipients needed professional medical care and had safety issues. However, these unfavorable perspectives of caregivers regarding formal care require further exploration because they may be due not only to a sense of filial obligation but also to dissatisfying experiences with formal care.

4.2. Caregiving Situations

Caregiving situations reported in our study were defined by strains and rewards. Caregivers faced physical, emotional, and relational challenges, and they frequently reported fatigue, sleep deprivation, personal health issues, and symptoms of depression and anxiety. Social relationships were affected by conflict within the family and alienation from friends and the community. It is particularly concerning that caregivers could not attend adequately to self-care. When caregivers were injured (e.g., fractured finger, herniated disk, and back surgery), they tended to neglect their own healthcare needs. Caregivers also tended to overlook their own mental health and emotional needs. Future studies can examine cultural notions of sacrifice and suffering within the context of family devotion. Nevertheless, caregivers acknowledged positive aspects of caregiving as well: a sense of contentment and achievement, the fulfillment of cultural and religious expectations, improved relationships with care recipients and other family members, personal growth, and renewed perspectives on aging, health, and family. Caregivers tried their best to provide care, even at personal cost, while experiencing some unexpected areas of growth.

4.3. Formal Service Use

The themes of formal service use illustrate circumstances that facilitate or inhibit the use of formal services for those with ADRD. Participants appreciated living in an ethnic enclave where a variety of choices and services were available in the Korean language. This geographic advantage enabled caregivers and care recipients to use culturally sensitive services such as care from Korean-speaking home health workers or being served Korean food in care facilities. Apart from such advantages, however, some caregivers felt that their choices were restricted by language barriers and economic constraints. In addition, most caregivers were unprepared for dementia caregiving, and their lack of knowledge about
ADRD and limited service awareness made them vulnerable. The caregivers indicated a desire to learn more about ADRD and network with other caregivers. Such findings suggest the benefit of ADRD education, caregiver support groups, and advocacy for ethnic minority caregivers. Finally, social support and cultural stigma emerged as key themes. Some caregivers maintained strong support networks, but many struggled to make critical decisions about formal service use in isolation from or in conflict with other family members. Many caregivers associated dementia with family heritage and shame and indicated an unwillingness to disclose this condition outside the family context. The stigmatization of dementia played a powerful role in shaping caregivers’ attitudes and utilization of formal services.

4.4. Linking Care Decisions, Caregiving Situations, and Formal Service Use

As Figure 1 shows, care decisions, caregiving situations, and formal service use are interconnected. For Korean Americans, on the one hand, caregivers with strong motivations to fulfill filial responsibility and religious expectations were likely to report psychological rewards from caregiving and were reluctant to use institutionalized care. On the other hand, those who assumed the role of caregiver unwillingly because of the unavailability of other family members or because of filial obligations were prone to caregiving strains and psychological distress. Dissatisfaction with formal services and desire to keep family harmony also motivated family care at home. Although caregivers used various types of services for their care recipients (e.g., home health services, hospice care, adult daycare services, and nursing homes), caregivers rarely used services for their own physical and mental health needs. Caregivers’ symptoms of depression and anxiety were not appropriately attended to, and this may contribute to burnout or fatigue, which, in turn, influences whether caregivers resort to nursing homes and other formal care options. The dynamic interplay between care decisions, caregiving situations, and formal service use also points toward gaps in the service system and the need for culturally responsive programs and services to promote caregivers’ self-care and emotional well-being among Korean Americans who may be prone to sacrifice and suffer without seeking help. Indeed, caregivers with racial/ethnic minority backgrounds, particularly immigrants with English language barriers, have often been excluded from interventions to alleviate caregiving stress and enhance caregivers’ health and well-being (Gallagher-Thompson et al. 2003; Gitlin et al. 2015).

4.5. Culture and Place

Consistent with the sociocultural model of dementia caregivers’ service use (Roberto et al. 2022), the underlying influence of culture and place among Korean caregivers was evident. Their course of caregiving was shaped by personal adherence to cultural values and norms, such as filial responsibility, patriarchal family structure, and the gendered role of caregiving (E. Lee and Mock 2005; Sung and Song 2001). Stigmatized beliefs about ADRD, saving face, and avoidance of family shame also influenced the way in which caregivers perceived and responded to dementia caregiving and formal service use (Chan 2010; Jang et al. 2019; Liang et al. 2021). Caregiving was further contextualized by factors associated with immigration and acculturation. Immigrants often experience a reduction in networks of family and friends, disruption in social relationships, and limited access to resources and services (Jang and Kim 2019), and such challenges are exacerbated by dementia caregiving (Morhardt et al. 2010). The impact of place was shown in that those living in an ethnic enclave were advantaged in their access to culturally and linguistically appropriate resources and services. However, participants did speak of issues with service quality and autonomy in selection. The Korean cultural norms found within family systems require further examination, as the family serves as a critical source of both support and conflict. Given this finding, family conflicts should be addressed in psychoeducational interventions for Korean dementia caregivers.
4.6. Limitations

This study has limitations that should be considered. First, a small sample based on purposive sampling may not represent the larger population of Korean American family caregivers or other ethnic minority caregivers. Second, the use of a sample of Korean American family caregivers who live in the greater Los Angeles area may limit generalizability. Although we considered place as a key contextual factor and explored both the advantages and disadvantages of living in an ethnic enclave, future studies should include samples from diverse geographic locations to fully address the role of place. Third, despite our multiple approaches to ensure the trustworthiness of the study findings, our own subjectivity or biases might have influenced our interpretation of the data. Finally, given the sensitive nature of dementia caregiving, it is strongly recommended to conduct in-person interviews with caregivers.

4.7. Implications

Despite these limitations, this study provides implications for research and practice by shedding light on diverse contexts of dementia caregiving among Korean American family caregivers, with a particular emphasis on the role of culture and place. Given the progressive nature of ADRD as well as the significant role of filial piety in providing care, much of the burden of caregiving falls on the family regardless of the family’s knowledge, capacity, or resources. Diverse training and support programs that proactively address the needs of dementia caregivers who face language barriers and have low levels of acculturation are needed at community and governmental levels. Services and programs that could help caregivers navigate available supportive services and manage caregiving stress are highly recommended.

4.8. Conclusions

Korean American family caregivers of persons with dementia may have culture-specific experiences making care decisions, navigating caregiving situations and seeking services within cultural and geographic contexts. Future studies can further elaborate on these experiences to inform culturally tailored outreach efforts and services.

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