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Bridging ADRD Gaps: Insights from Community-Led Listening Sessions among the Korean American Immigrants in New York

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ABSTRACT: With an aging population, there is a growing concern regarding Alzheimer's disease and related dementia (ADRD). Underserved racial and ethnic groups, including Korean Americans (KAs), face challenges in accessing ADRD information. To better understand the issues on ADRD among KA elders and involve them in community initiatives, the Korean Community Services (KCS) in New York conducted three listening sessions: two sessions with individuals of different age groups (40 and above and 65 and above) and one with caregivers or individuals who interact with ADRD patients. Negative perceptions and a lack of ADRD knowledge were reported, with an openness to utilizing long-term care among KAs. Recommendations included support groups, seminars from medical professionals, and early screening. Continuing efforts on culturally-tailored campaigns and initiatives targeting the KA community are needed to bridge knowledge gaps and increase awareness of ADRD. The listening sessions offer valuable insights for tailoring health campaigns for diverse populations.

KEYWORDS: Korean Americans, Asian Americans, Community Listening Sessions, ADRD, Alzheimer's Disease and related Dementia, Community health research, Mental Health, Health disparities, Delirium, Dementia, Amnestic, Cognitive Disorders

With increased life expectancy and a growing aging population, age has become a critical health risk factor, leading to a higher prevalence of Alzheimer's disease and related dementia (ADRD). Currently, it is estimated that about 6.7 million older adults in the U.S. have clinical Alzheimer's disease and mild cognitive impairment, and this figure is projected to increase to nearly 14 million by 2060.[1] Evidence indicates that individuals from underserved racial and ethnic groups have a higher prevalence of ADRD than non-Hispanic White older adults.[2,3] Although culturally tailored education and information about ADRD can promote healthful behavior change and action, many underserved racial and ethnic groups face challenges in accessing information, services, and care.[2–4] A report on racial and ethnic disparities in ADRD reported that critical factors, including cultural values, availability, and capacity to develop culturally-tailored and in-language information on ADRD are often lacking for underserved communities.[5]

Although Asian Americans are the fastest-growing racial and ethnic group in the U.S., there is a significant information gap.[2,6,7] Many Asian Americans, including Korean Americans (KAs)–the fifth largest Asian American group in the U.S.[8]– are concerned about developing ADRD and caring for ADRD patients but are not prepared for the potential development of ADRD due to a lack of educational information and knowledge.[4] Both the availability and quality of culturally-tailored and in-language information need to be improved for diverse Asian American groups.[3,9,10] Moreover, a better understanding of how to best reach and educate the communities is needed to address the information gap. Previous large-scale surveys of KAs have consistently reported a lack of knowledge and information about ADRD among the community members and recommended tailored education campaigns and outreach to mitigate that.[11–13]

One effective approach to bridging the health-related knowledge gap is through local community-based organizations (CBOs) that possess a deep understanding of the community and its culture. These organizations can act as bridges to the healthcare system to build a trusting relationship with the community and facilitate the access.[14] They can empower communities to gain more meaningful engagement, education, and awareness about ADRD.[3,5]

History of KCS and their Role for KA Elders in New York

New York City is home to the second highest KA population in the U.S., who are mostly older (median age of 49) than the overall immigrants (median age of 46) and limited English proficient (49%).[15] Founded in 1973 by Korean immigrants, The Korean Community Services of Metropolitan New York (KCS) is the oldest and largest community-based, non-profit organization in the New York Metropolitan areas, including New

Jersey and Connecticut. Its mission is to empower Korean immigrants through economic, social, and health initiatives. KCS envisions immigrant communities to maintain their heritage, while supporting their distinct needs as immigrants by operating seven departments, including senior centers, adult daycare, public health and research, workforce development, education, immigration and legal services, and a mental health clinic. KCS serves older adults at five different sites across NYC, offering educational and recreational activities, Korean meals, and cultural events. Approximately a total of 1,300 individuals aged 60 and over participate across the sites. In 2022 alone, KCS provided 203,568 instances of home-delivered meal programs, 6,695 diverse health education and recreation programs, and 9,378 instances of critical case assistance (including government benefits, social services, and housing resources) to elders facing language and cultural barriers.[16] The KCS Older Adult program specifically caters to improving the quality of life for KA older adult populations.

KCS-NYU Partnership

Despite the extensive services provided by KCS, the organization experienced low participation in ADRD education and screening programs. This prompted KCS to seek a better understanding of the community's needs and perspectives on ADRD. KCS applied for and was awarded an NYU CTSI Community-led Pilot Program Grant from the NYU Clinical and Translational Science Institute (CTSI) to conduct listening sessions with KAs to inform the development of their health and educational programs. The pilot grant program was launched to support quality improvement and evaluation of projects within CBOs in NYC. It is designed to foster community leadership in generating community-centered, practiced-based evidence that can inform researchers, practitioners, and policymakers, and to disseminate the evidence to wider communities. It is a competitive grant that requires CBOs to undergo a thorough review process for their proposals.

As a community-led pilot project grant awardee, KCS received one year of funding and took the lead in designing and conducting a quality improvement project, while NYU, including the CTSI and the Center for the Study of Asian American Health (CSAAH) at NYU Grossman School of Medicine, provided technical support for the project. CSAAH is a National Institutes of Health (NIH) National Institute on Minority Health and Health Disparities (NIMHD)–funded Specialized Center of Excellence housed in the Section for Health Equity in the Department of Population Health. The center is dedicated to researching and evaluating the health of Asian Americans and addressing health disparities. KCS and CSAAH have cultivated a robust partnership since 2009. With the shared vision, the partnership allowed the development of a community health worker (CHW) model to study diabetes, hypertension, and COVID-19 vaccination acceptance over time and made crucial contributions to the underprioritized immigrant communities. Through their collaborative efforts, they have made contributions to both the community and the academic field through publications,[17,18] and conference presentations.[19] Just last year in 2023, KCS was awarded the Best Community-Based Organization Research Poster at the 9th Annual NYU Health Equity Symposium for presenting the findings from the listening sessions.[19]

KCS held regular meetings with NYU members to discuss concerns, share updates, and receive consultations on the project (e.g., project design, facilitator training, refining the question guide), methods (e.g., recruitment process, completing the IRB self-certification for the quality improvement project), data collection, analysis of the qualitative data, and dissemination through presentations and publications. KCS also received library resources and access to literature through the NYU Langone's Health Science libraries.

Study Design and Participants

We conducted three listening sessions with KA community members aged 40 and older, seniors aged 65 and older, and lay and professional caregivers of individuals with ADRD. Additional eligibility criteria included being Korean, residing in the Greater New York area, fluency in Korean, and being willing to participate in a discussion. We invited KA adults from KCS senior centers, adult daycare, and the general community by using in-language advertisements, social media, local Korean newspapers, and broadcasts, which many KAs are exposed to. All participants received a $50 gift card and lunch. The listening sessions were anonymous, and we only collected minimum basic demographic information, including gender, age, area of residence/zip code, and how they heard about the listening session, to verify their eligibility. This pilot was considered a quality improvement project, and obtaining a self-certification was sufficient to fulfill the institution's IRB approval.

Data Collection

Each community listening session, which lasted about 50-60 minutes, was held at KCS between March and May 2022. A KCS staff member, who was trained by the NYU CTSI program and has a master's degree in counseling, led the discussions in Korean. The question guide included questions about one's general knowledge and perceptions about ADRD, experiences, and beliefs related to ADRD care, and the community's needs (see Appendix A). All sessions were audio-recorded, then transcribed using a computerized system, called Naver Clova Note[20] to generate the initial transcription of the audio-recordings, which were then reviewed by YS from NYU CSAAH and KCS staff (JP, SH, YW), who were involved in the listening sessions, for accuracy. Moreover, YS trained KCS staff in qualitative analysis and manuscript writing, which involved developing a codebook with them, conducting high-level analysis on all transcripts, and summarizing and reporting the findings in a manuscript. The KCS-NYU team used Taguette[21] to analyze the listening sessions and met on a weekly basis to review the quotes and address discrepancies in coding. Table 1 contains the quotes from listening sessions grouped into different themes (Korean quotations can be found in Appendix B). To our knowledge, it was the first community-led listening session on ADRD for KA elders on the East Coast. In this paper, we will reflect on the findings from the community-led listening sessions and their implications.

Findings from the Listening Sessions

A total of 41 adults participated in three listening sessions, including 13 males (31.7%) and 28 females (68.3%), with ages ranging from 53 to 90 years and a mean age of 67.6 years (SD=8.67). The first session included 16 community members aged 40 years and older, with a mean age of 62.4 years (SD=8.84). The second session consisted of 15 members aged 65 years and older, with a mean age of 73.1 years (SD=7.30), and the third session with 10 adult caregivers, either having a family member with ADRD or working as professional caregivers, with a mean age of 67.5 years (SD=8.13). All participants were immigrants from Korea, residing in the NYC metropolitan area, and were fluent in Korean, as they only communicated in Korean throughout the listening sessions. Participants reported that they learned about the listening sessions through advertisements in local Korean broadcasts and newspapers (41.5%), recommendations from others (29.3%), and referrals from other KCS programs (12.2%). Only one person reported seeing the information from social media.

Community-level negative perceptions of ADRD

Community members exhibited various negative perceptions regarding ADRD, and many conversations revolved around how others would perceive individuals with ADRD. Strong words like "fool (□ □ /*babo*)" and "look down (□ □ /*mu-shee*)" were used to illustrate the negative perception toward ADRD patients (Quotes 1, 2, see Table 1). A community member compared the misperceptions toward ADRD patients with people with disabilities, stating her own experience of bullying and name-calling due to her disability (병신/*byungshin:* meaning retarded, Quote 3). There was also fear of potentially developing ADRD (Quotes 4, 5, 6). One described that developing ADRD might be worse than having cancer because it is unmanageable (Quote 5). One participant attributed the different attitudes partly to a lack of exposure and awareness of ADRD among the younger generation (Quote 6).

Lack of information on causes and symptoms

There was an overall lack of knowledge about the causes and symptoms of ADRD among KA older adults. For instance, some participants mentioned stress, environmental hormones (Quote 7), and alcohol (Quote 8) as potential causes of ADRD. None of them believed that a single cause was responsible for ADRD.

Some believed that ADRD resulted from not actively stimulating one's brain, such as through extensive television watching (Quotes 8). A few participants even believed that karma and a good personality could determine the type of ADRD symptoms one might develop. For example, a participant suggested that someone with a good heart would potentially experience milder symptoms than someone without one (Quote 9). However, some participants in the caregiver group were aware of screening tests and shared that computerized tomography (CT) and magnetic resonance imaging (MRI) scans of the patient's brain can detect any abnormalities and changes in the brain (Quote 10).

Perceptions on ADRD care and treatment

KA members' views on ADRD patient care were closely tied to family responsibilities. Acknowledging the significant sacrifices caregivers need to make, they preferred long-term care to avoid burdening their family members, especially their grown children (Quotes 11, 14, 15, 16). They recognized that, due to the tradition of "*hyo*" (filial piety: a Confucian tradition to respect parents and ancestors),[22] caregiving could pose more difficulties for the family (Quotes 11, 12). As members of the KA community are familiar with both the long-term care system in the U.S. and Korea, and with increased utilization of professional care facilities in Korea, they did not have difficulty in accepting its utilization (Quotes 13, 14, 15, 16). However, they also mentioned that cultural factors, like eating Korean food and engaging with Korean people and culture, may contribute to improving symptoms (Quotes 13, 15). Participants in the third listening session, where many caregivers participated, shared detailed caregiving experiences and challenges, emphasizing that empathy and patience are essential in caregiving (Quote 17).

Resource needs and recommendations

Community members expressed the need for more events and educational programs, such as seminars and group discussions, that involve medical professionals to provide scientific information on ADRD and related topics (Quotes 18, 19, 20). They believe that these initiatives will not only provide accurate information but also increase awareness. The community also relies on KCS to connect and provide linkages to relevant clinical and service-related resources, including online programs (Quote 19). Additionally, they stressed the need for support groups and mental health resources for families and caregivers, as caregiving is extremely challenging (Quote 18, 19, 21). A professional caregiver shared how the continuous care for patients led her to feel depressed and sad, that she would like to do regular depression screening every six months (Quote 21). Furthermore, they expressed a need for early screening of ADRD (Quote 22, 23), although some members were more aware of the screening policies in Korea than in the U.S.

Reflections and Implications

The community-led listening sessions allowed members of the KA community in New York to express their lived experiences, perspectives, and needs regarding ADRD. The majority of participants were female, and we also found that significantly more women than men are involved in caregiving, consistent with CDC reports that two-thirds of caretakers are women.[23] Across the three listening sessions, we observed that KAs generally hold negative perceptions of ADRD, most likely due to a lack of knowledge. There were also group differences in their perspectives. The most negative attitudes toward ADRD were expressed during the first listening session, which included comparatively younger participants. In contrast, during the second session, where more number of older participants were involved, we observed greater fear of being diagnosed with ADRD, likely due to their age and higher perceived risk of developing the condition.[24,25] Compared to other groups, participants in the caregiver group shared more detailed personal stories related to ADRD, which made the tone of the discussion more emotionally intense. For instance, some participants became emotional and cried when sharing about their plans for ADRD care.

We noticed a lack of basic information among KAs on the causes, treatments, and screening of ADRD, potentially influencing negative perceptions and causing delays in taking action.[11–13] Findings also revealed that the members of the KA community in New York are open and willing to share their thoughts on ADRD, highlighting the need and importance of ongoing health promotion and educational campaigns. Designing educational campaigns that target older adults specifically to reduce the fear of ADRD and the general public in providing basic information should be considered as a potential future design. We believe that continuing efforts to promote public awareness can publicly socialize and normalize sensitive topics, like ADRD among the KA community.

Moreover, community members demonstrated an openness to using formal services for care. This may be partly due to the immigration context; there may be fewer extended family members to share family caregiving support because family members often work and live away from home. Many KA older adults who participated in the listening sessions lived alone. The acceptance of long-term care options and the recognition of cultural factors, such as diet and engagement with the community (even maintaining transnational social ties with family members and friends in the home country may help)[26], highlighted the importance of culturally sensitive care approaches. These cultural considerations should be integrated into future educational and support initiatives.

We also learned that efforts to provide culturally sensitive information and resources, particularly in the Korean language, are essential to bridge the knowledge gap. Many Korean immigrant elders lack English proficiency.[27] Studies repeatedly reported the relationship between low language proficiency and increased health risks,[28] as well as limited health literacy among KA older adults due to limited English competency.[27,29] It appeared that KA older adults were not getting ADRD information locally as most information is in English, but rather through South Korean media or Korean YouTube channels that might include non-generalizable or even misleading information. The fact that participants were more familiar with policies in Korea indicates that they rely on information from Korean sources, in the language they prefer. Therefore, to prevent older adults from receiving inaccurate health information, it is recommended to develop strategies that bridge the language gap. Moreover, such information can be shared with the community members by KA physicians and experts, which might be an effective way to distribute and translate relevant ADRD information to KA elders. Research shows that Asian Americans prefer to be treated by medical providers of their own ethnicity, with preference rates increasing if they experience communication issues.[30] Furthermore, KA elders with limited English communication skills favor and trust receiving health information from doctors or healthcare professionals.[31] In fact, during the listening sessions, participants suggested that CBOs like KCS hold educational sessions in Korean facilitated by Korean physicians with expertise in ADRD.

KCS can be an excellent channel for addressing these needs, as they understand both cultures and can adapt and translate information for KA older adults experiencing limited English proficiency. Additionally, with their long history of working with the community and established partnership with academic institutions and resources, KCS is well-equipped to leverage the meaningful assets in the community and bridge the needs of KA older adults. We also believe that the listening sessions were successful because the discussions were done in Korean and facilitated a more comfortable environment, encouraging individuals to open up and share. Thus, to meaningfully and successfully engage the KA community, culturally appropriate and in-language ADRD information and community resources are key recommendations.

KCS has already incorporated some of the findings from the listening sessions into practice. KCS hosted educational events by KA experts on brain health, providing medical and policy information about ADRD and caregiving. Moreover, listening sessions prompted a joint departmental collaboration between the KCS Public Health Research Center and Mental Health Clinic and initiated a support group for ADRD caregivers and families. KCS is also involved in research studies on ADRD caregiver support and education at various academic institutes. We believe that continuous efforts that KCS take in community engagement, culturally appropriate in-language services, and research partnerships will contribute to make sensitive topics like ADRD more accepted and understood within the community.

Limitations

While this study provides valuable insights on ADRD of Korean American immigrant elders, several limitations exist. First, although the KCS staff made considerable effort to create an optimal environment for the listening sessions, there is a possibility that some participants did not entirely feel comfortable to openly discuss ADRD in a group setting, as ADRD is a sensitive topic. Similarly, group dynamics may have influenced individuals in the discussion. Moreover, we were not able to recruit more participants in the younger age group, as ADRD is generally more prevalent among older adults. Future studies should explore the perspectives of younger generations on ADRD to gain a more comprehensive understanding of the issue. Given that younger generations are more likely to be born in the U.S., it would be particularly interesting to examine their views with those of older adults or immigrant generations. Moreover, knowing that more female members participated in the listening sessions and traditionally women are expected to be the caregiver, we would like to know more about the role and gender expectation on women in caregiving in future studies. The listening sessions were a good place to begin to gain valuable insights, but further studies are needed to provide more in-depth understanding.

Conclusions

The community-led listening sessions have not only provided a better understanding of the current perspectives, information, and knowledge of ADRD in the KA community, but have also suggested actionable implications that can inform future initiatives. Efforts for educational health promotion and practices that are culturally-tailored and target different age groups are needed to socialize and normalize views on ADRD in the community. Our findings are not limited to the KA community but may inform activities and efforts in other underserved and largely limited English proficient communities. The past and current studies have provided valuable insights into the health disparities faced by the Korean American immigrant community for both KCS and NYU, allowing us to approach these issues with evidence-based solutions and prolong the partnership.

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Table 1. Example quotes from the Korean American community during the listening sessions.

Community-level negative perceptions of ADRD

1. (…) But now, when you go out alone and your behavior becomes erratic and your body deteriorates, it's obvious that people will ignore you and treat you like a fool. (Female Older Adult, Session 1)
2. I don't want others to find out if I am diagnosed with ADRD. Others will look at me as if there is something wrong with me and I will be wrongly perceived by others. (Female Caregiver, Session 3)
3. I'm afraid to go anywhere (...) I'm afraid to speak up because I've been ignored a lot. (…) When I ask for help among Koreans, people look at me and call me *byungshin* (병신; retarded). (Male Older Adult, Session 1)
4. Since I'm turning close to 70 years old, what scares me the most about dementia is not the physical pain or getting sick, but the fear that it can happen to anyone. (Female Older Adult, Session 1)
5. It's really scarier than cancer. (…) We can somewhat manage cancer, but Alzheimer's is a very scary disease (Female Older Adult, Session 2)
6. Older Adults expect that they may have ADRD in the future, so they prepare. Yet, younger people may not think it as an imminent issue. I believe there are some generational differences. (Female Older Adult, Session 2)

Lack of information on causes and symptoms

7. (…) it is said that people develop dementia in their brains due to the way we live, (…) and stress. However, there are still things that don't work because nowadays there are various issues related to environmental hormones in our food, so it's difficult to summarize it into one thing cause. (Female Older Adult, Session 1)
8. As far as I know, there is one type called alcohol-related dementia. For those who drink a lot, dementia comes quickly, as the brain shrinks. (…) many people who don't use their brains much experience dementia more quickly. (…) elderly people spend a lot of time alone. (…) when they just watch TV, I think dementia increases even faster. (Male Older Adult, Session 1)
9. (…) there are definitely good dementia and bad dementia. It's said to come from personality. (Female Older Adult, Session 2)
10. I know that MRI is more commonly used, especially in the field of neurology. However, it seems that these are mostly used to check for any damage in the brain. (Male Caregiver, Session 3)

Perceptions on ADRD care and treatment

11. There might be economic reasons (that family needs to be the caretaker), but for Asians or Koreans, there is also a sense of responsibility that children should provide care, or family should do it. I've seen cases where despite the economic difficulties, family members quit their job to take care of their parents and then they keep falling into the cycle of economic difficulties. (Female Older Adult, Session 1)

12. We are the last generation that practices *hyo* (효; filial piety), but we are a generation that doesn't receive it at all. (…) my friend had to quit her job to take care of her mother-in-law (in return of her mother-in-law's contribution/favor to her earlier days). So, as a family responsibility, she (my friend) cooks eight or nine meals a day at home. (Female Older Adult, Session 1)
13. I think the concept of patient care used to be different, but I don't see much difference nowadays in how Americans or KAs handle these things. But one case I know is a 94-year-old person who has developed dementia. The family sent them to Korea to a senior facility called "Silver Town". The person interacted with Koreans, ate Korean food, and engaged in activities there, and the symptoms have actually improved. So, I think there are cultural factors at play as well. (Female Older Adult, Session 2)

14. If I gradually start forgetting things and such, I think I should go to a nursing home. I have already talked to my children about it. (…) because for a day or two, the children might be fine and able to take care of me, but they also have their own lives and responsibilities. (Female Caregiver, Session 3)

15. When families reach a point where they can no longer take care of their loved ones, they resort to long-term care. (…) I know some people who went there for a while and then passed away quickly. The food is not culturally appropriate for them and there may be a higher chance of reducing the symptoms when family members take care of them. But it is extremely difficult for family members to live. (Female Older Adult, Session 2)

16. We are in the United States, the social system is such that parents should be independent from their children, and children should live their own lives when they reach the age of 20, and parents should live their own lives. I believe we need to follow the U.S. system as we live here. (Female Caregiver, Session 3)

17. In the past, I worked multiple shifts of 8 hours caring for someone with dementia. Often, when I arrived, the patient would claim that her ring or money was missing and that the previous caregiver had taken her belongings. She would say the same thing to the next caregiver when I left. This happened regularly, and while it was frustrating at first, most of us have now come to accept it as part of the job and learned how to handle such situations. For example, I often search with the patient and help find the lost items as money might be hidden under a pillow and then forgotten. However, new

caregivers often become so upset by this that they end up quitting. (Female Caregiver, Session 3)
Resource needs and recommendations
Educational programs and support services by KCS/community-based organizations: 18. As KCS is an organization created within the Korean community, it would be great if they could organize more educational sessions by dementia medical specialists, (…) they could also arrange listening sessions and gatherings like this where families can share their experiences, as we don't have dementia specialists here. (Male Older Adult, Session 1) 19. I heard that it is extremely challenging for families (so there should be support) on a social and national level. So, it would be helpful to see how much assistance is available and to actively seek out support programs (for families) from organizations like KCS. Additionally, with the advancement of computers these days, I think there might be online support groups for ADRD patients. I would actively participate in such platforms. Rather than just accepting the situation as it is, I would search and seek out options. Although it may not be possible to completely revert to the original state, by making such efforts, we can delay or alleviate the condition to some extent. (Female Older Adult, Session 1) 20. Through events and activities like this, we can not only raise awareness about dementia but also create a sense of urgency and explore ways to prevent it. (…) It is necessary to provide (medical and scientific) information. (Male Older Adult, Session 2) 21. You mentioned that depression screening is done once a year. It would be better if it was done more frequently, like every six months, like dental scaling. This is because as someone who continuously takes care of patients, I also feel very sad. (Female Caregiver, Session 3) ADRD screening needs: 22. In Korea, once individuals reach the age of 66, they are obligated to undergo mandatory (ADRD) testing every two years. It is said that these tests can also be conducted at public health centers. Korea has a large number of public health centers, but in the United States, they are not well-known. There's a lack of interest and awareness. As I continued to show interest as a caretaker, I realized that in Korea's situation is much better. (Female Caregiver, Session 3) 23. I believe that lowering the age for ADRD screening (to like 40 or 45 years old) will increase some awareness when getting older. (Female Older Adult, Session 1)

Appendix A. Question Guide for Community Listening Session

1. Perceptions, knowledge and experiences with ADRD
    - Have you ever heard of Alzheimer's and Dementia? What do you know about the diseases?
    - Do you know anyone who has had ADRD?
    - What were their experiences like?
    - Why do you think they got the disease?
    - Were there differences in your attitudes towards ADRD patients after interacting with them?
    - How would you feel if you get ADRD?
    - How do you feel the Korean culture treats people with ADRD?
2. Care in older age
    - Have you or your family ever talked about how you'd like to be cared for when you're older?
    - How you'd like to be cared for if you couldn't take care of yourself?
    - Have you talked about assisted living? Have home care?
    - Have you thought about living wills and advanced directives?
    - Have you talked about these with your family?
    - What are the challenges that ADRD patient families face?
3. Screening
    - Do you know how ADRD is screened for?
    - How much do you know about screening?
    - Do you think cognitive screening should be a requirement? (e.g., in Korea, older adults aged over 66 get ADRD screening every 2 years for free)
    - How would you feel about being screened for ADRD?
    - Is there anyone who had your family screened?
    - What do you think about the impacts of being screened? If your screen results recommend you to go to see a neurologist for a diagnosis, what would happen? Do you have any concerns?
    - If your screening results don't show anything, how would you feel?
4. Needs and Recommendations
    - Do you have any needs and recommendations for us or related to ADRD?

Korean Version:

1. 인지장애에 대한 한인들의 인식에 대한 질문
    - 인지장애에 대해 들어본 적이 있나요? 이 질병에 대해 무엇을 알고 있나요?
    - 인지장애에 걸린 사람을 아시나요?
    - 그들과의 경험은 어땠나요? 그들과 교류했을 때의 느낌은 어땠나요?
    - 왜 그들이 병에 걸렸다고 생각되시나요?
    - 인지장애가 있는 사람들과 교류한 후 인지장애에 대해 이해하는데 차이가 있었나요?
    - 인지장애 진단을 받으면 어떨 것 같나요?

- 인지장애 진단을 받은 사람들에 대한 한국 문화에 대해서 어떻게 생각하시나요?

2. 노년층의 돌봄
    - 나이가 들었을 때 어떻게 보살핌을 받고 싶은지에 대해 이야기 해보신 적이 있나요?
    - 만약 스스로를 돌볼 수 없는 상태가 되면 어떻게 돌봄을 받고 싶으신가요?
    - Assisted living, 홈케어에 대해 생각해본 적이나 이야기해 본적이 있나요?
    - 생전 유언장이나 구체적인 돌봄에 대한 지시를 생각해 본적이 있나요?
    - 이에 대해 가족과 이야기 한적이 있나요?
    - 치매환자 가족에게 가장 어려운 일은 무엇인가요?
3. 치매/알츠하이머병 검사
    - 치매 또는 알츠하이머병을 어떻게 검사하는지를 아시나요?
    - 치매 또는 알츠하이머병 검사에 대해 아시는 것이 있나요?
    - 인지장애 검사가 의무화되어야 한다고 생각하시나요? (예, 한국에서는 현재 66 세 이상의 노인은 2 년마다 치매 검사를 무료로 받고 있습니다)
    - 치매 검사를 받는 것에 대해 어떻게 느끼시나요?
    - 가족 중에 검진을 받아보신 분이 계시나요?
    - 검사를 받으면 본인에게 어떤 영향이 있을 것 같나요? 만약 치매 검사에서 경증 또는 치매 판정이 나온다면 어떨까요? 이에 대한 걱정이 있나요?
    - 만약 치매 검사에서 정상이 나온다면 어떨 것 같으세요?
4. 요청 및 추천
    - 인지장애와 관련하여 요청하거나 권고하실 것이 있나요?

Appendix B. Quotations in Korean

Community-level negative perceptions of ADRD
24. (…) 근데 이제 혼자서 가가지고 몸이 분이 횡서수설하고 몸이 상하다 그러면 사람들이 무시하는 것도 당연하고 바보 취급하는 것도 많이 있고 그래요. (Female Older Adult, Session 1)
25. 진단받으면은 네 가족은 뭐 알려야죠 근데 남한테는 알리고 싶지 않잖아요. 본인은 잘 모르는데 옆에서 볼 때는 저게 잘못된 일이고 잘못된 의견인데 그걸 자꾸 이제 주장을 하니까 [잘못 보여질거 같아요] (Female Caregiver, Session 3)
26. 저도 한국 사람이기 때문에 한국 사람들은 굉장히 좋아하는데 무시당하기 [시작할 때]부터는 제 마음이 굉장히 작아진다고 그럴까 어디 가서 의견 발표할 수도 없어요. 모든 사람들이 외국 사람들은 안 그래요 (…) 유독 우리 한국 사람은 저 보고 병신이라 그래요 (병신; retarded). (Male Older Adult, Session 1)
27. 그리고 처음 치매에 대해서 진짜 이제 나이가 70 에 가까우니까 제일 두려운 게 몸이 아픈 것도 두렵고 막 병이 날까 봐 두렵지만 이 알츠하이머라는 게 어느 누구한테 올지 이거는 아무도 알 수 없는 거잖아요. (Female Older Adult, Session 1)
28. 네 그게 굉장히 정말 정말 암보다도 [위협적인 병이에요]. 암은 어느 정도 수습할 수 있고. 어느 정도 되면 굉장히 이게 무서운 병이에요. (Female Older Adult, Session 2)
29. 나이 먹은, 나이가 좀 먹은 분들은 나도 앞으로 이런 일이 올 것이다 이런 걸 대비를 하는데 젊은 사람들은 아직 이런 일은 멀었다고 생각하는거 같아. 세대차이가 좀 있는 것 같아. (Female Older Adult, Session 2)
Lack of information on causes and symptoms
30. 사람이 뇌에 치매가 걸린다는 것은 우리가 어떻게 살아가는데 적당한 역량을 하고 상처 봉급을 했느냐에 달렸단 말이에요. 아까 누가 말씀하신 스트레스, 스트레스를 하게 되면 그게 또 (…) 그렇게 되는 거죠. 그래서 그거는 이제 항상 젊었을 때부터 노력을 해야지. 그래도 안 되는 게 있죠 왜냐하면 이제 우리가

음식에서 캐릭터 같은 환경 호르몬 문제 여러 가지가 많기 때문에 한 가지로 정리할 수는 없는 것 같아요. (Female Older Adult, Session 1)

31. 제가 알기로 한 가지 종류는 알코올성 치매가 있고요 알코올성은 술을 많이 드시는 분들은 치매가 빨리 온다고 아마 뇌가 쪼그라든다고 제가 알고 있는데 퇴행성 물론 그런 게 있죠. 근데 퇴행성 중에서도 제가 볼 때는 제가 그냥 생각할 때는 많은 분들이 이렇게 뇌를 이렇게 안 쓰면서 더 이렇게 치매가 빨리 온다. (…) 그런 것 중에 하나가 이렇게 티비만 보는 거 티비만 그냥 이렇게 보는 거는 뇌를 전혀 움직이지 않아도 되는 그런 거기 때문에 그리고 집에 가시면 사실은 노인분들이 혼자 있는 시간이 많으세요. 이렇게 말벗이 있어서 이렇게 자게 대화를 하거나 이러면 뭔가 이렇게 더 뇌가 활력적으로 움직이는데 그냥 혼자 앉아서 때로 주무시고 티비나 봅시다 하니까 이게 치매가 제가 볼 때는 더 이렇게 빨리 증가한다라고 생각을 합니다. (Male Older Adult, Session 1)

32. (…) 좋은 치매가 있고 나쁜 치매가 있다고, 그게 성품에서 온다고 그러더라고요 어떤 예를 이제 보니까 그분이 굉장히 좋은 상품을 가진 사람 좋게 또 조용하게 오신대요. 그렇지 않은 분은 굉장히 난폭하게 들어 오시는 분이 있어요. (Female Older Adult, Session 2)

33. MRI 는 많이 사용하고 neurology 쪽에서 사용을 하고 있는 걸로 알고는 있는데, 글쎄요 글쎄 브레인에 무슨 대미지가 있나 그런 거 보는 정도겠지. (Male Caregiver, Session 3)

Perceptions on ADRD care and treatment

34. 경제적인 이유 때문에도 힘들기도 하지만 또 우리 아시안들이나 한인들 같은 경우에는 부모님이 내 자식이 해야 된다 가족이 해야 한다는 어떤 책임감 같은 것도 있다. 보니까 경제적인 어려움이 있음에도 불구하고 한 명이 직장을 그만두는 경우도 있더라고요 그러면서 이제 어머니나 아버지 돌보려고 또 경제적인 어려우니까 자꾸 그 굴레에 자꾸 빠지는 경우도 좀 있었던 것 같아요. (Female Older Adult, Session 1)

35. 저희가 이제 효도를 하는 마지막 세대고 효도는 전혀 받지 못하는 세대인데요(…) 제 친구 시어머니는 굉장히 성격이 온순하시던 분이 굉장히 나빠지고 남을 의심하고 특히 이제 그 며느리를 제 친구가 직장을 그만뒀어요. 왜냐하면 시어머니를 테이크 케어 하기를 위해서 그리고 시어머니도 젊었을 때는 고생을 많이 했을 거 아니에요. 그래서 가족의 책임으로 해가지고 집에서 사는데 밥을 하루에 여덟 번 아홉 번 차려요. (Female Older Adult, Session 1)
36. [환자를 돌보는게] 지금은 그렇지는 않은 것 같아요. 한국사람이다 미국사람이 이런 거에 대해서 큰 차이는 없는 것 같아요. 그런데 제가 아는 한 케이스는 94 이신 분인데 이제 치매기가 왔어요. 가족들이 한국으로 보냈어요. 한국의 실버타운 그런 대로 그래서 거기를 가시더니 이 한국 사람들 하고 이야기하고 음식 먹고 이렇게 저기를 하니까 오히려 나아졌어요. 그런 케이스도 봤을 때 이런 문화적인 그런 것도 있는 것 같아요. (Female Older Adult, Session 2)
37. 이게 서서히 이제 뭐 잊어버리고 이런다면 나는 요양원으로 가야 되겠다라는 생각을 저는 이제 그게 만약에 자녀들한테 얘기를 했어요. 만약에 내가 이런 경우가 있을 때는 절대 집에서 돌보지 말라고(…) 이게 하루 이틀 사이는 자식도 괜찮아요. 돌볼 수 있지만 얘들도 자기 할 일이 다 있잖아요. (Female Caregiver, Session 3)
38. 그런데 이런 것이 진짜 가족들도 그냥 이렇게 하다가 돌보다가 어느 정도까지 가면 가족들이 더 이상 할 수도 없으니까 이제 이런 롱텀 케어를 이렇게 하게 되는데. (…) 그러면 제가 아는 경우에는 몇 분 이렇게 보면은 그냥 금방 돌아가시더라고요. 그런 데 다 가시면 왜냐하면 식사하시는 것도 마땅치 않고 그래서 그래도 이제 가족들이 있어서 잘 할 수 있을 정도 되는데 그것이 또 굉장히 높잖아요. 지금 이게 심하면 가족들이 생활을 못해요. (Female Older Adult, Session 2)
39. 미국은 사회 제도가 시스템적으로 부모는 자식한테 독립해야 되고 자식은 부모한테 스무 살만 되면은 각자 자식은 자식대로 살아야 되고 부모는 부모대로 이게 벌써 분리가 다 돼 있어요. 네 제도가 그렇기 때문에 우리는 미국에 사니까

미국에서 제도를 저는 따라야 된다고 생각을 하거든요. (Female Caregiver, Session 3)

40. 예전에 그 내가 이제 8 시간 일을 하고 다른 사람도 8 시간 일을 하고 또 가서 8 시간 일을 해요. 그분이 지금 치매이신데 그러면 제가 이제 일을 하러 가면 그 앞전에 있는 분이 반지도 가져갔다 다 내 돈도 가져갔다 뭐도 가져갔다 계속 그러는 거예요. 그러면 내가 일을 끝마치고 가면 내 다음 간병인한테 또 가져갔다 이렇게 되는 거예요. 우리 간병인들은 그게 이제 당연한 거다라고 생각을 하는 거죠. 그런데 이제 이제 처음으로 와서 일을 하는 사람은 그게 기분이 너무 나빠서 그만두는 거야 일을. 그런데 이게 좀 더 이렇게 인식이 되고 그 사람은 좀 긍휼한 마음을 갖고 이러면 이제 그 환자분이랑 같이 얘기도 하면서 한번 같이 한번 찾아보자 그 장롱도 같이 열어보고 그러면서 이제 사실은 또 때로는 그분이 넣어놓고 잊어버리는 경우가 있어요. 그러니까 봉투에 돈이 그대로 있어요. 그런 경우 그니까 예를 들어서 말하자면 이렇게 이제 너무 가져갔다. 그러니까 돈 있는 돈을 다 베개 밑에 다 넣어놨어요. 넣어놨는데 또 없어졌다. 그러면 또 계속 이렇게 이제 저 같은 경우에는 이제 그런 식으로 해서 같이 찾아갔고 그분이 말하는 거를 찾아주는 경우가 있는데 근데 이제 간병을 처음들어온 사람들은 그 얘기도 기분이 너무 나쁘잖아요. 그러니까 당장 그만두는 거예요. (Female Caregiver, Session 3)

Resource needs and recommendations

Educational programs and support services by KCS/community-based organizations:

41. 그러니까 KCS 는 한인 커뮤니티로서 한인 커뮤니티에서 생성된 이 봉사단체이기 때문에 우리 교포들한테 좋은 이 치매 강연 전문 의사에 의한 전문 강연을 많이 열어주시며는 그것이 굉장히 좋을 것 같아요. 네 그리고 이런 간담회도 열고 실제 그 가족 경영 경험을 서로 쉐어할 수 있고 우리가 전문 의사가 여기 지금 없잖아요. (Male Older Adult, Session 1)

42. [환자를 돌보는게] 사회적 국가적 차원 그러니까 가족들이 하기는 너무 힘든 작업이라는 거를 많이 들었거든요. 그런 도움이 얼마나 있는지 찾아보고 또 이런 KCS 와 같은 어떤 기관에서 이런 서포트 해 주는 프로그램이랑 있는지 찾아보고 그들과 적극적으로 이렇게 만나고 만나서 도움이 있는지 물어보고 아니면 또 이제 요즘은 컴퓨터가 발달됐으니까 이제 블로그 같은 데 치매에 걸리는 사람들 그런 모임이 있을 것 같아요. 그런 데에서 적극적으로 참여를 할 것 같아요. 그래서 그냥 있는 것보다 좀 적극적으로 서치하고 찾아서 100 프로 이렇게 원래대로 돌릴 수는 없지만 그래도 그렇게 노력을 하면 어느 정도 지연시키거나 완화시킬 수 있는 됐다고 이제 배웠으니까 좀 더 적극적으로 하고. (Female Older Adult, Session 1)

43. 이런 활동을 통해 우리는 치매에 대한 인식을 높일 수 있을 뿐만 아니라, 치매 예방을 위한 방법을 모색하고 인식을 개선할 수 있습니다. (…) 의료 및 과학적 정보가 필요합니다. (Male Older Adult, Session 2)

44. 기간이 1 년에 한 번씩 우울증 검사를 한다고 하시잖아요.이렇게 좀 더 6 개월 정도가 아니라도 이제 스케일링 할 때 6 개월에 한 번 하잖아요. 이제 그랬으면 좋을 것 같아요. 왜냐하면 저도 이제 환자를 계속 돌보다가 저도 너무 슬픈 거예요. (Female Caregiver, Session 3)

ADRD screening needs:

45. 한국 같은 경우는 만 66 세가 되신 노인들은 2 년에 한번 의무적으로 진행을 하고 있어. 한국은 보건소에서도 검사할 수 있다고 하더라고요. 보건소가 굉장히 많이 되었는데 미국은 이 자체를 모르고 있는 거예요. 관심이 없어 모르는 거고

저도 관심을 계속 갖다가 보니까 이제 내 환자 내가 돌보는 사람 그러다 보니까 한국에 법인이 들어 계속 보다 보니까 한국은 너무 잘 되어 있는 거예요. (Female Caregiver, Session 3)

46. 연령층이 정말 한 적어도 40 대 45 세 부터 해가지고 검사를 [시작해서] 인지를 시키면은 좀 더 많이 정말 그 나이가 됐을 때 [나이가 들었을 때] 내 스스로가 some awareness 가 조금 일어나지 않을까 하는 생각을 해봅니다. (Female Older Adult, Session 1)