National Asian Pacific Center on Aging

Cultural Translation of TCARE® for Korean and Vietnamese Caregivers

Final Report
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1511 Third Avenue, Suite 914
Seattle, Washington 98101

p. 206-624-1221
f. 206-624-1023

http://napca.org/resource/

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About the National Asian Pacific Center on Aging (NAPCA)

Our mission is to preserve and promote the dignity, well-being, and quality of life of Asian Americans and Pacific Islanders (AAPI) as they age. NAPCA's National Resource Center on Asian American and Pacific Islander Aging is the nation's first and only technical assistance resource center dedicated to building the capacity of long-term service and support (LTSS) systems to equitably serve AAPI older adults and their caregivers across the nation.

Sponsors

This project was supported in part by funding from the City of Seattle, Human Services Department through grant number DA17-1324 and grant number 90HD0013-02-00 from the U.S. Administration for Community Living (ACL), Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL or City of Seattle, Human Services Department policy.

Authors

Heather Chun, MSW

Jessica Jacobs-Vechinski, MSW

Introduction

Introduction

Through support from the City of Seattle Human Services Department and Administration on Community Living, and in partnership with Tailored Care Enterprises, Inc. (Tailored Care) and the Korean Women's Association (KWA), NAPCA's National Resource Center on AAPI Aging implemented a special project, *"Increasing the Capacity of Family Caregiver Interventions,"* to increase Korean and Vietnamese caregivers' access to evidence-based LTSS in Seattle, Washington.

AAPI's are the fastest growing minority group in America, according to the U.S. Census. Between 2010 and 2030, the AAPI older adult population is projected to increase by 145%. AAPI are Washington State's largest minority group, making up 8.7% of the state's total population (Washington Office of Financial Management, 2017). A rapidly increasing aging population demands resilient, capable, and enduring systems of care.

Familial systems of care are more prevalent in AAPI communities than other racial groups, with 42% of AAPIs providing care to an older adult, compared to 22% of the general population (AARP, 2014). As two of the largest AAPI populations, Korean and Vietnamese caregivers face grave disparities in accessing help due to cultural barriers and high rates of limited English proficiency. Caregiving is inherently part of Korean and Vietnamese (and many other AAPI) cultures due to the cultural value of filial piety, which is based on strict principles of hierarchy, obligation and obedience, with the responsibility to respect and care for one's parents and elder family members on the basis of individual moral conduct and social harmony. For all that parents have given their children, there is an eternal obligation to reciprocate that care. Consequently, the virtue of filial piety may contribute to generational burdens where Korean and Vietnamese caregivers feel conflicted about how to balance their personal and parental responsibilities.

Overview of Tailored Caregiver Assessment and Referral (TCARE®)

The Tailored Caregiver Assessment and Referral® (TCARE®) program is an ACL approved, evidence-based, care management software platform designed to enable care managers to more effectively support family caregivers by efficiently targeting services to their needs and strengths. The program is grounded in and reflects the insights of the Caregiver Identity Discrepancy Theory, as articulated by Dr. Rhonda JV Montgomery and Dr. Karl Kosloski. Both the theory and the TCARE program address the great diversity among caregivers in terms of the type and quantity of tasks they undertake, the duration of time over which they serve in this role, the costs they incur, and the benefits that caregivers perceive as a consequence of their caregiving role. By identifying sources of distress and explaining the pathways of caregiving journeys, the Caregiver Identity Theory points to support strategies that have been integrated into the TCARE protocol to alleviate caregiver stress and depression and reduce placement in a nursing home or assisted living facility.

TCARE® guides care managers through an assessment and care planning process that helps them examine the care context and identify the sources and types of stress that a caregiver is experiencing. Because the protocol is designed to assist with targeting appropriate services, the services recommended for use by caregivers is appropriately tailored to their needs and strengths and that caregivers served will be more apt to use these services. TCARE has demonstrated positive outcomes for caregivers, and more effective use of resources. TCARE has been proven through two national randomized controlled studies conducted in collaboration with 20 organizations in four states to reduce caregiver depression, stress & relationship burdens, increase uplifts, delay placement in a nursing home/assisted living facility and improve the overall health of the caregiver and care recipient. In addition, the State of Washington's Family Caregiver Support Program, who began using the program in 2009, conducted their own independent statewide study from 2014-2016. Findings revealed that TCARE reduced Medicaid Service enrollment by 20%, delayed placement into a nursing home by 18-24 months and improved caregiver stress and depression by 84%. The TCARE program has impacted over 40,000 caregivers to date and is used by over 250 organizations nationwide.

Methods

The successful translation of evidence-based programs, such as TCARE, for Korean and Vietnamese caregivers hinders on their engagement in the translation process. Using a community-based participatory approach, this project used culturally appropriate qualitative methods to examine the readiness of TCARE for Korean and Vietnamese caregivers. Qualitative data was collected through focus groups with Korean and Vietnamese caregivers, and through focus groups with Korean- and Vietnamese-serving Seattle-based service providers. The methods for each focus group are described below.

Caregiver Focus Groups

During January 2018, NAPCA partnered with KWA to facilitate two focus groups, one with Korean and one with Vietnamese caregivers, leveraging the trusted relationships they have developed with Korean and Vietnamese communities in Seattle. NAPCA and Tailored Care Inc. provided training to KWA leadership and Korean and Vietnamese speaking facilitators on the project methodology, including the facilitator script, and in-language participant surveys, which included TCARE® assessment measures that measure identity discrepancy. KWA facilitated focus groups with Korean and Vietnamese caregivers, testing caregiving terminology and foundational TCARE® theories, such as identity discrepancy, and the different forms of caregiver stress (relationship, objective & relationship burdens) with participants. Ten Korean (1 50-60yrs, 9 60+yrs; 1 man, 9 women) and ten Vietnamese (1 40-50yrs, 2 50-60yrs, and 7 60+yrs; 3 men, 7 women) caregivers participated in the focus groups. Focus groups were 90 minutes each and were recorded and transcribed into English for analysis.

Community Focus Groups

In December 2017, NAPCA facilitated a community focus group with AAPI-serving service providers to integrate their feedback on the need for cultural adaptations to TCARE and barriers facing Korean and Vietnamese caregivers in Seattle. Twelve service providers, representing eight AAPI-serving Seattle community-based organizations, participated in the focus groups. Of those who participated, 58% were service providers from an organization that currently administers TCARE to AAPI caregivers. Participant surveys, which mirrored the focus group discussion questions, were also administered.

Project Findings

The following section details the project's findings. Most significantly, within all focus groups, NAPCA heard from caregivers and service providers that caregiver and burden concepts do not resonate within Korean and Vietnamese communities, which makes answering some of the TCARE questions difficult. For example, a Korean focus group participant shared, "I do not want to label myself as a "giver" and my husband as a "receiver." For this reason, when asked to identify more appropriate terminology, no suggestions were given as the concepts are foreign. Summarized by one service provider, "East Asians define the self relationally and not autonomously. This renders the identity questions in TCARE nonsensical and even offensive to some AAPI caregivers. 'Caregiving' is subsumed within relational duties," and defining caregiving using western labels "causes shame [and] identity burden" for Korean and Vietnamese caregivers.

Vietnamese Focus Group

Despite project challenges, described in the next section, limited findings from the Vietnamese focus group will have a significant impact on future implementation and expansion of TCARE in Seattle. First, as discussed, the concepts of "caregiving" and "burden" are foreign to Vietnamese caregivers, as their identity is subsumed within a family context. For example, one focus group participant shared, "caregiving is just a duty and responsibility of the wife toward to her husband." Another Vietnamese caregiver shared, "My happiness now depends on how good [my mom's] health is." The well-being of both caregivers and care recipients, therefore, is interconnected.

However, although Vietnamese focus group participants indicated some of the questions were culturally inappropriate, especially those that identify the individual using the Western caregiver terminology, the Caregiver Identity Discrepancy measure, which is the foundation of TCARE, resonated with all the caregivers. It is also interesting to note that the majority of participants scored high in the identity discrepancy threshold, meaning that they were struggling with their identity as a family caregiver versus their familial role as daughter/son, husband/wife, evidencing the need for programs, like TCARE.

Korean Focus Group

Caregiving and burden concepts manifest similarly in Korean communities. In the Korean culture, 'caregiver' has a connotation of 'looking down' and focus group participants were ashamed to call themselves a caregiver. Similar to Vietnamese and other AAPI cultures, Korean communities' cultural value of filial piety contributes to high rates of identity discrepancy among caregivers. For example, one Korean caregiver shared that when she got married, she was told, "Now that you are the daughter-in-law, you should do this [caregiving] because it is your duty as long as you live with my son," while another shared, "I am the eldest daughter-in-law, so I thought I should do it all." Lastly, there was one profound statement made during the focus group that must not go unnoted. One Korean caregiver shared, "Living in a nursing home is extremely stressful. Some would rather

commit a suicide." Given that, among females from all racial backgrounds between the ages of 65 and 84, Asian Americans have the highest suicide rate, this comment is especially profound, and reinforces the extreme consequences for Korean, and other AAPI families, without culturally appropriate caregiving support, further reinforcing the need for ensuring Korean caregivers have access to programs such as TCARE (American Psychological Association, 2012).

Community Focus Group

There were two significant findings that came from the community focus group. First, Korean and Vietnamese serving providers do not demonstrate an understanding of the purpose and process steps of the TCARE program, including providers who are trained TCARE care managers. For example, one service provider shared that their staff choose not to ask the assessment questions when working with Vietnamese caregivers, instead preferring a culturally appropriate conversation about caregiving, completing the TCARE assessment tools after meeting with caregiver. Some care managers shared feelings that the TCARE assessment tools take too much time to complete, with one service provider questioning, "why are there so many questions? [Korean and Vietnamese caregivers] just need a little support… [it's a] painful experience." A cultural bias among some service providers restrict the program's fidelity and impact through untested modifications to the processes, and service recommendations that are based on care managers' cultural judgments. One care manager summarized the challenge with implementing TCARE in Seattle's Korean and Vietnamese communities by sharing that she has "trouble translating and communicating the intent of the [TCARE] processes."

Despite concerns about TCARE's readiness for Korean and Vietnamese caregivers in Seattle, however, service providers have found it beneficial and are seeing positive outcomes for caregivers, including reduced stress and burdens. It is important to note, however, that service providers see these positive outcomes only when family members identify themselves as a 'caregiver,' acknowledging that Korean and Vietnamese caregivers need more education to understand caregiving labels.

Project Limitations

Although these project findings are significant, a few limitations should be mentioned for future discovery and adaptations.

1) **Participant Engagement**: At the project's onset, NAPCA scheduled focus groups and had planned to facilitate these internally. Flyers were distributed within Seattle's Korean and Vietnamese communities and through Aging Network providers, however both focus groups needed to be rescheduled due to low participant numbers. As a result, NAPCA sub-contracted with KWA, a Seattle community-based organization, leveraging the trusted relationships they have developed with Korean and Vietnamese communities in Seattle. Despite the initial challenge, KWA was able to recruit ten caregivers, as planned, for each focus group.
2) **Focus Group Structure**: Although focus group facilitators were given a structured agenda with specific questions to ask, neither group followed the script, especially the Vietnamese group. This could have been the result of having a third-party facilitator who was not adequately educated on the goals of the project nor understood the TCARE program, despite receiving training from NAPCA and Tailored Care. In addition, participant surveys were only administered in the Vietnamese focus group, limiting quantitative data that would have further informed the project's findings and recommendations.
3) **Focus Group Purpose:** Korean and Vietnamese focus group participants focused more on if the questions were applicable to them and their life rather than focusing on if the questions were understandable. It is unknown whether participants poor understanding of the focus group purpose was attributed to cultural stigmas or facilitation limitations.
4) **Limited Exposure to TCARE® and Family Caregiver Support Program (FCSP) Programs**: Most participants, especially those in the Korean focus group, had never participated in either TCARE or Washington's FCSP program. Participants may have benefited from more up-front education outlining the purpose and proven outcomes of the programs. For example, in the Korean focus group, a comment was made, "What they [caregivers] are going through in actual caregiving is a lot more than answering some questions through TCARE." This comment clearly demonstrates a lack of understanding for the purpose and effectiveness of TCARE.

Discussion

Using community-based participatory research methods, *"Increasing the Capacity of Family Caregiver Interventions,"* – a special project of NAPCA's National Resource Center on AAPI Aging, in partnership with Tailored Care and the Korean Women's Association – evaluated the readiness of TCARE for Korean and Vietnamese caregivers in Seattle, Washington. Project findings, and the lessons learned throughout, culminate into the following four recommendations. Once implemented, Korean and Vietnamese caregivers will have access to a culturally and linguistically adapted TCARE program throughout Washington.

Recommendation #1: Translate and Culturally Tailor TCARE

Although there are differences between Korean, Vietnamese and Western cultures, participants in this project expressed the same stress points as caregivers from other populations. The tasks, responsibilities, emotions and time spent that come with providing care is a universal hardship. This project revealed, however, that caregiving stigma permeates Korean and Vietnamese communities. As such, in addition to language translation, the explanation of the purpose needs to be adapted within the TCARE process. NAPCA recommends TCARE be culturally adapted to add culturally appropriate and in-language pre-education to the TCARE protocol. Examples of cultural adaptations that AAPI-serving community-based organizations who implement TCARE have made include recruiting with flyers and information in Korean and Vietnamese languages and an explanation of program benefits. Additional education on caregiving and related concepts, like burden, "could [elicit] expanded outcomes, [as Korean and Vietnamese caregivers] learning to identify caregiving labels at the start," as one service provider in the focus group pointed.

Recommendation #2: Pilot TCARE

NAPCA recommends a five-step project to pilot TCARE with Korean and Vietnamese caregivers in Seattle, Washington:

STEP 1: Establish a culturally representative planning group comprised of representatives of organizations that are willing to devote staff time or other resources to an initiative aimed at adapting TCARE for Korean and Vietnamese caregivers and conduct a pilot project to evaluate the fidelity of the program after language translation and cultural adaptations.

STEP 2: Seek funding from public and or private sources to implement a pilot project with Korean and Vietnamese caregivers in Seattle, Washington. See *Figure 2* below for a breakdown of the anticipated project costs.

STEP 3: Augment and revise TCARE tools, including questions and measures included in the TCARE Screening tool and the TCARE Assessment tool. This effort would require:

1. Establishing a work group comprised of care managers and key informants to collaborate with Tailored Care to modify questions based on the feedback received from workgroups conducted.

2. Translate all the TCARE tools (Screen, Assessment, Guide for Selecting Support Services, Consultation Worksheet & Care Plan) into Korean and Vietnamese
3. Create Korean and Vietnamese versions within the TCARE web-based software

STEP 4: Implement an 18-month pilot project to test the feasibility and benefits of using TCARE to support caregivers of persons in the AAPI community. Specific tasks would include:

1. Identification of two or more partner organizations who serve Korean and Vietnamese caregivers in Seattle, Washington and who are willing to test the TCARE protocol.
2. Establishing a research design and protocol that organizations are able to comply with.
3. Training staff to use the TCARE protocol.
4. A 15-month implementation and observation period.

STEP 5: Integrate the final Korean and Vietnamese TCARE versions within Washington's state-wide database (which differs from TCARE's web-based software).

Figure 1: TCARE® Pilot Project Processes

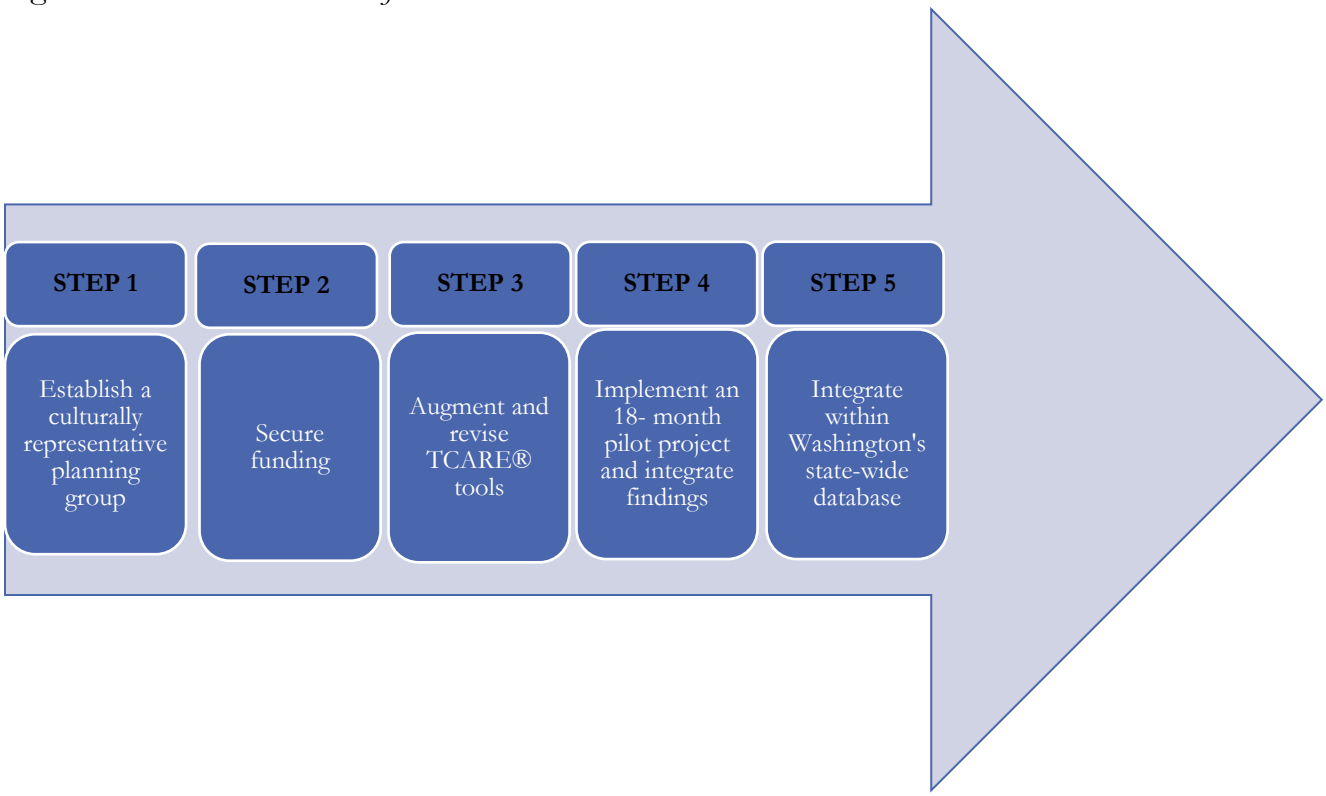

Figure 2: Estimated Pilot Cost Breakout

Translation of TCARE Tools *Includes: Screen, Assessment, Guide for Selecting Support Services, Consultation Worksheet, Care Plan and the TCARE User Manual for Care Managers*	**$20,000** per language
Translation of the TCARE Training PowerPoints *-13 powerpoints*	**$10,000** per language
Adapt eLearning Curriculum for Each Community *Includes: Integrating 13 translated powerpoints, providing voice narrative for each powerpoint & filming a consultation role play video in language*	**$65,000** per language
Customize TCARE's Web-Based Software to Integrate Translations	**$20,000** per language
Resource Database Integration into TCARE Web-Based Software	**$10,000**
Comparison Pilot Study *-Train 20 Care Managers to become TCARE Assessors*	**$50,000** per community
Pilot Setup, Data Analysis & Report Writing	**$11,500** per pilot
Tailored Care to Assist with Integrating Translated Platforms in Washington State's System	**$5,000** per platform

Total Estimated Costs: $373,000
($186,500 per language)

Recommendation #3: Expand Culturally Appropriate Caregiver LTSS

A Washington legislative directive mandates an evidence-based tailored caregiver assessment and referral tool be used within the FCSP; however, other LTSS programs are not subject to this policy. Some Korean and Vietnamese caregivers receiving other LTSS, such as those funded by Medicaid, do not qualify for FCSP services, prohibiting access to TCARE.

Also restricting access, only organizations with a contractual relationship with Aging and Disability Services (ADS), the Area Agency on Aging (AAA) for Seattle and King County, can administer TCARE in Washington. For organizations not administering TCARE®, referrals to organizations with TCARE contracts are necessary to facilitate access for Korean and Vietnamese caregivers. Without a TCARE contract, however, organizations have little incentive to refer their clients to another organization, creating additional barriers for Korean and Vietnamese caregivers to access TCARE®.

ADS will release a RFP to identify TCARE partners in 2019. Based on this project's findings, NAPCA recommends targeted outreach to Korean and Vietnamese serving organizations be conducted to expand culturally appropriate TCARE providers. Technical assistance should be provided to these organizations to reduce cultural biases and stigma, also building buy-in from

organizations with established and trusted relationships with Korean and Vietnamese caregivers. Similar outreach and technical assistance should be provided to Korean and Vietnamese serving organizations during other FCSP funding competitions; this will further expand culturally appropriate caregiver LTSS for diverse populations in Seattle, including Korean and Vietnamese caregivers.

Recommendation #4 Targeted Education for Korean and Vietnamese Serving Service Providers

Finally, similar to caregivers, Korean and Vietnamese serving service providers need more targeted education on TCARE's purpose and benefits to reduce stigma and biases among these professionals. NAPCA recommends, at minimum, quarterly education for TCARE care managers to maintain the fidelity of the program, ultimately strengthening outcomes for Korean and Vietnamese caregivers.

Appendix: Best Practices for Korean and Vietnamese Caregiver Engagement

Organizations using TCARE are seeing positive outcomes, including reducing stress levels, but only when the family members begin to recognize themselves as a 'caregiver.' During the community focus group, a service provider shared, "making caregiving out to be a burden is not culturally acceptable," going on to question, "in what ways are we generating shame by using labels for caregivers and care recipients?" When navigated by a culturally competent service provider, Korean and Vietnamese caregivers will be more likely to self-identify as a 'caregiver' and be more receptive to TCARE and other caregiver programs.

Dedicated to building the capacity of LTSS systems to equitably serve AAPI older adults and their caregivers, and based on this project's findings, the National Resource Center on AAPI Aging offers the following five best practices for service providers who engage Korean and Vietnamese caregivers using TCARE:

Best Practices for Service Providers

1. **Be aware of cultural barriers that prohibit acceptance of Korean and Vietnamese "caregiver" self-identification using western labels.** In Korean and Vietnamese communities, "caregiver" often connotes an individual paid to provide care to another person and using this western label may elicit feelings of cultural shame. A Korean focus group participant shared, "I do not want to label myself as a "giver" and my husband as a "receiver." Service providers must be cautious of labeling Korean and Vietnamese clients as "caregivers," instead listening to, and acknowledging the individual by how they define these roles. One service provider shared, "East Asians define the self relationally and not autonomously. This renders the identity questions in TCARE nonsensical and even offensive to some AAPI caregivers. 'Caregiving' is subsumed within relational duties," and defining caregiving using western labels "causes shame [and] identity burden [for Korean and Vietnamese caregivers']."

2. **Address cultural roles and expectations.** Caregiving is a cultural tradition within Korean and Vietnamese populations; defined cultural roles and expectations further prohibit caregiver self-identification. For example, a Korean focus group participant shared a comment from her father-in-law after getting married; "Now that you are the daughter-in-law, you should do this because [caregiving] is your duty as long as you live with my son." During the same focus group, another participant shared, "I am the eldest daughter-in-law, so I thought I should do it all." Generational shifts in expectations, abilities, and constraints, which were shared as barriers during the community focus group, add to the complexity of culturally defined caregiving roles within Korean and Vietnamese communities. Expectations that arise from filial piety may contribute to adverse outcomes for Korean and Vietnamese caregivers. Cultural resistance to long-term care facilities, for example, may heighten feelings

of burden among caregivers. One Korean focus group participant shared "Living in a nursing home is extremely stressful… some would rather commit a suicide." Given that, among females from all racial backgrounds between the ages of 65 and 84, Asian Americans have the highest suicide rate, this comment from a female Korean caregiver is especially profound, further evidencing the critical role of culturally appropriate service providers in addressing cultural roles and expectations (American Psychological Association, 2012).

3. **Mobilize the family's cultural strengths within TCARE support planning.** As Korean and Vietnamese caregivers' identity is defined through a relational lens, cultural values - such as strong family obligation and loyalty, filial piety, and work ethic - can be leveraged while caring for older family members. It is important for service providers to understand that caregiving does not elicit feelings of burden for all Korean and Vietnamese caregivers. For example, one Vietnamese focus group participant shared, "I feel like I am comfortable when taking care of my family members, I don't feel sad at all. Instead, I am happy to care for (them)."

4. **Match service providers that share cultural values and language abilities with Korean and Vietnamese caregivers.** Korean and Vietnamese caregiver self-identification requires culturally appropriate in-language education and time. A Korean focus group participant shared, "At first, it was not easy to accept many things, such as my new [caregiver] identity. However, now I tend to accept [it] more naturally as things are repeated over and over." When this education, and the TCARE protocol, are delivered by a service provider who shares cultural values and language abilities, Korean and Vietnamese caregivers are more likely to self-identify as a caregiver and be willing to accept LTSS, such as TCARE.

5. **Commit to cultural humility, or the lifelong journey of cultural competence and minimizing power imbalances between the client and provider.** As evidenced through this project, Korean and Vietnamese serving service providers need more targeted education on TCARE's purpose and benefits to reduce stigma and biases among these professionals.

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