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Examining Utilization of Formal Supports and Related Impacts on Overall Well-Being Among East Asian American Family Caregivers of Persons With Dementia: A Mixed-Methods Study

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Abstract

Background and Objectives: Although East Asian American family caregivers are known to underutilize formal support services, there is a lack of evidence regarding the associations of formal service utilization with caregivers' well-being. This study examined the prevalence of different types of home- and community-based formal service utilization among Korean and Chinese American family caregivers of persons with dementia and how utilization of such services was associated with their well-being. We also explored their overall experience in accessing and utilizing formal dementia support services and programs.

Research Design and Methods: We employed a convergent mixed-methods study design. In a convenience sampling method, we recruited 62 family caregivers. Logistic regression and thematic analysis were utilized to analyze data.

Results: The results showed in-home services were mostly utilized among family caregivers of these ethnic groups. Out of 9 different support services, those who utilized nutrition programs and case management were more likely to report higher overall well-being. Four themes were developed: (1) awareness of formal support services but uncertainty on how to access them, (2) language barriers imposing additional challenges in accessing formal support services, (3) traveling to access culturally appropriate services, and (4) desire for culturally tailored medical and long-term care services.

Discussion and Implications: Findings from this study suggest the importance of case management services to overcome barriers to accessing and utilizing a wide range of formal support services and provision of culturally appropriate food in formal support services to increase East Asian American family caregivers' utilization of long-term care services.

Keywords: Caregiving, Cultural factors, Diversity in aging, Formal support services, Minority aging (race/ethnicity)

As older adults aged 65 and older in the United States continue to grow in number and diversify in racial and ethnic composition, there is recognition that populations of racially and ethnically diverse family caregivers will also grow (Dilworth-Anderson et al., 2020). Existing evidence indicates Chinese and Korean American family caregivers of persons with dementia often experience depression, stress, and anxiety (Holland et al., 2010; Hu et al., 2021; Kim et al., 2019; Pinquart et al., 2005). High prevalence rates of negative mental health outcomes and significant levels of physical demands among Korean and Chinese American family caregivers of persons with dementia are often attributed to difficulties in understanding the U.S. health care system, limited knowledge of community support services, and limited availability of

culturally appropriate services (Kim et al., 2019; Liu, Lou, et al., 2021). Subsequently, underutilization of formal support services and a lack of self-care are frequently reported trends observed among Korean and Chinese American family caregivers of persons with dementia (Gallagher-Thompson et al., 2012; Liu, Badana, et al., 2021). However, formal services, which may be defined as respite care services, congregate and home-delivered meals, transportation services, case management, and support groups are often emphasized across the literature to reduce levels of caregiver burden among individuals caring for persons with dementia (Robinson et al., 2013), suggesting a need to identify strategies to overcome various barriers associated with East Asian Americans' underutilization of formal services.

Despite the increasing number of these ethnic groups, Korean and Chinese American caregivers of persons with dementia are underrepresented across the caregiving literature with particular gaps in understanding strategies for promoting their use of community-based formal support services (Dilworth-Anderson et al., 2020; Gallagher-Thompson et al., 2012; Hu et al., 2021). Specifically, cultural norms, such as filial piety and disease-related stigma towards dementia, and the lack of culturally tailored community-based programming are frequently cited factors contributing to underutilization of formal dementia support services among Korean and Chinese American family caregivers of persons with dementia (Gallagher-Thompson et al., 2012; Han et al., 2008; Kim et al., 2019). In addition, some evidence has indicated that Asian Americans tend to rely on their informal support systems over formal support services due to strong familial values (Tang et al., 2011).

Andersen's health behavior model describes predisposing characteristics, enabling resources, and personal needs affect accessibility and utilization of health care services (Andersen, 1995). However, it also highlights that these factors may affect personal health practices or personal health behaviors, which may not be applicable for immigrants (Yang et al., 2016). Yang et al. (2016) developed a conceptual framework for understanding underutilization of health care services among immigrants, which emphasizes the importance of examining immigrants' health care needs in relation to a specific type of disease, resources available, and cultural factors that may affect their health service utilization. Furthermore, this framework explains the lack of "cultural alternatives" to fulfill immigrant ethnic groups' cultural beliefs and preferences is more related to social and contextual conditions, rather than individual-level issues (Yang et al., 2016, p. 8).

Although there is evidence of barriers to accessing and utilizing formal support services among East Asian family caregivers of persons with dementia, there is a lack of research examining the relationships of family caregivers' formal support service utilization, if used, with those caregivers' well-being. Several qualitative studies have explored caregiving experiences of East Asian family caregivers of persons with dementia with the majority reporting themes related to negative physical and mental health, reliance on informal care, and difficulties finding or utilizing formal support services (Han et al., 2008; Kim et al., 2019; Liu, Lou et al., 2021; Richardson et al., 2019). Although several studies have quantitatively examined caregivers' well-being in East Asian American groups (Holland et al., 2010; Pinguart et al., 2005), there is limited quantitative evidence investigating caregivers' well-being in relation to utilization of formal services among Korean and Chinese American family caregivers of persons with dementia. Quantitative studies examining service utilization of formal services in East Asian family caregivers of persons with dementia have reported an association between greater knowledge of dementia-related services and higher levels of acculturation among Korean American family caregivers (Jang et al., 2010). In addition, Liu et al. (2022) reported that greater knowledge about services was associated with the likelihood of utilizing different types of educational and psychological services, whereas greater experience in dementia care was associated with the likelihood of utilizing home health care services.

To the author's knowledge, prior research has not examined the relationships of formal support service utilization

among East Asian American family caregivers of persons with dementia with their well-being through a mixed-methods design. To address this gap in the literature, we examined the prevalence of different home- and community-based formal support services among Korean and Chinese American family caregivers of persons with dementia and if and to what extent such service utilization affect their overall well-being. Qualitative interviews explored overall experiences of Korean and Chinese American family caregivers of persons with dementia in accessing and utilizing formal services. Based on the results, we also made recommendations for increasing East Asian American family caregivers' utilization of formal support services.

Method

Study Design

We employed a convergent mixed-methods design due to the ability to compare the quantitative and qualitative results and understand differences and similarities between the two data sets (Creswell, 2014). During the midst of the COVID-19 pandemic (May 2020–August 2021), recruitment was primarily performed virtually (e.g., local newspapers, online advertisements, and word of mouth). Also, six nonprofit organizations serving Korean and Chinese American older adults and family members across the nation supported our recruitment process. The staff of these organizations shared our flyer with their members and promoted the study through organizational newsletters. Those interested in this study directly reached out to the research team. The inclusion criteria included (1) those who self-identified as Korean, Chinese, or Taiwanese Americans, (2) providing unpaid care for their loved one with dementia, and (3) were age 18 or older. Paid caregivers were ineligible to participate in this study. Everyone who expressed their interest in participating in this study was eligible for this study.

We developed a survey based on the National Survey of Older Americans Act Participants conducted by the Administration on Aging (Avison et al., 2018). The original survey has seven sections, including the use of the National Family Caregiver Support Program services and knowledge and use of formal services. Our survey collected participants' demographic information, preference and utilization of home- and community-based services and health care services, usage of technology, perceived levels of social support, and needs for a caregiver support workshop. The survey was mainly self-administered online using QuestionPro. On the survey introduction page, an acceptance checkbox was used to record and validate the participant's informed consent to participate in the study. Bilingual graduate research assistants also administered the survey over the phone if the participant preferred to do so.

To deepen the understanding of participants' quantitative responses, we also conducted semi-structured individual interviews. A total of 13 questions assessed details, such as their caregiving experience, formal and informal support, and health care experience. The interview lasted about 1 hr and was conducted over the phone, audio-recorded, transcribed verbatim by bilingual trained research assistants, and translated into English. At least two different bilingual research assistants reviewed an initial version of the translations to ensure the accuracy. The participants had an option to participate in either the survey, the interview, or both. Only

three Korean American family caregivers who completed the survey declined to participate in the qualitative interview. All the others completed both the survey and the interview. The research team obtained a separate consent prior to the interview which was completed in the participant's preferred language—English, Korean, or Mandarin. Only two Korean American family caregivers completed the interview in English. All the others completed the interviews in either Korean or Mandarin Chinese. The participants received a \$10 Amazon e-gift card for completing the survey and a \$20 Amazon e-gift card for completing the individual interview. This study was reviewed and approved by the University of Texas at Arlington Institutional Review Board (#2020-0436).

Measures

Overall well-being

Overall well-being was asked in a single five-point Likert scale item (i.e., In general, how would you rate your overall well-being?), from (1) *poor* to (5) *excellent*.

Service utilization

The participants were asked whether they had ever used any of the nine different home- and community-based services: case management services, senior center services, in-home services, transportation services, nutrition program (e.g., nutrition screening and education), meals-on-wheels, senior center group meals, family caregiver support program, or health promotion and disease prevention services. These items were binary variables.

Service index

The service index represented the number of services used and ranged from 0 to 9.

Covariates

A subset of demographic characteristics from [Table 1](#) was used as covariates for analyses. Specifically, we asked the participant's demographic characteristics (i.e., gender, age, marital status, highest educational background, employment status), caregiving situation (i.e., relationship to their care recipient, living arrangement, average hours to provide informal care per week, the total caregiving duration), care recipient's status (i.e., whether the care recipient has Medicaid, the number of limitations in activities of daily living and instrumental activities of daily living), and caregivers' perceived levels of information and resources available.

Analysis

Quantitative analysis

Demographic characteristics of the study participants were reported using median and interquartile range (IQR) for continuous variables and frequency and percentage for categorical variables, respectively. A series of univariable logistic regression models were fitted to identify factors associated with service utilization. Cumulative logistic regression models were fitted to examine the effect of service utilization on the overall well-being of family caregivers. Potential odds assumption was checked for each model and there were no severe violations of the assumption. The odds ratio (OR) and its 95% confidence interval (CI) were reported. A pre-specified set of covariates (age and gender of caregivers) were considered in adjusted models to estimate the adjusted effects

of service utilization on the overall well-being of family caregivers. A two-sided p value less than .05 was considered statistically significant. All analyses were conducted in R 4.2.1 (R Foundation for Statistical Computing, Vienna, Austria; <http://www.r-project.org/>).

Qualitative analysis

We examined the qualitative data through thematic analysis as outlined by [Braun and Clarke \(2006\)](#). Using an inductive approach, four research assistants who conducted interviews separately generated initial codes in Microsoft Excel. The initial codes were refined through the process of consensus between all four coders and the Principal Investigator (PI; Lee) to produce broader codes based on the frequency of responses, the richness of data segments, and shared relationships. Codes were then analyzed to understand common themes in relation to the participants' experiences in accessing and utilizing formal support services. The PI and the second author reviewed initial themes comparing them to our quantitative findings. Then, both jointly developed the themes and developed integrated findings. Two other researchers with expertise in dementia care were invited for audit trails to establish the credibility of our findings ([Wolf, 2003](#)). They reviewed preliminary themes and quotes to ensure the accuracy of each representation. After reaching a consensus from the reviewers, final themes were selected.

Results

Participants

A total of 62 Korean and Chinese American family caregivers of persons with dementia participated in this study (median age = 64 years; IQR = 59–68). As seen in [Table 1](#), 36 Korean and 26 Chinese American family caregivers completed the survey, and 33 Korean and 26 Chinese American family caregivers completed the individual interview. Most participants were females (72.6%), married or cohabitated (71.0%), held a bachelor's degree or higher (67.7%), and were not working (58.0%). Nearly half of the participants were adult children of their parent(s) living with dementia, and about one third of the participants were spousal caregivers. The participants indicated their overall well-being was good (36.1%), very good (23.0%), or excellent (1.6%) at the time of the survey.

Use of Community-Based Services

The most frequently used programs among the family caregivers from both ethnic groups include in-home care services (33.9%), senior centers (32.3%), family caregiver support programs (24.2%), and transportation services (22.6%) ([Table 2](#)). Only a few participants utilized meals-on-wheels programs (8.1%) or health promotion and disease prevention services (6.5%).

Factors Associated With Service Utilization

Across the nine different services, factors associated with the utilization of these services include ethnicity, educational background, caregiving time, the level of information and resources available, and whether they had Medicaid. As seen in [Table 3](#), Korean Americans were underutilizing in-home services (OR [95% CI]: 0.15 [0.04, 0.45], $p = .001$). Those who were providing care longer than 108 months (OR [95% CI]: 4.43 [1.05, 20.69], $p = .047$), those who showed greater perceived levels of information and

Table 1. Demographic Characteristics of Caregivers in the Sample (*N* = 62)

Variable	All (<i>N</i> = 62)		Korean (<i>N</i> = 36)		Chinese (<i>N</i> = 26)		<i>p</i> Value
	<i>N</i>	Freq (%) Median (IQR)	<i>N</i>	Freq (%) Median (IQR)	<i>N</i>	Freq (%) Median (IQR)	
Gender (female)	62	45 (72.6%)	36	24 (66.7%)	26	21 (80.8%)	.260
Age (years)	45	64 (59–68)	28	62.5 (58.8–70.2)	17	65 (59–67)	.690
Marital status	62		36		26		.675
Married/cohabitating		44 (71.0%)		24 (66.7%)		20 (76.9%)	
Divorced		7 (11.3%)		4 (11.1%)		3 (11.5%)	
Never married		6 (9.7%)		3 (8.3%)		3 (11.5%)	
Separated		1 (1.6%)		1 (2.8%)		0 (0%)	
Widowed		3 (4.8%)		3 (8.3%)		0 (0%)	
Other		1 (1.6%)		1 (2.8%)		0 (0%)	
Highest educational background	62		36		26		.007
Less than high school		2 (3.2%)		0 (0%)		2 (7.7%)	
High school graduate or equivalent		6 (9.7%)		1 (2.8%)		5 (19.2%)	
Some college		12 (19.4%)		5 (13.9%)		7 (26.9%)	
Bachelor's degree		31 (50.0%)		24 (66.7%)		7 (26.9%)	
Master, professional, or doctoral degree		11 (17.7%)		6 (16.7%)		5 (19.2%)	
Relationship to care recipient	61		35		26		.888
Spouse		20 (32.8%)		12 (34.3%)		8 (30.8%)	
Adult child/parent		29 (47.5%)		17 (48.6%)		12 (46.2%)	
Other		12 (19.7%)		6 (17.1%)		6 (23.1%)	
Medicaid (recipient)	61	26 (42.6%)	35	14 (40.0%)	26	12 (46.2%)	.794
Living with the care recipient	61	42 (68.9%)	35	21 (60.0%)	26	21 (80.8%)	.101
Hours cared for (per week)	61		35		26		.024
0–20 hr		18 (29.5%)	35	15 (42.9%)	26	3 (11.5%)	
20–40 hr		11 (18.0%)	35	6 (17.1%)	26	5 (19.2%)	
>40 hr		32 (52.5%)	35	14 (40.0%)	26	18 (69.2%)	
Duration of a caregiver's role	62		36		26		.549
0–36 months		25 (40.3%)		17 (47.2%)		8 (30.8%)	
36–72 months		19 (30.6%)		9 (25.0%)		10 (38.5%)	
72–108 months		6 (9.7%)		3 (8.3%)		3 (11.5%)	
>108 months		12 (19.4%)		7 (19.4%)		5 (19.2%)	
Employment	62		36		26		.165
Full time		15 (24.2%)		10 (27.8%)		5 (19.2%)	
Part time		11 (17.7%)		7 (19.4%)		4 (15.4%)	
Retired		26 (41.9%)		11 (30.6%)		15 (57.7%)	
Homemaker, no pay		8 (12.9%)		7 (19.4%)		1 (3.8%)	
Unemployed		2 (3.2%)		1 (2.8%)		1 (3.8%)	
Overall well-being	61		35		26		.068
Poor		7 (11.5%)		5 (14.3%)		2 (7.7%)	
Fair		17 (27.9%)		9 (25.7%)		8 (30.8%)	
Good		22 (36.1%)		16 (45.7%)		6 (23.1%)	
Very good		14 (23.0%)		4 (11.4%)		10 (38.5%)	
Excellent		1 (1.6%)		1 (2.9%)		0 (0%)	
Number of limitations in ADL	62	4 (1–5)	36	3 (1–5)	26	4 (2–5)	.376
Number of limitations in IALD	62	5 (4–6)	36	5 (2–5)	26	6 (6–6)	<.001
Level of information and resources available	62		36		26		.349
Not sufficient at all		6 (9.7%)		5 (13.9%)		1 (3.8%)	
Not sufficient		20 (32.3%)		14 (38.9%)		6 (23.1%)	
Neutral		17 (27.4%)		8 (22.2%)		9 (34.6%)	
Sufficient		14 (22.6%)		7 (19.4%)		7 (26.9%)	

Table 1. Continued

Variable	All (N = 62)		Korean (N = 36)		Chinese (N = 26)		p Value
	N	Freq (%) Median (IQR)	N	Freq (%) Median (IQR)	N	Freq (%) Median (IQR)	
Very sufficient		5 (8.1%)		2 (5.6%)		3 (11.5%)	

Notes: N = number; Freq = frequency; IQR = interquartile range. ADL (activities of daily living): personal hygiene, dressing, eating, maintaining continence, and transferring. IADL (instrumental activities of daily living): managing finances, managing transportation, shopping/meal preparation, house cleaning/home maintenance, managing communication, and managing medications. Wilcoxon rank sum test and Fisher's exact test were used for continuous and categorical variables, respectively. Bold values denote statistical significance at the $p < .05$ level.

Table 2. Descriptive Statistics of Service Utilization

Services	All (N = 62)
In-home services	21 (33.9%)
Senior center services	20 (32.3%)
Family caregiver support	15 (24.2%)
Transportation	14 (22.6%)
Nutrition programs	8 (12.9%)
Senior center group meals	8 (12.9%)
Case management	7 (11.3%)
Meals-on-wheels	5 (8.1%)
Health promotion/disease prevention services	4 (6.5%)
Total Number of services used	1 (0–2)

Note: N = Number.

resources available (OR [95% CI]: 3.36 [1.09, 11.86], $p = .043$), and Medicaid recipients (OR [95% CI]: 4.67 [1.55, 15.22], $p = .008$) were more likely to utilize in-home services, compared to their counterparts. In addition, educational background was negatively associated with transportation service utilization (OR [95% CI]: 0.25 [0.07, 0.86], $p = .029$). When they showed greater perceived levels of information and resources available, the family caregivers were more likely to utilize family caregiver support (OR [95% CI]: 6.78 [1.64, 46.51], $p = .019$; see [Supplementary Material](#) available online for factors associated with utilization of all services).

Effects of Selected Services on Overall Well-Being

Table 4 shows unadjusted effects of service utilization on the overall well-being of family caregivers. Utilizing a nutrition program (OR [95% CI]: 5.01 [1.22, 23.58], $p = .030$) and case management (OR [95% CI]: 5.77 [1.15, 34.43], $p = .038$) was significantly associated with greater overall well-being of family caregivers. Transportation (OR [95% CI]: 2.75 [0.93, 8.52], $p = .071$) and the total number of services used (OR [95% CI]: 1.24 [0.99, 1.58], $p = .064$) showed a marginal effect ($p < .1$) on overall well-being.

Qualitative Findings

The results of our qualitative analysis helped shed light on factors influencing their access to and utilization of home- and community-based services and programs. Our study participants addressed a wide range of challenges affecting their overall caregiving experiences.

Awareness of formal support services but uncertainty on how to access them

Participants often described their experiences with using formal services were limited due to lacking information on how to access such services. Many participants described awareness and interest to use services; however, they were unsure how to access formal support services. Among these caregivers, we observed underlying feelings of frustration related to this dilemma.

I simply don't know where these services are. People told me that I could send my mother to a senior center or a day-care. That's it. I don't know the rest of the information, like where to find them or who to contact to use these services. (Chinese family caregiver A)

A person like me will be another victim in this [caregiving] situation. Others in my family also don't know what to do for my mother [with dementia]. In addition to her cognitive declines, she broke her ribs after she fell on the floor. Nurses at the hospital told me that I should find a sitter. If I knew how, I would have already found someone. (Korean family caregiver A)

One Chinese American family caregiver described that she ended up deciding to move her mother to China to receive formal services after exhausting experiences in locating and accessing formal services in her local community in the United States.

I don't know how to find information for my mother living with dementia or my caregiving work. I haven't been able to find the right person who can help me with locating services. I tried to ask everywhere. I ended up finding a hospital in mainland China. (Chinese family caregiver B)

Furthermore, during the COVID-19 pandemic, social distance mandates restricted caregivers' ability to exchange information with others, whereas such restrictions reduced the number of support services available for family caregivers in general.

I wish I could get resources from others, especially from those who are also family caregivers for their loved ones with dementia. I would like to know how they handle different situations and learn from their experiences. Right now, we can't meet other people because of COVID-19. I can't give or receive any help. The pandemic has made everything extra challenging. (Korean family caregiver B)

Language barriers imposing additional challenges in accessing formal support services

Our participants perceived their experiences accessing formal services as time consuming and overwhelming due to their

Table 3. Factors Associated With Utilization of In-Home Services

	In-home services		
	Freq (%)	OR (95% CI)	<i>p</i> Value
Gender			
Female	18 (40%)	Ref	
Male	3 (17.6%)	0.32 (0.07, 1.16)	.108
Ethnicity			
Chinese	15 (57.7%)	Ref	
Korean	6 (16.7%)	0.15 (0.04, 0.45)	.001
Highest educational background			
Some college or less	8 (40%)		
Completed at least college	13 (31%)	0.67 (0.22, 2.08)	.483
Employment			
Full time	3 (20%)	Ref	
Part time	3 (27.3%)	1.5 (0.23, 10.03)	.665
Retired	2 (25%)	1.33 (0.15, 10.36)	.782
Homemaker no pay	12 (46.2%)	3.43 (0.85, 17.73)	.103
Unemployed	1 (50%)	4 (0.13, 124.48)	.373
Relationship to care recipient			
Spouse	5 (25%)	Ref	
Adult child/parent	11 (37.9%)	1.83 (0.54, 6.92)	.346
Other	5 (41.7%)	2.14 (0.46, 10.32)	.329
Living with the care recipient			
No	8 (42.1%)	Ref	
Yes	13 (31%)	0.62 (0.2, 1.92)	.398
Caregiving time (months)			
0–36 months	6 (24%)	Ref	
36–72 months	6 (31.6%)	1.46 (0.38, 5.68)	.577
72–108 months	2 (33.3%)	1.58 (0.19, 10.52)	.641
>108 months	7 (58.3%)	4.43 (1.05, 20.69)	.047
Level of information and resources available			
Not sufficient or not sufficient at all	5 (19.2%)	Ref	
Neutral, sufficient, or very sufficient	16 (44.4%)	3.36 (1.09, 11.86)	.043
Medicaid (recipient)			
No	7 (20%)	Ref	
Yes	14 (53.8%)	4.67 (1.55, 15.22)	.008

Notes: Freq = frequency; OR = odds ratio; CI = confidence interval; Ref = reference. Bold values denote statistical significance at the $p < .05$ level.

limited ability to speak English. Although adult children caregivers identified themselves as first-generation Korean or Chinese Americans and fluent in speaking English, they explained this advantage did not necessarily aid in their ability to navigate U.S. health care systems.

I am wondering how I can find a dementia specialist who speaks Korean. I have been living in the U.S. for a long time. I don't have any difficulties communicating in English, but I have no idea how to find a doctor. Even calling an insurance company is not easy. I am afraid to reach out for help. (Korean family caregiver A)

There is a language problem. Although I grew up in the U.S., it is not easy, you know, especially when I have to deal with copay, Medicare, and more. I am worried for others who do not have children who can help them [living with dementia]. What if their language is not good? (Chinese family caregiver C)

In particular, the majority of participants indicated their care recipients preferred working with bilingual medical doctors. However, due to the limited number of bilingual doctors, they expressed additional frustrations when searching for a doctor fluent in their language and familiar with their culture. A few participants shared they had to relocate their loved ones to a community with a larger population of their own ethnic groups due to easier access to formal services to alleviate difficulties finding culturally appropriate health care providers.

With the insurance my father has, we were only able to find a few doctors who speak Mandarin. What if the chemistry between the doctor and my father is not compatible? I guess I will have to change the doctor, but it will be frustrating because it is not easy. (Chinese family caregiver D) Because my mother does not speak English, she had to move to a Koreatown. If she had continued to live with me

Table 4. Effects of Service Utilization on Overall Well-Being

Services	Unadjusted		Adjusted	
	OR (95% CI)	<i>p</i> Value	OR (95% CI)	<i>p</i> Value
In-home services	2.2 (0.83, 6.02)	.117	1.21 (0.38, 3.9)	.750
Senior center services	0.73 (0.27, 1.93)	.527	0.98 (0.28, 3.4)	.976
Family caregiver support	1.74 (0.61, 5.04)	.300	1.58 (0.45, 5.65)	.474
Transportation	2.75 (0.93, 8.52)	.071	2.56 (0.62, 11.31)	.199
Nutrition programs	5.01 (1.22, 23.58)	.030	4.78 (0.57, 49.02)	.153
Senior center group meals	1.63 (0.38, 7.43)	.513	1.12 (0.16, 7.66)	.908
Case management	5.77 (1.15, 34.43)	.038	2.79 (0.44, 19.28)	.276
Meals-on-wheels	1.99 (0.34, 11.56)	.432	1.17 (0.02, 78.3)	.943
Health promotion/disease prevention services	4.68 (0.58, 54.3)	.168	0.5 (0.02, 16.07)	.667
Total number of services used	1.24 (0.99, 1.58)	.064	1.16 (0.85, 1.61)	.360

Notes: OR = odds ratio; CI = confidence interval. Adjusted models are controlled for age and gender. Bold values denote statistical significance at the $p < .05$ level.

[far from the Korean community], she would not have felt belongingness and would have had more difficulties finding services. Now she lives in the Koreatown, and she has her doctor there too. (Korean family caregiver C)

Finding the right medical services for their loved ones was observed to be a daunting task for many caregivers due to challenges, such as limited translation services and the limited capacity to test and diagnose dementia in other languages. Some participants also emphasized challenges encountered even when health care providers used translation services.

The current system (e.g., dementia screening and assessment) for dementia patients and their family caregivers is mainly, culturally and linguistically, for Americans, not for Korean Americans who are considered a historically underserved group. (Korean American family caregiver D)
I haven't been able to find good medical information about dementia or bipolar disorder. In this area, I rarely find a doctor who speaks Mandarin. Every time my parents and I have to talk to their doctor, we use the video translation service. I don't think it is very accurate. There is also a cultural difference. It is very important. (Chinese family caregiver E)

Traveling to access culturally appropriate services

Transportation was observed to be an important factor when East Asian American family caregivers utilize formal support services. Many participants did not drive and were unable to access formal services due to a lack of transportation. Moreover, several participants identified a need to travel significant distances for bilingual services (e.g., bilingual health care providers). In addition, some participants found private transportation services inconvenient due to cost and scheduling arrangements.

I don't drive. I took a written test in the past August, but I haven't scheduled for a driving test. I don't want anything else for my caregiving support but having someone who can give us a ride. My husband [with dementia] and I can barely go to the hospital and grocery store because we don't have family nearby who can give us a ride. That's it. (Korean family caregiver D)

My mother [with dementia] and I called a cab two days ago because I wanted to take my mother to buy something for the first time. We had to wait for half an hour or an hour until the car picked us up. That was the most painful experience for me. (Chinese family caregiver F)

Similar to a Korean family caregiver who relocated her mother to another city to better meet the medical and social needs of her mother after being unable to find one in close proximity, a Chinese American participant complained about the distance required for meeting a doctor.

We are still looking for a doctor. I found one doctor I liked to meet for my husband [with dementia], but the distance is too far. Even driving for one hour is a lot to me. I think this doctor is about two hours away. It is very inconvenient. (Chinese family caregiver G)

During the COVID-19 pandemic, the participants expressed additional challenges with limited transportation options. Due to safety concerns, many decided to stay home and limited activities their loved ones living with dementia previously enjoyed. Additionally, some participants started seeking and using in-home services.

I used to take my mother out on the bus to go around the city and enjoy the scenery. That was one of our favorite activities we did together before the pandemic. However, we are now afraid of getting sick on the bus. (Chinese family caregiver H)

Because of Coronavirus, we can't go out. I started using in-home services. They come two days a week to help us out. There used to be a congregate meal program that provided lunch every day. We used to go there four days a week at the center. Now, the center brings us lunch. That helps a lot. (Korean family caregiver E)

Desire for culturally tailored medical and long-term care services

Many participants were looking for programs that were not only language-specific but also culturally tailored to support their loved ones. Especially when they interacted

with medical doctors, cultural factors seemed to play an important role.

My parents are not used to talking with others about their problems. Our family doctor had to refer my parents to the Neurodegenerative and Dementia Center. My parents and I met with the doctor there twice, then I didn't bother to follow-up. I didn't think my parents developed a deep relationship with their doctor as they had hoped. The doctor also didn't get to know much about them either. (Chinese family caregiver E)

I found a Korean American doctor for my mother who speaks Korean. The doctor considered something like ethnic cultural bias and modified a dementia test. My mother's result was very clear. My sister and I were there at that time and the doctor answered all of our questions. (Korean family caregiver F)

In addition, food was very critical for both ethnic groups to utilize the services. Due to the lack of ethnic food available at existing programs, especially at long-term care facilities, several participants mentioned they still had to step in and bring their own food to their loved ones.

My father didn't get used to the nursing home. He didn't like eating the food there. One day, I went there to see him and saw that he had lost weight. I started bringing some Chinese food from home every day. He was finally willing to eat the food I made. I did it for about a month. I got so tired of it and took a break for a month. He still didn't want to eat the food from the nursing home during that time. (Chinese family caregiver H)

At first, my mother refused to move to a senior housing [apartment] because she can't eat Korean food there. I got to know this organization [that provides Korean food for lunch] and started taking my mother there. She seems okay living at this new senior apartment now. We feel so lucky to find this place. (Korean family caregiver G)

Integrated Findings

See [Table 5](#) for a joint display of the integrated findings. Comparing services associated with overall caregiver well-being with the qualitative data regarding their experiences with accessing and utilizing formal support services, we made two recommendations for increasing East Asian American family caregivers of persons with dementia: (1) Case management services may help overcome barriers to accessing and utilizing formal support services; and (2) Providing culturally appropriate food in formal support services may increase their utilization of such services.

Discussion

Overall, our study participants were underutilizing home- and community-based services. Similar to [Yang et al. \(2016\)](#) postulation regarding the lack of "cultural alternatives" providing culturally appropriate services, their underutilization of formal support services seemed more related to social and contextual conditions, rather than individual-level issues ([Yang et al., 2016](#), p. 8). Our qualitative findings helped expand our quantitative results by highlighting several significant challenges related to underutilization of formal services, including

uncertainty of how to access services as well as language and transportation barriers. Furthermore, we observed a marginally significant association between those using a wide range of formal services and reporting greater feelings of well-being. This finding may be explained by descriptions regarding the number of challenges experienced in using formal services. Taken together, the findings of this study emphasize that ease of access is desperately needed to improve the overall well-being of East Asian American family caregivers of persons with dementia as well as the quality of care provided to East Asian Americans living with dementia.

Researchers have described that disease-related stigma may be associated with the underutilization of formal support services among East Asian Americans ([Cheng et al., 2011](#); [Lee et al., 2021](#)). However, our qualitative findings show that these East Asian American family caregivers spoke openly with others in their community to learn about existing formal services. Using informal networks within their ethnic communities seemed to be a trusted method for learning new resources and disease-related information. Given the sense of community shared among East Asian family caregivers of persons with dementia, these findings suggest the importance of community-level efforts to raise awareness of dementia and dementia caregiving as well as to provide dementia-related education.

Out of all services, the study participants mostly used in-home services. Participants described their preference of in-home services was due to the convenience in overcoming transportation barriers and the ability to provide culturally appropriate meals. Of those using formal support services outside the home, we observed case management services and nutrition programs were associated with greater overall well-being of the participants. The integrated findings of this study suggest case management may be a useful support to East Asian American family caregivers in overcoming historic challenges to accessing formal services and can potentially increase their overall well-being. The positive effects of case management on the well-being of older adults of ethnic backgrounds have been studied at times. For example, [June et al. \(2009\)](#) discovered that Korean older adults who received case management services evidenced improved levels of functional health and reductions in depression than individuals who did not receive comprehensive assessment and referrals. Furthermore, case management provided by trained volunteers has indicated improvements in depression and life satisfaction of Korean older adults living alone ([Choi & Won, 2012](#)).

In addition, the merged results of our qualitative and quantitative data supported increased caregiver well-being in association with use of nutrition programs. Additional studies have indicated the importance of ethnically appropriate food related to use of formal support services by Asian American caregivers through qualitative analysis ([Han et al., 2008](#); [Tang, 2011](#)). We suggest accommodating and providing for their loved one's dietary needs may be an important factor for utilization of formal services among East Asian American family caregivers of persons with dementia. Furthermore, provision of culturally appropriate food in formal support services may increase their utilization of existing programs (e.g., adult day care centers, meals-on-wheels). Increased access to formal services by offering culturally appropriate food options may not only increase utilization by East Asian family caregivers of persons with dementia but may also promote their well-being.

Table 5. Integrated Results

Service associated with greater well-being	Experiences with accessing formal services	Exemplar quotes	Integrated finding
Case management (OR [95% CI]: 5.77 [1.15, 34.43], $p = .038$)	Awareness of formal support services but uncertainty on how to access them	A person like me will be another victim in this [caregiving] situation. Others in my family also don't know what to do for my mother [with dementia]. In addition to her cognitive declines, she broke her ribs after she fell on the floor. Nurses at the hospital told me that I should find a sitter. If I knew how, I would have already found someone. (Korean family caregiver A)	Case management services may help overcome barriers to accessing and utilizing formal support services <ul style="list-style-type: none"> •The merged findings suggest case management may be significantly associated with greater feelings of well-being due to reducing several barriers to accessing and utilizing formal support services described in the qualitative data •Case managers can assist East Asian American family caregivers to identify appropriate services, provide education on accessing services, and connect these caregivers with needed resources to utilize recommended services
Language barriers imposing additional challenges in accessing formal support services	Language barriers imposing additional challenges in accessing formal support services	There is a language problem. Although I grew up in the U.S., it is not easy, you know, especially when I have to deal with copay, Medicare, and more. I am worried for others who do not have children who can help them [living with dementia]. What if their language is not good? (Chinese family caregiver C)	
Traveling to access culturally appropriate services	Traveling to access culturally appropriate services	I don't drive. I took a written test in the past August, but I haven't scheduled for a driving test. I don't want anything else for my caregiving support but having someone who can give us a ride. My husband [with dementia] and I can barely go to the hospital and grocery store because we don't have family nearby who can give us a ride. That's it. (Korean family caregiver D)	
Nutrition program (OR [95% CI]: 5.01 [1.22, 23.58], $p = .030$)	Desire for culturally tailored medical and long-term care services	At first, my mother refused to move to a senior housing [apartment] because she can't eat Korean food there. I got to know this organization [that provides Korean food for lunch] and started taking my mother there. She seems okay living at this new senior apartment now. We feel so lucky to find this place. (Korean family caregiver G) My father didn't get used to the nursing home. He didn't like eating the food there. One day, I went there to see him and saw that he had lost weight. I started bringing some Chinese food from home every day. He was finally willing to eat the food I made. I did it for about a month. I got so tired of it and took a break for a month. He still didn't want to eat the food from the nursing home during that time. (Chinese family caregiver H)	Providing culturally appropriate food in formal support services may increase East Asian American family caregivers' utilization of such services <ul style="list-style-type: none"> •Food is an important factor related to Asian Americans' ability to access long-term care services •Quantitative data supporting increased caregiver well-being in association with use of nutrition programs further suggests the importance among these Asian American caregivers regarding their loved one's culturally appropriate dietary needs

Notes: OR = odds ratio; CI = confidence interval.

Overall, the findings of this study point to the need for development of culturally tailored interventions that reflect their cultural norms (Richardson et al., 2019). Some researchers have cited benefits of partnerships with religious organizations to provide linguistically and culturally tailored interventions for East Asian family caregivers of persons with dementia (Sun et al., 2017; Ta Park et al., 2021). Therefore, we suggest that partnerships between existing home- and community-based organizations with local religious organizations serving East Asian Americans may be useful for the organizations to understand the unmet needs of East Asian American family caregivers of persons living with dementia and their loved ones. The formal support services may be provided in these ethnic religious organizations that are more likely to be located near the residence of Korean and Chinese Americans. Furthermore, volunteers from these ethnic religious organizations may play an important role to overcome barriers associated with East Asian Americans' underutilization of formal services. They may be able to not only share insights for tailoring existing programs to be more culturally and linguistically appropriate but also directly support this vulnerable group of family caregivers of persons with dementia in various ways (e.g., cooking, translating, and driving). There is a dire need to simplify dementia caregivers' access to formal support services so that we may increase the ability of East Asian family caregivers of persons with dementia to utilize available supports.

Limitations

This study had some limitations. First, results from quantitative analyses may be interpreted as descriptive and exploratory due to our small sample size ($N = 62$). Despite the various efforts we made to recruit participants, it was challenging to recruit family caregivers of persons with dementia from these ethnic groups especially during the midst of COVID-19. Though they may be underpowered, regression analyses revealed some statistically significant factors that are associated with service utilization and the overall well-being of these family caregivers. It will be important for future research to confirm such association with a larger sample. Also, our recruitment heavily relied on partner organizations, which could have potentially influenced participants' knowledge or utilization of available home- and community-based resources. Although these participants still showed a lack of knowledge of how to locate or access these services, particularly medical providers, indicating their challenges regardless of such advantages, they may not accurately represent a larger group of these ethnic groups. Thirdly, the majority of interviews were conducted in the participants' native languages. Although the research team made additional efforts to ensure the accuracy by having two different bilingual research assistants review the translations, it is possible to have lost important nuance in translation. Lastly, most of the survey data were collected online, we were not able to track how many participants participated in the survey online versus over the phone. We acknowledge that different modes may have influenced the interpretation of our findings.

Conclusion

In conclusion, these results suggest that to effectively respond to a growing number of East Asian family caregivers of persons

with dementia, we should more greatly examine and increase the accessibility and utilization of home- and community-based services. Moreover, considering COVID-19 drastically impeded dementia caregivers' ability to access support services, it seems critical to identify strategies for continuing these services in the event of future public health emergencies. The findings of this study suggest case management services may be helpful to promote access and utilization of culturally appropriate formal support services as well as feelings of well-being among East Asian American family caregivers of persons with dementia. We should persist in our efforts to increase the provision of culturally appropriate services for East Asian American family caregivers of persons with dementia by not only increasing our bilingual professional workforce but also considering other important factors, such as offering culturally appropriate food.

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Conflict of Interest

None.

Data Availability

Data including analytic methods and materials used for this study are available to other researchers for replication purposes upon request. This study is not preregistered.

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