Attitudes Toward Community-Based Services Among Japanese American Families

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**Purpose:** This descriptive study explored attitudes toward community-based long-term care services and factors influencing service utilization among Japanese American families. **Design and Methods:** Using grounded theory methodology, the Japanese American sample included 26 family caregivers, 4 persons receiving care, and 14 professional providers \( n = 44 \). **Results:** Attitudes toward services were identified along six dimensions: ability to meet care needs, autonomy in daily life, quality of care and staff, cost, emotional connotations, and social and physical environment. Participants used formal services in a dynamic manner, meeting both episodic and chronic needs. Families played an active role in sustaining and augmenting the caregiving situation, regardless of living arrangement. **Implications:** This research highlights the range of criteria included in attitude formation about services and the dynamic nature of the interplay between families and formal services.

**Key Words:** Family caregiving, Decision making, Assisted living, Adult day care, Home care, Adult family homes

**Introduction**

At a time when our population is aging and the need for functional and health support is growing, individuals are becoming more reliant on formal services to manage long-term care. A variety of community-based services are available to the consumer, including nursing homes, assisted living, adult family homes, adult day care, and home care. With a range of options, the decision has become more complex than in the past when nursing home placement was the most obvious solution for families who could no longer provide the necessary support. Decisions about services are multifaceted and include characteristics of the person needing care, caregiver factors, features of the service itself, and attitudes toward the service. Cultural factors potentially influence consideration of services as individuals appraise the meaning of their situation and options.

Asian Americans are the fastest growing minority group in the United States, with an increase in population from 6,908,638 in 1990 to 10,242,998 in 2000 (U.S. Bureau of the Census, 1990, 2000). Japan has the highest life expectancy at birth, and U.S. life expectancy estimates anticipate lower mortality at late ages for Asians and Pacific Islanders, with longevity predicted to be 86.2 years for women and 80.2 years for men (Manton, 1996). With greater longevity and potential concomitant functional dependence, Asian Americans are an important population to consider in planning community-based services.

**Patterns of Long-Term Care Use Among Japanese Americans**

Despite a longstanding tradition of family caregiving, Japanese families in both Japan and the United States are facing challenges common to other populations, with fewer available caregivers owing to greater workforce participation and geographic mobility (McCormick, Imai, & Rubenstein, 1995). Formal services are an increasingly salient option for families in both countries. The Japanese government is implementing the Gold Plan, a long-term strategy to promote health and welfare of aged people in the long-term care system, with increasing participation among older adults and their families in formal services (Imai & Hasegawa, 1995; Murashima, Zerwekh, Yamada & Tagami, 1998; Nagatomo, Akasaki, Uchida, Tominaga, Hashiguchi, & Takigawa, 1999).

Research in Japan has elucidated cultural influences on formal service utilization. In a qualitative study of family caregivers, Yamamoto and Wallhagen...
(1998) identified three issues influencing the decision to use services: availability of services, the authority level of the caregiver within the family, and whether the caregiver could justify her tolerance limit to other family members. Availability consisted of elements of quality, distance, potential sanctions, knowledge of the service, and quantity of the service. The tolerance limit incorporated societal norms about caregiving, the kind of attachment to the care receiver, and personal beliefs about how care should be given. This study highlighted the complex interaction among influential factors as well as the thoughtful negotiation engaged in by caregivers as they make service decisions. In a review of evolving gender issues for women in Japan, Hashizume (2000) reflected on the Japanese value for privacy and the reluctance to endure the embarrassment and fear of having service providers in the home, as well as the powerful cultural expectations for family caregiving and the perception of failing one’s responsibilities when tasks are relinquished to others.

Previous work among Japanese Americans (Nikkei) in Washington State has demonstrated that despite stereotypes about family caregiving for Japanese, nursing homes generated a level of interest comparable to that of the general population, indicative of changing attitudes toward this option (McCormick et al., 1996, 2002). However, in a recent survey of family caregivers, Asian Americans reported the lowest use of supportive services available in the community (including delivered meals, adult day care, or personal care), with only 15% of Asian families using personal or nursing services, half the rate of other ethnic groups. Not only was utilization lower, but a high percentage of the respondents (49%) indicated that they did not know what kind of help or information could be useful, compared with 38% overall reporting a lack of knowledge (National Alliance for Caregiving [NAC] and American Association of Retired Persons [AARP], 1997).

**Factors Influencing Long-Term Care Use**

A significant body of research exists on factors influencing nursing home use. A variety of important variables have been identified, including both caregiver and care receiver characteristics that are predictive of the intention to institutionalize as well as actual placement in a nursing home (Aneshensel, Pearlman, & Schuler, 1993; Cohen et al., 1993; Hanley, Alexcixh, Wiener, and Kennell, 1990; Kao & Stuifbergen, 1999; Lieberman and Kramer, 1991; Montgomery & Kolski, 1994; Pruchno, Michaels, & Potashnik, 1990). In conjunction with the expansion of noninstitutional community-based services, there is a growing focus on predicting utilization of these formal service options.

Care recipient factors predictive of formal care in the home include a greater need for assistance with activities of daily living (ADLs) and living arrangements, with those in senior housing and in households with fewer members using more paid assistance. In addition, older age, being female, and hospitalization in the previous year predict higher utilization, whereas more hours of family care lowers the likelihood of paid assistance. Several caregiver factors are also significant in predicting formal service use, including difficulty getting around outside, the need to rearrange work hours, and the provision of bowel and bladder care (Houde, 1998).

With the recognition of cultural contributions to health service patterns, a number of studies have explored utilization among various ethnic groups. Latino elders exhibit patterns similar to the general population (Wallace, Campbell, & Lew-Ting, 1994), with higher use of visiting nurses, home health aides, or homemakers associated with greater ADL need, use of medical care in the past year, greater age, ancestry (with Puerto Ricans more likely to use services than Mexican Americans), low income, Medicaid eligibility, living alone, and not having children nearby. Importantly, this study did not substantiate an acculturative effect in predicting service use. In a comparison across groups (Hispanic, African American, and Caucasian), ethnicity played a significant predictive role in utilization, with greater use of in-home services and nursing homes by Caucasian elders and higher use of community-based services by Hispanic elders (Mui & Burnette, 1994). A greater preference for in-home care was documented among African American elders in comparison to Caucasian elders, influencing patterns of discharge disposition after an acute hospital stay (Morrow-Howell, Chadiha, Proctor, Hourd-Bryant, & Dore, 1996).

The decision to use formal services is complex and multifactorial and involves an unfolding over time. Collins, Stommel, King, and Given (1991) identified reasons for not using formal services, including a sense of obligation to provide exclusive care, cultural expectations, a preference for informal support and not relying on the system, concern about quality of community services, and a lack of desire to relinquish control to strangers. Their development and testing of an instrument to assess attitudes toward community services supported five dimensions of influence among the subscales: concern for the opinions of others, confidence in the service system, belief in caregiver independence, acceptance of government services, and preference for informal care, with the last subscale having the greatest predictive power for service use.

**Attitudes Toward Long-Term Care Services**

Because individuals with similar functional and health needs can be managed in different settings, it is likely that attitudes toward services make an additional contribution to decision making, beyond characteristics of the caregiving situation. As operationalized in the theory of reasoned action (Ajzen & Fishbein, 1980), attitudes are a function of the salient beliefs an individual holds about an action and may be the result of direct experience or developed indirectly through information provided by others or by inference.

Differences in attitudes toward services have been documented between rural and urban elderly people,
playing a role in utilization patterns (Schoenberg & Cowen, 1998). Understanding attitudes behind health service choices enhances the acceptability of the program to recipients (Schoenberg, Campbell, Garry, Snider, & Main, 2001). In a large survey carried out by AARP (1984), 80% of members preferred home care to nursing home care. General observations include these: (a) Older persons prefer to avoid nursing home use if possible, (b) they prefer not to disrupt the lives of their relatives (although their relatives are willing, and see a duty, to help them), and (c) elderly people are willing to accept welfare to pay for long-term care (Kane & Kane, 1987). Still, little is known regarding attitudes among ethnic subpopulations or toward specific program features among the various community-based long term care choices.

In 1993, the Nikkei Long Term Care Project began to examine attitudes toward long-term care among healthy Japanese American elders. It has substantiated their willingness to consider both nursing homes and home care, particularly those services provided within the Japanese American community (McCormick et al., 1996). The local Nikkei community has over the past 25 years provided formal services for their older members (including a nursing home, assisted living, adult day care, and meal services). The provision of such services, within the boundaries of and with the volunteer support of the ethnic community, has fostered a perception of services as an extension of family caregiving. In addition to longitudinal data on functional and cognitive status and caregiver characteristics, preferences and attitudes toward long-term care services have been evaluated, using the model proposed by Ajzen and Fishbein (1980) to understand social behavior. The current study was undertaken to augment the quantitative information already obtained and to explore in more detail preferences and attitudes about specific community-based services.

Design and Methods

This descriptive study used naturalistic methods to explore attitudes toward long-term care services among Nikkei families. Because attitude formation includes both direct experience and inference, participants were selected to represent those actually using services, those not using services, and those involved in decision making about services. Qualitative data were collected and analyzed using grounded theory methodology (Bowers, 1988; Glaser, 1978; Lincoln & Guba, 1985; Strauss & Corbin, 1990). Critical features of the methodology include theoretical sampling and constant comparative analysis, with the development of a coding scheme to account for the data. In this study, the aim of theoretical sampling was to gain adequate representation of perspectives on care choices available to older adults.

Data Sources and Data Collection Procedures

Sample Recruitment.—The sample for this study was selected from participants in a large population-based research program including the Kame and Nikkei Long Term Care Projects, longitudinal studies of dementia and long-term care use among Japanese Americans. Using a census directory developed by the research staff, all Japanese Americans over 65 in King County were identified and invited to participate; this census located 90% of the population indicated on the U.S. Census. Starting in 1992, the Kame Project enrolled 1,985 participants (out of a census of 3,043) and the Nikkei Long Term Care Project enrolled 1,330. There were no differences in age, gender, education, or place of birth between nonparticipants, Kame participants, and Nikkei Long Term Care participants. Of the 1,330 participants in the Nikkei Long Term Care study, 188 were found to have impairment in cognition and/or function and were designated as care receivers. Their respective caregivers were also enrolled.

Participants in this study were selected from the Nikkei Long Term Care Project, to represent a range of care receiver cognitive and functional ability, and included family caregivers and care receivers as well as formal service providers. The sample was recruited using both random selection and purposive approaches, initially by randomly selecting individuals from the master list of enrollees in the Nikkei project. Providers were selected to represent a variety of services available in the Japanese American community and for their experience in working with Nikkei families in the long-term care arena. As participant observation and interview data were collected and analyzed, theoretically relevant participants were recruited, using demographic and health data to ensure that the sample represented the total population along the following general descriptors: gender, age, marital status, caregiving situation, health status, functional ability, and use of long-term care services. As data analysis progressed, the sample recruitment focused on relevant themes, for example, to include providers who could address adult day care issues.

Methods.—After obtaining informed consent, data were collected through in-depth semistructured interviews (see Appendix). Interviews were conducted in private, in the primary language of the participant, taped recorded, translated if needed, and transcribed verbatim for analysis. Data were entered into the QSR Nud*ist (1997) Version 4.0 software program that facilitates processing and analyzing text. Data analysis was conducted following established procedures for constant comparative analysis and grounded theory. Text was broken down into fragments representing a single idea. Systematic guidelines for coding the data at consecutively higher levels of abstraction facilitated concept development. Data collection and analysis were iterative and were conducted concurrently as conceptual understanding evolved. Ideas were categorized and organized to determine common themes and relationships among ideas. Contributing factors or consequences of a given idea category were identified. As themes, relationships, and contributing factors were identified, the interview guide was
modified interviews to explore these in more detail. For example, early interviews suggested that family caregivers used formal services episodically; probing about this pattern was included in subsequent interviews. The results of the focused interviews are reported in the form of the major themes evident.

Standard strategies were implemented to achieve auditability, credibility, and fittingness in order to maximize the trustworthiness of the findings (Lincoln & Guba, 1985). Before data collection, face and content validity for the interview schedules were established through consultation with experts in health care and social services. Transcribed interviews were audited for procedural consistency and spot checked for accuracy. One investigator primarily (Young) conducted qualitative data analysis, then a second researcher (Sikma) reviewed samples of the analysis, categories, and themes to establish reliability. Data were checked for representativeness as a whole as well as the individual coding categories and the examples used to represent each. Fittingness or applicability of the findings was ensured through theoretical sampling of participants according to functional and cognitive status, as well as experience with long-term care services. Member checks, in the form of validation from participants, ensured that the findings fit the data from which they were derived and that they captured the essence of the experience. The researcher (Young) presented categories and relationships for review and discussion to several participants, a process that refined definitions more precisely. Procedures and strategies used for collecting, analyzing and reporting data were recorded as procedural field notes to facilitate independent audit.

Description of Participants.—The study (N = 44) included 26 family caregivers, 4 persons receiving care, and 14 professional care providers. All participants were Japanese American, with 38 speaking English as the primary language (see Table 1).

Eighteen family caregivers provided care in the same home, two provided care to relatives who lived alone, and six provided care to relatives in institutional settings (two in assisted living, three in adult family homes, and one in a nursing home). The age of the caregiver informants ranged from 52 to 85 with a mean of 69.8 years (SD = 10.3), and the age of those for whom they were caring ranged from 73 to 103, with a mean of 88.7 years (SD = 8.4). Caregivers were predominantly women (69%), as were their care recipients (62%). The relationships of the caregiver to the care recipients were spouses (35%), sons (15%), daughters (35%), sons-in-law (4%), and daughters-in-law (12%). Of half of those receiving care (56%) had cognitive test scores indicative of significant impairment. Fifty-two percent of those receiving care needed assistance with three or more basic ADLs.

Among the 4 care receiver informants, 2 lived in the same home with the caregiver and 2 lived in an assisted living community. Three were women, none had cognitive impairment, and 2 required help with more than three basic ADLs. Age of care receiver informants ranged from 73 to 88, with an average of 79.3 years (SD = 6.8).

Most of the caregivers and care receivers had experience with various community-based services, with only 6 caregivers (23.1%) having had no experience with any service and 13 (50.0%) having experience with multiple services. Service use was dynamic, with 11 (42.3%) having used temporary overnight respite or short stays in residential facilities (nursing homes, assisted living, or adult family homes).

Service providers were selected from the array of services available within the Nikkei community, including community services (e.g., meal services, adult day care, churches) and facilities (e.g., nursing home, assisted living), and were all actively involved in delivering services to Nikkei older adults. The professionals represented a variety of disciplines (2 social workers, 1 nurse, 2 physicians, 4 administrators, 2 ministers, and 3 Board members/community volunteers). This informant group consisted of 9 women (64.3%) and 5 men (35.7%), ranging in age from 42 to 89, with a mean age of 65.0 years (SD = 15.36).

Results

Participants formed attitudes toward community-based services from direct experience, the perceptions of others, and their own beliefs and expectations. A number of factors emerged that either facilitated or impeded consideration of community-based alternatives. Families revealed a number of strategies that they used with community-based services in order to augment the care provided and enhance services for their caregiving situation.

Attitudes Toward Services

Attitudes were formed along six major dimensions: ability to meet care needs, autonomy in daily life, quality of care and staff, cost, emotional connotation, and social and physical environment. Table 2 summarizes these dimensions as they pertain to five options for community-based care: (nursing homes, assisted living, adult family homes, adult day care, and home care).

The first dimension, ability to meet care needs, reflects an assessment of the capacity of the service to manage the specific requirements of the care recipient. Nursing homes were perceived as the most equipped to manage heavy or complex care needs and were recognized as an extension of hospital services. Home care was seen as another alternative to manage heavy care demands (e.g., transferring, incontinence), as well as a means to reduce the physical and mental demands for the caregiver. Both assisted living and adult family homes were recognized for providing assistance with basic ADLs; however, assisted living and adult day care were identified as richer social environments, with the provision of structured activities and appropriate social stimulation. The transportation and supervision associated with adult day care enhanced the attractiveness of this option, yet the short hours and emphasis on social services rather than
health services limited the perceived benefits of this program. The value of autonomy in daily life was an important factor in decision making about services, with the recognition that all services impinge to some degree on privacy and independence. Assisted living was recognized for promoting independence by providing the support and structure to enable care receivers to manage for themselves. In the words of one professional provider, I think in-home care signals a loss of independence. More so than assisted living, for example. When you go into an assisted living situation, the community, that I've talked to, feels that that's a place where you still—it's designed so you can still be independent. The moment that you bring someone into the house to do something for you, it feels like, to some I think feels like that's a major loss of independence.

The shared space and programs and the presence of staff fostered a loss of privacy in residential services (nursing home and assisted living). Yet, having a stranger in the house also compromised privacy. Adult
### Table 2. Attitudes Toward Services

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Nursing Home</th>
<th>Assisted Living</th>
<th>Adult Family Home</th>
<th>Adult Day Care</th>
<th>Home Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autonomy in daily life</td>
<td>There is no privacy.</td>
<td>Promotes independence. There is a lack of privacy.</td>
<td></td>
<td>There are high social demands for those who are antisocial.</td>
<td>There is a loss of independence. There are too many rules. There is a stranger in the house.</td>
</tr>
<tr>
<td>Quality of care and staff</td>
<td>Care is much improved. There is worry about abuse/neglect. There is short staffing, inconsistent quality. Appreciate caring staff, involved volunteers, and culturally sensitive programs/language. Provides low-quality food.</td>
<td>Provides higher quality food. There is a concern about availability of qualified staff.</td>
<td>It is hard to know quality of care. Provides low quality food. Provides unskilled staff.</td>
<td>Provides caring people. Volunteers are involved.</td>
<td>It is hard to hire/keep consistent staff. It is difficult to coordinate.</td>
</tr>
<tr>
<td>Cost</td>
<td>Cost is high.</td>
<td>Is cheaper than nursing home. Costs more than home.</td>
<td></td>
<td></td>
<td>Is cheaper than nursing home. Insurance may pay.</td>
</tr>
<tr>
<td>Emotional connotation</td>
<td>Is hard to rely on others and to accept stigma.</td>
<td>It is an easier choice. Reduces family burden. Has a stigma.</td>
<td>Promotes isolation.</td>
<td>Reduces worry for caregivers.</td>
<td>Treat the help as a guest—creates work. Promotes isolation. Enables staying at home.</td>
</tr>
<tr>
<td>Social and physical environment</td>
<td>Space is small. Have to give up belongings.</td>
<td>Quarters are small. Have to give up belongings. Has studios—combined bed and living area. Is not as familiar as home.</td>
<td>Is small and intimate. Is inviting. There are language barriers (non-English- and non-Japanese-speaking staff).</td>
<td>There is poor access from distant neighborhoods.</td>
<td>Provides familiar surroundings. There is low disruption.</td>
</tr>
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</table>
day care was viewed as posing too many social demands on persons who are more reclusive.

**Quality of care and staff** was the dimension most discussed by participants, particularly as they compared their own abilities to manage the situation themselves versus involving other providers. Consistent quality in services and a caring staff were emphasized repeatedly. Participants expressed concern about the potential for abuse/neglect and care by unskilled staff as major issues in selecting services as well as an ongoing matter for monitoring. Across settings, participants bemoaned the challenges of evaluating the quality of care as well as ensuring adequate, well-qualified staff. There was a perception that quality of care in nursing homes has improved and a particular appreciation for the quality of care provided in the Nikkei nursing home. The high involvement of volunteers in the services provided by the Nikkei community was a major factor in having a sense of caring as well as enriching the quality of the programs. A daughter caring for her mother in the nursing home reflected,

I actually really like it very much . . . the aides seem to treat all of the residents in a really respectful manner. And for my mother it is really nice because some of the aides and nurses speak Japanese. My mother does not realize it but she speaks mostly Japanese now although she is really bilingual. . . . It is so fortunate that we have this facility in the community. We are just very lucky because had she remained at the other one we probably would have taken her home, and I would have been just a wreck.

Finally, food was identified as an essential element of quality of life, with perceptions varying according to ability to accommodate preferences as well as the quality of the meals and preparation. Meals in nursing homes and adult family homes were viewed as the most unsatisfactory. A daughter whose parents both resided in an adult family home stated,

I saw some of the meals, and I am not really pleased with that. I think all places like that serve the simplest, cheapest kind of dish. My dad complains that they serve all this gooey stuff, and I agree that some of the things they serve do not look so appetizing. They cook a lot of Chinese or Thai kinds of dishes which are a little different from Japanese food.

The fourth dimension was **cost**, conceptualized in comparison to nursing home care or living at home without care. Participants perceived nursing homes as the most expensive alternative and being at home as the least expensive. Long-term care insurance and federal or state aid were infrequently mentioned in discussions of managing service expenses.

Participants identified **emotional connotations** with the various services. Concern for the isolation of the care receiver was common among nursing homes, adult family homes, and in-home care. Assisted living and adult day care were identified as having positive effects for family caregivers by reducing burden and worry. Participants reported that they struggled with the stigma of institutionalization and of turning to alternate living situations when considering nursing homes and assisted living. Given the emotional impact on both the caregiver and the care recipient, nursing homes were the most difficult choice to accept. In fact, families saw nursing homes as a last resort:

Well, I think it is wonderful, but nobody wants to be in a nursing home. From what I’ve seen, the people who are there live sort of robotic lives. But sometimes there aren't any other options. The family can’t always take care of their needs. So, it definitely would be an option if she needed more care, because right now we couldn’t take on much more care with all that we are involved with.

The final dimension was the **physical and social environment**. Physical space (size and ability to personalize) was a negative consideration for nursing homes and less so for assisted living. The adult family home environment, while perceived as small, was also seen as more intimate and inviting. Having to give up belongings was identified as a loss associated with both nursing homes and assisted living. In contrast, staying at home was highly valued, with familiarity and the ability to retain possessions recognized as comforts. Selecting a compatible, appropriate home care worker posed the greatest challenge. A professional provider discussed this issue:

One thing is that they have to find someone with whom they can get along. Some want a Japanese home care person, which is difficult. In this community, it is more common to hire someone introduced by acquaintances [than to hire] someone through an agency. I have been asked if I knew someone. I can give them the list of agencies, but the agencies do not have so many Japanese-speaking persons. So eventually people find the care person, through friends, churches, community, and so on.

Interestingly, some participants found home care to be stressful because they felt compelled to make preparations and accommodations for the care provider, as highlighted by this professional provider:

The biggest impediment with regard to people seeking out home care is that a lot of older homemakers see their home help as a guest, and so they do all this extra work getting the house straightened up, which sort of defeats the purpose.

Particularly in adult family homes, language barriers (staff who spoke neither Japanese nor English) were identified as problematic. The most important environmental issue for adult day care was access from remote neighborhoods to this service.

**Facilitating Factors and Barriers for Considering Services**

A number of factors influenced consideration of services. The availability of services created by the Japanese American community for their own members was an important facilitating factor for considering services. Two professional providers discussed services:
One purpose of the adult day care is to keep them from the isolation. Also the Nikkei, there are quite a few who prefer to speak Japanese rather than English. In the aspect of the language, the culture, food, it would be nice for the Nikkei to get together with other Nikkei people. So one aspect of adult day care is to socialize with others. We encourage the older people not to just stay home but to come out and see other people.

With the nursing home, they can see some of their friends there, they can eat rice, the language is something they understand, the culture is geared for them so they feel a little bit more comfortable.

In general, participants gathered more information about services that they were considering as immediate possibilities rather than about the full range of services. In discussing the various options, participants expressed feeling confused about the actual services provided, the financial aspects, and their eligibility for the services. Those who had confidence in their knowledge of a service were more likely to plan to consider that option. Frequently, participants mentioned that they would find out more about services when they thought they needed them. According to a caregiving spouse,

If he can’t walk, I do not think I can manage taking care of him. Then he may need to go to the nursing home. I hear it is possible to hire some help but the helper probably can’t stay for 24 hours. I think it is very normal to take care of my husband at home. It is the way of life. Only when it becomes really impossible in the future, I would consider the nursing home. For example, if I become ill or if my daughters can’t manage or if we can’t lift him, we can’t help admitting him to the facility.

Costs and payment sources were important factors. Again, knowledge of actual costs and eligibility was not widespread. Participants formed attitudes about the relative expense of services and sometimes based decisions on incomplete information. Those who had an identified payment source were more confident in selecting services.

Positive or negative views of the services (quality, environment, staff, emotional impressions) heavily influence consideration of the possibility of taking advantage of the option. Even when impressions were not based on direct experience, participants formed strong preferences about various services. An elderly professional provider reflected on the changing views:

I think there’s been a major shift. I think when I was growing up, the youth group used to go to entertain at a nursing home. So that image of what that was like, dark, dreary, smelly, it was real depressing. That image is burned into my memory and even more so in my parents and the elders. So, I think that’s the image that led many of them to say “Never put me in a nursing home.” . . . But with assisted living and improvements in the nursing homes, I think my generation, our generation, is more open to considering that, even though we have that parental prohibition. . . . I think it’s because there’s a sense of community providing something for them where they could be with others of their community.

The recommendations of others made a difference in forming an attitude about a service, both negatively and positively. Caregivers and care receivers were influenced by recommendations for specific services made by trusted contacts (commonly health care providers, ministers, or family members); several cited such a recommendation as the deciding factor in selecting a service. The absence of recommendations was also influential, with the caregiver assuming that if the service had not been recommended, it was not indicated.

Formal providers observed that caregivers and care receivers were more likely to accept recommendations when the ideas or services were introduced slowly and over time. Providers identified that the opportunity to have a positive experience with a less invasive service, such as help with gardening or transportation, fosters acceptance of services of higher intensity at a later time. Availability of the specific service influences consideration, particularly for those living in outlying neighborhoods with less access to the services provided by the Nikkei community. A final factor of importance was accommodation for couples, specifically those who have different care needs but prefer to remain living together.

Ways Families Augment Services

Service use by families was dynamic, with both long-term and episodic utilization as well as fluctuations in needs over time. Family caregivers augmented the use of community-based services in a variety of ways and played an active caregiving role regardless of the care recipient’s living situation. By augmenting the service, they were able to overcome negative aspects of their attitudes toward a service. A common strategy to manage care demands was to combine services; for example, by using an adult family home for residential care in conjunction with adult day care to enhance socialization and stimulation. Episodic use of residential services (e.g., nursing home, assisted living, or adult family homes) was typical for caregivers seeking respite or postacute care. A daughter-in-law described how she has accommodated:

I think the situation is working out because she is in a separate quarter. I can close the door and do not think about her. If we only had a small house and she was making a mess in my living room, I would have been upset. She can’t hear well, and she lives in her own peaceful life by herself. I am grateful that we have a big house and we can hire a helper. Adult day care is also very helpful. Three times a week she goes to there and won’t be home most of the day which makes a great difference to me. On those three days, I can concentrate on what I am doing without worrying about Mama.

A priority for caregivers was ensuring quality of care and monitoring the health and safety of the care receiver, particularly when formal caregivers were providing assistance with basic ADLs (e.g., nursing home, assisted living, adult family home, home care). Strategies included observing the hired caregivers, assessing the physical and emotional condition of the care
receiver, and watching for specific health outcomes, such as food intake or blood glucose control. A daughter whose father lives alone described how she monitors his care:

My husband and I felt that we had to be here all the time. . . . Now we can say we have dependable nurses, and we can depend on them to take good care of Papa. So we are getting to be more relaxed. We kind of makasu [meaning we let them have responsibilities], but it depends on the nurse. If we have a new nurse, I will come observe her until I feel confident with her. I don't leave Papa with a new nurse alone. . . . Although I have 24-hour care, my nurse knows that I want to take care of him every once in a while myself. When I want to spend quality time with my Papa, they will sit there and let me take care of him. I want to do this because I want to let him know that we still care for him, and we are not just letting the nurse take care of him and leaving him.

Families augmented residential services (nursing homes, assisted living, adult family homes) by providing favorite foods and needed supplies, repairing clothing and equipment, procuring medications (in assisted living and adult family homes), and responding to emergencies. A caregiver described how she supports her husband in the nursing home:

The meal is the only problem. My husband did not want to eat their food. So I brought some food to the home at daytime and at nighttime my daughter picked up something from Japanese deli and brought them. Those he liked to eat.

Regular visits to the care receiver included helping with meals, participating in the social life of the residence, and keeping the memories of important people and times alive. Families also provided transportation and escorts to health care appointments and recreational outings. A daughter noted how she enriched her visits with her mother in assisted living:

I like to take old photos. . . . She loves to look at those pictures, and she can remember where they were . . . she can remember where they were taken what the occasion was and what color her dress was. . . . She really enjoys looking at those old things.

Families solved the challenges of their caregiving situations in a variety of ways, including their own efforts, ranging from coresidence to intermittent assistance, as well as by delegating certain aspects of care to other family or friends or to providers of community-based services. Families were most satisfied with services when roles were clear and there was good communication among those providing care.

Discussion

This study focused on attitudes toward community-based services among Nikkei caregivers, care receivers, and care providers, elucidating service-specific attitudes as well as dimensions that families use in evaluating options and sustaining choices. Several of the factors identified by Collins and associates (1991) were echoed in the dimensions reported in this study, including confidence in the service system, preference for informal care, and belief in caregiver independence. The quality of the services and staff, availability of services, and emotional connotations of various services were also salient in the work of Yamamoto and Wallhagen (1998). Issues of privacy and independence reflected the Japanese cultural beliefs described by Hashizume (2000). Unfortunately, although the physical environment has been recognized as an important aspect of quality of life in nursing homes and senior housing (Moos & Lemke, 1980; Young, 1998), this dimension has not been emphasized in research predicting institutionalization. However, these findings highlighted expectations of the physical environment to provide privacy and a sense of home, with adequate space for living and personal possessions.

This study identified issues that are salient to family caregivers as they compared services. Participants held attitudes that influenced their willingness to consider a service, whether or not they had direct experience and knowledge of the service. This finding is consistent with models explicating the complexity of forming beliefs and predicting behaviors (Ajzen & Fishbein, 1980). Beliefs, whether accurate or not, influence decision making. Misinformation or lack of information was a barrier, consistent with previous findings (Yamamoto & Wallhagen, 1998). In addition, the focus on gathering information about immediate need, as perceived by the caregiver, rather than understanding the range of options echoes the observation that a high proportion of Asian caregivers were not aware of available help, information, or support (NAC & AARP, 1997). Timing and pacing of the information and use was a facilitating factor for considering services, suggesting that the process of decision making may evolve over time as caregivers reassess their situation, the needs of the person receiving care, and changes in the acceptability of potential services, and the information they have gathered at that juncture.

The importance of recommendations, or the lack of recommendations, suggests that health care providers could play a more active role in assisting families with service identification, information, and evaluation. This potential contribution in providing education and assistance to families has previously been suggested (Schoenberg & Coward, 1998; Yamamoto & Wallhagen, 1998) and was identified by families as a desired support in managing their ever-changing caregiving situation.

The actual experience of the participants with long-term care services elucidated a pattern of dynamic use, with a high rate of temporary housing for respite or postacute care, the employment of multiple services, and a nonlinear progression of service utilization. In discussion of formal services and institutionalization, there is a tendency to conceptualize the range of services as a continuum designed for increasing dependence and decline. Kane, Kane, and Ladd (1998) exploded the myth of the “conveyor belt decline and pigeon hole classifications” (p. 72), suggesting that services be conceptualized as an array of options available for consumers. Participants in this
study described both episodic and chronic needs, with fluctuations in the types and intensity of assistance over time and with their utilization of formal services coinciding with times of higher need. The finding that families used services to augment their own efforts is consistent with the findings of Tennstedt, Crawford, and McKinlay (1993), who reported a common pattern of temporary formal service use and no evidence that families voluntarily withdraw their help in favor of formal services among community-dwelling elders receiving home care. The dynamics and complexity of service utilization seen in this study is supported by Hanley and colleagues (1990), who observed that receiving help from an informal caregiver did not necessarily prevent institutionalization of disabled elderly persons, suggesting that utilization is more complicated than simply inadequate availability of in-home informal help.

This study makes a contribution to our understanding of ways in which families augment services. In fact, families remained involved and played important roles in sustaining services, ensuring quality of care, and sharing responsibility for overall care, even when domiciliary care was not provided by them. In settings where housing is emphasized over health care (such as assisted living and adult family homes), families provided health care support in accessing health care appointments, obtaining medications, and responding to emergencies. Instrumental support and enriching the quality of life for the care receivers remained high priorities for caregivers, regardless of living situation. These findings illustrate the shared responsibility of informal and formal care providers and the importance of communication and coordination, an area of research that could identify ways for improving collaboration and effectiveness among families and providers.

This study supported previous findings of the acceptability of services among this population (McCormick et al., 1996) and provided more specific information about the formation of attitudes toward as well as features of various services. Citing the work of the Nikkei community in identifying the need, developing the programs, and providing volunteer support, participants had a positive view of these services. Many stated a preference for having Japanese American care providers because of their cultural understanding, with greater reluctance to engage helpers with other ethnic backgrounds. For older care receivers, care providers who spoke Japanese were preferred; however, for second-generation Japanese who were educated in English, this was less important. Food and activity preferences also reflected cultural underpinnings, with participants valuing traditional Japanese meals and interests for their enjoyment, familiarity, and meaning.

This descriptive research provides a comparison of strengths and weaknesses of various formal services along six dimensions. These dimensions, along with the salient cultural aspects, provide a basis for developing structured measures of attitudes toward specific services. The dimensions constitute a rich source for general content areas, and the specific attitudes within each service type have the potential to be developed into scalable items. Such an instrument has the potential for both predictive models and improving needs assessments or case management.

The sample was limited to members of the Nikkei community in Seattle, where the remarkable commitment and ongoing involvement of community volunteers has contributed to a strong reputation and potentially to greater acceptability of these services for Nikkei families. It is possible that services may be viewed differently in another Japanese American community with different challenges. The total size of the community as well as the geographic proximity of services to families might differ in larger cities with a more dispersed population, resulting in less cultural identification with the services. A further limitation of this research is the recall bias of a cross-sectional sampling of impressions of services. A longitudinal study of the caregiving trajectory and salient issues around serial decisions would be useful, as well as exploration of caregiver attitudes toward services once they are using certain options.

We believe that the contributions of this study outweigh these limitations for several reasons. The Japanese American population is a significant and growing group of older adults in the United States. Despite their prominence among the oldest old, this group has remained relatively neglected, particularly in exploring attitudes toward services. As one of the earliest Asian groups to become acculturated, Japanese Americans offer researchers the means to understand the challenges and opportunities inherent in designing and providing culturally sensitive services, a trend that will grow with the expansion of other Asian populations. This work provides detailed information about a range of services from multiple perspectives, including partners, daughters, sons, in-laws, care recipients, and professional providers. Because attitudes are formed through experience and beliefs shaped by others, the variety of perspectives strengthens the findings.

In conclusion, this study identified attitudes toward specific services available to family caregivers and illuminated the dynamic nature of the interplay between families and formal services. Clearly, with the growing population of the oldest old in the coming years, the demand for community-based care options will expand as the ability and availability of younger caregivers to shoulder the sole responsibility for elder care lessens. Ongoing research is indicated to explore shared roles between families and formal systems and to develop interventions to promote timely, cost-effective, appropriate services that capitalize on the relative contributions of families and formal providers and optimize the delivery of services for older and disabled populations. It is increasingly important to understand family decision making and to explicate systematic approaches to support the informal care network. Furthermore, research exploring family attitudes toward services is necessary for understanding disparate access to services among minority populations.
and improving sensitivity of providers to the needs and perspectives of their clients.

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Appendix

Focused Interview Questions
(Caregivers and Care Receivers)

1. Please describe a typical day for the care receiver (CR). How does he/she/you manage activities of daily living?

2. Tell me about the living situation—what helps him/her you to stay there? Is there anything you would like to change about the living situation? Is he/she/you getting the support needed?

3. Has CR had any recent changes in health or living situation? Please tell me about it. How has this affected CR and how has it affected caregiving?

4. When you think about CR’s future health and living situation, what do you think will happen? What would you like to happen?

5. Are there any services (such as personal care assistance, meals, household help, transportation, health care) you would like to have for CR that you are not getting now?

6. Has anyone ever recommended any services for CR? What happened?

7. What options do you know of in your community if CR were to need daily care from another person? What do you think about these options?

8. Please describe your impressions of the following services: In-home care (such as help with cooking, bathing, or medications) Assisted living Adult day care Adult family homes Nursing homes

Which of the above would you consider for CR? Why or why not?

If any have been used, ask about the experience with that service, (i.e., when, for what reason, positive and negative aspects of the service).
9. Is there anything else you would like to tell me about your impressions of health and personal care services?

**Focused Interview Guide**
*(Professional Care Providers)*

1. Please describe the type of services you provide to older adults.
2. Describe a “typical” client in your caseload.
3. For your clients, what constitutes “functioning well”? What about “functioning poorly”?
4. What is it about a living situation that you think supports daily functioning?
5. How do you identify clients at risk for functional, behavioral, or health changes?
6. Among your client population, what types of services are most readily accepted? Please describe the services and factors that promote acceptance.
7. Among your client population, what types of services are least readily accepted? Please describe the services and factors that impede acceptance.
8. Please give examples of referrals you have made for long-term care services.
9. In general, please comment on factors that promote or impede acceptance of the following services:
   - In-home care
   - Assisted living
   - Adult family homes
   - Adult day care
   - Nursing homes