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Practitioner's Essay

A Model for Developing and Implementing a Theory-Driven, Culture-Specific Outreach and Education Program for Korean American Caregivers of People with Alzheimer's Disease

Herb Shon and Ailee Moon

Abstract

The rewards of providing care to an aging family member are numerous, but psychological, social, physical, and economic stressors are often present. Moreover, although community programs and services designed to provide education, resources, and respite to caregivers and therapeutic benefit to seniors exist, Asian and Pacific Islander American caregivers may still confront significant cultural and structural barriers to service use.

This paper is based on a well-attended community-wide outreach and education program conducted in the Koreatown area of Los Angeles, California, in 2003 that targeted current and future Korean American caregivers. It employed tenets of French and Raven's original model of social power and interpersonal influence. We present details of how the authors addressed cultural and structural barriers to enhance access to services, as well as recommendations for future research in this area.

Introduction

Alzheimer's disease (AD) is a progressive and fatal brain disorder. Approximately 5.3 million Americans, mostly older adults, live with the disease, the seventh-leading cause of death (Alzheimer's Association, 28 August 2009a). AD is the most common type of dementia, representing 60 to 80 percent of dementia cases, with vascular-related diseases a distant second (Alzheimer's Association, 28 August 2009a). Dementia is used to describe a general loss of memory and other cognitive and physical abilities that affect

many areas of functioning and daily living. Although AD is the primary degenerative type of dementia, there are other types of dementia, including partially reversible dementia such as vascular and infection-related dementia, stroke-related dementia, and other neurological disorder-related dementia such as Parkinson's disease (Toseland and Parker, 2006). The ten warning signs of AD are memory changes that disrupt daily life; challenges in planning or solving problems; difficulty completing familiar tasks at home, at work or at leisure; confusion with time or place; trouble understanding visual images and spatial relationships; new problems with words in speaking or writing; misplacing things and losing the ability to retrace steps; decreased or poor judgment; withdrawal from work or social activities; and, changes in mood and personality (Alzheimer's Association, 28 August 2009b).

Although caring for loved ones with AD can be a rewarding experience, it can have deleterious social, psychological, physical, and financial consequences for caregivers. These consequences can include social isolation, stress, depression, physical exhaustion, decreased subjective well-being and physical health, loss in earnings from absenteeism, and concomitant decreased savings. Caregiver support services, such as caregiver trainings, support groups, and respite services, can help mitigate these effects; however, benefits cannot be realized unless caregivers know of these services and understand and value the intent of such programs. It is then that the services are culturally appropriate and sensitive.

This paper is based on a well-attended community-wide outreach strategy and education program conceptualized by the authors and implemented by Master of Social Welfare (MSW) interns and event presenters who targeted current and future Korean American caregivers in the Koreatown area of Los Angeles, California, in March 2003. The marketing strategy was designed to facilitate the target audience's access to this event in order to decrease cultural and structural barriers. We used a marketing strategy based on French and Raven's (1959) social psychology model of social influence and interpersonal power.

The Korean American Population and Prevalence of Alzheimer's Disease

Although Korean immigration began before the turn of the twentieth century, the Korean American population in the United

States did not significantly increase until after the passage of the 1965 Immigration and Naturalization Act. During the past three decades, the Korean American population has increased more than fifteenfold, from 70,000 in 1970 to 1.23 million in 2000 (Moon, 2006). Korean Americans are the fifth-largest Asian American ethnic group in America, with 78 percent being foreign born. Approximately one-third of the Korean American population lives in California. The number of older Korean Americans has grown at an even faster rate, increasing twentyfold during the past three decades, from 3,270 in 1970 to 66,254 in 2000 (Min and Moon, 2006). According to the 2000 Census data, 94 percent of the Korean American population aged sixty-five and older were foreign born, and 77 percent were “linguistically isolated.”

In Los Angeles County, the Korean American population increased from 145,431 in 1990 to 186,350 in 2000. In 2000 the Korean American population in Koreatown of Los Angeles, where the largest concentration of Korean Americans resides in the United States, represented 20.1 percent (46,664) of that area’s total population of 232,708 (Korean American Coalition—Census Information Center, 2003).

In March 2008, the Alzheimer’s Association released the information that one out of every eight people aged sixty-five years or older in the United States has AD (Alzheimer’s Association, 2009a). Although some researchers suggest that the age-specific prevalence of dementia among Asian American populations is similar to that of the U.S. population as a whole (Braun et al., 1995), some suggest that dementia may be a greater problem for Korean Americans than for other Asian American groups. For example, based on a comparative study of the lifetime prevalence rate of cognitive deficits, measured by a mental screening test, dementia was higher among Korean American older adults in Los Angeles than among other Asian American groups (Yamamoto, Rhee, and Chang, 1994; Watari and Gatz, 2004). Moon (2006) adds that with continued Korean immigration to the United States and the aging of the present and growing Korean American population, the number of those with dementia will grow significantly.

Cultural and Structural Barriers

Although community programs and services may provide education, resources, and respite to caregivers and therapeutic

benefit to seniors, Korean American caregivers may confront significant cultural and structural barriers to service use. Cultural barriers in particular may be more significant if the care recipient has a mental illness, or a disease conceptualized as such.

Cultural barriers may include shame, stigma, and loss of face associated with a family member suffering from an actual or perceived mental illness (such as AD) and the value and expectation that caregiving should remain a family's, and not an outsider's, responsibility. As the result of shame and stigma, some caregivers delay seeking help until their situations have reached a crisis level (Watari and Gatz, 2004). Such delays deny care recipients the benefits of early detection, diagnosis, and timely treatment of symptoms associated with AD and contribute to the premature institutionalization of care recipients (Watari and Gatz, 2004).

Jones, Chow, and Gatz (2005) found that a sample of Chinese, Japanese, and Korean American caregivers, although keenly aware of AD, nonetheless held beliefs about it that can best be described as "influenced at least as strongly by folk wisdom and culturally acceptable partial truths as by scientific information" (11). A study of Korean American older adults and caregivers suggests that persons with dementia continue to be stigmatized. Moon (2005) found that 75 percent of the Korean American older adults and caregivers in her study attributed dementia to the demented individual's personality characteristics (e.g., passivity, stubbornness, or being quiet) and the hardships and stress that she or he has confronted during a lifetime. Additionally, nearly one-half of Moon's sample believed that having a parent or sibling with dementia increased the likelihood of developing dementia, and more than one-third believed that older men are at a higher risk of developing dementia than older women. Thus, Korean American older adults' perceptions of dementia may originate from a range of sources, including folklore, experiences with or observations of demented individuals and/or their family members, and information derived from reputable sources.

Structural barriers may include services not being offered in the caregivers' native language, lack of knowledge or understanding about the services, distance to and inconvenience of the service location, and not having or being able to pay a substitute caregiver to provide custodial care in the caregiver's absence. A study of Korean immigrant older adults in Los Angeles found that they had

very low levels of awareness and utilization of most of the fifteen community-based long-term care health and social services available to them (Moon, Lubben, and Villa, 1998). Moon's (2005) survey found that most older adults and their family caregivers had little or no such information, which is critical for quality of care and life for people with dementia and their family caregivers.

Linguistically, 76 percent of U.S. Korean Americans speak a language other than English at home, 46 percent are limited when speaking English, and 39 percent are linguistically isolated (Asian and Pacific Islander American Health Forum, 2006). In California, 71 percent of Korean Americans are foreign born and 52 percent of California Korean Americans are limited English proficient (LEP) (Asian Pacific American Legal Center of Southern California, n.d.). A linguistically isolated household is defined as one in which no member fourteen years of age or older speaks English, and 41 percent of Californian Korean Americans are linguistically isolated. Thus, language barriers for caregivers and care recipients with AD are likely structural barriers to service use.

Education Program for Korean American Caregivers of People with Alzheimer's Disease

In light of the aforementioned research findings, we performed a needs assessment of the Korean American community in Los Angeles in 2003 regarding community education about AD and support groups. We found that no community-wide education program had ever been offered to this community, and that no Korean-language caregiver support groups were currently being offered. Consequently, the two authors and our two University of California, Los Angeles (UCLA) MSW interns conceptualized and developed an outreach/education program about AD targeting current and future Korean American caregivers. We will highlight key components that we believe contributed to the success of this project: 1) reduced caregivers' cultural barriers, 2) reduced structural barriers to attending this event, and 3) culture-specific outreach/education strategies based on Korean Americans' values and a model of social power/interpersonal influence.

Reduce Cultural Barriers

The event was purposely titled, publicized, and marketed as "An Educational Conference on Alzheimer's Disease." We be-

lieved that we could reduce stigma associated with AD by associating this event with the word *education* in lieu of the words *caregiver* and *support*. Including the word *education* into this event's title was a conscious decision because we believed that it is congruent to the value placed on education by Korean Americans, which is in keeping with Confucian tradition.

If we included a word like *caregiver* we believed that Korean American caregivers might have felt more visible, or that their anonymity would have been compromised. We also believed that use of a word such as *support* might be perceived by caregivers as a reflection on their ability to adequately perform their caregiver roles, or that they required "outside help" in order to do so. We believed that the words, *caregiver* and *support*, may have perpetuated stigma rather than mitigating it. It should be noted here that use of destigmatizing language has proven successful for other stigmatized diseases as well, such as mental health center names (e.g., family services centers) and educationally advertised programs for parents of at-risk youth couched as improving their children's academic performance.

In keeping with traditional Korean culture, our team believed that a traditional Korean meal and entertainment provided at the event was a gesture of gratitude and respect, and it created a sense of solidarity by sharing a meal together as a group. Several singers and a guitarist volunteered to perform traditional Korean songs, which the audience sang as a group, and a traditional Korean lunch was generously provided by one of the authors. Generosity shown to "guests" through providing food and entertainment with humility is a traditional Korean cultural value and norm.

Reduce Structural Barriers

In light of the above statistics on LEP and linguistic isolation among Korean Americans, all media interviews were conducted in Korean by bicultural, bilingual Korean American professionals who were respected and trusted in the Korean American community. The Alzheimer's Association's California Southland Chapter provided the event with written materials about AD in Korean, and, where none existed, our interns translated and transcribed Alzheimer's Association materials into Korean for this event's audience.

In terms of time and convenience, we developed a half-day event for Korean American caregivers that was presented on a

Saturday. This was based on our judgment and experience running caregiver support groups; we felt that caregivers would find committing to more than a half-day event on a weekday difficult due to caregiver and work responsibilities. To further reduce structural barriers to attending the event, we offered free custodial care in our Alzheimer's Day Care program during the event, and the event was held at St. Barnabas Senior Services, which is located on the outskirts of Koreatown and staffed by a significant proportion of bilingual Korean American social workers. Lastly, to overcome lack of transportation, the St. Barnabas Senior Services transportation department provided rides to and from this event for approximately fifteen individuals.

Develop Culture-Specific Outreach/Education Strategies Based on Korean Culture and a Model of Social Power/Interpersonal Influence

When conceptualizing this event, our team wanted to ensure its attractiveness to current and future Korean American caregivers in order to reach as many caregivers as possible. We referred to a model of social power and interpersonal influence developed by French and Raven (1959) and further refined by French (1965). The model and theory has been applied to power relationships within organizations, health psychology, close relationships, and educational settings; however, it appeared that it had never been applied to influencing community behavior.

Although the model has been expanded throughout the years, its original sixfold categories of social power/interpersonal influence include reward power, coercive power, legitimate power, referent power, expert power, and informational power. We used the three bases that we felt were most appropriate for influencing Korean American caregivers' attitudes and behavior in a community context: expert power, referent power, and informational power.

Expert power is based on the influencing agent's highly specialized knowledge, training, experience, ability, or skill that the target audience respects and trusts as a credible source for relevant information. To generate expert power, we assembled a panel of presenters with high educational status, professional backgrounds, and affiliations with the two major teaching and research institutions in Los Angeles (UCLA and University of Southern California [USC]).

They included an associate professor in the Department of Social Welfare, UCLA; an assistant professor of clinical medicine and director of the Geriatric Medicine Training Program at the Keck School of Medicine, USC; a master's level geriatric nurse from the Neuropsychiatric Institute, UCLA; and two UCLA MSW student interns.

Referent power is based on the target's identification with, admiration or positive regard for, and/or desire to follow the example set by the influencing agent. We established referent power through the following: all presenters were first-generation Korean Americans, spoke Korean fluently, held advanced degrees, and were affiliated with major teaching and research universities, and three of the four presenters were female, roughly approximating what we estimated to be the proportion of Korean American female to male caregivers in the Korean American community.

Additionally, two Korean American caregivers volunteered to provide their testimonies to the event's audience on the benefits of using adult day care programs, which we believe further strengthened the event's referent power. Two similar stories were shared through the presenters' media interviews for the purpose of increasing referent power, normalizing Korean American caregivers' experiences, educating them about the benefits of adult day care programs to their loved ones as well as to themselves, and publicizing our event.

Informational power is based on the persuasiveness of the influencing agent's logical, believable, and compelling message that contains information that the target regards as valuable and/or necessary. We established informational power through the following: 1) the presenters' educational and professional backgrounds, affiliations with UCLA and USC, and public-speaking skills during their interviews and 2) the two MSW interns' public-speaking skills during their interviews. St. Barnabas Senior Services', with its positive reputation and trust established in the Korean American community, was the host site of this event and was also viewed as a source of expert, referent, and informational power.

Content of the Conference

The content of the conference included an overview of the presentations by our social welfare professor and discussion of the significance of this event given our country's rapidly growing elderly population and number of people with AD. The causes of

AD were presented by our physician presenter, followed by updates on current research findings and treatments. A discussion of self-care for the caregiver and care recipient were provided by our nurse presenter, and our social welfare intern presented information about available social services and other caregiver support services in the Korean American community and the city of Los Angeles. Each presentation elicited a considerable number of questions and personal caregiving stories from the audience.

Results

More than ninety Korean Americans, apparently the majority of whom were current and future caregivers, attended this event. The room selected for the event comfortably held eighty people, thus some attendees had to stand for the presentation. At the close of the event, our interns successfully recruited ten Korean American caregivers and began the first Korean-language caregiver support group at the host agency. Most of these caregivers continued to attend follow-up caregiver support-group sessions, while others stopped attending after they reportedly received the information and help that they sought. The MSW interns who cofacilitated this group reported that the caregivers who remained until the end of the program had become friends and had plans to continue interacting with each other after the caregiver support group ended. All participants were provided with information through the presentations, as well as through the written materials assembled by the MSW interns.

Based on the success of this event, the executive director of St. Barnabas Senior Services applied for foundation funding to replicate and improve on the 2003 event. As a result, another event was held in July 2005 at St. Barnabas Senior Services. This time, it was called a "Dementia Workshop for Family Caregivers and Service Providers" and more than 140 Korean Americans, including 19 service providers from 15 various organizations (including nursing homes, adult day-care centers, senior citizen associations, and social- and health-service agencies in the Korean American community) attended the workshop. Much of the transportation services were provided for elderly participants by St. Barnabas Senior Services' transportation department.

Although the content of the second workshop was similar to the first one, one of the authors who took the leading role in the

planning for the second workshop identified three areas for improvement: 1) formal and greater involvement of various service organizations in the workshop, 2) improvement in the removal of barriers to attending the workshop for family caregivers who needed someone to care for their family members with dementia while attending the workshop by arranging volunteer caregivers on the workshop site, and 3) expanded coverage of the workshop and the topic of dementia by the Korean American media. All three areas for improvement were successfully implemented during the second workshop.

In order to increase dementia or senior service-related organizations' participation in the workshop, an invitation letter was mailed to all major social- and health-service agencies, adult day-care centers, nursing homes, and senior citizen associations whose clients and memberships are primarily Korean Americans, with an opportunity for them to reserve a free table for display of their organization's brochures and for consultation with attendees. Thirteen such organizations set up tables at the workshop, provided information about the services they provide, and interacted with participants.

Our impressions of the 2005 Korean American caregiver event suggested an increased openness to discuss dementia, caregiver challenges, and the use of the terms *dementia* and *AD*. Additionally, following the 2005 project, a Korean American newspaper began running follow-up articles on dementia and caregiving to further educate the Korean American community about the disease, ways to cope, and how to reach out for help. We believe that in light of these events, the 2003 program helped to begin a conversation about dementia and caregiving among members of the Korean American community and helped decrease the stigma and shame (cultural barriers) associated with the disease. Additionally, we believe that the outcome of the 2005 program, including the Korean American newspaper's articles on dementia and caregiving, reflects increased progress to these ends.

Recommendations

At the end of this event, although success was measured by participant attendance, we could not determine which of our strategies were most effective in influencing participants to attend this event or the extent to which participants learned something new

or different about AD, caregiving, and self-care. Despite our belief that all efforts probably helped to some degree, future outreach and education programs targeting the Korean American (or any) community should include an evaluation component to answer these questions.

For example, it would be helpful to develop a survey instrument to evaluate the extent to which each of the employed outreach strategies was effective in influencing participant attendance. What percent of the participants learned about the event through a particular Korean American newspaper, radio or television interview, a flier left at a Korean American grocery or electronics store, their pastor, or any combination of these? These data could inform us of the most effective ways to outreach to Korean Americans and where to focus an agency's resources and time.

Measuring other variables to determine if they influenced participant attendance can also be helpful. For example, developing questions and using a four-point Likert scale (e.g., very unimportant, somewhat unimportant, somewhat important, very important; or, strongly disagree, disagree, agree, strongly agree) for answer options can assess the relative importance of each of the strategies used to reduce cultural and structural barriers and those based on the model of influence employed. For example, was it important to participants that the event emphasized "education," was it important that the agency provided transportation and on-site custodial care, was the day and time of the event convenient, was it important to have Korean-speaking presenters who did not require translators, and were the presenters' level of education and reputations (e.g., where they attended school, where they currently work, their job titles) important to participants?

It would also be helpful to assess the effectiveness of the event in educating participants about, for example, AD, caregiving, self-care, and community resources. This can be accomplished by developing and administering a pretest/posttest survey to the participants, which we believe should use a multiple-choice answer option format. Having participants answer open-ended questions to which they do not know the answers may lead to embarrassment, discouragement, and refusal to complete the survey. We would also recommend that the pretest be administered clearly before the program starts, even if this requires volunteers to assist participants, so that completion of the pretest survey is expected

before the program begins. Similarly, we would suggest that the posttest survey (which can be integrated with the above questions that address cultural and structural barriers and the model of influence) be administered before officially ending the program and before giving participants their “gift” for attending the conference. This will communicate to participants that ending the conference is contingent upon their completion of the survey. The gift mentioned above may include self-care items, articles and brochures in Korean, lists of community resources, and anything else that the event planners can afford or have donated that would be of use to caregivers. We feel that it is important to give participants something physical to take home with them that conveys our gratitude and appreciation for their participation.

Other questions that can be included in the exit survey can address where caregivers receive their information about AD and other health-related issues, their suggestions about the best ways for event planners to advertise future events (e.g., newspaper, radio, television, churches, and stores), the topics that they would like addressed in future events that were not addressed in the current one, and how they would rate the event overall for its usefulness, importance, and convenience.

Although not originally designed to influence community attitudes and behaviors, we believe that using the three types of social power and interpersonal influence developed by French and Raven (1959) and French (1965) was helpful in marketing this event to the Korean American community. These bases of power and influence (expert, referent, and informational power) are commonly used in television, newspaper, and radio advertisements (e.g., a well-known physician advocating the use of a medication or treatment, a celebrity endorsing a product or service, and a law firm advertising expertise of a new, unfamiliar tax law affecting Americans), thus their application to the community level is feasible.

The remaining three bases of power in the model (coercive, reward, and legitimate power) were not used because they were infeasible and inappropriate for our purposes. Coercive power is based on the influencing agent using coercion to elicit a behavior in the target, to which the latter feels compelled to comply in order to avoid a punishment. Reward power is based on the target performing a behavior in order to receive a reward from the influencing agent. Legitimate power is based on the target’s obligation to

perform a behavior because of the influencing agent's superior position and influence within the context of an organization. We believe that other models may and should be explored for conceptualizing, developing, implementing, and evaluating the effectiveness of this type of community project. One such model may include one developed by Robert Cialdini (1985), which consists of six principles of influence and reportedly has good cross-cultural application.

Our program targeted Korean Americans in or near Koreatown in Los Angeles, the oldest and largest home to Korean Americans in the United States. Our efforts were greatly facilitated by an availability of bilingual, bicultural Korean American professionals, social work interns, the Korean media, and Korean churches. Additionally, many Korean Americans are avid listeners of Korean radio programs and their literacy level may differ from other groups. Developing and implementing an outreach and education program for communities that differ significantly from the Los Angeles Korean American community should take these and other differences into consideration when conceptualizing, developing, and implementing this type of project to ensure its success.

With the increasing diversity of our country and particularly those areas in which large concentrations of ethnic groups reside, practitioners need to explore and find creative ways to address their diverse and unmet needs. If carefully and properly designed, these types of projects can generate data for evidence-based practice.

Notes

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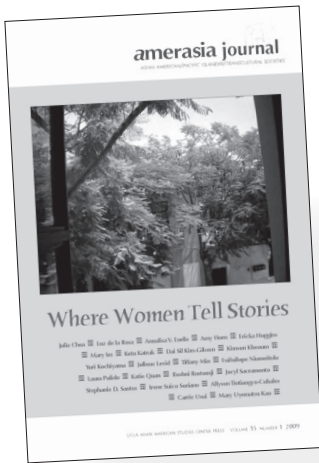
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