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Dementia Care Programs and Services for Chinese Americans in the U.S.

Bei Wu · Nancy Emerson Lombardo · Kun Chang

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Abstract The purpose of this study is to provide an overview of development of dementia caregiving models for Chinese Americans in the U.S. This study reviewed some existing programs and interventions for Chinese dementia caregivers that were provided by service organizations and academic institutions. The recommendations for development of dementia care models include: 1) Collaborating with local community agencies that work with the Chinese population; 2) Create, maintain, and expand existing Chinese-language help-lines with individualized counseling, skills training, and support system-building services; 3) Increase caregiving information available in the Chinese language; 4) Sustain adequate funding for existing programs and services; 5) Raise public awareness through ongoing publications, media outlets, and workshops in senior housing and centers; 6) Raise health care and social service providers' awareness; and 7) Increase program evaluation effort.

Keywords

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Introduction

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There is a growing need for dementia care services in the United States that are targeted to minority populations. Researchers have shown that appropriate services, programs, and interventions can help individuals with dementia and their family members to cope with the disease and improve overall health outcomes for both patients and caregivers (Schulz et al. 2002). However, the general lack of culturally-sensitive dementia care services presents unique challenges for Chinese American communities. This study provides an overview of existing dementia caregiver support services for Chinese American families and provides recommendations for the further development of culturally-sensitive dementia care programs.

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An estimated 14% of elderly individuals in the United States (U.S.) suffer from dementia (Plassman et al. 2007) and as the number of older adults increases in the U.S population , the prevalence of dementia is expected to increase significantly by 2030 (Alzheimer's Association 2008). While there has been an increase of culturally specific programs and services for minority caregivers in the U.S., the number is still very limited. Language barriers, cultural belief systems, and a lack of awareness about existing programs and services also contribute to gaps in dementia care services for minorities.

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Chinese Americans are the largest ethnic group of Asian origin in the U.S. The number of Chinese Americans reached approximately 3.54 million in 2007 and has been projected to continue to grow 6–15% by 2050. The largest concentrations of Chinese Americans are found on the West and East Coasts including California and New York. Adults over the age of 65 comprised approximately 11.2% of the Chinese American population in 2007; of these individuals, only 16.8% speak English only, whereas 40% speak English less than “very well” (U.S. Census Bureau 2007).

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Research shows that Chinese families providing care to an elder with dementia tend to use fewer support services than families from other ethnic groups (Ho et al. 2000; Wu 2000). Chinese Americans with dementia and their family members face multiple culturally-relevant barriers that disrupt the process of finding and utilizing important resources and services. Explanations for the low use of services by Chinese Americans include the view that dementia symptoms are part of normal aging, a stigma toward Alzheimer's disease and other conditions with mental abnormalities, the Confucian value of filial piety (the importance of children taking care of elders), and a lack of culturally competent service and educational information (Chow et al. 2000; Delgado 2000; Elliott et al. 1996; Guo et al. 2000; Levkoff et al. 2000; Ren and Chang 1998; Tabora and Flaskerud 1997).

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One of the common responses to dementia among Chinese Americans (as well as many other ethnic groups) is viewing the symptoms of dementia as a normal consequence of aging. Since many Chinese American families do not perceive dementia as an illness, they do not seek services at all or may only seek services late in the disease process. Among Western-trained doctors, ethnically Chinese primary care physicians may also share and reinforce this perception of dementia and its relationship to aging with their patients.

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Alternately, many Chinese view dementia as a form of madness or mental sickness due to a retribution for past culpable deeds by individual self, family, or ancestors (Sundaram 2007). There are no spoken terms in Chinese equivalent to the

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diagnostic terms such as Alzheimer's disease or dementia (Vickrey et al. 2007). 71
Instead, individuals with Alzheimer's disease and dementia are often described as 72
"confused", "stupid," "losing one's mind" or "catatonic" in the Chinese language. 73
Moreover, some Chinese believe that a traumatic emotional experience can lead to 74
dementia and episodic forgetfulness (Alzheimer's Association 2002). Thus, a person 75
with mental disease such as dementia could reflect badly on the entire family, which 76
in turn causes embarrassment and shame to the other family members. 77

Because of the strong stigma attached to mental illness in the Chinese culture, 78
some friends and relatives may even stop contacting caregivers. Lack of social and 79
family support may add psychological stress to family members who care for an 80
elder with dementia. More importantly, stigmatization serves as a barrier for Chinese 81
families to seek timely dementia diagnosis and interventions (Zhan 2004). Knowing 82
that a label of dementia can bring shame to the entire family, Chinese American 83
physicians also may not voice their suspicions about Alzheimer's disease or 84
dementia if the family has already successfully adapted to the changing needs of the 85
elder with dementia (Hicks and Lam 1999). Thus, only when the situation has 86
deteriorated to the point that the family can no longer handle things on their own is a 87
diagnosis offered by a Chinese health care provider. By the time families seek help, 88
the situation is usually desperate, and there is immediate need for assistive services 89
or nursing home placement. 90

Traditional Chinese viewpoints derived from Confucian culture emphasize 91
harmony and respect among family members. Individuals are encouraged to share 92
personal and emotional problems with family members and to avoid interpersonal 93
conflicts. Therefore, Chinese families tend to assume caregiving responsibilities for 94
their elderly family members with mental illness instead of accepting the advice or 95
assistance from others (Zhan 2004). 96

Thus, it is necessary for policymakers, researchers and service providers to 97
develop strategies for overcoming cultural barriers that impede the delivery of 98
appropriate services and programs to Chinese Americans with dementia and their 99
caregivers. This can significantly improve the quality of life for both patients and 100
their family members. The purpose of this study is to identify and provide 101
descriptions of culturally-sensitive services and programs currently available to 102
Chinese American families. We conclude with recommendations that originate from 103
our own experiences developing dementia care programs for Chinese Americans in 104
the greater Boston area. 105

Methods 106

First, we conducted a review of existing programs and services for dementia 107
caregivers among Chinese Americans. We searched multiple databases to identify 108
articles, book chapters, and reports mapping to the subject headings: *Chinese* 109
American, dementia caregivers, services and programs, and either dementia or 110
Alzheimer's disease. The databases included PsycINFO, Cumulative Index to 111
Nursing and Applied Health (CINAHL), MEDLINE via PUBMED, and Google 112
Scholar. Citations yielded from this search written in the English language and 113
published prior to October 2009 were evaluated for inclusion in this review. Second, 114

we describe the Chinese Dementia Awareness and Intervention Project (CDAIP)—a multidimensional program providing outreach, education, and support for family caregivers. The project was a three-way collaboration between an academic institution (Wellesley College), Chinese American community-based agencies, and a mainstream agency (the Massachusetts chapter of the Alzheimer's Association), with each of the organizations learning from and empowering the others.

Results

Services and Programs Provided by Agencies

Health care agencies and community organizations are the major providers of services and programs for caregivers. While a few services and programs are available for Chinese American dementia caregivers across the United States, most of them had limited published information available for evaluation. The following are some of the organizations that have provided services for Chinese dementia caregivers.

Alzheimer's Association

In the past decade, the Alzheimer's Association increased its outreach efforts to minority populations. The organization, through its local chapters, provides various services to caregivers of family members with dementia. Bilingual services are often provided for Chinese immigrants and their families. For instance, Chinese family care specialists can assess patients with dementia and consult with families as they determine how best to meet the patients' caregiving needs. The Alzheimer's Association operates a 24/7 Toll Free Helpline where callers may receive referrals and information at any time. A crisis consultation program offers supports for nursing home placement, family conflict resolution, and guidance for the management of challenging situations that arise for persons with dementia. In addition, many chapters operate educational intervention programs to train staff in long term care skills and host open lectures for community audiences on topics such as managing caregiver stress (Alzheimer's Association 2009). However, only limited number of chapters have ethnic Chinese or bilingual staff available to serve Chinese American patients and families. Translational services and Chinese-language materials are available through the national office and some chapters.

A similar model of care was implemented for Asian and Pacific Islanders, once the Latino Alzheimer's Project in the Alzheimer's Association of Los Angeles, Riverside, and San Bernardino Counties Chapter demonstrated success for the Association's outreach efforts. The Dementia Care Network was developed in conjunction with the California Department of Aging and supported by a grant from the U.S. Administration on Aging (Alzheimer's Association 2002). A two-phase focus group project was conducted during 2002 and 2003 to obtain information about the needs and experiences of Chinese caregivers of family members with dementia. Based on the findings from the focus group project, the Network members found that incorporating education into monthly support groups helped to overcome

some of the cultural stigmas associated with dementia and support groups. The curriculum and brochure were translated into Chinese in order to provide better bilingual in-home support services and to introduce families to the benefits of adult day services (Alzheimer’s Association 2004).

In collaboration with local community based organizations serving the Chinese communities in Northern California, the Dementia Care Network currently has two Chinese American staff dedicated to outreach efforts. The program provides a Chinese-language telephone helpline offering information and referrals, a Care Consultation service, support groups for Chinese family caregivers, a MedicAlert + Safe Return service, and respite care services. From March 2007 to October 2009, 3,754 people attended the Network’s educational community presentations and a Chinese caregiver conference. Within a two-year period, 268 Chinese dementia caregivers attended monthly support group meetings hosted by the Network and 124 people called the Chinese-language helpline. The program also distributes educational materials in Chinese, including DVDs for Chinese and Chinese American caregivers (P.N. Chang, personal communication, November 13, 2009).

California Caregiver Resource Centers

Funded by the California Department of Mental Health, the California Caregiver Resource Centers (CRCs) have provided information, education, and emotional support to more than 260,000 families who provide long-term care at home for mentally ill family members, including support services targeted specifically to Chinese American families (Caregiver Resource Centers 2005). Several CRCs employ full-time bilingual consultants work with service providers and other staff to communicate effectively with non-English or limited English speaking Chinese family caregivers of persons with dementia (“California Caregiver” 2007).

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Interventions Conducted by Research Institutes

The Chinese Caregiver Assistance Program (CCAP) at the Stanford University School of Medicine designed one of the first randomized clinical interventions specifically for Chinese dementia caregivers. The In-Home Behavioral Management Program (IHBMP) consisted of a series of dementia care intervention projects to improve in-home care skills for Chinese caregivers and thus, help to minimize caregiver stress (Stanford University School of Medicine, n.d.). In the first stage, a theoretically-grounded intervention using Cognitive Behavioral Therapy (CBT) was developed by psychologists in conjunction with Chinese American caregivers and local Chinese professionals who work with caregivers. The CBT approach was tailored for Chinese American caregivers and was empirically tested by comparing the experiences of Chinese American and White family caregivers (Gallagher-Thompson et al. 2006). The second phase of project compared the IHBMP to a telephone support condition among 35 Chinese caregivers over a 16-week period (Gallagher-Thompson et al. 2007). The findings indicated that Chinese American caregivers in IHBMP were less bothered by caregiving-specific stressors and had lower depression levels than caregivers who received support over the telephone. Caregivers with low baseline levels of self-efficacy for obtaining respite benefited

from in-home visits by program staff, but showed little improvement if they only received assistance via the telephone. Caregivers with higher self-efficacy at baseline benefited from both treatments.

The research team at the Chinese Caregiver Assistance Program further developed DVDs to educate Chinese American caregivers on ways to improve their skills for handling everyday stressful situations. The DVDs were developed in Mandarin Chinese with both English and Chinese sub-titles. Participants reported greater improvement in knowledge and skills in areas such as stress management. Participants also believed that watching this DVD enhanced their ability to care for their afflicted family member more than those in the English-only DVD group.

The Chinese Dementia Awareness and Intervention Project (CDAIP)

To address problems surrounding dementia care in the Chinese immigrant and Chinese American communities of the greater Boston area, the Chinese Dementia Awareness and Intervention Project (CDAIP) was launched in 1998. The CDAIP was spearheaded by one author of this study (Emerson-Lombardo), along with professionals affiliated with the Greater Boston Chinese Golden Age Center (GBCGAC), the Wellesley College Center for Research on Women, Midtown Health Care, Inc., and the Massachusetts Chapter of the Alzheimer's Association (Emerson-Lombardo et al. 2007). Funded by the Boston Foundation and subsequently by the EHA Foundation, the project team was able to identify and successfully serve a group of caregivers and persons with dementia with unique cultural needs who probably would not have otherwise been identified and served by the mainstream organizations. Over two years, the team created an outreach/public education effort, a train-the-trainer program (called the Chinese Dementia Specialist Education Program or CDSEP), a phone help-line, bilingual brochures and educational materials, and an individualized caregiver counseling and support program.

Each of the three collaborative partners contributed unique elements to the overall project. The community agency staff offered concrete experiences and authentic perspectives from persons who work with Chinese Americans. The Alzheimer's Association learned how to reach out more effectively to the Chinese American community while in turn offering their expertise about Alzheimer's disease and dementia. The Alzheimer's Association also provided training for the phone helpline as well as speakers and materials for CDSEP. The researchers provided funding (through foundation grants), information, and expertise to organize and facilitate the intensive sustained education and service development efforts. This program represents an effective model for building and maintaining an enduring network to serve Chinese American families dealing with dementia that could be replicated in other multilingual communities.

We found that networking with preexisting minority community organizations, including religious groups, facilitates minority outreach efforts. In addition, existing services and informational materials need to be modified to meet the cultural and language needs of the minority group. Our long-term commitments to minority

outreach efforts necessitated a sustained investment of time and effort and helped us 243
achieve sufficient penetration into ethnic Chinese communities. 244

The Chinese Dementia Specialist Education Program 245

Our train-the-trainer program, called the Chinese Dementia Specialist Education 246
Program (CDSEP), reflected both the literature and the team members' experiences 247
and beliefs in the importance of capacity building for existing staff as opposed to 248
continually bringing in outside experts for in-service training. Its design was based 249
on previous informal need assessments by our own team. 250

The CDSEP featured 11 lecture topics, presented by various faculty experts and 251
chosen for their relevance to the prospective participants (Emerson Lombardo et al. 252
2002). Topics included the signs and symptoms of dementia, the differences between 253
dementia and normal aging, the latest research and medical treatment, drug 254
reactions, cultural issues, communication issues, behavioral issues, services offered 255
by the Alzheimer's Association, therapeutic activities, Chinese medicine, acupunc- 256
ture and more. 257

Cultural issues related to dementia services were integrated into each session. 258
Participants were encouraged to share their experiences with Chinese elders and 259
families. As part of the cultural appropriateness efforts, most speakers were 260
knowledgeable about both Chinese American culture and dementia. The CDSEP 261
participants received more than 300 pages of written materials in both English and 262
Chinese on designated curriculum topics. These materials could also be used for 263
later personal references, for sharing with others, and for subsequent training of 264
other people. 265

The CDSEP trained 22 people from various agencies, of which 16 were certified 266
as bilingual Dementia Specialists. The CDSEP graduates helped more than 70 267
families within 10 months of completing the training program. In addition, they held 268
76 workshops and discussions that we estimate reached approximately 300–400 269
people. Furthermore, one CDSEP graduate served as a panelist on a television show 270
on Alzheimer's disease and another spoke about Alzheimer's disease on a local 271
Cantonese radio station. 272

Feedback from participants on improving the course included having information 273
about new research, including alternative treatments for Alzheimer's disease; using 274
more case studies; adding more tests and quizzes to reinforce learning; and adding 275
additional information on patient advocacy and how to help caregivers address 276
behavior issues. Participants were also interested in learning how to administer 277
simple cognitive screens in Chinese and English to help staff recognize persons with 278
dementia. This request highlights the need for culturally sensitive cognitive 279
screening tools that are short and easy to administer. 280

The CDSEP demonstrated that the train-the-trainer model is an effective 281
approach for building dementia care capacity in community-based agencies, 282
increasing outreach to people with dementia and their families, and raising 283
dementia awareness in bilingual and minority communities. In addition, once staff 284
members are trained, they can be effectively involved in choosing priorities and 285
shaping programs to meet the needs of clients about whom they have become 286
more knowledgeable. 287

Bilingual Help-line 288

An important component of the CDAIP was the creation of a Chinese-language dementia help-line that offered an immediate solution to people who needed information about the process, treatments, and services associated with dementia.

The Alzheimer's' Association of Eastern Massachusetts provided the initial help-line training, follow-up training, peer support, and backup for questions and concerns. The two help-line staffers were also trained through the CDSEP program. We also collected Chinese-language materials on dementia and aging from around the world; when Chinese-language materials simply did not exist, the team translated materials from English. We created three libraries on Chinese dementia in the GBCGAC branch offices, from which the help-line workers could retrieve, copy, and distribute relevant information. In addition to running the help-line, they also offered longer-term services, including consultation and counseling.

The help-line quickly became a key aspect of our efforts, proved itself to be a great asset to the Chinese-speaking communities, and helped approximately 40–50 families per year who found it a convenient and culturally appropriate service. The topics discussed during calls included home safety, available services, transportation, dementia symptoms, care methods, home-based activities for the person with dementia, emotional concerns, and behavior issues. Encounters included emotional support for the client and families.

Among both the help-line and the caregiver advocacy families, almost none of the Chinese elders with probable dementia spoke English, and less than half of their family caregivers did. Most of the caregivers who did speak English were not fluent enough to deal with complicated issues surrounding services in the general long-term care system. Since our help-line staffers spoke English, Mandarin, Cantonese, Taishanese, and various dialects, they were equipped to overcome the language barrier within this community and help introduce and even escort families to appropriate services. Thus, this bilingual, bicultural service was essential.

Individualized Caregiver Counseling and Support Intervention 318

In 1999, the Chinese Caregiver Intervention was developed as an adaptation of a National Institute on Aging (NIA) grant titled the Multicultural Memory Loss Awareness Project (MMLAP) (Emerson Lombardo et al. 2001; Emerson Lombardo and Ooi 1998). The primary participants in this study were caregivers of persons with dementia. For eligibility purposes, all elders with dementia in the caregiver/elder dyads ($n=11$) had symptoms of memory loss. Recruitment occurred via hospitals, home care agencies, clinics, and day care services. In addition, advertisements were placed in Chinese newspapers and on radio programs. The interventionist received training and certification through the CDSEP. The interventionist was trained for an additional 4 weeks on (a) becoming a caregiver advocate, (b) assessing caregiver needs, (c) using the assessment instrument, and (d) conducting in-home skill training interventions consisting of education, counseling, and service acquisition.

The specialist made home visits to families, teaching them skills for caring for their elders with dementia and offering them information about caregiving options and assistance in securing supportive services and community support. She offered counseling and emotional support as needed, and guided them in relieving their own stress.

This program included a complete assessment of patient and caregiver status and issues adapted from a previous caregiver intervention assessment developed under the NIA-funded Multicultural Memory Loss Awareness Project effort and translated into Chinese. The assessment instrument was designed to be completed over several meetings and be part of the therapeutic intervention. Domains covered by the instrument included caregiver status; caregiver moods and sense of burden/stress; history of client memory and cognitive issues; physical, cognitive, and emotional condition of the client; behavioral symptoms; and client and family financial and legal status. In addition, the Mini-Mental State Examination (MMSE) (in Chinese) was used to give a direct assessment of cognitive status. The assessment guided the interventionist and family in setting priorities and making decisions.

The assessment, education, and training occurred in the caregiver's home to allow firsthand observation of the caregiving situation to accommodate caregivers with limited free time. All documentation was made in English so that the answers, orally given in Chinese, did not require translation. Evaluations were also based on the interventionist's case notes.

Approximately 15 families were helped during the 18-month intervention demonstration period. The majority of caregivers (60%) resided with the person with dementia. The caregivers' ages ranged from 42 to 80 (mean 59 years);¹ 70% lived in Boston. Only 40% of caregivers could speak some English. Most spoke Cantonese (70%), the rest spoke Mandarin (20%), and Taishanese (10%).

The elders with dementia ages ranged from 68 to 93 years (average age was 83)² and were mainly women (90%); 40% of elders lived alone and 60% with their caregivers. None of the elders spoke English but instead spoke Cantonese (50%), Taishanese (30%), and Mandarin (20%).

Types of counseling/consultation services used included needs assessments (29%), counseling (33%), service acquisition (13%), follow-up (17%), and referral (8%). Service-related topics discussed during sessions with caregivers included adult day health (50%), Medicaid (21%), "general questions" (13%), nursing homes (13%), and home safety (4%). Other issues addressed most frequently included embarrassing behaviors, verbal abuse, isolation, learning how to make positive financial arrangements, and handling challenging behaviors as well as emotional support for the caregiver.

Because of the stigma associated with dementia, some families met the interventionist with great reluctance and wanted fewer and shorter interventions. Thus, the length of visits varied greatly, with some families wanting between one and four visits and others wanting more than 10. The planned 24 h of the intervention was divided among approximately 10–14 home visits at mutual convenience, visits to the caregiver's home, and caregivers coming into the office to see the social worker.

This caregiver intervention successfully identified and served a group of caregivers and persons with dementia who were, in the late 1990's, overlooked by

the mainstream service system that did not address Asian American minority issues 379
or provide culturally-sensitive resources. During this intervention, barriers that 380
inhibited Chinese-speaking Americans from obtaining proper services were 381
uncovered including: lack of trained health care professionals, lack of knowledge 382
among Chinese-speaking caregivers, language barriers, and the lack of advocacy, 383
diagnosis, and statistics. Caregivers were very satisfied with this individualized, 384
personalized program. Their knowledge on dementia and services improved. They 385
were more aware of the services available, and more open to discuss alternative 386
ways of seeking outside help. 387

Discussion 388

The results from our program and others have shown that that Chinese American 389
elders and families responded as positively to caregiver support programs as 390
other ethnic groups once the programs were created and offered to families in a 391
bilingual format with a culturally attuned staff delivering the services in familiar 392
settings and organizations. Several factors are important for the implementation 393
of the programs. 394

Collaborative Efforts 395

It is essential to have the researchers and key decision makers embrace the agenda 396
and pursue the funding to initiate and maintain the programs. Collaboration is a key 397
element for successful implementation of a model for dementia care. Having an 398
advisory group including representation from various organizations such as 399
community gate keepers, academic institutions, and mainstream organizations would 400
be helpful to guide the design and implementation of the program. Academic 401
institutions have the expertise and skills to train staff in community-based 402
organizations, and conduct evaluation of the programs. In many cases, the academic 403
institutions have the research or program funding to initiate the project. The 404
mainstream agency, such as Alzheimer's Association, has the information, skilled 405
staff, and potential funding to facilitate the services and programs. The success of 406
the program heavily relies on the community-based agencies. These agencies have 407
the Chinese staff in place and have served the Chinese population on a regular basis. 408
Each of the three organizations learns from and empowers the other two. In addition, 409
working with community-based organizations is an important way to sustain the 410
project. Another important aspect to our strategy was to create "experts" within the 411
Chinese community who were likely to stay in place to continue delivering needed 412
services and lead efforts to disseminate knowledge. Although the programs ended 413
after the completion of the project, many of the project outcomes are still being 414
utilized in the community. For instance, the training manual for health care 415
professionals was shared by the Alzheimer's Association Los Angeles Chapter and 416
the model developed for dementia caregivers was adapted by the Chinese Golden 417
Age Center to programs that serve elders with other chronic conditions such as 418
Parkinson's disease. In addition, the CBCGAC has since become involved in other 419
collaborative dementia research projects. 420

Outreach Effort

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To best meet the needs of Chinese Americans with dementia and their caregivers, researchers and outreach workers need to develop collaborative and cooperative relationships between informal and formal support systems. The formal system, as such, should be recognized as parallel and complementary to the informal system. Helpful strategies for outreach and recruitment to minority populations include collaborating with relevant “gatekeepers” and using focus groups to shape recruitment materials and approaches (Sinclair et al. 2000). One key element is to having outreach carried out by a bicultural person who either lives in the target community or has a familiarity with it. Personal ties can add further legitimacy to an effort.

Types of Services and Programs

431 Q7

Dementia burden occurs in the context of significant stigma to Chinese Americans (Liu et al. 2008; Zhan 2004). In order to reduce stigmatization of dementia, it is critical to educate the Chinese communities, health care providers, and families about the disease, diagnosis, available services and treatment options. Our evaluation of existing dementia caregiver interventions and programs demonstrates a strong consensus that all caregivers are likely to benefit from enhanced knowledge about the disease, the caregiving role, and resources available to caregivers. Therefore, providing knowledge on dementia for Chinese elders and their families would play an essential role in this process. It is also critically important to develop other culturally appropriate and acceptable programs and services to meet the needs of Chinese dementia caregivers. As an illustration, studies have shown that psychotherapy is effective in reducing caregivers’ stress and depressive symptoms (Brodaty et al. 2003; Steffen et al. 1998); however, many Chinese Americans are reluctant to engage in psychotherapy. The first author and colleagues conducted a study among Chinese immigrant elders aged 60 and above and found that although 22% of elders had depressive symptoms, no one visited a psychiatrist in the past 12 months (Wu and Tran 2004). On the other hand, a psychoeducational approach is an appropriate intervention to minimize the possible stigma of participation (Gallagher-Thompson et al. 2007). In addition, our study along with others (Zhan 2004), suggests that it would be helpful to form support groups for Chinese caregivers and provide informal peer support sessions that could be facilitated by Alzheimer’s and dementia experts and a social worker. Further, studies have suggested that Chinese dementia caregivers are in greater need of adult day care than many other home care services (Wu 2000).

Q8

Recommendations for Development of Dementia Care Models for Chinese Americans

455 Q7

456

Currently, very limited interventions, programs and services are available for Chinese Americans. In addition, most of these programs and services are only targeted for caregivers and with limited evaluation of caregiver outcomes. In the past decade more patients of all ethnic backgrounds including Chinese Americans are

being diagnosed earlier in their disease and may seek help for themselves. This trend reflects growing awareness and media attention to “brain health” as well as increased provider motivation to diagnose because of available prescription medications for Alzheimer’s disease. Recent intervention studies have suggested that there may be important synergies achieved by simultaneously treating care recipients (e.g., giving medications or memory retraining) and caregivers, and by altering the social and physical environments via multi-component interventions. Therefore, development of care models that target both caregivers and care recipients would be an optimal approach. For researchers, there is considerable room for methodological improvement in the field (Brodaty et al. 2003). Future research should be conducted with more rigor: randomized, controlled, blinded outcome assessments, with follow-ups for at least 6 months, together with use of well-validated and reliable outcome criteria measuring outcomes proximally (burden, knowledge) and distally (depression, quality of life).

From the program development perspective, we developed the following recommendations: 1) Collaborating with local community agencies that work with Chinese population; 1) Create, maintain, and expand existing Chinese-language help-line, individualized counseling and skills training, and support system-building services for Chinese American family caregivers of persons with dementia; 3) Increase caregiving information available in the Chinese language about dementia and dementia-related services; 4) Sustain program funding. Ways to sustain program funding is an issue that academic institutes and service organizations face. Adequate funding is needed to sustain programs and services for Chinese dementia caregivers; 5) Raise public awareness through ongoing publications, media outlets, websites, and workshops in senior housing and centers as outreach efforts for the target population; 6) Raise health care and social service providers’ awareness through training or education courses, information dissemination, and requests for culturally and linguistically appropriate services; and 7) Increase program evaluation effort. Quality services include adequate training of staff about dementia care. As a growing number of dementia programs and services have been established, it becomes increasingly important to evaluate the effectiveness of these programs and services.

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- Q9. "Massachusetts Councils on Aging. (2007, August). MCOA news. Retrieved September 13, 2009, from http://www.mcoaonline.com/content/pdf/news_aug_07.pdf" was present in reference list but was not cited in the body. Please check.