

**Alzheimer's Association of Los Angeles
Riverside and San Bernardino Counties**

Asian and Pacific Islander Dementia Care Network Project

**Phase I Focus Group Report
*(Northern California)***

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Section I: **Executive Summary**

Project Purpose. Broad demographic changes throughout the United States and the State of California point to the “graying of the population” in general and a disproportionate growth in both the Asian and Pacific Islander (API) population in general and the older adult API population specifically. These demographic trends emphasize the overwhelming need to develop culturally and linguistically sensitive older adult programs and services to meet the current and future needs of this growing population.

In recognition of the above-mentioned demographic changes and the ongoing confusion about Alzheimer’s disease and dementia among Asian and Pacific Islander families, the Alzheimer’s Association of Los Angeles, in conjunction with the California Department of Aging, received a three-year grant from the U.S. Administration on Aging. This statewide project, the Asian and Pacific Islander Dementia Care Network, involves the needs assessment, program design, and implementation of an innovative, creative, and culturally sensitive model for Asian and Pacific Islander communities regarding the topic of dementia care. Phase I of this project was conducted in Northern California in collaboration with Alzheimer’s Association of the Greater San Francisco Bay Area during the months of March through October 2002. This report provides the results and recommendations from the Phase I needs assessment. Phase II of this project is planned for Southern California during fiscal year 2002-2003 in collaboration with the Little Tokyo Services Center and Chinatown Services Center. In total, this project is an important step for advocating services, keeping families together, and improving the safety and security of elders in the Asian and Pacific Islander communities of California.

Needs Assessment Design. The primary objectives for Phase I of this project were to assess the needs, concerns, and attitudes of the caregivers of dementia patients in the Vietnamese and Chinese communities of the Greater San Francisco Bay area. The initial planning meetings regarding the design of this study began during the month of May 2002 and continued through June 2002. During the months of May through June, bilingual and bicultural translators and interpreters were identified through the Alzheimer’s Association of the Greater San Francisco Bay Area. They were trained for focus group moderation during the month of June 2002. In the meantime, a purposive sample of thirty-two (32) focus group participants was recruited primarily from the client base of community-based organizations serving the Vietnamese and Chinese communities in San Jose, California. Three focus groups, two in Chinese/Mandarin and one in Vietnamese were co-moderated by the trained bilingual focus group moderator and an independent consultant working with the Alzheimer’s Association of Los Angeles during the month of June 2002. All focus groups were tape recorded and subsequently transcribed and translated into English language transcript to produce the source documents for analysis and interpretation. The results of this analysis for the Phase I (*Northern California*) focus groups are provided in this report.

Needs Assessment Results. The primary results of the Phase I (Northern California) focus groups are reported in four separate categories: attitudes toward Alzheimer's disease and dementia within the Asian and Pacific Islander (API) community, challenges faced by API caregivers, the needs expressed by API caregivers, and recommendations for promoting culturally sensitive dementia care.

1) Asian and Pacific Islander Attitudes Toward Alzheimer's Disease and Dementia.

Attitudes Toward Dementia and Alzheimer's Disease. Attitudes toward dementia and Alzheimer's disease among the focus group participants varied from sympathy for the family members for whom they cared to frustration with the daily toil of providing care. Regardless of the degree of frustration expressed, however, caregivers emphasized that the care of an aging spouse or parent was a filial duty that was accepted without question.

Confusion About Cause of Dementia. With regard to the perceptions about what Alzheimer's disease and dementia is or is not, caregivers exhibited considerable confusion about possible causes. Some caregivers believed conditions such as forgetfulness and memory loss were just a natural process of aging. Others believed they could be caused by other factors such as mental illness or a shocking emotional experience.

A Continuum of Preferred Terminology. When asked about preferred terminology, caregivers indicated a preference for the terms "forgetfulness" or "dementia" over the term "Alzheimer's disease." Forgetfulness and dementia were perceived to be more discreet, culturally sensitive terms of reference. Alzheimer's disease was viewed in a more harsh light. For most caregivers, the latter term implied a shameful image associated with mental illness.

2) Challenges Faced by Asian and Pacific Islander Caregivers of Dementia Patients.

The primary challenge discussed by caregivers was the constant need to monitor the activities of the dementia patients for whom they cared. This emotional burden was often motivated by the need to keep the family member out of the danger they may encounter during their daily activities. Caregivers often described themselves as the "second casualty" because they not only became physically exhausted during their daily experiences of caring for a family member with dementia, but also endured the financial burden of providing 24-hour care. Such responsibilities ironically made it impossible for caregivers to maintain jobs outside of the home in many instances.

3) The Needs of Asian and Pacific Islander Caregivers of Dementia Patients.

In order to balance their own lives and their responsibilities as the primary caregivers of family members with dementia, caregivers articulated a number of services and programs that they would find useful. For themselves, caregivers communicated the need for professional, licensed home health care support to help them with lifting the family member, dispensing medication to them, and supervising them when the caregivers had

to run errands outside of the home. Caregivers also expressed the need to have general support in the form of paid or volunteer help with household domestic chores, grocery shopping, and completing complicated health-related paperwork.

In addition to the needs they expressed for themselves, caregivers also expressed the need for culturally sensitive programs and services. While such programs and services may already exist in some communities, the general perception was that they did *not* exist. Requested services included training programs to caregivers on how to care for dementia patients in the home.

Finally, in their quest to obtain culturally sensitive health and social services, caregivers expressed the need for senior care centers specializing in Alzheimer's disease and dementia. One of the most critical missing elements of such centers was the availability of bilingual medical and social services staff, directed activities to forestall depression, and liberal visitation policies that recognized the importance of family connections within Asian communities. Whether bilingual staff was available or not, however, caregivers still felt strongly that all health care and social service providers who interact with the elderly should receive extensive training with regard to the different cultural beliefs and needs of Asian dementia patients and family caregiver.

4) Recommendations for Promoting Culturally Sensitive Dementia Care.

When approached about the most effective ways to increase awareness about Alzheimer's disease and dementia in Asian communities, caregivers discussed different strategies for reaching caregivers themselves versus providers in the health and human services industry. Radio and newspaper advertisements in linguistically relevant ethnic press and the posting and distribution of promotional flyers at culturally relevant churches, temples, and supermarkets were cited as the best way to reach targeted Asian caregivers. Bilingual direct mailings to major employers in areas with large Asian populations were an additional suggestion. Equally important, caregivers pointed to the need to promote directly to professional health and social service providers in such neighborhoods, both as individual providers and as institutions such as hospitals, clinics, and community-based organizations.

Project Recommendations. Based upon the results of this study, the following recommendations are made with regard to the meeting the needs of caregivers who provide assistance and support for patients of dementia and Alzheimer's disease in the Asian communities of California.

Short Term Recommendations (One to Two Years)

1. Actively Promote the Availability of Dementia Care Programs and Services Through Asian Media and Retail Locations. It is recommended that outreach efforts be expanded through promotional efforts utilizing Asian ethnic newspapers and radio stations in particular, especially those editions and or shows that focused upon health issues. Posting and distributing flyers at supermarkets, temples, and churches in areas

with large Asian populations would also provide a strong grassroots reinforcement of mass media advertisements. Finally, it is recommended that direct mail advertisements targeting major employers in geographic areas with large Asian populations would offer the opportunity to expand awareness levels to potential caregivers about available programs and services.

2. Develop Expanded In-Home Support Services for Asian Family Caregivers. It is recommended that the types of services provided to such family caregivers be expanded to include **bilingual** home health care training for family caregivers, professional in home nursing services (bathing, lifting, dispensing medication, etc.), and volunteer or professional in home household assistance (cooking, cleaning, etc.). Training for family caregivers should include educational components to correct misperceptions about Alzheimer's disease and dementia, including their symptoms and causes.

3. Broaden Needs Assessment Efforts Among Primary Asian Populations in California (and Nationwide) Regarding the Attitudes and Needs of Caregivers. Since this needs assessment is exploratory in nature and a review of the literature has revealed a scarcity of studies directed at understanding dementia care in Asian and Pacific Islander communities, it is recommended that the efforts started in this particular needs assessment (Asians in Northern California) be expanded to Southern California and other Asian ethnic populations. *(Note: Phase II of this needs assessment has already been designated to accomplish this task in the Japanese and Chinese communities of Southern California during fiscal year 2002-2003.)*

Long Term Recommendations (Two to Five Years)

1. Implement Expanded In-Home Support Services for Asian Family Caregivers. Once expanded programs to support Asian family caregivers are developed, it is recommended that they are implemented first on a pilot basis and then full-scale as funding allows.

2. Increase Public Advocacy Regarding the Culturally Specific Needs of Asian Family Dementia Caregivers. It is recommended that the culturally specific needs such as the need for bilingual support services in particular be escalated to public policy makers through promotional efforts, lobbying, and continued persistence. Such efforts should be targeted at increased funding for culturally sensitive programs and services, culturally sensitive senior care centers, and continued needs assessment of growing ethnic communities that are affected by the phenomenon of an aging population.

Section II: **Project Rationale and Description**

This section provides a description of some of the national and local demographic trends that are impacting organizations serving the needs of older adults in the United States.

National Demographic Trends: The “Graying” of America. The “graying” of the American population presents both tremendous challenges and incredible opportunities for the “elder care” industry. On one hand, it is challenged by a dearth of programs, policies, and structural support for meeting the needs of a rapidly aging population. This dilemma is complicated by the fact that older Americans are increasingly more educated, healthy, and active than their parents were at the same age. These characteristics are especially true of the “baby boomer” cohort, the oldest of whom will turn 65 in the year 2011. Since this group has earned the well-deserved reputation of reshaping virtually every industry they have encountered, it is anticipated that they will also do the same for the elder care industry.

The challenges of providing services to culturally and linguistically diverse older Americans present an even more daunting dilemma for the elder care industry. The fastest growing population among such non-white minority groups is Americans of Asian and Pacific Islander descent. Since many of these older adults are foreign born, the normal challenges of aging in such a youth oriented culture are further confounded by language barriers. These barriers often reduce and even prevent access to much needed social and health care services. Even when language is not an immediate barrier, as is the case for those born and raised in the United States, numerous cultural barriers still prevail.

Predictions of a more diverse, educated, and active population of older adults bring the mixed blessing of both an industry challenge and a marketing opportunity. The opportunities appear to be tremendous. However, it is important to remember that the baby boomers who will begin seeking such services within the next ten years are a relatively educated, healthy, empowered group of consumers with strong expectations for new services and amenities that still remain largely undefined. In the same manner, the unpredictable demands of a culturally and linguistically diverse population will present unforeseen circumstances that will undoubtedly impact the myriad of organizations providing products and services to such populations.

Local Demographic Trends. In the local context of Los Angeles County, California, the number of older adults over the age of 65 comprises approximately 9.6% of the population in the year 2000. That percent is expected to double by the year 2030 to approximately 18.6% of the population. Similar trends are evident in the older adult population that is age 85 or more. In the year 2000, this latter group represented approximately 1.2% of the total county population. More specifically, racial and ethnic minorities represented 45.4% of this group with almost one-third of that rapidly increasing percentage (12.6%) consisting of Asian and Pacific Islander older adults. By the year 2030, the total county population of older adults over the age of 65 is expected to

double to approximately 2% of the total population. Racial and ethnic minorities are expected to comprise 64% of that growth, primarily as a result of the projected growth in the Asian and Pacific Islander and Latino older adult populations. Specifically, the Asian and Pacific Islander older adult population in Los Angeles County is expected to increase from 12.6% today to 16.6% by the year 2030.¹ Clearly, these demographic trends point to the overwhelming need to develop culturally and linguistically sensitive older adult programs and services to meet the current and future needs of this growing population.

Project Description. In recognition of the above-mentioned demographic changes and the ongoing confusion about Alzheimer’s disease and dementia in Asian and Pacific Islander families, the Alzheimer’s Association of Los Angeles, in conjunction with the California Department of Aging, received a three-year grant from the U.S. Administration on Aging. This statewide project, the Asian and Pacific Islander Dementia Care Network, involves the needs assessment, program design, and implementation of an innovative, creative, and culturally sensitive model for Asian and Pacific Islander communities regarding the topic of dementia care.

The needs assessment phase of this project began in March 2002 with planning meetings conducted to determine the scope and sequence of the related focus group needs assessment. At that time, the needs assessment phase of the project was divided into two phases, one in Northern California and the other in Southern California. Due to funding restrictions on travel, Northern California was selected as the first region to conduct needs assessment focus groups (Phase I). In that region, Alzheimer’s Association of Greater San Francisco Bay Area performed as the primary partner assisting with the coordination and implementation of focus groups in the Chinese and Vietnamese communities. Needs assessment focus groups for Southern California (Phase II) are planned to take place during the 2002-2003 fiscal year that began in July 2002. In that region, the Little Tokyo Service Center (LTSC) and Chinatown Service Center (CSC) have been contracted to deliver information, education, referral, and service coordination through their extensive care management network of Japanese and Chinese families in Southern California. This project is an important step for advocating services, keeping families together, and improving the safety and security of elders in the Asian and Pacific Islander communities of California.

¹ “*We the American...Elderly*,” U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, September 1993.

Section III:
Needs Assessment Design

The initial planning meetings regarding the design of this study began during the month of May 2002 and continued through June 2002. During these planning meetings, decisions were made regarding the objectives, questionnaire and survey design, sample design, data collection methods, participant and supporting staff recruitment process, and time lines for the project. Please refer to Table 1 below for a list of the research team members involved. In addition, please refer to Section VII of this report for copies of the final focus group moderator guide (questionnaire), demographic information survey, sign-in sheet, and acknowledgement sheet.

Table 1

**Asian and Pacific Islander Dementia Care Network Project
Primary Needs Assessment Team Members**

Team Member	Organizational Affiliation
Ms. Canossa Chan <i>(Manager, Outreach and Education)</i>	Alzheimer’s Association of Los Angeles
Ms. Edie Lau <i>(Manager, Multicultural Outreach and Education)</i>	Alzheimer’s Association of the Greater San Francisco Bay Area
Dr. H. Rika Houston <i>(Research Consultant)</i>	California State University, Los Angeles

Needs Assessment Objectives. The primary objectives for Phase I of this project were to assess the needs, concerns, and attitudes of the caregivers of dementia patients in the Vietnamese and Chinese communities of the Greater San Francisco Bay area. Please refer to Section VII, Appendix A for a copy of the questions that were posed during the focus group interviews. Table 2 provides an overview of the project timelines for Phase I.

Table 2
Asian and Pacific Islander Dementia Care Network Project
Project Time Lines
(Needs Assessment Activities for Phase I Only)

Phase I Project Activity	Project Time Line (Actual)
Project Planning	May - June 2002
Needs Assessment Design	April - June 2002
Literature Review	April – May 2002
Identification, Recruitment, and Training of Bilingual Translators and Interpreters	May – June 2002
Recruitment of Participants	May - June 2002
Data Collection & Translation	June – July 2002
Data Analysis	July - September 2002
Alzheimer’s Association Los Angeles: Presentation of Project Results	October 2002
Completion of Phase I Report	November 2002

Sample Design. A purposive sample was used for the purposes of this study. The logic and power of purposive sampling lies in selecting participants who can provide information-rich cases for in depth study. Purposive sampling increases the range of data exposed and maximizes the researcher’s ability to identify emerging themes that take adequate account of contextual conditions and social norms. As a result, it was the most appropriate sampling method for this study. The resulting focus group sample of thirty-two (32) participants is deemed more than adequate to assess the attitudes and opinions of the targeted population. Indeed, according to established sampling design standards for qualitative interviews, eight informants are considered to be a sufficient quantity to identify existing beliefs and patterns of behavior.² This factor can be attributed to the fact

² “Focus Groups: Theory and Practice,” David Stewart and Prem Shamdasani, SAGE Publications, Newbury park, California, 1990.

that the purpose of qualitative research is to gain access to the cultural categories and assumptions that are important for the participants.

After careful consideration, the research team members decided to conduct four focus groups consisting of two for each of the designated ethnic groups (Chinese/Mandarin and Vietnamese). Due to the challenges of securing participants from the Vietnamese community, we only conducted one focus group with this population. The final sample population is described in Table 3.

Data Collection. During the months of May through June, bilingual and bicultural translators and interpreters were identified through the Alzheimer's Association of the Greater San Francisco Bay Area. Please refer to Table 4 for a list of the resulting supporting staff. Once this staff was secured, instructions were provided as to their areas of responsibilities and the related project time lines and expectations. All focus groups were co-moderated between Dr. Rika Houston, an independent consultant working for the Alzheimer's Association of Los Angeles, and the assigned bilingual/bicultural interpreter as listed in Table 4. Dr. Rika Houston also provided focus group moderation training for these support staff members on June 18, 2002 before the focus groups were conducted.

Focus groups, originally called focused interviews, are a type of qualitative research methodology that allows the researcher to produce a very rich body of data expressed in the words of the participants. Their continued popularity as a data collection method can perhaps be attributed to their extreme flexibility in a variety of situations. In exploratory research such as the Asian and Pacific Islander Dementia Care Project, focus groups can serve a very useful starting point for the design of large-scale survey questionnaires because they provide a means for exploring the ways participants talk and think about objects and events. In confirmatory research, focus groups can be just as useful in interpreting previously obtained quantitative results or explaining corresponding variances²

All focus group participants received a participation incentive of a \$40 gift certificate for Ranch 99 Markets, a popular Asian grocery chain. All focus groups were conducted in the native language of the focus group participants and tape recorded in order to reserve the accuracy of the discussions. Upon completion of the focus groups, interview data were subsequently transcribed and translated during the months of June and July 2002. A total of 32 Asian adults participated in the three focus groups conducted during Phase I (Northern California) of this project.

² *"Focus Groups: Theory and Practice,"* David Stewart and Prem Shamdasani, SAGE Publications, Newbury Park, California, 1990.

Table 3

**Asian Caregiver Needs Assessment Project
Sample Characteristics**

Sample Size = 32

Variable	Chinese (Group 1)	Chinese (Group 2)	Vietnamese
Gender	Males = 4 Females=6	Males = 3 Females= 7	Males =6 Females= 6
Age	Range: 64-86 Years	Range: 72-88 Years	Range: 44-85 Years
Foreign Born	90% (9)	90% (9)	90% (11)
U.S. Born	10% (1)	10% (1)	10% (1)
English as First/Native Language	0%	0%	0%
Other Language as First/Native Language	100% (Mandarin)	100% (Mandarin)	100% (Vietnamese)
Years Lived in U.S.A. (Foreign Born Participants Only)	Range: 5-22 Years	Range: 8-27 Years	Range: 8-22 Years

Table 4

**Asian Caregiver Needs Assessment Project
Independent Bilingual/Bicultural Research Support Staff**

Name	Organization	Target Ethnic Group and Language
Ms. Karen Zhang	Alzheimer's Association of San Jose Position: Intern	Chinese/Mandarin
Ms. Phoung Pham	Kaiser Permanente Position: Nurse/Educator	Vietnamese

Table 5

**Asian Caregiver Needs Assessment Project
Focus Group Schedule ***

Asian Ethnic Group	Moderators	Date & Location Of Focus Group
Chinese/Mandarin (Bilingual)	Dr. Rika Houston Ms. Karen Zhang	June 18, 2002 (10:00AM) St. John XXIII Multicultural Center San Jose, California
Chinese/Mandarin (Bilingual)	Dr. Rika Houston Ms. Karen Zhang	June 18, 2002 (4:30PM) St. John XXIII Multicultural Center San Jose, California
Vietnamese (Bilingual)	Dr. Rika Houston Ms. Phuong Pham	June 19, 2002 (10:00AM) St. John XXIII Multicultural Center San Jose, California

* (All focus groups were conducted in respective native languages.)

Data Analysis. Data analysis of the translated focus group transcripts took place during the months of August through October 2002. The data were analyzed according to grounded theory methodology. Grounded theory is a social scientific research method that uses a systematic set of procedures to explain phenomena from the perspective of “insiders.” It is a data-driven, qualitative methodology rather than a theory-driven, quantitative methodology. In practice, it begins with a structured reading of the interview text then identifies key concepts from each interview and themes that emerge across all interviews. Finally, the contextual conditions, strategies, and causal relationships perceived as important to the informants are recorded and categorized to develop a theoretical model.³ The findings are presented in Section IV of this report.

³ “*Basics of Qualitative Research: Grounded Theory Procedures and Techniques*,” Anselm Strauss and Juliet Corbin, SAGE Publications, Newbury Park, California, 1990.

Section IV: **Needs Assessment Results**

The following results of the Phase I (Northern California) focus groups are reported in four separate categories: attitudes toward Alzheimer's disease and dementia within the Asian and Pacific Islander (API) community, challenges faced by API caregivers, the needs expressed by API caregivers, and recommendations for promoting culturally sensitive dementia care.

Asian and Pacific Islander Attitudes Toward Alzheimer's Disease and Dementia

Attitudes Toward Dementia and Alzheimer's Disease. Attitudes toward dementia and Alzheimer's disease among the focus group participants varied from sympathy for the family members for whom they cared to frustration with the daily toil of providing care. Regardless of the degree of frustration expressed, however, caregivers emphasized that the care of an aging spouse or parent was a filial duty that was accepted without question. Some of the following comments illustrate these complex attitudes toward dementia and Alzheimer's disease.

“There is nothing you can do about it. I think that we are sympathetic towards the patients. We feel heavy hearted. We need to comfort them by talking to them. As patients, they feel depressed. We should try to help them feel better. Give them sympathy and condolence, and hopefully they could get better. Sometimes, if you help them it is easier for them to regain their memory. If you don't help them, they will become worse. So to these kinds of patients, we shouldn't say anything to annoy them. We should show sympathy and try to help them.” *(Chinese caregiver)*

“...It's hard to keep a nice attitude over a long period of time. Doctors say that it doesn't help to tell her what to do or even write it down. It is true. This disease is just like that. There is no way you could figure out whether she understands what you say. I could tell her the same thing day in and day out, but she just could not remember. There is no simple way to cope with it.” *(Chinese caregiver)*

“...When you children are young, it is the same thing. You are taking care of their daily needs. *(With Alzheimer's disease)*, it is different. For children, they grow up and become better. But for my wife, she is becoming worse. *(Chinese caregiver)*

“...For a brain illness like Alzheimer's, we can only be sympathetic, caring and ready to help.” *(Chinese caregiver)*

“About taking care of patients, I think it is not just the money, but it is also the love that you provide since you come to the patient’s home. It already takes you a lot of time and gas to arrive at that patient’s house so eventually, I always take care of them from my love...love can conquer everything.” (*Vietnamese caregiver*)

“I tell her (*my mother-in-law*) not to comb her hair again. The next thing I know there is a comb in her hands. I get upset so they (*other family members*) will calm me down. When they are upset, I will calm myself down. That is the process.” (*Vietnamese caregiver*)

Confusion About Cause of Dementia. With regard to the perceptions about what Alzheimer’s disease and dementia is or is not, caregivers exhibited considerable confusion about possible causes. Some caregivers believed conditions such as forgetfulness and memory loss were just a natural process of aging. Others believed they could be caused by other factors such as mental illness or a shocking emotional experience. The following comments reveal this range of perceptions and beliefs.

“In my opinion, Alzheimer’s is caused by some kind of shock...”
(*Chinese caregiver*)

“This (*Alzheimer’s disease*) is the result of aging...some part of the brain becomes dry and dead...” (*Chinese caregiver*)

“I admired her (*my mother*) so much...Her sudden death had a great effect on me. I felt that God shouldn’t take her away. I had high blood pressure as a result of that. Over the past 7 or 8 years, I feel that I’m getting on in age. I don’t have the courage to face all the hardships in life. That made me become old quickly. That might be a reason to cause the Alzheimer’s. Like what was said just now about a wife becoming odd after losing her husband.” (*Chinese caregiver*)

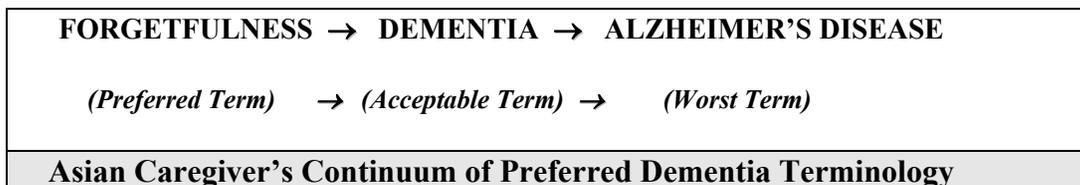
“The behaviors between forgetfulness and dementia are the same. But if you deal with these persons I can say that a person with short term memory meaning that they forget right away after 10 to 15 minutes, the other forget completely. So if the caregivers will have to take care of both types, the caregivers don’t really know how. Again, old people forget things they are told right away, Alzheimer’s persons forget what is in the past and the future...It’s seems to me that it is a brain disease...”
(*Chinese caregiver*)

“ I think forgetfulness and Alzheimer’s have fundamental differences. Alzheimer’s is a disease. The patients couldn’t take care of their own daily needs. Forgetfulness is not an illness. Old people all tend to be forgetful. Alzheimer’s could be a fundamental change. Forgetfulness (*then*) turns into illness.” (*Chinese caregiver*)

“...but the disease (*Alzheimer’s disease*) gets very low exposure on the whole. It’s very foreign to Chinese people. Many people never heard about Alzheimer’s, or they don’t know what it is. It’s a complicated disease.” (*Chinese caregiver*)

“...It’s (*Alzheimer’s disease*) part of the natural process of aging...”
(*Chinese caregiver*)

A Continuum of Preferred Terminology. To a certain extent, caregivers exhibited a certain amount of denial about the need to address the issues of Alzheimer’s disease or dementia. In such instances, they expressed the inevitability of old age and death and believed that it should just be accepted as a fact of life. When asked about preferred terminology, caregivers indicated a preference for the terms “forgetfulness” or “dementia” over the term “Alzheimer’s disease.” Forgetfulness and dementia were perceived to be more discreet, culturally sensitive terms of reference. Alzheimer’s disease was viewed in a more harsh light. For most caregivers, the latter term implied a shameful image associated with mental illness. The diagram below and the following comments from focus group participants help to illustrate this point.



“Forgetfulness is one word. It is more pleasant to the ear. Dementia is not as nice. And Alzheimer’s is the worst.” (*Chinese caregiver*)

“I don’t think we need to discuss about what the disease is called. Whether you call it dementia, forgetfulness, or Alzheimer’s, he will die in the end. You can’t do anything about death.” (*Chinese caregiver*)

“For Chinese people, some might think Alzheimer’s is a shameful word. Your family members will feel embarrassed.” (*Chinese caregiver*)

“I don’t see any real sense in discussing about how the disease is going to be called. Those who have the Alzheimer’s don’t even know how to move around. How could they care about what you call them? Even if you curse them, they will not remember.” (*Chinese caregiver*)

“...Memory loss often makes you think you are having Alzheimer’s. Since it is a disease, so people understand no matter what words you use to call it, whether it is Alzheimer’s or dementia. If you want to use a more pleasant word, use dementia. The unpleasant one will be Alzheimer’s.”
(*Chinese caregiver*)

Challenges Faced by Asian and Pacific Islander Caregivers of Dementia Patients

The primary challenge discussed by caregivers was the constant need to monitor the activities of the dementia patients for whom they cared. This emotional burden was often motivated by the need to keep the family member out of the danger they may encounter during their daily activities. The danger of wandering away and getting lost was frequently cited as a major concern. Caregivers often described themselves as the “second casualty” because they not only became physically exhausted during their daily experiences of caring for a family member with dementia, but also endured the financial burden of providing 24-hour care. Such responsibilities ironically made it impossible for caregivers to maintain jobs outside of the home in many instances. Some caregivers express these challenges and responsibilities in the following statements. The following comments from caregivers help to illustrate these points.

“The other day, I had to take her (*my mother*) back to emergency again. This time I called Outreach transportation to pick us up and the driver dropped my Mom outside of the hospital. I couldn’t carry her on the stairs so I was begging for help while my Mom was in her wheelchair. I was upset since nobody stopped by to help us...” (*Vietnamese caregiver*)

“...I know a lady taking care of her Alzheimer’s husband, 24 hours a day. One night, she was awakened by knocks on the door. When she opened the door, she found her husband standing there. She didn’t know when he went out. It is lucky that the main entrance of the apartment complex was locked so he could not go out. He found his way back but this is very dangerous. Even if the patient is *well taken care of at home, it is still dangerous...*” (*Chinese caregiver*)

“The general feeling is that patients with the Alzheimer’s need to be taken care of by others. They can’t function normally by themselves. If they are left alone, they might be in dangerous condition.” (*Chinese caregiver*)

“The main problem is it prevents me from working, such as I don’t have free time. Even if I go to work, I am still worried. Therefore it affects my work productivity...” (*Vietnamese caregiver*)

“In my case, I told my mother-in-law not to cook rice since she would not turn off the stove. When I leave the house, she will cook rice because she wants to do things that he told her not to do. When I tell her not to leave the house, a moment later, she is out of the door. I tell her not to go upstairs, later she is upstairs. I think they all want to do things differently from what they are told.” (*Vietnamese caregiver*)

“To me, medication is the challenge. I have to ask them all the time, did you take medications yet since they have cardiac disease or I have to remind them to exercise.” (*Vietnamese caregiver*)

“...My current wife has some memory problems, such as burning the pot on the stove. This happened twice...(*Chinese caregiver*)

“Her daughter has to take her Mom with her wherever she goes, including visiting friends and going to the restroom. For patients like that, professional care is needed. Otherwise, it is dangerous. Care is greatly needed...(*Chinese caregiver*)

“He (*a friend who is a caregiver*) did not want to reveal his situation to get outside help. So, he ended up attending his wife all by himself. In the daytime when his wife was asleep, he would go grocery shopping. They are living by themselves. There are no children living with them. At night, when his wife wakes up, he also could not sleep...(*Chinese caregiver*)

The Needs of Asian and Pacific Islander Caregivers of Dementia Patients

In order to balance their own lives and their responsibilities as the primary caregivers of family members with dementia, caregivers articulated a number of services and programs that they would find useful. For themselves, caregivers communicated the need for professional, licensed home health care support to help them with lifting the family member, dispensing medication to them, and supervising them when the caregivers had to run errands outside of the home. Home health care was often viewed as preferable to out of home care due to the emotional needs of the dementia patient. Caregivers also expressed the need to have general support in the form of paid or volunteer help with household domestic chores, grocery shopping, and completing complicated health-related paperwork. In the latter case, many caregivers were limited English speakers who faced considerable challenges when trying to complete the complicated paperwork requirements for health care insurance and social service requests.

In addition to the needs they expressed for themselves, caregivers also expressed the need for culturally sensitive programs and services. While such programs and services may already exist in some communities, the general perception was that they did *not* exist. Requested services included training programs to caregivers on how to care for dementia patients in the home. While caregivers felt a strong filial duty to care for aging family members, they recognized their limited knowledge with regard to nursing skills and felt a training program would help considerably to relieve them of many of their basic care-giving frustrations.

Finally, in their quest to obtain culturally sensitive health and social services, caregivers expressed the need for senior care centers specializing in Alzheimer’s disease and dementia. One of the most critical missing elements of such centers was the availability of bilingual medical and social services staff, directed activities to forestall depression, and liberal visitation policies that recognized the importance of family

connections within Asian communities. Whether bilingual staff was available or not, however, caregivers still felt strongly that all health care and social service providers who interact with the elderly should receive extensive training with regard to the different cultural beliefs and needs of Asian dementia patients and family caregivers. With existing government-subsidized adult day care centers, caregivers expressed their frustrations with rigid regulations and the lack of bilingual staff and programs. Such constraints in turn contributed to the emotional and financial burdens faced by many caregivers. The following comments from caregivers help to illustrate the needs expressed in this section.

“It is better to have a professional nurse. You cannot just cope with anything by yourself. It is just going to wear you out. How can you cope with 24 hours of labor each and every day? You can take shifts with nurses. For example, nurses *will work during daytime and you work at night.*” (Chinese caregiver)

“Even if the volunteers are not in a position to take care of the patients, they could help with some housework, such as shopping and driving around. Otherwise, over time, no one is able to put up with it (the daily responsibility).” (Chinese caregiver)

“...but each individual has a different situation, like us just a son and his mother. As a male takes care of his mother, there are many troubles. For example, it is OK to cook and give medication with other things but the problem is giving her a bath. As you can see that is a big barrier if the community can help with this matter, I would greatly appreciate it.” (Vietnamese caregiver)

“...My father doesn't know the time so I can't leave him unattended. If I turn around, he will sneak out. If I beg him to go grocery shopping with me, he doesn't want to go, but if I forget him then he will be out of the door fast. Then, next in case of an emergency, 911 takes us to San Jose Hospital for medical emergencies only. When we take the patient to emergency, they will ask for patient history but they don't have a Vietnamese translator. I tell the doctor about the history sometimes but I don't know all of it. That is a barrier. If I go to Alexian Brothers Hospital it is better, but when I call 911 they usually take us to San Jose Hospital.” (Vietnamese caregiver)

“...my Mom's primary doctor is very nice. Sometimes I don't have to carry any paperwork but he would arrange everything for me including his nurses too. The other day, the doctor sent out someone to take care of my Mom, but my Mom is very afraid of strangers. It is only OK with me. Even my husband does not work because she is afraid of someone who is going to take her away from home.” (Vietnamese caregiver)

“To me, if a patient has a caregiver or not it is up to that family. In my case sometimes I need someone to watch my father so I can go out for one day. If the government has some program to relieve me, I can have someone come in for four hours. But I have to arrange this a week in advance. Sometimes, I need help right away so that is a problem. When I gave to go to Bascom Hospital for a medical appointment and then wait in line for medications, it would take me a whole day already. If I have four hours I have to take my father with me because he can’t stay home by himself. Therefore, if we can have some places for emergency at least like a day care center from eight hours to one day only (*without advance notification*)...” (*Vietnamese caregiver*)

“The government needs to give more time for caregivers...The government pays only a few hours for my daughter, so she has to go to work...” (*Vietnamese caregiver*)

“It is weird that they don’t look at patient’s needs. They just give a certain number of hours and it doesn’t matter if it will satisfy that patient’s needs or not since they (*the government*) controls all of the budget...” (*Vietnamese caregiver*)

“Yes, you must have somebody to help you. You can’t do this by yourself...” (*Chinese caregiver*)

“The Canadian government puts these (*dementia*) patients into a senior care center. It has a very big courtyard. Every household has its own place to live. Patients won’t walk out of the courtyard. The nurse keeps an eye on them. This way they live a healthy life...so a senior care center is one suggestion (*for what is needed*).” (*Chinese caregiver*)

“A senior care center has to be equipped with good facilities. Otherwise it won’t help much. There should be activities such as growing flowers and raising chickens and ducks...There is life in those activities...So, a senior care center is the best solution. It saves a lot of labor ...” (*Chinese caregiver*)

“...In one family, at least one member will fully contribute (*take care of*) the (*dementia*) patient. And that may not be enough. Besides, patients could be heavy. One person can’t handle moving them around or taking them to the restroom....(*At a senior care center*), patients get professional services. One’s own family members are not as good.” (*Chinese caregiver*)

“...but it (a senior care center) should only be designed for the Alzheimer’s patients...with good facilities...and family and friends are also supposed to visit patients frequently...” (*Chinese caregiver*)

“...Financial support from the society is very important. A senior care center is one of the (needed) supports. There are many other types of supports that are needed...Some charity stores donate money for mentally disabled people. If only we could create such an environment for Alzheimer’s patients. In every country, people are living longer...A unified force should be established...the unified force should be able to raise money and allocate resources for Alzheimer’s...People could also help out by volunteering at senior care centers...” *(Chinese caregiver)*

“In the U.S., there are very few senior centers just for Chinese. Chinese who stay at non-Chinese senior centers are very lonely. We should encourage more of their Chinese friends and family members to visit them. Otherwise, they don’t want to stay there...Other places are all for White people...” *(Chinese caregiver)*

Recommendations for Promoting Culturally Sensitive Dementia Care

When approached about the most effective ways to increase awareness about Alzheimer’s disease and dementia in Asian communities, caregivers discussed different strategies for reaching caregivers themselves versus providers in the health and human services industry. Radio and newspaper advertisements in linguistically relevant ethnic press and the posting and distribution of promotional flyers at culturally relevant churches, temples, and supermarkets were cited as the best way to reach targeted Asian caregivers. Bilingual direct mailings to major employers in areas with large Asian populations were an additional suggestion. Equally important, caregivers pointed to the need to promote directly to professional health and social service providers in such neighborhoods, both as individual providers and as institutions such as hospitals, clinics, and community-based organizations. The following comments support these recommendations for promotion and outreach to caregivers and professional providers regarding the availability of health and social services for caregivers of elderly Asian family members with dementia. (Additional comments were revealed during post-focus group debriefing sessions.)

“First you need to broadcast via newspapers but radio is the fastest since when people usually turn on radio while driving home from work, especially at night. Newspaper is good too, when they are free, they usually read, but they listen to radio at night.” *(Vietnamese caregiver)*

“Another good way (to promote) is to post flyers, especially at supermarkets or shopping centers, since we all go for food at least once a week, therefore flyers would be good.” *(Vietnamese caregiver)*

“I think charity places can spread the words.” *(Vietnamese caregiver)*

“To me, in San Jose, we have three Vietnamese radio stations...then you can ask them to advertise for you. I think it costs about \$500.”

(Vietnamese caregiver)

“Radio station (programs) such as “Health is Precious” (in San Jose) and other ones are willing to do this.” *(Vietnamese caregiver)*

“You can always ask community services fro either Northern or Southern California for assistance.” *(Vietnamese caregiver)*

Section V: **Project Recommendations**

Based upon the results of this study, the following recommendations are made with regard to the meeting the needs of caregivers who provide assistance and support for patients of dementia and Alzheimer's disease in the Asian communities of California:

Short Term Recommendations (One to Two Years)

1. Actively Promote the Availability of Dementia Care Programs and Services Through Asian Media and Retail Locations. The general perception of caregiver participants in Phase I of this needs assessment was that culturally sensitive programs and services addressing their needs as caregivers of Asian dementia patients did not exist or were underrepresented among existing programs. It is recommended that outreach efforts be expanded through promotional efforts utilizing Asian ethnic newspapers and radio stations in particular, especially those editions and or shows that focused upon health issues. Posting and distributing flyers at supermarkets, temples, and churches in areas with large Asian populations would also provide a strong grassroots reinforcement of mass media advertisements. Finally, it is recommended that direct mail advertisements targeting major employers in geographic areas with large Asian populations would offer the opportunity to expand awareness levels to potential caregivers about available programs and services.

2. Develop Expanded In-Home Support Services for Asian Family Caregivers. Since the results of this study point strongly to the likelihood that caregivers of dementia patients in Asian communities are most likely to be family members rather than professional caregivers, it is recommended that the types of services provided to such family caregivers be expanded to include **bilingual** home health care training for family caregivers, professional in home nursing services (bathing, lifting, dispensing medication, etc.), and volunteer or professional in home household assistance (cooking, cleaning, etc.). Training for family caregivers should include educational components to correct misperceptions about Alzheimer's disease and dementia, including their symptoms and causes. Expanded support services, when provided by bilingual providers, were viewed to be critical in relieving the emotional burden and physical exhaustion associated with caring for a family member with dementia. See the following long term recommendations for implementation of such services.

3. Broaden Needs Assessment Efforts Among Primary Asian Populations in California (and Nationwide) Regarding the Attitudes and Needs of Caregivers.

Since this needs assessment is exploratory in nature and a review of the literature has revealed a scarcity of studies directed at understanding dementia care in Asian and Pacific Islander communities, it is recommended that the efforts started in this particular needs assessment (Asians in Northern California) be expanded to Southern California and other Asian ethnic populations. *(Note: Phase II of this needs assessment has already been designated to accomplish this task in the Japanese and Chinese communities of Southern California during fiscal year 2002-2003.)*

Long Term Recommendations (Two to Five Years)

1. Implement Expanded In-Home Support Services for Asian Family Caregivers.

Once expanded programs to support Asian family caregivers are developed, it is recommended that they are implemented first on a pilot basis and then full-scale as funding allows. It is expected that collaborations with other existing community-based and public sector organizations will be included for the effective implementation of these expanded services.

2. Increase Public Advocacy Regarding the Culturally Specific Needs of Asian Family Dementia Caregivers. As the results of this needs assessment has revealed, family caregivers of Asian dementia patients often identify themselves as the “second casualty.” At times, the emotional, physical, and financial burden of caring for their dementia patient is overwhelming. It is therefore recommended that the culturally specific needs such as the need for bilingual support services in particular be escalated to public policy makers through promotional efforts, lobbying, and continued persistence. Such efforts should be targeted at increased funding for culturally sensitive programs and services, culturally sensitive senior care centers, and continued needs assessment of growing ethnic communities that are affected by the phenomenon of an aging population.

Section VI: **Limitations of this Study**

The following limitations are noted in this study. While they may impact the validity of the results, it is also noted that such limitations are not unusual given the funding and time constraints faced by the majority of non-profit and public sector organizations.

- 1. Small Number of Focus Groups.** Under ideal conditions, focus group methodology recommends that at least four focus groups be conducted for each population from which you wish to obtain feedback. In the case of this particular study, two focus groups were conducted for the Chinese population and only one was conducted for the Vietnamese population. Coupled with the impact of the two limitations listed below, there is cause for concern regarding the validity of the themes that have emerged from the focus group discussions. Future research and/or needs assessment should address this concern by expanding the number of focus groups conducted in each population to at least four as funding allows.

- 2. Inexperienced Bilingual Focus Group Co-Moderators.** As is often the case when conducting needs assessment in the non-profit world, funding restrictions create constraints with regard to research design and implementation. In an effort to cut costs and remain on budget for this project, the bilingual focus group co-moderators recruited to conduct the focus groups were not professional focus group moderators. Professional focus group moderation training was provided shortly before the focus groups were conducted, but such training is not a substitute for the professional expertise required to extract detailed information from focus group participants on every aspect of the study. As a result, the translated focus group transcripts that were used as the source documents for analysis in this report were considerably sketchy and lacking in the level of detail needed to conduct a full-scale analysis. In particular, there is concern that focus group participants were not probed to the fullest extent possible regarding their attitudes on these important dementia care variables.

- 3. Sample Bias.** Again because of the budgetary and time constraints on this project, agency staff was utilized for recruiting focus group participants (rather than a professional research agency). The pool of focus group participants was therefore drawn primarily from agency clientele. The resulting focus group participants were primarily a mixture of elderly Asian caregivers of a spouse with dementia and the dementia patients themselves. The effect of this sample bias was to reduce the number of caregivers that actually participated. In future needs assessment efforts, it is recommended that focus group participant recruiting efforts be more tightly controlled and longer planning horizon is utilized to ensure time to screen the initial pool of participants so that they closely meet the sample criteria requested. It is also recommended that separate on-site activities for the dementia patients be provided during the focus groups so that caregivers can participate without the added stress of simultaneously caring for and/or watching over their family member. This factor is especially true since such dementia patients cannot be left alone at home while the caregiver attends the focus group interview.

Section VII:
Appendices

- A. Focus Group Moderator's Guide (*English Language Questionnaire*)**
- B. Demographic Information Survey (*English Language*)**
- C. Focus Group Sign-In and Consent Form (*English Language*)**
- D. Focus Group Acknowledgement Form (*English Language*)**

**ALZHEIMER'S ASSOCIATION OF LOS ANGELES
Asian and Pacific Islander Caregiver Project**

Focus Group Moderator Guide

June 2002

Introduction

1. Opening Comments.

Welcome to the focus group discussion to assess the needs of the caregivers of aging Asian adults. This project is sponsored by the Alzheimer's Association of Los Angeles, California.

2. Introduction of Moderators.

Our names are _____ and Rika Houston. We will be conducting today's focus group discussion. In this capacity, we will ask you questions and direct the group discussion so that everyone has the opportunity to discuss his or her opinions.

3. Focus Group Objective.

The primary reason for today's group discussion is to determine the needs of individuals and families who are faced with the responsibility of caring for aging Asian adults. The opinions you express today will be used to develop programs and services to assist you.

4. Reminder of Confidentiality.

As we discuss your opinions today, each of you should feel free to say anything you feel like saying. The discussion will be tape recorded so that we can be sure to record all of the opinions discussed today. However, any information or opinions you express will remain completely confidential. Individual names will not be associated with individual opinions at any time. At the end of the discussion, all of the opinions discussed today will be grouped together for a final report.

5. Focus Group Rules.

Every person here today has been invited to participate in this group discussion because his or her opinions are important. As a result, it is important to follow these four simple rules during our discussion today:

- A) Only one person should speak at a time.
- B) When one person is talking, please do not talk separately with the persons sitting next to you. Instead, please express your opinions with the entire group.
- C) There is not such thing as a right or wrong answer. Please be sure to discuss any opinion you have. Do not worry about what other people will think. Every person has the right to his or her own opinion.
- D) This group discussion will take about two hours to complete. During this time, we must all continue the discussion without interruptions or breaks. As a result, we will now take a few minutes for everyone to use the rest room before we begin.

At this time, the focus group moderators should allow approximately five minutes for a rest room break.

Warm Up Questions

6. Introductions.

Now that we are ready to begin, let us take a few minutes to go around the room and introduce ourselves to each other. Each of you may now please give your name and tell a little about yourself.

At this time, the focus group moderators will allow approximately ten minutes for the focus group participants to introduce themselves. They should also make sure that everyone takes a turn.

7. Introduction of General Topic.

Thank you very much for attending today's group discussion. As mentioned earlier, we are currently assessing the needs of individuals and families who are the caregivers of aging Asian adults. The opinions and comments you provide today will help us to develop the types of programs and services that will make it possible for you to help the aging adults in your lives.

General Questions (*General Attitudes and Barriers*)

8. What are the primary needs and concerns of the older adults for which you provide care?
9. How do you currently meet these needs and address these concerns?

Specific Questions (*Cultural Attitudes and Barriers*)

10. *How would you describe an older Asian adult who is confused or has problems remembering things because they are growing older?*
11. What do you think about older Asian adults who are confused or have problems remembering things?
12. In your family, who is the primary person or persons who take care of the older family members with confusion or memory problems?
13. What daily challenges do you have as the caregiver of an older Asian adult with confusion or memory problems?
14. What programs and services would be most helpful to you as the caregiver of an older Asian adult with confusion or memory problems?
15. What type of information or help do you need from such programs and services?
16. What personal contacts or advisors do you currently seek help from when you need advice about the care of the older adults in your family? Why did you choose such persons?
17. What professional organizations and professionals do you currently seek help from when you need advice about the care of the older adults in your family? Why did you choose such organizations or professionals?
18. What is the best way for an organization to promote information about memory loss and confusion during the aging process to caregivers such as you?

Wrap Up and Close

19. Thank Participants and End Focus Group.

Thank you for your participation in today's group discussion. The information you have provided is very important and we look forward to using it to develop the types of programs and services that will make easier your life as caregivers.

ALZHEIMER'S ASSOCIATION OF LOS ANGELES

Confidential Participant Information Survey

Today's Date: _____
Focus Group Code: _____

General Participant Information

1. Last Name: _____
2. First Name: _____ 3. Middle Initial: _____
4. City of Residence: _____, California
5. Zip Code of Residence: _____
6. Home Telephone Number: (____) _____
7. Best Days and Times to Call: _____
8. Country of Birth: _____ 9. City and State of Birth: _____
9. If Not Born in U.S.A., Please State Year First Arrived in U.S.A.: _____
10. Month and Year of Birth: _____, _____
11. Primary Language Spoken at Home: _____
12. Other Languages Spoken: _____
13. *Annual Household Income (Rounded to Nearest \$1,000):* \$ _____
14. Number of Persons Living in Household: _____
15. Number of Children Living With You: ___ Adult ___ Minor Children
16. Number of Parents or Other Adult Relatives Living With You:
___ Parents _____ Other Adult Relatives (*Not Including Adult Children*)

**ALZHEIMER’S ASSOCIATION OF LOS ANGELES
Asian and Pacific Islander Caregiver Project
Focus Group Sign-In and Consent Form**

Today's Date: _____

Focus Group Code: _____

I agree to participate in today’s focus group discussion about the needs of caregivers serving older Asian adults with memory loss and/or dementia. The compensation or incentive for my participation will be _____. It is my understanding that the information I discuss will remain completely *confidential* and my name will not be associated with this information when it is utilized in public planning reports in the future.

Name (Please Print)

Signature

1.	_____	_____
2.	_____	_____
3.	_____	_____
4.	_____	_____
5.	_____	_____
6.	_____	_____
7.	_____	_____
8.	_____	_____
9.	_____	_____
10.	_____	_____
11.	_____	_____
12.	_____	_____
13.	_____	_____
14.	_____	_____
15.	_____	_____

**ALZHEIMER’S ASSOCIATION OF LOS ANGELES
Asian and Pacific Islander Caregiver Project
Focus Group Acknowledgment Form**

Today's Date: _____

Focus Group Code: _____

I acknowledge that I have received an incentive of a grocery store gift certificate in return for my participation in the focus group discussion conducted today by Alzheimer’s Association of Los Angeles.

Name (Please Print)

Signature

1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
6. _____	_____
7. _____	_____
8. _____	_____
9. _____	_____
10. _____	_____
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13. _____	_____
14. _____	_____
15. _____	_____

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