

Nancy Hikoyeda, DrPH, MPH

Biographical Sketch

Dr. Nancy Hikoyeda is the former Director of the San Jose State University Gerontology Program. She has a B.S. in Education from the University of Utah and an M.P.H. and Certificate in Applied Social Gerontology from San Jose State University. She received her Doctor of Public Health (Dr.P.H.) from the UCLA School of Public Health. Dr. Hikoyeda's areas of expertise are in ethnogerontology and ethnogeriatrics – issues of aging, ethnicity, and health with a focus on health literacy, long term care policies/utilization, and end-of-life issues. She has co-authored and edited numerous curriculum and training materials as well as chapters on Asian American elders in *Social Work Practice with the Asian American Elderly*; the *Encyclopedia of Aging*; *Cultural Issues in End-of-Life Decision Making*; the *Handbook of Geriatric Care Management*; and *Ethnicity and the Dementias (2nd ed)*.

Dr. Hikoyeda is an Ethnogeriatric Specialist for the Stanford Geriatric Education Center. She is Coordinator for the Healthy Transition Companion Program, a hospital-to-home project of the Multicultural Aging Providers Consortium. She is also immediate Past President of the California Council on Gerontology and Geriatrics.

***Assessment of Dementia
and Caregiving for
Japanese American Elders***

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***Background of
Japanese Americans (JAs)
in the United States***



Demographics & Early History



- 2004 census data
 - Approx. 790,000 JAs overall
 - 240,527 JAs (age 55+)
 - 2/3 American-born
 - Within-group diversity – image of the Model Minority, SES, geographic location
- Number of older Japanese Americans is declining due to:
 - Fewer immigrants from Japan
 - Assimilation & out-marriage

Early History in the U.S.

- 1860s - First immigrants worked on Hawaiian plantations & as mainland laborers
- 1882 Chinese Exclusion Act increased demand for Japanese laborers
 - 1910-1920 70,000+ from Japan
 - 1900 – 410 married women
 - 1920 – 22,193 married women
- Japantowns or *Nihonmachi*
 - Cultural, social, religious centers
 - San Francisco, Los Angeles, San Jose
- Most JAs live on the U.S. West Coast & Hawaii



Generational Identity

- Issei** - First generation, pioneer immigrants, most are now gone
- Nisei** - Second generation – today's elders
 - Kibei** - educated in Japan
- Sansei** - Third generation – today's caregivers
- Yonsei/Gosei** - Fourth & Fifth generations
- War Brides, Shin Issei** - Newcomers
- Nikkei** - all Japanese Americans

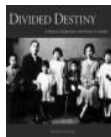


**Cohort History:
Discrimination & WW II Internment**



**Traditional JA Family Values
Meiji Era Confucian Teachings**

- Respect & deep regard for elders
- Family emphasis vs. individual focus
- Deference to authority
- Avoidance of conflict & confrontation
- Indirect communication
- Family privacy/confidentiality
- Male dominance



Traditional Japanese Values (cont'd)

- **Oyakoko** – Filial piety, duty, reciprocity
- **Shikataganai** – Fatalism -- “It cannot be helped” or “nothing can be done”
- **Gaman** – Stoicism in adverse situations
- **Haji** – Sense of shame (e.g., stigma of a mental problem such as dementia), loss of face
- **Enryo** – Refusal of assistance



Issues in Assessment of Dementia Among JA Families



Dementia in Japanese & JA Elders

- Research on JAs & dementia is sparse
 - Honolulu-Asia Aging Study (HAAS) (N=3734)
 - 1965: Longitudinal study of risk factors for cardiovascular & neurodegenerative diseases in old age
 - Men born between 1900-1919; some women
 - KAME Project, King County, Washington (N=1985)
 - 1992-2001 - Started as Ni-Hon-San Project; cross-cultural study of AD prevalence & incidence rates & vascular dementia among Japanese in Japan, Hawaii, and Seattle, WA; caregiving issues
 - Stanford/VA Alzheimer's Disease Center closed in 2009 due to lack of state funds
 - NIA Alzheimer's Center closed in 2006



Perceptions of Dementia Among JAs



- Relatively little research
- Dementia thought to be normal aging; but bad behavior = *Kichigai* label (crazy or insane)
- JA males better able to hide cognitive deficits
- JA females accept/adapt to caregiving stress due to *shikataganai* & *gaman*
- Reluctance of family/patients to report symptoms: reflects genetic defect; punishment or karma; poor family guidance
- Dementia/AD -- silent epidemic among JA families -- failure to recognize early cognitive & behavioral changes; wait for a crisis to seek help

(Ross, et al, 1997; Braun & Brown, 1998)

Language Issues

- Need for culturally relevant assessment instruments for use in the Japanese-speaking community
- Important for monolingual non-English-speaking elders (*Kibei*, warbrides, Newcomers)
- Not enough to simply translate words from original version; tests must also be culturally relevant
- Must also consider health literacy levels



Specific Measures & Their Effectiveness

- KAME project translated all instruments including: Cognitive Abilities Screening Instrument (CASI); Blessed Dementia Rating Scale; Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE); Consortium to Establish a Registry for Alzheimer's Disease (CERAD) neuropsychological battery; CES-D; Clinical Dementia Rating Scale (CDR); and others
- Satisfactory equivalence achieved between English & Japanese



Working with Family Caregivers



Case Example & Discussion

- This case illustrates intergenerational JA family issues when an elder suffers from dementia, caregiving challenges that arise, and cultural issues that affect the use of mental health services.
- This example describes a multigenerational, multiracial JA family caring for parents with dementia/AD. This case highlights cultural issues, family values, and family dynamics.
- See handout



JA Perceptions & Attitudes Toward Caregiving



- Traditional beliefs:
 - Mental health problems are a stigma among traditional JA families
 - *Oyakoko* – JA family caregivers have a duty & obligation to care for parents
 - Privacy issues sustain a belief that problems with a family member should be solved within the family
 - Reluctance to seek help & to report embarrassing, shameful, or troublesome symptoms

JA Perceptions/Attitudes (cont'd.)

- Next generation:
 - JAs most acculturated/assimilated of APIA subgroups
 - English-speaking
 - Out-marriage rates (50%+)
 - Dilution of traditional JA values
 - Shifts in parental expectations
 - Changes in expectations for family care
 - Changes in women's roles, increased acceptance of outside services



**JA Perceptions/Attitudes
(cont'd.)**



- Sansei caregivers
 - Limited family care due to increasing employment & other demands
 - Preference for blended rather than ethnic-specific services
 - More open to outside assistance resulting in increased demands for services/programs
 - Changing attitudes toward institutionalization

(Young, McCormick, & Vitaliano, 2002)

**Suggestions for Providers Working
with JA Family Caregivers**

- Acknowledge the diversity within the JA population
- Be sensitive to the past experiences of JA elders & their families
- Train providers about the importance of establishing rapport & trust; language/food preferences; family decision-making; other unique differences
- Educate JA caregivers about dementia/AD & available supportive care services



Unique JA Community Model

- Network of JA services (San Francisco Bay Area, Seattle, Sacramento, Los Angeles, Central Valley, Chicago)
 - Array of culturally appropriate services; combinations vary by location (e.g., senior centers, ADCs, social services, etc)
 - RCFEs – Board & care, assisted living, dementia care units
 - Skilled nursing facilities
 - Caregiver support groups (Yu-Ai Kai/San Jose)
 - Caregiving skills: coping, stress reduction, problem-solving
- Formal care provided by Nikkei service providers is seen as an extension of family care (Young et al, 2002)



Other Recommendations

- Policies
 - Increase family caregiver resources (e.g., financial assistance, hands-on help, mental health services)
 - Develop educational materials in varying formats & in English/Japanese
- Research
 - Need culturally relevant assessment tools for monolingual Japanese-speaking elders
 - Reestablish/refund AD assessment centers to study dementia in JA populations



Conclusion

JAs are the most assimilated of all Asian/Pacific Islanders, however, many elders/caregivers maintain traditional Japanese language, customs, beliefs, & values. Cultural factors play a significant role in delivering appropriate care to JA elders with dementia & contribute to a better quality of life for caregivers & their loved ones.



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Case Study - Japanese American Caregivers

Mrs. DM (DM) is the mother of two children and new caregiver of her mother-in-law who has Alzheimer's Disease. DM is a second generation Chinese-American. Her parents were born in China and immigrated to the United States. Her in-laws are Japanese Americans. Her father-in-law is a *Kibei Nisei* (born in the US and raised in Japan) and her mother-in-law was born and raised in Japan. Her husband, RM, was born in the US, the youngest of three sons.

DM's in-laws moved from Los Angeles to live with their family last summer. They were welcomed after her father-in-law was asked to leave his oldest son's home because his wife couldn't get along with her father-in-law. The daughter-in-law was from Japan.

The father-in-law, "*Jiichan*" (Grandfather), is critical of the household and is particularly critical of DM. They agreed to take care of the mother-in-law, "*Baachan*" (Grandmother), because *Jiichan* admitted he could no longer take care of her alone. To take care of *Baachan*, DM had to quit her job as a teacher. In return, *Jiichan* agreed to give financial assistance to build an extension on their home.

DM brought her mother-in-law to the senior center for the first time in January. The social worker noticed that DM was stressed and depressed and recommended she join the caregivers' support group. When interviewed for the support group, DM admitted that she was not sleeping well and was tearful. She said that *Jiichan* was constantly critical of her and rude. He said she did not take care of her children correctly and he would interfere by complaining constantly. DM felt that he was critical of her because she was not Japanese and he did not approve of her as a wife to his son. DM stated that she wanted this move to work because of her religious faith (7th Day Adventist) which encouraged extended families. DM felt inadequate in her efforts to please him. She also felt her husband was not supportive because he did not understand how much *Jiichan's* criticism affected her and didn't really understand how abusive the criticism was. It became evident that the family was being split apart and that there was a clash of cultures.

In addition to the support groups, DM sought individual counseling and soon after, her husband came to counseling. In the couples' counseling, RM admitted that he felt the tension between his wife and his father but felt helpless trying to mediate. He had talked to his father but was not sure his father listened. The sessions between DM and RM bonded the two and they were ready to have *Jiichan* join them in family counseling.

In subsequent counseling sessions with the entire family including the two grandchildren, a 15 yr. old girl and a 12 year old boy, *Baachan* was eventually assigned a Japanese speaking case manager, and it became clear that there were many factors involved in the conflicts within this family. These included *Jiichan's* borderline personality disorder,

issues with his mother whom he states, abandoned him in Japan, and his increasing paranoia caused by his dementia and the stress of taking care of *Baachan*. Cultural differences between the Japanese father-in-law and his Chinese American daughter-in-law, between *Jiichan* and *Baachan*, and the generational differences between father and son made living together almost unbearable.

Counseling strengthened the bond between DM and RM and respected *Jiichan's* pride. *Jiichan* acknowledged his fear of losing control of his memory and finally his independence due to his increasing symptoms of dementia. After a few sessions, RM said, "I realize that my father will not change and I will have to learn to cope with that." This was profound and insightful. RM realized the responsibility he had to take care of his parents with the hope of giving his children the experience of living in an extended family situation. DM has grown to appreciate her husband's support as well as his determination to care for his mother and father.

RM has become more involved with the internal issues of the family since he has been staying home for the summer, communicating more with his father, helping his wife and interacting with his children. He has an appointment to test his father for dementia and his mother to determine the stage of her Alzheimer's Disease. Meanwhile, counseling with DM will continue along with the caregivers' support group. Family counseling will continue after *Jiichan* and *Baachan* are tested.

Topics Include:

Part I: Risk of Dementia

Part II: Assessment of Dementia in Diverse Populations

Part III: Treatment and Management of Dementia

Part IV: Working With Families
(14 chapters featuring diverse populations)

Part V: Community Partnerships for Support of Ethnic Elders and Families

Preview Available at: 

Ethnicity and the Dementias

Second Edition



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