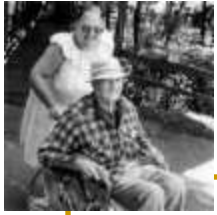

Modifying Evidence-Based Interventions for use with Ethnically Diverse Dementia Family Caregivers

Dolores Gallagher-Thompson, Ph.D.
Dept. of Psychiatry & Behavioral Sciences &
Director, Stanford Geriatric Education Center
Stanford Univ. School of Medicine

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Culture Counts



Presentation Outline

- **Background: The Demographic Imperative**
 - **Key Issues to Consider (e.g., “TAILORING”)**
 - **Successful Example: DVD Project with Chinese American Caregivers**
 - **Work in Progress: “Fotonovela” Project with Latino/ Hispanic American Caregivers**
 - **Accessing the Alzheimer’s Association “Diversity Toolkit” and other Helpful Resources**
-

The Diversification of America

- Although Caucasians will continue to represent the majority of the aged population, ethnic minority elderly constitute the **fastest growing segment** of the elderly population
 - The number of ethnic minority elderly is expected to increase more than 500%, from 4.3 million persons in 1990 to 22.5 million by the year 2050
 - Ethnic minority elderly will account for more than 15% of older persons by 2020 and more than 21% of older persons by 2050.
 - For example, by 2020 in California, two of every five elders will be non-Anglo/ non Caucasian

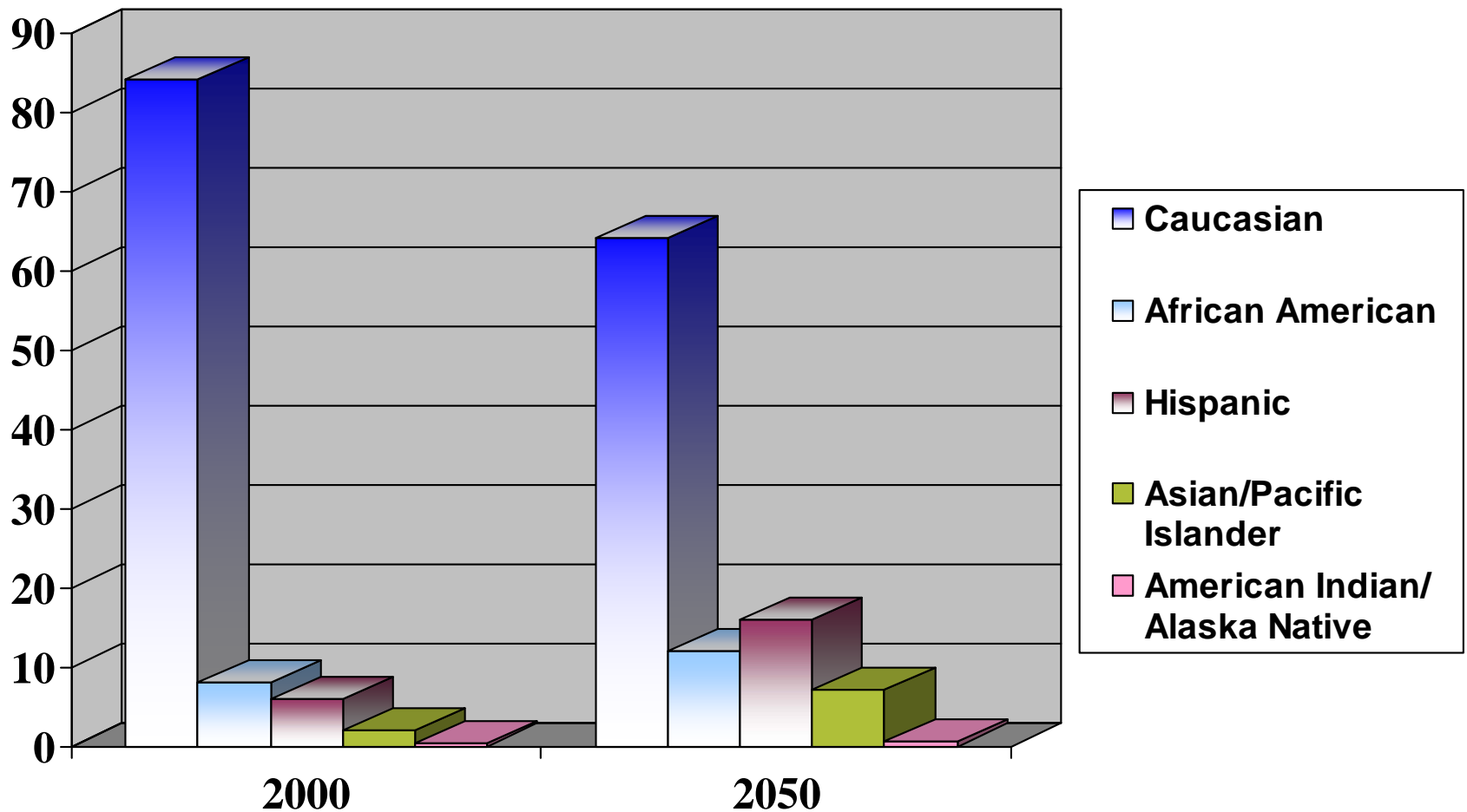
Who are the Ethnic Minority Elderly?

- Generally, identified and classified as members of four non-European racial populations: Black/African American, Hispanic/Latino, Asian/Pacific Islander, and Native American/Alaska Native/
 - These racial categories represent highly diverse, heterogeneous populations
 - **Black/African American** population is comprised of individuals of mixed ethnic and cultural heritage and includes people from Haiti and other Caribbean Islands, South and Central American and Africa
 - According to the 2000 U.S. Census, **Spanish/Hispanic/Latino** category is comprised of those individuals of from Cuba, Mexico, Puerto Rico, South or Central America, or other Spanish speaking countries, regardless of race.
-

Diversity, continued

- The regional use of the terms differs, with the Eastern US using the term “Hispanic” more frequently and the Western US using the term “Latino” more often.
 - **The Asian/Pacific Islander** population consists of over 43 ethnic groups (including Chinese, Japanese, Filipino, Thai, Korean, Vietnamese, Hmong, Laotian, Asian Indian, Pakistani, Samoan, Hawaiian and other Pacific Islander) speaking over 100 languages and dialects
 - **Native American/Alaska Native** category currently comprises 558 federally recognized tribes/nations with over 100 languages spoken
-

Percent of U.S. Population Over 65 by Race & Hispanic Origin



Adapted from U.S. Census Bureau (2001)

Key Issues to Consider

- 1. Get information: about cultural values and attitudes; immigration history; and beliefs about dementia (What causes it? How should it be treated?) incl. who is supposed to be the primary caregiver (CG); what is the family role structure (in general) and what are commonly used, culturally acceptable coping strategies, to manage CG stress?
-

-
- 2. Recognize that accurate knowledge about the causes of dementia and how to treat the various kinds of dementia is less often found among ethnically diverse communities- particularly among those who have recently come to the US. This is a GENERALIZATION yes but there's truth in it. We recently completed a study asking about knowledge of AD (Amer J Ger Psych, Nov. 2009) which confirmed, and extended, prior findings.
-

Knowledge of Alzheimer's Disease (KAD) survey of 236 CGs

- **Chinese & Hispanic CGs were significantly more likely than Caucasian CGs to believe (incorrectly) that:**
 - ❑ **There are medications that will prevent AD**
 - ❑ **Significant loss of memory and mental ability commonly called senility is a normal part of aging**
 - ❑ **People with AD usually die within a year or two after developing the disease**
-

Knowledge of Alzheimer's Disease (KAD) survey of 236 CGs (cont'd.)

- **Chinese & Hispanic CGs worried more than Caucasians that they would get AD.**
 - **Caucasian CGs were more likely than Chinese or Hispanic CGs to believe that AD is one of the worst diseases they knew.**
 - **Caucasians CGs were more likely to obtain information about AD from books, journals the internet, and health professionals.**
 - **Chinese and Hispanics were more likely to obtain information about dementia from family than from health professionals.**
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- 3. “TAILORING” – a key concept – take an evidence-based treatment developed primarily for/with another cultural group, and make that intervention (or portions of it) culturally appropriate and acceptable for the target population. How to do this? Start by engaging the community of interest.
 - ** conduct focus groups with key stake-holders and representatives of the ethnic group you want to work with, and LISTEN to what they have to say – incorporate it into your project!
-

-
- ** Establish an Advisory Committee so that there's an ongoing feedback loop as the project is implemented. Look to them for help with problem-solving as needed.
 - ** Hire staff from the community you are targeting: e.g., bilingual/bicultural staff are often needed when there are significant language and cultural barriers.
 - ** Provide accurate information about dementia and Alzheimer's disease and be available to do presentations, have a table at health fairs, attend special festivals, etc.
-

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- ** Do culturally appropriate OUTREACH – work with the faith community for African Americans use radio PSA's and the faith community for Latino/ Hispanic Americans; use media & the internet for many Asian groups such as Chinese Americans and Asian-Indian Americans.
 - ** Virtually all groups studied say that the most important factor in their joining a program is that they are informed about it by a TRUSTED PROFESSIONAL – who very likely is a member of your Advisory Group and who may have participated in several of your Focus Groups.
-

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- Beyond “tailoring” content and partnering with relevant professionals and agencies in the target community, it’s also essential to try to solve practical problems that may pose formidable barriers to participation – transportation to the program site & paying for the services. Offer scholarships (not “financial aid”). Have easy-to-understand materials that describe the program or service & have well-trained, culturally sensitive staff from the same community, whenever possible. When not possible, be sure existing staff are trained in cultural competence.
-

**DVD Project
for Chinese American Caregivers**

Chinese American Caregivers



The Sandwich Generation

Source: AARP Multicultural Survey, 2001

The true prevalence of dementia in this ethnic group is unknown since there are currently no large scale prospective population-based studies examining the prevalence of Alzheimer's disease and related disorders among Chinese Americans.

Chinese

- Provide intergenerational care across the oceans
- More time-consuming forms of care than any other race
- More **guilt** about not caring enough than any other race
- Expect children to continue caring for elders even though they are becoming more acculturated

Caucasian

- Most likely to live with spouse & own children but not with aging parents in the home
- Less likely to provide direct care for elderly parents
- Guilt, depression, and stress are reported by many
- Elders themselves may be conflicted about whether or not to expect long term care from their adult children

Chinese Culture-Specific Sources of Stress & Burden



- Caregiving demands
- Traditional cultural expectations

● Strained Interpersonal relationships



● Lack of resources or access to those that exist

Views about Dementia

Chinese Views about Dementia

- Memory loss is a normal part of aging
- Difficult behaviors viewed as part of regression to a childlike state
- Often considered a form of mental illness/ “crazy”
- Retribution for sins of ancestors or family’s bad karma or due to poor feng-shui



Family Values Related to Caregiving

- Filial piety = child supports aged parents
- Family’s/Parents’ interests above individual’s
- Women faithfully serve in-laws, particularly mother-in-law
- Interpersonal harmony over individual expression
- Provide for the parents, materially & spiritually
- Oldest son and wife take care of aged parents

Service Needs & Barriers to Help Seeking

■ Hinton (2001)

- “This is the obstacle because I can’t communicate with the doctor. He didn’t talk much when the doctor asked him questions because he did not know how to explain.”
 - “They {healthcare providers at a local clinic} will be nice to Americans {non-Chinese}. They don’t like {those} especially from mainland China. I also think that income is another reason. Mostly, they treat different people differently.”
-

Service Needs & Barriers to Help Seeking

- Pang et al. (2003)
 - “I will not bother my family if I can take care of the problem myself.”
 - “{My children} have their own work to worry about. Only when I have some serious disease will I think about bothering them.”
-

Chinese Caregiver Assistance

Project (CCAP #1)

■ Overview:

- This randomized trial enrolled 51 Chinese or Chinese American women who provided primary care for an elder relative with Alzheimer's Disease or another dementia.
 - It compared the effectiveness of a home-based intervention (IHBM) vs. an education/ telephone support comparison condition (TSC).
 - The in-home program was derived from evidence based treatment programs developed by a team of us at Stanford for use with Latino and Anglo CGs.
 - That program, called "Coping with Caregiving," was designed to teach CGs a range of skills for managing their situation, and their feelings, with less distress.
-

Chinese Caregiver Project Design

■ Pre-Treatment Assessment

- Interview (2 sessions)
 - Collect psychological and biological data
- Participants randomized to one of two conditions
 - Education/Telephone Minimal Support (TSC)
 - In-Home based Intervention (IHBM)

Post-Treatment Assessment

- Interview (1 session)
 - 4 to 6 months after Pre-Treatment Assessment
 - Collected the same psychological and biological data



In-home CBT Intervention

- Total of 12 weekly sessions, each lasting 1.5 to 2 hrs.
- We took the evidence-based intervention developed at Stanford (for Latino and Caucasian CGs) called the “Coping with Caregiving” program, and “tailored” it to be culturally relevant and appropriate for Chinese Americans.
- We started by conducting a series of focus groups, in Mandarin and Cantonese, throughout the region.
- From that experience we learned that traditional support groups, even when conducted in Mandarin or Cantonese, were not likely to attract participants – since it’s a cultural value not to air “dirty laundry” & to “save face” whenever possible.



-
- Translated materials were used for the program, as were bilingual/ bicultural interventionists. There were 6 modules that were more or less emphasized with each CG based on presenting problems:
 1. Relaxation techniques/ stress mgmt
 2. Trigger-Behavior-Reaction “chain”
 3. Restructure habitual thought patterns
 4. Communication skills: asking for help
 5. Increasing everyday pleasant events
 6. Preparing for End-of-Life
-

Education/Telephone Support

- 6 phone calls made to the Caregiver at 2-week intervals over a 12-week period
 - Each call lasted between 15 to 30 minutes
 - Each call began by the interventionist inquiring about how things were going for CG and the Care Recipient
 - Usually, one or more problems were identified by the interventionist during these preliminary inquiries
 - Common themes were wandering, incontinence, incessant repetitive questioning, temper outbursts, frequent awakenings during the night, legal issues, etc.
 - Relevant material concerning issues discussed was mailed, in Chinese or English, as preferred by the CG.
-

Demographic Characteristics

- Caregivers were, in both intervention conditions, about 58 years old. Most were daughters or daughters-in-law (2/3 in each condition). They averaged 30 years in the US; about 13 years of education; and were in this role close to 4 years before seeking help for themselves. None had participated in prior research or service programs for their situation.
 - Care-recipients averaged 80 years of age, with less education.
 - Household income was reported to be under \$40,000 per year.
-

Results

- There was a significant between group difference at the post evaluation *(with pre scores adjusted for) on 2 of the 3 outcome measures:
 - Caregivers in the In-Home condition were significantly less depressed than those in TSC, as measured by the CES-D total score.
 - They also reported less distress (“bother” scores from the Revised Memory & Behavior Problem Checklist), suggesting greater ability to manage everyday problems more effectively.
-

Caregiver Satisfaction with the Intervention Programs

- Those in the In-Home program reported learning more specific skills to help them with caregiving, along with a higher likelihood of keeping their loved one at home, compared to those in TSC.
 - In both conditions caregivers reported that participation in the program was at least “moderately” helpful, and that they would participate in a similar research program again and recommend it to other CGs.
-

Results from a Second, Novel Intervention Program for Chinese American Caregivers

- Based on these encouraging findings, we were funded by the Alzheimer's Assn's national office to develop a less expensive and more "portable" version of the In-Home program. Again, with substantial assistance from Chinese CGs and professionals, through Focus Groups and an Advisory Board, we created script for a **comprehensive DVD**, in Mandarin Chinese, based on the most useful content of the In-Home Program, according to CG ratings.
-

CCAP #2: The DVD Program

- In this study the new Skills Training DVD (in Mandarin Chinese with an accompanying notebook that expanded on DVD content) was compared to an Educational Program only DVD (also in Chinese). So this is an example of taking an evidence based program one step further: to a media platform of presentation.
 - This DVD has 6 segments, similar to the modules in the in-home program. It was professional produced, using volunteer Mandarin speaking actors, over a 1-yr period. It has English and Chinese sub-titles.
 - The workbook was also written in English & Chinese.
-

DVD Treatment Condition

■ Skill-Training Program

- ❖ Information describes and enacts how to handle common problems and emotions that CGs experience, including how to manage, modify, and/or change specific troublesome behaviors, and how to improve communication with family and the health care system.

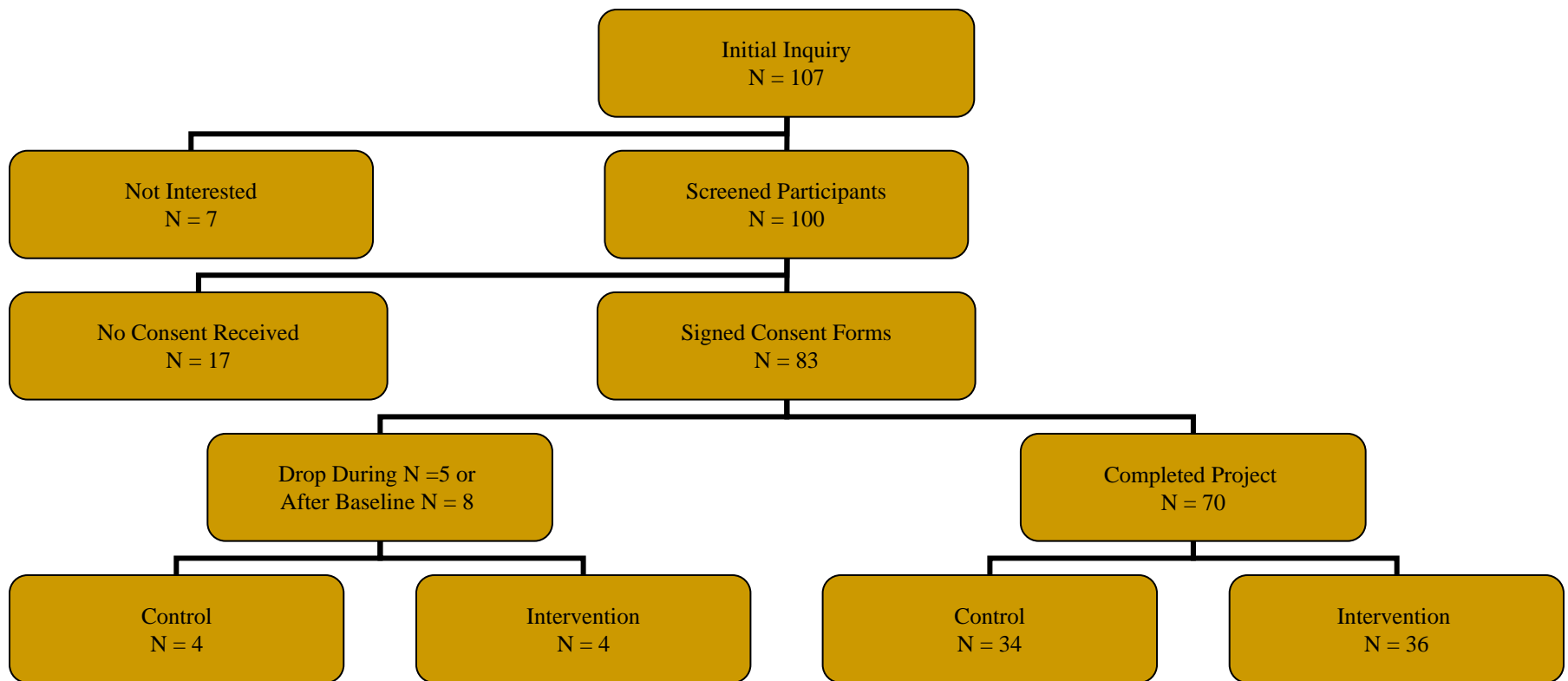
- ❖ Uses Cognitive-Behavioral Therapy Techniques to demonstrate, through Role Plays, “less effective” vs. “more effective” ways to handle typical problems (e.g., repetition, losing things) and the CGs reaction to these problems.
- ❖ Workbook gives additional information and contains practice exercises, to reinforce learning.



DVD Control Condition

- Education-only DVD:
 - Provided up-to-date information about dementia
 - ❖ How to recognize it; common signs & symptoms
 - ❖ What to do to help care recipient
 - ❖ This was available also in both Chinese and English.
 - ❖ At the conclusion of the study, caregivers who received the Education-only program were mailed the Skill Training DVD if they so requested.
-

CCAP Participants



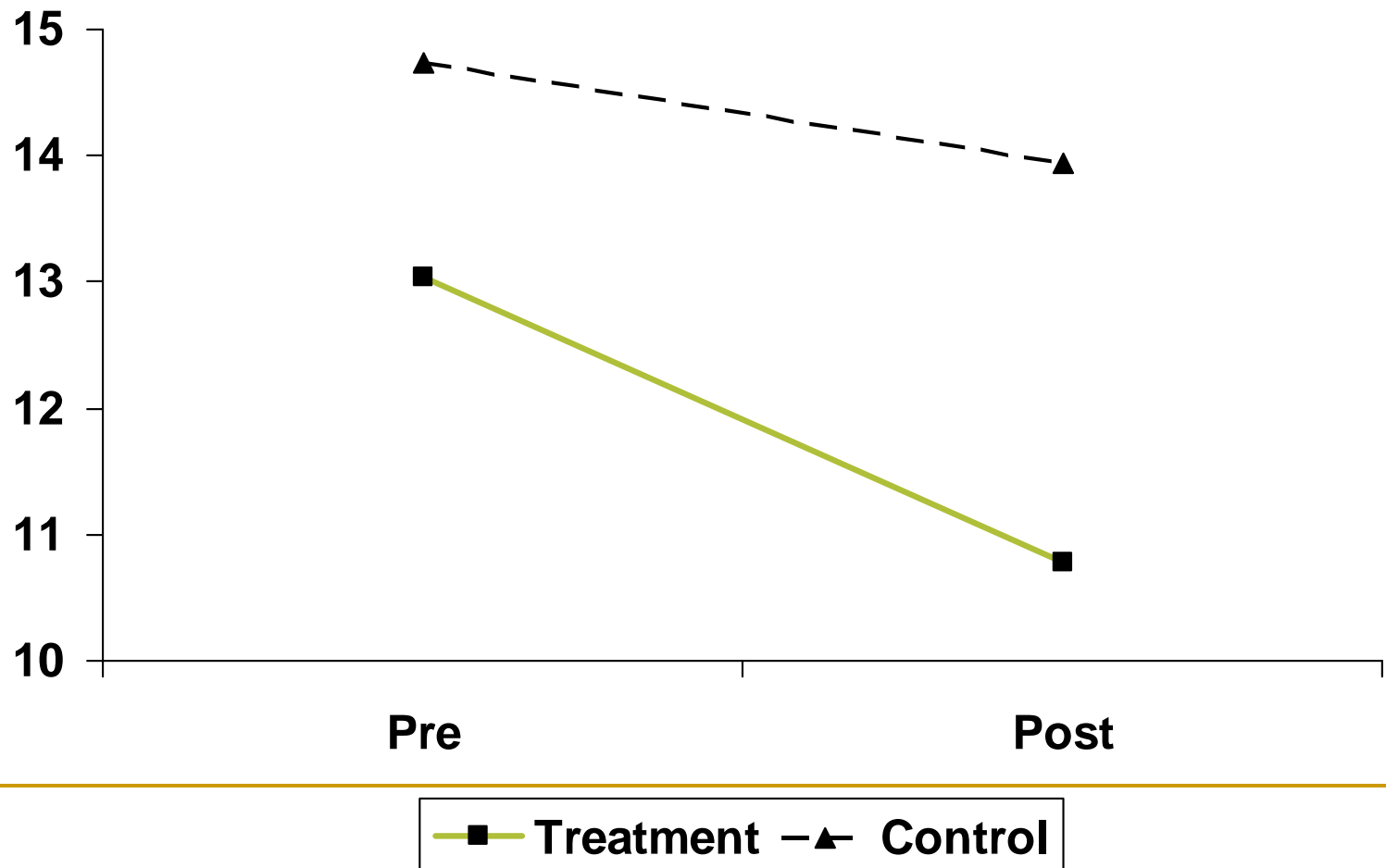
Demographic Characteristics

- These caregivers are about the same age as in the first study; again, most were daughters or daughters-in-law with about 1/3 spouses.
 - There were also 12 paid caregivers (not family members) in this study, and there were 10 men enrolled.
 - Most of the 13 drops were either men family caregivers (5) or paid CGs (the remaining 8) suggesting that this may not be the most effective intervention for these sub-groups of Chinese caregivers.
-

Results of DVD Study

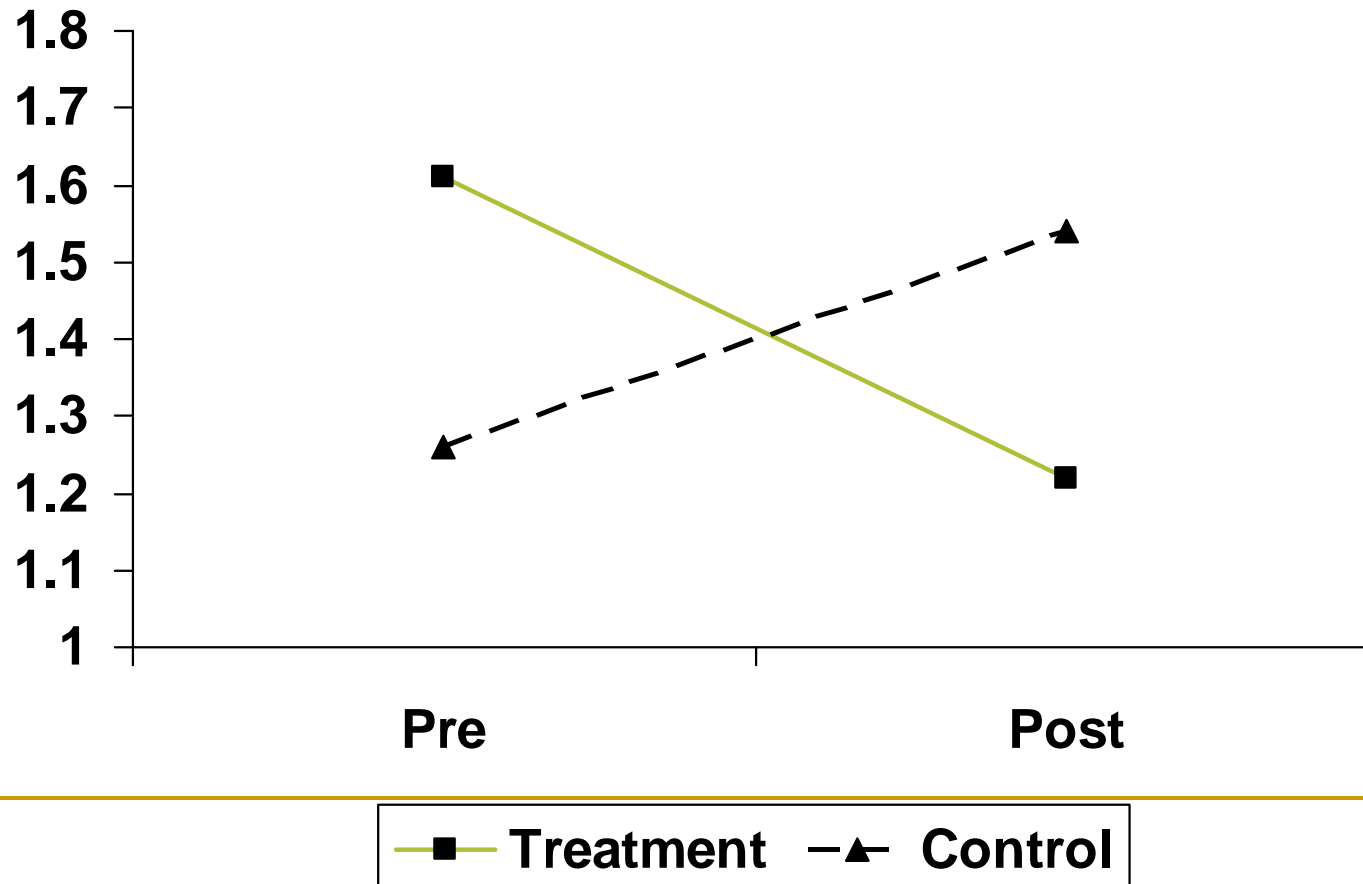
- 1. CGs reported improved ability to manage problem behaviors on the RMBPC (as in the first study) --those who got the Skill Training DVD had significantly less stress at the post interview compared to those who got the Education only DVD. This was true even though the total number of memory and behavior problems did not change.
 - 2. There was no significant reduction of depressive symptoms (CES-D) although there was a trend (as predicted) and there was a significant change in the “positive affect” sub-scale, with those in the STP reporting an increase in positive affect over time compared to those in the Education only condition.
-

**NS Effect of Treatment on Change in CES-D Total Score
(N=70; $t = 1.41$; $p = .164$)**



Effect of Treatment on Change in Reaction to Memory and Behavior Problems: Total Score

($N=70$; $t = 2.58$; $p = .010$)



Other Results from the DVD Study

- In addition, CG satisfaction with the program was measured, and it was found that CGs in the ST DVD program reported learning more useful skills, and reported higher satisfaction overall, versus those who watched the education-only DVD.
 - They also indicated they would recommend it to a friend, and that they had shared it with other family members.
-

Ongoing Work :
The *Fotonovela* Project
for Latino Caregivers

Hispanic/Latino Caregivers



Dementia Facts and Statistics

- Hispanic/Latino Americans may be 2x more likely than Caucasians to develop Alzheimer's disease by age 90
- Hispanics/Latinos are at risk for both AD **AND** vascular dementia due to high prevalence of Type 2 diabetes & hypertension, leading to multiple strokes & in turn, VD.

SALSA (*Sacramento Area Latino Study on Aging*)

- Longitudinal epidemiologic cohort study of a group of older Latino individuals & their families.
- Prevalence of dementia among all SALSA participants was 4.8%, but it was 31% above age 85
- This study is the first to link dementia with diabetes and hypertension; these are considered much more important (and potentially modifiable) risk factors than genetic predisposition.



Hispanic/Latino Caregivers: Characteristics



Majority are women and as with African Americans and Chinese Americans, they are more likely to be adult children (or grandchildren) than spouses.

Lower incomes and lower levels of education are common, as is poorer self-reported health

Latino caregivers are reluctant (at times, unable) to use formal health care services since few agencies have significant bilingual and bicultural staff needed:

- ❑ to provide accurate assessment and treatment;
- ❑ to facilitate cultural bridges between the health care agency and the needs of Latino families;
- ❑ to effectively engage them in a wide variety of treatment options

Hispanic/Latino Caregivers: Cultural Beliefs Associated with Memory Loss

- Etiology is often attributed to:
 - **“Locura”** (craziness)
 - **“Nervios”** (nerves)
 - **Punishment from god**
 - **Poor nutrition**
 - **Stress earlier in life**

 - Among Latinos, the diagnosis of AD is interpreted as a result of:
 - a family tragedy (*Ortiz, Simmons, & Hinton, 1999*)
 - lack of social support (*Levy, Hillygus, Lui & Levkoff, 2000*)
 - normal aging (*Ortiz, Simmons, & Hinton, 1999; Levy et al., 2000*)

 - Diagnosis is difficult since medical co-morbidities (diabetes, heart disease) are common.
-

More on Latino Caregivers

- Most are reluctant to admit to caregiving being a "burden" - This implies they do not accept their role and are not grateful for the care they have received from her parents and spouses. Depression, however, is more readily described.
 - Multiple roles
 - More than half of all Latino caregivers work outside the home and also have at least one child age 18 or younger living at home.
-

Culturally Sensitive Services Reduce Barriers

- Language,, information, and bureaucratic simplicity (Montoro-Rodriguez, Kosloski, & Montgomery, 2003)
 - Examples:
 - El Portal (Los Angeles; full service model)
 - REACH II (home visits and other components)
 - Coping with Caregiving small group program
 - Novel interventions: support groups by phone and promotion of learning materials such as DVD's and *Fotnovelas* that are provided in the target group's language and that can be used in the home.
-

Fotonovela Project

- This new project is designed to meet some needs of Latinos with low literacy for health care information. This study is now in progress; it is funded by the national office of the Alzheimer's Assn.
 - Year 1: we have created the *Fotonovela*: 20 pages in Spanish & 20 pages English.
 - It is a “picture book” with a dramatic story line, photos of real actors depicting specific scenes designed to illustrate key points, and strong use of color to get points across. Content was determined based on 12 focus groups held with professionals and Latino caregivers in northern and southern CA and includes: how to ask for help from family members, how to manage difficult behavior on the part of the “arbuelita” with dementia, and how the CG can take better care of herself.
-

Disparity in Health Literacy

Health Literacy: a person's understanding of a specific health technical language and its accompanying instructions.


- Minority older adults have lower health literacy skills when compared to Whites, overall.
 - Over half have 8 years of schooling or less & 1 in 10 Hispanic/Latino elders has no formal education. (Alzheimer's Association, 2004)
 - Hispanics/Latinos are not receiving the health care information that they need to reduce their risk for dementia and/or to reduce associated CG stress.
-

Which leads to our study: Develop and Evaluate an educational tool referred to as “Managing Difficult Behaviors Fotonovela.”

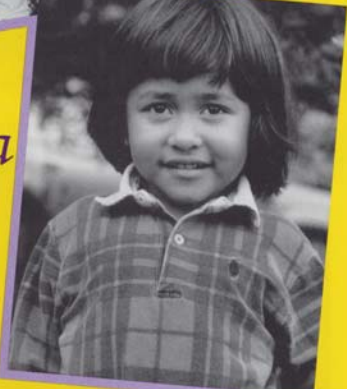
- Educational *fotonovela* is an adaptation of a popular culture medium used extensively to impart health care information
 - Combines “education” and “entertainment”
 - Has “vicarious modeling” potential
 - Specifically targets low-literacy (6th grade & below) Hispanics/Latino population
-

Example of a Health Oriented *Fotonovela*

¡El plomo!



¡Amenaza a la familia!



Washington State Department of Health

¡Qué buena idea! Le avisamos a doña Lupe. Ella sabe mucho de remedios caseros y de cuestiones de salud.



También conoce a todos en el barrio y nos puede ayudar a informar a los demás.

Al llegar a casa, se encuentran con Jaime y Tomás.

Vamos a llamar a los vecinos y invitarlos a que vengan el jueves en la noche para una plática de información sobre el plomo...



¡Qué buena idea!

Así podremos informar bien a todas las familias para que cuiden bien a sus niños.

El día jueves, se reúnen algunas familias del barrio...



Les queremos brindar esta información para proteger la salud de todos los niños del barrio.

Si usted vive en casa vieja, no deje que los niños jueguen en la tierra muy cerca de las paredes de la casa. Mejor que jueguen en el pasto o en donde está pavimentado.



La limpieza de la casa es muy importante. Mantengan limpias las áreas donde juegan los niños.

Limpian las superficies donde puede haber polvo o pedacitos de pintura con trapo o trapeador mojado. Limpian los pisos, los bordes de las ventanas y los juguetes.



Así que tú también te informaste sobre el plomo, ¿eh?



¡Si tú no eres el único inteligente en esta casa, mi vida!

Cuando limpien el piso, hágalo con el estropajo o trapeador mojado.

Tengan cuidado con la loza de barro. Muchas de las ollas, comales y cazuelas que vienen de México contienen plomo.



No guisen la comida en loza de barro porque lo caliente es lo que suelta el plomo.

Phase I: Develop & Field-Test the New *Fotonovela*

- Conduct focus groups with professionals/service providers serving Hispanic/Latino communities in the dementia field, as well as with Latino caregivers, to obtain information about the most important content to be included in the FN.
 - GOAL: Produce a *fotonovela* in Spanish and English that is culturally appropriate and that imparts new information in a manner likely to be acceptable to individuals with low reading comprehension skills.
-

Project Timeline

- Phase I: took 10 months
 - Conduct focus groups: October & Nov.
 - Review data: December & January
 - Produce FN first draft by March 2009
 - Field test in April
 - Revise in May and June/ finish back-translation
 - Finished copy: available by mid July
-

Focus Group Study Overview

- 10 focus groups
Caregivers (4) & Professionals (6)
 - 32 Caregivers, 34 Professionals
 - Conducted in English and Spanish
 - Topics covered: important difficult behaviors, coping strategies, critical fotonovella content
 - Tape-recorded with detailed notes
 - Thematic analysis
-

Behavioral problems

- Behavioral problems are a major issue from the perspectives of both caregivers and professionals
- Specific behavioral problems commonly mentioned as problematic
 - Aggression (verbal and physical), plus mood/depression, hygiene, sexually inappropriate behaviors
- Alzheimer's disease is like a tree with behavioral problems as the branches

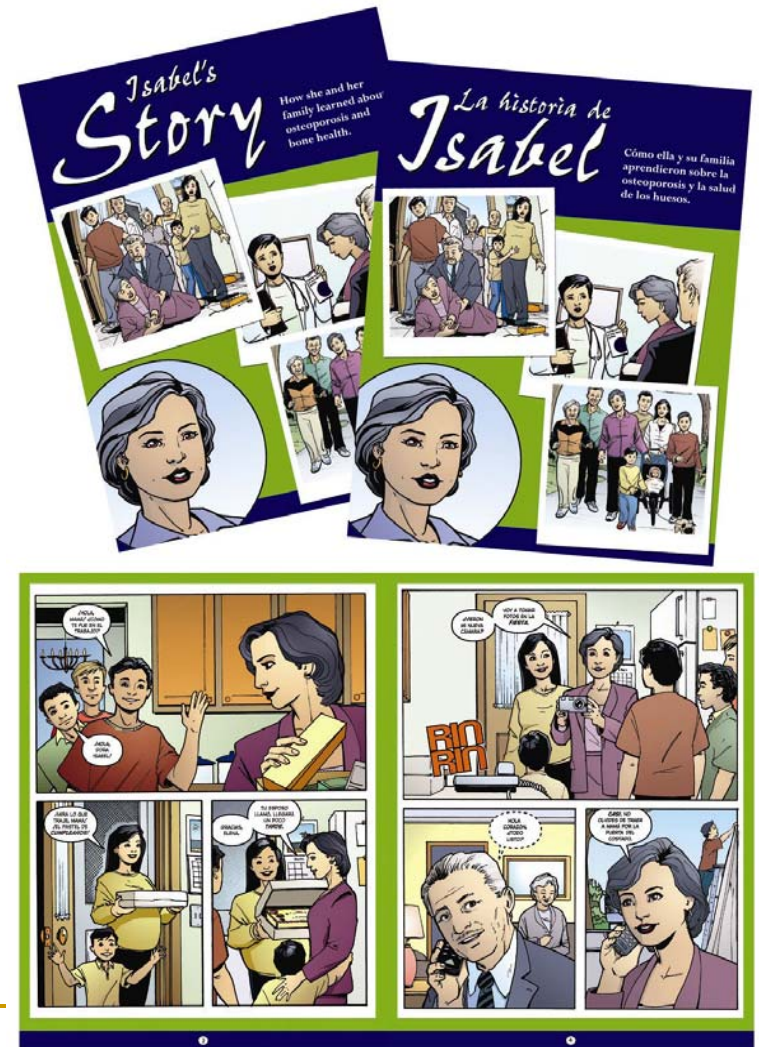
Emergent themes

- Caregiver isolation/depression critical
 - Lack of basic knowledge about AD and behavioral problems
 - Family context is critical
 - Family often ignorant of behavioral problems
 - Family conflict a major source of stress for caregivers
 - Alternatives to FN might be useful: DVD, tele-novella (TV series)
-

Phase II:

Evaluate the Effectiveness of our new *Fotonovela*

- GOAL: Compare this *fotonovela* with usual educational materials currently available that provide general information about dementia but do not focus on managing CGs stress.



Final Product - *Fotonovela*

Together We Can!



Caring for a Person with Memory Loss

No sé, Socorro. Yo no estoy dispuesta a hablar con otros de mis problemas.

Dos semanas después...

¡Ay, Dios mío! Ahora tengo que actuar de prisa pero con calma y distraerla sin asustarla.

No tienes que hablar si no quieres. Es posible que aprendas de otras personas que están en la misma situación.

Mamá venga conmigo, por favor. Mercedes le quiere enseñar su nuevo vestido.

Mercedes, una muchacha inteligente, entiende lo que se tiene que hacer... Abuelita, a ver qué le parece el vestido que voy a estrenar en el baile.

12

¡Qué susto! Mamá podría haber quemado la casa. Pero reaccionamos con calma y pudimos distraerla. Ya vamos aprendiendo cómo sobrellevar este reto.

Verás lo que hizo mamá. Yo creo que está empeorando.

¿Pero qué puedo hacer yo? ¡Ponle más atención!

Delia ha aprendido una técnica muy importante para los cuidadores: Cómo distraer al paciente.

Socorro, Manuel no entiende qué tan seria está la situación con mamá. Necesito ayuda. Voy a llamar a la trabajadora social a quien me recomendó el Dr. Martínez.

Tienes que actuar inmediatamente. Asegura la casa para evitar un terrible accidente. Asegura que ella no pueda prender la estufa.

Buena idea, Delia. Busca ayuda.

13

The Jiménez family...

The Storyline...

- Getting an Alzheimer's diagnosis
- Caregiver in stress, including scenarios like: reacting to a confused grandmother; safety concerns - burning pots and pans; and dealing with a "not quite on board" brother.

Coping Strategies

- The "distraction" technique
- Seeking support from family, friends, and community resources (i.e. support group, adult day care center)
- Family meeting mediated by a social worker

Other Information

- What is dementia?
 - Tips on taking better care of YOURSELF
 - Depression checklist
-

Project Timeline: Phase II

- Phase II: June/ July 2009: begin networking and outreaching for the research component
 - September 2009 through October 2010: enroll caregivers in Southern CA (San Diego area) and northern CA (primarily Salinas and San Jose).
 - It is anticipated that it will take about 15 months to enroll 150 CGs (10 per month, 5 each location).
 - Project follow-ups completed by June, 2011.
 - *Fotonovela* ready for distribution Fall 2011.
-

Challenges Confronting the Research Team

- Should we be developing a comparable product but using electronic medium (e.g, DVD) instead of the print medium of the FN? Will the FN be “obsolete” by 2011?
 - Low literacy Latinos are difficult to recruit for research: there are problems with obtaining informed consent; they may not be able to complete the project questionnaires without assistance; they may not agree to random assignment; they may drop out due to other life stresses during the 6-month interval.
-

Why is this Study Important?

- It will be the first to use rigorous scientific methodology to document the effectiveness of this kind of low-budget educational/ support program to improve Latino CGs quality of life.
 - Prior studies have used quasi-experimental designs, had small numbers, and/or used crude outcome measures. We anticipate that stronger effects will be seen by employing the randomized design.
-

Other Reasons?

- If successful, we will have developed a useful cost-effective tool that can be distributed widely to families, used in support group discussions, shared with MDs and other health care providers, as well as other family members.
 - Presently such a tool does not exist for this community. Furthermore, if successful, this could lead to the development of other “user friendly” methods for educating and training caregivers of low health literacy from a variety of backgrounds.
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Selected References

1. Alzheimer's Association. (2004). *Hispanics/Latinos and Alzheimer's Disease*. Retrieved November 14, 2008, from http://www.alz.org/national/documents/report_hispanic.pdf
 2. Centers for Disease Control and Prevention. (2007). *The state of aging and health in America 2007*. Retrieved November 14, 2008, from <http://www.cdc.gov/aging/saha.htm>
 3. Family Caregiver Alliance. (2004). Cultural competency in working with Latino family caregivers. Retrieved November 14, 2008, from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1095
 4. Pinquart, M., & Sorensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist*, 45, 90-106.
 5. Valle, R. (2008). Occasional papers- obtainable from Dr. Gallagher-Thompson: dolorest@stanford.edu
 6. US Census Bureau. (2005). *65+ in the United States: 2005*. Retrieved November 14, 2008, from <http://www.census.gov/prod/1/pop/p23-190/p23-190.html>
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Two Useful Books

- Valle, R. (1988). *Caregiving Across Cultures*. Washington, DC: Taylor & Francis.
 - Yeo, G. & Gallagher-Thompson, D. (2006) *Ethnicity and the Dementias*, 2nd ed. NY: Routledge/ Taylor & Francis.
-

Accessing the Diversity Toolkit of the National Alzheimer's Assn.

Note: The Alzheimer's Association Website "Diversity Toolkit" is now under the Professional Resources Section

■ Please visit the Alzheimer's Association Home Page at: www.alz.org

The screenshot shows the Alzheimer's Association website homepage. The browser window title is "Alzheimer's Association | Home - Windows Internet Explorer". The address bar shows "http://www.alz.org/index.asp". The website header includes the logo "alzheimer's association" and a search bar. Below the header is a navigation menu with links: "National Site", "About Us", "Donate", "Advocate", "Media", "Contact Us", and "Español". A secondary navigation bar contains "Our vision is a world without Alzheimer's" and "Change Location". A third navigation bar lists: "In My Community", "Alzheimer's Disease", "Living with Alzheimer's", "We Can Help", "Join the Cause", "Professionals & Researchers", and "News & Events".

The main content area features a "Memory Walk" campaign. The text reads: "Memory Walk: Our goal is 30,000 teams". Below this is a map of the United States with state abbreviations. To the left of the map, it says: "Every 70 seconds, someone will develop Alzheimer's. This fall, a nation is walking together to move us closer to a cure. [Join or start a Memory Walk team.](#)". Below the map, a box displays "Teams so far: 27,975".

On the right side, there is a "Find us anywhere" section with a "Search By State" dropdown menu and a "GO" button. Below that is a "24-hour helpline" section with the number "1.800.272.3900" and the email "info@alz.org".

At the bottom right, there is a "Help us raise awareness" section with "SIGN UP" and "DONATE" buttons. Below that is a "Quick Links" section with "MESSAGE BOARDS" (Share support, experiences and advice with alz community members.), "E-MAIL NEWS SIGN UP" (with an "E-mail address" field and "SIGN UP" button), and "SHOP".

The footer contains the text "NUEVO: Our bilingual Español site has a fresh new look" and "CLINICAL STUDIES". The browser status bar at the bottom shows "Waiting for http://www.alz.org/index.asp..." and "Internet".

First, click
“Professionals &
Researchers”

Then, click
“Alzheimer’s
Disease”

Finally, click
“Tools for
Professionals”

The screenshot shows the Alzheimer's Association website in a Windows Internet Explorer browser window. The address bar displays http://www.alz.org/professionals_and_researchers_pr. The website header includes navigation links: National Site, About Us, Donate, Advocate, Media, Contact Us, and Español. The main navigation menu contains: In My Community, Alzheimer's Disease, Living with Alzheimer's, We Can Help, Join the Cause, Professionals & Researchers, and News & Events. The breadcrumb trail reads: Home > Professionals & Researchers > Alzheimer's Disease. A left sidebar menu lists: Professional Care Providers, Physicians, Alzheimer's Disease (highlighted), Diagnosing Alzheimer's, Treating Alzheimer's, Counseling Families, Tools for Professionals (highlighted), Researchers, ISTAART, and Senior Housing Finder. The main content area is titled "Alzheimer's Disease" and includes sub-links for Introduction, Pathology, and Management. An "Introduction" section begins with: "Alzheimer's disease is a progressive, ultimately fatal, disorder in which certain types of nerve cells in particular areas of the brain degenerate and die for unknown reasons." Below this, it states: "Vulnerable brain regions include the amygdala as well as the hippocampus and areas around the hippocampus, and affected cell populations include cortical pathways involved in catecholaminergic, serotonergic and cholinergic". A right sidebar features an "act" logo with the text "Visit our action site" and a "Find us anywhere in the U.S." section with a "Search By State" form.

Tools for Professionals - Windows Internet Explorer

http://www.alz.org/professionals_and_researchers_11

alzheimer's association®

Our vision is a world without Alzheimer's

In My Community | Alzheimer's Disease | Living with Alzheimer's | We Can Help | Join the Cause | Professionals & Researchers | News & Events

Home > Professionals & Researchers > Alzheimer's Disease > Tools for Professionals

Professional Care Providers
Physicians
Alzheimer's Disease
Diagnosing Alzheimer's
Treating Alzheimer's
Counseling Families
Tools for Professionals
Caring for Diverse Populations

Tools for Professionals

This section includes educational materials for diverse communities, including issues related to dementia care, multicultural outreach and culturally appropriate assessment tools.

- [Caring for Diverse Populations](#)

act
Visit our action site

Find us anywhere in the U.S.
Enter ZIP
GO
Search By State

Click on “Caring for Diverse Populations” to access the Diversity Toolbox

Caring for Diverse Populations - Windows Internet Explorer

http://www.alz.org/professionals_and_researchers_11

alzheimer's association®

Our vision is a world without Alzheimer's

In My Community | Alzheimer's Disease | Living with Alzheimer's | We Can Help | Join the Cause | Professionals & Researchers | News & Events

Home > Professionals & Researchers > Alzheimer's Disease > Tools for Professionals > Caring for Diverse Populations

Professional Care Providers
Physicians
Alzheimer's Disease
Diagnosing Alzheimer's
Treating Alzheimer's
Counseling Families
Tools for Professionals
Caring for Diverse Populations
About Diversity Resources
African-American Communities
Chinese Communities
Hispanic/Latino Communities
Korean Communities
General Resources
Researchers
ISTAART
Senior Housing Finder
MAKE A DONATION

Caring for Diverse Populations

Alzheimer's disease and other disorders that cause dementia know no boundaries. Many individuals and families in ethnic and cultural minority groups in the United States encounter obstacles that limit information, care and health resources. Also, many medical and care services are not designed to meet needs in diverse communities.

The Diversity Resources were developed for people with dementia, family and friends, and health and social service professionals to meet the following goals:

- provide resources to people of diverse backgrounds with culturally relevant educational materials
- raise awareness of the health care challenges in a diverse society
- offer tools for volunteers and professionals who are striving to meet those challenges

The diversity resource materials were reviewed and recommended by leaders in research and care in ethnic and cultural minority groups.

In this section:

- [About the Resources](#)
- [African-American Communities](#)
- [Chinese Communities](#)
- [Hispanic/Latino Communities](#)
- [Korean Communities](#)
- [General Resources](#)

act
Visit our action site

Find us anywhere in the U.S.
Enter ZIP
GO
Search By State

Diversity Toolbox Topics

Tools for Professionals

Caring for Diverse Populations

About Diversity Resources

African-American Communities

Chinese Communities

Hispanic/Latino Communities

Korean Communities

General Resources

African-American Communities

- ▶ [Education](#)
- ▶ [Outreach](#)
- ▶ [Videos](#)
- ▶ [Bibliography](#)
- ▶ [Comments and questions](#)
- ▶ [Help with PDF files](#)

Education

This section includes educational materials about issues related to dementia care in diverse communities and challenges to organizations that would like to expand their services to diverse audiences.


 [African-American Communities](#)

 [Women's Health](#) (11 pages)

[African-American Communities](#)

Outreach

This section includes information about outreach materials, assessment tools, glossary of terms, bibliography, comments and questions, and help with PDF files.

 [Diversity Programmatic, Policy and Research Implications Report](#) (3 pages)

 [Getting Started](#)


 [Common Questions](#)

Chinese Communities

- ▶ [Educational materials](#)
- ▶ [Outreach materials](#)
- ▶ [Assessment tools](#)
- ▶ [Videos](#)
- ▶ [Glossary of terms](#)
- ▶ [Bibliography](#)
- ▶ [Comments and questions](#)
- ▶ [Help with PDF files](#)

Education

This section includes information about issues related to dementia care in diverse communities and challenges to organizations that would like to expand their services to diverse audiences.


 [An Overview of Dementias](#)

 [Introduction](#)

 [Introduction to Caregivers](#)

 [Living with Dementia](#) (11 pages)

 [Steps to Responding to Dementia](#) (11 pages)

 [Diversity Programmatic, Policy and Research Implications Report](#) (3 pages)

Hispanic/Latino Communities


- ▶ [Educational materials](#)
- ▶ [Outreach materials](#)
- ▶ [Videos](#)
- ▶ [Glossary of terms](#)
- ▶ [Bibliography](#)
- ▶ [Comments and questions](#)
- ▶ [Help with PDF files](#)

Educational Materials


This section includes information about issues related to dementia care in diverse communities and challenges to organizations that would like to expand their services to diverse audiences.


 [Español Web site](#)

 [¿Qué le pasa?](#)

 [Actividades](#)

 [Alimentación](#)

 [Alucinaciones](#)

 [Aseo Personal](#)

 [Hospitalización](#)

Korean Communities

- ▶ [Educational materials](#)
- ▶ [Outreach materials](#)
- ▶ [Assessment tools](#)
- ▶ [Glossary of terms](#)
- ▶ [Bibliography](#)
- ▶ [Comments and questions](#)
- ▶ [Help with PDF files](#)

Educational Materials


This section includes information about issues related to dementia care in diverse communities and challenges to organizations that would like to expand their services to diverse audiences.

 [Getting Started](#)

 [Common Questions](#)

 [Combating Stigma](#)

 [Sundowning](#)

 [Common Questions](#)

 [Making Care? \(3 pages\)](#)

General Resources

- ▶ [Education](#)
- ▶ [Outreach](#)
- ▶ [Translation](#)
- ▶ [Bibliography](#)
- ▶ [Comments and questions](#)
- ▶ [Help with PDF files](#)

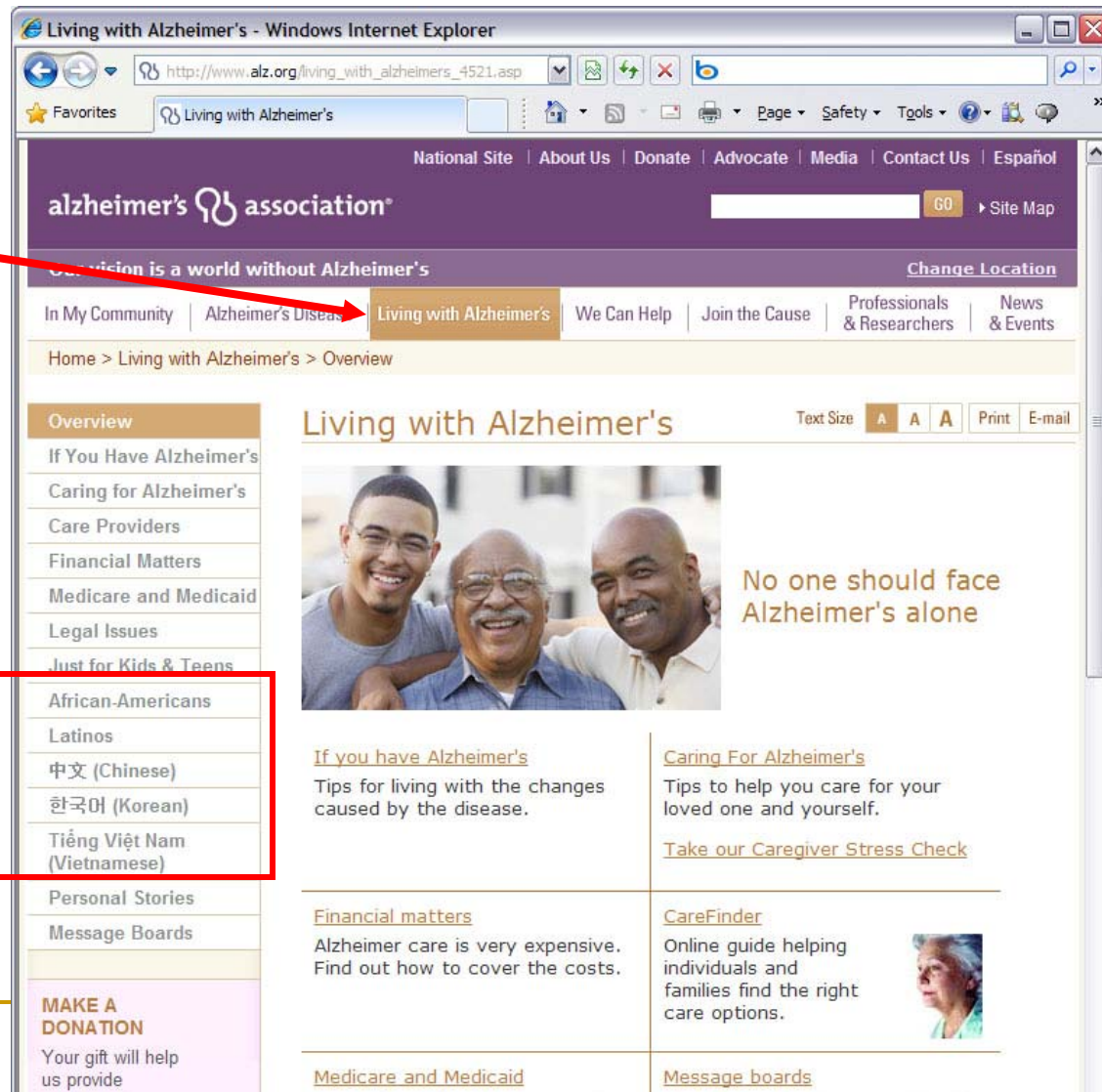
Education

This section includes educational materials about issues related to dementia care in diverse communities and challenges to organizations that would like to expand their services to diverse audiences.

 [Diversity Programmatic, Policy and Research Implications Report](#) (3 pages)

More Multicultural Resources on www.alz.org

Click “Living with Alzheimer’s” to access multicultural resources for caregivers and the general public



The screenshot shows the Alzheimer's Association website in Internet Explorer. The browser address bar displays http://www.alz.org/living_with_alzheimers_4521.asp. The website header includes navigation links: National Site, About Us, Donate, Advocate, Media, Contact Us, and Español. The main navigation menu features: In My Community, Alzheimer's Disease, Living with Alzheimer's (highlighted with a red arrow), We Can Help, Join the Cause, Professionals & Researchers, and News & Events. A breadcrumb trail reads: Home > Living with Alzheimer's > Overview. The left sidebar contains a list of topics: Overview, If You Have Alzheimer's, Caring for Alzheimer's, Care Providers, Financial Matters, Medicare and Medicaid, Legal Issues, Just for Kids & Teens, African-Americans, Latinos, 中文 (Chinese), 한국어 (Korean), Tiếng Việt Nam (Vietnamese), Personal Stories, and Message Boards. A red box highlights the multicultural options, with a red arrow pointing from the text on the left. Below this is a 'MAKE A DONATION' section. The main content area is titled 'Living with Alzheimer's' and includes a photo of three men with the text 'No one should face Alzheimer's alone'. Below the photo are sections for 'If you have Alzheimer's', 'Caring For Alzheimer's', 'Financial matters', 'CareFinder', 'Medicare and Medicaid', and 'Message boards'. A 'Text Size' control and 'Print E-mail' links are also visible.

Overview
If You Have Alzheimer's
Caring for Alzheimer's
Care Providers
Financial Matters
Medicare and Medicaid
Legal Issues
Just for Kids & Teens
African-Americans
Latinos
中文 (Chinese)
한국어 (Korean)
Tiếng Việt Nam (Vietnamese)
Personal Stories
Message Boards
MAKE A DONATION
Your gift will help us provide programs for people affected by Alzheimer's.

African-Americans and Alzheimer's Disease

Text Size



- ▶ [Introduction](#)
- ▶ [Alzheimer's disease](#)
- ▶ [Impact on community](#)
- ▶ [Vascular dementia](#)
- ▶ [The heart-brain connection](#)
- ▶ [Be a healthy caregiver](#)

Introduction

As we age, most of us eventually notice some slowed thinking and problems remembering certain things. However, serious memory loss, confusion and other major changes in the way our minds work are **not** a normal part of aging. They could be signs of Alzheimer's disease.

Today more than 5 million people have Alzheimer's. And African-Americans may be at especially high risk for the disease. But there are things you can do. Learn more about Alzheimer's, how you can reduce your risk and how to get stress relief if you are caring for a loved one with dementia.



Alzheimer's disease

Alzheimer's (AHLZ-high-merz) is a disease that results in the loss of brain cells. It is the most common form of dementia, which is a group of brain disorders that cause

Overview
If You Have Alzheimer's
Caring for Alzheimer's
Care Providers
Financial Matters
Medicare and Medicaid
Legal Issues
Just for Kids & Teens
African-Americans
Latinos
中文 (Chinese)
阿滋海默症資訊簡介
附加資源
한국어 (Korean)
Tiếng Việt Nam (Vietnamese)
Personal Stories
Message Boards
MAKE A DONATION
Your gift will help us provide

這是不是阿滋海默症

Text Size **A A A** Print E

[Have display problems](#)

- Chinese**
- [Korean](#)
- [Vietnamese](#)



這是不是阿滋海默症?

10 Warning Signs

阿滋海默症資訊簡介

A Guide to Alzheimer's Disease

探索大腦之旅: 點圖解密

Brain Tour

附加資源

Additional Resources

阿滋海默症是一個腦部退化的疾病,它的起因無人知道,現在仍未有治癒的方法。

下列十項警告徵兆可以幫助您了解, 您的記憶力衰退現象是否已構成嚴重的健康問題。如果您發現自己或是身邊的任何人有下列任何一項徵兆, 請不要忽視它, 要盡快找醫生作檢查以確認病因。有些疾病也會出現這些徵兆, 而這些疾病有些是可以治療的。

Overview
If You Have Alzheimer's
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African-Americans
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한국어 (Korean)
Tiếng Việt Nam (Vietnamese)
Personal Stories
Message Boards

Latinos

Text Size **A A A** Print E-r

Latinos in the United States have higher rates of vascular disease, so they may also be at greater risk for developing Alzheimer's.*

According to a growing body of evidence, risk factors for vascular disease – including diabetes, high blood pressure and high cholesterol – may also be risk factors for Alzheimer's and stroke-related dementia.

While we don't know yet what causes Alzheimer's disease or exactly how these conditions and dementia are connected, what we do know are that there are things you can do.

Go to our bilingual [Español section](#) and learn more about:

- Alzheimer's disease, including diagnosis and treatments
- The connection between Alzheimer's and diabetes
- Ways to care for a person with dementia
- Resources available, such as brochures and Web links to organizations serving the Latino community

[Espanol secton >>](#)

* [Hispanics/Latinos and Alzheimer's Disease](#). Alzheimer's Association. May 2004.

For further information:

- Please feel free to contact Dr. Dolores Gallagher Thompson by email: dolorest@stanford.edu,
 - phone: 650 400 8172.
 - Website: <http://sgec.stanford.edu>
 - The National Office of the Alzheimer's Assn has a **24-hour helpline: 1.800.272.390** and **excellent website: info@alz.org**
-