Assessment of Dementia and Caregiving for Latino Elders

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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

- Their number is expected to increase more than 500%, from 4.3 million persons in 1990 to 22.5 million by the year 2050
- Overall, ethnic minority elderly will account for more than 15% of older persons by 2020 and more than 21% of older persons by 2050.
- However, in some states (e.g., California) by 2020 2/5 elders will be non-Anglo/ non Caucasian.
Percent of U.S. Population Over 65 by Race & Hispanic Origin

Adapted from U.S. Census Bureau (2001)
Diversity Among Latino Populations in the United States

- Mexico
- Central America
- South America
- Puerto Rico
- Cuba
Latino Sub Group Variances

- Cultural Traditions
- Values
- Religions
- Belief Systems
- Dialect
- Education
- Literacy
Common Etiquette Guidelines for working with Latino populations:

- Address the elder by last name
- Often communication is indirect through the son or eldest child. Eye contact is often limited or indirect.
- Spatial relation is often reserved initially until familiarity is established, then it is close with embracing or cordial touch on the hand/arm
- Establish familiarity with casual conversation especially about family history, culture and food customs
Etiquette continued

- Customs around food are important; be prepared to be offered a beverage or snack
- Taboo topics (including body functions, body parts) should be prefaced with explanation of medical significance to assessment
Communication Challenges: Language

Language:
- Monolingual
- Dialect Variances
- Indigenous Languages
- Social v Academic Language
Communication Challenges: Literacy

Limited education
Low literacy/no literacy
English-language or Spanish-language
Content-specific vocabulary
Low vision issues: small print, fonts with serif, reverse color text (white on black) italics
Family Structure

- Multiple generations often live under one roof
- Emphasis on whole family inclusion
- Nuclear family with large extended family
- *Compadrazo* (Godparents) may play a significant role or take on role of caregiver
Cultural Beliefs Associated with Memory Loss

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

- 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: Few distinctions between physical illness, emotional disorders, and social problems
Traditional Beliefs on Healing

- Curanderas (herbal/traditional healer)
- Espiritistas (spiritual healer)
Traditional Healing

- Remedios (herbal/dietary remedies)
Traditional Healing

- Prayer: candle lighting, rosary, estampas religiosas (prayer cards) and escapulario (necklace worn as blessing or protection)
Assessment Issues in Evaluating the Person with Dementia

- Cognitive impairment is determined from patient history (family’s observations & reports) & from mental status examination.
- Several relatively brief, easy-to-administer measures are available to help identify those for whom a “high index of suspicion” exists that cognitive impairment may be present, and that further neurological and neuropsychological assessments are needed for clarification.
Challenges to Assessing Dementia in Latino Elders

- Under-recognition of cognitive impairment by physicians/trusted helpers: reluctance to test
- Although there are several culturally and linguistically appropriate measures to use for assessment, choice of which to use is a “local matter” so scores may not be directly comparable across different versions of the same test, or across different regions of the country
- Insufficient normative data for existing tests among Latino elders.
MMSE: Most Commonly Used Screening Tool for Cognitive Impairment

- The Mini-Mental Status Examination (MMSE; Folstein et al., 1975) takes 10 -15 min. & asks about orientation, attention, concentration, recent memory, naming, repetition, comprehension, constructional praxis & ability to construct a sentence. Max. score = 30.
- Cut-off score $\leq 23$ from person with high school education suggests impairment.
- Cut-off score $\leq 18$ from person with 8th grade education or less suggests impairment.
- Scores are thus affected by education and age & there are corrected/ adjusted norms available. *Crum et al., JAMA, 1993.*
Value Of MMSE

- MMSE has been used for many years & studied extensively around the world.
- It has a number of strengths:
  -- it is brief & needs short administration time
  --translated into multiple languages
  --useful screen for cognitive impairment when appropriate cut-off scores are used
Weaknesses of MMSE

Not always administered in a “standardized” manner (serial 7’s vs. “world” backwards)

It is now copyrighted and copies in English, and authorized translations, must be purchased (no longer free) from Psychological Assessment Resources.

It is only a screen: does not give diagnosis.
Utility with Ethnically Diverse Elders?

Scores are affected not only by age and education (Escobar, 1986) but also by cultural background: the “usual” MMSE appears to under-estimate cognitive capacities of Black/African American and Hispanic/Latino persons compared with Whites – so a high rate of “false positives” can occur in these groups.

Study of Differential Item Functioning (DIF) shows that there is item bias in the MMSE – e.g., certain items perform poorly for Spanish and Chinese speaking elders, and for African Americans. Examples: “serial 7’s” are more difficult for Latinos and African Americans with low education compared to Whites. Date of the month and year questions are not relevant to immigrant Chinese elders who use a different calendar than the “majority culture” – but asking: which direction does the sun set? Is more culturally appropriate.
Variations on the “standard” MMSE

- “Semantic equivalence” rather than literal translation is usually done – e.g. in Spanish, there are idiomatic nuances that force different translations for different sub-groups speaking the same language—“No ifs, ands, or buts” is not identical if you compare MMSE versions across Mexican Americans, Puerto Ricans, Cubans, and Spaniards. For example, some versions use the phrase: “Mas vale tarde que nunca” which means “Better late than never.”

- The “3 objects” recall item is likewise different across most versions- different words are used for memory testing.

- There is, at present, no one accepted translation or adapted version of the MMSE that is widely used in Latino communities. Rather, there are translations/ adaptations that are more or less popular in different regions of the country. Generally they tend to use more of the local dialect / vernacular whenever possible.
The Value of “correcting” MMSE scores

Dr. Dan Mungas & colleagues from Univ of CA at Davis developed a formula to apply to “usual” MMSE scores to correct for age and education differences –primarily arising from their work with Latino older adults in the SALSA project.

The new formula was tested in a sample of 2,983 ethnically diverse patients evaluated in the CA Alzheimer’s Disease Diagnostic & Treatment Centers.

It was found that the adjusted score, when used with low- and high-education groups and across Whites, Hispanic/Latinos, and Blacks showed greater sensitivity and specificity (compared to the unadjusted MMSE).

This suggests that the MMSAdj is a preferable measure of cognitive impairment for low-education minority elders.
MMSAdj Formula

MMSAdj equals Raw MMS minus (0.471 times {Education-12} plus (0.131 times {Age-70}).

- Published in Neurology, 1996, vol. 46, 700-706 by Mungas et al. Title of the article: Age and education correction of the Mini-Mental State Examination for English and Spanish speaking elderly.
Alternatives to MMSE

- Mini-Cog
- Clock Drawing Test
- Montreal Cognitive Assessment (MoCA)
Mini-Cog

- Mini-Cog is a quick to administer (5 min) & simple to score cognitive screening measure.
- It consists of 3-item memory registration and delayed recall, plus clock drawing.
- Translated versions exist; Mini-Cog has been used successfully with Spanish speaking and Chinese, Japanese, and Vietnamese speaking older adults –typically in primary care settings.
- Copies can be obtained from Dr. Soo Borson, M.D., Univ of Washington (Seattle): email: soob@u.washington.edu
- No charge for copies, but the measure is copyrighted, so permission to use is needed.
Clock Drawing Test

- Can be used as a screening tool with virtually all elders, whether literate or not.
- Instructions are: draw a clock, put in all the numbers; set the hands at 10 past 11.
- No charge for use & easy to interpret so it’s worth considering as an addition to your main cognitive screening measure.

http://alzheimers.about.com/od/diagnosisis sues/a/clock_test.htm contains downloadable instructions & 5 point scoring.
Montreal Cognitive Assessment (MoCA)

- The MoCA is a brief cognitive screening tool with high sensitivity and specificity for detecting Mild Cognitive Impairment (as currently defined) in persons with a normal score on the MMSE.
- Intended for use by busy physicians/clinicians who can administer it in 10 minutes or less.
- It is free, and translated versions are available free from website: http://www.mocatest.org (including Spanish).
- Clinical Implications:
  1. Useful screening tool for the detection of mild AD and MCI – thus allowing intervention to begin sooner;
  2. Useful predictive tool for the development of dementia in clients with MCI – again, early intervention is then possible.
- Limitation: May not be sensitive to change over a 6-month period – this is still being researched.
Assess Depression Too!

- Depression is a common contributor to cognitive impairment: often as depression improves, so does cognitive function. So it’s good to evaluate if depression is present, and if so, the severity level.

- Two common measures: Geriatric Depression Scale and Beck Depression Inventory II.
Comparison of GDS vs. BDI II

- GDS is available in every major language; BDI II is available in English and Spanish only.
- GDS is free: download from internet; BDI has to be purchased from the Psychological Corporation.
- GDS does not, however, assess “traditional” symptoms of depression; it focuses on negative self-worth, pessimism re the future, & other more “psychological” signs of depression. BDI asks about usual symptoms: sleep, appetite disturbances; low energy; sad mood, etc.
- GDS has simple response format: yes/ no so it can often be completed by those with cognitive impairments. BDI uses more complex response format & is too challenging for those with cognitive impairments to complete accurately.
- The GDS is available at:

  http://www.stanford.edu/~yesavage/GDS.html
What to do next if screening suggests cognitive impairment?

- In northern CA: Stanford Neurology Dept. has a “Memory Clinic” that provides a similar service but is more equipped to handle persons for whom English is not the primary language since interpreter service is available through the medical center. Contact: 650 723 6469 or see website: [http://med.stanford.edu/neurology/index.html](http://med.stanford.edu/neurology/index.html)

- Throughout California there are Alzheimer’s Disease Centers that provide diagnostic work-ups for persons with suspected dementia. There are certain eligibility criteria & English is the preferred language at most Centers. Other states may have similar resources.

- Up-to-date information about evaluation options throughout the USA can be obtained from your local Alzheimer’s Association office.
Successful Interventions with Latino Dementia Family Caregivers

- A variety of interventions have achieved the status of being “evidence based” and so can be recommended for consideration.

- Gallagher-Thompson & Coon’s 2007 review found that psychoeducational interventions had the strongest research base. Several studies have been done with Latino caregivers, in CA and FL primarily, that taught a variety of cognitive and behavioral skills to improve adaptive coping (e.g., reframing the situation; learning how to ask for help from family; communicating better with the person with dementia). Findings generally showed improvement in depression and in self-reported stress from dealing with everyday problems of the PWD.
“Coping with Caregiving” Program

- This is a small group intervention that we’ve studied in 3 randomized clinical trials with over 300 Latino caregivers in northern CA. It is an 8 to 12 week series of workshops, conducted in Spanish by trained Promotoras at convenient community locations, designed to teach adaptive coping skills in a supportive atmosphere. Extensive role-playing is used to encourage learning & home practice assignments are made.

- Content includes: stress management exercises; tools for managing negative emotions (frustration, depression); increasing everyday positive activities; obtaining respite; & communicating more effectively.

- This program has been very well received & is in use in other regions of the country (in modified, adapted formats).
REACH II Intervention Program

- This is a multi-component program that includes 6 – 9 home visits, scheduled telephone support groups, a “caregiver notebook” & “health passport” to promote greater self-care, & individualized plans (developed by CG & interventionist) to manage difficult behaviors of the PWD. Spanish language materials & interventionists were available.

- Data from over 600 CGs in a randomized clinical trial demonstrated the efficacy of this program (compared to a control condition) for reducing depression & improving quality of life. About 1/3 of these CGs were Latino from all over the US.

- This intervention, though expensive to provide, is now being modified (and shortened) for use by a greater variety of community-based service providers across the US.

- An adapted version for Latino CGs is being developed and will be field-tested in the San Diego area of CA in the next 2 years with funding from the Rosalynn Carter Institute.
Support Groups

- Support groups are offered throughout the US by agencies such as the Alzheimer’s Association, through its network of local chapters. They have been widely attended by CGs of diverse backgrounds – particularly when offered in the language of choice of the CG.

- Although little research has been conducted on their efficacy, they are often reported to be very helpful to participants who learn that they are not alone, and who learn methods of problem-solving from each other.

- On the down side, some say that support groups are “not for everyone” – they may be upsetting to relatively “new” CGs who see what’s ahead as their loved one’s disease progresses. To others, they are “not enough” as there are no leaders (generally) and therefore individual problems and issues aren’t really addressed in depth.

- Typically, support groups are most effective when they are part of a larger more individualized network of services.
Fotonovela Project with colleagues Dr. Ramon Valle (San Diego) & Dr. Ladson Hinton (Sacramento)

- 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 “abuelita” 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
Content was Derived from a Series of Focus Groups

- 10 were conducted: Caregivers (4) & Professionals (6) in English & Spanish
- 32 Caregivers, 34 Professionals
- 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 according to both CGs & 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.

Source: National Institute of Arthritis and Musculoskeletal and Skin Diseases website
Final Product – new Fotonovela
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 for Completion

- June/July 2009: began networking and outreaching for the research component.
- September 2009 through October 2010: now enrolling caregivers in Southern CA (San Diego area) and northern CA (primarily Salinas, Sacramento, and San Jose).
- We anticipate that it will take about 15 months to enroll 150 CGs in the project.
- Project follow-ups completed by June, 2011.
- Fotonovela ready for distribution Fall 2011.
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.
Selected References


Two Useful Books

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
First, click “Professionals & Researchers”

Then, click “Alzheimer’s Disease”

Finally, click “Tools for Professionals”
Click on “Caring for Diverse Populations” to access the Diversity Toolbox.
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
- Educational materials
- Outreach materials
- Videos
- Glossary of terms
- Bibliography
- Comments and questions
- Help with PDF files

Chinese Communities
- Educational materials
- Outreach materials
- Videos
- Glossary of terms
- Bibliography
- Comments and questions
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Korean Communities
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- Outreach materials
- Videos
- Glossary of terms
- Bibliography
- Comments and questions
- Help with PDF files

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
More Multicultural Resources on www.alz.org

Click “Living with Alzheimer’s” to access multicultural resources for caregivers and the general public.
African-Americans and Alzheimer's Disease

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 our way of mind's 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 (AH-LZ-high-morz) 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

Latinos
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

Español section >>

For further information:

- Please feel free to contact Dr. Dolores Gallagher Thompson by email: dolorest@stanford.edu,
- 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