Evidence Based Interventions for Family Caregivers of Persons with Dementia

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“Evidence Based Interventions for Family Caregivers of Persons with Dementia”

Dr. Gallagher-Thompson received her degree in clinical psychology/adult development and aging from the University of Southern California in 1979 and has been in the field ever since as a practicing geropsychologist, conducting research, teaching, and providing clinical care to patients and families. She has taken on NIH funded clinical researcher for the past 30 years and is most noted for her empirical studies on the efficacy of different types of psychosocial interventions to reduce stress and improve the psychological status of family caregivers of older adults with Alzheimer’s disease or other forms of dementia. She recently completed the first efficacy trial of psychosocial interventions for dementia caregivers, which was implemented in the San Francisco Bay area. Her work on the development and evaluation of educational “coping classes” with caregivers has been translated into Spanish, Chinese, Japanese, and Farsi. Dr. Gallagher-Thompson has authored over 150 papers in major journals in the field and has co-edited the critically acclaimed second edition of “Diversity and the Dementias” (with Gwen Yeo, senior editor) and the book “Interventions to Reduce Caregiver Distress” (David Coon, senior editor). She is currently co-editor in chief of the journal Clinical Gerontologist and has served as the senior editor of a comprehensive new volume entitled “Cultural Competence in Geriatric Mental Health.” She has held board positions with the Alzheimer’s Association in northern California and is currently developing online intervention programs for caregivers of older persons with significant memory loss. She is a Professor of Research in the Department of Psychiatry and Behavioral Sciences at Stanford University School of Medicine, and Director of the Stanford GEC.

About the Presenter

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Objectives

1. Learn about dementia caregiving
2. Understand issues in African American, Latino and Chinese American family dementia caregivers
3. Learn various evidence-based interventions for family dementia caregivers and best practices in choosing an intervention
4. Identify components of a culturally sensitive intervention for family dementia caregivers
Dementia Caregivers: Who are they?

Alzheimer’s and Other Dementia Caregivers: Demographics

- 62% are women
- 50% had some college education or beyond
- 59% currently employed, a student, or homemaker
- 70% married or in a long-term relationship

Age

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 55</td>
<td>10%</td>
</tr>
<tr>
<td>56-65</td>
<td>34%</td>
</tr>
<tr>
<td>66-75</td>
<td>20%</td>
</tr>
<tr>
<td>76 and older</td>
<td>36%</td>
</tr>
</tbody>
</table>

[Data from Alzheimer’s Association]

Proportion of Alzheimer’s and Dementia Caregivers vs. Caregivers of Other Older People by Duration of Caregiving

[Graph showing proportions over time]

[Graph created from data from the National Alliance for Caregiving and AARP]
Dementia Caregiving Tasks

**Activities of Daily Living**
- Bathing & Toileting
- Grooming & Dressing
- Getting in & out of bed
- Walking
- Feeding

**Instrumental Activities of Daily Living**
- Shopping & Cooking
- Housework & Errands
- Transportation & Finances
- Managing & dispensing medications

**Other Areas of Assistance**
- Home modifications and assistive devices
- Arranging, attending, advocating medical care and other services
- Community integration, socialization and emotional well-being
- Managing difficult behaviors (i.e. repetitive questioning, waking family members, arguing/complaining)

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Effects of Caregiving on Work

<table>
<thead>
<tr>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0%</td>
</tr>
<tr>
<td>10%</td>
</tr>
<tr>
<td>10%</td>
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<td>10%</td>
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<td>10%</td>
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<tr>
<td>10%</td>
</tr>
</tbody>
</table>

*Note: Data from the Alzheimer's Association.*

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Impact/Risks of Dementia Caregiving

**Physiological Health Outcomes**
- Compromised immune system
-Decreased physical activity levels
- Sleep disturbances
- Increased use of psychotropic drugs
- Increased risk for cardiometabolic disease
- Increased risk of delirium
- Decreased risk of cardiovascular disease

**Psychological Health Outcomes**
- Increased depression symptoms
- Decrease in quality of life
- Increased anger/frustration
- Increased social isolation

**Other**
- Increased cost of care
- Increased stress levels
- Early onset of nursing home placement

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Impact on Caregivers of Individuals with Severe Memory Problems/Dementia vs. Caregivers of Individuals with Problems Other Than Memory/Dementia

<table>
<thead>
<tr>
<th>Impact on Caregiver</th>
<th>Severe Memory Problems/ Dementia</th>
<th>Problems Other Than Memory/ Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotionally stressful</td>
<td>44%</td>
<td>30%</td>
</tr>
<tr>
<td>Sleep interrupted</td>
<td>32%</td>
<td>22%</td>
</tr>
<tr>
<td>Physical strain</td>
<td>24%</td>
<td>13%</td>
</tr>
<tr>
<td>Financial hardship</td>
<td>19%</td>
<td>11%</td>
</tr>
<tr>
<td>Excellent or very good health</td>
<td>36%</td>
<td>44%</td>
</tr>
</tbody>
</table>


What Causes Caregiving to be Stressful?

- Lack of control & predictability
- Social isolation
- A perception that things are getting worse
- Feelings of helplessness

African American Dementia Caregiver Issues

- Reported less distress, burden and depression compared to other groups
- Less likely to perceive caregiving as a disruptive experience
- Worse perceived physical health
- Showed higher level of caregiving satisfaction and mastery
- Larger and more diverse social network
- Religion/spirituality: the church are strong sources of support and seem have a buffering effect
**Latino Dementia Caregiver Issues**

- Exhibit more depression & stress compared to Whites or African Americans, and higher rates of diagnosed depression.
- Majority of care provided by middle age daughters who often care for parents and parents-in-law.
- More than half work outside the home and also have at least one child age 18 or younger in the home.
- Unable to use formal health care services since few agencies have significant bilingual and bicultural staff needed for accurate assessment and treatment.
- Spend about 10-14 hours more per week caregiving than non-Hispanic white CGs and Asian-American CGs.
- ~45% report experiencing higher burden from caregiving (this compared to 33% of non-Latino whites and Asian-Americans).

**Reasons why:**
- Latino dementia patients exhibit more neuropsychiatric and behavioral symptoms compared to non-Hispanic White age-matched controls. (Orz et al., 2006)

**Cultural values**

- Filial piety = child supporting the aged parent without question
- Family's/Parents' interests above individual's
- Women faithfully serve their in-laws, particularly mother-in-law
- Interpersonal harmony over individual expression
- Oldest son and wife take care of aged parents

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**Chinese Dementia Caregiver Issues**

**Chinese 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
- Retribution for sins of ancestors or family’s bad karma or due to poor feng-shui

**Family Values Related to Caregiving**

- Filial piety = child supporting the aged parent without question
- Family’s/Parents’ interests above individual’s
- Women faithfully serve their 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

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**Dementia Caregiver Issues: Other Asians**

- Korean American CGs:
  - Scored higher on depression and burden measures when compared to Whites
  - Highest level of burden reported
  - Internal conflict between Korean and American values
- Japanese American CGs experience high levels of caregiver stress associated with:
  - Social expectancies (sekentei, sekinin kan -> forms of haji)
  - Oyokotane (Okinawan): “It cannot be helped” or “Nothing can be done”
  - Unfamiliar and uncomfortable in going to a hospital/medical center
  - Language/self-expression barriers, lack of bilingual/bicultural staff
  - Help should only be sought when caregivers are about to burnout
- Filipino American CGs:
  - Family caregiving is norm and integrated into family life cycle
  - Cultural values: atemporal level (opportunity to make sacrifices); kapatribu rate (relax on ourselves); waman rate (retry to help them)
  - Larger, diverse support system: intergenerational household, church, workplace, neighborhood
  - Less inclined to join support groups
- Vietnamese American CGs: reluctant to use formal services. A sense of obligation for family members to take care of PWD.
Evidence-Based Programs for Dementia Family Caregivers

The Sociocultural Stress and Coping Model

Evidence-Based Interventions for Dementia Family Caregivers

<table>
<thead>
<tr>
<th>Intervention</th>
<th>Brief Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual and Family Counseling</td>
<td>Individual and family counseling provided by trained providers for treatment of caregiver depression and managing stress.</td>
</tr>
<tr>
<td>Psychoeducational Programs, i.e.:</td>
<td>Teach caregivers a set of behavioral and cognitive skills for coping with caregiving demands and stress using a structured format.</td>
</tr>
<tr>
<td>a. Coping with Caregiving</td>
<td></td>
</tr>
<tr>
<td>b. Savvy Coping</td>
<td></td>
</tr>
<tr>
<td>Specialized skill training, i.e.:</td>
<td>Trainings that focus on a specific skill such as home modifications, managing dementia patients' difficulty behaviors, dealing with frustrations, managing sleep disruption, and promotion of exercises to alleviate stress.</td>
</tr>
<tr>
<td>a. Behavior Management</td>
<td></td>
</tr>
<tr>
<td>b. STAR-C</td>
<td></td>
</tr>
<tr>
<td>c. In-Home Modifications</td>
<td></td>
</tr>
<tr>
<td>Multi-Component Programs, i.e.:</td>
<td>Consist of: (1) Home visits that create individualized plans for each caregiver to manage their stress; (2) “Health Passport” for recording their health information; telephone support group calls; and access to various local resources.</td>
</tr>
<tr>
<td>a. REACH X</td>
<td></td>
</tr>
<tr>
<td>b. The Dementia Carers’ Programme</td>
<td></td>
</tr>
<tr>
<td>(Australia)</td>
<td></td>
</tr>
<tr>
<td>Psychotherapy / Cognitive Behavioral Therapy</td>
<td>Treat caregivers who are clinically depressed or have other significant mental health problems.</td>
</tr>
</tbody>
</table>

(Gallagher-Thompson et al., 2012)
Interventions Targeting CGs can Yield Patient Benefits

- 23 CG interventions reviewed
- Two-fold advantage: Significant treatment effects for reductions in behavioral symptoms and CG negative reactions
- Improvements compared more than favorably with pharmacologic trials and are clinically meaningful – notably, these gains were achieved WITHOUT adverse events or known risks.
- Characteristics of successful interventions: (1) tailoring to specific behaviors, needs and contexts; (2) providing an average of 9-12 sessions; (3) assessing needs from which to link intervention strategies.
- More research required to optimize clinical potency, relevance of interventions, and implementation considerations (i.e. cost analyses).

Barriers to Accessing Evidence-Based Interventions

- Lack of provider knowledge concerning the efficacy of nonpharmacologic interventions
- Limitations imposed by reimbursement mechanisms
- Low health literacy and/or poor language proficiency
- Culturally-based beliefs about dementia
- Lack of adequate knowledge about AD and related disorders among patients and family caregivers

How to choose an intervention?

Questions to ask...

- For whom is this intervention likely to be most beneficial?
- At what stage in the caregiving process should this intervention be introduced for maximal effectiveness?

Choose one based on specific family needs and your context of care delivery, such as the available professional and financial resources for delivering any one intervention.
Example of an Evidence-Based Intervention for Dementia Caregivers

Coping with Caregiving (CWC) – Historical Development

- 4 randomized clinical trials over the past two decades comparing CWC with a) support groups; b) enhanced support groups; c) telephone support condition; and d) treatment as usual.
- CWC showed improved depression, reaction to problematic behaviors and general life satisfaction compared to all other conditions.
- Participants (N>500) in above studies were about half Caucasian & half Latino women family caregivers.
- Consultation with focus groups and formative evaluation studies resulted in CWC intervention more appropriate for work with ethnic minorities.
- Major components based on Cognitive Behavioral Therapy Model

Structure of CWC

- Time-limited (e.g. 6-12 sessions)
- Small group format: Usually 6-10 caregivers + 2 co-leaders
- Detailed agendas with specific goals; a structured treatment manual is followed
- Active in-class participation to learn skills (e.g. role plays)
- Extensive use of homework assignments
- This program has been very well received & is in use in other regions of the country (in modified, adapted formats).
Coping with Caregiving – Skills Taught

- Behavioral Management
  - Managing problem/disruptive behaviors of care-receiver
  - Relaxation techniques
- Cognitive Reappraisal
  - Change unhelpful thoughts
  - Modify thought patterns to become adaptive
- Communication Skills
  - Better communication with their loved one, with doctors, and with others about their needs: includes assertiveness training
- Increasing Everyday Pleasant Events
  - Incorporate pleasurable events in everyday life to improve mood
- Planning for the Future
  - Prepare for different options for care; open the discussion regarding end of life care

Coping with Caregiving REACH I - Results

- Palo Alto, CA site, CWC is compared to:
  - a telephone support program
  - Community support groups
- 122 Caucasian and 91 Latino CGs enrolled.
- Results: CWC program more beneficial than both comparison conditions in reducing depressive symptoms and perceived burden for both Latino and Caucasian caregivers.
- 1 yr follow-up found that benefits were maintained in both ethnic groups.

Coping with Caregiving – Stress Management Program

- Enrolled 184 middle-aged and older women (95 Non-Hispanic White and 89 Hispanic/Latino) who provided in-home hands-on care to an elderly relative with Alzheimer’s disease or another form of dementia.
- Within each ethnic group, they were randomly assigned to either the “Coping with Caregiving” (CWC) group or a minimal telephone based control condition (TSC).
- Intervention lasted 4 months, one post-treatment assessment was completed 6 months after baseline by interviewers blind to the intervention condition.
Stress Management Project - Results

- Similar results were obtained as in REACH I.
- CGs in CWC showed greater improvement on measures of depressive symptoms, overall life stress and caregiving-related stress.
- CGs in CWC reported greater frequency of use, and greater perceived helpfulness, of these skills at post intervention compared to caregivers in the TSC.
- Use of skills taught interacted with the conditions, such that CGs who said they used specific cognitive & behavioral skills (between meetings and after program ended) had strongest positive outcomes. Tests for mediation suggest that effective skill utilization mediated the effect of treatment on outcome.

Case Example = Mercedes (1)  

- Mercedes is a 55 year old woman of Mexican heritage who is caring for her mother. Her mother has significant memory problems for the past 3 years.
- Her mother also has Type II diabetes and no longer remembers to take her medications. She is often confused about where she is and what she is supposed to be doing.
- Mercedes is moderately stressed with the caregiving demands, particularly when her mother repeats questions over and over again to her.

Case Example = Mercedes (2)  

- Mercedes identified her mother’s repeated questioning as a very distressing behavior she would like to change.
- Use of Behavior Logs (T-B-R): tracked the incidence, triggers, and her reactions to the behavior
- Triggers identified: (1) Seeking attention; (2) Feeling bored
- Mercedes’s reactions that affected her level of stress (identified by the group): (1) Replying to each question as one would in normal conversation; (2) Saying loudly “I just told you!” and becoming frustrated
**Case Example – Mercedes (3)**

- Mercedes tried **changing the triggers:**
  - Provide mother with more activity (e.g., looking at old photos)
  - Post a calendar in a conspicuous place with appointments, family visits, etc. that she can refer to

- Mercedes tried **changing the reactions:**
  - Distraction instead of answering every question
  - Use relaxation techniques (mindful breathing) when stressed

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**Case Example – Mercedes (4)**

**Other Techniques to Reduce Stress**

- Use of **Thought Records:** Examine the validity of negative thoughts/beliefs/feelings and replace with more helpful thoughts
- Use of the **5-Column Technique:** changed her thoughts about caregiving
  - Example: Changing “My life is not my own” to “My schedule is restrictive, but I can make some time to do things for myself”
- Practiced **Assertiveness Skills** through role-play:
  - Example: Role played with another group member on asking her sister to share caregiving duties on a regular basis
- Identified **Pleasant Activities:**
  - Example: She began taking a walk during her lunch hour and started going to a cooking class one evening per week
- **Future Planning:** Discussed Advanced Directives with her family.

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**REACHing OUT in San Diego – Dissemination Research**

- Collaborative agreements between Stanford & the Southern Caregiver Resource Center, & with grant funding from San Diego county, the Weinburg Institute, and the Rosalynn Carter Institute
- The core features of both REACH projects are “tailored” for the Latino communities in San Diego & Imperial counties
- Combination of 4 home visit, 2 phone calls or 1 month small group program
- These communities have large numbers of Latinos, many of whom are of low literacy and have never before been approached for services of this kind
- Emphasizes education, behavior management, community involvement, stress management, and relaxation techniques to improve the quality of life of AD patients and caregivers.
REACHing OUT Preliminary Results

- Participants: From April 2010 to February 2012, over 300 participants were enrolled.
- All participants were Hispanic or Latino, and the majority were female (95.1%), and over 45 years old (80.6%).
- Over 99% of participants reported “Knowing where to get help when I need it”, “more comfortable seeking help”, “better able to handle things” and “satisfied with the services received.”

Fotonovela Project

- Aim: meet the needs of Latinos with low literacy for health care information
- 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.

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
Findings

- Improved Latino caregivers’ quality of life (e.g., reduced symptoms of depression for CGs who received FN compared to “useful information”) with a relatively inexpensive intervention.
- However, FN alone was probably not responsible for this positive change. All CGs were also invited to attend a discussion group (led by project staff) to learn more about the materials provided. About 50% did so – with more in the FN condition attending compared to usual EM.
- Recommend that CGs be encouraged to attend at least one meeting to discuss the contents of the FN & clarify how it can be helpful to them. To assist with this, we created a “TEACHING GUIDE” that leaders can use to facilitate discussion. Downloadable at: http://sgec.stanford.edu/resources/dementia_and_caregiving.html

iCARE Project

- One of the first online training programs specifically for dementia caregivers.
- Who: Available to all CGs who can read/understand English.
- What: ADVD/online video training program (with accompanying workbook) designed to help enhance CG skills to deal with the demanding tasks of caregiving, and to reduce stress & improve quality of life.
- How: Professional actors filmed common behavioral problems to show less effective vs. more effective ways to manage these problems.
- Results:
  - Decrease in level of depressive symptoms, caregiving-specific reported stress, general stress
  - Improved quality of life
  - Greater numbers of hours spent on caregiving is associated with higher baseline level of depressive symptoms (measured by CES-D), and with less improvement from pre to post intervention
  - For CGs who are well educated and highly acculturated, the website approach was very effective

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Practical Strategies to Help Anglo & non-Anglo CGs Cope with Caregiving Stress

Cognitive Strategies
1. Reframe the problem as something you can cope with.
2. Watch out for the "all or none" trap.
3. Learn that you can adapt to things as they are now, and they are
   not all bad.
4. Learn new forms of "self talk": encourage yourself mentally as you
   go through the day.

Behavioral Strategies
1. Learn ways to relax in stressful moments.
2. Take "time out" for yourself (increase pleasant activities).
3. Learn problem-solving strategies so behavioral problems can be
   tackled more readily.

Preparing for the Future
1. Open the conversation with family members on advance directives, end of life
   care, and financial planning etc.
2. Recognize that it is not wrong to feel a variety of conflicting emotions as you go
   through this process.

Culturally Sensitive Dementia Caregiver Interventions

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Cultural Tailoring of Psychosocial Support Interventions – A Review

- Review of literature published from 1980-2009
- Only 18 studies (African Americans: 10, Latinos: 11, Chinese Americans: 1) reported outcomes stratified by CG ethnicity
- Most of these studies described no or little ethnic tailoring of interventions
- Components of a culturally tailored intervention:
  - Address cultural attitudes including familism, distrust, perceived discrimination, reticence toward having strangers in the home, and preferences for caregiving without receiving support from those outside the family
  - Language, bilingual/bicultural staff
  - Literacy
  - Recognize the need for advocacy

Effectiveness of Culturally Tailored Interventions

<table>
<thead>
<tr>
<th></th>
<th>African American</th>
<th>Latinos</th>
<th>Chinese American</th>
</tr>
</thead>
<tbody>
<tr>
<td>Better affect / more happy</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decreased burden</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>More positive ratings of caregiving</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better self-efficacy</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Decreased depression</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Decreased negative coping</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decreased stress</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decreased behavioral bother</td>
<td>✓</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better anger control</td>
<td>✓</td>
<td></td>
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</tr>
</tbody>
</table>

Thank you!

Stanford Geriatric Education Center
http://sgec.stanford.edu
(650)721-1023

More resources on dementia and Alzheimer’s disease at:
http://sgec.stanford.edu/resources/dementia_and_caregiving.html

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References


Q & A

- We now have some time to answer your questions. If you have any questions, please use the “Chat” feature located on the right side of your screen. Please send your chat to everyone if possible.
- After the Q and A, we would like to ask each of the participants to answer the short evaluation questionnaire.

Final Question

Thank You for Participating!

NOTE: Continuing Education Participants must complete a final survey in order to receive CEU/CME credit.