Caregiving from Coast to Coast:

Findings and Implications of Two Statewide Surveys of Culturally Diverse Informal Caregivers

Center for the Advanced Study of Aging Services
University of California, Berkeley

The New York State Center for Aging Policy Research
State University of New York, Stony Brook

Gerontological Society of America, 57th Annual Scientific Meeting
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Center for the Advanced Study of Aging Services

- Formal Caregiver Support Service Use in California: Is Race Ethnicity a Predictor?
- Focus Groups with Culturally Diverse Family Caregivers Findings from California
New York State Center for Aging Policy Research

- Informal, Unpaid Care Giving to New York State Elders: A Telephone Survey
- Ethnocultural Variation in Need for Support Among Unpaid, Family Caregivers to the Elderly
Objectives

- Better understanding of family caregivers’ experiences across racial/ethnic groups
- Identify important features of mixed methods to study culturally diverse populations
- Identify opportunities for new interventions & policies to address caregivers’ diverse needs
Formal Caregiver Support Service Use in California: Is Race/Ethnicity a Predictor?

Julian Chow, PhD
Nancy Giunta, MSW
Erica Auh, BS

Center for the Advanced Study of Aging Services
http://cssr.berkeley.edu/aging
Literature Review

- Family caregivers are the main source of long-term care for older persons (Liu et al., 2000).
- Mixed evidence of racial/ethnic differences in CG service use (Dilworth-Anderson et al., 2002).
- Most studies compare Whites with one ethnic group, most often African Americans (Ajrouch, et al., 2001).
Methods

- Random Digit Dialing
- Respondent caring for someone over age 50
- Surveys conducted in English and Spanish
- Interview lasted approx. 30 minutes
- N = 1,643
Caregiver Questionnaire

1. Demographic characteristics of CGs & CRs
2. CR health and functioning
3. CR assistance required with ADLs/IADLs
4. Assistance provided by the CG
5. CG’s met and unmet service needs
6. Impact of caregiving on work, emotional health, physical health, and family
<table>
<thead>
<tr>
<th>Ethnic/Racial Category</th>
<th>Sample</th>
<th>CA</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>61.1%</td>
<td>58.2%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>24.8%</td>
<td>22.3%</td>
</tr>
<tr>
<td>African American</td>
<td>6.2%</td>
<td>6.7%</td>
</tr>
<tr>
<td>Asian/ Pacific Is.</td>
<td>4.6%</td>
<td>9.5%</td>
</tr>
<tr>
<td>American Indian</td>
<td>1.0%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Other</td>
<td>2.2%</td>
<td>2.3%</td>
</tr>
</tbody>
</table>
## Bivariate Comparisons: Race and Ethnicity

<table>
<thead>
<tr>
<th></th>
<th>WH</th>
<th>LAT</th>
<th>API</th>
<th>AA</th>
<th>OTH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age**</td>
<td>54</td>
<td>44</td>
<td>45</td>
<td>49</td>
<td>49</td>
</tr>
<tr>
<td>% College Ed**</td>
<td>25</td>
<td>18</td>
<td>43</td>
<td>21</td>
<td>22</td>
</tr>
<tr>
<td>% “Poor” or “Fair” Health**</td>
<td>23</td>
<td>27</td>
<td>30</td>
<td>39</td>
<td>42</td>
</tr>
<tr>
<td>% Reporting Financial Strain**</td>
<td>11</td>
<td>18</td>
<td>17</td>
<td>26</td>
<td>16</td>
</tr>
<tr>
<td>% with children in HH**</td>
<td>24</td>
<td>47</td>
<td>41</td>
<td>36</td>
<td>33</td>
</tr>
</tbody>
</table>

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### Bivariate Comparisons: Race and Ethnicity

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<th>OTH</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Situation brought family closer together (%)</strong>*</td>
<td>61</td>
<td>69</td>
<td>75</td>
<td>63</td>
<td>73</td>
</tr>
<tr>
<td><em><em>Hours per week providing care</em> (Mean)</em>*</td>
<td>37</td>
<td>49</td>
<td>46</td>
<td>56</td>
<td>N/A</td>
</tr>
<tr>
<td><strong>HH Income</strong> <strong>(Mean % under 30K)</strong></td>
<td>35</td>
<td>53</td>
<td>34</td>
<td>53</td>
<td>24</td>
</tr>
<tr>
<td><strong>% Reporting Emotional Support</strong></td>
<td>81</td>
<td>72</td>
<td>73</td>
<td>77</td>
<td>62</td>
</tr>
</tbody>
</table>

*P < .05, **P < .01
Formal Service Utilization

Caregiver assistance received from sources other than family or friends.

“Have you received…”

- Information about community services for yourself or your [CR]?
- Help getting or using community services?
- Information about your legal rights and obligations as a care provider?
Formal Service Utilization

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>LAT</th>
<th>API</th>
</tr>
</thead>
<tbody>
<tr>
<td>WH</td>
<td>1.5</td>
<td>1.9</td>
</tr>
<tr>
<td>AA</td>
<td>1.9</td>
<td>2.6</td>
</tr>
</tbody>
</table>

- White CGs are 1.5 times more likely than Latino CGs and 1.9 times more likely than Asian/PI CGs to use formal services.
- African American CGs are 1.9 times more likely than Latino CGs and 2.6 times more likely than Asian/PI CGs to use formal services.
Theoretical Framework: Andersen’s Behavioral Model of Health Care Utilization*

Predictive factors of service use:
- Predisposing
- Enabling
- Need (CG & CR)

*Andersen & Newman, 1973
## The Andersen Model Framework

<table>
<thead>
<tr>
<th>Predisposing</th>
<th>Enabling</th>
<th>Need</th>
</tr>
</thead>
<tbody>
<tr>
<td>CG Race/Eth</td>
<td>CG Emotional support</td>
<td>CG Health</td>
</tr>
<tr>
<td>CG Born in U.S.</td>
<td>CG Employed</td>
<td>Hours of Care/Week</td>
</tr>
<tr>
<td>CG Age</td>
<td>Income</td>
<td>Emotional Strain</td>
</tr>
<tr>
<td>CG Gender</td>
<td>Service Barrier(s)</td>
<td>Physical Strain</td>
</tr>
<tr>
<td>CG Education</td>
<td>Obligation to family</td>
<td>Financial Strain</td>
</tr>
<tr>
<td>CG/CR Relationship</td>
<td>Situation perceived as hardship</td>
<td>CR uses formal svces</td>
</tr>
<tr>
<td>Living Arrangement</td>
<td>Situation perceived as bringing family closer</td>
<td>CR needs ADL assist</td>
</tr>
<tr>
<td>CG Marital Status</td>
<td></td>
<td>CR memory impaired</td>
</tr>
<tr>
<td>Spiritual/religious practices</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## The Andersen Model Framework

<table>
<thead>
<tr>
<th><strong>Predisposing</strong></th>
<th><strong>Enabling</strong></th>
<th><strong>Need</strong></th>
</tr>
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<tbody>
<tr>
<td>CG Race/Eth**</td>
<td>CG Emotional support**</td>
<td></td>
</tr>
<tr>
<td>CG Born in U.S.**</td>
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<td></td>
<td>CR memory impaired**</td>
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Multivariate Analysis

- Logistic Regression

- Dependent Variable: Formal Service Utilization (Yes/No)

- Independent Variables (four blocks):
  - Predisposing
  - Need
  - Enabling
  - Interactions
Logistic Regression: Formal Service Utilization

Independent Variables (4 Blocks):

<table>
<thead>
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<th>Enabling</th>
<th>Need</th>
<th>Interactions</th>
</tr>
</thead>
<tbody>
<tr>
<td>CG Race/Eth</td>
<td>Emot. support</td>
<td>Emotional Strain</td>
<td>Fam. closer x API</td>
</tr>
<tr>
<td>CG Born in U.S.</td>
<td>Service Barrier(s)</td>
<td>Physical Strain</td>
<td>Fam. closer x LAT</td>
</tr>
<tr>
<td>CG Education</td>
<td>Fam. obligation</td>
<td>CR - Formal Services</td>
<td>Fam. closer x AA</td>
</tr>
<tr>
<td>CG Age</td>
<td></td>
<td>CR - ADL needs</td>
<td></td>
</tr>
<tr>
<td>Spiritual &amp; Relig Practice</td>
<td></td>
<td>CR –Memory Impaired</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>CG - Poor Health</td>
<td></td>
</tr>
</tbody>
</table>
Multivariate Results

Significant Predictors of Formal Service Use:

- CG Education > HS (+)
- CG has emotional support (+)
- CG feels family obligation (+)
- CR needs ADL help (+)
- CR uses formal services (+)

*Situation brought family closer x Asian/PI (−)*

R-squared = .178
Conclusions

- Looking at bivariate relationship, service utilization differs by race & ethnicity – BUT…

- When other caregiver characteristics are controlled for, racial and ethnic differences are no longer significant (Why?).

- Several variables transcend & interact with race/ethnicity in predicting formal service use.
Conducting Focus Groups with Culturally Diverse Family Caregivers

Andrew Scharlach, PhD
Roxanne Kellam, MA
Kristen Gustavson, MSW

Center for the Advanced Study of Aging Services
http://cssr.berkeley.edu/aging
Focus Groups

- Northern California (UC Berkeley)
  - Filipino
  - Cantonese speaking Chinese
  - Russian speaking
  - African American
  - Gay
  - Lesbian
Focus Groups

- Southern California (Inland Empire Research Consortium)
  - Vietnamese
  - Korean
  - Native American
  - Rural Hispanic
  - Rural non-Hispanic
Recruiting Minorities for Research

- What the literature tells us
  - Culturally sensitive
  - Target groups
  - Community Contacts

- What we have done
  - Recruited culturally-matched facilitators
    - Community
    - Graduate students
  - Design of the materials
    - Interactive process with the facilitators
# Recruitment Process

<table>
<thead>
<tr>
<th>Focus Group</th>
<th># of Participants</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>African-American</td>
<td>12</td>
<td>Over Sixty Health Center in Berkeley</td>
</tr>
<tr>
<td>Cantonese</td>
<td>8</td>
<td>Asian Community Center in Sacramento</td>
</tr>
<tr>
<td>Filipino</td>
<td>9</td>
<td>Filipino American Council in San Francisco</td>
</tr>
<tr>
<td>Gay Men</td>
<td>10</td>
<td>New Leaf in San Francisco</td>
</tr>
<tr>
<td>Korean</td>
<td>9</td>
<td>Department of Aging in Los Angeles</td>
</tr>
<tr>
<td>Lesbian</td>
<td>6</td>
<td>San Leandro Community Church</td>
</tr>
<tr>
<td>Native American</td>
<td>11</td>
<td>First Nations Center in San Bernardino</td>
</tr>
<tr>
<td>Rural Hispanic</td>
<td>5</td>
<td>Assisted living facility in Palm Desert</td>
</tr>
<tr>
<td>Russian</td>
<td>9</td>
<td>Institute on Aging in San Francisco</td>
</tr>
<tr>
<td>Vietnamese</td>
<td>12</td>
<td>Community Center in Santa Ana</td>
</tr>
</tbody>
</table>
Focus Group Discussion Guide

- Care experiences
- Reactions to providing care
- Existing sources of support
- Experiences seeking assistance
- Services desired
Analytic Process

- Summaries prepared by moderator and note-taker
- Translation of transcripts
- Identification of general coding categories
- Identification of key issues in raw data
- Detailed descriptions of focus groups, contextualizing key issues
- Identification of cross-cutting themes
- Selection of examples
Caregiver Focus Groups: Cross-Cutting Themes

- Familism as a motivation for caregiving
- Caregiving as a source of fulfillment
- Positive and negative impacts of adversity
  - a. Personal/family resilience
  - b. Group solidarity ("Us" vs. "Them")
- Cultural norms in transition
- Barriers to service use
  - a. Lack of knowledge
  - b. Mistrust of formal services
  - c. Services unavailable and/or inappropriate
Conclusions

- Culture transforms family care experiences and their meaning
- Caregiver supports rest within a cultural, social, economic, and political context
- Culturally-competent caregiver services transcend language
  - Culturally-competent service providers
  - Culturally-specific services
  - Design and Implementation by cultural groups themselves
Conclusions (cont’d)

- Increased attention to the support needs of culturally-specific families, from their own perspectives
  - CG Training
  - Respite
  - Services for CR
- Research and programs by, for, and about culturally-specific populations