The NYU Caregiver Intervention
Improving Caregiver Well-being Delays Nursing Home Placement Of Persons With Alzheimer Disease

Partners
Minnesota Board on Aging
Alzheimer’s Association
Minnesota/North Dakota Chapter
New York University
Mary Mittelman and Cynthia Epstein
Federal Administration on Aging:
Alzheimer’s Disease Support Services Program
Partners – 14 Sites

**Metropolitan AAA**
- VOA – Mpls
- CLUES
- Alz Assoc Metro Reg Office

**MN River AAA**
- Mankato Clinic
- Mayo Health System:
  - Waseca Clinic
  - Madelia Clinic
  - Immanuel St Joseph's

**Arrowhead AAA**
- Carlton County Public Health
- Community Partners
- Range Respite
- Northwoods Hospice/Respite Partners

**Central MN AAA**
- Memory Care Clinic
- Rural Stearns Faith-In-Action

**Southeastern MN AAA**
- Mower County Caregiver Support Program

Land of the Dancing Sky AAA
- Arrowhead AAA
- Arrowhead Family Memory Care
- Central AAA
- Central Family Memory Care
- Metropolitan AAA
- Minnesota River AAA
- Minnesota River Family Memory Care
- Southeastern AAA
- Southeastern Family Memory Care

Minnesota Tribes
- Bois Forte
- Grand Portage
- Leech Lake
- White Earth
- Red Lake
- Fonda-Lac
The Original Study

New York University
Spouse Caregiver Intervention 1987-2009
Mary Mittelman, DrPH and Cynthia Epstein CSW

A Randomized Controlled Trial to Test the Efficacy of Counseling and Support for Family Caregivers

406 spouse-caregivers of people with Alzheimer’s disease living with the person with AD at intake with at least 1 close relative in the area.

Treatment Strategy

• Within 4 to 6 months
  - An individual counseling session
  - 4 family counseling sessions
  - A second individual counseling session

• Over the entire course of the disease
  - Participation in a support group
  - Telephone consultation for caregiver or family member as needed.
Time to Nursing Home Placement of Patients Is Delayed by Counseling and Support of Caregivers

Minnesota Translation Proposed Outcomes

- Reduced negative impact of caregiving behaviors
- Decreased level of depression
- Enhanced support network composition and effectiveness (expanded and improved)
- An average 18 month delay in nursing home placement
Program Progress

400+ Invited – Many will enroll later (being “courted”)

93  Spousal Caregivers Enrolled

46  Completed the Counseling Phase
   – 46 Completed 4 Month Follow-up
   – 33 Completed 8 Month Follow-up
   – 27 Completed 12 Month Follow-up
   – 17 Completed 18 Month Follow-up
   – 1   Completed 24 Month Follow-up

Caregiver Example

• Caregiver of husband with Alzheimer’s Disease
• Caregiver is 79 years old, husband is 82 (driving)
• Providing care for 3 years (no services)
• 6 children (3 of his, 3 of hers)
• Caregiver has Parkinson’s disease (not driving)
• Husband in Alzheimer’s Mid Stage – no other health issues
Caregiver Experience

Family assigned themselves “jobs”
Husband stopped driving
Hired Respite/Driver
Couple joined the Community Center
Family continued to meet

Outcomes at End of Counseling Phase

<table>
<thead>
<tr>
<th>Average Scores</th>
<th>Baseline</th>
<th>4 months</th>
<th>8 months</th>
<th>12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Global Deterioration Scale</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Depression (CES-D)</td>
<td>21</td>
<td>15</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Memory and Problem Behaviors (RMBC)</td>
<td>low</td>
<td>low</td>
<td>low</td>
<td></td>
</tr>
<tr>
<td>Stress Burden (Montgomery Burden Scale)</td>
<td>12</td>
<td>8</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Support Network (Stokes)</td>
<td>10</td>
<td>16</td>
<td>20</td>
<td></td>
</tr>
</tbody>
</table>
Agency Experience

- Adds evidence-based programming (award-winning) to current menu of services
- Participants engage in agency functions (Memory Walk teams, Meeting of the Minds, support groups)
- Data implications for future spouse caregivers
- Caregiver coach value (continuing education opportunities, work group, rich learning experience/retention)

Evaluation of the Minnesota Translation

- Participant Experience
  - Coach logs on participant activity
  - Experience Surveys (Caregiver & Family Member)
  - TCare+ assessment at baseline and every 4 months the first year and 6 months thereafter

- Site Experience
  - Baseline interviews, follow-up interviews
  - RE-AIM Tracking Tool
  - Cost Analysis
  - Fidelity to research (NYU researchers consultation & monitoring)
**Simplified Logic Model**

**Target Pop.**
Spousal Caregivers of PWAD; live in one of 14 areas

**Variables**
- Age of Caregiver
- # Family members
- Service availability

**Inputs**
- Caregiver consultation
- Assessments
- Family meetings
- Phone calls
- Education
- Info & referral
- Support Grps

**Intermed. Outputs**
- Reduce caregiver stress
- Increase awareness of symptoms/behaviors. AD
- Enhance family involvement
- Provide connections to resources/svcs

**Outcomes**
- Avoid caregiver burnout
- Extend level and duration of family support
- Delay nursing home admission of PWAD

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**RE-AIM – Framework for Evaluation**

<table>
<thead>
<tr>
<th>REACH:</th>
<th>Did this program reach the intended audience?</th>
</tr>
</thead>
<tbody>
<tr>
<td>EFFECTIVENESS:</td>
<td>How do we know the program was effective?</td>
</tr>
<tr>
<td>ADOPTION:</td>
<td>What was needed to support the organization to implement the intervention?</td>
</tr>
<tr>
<td>IMPLEMENTATION:</td>
<td>How did we ensure the intervention was properly implemented?</td>
</tr>
<tr>
<td>MAINTENANCE:</td>
<td>How do we incorporate the intervention so it is effective long-term?</td>
</tr>
</tbody>
</table>
Reach

- Recruitment strategies
- Profile of participants
- Participation level
- Disenrollment

<table>
<thead>
<tr>
<th>Participant Profile N = 93 (3-11-10)</th>
<th>Caregiver</th>
<th>Care Receiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (% Female)</td>
<td>59%</td>
<td>41%</td>
</tr>
<tr>
<td>Age (average) (CG youngest 48, oldest 97)</td>
<td>75</td>
<td>77</td>
</tr>
<tr>
<td>Race (%white)</td>
<td>97.8%</td>
<td>98.9%</td>
</tr>
<tr>
<td>Marital Status (% Married/living with partner)</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Education (% more than high school)</td>
<td>48%</td>
<td></td>
</tr>
<tr>
<td>Income (% $15,000 - $34,999)</td>
<td>52%</td>
<td></td>
</tr>
<tr>
<td>PWAD Impairment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s Disease Diagnosis</td>
<td></td>
<td>86%</td>
</tr>
<tr>
<td>Global Deterioration Score (initial - mean)</td>
<td>4.24</td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Health</td>
<td></td>
<td>Good</td>
</tr>
<tr>
<td>Length of Time Providing Care</td>
<td>47.3%</td>
<td></td>
</tr>
<tr>
<td>(% 2 to 5 years)</td>
<td>27.9%</td>
<td></td>
</tr>
<tr>
<td>(% more than 5)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Effectiveness

- Effect on caregivers, family members
- Changes in scores
- Effect on staff

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<th>Baseline</th>
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<th>8 months</th>
<th>12 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Global Deterioration Scale</td>
<td>4.24</td>
<td>4.81</td>
<td>5.29</td>
<td>5.25</td>
</tr>
<tr>
<td>Depression (CES-D)</td>
<td>19.46</td>
<td>19.04</td>
<td>18.15</td>
<td>18.7</td>
</tr>
<tr>
<td>Memory and Problem Behaviors (RMBC)</td>
<td>36.09</td>
<td>39.72</td>
<td>37.64</td>
<td>38</td>
</tr>
<tr>
<td>Stress Burden (Montgomery Burden Scale)</td>
<td>12.29</td>
<td>11.7</td>
<td>9.15</td>
<td>8</td>
</tr>
<tr>
<td>Support Network Composition and Effectiveness</td>
<td>2.35</td>
<td>3.29</td>
<td>3.35</td>
<td>4.24</td>
</tr>
<tr>
<td>(Stokes Social Network Scale)</td>
<td>1.72</td>
<td>1.85</td>
<td>1.73</td>
<td>2.96</td>
</tr>
<tr>
<td>Close Relatives</td>
<td>4.2</td>
<td>5.11</td>
<td>4.97</td>
<td>5.15</td>
</tr>
</tbody>
</table>

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Adoption

• Changes to “usual care” as a result of the program/intervention
• Impact on organization
• Issues of imbedding the program
• Environmental factors – affect on implementation

Implementation

• Experience with program elements
• Barriers & Facilitating Factors
• Cost
Maintenance

- Lasting effects – caregivers, families, staff, programs
- Ongoing Assessment (even after placement or bereavement)
- Sustainability issues
- Lessons Learned

Translating from Research to Practice

- Assessment tool
- Participant criteria
- Staff background, education, training
- Family sessions - timeframe
- Support groups - frequency
**Program Challenges and Solutions**

- **Recruitment**
  - Redesigned materials/refined message
  - Champions – word of mouth
  - Continuous Recruitment
  - Persuasion – success stories

- **Assessment - Combining two assessments**
  (TCare® and NYUCI instruments)
  - Experience and Mentoring
  - Training – Neuropsychologist – importance and use of the assessment to the caregiver and family – interpreting the results

- **Family Sessions – Reluctant to Include Family**
  - Call the children
  - Schedule all family sessions at once

- **Reassessment after 12 months**
  - Shortened the reassessment tool to include only outcome measures

- **Ad Hoc Contacts**
  - Contact the caregiver to check in

- **Data Collection/Tracking**
  Training and one-on-one support
Sustainability Factors

- Ease/difficulty of implementing program intervention
- Acceptance and perceived value of the program by organizations and coaches
- Acceptance and perceived value of the program by caregivers and families
- Cost to implement

Sustainability Issues

- Staff turnover – program intervention highly dependent on the trained caregiver consultant
- Organizational stability
- Continuous recruitment and caregiver reticence
- Cost at “steady state” – potential for reimbursement?