Family Perceptions of Mild Cognitive Impairment: Individual Changes and Relationship Challenges

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March 10, 2010
Mild Cognitive Impairment (MCI)

Age-related decline in memory and executive functioning

*Executive Function*
- reasoning, planning, speech, movement
- emotions, problem-solving

Frontal Lobe
- vision

Occipital Lobe
- perception of touch, pressure, temperature, pain

Parietal Lobe
- perception and recognition of auditory stimuli, memory

Temporal Lobe
Mild Cognitive Impairment (MCI)

- Criteria for assessing MCI include:
  - self-reported complaint of memory loss that interferes minimally with activities of daily living and personal relationships
  - uncharacteristic memory loss for the person’s age
  - normal functioning in other cognitive domains
  - no evidence of dementia

- Possibly a transitional phase between normal cognitive aging and early dementia

(Petersen et al., 1999)
MCI Research at Virginia Tech

  - identify information and support needs of family members of older adults with MCI

  - investigate whether, how, and to what extent care needs change over time
    - influence such changes have on the families’ relationships, care strategies and needs, health and psychological well-being, and overall quality of life

Funded by the Alzheimer’s Association (IIRG-03-5926, IIRG-07-59078)
MCI Research (cont’)

- Caring for a Spouse with Mild Cognitive Impairment: Daily Challenges, Marital Relations, and Physiological Indicators of Health (2008-2009)
  - Examine the effects of having a spouse with MCI on older care partners’ physical health, psychological well being, and marital relationship

Funded by the Virginia Alzheimer’s and Related Diseases Research Award Fund
Families and Mild Cognitive Impairment

Methodology
Conceptual Framework

Pearlin’s Caregiving Stress Process Framework

- Background and Context
- Primary Stressors
- Secondary Role Strains
- Secondary Intrapsychic Strains
- Outcomes

Mediators
Methods

- Memory Clinics

- Family Focus - Level Data
  - Elder with MCI (E), age 60+
  - Primary care partner (PCP)
  - Secondary care partner (SCP)

- Mixed Methods

- Three Contacts (face-to-face/telephone)
  - T1 (99 families) $M = 10.1$ months post diagnosis
  - T2 (72 families) $M = 13.5$ months from T1
  - T3 (49 families) $M = 23.6$ months from T2
Benefits of Multiple Informants

- Family-level analyses more accurately reflect lived experiences of elders and relatives
- Multiple views contribute depth and breadth of information
- Possibility of filling in “missing data” and confirming statements, perspectives, findings
- Opportunity to explore reasons for differing perceptions, beliefs, interpretations
Challenges with Multiple Informants

- Missing data/cases: inability to recruit and retain all intended informants
- Issues of interpretation: whose perspective is privileged, when?
- Need large data sets & multiple occasions of measurement for advanced statistical analyses
- Coding and analyzing family-level qualitative data
Measures

**Background Characteristics**
- Age
- Sex
- Education
- Income
- Health
- Household Configuration
- CESD

**Objective**
- MMSE
- Deficit Awareness
- Apathy Evaluation
- Memory & Behav. Problems Checklist
- PADL, IADL

**Subjective**
- Role Overload
- Role Captivity
- Intimate Exchange
- Appraisal of Daily Stressors

**Daily Primary Stressors**

**Daily Secondary Stressor**
- Non-caregiving stressors:
  - Family & Marital Conflict
  - Work Conflict
  - Financial Strain
  - Constriction of Social Life
- Daily Marital Interactions

**Subjective (Intrapsychic)**
- Environment Mastery
- Zarit Burden Interview

**Daily Outcomes**
- Psychological: Distress, Affect
- Relations/Social: Marital Adjustment
- Physical: Physical Health Symptoms
- Biological: Diurnal Rhythm of Cortisol, a stress hormone

Figure 1: Conceptual Framework & Study Measures
## Sample Characteristics

<table>
<thead>
<tr>
<th></th>
<th>Elders (121)</th>
<th>PCP (121)</th>
<th>SCP (92)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age ($M, R$)</strong></td>
<td>75.4, 60-91</td>
<td>66.3, 25-92</td>
<td>49.7, 24-91</td>
</tr>
<tr>
<td><strong>Female (%)</strong></td>
<td>33.9</td>
<td>83.5</td>
<td>69.6</td>
</tr>
<tr>
<td><strong>White (%)</strong></td>
<td>79.3</td>
<td>81.8</td>
<td>83.7</td>
</tr>
<tr>
<td><strong>Education (% &gt;H.S.)</strong></td>
<td>57.8</td>
<td>63.7</td>
<td>79.3</td>
</tr>
<tr>
<td><strong>Married/Partner (%)</strong></td>
<td>69.4</td>
<td>82.6</td>
<td>67.4</td>
</tr>
<tr>
<td><strong>Years Married ($M, R$)</strong></td>
<td>41.1 &lt; 1 - 67</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Employed FT/PT (%)</strong></td>
<td>5.8</td>
<td>29.0</td>
<td>66.3</td>
</tr>
</tbody>
</table>
**Sample Characteristics (cont’)**

<table>
<thead>
<tr>
<th></th>
<th>Elders (121)</th>
<th>PCPs (121)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health good - excel (%)</td>
<td>67.8</td>
<td>66.9</td>
</tr>
<tr>
<td>Health interferes a little - not at all (%)</td>
<td>67.0</td>
<td>77.7</td>
</tr>
<tr>
<td>Monthly income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ $1,999</td>
<td>32.3</td>
<td>29.8</td>
</tr>
<tr>
<td>$2,000-3,999</td>
<td>28.9</td>
<td>26.4</td>
</tr>
<tr>
<td>≥ $4,000</td>
<td>38.8</td>
<td>43.8</td>
</tr>
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</table>
## Sample Characteristics (cont’)

<table>
<thead>
<tr>
<th></th>
<th>Elders (121)</th>
<th>PCPs (121)</th>
<th>SCPs (92)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live Alone (%)</td>
<td>18.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Coreside Spouse (%)</td>
<td>68.6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other relative (%)</td>
<td>12.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nonrelative (%)</td>
<td>0.8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Miles to Elder ($M, R$)</td>
<td>25.7, 1 - 150</td>
<td>171, 1 - 2,500</td>
<td></td>
</tr>
<tr>
<td>Relationship to Elder</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse/prtnr (%)</td>
<td>66.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child/Stepch (%)</td>
<td>21.5</td>
<td>73.9</td>
<td></td>
</tr>
<tr>
<td>Sib/Other rel (%)</td>
<td>8.3</td>
<td>18.5</td>
<td></td>
</tr>
<tr>
<td>Friend/other (%)</td>
<td>3.3</td>
<td>7.6</td>
<td></td>
</tr>
</tbody>
</table>
Understanding MCI
Signs & Symptoms of MCI

- Lack of initiative in beginning or completing activities
- Loss of focus during conversations and activities
- Repeat the same question over and over again
- Retell the same stories or providing the same information repeatedly
- Trouble managing number-related tasks (e.g., bill paying)
- Inability to follow multi-step directions
Confusion about the Nature and Diagnosis of MCI

- Inconsistent diagnoses & treatment advice
- Lack of resource materials
- Assumption of dementia
- Unpredictable memory functioning
- Misinterpretation of life-long patterns
- Future uncertainty
Acknowledgement of MCI

Key: + yes
- no

Family Accepters

Primary Doubters

Elder Accepters

Elder Deniers

Secondary Skeptics

Elder

PCP

SCP

MCI

MCI

MCI

MCI

Elder

PCP

SCP

Elder

PCP

SCP

Elder

PCP

SCP

Family Accepters

Primary Doubters

Elder

PCP

SCP

MCI

MCI

MCI

MCI

Elder

PCP

SCP

Elder

PCP

SCP

Elder

PCP

SCP

Family Accepters

Primary Doubters

Elder

PCP

SCP

MCI

MCI

MCI

MCI

Elder

PCP

SCP

Elder

PCP

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Elder

PCP

SCP

Family Accepters

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Elder

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Elder

PCP

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PCP

SCP

Elder

PCP

SCP

Family Accepters

Primary Doubters

Elder

PCP

SCP

MCI

MCI

MCI

MCI

Elder

PCP

SCP

Elder

PCP

SCP

Elder

PCP

SCP
Family Interactions & Relationships
Containing Daily Life

- Less Engaged

- Reduced Social Contacts
  - Interest
  - Abilities

- Increased Health Limitations
  - Elder
  - PCP

- Smaller Living Space
Shifting Roles and Responsibilities

- **Monitor**
  - need to keep track of the elder

- **Motivator**
  - assign activities and tasks to the elder

- **Decision maker**
  - sole responsibility instead of shared

- **Manager**
  - take charge of elders’ health & well being
Coming to Terms with Changes

- Greater Togetherness
  - Elder wants PCP nearby
  - PCP uncomfortable leaving Elder alone

- Altered Relationships
  - Harmonious . . . Argumentative
  - Intertwined . . . Parallel . . . Dependent
  - Intimate . . . Distant

- Realign Priorities and Expectations
  - Focus on what is important
  - Acknowledge loss
Managing Daily Life with MCI
Effective Management Strategies

- Support and Encouragement
- Patience and Respect
- Technology
- Daily Tasks & Appointments
  - Medication Management
  - Household Responsibilities
Ineffective Responses

- **Catastrophizing**: Believing the situation is far worse than it really is
- **Dichotomous Thinking**: Perceiving issues as either black or white; unable to find a middle ground
- **Personalization**: Interpreting negative events as indicative of one’s flaws or negative characteristics
- **Magnification**: Exaggeration of negative attributes
Stressors among Care Partners

- Problems appearing early in the care cycle have long-term implications for caregivers’ health and well-being and the family’s overall quality of life.

- Stressors can pile up over time and contribute to negative health outcomes.
Daily Diary Study

- To document daily symptoms and behaviors of persons with MCI
- To assess how and to what extent MCI-related symptoms, care needs and other stressors influence psychological well-being of care partners and marital relationships
- To examine effects of MCI-related symptoms, care needs and other stressors on spouse care partner’s physiological indicators of health
Methods

- 30 spouse care partners
- 7 consecutive daily diary interviews
  - Daily Psychological Distress
    - Negative & Positive Affect
  - Daily Marital Interaction
    - Occurrence of Pleasant and Unpleasant Couple Interactions
- 4 days of Saliva Collection
  - 5 times each day (wake up, 30 mins after waking, lunch, evening and before bed)
Primary Stressors

Percentage of Study Days

- ADL
- Restlessness
- Mood Disturbances
- Disruptive Behavior
- Memory Problems

Waking Up

During Day

In Evening
Secondary Role Strain

<table>
<thead>
<tr>
<th>Activity</th>
<th>Percentage of Study Days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work</td>
<td></td>
</tr>
<tr>
<td>Leisure</td>
<td></td>
</tr>
<tr>
<td>Run errands</td>
<td></td>
</tr>
<tr>
<td>Housework</td>
<td></td>
</tr>
<tr>
<td>Exercise</td>
<td></td>
</tr>
<tr>
<td>Spent time with friends or family</td>
<td></td>
</tr>
<tr>
<td>Go to religious services</td>
<td></td>
</tr>
</tbody>
</table>
## Psychological Affect

<table>
<thead>
<tr>
<th></th>
<th>Positive Affect</th>
<th>Negative Affect</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary Stressors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADL Related Problems in Evening</td>
<td>-9.61 **</td>
<td>5.59 **</td>
</tr>
<tr>
<td>Restlessness in Evening</td>
<td>-6.17 **</td>
<td>Ns</td>
</tr>
<tr>
<td>Disruptive Behavior in Evening</td>
<td>6.93 *</td>
<td>Ns</td>
</tr>
<tr>
<td><strong>Secondary Stressors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary Role Strains</td>
<td>Ns</td>
<td>0.58 **</td>
</tr>
<tr>
<td>Any cutback of work/task</td>
<td>-4.38 **</td>
<td>1.44 *</td>
</tr>
<tr>
<td>Any non-caregiving stressor</td>
<td>Ns</td>
<td>1.88 **</td>
</tr>
</tbody>
</table>

Analyses controlled for background characteristics
## Marital Interactions

<table>
<thead>
<tr>
<th>Primary Stressors</th>
<th>Unpleasant Marital Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Restlessness during the day</td>
<td>0.81 **</td>
</tr>
<tr>
<td>Mood Disturbances during the day</td>
<td>0.51 **</td>
</tr>
<tr>
<td>Disruptive Behavior during the day</td>
<td>0.75 *</td>
</tr>
<tr>
<td>ADL Related Problems in evening</td>
<td>0.64 **</td>
</tr>
</tbody>
</table>

Analyses controlled for secondary stressors and background characteristics
PCP Salivary Cortisol Levels

Salivary Cortisol (ng/mL)

0 2 4 6 8 10 12

30 Mins after Waking  Lunch  Evening  Before Bed

No Memory-Related Problems Reported (Cortisol)

Memory Related Problems Among MCI Persons Reported (Cortisol)
Final thoughts . . .

- There is no one right way to be a care partner

- Providing care is an evolutionary journey
  - Take one day at a time
  - Navigation is more important than speed
  - A family approach is key to success
  - Conditions will change and strategies will need to change as well

- Different types and levels of interventions are necessary to address family needs and personal characteristics
Translating the Research

Mild Cognitive Impairment (MCI):
What do we do now?

http://www.gerontology.vt.edu/docs/Gerontology_MCI_final.pdf
Acknowledgements

Co-Investigators: Rosemary Blieszner, Ph.D.
Jyoti “Tina” Savla, Ph.D.

Clinics:
- Carilion Healthy Aging Center, Roanoke
- Glennan Center for Geriatrics and Gerontology, Norfolk
- Veterans Affairs Medical Center, Salem
- University of Chicago’s Center for Comprehensive Care and Research on Memory Disorders (UC-CCCRMD)
- Indiana University Center for Aging Research’s Regenstrief Institute in Indianapolis (IUPUI)
- Emory University Alzheimer’s Disease and Related Disorders Memory Clinic in Atlanta (Emory).

Staff: Martha Anderson, Carlene Arthur, Nancy Brossoie, Gail Evans, Kye Kim, Marya McPherson, Kristen Pujari, Tammy Stevers, & Karen Wilcox
Questions . . .

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