Innovative Care-partnering in Families Affected by Mild Cognitive Impairment

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Mild Cognitive Impairment (MCI)

- Age-related decline in memory and executive functioning

- 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)
Purpose

To examine the effects of memory-related changes in decision-making and ability to carry out daily tasks on family interactions and relationships over time when one member has mild cognitive impairment.
Conceptual Frameworks

I. Pearlin’s Caregiving Stress Process Framework

II. Boss’s Theory of Ambiguous Loss
  - Boundary ambiguity
  - Role ambiguity
Mixed Methods
Longitudinal Design
Methods

- Memory Clinics

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

- Scales and open-ended questions

- Three Contacts (face-to-face/telephone)
  - T1 (121 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
Qualitative Analyses

- Open-ended interview questions
- Open coding process – multiple coders
- Final coding scheme – 41 overarching categories
- Codes used:
  - Perceptions of Change
  - Life Changes
  - Household Responsibilities
  - Positive Emotions
  - Negative Emotions
- Used ATLAS.ti (Muhr, 2004) to organize and manage the data, coding scheme, and emergent findings
Overview of Family Perceptions of 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
Family Triad Data: MCI Changes & Challenges
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Elder n=40</th>
<th>Primary Care Partner n=49</th>
<th>Secondary Care Partner n=39</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age (SD)</td>
<td>74.0 (7.3)</td>
<td>67.0 (13.3)</td>
<td>47.8 (8.8)</td>
</tr>
<tr>
<td>% Female</td>
<td>28</td>
<td>86</td>
<td>64</td>
</tr>
<tr>
<td>% White</td>
<td>93</td>
<td>95</td>
<td>97</td>
</tr>
<tr>
<td>% Married/Partnered</td>
<td>80</td>
<td>87</td>
<td>77</td>
</tr>
<tr>
<td>% &gt; HS Education</td>
<td>52</td>
<td>61</td>
<td>89</td>
</tr>
<tr>
<td>% Monthly income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤ $1,999</td>
<td>30.8</td>
<td>28.3</td>
<td></td>
</tr>
<tr>
<td>$2,000-3,999</td>
<td>25.6</td>
<td>30.4</td>
<td></td>
</tr>
<tr>
<td>≥ $4,000</td>
<td>43.6</td>
<td>41.3</td>
<td></td>
</tr>
<tr>
<td>Relationship to Elder</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>% Spouse</td>
<td>-</td>
<td>74</td>
<td>-</td>
</tr>
<tr>
<td>% Adult Child</td>
<td>-</td>
<td>17</td>
<td>83</td>
</tr>
<tr>
<td>% Sibling</td>
<td>-</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>% Other Relative</td>
<td>-</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>% Friend</td>
<td>-</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>
# Changes in Background Characteristics (T1 - T3)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Elder</th>
<th>Primary Care Partner</th>
<th>Secondary Care Partner</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1</td>
<td>T3</td>
<td>T1</td>
</tr>
<tr>
<td>% Lives Alone</td>
<td>10.0</td>
<td>2.5</td>
<td></td>
</tr>
<tr>
<td>% Lives with Elder</td>
<td></td>
<td></td>
<td>83.7</td>
</tr>
<tr>
<td>% Employed Now</td>
<td>5.0</td>
<td>2.5</td>
<td>34.7</td>
</tr>
<tr>
<td>% Health Fair/Poor</td>
<td>20.0</td>
<td>39.5</td>
<td>17.0</td>
</tr>
<tr>
<td>% Health Interferes</td>
<td>72.5</td>
<td>58.3</td>
<td>66.0</td>
</tr>
<tr>
<td>M MMSE (SD)</td>
<td>26.7</td>
<td>23.1</td>
<td>(2.95)</td>
</tr>
<tr>
<td>M Behavioral Problems (SD)</td>
<td>7.2</td>
<td>8.1</td>
<td>(4.7)</td>
</tr>
</tbody>
</table>
3 Major Themes

- Constrained Daily Life
- Shifting Roles and Responsibilities
- Coming to Terms with Changes
Constrained 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**
  Exaggerating negative attributes
Conclusions

- Providing care is an evolutionary journey

- 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

- 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
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