Caring for a Spouse with Mild Cognitive Impairment: Daily Challenges, Marital Relations, and Physiological Indicators of Health

Dr. Tina Savla
Assistant Professor, Department of Human Development
Research Methodologist, Center for Gerontology
Virginia Polytechnic Institute and State University

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Outline of Webinar

- What is Mild Cognitive Impairment?
- Care Partners: The 1\textsuperscript{st} line of support
- Stress Process Model
- 3 Studies by Center for Gerontology
- Is Caring Hazardous to Care Partner’s Health?
  - Daily stressors
  - Marital stressors
  - Effects on Physiological indicators of health
- Summary and Recommendations
What is Mild Cognitive Impairment (MCI)?
Mild Cognitive Impairment

- MCI is characterized by early decline in memory, executive functioning and abilities to carry out a series of steps in sequence
- Appear to be healthy and able to function normally
- YET show signs of memory loss, confusion, apathy and have some difficulties in daily life tasks
- Compensation strategies are used by MCI patients to carry out daily living tasks and responsibilities
- Physicians cannot predict whether or when MCI might worsen
Markers to Examine Progression of Dementia
Diagnostic Criteria for MCI

- No GOLD STANDARD for diagnosis:
- Self-reported complaints 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
Some Signs and 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
MCI: Transitional Phase

- It is an ambiguous condition
- Physicians usually cannot predict whether or when the MCI might worsen
- Possibly a transitional phase between normal cognitive aging and early dementia
Care Partners: The 1st Line of Support
MCI and Care Partners

- Spouses represent 62% of caregivers living with non-institutionalized family members who have physical and cognitive impairments.
- Older spouses spend an average of four hours each day providing assistance with a variety of household and personal care tasks.
MCI and Care Partners

- Among spousal caregivers 75+, both husbands and wives provide equal amounts of care.
- Wives are more likely than husbands to suffer from high stress due to care giving (35% vs. 25%).
- Women caregivers take an emotional care giving role; men caregivers take an instrumental care giving role.
• **Stressors:**
  Problematic conditions or situations that pushes one’s emotional, cognitive and physical **capacities to the limit**

• **Distress:**
  Failure to cope with stressors that results in **immediate and long-term consequences** on one’s behavioral, psychological and physical well-being
Biopsychosocial Model of the Stress Process

Background & Contextual Factors

- Caregiving Situation
- Primary Stressor Objective
- Primary Stressor Subjective
- Secondary Stressors
  - Role Strains
  - Intrapsychic Strains
- Outcome

Buffering Sites
Hans Selye: Eustress vs. Distress

- **Eustress**
  - Performance
  - Health
  - Tension

- **Distress**
  - Fatigue
  - Exhaustion
  - Ill-health

**Arousal of Stress**
Daily Stressors

- Defined as routine everyday challenges
- Have minor but immediate and direct effects on one’s well-being
- Pile up over time and form foundations for major health outcomes
- Little is known about immediate impact of daily stressors and its spillover onto other areas of life & health
Distress Outcomes

- **Behavioral Aspects**
  Spillover of Stressors in Other Life Domains, Poor Health Behaviors

- **Psychological Aspects**
  Affect, Depression, Anxiety

- **Physiological Aspects**
  Physical Symptoms, Changes in Immune System; Dysregulation of Hormones
Everyday Stress & Health Effects

Before Work

After Work
Threat triggers a cascade of behavioral, psychological and biological responses to increase chances of survival.

Biologically wired to immediately activate the Sympathetic Nervous System to trigger the “fight-or-flight” response.
Two Major Stress Systems

Sympathetic-Adrenal-Medullary System (SAM)
- Activated First and Fast
- Stimulate rapid reaction to threat or challenge
- Measured by Epinephrine (adrenalin) and Norepinephrine, blood pressure, heart rate, respiration

Hypothalamic-Pituitary-Adrenal Axis (HPA)
- Activated Slower, but Longer lasting
- Reinforces or Modulates Initial SAM response
- Measured by cortisol from blood, urine or saliva
Dysregulation of HPA or SNS-Axis Activation

- Release of stress hormones mobilizes energy to adapt to stressors
- But, *repeated and chronic activation* of the stress response system can cause *dysregulation* of the negative feedback loop
- Overproduction of cortisol or alpha-amylase is associated with destruction of hippocampal neurons, leading to problems in memory, learning, attention, depression
Diurnal Rhythm of Cortisol

Area Under the Curve

Daily Decline

Morning Rise

Wake 30 Min. Lunch Bed
Diurnal Rhythm of Alpha-Amylase

- Wake
- 30 Min.
- Lunch
- Bed

Daily Increase

Morning Rise
Studies on MCI by the Center for Gerontology, Virginia Tech (2003-2012)
Study 1: 2003-2006

Aim: Identify information and support needs of family members of older adults with MCI

- 99 families were interviewed twice
- Recruited from three memory clinics in VA

*Funded by the Alzheimer’s Association (IIRG-03-5926, IIRG-07-59078)
Study 2: Transitions in Care Needs

Study 2: 2007-2010

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

- Interview 3rd time
- Include minority Elders

*Funded by the Alzheimer’s Association (IIRG-03-5926, IIRG-07-59078)
Study 3: Is Everyday Caring Hazardous

Study 3: 2008-2009
Aim: Assess the daily frequency and intensity of behaviors and symptoms associated with mild memory loss and the relationship between these daily experiences of living with a person with MCI and its effects on personal relationships, health, and well being.

- Daily Diary Reports of 30 Care Partners
- 8 consecutive daily diary interviews
- 4 days of Saliva Collection (5 times each day)
- 30 Care Partners

*Funded by Alzheimer’s and Related Diseases Research Award Fund, Richmond, VA,
Daily Life of Care Partners: A Biopsychosocial Approach
Biopsychosocial Model of the Stress Process

Background & Contextual Factors

- Caregiving Situation
- Primary Stressor Objective
- Primary Stressor Subjective
- Secondary Stressors Role Strains
- Secondary Stressors Intrapsychic Strains

Buffering Sites

Outcome
Question 1

How do memory and behavior problems change during the day in individuals with MCI?
Severity of Memory and Behavior Problems

<table>
<thead>
<tr>
<th>Percentage of Study Days</th>
<th>ADL</th>
<th>Restlessness</th>
<th>Mood Disturbances</th>
<th>Disruptive Behavior</th>
<th>Memory Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Waking Up</strong></td>
<td>10%</td>
<td>10%</td>
<td>10%</td>
<td>10%</td>
<td>50%</td>
</tr>
<tr>
<td><strong>During Day</strong></td>
<td>20%</td>
<td>20%</td>
<td>20%</td>
<td>20%</td>
<td>40%</td>
</tr>
<tr>
<td><strong>In Evening</strong></td>
<td>30%</td>
<td>30%</td>
<td>30%</td>
<td>30%</td>
<td>30%</td>
</tr>
</tbody>
</table>
Role Strain: How did the Care Partner spend their day?

![Bar chart showing the percentage of study days spent on various activities.](image-url)
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 Care Partner nearby
  - Care Partner uncomfortable leaving Elder alone

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

- Realign Priorities and Expectations
  - Focus on what is important
  - Acknowledge loss
Question 3: Outcomes

How do MCI-related symptoms and care needs influence the daily psychological well-being of care partners and their perceptions of marital interactions?
## 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>- Significant</td>
<td>+ Significant</td>
</tr>
<tr>
<td>Restlessness in Evening</td>
<td>- Significant</td>
<td>+ Significant</td>
</tr>
<tr>
<td>Disruptive Behavior in Evening</td>
<td>- Significant</td>
<td></td>
</tr>
<tr>
<td><strong>Secondary Stressors</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Role Strains</td>
<td></td>
<td>+ Significant</td>
</tr>
<tr>
<td>Cutback of work/task</td>
<td>- Significant</td>
<td>+ Significant</td>
</tr>
</tbody>
</table>
## 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>+ Significant</td>
</tr>
<tr>
<td>Mood Disturbances during the day</td>
<td>+ Significant</td>
</tr>
<tr>
<td>Disruptive Behavior during the day</td>
<td>+ Significant</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Secondary Stressors</th>
<th>Unpleasant Marital Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>ADL Related Problems in evening</td>
<td>+ Significant</td>
</tr>
</tbody>
</table>
How do MCI-related symptoms and care needs influence daily physiological indicators from saliva (cortisol and alpha-amylase)?
Salivary Cortisol Among Care Partners

- No Memory-Related Problems Reported
- Memory Related Problems Among MCI Persons Reported

Salivary Cortisol (ng/ml)

- 30 Mins after Wake
- Lunch
- Evening
- Before Bed
Salivary Alpha-Amylase Among Care Partners

No Memory-Related Problems Reported

Memory Related Problems Among MCI Persons Reported
Management Strategies
Effective Management Strategies

- Support and Encouragement
- Patience and Respect
- Using Technology
- Keeping Daily Tasks & Appointments
  - Medication Management
  - Household Responsibilities
- Exercise
- Confiding in Others vs. Rumination
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
Summary and Recommendations
Summary

- Support for care partners is needed even at the early stages of impaired cognitive functioning
- Elevated levels of stress hormones, signal high levels of stress
- Chronic activation of the related physiological systems (HPA and SNS) could lead to detrimental health over time
Managing Daily Life with MCI
Be Supportive & Encouraging

- Accept the memory loss as real
- Help the person stay physically healthy
- Allow people with MCI to complete their daily routine at their own pace
- Provide uninterrupted moments to allow for recalling information
Be Supportive & Encouraging (cont’)

- Encourage nurturance by suggesting responsibility for caring for a pet or plants

- Encourage usefulness by suggesting responsibility for completing household tasks

- Promote feelings of success by giving one task to complete at a time

- Avoid becoming over protective
Be Patient & Respectful

- Include the person in social events and community activities
- Avoid interrupting the person with MCI when s/he is speaking
- Respond to the same question as if it were the first time, every time
  - Avoid beginning/ending sentences with “I already told you…”
Enhance Resilience

- Engage in Positive Coping & Psychological Framing
- Spiritual Awareness
- Participate in Cognitive and Physical Exercises and Engaging Tasks
Take Care of Yourself
Personal Care

- Include “me” on your list of people to care for
- Talk with a confidante or professional
- Network with other care partners
- Rest, eat well, and exercise
- Seek your own medical care as needed
Intrapersonal Care Strategies

- Take one day at a time - some days are better than others
- Pick your battles, don’t sweat the small stuff
- Be willing to accept help
- Set limits on what you will do
- It is OK to say “NO”
Contact that is not only care based – conversing, doing activities together, and sharing meals – helps maintain the non-caretaking family relationship

- Prioritize non-care relationships
- Maintain social connections
- Recognize how all family members may contribute to the well-being of the family with their gifts
- Laugh!
Care Career. . .

- 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 team approach is key to success
  - Conditions will change and your strategies will need to change as well
- Research, investigate, and stay informed
- Manage for your own needs first!
Recommendations for Care Service Providers

- Acknowledge diverse manifestations of MCI
- Acknowledge diverse ways care partners adjust to caring for a spouse with MCI
- Acknowledge diverse support needs for individuals with MCI and their spouse care partners
• Needs for individuals with MCI and care partners vary during the day
• Special attention and support should be provided during the late-afternoon hours when there are higher rates of memory and behavior problems
Summing Up

- Everyday stressors affect daily well-being of care partners
- Stress gets under the skin of individuals that could have long-term repercussions on health
- Effective Management Strategies could be used as a buffer against the harmful effects of stress
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Thank you for your attention!

For inquiries: JSAVLA@VT.EDU