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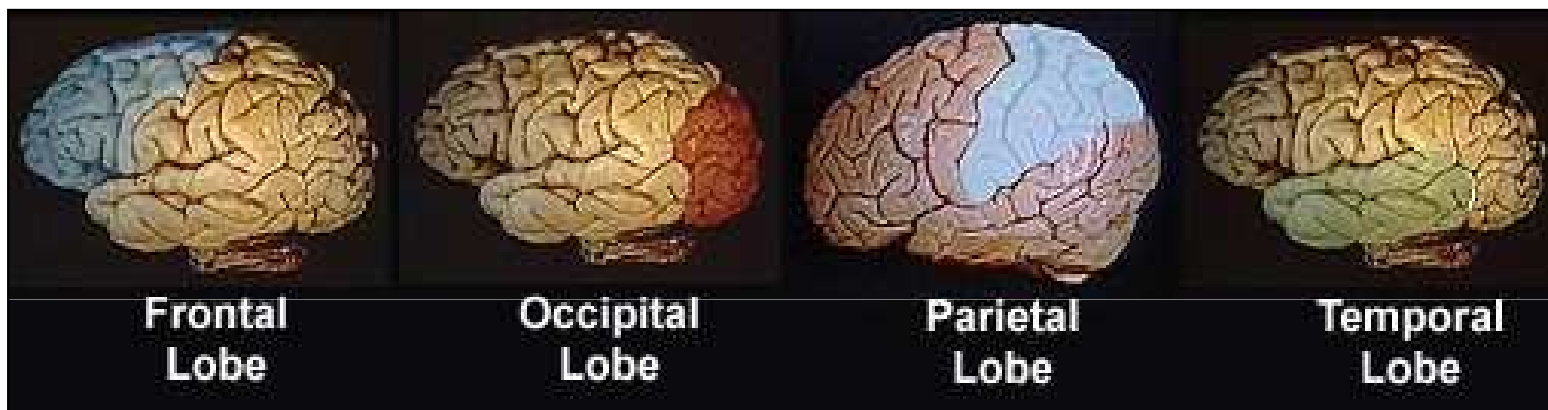
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Mild Cognitive Impairment (MCI)

Age-related decline in memory and executive functioning

Frontal Lobe	Occipital Lobe	Parietal Lobe	Temporal Lobe
Executive Function	vision	perception of touch, pressure, temperature, pain	perception and recognition of auditory stimuli, memory
reasoning, planning, speech, movement emotions, problem-solving			

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

- **Caregivers of Persons with Mild Cognitive Impairment: Information and Support Needs (2003-2006)**
    - identify information and support needs of family members of older adults with MCI

- **Understanding Mild Cognitive Impairment: Family Dynamics and Diversity (2007-2010)**
    - 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

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
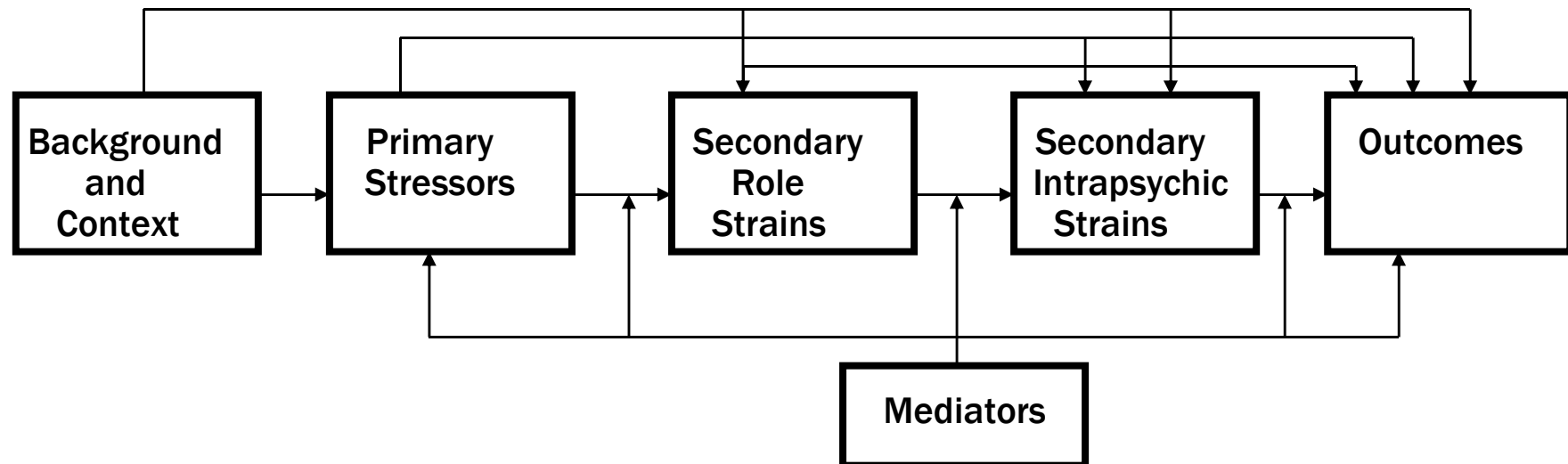
Families and
Mild Cognitive Impairment

Methodology

Conceptual Framework

Pearlin's Caregiving Stress Process Framework

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**
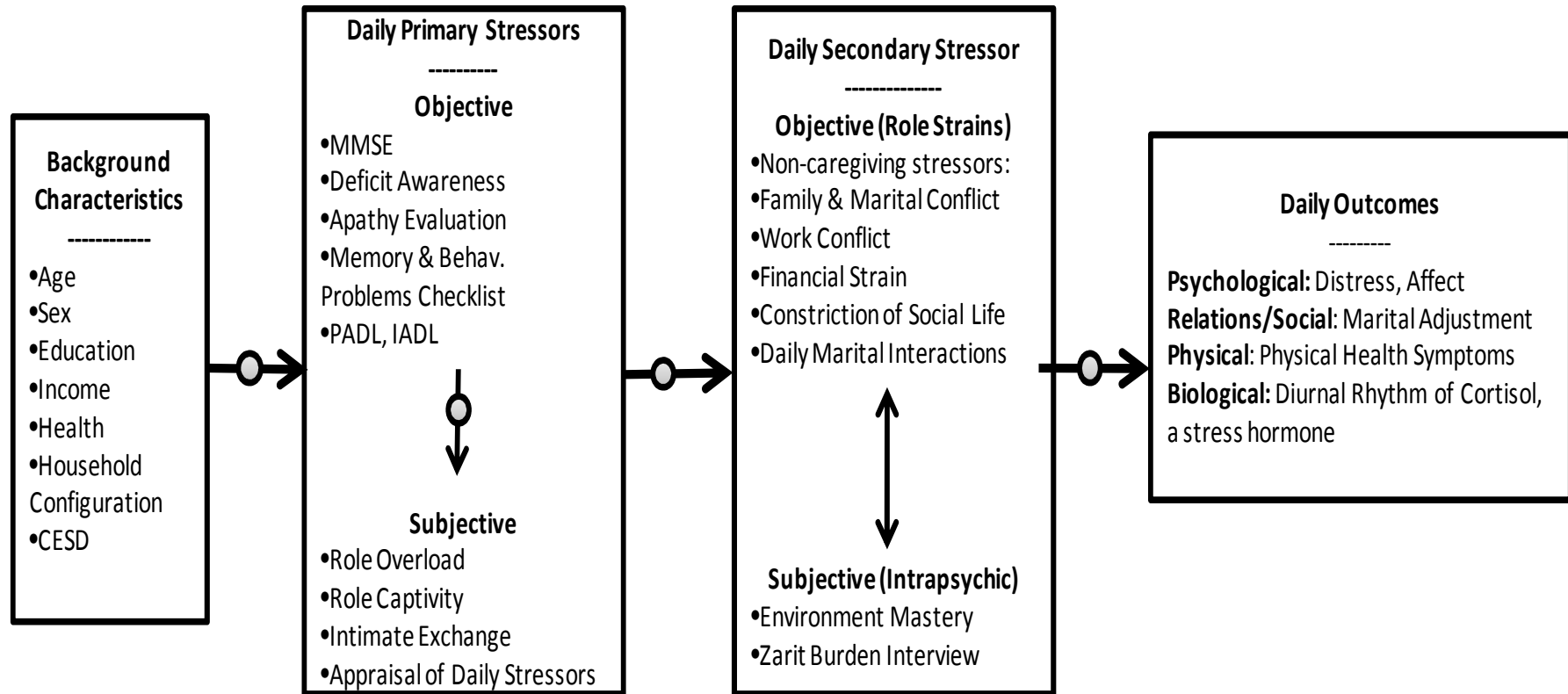 - **T3 (49 families) M = 23.6 months from T2**

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

Daily Primary Stressors

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

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

Daily Secondary Stressor

Objective (Role Strains)
- 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

◯ = Personal Resources Buffers these Relations ((e.g. Management of Meaning (coping); Social Provisions Scale (social support))

Figure 1: Conceptual Framework & Study Measures

Sample Characteristics

	Elders (121)	PCP (121)	SCP (92)
Age (*M, R*)	75.4, 60-91	66.3, 25-92	49.7, 24-91
Female (%)	33.9	83.5	69.6
White (%)	79.3	81.8	83.7
Education (% >H.S.)	57.8	63.7	79.3
Married/Partner (%)	69.4	82.6	67.4
Years Married (*M, R*)		41.1 < 1 - 67	
Employed FT/PT (%)	5.8	29.0	66.3

Sample Characteristics (cont')

	Elders (121)	PCPs (121)
Health good - excel (%)	67.8	66.9
Health interferes a little - not at all (%)	67.0	77.7
Monthly income		
≤ $1,999	32.3	29.8
$2,000-3,999	28.9	26.4
≥ $4,000	38.8	43.8

Sample Characteristics (cont')

|	Elders (121)	PCPs (121)	SCPs (92)
Live Alone	18.2		
Coreside Spouse (%)	68.6		
Other relative (%)	12.4		
Nonrelative (%)	0.8		
Miles to Elder (*M,* R)		25.7, 1 - 150	171, 1 - 2,500
Relationship to Elder			
Spouse/prtnr (%)		66.9	
Child/Stepch (%)		21.5	73.9
Sib/Other rel (%)		8.3	18.5
Friend/other (%)		3.3	7.6

Understanding MCI
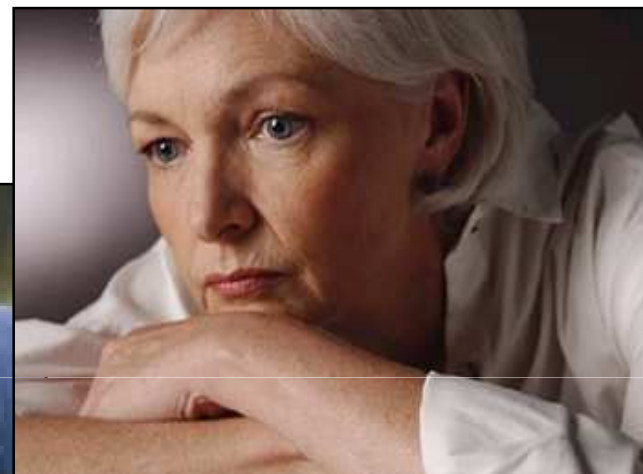
Signs & Symptoms of MCI

- 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
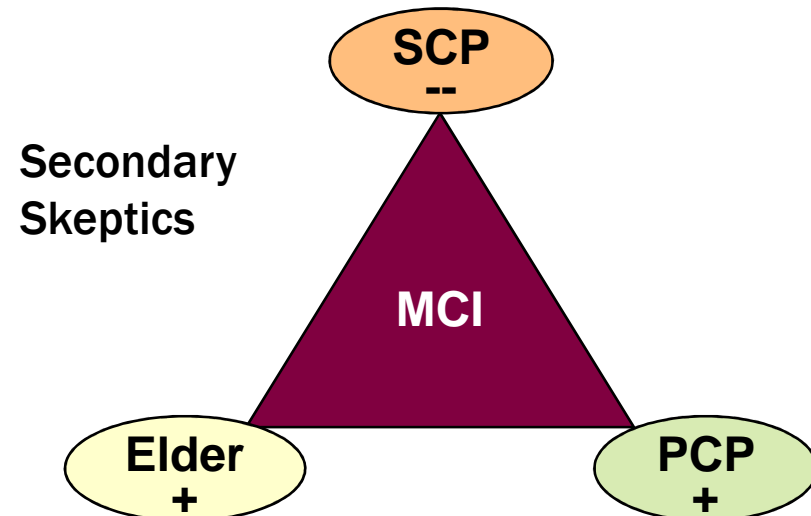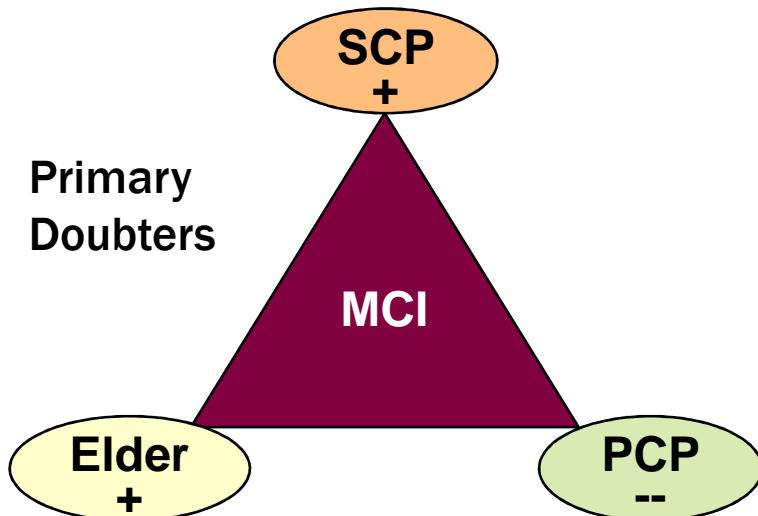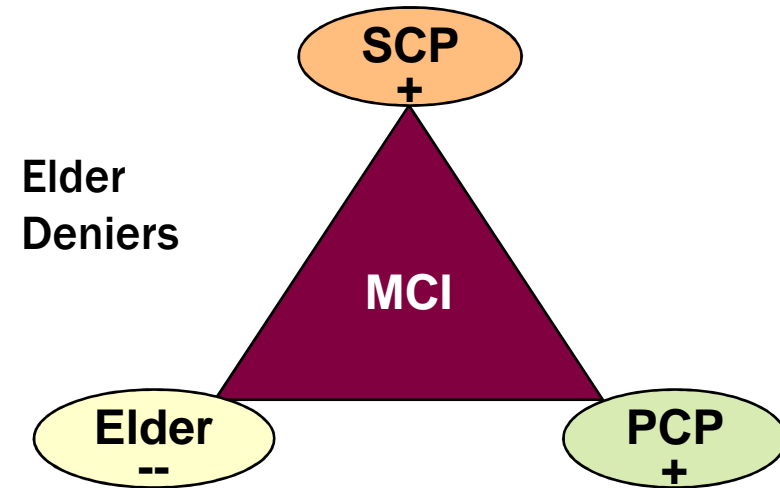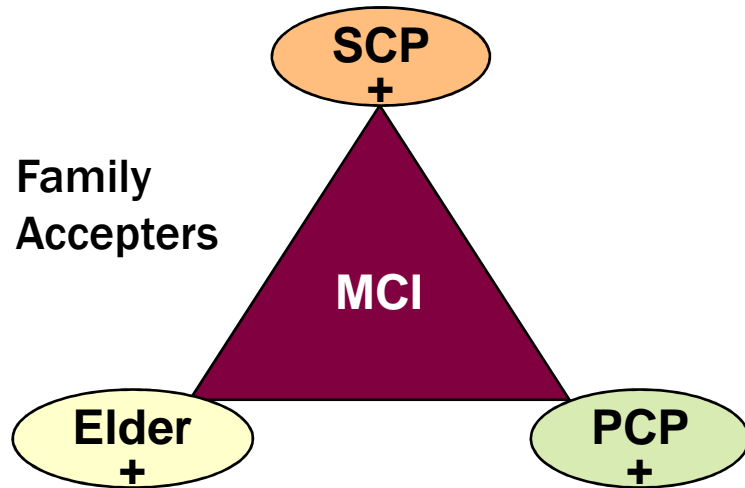
Family Interactions & Relationships

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

- <u>Catastrophizing</u>: Believing the situation is far worse than it really is

- <u>Dichotomous Thinking</u>: Perceiving issues as either black or white; unable to find a middle ground

- <u>Personalization</u>: Interpreting negative events as indicative of one's flaws or negative characteristics

- <u>Magnification</u>: 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
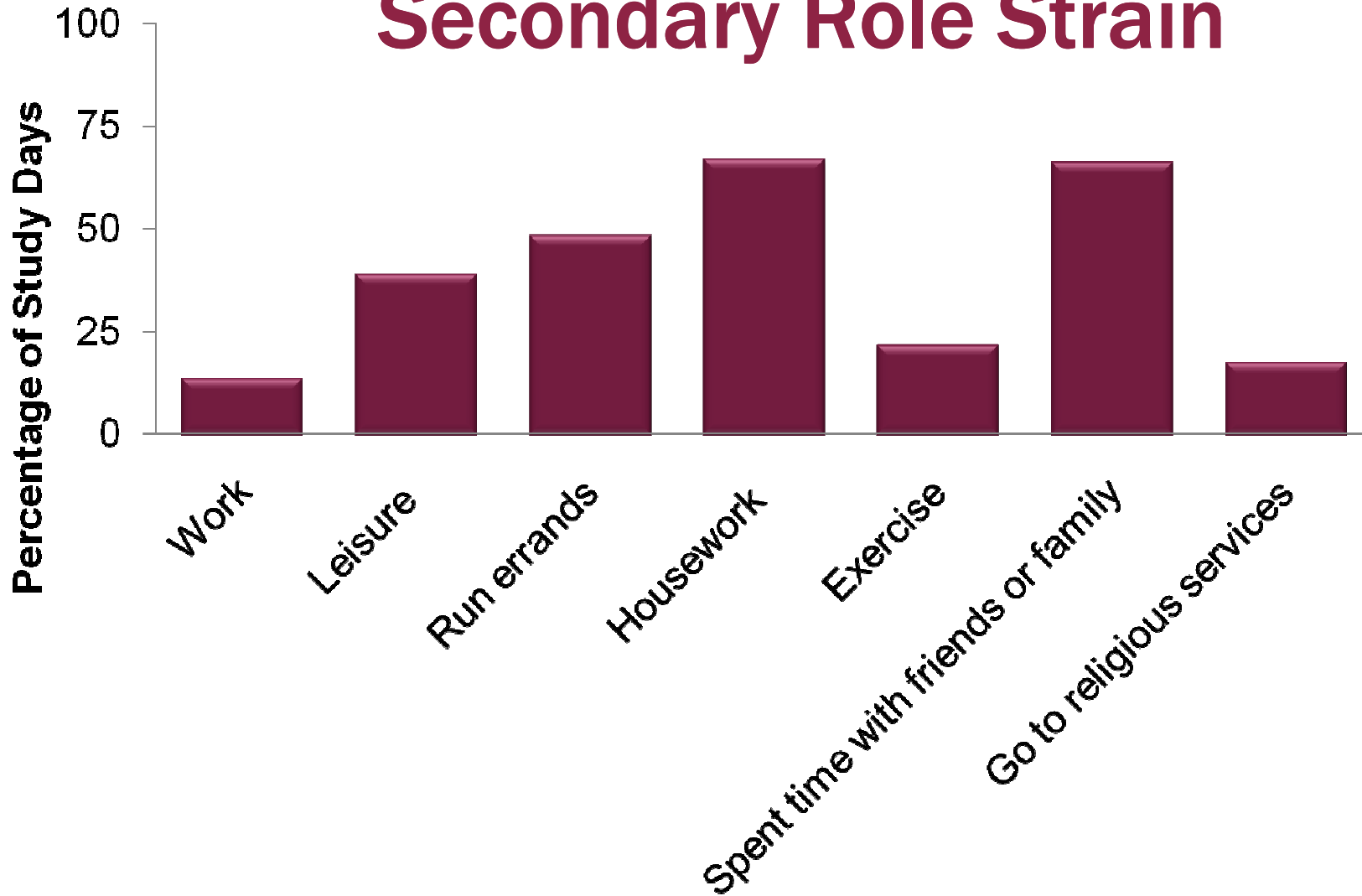
Methods

- **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)

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Invent the Future
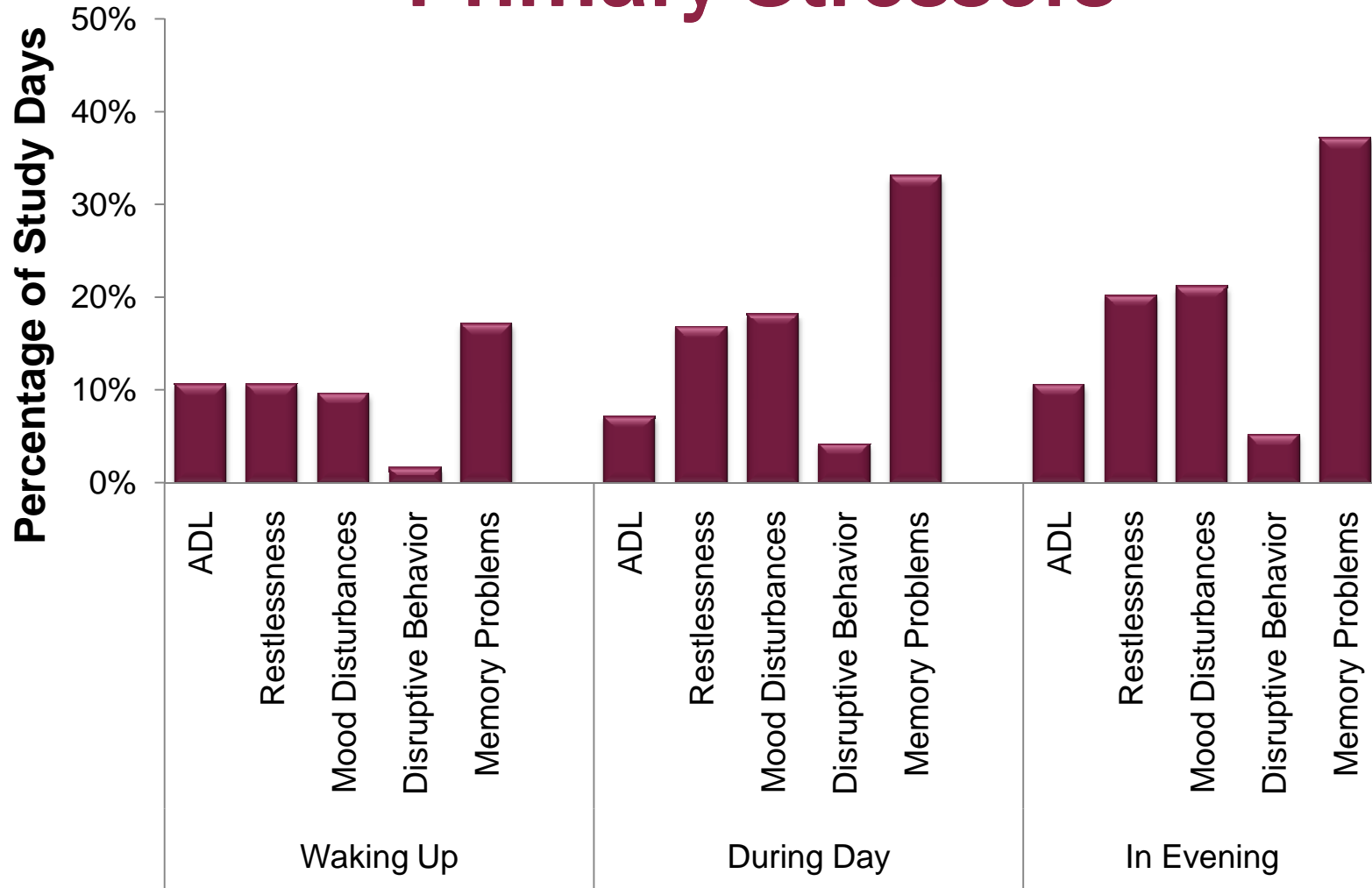
Secondary Role Strain

Psychological Affect

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

Analyses controlled for background characteristics

Marital Interactions

	Unpleasant Marital Interaction
Primary Stressors	
Restlessness during the day	0.81 **
Mood Disturbances during the day	0.51 **
Disruptive Behavior during the day	0.75 *
ADL Related Problems in evening	0.64 **

Analyses controlled for secondary stressors and background characteristics
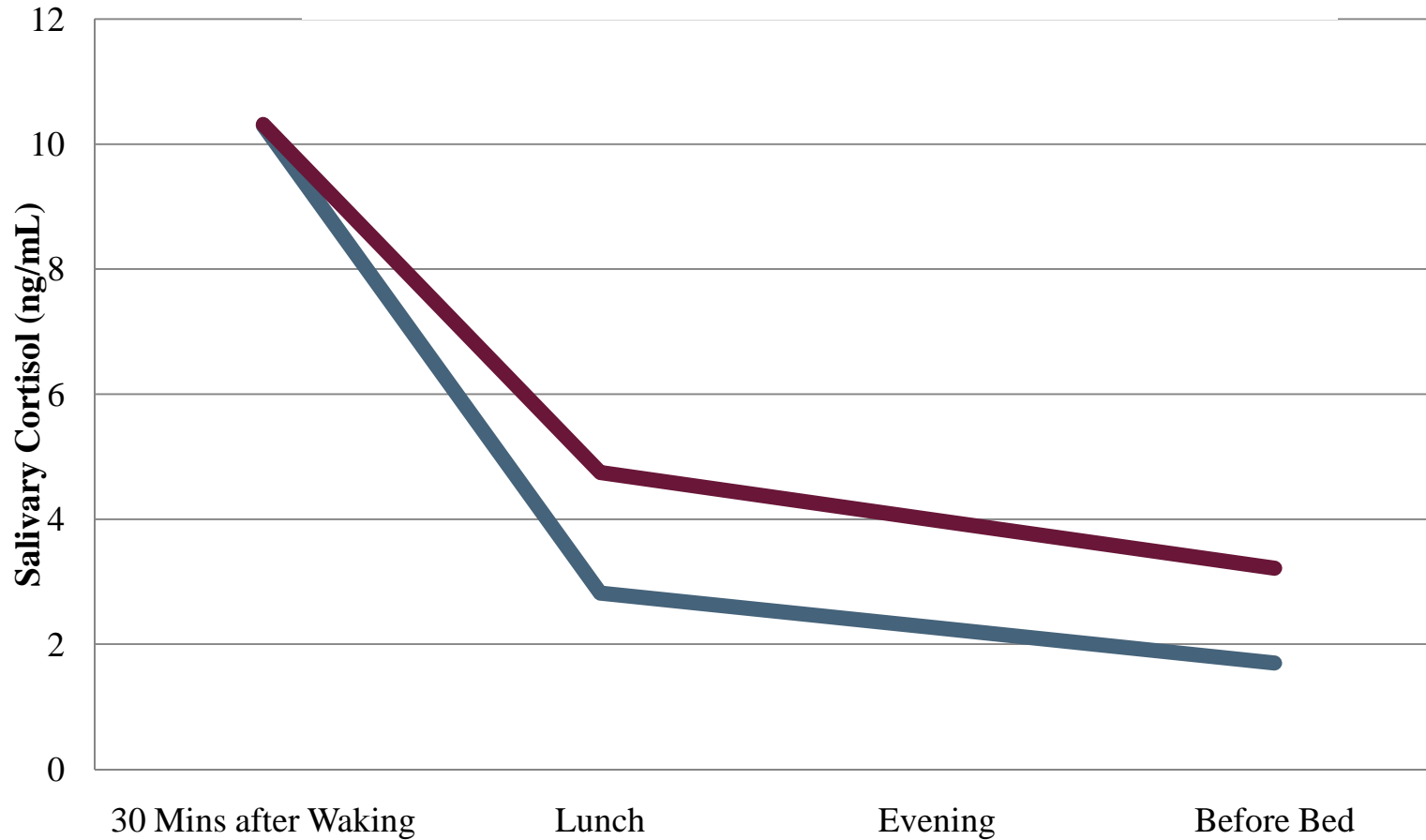
Final thoughts . . .

- 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

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Questions . . .

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