

# **Being a caregiver: How to minimize the strains, and maximize the gains**

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# Goals for today

- Overview the issue of family caregiving
- What makes caregiving stressful?
- What are some of the benefits of caregiving?
- What factors help people cope successfully with caregiving?
- Advice for caregivers
- Questions and comments

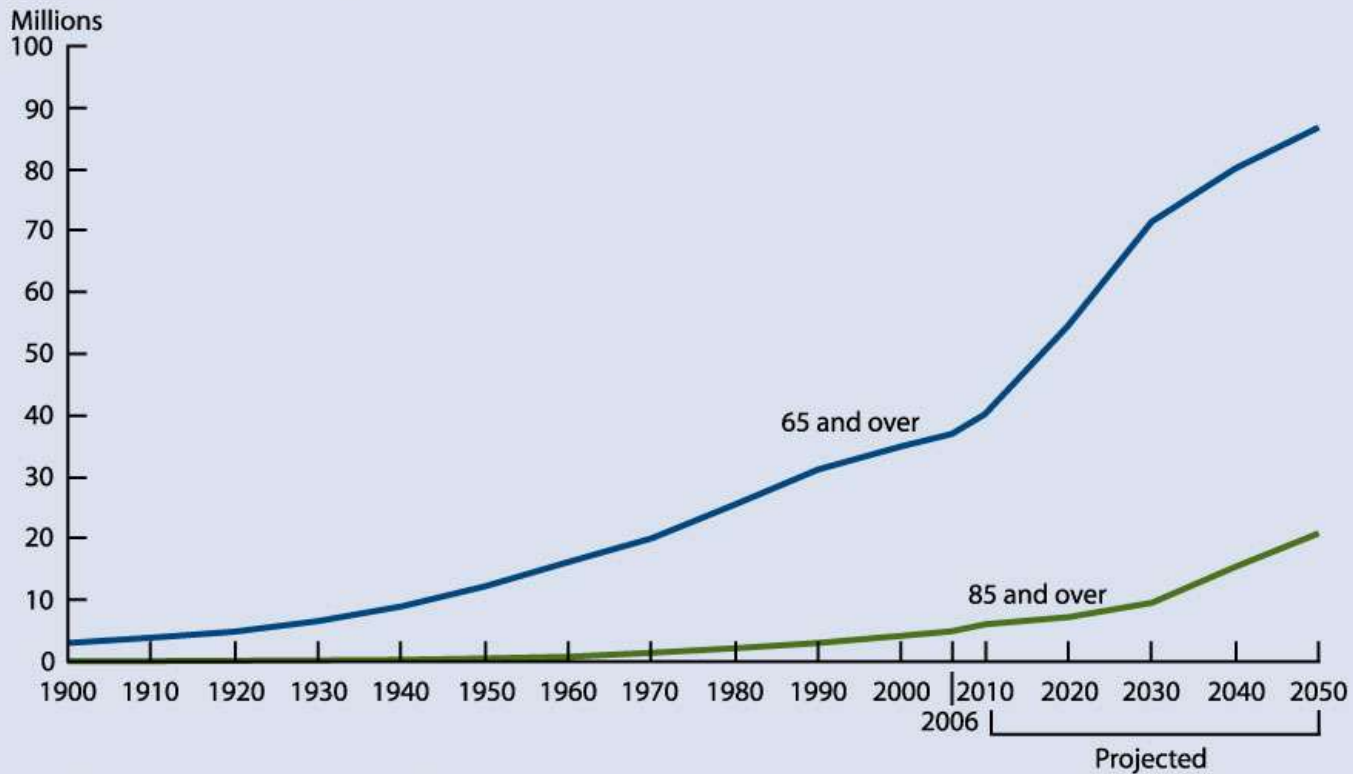
# A historical perspective

- 4% of US population was over 65 in 1900
- Currently 13% nationally, 17% in Florida
- Life expectancy at birth has risen from 47 (1900) to 79 (2010)
- Leading causes of death in 1900: pneumonia/influenza, tuberculosis
- Leading causes of death in 2010: heart disease and cancer

# What this means

- Gift of long life
- More people survive with some impairment
- Unprecedented numbers of older adults requiring assistance would overwhelm healthcare and long term care
- Family members provide assistance when they can

## Number of people age 65 and over, by age group, selected years 1900–2006 and projected 2010–2050



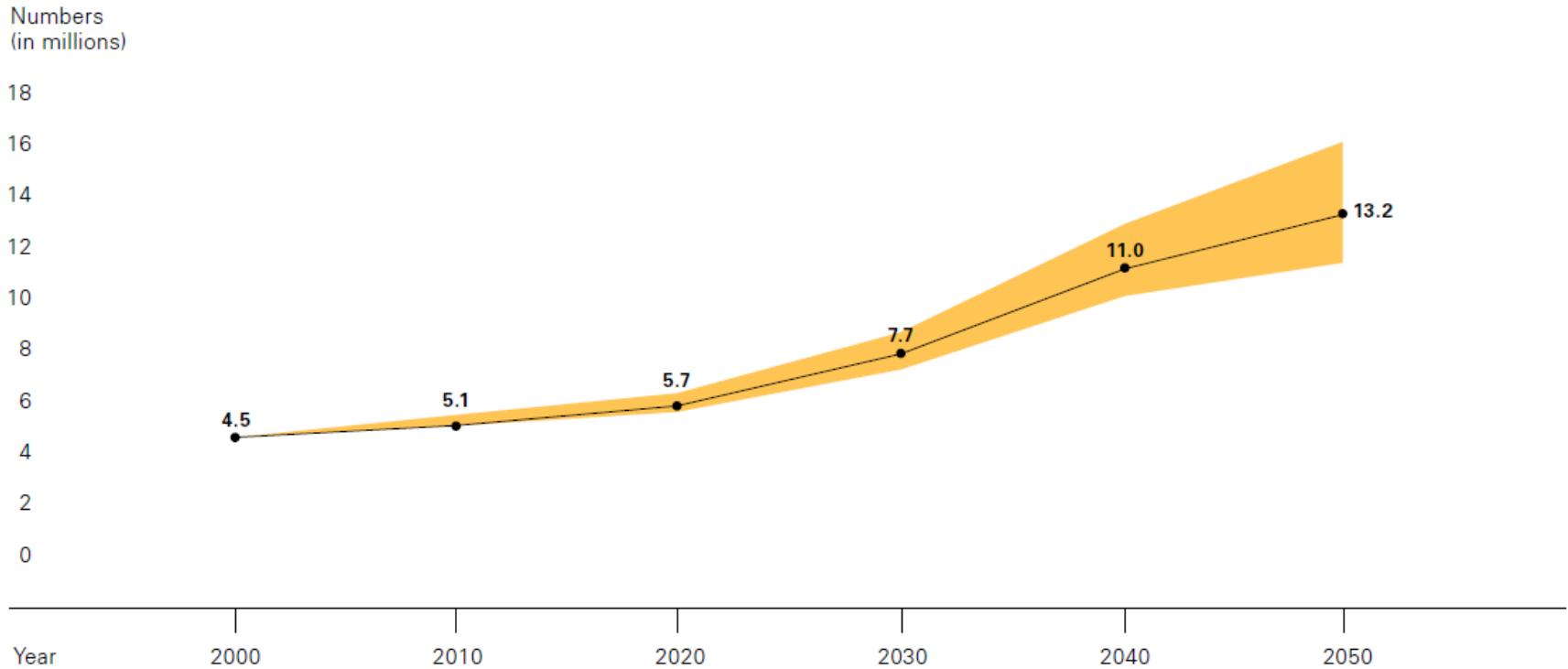
Note: Data for 2010–2050 are projections of the population.

Reference population: These data refer to the resident population.

Source: U.S. Census Bureau, Decennial Census, Population Estimates and Projections.

figure 4:

**Projected Numbers of People Age 65 and Over in the U.S. Population with Alzheimer's Disease Using the U.S. Census Bureau Estimates of Population Growth\***



# Caregiving is increasingly common

- 52 million informal and family caregivers provide care to someone aged 20+ who is ill or disabled
- 34 million adults involved in caregiving to persons aged 50 or over
- 8.9 million informal caregivers provide care for someone aged 50+ with dementia

Family Caregiver Alliance, <http://www.caregiver.org>

# Fundamentals of caregiving

- Most family caregivers are women; spouses and daughters; “informal” (unpaid)
- Can start with small amounts of help and escalate
- AD caregiving, 60 hours per week at home; 9 hours even after NHP; 5-10 year “career”
- Hospice lung cancer caregivers, over 100 hours per week



# What do caregivers do?

- “Whatever it takes”
- May range from occasional assistance to full-time care
- Includes physical care, symptom management, emotional support, help with activities of daily living
- Includes support while care recipient is in a facility

# Why do we become caregivers

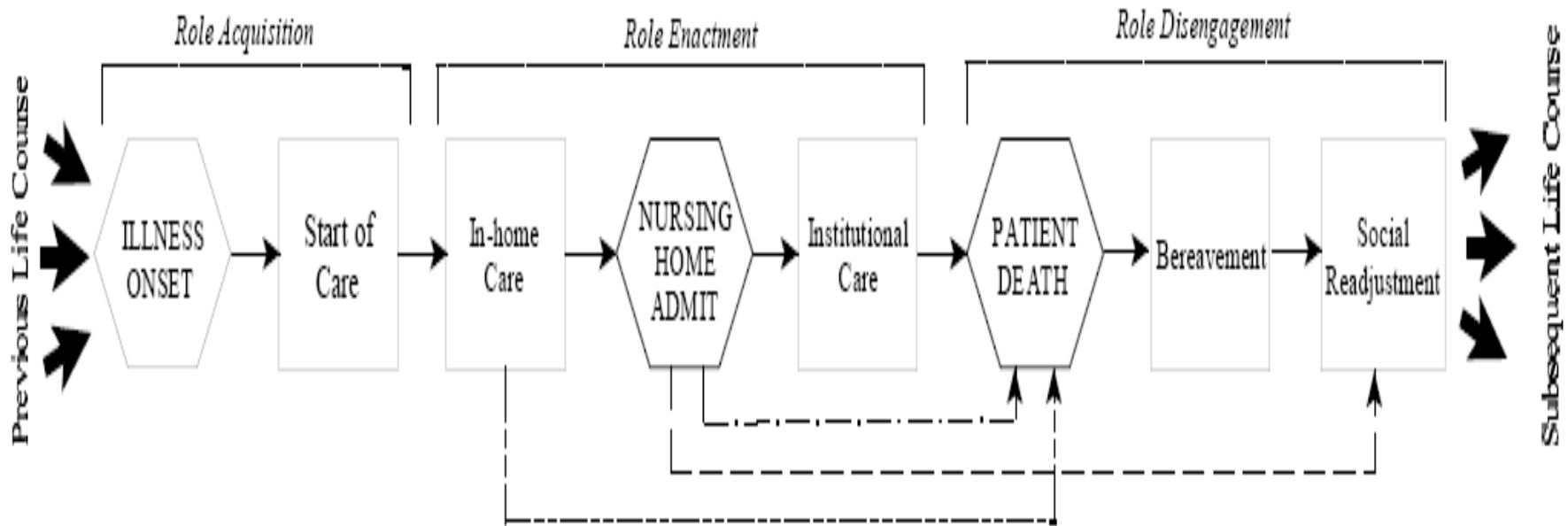
- Loyalty & care provision to family likely has evolved as a useful process—Empathy
- Giving back
- Home care preferred by older adults and families
- Disadvantages of care in a facility
- Cost and sense of obligation
- Cultural issues can be very important

# Different kinds of caregiving

- Intellectual disability (lifelong by parents)
- Spinal cord injury (young adults)
- Mild Cognitive Impairment (MCI)
- Stroke
- Alzheimer's
- Each presents its own challenges

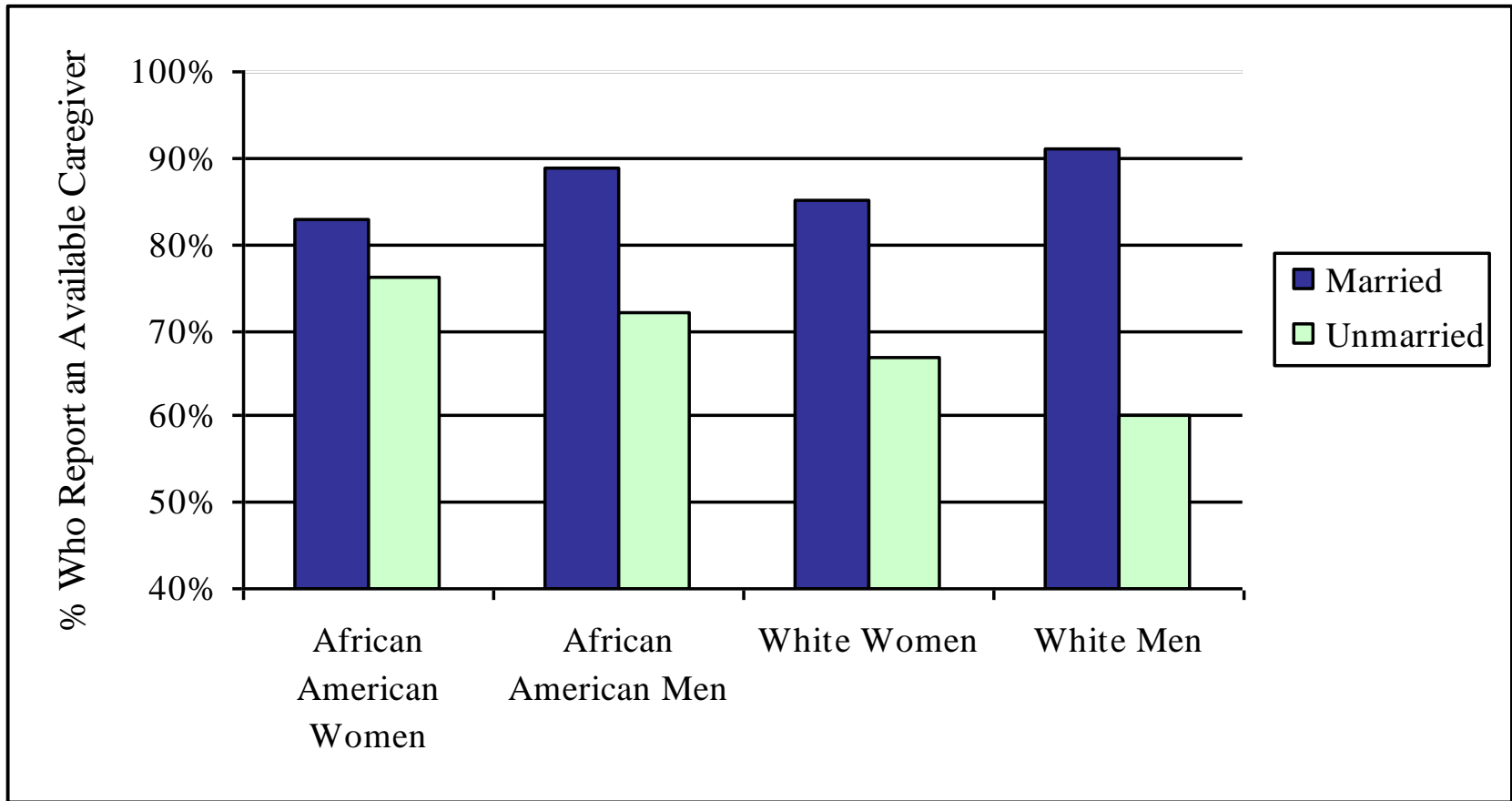
# The Caregiving Career:

## Role acquisition, Role enactment, and Role disengagement



From "Profiles in Caregiving: The Unexpected Career," by C. S. Aneshensel, L. I. Pearlin, J. T. Mullan, S. H. Zarit and C. J. Whitlatch, 1995, p.24.

# Perceived Caregiver Availability



Roth, D. L., Haley, W. E., Wadley, V. G., Clay, O. J., & Howard, G. (2007). Race and gender differences in perceived caregiver availability for community-dwelling middle-aged and older adults. *The Gerontologist*, 47, 721-729.

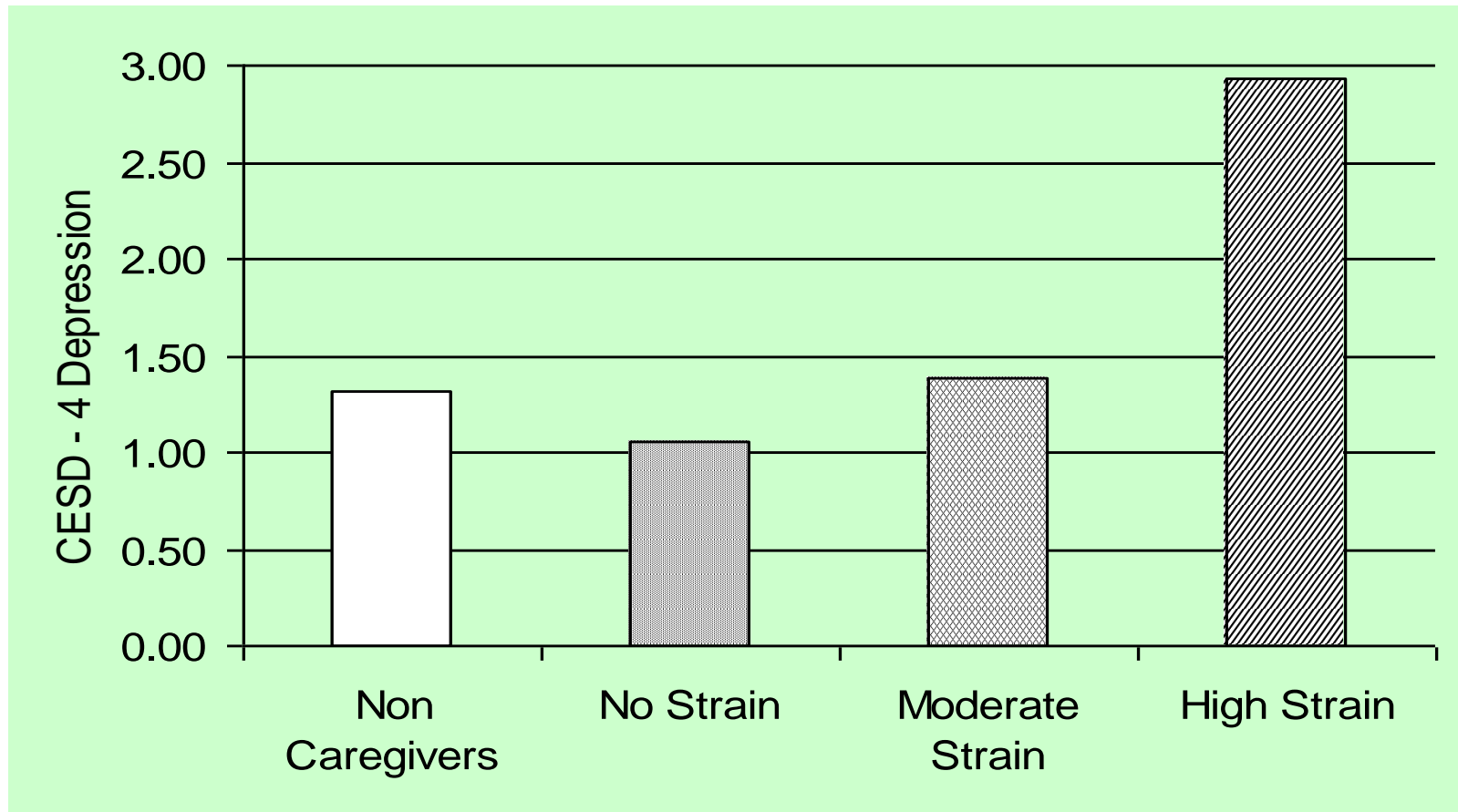
# Caregiving and strain

From our survey of 43,099 adults over 45:

- Are you currently providing care on an ongoing basis to a family member with a chronic illness or disability?
  - **12% say yes**
- How much of a mental or emotional strain is it on you to provide this care? (none, some, a lot)
  - **33% report no strain, 49% “some” strain, 18% “a lot” of strain**

Roth et al., 2009

# Caregiving Strain and Depressive Symptoms



Roth, D. L., Perkins, M., Wadley, V. G., Temple, E., & Haley, W. E. (2009). Family caregiving and emotional strain: Associations with psychological health in a national sample of community-dwelling middle-aged and older adults. *Quality of Life Research, 18*, 679-688.

# Caregiver reports of the most stressful patient problems in dementia

- Dangerous behavior
- Getting lost
- Embarrassing behavior
- Waking the caregiver
- Agitation, restlessness
- Anger, suspiciousness
- Depression
- Not memory problems or ADL problems, incontinence



# Caregiving, Health, & Mental Health

- High CG strain associated with 63% increased mortality (vs. nonCG & low strain)
- High perception of CG strain (vs. no or low strain) associated with 12% increase in stroke risk
- AD caregivers show slower wound healing
- Caregivers with high strain show increased depression

**Schulz & Beach, 1999; Haley et al., 2010; Kiecolt-Glaser et al., 1995; Pinquart & Sorensen, 2003; Roth et al., 2009**

# Examples of perceived benefits reported by caregivers

- Giving back to someone who has cared for them.
- A sense of pride, accomplishment, meaning, or purpose to life.
- Enjoyment of the little moments of pleasure with a loved one.
- Feeling pleased that they can keep providing care despite being told by doctors and family members that it is impossible to continue providing care.
- Sense of personal growth, becoming a more caring and sensitive person, more empathy for others.

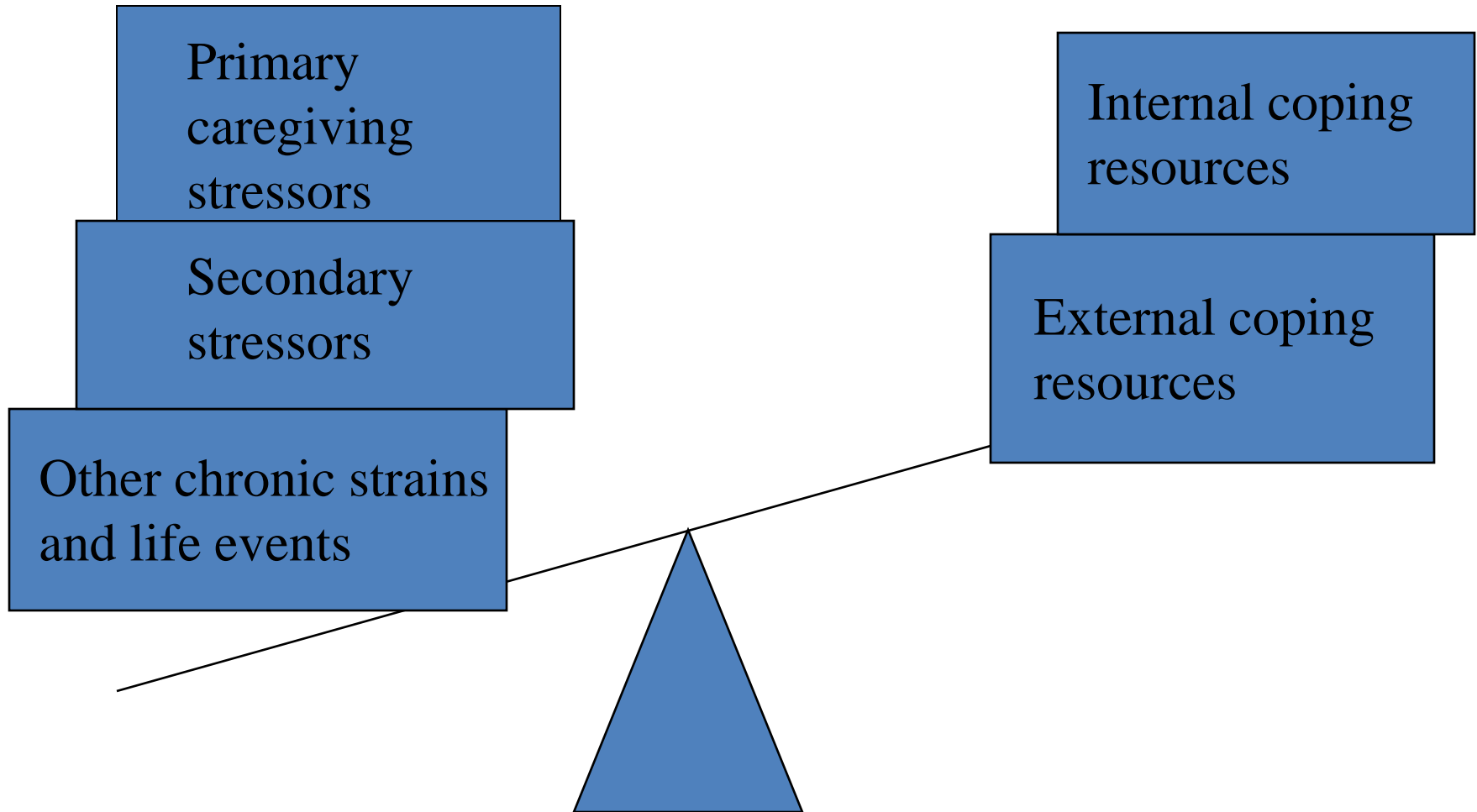
# A mortality benefit to caregiving?

- Four recent studies show that caregivers have LOWER death rates than noncaregivers
- Our study, 28,366 adults followed for 6 years
- Only 7.5% of caregivers died, compared with 9% of noncaregivers
- About 18% decreased mortality for caregivers compared with carefully matched controls

# What factors affect caregivers?

- **Witnessing suffering** (physical, psychological, spiritual)
- **Primary stressors**—actual care (wandering, toileting)
- **Secondary stressors**—spillover effects (job, family)
- **Contextual stressors**—life goes on (crime, home repair)
- **Psychosocial resources** can include **internal** (appraisal, coping, personality) and **external** (social support, finances)
- **Stress appraisal**—affected by perceived resources

# Stress and coping: A balancing act



# Ways for caregivers to get help

- Decrease stressors (lighten the load)
- External resources
  - Social support
  - Services
- Internal resources
  - Knowledge
  - Skills
  - Spirituality/Optimism/Self-confidence
- Appraisals (learn to react calmly, constructively)
  - If we feel prepared, we can handle anything
  - Benefit finding

# Practical advice

- Don't wait to ask for help until you are desperate!
- Informal help (family, friends, church)
  - How to ask for help
  - You may need to help them understand
- Formal (paid) help
  - Area Agency on Aging
  - Alzheimer's Association
  - Geriatric Care Manager

# Counseling for caregivers

- Caregivers who receive the right kind of counseling receive many benefits
  - Improved caregiver quality of life and depression
  - Lower feelings of burden
  - Delay in nursing home placement
- Of special value: Skill building, and family therapy
  - More than a support group
  - Positive effects for Alzheimer's, cancer, and hospice caregivers



# NYU Family Caregiving Project

- “AD Caregiver Well-Being Counseling/Institutionalization” (M. Mittelman, PI), begun in 1987
- National Institute of Mental Health, 1R01 MH42216, 2001-2004, 2005-2007
- 406 spouse caregivers randomized to treatment and control conditions
- Treatment: 2 individual counseling sessions, 4 family counseling sessions, phone support, support groups
- Control: usual care

# Unique features of the NYU study

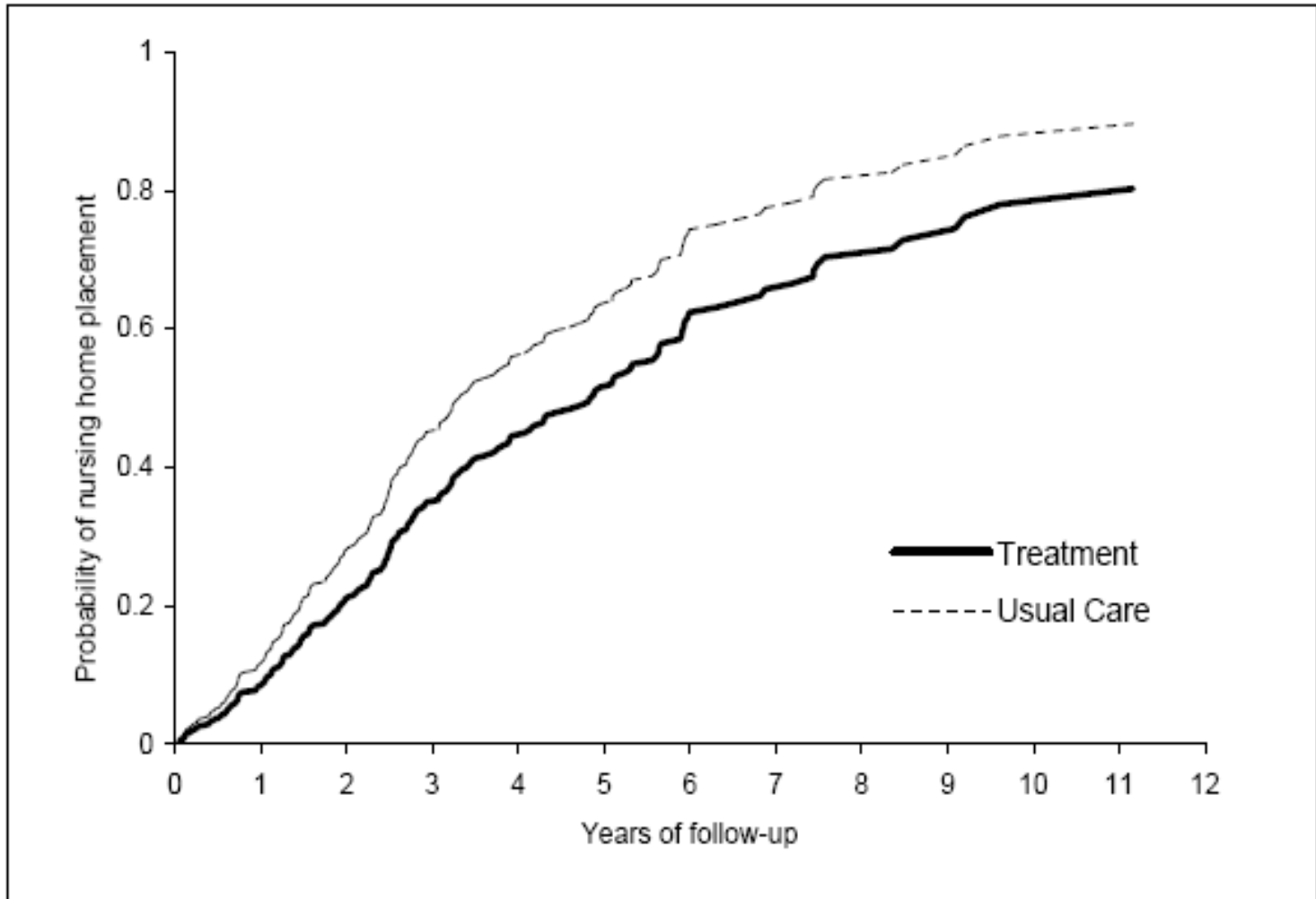
- Project began in 1987, some caregivers followed 20 years
- Less than 5% refusals on follow up interviews
- Flexible and sustained caregiver intervention administered by highly skilled and dedicated counselors

# Results

- Caregivers who received counseling were less depressed for 3 years
- Caregivers who received counseling showed delay in nursing home placement of **557 days**
- Recent data shows that average NH care in Florida costs \$80,000 per year

Mittelman, M., Roth, D., Coon, D., & Haley, W. E. (2004). Sustained benefit of supportive intervention for depressive symptoms in Alzheimer's caregivers. *American Journal of Psychiatry*, 161, 850-856.

Mittelman, M., Haley, W. E., Clay, O., & Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology*. 67, 1592-1599.



# **A Caregiver Intervention to Improve Hospice Outcomes**

Principal Investigator:

Susan C. McMillan, PhD, RN, FAAN

# Study Sample

- **354 patient/caregiver dyads**
- **Patients had cancer and were admitted to hospice**
- **Randomized into 3 groups**
  - Usual care (hospice)
  - Usual care plus 3 supportive visits
  - Usual care plus COPE (problem solving approach)

McMillan, S. C., Small, B. J., Weitzner, M., Schonwetter, R. S., Tittle, M., Moody, L., & Haley, W. E. (2006). Impact of coping skills intervention with family caregivers of hospice patients with cancer: A randomized clinical trial. *Cancer, 106*, 214-222.

# COPE

- Creativity
- Optimism
- Planning
- Expert advice
- Example: Husband with cancer wants to attend a reunion. 8 hour drive is too long, pain with sitting.

# Findings

- At the 30 day follow-up, the coping skills intervention led to significantly greater improvement in
  - Patient perception of symptoms
  - caregiver quality of life
  - burden of caregiving tasks, and
  - burden of patient symptoms, than did the other two conditions.



# Final comments

- An aging society provides many benefits and challenges
- Families will be challenged to provide care for growing numbers of impaired older adults
- Caregiving can be stressful and challenging but can also be a growth experience
- Caregivers need more help-Informal and formal
- As a society we must do more to support caregivers