Family Caregiving:
Research to Policy in 40 Years

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Overview

- Caregiving in the U.S.
- Caregiving and Health
- Interventions for Caregivers
- Caregiver Policy
- 7 Recommedations: Future Research

Caregiving in the U.S.

- **17.7 million provide support to older adults**
- **8.5 million provide support to severely impaired (dementia and or self-care needs)**
- **Mean hours of care per month:**
  - 85 for household activities only
  - 118 for persons with 1-2 self-care needs
  - 253 for persons with >2 self-care needs
- **Value of "free" care $250-450 billion**

Caregiving as a Research Platform

- Important social problem affecting individuals and society
- Incorporates numerous transitions of interest to psychologists (e.g., increasing/decreasing levels of demand/chronic stress, bereavement, institutionalization)
- Enables multiple levels of analysis from macro (e.g., social policy) to micro (e.g., psychobiological processes)
- Many relevant theoretical approaches (e.g., stress-coping, interpersonal relationships, helping behavior, altruism, emotion regulation)
- Multiple methods (e.g. descriptive studies, randomized trials, experiments)

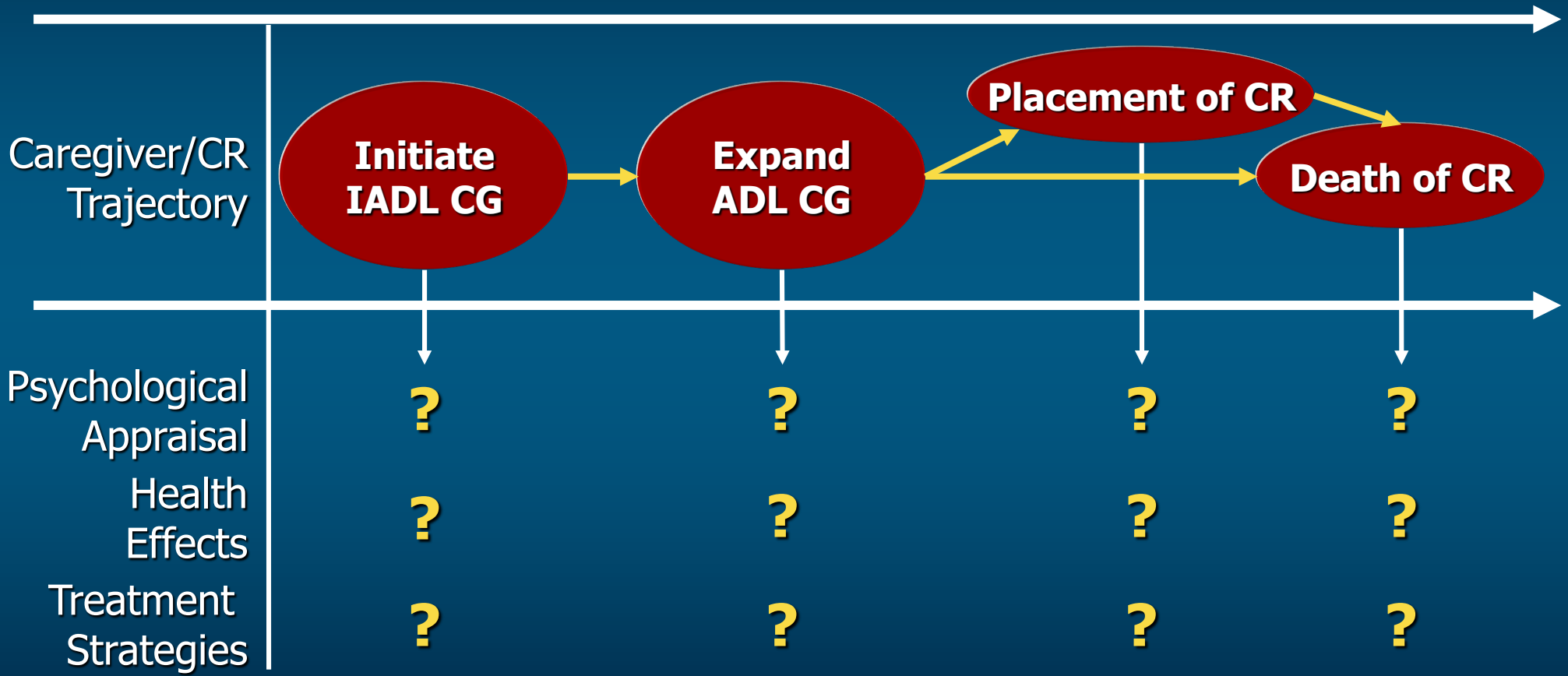
Caregiving as Chronic Stress Exposure

- Stressor is persistent, uncontrollable, unpredictable—requires high levels of vigilance
- Generates physical and psychological strain
- Generates secondary stress in multiple life domains

Causal Linkages Between Caregiving and Health

Unraveling health effects by studying the effects of moving into and out of the caregiving role

Caregiver (CG)/Care Recipient (CR) Trajectory and Health



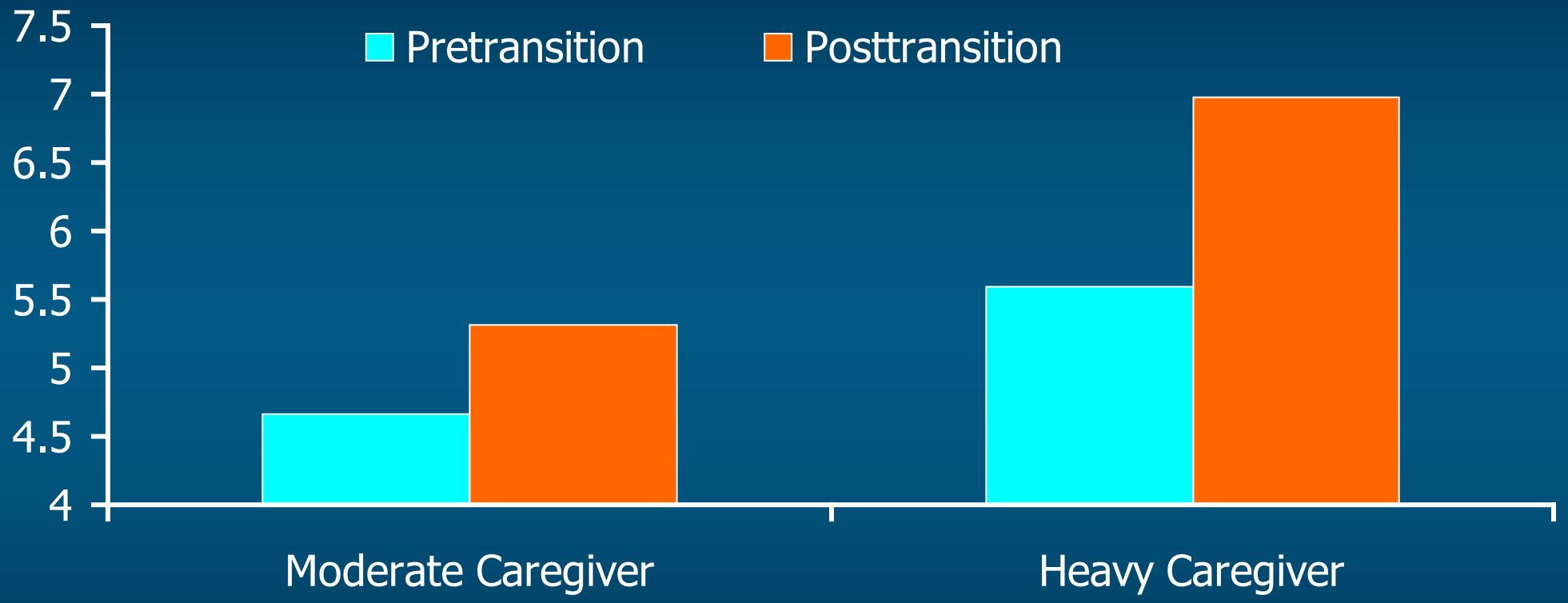
IADL=Instrumental Activities of Daily Living (cooking, cleaning, finances, etc.); ADL=Activities of Daily Living (bathing, dressing, eating, etc).

Caregiver Transitions

Longitudinal Health Effects: Transitions Into the Caregiving Role

How do increasing levels of caregiving stress affect health status of caregivers?

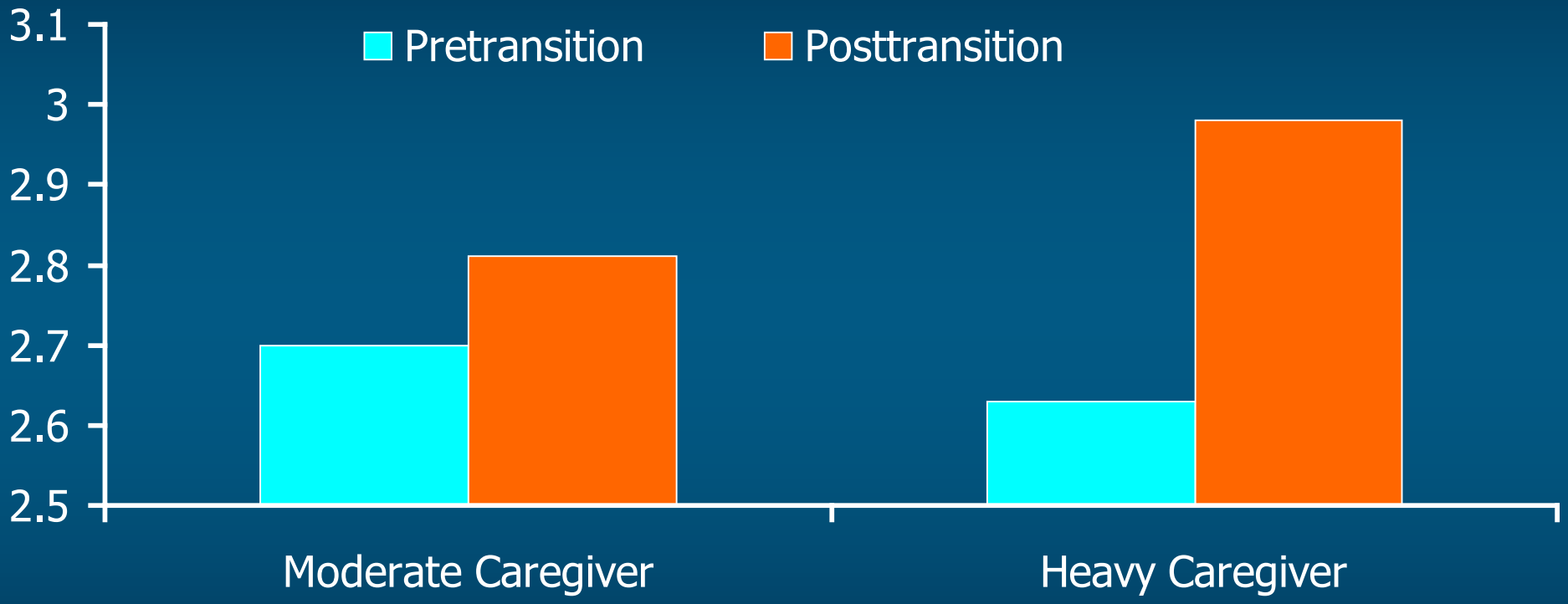
Depressive Symptoms Pre- and Post-transition, by Transition Group



Repeated measures ANCOVA statistics. Main test for transition group, F=4.06, *P*<.05. Main effects test for time, F=4.66, *P*<.05. Interaction of transition category and time not significant. Control variables: age, education, gender, self-reported health, race and income. Possible range of depressive symptoms 0-30. Higher scores indicate more symptoms of depression.

Burton et al., 2003, Gerontologist, 43:230-241.

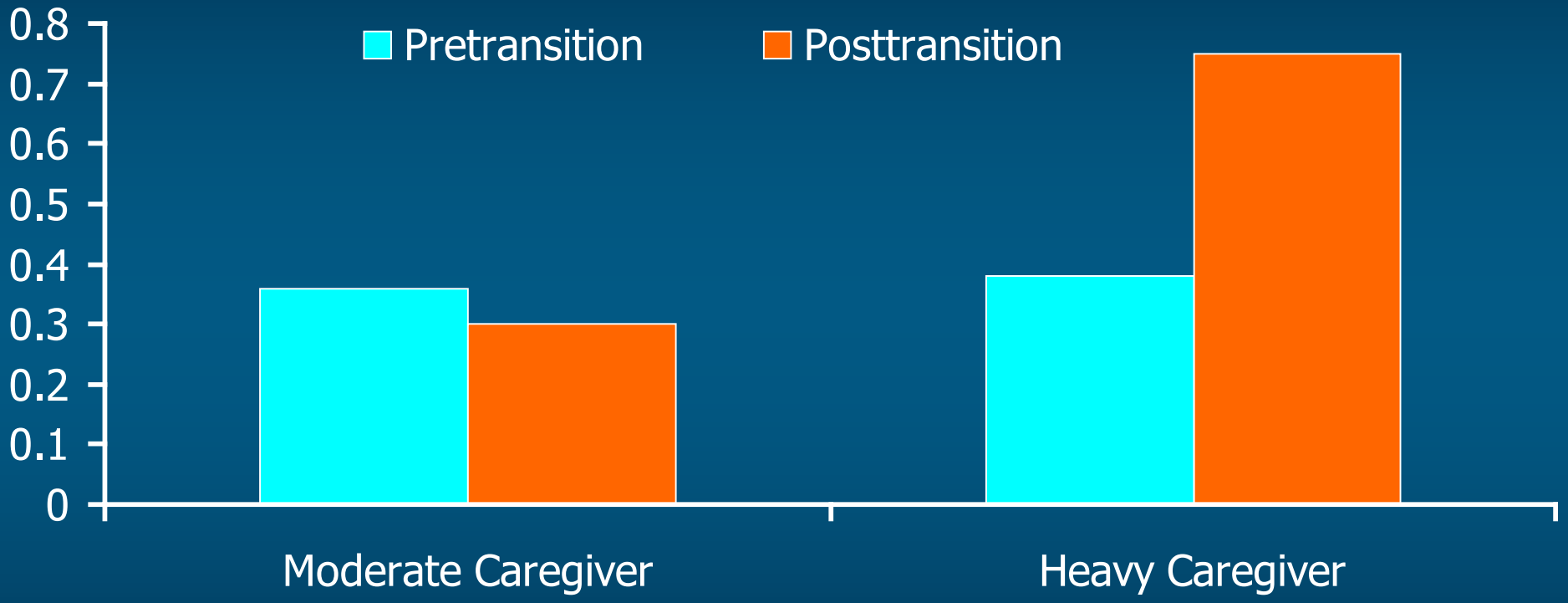
Self-Reported Poor Health Pre- and Post-transition, by Transition Group



Repeated measures ANCOVA statistics. Main effects test for transition group not significant. Main effects test for time not significant. Interaction of transition category and time marginally significant, F=3.59, *P*<.07. Control variables were age, education, gender, race and income. Possible range of self-reported health 0-5, with higher scores indicating poorer health.

Burton et al., 2003, Gerontologist, 43:230-241.

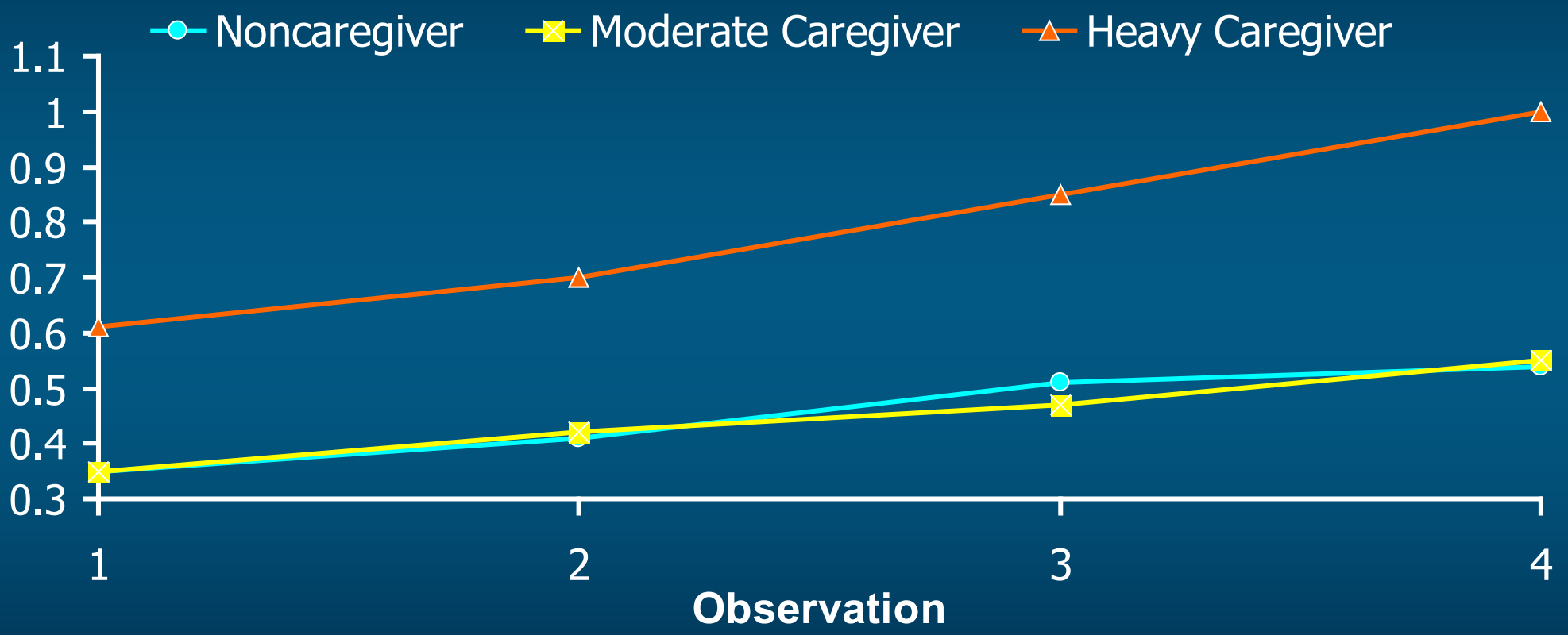
Health Risk Behaviors Pre- and Post-transition, by Transition Group



Repeated measures ANCOVA statistics. Main effects test for transition group, F=5.46, *P*<.05. Main effects test for time not significant. Interaction of transition category and time, F=11.23, *P*<.01. Control variables were age, education, gender, race, self-reported health, and income. Possible range of health risk behaviors was 0 to 6 with higher scores indicating more health risk behaviors.

Burton et al., 2003, Gerontologist, 43:230-241.

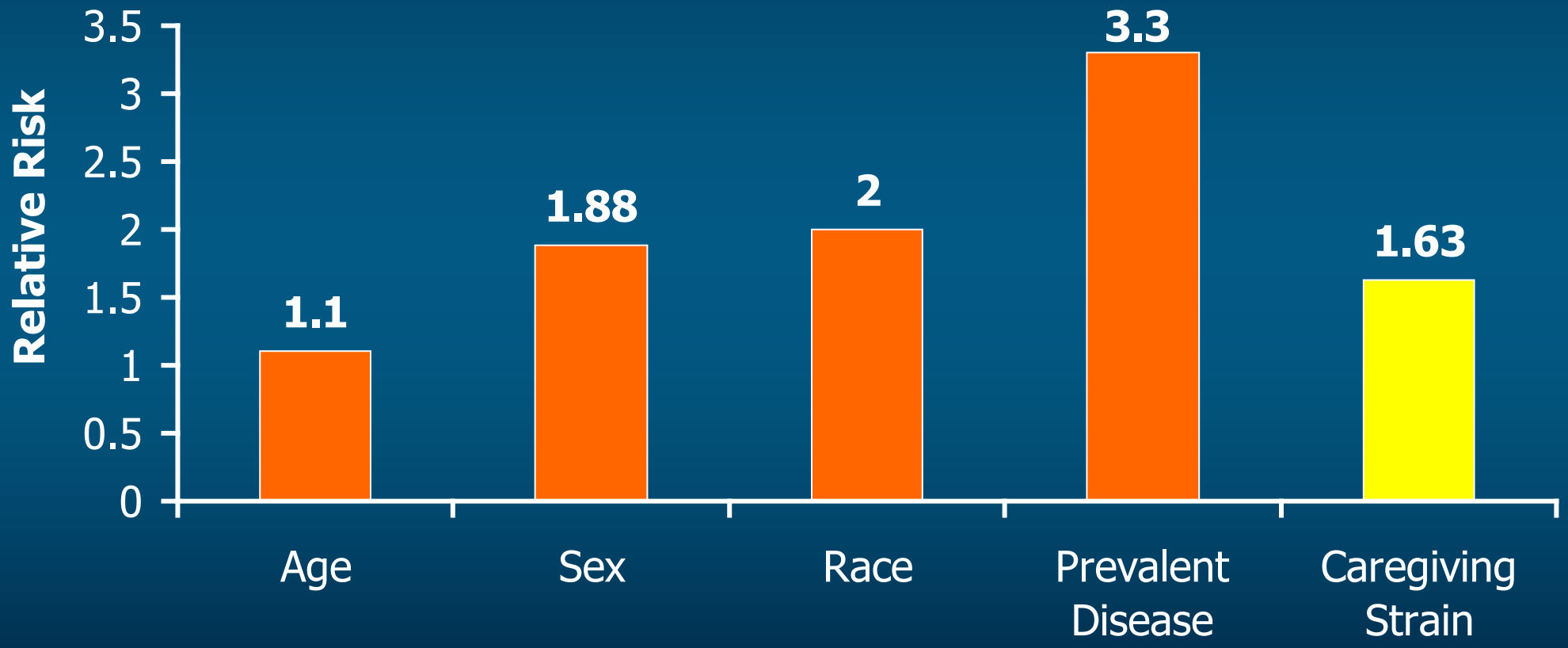
Prevalent Disease Count at 4 Observations, by Transition Group



Repeated measures ANCOVA statistics. Main effects test for transition group, F=5.37, *P*<.01. Main effects test for time not significant. Interaction of transition category and time, F=2.19, *P*<.05. Control variables were age, education, gender, and baseline prevalent disease count.

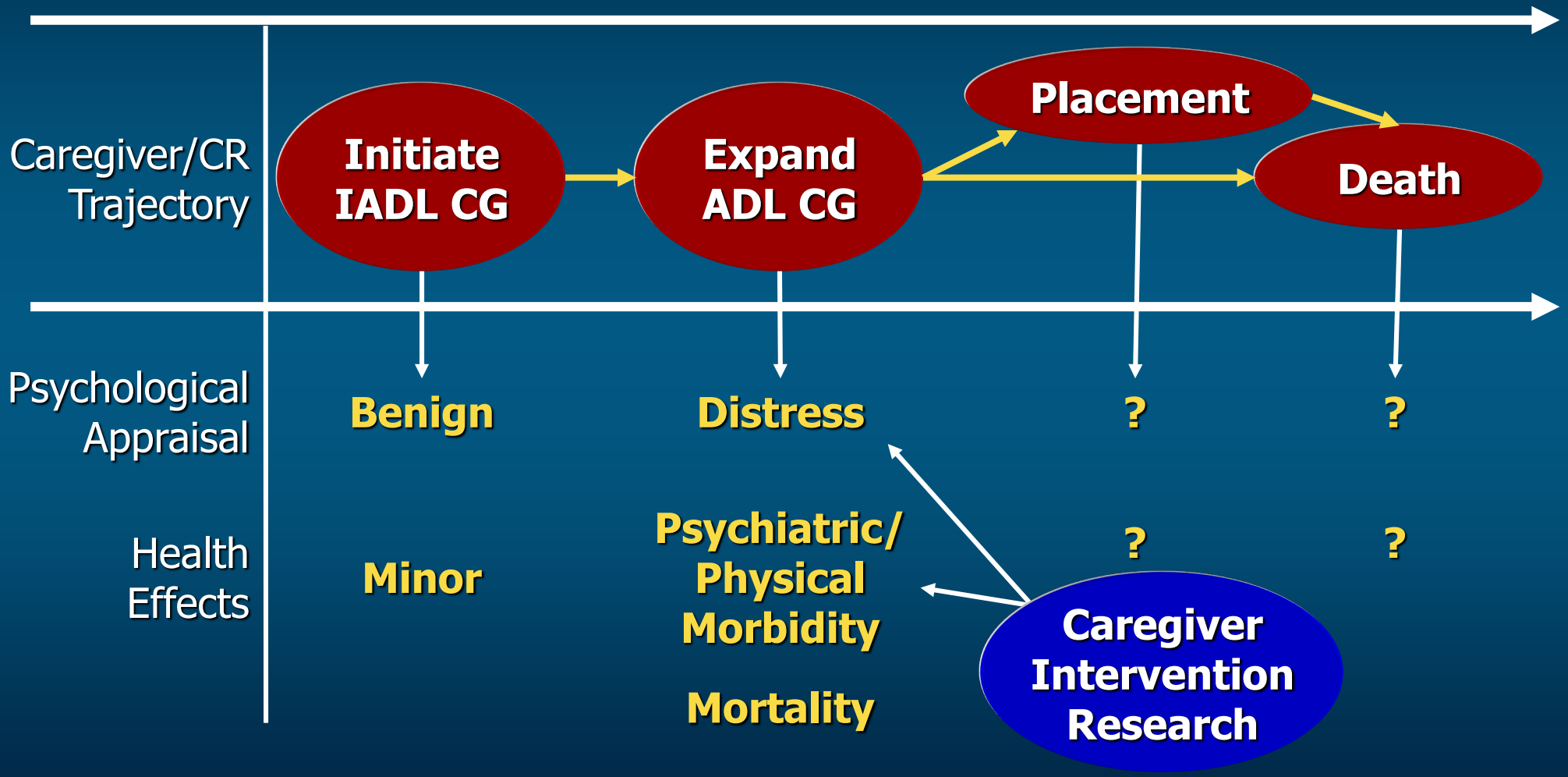
Burton et al., 2003, Gerontologist, 43:230-241.

Adjusted Relative Risk of Mortality: Significant Predictors (Complete Model)



Schulz et al., 1999, JAMA, 282:2215-2219.

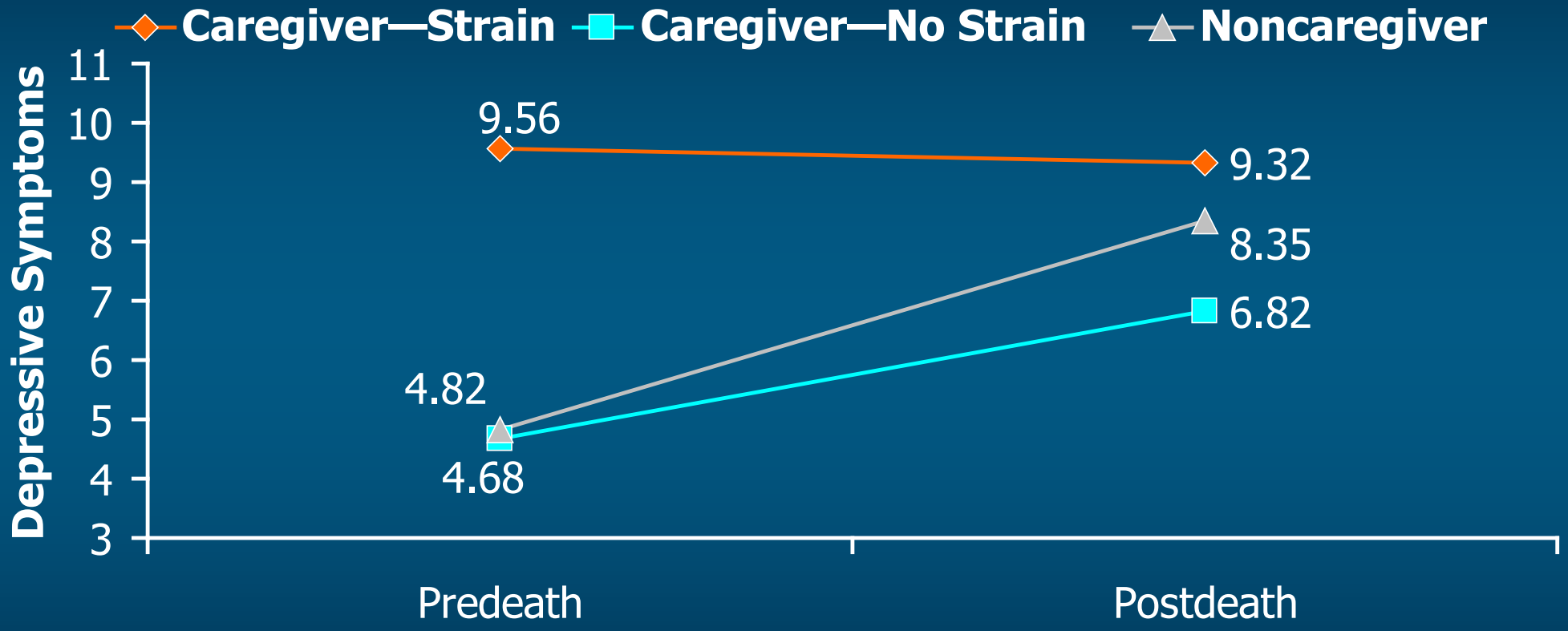
Chronic Stress Trajectory of Caregiver



Caregiver Exit Transitions

- **Death of care recipient—the bereavement transition**

Pre- and Post-death CES-D Depression Symptoms as a Function of Pre-death Caregiving Status (CHES)

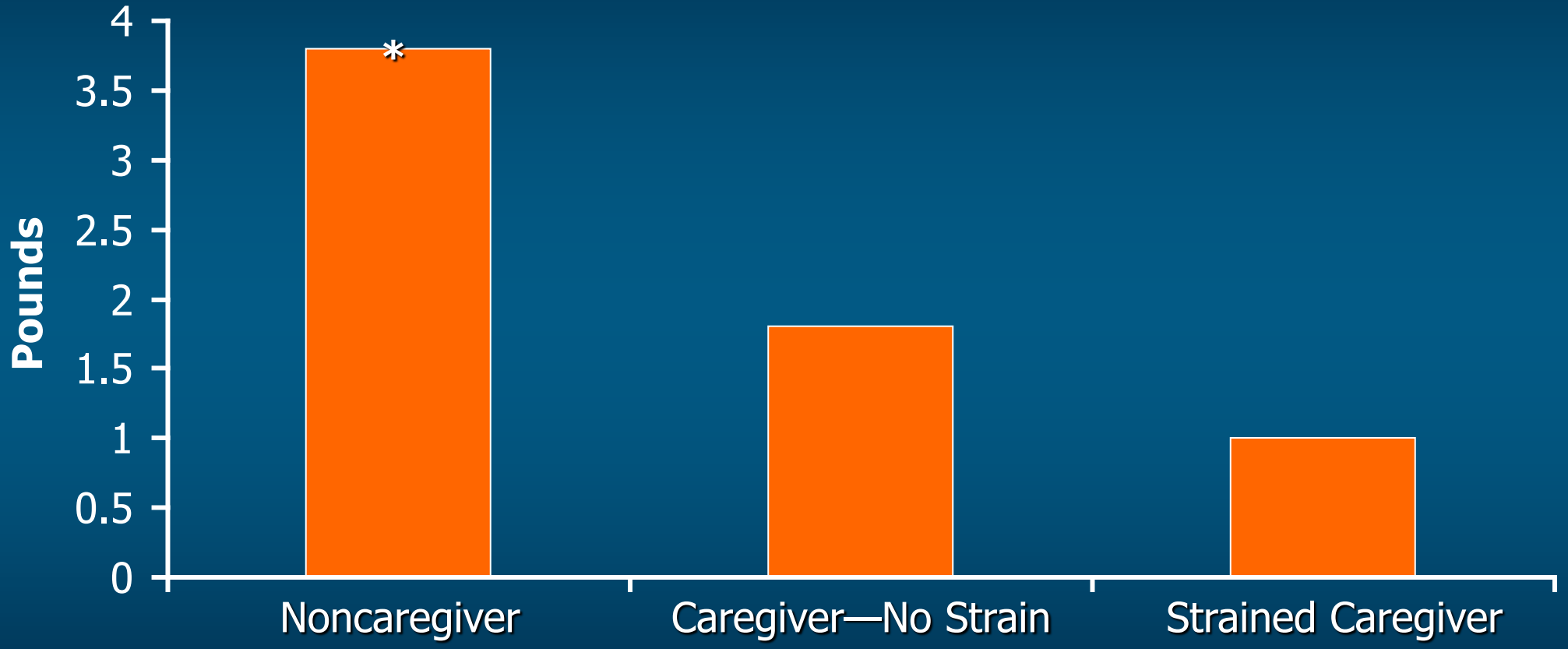


CESD=Center for Epidemiologic Studies-Depression.

Means adjusted for age, education, gender, race, time between pre-death interview and death, and time between post-death interview and death.

Schulz et al., 2001, JAMA, 285:3123-3129.

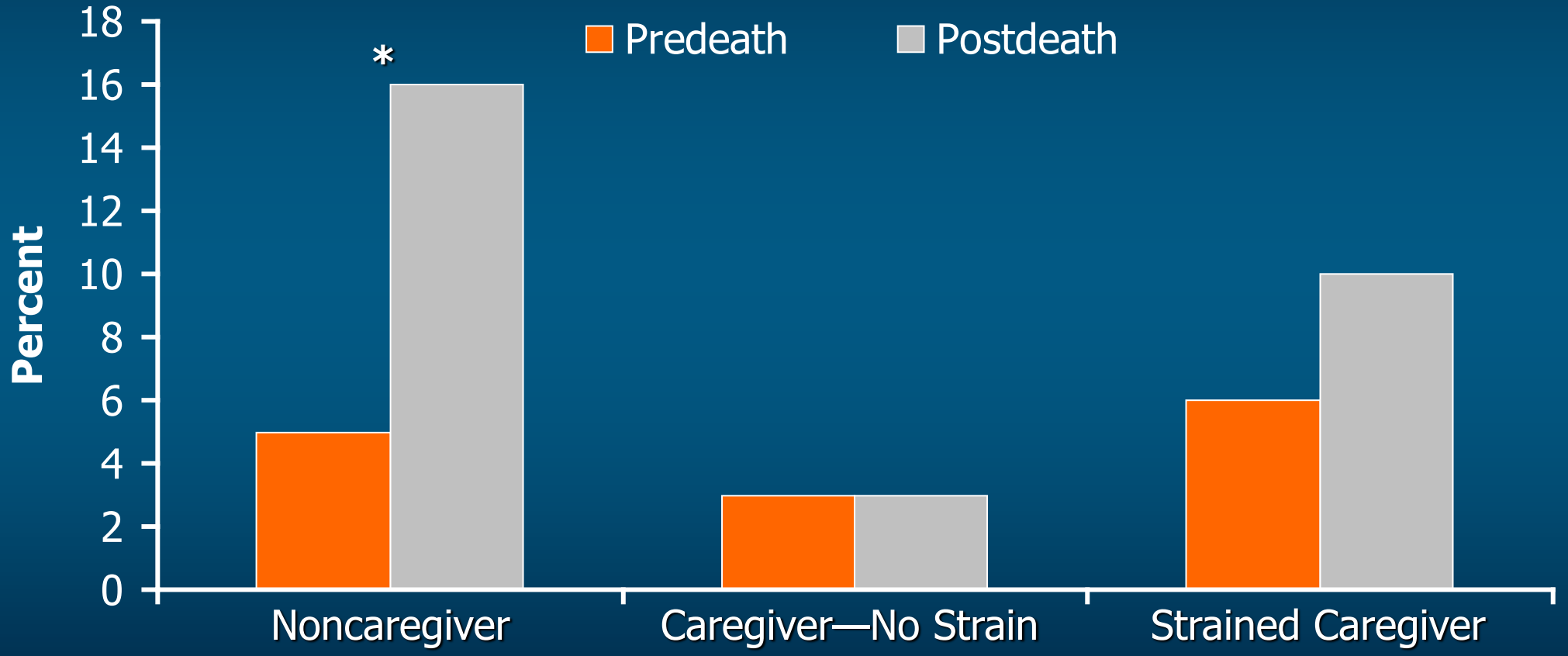
Mean Pre- to Post-bereavement Weight Loss in Pounds by Caregiving Status (Adjusted)



*$P<.05$.

Schulz et al., 2001, JAMA, 285:3123-3129.

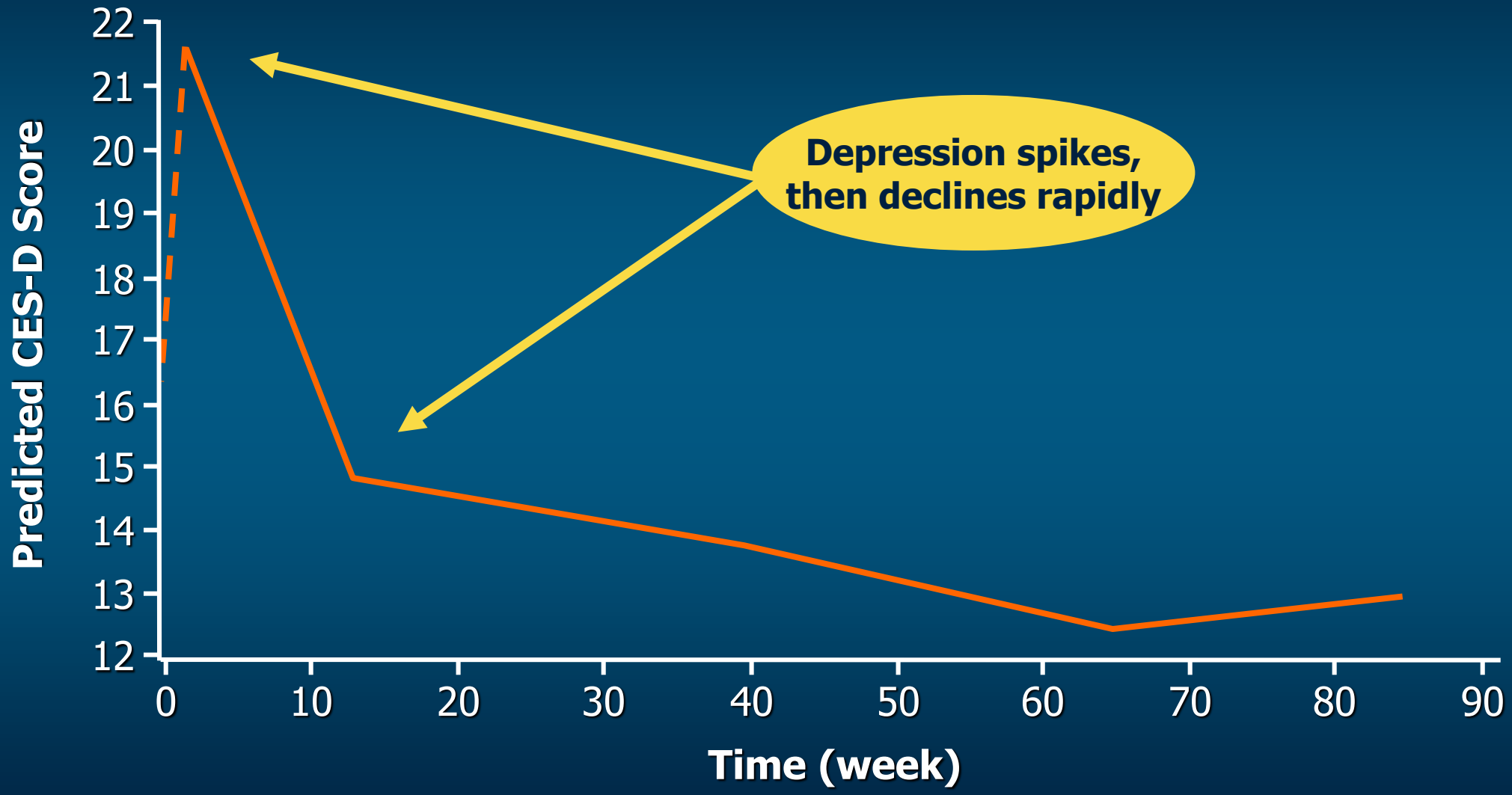
Percent Taking Antidepressant Medication Before and After Death of Spouse by Caregiver Status



*$P<.05$.

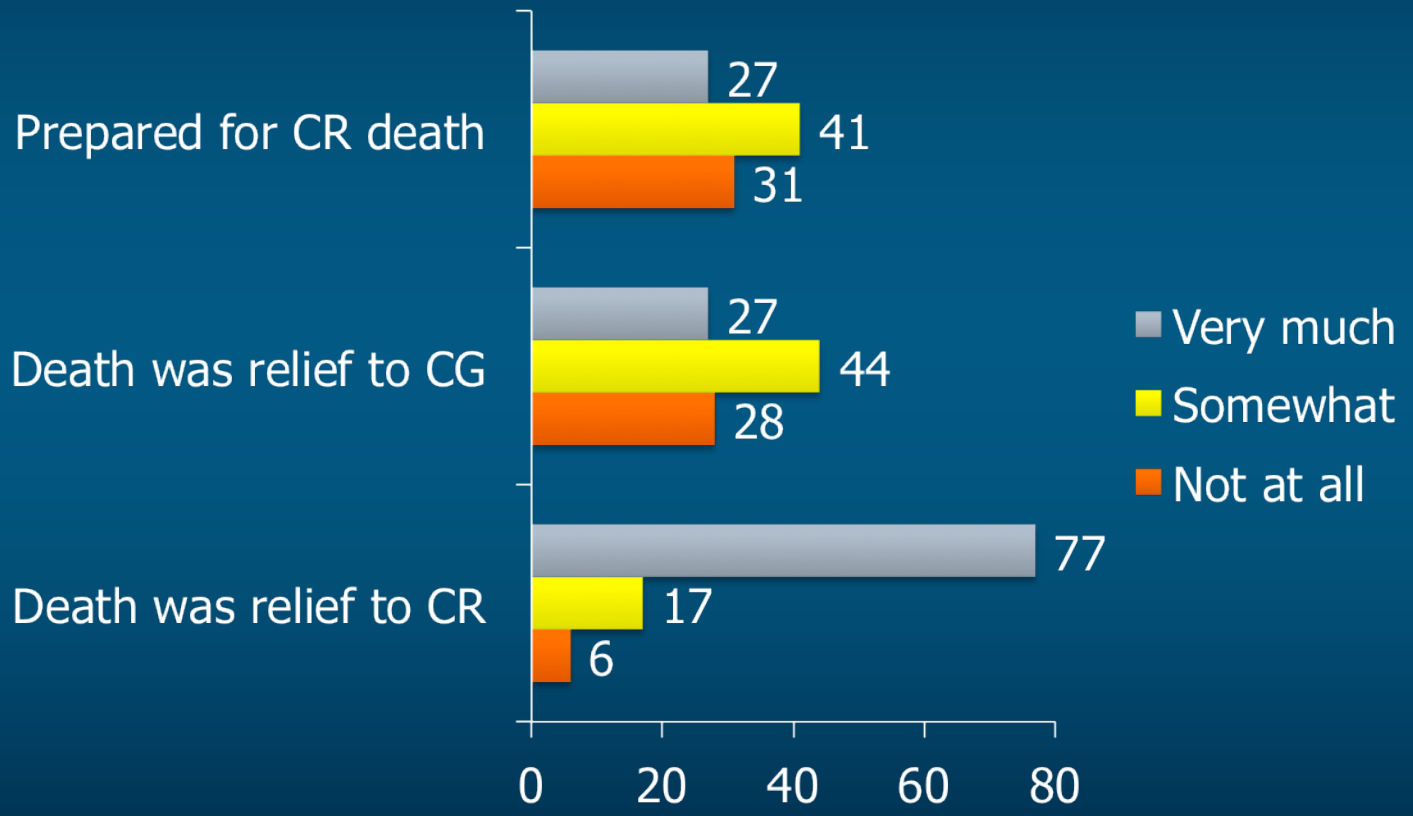
Schulz et al., 2001, JAMA, 285:3123-3129.

Piecewise Linear Function of CES-D Scores Post-bereavement



Schulz et al., 2003, NEJM, 249:1936-1942.

Caregiver Report of Relief after Death of Patient with AD (%)

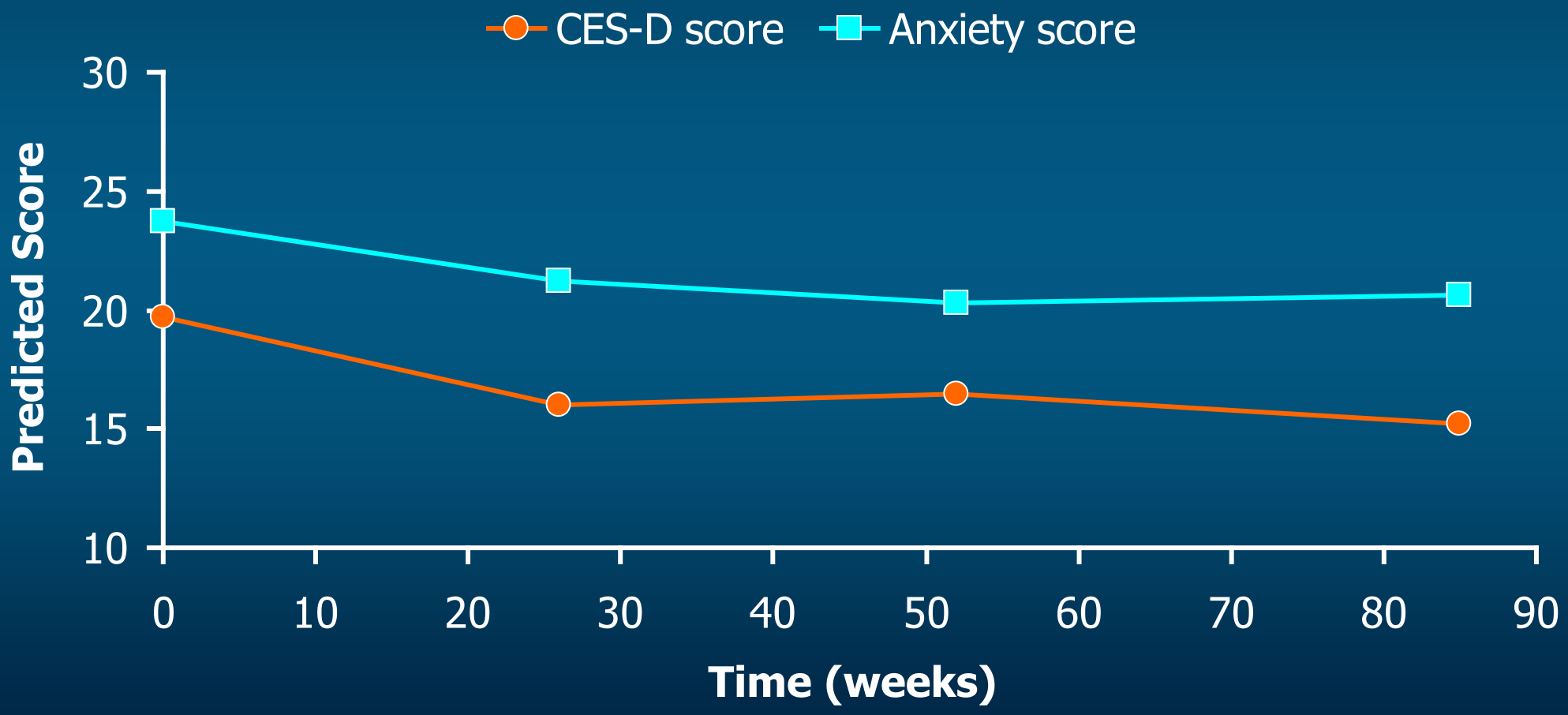


Source: Schulz et al. (2003), NEJM, 249;936-1942.

Caregiver Transitions: The Placement Transition

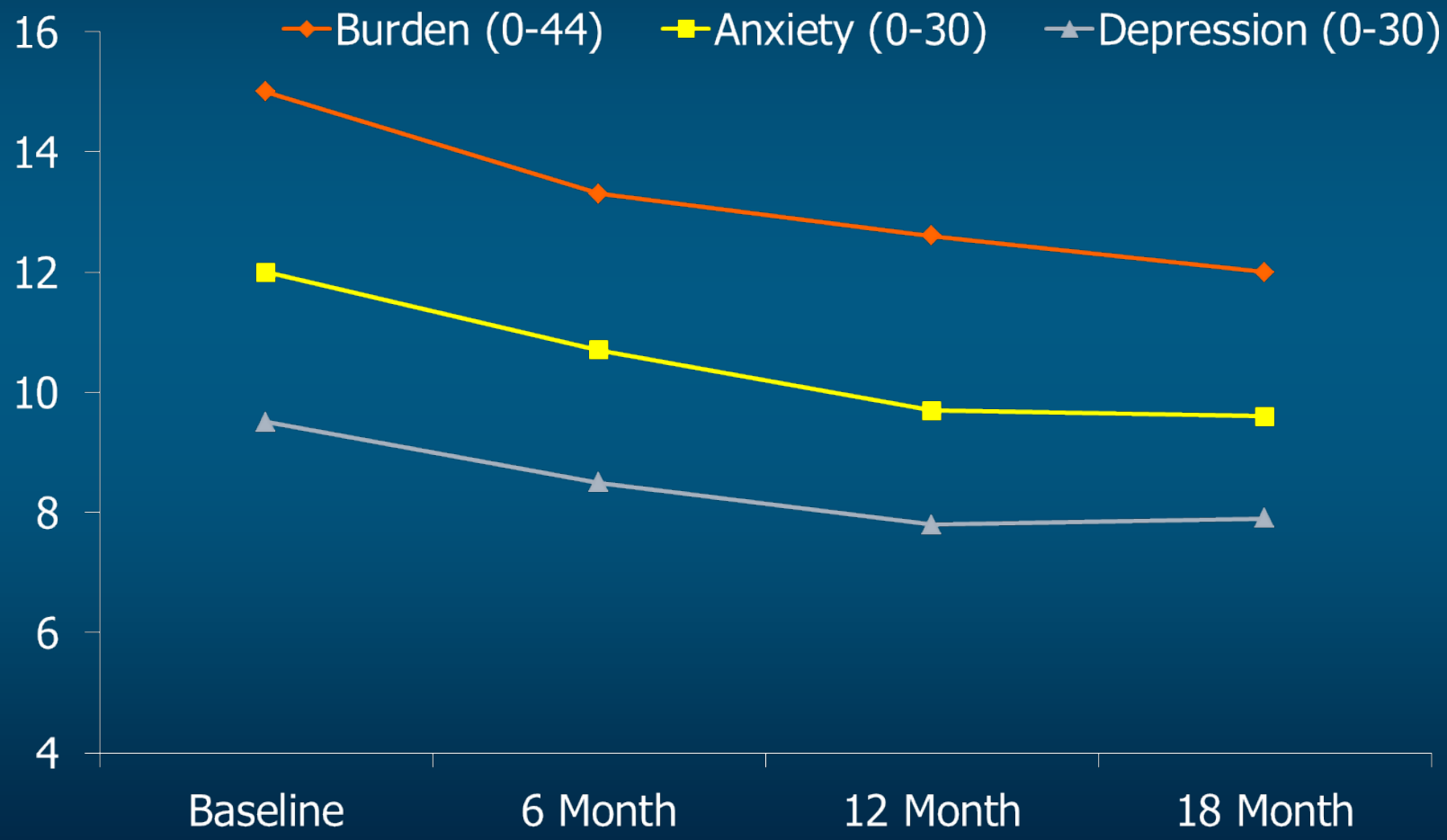
What happens to the caregiver when the care recipient is placed in a long-term care facility?

Post-placement CES-D Scores (Depression) and Anxiety Scores as a Function of Time Since Institutionalization (n=179)

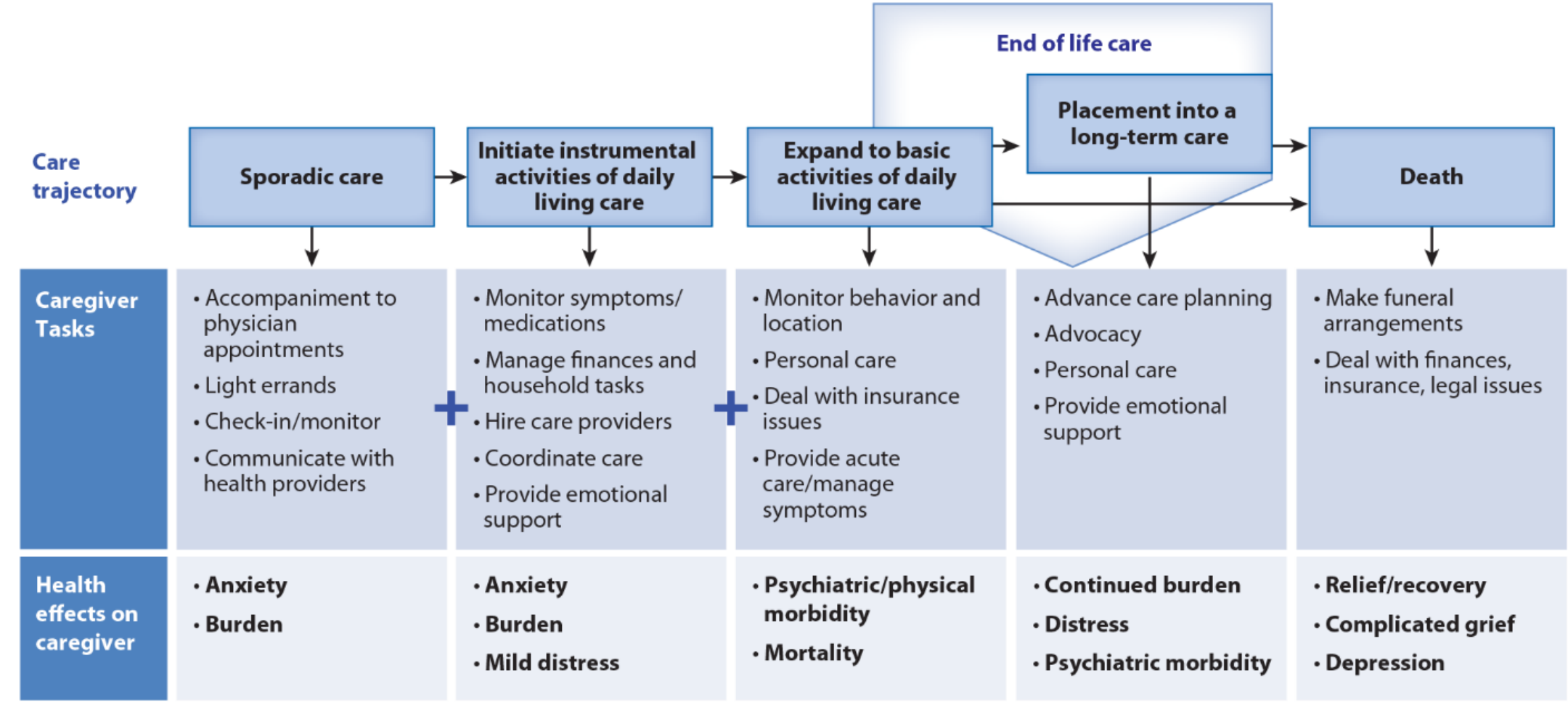


Schulz et al., 2004, JAMA, 292:961-968.

Burden, Anxiety and Depression Caregivers with CR in Nursing Home (n=212)



Care Trajectory, Tasks, and Health Effects



Schulz et al. (2020), Annual Review of Psychology

…so we understand some of the effects of caregiving

What can we do about it?

Reach

Resources For Enhancing Alzheimer's Caregiver Health

Cooperative agreement among NIH (NIA and NINR)

6 intervention sites:

- **Birmingham, AL**
- **Boston, MA**
- **Memphis, TN**
- **Miami, FL**
- **Palo Alto, CA**
- **Philadelphia, PA**

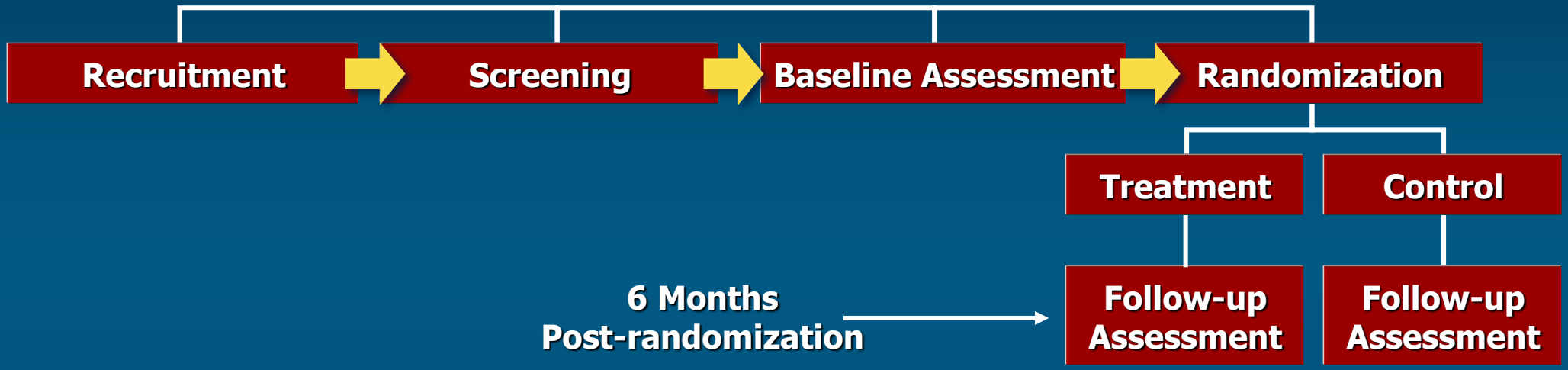
Coordinating Center

- **Pittsburgh, PA**

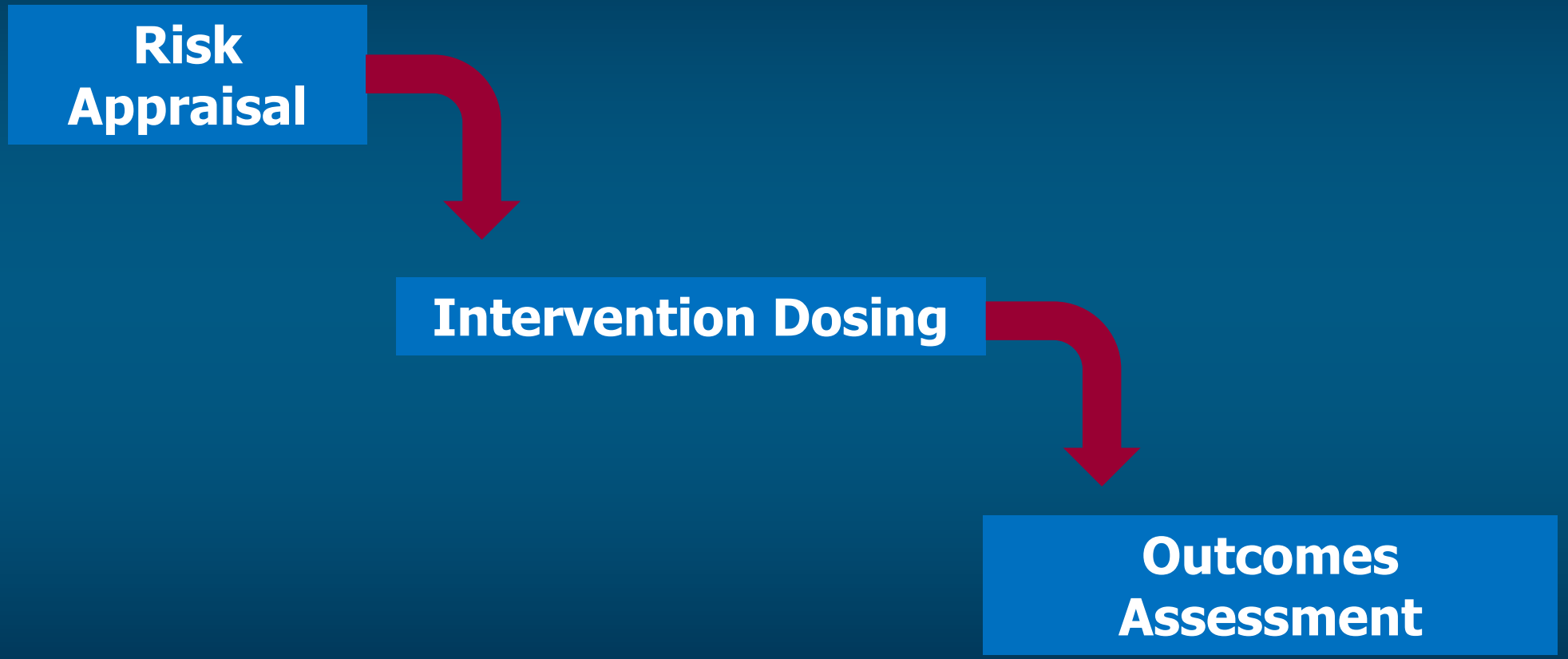
REACH II Design

- Randomized Clinical Trial—1 active treatment and 1 control condition implemented at all sites
- 5 sites (Birmingham, Memphis, Miami, Palo Alto, and Philadelphia)
- Recruit equal numbers of African Americans, Whites, and Hispanic Americans (N=600 total)

Study Design and Assessment Intervals



Intervention Strategy



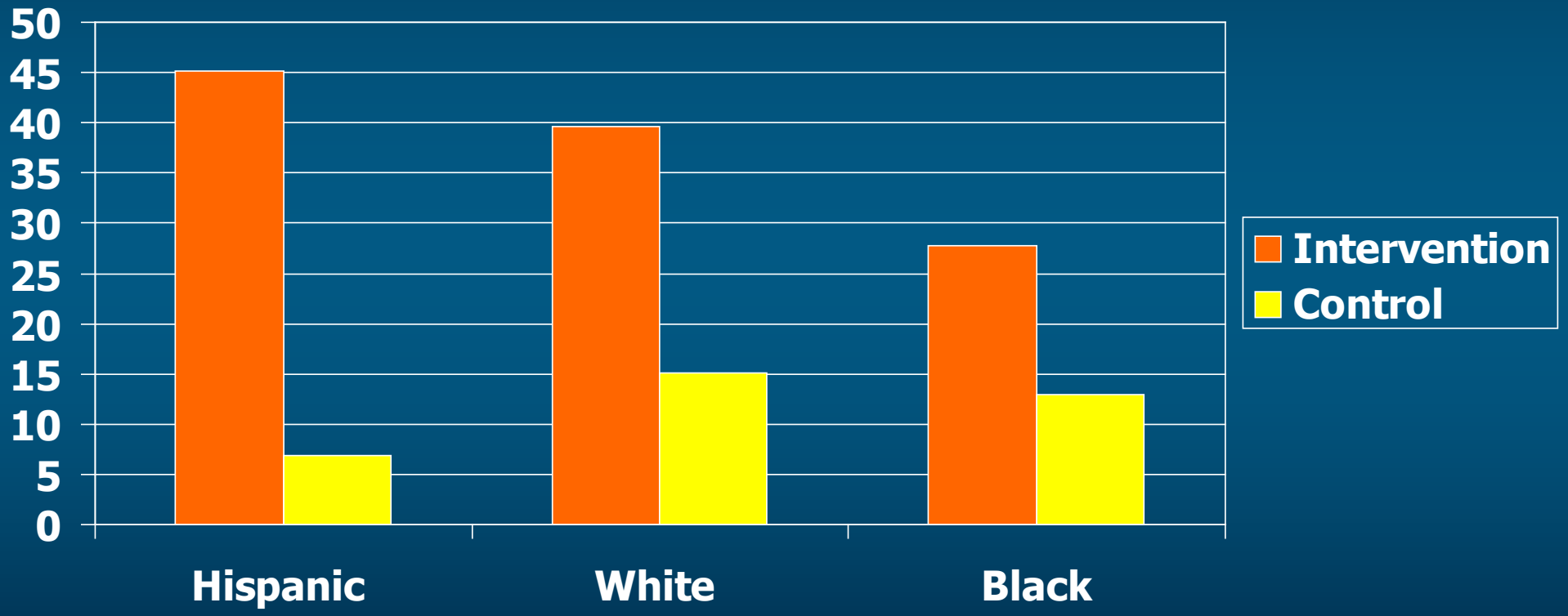
Risk Appraisal and Intervention

Intervention designed to address six areas:

- **Burden**
- **Problem behaviors**
- **Social support, social integration**
- **Self-care/physical health**
- **Emotional well-being**
- **Safety (Pt driving, access to weapons)***

*Treatment and Control Condition

Clinically Significant Net Improvement* Across All 5 Domains (depression, support, self-care, burden, pt. problem behaviors) by Treatment Group and Race/Ethnicity



*Net Improvement = Improved-Worsened

Reach Investigators, 2006, Annals of Internal Medicine, 145:727-738.

Editorial on REACH II Results (*Annals of Internal Medicine*)

"If these interventions were drugs, it is hard to believe that they would not be on the fast track to approval."

Covinsky & Johnston (Editorial), 2006, Annals of Internal Medicine, 145: 770-771.

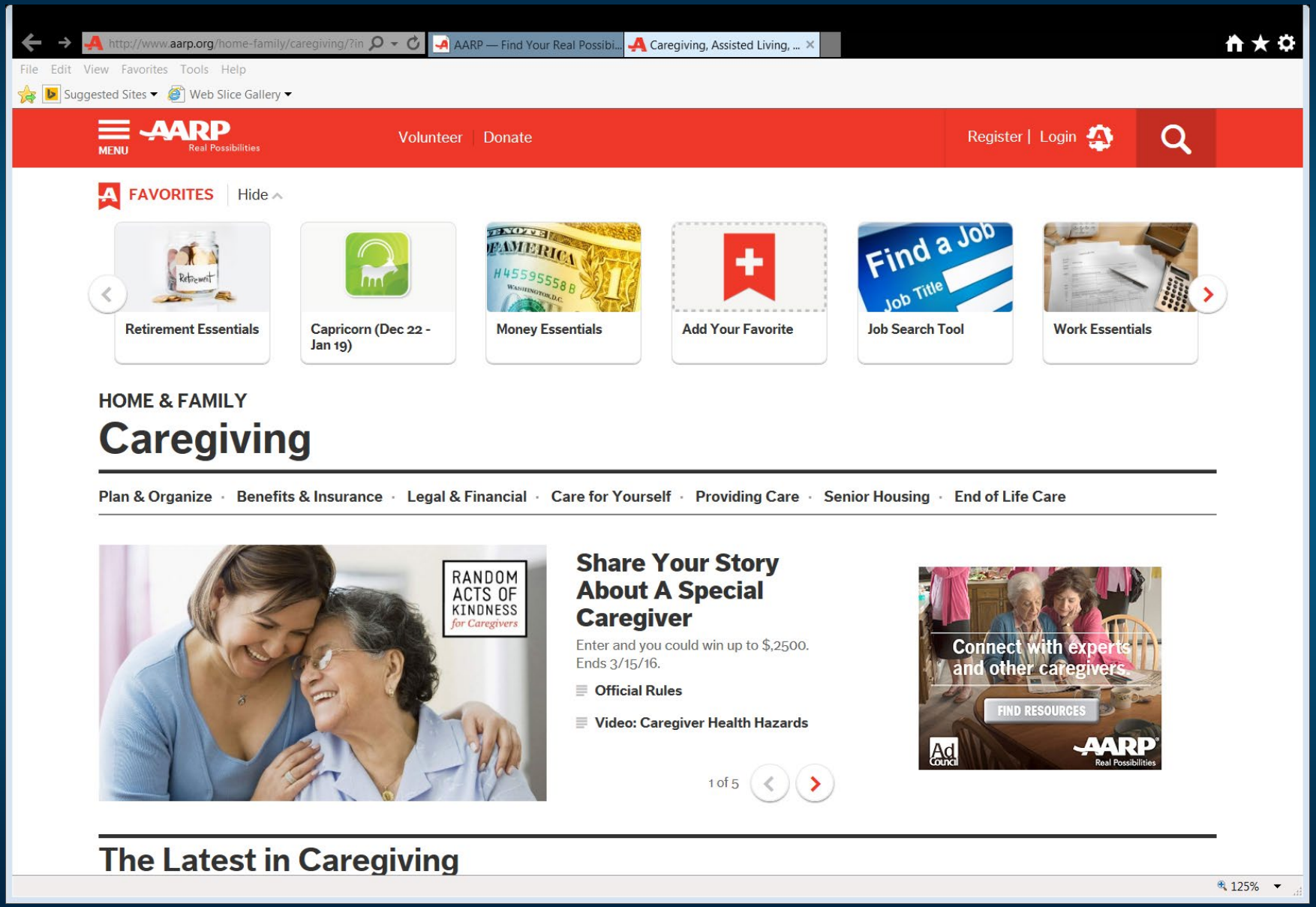
Extending REACH

- REACH VA—adaptation for veterans living at home
- Adopted in numerous states as part of Area Agencies on Aging (Aging Services programs)
- Replicated/applied in Hong Kong, Korea, Germany, adapted for mainland China
- Adopted by Indian Health Service

Translating Research into Policy

- Advocacy—late 90s
- Legitimization—mid 2000s
- Legislation—2012 on

Advocacy


http://www.aarp.org/home-family/caregiving/?in
AARP — Find Your Real Possibi...
Caregiving, Assisted Living, ...
File Edit View Favorites Tools Help
Suggested Sites
Web Slice Gallery
MENU
AARP
Real Possibilities
Volunteer
Donate
Register | Login
FAVORITES
Hide
Retirement Essentials
Capricorn (Dec 22 - Jan 19)
Money Essentials
Add Your Favorite
Job Search Tool
Work Essentials
HOME & FAMILY
Caregiving
Plan & Organize · Benefits & Insurance · Legal & Financial · Care for Yourself · Providing Care · Senior Housing · End of Life Care
RANDOM ACTS OF KINDNESS for Caregivers
Share Your Story About A Special Caregiver
Enter and you could win up to $,2500.
Ends 3/15/16.
Official Rules
Video: Caregiver Health Hazards
1 of 5
Connect with experts and other caregivers
FIND RESOURCES
Ad Council
AARP
Real Possibilities
The Latest in Caregiving
125%

http://www.alz.org/care/overview.asp

AARP — Find Your Real Possibi... | Dementia & Alzheimer's Ca...

File Edit View Favorites Tools Help

Suggested Sites | Web Slice Gallery

alz.org | National Office

alz.org® | alzheimer's association

Submit

About Us | eNewsletter | Message Boards | Action Center | Advocate | Walk to End Alzheimer's | Shop | Donate

Alzheimer's and Dementia Caregiver Center

24/7 Helpline: 1.800.272.3900

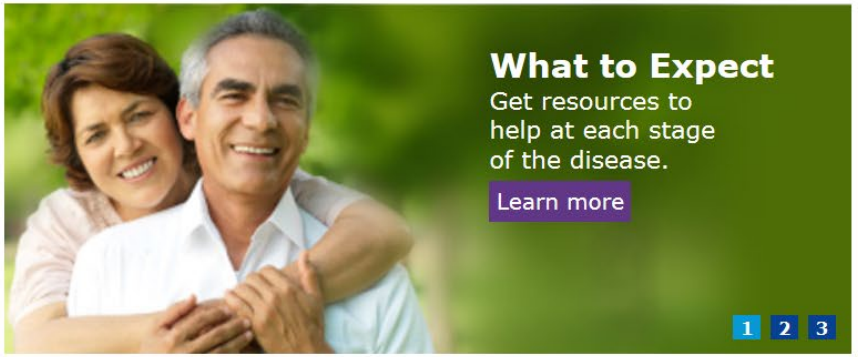
Caregiver Home | Daily Care | Stages & Behaviors | Get Support | Safety | Care Options | Financial & Legal Planning

Chapter Home » Caregiver Center » Dementia Care & Support

Text size: A A A

Caregivers for Alzheimer's and Dementia Face Special Challenges

You are not alone. Whether you need information about early-stage caregiving, middle-stage caregiving, or late-stage caregiving, the Alzheimer's Association is here to help.



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Get day-to-day help

- Behaviors
- Communication

Get support

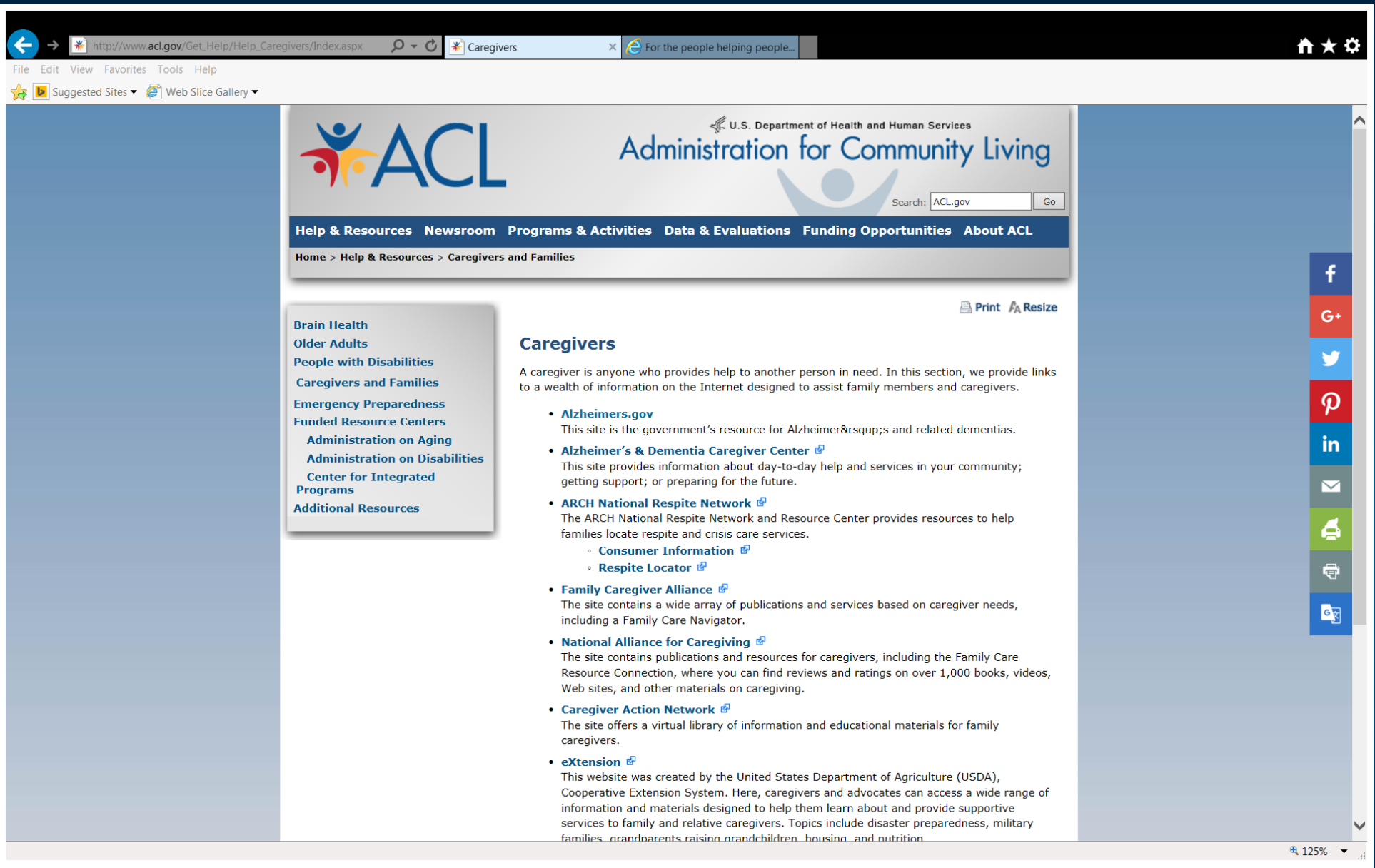
- Your local chapter
- Message boards

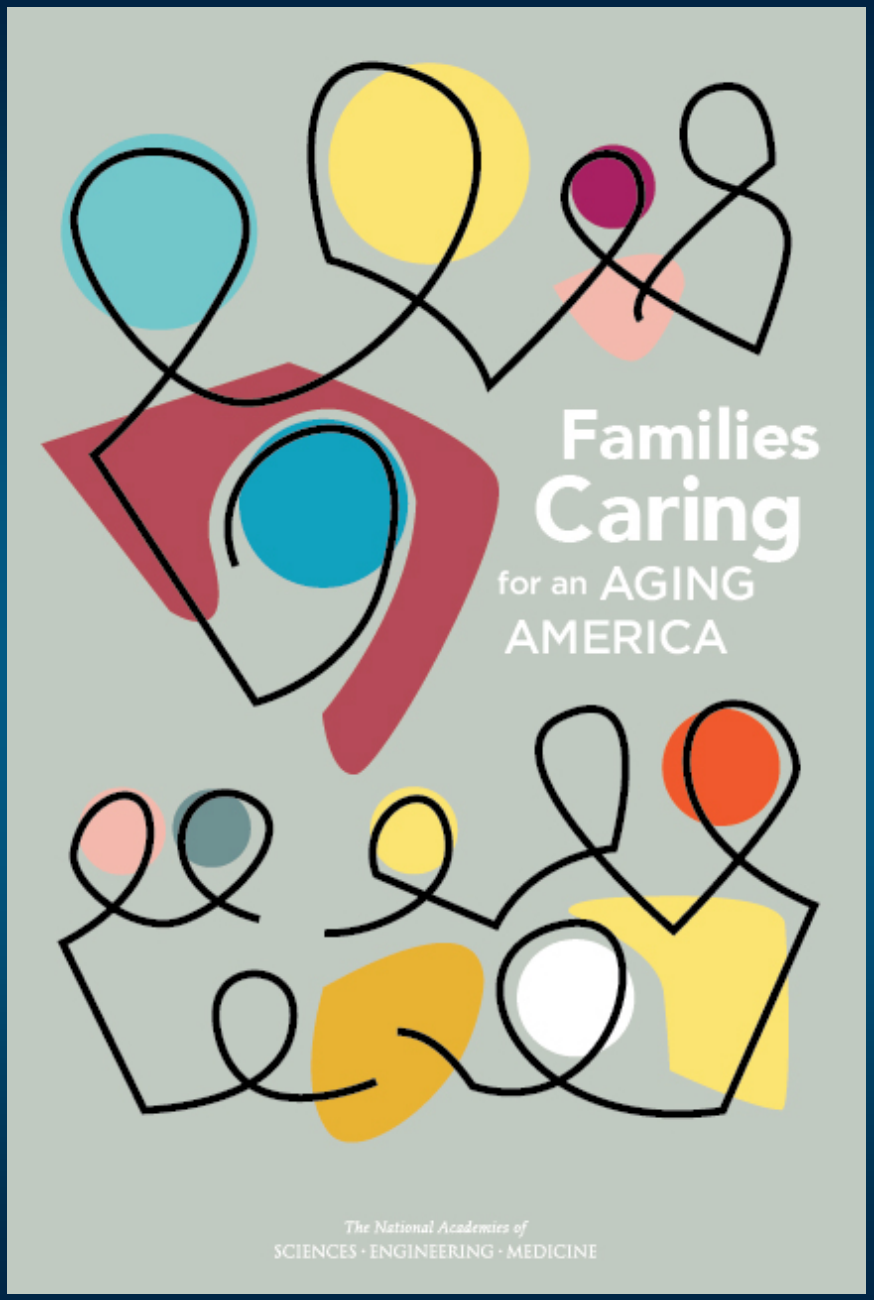
Plan for the future

- Legal matters
- Care options

125%

Legitimization


http://www.acl.gov/Get_Help/Help_Caregivers/Index.aspx
Caregivers
For the people helping people...
File Edit View Favorites Tools Help
Suggested Sites
Web Slice Gallery
U.S. Department of Health and Human Services
Administration for Community Living
Search: ACL.gov Go
Help & Resources Newsroom Programs & Activities Data & Evaluations Funding Opportunities About ACL
Home > Help & Resources > Caregivers and Families
Print Resize
Brain Health
Older Adults
People with Disabilities
Caregivers and Families
Emergency Preparedness
Funded Resource Centers
Administration on Aging
Administration on Disabilities
Center for Integrated Programs
Additional Resources
Caregivers
A caregiver is anyone who provides help to another person in need. In this section, we provide links to a wealth of information on the Internet designed to assist family members and caregivers.
Alzheimers.gov
This site is the government's resource for Alzheimer&rsqup;s and related dementias.
Alzheimer's & Dementia Caregiver Center
This site provides information about day-to-day help and services in your community; getting support; or preparing for the future.
ARCH National Respite Network
The ARCH National Respite Network and Resource Center provides resources to help families locate respite and crisis care services.
Consumer Information
Respite Locator
Family Caregiver Alliance
The site contains a wide array of publications and services based on caregiver needs, including a Family Care Navigator.
National Alliance for Caregiving
The site contains publications and resources for caregivers, including the Family Care Resource Connection, where you can find reviews and ratings on over 1,000 books, videos, Web sites, and other materials on caregiving.
Caregiver Action Network
The site offers a virtual library of information and educational materials for family caregivers.
eXtension
This website was created by the United States Department of Agriculture (USDA), Cooperative Extension System. Here, caregivers and advocates can access a wide range of information and materials designed to help them learn about and provide supportive services to family and relative caregivers. Topics include disaster preparedness, military families, grandparents raising grandchildren, housing, and nutrition
125%



Download the report for free at:

www.nationalacademies.org/caregiving

Legislative Initiatives

- RAISE (Recognize, Assist, Include, Support, and Engage) Family Caregivers Act
- Credit for Caring Act—tax credit up to $3000 for financially helping relative
- Caregiver Advise, Record, Enable (CARE) Act —discharge planning, Adopted in 30 states

Future Directions

① Assess prevalence and impact of caregiving

② Not all caregivers need help

③ Shift from efficacy to implementation/ pragmatic trials

④ Change health care and support systems to incorporate caregiver

⑤ Monetize the effects of caregiving

⑥ Embrace technology

⑦ Educate and prepare all adults for caregiving

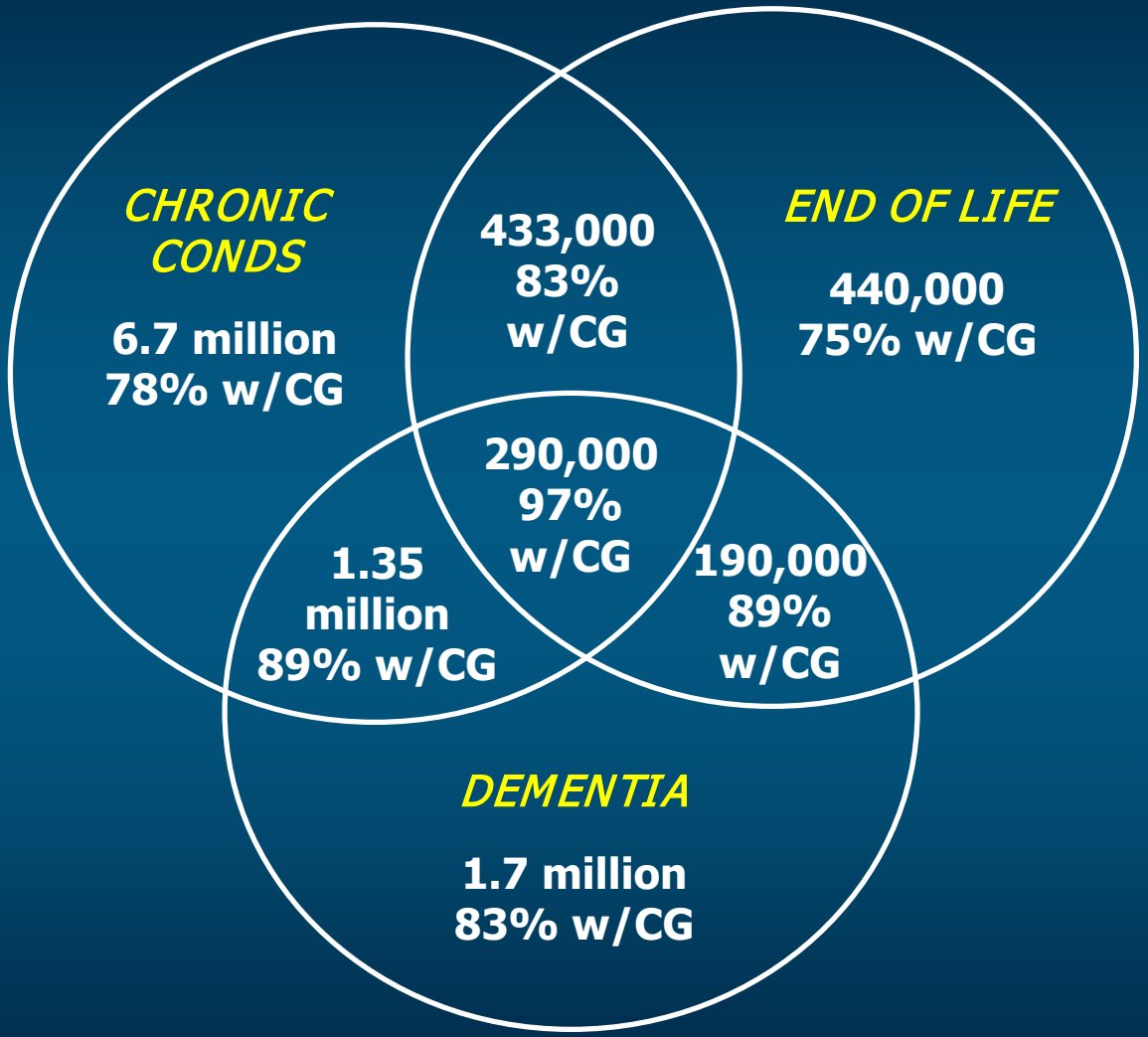
1. Assess the Prevalence and Impact of Caregiving

- Adopt consensus definition in population surveys of prevalence
- Assess population level effects on time use, finances, employment, social isolation, lifestyle changes, and health
- Assess caregiving over the life-course

2. Not All Caregivers Need Help—Identify High Risk Caregivers/Patients

- Many caregivers do fine, particularly in early stages of caregiving career
- Allocation of limited resources to highest need at risk caregivers
- Well established risk profiles available

High Need/High Cost Patients and Their Caregivers



CHRONIC CONDS = **at least 3 chronic conditions and 1ADL/IADL limitation; dementia excluded as chronic condition**

END OF LIFE = **died within 1 year of baseline assessment**

DEMENTIA = **diagnosis of probable dementia**

NONE OF THE ABOVE
24.1 million, 67% w/CG

Source: National Health and Aging Trends Study (NHATS, 2011, N=7609); non-institutionalized U.S. older adults aged 65 and over, 35.3 million, weighted population estimates. *Schulz et al., (2018) J Pal Med*

High Need/High Cost Patient Caregiver Impacts*

- More hours of care (1/3 report >100 hours per month)
- Provide help with more types of tasks
- Increased caregiver psychological and physical morbidity
- Increased financial strain (e.g., out-of-pocket expenditures, labor force participation)
- More unmet needs

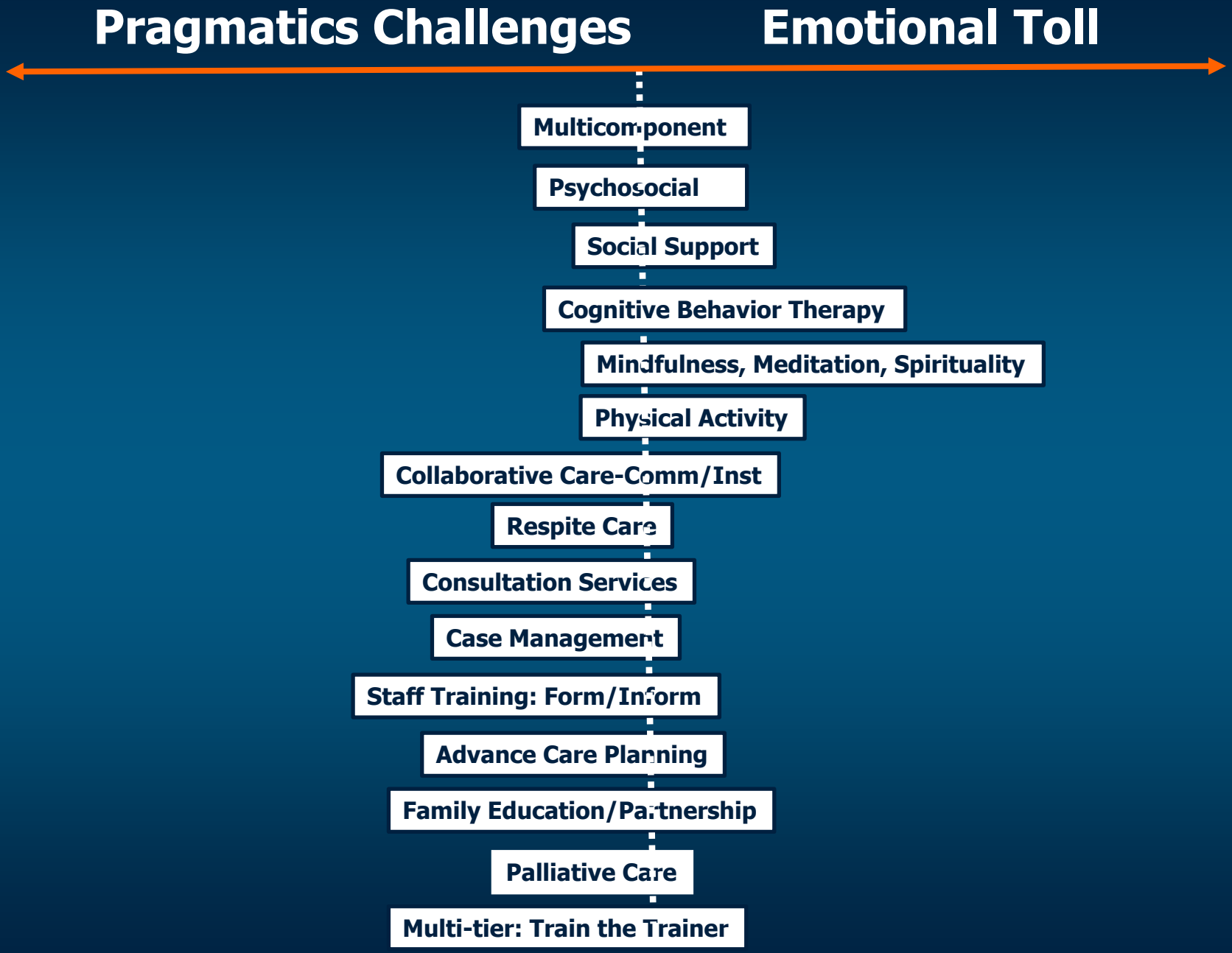
*Compared to caregivers of low need patients; Schulz et al., *J. of Palliative Medicine*, 2018

3. Shift from Efficacy to Implementation Research

- Vast published intervention literature
- More than 50 systematic reviews/ meta-analysis since 2000
- 5 systematic reviews of systematic reviews

Successful Interventions

- **Address pragmatics of providing care**
  - Knowledge about illness, symptoms and progression, available support service
  - Skills to address needs of care recipient, assisting with functional disabilities, managing behaviors, accessing professional services
- **Coping with emotional toll of caregiving—**
  - Living with, watching loved one suffer and decline, with little or no ability to mitigate conditions
  - Meditative strategies and cognitive behavior therapies


Pragmatics Challenges
Emotional Toll
Multicomponent
Psychosocial
Social Support
Cognitive Behavior Therapy
Mindfulness, Meditation, Spirituality
Physical Activity
Collaborative Care-Comm/Inst
Respite Care
Consultation Services
Case Management
Staff Training: Form/Inform
Advance Care Planning
Family Education/Partnership
Palliative Care
Multi-tier: Train the Trainer

Efficacy Research—A Litany of Woes

- **Small to moderate effect sizes for some outcomes**
- **Risk of bias in published RCTs is moderate to high**
  - Sequence generation and allocation concealment not described
  - Outcome assessors not blinded (interventionist is assessor)
  - Methods for dealing with missing data not reported
  - Selective (opportunistic) outcome reporting
  - Small sample size, poor quality control in treatment implementation and data collection, limited follow-up
- **Increasingly fragmented treatment approaches Care** *AHRQ (2020): Interventions for People Living With Dementia and Their Caregivers*

4. Formally integrate caregivers into Health Care and Support Systems

- **Consensus core outcomes**
  - Meaningful improvement of adverse symptoms
  - Maintain/improve quality of life
  - Societal significance—service utilization, cost
- **Develop context and disease assessment tools tailored to disease and treatment trajectory**
- **Train and certify health care providers**

5. Monetize the Economic Costs/Benefits of Caregiving

- **Caregivers replace or delay formal care**
- **Recent review* of 45 studies - 3 studies stand out**
  - Van Houtven & Norton, 2008: decreased Medicare costs
  - Torbica et al., 2015: increased healthcare costs after stroke
  - Coe et al., 2016: small (not statistically significant) reduced health care utilization

*Friedman et al. (2019), *Gerontologist.*

The Ideal Monetizing Study

- Longitudinal study of representative subset of population with and without caregiver
- Capture people before they become ill
- Track work related impacts on caregiver
- Assess healthcare utilization for both care recipient and caregiver—both during and after care
- Track out-of-pocket expenditures for caregiver and care recipient

6. Embrace Technology to Support Caregivers

- Computers, smart phones, and web-based clinical care tools
- Symptom monitoring
- Advice and coaching
- Accessing services
- Barriers: digital divides, usability issues, reliability, trust

7. Educate and Prepare all Adults for Caregiving

- **Implement population based preventive strategies?**
- **Population level training on**
  - Likelihood of becoming caregiver/care recipient
  - Planning for support needs
  - Roles and responsibilities of caregiving
  - Rudimentary caregiving skills