

Interventions to Ease Burden and Stress of Caregiving (The Reach II Project)

Alan B. Stevens, PhD

Professor, Department of Medicine

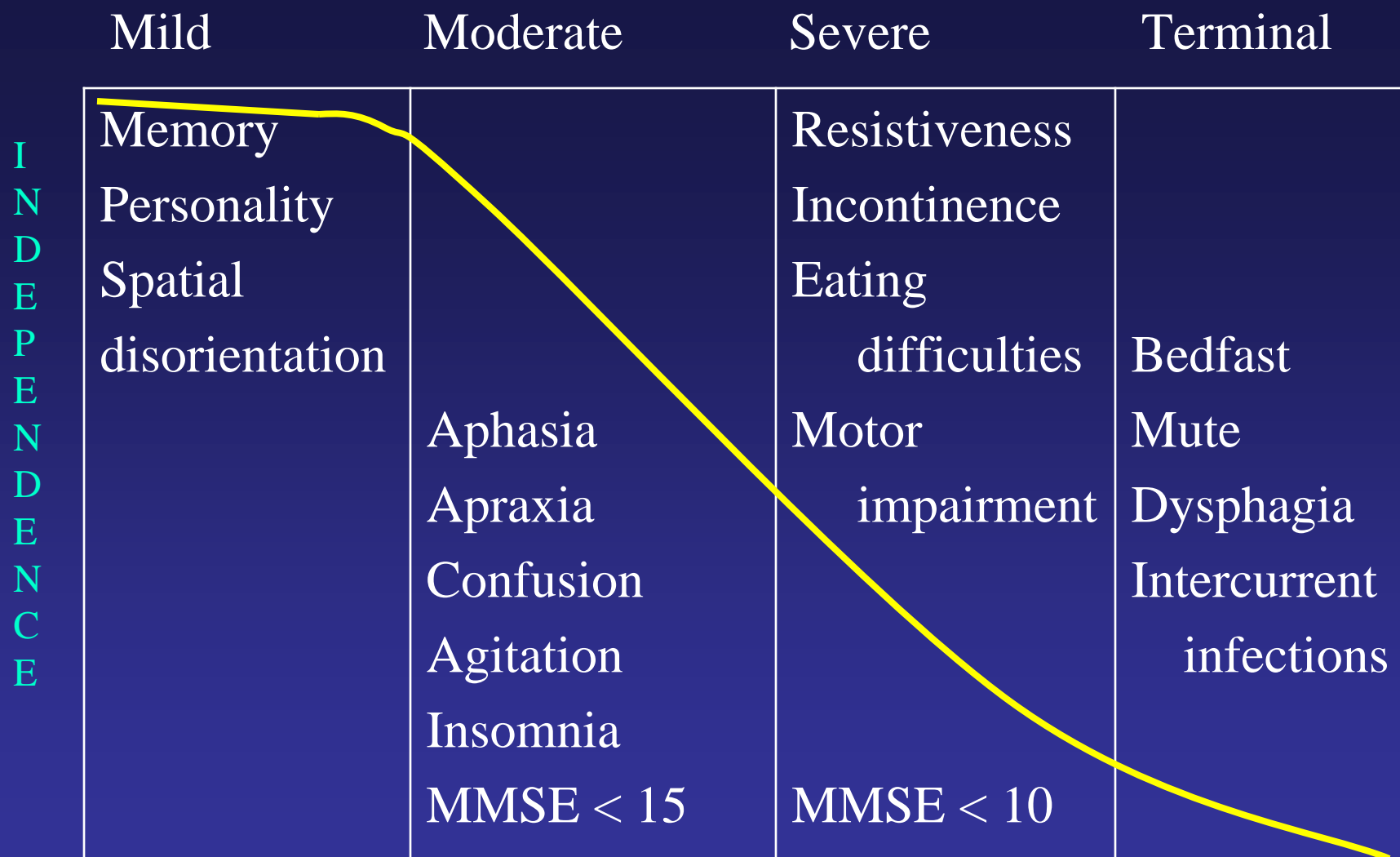
Vernon D. Holleman-Lewis M. Rampy

Centennial Chair in Gerontology

Scott & White Memorial Hospital

The Texas A&M University System Health Science Center

Symptoms and Stages of Progressive Dementias



Care Needs of the Patient and Family

- Medical treatments are necessary but not sufficient
 - Tacrine, Donepezil, Rivastigmine, Galantamine
(Lingler et al., 2005, Raskind et al., 2005)
 - Memantine (Reisberg et al., 2003; Doody et al., 2004)
 - Typical and atypical antipsychotics Martin-Cook et al., 2005, Profeno and Tariot, 2004; Woolterton, 2002; FDA Advisory, 2005, Schneider et al, 2006
 - Antibiotics Van der Steen et al, 2005, artificial nutrition Ritchie and Kvale, 2005

Care Needs of the Patient and Family

- Informal caregivers provide the most significant treatment – supervision and daily care
 - 70% of dementia patients are living in the community with family caregivers
 - Physician instructions are carried out by the caregivers
 - Patient quality of care and quality of life is inextricably linked to the caregiver
- The burden of care is defined by both “work” and “worry” and places the caregiver at risk for negative health and well being outcomes

Consequences of Caregiving

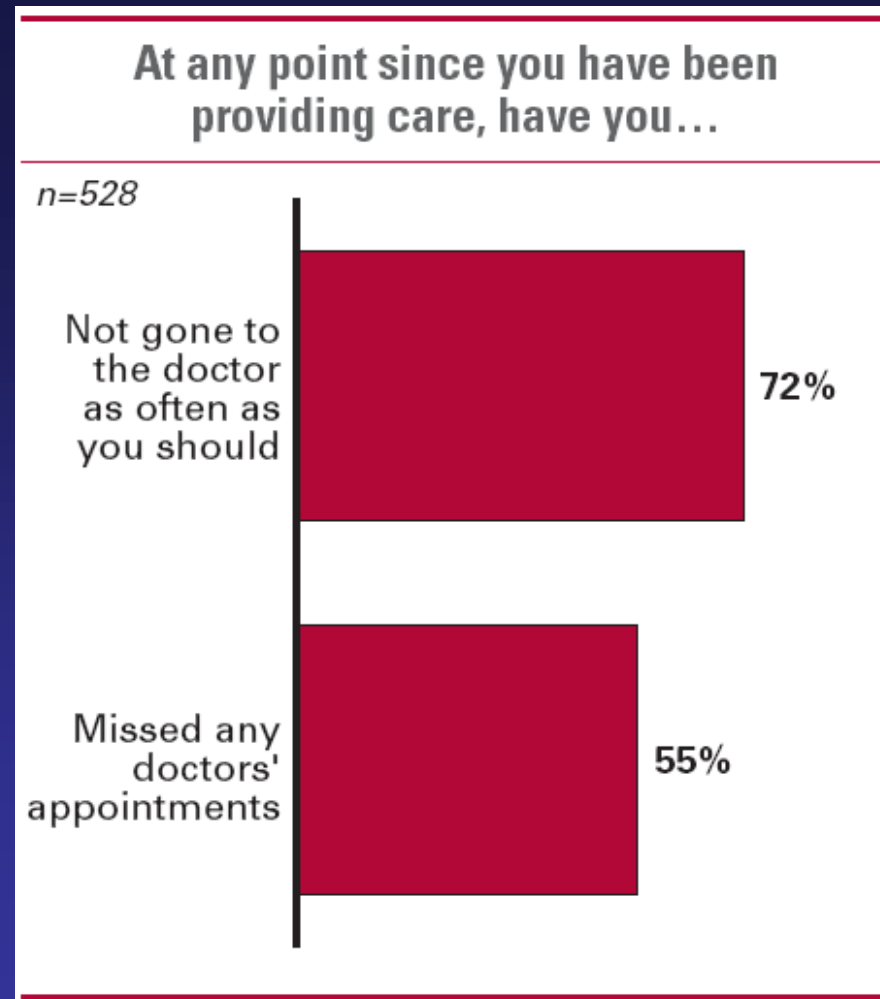
- Nearly 50% of caregivers report symptoms of depression and high levels of anxiety Teri et al., 1997; Sansoni et al., 2004
- Caregivers who placed their relative reported depressive symptoms and anxiety to be as high as they were while in-home caregivers Schulz, Belle, Czaja, McGinnis, Stevens, and Zhang, 2004, JAMA
 - No change in antidepressant use
 - Significant increase in anxiolytics

Negative Health Effects Result From Care

- Caregivers consistently rate their health as significantly worse than non-caregivers
- Evidence suggests poorer health care utilization and immune functioning in caregivers

Vedhara et al., 1999, Kiecolt-Glaser et al., 1995

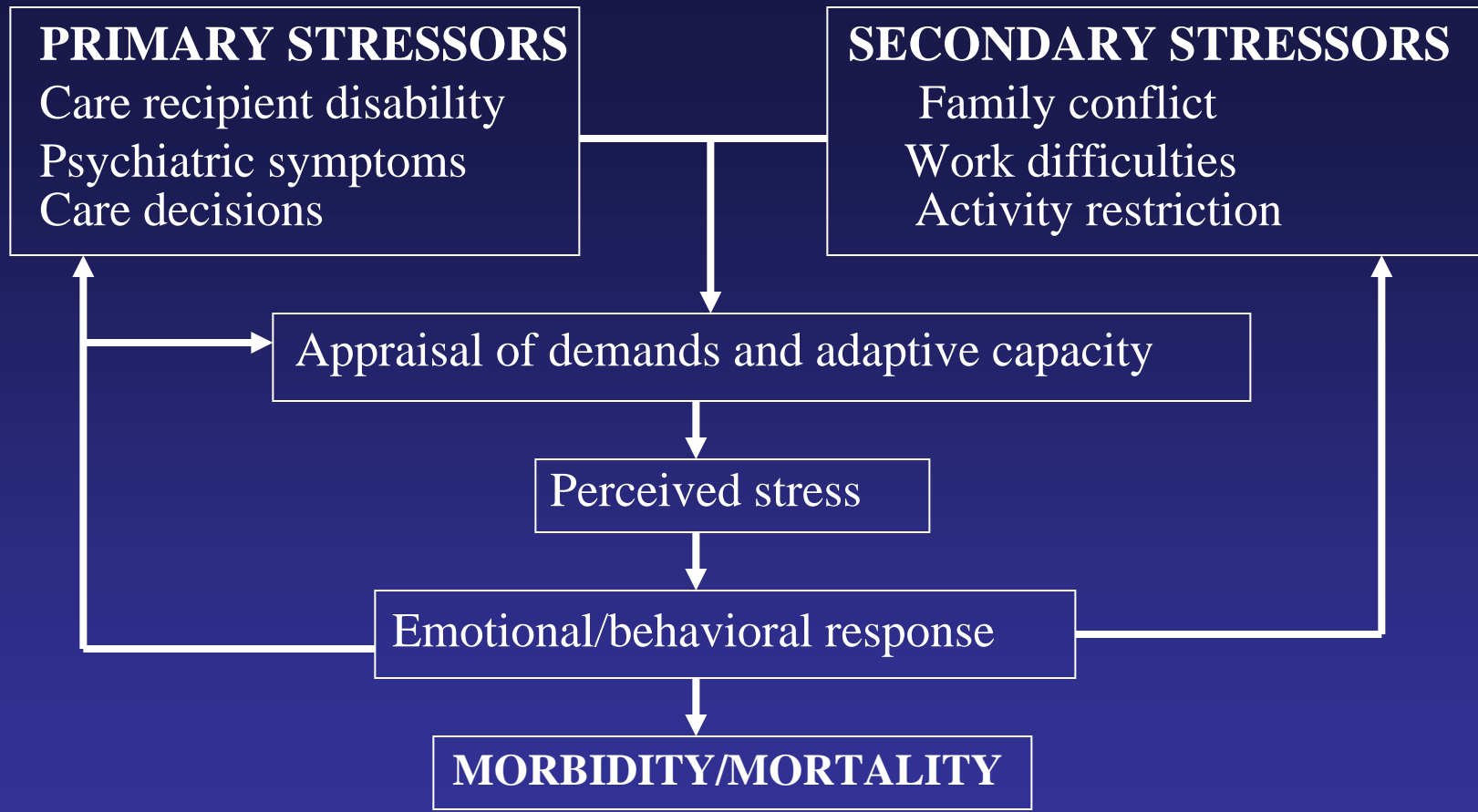
Self Care is Affected by Caregiving



Caregiving and Mortality

- Spouses who provided care and experienced caregiving stress had 63% higher risk (relative risk, 1.63, 95% confidence interval, 1.00-2.65)
- Spouses who provided care but did not experience stress and disabled spouses who did not provide care had mortality rate similar to control

Caregiving Burden



Adapted from Schulz and Martire, Am J Geriatr Psychiatry 12:204, 2004

Interventions to Improve Patient Functioning *Primary Stressor*

- Increased functional/meaningful engagement Beck et al., 1987, Kovach & Magliocco, 1998, Stevens, et al., 2005
- Decreased patient depressive symptoms Teri et al., 1987, Stevens et al., 2005
- Decreased patient problem behaviors Burgio et al, 2003, Teri et al., 1987, Stevens et al., 2005

Multi-component Interventions Focused the Caregiving Experience

- Decreased caregiver burden and depressive symptoms Burgio et al., 2003, Eisdorfer et al., 2003, Middelman et al., 2004
- Increased social support Middelman et al., 1995
- Delayed institutionalization of patient Reach II, Middelman et al., 1996, Middelman et al, 2006

The REACH II Study

Resources for Enhancing Alzheimer's Caregiver Health

- Second in a series of multisite research program to develop and test effective caregiver interventions
- Sponsored by the National Institutes of Health (NIH), National Institute on Aging (NIA), National Institute of Nursing Research (NINR)

REACH II Study

- One intervention tested at 5 sites: Birmingham, AL, Memphis, TN, Miami, FL, Palo Alto, CA, and Philadelphia, PA
- Ethnically Diverse Sample of 642 Care Recipient/ Caregiver dyads
- Carefully defined eligibility requirements ensured sample was composed of family caregivers of person with dementia who were experiencing caregiving related burden

REACH II Study

- Randomized, two group design for each of the ethnic and race samples
 - Hispanic or Latino: control 106, intervention 106
 - White or Caucasian: control 106, intervention, 113
 - Black or African American: control 107, intervention 104
- Control group received packets of educational materials and two brief “check in” calls
- Standardized assessments at baseline and at a 6-month follow
- Interviewers were blind to group assignment

REACH II Intervention

- Number of therapeutic contacts
 - 9 in home, 1.5 hour sessions
 - 3 telephone sessions, one-half hour each
 - 5 structured telephone support groups
- Delivered by Interventionist certified in the treatment protocol
 - Bachelor or Master's in social science disciplines (e.g., psychology, social work)
 - Computerized telephone system placed in the home to support intervention delivery
- Intervention strategies allowed tailoring of the intervention to meet specific needs of the caregiver

Target Areas of Intervention

- Depression
- Burden
- Self-care and healthy behaviors
- Social support
- Problem behaviors

Risk assessment was used to identify the unique needs of each caregiver

Treatment Strategies for Depression

- Teach and practice strategies for engaging in pleasant events
- Teach and role play strategies for mood management and use of thought record
- Establish schedule of pleasant events

Treatment Strategies for Burden

- Teach and practice three stress management techniques – breathing exercises, music, and stretching
- Refer to stress management feature on computerized telephone system

Treatment Strategies for Self-care and Healthy Behaviors

- Demonstrate and review use of health passport
- Teach healthy behaviors and compliance with preventative health behaviors
- Refer to healthy living feature of computerized telephone system

Treatment Strategies for Social Support

- Teach how to access community resources
- Practice role-play strategies to enhance communication with health care providers and family members
- Reinforce participation in telephone support groups
- Refer to resource guide and communication and respite features of computerized telephone system

Treatment Strategies for Problem Behaviors

- Engage in structured problem solving and brainstorming of strategies
- Provide written behavioral prescription that specifies step-by-step strategies to manage troublesome behaviors
- Demonstrate and practice specific strategies using role-play

Objectives of the Intervention

- Assess risks and needs
- Present and teach educational information
- Tailor content of each of the five target areas to the unique risks and needs of caregiver
- Practice and role play strategies
- Integrate strategies of the five target areas via a supportive therapeutic relationship with a trained interventionist

REACH II Outcomes

- 5 Measures central to caregiver's quality of life and closely linked to intervention components modeled into a single primary outcome
 - Depression
 - Caregiver burden
 - Self-care
 - Social Support
 - Problem Behaviors of the CR
- Clinical Depression
- Institutional Placement of CR at 6 months

REACH II Primary Outcome

- Intervention group displayed significant improvement on the multidimensional Quality of Life Variable for *Hispanic or Latino*, $p < .001$, *White or Caucasian*, $p = .032$, but not Black or African American, $p = .23$
- Improvement from baseline to the 6 month assessment met the study criterion of clinical significance by exceeding .5 SD for Hispanic or Latino and White or Caucasian caregivers
- A significant improve was found for African American spouse, that is, intervention x spouse interaction, $p = .008$

REACH II Secondary Outcomes

- Clinical Depression
 - The overall prevalence for clinical depression at follow was significantly greater among caregivers in the control group than in the intervention group, $p=.001$
- Institutional Placement
 - Groups differences were not significant, 7.2% in control, 4.3% in intervention

REACH II Implications

- Intervention had a meaningful impact on quality of life and rates of caregiver depression were halved
- However,
 - “The REACH study offered a level of caregiver support that few clinicians will be equipped to offer to their patients.”
 - “...much of the care that patients with dementia and their caregivers need cannot be delivered in the office setting. The usual fee-for-service works poorly for dementia care.”

How Do We Respond?

- Policy and Systems Change
 - Translational research and demonstration projects
 - Scott & White Memorial Hospital Family Support Program
 - A program to identify and assess the needs of family caregivers during a hospitalization of the care recipient
 - Funded by Johnson & Johnson and Rosalynn Carter Institute Caregiver Program

How Do We Respond?

- Partner with the Community
 - Area Agency on Aging of Central Texas
 - Support Teams for Caregivers, Funded by Johnson & Johnson and Rosalynn Carter Institute Caregiver Program
 - Capital of Texas Alzheimer's Association
 - Support Teams for Caregivers

Support Teams for Caregivers

- Support Teams for Caregivers merges a nationally recognized volunteer program, the Support Team Network, with the REACH II intervention
- Support Teams serve as the delivery system for the intervention components included in REACH II
- Intervention components are delineated in the **Caregiver Guidebook**
- A **Family Profile** tailors intervention components based on findings from a standardized risk appraisal of the caregiving family

Questions

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