Taking Care of Dementia Caregiver

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Learning Objectives

- Appreciate the impact of care giving for dementia person compared to other illnesses
- Understand prevalence and demographics of spousal care giving in dementia persons
- Recognize risk factors for increased care giver burden
- List barriers for preventive health participation
- Identify strategies for self care enhancement

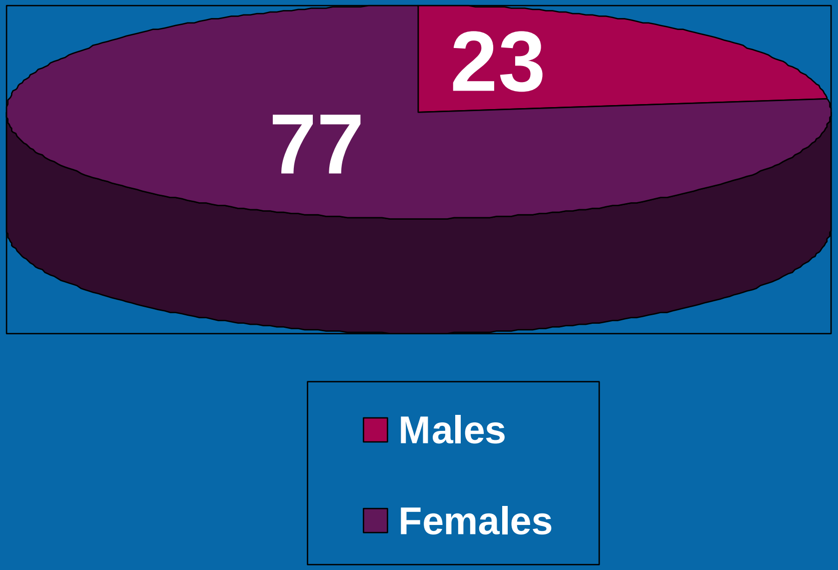
Unique Care Giving in Alzheimer’s Disease

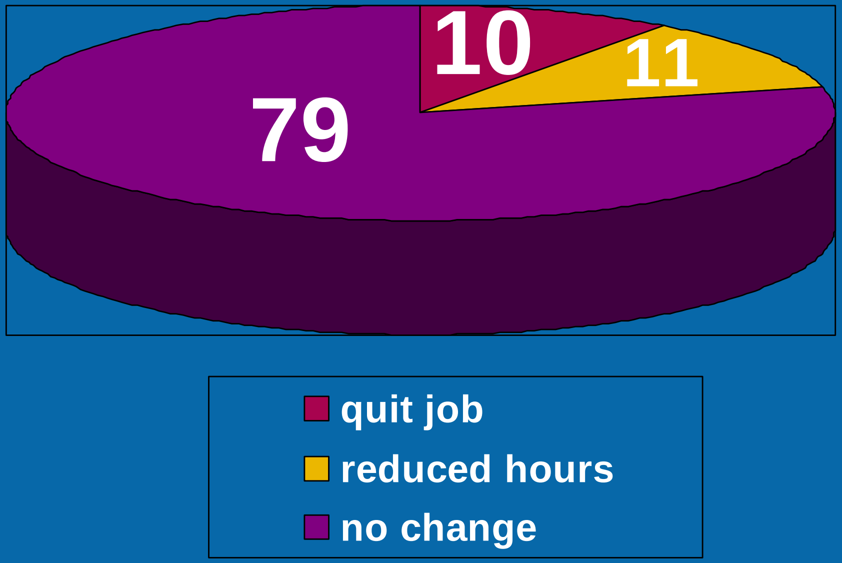
- Role lasts longer
- Role changes as disease progresses
- Cognitive decline causes personality changes
- Greater supervision with self care
- Greater physical and emotional strain [1]
- Fewer vacations, hobbies, more work difficulties [2]

1. Alzheimer’s Disease Association website
www.alz.org/news_and_events_rates_rise.asp. Assessed April 2,2007

2. Ory MG et al “Prevalence and impact of care giving: a detailed comparison between dementia and non-dementia care givers” Gerontologist 1999; 39 (2) 177-185

Caregiver Characteristics



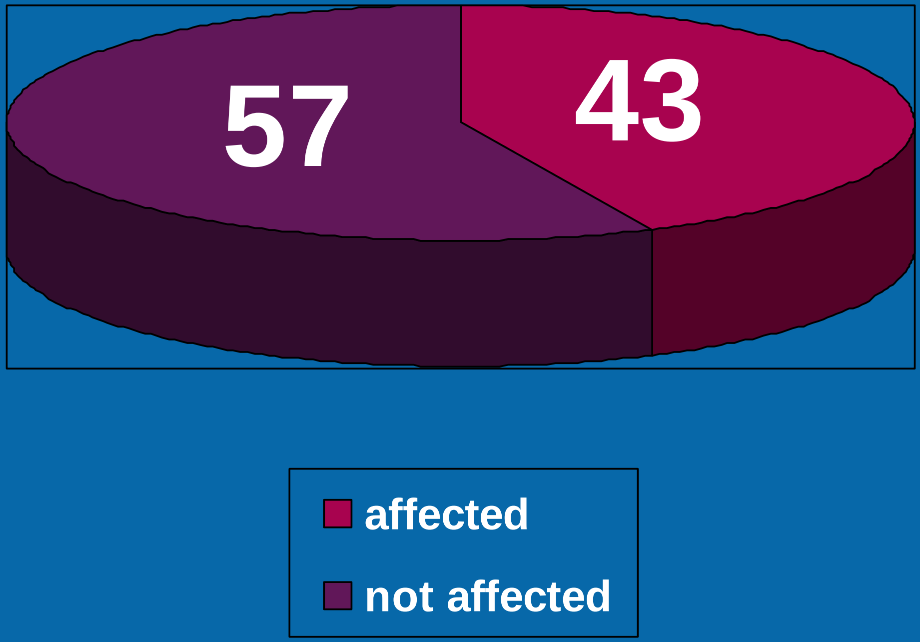


2004-2005 California Statewide survey of caregivers of brain impaired adults
Family Caregiver alliance 2001, Selected Caregiver Statistics (Fact Sheet) San Francisco

Case presentation # 1

- Mrs. A is a 84 yo retired dentistry professor, relocated to Florida from Massachusets. Lives in a single family home on the beach. Takes care of husband with Alzheimer's disease dementia. Husband suffering from behavioral complications, aggressive behaviors, and is increasingly disoriented. Mrs. A cannot leave her husband at home alone. Mrs. A is depressed about seeing her husband’s deterioration.

Depression Prevalence



Depression Predictors

- Older caregiver age
- Female caregiver gender
- Living with the patient
- Less education
- Being the spouse or daughter
- More time spent
- Worse physical function

Covinsky et al “Patient and Caregiver Characteristics Associated with
Depression in Caregivers of Patients with Dementia” J Gen Intern Med 2003; 18:1006-1014

Patient Characteristics as Depression Predictors

- Younger patient’s age
- Dementia severity

Covinsky et al “Patient and Caregiver Characteristics Associated with
Depression in Caregivers of Patients with Dementia” J Gen Intern Med 2003; 18:1006-1014

Case Presentation # 2

- Mrs S is 83 yo woman is taking care of her Alzheimer’s disease husband. She raised 5 children, and ran a non-for profit foundation until her husband care needs increased. She presents for a problem visit, and is found to be overdue for mammogram, colonoscopy, and bone density test. With osteoporosis history she is neither exercising, nor taking calcium or bisphosphonates.

Caregivers and Preventive Health

- Less likely to engage in preventive health behaviors

Schultz R et al “ Health Effects of Caregiving: the Caregiver Health Effects Study: ancillary study of the cardiovascular health study” Ann Behav Med 1997; 19:110-116

Physiological consequences of Care giving

- Reduced immune function
- At higher risk for serious illness

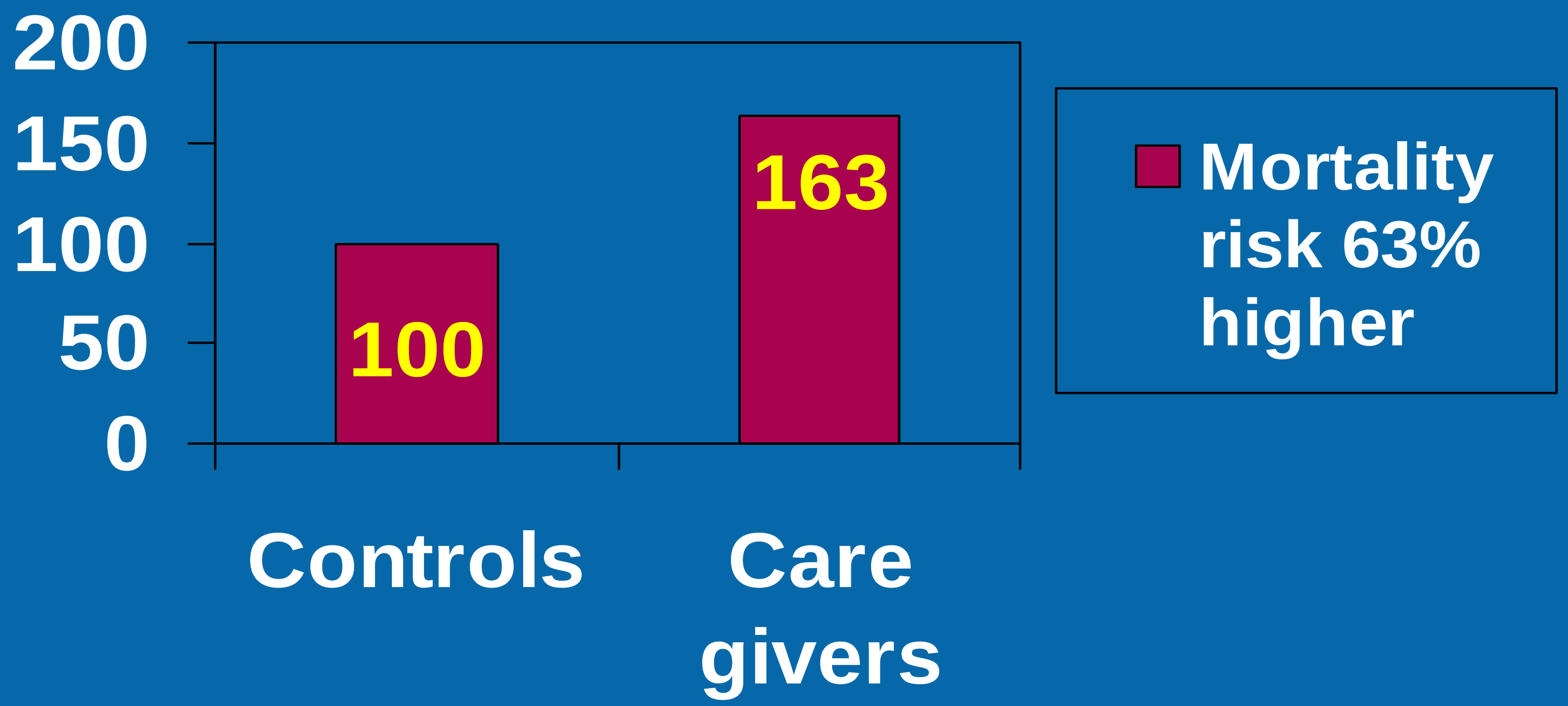
Vitaliano P et al “Physiological and physical concomitants of caregiving: introduction to special issue” Ann Behav Med. 1997; 19: 75-77

Physiological consequences of Care giving

- Poor wound healing

Kiecolt-Glaser JK et al “Slowing of wound healing by psychological stress”
Lancet 1995; 346: 1194-1196

Care giving as independent risk factor for mortality



Schulz R et al “Caregiving as a Risk Factor for Mortality” JAMA December 15, 1999-Vol 282, No. 23: 2215-2219

Case presentation # 1, cont

- Mrs. A moved her husband to nursing home, where she visits him regularly. She continues to feel depressed as her husband now does not recognize her and she feels nursing staff does not do a good job feeding him when she is not there.

After the patient is institutionalized

- Risk for adverse health outcomes continues
- Depression continues

Schulz R et al “Long Term Care Placement of Dementia Patients and Caregiver Health and Wellbeing” JAMA 2004; 292:961-967

Case Presentation # 1 cont

- Traveling to nursing home several times a day is increasingly burdensome for Mrs. A. She buys a house on mainland in the development that has Alzheimer’s unit in hopes to move her husband there. She is unable to sell her island home, and does not feel connection to her new neighbors. Feeling depressed she is uncompliant with her BP and cholesterol medications.

Caregiver needs

- General information 68%
- Emotional support 59%
- Respite care 53%

California Survey 2004-2005


How Did your memory Improvement class go last night?
I Completely forgot about it!!
Jonny Hawkins

Case Presentation # 2

- Mrs. S is despirately needing a break, she wears a cast for orthopedic condition, and has to make a 2 hour trip to see her surgeon regularly. She cries easily over the last 2 weeks. She does not know of local day care center or respite care resources despite her connections with non-for profit organizations.

Caregiver Resources

- National Center on Care giving
- Departments on Aging
- Alzheimer’s Association

Caregiver Resources

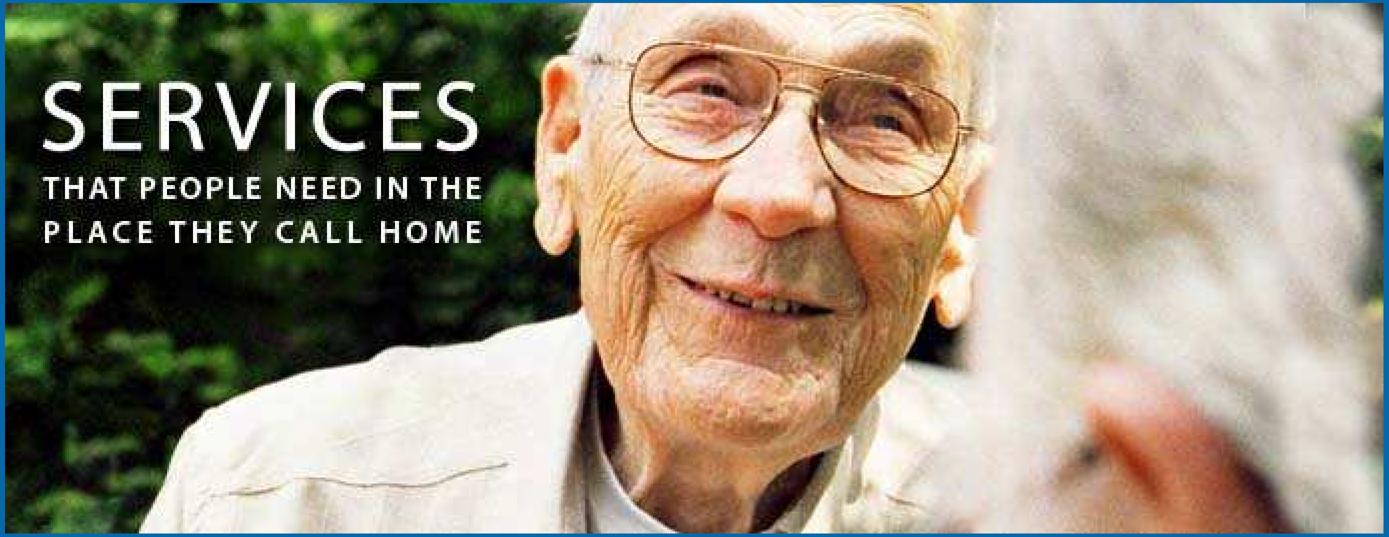
- http://www.eldercarelink.com

Caregiver Resources

http://www.healthinaging.org/agingintheknow

Caregiver Resources

- American Association of Home and Services for the Aging
- http://www.aahsa.org/

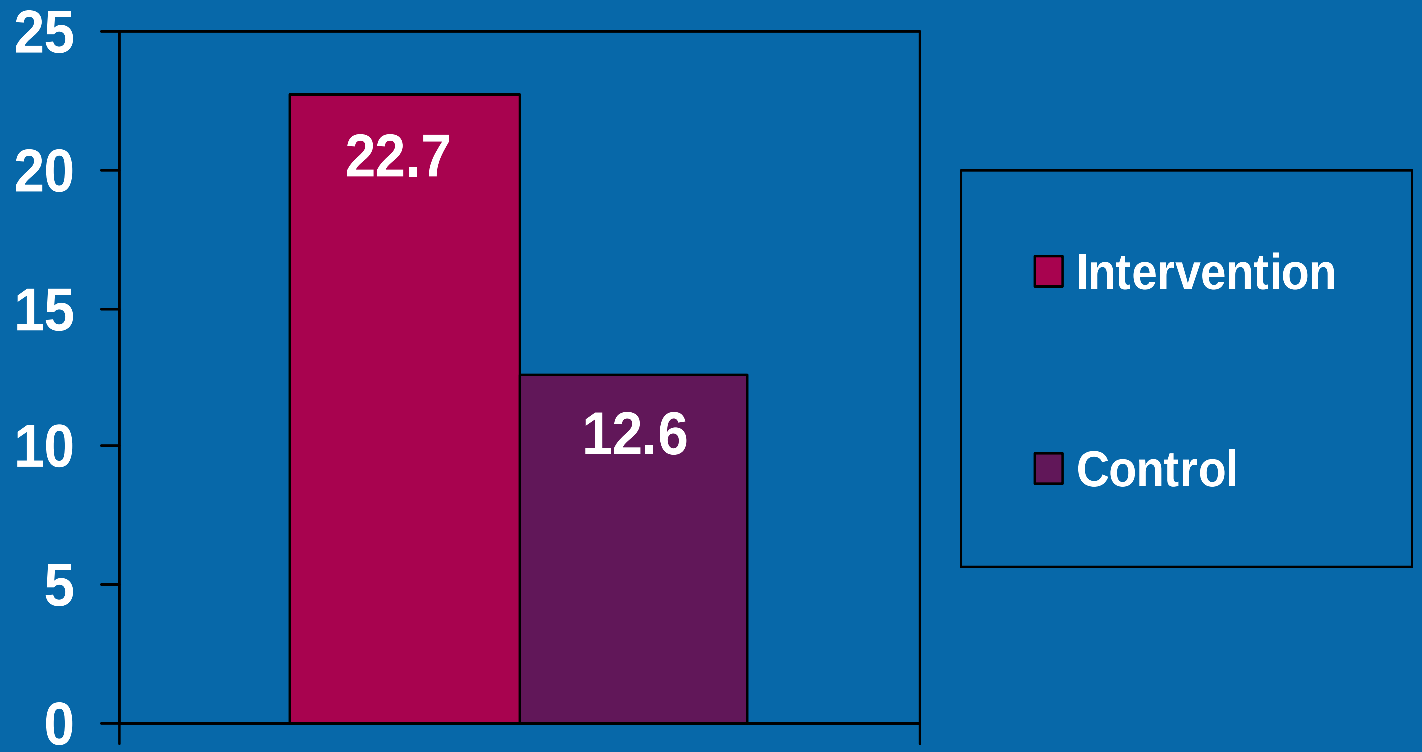


Quality of Life of Dementia Caregivers

- 12 in-home and telephone sessions over 6 months
- Caregiver education, management of troublesome behaviors, social support, cognitive strategies for reframing negative emotional responses , strategies for enhancing healthy behaviors, stress management

Steven H Belle et al "Enhancing the Quality of Life of Dementia caregivers from Different Ethnic or Racial Groups" Ann Intern Med 2006 November 21; 145 (10):727-738

Improved Quality of Life



Steven H Belle et al “Enhancing the Quality of Life of Dementia caregivers from Different Ethnic or Racial Groups” Ann Intern Med 2006 November 21; 145 (10):727-738

REACH II

- Design – RCT
- Setting – in home caregivers in 5 US States
- Participants – 212 Hispanics, 219 Caucasians, 211 African Americans

Steven H Belle et al “Enhancing the Quality of Life of Dementia caregivers from Different Ethnic or Racial Groups” Ann Intern Med 2006 November 21; 145 (10):727-738

REACH II Caregiver eligibility

- Over age 21
- Providing care for 4 hours/day x 6 months
- Reported distress (2 out of following):
  - overwhelmed
  - felt like crying
  - angry or frustrated
  - felt cut off from family
  - moderate to high stress
  - felt their health had declined

REACH II Care Recipient Eligibility

- MMSE less than 23, greater than 0
- AD or related diagnosis
- Bedbound excluded

REACH II Design

Intervention

- Depression assessment
- Self care
- Social support
- Care recipient problem behaviors
- Via 12 in home and telephone sessions

Control

- 2 brief “check-in” telephone calls
- Mailed educational hand out

REACH II Intervention

Depression	-Education on well being importance -Teach and practice engagement in events -Role play mood management
Burden	-Stress education -Practice stress management (breathing, music, stretching)
Healthy Behaviors	-Preventive health education -Use of health passport -Teach nutrition, medication compliance
Social Support	-Education on social support importance -Teach to access community resources -Role play communication with providers
Problem Behaviors	-Education on dementia symptoms, managing behaviors -Problem solving strategies, written step by step prescriptions -Role play practice

REACH II Outcomes

Primary	**Secondary**
5 measures of caregiver quality of life 0.5 SD improvement clinically significant	Care giver depression Institutional placement at 6 months

REACH II Statistical Analysis

- Simple and multiple linear regression
- Sample size provided 80% power to detect effect size of 0.5 SD

REACH II Primary Outcomes

- **Care giver burden** : 11 questions i.e. felt stressed between caring and other responsibilities, rated on 5 point scale
- **Self care**: 11 yes and no questions i.e. getting enough rest when sick, seeing a physician when needed
- **Social support**: 4 point scale assessment for receiving and satisfaction with support

REACH II Primary Outcomes

- **Problem Behaviors**: 3 questions about decline in memory, depression, disruption in care recipients on 5 point scale from 1 (substantial improvement) to 5 (substantial decline)

- **Depression**: 10 item version of the Center for Epidemiologic Studies Depression Scale. For each statement respondents answered how often they felt that way from 0 to 3 (rarely, most of the time).

REACH II Study Flow

Intervention	Control
60% completed all 12 sessions	90% received telephone contacts

All included in the outcomes analysis

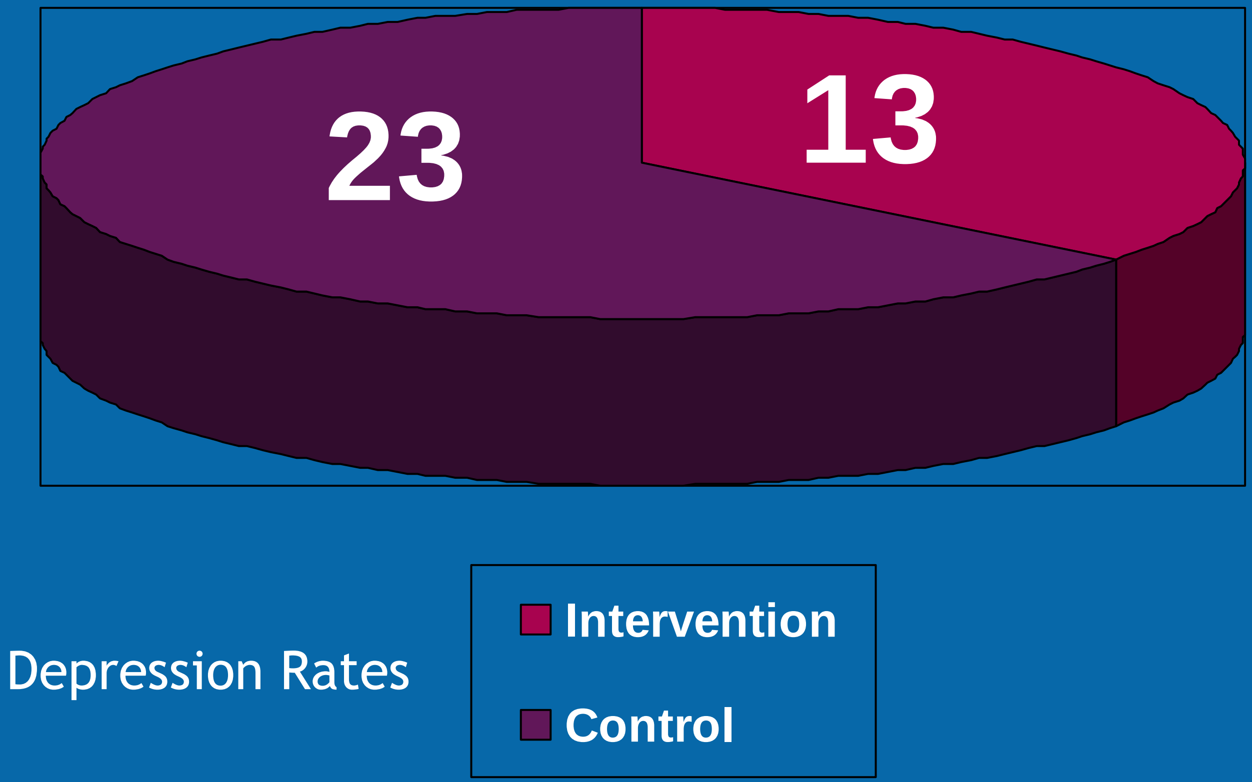
REACH II Results

5 primary outcomes improved

Hispanics	**Whites**
0.3 SD or more $p < 0.001$	2.0 SD or more $p = 0.032$

Black spouses in intervention group improved significantly greater

REACH II Results, Secondary Outcomes



REACH II Limitations

- Duration – 1 year required to assess institutional placement
- One follow-up assessment of long term effect
- Asians not represented
- Controls reported “some” or “great” benefit suggesting positive effects of minimal support

Summary

- Care giving can be hazardous to your health
- Effective strategies exist
- Refer to community resources