

# **The NYU Caregiver Intervention**

## **Translating an Evidence-based Intervention for Spouse-Caregivers into Community Settings**

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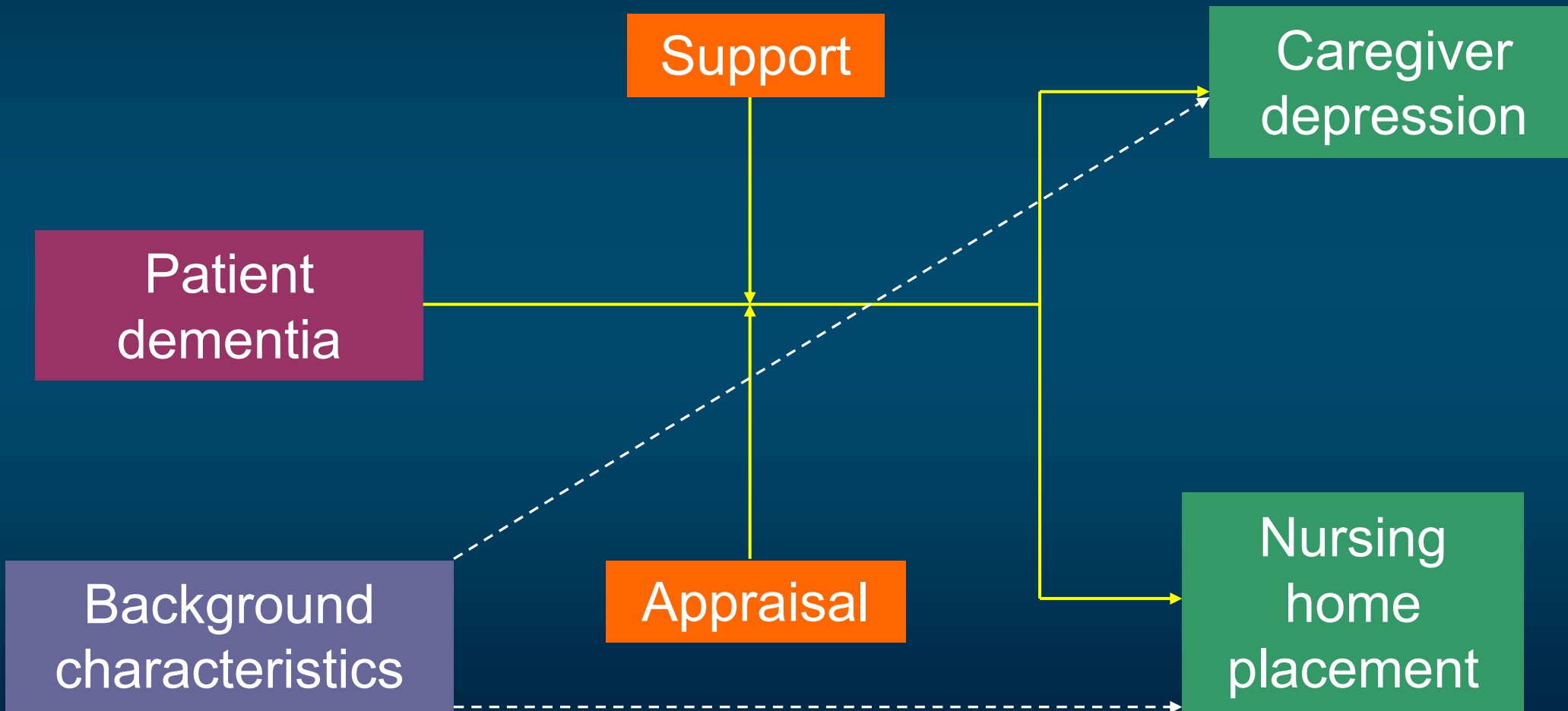
# **Special Challenges Faced by Spouse Caregivers of People with Alzheimer's Disease**

- ◆ **Alzheimer's disease typically lasts for 5-15 years**
- ◆ **The symptoms change over time**
  - Early: memory problems
  - Middle: troublesome behavior
  - Late: Activities of daily living
- ◆ **Increasing cognitive and functional impairments ultimately lead to complete dependence on others for survival**
- ◆ **Spouse caregivers often become isolated**
- ◆ **Spouse caregivers are generally over 65 and may have one or more chronic illnesses themselves.**

# Origin and Theoretical Underpinning of the NYUCI

- ◆ **Clinical experience at NYU**
  - 1980-85
- ◆ **The Stress Process Model**
  - 1990

# The Stress Process Model



# **NYU Spouse Caregiver Intervention Study 1987-2009**

A Randomized Controlled Trial to Test the Efficacy of  
Counseling and Support for Spouse Caregivers

# NYU Caregiver Intervention Study Participants

- ◆ 406 spouse caregivers of people with Alzheimer's disease
- ◆ Enrolled from August 1987 to February 1997
- ◆ Living with the person with AD at intake

# NYU Caregiver Intervention Study Design

- ◆ Comprehensive baseline interview
- ◆ Random assignment to treatment or control group
- ◆ Regular comprehensive follow-up interviews
- ◆ All participating caregivers receive the services routinely available at the NYU ADC.

# Components of NYU Caregiver Intervention

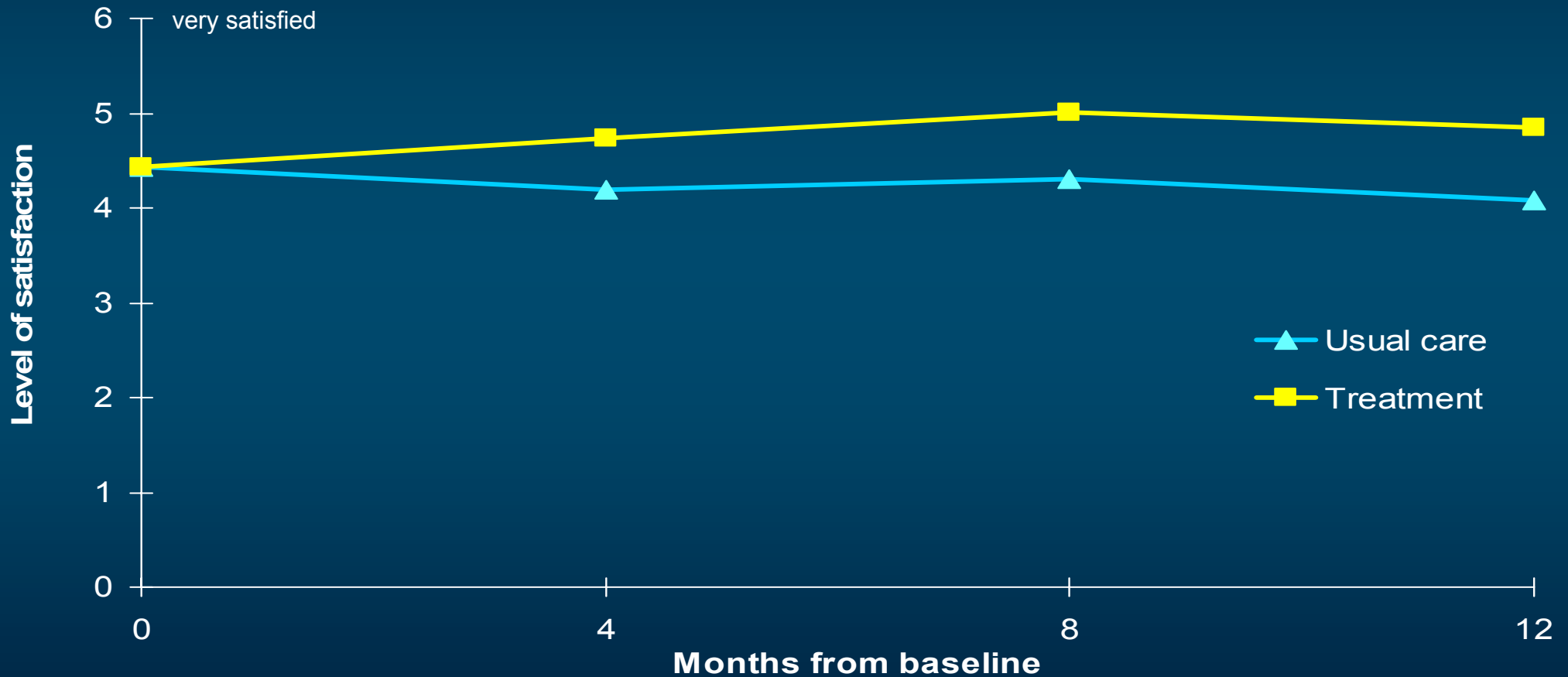
- ◆ **Within a fixed period of time,**
  - 6 individual and family counseling sessions
    - An individual counseling session
    - 4 family counseling sessions
    - A second individual counseling session
- ◆ **Over the entire course of the disease,**
  - Continuous participation in a support group
  - Ad hoc counseling - telephone consultation on request of caregiver or other participating family member.



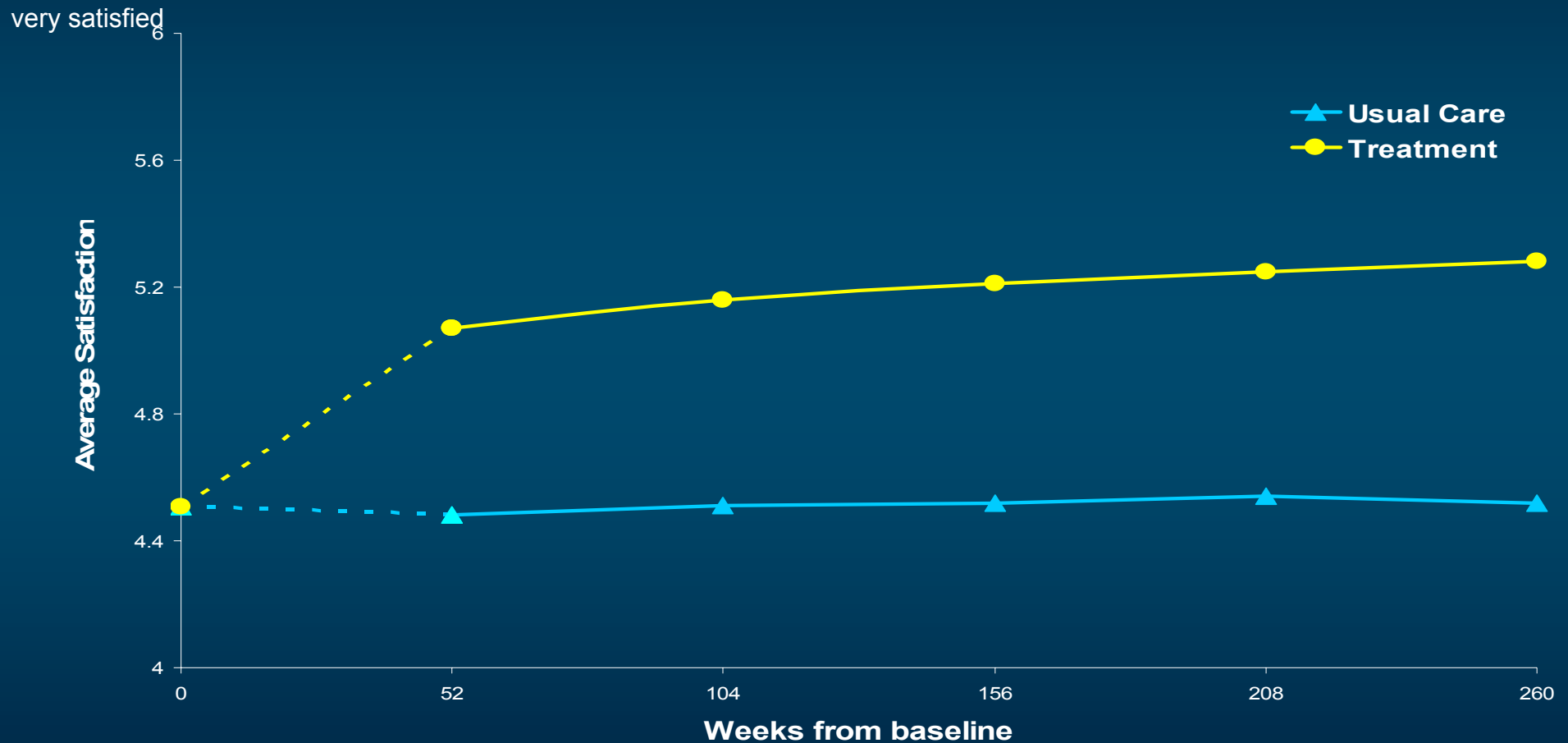
# **NYU Caregiver Intervention**

## **Study Results**

# NYU Caregiver Intervention Improves Caregiver Satisfaction With Support from Social Network

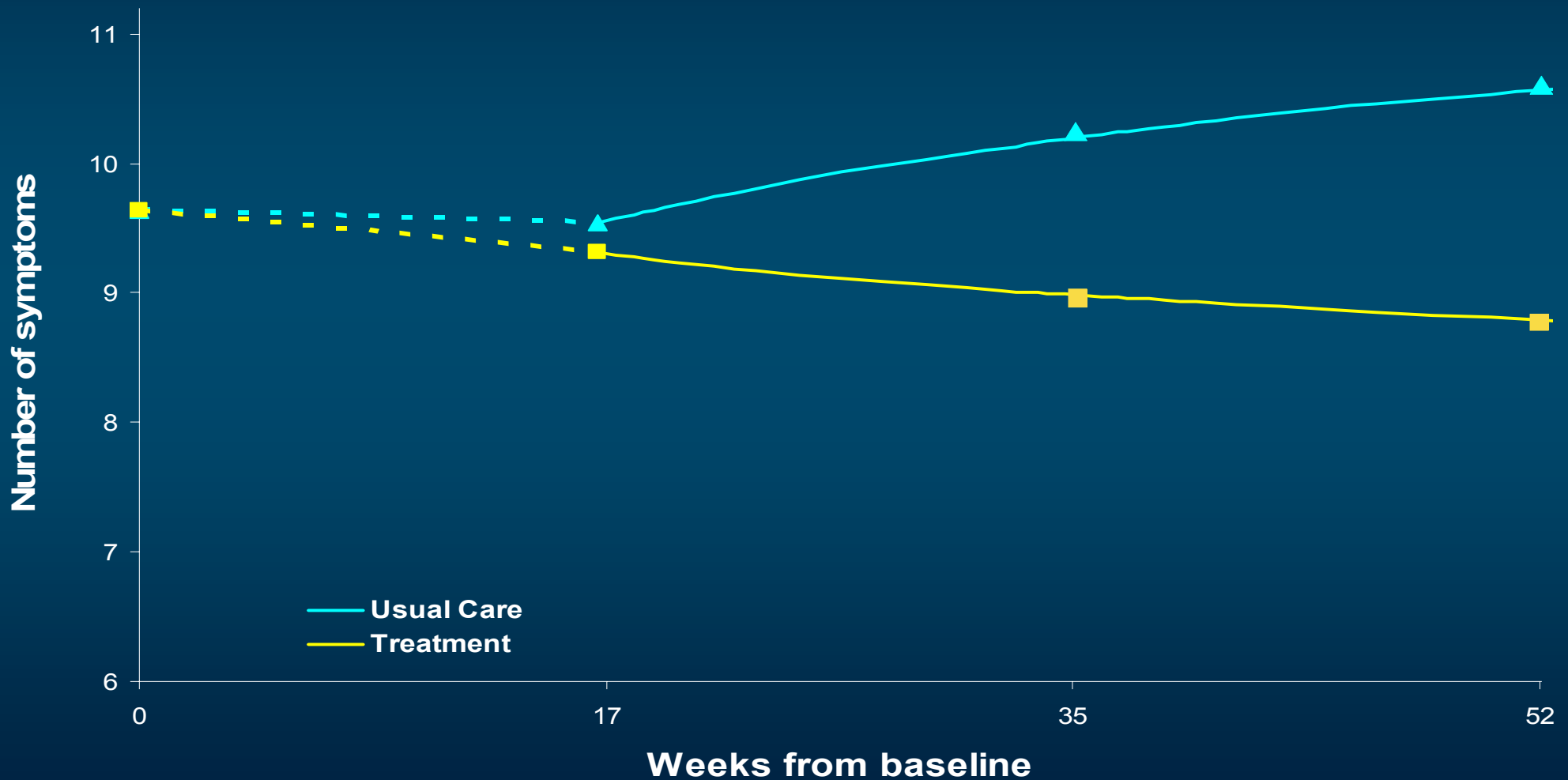


# The Effect of NYU Caregiver Intervention on Satisfaction with Support Continues for at Least 5 Years



Covariate-adjusted trajectories for average satisfaction with social support over the first 5 years of intervention  
Drentea, P; Clay, OJ; Roth, DL & Mittelman, M.S, Social Science in Medicine, 2006

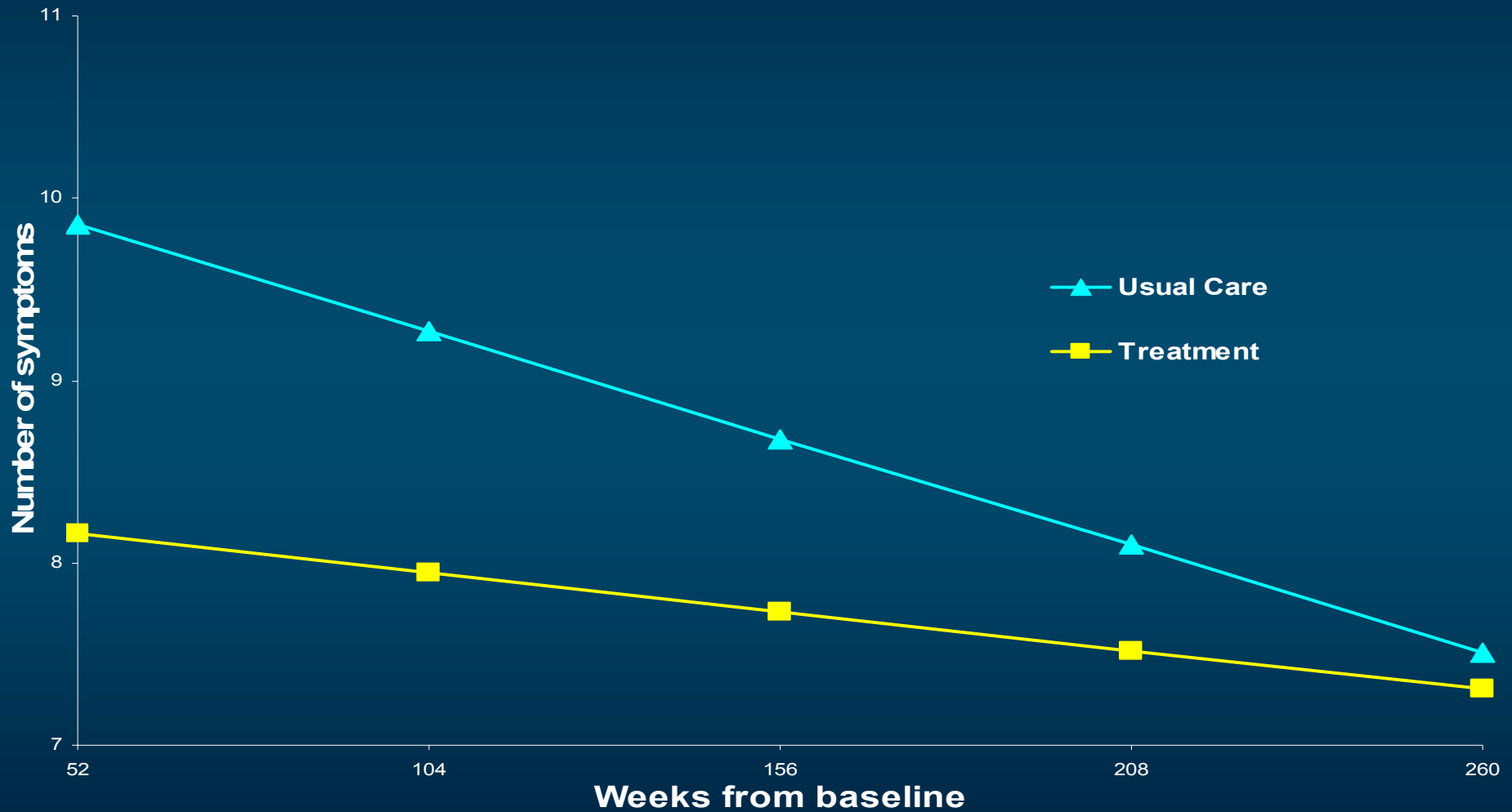
# NYU Intervention Reduces Caregiver Symptoms of Depression



Covariate adjusted scores from linear model, years 1-5

Mittelman MS, Roth DL, Coon, DW & Haley, WE, *American Journal of Psychiatry* 2004; 161:850-856.

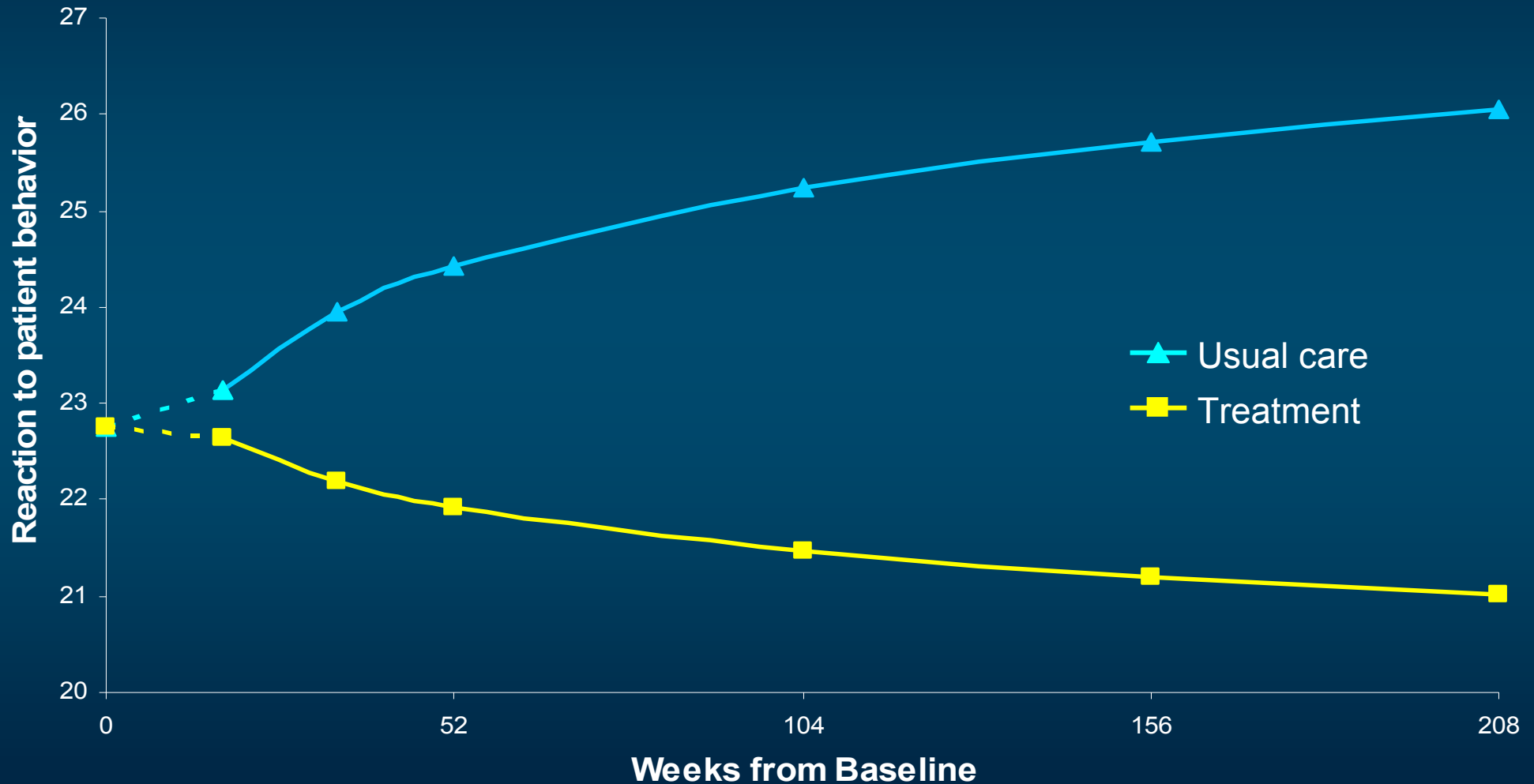
# Effect of NYU Intervention on Caregiver Depression Continues for at least 3 Years



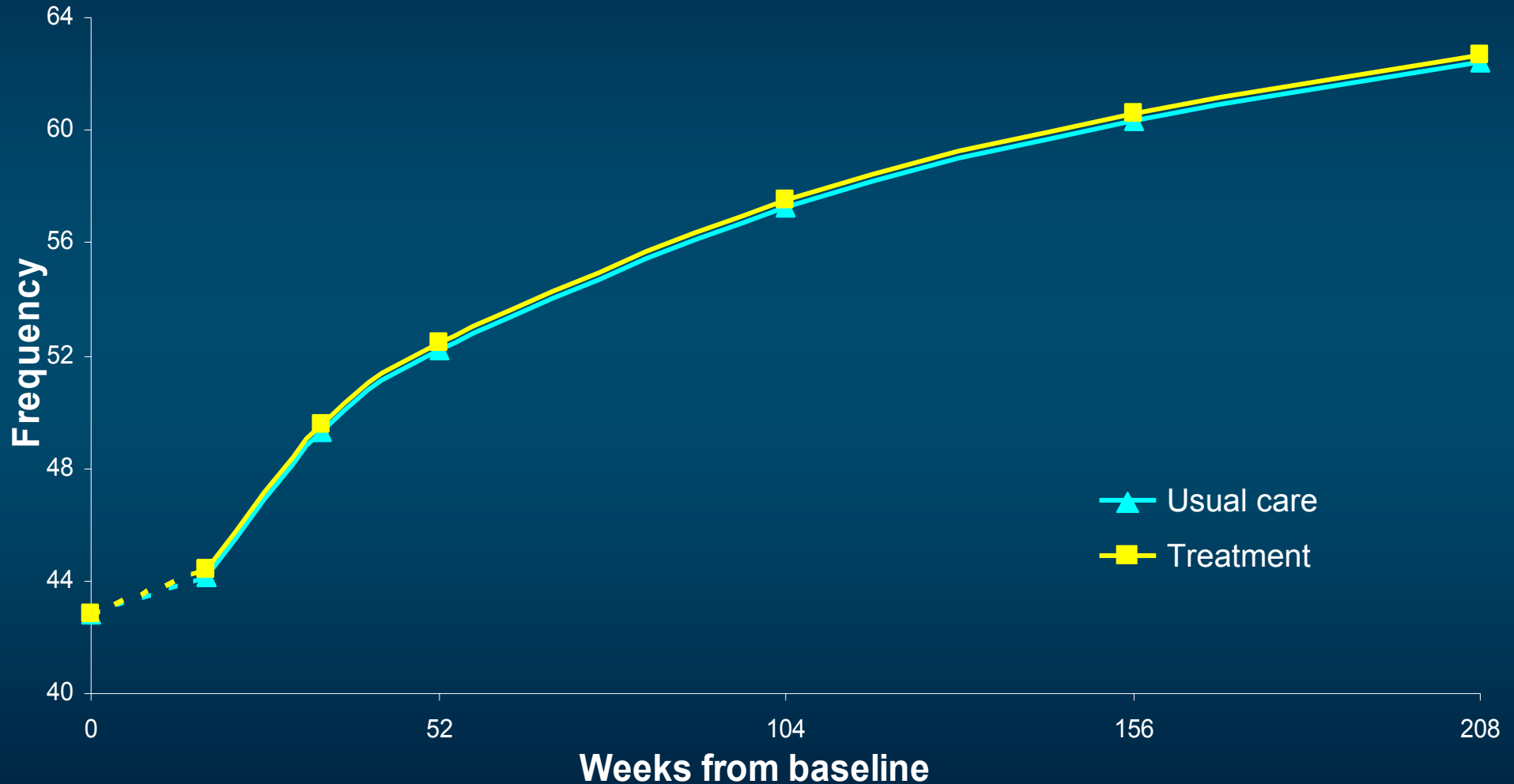
Covariate adjusted scores from linear model, years 1-5

Mittelman MS, Roth DL, Coon, DW & Haley, WE, *American Journal of Psychiatry* 2004; 161:850-856.

# Caregiver Reaction to Problem Behavior Improves with NYU Caregiver Intervention



# NYU Caregiver Intervention Has No Effect On Frequency of Problem Patient Behaviors



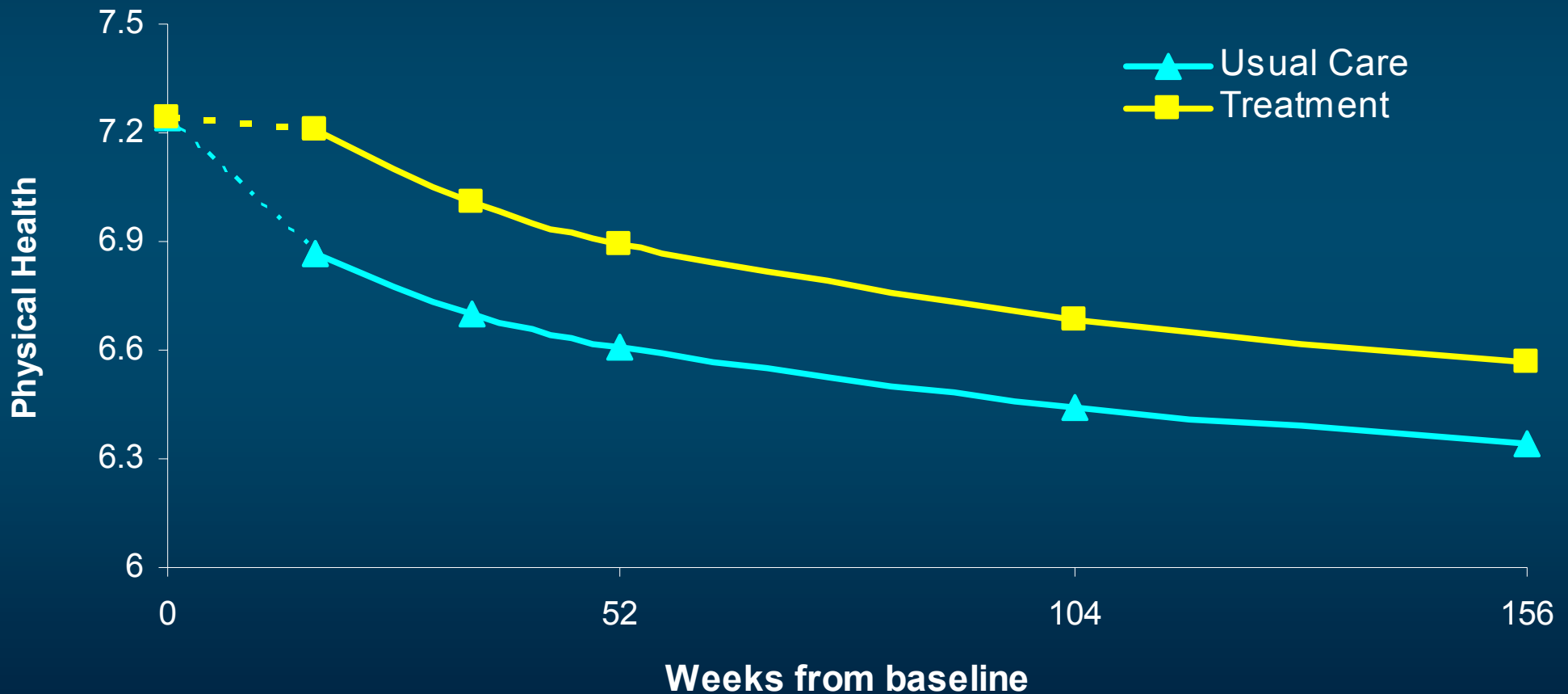
# **How Does the NYU Caregiver Intervention Achieve its Effects on Caregiver Depression and Reaction to Patient Behavior?**

**By increasing:**

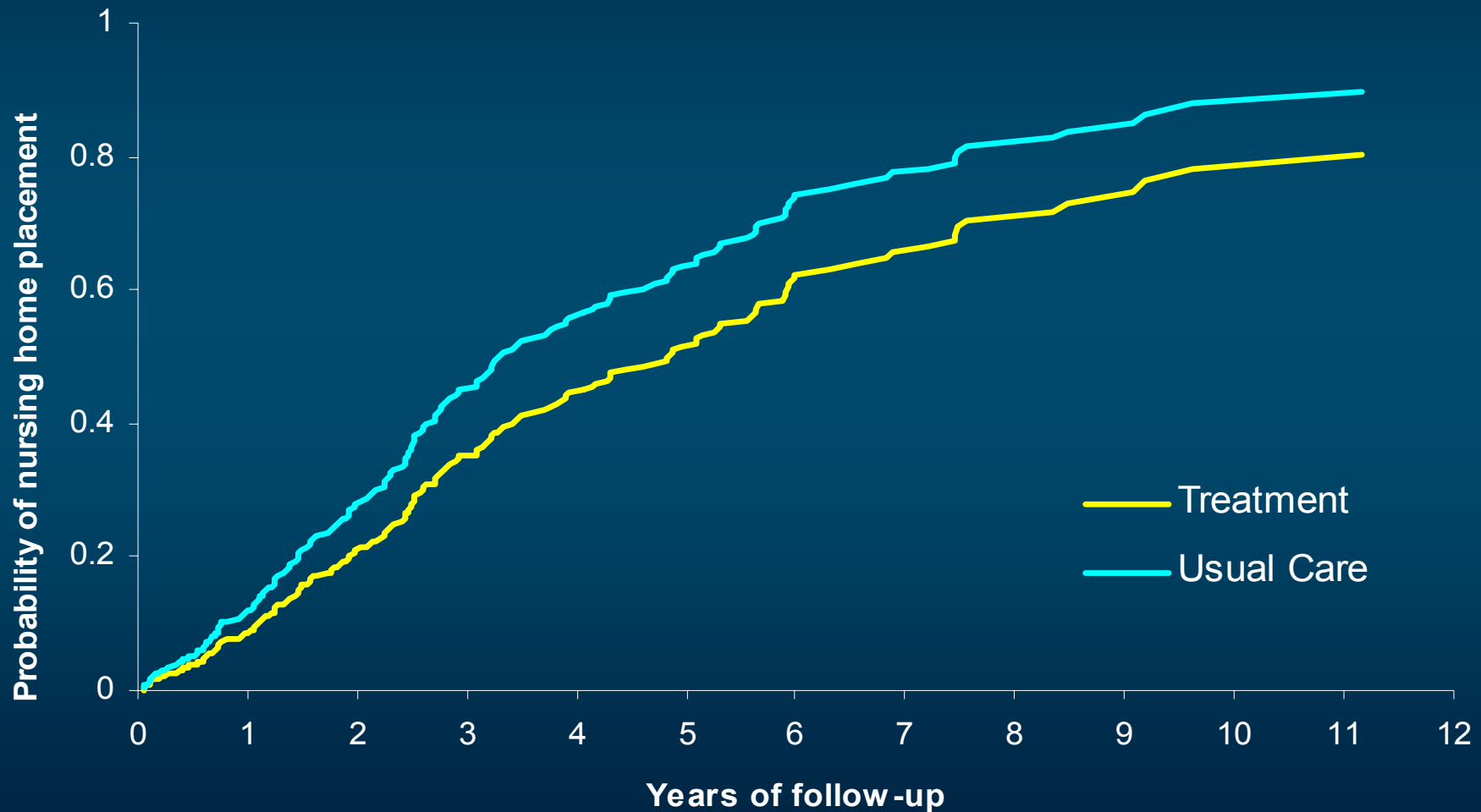
- ◆ **Number of friends and relatives the caregiver considers to be “close”**
- ◆ **Satisfaction with emotional support from friends and relatives**
- ◆ **Satisfaction with assistance from friends and relatives**



# NYU Caregiver Intervention Improves Physical Health of Family Caregivers



# Time to Nursing Home Placement of Patients is Delayed by Counseling and Support of Caregivers



# **The NYU Caregiver Intervention's Effects Persist through Nursing Home Placement**

- ◆ **Nursing home admission itself significantly reduced burden and depressive symptoms**
- ◆ **The NYU Caregiver Intervention significantly reduces caregiver burden and depressive symptoms during the transition to nursing homes.**

# The NYU Caregiver Intervention's Effects Persist through Bereavement

- ◆ The death of the care recipient led to reductions in depressive symptoms.
- ◆ NYUCI led to lower depressive symptoms compared with controls both before and after bereavement.
- ◆ Post-bereavement group differences were stronger for caregivers of spouses who did not previously experience a nursing home placement.
- ◆ NYUCI led to long term patterns of fewer depressive symptoms suggesting greater resilience.



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# Counseling the Alzheimer's Caregiver

A Resource for  
Health Care Professionals

Mary S. Mittelman  
Cynthia Epstein  
Alicia Pierzchala

## Counseling the Alzheimer's Caregiver

A Resource for Health Care Professionals

"All long last—a research evidence-based practice guide for counseling Alzheimer's families. Full of field vignettes and practical "how-tos," this book pulls together what we know about Alzheimer's care and families in a cohesive whole for any health or human service professional. I bet it will become a desk reference for the full range of disciplines and professionals working with Alzheimer's families."

David Crocker, MD, MPH  
Rush Alzheimer's Disease Research Center  
Rush University Medical Center

"The manual describes a specific approach to counseling caregivers. The topic is certainly of interest to many non-physician and physician who have contact with patients with AD and their families. The strength of what is presented here is that it has been tested in an efficacy trial. This is a well-written clear manual from an author and a group with very broad experience. I know of no other book that provides such directed guidance. I would highly recommend it."

Debra L. Jackson, MD  
Johns Hopkins Medical Institutions  
Department of Psychiatry & Behavioral Sciences

"Very useful resource for many workers involved in the provision of care to Alzheimer's patients and their families. . . . I would recommend it to others."

James O'Brien, MD  
The Maryland System of Social Programs for Residents  
University of Maryland, Baltimore

The devastation of Alzheimer's disease reaches far beyond the people afflicted with it. Those who care for the patients suffer from physical and emotional stress that can prevent them from providing their loved ones with the best care possible.

*Counseling the Alzheimer's Caregiver* provides specific strategies you can use to help caregivers meet the daily and long-term challenges of caring for an AD patient at every stage of the disease.

This manual covers the full spectrum of AD disease from diagnosis to end of life and shows how to coach caregivers to deal with them effectively. Strategies were tested in over 15 years of empirical clinical treatment interventions at New York University School of Medicine's Alzheimer's Disease Center, where hundreds of caregivers have learned techniques to deliver significantly improved patient care while maintaining their own physical and emotional well-being. The strategies that have helped them are now available to you.

For a free information booklet, visit [www.ama-assn.org/care](http://www.ama-assn.org/care)  
or call 1-877-621-8777

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# Conclusion

- ◆ **Comprehensive care for people with dementia should include more than prescriptions for medication**
- ◆ **Widespread availability of counseling and support can have a major impact on the well-being of family caregivers and on their relatives with Alzheimer's disease.**

# **Next Steps**

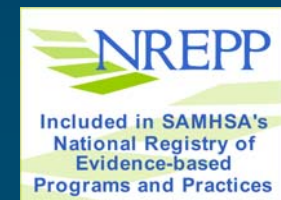
**Adapt and Test  
Successful Research Interventions  
in Community Settings**



# Recent Recognition of Importance of Interventions for Caregivers

- ◆ Evidence-based interventions for caregivers included in National Registry of Evidence-based Programs and Practices (NREPP) of the SAMHSA

Web site at <http://nrepp.samhsa.gov>



- ◆ Administration on Aging began awarding grants to states in 2007 for community replications of effective caregiver interventions
- ◆ Rosalynn Carter Institute awarded 2 year funding to partnerships of researchers and community sites for pilot replications of evidence-based interventions.



# Barriers to Effectiveness in Community Settings

- ◆ **Cultural values**
  - Drug treatment for illness
  - Treat only the patient, not the family
- ◆ **Physicians**
  - Reluctance to diagnose dementia
  - Unaware of value of counseling and support for caregivers
- ◆ **Patients and families**
  - Unaware of reasons to seek evaluation of memory problems
  - Unaware of available services and value of caregiver interventions
  - Overburdened, physically ill.
- ◆ **Lack of funding to reimburse for counseling and support services**
- ◆ **Lack of trained professionals to provide new interventions.**

# Strategies to Overcome Barriers

- ◆ **Physician education**
- ◆ **Community leader education**
- ◆ **Demonstration projects: Partnership of researchers and community service providers**
  - Use training materials developed by original researchers
  - Training and ongoing support for providers provided by clinicians who implemented original interventions.
- ◆ **Adapt interventions to community needs.**

# What Should We Measure?

## ◆ Process

- How acceptable is intervention in community?
  - To service providers
  - To clients
- Fidelity
  - Tension between what must be done to adapt intervention to community settings and maintaining original intervention.

## ◆ Outcome

- How to evaluate success
  - Can we justify a randomized controlled trial?
  - What outcomes should be measured?

# Community Implementation

## ◆ Goals

- More widespread availability of counseling and support for family caregivers
- Make intervention responsive to local needs
- Adapt intervention to changes in “the marketplace”

## ◆ Challenges

- Retain fidelity to original intervention
- Determine fidelity to original intervention
- Measure success of community intervention

## ◆ Community implementation projects currently in

- Minnesota
- Rural Vermont
- Underserved in New York City
- Latino Caregivers
- Netherlands

# AoA-funded Replication of NYUCI in Minnesota

- ◆ **Setting and Population:**
  - Rural and underserved minority as well as urban caregivers in Minnesota
  - Supported by AoA, MN Board on Aging, Alzheimer's Association MN/ND Chapter, Area Agencies on Aging, a county public health agency, medical clinic and memory disorders clinic.
- ◆ **Challenges:**
  - Evaluate ability to embed NYUCI in service systems
- ◆ **Modifications:**
  - Using TCare Assessment, plus outcome measures from original NYUCI
  - Person with dementia included in one family session if in the early stage.
- ◆ **Lessons Learned:**
  - Focus on family requires training of coaches
  - Often requires more than one contact before caregiver is willing to involve family.

# Progress of Minnesota Replication

- ◆ **90 assessments as of 1/29/09**
- ◆ **50 caregivers enrolled**
- ◆ **Reasons given for not enrolling**
  - Too tired and worn out to participate
  - Caregiver health issues
  - Have no family able or willing to participate in family sessions
  - Not willing to make the time commitment to the program
  - Privacy issues- don't want to open up their personal lives to this project
- ◆ **September 2008: AoA additional funding expanded intervention to 8 sites in Minnesota.**

# **Modified NYUCI Being Tested in Rural Vermont and Underserved in NYC**

- ◆ **Assessment used to tailor intervention and measure outcome**
  - Identified family caregiver
  - Person with dementia
- ◆ **Individual and family counseling sessions**
  - Primary caregiver: Two sessions
  - Family counseling
    - Three sessions without PWD
    - One session with PWD if in the early stage of dementia
- ◆ **Ad hoc counseling**
- ◆ **Support group participation for caregiver**
- ◆ **Respite offered to primary caregiver during counseling sessions.**

# Rural Vermont: Offering the Program through Physicians

- ◆ **Setting and Population:**
  - Primary Care Practice Division of Fletcher Allen Healthcare.
- ◆ **Challenges:**
  - Physicians, patients and families unaware of value of supportive services.
  - Family members don't call themselves caregivers.
  - Family members often don't live within commuting distance of primary caregiver.
- ◆ **Modifications:**
  - Program offered primarily to patients/families who come in to see their doctor.
  - Social worker educated physician's staff, who then referred caregivers.
- ◆ **Lessons Learned:**
  - Over time primary care physicians learn to use social worker as a resource for their own staff training and consultation.
  - Physicians don't want to refer to a randomized control trial.



# Medicaid Managed Long Term Care in NYC

## ◆ **Setting and Population:**

- Multilingual/multicultural membership.
  - Average member age is 79 years old;
  - Medical co-morbidities common.

## ◆ **Challenges:**

- Nursing assessment missed caregiver challenges and cognitive impairment of potential participants.
- Nurses had a poor understanding of social worker's role.
- Caregivers were reluctant to get help for themselves.

## ◆ **Modifications and Lessons Learned:**

- Train RN Care Managers to identify dementia and increase caregiver acceptance of supportive counseling during home visits.
- Nurses trained to see value of social support.
- Nurse goes with social worker on first visit, "Endorsement" from trusted RN increases enrollment.

# Implementing NYUCI in Latino Community in NYC

- ◆ **Setting and Population:**
  - Latino caregivers in community-based social service agency in Washington Heights (75% Latino).
- ◆ **Challenges:**
  - Lack of information about AD.
  - Structural barriers (language, financial, geographic, legal status).
  - Participants have marked psychosocial stressors, significant levels of anxiety and depression, and require and use significant amount of case management/ad hoc counseling.
  - “Myth” in Latino community that there is an extended supportive family united (Familismo). Caregivers report family members don’t help.
- ◆ **Modifications and Lessons Learned:**
  - Partnership with community-based agencies for outreach/education/recruitment.
  - Added case management to address biopsychosocial needs.
  - Focus on enhancement of support in individual/family sessions.

# Family Meetings in Memory Clinics (FaMe) Reveals Danger of Decomposing Multi-component Intervention

- ◆ **Setting and Population:**
  - The Netherlands; Funded by Dutch government.
- ◆ **Challenges:**
  - Modeled after family counseling in NYUCI, but only includes one component.
  - First report is that 75% of caregivers don't want to sign up for family counseling.
- ◆ **Modifications:**
  - Suggest better integration with other services – service providers doing individual counseling should be trained to understand value of recommending family counseling.
- ◆ **Lessons Learned:**
  - Multicomponent intervention may need to be delivered as a package.

# Goals for the Future

- ◆ Evaluate NYUCI in additional community settings
- ◆ Evaluate NYUCI for family caregivers of people with other chronic diseases
- ◆ Develop and evaluate social support interventions that include people in the early stage of dementia and mild cognitive impairment.

To contact me for more information about the NYU Caregiver Intervention, call (212)-263-7560, or email [mary.mittelman@nyumc.org](mailto:mary.mittelman@nyumc.org)