

# Riding the Roller Coaster: Using Evidence-Based Strategies to Enhance Quality of Life in Persons with Neurocognitive Disorders

May 22, 2013

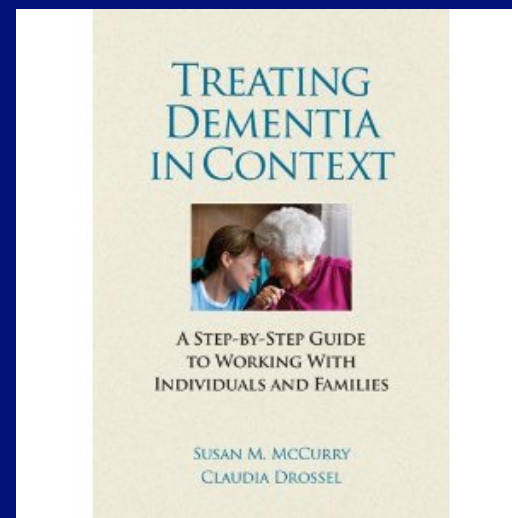
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# Disclosure Statement

*Some content from this presentation will be derived from books that Dr. McCurry has written on dementia care.*



# Dementia as Chronic Illness

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- Alzheimer's disease & dementia affects the fastest growing segment of our population
- One in 8 older Americans has Alzheimer's disease
- Nearly half (45%) of persons age 85 and older have AD
- Individuals are being diagnosed earlier and will most likely live with the disease for many years

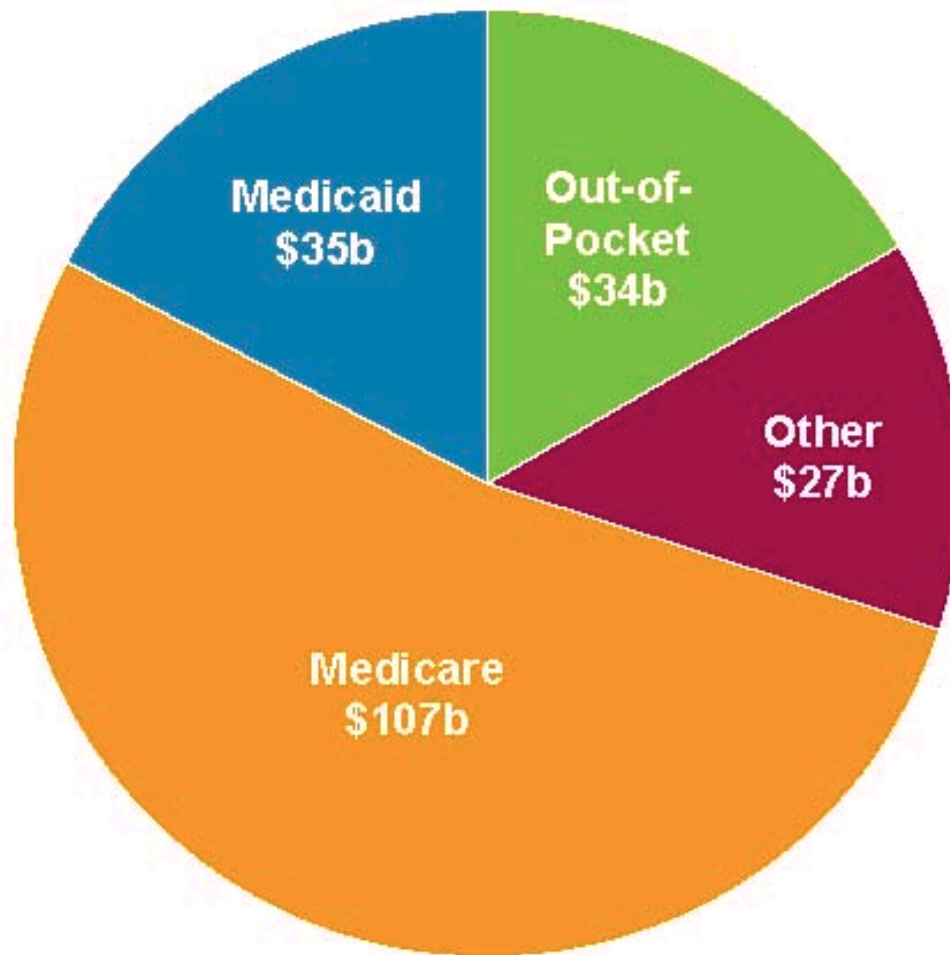
# The Toll on Families is High

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- Families provide the bulk of care for older adults with dementia
- In 2012, 15.4 million family and friends provided 17.5 billion hours of unpaid care
- Nearly 15% of caregivers are long-distance caregivers, living an hour or more away
- More than 60% of caregivers rate their emotional stress as high or very high

# The Costs Are Staggering

2013 Costs of Alzheimer's = \$203 Billion



Alzheimer's  
Association: [2013  
Alzheimer's Disease  
Facts & Figures](#)

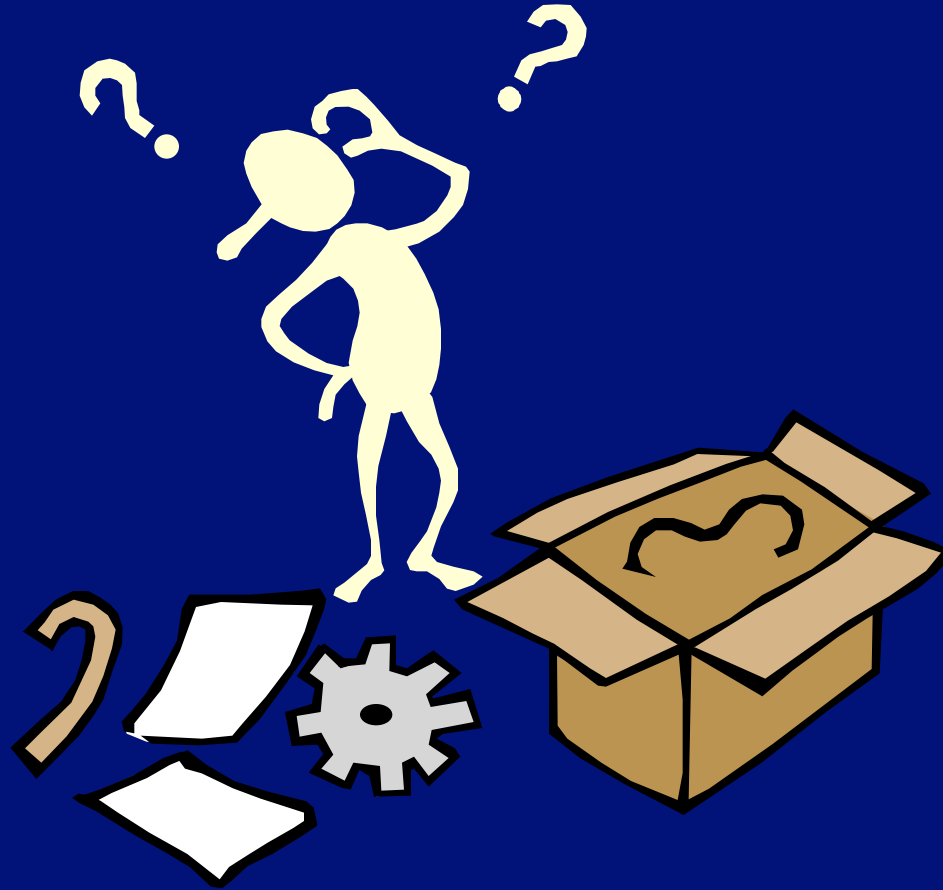
# Behavior and Mood Disturbances Are Widespread

- Occur in 70-90% of individuals at some point
- Increase as disease progresses from mild to severe stages
- Primary source of stress & burden to family and staff caregivers
- Common cause of institutionalization
- May be difficult to treat, and require more than one intervention



# So What Can We Do To Help???

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# Give Behavioral Treatment a Try

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Several international and national professional associations and government policies have recommended non-pharmacological interventions as the first-line treatment for the mood and behavior changes associated with cognitive decline.



# Sample Behavioral RTCs

## ◆ Skills training

- Improves depression
  - » Teri et al, 1997; Proctor et al., 1999; McCurry et al. 2005; Graf et al., 2007; Gitlin et al. 2008
- Decreases agitation
  - » Gerdner et al. 2002; Huang et al, 2003
- Improves physical activity
  - » Teri et al., 2003
- Decreases generalized behavioral problems
  - » Marriott et al., 2000; Teri et al., 2005; Moniz-Cook et al., 2008
- Reduces caregiver reactivity
  - » Teri et al, 1997, 2005; Chu et al., 2000; Gitlin et al., 2003, 2008, 2010; Burns et al., 2003

## ◆ Communication training

- Decreases problem communication
  - » Done et al., 2001
- Decreases problem behaviors and depression
  - » McCallion et al., 1999

## ◆ Family Counseling

- Delays institutionalization and improves caregiver reactivity
  - » Mittelman, 1996, 2004

## ◆ Environmental modifications

- Delays decline in IADLs
  - » Gitlin et al, 2001

# Characteristics of Behavioral Treatments

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- Mood and behavior changes are not “problems,” but attempts to communicate or compensate
- Understanding behavior requires thinking about both past and present circumstances
- The dyadic interaction is the focus of treatment
- Problems with verbal communication are a primary cause of mood and behavior changes
- Effective treatment requires responding to the underlying need/context, not just eliminating the “symptom” of concern
- Behavioral logs help identify behavioral patterns

# Focus on Quality of Life

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Quality of life for older adults with **chronic illness**: a sense of well-being, satisfaction with life, and self-esteem, accomplished through the care received, the accomplishment of desired goals, and the ability to exercise a satisfactory degree of control over one's life.



INSTITUTE OF MEDICINE  
OF THE NATIONAL ACADEMIES



# Seattle Protocols

**Depression**  
(1988, 2002)

**Agitation**  
(1993)

**Physical activity**  
(1993, 1998,  
2012)

**STAR**  
(1999, 2004)

**Sleep**  
(1993, 1998,  
2005)

**Early-stage  
memory  
loss** (2006,  
2011)

**RALLI/MCI** (2006)

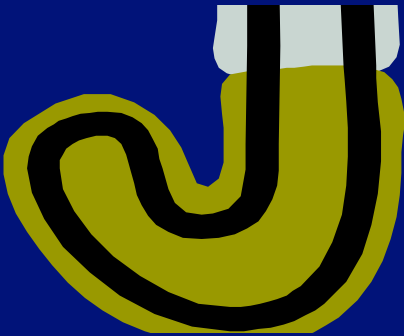
**STAR-C**  
(1999)

**AFH Sleep**  
(2006)

**STAR  
Effectiveness**  
(2009)

**AFH Staff  
Training**  
(2009)

**STAR-C  
Effectiveness**  
(2009, 2011)



Teri, et al. 2005. Research and practice in Alzheimer's disease and cognitive decline, Vol. 10, p. 153-158. New York: Springer.

# A Contextual/Behavioral Treatment: The Seattle Protocols

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- Evidence based
- Partnership with the dyad
- Standardized and individualized
- Caregiver skill building
  - ABC's of behavior change
  - Communication
  - Problem-solve difficult situations
  - Pleasant events
- Sustainability

Teri, et al., 2005. *Research and Practice in Alzheimer's Disease and Cognitive Decline*, 10: 153-158.

# Behavioral Treatments and QOL

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- **Maximize cognitive, social, and ADL function**
- **Support caregivers to reduce burden and enhance self-efficacy**
- **Treat depressive symptoms and encourage pleasant activities**
- **Improve or maintain physical mobility**

# Early Stage Support Groups

Logsdon RG, McCurry SM, & Teri L (2005). *Clin Gerontologist*, 30(2), 5-19.

Logsdon, R.G., Pike, K.C., McCurry, S.M., Hunter, P., Maher, J., Snyder, L., & Teri, L. (2010) *J Gerontol: Psychol Sci*, 65(6): 691-697

## Active treatment:

- Early Stage Memory Loss seminar program

## Control:

- Delayed treatment

Support Group Facilitators: Master's level social workers

9 weekly sessions, participant and care partner attend together

MMSE 18-30; Mean = 24

Assessments at baseline and post treatment (2 months)

# Early Stage Memory Loss Seminars

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Annual Facilitator Training and Update

Structured Manual with Outline, Discussion Topics, & Handouts

Session 1 — Introduction and Overview

Session 2 — Coping with Memory Problems

Session 3 — Medical Update-Diagnosis, Treatment and Research

Session 4 — Social and Family Relationships

Session 5 — Considerations in Daily Living

Session 6 — Legal and Financial Considerations (speaker)

Session 7 — Planning for the Future

Session 8 — Health considerations & Review



# Understanding the Diagnosis

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- Every person has unique brain pathology, symptoms, and progression (“If you’ve met one person with Alzheimer’s disease, you’ve met one person with Alzheimer’s disease”)
- Explain cognitive symptoms in terms of impact on daily function
- Identify areas of strengths as well as decline
- Focus on relationships and role identity
- Emphasis on hope and maintaining quality of life

# Dementia: Early Stage

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- Mini Mental State Exam 20-30
- Daily Living Skills
  - Ability to follow complex instructions
  - Ability to manage finances, bill paying, work
  - Memory limitations
- Safety Issues
  - Driving
  - Changes in medication regimen
  - Availability of firearms
  - Use of power tools (chain saw, woodworking tools, lawnmower)



# Special Challenges Early On

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- **Inconsistency of symptoms**
  - Forget “easy” information but recall past events
  - Function better in some contexts than others
- **Covering up/filling in the gaps**
  - Blaming others
  - Confabulation
- **Social language skills disguise underlying difficulties**
  - Executive functioning, communication, perceptual
  - Mood dysregulation

# Dementia: Middle Stage

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- **MMSE 10-20**
- **Daily Living Skills**
  - Household chores, laundry, shopping, cleaning
  - Ability to use the telephone
  - Physical mobility & balance
  - Ability to follow simple instructions
- **Safety Issues**
  - Home safety, kitchen appliances
  - Ability to stay home alone
  - Wandering, getting lost



# Special Challenges Midway

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- **Community isolation**
  - Caregiver reluctance to ask for help
  - Embarrassment over behavior changes
- **Caregiver health**
  - Stress-related chronic conditions
  - Lack of exercise
- **Care-receiver boredom and inactivity**
  - Loss of role identity can be profound
  - Identifying and providing pleasant, meaningful activities can be exhausting for caregivers
  - Deciding whether to try an adult day program

# Dementia: Late Stage

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- **MMSE less than 10**
- **Daily Living Skills**
  - Hands-on assistance with ADLs
  - Simple, structured, meaningful activity
- **Safety Issues**
  - Home safety, knives, cleaning supplies, etc
  - Eating nonfood items
  - Adequate nutrition & hydration
  - Choking & swallowing problems
  - Mobility & position changes
  - Communicating pain, discomfort

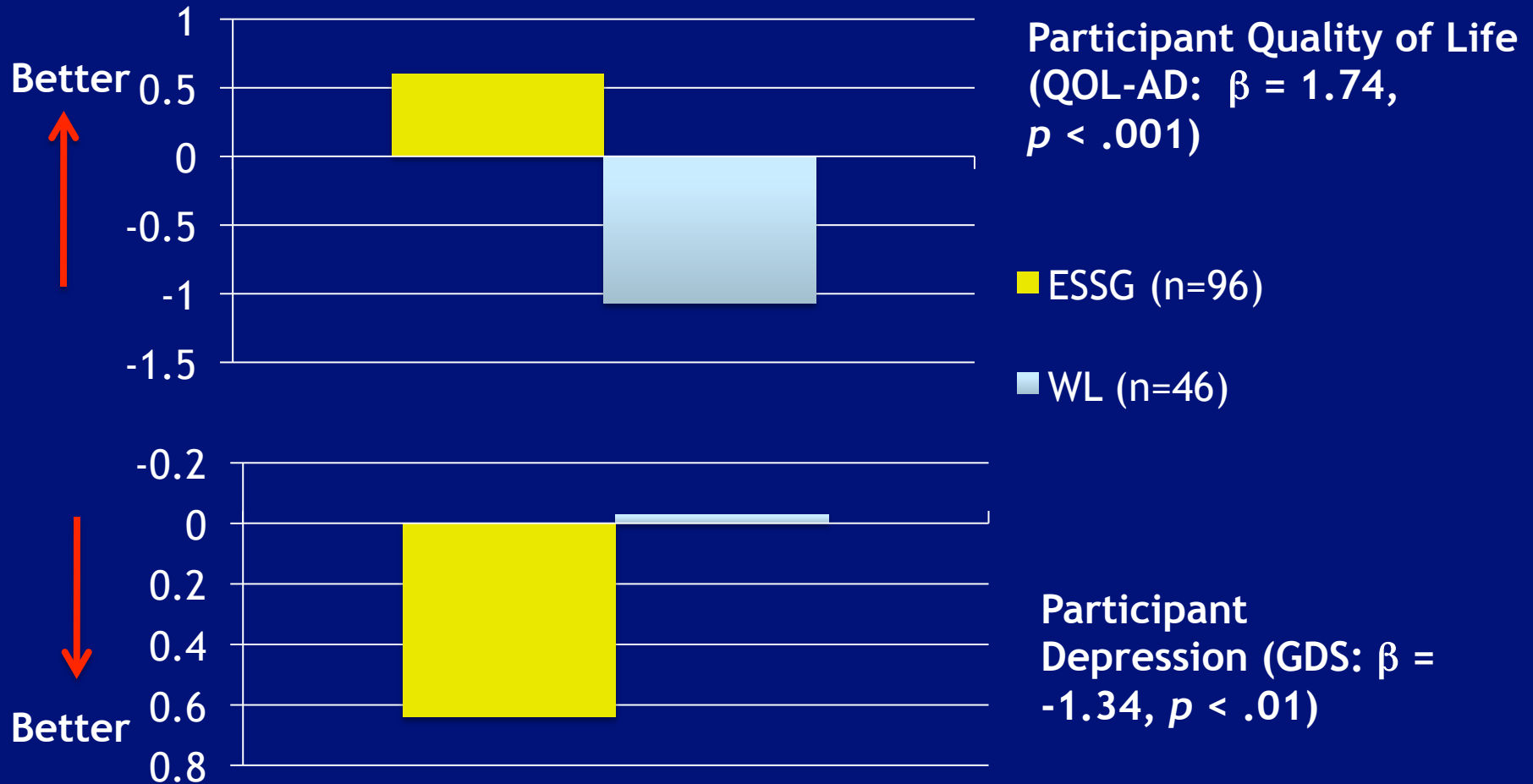


# Special Late Stage Challenges

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- **Residential placement questions**
  - Deciding when someone can no longer stay at home
  - Choosing among residential care alternatives
- **Legal/financial planning**
  - Problems if this hasn't been handled earlier
  - End of life decision making
- **Caregiver adjustment**
  - Establishing new life routines
  - Grief and relief

# Quality of Life Outcomes

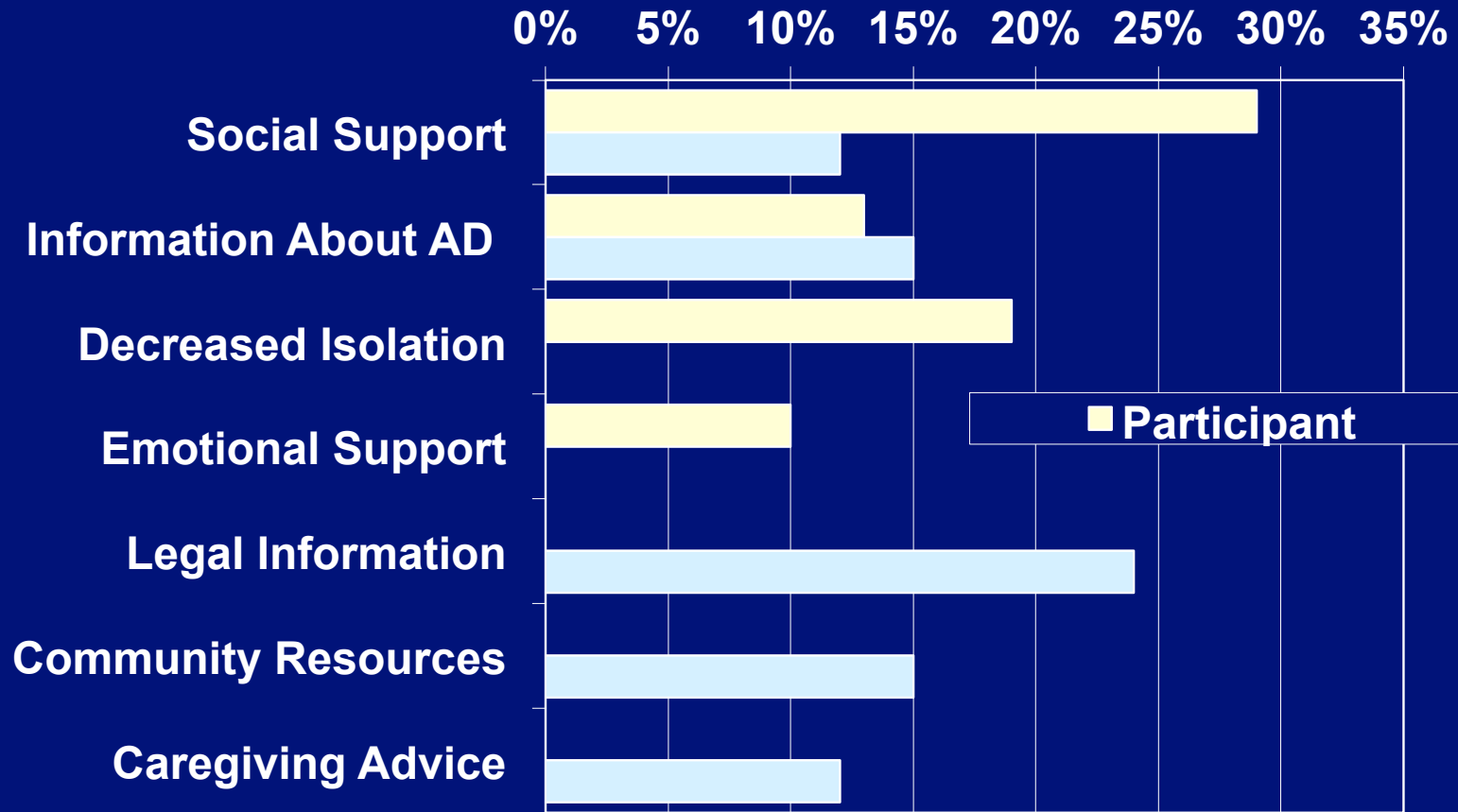




# ESML participants whose QOL improved also had significant improvement on:

- SF-36 Mental Health
  - Self Efficacy
  - Family Communication
  - Perceived Stress
  - Geriatric Depression Scale
  - RMBPC-Depression
  - RMBPC-Total
- 
- $p < .01$
- $p < .05$

# Benefits of Early Stage Groups



# Behavioral Treatments and QOL

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- Maximize cognitive, social, and ADL function
- **Support caregivers to reduce burden and depression**
- Treat depressive symptoms and encourage pleasant activities
- Improve or maintain physical mobility

# STAR-C: Caregiver Support

Teri L, McCurry SM, Logsdon RG, & Gibbons LE. (2005). Training community consultants to help family members improve dementia care: A randomized controlled trial. *The Gerontologist*, 45(6), 802-811.

## Active treatment:

- Seattle Protocols - communication, problem solving, pleasant events

## Control:

- Routine medical care

Caregiving consultants: Master's-level mental health counselors  
8 weekly sessions, monthly phone calls 4 months

MMSE 0-28; Mean = 14

Assessments at baseline, 3, 6, and 12 months

Funding: Alzheimer's Association Pioneer Grant P10-1800

# STAR-Caregivers: Overview

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- Focuses on mood and behavioral challenges in persons with dementia
- Systematic training approach
  - Standardized manual with session-by-session instructions
  - Handouts, tracking forms and reading materials for family members
- Gives caregivers a set of tools that can be used after treatment ends and at any stage of dementia care

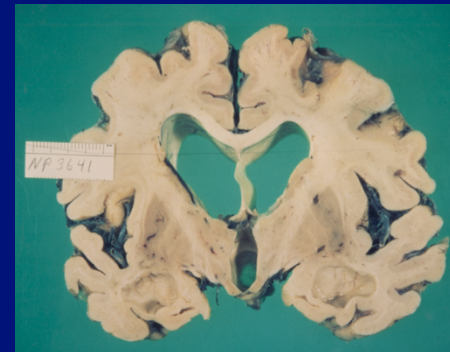
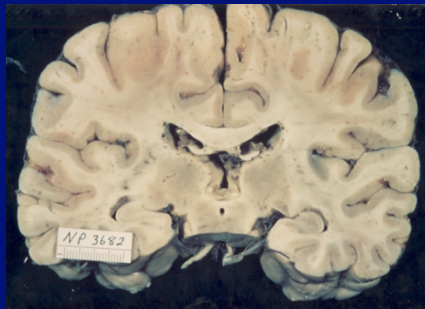
# STAR-C Content

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1. Introduction and identifying target behaviors
2. Realistic expectations
3. Communication
4. Observing the ABCs and problem-solving
5. Depression and negative thinking
6. Pleasant events
7. Caregiving issues
8. Maintenance and generalization

# Realistic Expectations

- Validate caregiver feelings
- Reinforce dementia education
- Explore alternatives for how to respond next time



Photographs courtesy of Dr. Thomas Bird, Seattle VAMC

# Communication

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- Communication can be an activator or a consequence.
- As cognitive decline progresses, nonverbal communication is more important; is your body sending the message you intend?
- Rapport building trumps information gathering or accuracy of facts
- Whenever there is a problem, check to see if there is a communication breakdown.





# Watch Nonverbal Cues: Be Polite!

Patience	Don't be in a hurry. Say/do one thing at a time. Focus on the relationship more than content.
Organization	Use prompts and reminders as needed. Don't keep people waiting. Make sure prosthetics are handy.
Laughter	Smile! Try to be pleasant and engaging. Don't be afraid of friendly humor. Sincere praise is a gift.
Ignore what you can	"Pick your battles." Don't correct or admonish unless the person is doing something unsafe or unhealthy. Watch for ageist stereotyping.
Tone of Voice	Cultivate a warm and respectful style. Try not to sound "bossy" or patronizing. Would <i>you</i> want to be talked to this way???
Eye Contact	Look directly at the person. Stand or sit at eye level. Smile/nod to acknowledge you heard what was said.

**“Listen with respect,  
comfort and redirect.”**

Linda Teri, Ph.D.



# Observing the ABCs

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Activator:

What happened before the behavior?



Behavior:

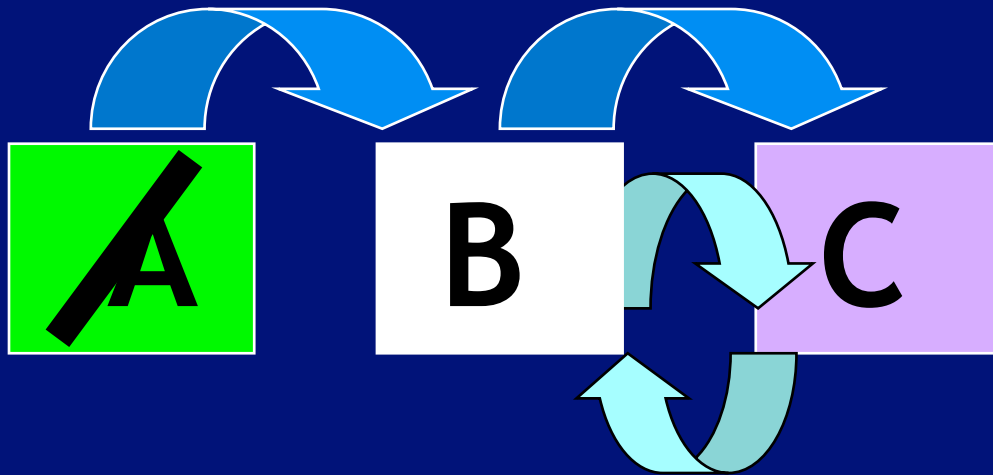
What exactly was the person with dementia doing? Paint a verbal picture!



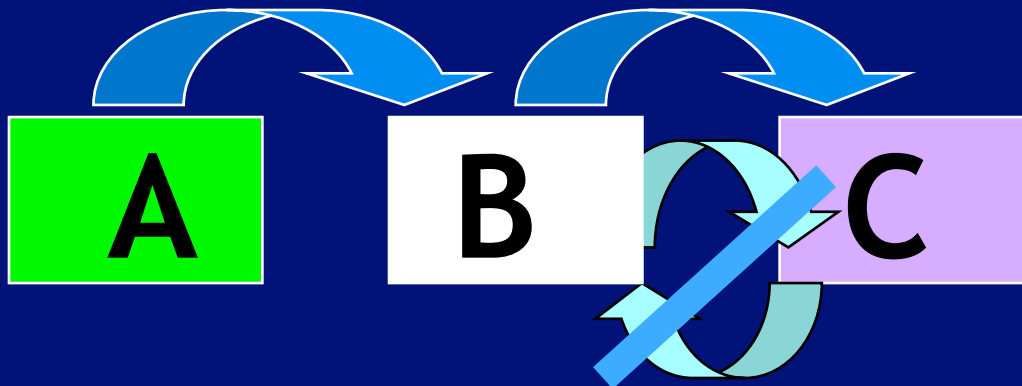
Consequence:

What happened after the behavior?

# Goals of the A • B • Cs



*Identifying and changing activators can prevent a behavior from happening*



*Changing your response to behaviors can reduce their duration, severity, and probability of occurring in the future*

# My Underlying Assumptions

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All behavior has a cause or serves a function.

The person with dementia is trying to make sense of the world, the same as you and I.

To understand behavior, you need to look at the context in which it occurs.

# A Case Example

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“Mom gets upset when she doesn’t get her way.”



# You Need to Get the Full Story

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“Mom has always been a controlling person. Lately she’s been causing trouble at the retirement home that she and dad moved to. She bosses people around at dinner and won’t let them sit at her table. She has a favorite chair that she always wants to sit in at community events and gets very angry when someone else tries to sit there. The staff say if she can’t learn to get along she and dad will have to move.

# A-B-C Card



What happened before? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_



What was the person with dementia doing? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Where did it happen? \_\_\_\_\_

\_\_\_\_\_

Who was there? \_\_\_\_\_

\_\_\_\_\_

When did it happen? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_



What happened after? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

**4 Ws: Which one behavior do you want to work on first???**





# Possible Target Behaviors

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1. Mom not letting other people sit at her dinner table.
2. Mom getting angry when people try to sit in her favorite chair at community events.
3. Mom “bossing people around”
4. Other behaviors?????

# A-B-C Card



What happened before? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_



What was the person with dementia doing? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

Where did it happen? \_\_\_\_\_

Who was there? \_\_\_\_\_

When did it happen? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_



What happened after? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

*What were possible activators (before the behavior)?*

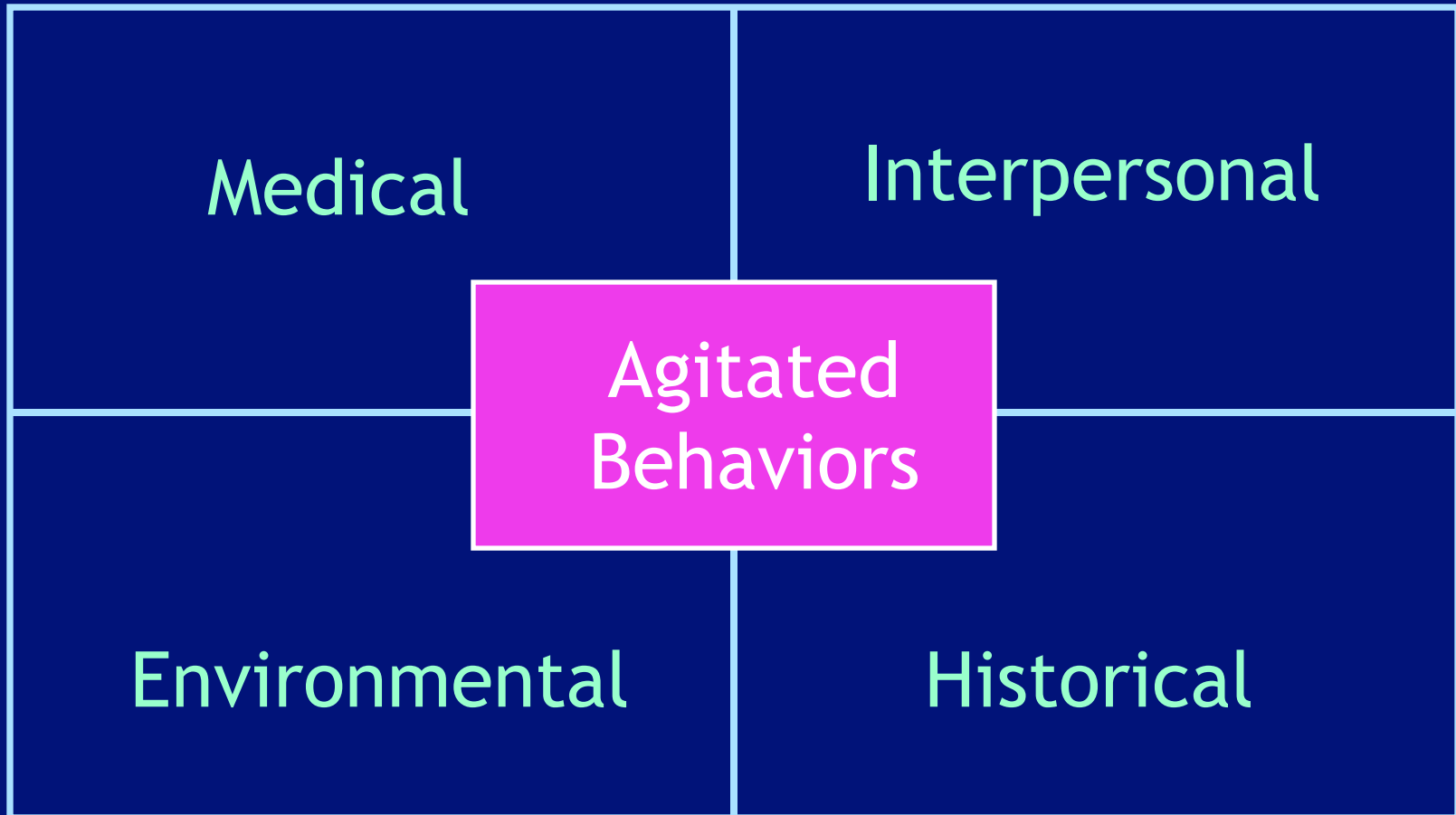
*What were some consequences that happened after the behavior?*

# Observation is How We Find Patterns




- Are there days that the behavior does *not* occur?
- Does it only happen around certain people?
- Does it have a cyclic pattern?
- Is it more likely under certain conditions?

# Brainstorming Activators and Consequences



# Keep the Whole Context In Mind

Activators	Behavior	Consequences
 <p data-bbox="156 619 620 711">Past <i>and</i> present “triggers” for behavior</p>		<p data-bbox="1296 636 1794 728">What happens after the problem behavior occurs</p>
<p data-bbox="98 782 475 825"><i>Get to know me!</i></p> <ul data-bbox="98 848 649 1310" style="list-style-type: none"><li>• Cultural background</li><li>• Past habits &amp; preferences</li><li>• Family &amp; social routines</li><li>• Religious beliefs</li><li>• Role changes</li><li>• Lifelong personality</li><li>• Education &amp; occupation</li><li>• Traumatic events</li></ul>	<p data-bbox="691 782 1031 825"><i>Gather history</i></p> <ul data-bbox="691 848 1234 1048" style="list-style-type: none"><li>• Is this a new behavior, or has it happened before?</li><li>• Is it a sudden onset or gradual change?</li></ul>	<p data-bbox="1271 782 1553 825"><i>What helps?</i></p> <ul data-bbox="1271 848 1789 1153" style="list-style-type: none"><li>• What does the behavior accomplish?</li><li>• What people, things or activities help the resident feel calm or happy?</li></ul>

## Steps for Developing and Evaluating Behavior Change Plan

What are you going to do differently? (to change antecedents or consequences)

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Did it work? \_\_\_\_\_

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What else can you try? \_\_\_\_\_

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*Brainstorm ideas  
for changing  
activators and  
consequences*

*Try it for a week*

*Modify the plan as  
needed*



**Video Observation**

**Looking for ABCs**

# STAR-C: RTC Design

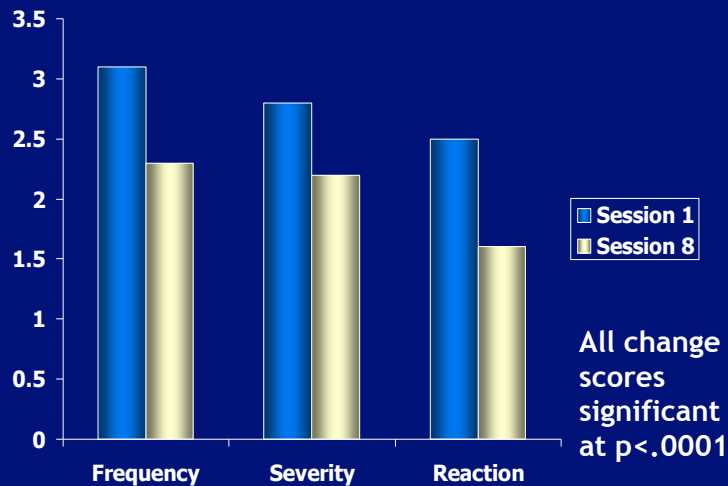
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- 95 caregiver/care recipient dyads
- Treatment conditions:
  - STAR-C intervention (n=47)
  - Routine Medical Care (RMC) (n=48)
- 8 weekly in-home sessions + 4 monthly phone calls
- Assessments conducted baseline, 2, and 6 months
- Interviewers blind to treatment conditions

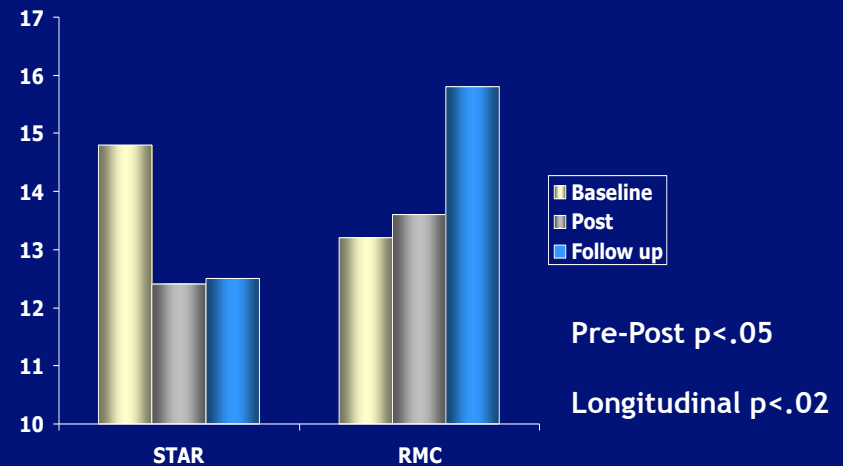


# STAR-Caregivers: RTC Results

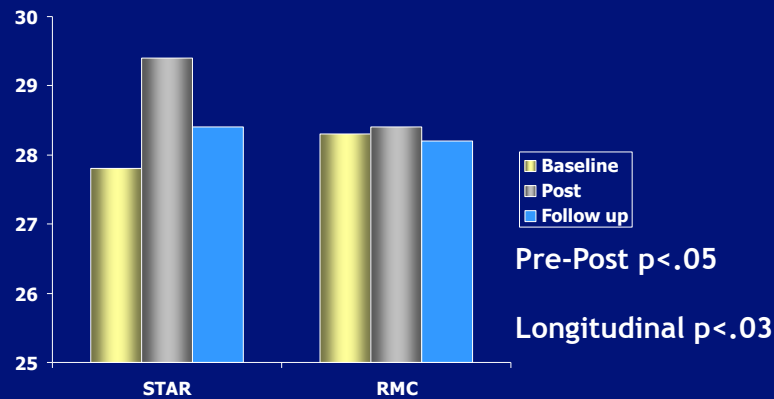
## Change in Target Behaviors During Treatment



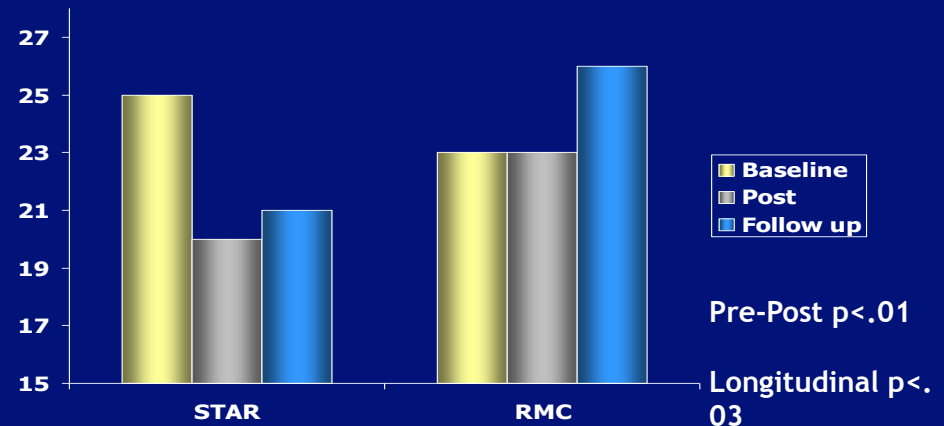
## Caregiver Depression: CESD



## Care Recipient Quality of Life (QOL-AD)



## Caregiver Burden: SCB



# Behavioral Treatments and QOL

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- Maximize cognitive, social, and ADL function
- Support caregivers to reduce burden and depression
- **Treat depressive symptoms and encourage pleasant activities**
- Improve or maintain physical mobility

# Depression & Pleasant Events

Teri L, Logsdon RG, Uomoto J & McCurry SM. (1997). Behavioral treatment of depression in dementia: A controlled clinical trial. *Journals of Gerontology: Psychological Sciences*, 52(4), 150-166.

**Active treatment:**

- Behavior Therapy-Pleasant Events/Problem Solving

**Control:**

- Typical Care or Wait List Control

**Therapists: PhD clinical psychologists**

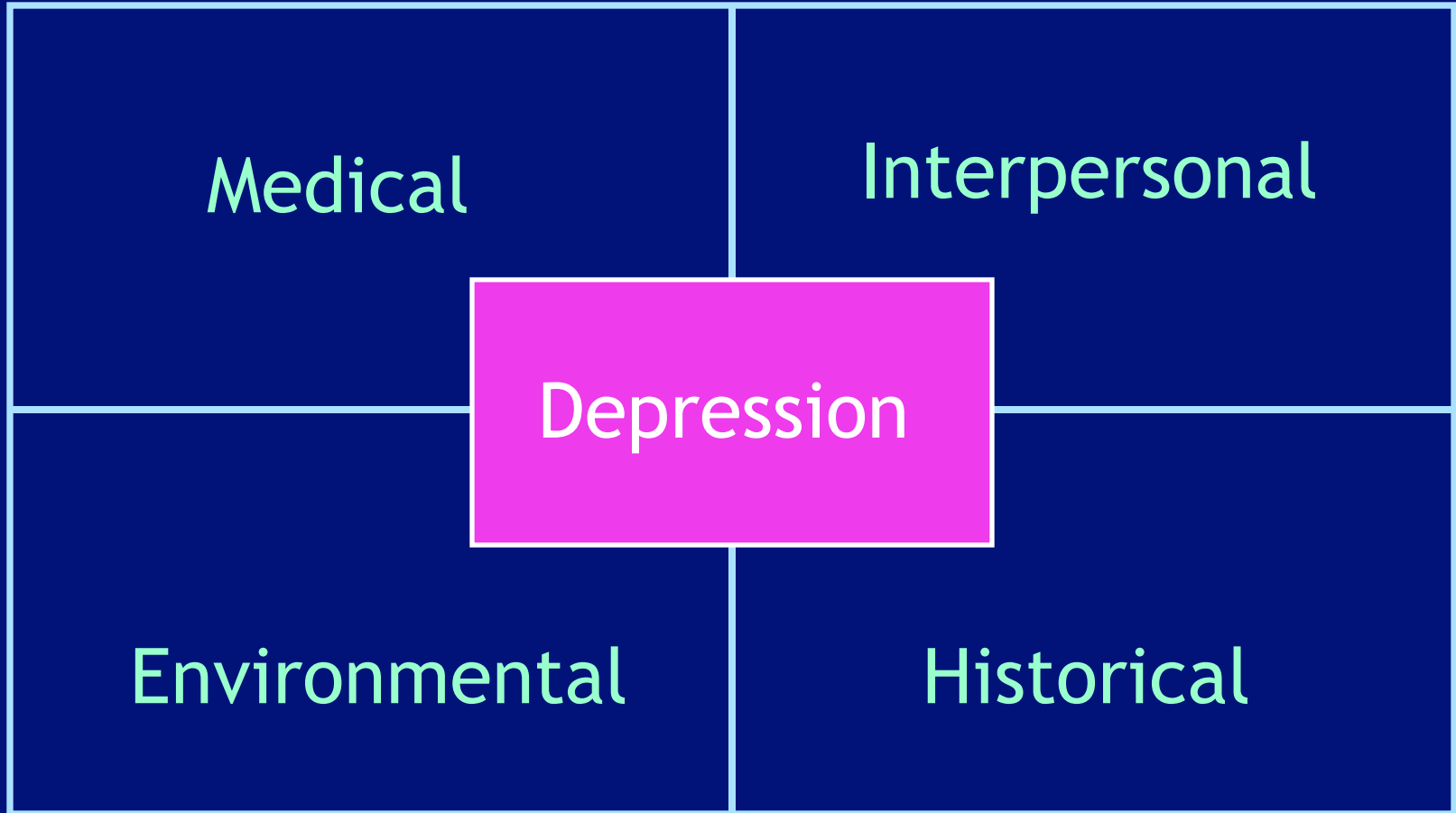
**9-week treatment duration**

**MMSE 0-29; Mean = 16**

**Assessments at baseline, post treatment, 6 months**

# Depression is a Behavior

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## Medical Causes

Brain changes from aging or dementia

Chronic medical illness

Stroke/heart disease

Medications

Physical frailty

Alcohol abuse

Sensory deficits

Insomnia

Lack of exercise

Seasonal depression (↓light)

## Environmental

Residential move

↓Household income

Stressful life events

Reminders of something sad

## Interpersonal

Boredom or loneliness

Lack of attention

Widowed or divorced

Unwanted role changes

Loss of independence

Being criticized or laughed at

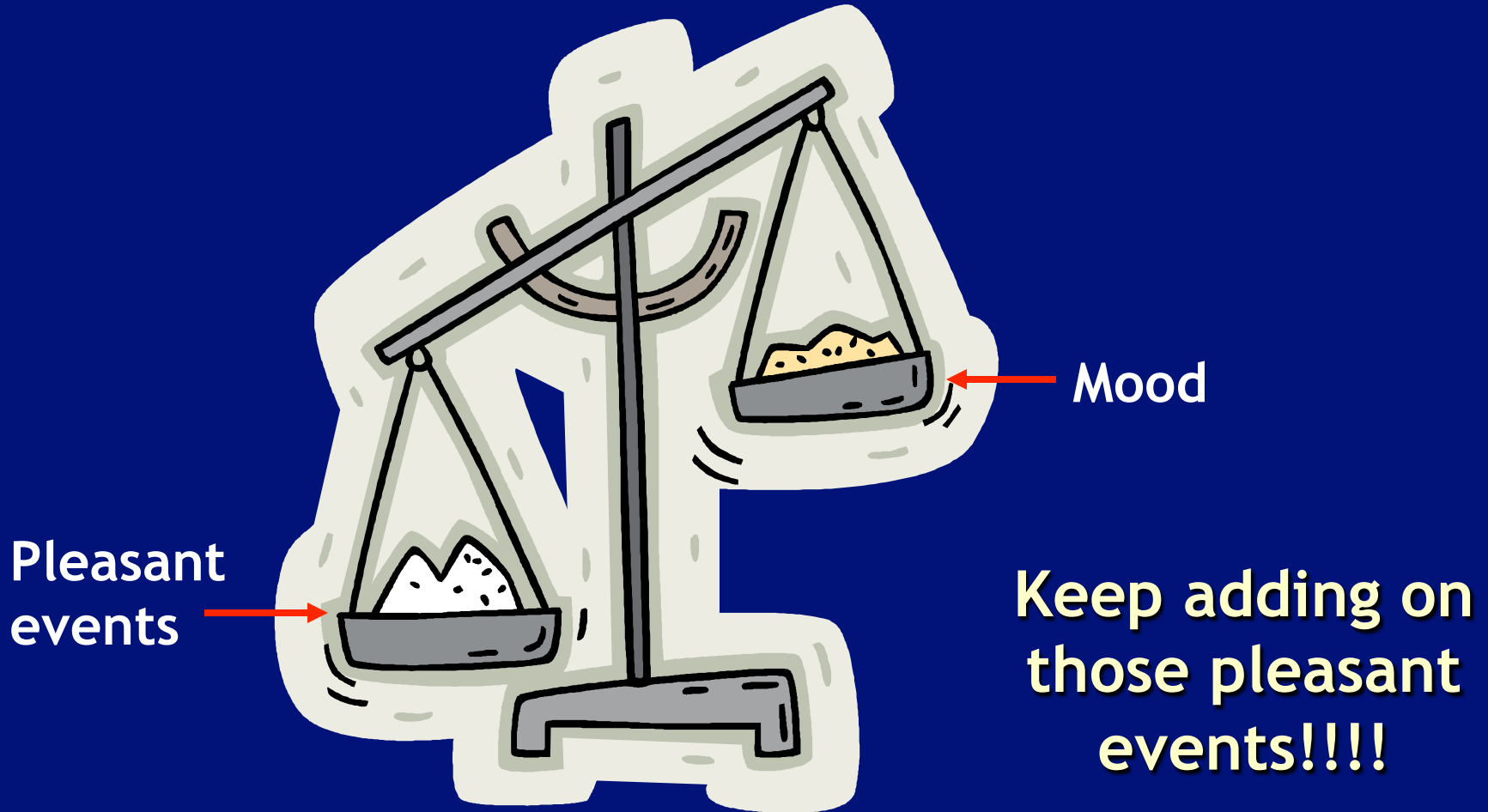
## Historical

Recurrent or family history of depression

Past traumas

Inability to do previously enjoyed activities

# Relationship between Mood and Pleasant Events



# Promoting Pleasant Events

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- Individuals with dementia retain many skills despite cognitive impairments.
- Interpersonal relationships are very important, and are fostered by shared pleasant activities.
- Caregiver depression and burden may be lessened by focusing on positive, rather than negative interactions.

# Identify and Reintroduce Pleasant Activities



- Not just any activity will do - it has to be tailored to the person.
- What did the person enjoy in the past?
- What does he/she enjoy now?
- Enhancing self-worth and satisfaction are as important as “fun.”
- How can tasks be modified to accommodate current abilities?
- Who is available to help with these activities?





## SLEEP STUDY

### PLEASANT EVENTS FOR OLDER ADULTS

- ◆ Seeing old friends
- ◆ Eating good meals
- ◆ Doing a job well
- ◆ Going for a walk
- ◆ Arranging flowers
- ◆ Sitting at a table
- ◆ Taking a shower
- ◆ Taking a bath
- ◆ Being with animals
- ◆ Sleeping soundly
- ◆ Listening to music
- ◆ Reading magazines
- ◆ Being acknowledged
- ◆ Being with happy people
- ◆ Breathing fresh air
- ◆ Being with children
- ◆ Getting a manicure
- ◆ Taking a bath
- ◆ Hearing a joke
- ◆ Wearing new clothes
- ◆ Talking on the phone
- ◆ Being invited out
- ◆ Holding hands
- ◆ Watching people
- ◆ Taking a walk
- ◆ Taking a nap
- ◆ Having visitors
- ◆ Telling stories
- ◆ Expressing love
- ◆ Solving a problem
- ◆ Having peace and quiet
- ◆ Complimenting someone
- ◆ Meeting someone new
- ◆ Being complimented
- ◆ Listening to the radio
- ◆ Talking on the phone
- ◆ Visiting with neighbors
- ◆ Hearing nature sounds
- ◆ Looking at a newspaper
- ◆ Having makeup applied
- ◆ Helping someone else
- ◆ Wearing clean clothes
- ◆ Seeing someone else happy
- ◆ Looking out the window at nature
- ◆ Reading a good story, play or poem
- ◆ thinking about something good in the future
- ◆ Feeling the Lord in his/her life
- ◆ Being told he/she is needed
- ◆ Sleeping under warm covers when it is cold outside
- ◆ Snuggling in a comfortable chair
- ◆ Having family members do something that makes him/her proud
- ◆ Taking care of plants and gardens
- ◆ Having his/her hair brushed
- ◆ Watching the clouds in the sky
- ◆ Having a good open talk with a friend
- ◆ Hearing about family activities

# Pleasant Events Schedule: AD

© 1995 R. G. Logsdon, Ph.D. & L. Teri, Ph.D.

Instructions: This schedule contains a list of events or activities that people sometimes enjoy. It is designed to find out about things your relative has enjoyed during the past month. Please rate each item twice. The first time, rate each item on how many times it happened in the past month (frequency); the second time, rate each event on how much your relative enjoys the activity.

Activity	Frequency			Enjoy		
	Not At All	1 to 6 Times	7 or more Times	Not At All	Some-what	A Great Deal
1. Being outside						
2. Shopping, buying things						
3. Reading or listening to stories, magazines, newspapers						
4. Listening to music						

**Ask the family:** *What does your relative enjoy doing “A great deal”?*  
*What activities does he or she enjoy “Not at all”?*

Every interaction can be a  
pleasant event.



Pleasant events are everyone's  
job!

## A-B-C Problem Solving Plan



**Activator:** What happens before? \_\_\_\_\_

\_\_\_\_\_



**Behavior:** What is the person doing? \_\_\_\_\_

\_\_\_\_\_

Where does it happen? \_\_\_\_\_

Who is there? \_\_\_\_\_

When does it happen? \_\_\_\_\_



**Consequence:** What happens after? \_\_\_\_\_

\_\_\_\_\_

### Steps for Developing and Evaluating Behavior Change Plan

What are you going to do differently? (to change antecedents or consequences)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Did it work? \_\_\_\_\_

\_\_\_\_\_

What else can you try? \_\_\_\_\_



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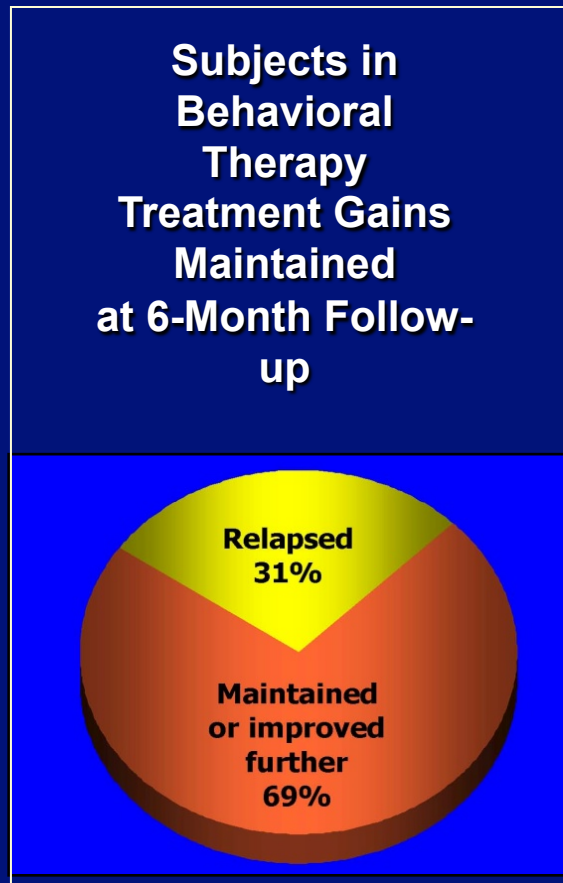
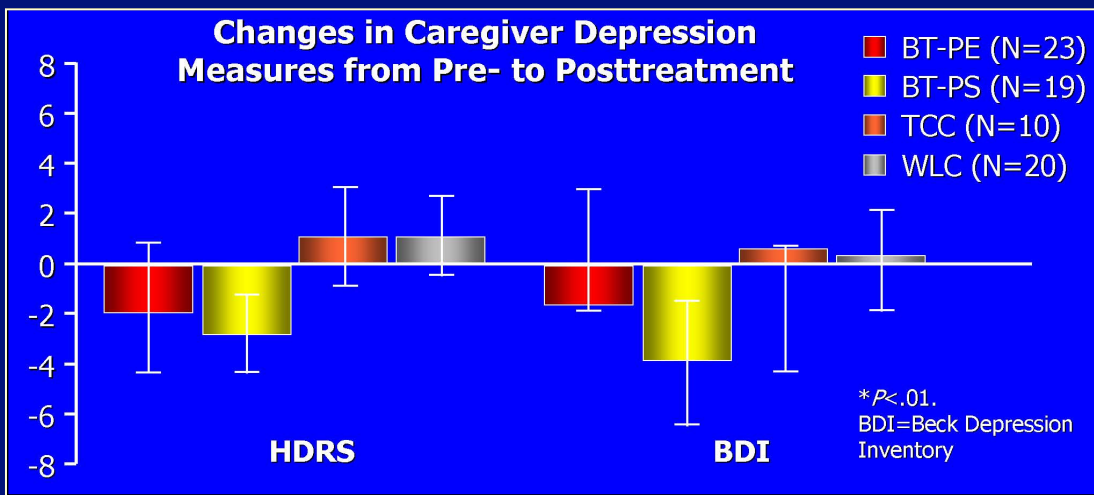
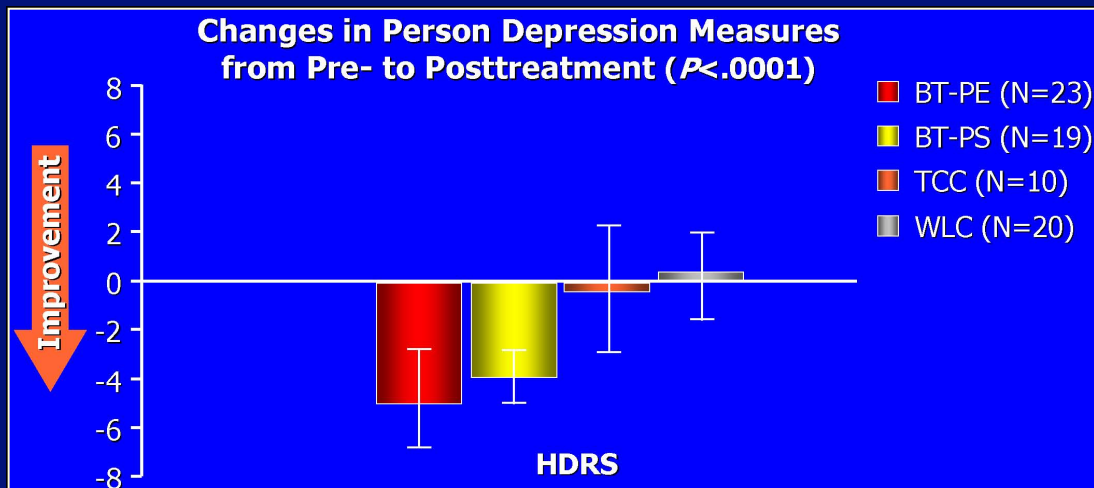
**Pleasant events can:**

- Reduce likelihood of a behavior occurring (activator)
- Reduce its duration/severity (consequence)
- Open up a world of possibilities to try when you feel “stuck”
- Generally improve everyone’s mood and quality of life

**Video Observation**

**Looking for ABCs**

# Behavioral Treatment of Depression in Dementia



# Behavioral Treatments and QOL

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- Maximize cognitive, social, and ADL function
- Support caregivers to reduce burden and depression
- Treat depressive symptoms and encourage pleasant activities
- **Improve or maintain physical mobility**

# Why Combine Exercise with Behavioral Treatment?

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Persons with AD, compared with age-matched controls:

- Are more undernourished
- Exhibit ambulation and mobility deterioration over 1 year
- Have 3 times higher risk for falls and fractures
- Are significantly less likely to recover from falls and fractures

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Wolf-Klein et al. *Int Psychogeriatr*, 1994, 6, 135-142, Buchner et al. *JAMA*. 1987, 257, 1492-1495, Morris et al. *J Gerontol*. 1987, 42, 412-417, Oleske et al. *J Am Geriatr Soc*. 1995, 43, 741-746, Tinetti et al. *J Am Geriatr Soc*. 1995, 43, 741-746, Krenz et al. *Med Care*. 1988, 26, 453-461, Magaziner et al. *J Gerontol*. 1990, 45, M101-M107.



# Physical Function

Teri L, Gibbons LE, McCurry SM, Logsdon RG, Buchner D, Barlow W, Kukull W, LaCroix A, McCormick W, Larson E. Exercise plus behavior management in patients with Alzheimer's disease: A controlled clinical trial. (2003) *JAMA*, 290(15); 2015-2022.

## Active treatment:

- Home-based exercise - aerobic, strength, balance, flexibility
- Behavior therapy - communication, ABC problem-solving

## Control:

- Routine Medical Care

Therapists: Master's level home health providers (SW & PT)

12-week treatment duration, monthly follow-up 4 months

MMSE 0 to 29; Mean = 17

Assessments at baseline, 3, 6, 12, and 24 months

N=153 dyads of persons with AD and family caregivers

Funded by the National Institute on Aging AG10845 and AG14777

# Challenges of Exercise for Individuals with Dementia

- Reluctance to try new activities
- Difficulty learning & remembering to do exercises
- Inability to exercise independently due to safety concerns
- Family caregivers lack knowledge about exercise, already burdened by daily tasks, may be physically frail



# Promoting Exercise for Individuals with Dementia

- What “exercise” did the person enjoy in the past?
- Provide support, assistance, lots of repetition for group programs
- Monitor for safety; simplify, avoid or closely supervise use of unfamiliar equipment
- Encourage family caregivers to incorporate a daily walk to the routine, and gradually increase the time, distance, and speed of walking
- Make physical activity a pleasant event





What happened before? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What was the person with dementia doing? Gene refused to exercise. He said he didn't feel like it and would do it later

Where did it happen? In the family room of their home

Who was there? Gene and Betty

When did it happen? In the morning, 10 am

What happened after? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



What happened before? Gene was looking at magazines while Betty did laundry. Betty came in and said it was time to exercise at the time they had agreed on earlier



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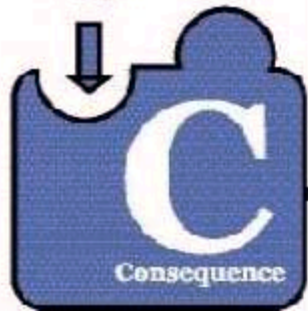
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Where did it happen? In the family room of their home

Who was there? Gene and Betty



When did it happen? In the morning, 10 am

What happened after? Betty was disappointed and said so. She reminded Gene that he promised to exercise today at 10, and that it is good for him. Pointed out that when he says he will do it later, he never does. When Gene still refused, Betty gave up and neither one did the exercises.

# Steps for Developing and Evaluating Behavior Change Plan

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What are you going to do differently? (to change antecedents or consequences)

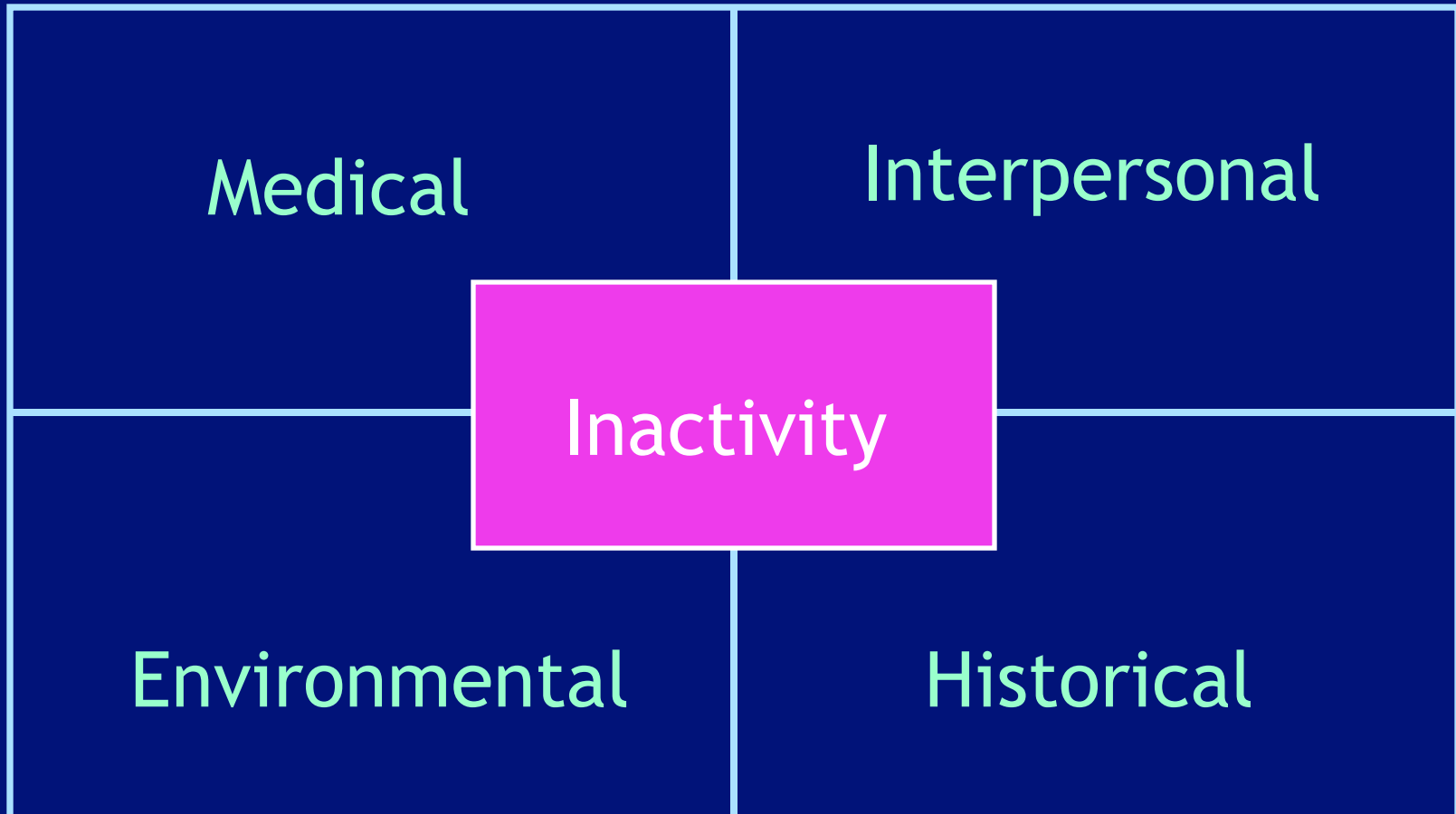
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*Brainstorm Ideas For Changing  
Activators and Consequences*

# Brainstorming to Increase Exercise



*Don't forget to think about communication!  
How can pleasant events be used?*



# Betty's Ideas

## Steps for Developing and Evaluating Behavior Change Plan

What are you going to do differently? (to change antecedents or consequences)

Possible Activators: 1) Exercise earlier in the day before Gene gets involved in something else or later in the day when he is bored; 2) Have Gene get dressed in his exercise clothes when he first gets up; 3) Offer Gene a choice: "Do you want to exercise now or in ½ hour?" rather than saying he has to do it now; 4) Invite their son to come exercise with Gene some days

Possible Consequences: 1) Betty won't argue or reason with Gene; 2) If Gene refuses, come back in ½ hour and try again; 3) Betty can start exercising in front of Gene & then ask him to join in & help her; 4) Tell Gene after exercise they will go out for ice cream or another treat

## A-B-C Problem Solving Plan



What happened before? Gene was looking at magazines while Betty did laundry. Betty came in and said it was time to exercise



What was the person with dementia doing? Gene refused to exercise. He said he didn't feel like it and would do it later

Where did it happen? In the family room of their home

Who was there? Gene and Betty

When did it happen? In the morning, 10 am



What happened after? Betty was disappointed, tried reasoning & various arguments to persuade Gene, then gave up when he still refused.

### Steps for Developing and Evaluating Behavior Change Plan

What are you going to do differently? (to change antecedents or consequences)

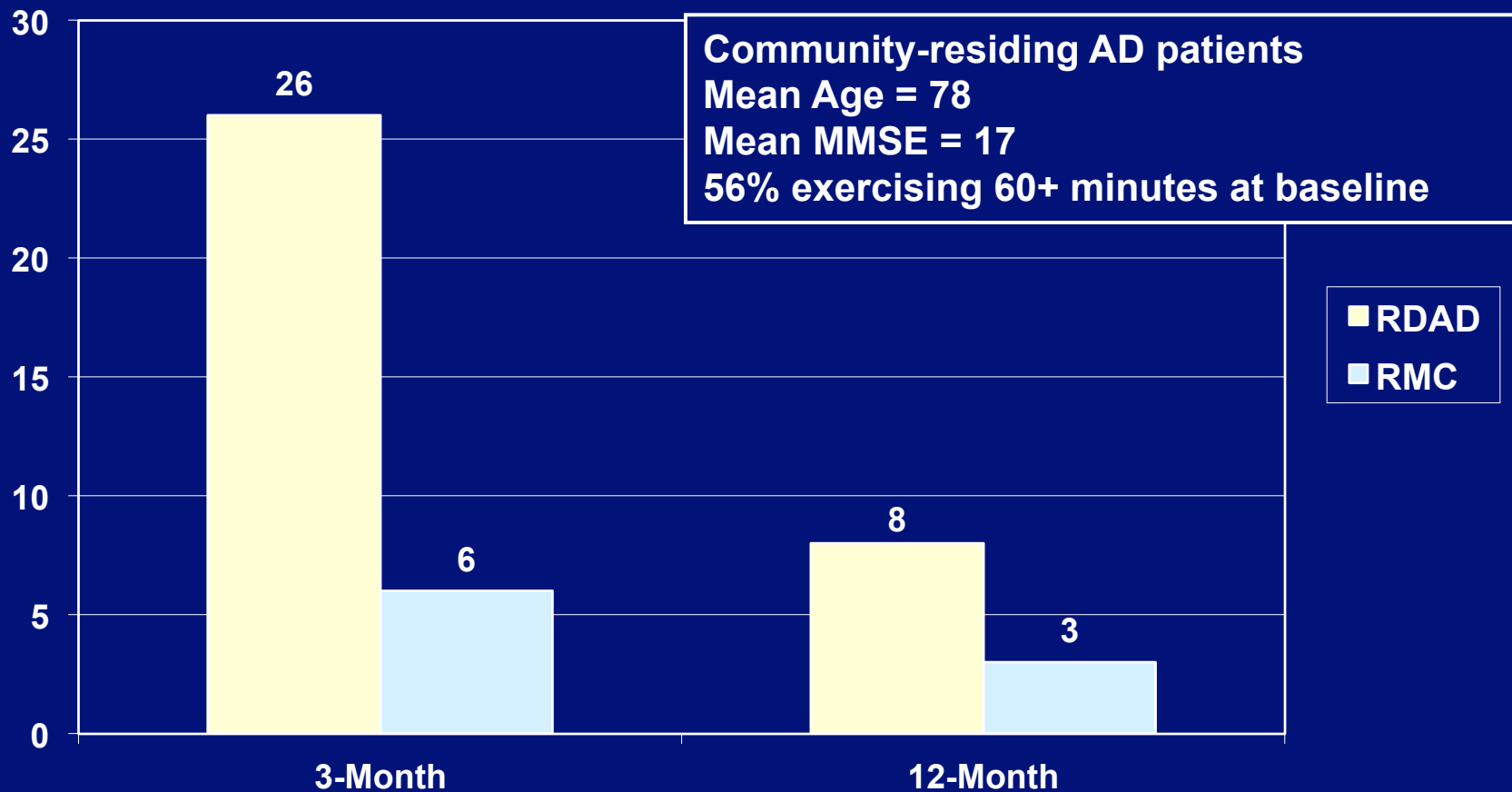
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Did it work? \_\_\_\_\_

What else can you try? One of the other ideas on the list above

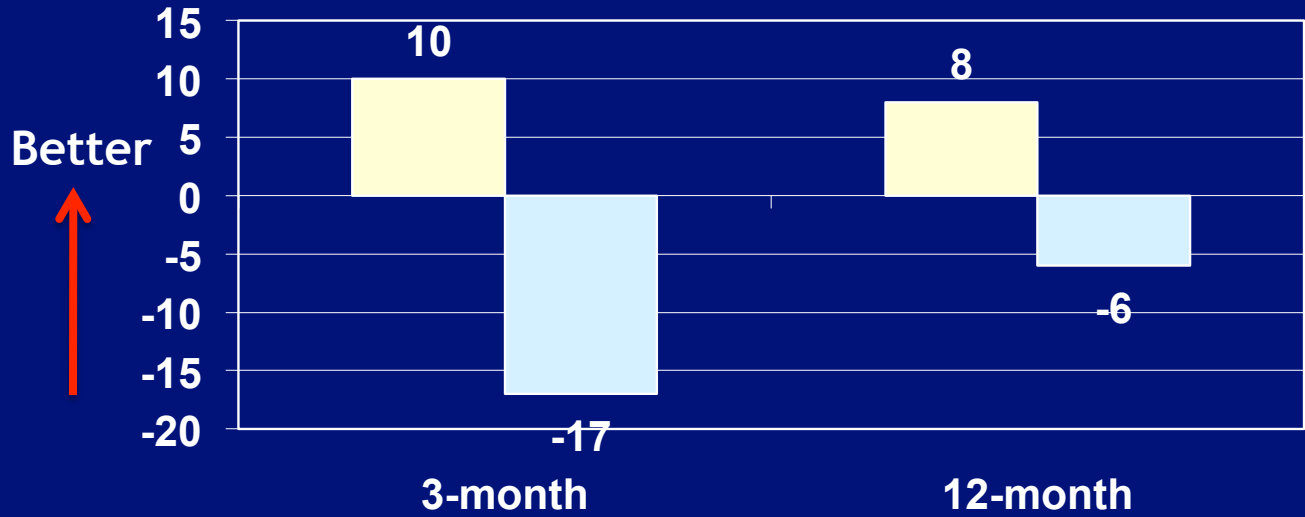
# Change in Percent of Subjects Exercising 60+ Minutes a Week



Teri, et al, 2003

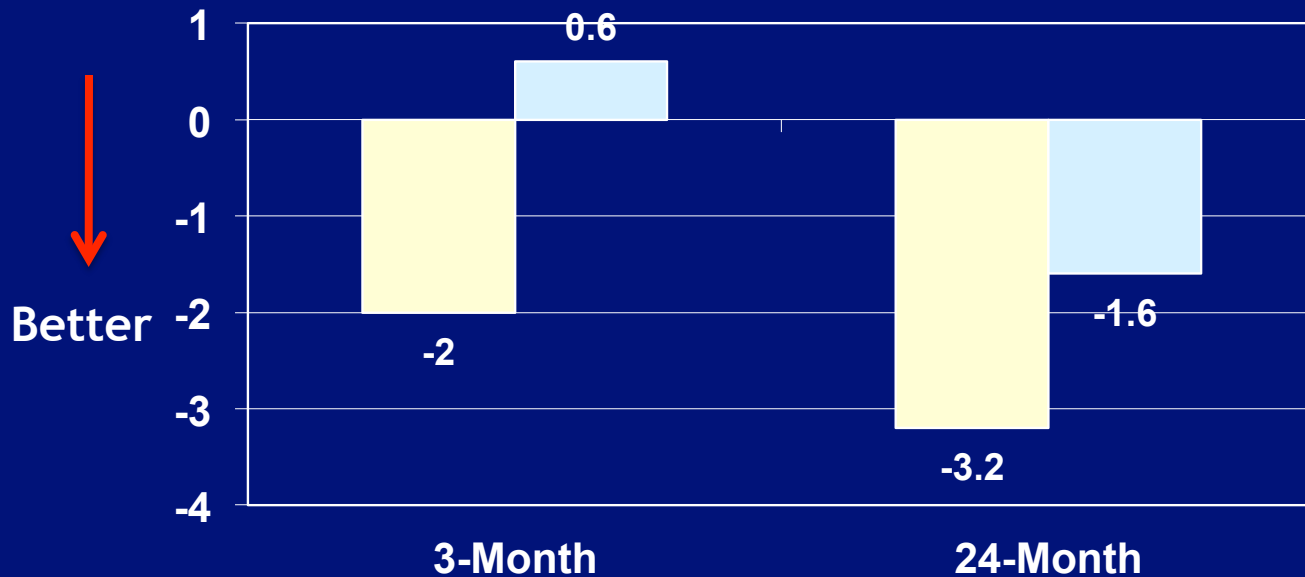
ITT: Pre-Post <.01

# Change in Activities and Depression



SF-36 Role Functioning

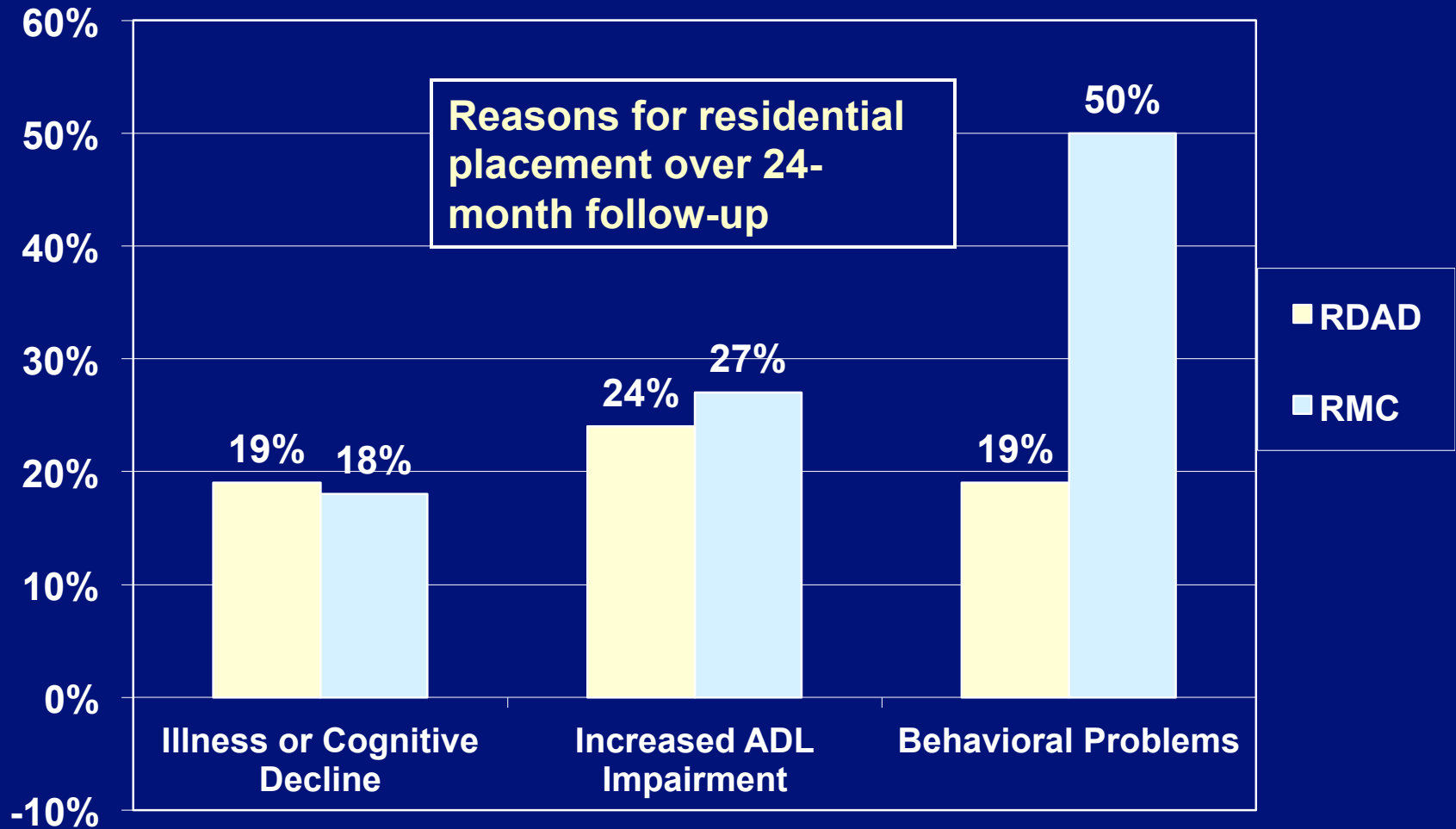
ITT: Pre-Post  
 $p < .01$



HDRS, Pts >6  
on Cornell at  
baseline

ITT: Pre-Post  
 $p < .05$   
Longitudinal  
 $p = .05$

# Change in Residential Status



# Summary: Non-pharmacological Treatment of Dementia

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- Neurocognitive disorders affect health and well-being both directly and indirectly.
- They change the lives of both the diagnosed person and her/his family and friends.
- Behavioral interventions may alter the experience of the disease & quality of life for both the diagnosed person and for those who care for him or her.

# Dementia and Quality of Life

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- Quality of life as perceived by the person with dementia does not necessarily decline due to memory loss or cognitive decline.
- Quality of life is strongly influenced by mood.
- Mood is influenced by pleasant activities, exercise, and social support.
- Family members, friends, and other caregivers can significantly impact QOL for individuals with dementia.
- What's good for the person with dementia is good for the caregiver.

# Work All The ABC Steps!!!

<b>Realistic expectations</b>	How is dementia impacting daily function at this stage of disease?
<b>Communication</b>	Verbal and nonverbal: both matter
<b>ABC Problem-solving</b>	Observe the 4 Ws (keeping a log can help)  Activators & Consequences: medical, environmental, interpersonal, historical  Brainstorming lots of ideas
<b>Pleasant events</b>	Every interaction can be a pleasant event!  Maintenance of self-worth and role identity is as important as “fun”



# A-B-Cs: Simple but Tricky

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- Creative brainstorming is not always easy
- Behaviors can be influenced by more than one thing at a time
- Some activators and consequences are easier to change than others
- The message being communicated is more important than the actual behavior

# Caregivers Hold the Keys to Success

- Energy, desire, ability to do things differently
- Willingness to ask for and accept help from others
- Flexibility in thinking and problem solving
- Sense of humor
- Patient, but able to be firm
- Belief that things can change
- Good prior relationship with care recipient





Perfection is  
not the goal.

# Limitations to Behavioral Treatments

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- Not crisis management.
- No treatment works for all people all of the time.
- Consistency is important, so everyone involved in care needs to be on board with the plan.
- Both caregiver and care-recipient factors influence what behavioral interventions are feasible and effective.

# Where Should We Head Next?

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- **Increased understanding of how to tailor interventions for caregivers and care-recipients**
  - Understanding heterogeneity of both caregiver and care recipient to improve outcomes on effectiveness.
- **Dissemination of evidence-based programs**
  - Effective strategies for dementia care easily accessible for families and health care workers
- **Improved care of persons with dementia across the continuum of disease**

# Seattle Protocol Translation Sites

## ■ STAR-C

### ◆ New Mexico

- State of NM - DSHS workers
- Funding: AoA (2008, E. Costilla)

### ◆ Oregon

- State of OR - Case managers
- Funding: AoA (2010, J. Mead)

### ◆ Washington

- State of WA- Case managers
- Funding: Internal WA DSHS funds (2011, L. Korte)

- ◆ An abbreviated training protocol has been piloted in Oregon, Washington states

## ■ RDAD

### ◆ Ohio

- Alz Assn counselors
- Funding: AoA (2008, S. Bollin)

### ◆ Washington

- State of WA - Case managers
- Funding: NIA (2012, L. Teri)

## ■ STAR-VA

- B. Karlin
- VA-CLC Mental Health Providers
- Funding: VA (2010, 2012, B. Karlin)

# The Seattle Protocols Core Research Team

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June van Leynseele

*And the many persons with dementia and family caregivers who have shared their lives and experiences with us.*

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