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RESOURCES FOR INTEGRATED CARE

Resources for Plans and Providers for Medicare-Medicaid Integration

Geriatric-Competent Care: Caring for Individuals with Alzheimer's Disease and Related Dementias

Understanding and Responding to Behavioral Symptoms Among Individuals with Alzheimer's Disease and Related Dementias

Overview

- This is the fourth session of a four-part series, "Geriatric-Competent Care: Caring for Individuals with Alzheimer's Disease and Related Dementias."

- Each session will be interactive (e.g., polls and interactive chat functions), with 60 minutes of presenter-led discussion, followed by 30 minutes of presenter and participant discussions.

- Video replay and slide presentation are available after each session at: www.resourcesforintegratedcare.com

Understanding and Responding to Behavioral Symptoms Among Individuals with Alzheimer's Disease and Related Dementias

Developed by:

- The American Geriatrics Society
- Community Catalyst
- The Lewin Group

Hosted by:

The Medicare-Medicaid Coordination Office (MMCO)
Resources for Integrated Care

Continuing Education Information

- **Accreditation:**

The American Geriatrics Society is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.

- **Continuing Medical Education (CME):**

The American Geriatrics Society designates this live educational activity for a maximum of 1 AMA PRA Category 1 Credit™.

- **Continuing Education Credit for Social Workers:**

The National Association of Social Workers (NASW) designates this webinar for a maximum of 1 Continuing Education (CE) credit.

NOTE: The following states do not accept National CE Approval or National NASW Programs: Idaho, Michigan, New Jersey, New York, Oregon, West Virginia

Support Statement

This webinar is supported through the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) to ensure beneficiaries enrolled in Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated, coordinated care to Medicare-Medicaid enrollees, MMCO is developing technical assistance and actionable tools based on successful innovations and care models, such as this webinar series.

To learn more about current efforts and resources, visit

Resources for Integrated Care at: **www.resourcesforintegratedcare.com**

Webinar Planning Committee and Faculty Disclosures

The following webinar planning committee members and webinar faculty have returned disclosure forms indicating that they (and/or their spouses/partners) have no affiliation with, or financial interest in, any commercial interest that may have direct interest in the subject matter of their presentation(s):

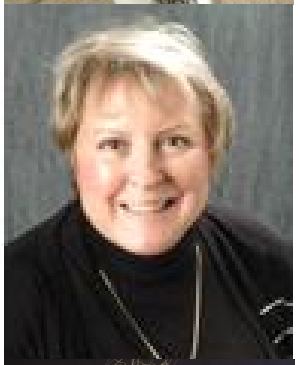
Planning Committee:

- Gregg Warshaw, MD
- Nancy Wilson, MSW

Faculty:

- Gregg Warshaw, MD
- Geri R. Hall, PhD, ARNP, GCNS, FAAN
- Beth Spencer, MA, LMSW

Introductions



- Gregg Warshaw, MD, Professor Emeritus of Family Medicine and Geriatric Medicine, University of Cincinnati (UC) College of Medicine
- Geri R. Hall, PhD, ARNP, GCNS, FAAN, Advanced Practice Nurse, Banner Alzheimer's Institute
- Beth Spencer, MA, LMSW, University of Michigan School of Social Work

Webinar Outline/Agenda

- Polls
- Context of behavioral changes associated with Alzheimer's disease and related dementias
- Preventing and managing non-cognitive behaviors in dementia
- Helping families with problem solving for behavioral changes
- Resources
- Q&A
- Evaluation

Webinar Learning Objectives

Upon completion of this webinar, participants will be able to:

- Define common behavioral changes in progressive dementias and identify characteristics of the person, environment, and other triggers for those behaviors
- Identify some key issues in effective assessment of behavioral changes
- Demonstrate basic knowledge of some evidence-based non-pharmacological strategies for preventing or reducing difficult behaviors

Context of Behavioral Changes Associated with Alzheimer's Disease and Related Dementias

Gregg Warshaw, MD

Alzheimer's Disease

- **Cognitive Symptoms**
  - Memory, Language, Thinking, Reasoning

- **Behavioral and Psychiatric Symptoms**
  - Occur in many adults with Alzheimer's disease
  - Early in the illness may appear as changes in personality
  - Distressing and challenging to families
  - Can be prevented and/or managed if caregivers are provided training and support

Dementia and Behavioral Symptoms

Disruptive

- Sleep Disturbance
- Appetite Change
- Irritability
- Disinhibition
- Wandering
- Hoarding

Mood

- Anxiety
- Apathy
- Depression

Aggression

- Agitation
- Verbal Disruptions
- Physical Aggression

Psychosis

- Delusions
- Hallucinations

Alzheimer's disease or a New Problem?

- First, is the symptom resulting from...
  - A new condition (e.g., infection)?
  - A pre-existing medical problem (e.g., chronic pain)?
  - An adverse drug event (e.g., new anticholinergic Rx)?
- Disturbances that are new, acute in onset, or evolving rapidly are most often due to a medical condition or medication toxicity

Assessment

- History from patient and informant; ideally someone who has directly observed the behavior
  - Temporal onset
  - Course
  - Associated circumstances
  - Recent stressors
  - Caregiver status

Behavior and Dementia Type (I)

CASE

- 80-year old woman
- 9-month history of impaired short-term memory
- Mini-mental 23/30; decline in executive functions
- Family concerned about her hallucinations of small children and animals
- More trouble walking and has hand tremors
- Exam: some increased muscle tone and resting tremors

Behavior and Dementia Type (II)

- Not all dementias in older adults are Alzheimer's disease
  - Fronto-temporal degeneration
  - Lewy Body Disease
  - Vascular dementia
  - Parkinson's disease

Treating Behavioral Disorders Associated with Dementia – Evidence-base (I)

- Atypical antipsychotics for aggression and psychosis – may have some benefit (controversial) but must be balanced with risks:
  - cerebrovascular
  - extrapyramidal symptoms (ETS)
  - metabolic (2006)
- All antipsychotic agents now carry an FDA warning regarding increased all-cause mortality in dementia

Treating Behavioral Disorders Associated with Dementia – Evidence-base (II)

- Need to understand precipitating factors and causes of excess disability - PREVENTION
- Interventions involve creativity and trial and error
- Use non-pharmacological treatments first to reduce risk of adverse drug events
- Always balancing risk and benefit of any medication use and individualizing approach

THE DAILY NEWS

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United States Proclaims Peace

Breaking News:

The United States of AMERICA has prolaimed peace with Canada.

The Canadian army has returned to Canada without causualties.

The United States of America is thankful for the brave efforte of the armed forces and the commanders for ending the dispute in a thrifty and heroic manner.

All military personnel are to receive recognition form the President.

Relations between Canada and the United States have spanned more than two centuries. This includes a shared British cultural heritage, and the eventual development of one of the most stable and mutually-beneficial international relationships in the modern world. Each is the other's chief economic partner and tourism and migration between the two nations has increased rapport. The most serious breach in the relationship was the War of 1812, which saw the United States attempt several invasions of Canadian territory, met by retaliatory invasions of US territory by Britain, until a military stalemate was reached.

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Case Study

- 82-year old husband/caregiver and his 80-year old wife with AD
- He is concerned because his wife has wandered out of their house several times in the past month and they live on a fairly busy street
- He wants to know if you can prescribe a medication that will keep her from wandering

Case Study

- The 83-year old wife/caregiver of your 85-year old patient with AD is on the telephone
- She is concerned because her husband is having increasing difficulty sleeping through the night
- The problem has developed slowly over the past several months
- He falls asleep ok but is awake again in a few hours and this is disturbing her sleep
- She is desperate and wants you to get the doctor to prescribe something that will “knock him out” at night

Case Study

- A 77-year old woman with AD presents with her 50-year old caregiver daughter. The woman lives in the daughter's home
- The daughter is concerned that for the past 6 months her mother spends much of the day looking out the front window and does not like to do much else
- The mother is eating and sleeping well and her weight is stable
- The daughter is concerned that her mother is depressed and she would like you to prescribe treatment

Case Study

- A home care nurse wants to talk to you about an 80-year old male with AD, who is persistently agitated and aggressive with the home health aides
- The nurse is concerned for the safety of her staff
- Physically and verbally aggressive behavior may be provoked by routine care requests (e.g., bathing) or appear without a clear precipitant
- The nurse would like you to discuss prescribing medication for this behavior with the patient's doctor

Case Study

- 79-year old man is experiencing changes in his behavior
- Diagnosed with AD 10 months ago
- Recently he has started to have episodic paranoid ideas about his children's interest in taking control of his stock portfolio
- No new medical problems; patient is not taking medication

Case Study

- While making a home visit you examine an 85-year old, female AD patient with a 6-week history of disturbing hallucinations
- The family state that that patient describes men coming into her room at night and threatening her; she becomes quite agitated during these experiences
- The family confirm that no men are actually coming into her room, and although the symptoms are intermittent, they would like you to intervene

Take Home Points

- Behavioral changes occur often in adults with AD
- A careful history and assessment searching for a precipitating medical cause is essential, especially if the symptoms are new onset
- Non-pharmacologic interventions are the first-line choice for all behavioral disturbances in dementia
- Medication effects on behavioral disturbances are modest and the evidence-base is weak for their use
- Listen, Be sympathetic, Understand precipitating factors, Be creative, Do No Harm

Preventing and Managing Non-Cognitive Behaviors in Dementia

Geri R. Hall, PhD, ARNP, GCNS, FAAN

Planning Care

- Premorbid personality – Who was this person?
- Type of dementia the person has
- Symptom presentation
- Presentation and causes of behavioral issues
- Usual disease trajectory
- Safety issues
- Caregiver/family issues and support network

Non-AD dementias need care that is modified

- Frontotemporal degeneration (FTD) – behavioral variant and moderate-to-advanced disease
  - Narcissistic, negative
  - Disinhibition, inappropriate behaviors
  - Obsessions (self-soothing)
  - Loss of empathy and interactions with others
  - No insight
  - Loss of boundaries with others
  - Grandiose behaviors
  - Decreased attention & concentration
  - Extremely poor judgment
  - Memory mostly preserved
  - Hyper-oral, hypersexual behavior is not uncommon
  - Antisocial behaviors
  - Retrogenesis
  - Aphasia
- FTD is often misdiagnosed or labeled as AD or bipolar disorder

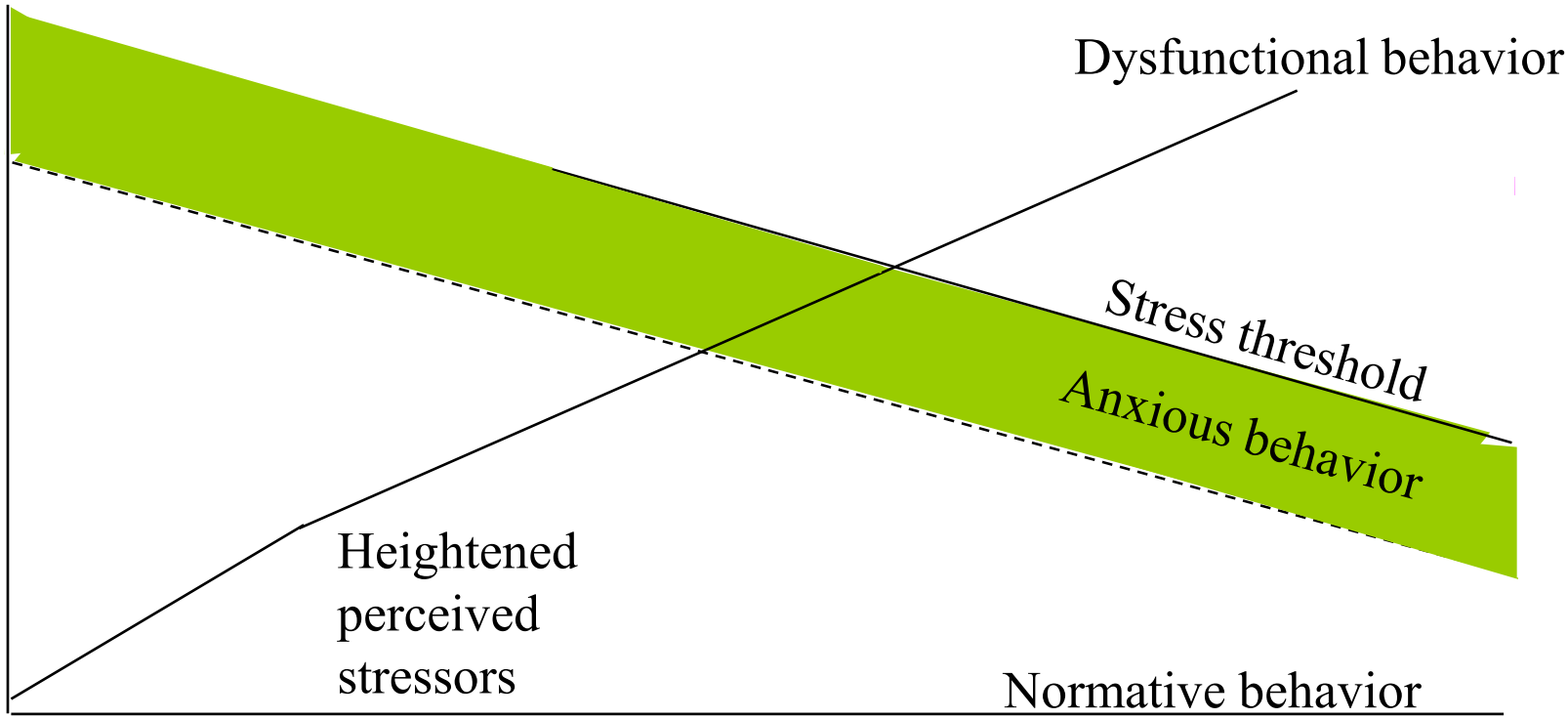
Non-AD dementias need care that is modified

- Lewy Body Disease
  - Fluctuating mental status over a span of days or weeks
  - REM sleep disorder for 2 or more years prior to dementia
  - Exquisitely sensitive to medications, especially PD and mood controlling medications
  - Psychosis – illusions and delusions
  - Parkinsonism that does not respond to medications for PD (dopamine or dopamine agonists)
  - Autonomic dysfunction – orthostasis (drop in blood pressure precipitating falls, passing out)

Using an evidence-based conceptual model helps to plan and evaluate care

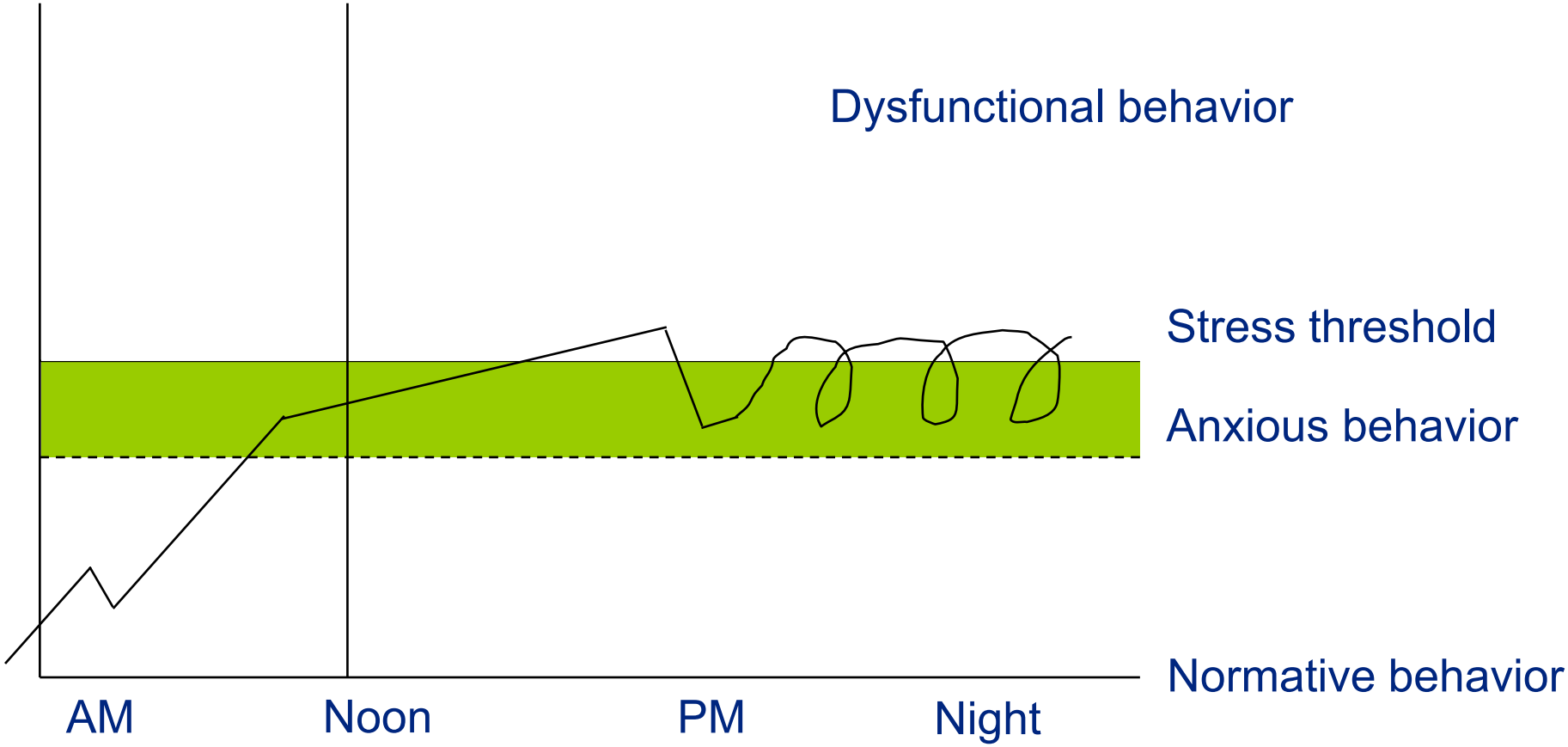
- Helps understanding of dementia symptoms versus non-cognitive behaviors
- Identifies triggers for non-cognitive behaviors and interventions to decrease them
- Progressively lowered stress threshold (Hall & Buckwalter, 1987)
- Helps caregivers make decisions about what to do to prevent behaviors and when they arise
- Provides standard outcomes for judging efficacy of interventions
- Has limits when using with non-Alzheimer dementias

Progressively lowered stress threshold in persons with AD & related dementias (ADRD)



Reprinted from: Hall, G., & Buckwalter, K. (1987). Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing, 1*(6), p. 403, ©1987, with permission from Elsevier and the authors.

Effects of stress during a 24-hour day in the person with ADRD



Reprinted from: Hall, G., & Buckwalter, K. (1987). Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing, 1*(6), p. 403, ©1987, with permission from Elsevier and the authors.

Symptom Clusters: What nobody tells the family

- Cognitive
  - Memory for recent events
  - Sense of time
  - Judgment & reasoning
  - Language losses, including reading
  - Visuospatial perception

Symptom Clusters: What nobody tells the family

- Affective Losses
  - Loss of affect
  - Increased self-absorption
  - Loss of inhibitions
  - Loss of tolerance of multiple stimuli

Symptom Clusters: What nobody tells the family

- Planning losses
  - Progression of functional loss
  - Apraxias (motor planning)
  - Executive control – Planning and pursuing a goal, getting the steps in the right sequence
  - Awareness and frustration with concentration

Symptom Clusters: What nobody tells the family

- Loss of stress tolerance
  - Night wakening
  - Sundowning/late day confusion
  - Repetitive behavior
  - Agitation
  - Aggression
  - Most secondary behavioral symptoms

Excess Disability

- Conditions characterized by increased functional and behavioral limitations or disability that are not directly attributable to the underlying pathophysiology

- These conditions are generally reversible and many can be prevented

Causes of Excess Disability

1. Fatigue – People with all types of dementia need regular daily rest periods

- Rest periods BID: Avoid naps in bed
- Short activities (90 minutes or less)
- No caffeine
- Intersperse high stimulus activities with rests
- **If up at night, increase rest during the day**
- Know patient's best time of day and plan activities (MD visits) for same
- Use mornings for meals and important things

Causes of Excess Disability

2. Change

- Routine daily sequence of activities
- Minimize environmental changes
- Travel (Oh My!)
- Consistent caregivers and caregiver routine
- Allow for relocation effects
- Day care at least 3 days per week
- Moderate holiday decorations & festivities

Causes of Excess Disability

3. Inappropriate sensory input

- Constant awareness of groups and noise
- Provide respite during high intensity activities
- Avoid large group dining rooms
- Watch for responses to TV, radio, pictures of people, mirror images
- Provide enough stimulus, but not too much - using patient behavior as a barometer
- Glasses on; hearing aid?

Causes of Excess Disability

4. Excessive demand

- Caregiver education not to push or question
- Assume patient is doing best at any time (use metaphor of an amputee)
- Non-confrontational approach
- Reminiscence, validation
- Judicious use of restorative services
- Teaching caregivers “prosthetic approach”
- Speech evaluation to enhance communication

Causes of Excess Disability

5. Affective responses to perception of losses

- Allowing person to grieve and discuss losses
- Substitutions for lost activities
- Group therapy (patient support groups)
- Activity-based care planning
- Evaluation of and treatment for depression
- Highly individualized activity planning
- Reminiscent activities (desk; driving simulator)

Causes of Excess Disability

6. Delirium resulting from infection, illness, discomfort, medication responses

- Recognize unmet physical needs such as constipation, thirst, discomfort
- Seek medical attention
- Simplify medications and treatment for concomitant conditions
- Treat pain, even mild age-related discomfort
  - Acetaminophen 1 gram BID or TID
  - Do not order pain medication prn, anticipate pain
- Wellness measures - avoid/treat constipation, UTIs
- Fight dietary battles you can win
- Watch cardiac function, serum albumin, and creatinine clearance

Problem Solving…

- Know usual level of function and pattern of decline
- If behavior changes, assess and treat causes of excess disability
  - If the change is sudden, unremitting, or is accompanied by changes in consciousness, it is a medical emergency unless proven otherwise.
- Don't reach for medications first… call for help
- Keep caregiver safe
- Keep a journal of non-cognitive behaviors: what, where, why, and what worked to solve the issues.

When behaviors become a problem

- Recognize that it is far easier to prevent the behavioral reactions than to treat them. There is no "magic medication."
- First, stop what you are doing. Try to move the person to a safe quiet place.
- Apologize that he/she is upset
- Agree with their point of view
- Tell the person you will try to "fix it"
- Distract with food, an activity, etc. or give a brief rest period
- Record what happened up to 36 hours prior to the incident and analyze the triggers
- Avoid that trigger in the future

Outcome Measures

- Low incidence of problem behaviors
- Hours of sleep at night
- Stable weight
- Low level of mood-controlling medications
- Slow disease progression, stable co-morbidities
- Caregiver/family satisfaction
- Low incidence safety issues

Helping Families with Problem Solving for Behavioral Changes

Beth Spencer, MA, LMSW

What does our use of language say about how we view people with dementia?

- Words have an impact – on our thoughts, on how we view the world, on others
  - Examples: Demented, Aggressive, Wandering, Toileting
- Discipline influences word choices
- Setting influences word choices
- How we discuss and document behaviors influences how we see and respond to the person

How we view behavior change

- Behavior as a form of communication
- Often reflects an unmet need or desire or environmental issue
- Our job is to learn how to interpret the meaning(s) behind the behavior
- Teaching this to families is very powerful

Aggressive behaviors

"Cognitive impairment and activity of daily living (ADL) impairment were strongly related to agitated behavior…. aggressive behaviors correlated positively with ADL impairment."

Cohen-Mansfield, Marx, & Rosenthal (1990). Dementia & Agitation in Nursing Home Residents: How Are They Related? *Psychology and Aging* 5(1), 3-8

- Aggressive behaviors during personal care reported
  - By 65% of community caregivers
  - By 86% of staff in nursing homes

Ryden et al. and Beck et al. cited by Sloane et al. (2004).

What are the implications?

- Assistance with personal care may elicit agitated or aggressive behaviors
- Person may feel humiliated, frustrated, angry, invaded, etc.
- Person may not recognize need for help
- Care partners' (staff or family) frustration and impatience may increase

Why is this important?

- Help caregivers understand the link between assistance with ADLs and increased agitation
- Teach ways of decreasing possible agitation during ADL care

Bathing study

- Evidence-based intervention study by Sloane et al. 2004
- Compared person-centered bathing, no-rinse towel bed bath, and control groups – 69 NH residents with dementia and agitation/aggression during bathing
- Control group = no change
- Person-centered bathing group = 53% decrease in behaviors
- Bed bath group = 60% decrease in behaviors

No-rinse towel bed bath

- Individuals bathed in bed with warm no-rinse soap towels.
- Remain partially covered at all times.
- Staff trained in person-centered bathing techniques

Barrick et al. (2008). *Bathing without a Battle,* Springer Publishing

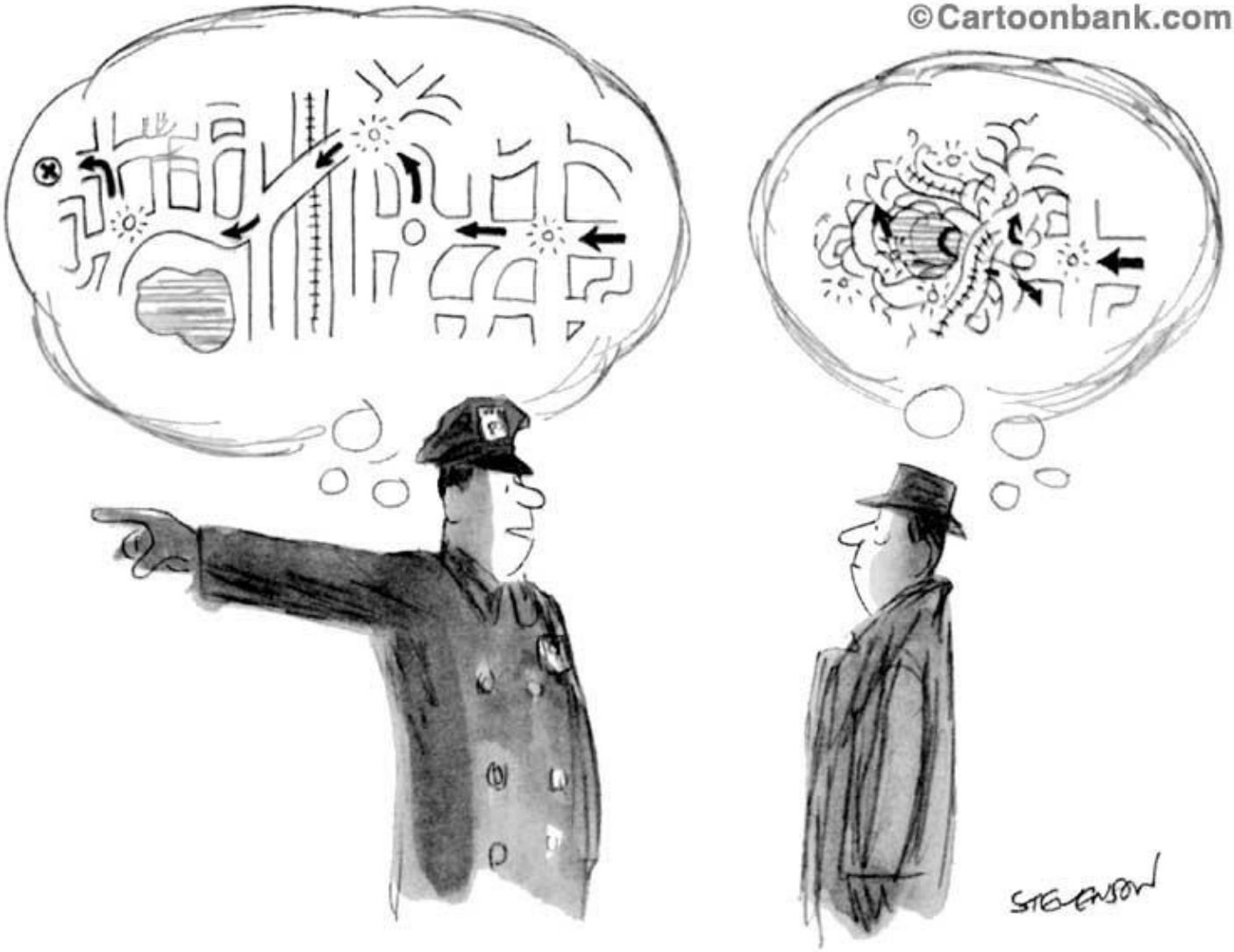
Person-centered bathing

- Focus on person rather than task
- Relationship building
- Choices provided
- Person kept partially covered
- Modifying temperature of room & shower spray
- Using distractions (food, music)
- Using products recommended by families

Helping care partners with bathing

- Apply to home setting
- Assist in understanding how complicated bathing is
- Analyze bathing situation with them
- Try to pinpoint triggers
- Consider room adaptations
- Discuss how to make more person-centered
- Role play conversations as needed

Common cause of behavior challenges: Poor communication



Late afternoon case study

- Mrs. Smith is frantic because her husband's behavior becomes difficult in the late afternoon.

- Between 3-5 pm each day, Mr. Smith's mood gradually changes and he becomes increasingly upset. He paces, wrings his hands, shouts and curses, and follows her around.

Examples of strategies for Mrs. Smith

- Empathize with Mrs. Smith
- Help her think about what Mr. Smith might be feeling
- Help Mrs. Smith identify possible triggers, e.g.,
  - Fatigue, hunger, needing bathroom, some environmental trigger such as TV, other people, being ignored by her, etc.
- Teach her ways of responding that can help de-escalate behaviors
- Help her come up with a list of strategies
- Discuss respite care options (e.g., in-home, adult day)

Examples of strategies for Mrs. Smith

- Think about what Mr. Smith might be feeling
- Examine her own behavior and responses
- Try getting Mr. Smith to rest after lunch
- See if he will sit down and eat a favorite snack
- Change her way of responding
- Think about the environment: Too noisy? Too quiet? Anyone else around?
- Take him out for a walk or drive—distraction
- Try respite care

Summary

- Listen to families and persons with dementia
- Recognize that their priorities are not always the same as ours
- Educate them about the disease
- Help them understand the complexities of behavior and the emotional and physical environments
- Develop a list of strategies with them
- Provide a place/number to seek help:

24/7 Alzheimer's Association Helpline
1.800.272.3900

University of Michigan *Certificate in Advanced Clinical Dementia Practice*

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Next cohort begins March 2016.
http://ssw.umich.edu/clinical-dementia

For more information:
Cassie Starback, Coordinator, cassiem@umich.edu
Beth Spencer, Faculty, elizspen@umich.edu

Resources

Suggested Books on Behavior Change for Staff and Families

- Barrick. A.L., Rader, J., Hoeffer, B., Sloane, P.D., & Biddle, S. (2008). Bathing without a Battle: Person-Directed Care of Individuals with Dementia, Second Ed., Springer Publishing.
  (Also available as a training DVD.)
- Friedman, J.H. (2013). Making the Connection between Brain & Behavior: Coping with Parkinson's Disease. DemosHealth.
- Gitlin, L. & Piersol, C.V. (2014). A Caregiver's Guide to Dementia: Using Activities and Other Strategies to Prevent, Reduce and Manage Behavioral Symptoms. Camino Books.
- Book on FTD Care: G Radin and L Radin (eds) (2013) What if it's not Alzheimer's? A caregiver guide to dementia, third edition. New York: Prometheus Books.
- Spencer, B. & White, L. (2015). Coping with Behavior Change in Dementia: A Family Caregiver's Guide. Whisppub.com.

Resources

- Seven years of Banner Beacon Newsletters on specific care issues such as driving, travel, living alone, holidays, weight loss, etc; http://www.banneralz.org/news-plus-media/bai-beacon-newsletter.aspx

- Hall, G. and Buckwalter, K. (1987) "A conceptual model for planning and evaluating care of the client with Alzheimer's disease." *Archives of Psychiatric Nursing,* 1:6, 399-406.

- Smith, M., Gerdner, L., Hall, G., & Buckwalter, K. (2004). History, development, and future of the Progressively Lowered Stress Threshold Model. *Journal of the American Geriatric Society. 52*(10), 1755-1760.

- Hall, G.R., Shapria, J., Gallagher, M., & Denny, S. (2013). Managing differences: Care of the person with frontotemporal degeneration. Journal of Gerontological Nursing. 39(3), 10-14.

Resources

- Beck C, Rossby L, Baldwin B. Correlates of disruptive behavior in cognitively impaired elderly nursing home residents. *Arch Psychiatr Nurs* 1991;5:281– 291.
- Beck C, Frank L, Chumbler NR et al. Correlates of disruptive behavior in severely cognitively impaired nursing home residents. *Gerontologist* 1988;38: 189–198.
- Cohen-Mansfield, Marx, & Rosenthal (1990). Dementia & Agitation in Nursing Home Residents: How Are They Related? *Psychology and Aging* 5(1), 3-8
- Ryden MB. Aggressive behavior in persons with dementia who live in the community. *Alzheimer Dis Assoc Disord* 1988;2:342–355.
- Ryden MB, Bossenmaier M, McLachlan C. Aggressive behavior in cognitively impaired nursing home residents. *Res Nurs Health* 1991;14:87–95
- Sloane et al. (2004). Effect of Person-Centered Showering and the Towel Bath on Bathing-Associated Aggression, Agitation, and Discomfort in Nursing Home Residents with Dementia: A Randomized, Controlled Trial. *J of the American Geriatrics Society,* 52(11), 1795-1804
- Understand Alzheimer's Educate Australia. Dementia Language Guidelines. www.fightdementia.org.au

Questions

The post test is now open. The post test must be completed by 2pm ET in order to receive CME or CE credit.

The evaluation is now open. The evaluation must be completed by 5pm ET in order to receive CME or CE credit.

Evaluation Form and Post-test

Thank you for joining our webinar. Please take a moment to complete a brief evaluation on the quality of the webinar.

If you are applying for CME/CE credit, you must complete the evaluation as well as the post-test at this time.

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