Understanding and Treating Difficult Dementia Behaviors...
and How to Talk About It with Your Physician

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www.californiacrc.org
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Sponsored by California’s Caregiver Resource Centers (CRCs) and the Department of Health Services, Alzheimer’s Disease Research Centers of California (ARCCs). Funded by the California Department of Mental Health and a Bristol-Myers Squibb Foundation grant to Family Caregiver Alliance.
• What is dementia?

• Why do we see so many behavior problems in dementia?

DSM IV Criteria

• Memory Problems

AND

One or more of the following:

Recognizing things

Speaking

Planning and Organizing

Motor Planning (Dressing)
DSM-IV Criteria Cont.

Problems interfere with:

Relationships (family and friends)

And

At Work

Common Causes of Cognitive and Psychiatric Problems or Dementia in the Elderly
Irreversible Dementias

- Alzheimer’s disease
- Multi-infarct or vascular dementia
- Parkinson’s disease
- Lewy Body disease
- Korsakoff’s dementia
- Creutzfeldt-Jakob disease
- FTLD
- Huntington’s disease
- AIDS dementia complex

AD Is the Most Prevalent Type of Irreversible Dementia

VaD, vascular dementia; DLB, dementia with Lewy bodies; FTD, frontotemporal dementia.
†, reflects difficulties diagnosing/reporting dementias; only estimations of prevalence can be made.
Why do you see so many psychiatric, behavior and thinking problems in Dementia?

Planning and Organizing

Speech
Verbal Memory and Language
Arithmetic

Relationships
Depression
Nonverbal Memory
Visuospatial

Seeing
Compare
Brain Atrophy with AD

Healthy Older Adult

Patient with AD

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3 VARIANTS OF FTLD
Behavioral and Cognitive Profile with Brain Atrophy

Can damaged brain tissue in dementia heal?

- No, unlike a broken hip, for example, brain tissue cannot heal.
- With dementia, neurons are dying and the tissue is dead.
- Problems are permanent.
- Problems are “progressive” because they get worse over time.
Reversible Causes of Cognitive and Psychiatric Problems

- Intoxications
- Infections
- Major depression
- Brain tumors
- Head injuries
- Metabolic disorders

What are some common thinking, behavior and psychiatric problems that persons with dementia have?
Common challenging behaviors
Average person with dementia develops about 3 of these:

- Wandering - Becoming lost in familiar places; being unable to follow directions.
- Aggression – physical and or verbal
- Repetitive questions or statements – perseveration
- Disruptive vocalizations – screaming, moaning
- Inappropriate sexual behavior
- Paranoia

Additional challenging behaviors:

- Throwing objects
- Hitting
- Scratching oneself
- Banging
- Pacing
- Severe restlessness
- Repeatedly and inappropriately interrupting others
Cognitive enhancers and NPS

- Meta-analysis indicated that treatment with cholinesterase inhibitors (CI) decrease behavioral symptoms (Trinh et al, 2003)
  - 16 studies
  - 10 show CI > placebo and 1 show placebo > CI
- More limited data on Memantine
- Modest improvement overall
- Upshot:
  - NPS may improve with cognitive enhancer treatment.
  - Initiate cognitive enhancer and monitor NPS.
  - NPS should not be primary indication
  - CI may worsen NPS in FTD

Antipsychotics

- Review of RCT shows that overall little significant impact on NPS
- Clinical experience suggests helpful in more acute situations
- Growing concerns about side effects
  - Elderly at increased risk tardive dyskinesia
  - LBD more susceptible to side effects
  - Black box warning (cerebrovascular events)
  - Increased mortality risk of death
Sensory changes:

- Persons with dementia have sensory problems that come with age. They may not be able to see or hear as well as before.
- Example: a shadow might be perceived as an uninvited “guest”. A radio in the next room may be perceived as “people living in the walls”. A change in taste might lead a person to believe that they are being “poisoned”.

Additional Features of Dementia

- **Delusion**: a strongly held false belief (e.g. thinking someone is out to get you when this belief has been shown to be false). With dementia, delusions tend to be more vague and less bizarre.
- **Examples of common paranoid delusions**: the person believes that someone is stealing something from them; the person begins hiding or hoarding things possibly due to distrust of others and/or self-preservation.
- **Examples of delusions related to disorientation to person/place**: the person believes s/he is living in the 1940’s, that deceased spouse is still alive, mistaking care workers for family members, etc.
Check for medical causes

• Be sure that the behavior is not because of a medical problem or possible side effects of a new medication.
• Have care receiver examined by their physician.
• Some medications can cause symptoms of “agitation”.

What are they really trying to tell us?

• These reactions are often labeled: “AGITATION”
• Does this label prevent us from thinking about the person with dementia’s experience?
• What might their behavior be telling us?
What is dementia like…?

Imagine you no longer recognize things as you used to. You have difficulty remembering where you are and why you are there. The people around you are unfamiliar. They often approach you but you are confused about why…

Behavior as Communication

- How do you feel when you get confused?
  😞
- What if you had no way of expressing or understanding why you were afraid, confused, or in pain?
  😞
- What might you try to do?

- These reactions are often labeled: “AGITATION”
- Does this label prevent us from thinking about the person’s experience?
- What might their behavior be telling us?
**Adaptive or Agitated?**

- Some of these challenging behaviors are actually adaptive.
- They help the person communicate
  - Remember: dementia has taken away their ability to communicate in other ways.
- How can we try to figure out what they want, and make changes in the environment to decrease the need for the behavior?

**Example:**

How *Agitation* can be *Adaptive*

- Every time you try to bathe your loved one, she kicks and screams, and bites.
  - Why is she doing this?
  - Is she resisting care?
  - How may this be adaptive?
Resistance vs. Communication

- Perhaps the person is communicating *FEAR* because she does not remember her caregiver, does not know she is in her own home, or that she needs to be bathed.
- Imagine a stranger comes into your room everyday, tries to disrobe and bathe you.
- How do you think you would respond?

ABC’s of Behavior

- Antecedent: What happened right before your loved one became agitated?
- Behavior: What does the behavior look like?
- Consequence: What happened right after the behavior?
Motivations behind behaviors

- **Attention**: Do they want you to pay more attention to them?
- **Stimulation**: Are they understimulated? Bored? Is there too much stimulation? Too much noise?
- **Escape**: Are they trying to get away from something or someone because they are afraid?
- **Tangible**: Are they trying to gain something, e.g. food or a favorite object?

How Can You Help?

- Be flexible
- Be open
- Be curious
- Be patient
More Communication Strategies

- Use short, simple words and sentences
- Use a soothing voice
- Speak slowly
- Provide ample time to respond

Communication styles to avoid

- **Do not talk loud or in a patronizing manner:**
  - Even those people with severe impairment still have some sense of how adults are supposed to talk to one another.
- **Do not command or use a commanding tone:**
  - “Get out of bed!”
- **Do not ask questions that rely on memory:**
  - This can cause extreme anxiety in your loved one.
- **Do not focus on logic or explaining yourself:**
  - Arguing with your loved one only leads to more confusion.
- **Do not view behavior problems as intentional**
  - The disease is the cause of these behaviors.
FINAL WORDS ON DEMENTIA

• Dementia is **not** a normal part of aging.
• Dementia results in slow **deterioration** of brain regions.
• Dementia affects cognition **and** behavior.
• Difficult behaviors in dementia may be their way of communicating their **needs**
• You need to also take care of **yourself**

Resources

• Family Caregiver Alliance:
• Communicating with someone who has Alzheimer’s Disease:
• Memory and Aging Center at the University of California, San Francisco School of Medicine Resources Guide for Caregivers:
  [http://www.memory.ucsf.edu/resources.html#caregiving](http://www.memory.ucsf.edu/resources.html#caregiving)
Pharmacological treatment of non-cognitive symptoms in AD

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Education Core Director, ADC
UC Davis
ladson.hinton@ucdmc.ucdavis.edu
Overview of talk

- Prevalence, etiological factors, & consequences
- General issues in assessment and management
- Role of medications

Neuropsychiatric symptom frequency in population-based studies

<table>
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<th>Individual neuropsychiatric symptoms</th>
<th>Dep</th>
<th>Irr</th>
<th>Anx</th>
<th>Agg</th>
<th>Apa</th>
<th>Dis</th>
<th>Hal</th>
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<td>%</td>
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<td>40</td>
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Legend: SALSA, CHS, Cache County
Neuropsychiatric symptoms (NPS)

- Signs and symptoms of disturbed perceptions, thoughts, mood, behavior in persons with dementia
- Clusters of non-cognitive symptoms
  - Mood/apathy: depression, apathy, sleep, appetite
  - Hyperactivity: agitation, irritability, euphoria, motor
  - Psychosis: delusions, hallucinations
  - Anxiety
- May underpin common behavior “problems” and help to guide pharmacotherapy approaches
- Common and recurrent: 50-95% with ADRD
- Measured with standard instruments
  - e.g., Neuropsychiatric Inventory (NPI)

Biopsychosocial model of NPS
Consequences of untreated NPS

- Excess disability
- Elevated caregiver depression and burden
- Risk of harm to person or others
- Increased service utilization
- Increased risk of institutionalization
- Lower quality of life

Barriers to medical care for NPS

- Family factors
  - Presentation of symptoms, knowledge
- Physician factors
  - Under-detection
  - Reactive care
  - Lack of training
  - Competing medical concerns
- Structural constraints
  - Time, reimbursement, access to mental health specialists
- Scientific: criteria and robust treatments
Symptom presentation:
The many faces of depression

- Agitation and aggression
- Irritability
- Somatic symptoms
- Paranoia and psychosis
- Delayed rehabilitation
- Conflicts with caregiver
- Refusal to eat
- Excessive functional impairment
- Alcohol or other substance abuse

To treat or not to treat?

Mild <----------Moderate -----------> Severe

Low CR/CG distress → High CR/CG distress
Low risk of harm → High risk of harm
Low environment impact → High disruption
Low impact CR QOL → High impact CR QOL

Treatment considerations:
- Underlying medication/drug cause → treat
- Mild: monitor or nonpharm rx, cog enhancer trial
- Moderate: nonpharm, possible drug or referral
- Severe: nonpharm + drug, referral, in-patient, ECT
Common medical triggers

- Delirium
- Medication side effect
- Metabolic imbalance
  - e.g. hypoglycemia
- Pain
- Infection
  - e.g. UTI, pneumonia
- Stroke

Overview of treatment modalities

- Family psychoeducation
- Non-pharmacological interventions
  - Identify unmet needs, environmental triggers, ABC patterns
- Pharmacological approaches
  - Data best for depression
  - New data shows higher mortality risk with antipsychotics
- Emerging data suggests multi-modal interventions may be more effective
Figure 1. Behavioral Symptoms in Alzheimer Disease

A Neuropsychiatric Inventory
- Morris et al, 1998
- Dubois et al, 1999
- Reskind et al, 1999
- Tarot et al, 2000
- Rockwood et al, 2001
- Winblad et al, 2001
- Summary Effect

Favors Cholinesterase Inhibitor
(-6.10)

Favors Placebo
(3.02)

Points

B Alzheimer Disease Assessment Scale, Nencognitive
- Davis et al, 1992
- Farlow et al, 1992
- Knapp et al, 1994
- Wood, 1994
- Forreto et al, 1995
- Becker et al, 1996
- Zelman, 1998
- Becker et al, 1998
- John et al, 1996
- Moeller et al, 1999
- Summary Effect

Favors Cholinesterase Inhibitor
(-1.79)

Favors Placebo
(3.82)

Points

Negative scores denote improvement. Error bars indicate 95% confidence intervals.

Trinh et al, JAMA, 2003
### Figure 2. Deaths by Individual Comparisons by Drugs and Overall Compared With Placebo

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<th>Source*</th>
<th>Treatment, No. of Events/Total No.</th>
<th>Placebo, No. of Events/Total No.</th>
<th>OR (95% CI)</th>
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<th>Favors Control</th>
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<td>3/125</td>
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<td>0/102</td>
<td>9.00 (0.48-189.32)</td>
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<td>HGEL&lt;sup&gt;30,45&lt;/sup&gt;</td>
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<td>0/47</td>
<td>4.02 (0.22-72.73)</td>
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<td>1/94</td>
<td>2.82 (0.33-23.76)</td>
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<td>1/90</td>
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<td>Quetiapine</td>
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<td><strong>Overall</strong></td>
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<td>41/1851</td>
<td>1.54 (1.06-2.23)</td>
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CI indicates confidence interval; OR, odds ratio.

*Unique identification code which identifies the study or the collection of posters, abstracts, unpublished manuscripts, or published trials of the study drug. The total number of placebo patients is 1757 and deaths, 40. The trial HGGU placebo group is used for both risperidone and olanzapine comparisons.
Implications for antipsychotics

- Re-assess risk/benefit ratio
- Inform patient and proxy of risks/benefits and involve in decision-making
- Consider alternative (non-pharmacological) treatments first
- Limit use to situations where symptoms pose significant risk of harm or reduced quality of life
- Taper off after 3-4 weeks in non-responders
- Give responders a “holiday” and re-evaluate need
- Stay tuned! ? cause of increased mortality

Antidepressants

- Antidepressants include TCAs and SSRI
- Duration 4-12 weeks
- Depressive symptoms or MDD
- In 10 double-blind placebo controlled, 6 favored active drug and none PBO
- High placebo response
Dementia in Alzheimer’s Disease Study

Lyketsos et al, Archives Gen Psych 2003

Antidepressant treatment algorithm

- Initiate SSRI and titrate to target dose
- 4-6 weeks
  - If some improvement, increase
  - If no improvement, switch class (e.g. bupropion, mirtazapine)
- 10-12 weeks
  - If remission, continue
  - If some improvement, augment
- Treatment resistant: venlafaxine, remeron, wellbutrin, nortriptyline, MAOI, stimulants, ECT

Mulsant et al, Int J Ger Psychiatry 2001
Summary

- NPS are common and costly
- Nonpharmacological rx underused
- Drugs
  - Data best for depression in Alzheimer’s
  - Cognitive enhancers may lower NPS as secondary benefit
  - Need to re-examine risk/benefit ratio of anti-psychotics in light of emerging data
- Drugs most effective in multi-modal approach
  - examination of underlying medical/drug causes
  - family education and support
  - social service referral
  - non-pharmacological treatment

Selected references

Alzheimer’s Disease Research Centers of California (ARCCs)

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