Dementia-related behaviors:

Where do they come from? Can we prevent them?

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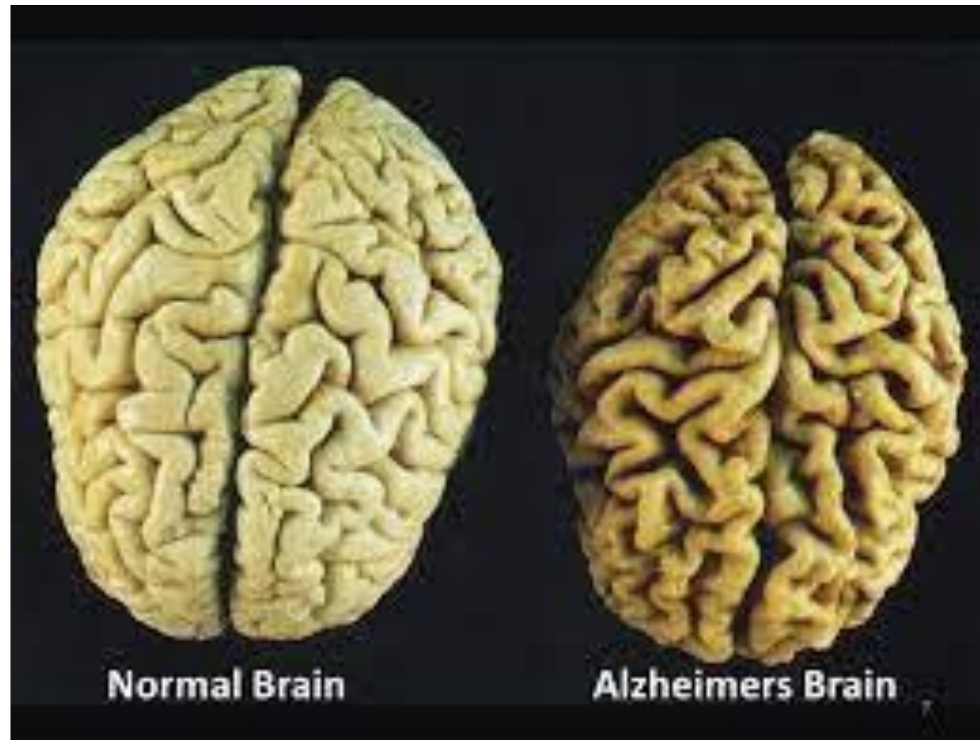
- There are no conflicts of interest pertinent to this presentation.
- Material in this presentation reflects the individual views of the presenter.

Learning Objectives:

- **Learn why behavior changes in dementia.**
- **Use a simple framework to help you understand what's happening.**
- **Identify three ways to reduce the risk of behavioral crises.**

It starts with the brain: the most complex known object in the universe
-EO Wilson



Dementia = Brain Failure

- Neurons shrink and have trouble talking to each other
- Control processes weaken – too much and too little activity
- Different dementia types affect the brain map differently

…What was the person like before?

_ Costa and McCrae, Saucier and Ostendorf

- **Neurotic: irritable, insecure, emotionally reactive**
- **Extroverted: sociable, unrestrained, assertive, adventurous**
- **Open to new experiences: intellectual, imaginative, creative, perceptive**
- **Agreeable: warm, affectionate, gentle, generous, modest, humble**
- **Conscientious: orderly, decisive, consistent, reliable, industrious**

- the "Big 5" personality traits and some of their common manifestations

And unhealed life experiences

- **Adverse Childhood Experiences (ACES)**
- **Psychological trauma at any age**
- **Long-term mental, emotional, and psychological disorders**

These contribute to many chronic medical conditions.

They influence behavior in dementia – and may increase vulnerability to developing dementia through chronic stress biology.

What are Adverse Childhood Experiences (ACEs)?

- Abuse – mistreatment (physical, mental, political, emotional, sexual)
- Neglect – starvation (physical, emotional, political, mental, relational)
- Witnessed aggression/violence at home, in the community, in war

Why talk about ACEs here?

- Often invisible but powerful causes of challenging behavior in dementia

And still more causes…

- **Pain – acute, chronic, or both**
- **Physical mobility limitations**
- **Inadequate sleep, food, fluids**
- **Acute infection, illness, injury**
- **Relationship factors**
  - **Caregiver communication – e.g. ‘elder speak’ (baby talk with older adults)**
  - **Caregiver fatigue, negative emotions, unmet support needs, insufficient joy**

Meet Miriam

- **83 years old when I met her, long-term resident of a skilled nursing community**
  - **Widowed in her 50’s, mother of a middle-aged daughter – no other family**
  - **Trained as a lawyer in Russia**
  - **Extensive history of trauma exposure**
    - **Young teenager in WW I**
    - **Young adult during Russian Revolution**
    - **Holocaust refugee – WW II**
  - **Worked as refugee/immigrant advocate after arriving in US**

The problem

- **Screams racist epithets, pushes, fights nursing interventions – won't allow dressing changes, especially at night**
- **Daughter at wits' end**
- **Staff avoid her (bare essentials)**
- **"Most hated patient in the nursing home"**

What we’re aiming for

“No-Crisi
s” Care

- **Assess systematically – see what's obvious, search for what isn't**
- **Accept what can't be changed**
- **Look for what *can* change**
- **Consider roles – mine, yours, others'**

Miriam’s Difficulties – One by One

- **Cognition: moderate dementia – mainly vascular + some Alzheimer/?Lewy body**
- **Emotional/behavioral status: PTSD unmasked by dementia + painful leg ulcers (how?), chronic anxiety, depressed mood**
- **General medical and functional status: severe generalized ischemic vascular disease; bedbound; immobilized by strokes; *intense pain with leg dressing changes***
- **Care partners: Daughter and NH staff stressed, frustrated, angry, afraid**
- **Health related social needs: chronic loneliness; no financial strain**
- **Health care framework: strict nursing assignments and schedules, management and nurse leaders at end of rope, willing to try anything**

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Behavioral Mitigation + Problem Prevention: Stress Management for Everyone is the Key

https://www.acesaware.org/

Thank you – keep talking!

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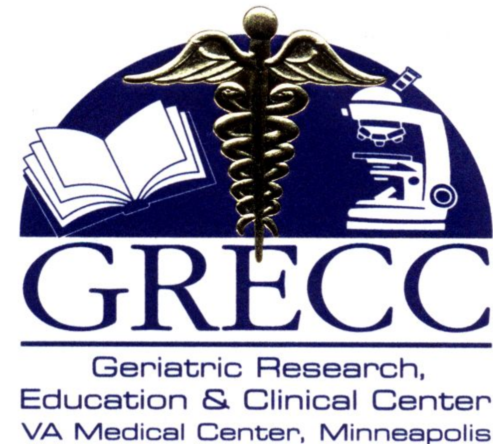
http://bolddementiadetection.org/resources

Medication Management of BPSD

Jamie Starks, MD

6/4/22



Disclosures

- No relevant financial or non-financial relationships to disclose
- Off-label use of medications will be briefly discussed (because there are no FDA-approved medications for BPSD*)

*BPSD: Behavioral and psychiatric symptoms of dementia

Learning Objectives

Attendees will be able to:

- List risks associated with medications used for behavioral and psychiatric symptoms of dementia (BPSD)
- Describe the role of medications for treatment of BPSD
- Identify indications for pharmacologic interventions for BPSD

Case

- 88 y/o retired high school shop teacher with Alzheimer's disease dementia and multiple recent admissions for behavioral concerns
  - 8/14-8/17:
    - Admitted from home due to disruptive behaviors in the neighborhood and "failure to thrive"
    - Discharged back home with family to provide 24/7 supervision
  - 8/17-8/23:
    - Readmitted a 3 hours later after getting into an altercation with a neighbor
    - Discharged to memory care ALF
  - 9/5:
    - Readmitted from ALF due to aggressive behaviors towards staff

Psychotropic Meds on Admission:

- Olanzapine (antipsychotic)
- Melatonin

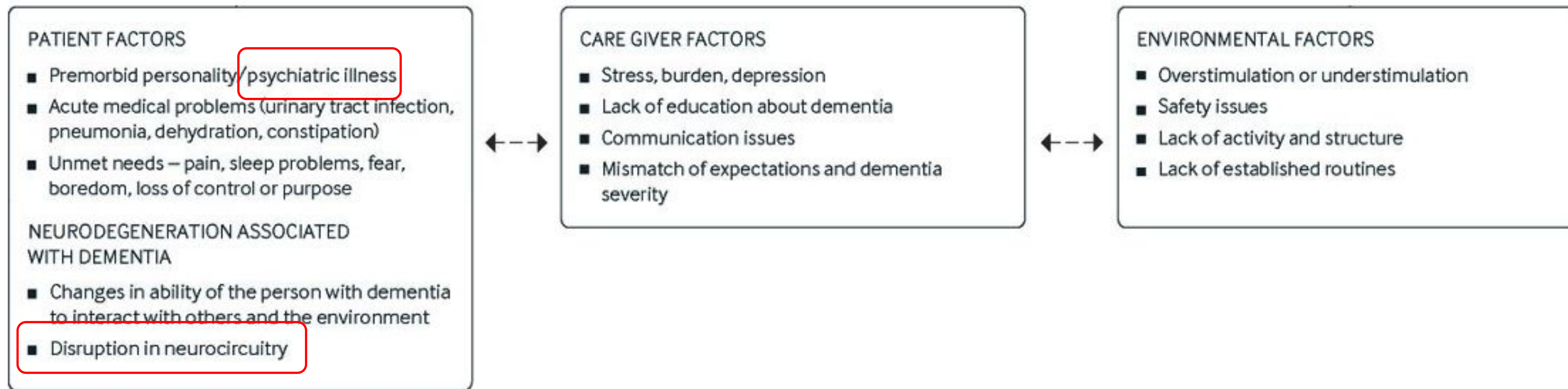
Case

- Behaviors:
  - Irritability, labile mood, intermittent tearfulness
  - Verbal and physical aggression towards staff
  - Exit-seeking
  - Paranoid delusions
  - Anxious perseveration
- Over the next 4 months, behaviors worsened despite multiple medication trials:
  - Escitalopram (antidepressant)
  - Valproate (mood stabilizer)
  - Risperidone (antipsychotic)
  - Haloperidol (antipsychotic)
  - Lorazepam (benzodiazepine)
  - Trazodone (antidepressant/anxiolytic)

To be continued...
SHARP

Causes of BPSD

- Can be categorized into factors relating to:
  1. Patient
  2. Caregiver
  3. Environment



Adapted from Kales HC, Gitlin LN, Lyketsos CG. BMJ 2015.

BPSD Causes:
Patient Factors

- Neurocircuitry disruption
  - Regional neurodegeneration
  - Neurochemical alterations associated with neurodegeneration
    - Dopamine Delusions/hallucinations
    - Serotonin Depression, anxiety
  - Sleep/wake disruption

- Psychiatric comorbidities
  - Increased incidence in neurodegenerative disorders
  - Symptoms may be atypical

Medications for BPSD

- Expectation:

Medications for BPSD

- Reality:

BPSD Management is Challenging!

- Complex causes
- Lots of guidelines about what NOT to do, not as much about what TO do
  - **No** FDA-approved medications
- Lack of good evidence to guide treatment

Non-Pharmacologic vs Pharmacologic Treatments

- Most guidelines & experts recommend non-pharmacologic treatments as first-line interventions
  - At least as effective than medications
  - Behavioral meds have significant risks & adverse side effects

- Challenges to non-pharmacologic interventions:
  - Often more time-consuming and more work to implement
  - Lack of provider education/training
    - Methods are often counterintuitive and contrary to traditional nursing training
  - Perceived lack of efficacy
  - Results often less immediate

Reus, V.I.; et al. The American Psychiatric Association Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia. Am. J. Psychiatry 2016, 173, 543–546.

Pharmacologic Treatments

- No FDA-approved medications for BPSD
- 2020 Annals of Internal Medicine systematic review & meta-analysis by Howard Fink, et al:

> "Current data do not provide clear guidance on whether any prescription drugs improve BPSD out-comes in patients with clinical Alzheimer's type dementia, let alone whether benefits outweigh harms, overall or in any patient sub-groups."

Table 3. CATD Drug Treatment Efficacy for BPSD From Trials of at Least 2 Weeks' Duration and With Low or Medium Risk of Bias

Test	Change in Agitation or Aggression*		Likelihood of Improved Agitation or Aggression†		Change in Psychosis‡		Likelihood of Improved Psychosis§	
	Trials (Patients)‖	**Direction (SOE) Median SMD (Range of Medians)¶**	**Trials (Patients)‖**	**Direction (SOE) Median ARD (Range of Medians)**	**Trials (Patients)‖**	**Direction (SOE) Median SMD (Range of Medians)¶**	**Trials (Patients)‖**	**Direction (SOE) Median ARD (Range of Medians)**
Prescription drugs vs. placebo**								
Antipsychotics	3 trials (*n* = 283)	Insufficient 0.00 (−0.59 to 0.26)	1 trial (*n* = 40)	Insufficient 25% (NA)	1 trial (*n* = 181)	Insufficient −0.30 (NA)	2 trials (*n* = 218)	Insufficient 30% (18% to 30%)
Antidepressants	3 trials (*n* = 508)	Insufficient −0.33 (−0.06 to −0.67)	1 trial (*n* = 186)	Insufficient 18% (NA)	2 trials (*n* = 160)	Insufficient 0.04 (−0.05 to 0.12)	1 trial (*n* = 186)	Insufficient 16% (NA)
Cholinesterase inhibitors	1 trial (*n* = 221)	No difference (low) 0.00 (NA)	1 trial (*n* = 221)	No difference (low) −1% (NA)	NR	NR	NR	NR
Antiseizure drugs	1 trial (*n* = 128)	Insufficient −0.16 (−0.12 to −0.21)	NR	NR	NR	NR	NR	NR
Supplements vs. placebo								
Yokukansan	1 trial (*n* = 145)	Insufficient††	NR	NR	1 trial (*n* = 145)	Insufficient††	NR	NR

Fink HA, Linskens EJ, MacDonald R, et al. Benefits and harms of prescription drugs and supplements for treatment of clinical Alzheimer-type dementia. A systematic review and meta-analysis. Ann Intern Med. 2020.

Antipsychotics

- Undesirable benefit/risk ratio
  - FDA Black Box Warning

WARNING: INCREASED MORTALITY IN ELDERLY PATIENTS WITH DEMENTIA-RELATED PSYCHOSIS

See full prescribing information for complete boxed warning.

Elderly patients with dementia-related psychosis treated with antipsychotic drugs are at an increased risk of death. RISPERDAL® is not approved for use in patients with dementia-related psychosis. (5.1)

- Long-term care standards require gradual dose reductions of antipsychotics and sedative/hypnotics (e.g. benzodiazepines)

Reus, V.I.; et al. The American Psychiatric Association Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia. Am. J. Psychiatry 2016, 173, 543–546.

Pharmacologic Treatments

- Can also make behaviors WORSE!
  - Akathisia (antipsychotics)
  - Paradoxical agitation (benzodiazepines)
  - Confusion, delirium
  - Sedation disruption of sleep/wake cycle

Pharmacologic Treatments

- So are antipsychotics or other medications EVER indicated?
  - Palliation of psychological distress
    - Concept of "total pain"
  - Safety of patient/others
  - Meds should never be used for staff convenience!

- Certain neuropsychiatric symptoms are more likely to respond to medications
  - Psychosis (antipsychotics)
  - Depression (antidepressants)
  - Cholinesterase inhibitors often very effective for neuropsychiatric symptoms in Lewy body disease
  - Sleep-wake dysregulation

Pharmacologic Treatments

- Trial & error often necessary
- Honest conversations with caregivers/POAs about risks/benefits are essential

Case Conclusion

Case

- Medication trials:
  1. Olanzapine (antipsychotic)
  2. Added escitalopram (antidepressant)
  3. Olanzapine □ risperidone (antipsychotic)
  4. Added valproate (mood stabilizer)
  5. Lorazepam (benzodiazepine) □ oversedation
  6. Trazodone (antidepressant) □ paradoxical agitation
  7. Risperidone □ haloperidol (antipsychotic)

Case

- He got better!

Key Points

- Non-pharmacologic interventions are first-line for BPSD
  - Medications often have limited efficacy
  - Most medications for BPSD have risks and significant potential for side effects (including worsening of behaviors!) – informed consent is essential
- Medications should target specific neuropsychiatric symptoms
  - Trial & error often necessary
- Goal of medication treatments should be palliation of distress and/or patient/staff safety (NEVER for staff convenience!)

Community Health Workers' Perspectives

Strategies for successfully managing dementia-related behavioral issues

Caregiving for People with Memory Loss

May 19, 2022

What is a Community Health Worker? (CHW)

- Commonly called CHWs
- Trained, front-line public health professionals
- Community connections (language, culture, life experiences)
- Bridges care gap (health/social services) and community
- Creates access to health/community services and resources
- Provides culturally appropriate health education, information and outreach in various settings (homes, clinics, hospitals, care centers, etc.)
- Advocates for inclusive and equitable healthcare for all

Importance of Caregivers

- Caregiving is Crucial :

- Promote overall happiness

- Mental well-being

CHW Strategies for Caregivers

- **Recognize behaviors as a form of communication**
- **Major challenges:**
  - Behaviors and personality changes
  - Agitation/irritability
  - Sleep (wakefulness/sleep disruption)
  - Wandering
  - Eating (too much/too little)
  - Fearfulness/crying spells

Triggers: What's Driving the Behavior?

- Assess the situation/behavior patterns
- Identify the causes: in the moment/progressive symptoms
- Environmental (unfamiliar surroundings, music, TV, voices, smells)
- Personal needs (hungry, thirsty, pain, bored)
- Disease progression-induced symptoms (wakefulness/sleep disruption)
- Historical driver/influencers (trauma, other chronic conditions)

Behavior Management Tips

Person-centered approach

- Meet the person where they are. Be in the moment.
- Personal preference: Utilize the person’s likes to re-direct or to get the person’s attention.
- Communication: Ask simple, answerable questions, use clear statements and calm voice.
- Listen with all your senses (eyes, ears and heart).
- Stress management (quietness, crafts, music, dancing, coffee, TV shows)
- When the going gets tough: Distract and re-direct!

Other Considerations

- Biological effects on memory loss (pre-disposition)
- Co-morbidities (chronic health conditions, substance use disorders)
- Lack of understanding of the brain, diseases and disorders
- Historical: lack of trust, economic factors
- Cultural considerations (brain health, aging and/or cognitive conditions)
- Lifestyle behaviors (diet, exercise, sleep hygiene, etc.)

Caregiver Burnout Prevention Self-Care

- **Don’t forget to take care of yourself!**
- **Build a team(s) and delegate**
  - Family and friends
  - Professional providers
  - Community-based organization (CBOs)

- **When enlisting community support/care sharing, consider**
  - Cultural norms
  - Biases/stigmas
  - Economic factors

Key Take-Aways

- Caregiving is a huge responsibility
- Individualize the style of care
- Be supportive and encouraging
- Be aware of environmental factors (calm/familiar environment)
- Encourage regular routines
- Prioritize self-awareness and care (take breaks, socialize with friends, keep up with hobbies)
- Connect with others: Attend caregiver support group

Thank you!

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- Community Health Worker
- Juniper program, Trellis
- MN CHW Alliance