Management of Dementia:
There is More to it than Drugs

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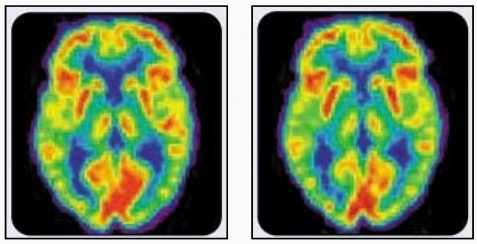
Objectives

At the conclusion of this session the participant will:

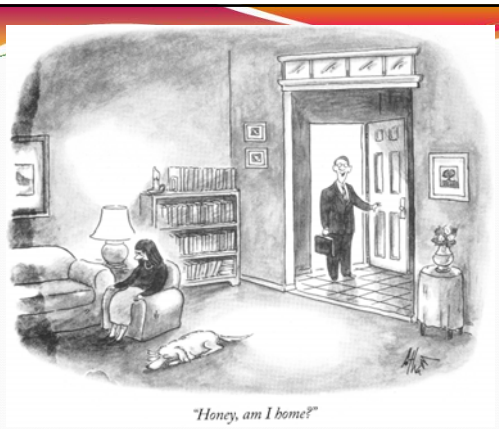
- Be prepared to discuss the scope and severity of the epidemiology of dementia
- Demonstrate an understanding of the complexities of the neurobehavioral aspects of dementia
- Recognize the societal and regulatory pressures associated with dementia care in today's skilled nursing homes
- Be able to educate staff about general trends in non-pharmacological treatment of dementia behaviors
- Be able to offer specific guidance about treatment of distressing behaviors

PET and Aging



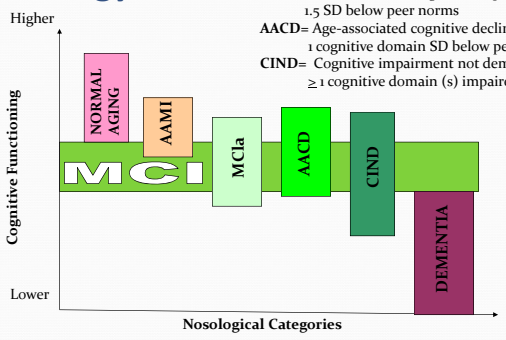
PET Scan of 20-Year-Old Brain **PET Scan of 80-Year-Old Brain**

ADEAR, 2003



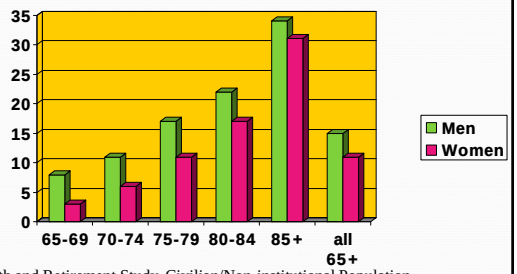
Nosology of MCI

AAMI= Age-associated memory impairment, 1 SD below young norms
MCIa= (amnestic) mild cognitive impairment, 1.5 SD below peer norms
AACD= Age-associated cognitive decline, 1 cognitive domain SD below peer
CIND= Cognitive impairment not dementia, ≥ 1 cognitive domain (s) impaired



Moderate to Severe Memory Impairment

(defined as recall of 4 or less words out of 20)

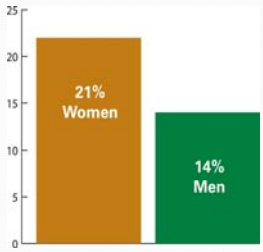


Health and Retirement Study, Civilian/Non-institutional Population

Impact on Baby Boomers

14 million baby boomers can expect to develop dementia, including Alzheimer's disease

- ~ one in five women
- ~ one in seven men
- ~ more women than men will develop dementia because women live longer, on average

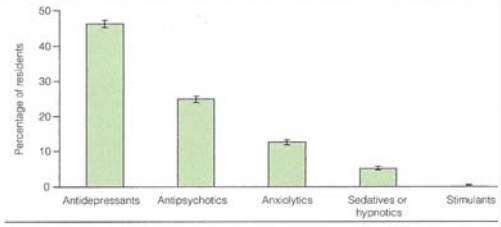


The Scope of the Issue

- Raising dementia numbers: Reported in 2010 (Chen, et al) at least 39.4% of NH residents had cognitive impairment, 80% with behavioral symptoms associated with dementia
- 2004: ADAMS reviewed representative community persons with dementia 21% AD, 5%CV, 26.8% other were prescribed antipsychotics
- 2007: Of 2.1 million residents, 304,983 (14%) had at least one Medicare claim for an atypical antipsychotic during the six-month period and represented 1/3 cost of care

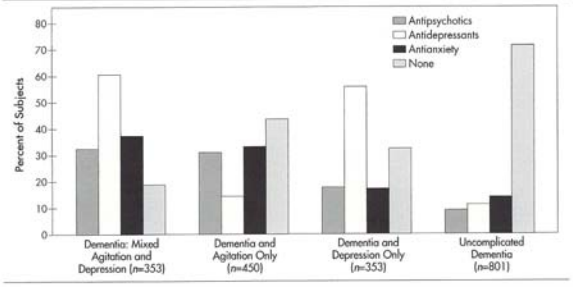
Figure 1

Psychotropic medication use among all elderly nursing home residents in 2004



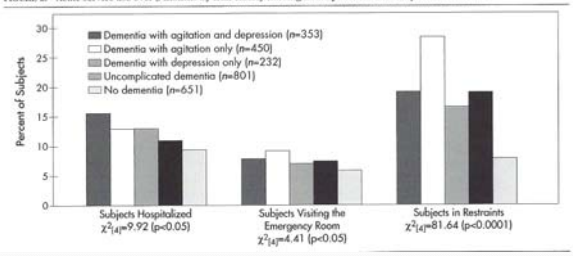
Bhattacharjee S, et al. Psychotropic drug utilization among elder nursing home residents in the United States Psychiatric Service 2010; 61:655-660.

FIGURE 1. Profiles of pharmacological treatment of complicated dementia in frail elderly patients in nursing homes



Bartels SJ, Horn SD, Smout RJ, et al. Agitation and depression in the frail nursing home elderly patients with dementia. Am J Geriatr Psychiatry 2003; 11:231-238.

FIGURE 2. Acute service use over 3 months by frail elderly nursing home patients with complicated dementia



Bartels SJ, Horn SD, Smout RJ, et al. Agitation and depression in the frail nursing home elderly patients with dementia. Am J Geriatr Psychiatry 2003; 11:231-238.

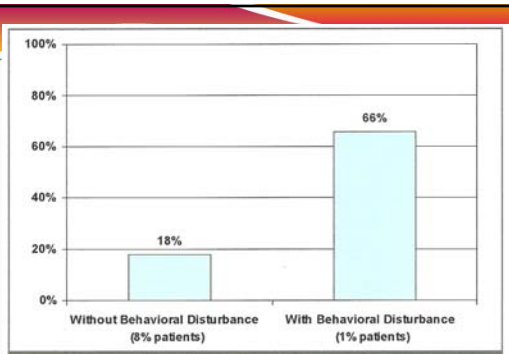


FIGURE 2. Proportion of Alzheimer's disease patients receiving antipsychotics
Source: Verispan PDDA, ICD-9 Diagnosis 294.10 (without behavioral disturbance) and 294.11 (with behavioral disturbance), May 2007 to April 2008

The QUALITY INITIATIVE

Safely Reduce Hospital Readmissions: By March 2015, reduce the number of hospital readmissions within 30 days during a SNF stay by 15 percent.
Increase Staff Stability: By March 2015, reduce turnover among nursing staff (RN, LPN/LVN, CNA) by 15 percent.
Increase Customer Satisfaction: By March 2015, increase the number of customers who would recommend the facility to others up to 90 percent.
Safely Reduce the Off-Label Use of Antipsychotics: By December 2012, reduce the off-label use of antipsychotic drugs by 15 percent.

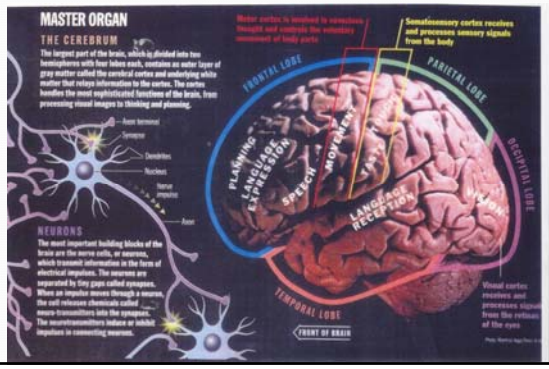
Dementia Impacts What Is Important

Pets
Hearing
Property
Possessions
Sports
Marriage
Home
Education
Laughter
Right NOW
Gardening
Money
Travel
Respect
Volunteer
Job
Eyesight
Work
Walking
Pain free
Religion
Children
Vacations
Reading

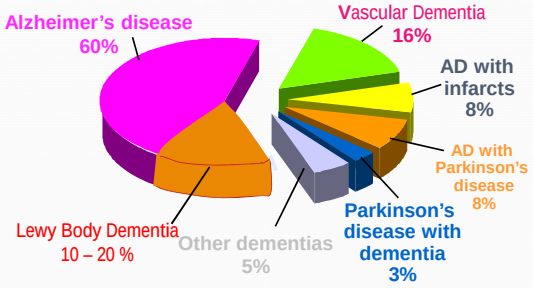
I believe that behavior itself is not a disease. Simply put, behavior is communication. In people whose ability to communicate with words is limited (such as patients with dementia), communication tends to be more nonverbal (i.e. behavioral). Our challenge is to figure out what they are trying to say, and if they are in distress, to identify the underlying causes and precipitants. Many of the behaviors that are commonly observed in patients with dementia and that are often labeled as difficult, challenging, or bad, such as agitation, wandering, yelling, inappropriate urination, and hitting are typically reactive, almost reflexive behaviors that occur in response to a perceived threat or other misunderstanding among patients who by the definition of their underlying illness have an impaired ability to understand. ...

Jonathan M. Evans, MD, MPH, FACP, CMD
Vice President, AMDA–Dedicated to Long Term Care Medicine

THE WHERE AND WHY DEMENTIA HAPPENS…



Causes of Dementia

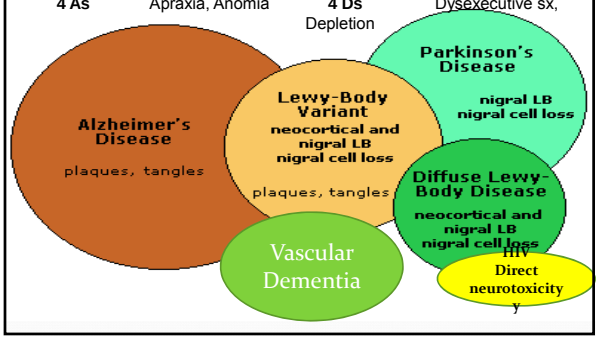


Morris JC. Clin Geriatr Med. 1994;10:257-276

Cortical to Subcortical

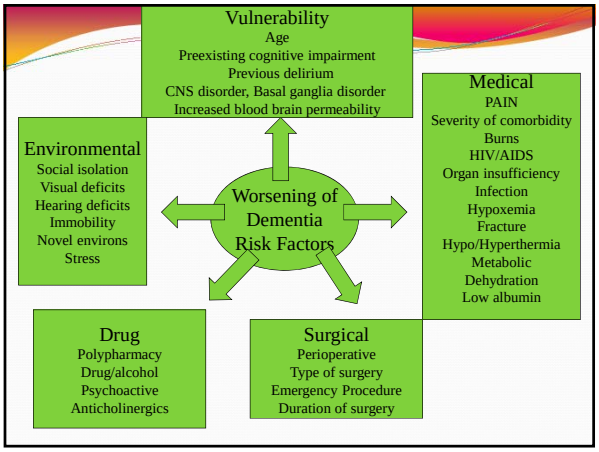
CORTICAL= 4 As Amnesia, Aphasia, Apraxia, Anomia

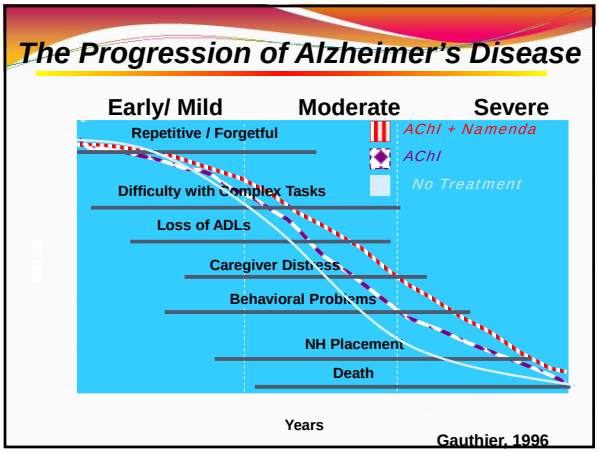
SUBCORTICAL= 4 Ds Dysmnesia, Delay, Dysexecutive sx, Depletion



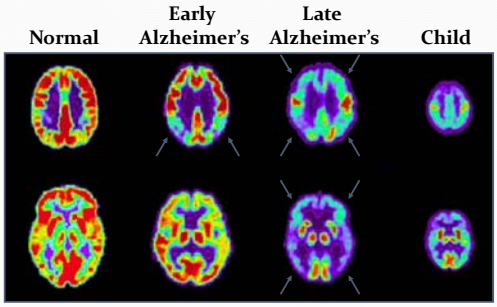
DIFFERENTIAL DIAGNOSIS FOR MENTAL STATUS/MOOD CHANGES

- ***D***= ***DELIRIUM, Drugs, Depression***
- **E**= **Eyes, Ears, Environment**
- **M**= **Metabolic (heart, lung, liver, kidneys)**
- **E**= **Endocrine (diabetes, thyroid)**
- **N**= **Neurological, Normal Pressure Hydrocephalus, Nutritional**
- **T**= **Tumor, Trauma**
- **I**= **Infection (CNS, general), Impaction**
- **A**= **Anemia, ALCOHOL**





Positron Emission Tomography (PET)
Alzheimer's Disease Progression vs. Normal Brains



G. Small, UCLA School of Medicine

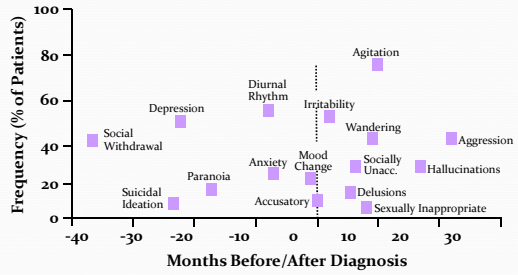
Principles of Dementia Care

- Something can be done at all stages!
- Excess disability is multi-determined
- Residual strengths matter
- Presume the person has feelings and needs, even if not verbalized
- Think of yourself and loved one as a unit
- Continuing education and support is crucial
- Sometimes behaviors require medication
- Ensure safety, dignity, and quality of life

The Who, What, Where, When, Why, and How of Behaviors

- **Who** has behavioral changes ?
- **What** is a behavior?
- **Where** to these behaviors happen ?
- **When** do behaviors happen?
- **Why** do behaviors happen ?
- **How** do we handle behaviors ?

PEAK FREQUENCY OF BEHAVIORAL SYMPTOMS AS AD PROGRESSES



Jost BC, Grossberg GT. J Am Geriatr Soc. 1996;44:1078-1081

Incidence of Behaviors

- Apathy (72%)
- Agitation (60%)
- Anxiety (45%)
- Irritability (42%)
- Motor restlessness (38%)
- Disinhibition (36%)
- Sleep disturbance (24%)
- Depression (23%)
- Delusions (22%)
- Hallucinations (10%)

The Stages of Alzheimer's Disease

Stage	Mild	Moderate	Severe
Symptoms	Memory loss Language problems Mood and personality changes Diminished judgment Withdrawal from activities	Require assistance with all IADLs* Unable to learn or recall new info Long-term memory affected Behavioral, personality changes Wandering, paranoia, aggression, Placement initiated	Loss of ADL's Incontinence **Dysphagia** **Mute** Motor disturbances Unstable gait Bedridden Placement common

*IADLs = Instumental Activities of Daily Life

THE A–B-C-Ds of Behavior Assessment

- A
  - The antecedent – What happens before the behavior
- B
  - The Behavior – Describe
- C
  - The Consequence – What happens after the behavior. Are there rewards or negative results?
- D
  - **THE DANGEROUSNESS- FOR BOTH THE INDIVIDUAL AND THE CAREGIVER**

Describe Specific Target Symptoms

Physical[1,2]	Verbal[1,2]	Passive
Hitting	Threats	Silence
Pacing	Accusations	Poor po intake
Kicking	Name-calling	Withdrawal
Biting	Obscenities	Dead weight
Pushing	Complaining	Listless
Spitting	Attention-seeking	Hand wringing
Scratching	Screaming	Blank Stare

1. Cohen-Mansfield J. Int Psychogeriatr. 1996(Summer);8(2):233-245. (Review)
2. Tariot PN, Mack JL, Patterson MB, et al. Am J Psychiatry. 1995(Sept);152(9):1349-1357

ANGER: A feeling of displeasure resulting from injury, mistreatment, opposition and usually showing itself in a desire to fight back at the supposed cause of this feeling

- **When are you more likely to feel angry?**
  - confronted with something you don't understand ?
  - slighted ?
  - someone does not listen to you ?
  - something unjust occurs ?
  - unfairly accused ?
  - you don't get your way ?
  - you're tired ?
  - impatient ?

AGITATION: Physical or vocal behavior that is distressing to the individual or those around the person and not in response to a specific need.

- Despite the physical or vocal behavior, it is NOT agitation if there is a physical or emotional unmet need
- A catch-all term that has little meaning
- Learn to describe the behavior specifically
- Learn to quickly assess the situation for causes of distress

Behavioral Interventions

- **Behavioral contracting**
- **Behavioral modification and token systems**
- **Brief directive psychotherapy**
- **Desensitization**
- **Distraction**
- **Family therapy**
- **Group therapy**
- **Hypnosis**
- **Milieu and attitude therapy**
- **Paradoxical therapy**
- **Reframing the problem**
- **Relaxation training**
- **Reminiscence and milestoning**
- **Time out**
- **Validation**
- **Restrictive and aversive therapies (Only in special units)**

GENERAL TIPS IN ADDRESSING BEHAVIORS:

- Modify the setting to "fit" demented resident's needs, not vise versa.
- Socialization to decrease loneliness, increase self esteem and well being.
- Integrating with community and familiar activities, especially intergenerational.
- When there is aggression, investigate roles of caregiver
- Offer a variety of choices but limit decision-making.

MORE GENERAL TIPS IN ADDRESSING BEHAVIORS:

- Offer a variety of choices but limit decision-making..
- Listen to what the person is trying to say (Validation)
  - **I want to go home**: "I'm lonely", "I'm lost", "Nothing looks familiar"
  - **I have to get to work:** "I don't feel important now", "I need something to do",
  - **Where is my mother?:** "I have to be taken care of..."

RESISTIVENESS:

- ❑Calmness
- ❑Matter-of-fact
- ❑Explain each procedure simply
- ❑Privacy and modesty are key
- ❑Offer single steps
- ❑Offer opportunity to participate
- ❑Talk during process.

SUSPICIOUSNESS:

- ❑ BE CALM
  - ❑ Please don't take it personally
  - ❑ Avoid arguments.
- ❑ Do not whisper or discuss things in front of the person as if they are not there
- ❑ Help look for missing items
  - ❑ Know hiding places
  - ❑ Keep duplicates
  - ❑ Reduce clutter
  - ❑ Always check the waste baskets and pockets

- Aggression severe restlessness:
  - BE CALM
  - Try music
  - Find constructive tasks
  - Use food and other pleasant distractions
  - HAVE AN EMERGENCY PLAN
- Wandering:
  - Identification
  - Label rooms and objects
  - Use pictures
  - Monitoring

Mental

- Learning
- Creativity
- Flexibility
- Focus

Examples of VALIDATION

- Rose has to get home to feed her children lunch.
- Bud has to catch a bus into the City.
- All Irene can do is rock
- Herb pounds on the desk or the chair table or anything he can get his hands on
- Helen seems angry (or sad, or frightened) most of the time

Physical

- Exercise
- Diet
- Sleep
- Share symptoms with your doctor
- Avoid medicating oneself

WHY EXERCISE ?

- Increases strength and vigor, therefore, increase opportunities for more interaction.
- Decreases depression, therefore, increases self esteem and well being.
- Fatigues elders, therefore, decreases wandering, agitation, pestering.
- Keeps person active in day, therefore, resynchronizes schedule for night-time sleep.
- Fostering reminiscence and relationships.

Dementia – Treatment

Non-pharmacologic alternatives to antipsychotics:

- Evidence grades from A (strongest) to D (weakest)
- RCT: randomized controlled trial

Treatment	Evidence/Results
Caregiver psycho education/support	Several positive RCT's (evidence grade A)
Music Therapy	6 RCT's positive in the short term (evidence grade B)
Cognitive stimulation therapy	Three-quarters of RCT's showed some benefit (evidence grade B)
Snoezelen therapy (controlled multisensory stimulation)	3 RCT's with positive short-term benefits (evidence grade B)
Behavioral management therapies (by professionals)	Largest RCT's with some benefits (evidence grade B)
Staff training/education	Several positive studies of fail-to-good methodological quality (evidence Grade B)
Reality orientation therapy	Best RCT showed no benefit (evidence grade D)
Teaching caregivers behavioral management techniques	Overall inconsistent results (evidence Grade D)

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Dementia – Treatment

Non-pharmacologic alternatives to antipsychotics:

- Evidence grades from A (strongest) to D (weakest)
- RCT: randomized controlled trial

Treatment	Evidence/Results
Simulated presence therapy	Only 1 RCT which was negative (evidence grade D)
Validation therapy	1 year RCT with mixed results (evidence grade D)
Reminiscence therapy	A few small studies with mixed methodologies (evidence grade D)
Therapeutic activity programs (such as exercises, puzzle play)	Varied methods and inconsistent results (evidence grade D)
Physical environment stimulation (such as altered visual stimuli, mirrors, signs)	Generally poor methodology and inconsistent results; best results with obscuring exits to decrease exit-seeking (evidence grade D)

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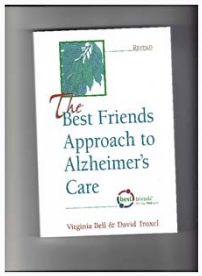
Emotional

- Getting and giving love
- Joy
- Awareness of one's emotions
- Control over reaction to emotions

How Can I Still Be A Friend?

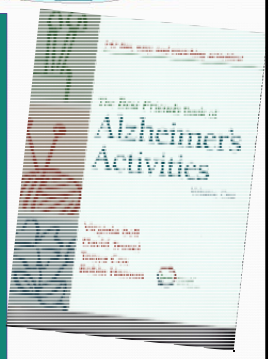


THE BILL OF RIGHTS

1. Know one's diagnosis
2. Have appropriate/ongoing medical care
3. Have the opportunity to be productive in work and play as long as possible
4. To be treated like an adult, not a child
5. To have expressed feelings taken seriously
6. To be free of unnecessary medications
7. To be in a safe, structured, predictable environment
8. To have meaningful activities available
9. To have the opportunity to be outdoors
10. To have physical contact
11. To have those around me know of my background, culture, and values
12. To be cared for by people who are trained in dementia care

What Can A Friend DO ??????

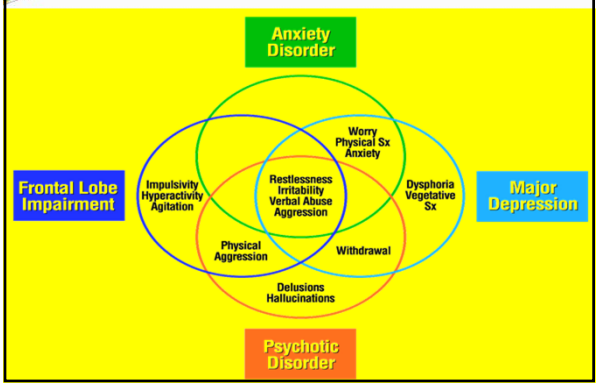
Acknowledge Me
Listen to Me,
Laugh with Me,
Give Me a Hug,
Walk with Me,
Ask for My opinion,
Join Me in a Song,
Let Me feel different things,
Wrap a present with you,
Make something with you,
Let Me hold your hand..
Maybe a hand rub as well,
Let's talk about the old times
Like they were today



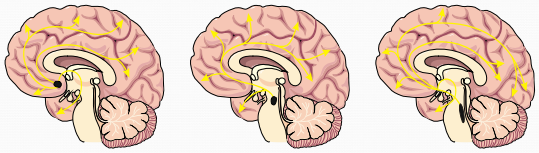
Spiritual

- Connection with something bigger than self
- Values
- May or may not be about organized religion

Symptoms and Syndromes Overlap



Neurotransmitter Deficiencies in AD



Nucleus basalis of Meynert (acetylcholine)

Locus ceruleus (norepinephrine)

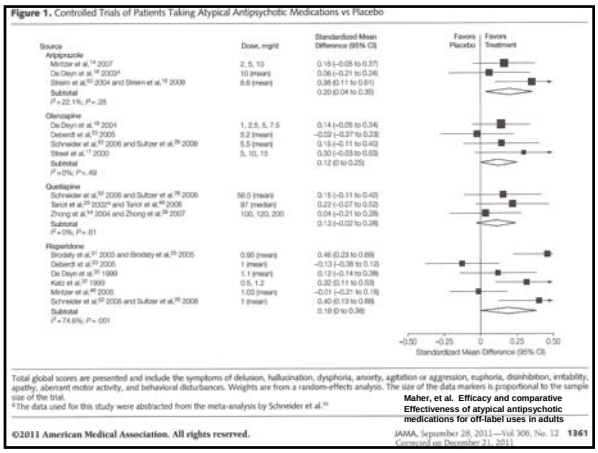
Raphe nuclei (serotonin)

Examples of Use of Metaphors

- "Depressive"
  - Irritable, pessimistic, sad, weepy, socially withdrawn,vegetative features
  - A place for antidepressant trial
- "Psychotic"
  - Angry when approached, overly suspicious, fragmented speech/thinking
  - A place for possible antipsychotic medications
- "Manic"
  - Euphoric, irritable, accelerated, hypersexual, silly
  - A place for mood stabilizers

Medications Available

- Cognitive enhancers
  - Cholinergic medications
  - NMDA receptor blockers
- Antidepressants
- Mood Stabilizers (AED)
- Antipsychotics
- Anxiolytics
- Hypnotics
- Barbituates / Miscellaneous



Maher, et al. Efficacy and comparative Effectiveness of atypical antipsychotic medications for off-label uses in adults

Dementia – Treatment

Pharmacologic alternatives to antipsychotics:

Treatment	Evidence/Results
Selective serotonin reuptake inhibitors	2 positive studies with citalopram (more effective than placebo for agitation in 1 trial and equivalent to risperidone for psychosis and agitation with greater tolerability in the other); 2 negative trials with sertraline
Other antidepressants	1 study showed trazodone was equivalent to haloperidol for agitation, with greater tolerability; another found trazodone was no different from placebo; other agents have only case reports or open label trials
Anticonvulsants	3 trials showed divalproex was equivalent to haloperidol for agitation, with greater tolerability problems in both; other agents tried only in case reports or open-label trials
Benzodiazepines/ anxiolytics	3 trials showed oxazepam, alprazolam, diphenhydramine, and buspirone were equivalent to haloperidol in effects on agitation, but none used a placebo control; trials had problematic methodologies and indicated cognitive worsening with some agents (especially diphenhydramine)
Cognitive enhancers	Some evidence of modest benefit in mostly post-hoc data analyses in trials designed to assess cognitive variables and often among participants with overall mild psychiatric symptoms; prospective studies of rivastigmine and donepezil specifically designed to assess neuropsychiatric symptoms have found no difference compared with placebo
Miscellaneous drugs	Failed trial of transdermal estrogen in men; small study showed propranolol (average dose 106 mg/d) more effective than placebo

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SIDE EFFECTS AS A DECISION-MAKING TOOL

Drug *Brand Name* (daily dose range)	Aripiprazole *Abilify* (2-10 mg)	Haloperidol *Haldol* (0.25-2 mg)	Olanzapine *Zyprexa* (2.5-7.5 mg)	Quetiapine *Seroquel* (12.5-150 mg)	Risperidone *Risperdal* (0.25-2 mg)
Movement Side Effects	■■	■■■	■■	■	■■
Central Nervous System					
Sedation	■■	■■	■■■	■■■■	■■
Confusion, delirium, cognitive worsening	■	0	■■	■	■
Worsening psychotic symptoms	0	0	■	0	0
Cardiovascular/Metabolic					
Orthostatic hypotension	■?	■■	■	■?	■?
Edema	■?	0	■	0	■■
Weight gain/glucose ↑	0	■?	■■■	■	■■
Triglyceride ↑	0	0	■■■■	■■■	0
Urinary incontinence, UTI	■■■	■■	■■	■■	■■

Before the Start of an Antipsychotic Medication, Consider:

- What is the indication, condition or target symptom(s)?
- Is any testing necessary to confirm a diagnosis?
- Might any already-prescribed medications be causally related to a target symptom?
- What safety goals must be considered; is there current dangerous behavior?
- Can a psychosocial or behavior treatment be started immediately?
- Who is providing informed consent for any new medication?
- Have medications other than antipsychotics received adequate trials?
- What baseline and follow-up monitoring will be recommended with an antipsychotic?
- Does a medical colleague support the use of antipsychotic treatment in this case?
- How will use of the antipsychotic medication be documented?[20]
- What endpoints for antipsychotic treatment will be considered within the first six months?

Informed Consent for Medication

Client name: _____

1. I have had the opportunity to discuss this medication with the physician and/or nursing staff.
2. The risks and benefits of this medication were explained to me.
3. The most common side effects were explained to me.
4. If I encounter any side effects, I will report them to the physician or the nursing staff immediately.
5. Treatment alternatives were discussed with me.
6. I understand that I have the right to accept or refuse medication by informing the physician or nurse.
7. I will be kept informed of the progress of my treatment, and also understand that if I consent to take this medication, the dosage range may not be increased or changed without my further agreement.
8. If I am to be taking antidepressant medications, the risk of suicidality has been explained to me, and I understand that if I experience this side effect, I am required to report this immediately to my treating physician and/or the nursing staff.
9. If I am to be taking an antipsychotic medication, the risks of tardive dyskinesia, diabetes, and dyslipidemia have been explained to me. I have also been told the Food and Drug Administration has recently determined that elderly patients with dementia who use certain medications in this class may be exposed to an increased risk of death. The studies indicate that, while the causes of death were varied, most were associated with cardiovascular disease, stroke, or infections.

Consents:
The medications explained were:

Medication Name _____ Dosage Range _____

Client's Signature if Agrees to Take _____ Date _____

__ Client agrees but will not sign.
__ Consent done by telephone with _____ (name of person)
__ Medication Education Sheet given

Parent/Guardian Signature or Durable Power of Attorney (DPOA) Signature _____ Date _____

__ DPOA has been activated.

Witness Signature _____ Date _____

ANTIPSYCHOTIC MEDICATION

INDICATION	YES	NO
1. Non-pharmacologic (psychosocial/environmental) interventions implemented and have been unsuccessful or require adjunct treatment.		
2. Being used for a primary psychiatric diagnosis, a dementia illness with psychotic symptoms, a dementia illness with persistent aggressive and or agitated behavior that poses a danger to self and or others and is not due to underlying medical condition or identifiable environmental conditions or delirium with manic or psychotic symptoms.		
3. Target psychotic or manic symptoms to be addressed, the behavioral symptoms present a danger to the resident or others, or the symptoms are significant enough that the resident is in persistent distress/experiencing a significant decline in function/unable to receive needed care.		
4. Acute psychiatric symptoms and re-evaluation within seven days of treatment initiation.		
5. Medication is not being used solely in response to environmental stressors, not solely due to psychological stressors, or in situations of non-dangerous behaviors (i.e. wandering, poor self-care, restlessness, impaired memory, insomnia, uncooperativeness).		
MONITORING		
1. Efficacy of medication monitored.		
2. Absence or control of adverse consequences.		
DOSE		
1. Dose threshold is within geriatric guidelines or variance documented.		
2. Rationale for any duplication of medications is well documented.		
DURATION		
1. Medications utilized for the minimum amount of time to achieve treatment goals.		
2. During first year, gradual dose reduction attempted in 2 separate quarters (at least a month between attempts) and then annually.		
3. Rationale for maintenance of medication without GDR: 1) Target symptoms have returned or worsened. 2) GDR would negatively impact function, increase distressed behavior, medical/psychiatric symptoms are such that risks outweigh benefits. 3) Treatment is for Tourette's, movement disorders of Huntington's Disease, hiccups, nausea and vomiting associated with cancer/chemotherapy, or adjunctive end-of-life symptoms. 4) Treatment is for psychiatric disorder other than dementia and that the GDR would produce instability or the symptoms worsened with previous attempts.		
4. With on-going use, prevention and addressing of any untoward consequences of medication.		