The Care of Human Beings with Dementia

Jonathan M. Evans MD MPH CMD FACP

Antipsychotic And Other Sedating Drugs that are Administered to Make People With Dementia Behave

- What's the problem? (Why is it a problem?)
- Why does this problem continue?
- (Why don't most health care providers recognize it as a problem)
- What can be done about it?

"Doctor,

what can

you do

for Pop?"

to help you relieve

the severe emotional upset

of the menopausal patient

THORAZINE*

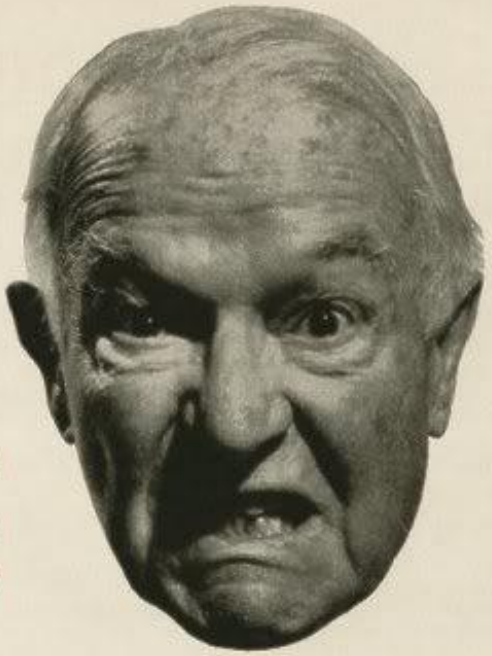
'Thorazine' can facilitate the over-all management of your menopausal patient. Its unique, non-hypnotic tranquilizing effect relieves anxiety, tension, agitated depression and helps you to restore to the patient a feeling of well-being and a sense of belonging.

'Thorazine' is available in ampuls, tablets and syrup (as the hydrochloride), and in suppositories (as the base).

For information write:

Smith, Kline & French Laboratories, Philadelphia 1

*T.M. Reg. U.S. Pat. Off. for chlorpromazine, S.K.F.



Tyrant in the house?

'Thorazine' can control the agitated, belligerent senile

and help the patient to live a composed and useful life.

When 'Thorazine' is administered to the agitated senile, there is a marked decrease in his nerve-racking outbursts of hostility, irritability, abusiveness, incessant talking and "day-and-night" pacing or restlessness.

On 'Thorazine' therapy, the patient often forms more regular eating and sleeping habits and improves in his personal hygiene. As the patient becomes more tractable and cooperative, he is able to live a composed and useful life.

THORAZINE*

chlorpromazine, S.K.F.

one of the fundamental drugs in medicine

Smith Kline & French Laboratories, Philadelphia

*T.M. Reg. U.S. Pat. Off.

What's the Problem?

- Millions of Americans with Alzheimer's disease and other forms of dementia 'misbehave' in ways that are distressing to caregivers and others (wandering, yelling, 'agitation', etc)
- **For 75+ years, doctors and nurses have *been taught to use tranquilizers* in these instances to try to make patients behave** (conform to the rules/norms/ routines of the environment) Medical Culture Vs. Human Culture
- Health care environments are inflexible, confusing, and often scary to most patients even without Alzheimer's disease.
- People with dementia have limited ability to reason/comprehend the world around them-
  - They often perceive the behavior of others as threatening and respond reflexively or inadvertently break rules like opening doors, entering places like other's rooms that are 'off limits', etc
  - **Doctors and nurses have not been taught what to do instead of using tranquilizers.**
- ***'If all you have is a hammer, everything looks like a nail'***

What's The Problem?

- In General, Drugs administered to Make People Behave Don't Make People behave Better
- They are way more dangerous than prescribers and others think
- The use of these medications in nursing homes is a reflection of facility culture
- Distracts from the real work of understanding people and meeting their needs
- No correlation between severity of symptoms/disease and drug use
- Growing area of litigation in LTC
- There has been little if any reduction in the use of antipsychotic drugs in patients living with dementia overall
- Antipsychotic drug prescribing actually went up in nursing homes during COVID-19 Emergency
- Requests from staff for prescription of sedating medications often represents caregiver stress

What's the Problem?

- Not just antipsychotics
- In nursing homes, efforts to discourage the use of antipsychotic drugs in people living with dementia resulted in:
  - Switch from antipsychotics to other sedating medications (benzodiazepines, anticonvulsants) with no net decrease in sedating medications overall
- A fourfold increase in diagnosis of schizophrenia, primarily in older adults previously diagnosed with dementia
- Not just nursing homes
  - Drug use in assisting living 'memory care' generally higher than in most nursing homes
  - 85% of antipsychotic drug prescriptions to Medicare beneficiaries are for people living with dementia (70% of people living with dementia live at home currently, but 70% reside in a residential care setting at time of death)

Fundamentally, this is a moral issue, not a medical issue

Behavior Case 1

- Male patient, resident of home for 18 months
- Requires ‘total care’
- Frequent agitation, yelling, crying, wandering
- Unable to communicate needs verbally
- Often ‘resists care’
- Frequently bites, scratches caregivers
- Destroys other residents’ property


Wheel Horse

Behavior is Communication

- Behavior is Communication

- *Behavior is not a disease!*

Agitation

- Exemplifies medical culture: agitation a disease/ drug deficiency state
- The word itself is pejorative and virtually useless
- Challenge its use and eradicate it
- Substitute “visibly upset” instead

Behavior Case 2

- You leave here in a hurry to pick up your child (or grandchild) from daycare this evening
- When you arrive, you are told by the director that your 3-year-old beloved had a rough morning, but he was given a medication that helped a lot. He is sleeping deeply now, with snoring respirations, falls back to sleep immediately when you try to wake him, and he has been incontinent of urine despite being successfully potty trained over a year ago.
- How do *you* feel?

Case 3

- 42-year-old healthy conference attendee
- Sleeping alone in hotel room
- Suddenly awakened from deep sleep by 3 strangers in the room standing over him, holding him down. Pulling at arms and clothing. Speaking in loud voices, telling him to cooperate.

- What should he do? What would you do?

Case 4

- 82-year-old retiree, former attendee of multiple conferences.
- Sleeping in own bed in nursing home
- Suddenly awakened from deep sleep by 3 strangers in the room standing over him, holding him down. Pulling at arms and clothing. Speaking in loud voices, telling him to cooperate.

- What should he do? What would you do?

Behavior Case:

- Great News!
- There is perfectly safe medicine with no side effects.
- It costs virtually nothing
- If you take it, within 5 minutes it will cause you to behave exactly the way the person giving it to you wants you to.
- *Would you take it?*
- Whom would you like to administer it to you? When? Under what circumstances?

Behavior is Communication

- Most ‘challenging’ behaviors in institutional settings are *reactive*
  - often caused by and/or exacerbated by *misunderstanding/misperception on the part of either patients or staff*
- Patients with confusion have altered perception by definition
- Patients with dementia lose the ability to comprehend, understand, reason
- Attempting to reason with someone who has lost the ability to reason is unreasonable

Behavior is Communication

- "Challenging" behaviors Most often represent a *conflict between the individual and their environment*
- *Especially the human environment*

Primary Task: Figure out *meaning*

. . . . Why do they do that?

. . . . What are they trying to say?

Interpret behavior in the context of one's life experience

Behavior is Communication

- *Are they telling you that they are in distress?*
  - or are they causing distress to others?
- The approach to prevention and management is quite different, depending upon the answer to this question
- For patients in distress, look for and modify/eliminate/treat the underlying cause (what or whom)

General approach

- What are they trying to say?
- What are they reacting to?
- Look for meaning
- Determine if patient is in distress and if so, evaluate cause
- Most often situational
- Behavior history to identify precipitants/antecedents, help interpret meaning
  - Get information from nursing assistants, families, nonmedical staff, staff on different shifts

Behavior as Communication

- Labeling of behaviors (and patients) as "bad" or "difficult" may create a set of expectations and foster a sense of futility or resignation
  - becomes self-fulfilling
- People with dementia often comprehend/respond to nonverbal communication (behavior) better than words
- *Mirroring* the effect of others (residents, caregivers)

Case 5

- You are at the airport, in an unexpectedly long line at the ticket counter
- You see the agent at some distance. He looks upset. He is flinging his arms. Others ahead of you are frowning and muttering to themselves, reaching for their cellphones.
- What are you thinking and feeling right now?
- How will your behavior change as a result?

Case 6

- Your boss sends you an email. She says she has bad news and will send you another email later.

Behaviors in People With Dementia

- “Undesirable” behaviors not planned, thoughtful, premeditated or even conscious
- Individual may have no awareness or recollection
- Individual must conform to environment but cannot because of cognitive impairment

"Resisting Care"

- Primitive, reflexive reaction to perceived threat
- Avoid surprising people who don't like surprises
- Communicate at eye level or lower
- Avoid standing over people (threatening position- think strange dogs)
- Talk in slow, calm, reassuring voice
- No (verbal and nonverbal) means no
- Stop and try again later
- Work around their schedule

Meaningful activities, roles

- Help people be successful
- Use abilities that remain
- Give people important things to do, that they relate to (overlearned behavior)
- Activities individualized to each nursing home resident
- Activities accessible at all hours (picture books, magazines, objects, music players, art supplies)

Case 7

- Patient with Alzheimer's awakens at 2 am. "Agitated" Impossible to Redirect. Demands breakfast

Routines: Resident versus Facility

- Many people are creatures of habit
- What is familiar is often of great comfort
- People with dementia have difficulty learning new things, old routines more important and more difficult to change
  - i.e. sleeping, eating, bathing (example: bath versus shower)
- By definition, being dependent on others limits choices- Many have difficulty accepting this. People with dementia have difficultly *comprehending* this

Reasonable Expectations

- Virtually every behavior will see in patients with dementia is predictable and in response to something. What is it they are responding to?
- What are your expectations of the patient, and why?
- Why do you expect them to behave differently?

Wandering

- What is it and what's wrong with it?
- Why do they *do* that?
- Is pt. in distress (yes/no)?

Wandering

- Moving about in an (apparently) aimless or disoriented manner
- Multiple causes and precipitants:
  - Lost- looking for something
    - Room, bathroom, food
  - Boredom
  - Desire to move
  - the need to exit a stressful situation
  - a search for something familiar and comforting

Wandering

- Lifelong pattern of coping with stress
- The need to keep busy
- A search for security
- Find the bathroom, a person, or a lost object
- Effort to "go home" or "go to work”
- Pain esp. DJD, restless legs, etc.
- Drug side effect
- Exercise

Case

- 85-year-old female nursing home resident with AD
- Independent in ambulation. Vision and hearing impaired
- Wanders frequently
- Pulled fire alarm in hallway 3 times
- Facility threatened with fines by fire department
- Resident's family notified of potential eviction if behavior cannot be controlled

Case: Dementia and Cancer

- 82-year-old resident with dementia. And prostate cancer. Recently enrolled in hospice.
- Nurse calls asking for Ativan prescription. Patient is reportedly agitated

Wandering: Approaches

- Movement is normal and good- facilitate physical activity and provide needed assistance
- Help people find their way (photos, large signs, redirection)
- Substitute other things
  - meaningful activities and familiar objects
  - Regular exercise scheduled and PRN
- Environmental adaptations (signs, locks, moving/changing door handles, wanderguards . . .)
- Accommodation, substitution, distraction, redirection

Case: 60 women with dementia

- 60 bed dementia unit all women
- “Always” fighting with one another
- Agitated

Case

- 60 women with dementia
- Only 3 baby dolls

Behavior in Dementia

- Tendency to blame the patient – “ bad”
  - Highly judgmental
  - patient becomes enemy
- Mistakenly assumes they are doing it ‘on purpose’ (in reality, they are reacting in a predictable, primitive, reflexive manner)
- Extremely counterproductive
- Represents bad judgement on part of staff/physicians
- Results in reactive approach that is always ‘too late’, fails to address underlying cause/precipitants
- Vicious cycle: reactive behavior elicits reactive behavior . . . .
- *They can’t all be bad, can they?*

Case

- 81-year-old widowed farm wife with AD living in AL facility
- Staff calling for medication order to control behavior
- Ambulates independently. Incontinent
- Described as always agitated, resists cares. Hit caregivers
- Wanders into others rooms and steals clothes
- Hides soiled clothing in her room
- Accuses residents and staff of stealing from her

Case

- Retired RN with AD living in nursing home
- Independent in ambulation
- “Agitation”, fighting with other residents
- Wanders into other residents’ rooms
- Pushes other residents’ wheelchairs causing them distress

“Unable to redirect”

Redirection

- This term is often misused
- Redirection is not reorientation (telling people they are wrong)
- Redirection is not telling people to “knock it off”
- Redirection is pointing people in the right direction
- Help them go where you both want
  - Think: steering, distraction, substitution
  - Takes advantage of limited attention, short term memory loss

Understanding and Approaching Behavior

- Personal/past experience of staff affect their own approach, response (often reflexive)
- Many experts within care setting (CNAs, housekeepers!)
- Boredom is the enemy
- Behaviors in families and staff to avoid
  - Correcting, blaming, punishing
- Facility culture can contribute to cause behaviors along with unwillingness to tolerate behaviors
- *Beautiful Building Syndrome*

Case

- 87-year-old woman with Alzheimer's
- "Agitated", "yelling out constantly" "paranoid"
- "Refuses to eat" "says she is being poisoned"
- Says "people are talking about her"
- Hard of hearing
- Meds being crushed and put into her food without her knowledge

Case

- 87-year-old woman complains of being poisoned- she is!
- *Don't do that*
- Discontinue, consolidate meds
- change time of essential meds (perhaps to when family reliably present)
- People talking about her- they are
- Hearing loss contributes to paranoia without dementia
  - Ear wax removal, simple inexpensive amplification

Case

- 76-year-old man with Alzheimer's Disease
- "Prefers" to stay in room
- On 3 occasions over the last 2 months, he was involved in physical altercations with residents wandering into his room
- Began with yelling (i.e. "get out") then escalated to hitting

Case

- Retired gynecologist with AD living in NH
- Wanders into other residents' rooms
- Found by staff on numerous occasions undressing and fondling several female residents against their will

Summary/Conclusions

- Behavior is communication
- Look and listen to what they are telling you
- Be aware of what you are telling them
- Search for meaning, precipitants
- Fix/modify underlying factors
  - Modify (human) environment to meet *patient's* needs
- Demedicalize situations as much as possible
- Adjust expectations/attitudes
- Assist others in problem solving, brainstorming solutions
- Get help from experts: family, CNAs, non-nursing staff