Dementia Care

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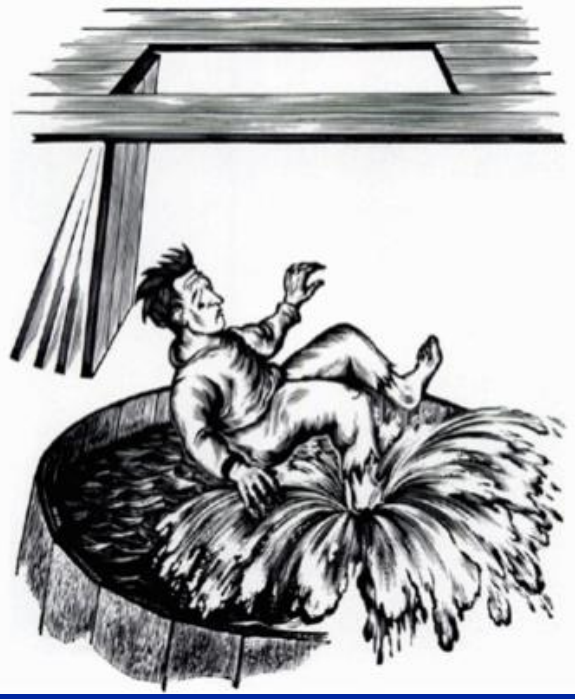
"Surprise Bath" used in colonial times to "restore the distracted to their senses." Original wood engraving by John De Pol.

to restore them to their senses

Less than 200 years ago, the mentally ill were bled, purged, beaten and sometimes nearly drowned in efforts to restore them to their senses.

The treatment of mental illness has progressed far beyond methods such as these. One of the major advances in psychiatry has come through chemotherapy—now an important factor in the treatment of mental illness, pioneered and developed with 'Thorazine'.

The importance of 'Thorazine' in psychiatry is twofold: (1) its continued widespread use has established it as a fundamental drug that can be used with confidence, and (2) it has led S.K.F. to the development of related drugs which offer the psychiatrist opportunities to help an even greater number of patients.



THORAZINE*

chlorpromazine, S.K.F.

Smith Kline & French Laboratories

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

"Doctor,

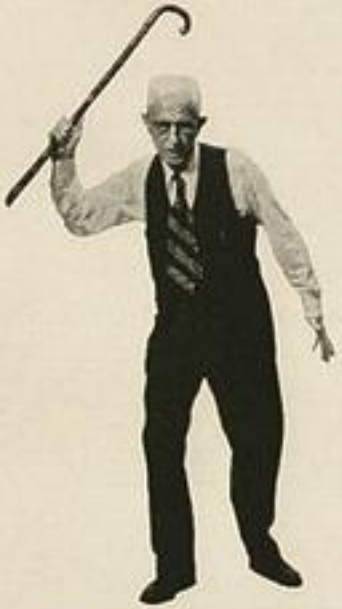
what can

you do

for Pop?"

for prompt control of

senile agitation



THORAZINE*

(chlorpromazine, S.K.F.)

'Thorazine' can control the agitated, belligerent senile and help the patient to live a composed and useful life.

Smith Kline & French Laboratories

Background

- 1990 Rates of antipsychotic drug use in nursing home residents approx 90%
- 1992 Federal regulations (OBRA 87) Fully implemented. Restrict use of antipsychotic and other psychotropic drugs in nursing homes.
  - Many studies, reports, texts on effectiveness of non-drug approaches to behavior in dementia from early 1990s to present
  - Dramatic decrease in prescribing until mid/late 1990s when atypical antipsychotic drugs are marketed
  - Steady increase in drug prescribing over next 15 years
- Numerous studies published over 10+ years identify increased risk of death in patients with dementia receiving atypicial (and typical) antipsychotic drugs (Rochon Annals 2008)
- 2005 FDA Black Box Warning. Personal letters from FDA sent to all prescribers nationwide warning of risks and reiterating drugs not approved for use in dementia (Second FDA warning 2008
- 2006 CATIE-AD Trial. Largest, most rigorous clinical trial to evaluate efficacy of antipsychotic drugs in dementia shows no benefit but worse clinical outcomes compared to placebo
- *Placebo effect: what is it?*

Antipsychotic and Other Drugs In Dementia

- These drugs are harmful and the don't do what we wish they would do
- Increased death from antipsychotics, anticonvulsants, benzodiazepines in patients with dementia
- JAMA Psychiatry2015: 100,000 veterans with dementia
- Number needed to harm = 8
- As many as one in eight patients died from the drug within 6 months compared to control group

Background

2008 DART-AD Trial. Randomized trial of antipsychotic drug discontinuation in AD shows no harm and no worsening of behavior following abrupt discontinuation of antipsychotic drugs

- **2011-2012 Medicare Part D spent approx $17 billion annually on atypical antipsychotics (largest outlay for any drug class)**
- **$10 billion + for 'off label' Rx mostly in dementia (mostly outside of NH)**
- **Compares to $4 billion annually spent on physician/np services in NH annually**
- **Various Studies: No correlation between patient symptoms/severity and use of antipsychotics in nursing homes**
- **Strong correlation between which facility admitted to and likelihood of receiving antipsychotic drug**
- **Use of antipsychotics in dementia correlates most closely with 'facility culture'**

Growing Pressure to Avoid Drugs to Control Behavior

- **Government:**
  - **CMS Regs,**
  - **GAO Report2015(Congress),**
  - **FDA**
  - **Senate hearings 2011**
- **Insurers**
- **Lawsuits**
- **Public**

Use of Antipsychotic Drugs Determined By Facility Culture

- **Unexplained Variation Across US Nursing Homes in Antipsychotic Prescribing Rates**
  - **Chen et al. Arch Int Med Jan 11, 2010**
- **Variation in Nursing Home Antipsychotic Prescribing Rates**
  - **Rochon et al. Arch Int Med April 2007**

"Food and Drug Administration. FDA public health advisory: deaths with antipsychotics in elderly patients with behavioral disturbances."
www.fda.gov/cder/drug/advisory/antipsychotics.htm

- **FDA issued advisory stating that atypical antipsychotics increase mortality among elderly patients.**
- **Metaanalysis of randomized controlled trials showed an 80% increase in death rate over a period of a few months following initiation of drug therapy**

Atypical Antipsychotic Drugs and the Risk of Sudden Cardiac Death. Wayne Ray et al. NEJM Jan 15, 2009

- Cohort study involving more than 90,000 users of antipsychotic drugs and 187,000 nonusers in Tennesee
- Incidence of sudden cardiac death approximately 100% higher in users of antipsychotic drugs (both typical and atypical) compared to nonusers. Incidence-rate ratio = 1.99
- No significant difference between atypical and typical agents. (Both had a similar increased risk of death compared to nonusers).
- Dose-response observed. Incidence-rate ratios increased from 1.59 for low dose atypical antipsychotics drugs to 2.86 for high dose atypical antipsychotic drugs.

Risk of Death in Elderly Users of Conventional vs. Atypical Antipsychotic Medications. Wang P et al. NEJM Dec 1 2005

- Cohort study involving almost 23,000 elderly patients using antipsychotic drugs over a 10 year period
- Significantly higher adjusted risk of death within days or weeks of initiation of therapy
- Risk of death even higher for typical antipsychotic use compared to atypical antipsychotics
- 18% of subjects taking typical antipsychotics died within 6 months vs. 15% taking atypicals.

Effectiveness of Atypical Antipsychotic Drugs in Patients with Alzheimer's Disease (CATIE-AD trial)

Schneider et al, NEJM 2006; 355:1525-38.

Effectiveness of Antipsychotic Drugs in AD

- Antipsychotic drugs frequently used in patients with AD, particularly to control undesirable behavior
- Increased rates of death consistently shown, even within weeks
- FDA warns docs that antipsychotics not indicated for AD, even with dementia associated psychosis
- But do they even work?

Atypical Antipsychotics and AD

- **Design: Multicenter double-blind placebo-controlled trial: olanzapine, risperidone, quetiapine or placebo**
- **Subjects 421 outpatients with AD and psychosis, aggression, or agitation**
- **Doses adjusted as needed**
- **36-week follow-up**
- **Clinical Global impression of Change (CGIC) Scale used to assess efficacy**

CATIE-AD Trial: Results

- No significant differences in improvement between drugs, placebo
- Significant differences in adverse effects drugs vs. placebo
- Extrapyramidal signs in up to 12% of drug groups (olanzapine, risperidone) vs. 1% placebo, 2% quetiapine
- Sedation in 15-24% with drugs vs. 5% placebo
- Confusion increased in drug group (up to 18%) vs. placebo
- 9 patients on drugs entered NH vs. 1 on placebo

Antipsychotic therapy and short-term serious events in older adults with dementia. Rochon PA et al, Annals of Internal Medicine May 2008.

- Retrospective cohort study
- A large study over 7 years involving almost 21,000 community dwelling subjects with dementia
- Subjects newly prescribed antipsychotic drugs 3.2 to 3.8 times more likely to develop serious adverse events within 30 days
  - 3.2 times for atypical antipsychotics
  - 3.8 times for typical antipsychotics
- Serious events are frequent following short term use of antipsychotic drugs

A randomised, blinded, placebo-controlled trial in dementia patients continuing or stopping neuroleptics (the DART-AD trial) Ballard C et al, Public Library of Science April 2008

- Aim: to determine impact of long-term treatment with neuroleptic agents on global cognitive decline and neuropsychiatric symptoms in patients with Alzheimers.
- Methods:
  - Randomized discontinuation trial in 165 subjects with AD taking antipsychotics for at least 3 months
- Results:
  - No significant difference in neuropsychiatric treatments among subjects continuing drug versus discontinuing
  - No significant difference in cognitive decline among subjects continuing drug versus discontinuing
- Overall, no significant benefit to continued antipsychotic treatment and no significant harm in discontinuing treatment

Mortality risk in patients with dementia treated with antipsychotics versus other psychiatric medications.

- Kales et al Am J Psychiatry. 2007 Oct;164(10):1568-76
- 10,600 patients all taking psych meds for agitation, etc
- Pts. Taking antipsychotics had significantly higher mortality rates (22.6%-29.1%) than patients taking nonantipsychotic medications (14.6%).

AHRQ Review 2011

- Review article evaluating previously published studies
- Some antipsychotics reduced agitation in some patients with dementia over short-term (12 weeks or less)
- More sedating drugs appear to have a greater effect on agitation

Treating Pain Reduces Agitation

- **Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial.**
  Husebo et al BMJ 2011
- **Significant reduction in agitation resulted from basic efforts at identifying and treating pain, starting with nondrug measures and acetamenophen in agitated patients with dementia**

2011 OIG Report

- May 4, 2011 OIG Report "Medicare Atypical Antipsychotic Drug Claims for Elderly Nursing Home Residents"
- Study requested by Sen. Grassley reviewed records, claims data for first half of 2007 calendar year
- 83% of use "off-label"
- 51% of Medicare claims for anitpsychotic drugs "erroneous"

2011 OIG Report: 4 Recommendations

- 1. “facilitate access to information necessary to ensure accurate coverage and reimbursement determinations”
- 2 “assess whether survey and certification processes offer adequate safeguards against unnecessary antipsychotic drug use in nursing homes”
- 3 “explore alternative methods beyond survey and certification processes to promote compliance with Federal standards regarding unnecessary drug use in nursing homes”, and
- 4 “take appropriate action regarding the claims associated with erroneous payments identified in our sample”

July 2012 OIG Report

- 99% of facilities nationwide deficient in assessment, developing, implementing comprehensive care plan when antipsychotic drugs used for behavior in dementia
- Antipsychotic drugs used *instead of* proper nursing care

- Bottom line: antipsychotic prescribing to control behavior a ‘red flag’ that invites regulatory scrutiny
- Antipsychotic drug use = care plan deficiency citation for facility

Antipsychotic Drugs in AD

- **These drugs are harmful**
- **They slow brain functioning**
- **They are relatively ineffective at controlling behavior**
- **In general, their use is often considered to be a ‘chemical restraint’**
- **There is strong opposition to medication use to control behavior among consumer, advocacy groups**
- **There is strong opposition from the FDA, Congress to the use of these medications in people with Alzheimer’s**
- **The FDA sent certified letters to prescribers in 2005 informing us that these drugs are NOT indicated in patients with Alzheimers even with Psychosis and added a Black Box Warning**
- **Antipsychotic drugs are associated with adverse outcomes in this population, including an increased risk of death**
- Death rates higher than previously reported. Other drugs (benzodiazapines, anticonvulsants) also increase death risk.

Antipsychotics, Other Psychotropics, and the Risk of Death in Patients With Dementia: Number Needed To Harm

- *Maust et al.: JAMA Psychiatry*. 2015;72(5):438-445. doi:10.1001/jamapsychiatry.2014.3018.
- Increased death rates in patients with dementia receiving antipsychotic drugs, benzodiazepines, or anticonvulsants
- Large VA Study
- Death rates higher than previously reported
- Number needed to harm ranged from 8 to 40 compared to patients receiving antidepressants or no meds

Antipsychotic and Other Drug Use in Dementia

- These drugs are dangerous
- They don't do what we wished they would do
- They are overused now
- Their use is actively discouraged by FDA, others
- Their use creates unrealistic expectations, distracts care providers from solving the underlying problems associated with undesirable behavior
- 75% or more of patients with dementia prescribed these medications do not live in nursing homes!

Physical Restraint Cases

- 75 year old man physically tied to bed in nursing home with wrist, vest restraints
- 75 year old man physically tied to bed at home by son with vest, wrist restraints
- 75 year old man physically tied to bed in hospital with wrist, vest restraints

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!***

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, multiple nurses (different shifts)

Taking a behavior history

- Team approach to behavior interpretation, response
- Precise evaluation of behaviors, circumstances, triggers
- What happened, when. Who was there? What were *they* doing? What was the patient doing before the behavior occurred?
- Context- an understanding of patient and their life, relationships, prior to dementia onset very helpful in understanding behavior and providing care
- CNAs those with the most patient contact and least power often most effective

Behavior History cont'd

- Consider that behavior may be a medical symptom of something other than dementia
- Behavior history similar to eval of pain- onset, duration, precipitating events, aggravating factors, alleviating factors, associated symptoms,etc. except that patient can't provide any history themselves
- Behavior log for facility staff

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 affect 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. Saying she has bad news and will send you another email later.**

Behaviors in 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

Case

- 86 year old woman with Alzheimer's. Involuntarily discharged from nursing home for wandering and agitation. Behaviors persisted despite psychiatric hospitalization, escalating doses of quetiapine (475mg/24 hours), venlafaxine. Wandered into others' rooms and slept in their beds. Fought with other residents over baby doll.

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

- 82 year-old man with mild ‘confusion’ hospitalized with CHF
- Bed and chair alarms in use
- Awakens frequently during the night and attempts to out of bed
- Each time, hospital staff respond promptly by reminding him it is night time and to lie back down to go to sleep
- Each time, he becomes progressively more agitated

Agitation: What is it?

- A *subjective* physical sign- not a disease!
- A nonspecific indicator of something else
- Often results in responsive behaviors such as hitting, yelling, attempted elopement, falls
- May represent anxiety, anger, sadness or several other emotions
- Frustration!
- Boredom!
- Pain!
- May be an indicator of underlying medical condition
  - Constipation, urinary retention, depression, anxiety

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

Case

- 86 year old woman with Alzheimer's. Involuntarily discharged from nursing home for wandering and agitation. Behaviors persisted despite psychiatric hospitalization, escalating doses of quetiapine (475mg/24 hours), venlafaxine. Wandered into others' rooms and slept in their beds. Fought with other residents over baby doll.

Case Continued

86 year old women with Alzheimer's. Also had end stage DJD of hip for which surgery had been recommended 10 years ago

Agitation

- History, intervention important to distinguish underlying illness from environmental causes
- Agitation caused by pain, constipation, etc vs situational
- What happened? Who was there? What did they do? What happened as a result?
- Get everyone (especially agitated staff) away from agitated resident

Case: Agitated Man in Hallway

- Unknown (to me) resident of alz. Unit (ALF). Grabs me in hallway. Appears agitated' trying to tell me something. Speech is unintellligible. Gets more distressed as I talk to him. I don't know what he wants. He's not my patient and I'm in a hurry

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
- 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?*

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

- 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

Processes Of Care

- Systematic facility wide approaches to preventing, identifying, evaluating, documenting, communicating, responding to behavior issues
- Staff education, care planning are critical ongoing activities
- (certain) CNAs among the best teachers
- Individualized activity plans
- Each staff working with a particular patient needs to know what to do and what not to do when
- Behavior teams are one approach (advantages, disadvantages)
  - Assessment, documentation, care planning,

Processes of Care

- Prevention:Facility wide: environmental, attitudinal
- Assessment (often nonexistent)
- Ask care providers (as surveyors do):
  - What makes this resident upset?
  - What do you do when that happens?
  - What other options have you tried (i.e. “less restrictive alternatives”)
- Be concerned when told
  - Behavior present ‘all the time’
  - ‘Nothing helps’
  - ‘I don’t have time’
  - ‘We don’t have enough help’

Processes of Care

- Documentation
- Review nurses' notes, interventions
- Narrative notes may be diagnostic of caregiver problems
- Checklist of interventions, esp. on MAR may be red flag
- Behaviors, interventions need to be' care planned'
- Does documentation indicate that care plan is being followed?

Case

- 78 year old farmer with Alzheimer's in nursing home
- "He's desecrating our plants!"
- Found to have urinated in potted plants, trashcans, on floor.
- Facility staff offended by behavior

“Inappropriate Behavior”

- “Inappropriate” requires awareness of and conformity with environment, social norms and expectations.
- Puppies, toddlers, and people with dementia don’t know what is ‘appropriate’ and what is not.
- Puppies and toddlers may learn and remember to change their behavior. People with dementia cannot
- “Beautiful building syndrome”

“Inappropriate Urination”

- Management similar to incontinence
- Scheduled/prompted and assisted voiding
- Urinal
- Eliminate meds that affect cognition or increase muscle activity (like metoclopramide, look at diuretic use

Understanding and Approaching Behavior

- Personal/past experience of staff affect their own approach, response (often reflexive)
- Many experts within facility (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

- 84 year old man with multiinfarct dementia requires total care
- Former radio host
- Wheelchair bound
- Placed near nursing station all day long
- Calls passersby names
- Uses profanity

Brain Impairments Often Manifest in Behavior

- Impaired impulse control
- Automatic Speech (“Brain Stem Speech”)
  - Profanity, repetitive phrases often automatic

  Overlearned speech well preserved
- Emotional incontinence
  - Loss of emotional modulation associated with frontal lobe impairment loss of executive brain function

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 Dz
- "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

- 78 year old man with Alzheimer's
- 'Constantly' taking clothes off
- Often seen walking or sitting nude in common areas of building
- Lifelong guitar player prior to admission

Case

- 84 year old retired minister
- Makes sexual comments to female staff
- Tries kissing, grabbing them
- Uses profanity
- Wife mortified. She accuses female staff of teaching him bad words and dressing suggestively

Case

- **Non-ambulatory nursing home resident with fecal incontinence, cognitive impairment reported by nursing staff to be ‘fingerpainting’ with and eating feces**

Feces 'Fixation'

- Behavior typical in young children
- In adults with cognitive impairment, typically:
  - Impaired defecation (vs. constipation) present along with inability to toilet self (functional impairment), boredom/inadequate supervision
  - Rx: scheduled toileting after meal (potty training)
  - Check diaper frequently
  - Other activities
  - Suppository or enema periodically to empty rectum more completely

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**

Cultural Issues

The ‘Culture’ Of Dementia Care?

- **Is the culture of healthcare the same as the culture of surrounding community? Nation?**
- **Subcultures?**
- **Doctor/Nurse/Aide/Housekeeper/Administrator/Consumer culture**
- **How people who work in health care perceive themselves, their roles, the world around them**
- **Attitudes, perceptions, values, expectations, behavior**
- **Culture created and maintained by training, history, peer interaction, organizational , training, history, Drives behavior of health care workers**
- **Way of thinking/seeing/interpreting/behaving**

Why Does Culture Matter?

- Culture influences/determines what people believe, how (many) people(within that culture) think, behavior
- Culture (always) resists change
- Culture = comfort, familiarity, tradition, doing the right thing)
- Culture = status quo
- Culture = maintenance of order
  - power/control

Health Care Culture is Very Unhealthy

Health Care Culture

- Culture of conformity, sameness
- “The nail that sticks out gets pounded down”
- Culture of fear, blame
- Desire to hang on, resist change in face of external threats
- Training/education = apprenticeship, obedience
- Training/education are static,in the past (precede employment)
- Always do things the way you were taught
- Hierarchical, command and control organizational structures
- Exclusionary- Keep people out
- Paternalistic

Command and Control Organizations

- **Rule #1The boss is always right**
- **Rule # 2 When in doubt, refer to rule # 1**
- **Positional power/ Might = right**

Influence of Money

- Changes in health care delivery over last 30 or more years driven by money
  - Medicaid 1960s created NH boom
  - Prospective payment 1990s fundamental change in hospital care, attitudes, values
  - Shift of dementia care away from nursing homes
- Form follows finance
- Prescription of drugs strongly influenced by money spent by mfrsResearch, ‘education, training’ re new drugs provided/paid for by manufacturers
- Lack of insight into effet of money on physician behavior (“uncorruptable”)
- Widespread, unregulated, irrational rationing at discretion of individual hcps

Culture of Health Care

- Culture of willful ignorance (culture of specialization)
- Discount, reject, demonize beliefs/ideas, factsImproving that are not consistent with ones own beliefs (orthodoxy)
- Righteousness
- Insecurity
- Irresistible urge to do something
- Blame patients
  - Language is hostile and derogatory (‘chief complaint’ ‘patient denies’ , ‘admits to’, ‘refuses’,‘noncompliant’ ‘obese’, ‘pendulous breasts’, ‘mammary hypoplasia’, ‘retardation’)
- Marginalize family members
  - (Limit roles, access to loved ones)

Medical Culture

- Culture of blame
- Superstitious fear
  - of doing things differently, of law, lawyers, regulators, outsiders, “trouble”
  - Ritualistic behavior as a talisman against

Culture of Dementia Care

- **Medical Model:**
- **Dementia = disease**
- **Disease = drug deficiency**
- **Dementia= drug prescribing**
- **Behavior = disease**
- **Behavior = drug deficiency**
- **Behavior= drug prescribing**

Culture of Dementia Care

- **Patients must conform to (rigid) health care environment**
- **Those who fail to do so must change or be restrained (physical and chemical) “for their own good”**

Dementia

- Loss of brain function bad enough to interfere with daily activities
- Results in loss of ability to reason
- (Loss of ability to comprehend, remember, and conform to social/environmental requirements, expectations, limitations)

Culture of Dementia Care

- Confrontational
- Power and control
- Patients placed at odds with human and physical environment
- Culture of conflict resolved through power
- Restraint of others is unilateral application of power (force/violence?)
- For what disease is use of force/violence preferred treatment?

A Healthier Culture For Medical Care/Health Care Delivery. . .

- Critical self assessment
- Leadership culture,
- quality engineering
- Continuous improvement
- Self reflection
- Focus on systems, processes not on blaming individuals
- Facts/evidence/critical appraisal of info
- Humility based upon acknowledgement of overwhelming ignorance
- Impossibility of knowing all
- Understanding, respect for, explicit acknowledgement of ethical, technical constraints

A Healthier Culture

- Respect for history, others, cultures of past
- Do no harm
- Selflessness, cognitive, physical skills, love for human beings not lust for technology
- Awe at mystery, perfection of human creation
- Respect for differences between people
- Patient, family centeredness
- Demedicalization of life/living

A Culture of Change

- Why do people change? Why should they?
- Why do we resist change? Why should we?
- What are we afraid of? (What should we be afraid of?)
- What do you need, in order to change?

A Culture of Change

- Changing your behavior sometimes requires changing your beliefs
- When, if ever, should you change your beliefs?
- Positive change should not require you to change your core values. Life Care's core values cannot ever change
- Don't get on the bus. . . . . .to hell!

Change happens

- In response to a clearly perceived better way
- When doing the same thing is expected to result in real, unacceptable, painful consequences, that are fairly immediate (i.e. fear)
- When people change their beliefs and come to see the world differently (personal growth, maturation)
- When others they trust change
- When people are bored, dissatisfied unfilled (sometimes)

Change doesn’t happen

- When people are afraid
- When people don’t know what to do
- When it is really hard
- When people feel all alone

Operational Strategies for Nursing Facilities, insurors, others Re: Antipsychotic Drugs in patients with dementia

Strategies For Specific Issues/Challenges

- Informed Consent
- Pharmacy/ Pharmacist
  - Drug dispensing, pharmacist oversight, communication
- Hospital/Facility transitions
  - Admission Care planning
- Psychiatric consultation hazards
- Family expectations
- Staff expectations
- Regulatory compliance re care plan
- Gaming the system (other drugs, diagnoses, psych permission)
- Alternative approaches
- Whack a mole
  - ALF, other settings
- Consistent, thoughtful, proactive communication

Strategies

- Meaningful informed consent prior to drug initiation
- Prior authorization approach
- Pharmacy/pharmacist
  - Drug reviews, GDR vs. d/c
- Stat box contents
- Expectations of consultants, prescribers
- Behavior change
- Approach similar to physical restraints
- Consistent enforcement of existing regulations
- Oversight, scrutiny of contracts with consultants
- Other government strategies

(Staff) Behavior Change Strategies

- Social cognitive theory
  - Peer interaction
- Replicating success
  - Identify champions
  - Appreciative inquiry

Communication Re: Antipsychotic Drugs

- Limit the number of people making these calls.
- Consistent message
- Positional Power. Nursing leadership=higher rank
- You may have staff who will undermine you unintentionally due to caregiver stress, uncertainty, fear, frustration, or habit

Reducing Antipsychotic Drugs

- May want to talk with the patient's family first before talking to physician
- Consent
- Power

(Telephone) Script

- **I‘m calling about Mrs. Jones. She is doing well. We would like to reduce her seroquel. We are confident that we can meet her needs (manage her behavior) without it.**
- **Federal law requires nursing homes to attempt dose reduction regularly. These regulations are being strictly enforced now.**
- **Our facility is trying to eliminate antipsychotic drugs in as many patients with dementia as possible**

More Script

- Mrs. Jones' family is aware of the increased risk of death and other adverse effects of antipsychotic drugs.
- They would like to reduce or eliminate all medications used to control behavior.
- (Be prepared to describe alternative steps you will take in place of medications)

Family Script

- We love your (husband/wife/mother/father)
- We are honored to care for him
- We want to ensure his/her safety
- We know that he has been on medication to control behavior, but we know he cant help it and we are confident that we can deal with that without having to use medication

Family Script Cont'd

- One (or more) of his/her medications (name) can increase the risk of death or other problems in people like your … with dementia
- Even though these medications are commonly used in hospitals and other settings for a variety of things, federal regulations for nursing homes require us to try to decrease or discontinue these medications for your (husband's safety).
- We work closely with your (husband)'s doctor (name) and together we will make sure that we help your (husband) to do and feel the best he/she can
- He/she has a home here and we will treat him/her like family

Administrator Role

- Positional Power
- Shape and communicate expectations, support staff, goals of care
- Communicate expectations to attending physicians, medical director
- Communicate plans, expectations, rationale with medical director to attending physicians in writing
- Communicate expectations, rationale to all staff
- Work with medical director, director of nursing to develop and implement policies and procedures regarding dementia care, communication
- Support individual staff in dealing with problems

Administrator

Personal Letter to all prescribers listing goals, expectations

- **Signed by administrator, Medical Director**

Sample Content For Letter to Prescribers

- The Use of Antipsychotic Drugs in Dementia is associated with an increased risk of death and other adverse outcomes
- As such, we agree with physician organizations such as AMDA, that these medications should be used only as a last resort.
- This facility is embarking on a program to substantially reduce or eliminate antipsychotic drugs and other drugs to control behavior in patients with dementia and to improve dementia care overall at our facility
- Your assistance is critical to this effort

Sample Content Cont'd

- The rate of antipsychotic drug prescribing in dementia is a negative quality indicator for nursing facilities.
- Rates of antipsychotic drug prescribing for your and our patients in this facility are posted on the internet.
- Federal regulations limit the use of these medications in patients with dementia
- Regular attempts to reduce or eliminate these and other psychotropic drugs in nursing facility residents are required by Federal Law.

Sample Content Cont'd

- In addition to the increased risk of civil lawsuits in cases of harm caused by these medications, this facility may be subject to additional penalties if rates of psychotropic drug prescribing are too high
- You will be contacted by our facility periodically regarding the use of medications to control behavior in your patients
- In addition, we will provide you with periodic feedback regarding your prescribing rates compared to other physicians