Understanding and Approaching Challenging Behaviors in Dementia

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Warning: Special Requirement For This Session
... you cannot think like a doctor or nurse!
The following letters are arranged in a familiar sequence and have a special meaning: What is it?

jf mam j  jason d
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
“To understand is to forgive”

Sigmund Freud
• Behavior is Communication

• *Behavior is not a disease!*
Behavior is Communication

- Especially in people whose ability to communicate with words is limited
  - Young children
  - Americans travelling to foreign lands
  - People who have had strokes (dysarthria, aphasia)
  - People with hearing impairment
  - People with dementia
Behavior is Communication

- People who have trouble communicating with words tend to have trouble comprehending words
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
Behavior is Communication

• Compare behavior in adults with dementia to normal behavior in very young children
  – Why do babies cry? What are they telling you?
• Compare how you and institutional staff approach these same behaviors in people with cognitive and/or communication abilities comparable to very young children
• “To understand is to forgive”
Behavior is Communication

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*

*What does your behavior tell them?*

*Analogy of ‘bad behavior’ and fever*
Goals and Objectives

- Think differently about behaviors in dementia
- Review common behaviors in people with dementia
- Try to identify potential meaning
- Develop an approach to prevention, behavior modification in people with dementia
  - General approach
  - Specific to each category/behavior
  - Specific to each individual
- Develop an approach to communication, behavior modification in institutional staff
  - Model behaviors
  - Manage expectations
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)
- Your role (analogous to falls): Help assess the potential causes of distress in order to reduce risk of future distress
Common Behaviors Seen in Patients with Dementia

- Wandering
- Agitation
- Combativeness
- Getting out of bed
- Inappropriate urination
- Sexually inappropriate behavior
- Yelling
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 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

• Family input, CNA input may be critical

• Behavior log for facility staff
  (often therapeutic for patient)
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)
Approach to behaviors associated with dementia

• “First seek to understand, then to be understood”

• Patients with dementia may be unable to understand
  – avoid multiple-step tasks or questions

• Be aware of your nonverbal communication

• Meet them where they live

• Change your behavior
  – If your behavior isn’t gentle, patient, and loving- you are part of the problem
  – No tough love (they can’t learn) just love
Case 2

• 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 3

- 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?
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
- Have patient participate in task (i.e., holding toothbrush or hairbrush) instead of doing it to them
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 difficulty comprehending this
Case 4

- 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.
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 5

- 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 6

- 82 year-old man with mild ‘confusion’ hospitalized with CHF
- Bed and chair alarms in use
- Awakens frequently during the night and attempts to get 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 7

- 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.
86 year old woman 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
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 8. 60 women with dementia

- 60 bed dementia unit all women
- “Always” fighting with one another
- Agitated
Case 8

- 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 9

- 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 10

• 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’
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 11

- 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 12

- 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 13

- 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 14

- 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 15

- 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 16

- 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 17

- 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 18

- 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 19

- 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
What is your role?

• What do you expect of yourself when informed of a problem or asked about a specific intervention?
• What do you say on the phone?
• What do you do when you are with the patient/family/staff?
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