An Approach to the Behavioral Complications of Dementia

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Clinical Scenario

- Mrs S is an 85 yr retired RN with dementia in a care facility. She has always 'been in charge' and 'loved to be busy and organised'. She was married to a dairy farmer for 60 yrs. They got up everyday at 4 am. She has never slept for more than 6 hours at night. She is now wandering into other people's room at 4 am trying to get them up and 'ready for rounds'. She hits out when attempts at redirection are made with the retort of 'who do you think is in charge here young lady?' She takes other people's walkers and lines them up in rows, becomes very agitated in the late afternoon and bangs on the nursing station door, perseverating ' Now now now now now'. Her calling out behaviour often occurs at night waking other residents who find it annoying and distressing. She refuses to bathe and hits out during personal care.

Terminology

- Challenging behaviours
- BPSD
- Neuropsychiatric Symptoms
- Complications of Dementia
- Non-cognitive symptoms associated with dementia
- Responsive behaviours

Common Descriptions

- “Un-co-operative”
- “Predatory”
- “Disobedient”
- “provocative”
- “premeditated”
- “obstructive”
- ‘ PRN’s not effective. Please prescribe a more effective stronger prn’
- ‘ He needs to be medicated’

Definitions

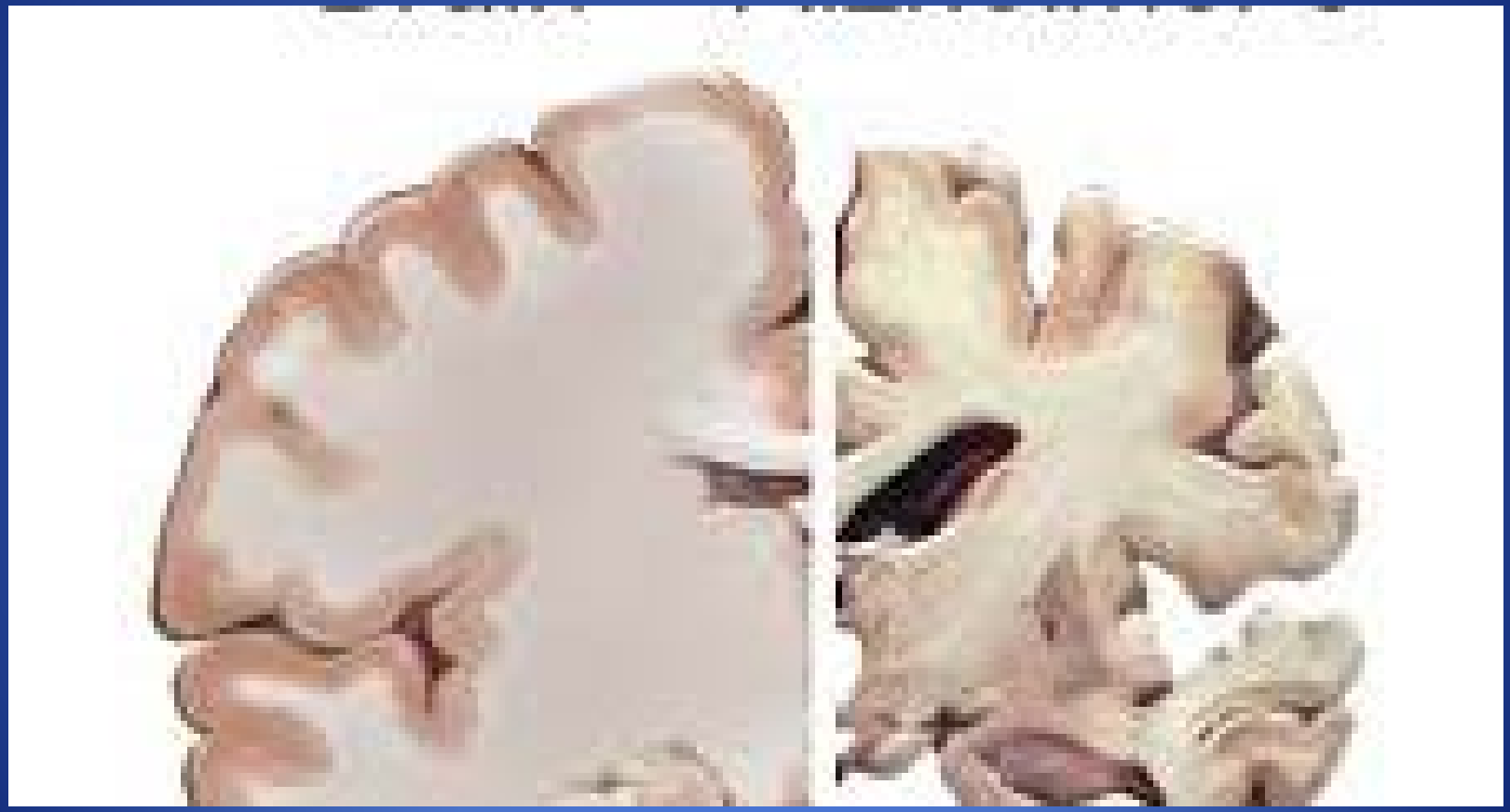
- IPA 1996 (International Psychogeriatrics Assoc)
  - " Signs and Symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia"
- In other words:
  - Non-cognitive consequences of dementia that affect the way a person thinks, behaves and feels

Why do these complications develop?

- If a person breaks her leg and has an cardiac arrest in the OR, resulting in an ICU admission.
- How do we think about this person?
- Who is to blame?
- Did the patient ask to break her leg and develop complications?
- Who would want dementia?
- Who would want to develop aggression and psychosis after developing dementia?

Who has the normal brain?

And yet who is often asked to make accommodations?



So….. What are they

- Awful complications of a terrible group of diseases.
- The main reason for admission to LTC and tertiary units
- The consequences of a cerebral atrophy and hypometabolism
- Repertoire of responses diminishes but the fullness of humanity is unchanged

The Evidence

- 5 main clusters:
  - Apathy
  - Depression
  - Psychosis (delusions and hallucinations)
  - Sleep disturbance
  - Agitation and aggression
    - (restlessness, repetitive statements, vocalizations, aggressive language, aggressive physical actions, sexual disinhibition)

Behaviors that do not respond to medication

- wandering
- exit seeking
- hiding and hoarding
- repetitive activity eg clapping/counting
- restlessness/pacing
- some sexualized behaviour
- inappropriate dressing /undressing
- tugging at seatbelts
- resistance to care
- sundowning
- swearing
- unsociable behaviour
- indifference to the surroundings
- inappropriate voiding
- eating inedible objects
- Spitting
- pushing wheel chair bound residents
- poor self care
- poor memory
- personality style

Decreased Risk

- Meaningful therapeutic activities
- Person centered approaches
- Small facilities
- Single rooms
- Well trained supported staff
- Champions
- Reversal of risks e.g. pain

Symptom Frequency

- Apathy most common then agitation
- Changes with disease progression
- Prevalence in LTC:
  - 60% dementia
  - Median prevalence of NPS: 78%
  - Depression ~40%
  - Aggression ~ 10-20%
  - Psychosis ~ 15-30%
  - Agitation ~ 30%

Consequences

- ⇧
  - Distress (caregivers, family, patients)
  - Health visits
  - Morbidity and mortality
  - Isolation
  - Costs
  - Institutionalization
  - Medication use- side effects
  - Use of restraints
  - Caregiver Burnout
  - Depression, anxiety and apathy in MCI increase risk for developing dementia

Evaluation Tools

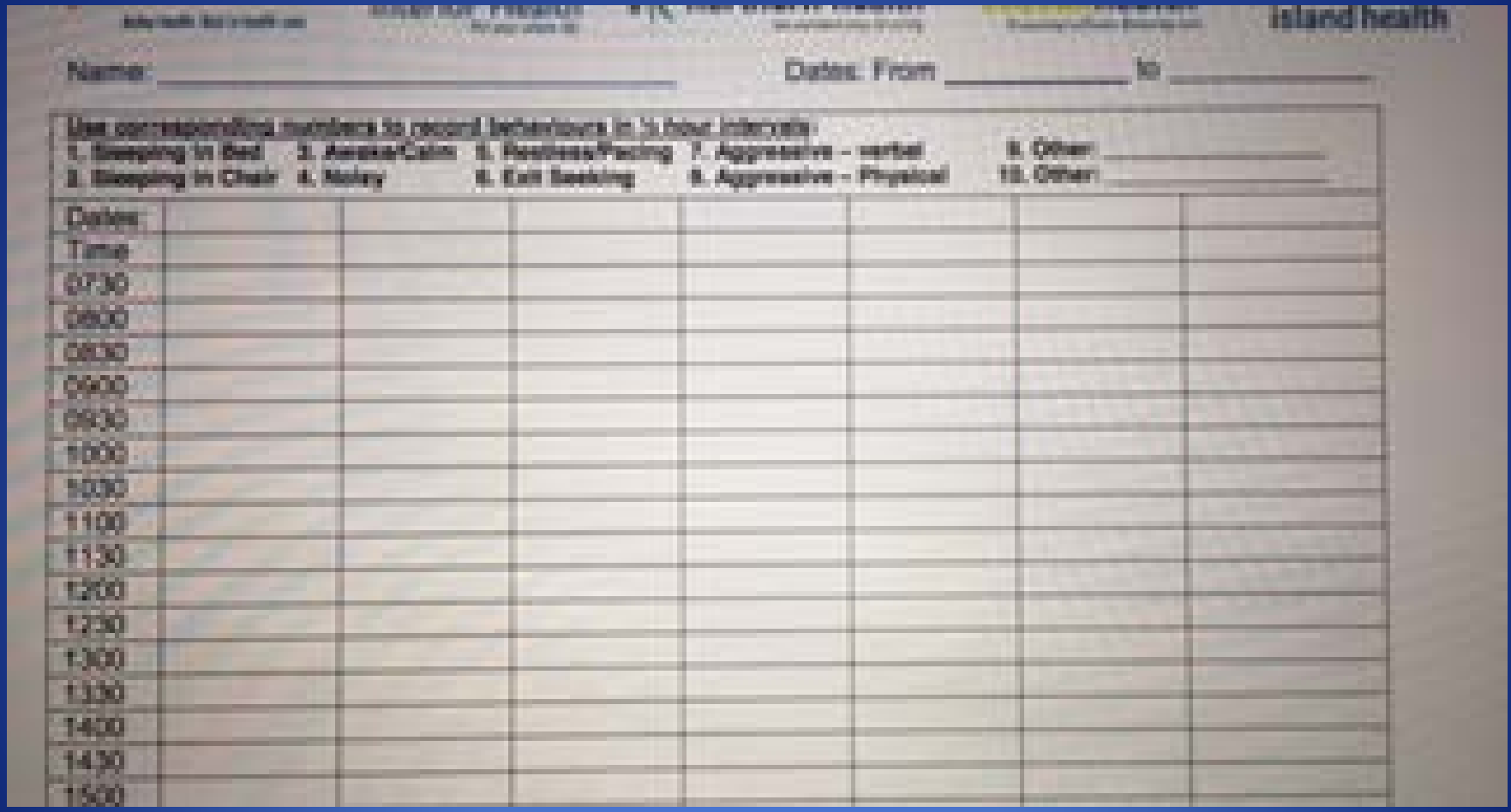
- ABC: identifies triggers, reinforcers, timing etc
- DOS system: patterns, timing, frequency
- Cohen Mansfield Agitation Inventory: rates frequency over last 2 wks, verbal agitation, non-aggressive and aggressive agitation
- Neuropsychiatric Inventory: different versions, frequency and severity, numerous domains
- Cornell Depression in Dementia Scale
- PAINAD and PASCLAC for pain

ABC Charting

Name: _____ **Grade:**__ **Age:** __ **Teacher:** _____**School:**_____

	A	B	C
Time	**Antecedents** (Describe what happens before the behaviour.)	**Behaviour** (Describe what the student does.)	**Consequences** (Describe what happens after the behaviour.)
	•	•	•
	•	•	•
	•	•	•
	•	•	•
	•	•	•

DOS Charting/Behavioral Mapping



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Name: _____ Dates: From _____ to _____

Use corresponding numbers to record behaviours in ½ hour intervals:

1. Sleeping in Bed 3. Awake/Calm 5. Restless/Pacing 7. Aggressive – verbal 9. Other: _____
2. Sleeping in Chair 4. Noisy 6. Exit Seeking 8. Aggressive – Physical 10. Other: _____

Dates:							
Time							
0730							
0800							
0830							
0900							
0930							
1000							
1030							
1100							
1130							
1200							
1230							
1300							
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1400							
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1500							

Management Principles

- Patient centered and patient specific interventions work best
- Team approach: including family
- Increased quality of life
- Builds rapport and relationships
- Avoids side-effects of medication
- Maximizes ability
- Medication may mask the real cause
- Still use non-pharmacological strategies when medications are appropriate (e.g. pain, delirium, depression, psychosis, aggression)

What Works: The Evidence

- Patient- Centered Care
- Mental Health Consultations
- Meaningful activities and pleasant events
- Exercise
- Sensory Stimulation
- Music
- Montessori
- Pet Therapy
- Other: aromatherapy, art therapy etc

What is common to these interventions?

- Person-centered
- Individualised
- Underlying assumption is that all behaviour has meaning

Person-Centered Care

- = Staff training and caregiver training approaches in behavioral management and communication
- Primary principal is to view the patient as fully human and deserving of a meaningful life
- Starting point is to get to know the person as well as possible so that care can be specific and person centered
- Self reflection is important (why do we want Mr S to sleep in his bed and not on the floor?)
- WHO HAS THE INTACT BRAIN?

My Story

- Who is this person?
- What were their interests, experiences, memories when they were in their prime?
- What are/were their strengths?
- What food, music, hobbies did they enjoy?
- Did they enjoy showering, bathing, the mornings, the evenings etc?
- What were their values?
- What was important to them?

Important components of Staff and Caregiver Training

- Psychoeducation
- Person-specific meaningful and pleasant activities
- Strategies to distract, redirect and avoid confrontation
- E.g. Gentle Persuasive Approach, Eden Alternative (Does your care plan include a Spa Party?), TREA Approach (based on theory of unmet needs)
- Partners such as Alzheimer's society
- Champions
- Specific dementia care management protocols. One study shows a drop of ~ 6 points on the NPI-equivalent of an antipsychotic.
- P.I.E.C.E.S: Physical. Intellectual. Emotional. Capabilities. Environmental. Social

Mental Health Consultation

- Specialist teams etc SORT: case management
- Evidence for decrease in NPS
- Co-ordinate care between physicians, other professionals, families and care staff
- Important communication and education role
- Backbone of community services
- Help optimize safety, QOL and function

Meaningful Activities and Pleasant Events

- 1:1 interaction for about half an hour three times a week: e.g. memory box, reminiscence therapy
- Reminiscence Therapy: Use tools such as photographs, stories, momentos, music from positive times in the past that create positive feelings and a sense of well being that can be transferred into the present
- Validation Therapy: treating patients with genuine respect

Exercise

- Good studies in LTC for reduction in NPS, improvement in physical functioning and depression.
- 30 min per day
- Include gentle aerobic activity, strength, flexibility, balance

Music

- Personalised music more effective
- Group music 3 times a week
- Most studies done with music therapists so difficult to translate but lots of anecdotal evidence.
- Music very evocative- can be helpful to engender a sense of safety and well-being

Montessori-Based Therapies

- Emerging evidence
- Maria Montessori: theory of 'Human Tendencies'- e.g. exploration, communication, repetition
- Aim to maintain or improve skills (rehabilitation)
- Balances stimulation and success
- Open-ended so avoids sense of not completing tasks
- Emphasis on meaningful practical activities
- Does not require a lot of verbal capability
- Breaks down activities into simple manageable pieces and then builds complexity

Sensory Stimulation

- Snoezelen (Multisensory Stimulation, Controlled Multisensory Environment):
  - Neologism from the Dutch words 'snuffelen' (explore) and 'doezelen' (snooze)
  - Exposure to both a soothing and stimulating environment
  - Is a registered trademark of the English Company, Rompa
  - Originally developed for people with autism
  - Client directed, verbal communication not required
  - Lights, colours, textures, sounds etc
- Aromatherapy with massage
- Therapeutic Touch
- Other Sensory Integration Strategies

Depression

- Meaningful and pleasant activities
- ‘Simple pleasures’ enhance well being, improve social engagement and affect. Address boredom and isolation
- Reminiscence and validation therapy
- Some studies have reported creative successes. E.g. decoy wandering carts, tackle boxes and wheelchair bicycling
- Exercise
- light

Sleep

- Address physical issues such as pain, nocturia
- Exercise
- Consistent wake time, sleep time and avoid napping (more practical in patients with mild dementia)
- Light: bright light therapy difficult. Try dawn simulator

Clinical Scenario

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Example

So……

- Who needs to adjust?
- Teepa Snow's pearls:
  - Hide your agenda
  - What is really being communicated?
- Introvert or Extravert
- Think outside of the box

Mrs S

- What works today may not work tommorow
- Clipboards
- Ward rounds
- “Good news, it’s Sunday, you can rest”
- “Lets let the youngsters do the work and we can check it later”
- Surgery
- Don’t correct, distract
- Bending the truth

The Rosetta Stone

- We need to decipher the meaning
- One behaviour may have many underlying meanings
- Emotional self regulation is challenging for people with intact brains when they are stressed. It is exponentially more difficult for those whose brains are failing

Who should get the purple dot?

- Code white example at Cowichan Lodge

Conclusions 1

- Very common
- Very serious consequences
- Non-pharmacological interventions should be the primary intervention
- Patients with psychosis, depression and aggression may need medication and are more likely to respond to medication than other neuropsychiatric symptoms of dementia but also need non-pharmacological interventions

Conclusions 2

- These strategies improve the quality of life for both patients and caregivers/staff.
- They build rapport and improve relationships
- They help to prevent escalation
- All the interventions share a person-centered approach where we meet how patients 'where they are at'
- All behaviour has meaning and is an attempt to communicate and interact with the environment

Questions/ Suggestions?

- National Dementia Strategy with best practice care
- BC BPSD guidelines
- Ongoing capacity building
- Champions
- Commitment to investment in clinicians- time, expertise and money