What is my patient trying to tell me? Management of behaviours and psychological symptoms of dementia

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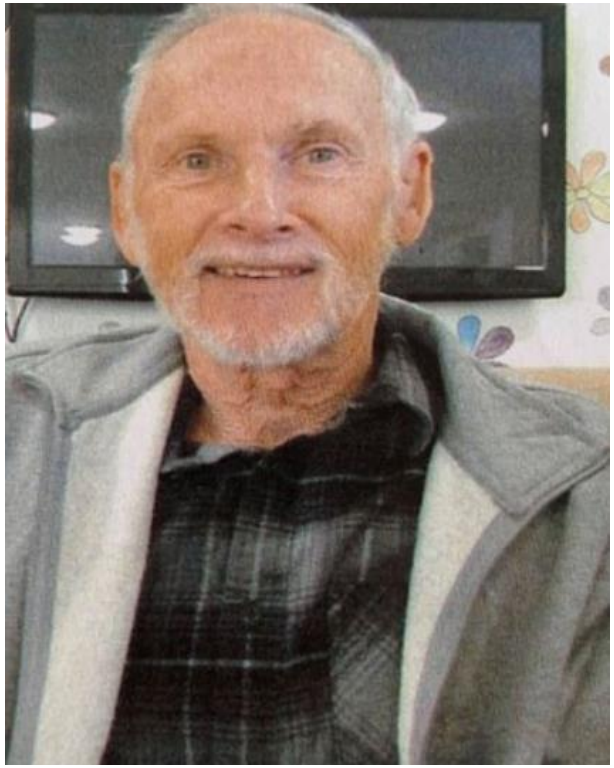
Objectives

- Understand what constitute behaviours and psychological symptoms of dementia
- Understand the mechanisms of causation, triggers and precipitants, and likely course
- Understand the basis for non-pharmacological management of these symptoms and signs
- Understand when to use pharmacological management, how to begin treatment and monitor progress
- Understand the process of informed consent for major medical treatment (use of psychotropic medication)

Management of BPSD has been very topical

Terry Reeves before and after use of antipsychotic medication whilst on respite care in a residential aged care facility 2019



Royal Commission into Aged Care Quality and Safety: Interim Report 2019

– **"A Shocking Tale of Neglect":**

- **Released 31st October 2019**
  - 'Dreadful' food, nutrition and hydration
  - Inadequate wound care
  - Poor continence care
  - High use of physical restraints
  - Overprescribing of psychotropic medications
  - Low availability of palliative care

– Substandard Care:

"…….widespread overprescribing, often without clear consent, of drugs which sedate residents, rendering them drowsy and unresponsive to visiting family and removing their ability to interact with people……"

Royal Commission into Aged Care Quality and Safety: Final Report

- Released February 2021
- 148 recommendations including:
  - Establishment of a post-diagnosis dementia support pathway (REC 15)
  - Review Specialist Dementia Care Units (REC 16)
  - Regulation of use of physical and chemical restraints (REC 17)
    - Be recommended by an independent expert
    - In an emergency to avert risk of immediate harm
    - As a last resort, and for the shortest time possible
  - Antipsychotics only to be prescribed by geriatricians and psychiatrists (REC 65)

Behaviours and Psychological Symptoms of Dementia (BPSD)

- **Symptoms of disturbed perception, thought content, mood or behaviour that frequently occur in patients with dementia** (IPA consensus group1996)

- Up to 95% of people with dementia will experience some behaviours and psychological symptoms associated with their dementia, with around 80% of these lasting up to 18 months
- BPSD are an integral part of dementia although cognition is studied more
- Symptoms can occur at any time during the disease from prodromal stages to severe dementia
- Presence of BPSD predicts functional decline, cognitive decline and institutionalisation
- BPSD are usually manageable, and can respond well to a combination of approaches and therapies

Steinberg 2008

Behaviours and Psychological Symptoms of Dementia (BPSD)

- aggression
- wandering
- restlessness
- agitation
- sexually disinhibited behaviour
- screaming or cursing
- hoarding
- anxiety
- depression
- hallucinations
- delusions
- apathy
- withdrawal
- irritability

Behaviours and Psychological Symptoms of Dementia (BPSD)

- elation
- confabulation
- perseveration
- misidentification (hallucinations)
- sundowning
- eating disorder (over-eating, or refusing food)
- shadowing (stalking)
- resistiveness to care

Prevalence of BPSD in Sydney Nursing Home Study

BPSD in Sydney Nursing Home Study (647 subjects in 11 aged care facilities):

- Aggression 52 – 88%
- Anxiety and agitation 22 – 88%
- Delusions 26 – 69%
- Activity disturbance 30 – 63%
- Mood disturbance 25 – 67%
- Diurnal disturbance 4 – 66%
- Also: Hallucinations, resistiveness to care

[1]Brodaty et al 2001

Prevalence of BPSD in Cache County Study

NPI BPSD items	Point prevalence at baseline (%)	Five-year period prevalence (%)
Delusions	18	60
Hallucinations	10	38
Agitation/Aggression	14	45
Depression/Dysphoria	29	77
Apathy/Indifference	20	71
Elation/Euphoria	1	6
Anxiety	14	62
Disinhibition	7	31
Irritability/Lability	20	57
Aberrant motor behavior	7	52
Any symptom	56	97

Steinberg 2008

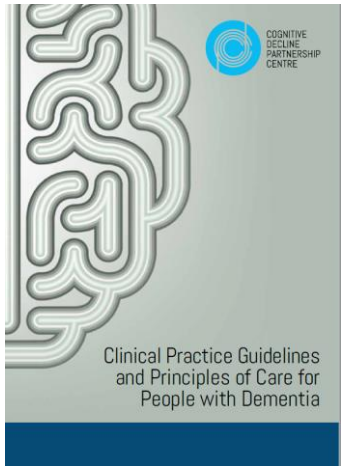
Behaviours and Psychological Symptoms of Dementia (BPSD)

- Different types of dementia can have different symptoms
  - Depression in Vascular Dementia
  - Hallucinations in Dementia with Lewy Bodies
  - Compulsive behaviours in Fronto-temporal Lobar Degeneration
  - Delusions in Alzheimer's disease
- Pathology in different brain regions can predict symptoms
  - Frontal pathology - behavioural disturbance; disinhibition; depression
  - Basal ganglia lesions - delusions
  - Temporal lobe pathology - delusions, hallucinations
  - Locus coeruleus - psychosis, depression
- Changes in neurotransmitter levels can predict symptoms
  - Decreased serotonin – see aggression, agitation, anxiety, depression
  - Decreased noradrenalin in neocortex – see depression

Causes of Behaviours and Psychological Symptoms of Dementia (BPSD)

- BPSD are multifactorial in aetiology with brain pathology only part of the cause
- Also need to consider:
  - Biological factors
  - Psychological factors
  - Environmental factors
  - Social factors
- Dementia Support Australia (home of DBMAS) has found at least 50 different factors contributing to BPSD
  - Pain 47%
  - Carer approach 34%
  - Over or under stimulation 27%
  - Also memory impairment, communication issues, frontal impairment, boredom

Non-pharmacological management of behaviours and psychological symptoms of dementia



Australian Clinical Practice Guidelines for Management of Dementia

Recommendation 77:

Health and aged care staff and carers and family **should identify, monitor and address** environmental, physical health, and psychosocial factors that may increase the likelihood of the person with dementia experiencing distressing symptoms…..

Recommendation 78:

People with dementia who develop behavioural and psychological symptoms should be offered a **comprehensive assessment** at an early opportunity **by a professional skilled in symptom assessment and management.** This should involve their carer(s) and families as appropriate….

https://cdpc.sydney.edu.au/research/clinical-guidelines-for-dementia/

Draper's 6 Rules for Management of BPSD

1. Any new behaviour that develops over hours to days is due to an acute medical problem unless proven otherwise
   - Delirium due to hypoxia, infection, metabolic disturbance, drugs etc
2. Most people get grumpy if they are in pain or discomfort
   - Pain, constipation, incontinence, immobility, pressure injuries, sensory impairment (vision, hearing), hunger, physical restraint, cold, heat
3. Behaviour can reflect how the brain is working ie cognitive impairment influences behaviour
   - Memory impairment causes repetitive questions
   - Frontal lobe damage – apathy, disinhibition
   - Language deficits – poor understanding of instructions
   - Increased incidence of BPSD with more severe cognitive impairment

Draper's 6 Rules for Management of BPSD (cont)

4. The person's behaviour is a way of communication
   - What is the person trying to say to you?
   - aggression or resistive behaviour during personal care may be due to misinterpretation of intentions of carer, embarrassment, fear

5. People tend to react to things they don't like about their environment
   - is it comfortable and pleasant and familiar, is there privacy, does it feel safe?
   - Are staff able to communicate, are they stressed or too busy?
   - Are there activities which are meaningful and purposeful? Can family and friends visit?
   - Are there problems with other residents interacting?

6. Is there a co-morbid mental illness?
   - People with dementia have an increased risk of clinical depression, anxiety or psychosis

Management of BPSD Summary

- What is the symptom/behaviour of concern?
  - Define each symptom
  - Why, when, where and with whom
  - What makes it better or worse
  - How frequently does it occur and for how long
  - Decide how to measure it eg diary, scale
- Does the behaviour require intervention?
  - Is it distressing to person, family, staff
  - Is it dangerous – is the person, or are family or staff, at risk
- Assess and correct any physical factors
  - acute medical illness, pain, constipation, fatigue, hunger, thirst, cold, heat, noise
- Correct sensory impairments – vision, hearing
- Assess and correct psychosocial factors
  - carer stress and behaviour, boredom
- Assess and correct environmental factors
  - Cottage model of care best for people with dementia

Management of BPSD

- Address environmental issues:
  - Provide a quiet, calm area away from noise or disruption
  - Identify person's room with orienting features
  - Ensure bright day lighting, and a night light
  - Ensure area is safe and secure, with concealed doors if necessary
  - Ensure adequate access to outside areas

- Address behavioural issues:
  - Allow person to walk around freely and redirect as needed
  - Have regular interaction with staff or volunteers to reduce feelings of isolation or loneliness
  - Provide regular reassurance and use of name

Non-pharmacological interventions for BPSD

- Many studies and systematic reviews in this area, however evidence is often low grade due to design of trials, and differences in outcomes measured
- Some evidence for:
  - Physical exercise – can be walking, dancing, simple exercises
  - Music therapy – individualised play lists, singing
  - Hand massage and gentle touch
  - Simulated presence therapy – record a video from family
  - Personally tailored meaningful, purposeful activity – folding clothes, peeling vegetables, working in the garden, hanging out washing
  - Animal assisted therapy – improved physical activity, anxiety, dietary intake
  - Aromatherapy – lavender, lemon balm – reduced agitation

- Good evidence for:
  - Family carer education, occupational therapy involvement
  - Professional carer education and training

Oyebode 2019; Yakimicki 2019






Mr Green

- 82 year old man, moderately severe mixed dementia, resident in aged care facility for 3 years
- Minimal language, not recognising family, required assistance with all ADLs, unable to mobilise independently
- Would occasionally call out 'help me' when he was thirsty or uncomfortable and needed repositioning, staff usually able to respond to his needs
- Began calling out constantly every few minutes and was given extra analgesia as staff thought he was in pain from arthritis
- Calling out continued for several days, developed diarrhoea, not eating or drinking much, not responding to attention from family or staff

Mr Green (cont)

- Reviewed by GP, no evidence of UTI, no obvious source of pain, but noted some bloating and tenderness over abdomen, and queried mild gastroenteritis
- On review 2 days later GP performed rectal examination and noted probable faecal impaction, and reduced then ceased codeine containing analgesics
- Had repeated Fleet enema and aperients with eventual clearing of impaction
- Calling out reduced to previous levels of once or twice a day

Mr Brown

- 84 year old man, resident for 2 years in dementia specific aged care facility in Sydney, appeared settled
- Diagnosis of Mixed dementia (vascular dementia and Alzheimer's disease) made 5 years earlier
- Over several weeks became increasingly aggressive towards staff and other residents and attempted to punch another (new) resident on several occasions
- Was checked for UTI, no change in medications, no evidence of pain or other source of discomfort

Mr Brown (cont)

- Discussion between care manager, GP and daughter revealed that 20 years earlier Mr Brown had a longstanding conflict with his next door neighbour over fence and tree issues. This was never resolved and he and his wife had to move.
- Daughter commented that the new resident bore a remarkable resemblance to the neighbour, as well as being quite intrusive and 'loud' in his interactions with others
- Senior care staff agreed to move new resident to another part of the facility as he was still on respite prior to becoming permanent
- Following this resident's move, Mr Brown settled down, and no further intervention was required

Mrs Smith

- 74 year old lady with moderate dementia in residential care.
- Had become quite withdrawn and appeared depressed but a course of antidepressants made very little difference
- Facility started a music therapy program with all residents getting an iPod with an individualised playlist.
- Mrs Smith initially refused to wear the earphones but staff persisted and she began to listen
- Over a few days of music for 2 hours morning and afternoon, she became more interactive and smiling, and one day began to hum along to what she was listening to.
- The improvement has persisted for over a year and she is on her second iPod.

Mrs Black

- 77 year old lady recently moved to residential care. She had a 4 year history of 'dementia'. She had lived with daughter but family found her constant complaining very hard to live with, and as her care needs increased they decided to move her into care
- After move she continued to make rude and unpleasant comments about staff and other residents, and eventually one of the residents pushed her over resulting in a fractured right wrist. This behaviour continued during her hospital admission
- MMSE was 16/30 with problems with STM, orientation and attention. She had no insight into her behaviour.
- Hospital staff tried distraction, OT made suggestions, and psychologist suggested redirection and positive reinforcement
- Facility not keen to have her return although they had to keep her place as she was permanent

Mrs Black (cont)

- Staff in hospital noted that she would sit and watch the ward budgie for hours
- On return to her facility, her daughter bought her a budgie that she was allowed to keep in her room with staff assisting with its care. Staff also put a bird feeder outside on her balcony attracting local native birds
- Mrs Black's behaviour improved and on a behaviour scale her nasty comments and complaints had reduced by more than half

Mrs White

- 84 year old lady with moderate AD, moved to NH with husband who has severe cardiac failure
- Admitted to hospital from NH after persistent aggressive behaviour towards her husband and some staff over several months following move
- not welcome back at nursing home due to her behaviours
- Family conference in hospital revealed that Mr White had had a number of affairs in his earlier life, and his wife had always been suspicious if he was home late from work
- Mrs and Mrs White were in separate wings of the care facility and daughter felt that her mother was convinced her father was having another affair
- After much negotiation with the facility, Mrs White moved into the same room as her husband and behaviours improved

Mrs Jones

- 84 year old lady with moderately severe dementia in residential care, chairfast following unsuccessful internal fixation of hip fracture
- Constantly calling out loudly for son, then not sure what she wants when he or others arrive
- Had lived on a sheep property most of her life
- Discussion about bringing a staff member's kelpie in to visit her
- Mrs Jones eyes lit up and she smiled for the first time in weeks
- Dog was allowed to spend several hours a day in her room and her calling out reduced significantly

Pharmacological management of behaviours and psychological symptoms of dementia

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Pharmacological management of BPSD

- Use medication only after a reasonable trial of non pharmacological management, and use judiciously
- Remember that efficacy of many of the treating drugs is quite modest, but side effects can be serious
- Decide which symptom or symptoms are being targeted for treatment, and measure response

- Make sure that any underlying causes of symptoms are diagnosed and treated
  - Always check for delirium and treat the underlying cause eg UTI
  - Consider analgesics for pain
  - Address constipation with laxatives, fluid etc

- Always involve the carer and other family members and staff

Pharmacological management of BPSD

- Agitation (and anxiety):
  - Selective serotonin reuptake inhibitors are as effective as antipsychotics with less side effects. Citalopram has most evidence (start at 10mg mane)
  - Analgesics have been shown to reduce agitation in moderately severe dementia (? Treating undiagnosed pain)
  - Antipsychotics may be effective – risperidone is the only PBS listed drug (start at 0.25mg BD), olanzapine may also be effective
  - Benzodiazepines may be effective short term (lorazepam 0.5mg BD), avoid long acting drugs such as diazepam

- Depression:
  - Selective serotonin reuptake inhibitors have shown some benefit (start citalopram 10mg mane increasing to 20mg over 2 weeks)
  - Selective noradrenergic reuptake inhibitors (start venlafaxine 37.5mg mane and increase after 2 weeks)
  - No evidence for use of sertraline or mirtazapine

Pharmacological management of BPSD

- Aggression
  - Antipsychotics- risperidone is only one PBS listed for BPSD (start 0.25mg BD titrating dose up for response to max of 3mg/day.) Watch for EPS, review after 1 week, must review within 3 months to continue prescribing
  - Olanzapine can be used IMI in extreme cases (2.5mg stat)

- Psychotic symptoms (hallucinations and delusions)
  - Only treat if there is distress to the patient or others
  - Antipsychotics – risperidone. Olanzapine and quetiapine may be useful if there are side effects from risperidone but are used off-label

- Sleep-wake cycle reversal
  - Use melatonin to induce sleep, may need short course of short acting sedative-hypnotic such as temazepam, aim to keep awake during day

Pharmacological management of BPSD

- Apathy:
  - Cholinesterase inhibitors such as donepezil (used for symptomatic treatment for cognitive symptoms in Alzheimers disease) can improve apathy
  - Antidepressants may be effective if apathy is part of depression

- Symptoms not often helped by medication include inappropriate vocalisations (calling or shouting out), restlessness and wandering, sexually inappropriate behaviours

Pharmacological management of BPSD

Obtaining consent for treatment:

- In NSW, psychotropic medication is a MAJOR medical treatment and hence requires written consent from the 'person responsible' or guardian with function of medical consent for ongoing therapy
- URGENT medical treatment is treatment necessary to prevent serious damage to health and does not need consent. In an emergency, use of psychotropic medications is covered by 'duty of care' and does not require prior consent but the 'person responsible' should be informed of the use of emergency sedation as soon as possible – usually within 24 hours

Mrs Smith

- 68 year old lady, lived with husband in own home, 2 year history of Alzheimers disease, on donepezil
- Was convinced her husband was having an affair and was going to leave her. She followed him around, got angry if he went to golf, stood at door and would not let him out.
- Commenced on risperidone on the basis that she was experiencing delusions
- After 2 weeks, husband reported "I have got my wife back". He was very reluctant to consider reducing dose of the "chill pill" after 3 months.
- Risperidone reduced to morning dose only after 6 months, and was ceased at 12 months (but husband keeps a box in the cupboard)

Mrs Short

- 87 year old lady with mixed dementia (vascular dementia and Alzheimer's disease) moved into residential care after death of husband who was her carer
- Became very agitated and anxious about where her husband was, constantly asked staff and other residents about him, then became extremely distressed when told he was dead
- All attempts at distraction, exercise, music therapy failed
- Commenced on citalopram and gradually increased to 20mg in the morning. Staff noticed reduction in questions (using behaviour chart) after 4 weeks. Has remained on citalopram as one attempt to withdraw it after 6 months led to recurrence of questions

Mr James

- 84 year old man, lives in dementia specific residential care unit with wife, he has mild dementia
- Started becoming more attentive to female residents and staff, gradually escalating to touching their arms and then their breasts
- Tried with distraction, regular monitoring, keeping him active in the garden. Then commenced on risperidone (as thought to have delusions) with no effect. Next was trialled with valproate up to quite a high dose. This made him drowsy but behaviour persisted.
- As residents reported the touching as sexual assault, this required reporting to the Aged Care Safety and Quality Commission and NSW Police were called. They spoke 'firmly' to the resident, and visited again on 2 more occasions to remind Mr James. After 3 months he has not yet repeated the touching.

Mrs Long

- 77 year old lady, lived with husband in own home, 5 year history of Alzheimer's disease, still relatively independent in activities of daily living with prompting
- During the 2019 bushfires she was convinced that she was the cause of the fires and they had been sent to punish her. She became extremely distressed and tried to stab herself with scissors
- She was commenced on both risperidone and venlafaxine as the old age psychiatrist was worried about her delusions and depression
- She required 3 weeks inpatient care but was markedly improved at 6 weeks after commencing treatment. Her risperidone was ceased after 6 months and she remains on the venlafaxine

Help with management of BPSD

- Dementia Support Australia runs the Dementia Behaviour Management and Advisory Service (DBMAS) which is available across Australia and is free
- The intervention implemented by DBMAS comprises a multifactorial and person-centred set of individualised behavioural management strategies
- Non-pharmacological interventions in a 1-year audit reduced number of symptoms, and severity of symptoms by half, and distress experienced by carers by two thirds

- The Specialist Dementia Care Program provides specialist dementia care accommodation, management and support for those residents unable to be managed in mainstream aged care with units across Australia (one per Primary Health Network area)

DS Dementia Support Australia

DBMAS | dementia behaviour management advisory service

24 hour helpline

1800 699 799

Thank you

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