Developing behavioural interventions to manage responsive behaviours

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DCRC
Dementia Centre for Research Collaboration

Overview

- Review evidence related to understanding why responsive behaviours / behavioural symptoms of dementia occur.
- Review current guidelines for managing responsive behaviour/BPSD.
- Work through the steps in developing a targeted behavioural intervention to reduce responsive behaviours.
- Apply these steps to clinical practice.

What are responsive behaviours?

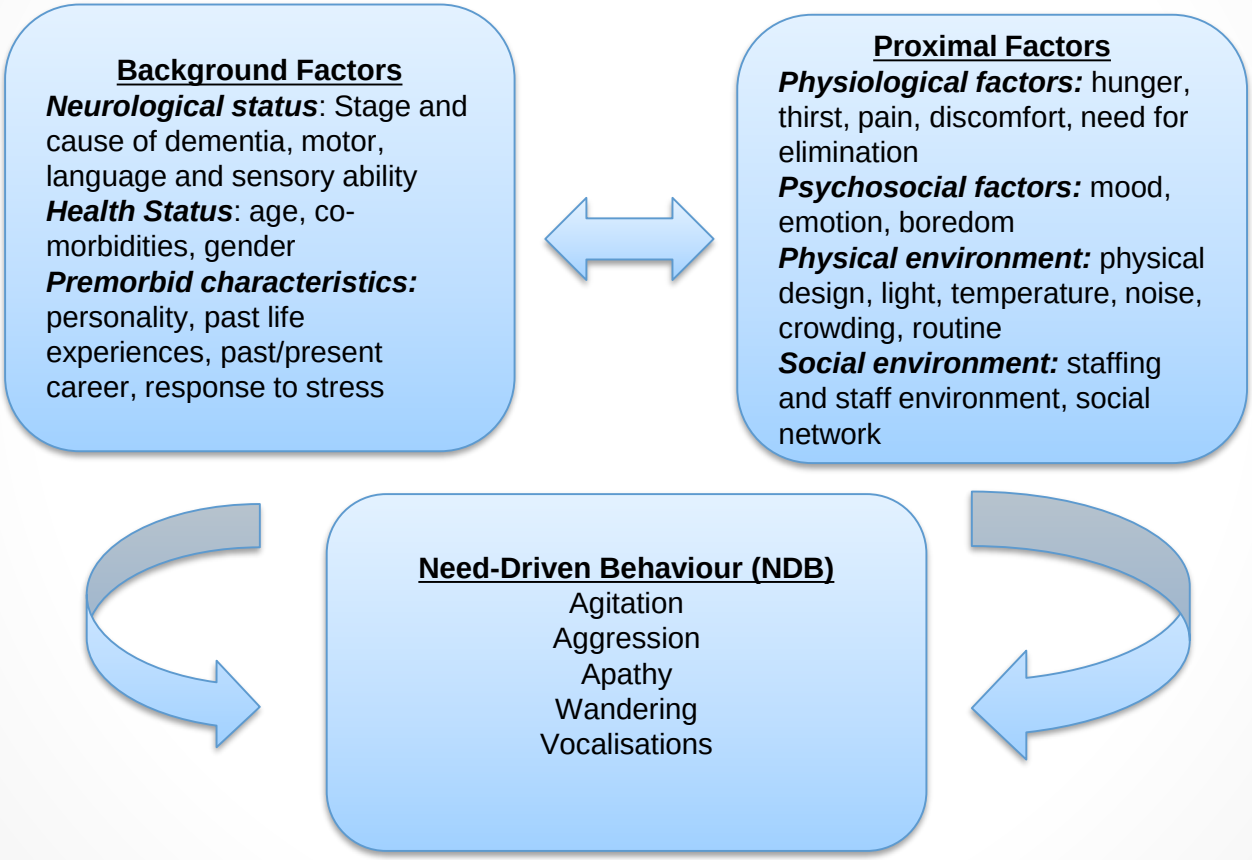
- Also known as Behavioural and Psychological Symptoms of Dementia (BPSD) or Neuropsychiatric symptoms.
- **Psychological symptoms**: hallucinations, delusions, depression, anxiety
- **Behavioural symptoms**: aggression, vocalisation, wandering, resistance to care.
  - Effects most people with dementia
  - Present at all stages of dementia
  - Disturbing to person with dementia, carers and others
  - Precipitates admission to long term care

Purandare, N., & Burns, A. (2000)

Why responsive behaviours occur.

- Pathophysiological causes – disease process, area of brain effected
- Psycho behavioural factors e.g. personality, life long habits
- Environmental factors e.g. noise, temperature
- **Need Driven Behaviour** –expression of unmet needs

Need Driven Behaviour Model



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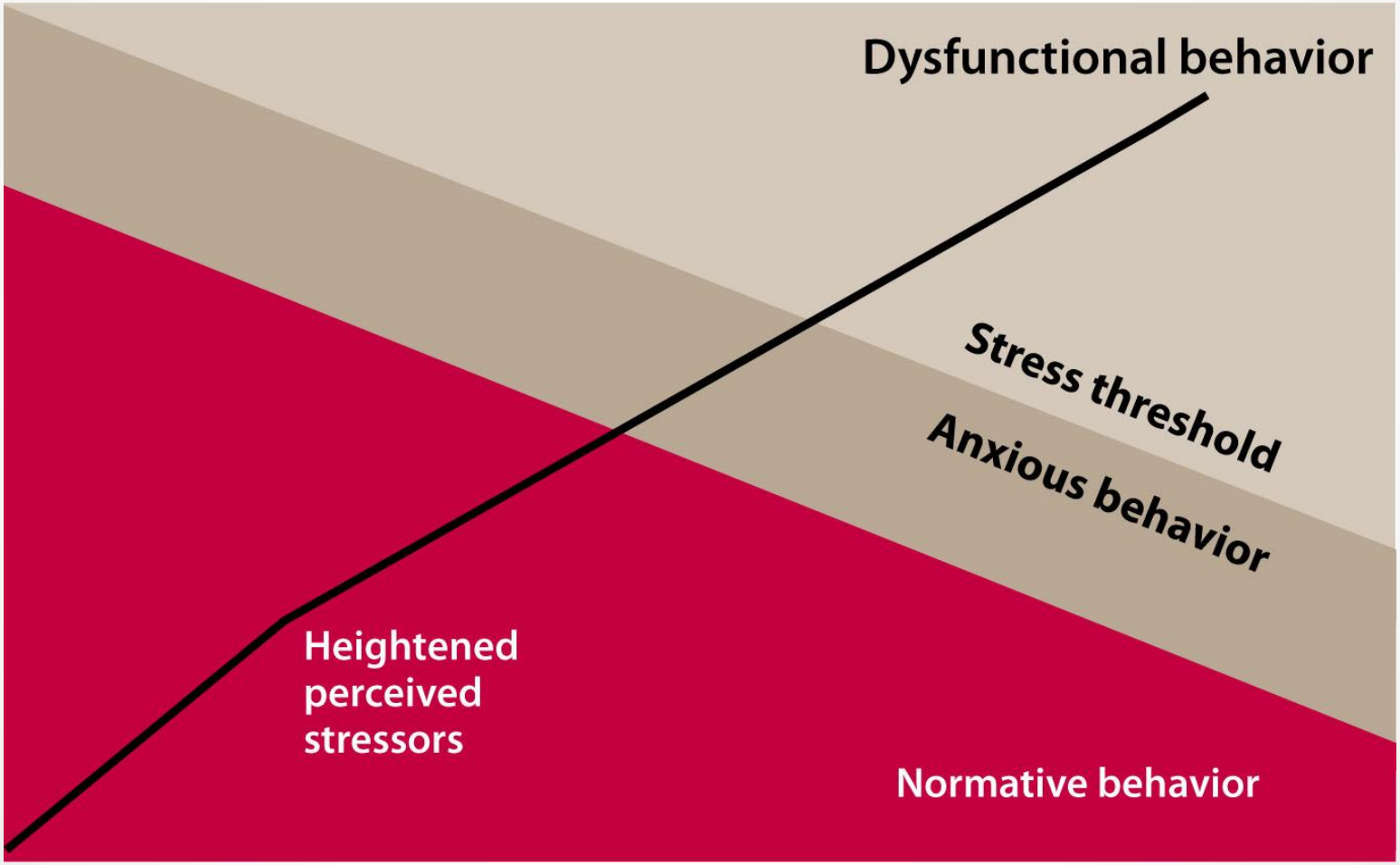
Progressively Lowered Stress Threshold



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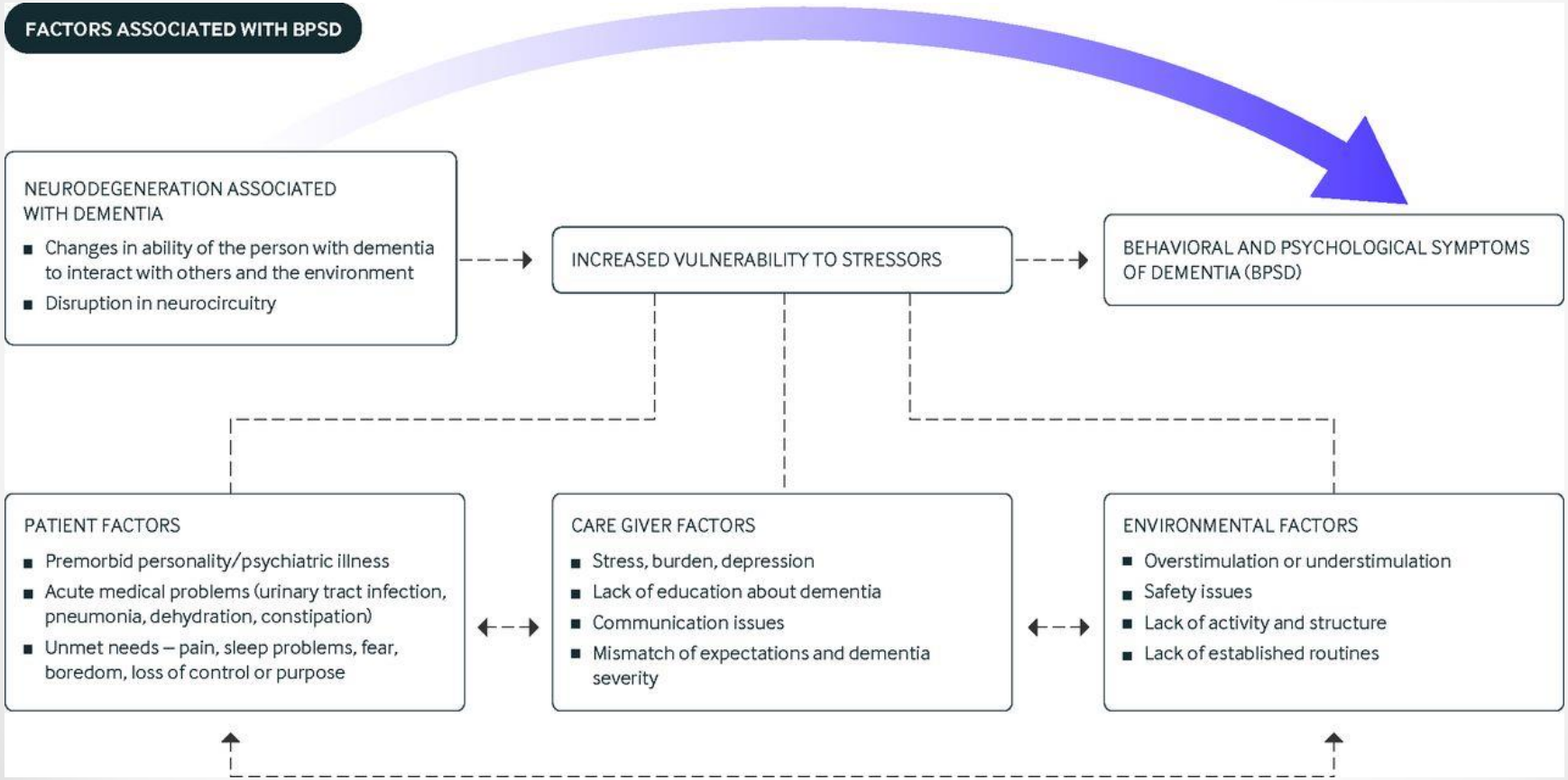
Why BPSD occur



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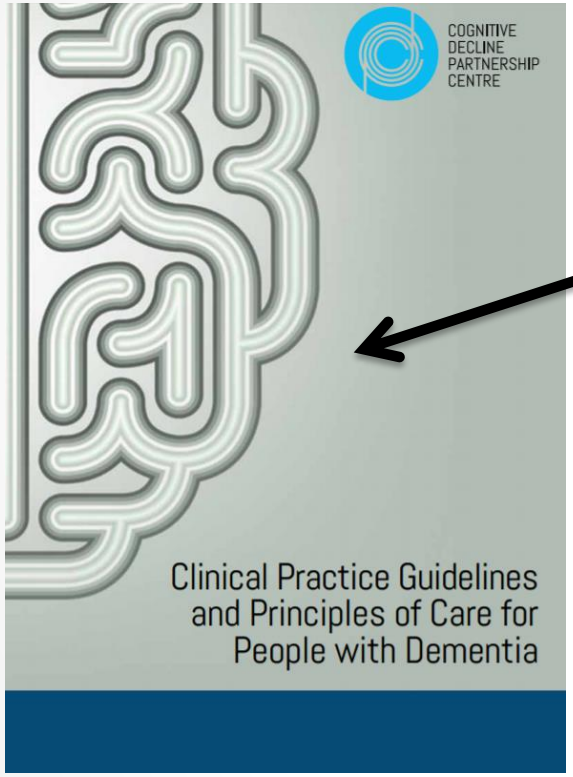
Evidence-based clinical guidelines for dementia care



Full report

Summary


Guidelines Clinical focus

Clinical practice guidelines for dementia in Australia

Summary

- About 9% of Australians aged 65 years and over have a diagnosis of dementia.
- Clinical practice guidelines aim to enhance research translation by synthesising recent evidence for health and aged care professionals.
- New clinical practice guidelines and principles of care for people with dementia detail the optimal diagnosis and management in community, residential and hospital settings. The guidelines have been approved by the National Health and Medical Research Council.
- The guidelines emphasise timely diagnosis, living well with dementia and delaying functional decline, managing symptoms through training staff in how to provide person centred care and using non pharmacological approaches in the first instance, and training and supporting families and carers to provide care.

Changes in management

Main recommendations

http://sydney.edu.au/medicine/cdpc/documents/resources/CDPC-Dementia-Guidelines_WEB.pdf

https://www.mja.com.au/journal/2016/204/5/clinical-practice-guidelines-dementia-australia

Clinical Practice Guidelines

Aims of the guidelines: provide recommendations for a standard of practice for the diagnosis and management of people with dementia →109 evidence-based recommendations

Scope:

1. Assessment & Diagnosis
2. Provision of Care
3. Appropriate use of medications
4. **Appropriate treatment of BPSD**

Laver et al., 2016

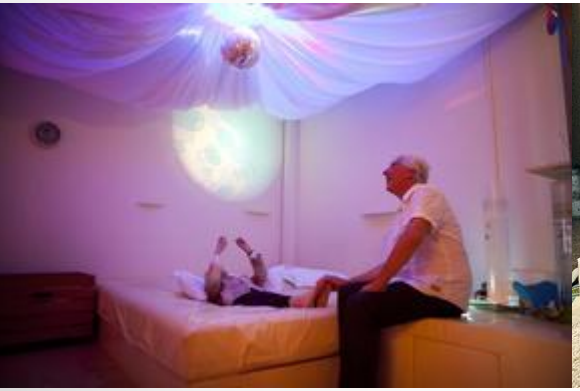
Appropriate Treatment of BPSD

- Understand and identify behavioural symptoms using ***validated and specific assessment tools***
- Identify Antecedents and Consequences →
  - **WHAT IS THE RISK ASSOCIATED WITH THE BEHAVIOR?**
  - **Consider treatable cause and reduce or eliminate e.g. pain**
- Use an ***evidence based non-pharmacological intervention*** that ideally involves ***engagement*** in activities that are ***enjoyable for the person*** with dementia and provide individualised support.
- If non-pharmacological approaches not effective and there is immanent danger, for severe behaviours antipsychotics may be prescribed
  - need to discuss pros and cons with PwD /carer and treatment should be reviewed every 4-12 weeks, considering the need for antipsychotics and possible cessation of medication.

Best practice: Non-Pharmacological Interventions

- First line treatment/management of responsive behaviours/BPSD
- As effective as medication with less risk
- Key factors determining approach
  - Understand the behaviour – What is the risk?
    - Identify possible triggers – Behaviour specific assessment
    - Eliminate triggers
  - Consider factor within the person and external to the person
  - Manage behaviour while maintaining freedom and dignity of PwD
  - Support PwD & Carer

A look at the evidence about Non-Pharmacological approaches



Types of Non-Pharm interventions: Focus on person with dementia

Non conclusive evidence for:

- Reminiscence therapy (discussion of past experiences)
- Validation therapy (working through unresolved conflicts)
- Simulated presence therapy (use of audiotaped recordings of family members' voices)
- Aromatherapy (use of fragrant plant oils)
- Snoezelen (placing the person with dementia in a soothing and stimulating environment known as a "snoezelen room")
- Cognitive training and rehabilitation
- Acupuncture
- Light therapy

Very limited evidence for management of agitation and wandering

Kales et al., (2015)

Some evidence available

- Engagement in physical activity and pleasant events → **reduced depression**
  - No impact of exercise on mood
- Sleep → **improves aggression, agitation and wandering**
- Distraction, backing away, and leaving the room have been reported to be helpful for symptoms of **aggression**
- Hand massage → **reduces agitation** in the short term and that touch → can **encourage eating**
- **Agitation and aggression** during bathing may be reduced by personalizing the bathing experience

Kale et al., (2015)
http://pubmedcentralcanada.ca/pmcc/articles/PMC4707529/

More quality RCT needed

Focus on carer factors

- ***Good dementia care and support programs for carers*** - integrated a tailored problem solving approach for working with care givers with regard to behaviors → **reduced BPSD**
- Eight sessions with occupational therapists to train care givers in ***customised activity, based on previous interests and cognitive/physical abilities*** → **reduced problematic behaviours** and time spent caring (Tailored Activity Program)

Kales et al., (2015)

Focus on environmental factors

Reduce BPSD by addressing environmental factors:

- **Overstimulation** (for example, excess noise, people, or clutter in the home) or **under stimulation** (for example, lack of anything of interest to look at)
- Protection against **safety** problems (for example, access to household chemicals or sharp objects or easy ability to exit the home)
- **Provide activity and structure** (for example, regular exercise or activities that match interests and capabilities)
- **Established routines.**

Kales et al., 2015

Meaningful Activity

- Meaningful activity – ability to participate in activities (work, leisure, family) is important for identity
- Providing meaningful or individualised activity in RAC can be effective in **reducing BPSD** and **improving quality of life** – evidence not strong
- Evidence often confounded by social interaction, 1:1 attention, and lack of clarity around causal effect.
- However, positively engaging a person with or without activity is beneficial
- Spending this time engaged in meaningful activity has a positive effect on BPSD
- More robust studies are needed to confirm these findings

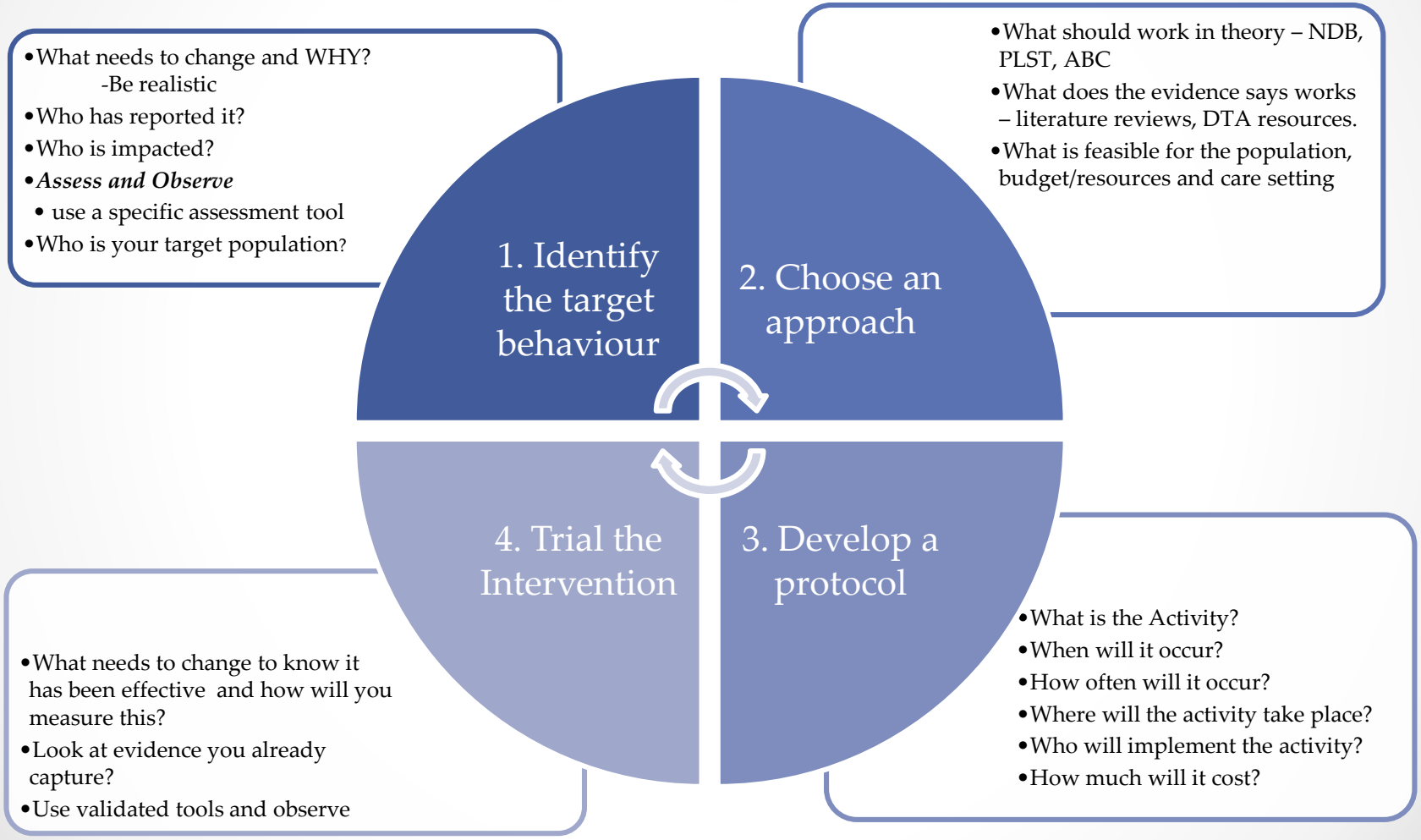
Travers et al., 2016

What is your experience?

1. What are the most common responsive behaviour /BPSD that you have experienced
2. What approaches have you tried?

How did you decide what to do?

Developing a behavioural intervention



Adapted from: Gitlin, L., Czaja, S. (2016). *Behavoral Intervention Research: Designing, Evaluating, and Implementing.* New York: Springer.

Identify the behaviour

- Determine if this is a new behaviour – eliminate delirium
- Use a validated and specific assessment tool
  - Neuropsychiatric Inventory (NPI) – general behaviour identify behaviours of concern
  - Behaviour mapping – ABC – **OBSERVE** the person
  - Behaviour specific tool:
    - Agitation – Cohen Mansfield Agitation Inventory; Pittsburg Agitation Scale
    - Anxiety – Rating Anxiety in Dementia
    - Apathy – Apathy Evaluation Scale
    - Wandering – Revised Algase Wandering Scale
    - Depression – Cornell Scale for Depression in Dementia

    http://www.dementia.unsw.edu.au/

- Assess the risk to person with dementia and others – safety first – **Is change needed?**

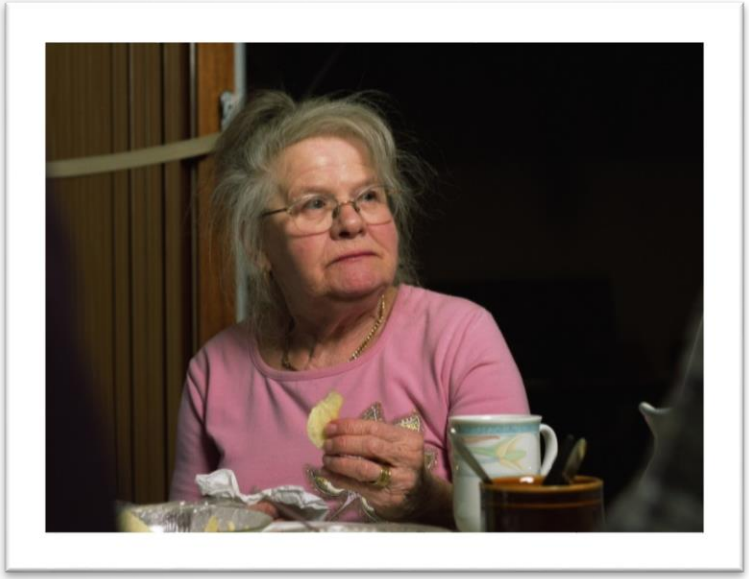
Choose an approach

- Look at the available evidence
  - What has worked before?
    - Literature review + evidence based resources (DTA app)
  - **Engagement / Meaningful activity**
- Follow care guidelines
  - **Non-Pharmacological** intervention first line approach
  - Provide carer **support**
- Work within the limits of available resources
  - Cost
  - Environment
  - Human resources

Develop a plan and try it

- Communicate the plan with the team
  - **What** is the intervention
  - **How** is it implemented – step by step
  - **When** is it implemented
  - **Where** will you implement it
  - **Who** will implement it
- Know what you want to change and measure that change
  - Be realistic!!!
  - Start small
- Persevere for a set time – observe for desired outcome
- Be prepared to try something else

Case Study



- 71 year old woman named Sharon
- Husband Ron
- Ex School Principal
- Early onset AD
- Keen golfer, accomplished gardener, volunteered her time
- Came to RAC after several events of leaving home and not being able to return

The behaviour

- Frequent intrusive wandering (boundary transgression) into other peoples' rooms and staff work areas
- Disturbed night time activity and close shadowing of staff
- She also walked constantly throughout the building, was often seen trying door handles on locked doors and on multiple occasions she became lost within the facility and unable to locate her own room.

Developing a tailored behavioural intervention

Identify the target behaviour

How will you assess Sharon?

What is the risk?

What needs to change?

Choose an approach

What does the evidence say?

What from her history will you consider?

Develop a protocol

What activity? When?

Trial the intervention

What would you measure?

Identify the behaviour

Wandering

*"syndrome of dementia-related locomotion behavior having a **frequent, repetitive, temporally-disordered and/or spatially-disoriented nature** that is manifested in lapping, random, and/or pacing patterns, some of which are associated with eloping, **eloping attempts, or getting lost** unless accompanied".*

Algase DL, Moore D Helen, Vandeweerd C, Gavin-Dreschnack D and the IWC (2007) Mapping the maze of terms and definitions in dementia-related wandering. (2007) *Aging and Mental Health.* 11 (6):686-98.

A Tool to Measure Wandering Behaviour

• The Revised Algase Wandering Scale (RAWS) (Nursing Home & Community versions) → type and intensity of wandering

• A 19 or 28-item questionnaire, based on three dimensions of wandering
  - Persistent walking
  - Spatial disorientation
  - Eloping Behaviour
  - Temporal aspects
  - Mealtime walking (Community version only)

• Differentiates between those who do not wander, those with occasional behaviour, those who wander but without issues and those whose behavior involves moderate to high risk (scale 1-4)

• Validated in an Australian community sample

Algase, DL, Beattie, ER, Bogue, E, & Yao, L. (2001). Algase Wandering Scale: Initial psychometrics of a new caregiver reporting tool. *American Journal of Alzheimer's Disease and Other Dementias*, 16(3), 141-152.
Algase, D. L., Beattie, E. R. A., Song, J., Milke, D., Duffield, C. & Cowan, B. (2004). Validation of the Algase Wandering Scale (Version 2) in a cross cultural sample. *Aging & Mental Health*, 8(2), 133-142.
Marcus, J., Cellar, J., Ansari, F. & Bliwise, D. (2007) Utility of the AWS in an outpatient AD sample. *International Journal of Geriatric Psychiatry*, 22(8):801-5.

What is the risk?

Contributing Factors

Stable Factors

Demographics: (age, gender, education & race)

Predisposing Factors (personality, response to stress, ApoE status)

Dynamic Factors

Enabling factors: (Mobility, function, health status, medications)

Neuro-cognitive factors: (Attention, cognition, memory, language/verbal skills, executive functioning)

Type and Intensity of Wandering

Type of wandering:

Spatial disorientation

Repetitive/routinised walking

Night time wandering

Intensity of wandering:

Distance walked in a day

Frequency and duration of each episode

Persistence over time

Immediate Adverse Outcomes for Wanderers

Meal time impulsivity

Inadequate food intake

Falls, fractures and injuries

Eloping behaviours (exit attempts, unescorted exits, and getting lost)

Cumulative Adverse Outcomes for Wanderers

Weight loss

Relocation

End of Home Care

Death

Algase, D.L., Beattie, E., & Son, G.R. (2006) A model of risky wandering. In Nelson & Algase (Eds) *Evidence-based Protocols for Wandering Behaviour (*2006), Springer:NY.

Sharon's behaviour

The behaviour

- Frequent intrusive wandering (boundary transgression) into other peoples' rooms and staff work areas
- Disturbed night time activity and close shadowing of staff
- She also walked constantly throughout the building, was often seen trying door handles on locked doors and on multiple occasions she became lost within the facility and unable to locate her own room.

Sharon's risk

1. Entry into out of bounds areas and exit attempts
   - → Resident to resident violence
   - → Become lost
   - → Unintentional exit

2. Night time walking
   - → Fatigue
   - → Sleep deprivation

3. Repetitive & frequent walking
   - → Fatigue / exhaustion
   - → weight loss

What characteristic of wandering has the greatest risk?

Wandering	Risk estimate	Interpersonal	Technological	Policy
Excessive wandering; Wandering disrupts necessary	Low	Engagement; diversion; collusion, behaviour modification	Sensory enhancement	Risk screening assessment; behaviour logs; scheduled location checks
Losing one's way indoors	Low-medium	Verbal re-direction; train to use same route every time.	Environmental design and cueing	Risk screening assessment; behaviour logs; scheduled location checks
Trespassing into off-limits or hazardous areas or beyond mastery level; night wandering; stating intent to leave; preparing to leave	Medium	Verbal redirection; behavioural modification; structured activity programs; wandering registry; intensified supervision.	Alert/alarm systems; barricades, locks/subjective exit barriers, e.g. mirror, mural, door and floor camouflage, environmental design & cueing; surveillance	As above with increased frquency of location checks

Wandering	Risk estimate	Interpersonal	Technological	Policy
Exit door lingering and testing	Medium to high	Redirect using verbal and non-verbal cueing & diversion; conceal cues for leaving, e.g. keys; intensified supervision; alert responsible parties to heightened risk	Subjective exit barriers	Lost residents plans; door alarms, drills/checks; incident reports; medication review
Seeking means or opportunity to exit	Medium to high	Verbal redirection; behavioural modification; structured activity programs; wandering registry; intensified supervision.	As above	As above
Un-approved exiting	High	Promptly respond to alert/alarms Contain, monitor	As above	As above
Eloping; losing one's way beyond care; getting lost	High, critical	Track, return. Promptly recognise absence, rapidly locate and return to supervised care, assess health status	Wandering registry, local or state police; search and recovery mission	GPS

Sharon's risk

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   - → Sleep deprivation

3. Repetitive & frequent walking
   - → Fatigue / exhaustion
   - → weight loss

What characteristic of wandering has the greatest risk?

Choose an approach – what does the evidence suggest?

- Need driven behaviour
  - Can you eliminate the trigger?

- Non-Pharmochological approach recommended
  - Engagement & Meaningful activity
    - Ex-teacher
    - Keen golfer and gardener
    - Volunteered to help others

Develop a protocol

- Target behaviour – entry into other residents bedroom
- What activity – Gardening/weeding and planting
- When – need to observe the behaviour
- Where – outdoors in garden
- Who ?????

How to measure efficacy?

An example of 2 behavioural interventions to reduce risky wandering

Two approaches to reducing risky wandering

- **Aim**: To trial the feasibility of two behavioural interventions implemented with people with severe dementia who wander in RAC.
- **Target of the intervention**: frequent/repetitive walking & boundary transgression
- **Protocol development**
  - Consulted with potential end user
    - → Exercise based activity & Music
  - Considered theoretical frameworks
    - Wandering is an expression of unmet needs.
      - Eliminate / modify underlying cause
      - **Make the behaviour safer**
  - Considered the evidence
    - No previous RCTs specific to wandering
    - **BUT** Walking programs had the strongest evidence
    - **AND** Listening to preferred music effective for agitation

Intervention protocols

Supervised walking program

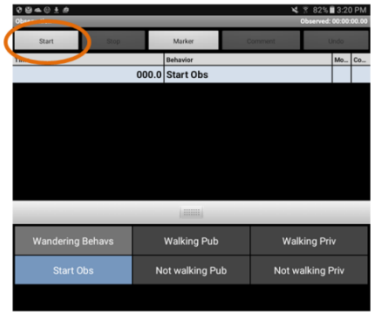
- Daily 30 minute walk with a trained RA or care staff
- 30 minutes before peak activity periods
- Outside care facility
- 3 week trial

Listening to preferred music

- Daily 20 minute session with trained RA
- Listened to selection of preferred music 30 minutes before peak activity (condition 1) OR at random times (condition 2).
- 3 week trial

Outcome measures

- Pre, during and post measures
- **Protocol fidelity** – length of session, reason for deviations from protocol/no intervention.
  - IRR 10% - check protocol fidelity and types of communication used
- **Characteristics of wandering**:
  - Direct observation – 2 x 2 hours per week per participant
    - ***Locomoting / non locomoting – frequency & duration***
    - Pattern – pacing, lapping, random, direct
    - ***Boundary transgression – entry into out of bounds/hazardous areas***
  - 24/7 step count – Actigraph™ Activity monitors
  - Trialled Noldus Pocket Observer™
- **Immediate pleasure** (music intervention)
- **Staff/family members perception** (interviews)
- Others: wandering status agitation, sleep, falls, weight



Participants

Supervised Walking

- 2 participating facilities
  - 60 bed dementia specific locked unit
  - 120 bed mixed frail aged ad people with dementia (not locked)
- 7 residents with severe dementia who were known to wander and tolerated Actigraph™

Preferred Music

- 2 participating facilities
  - 60 bed dementia specific locked unit – condition 1
  - 94 beds – 16 beds in locked dementia specific unit – condition 2
- 10 residents with severe dementia who were known to wander and enjoyed listening to music

What did we find?

- Protocol fidelity

  Supervised Walking Program – 80% of planned walks were completed

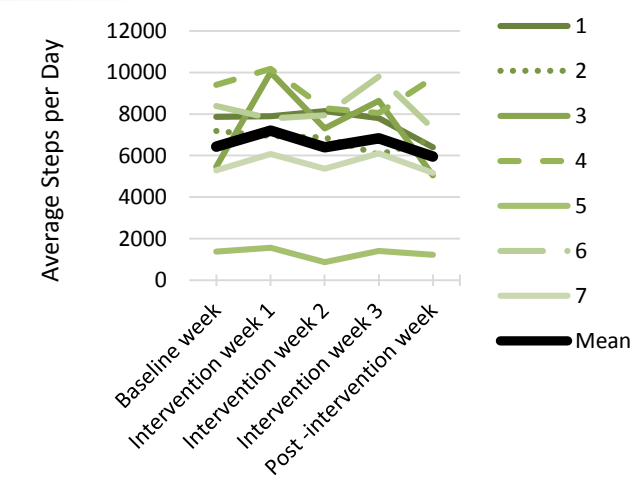
  - **Reasons for not starting/completing walk:** participant refused (n=5), participant fatigue (n=4), self-reported Illness (n=3), staff reported participant illness (n=3), participant asleep (n=3), staff unavailable to conduct walk (n=1).
  - **Reasons for not taking planned route:** road work, participant choice, weather

  Listening to Preferred Music– 61% of scheduled sessions were initiated; only 60% of sessions initiated went for full 20 minutes

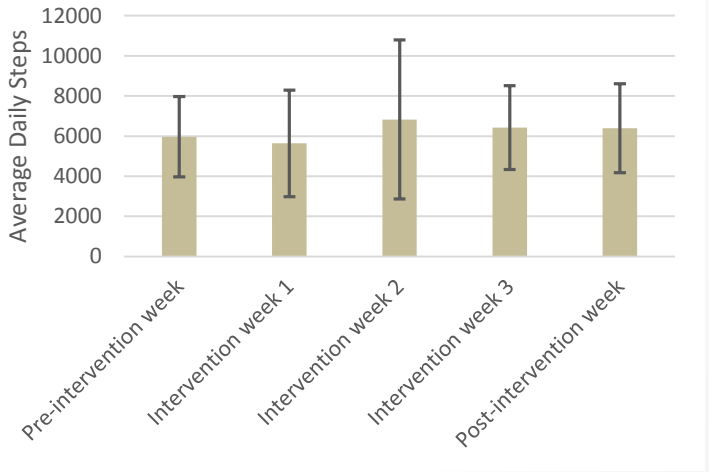
  - **Reasons for not commencing** – involved in other activity, planning another activity, absent from facility
  - **Reasons sessions ending early** – participant walked away from speaker or removed headphones
  - 1 participant refused all sessions

Effect of interventions on wandering

- No significant findings BUT characteristics of wandering were not exacerbated during intervention weeks



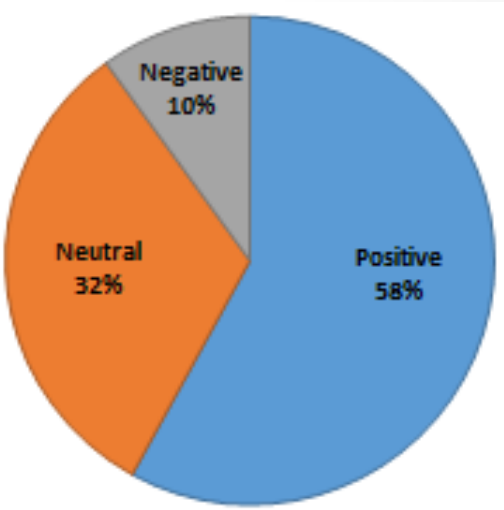
Supervised Walking



Listening to Preferred Music

Impact of music on mood

- Participants were asked 'Did you enjoy listening to music' at the end of each session:
  - **51% said YES**
  - **33% did not respond**
  - 13% said NO or were neutral
  - 3% response not recorded
- **More positive mood observed during music sessions**



Observed mood during interventions

Staff perceptions of walking program

- **Improved participants' mood and engagement** with others.
- Staff found it was an **enjoyable activity** that helped **build rapport with residents**.
- Walking outside the facility was an important part of the program.
- Participants seemed to enjoy going for a walk – after some initial anxiety, were **very enthusiastic**.
- Didn't notice change in amount of walking but seemed to **walk more in common spaces – more social.**
- BUT worried about **interfering with staff routine** and taking staff from care duties.
- Should **use volunteers or activity officers** and consider group walks for socialisation

General observations

- Participants initially had trouble adjusting to being outside
  - Some had not been outside facility for many years
    - Uneven ground, grass and breeze
- **No participant tried to run away**.
- The participants were very aware of the new surroundings and noises.
- Had trouble sticking to strict time schedule as participants keen to leave.
- **Some residents became very fatigued** – had low step counts but were elopement risk.
- **Suited some participants but not all – low step count.**

Staff/family perceptions of music program

- Participants **enjoyed** listening to music.
- **Positive** changes in the person's mood and behaviour were observed.
- The program caused **minimal impact on the facility** and it should continue BUT no consensus on who should implement the program.
- Suggested using the music at set times e.g. after lunch or dinner.

General observations

- Very hard to get some residents to come to a designated area to listen to music – sometimes listened in areas with many distractions.
- Family may not know current likes and dislikes.
- Other residents entering bedrooms interrupted sessions.
- Expecting residents to sit for 20 minutes may not have been realistic.
- **Suited some participants but not all.**

Proposed modifications to the protocol

Supervised Walking Program

- Groups of residents walking in groups.
- Morning or afternoon sessions.
- Continue to walk outside the facility.
- Use staff / volunteers provided by facility to lead walks.
- Need to exclude residents with low step counts.

Listening to Music

- Check music selection with the person with dementia if possible.
- Need to be able to tolerate headphones.
- Involve facility staff more.
- Reduce the length of the intervention to 10 minutes.
- Consider adding a visual component e.g. video clips of artist or related /meaningful images.

Top Tips.

- Before planning care related to managing responsive behaviour/BPSD:
  - Establish need for change
    - Use validated assessment tools and observe the behaviour over many time points → Is there a safety risk?
    - Who will the intervention benefit?
  - Understand origin/trigger of behaviour – **understand the person with dementia**
- Use evidence based approaches:
  - Non-Pharmacological approaches best practice
  - Interventions should be engaging and meaningful to person with dementia
- The plan should be shared with all members of the team.
- Have realistic expectations but be persistent.
- Be prepared to modify your plan!!!
- **ONE SIZE DOES NOT FIT ALL!!!!**

Questions???

References

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