Non-Pharmacologic Strategies for Addressing Behavior and Psychological Symptoms of Dementia

AIDA WEN, MD
ASSOCIATE PROFESSOR
UNIVERSITY OF HAWAII
DEPARTMENT OF GERIATRIC MEDICINE
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Objectives

1. To be able to characterize and identify treatment targets for managing challenging behaviors.
2. To describe evidence-based non-pharmacological interventions for dementia behavior management.
3. To be able to provide counselling and resources to caregivers for dementia behavior management.

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Mr. Sato

You are seeing Mr. Sato and his family. He is 85 years old. You have known him for at least 10 years. He is a retired professor. He is relatively healthy with PMH of HTN, BPH and macular degeneration. He was diagnosed with early dementia 5 years ago and has been on Aricept since then. He moved in with his daughter’s family 2 years ago as he needed help with his IADLs. He often refuses help, especially with bathing, and brushing teeth. It is Monday morning and his daughter is exasperated.
He had a fall...
She tells you that he had an unwitnessed fall Friday night in the bathroom as he was showering, and bruised his left hip. He says abruptly, “I’m fine!”
She says he has been more irritable than usual this weekend, yelling and screaming about everything, and telling her to leave him alone. AND to top it all off, he hasn’t been sleeping well at night!
He leans forward and says to you

“He is driving me crazy!”
The daughter appears tired and exasperated. She tells you that when he first moved into her house, things worked out “fine”, but right now...

Caregiver Burnout: the “Invisible Patient”

<table>
<thead>
<tr>
<th>Depression risk</th>
<th>Caregiver Burnout: the “Invisible Patient”</th>
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<tr>
<td>Female, lower education level, same home, lack of choice</td>
<td>Depression: 30% of caregivers experience depression, compared to 15% of the general population.</td>
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Adelman 2014, Cooney 2015, NSDUH 2017
General Approaches

- How you communicate matters:
  - Approach from the front
  - Speak slowly calmly
  - Don’t argue, reason, shame or demand.
  - Instead, reassure, repeat, demonstrate, encourage.

- TADA! = Tolerate, Anticipate, Don’t Agitate!
  - If it’s not dangerous, let them be.
  - Anticipate their needs before they get upset. Having a familiar routine is helpful
  - Don’t do or say things to upset them—Restraints make people upset. Sometimes “re-orienting” them can make people upset.

Safety:
- Grab bars, no sharp edges
- Concealed exits

Orientation:
- Routines, clocks
- Encourage ADLs
- Hearing aids
- Written communications

Environment:
- Not understimulating
- Not overstimulating


General Approaches

FIRST: Rule out Medical Causes

Evaluate for Delirium!
- Acute onset
- Inattention
- Disorganized thinking
- Altered consciousness

He may have a Medical illness that should be treated!
Rule out “reversible Dementia”—check CBC, TSH, Vit B12, BMP

GET A MEDICAL EVALUATION
SECOND: Identify any triggers

PHYSICAL: Pain, Hungry, Thirsty, Cold, Constipated?
ENVIRONMENT: too much/ too little stimulation?
PSYCHOLOGICAL: frustrated, depressed, bored, scared?

Get Practical Tips for Common Challenges

Bathing       In the Car
Oral Care     Dressing
Using the Bathroom   Going out
Pacing       Holidays

Websites:  www.alz.org---> Life with Alz --> Caregiver Center --> Daily care -->
                       Personal Care --> Bathing

Sleep

**AVOID**

Too much time in bed at night
Too much daytime napping
Getting over-tired
Not enough exercise
Caffeine/ alcohol
Too much fluid after dinner
Hunger

**SUGGEST**

Medical evaluation: pain, Restless legs, Sleep apnea, depression, medication side effects, etc.
Try to maintain a routine
Keep occupied/awake in the day (or short nap after lunch)
Daytime exercise
Don’t go to bed too early
Treat pain- Tylenol at bedtime
Give something soft to hold
Snack & Early evening activities
Use nightlight, bathroom or hallway lights- darkness can be disorienting
Wake up same time of the day
...and if all else fails, allow them to be awake at night and hire a nighttime companion!
THIRD: Try Non-pharmacologic Strategies

Behaviors = Communication

Can’t find the words
Decreased coping capacity

➤ Ask “Why?”
➤ Try to see things from the person’s viewpoint
➤ Adapt the caregiver approach, communication style, environment or activities

Communication of UNMET NEEDS

Ask about the typical day at home

Daughter is working from home.
After the kids go to school, she gets dad up.
She tries to leave dad alone most of the morning to read the paper or watch TV, but he is often disruptive.
Has lunch with dad
She gets kids home from school at 2:30
Household becomes busy and noisy
Evenings are the worst-full of confrontations.
...Weekends are just unpredictable!
He is up and down all night long.
Ask “Why”?

Daughter is working from home. After the kids go to school, she gets dad up. She tries to leave dad alone most of the morning to read the paper or watch TV, but he is often disruptive. Has lunch with dad She get kids home from school at 2:30 Household becomes busy and noisy Evenings are the worst- full of confrontations. ...Weekends are just unpredictable! He is up and down all night long

...and Listen to what he is saying

Daughter is working from home. After the kids go to school, she gets dad up. She tries to leave dad alone most of the morning to read the paper or watch TV, but he is often disruptive. Has lunch with dad She get kids home from school at 2:30 Household becomes busy and noisy Evenings are the worst- full of confrontations. ...Weekends are just unpredictable! He is up and down all night long

Try to Understand their needs at different stages...

Teepa Snow, OTR

Teach caregivers to understand each person and their changing abilities (GEMS)

SAPHIRE (very early)- Leaving a legacy DIAMOND (Early)- Wants a sense of control, choice EMERALD – Enjoys having a job AMBER- (Mid) Enjoys things to mess with and explore RUBY- Enjoys holding, rubbing PEARL (Advanced)- enjoys warmth and comfort

A more positive approach...
Cohen-Mansfield Agitation Inventory (CMAI)

Assess the frequency of agitated behaviors

- Physically Aggressive
- Physically Non-aggressive
- Verbally Agitated

Short Form - 14 items
Long Form - 29 items

A Systematic Evidence Review of Non-pharmacological Interventions for Behavioral Symptoms of Dementia

2011

VA Health Services Research & Development Service

Good quality systematic reviews

- 21 focused on single intervention
- 7 variety of interventions

A systematic review of the clinical effectiveness and cost-effectiveness of sensory, psychological and behavioral interventions for managing agitation in older adults with dementia

2014

Literature search screened 1916 papers

160 papers met inclusion criteria (high-quality papers)

(although only 33 RCT which were reasonably-sized [n >45])

Compared Standard Effect Sizes (SES)

- For meta-analyses - Standard error of effect sizes weighs effect sizes to larger studies

Most studies measured agitation using the CMAI

Calculated cost per unit improvement
Systematic review of systematic reviews of non-pharmacological interventions to treat behavioral disturbances in older patients with dementia. The SENATOR-OnTop Series 2017


Literature search screen x papers from 4392 PubMed, EMBASE, Cochrane Database of Systematic Reviews, CINAHL, and PsychINFO from 2009-2015.

>4000 papers excluded based on abstract review

38 Systematic review/meta-analysis papers met inclusion criteria (after full text evaluation)

142 Primary studies included

Outcomes: NPI, CMAI, Cornell Scale for Depression, Brief Psychiatric Rating Scale

What works

- Music Therapy
- Sensory Stimulation
- Meaningful Activities
- Caregiver Training with Support

Music Therapy
**Music Therapy (with Protocol)**

- It is NOT background music. It led by trained therapist.
- Followed a specific protocol:
  - Ex: Warm up of a well known song, listening to music, then joining in with music.
- HTA, Livingston Study: 10 studies
- Largest study (n=55) had music therapy sessions twice a week x 6 weeks improved the mean level of agitation symptoms.
- Most studies had music therapy 2-3x per week.
- Focused on Active Participation.
- From the SENATOR ON-TOP SERIES, Ueda 2013: 9 RCT, 9 CCT
  Mean: 36 min/day for 2-3x per week for 10 weeks.

**SHORT TERM EFFECTS**

- N=397: Significant reduction in BPSD
  SMD -0.49 (95% CI -0.82 to -0.17)
- N=250: Significant reduction in Depressed
  SMD -0.32 (95% CI -0.68 to -0.06)
- N=258: Significant reduction in Anxiety
  SMD -0.64 (95% CI -1.05 to -0.24)

**Examples:**
- Music along with:
  - Singing
  - Playing instrument
  - Tapping Rhythm
  - Moving
  - Dancing
  - Exercise
  - Reminiscence
  - Mealtime
  - Live Music
  - Sensory Stimulation
Sensory Stimulation

Especially for Later Stages of Dementia

Visual Color Gentle Touch Aromatherapy Quiet Environment Soothing Sounds

Snoezelen Multisensory Stimulation Therapy for Dementia

Two out of Three studies demonstrated significant effects:
- Baker et al, 2003; inpatients 15 months, N=136 from 3 countries: UK n=94, Dutch n=26, Swedish n=16
- Van Weert, et al 2005; n=125 in old age psychiatric ward

Significant effects on Enjoying oneself (MD -0.74, 95% CI -1.29 to -0.19, p<0.01)
Significant effect on Bored/Inactive (MD -0.56; 95%CI -1.11 to -0.01, p=.05)
Significant effect on Happier/Content (MD -0.84; 95%CI -1.39 to -0.29, p<0.001)

Other Sensory Interventions

Aromatherapy
- Mixed results

Acupressure
- Only one RCT study met criteria
- N=133, 28 sessions over 2 weeks
- Agitation, aggression and physically non-aggressive behavior all declined significantly

Massage Therapy
- One study
- Remington, 2002
- Hand Massage and calming music RCT, n=51
- Significant decrease in Agitated Behaviors
- Other massage studies had poor methodological scores
Meaningful Activities

Meaningful Activities and Continuous Programming

Examples of Activities Valued by Adults

- Work activities (being productive and helpful)
  - Ex: gardening, cooking, cleaning, laundry, woodwork, fundraising, etc
- Self-care ("independence", ADLs, exercise)
- Leisure (visiting, games, watching musical/movie)
- Rest (napping, rocking, holding hands, massage, watching fish, petting dog)

Person-centered

• Varied activities matched to skill, interest, self-identified roles, arousal (7)
• Indoor gardening (1)
• Cooking group (1)
• Montessori activities (1)

Engaging

Failure Free

SES (C)

Short Term Effect: -0.8 to -0.6
Long Term Effect: none (HTA study, Livingston)
Cognitive Stimulation

- Ex: word games, puzzles, cooking, gardening, reminiscence. Small groups of 4-5 people, usually 45 minutes, minimum of 2x per week
- Seven reviews were identified; most studies were of poor quality
- 2 review found significantly significant reduction of BPSD
- 1 review showed cognitive stimulation had greater improvement than cognitive training.
- 3 reviews had non-statistically significant effect on behaviors
- 1 review—mixed

Activities: Indoor Gardening

Kahala Nui

Memory Support Unit

Outdoor patio area

Activities: Garden

Hale Kuki

Beauty in Nature

Flower Arranging
Activities: Cooking

Making Lasagna!

Activities: Cooking

Setting the Table

Fishing!

Catching Tilapia in the Fish Pond
Activities: Las Vegas

Simulated slot machines, Roulette, Craps Table, Black Jack, Poker

Social Stimulation

Intergenerational Program/ Visitors

Socialization: Fun Outings!

Making friends!
Food Oriented Outings

Hale ʻia ʻAʻaha
Pizza Party! Zippy’s! Candy Store!

Clubs & Ceremonies

Maululani
Monthly Veterans Club
NOVEMBER 11
Recognizing our Veterans with Plaques and Awards

Traditions

Tea Cookie and Tea, please!
Behavioral Management Techniques

9 studies (7 RCT)

- Training on Dementia Approach
  - Communication Skills (3)
  - General Training (2)
  - Training in Bathing (2)
  - Dementia Care Mapping (2)
- Training with Supervision/Support

Training is NOT effective without supervision!

Training Paid Caregivers

- Short Term Effect: -1.5 to -1.3
- Long Term Effect (8 weeks to 6 months): -1.5 to -1.3

Examples:

- Training plus 2 site visits and telephone-based supervision
- Communication skills training with ongoing support
- Communication and behavior management skills training plus training of managers to provide supervision
- Training in person-centered bathing with support implementing
- Training including staff instruction cards and ongoing support
- Dementia Care Mapping plus implementation support
Hand-in-Hand Toolkit (CMS)

http://www.cms-handinhandtoolkit.info/

Teaching caregivers to understand each person and their changing abilities (GEMS)
Teaching communication skills and positive approach for dementia caregiving
Practical strategies for modifying the environment

Positive Approach to Care
(Teepa Snow, OTR)

Teaching caregivers to understand each person and their changing abilities (GEMS)
Teaching communication skills and positive approach for dementia caregiving
Practical strategies for modifying the environment

Dementia Care Mapping (DCM)

- Developed in the UK
- An observational tool that looks at the care of people with Dementia from the viewpoint of the person with Dementia.
  - Continuous observation over a 6-h period (5 min intervals) by 1-2 trained mappers
  - Behavior Category Code
  - Working/Not Working tool
  - Find out what works
  - What doesn’t work
  - How does he/she communicate certain needs? (bathroom, thirst, etc)
  - These results can assist with the development of person-centered care. Create a one-page summary for caregivers

http://www.teepasnow.com/about.html

http://www.helensandersonassociates.co.uk/media/38803/usingpcttoimplementdementiacaremapping.pdf
Another Example: ABC Log

needs more evidence...

BEHAVIORAL ACTIVATION
INDIVIDUALIZED MUSIC INTERVENTION
PET THERAPY
EXERCISE
Behavioral Activation (for Dementia)

- For the Treatment of Depression
  - (Note: many behavior problems are due to depression and improve with antidepressants)
  - Participate in **personally important** goals
  - Participate in activities that enhance the mood
  - Track activities and mood/PHQ-9/ and target symptoms/behaviors

Behavioral Activation
for Depression Treatment

“Outside in” approach that focuses on engaging the resident in behaviors that improve mood and counter depressive tendencies to isolate and be inactive.

“Textbook” BA: resident records activity and mood, and to engage in analysis with a therapist of their situation and lifestyle.

In LTC, BA may be adapted to an even more behaviorally focused program than “textbook” BA.

Staff may provide important input to identify pleasurable activities for the resident (as opposed to relying on the resident)—based on who they are. (like DCM)

No large studies in the nursing home setting.

Behavioral Activation Steps

1. Review PHQ-9 and/or behaviors
2. Help resident identify pleasurable activities
   a. Physical activity
   b. Social Interaction
   c. Pleasant events
3. Help resident choose
4. Schedule a daily pleasant activity
   Also identify potential barriers (feasibility, realistic activities)
5. Help resident mentally rehearse the selected activity (before activity)
6. Mark off that Activity was done, and reinforce the “fun” that they had afterwards
PIE Outcomes

**Improvement in Depressive Symptom (PHQ-9) scores**

- **Music Therapy with no protocol**
  - 11 studies
  - Small participant numbers (n=5-45)
  - Lower quality studies
  - Mixed results

**EXAMPLES**
- Preferred music tape
- Preferred music played while bathing
- Individualized music on cassette 2x per week for 6 weeks
- 10-15 min of preferred music/calming music played while agitated
- Soothing music/sounds played at lunchtime
- Family CG played preferred music prior to peak agitation 2x per week for 2 weeks
- Music played on CD every day x 2 months

- 11 studies
- Small participant numbers
- Lower quality studies
- Mixed results

Short-term:
- Significant improvement in 6 studies
- Non-significant in 4 studies
- Significant worsening in 1 study (nature sounds)

No long-term outcomes reported

**Improvement in medication use**

N=66

- Significant improvement in 6 studies
- Non-significant in 4 studies
- Significant worsening in 1 study (nature sounds)

No long-term outcomes reported
iPod Music & Memory Program

Widely publicized
- Alzheimer’s Association, NPR, NYT, CNN, etc
- “Alive Inside” Documentary (Dan Cohen)

- Personalized music playlists
- Musical favorites tap deep memories bring residents and clients back to life
- Best used during Transitions.

The intervention involves carefully selected music, based on the person’s preference, prior to the onset of cognitive impairment.
Assessment of Personal Musical Preference (L Gerdner)
Anecdotal notes and qualitative interviews also indicate that individualized music promotes positive affect, expressed satisfaction, and meaningful interaction with others; thereby supporting personhood
Better than just “relaxing music”

Individualized Music Intervention

Assessment of Personal Music Preference
Individualized Music

Maunalani Nursing & Rehabilitation Center

Enjoying the Everly Brothers

Animal Assisted Therapy (Pet Therapy)

Hale Ho Aloha

Zyprexa the Guinea Pig

Pet Therapy

10 studies, no RCT, small studies
3 case controls, and 7 repeated measures

Included:
• Animal Assisted Therapy
• Plush Toy
• Robotic animal

AAT may have positive influences on patients with dementia by reducing the degree of agitation and improving the quality of social interaction—BUT more studies are recommended.

SENATOR ON-TOP
The Eden Alternative

Pets, Plants, and Children
- Caring for nature and other beings promotes harmony and wellness for the entire community.
- Addresses the "three plagues": loneliness, helplessness, and boredom
- There are few studies examining the Eden Alternative model

Plants, Pets, Children

Walking Garden

Exercise

<table>
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<th>HTA REVIEW</th>
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<tr>
<td>4 studies</td>
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<tr>
<td>Lower quality studies</td>
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<tr>
<td>Examples</td>
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<tr>
<td>Exercise group</td>
</tr>
<tr>
<td>Walking group</td>
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<tr>
<td>Exercise session with music</td>
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<tr>
<td>Significant improvement in 1 study - the largest study with n=112 (less aggression on walking group days)</td>
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<tr>
<td>NS in 3 other studies</td>
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<td>No long-term outcomes</td>
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<tr>
<th>VA REVIEW</th>
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<tbody>
<tr>
<td>Small studies</td>
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<tr>
<td>No rigorous methodology</td>
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| The most consistent evidence showed that exercise did increase sleep duration and decrease nighttime awakenings.
Exercise

Daily Morning Exercises

Manoa Cottage Kaimuki

S-T-R-E-T-C-H !!!

Exercise and Wandering

Masking exits
- Visual barriers, camouflage of doors/knobs

Wander garden/path

VA review:
- 2 RCT showed exercise and walking therapy had no impact on wandering.
- No studies on efficacy of wander gardens

Other Exercise Ideas

Wii games:
- Wii Fit: strength training, aerobics, balance
- Wii Sports: Bowling, Boxing

Tai Chi
Validation Therapy

Encouraging and validating expressions of feeling rather than marginalized or dismissed.
They are acknowledged, respected, heard (regardless whether or not the listener actually agrees with the content)
Treated with genuine respect

VA review
- 3 RCT, mixed results.
- Insufficient evidence for efficacy

Reminiscence Therapy

The use of life histories - written, oral, or both to improve psychological well-being.

- Play songs from the 1930s and talk about favorites
- Show photographs and tell stories- school days, carnival, children, pets, sports.
- Reminiscence box (with familiar items of younger years)
- Shadowbox cards (with conversation starters)

Reminiscence Therapy

Cochrane Database of Systematic Reviews 20 April 2005
- Four trials with a total of 144 participants had extractable data
- Significant for cognition and mood (at follow-up) and on a measure of general behavioral function (at the end of the intervention period) vs. no treatment and social contact control
- Need for more robust studies

- Significant decrease in caregiver strain
- Staff knowledge of group members' backgrounds improved significantly
- No harmful effects
Getting to know all about you!

Maunalani Nursing & Rehabilitation Center

You are important!

We Honor You!

What doesn't work

Bright Light Therapy
Aromatherapy
Home-like Care
Caregivers & Providers
don’t have to do it on their own

- Alzheimer’s Association
- Hawaii Memory Care Navigators
- Case Management
- Adult Day Care Centers
- Respite Care
- Care Homes
- Nursing Homes

Community Resources
Alzheimer’s Association –Aloha
Chapter
- www.alz.org/hawaii/
- Tel: 591-2771

Elderly Affairs Division
- www.elderlyaffairs.com
- Tel: 768-7700

Hawaii Memory Care Navigators
- Tel: 956-8340

Other Communication and Behavior Resources
Alzheimer’s Association (activity ideas)

NIA

Electronic Dementia Guide for Excellence (EDGE) Project
What are your ideas for Mr. Sato?

- I can't find that tool I need to fix the dresser.
- I can't find that tool I need to fix the dresser.
- Everyone is busy and the kids are yelling again. Why can't they just shut up!
- I need a peaceful quiet.
- I already took a bath! Don't tell me what to do! And I don't need your help!
- I need meaningful work.
- I need some autonomy.

Remember...

A person with dementia lives from moment to moment...

Focus your energies on

Creating Moments of JOY

-- Jolene Bracey

Become "Best Friends"

- Validates feelings
- Reassure
- Listen
- Show affection
- Asks for permission
- Encourage
- Give compliments
- Are equals - help each other "save face"
Become “Best Friends”

- KNOW EACH OTHER - REMinisce
- DO FUN THINGS TOGETHER
- ENJOY SIMPLE THINGS TOGETHER
- CELEBRATE SPECIAL OCCASIONS TOGETHER
- TELL FUNNY STORIES OFTEN
- LAUGH TOGETHER

... Honor the Spirit Within