A Holistic Approach to Non-Pharmacological Management of Dementia

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Blue Ridge PACE

Blue Ridge PACE opened in March of 2014 in Charlottesville, Virginia. Our service area covers 5+ counties and is a mix of very rural, suburban, and urban areas. Currently, we have a census of 77 with an expected max enrollment of 175 participants.
Goals

• Identify strategies to increase engagement in ADLs and stimulating activities and decrease negative behaviors in participants with dementia.

• Understand environmental impacts on behavior and identify budget-friendly ways to modify your environment to increase engagement and decrease agitation.

• Identify testing resources used to monitor and document behaviors in participants with limited communication related to dementia.

• Determine opportunities and barriers to starting a dementia-management program at your PACE center.
Why did we decide that we needed a dementia management program?
1. Needs analysis: Could we reasonably expect that we would continue to enroll a substantial number of participants with dementia?

- Statistics indicate that the percentage of PACE participants with dementia will increase, due to an overall increase in dementia in the general population.
  - Starting at age 65, the risk of developing the disease doubles every five years.
  - By age 85 years and older, between 25 and 50 percent of people will exhibit signs of Alzheimer’s disease.
  - Up to 5.3 million Americans currently have Alzheimer’s disease. By 2050, the number is expected to more than double due to the aging of the population (Centers for Disease Control).
2. Utilization analysis: Is there a correlation between dementia and nursing home placement?

- Approximately 70% of persons with dementia die in nursing homes.

- The cost of nursing home care has increased more than 4% a year over the last decade to a median annual cost of $83,950. (Mitchell SL et al A national study of the location of death for older persons with dementia. *J Am Geriatr Soc.* 2005;53(2):299-305.)
3. From a caregiver perspective:

Caregivers for persons with dementia often bear a heavier burden as compared to other caregivers. In fact, 25% of these caregivers provide at least 40 hours a week of care for their loved one (Alzheimer’s Association & National Alliance for Caregiving, 2004).
4. From a facility standpoint:

- Participants with dementia were not able to participate fully in the activities offered in the day center.
- Large group activities were increasing behaviors such as agitation, aggression, wandering. Other participants were distracted by these behaviors.
- Participants with dementia were resistant to personal care attempts from our Universal Care Partners (UCP’s).
- Family caregivers were reaching out to us reporting significant stress and difficulty with providing care at home.
The evidence indicated that providing specialized and holistic care to our dementia participants made sense from a medical perspective, from a quality of life perspective, from a caregiver perspective, and from a utilization perspective.

Win-win!
Target Population

• Focus today on participants with moderate to severe dementia
  • GDS levels 6-7 (maybe 5)
  • Allen Cognitive Levels 1-2 (maybe 3)
  • We do not expect to improve cognition. We can however improve performance by modifying the environment and the task.
  • We no longer use Reality Orientation for this population. We use Validation Therapy.

• Resources for understanding dementia
  • teepasnow.com
  • alz.org
  • My Past Is Now My Future: A Practical Guide to Dementia Possible Care by Lanny Butler and Kari Brizendine
Why Non-Pharmacological

• Negative behaviors are common in persons with dementia including agitation, aggression, repetitive behaviors/vocalizations, wandering, and apathy. These behaviors increase caregiver burden and stress, levels of depression and anxiety in pts. and caregivers, and can lead to caregiver burnout, institutionalization, and increased health care cost.

• Research suggests that these behaviors are often better managed with non-pharmacological interventions as opposed to medications

• Medications pose increased risk for falls, medical complications, lethargy, increased confusion, and even death....

• Some medications are now considered restraints.

Gitlin & Vause Earland, 2010
Program Expectations

• We hope to see
  • Decreased agitation
  • Decreased apathy
  • Decreased caregiver strain
  • Increased participation in activities
  • Increased engagement with the environment
  • Increased socialization
  • Increased ability to adhere to daily routines
  • Positive impact on medication needs

• **Increased quality of life for participants and caregivers**
We determined that our program should be multi-faceted, and should include the following:

• The Dogwood Program- to address the needs of our participants while they are at the Day Center
• Home visits to address home safety and caregiver training
• Additional caregiver training and support provided at the PACE Center
• Staff training
Activities
Why

• Engaging in meaningful and interesting activities
  • Decreases agitation
  • Decreases fall risk
  • Improves quality of life
  • Improves interaction with others and the environment
  • Provides cognitive stimulation
  • Helps maintain/slow regression of functional abilities
  • Keeps participants awake – improves sleep/wake cycle
  • Decreases caregiver stress and burden
  • Decreases need for pharmacology
    (Gitlin & Vause Earland, 2010; Letts, et al. 2011; Padilla, 2011)
How to Choose the “Right” Activity

• Understand your participants
  • What do they like now? What do they dislike?
  • What did they like before their dementia?
  • What are they able to do now physically and cognitively?
  • What was their profession? Hobbies?
  • What are their sensory preferences?

• Can you tap into past roles of each of the participants.
  • Examples: a mechanic may enjoy fiddling with nuts and bolts, a farmer may enjoy helping with potted plants, the family cook/chef may enjoy supervising during meal prep or helping with simple tasks like stirring, etc.
How to Choose the “Right” Activity

• “Failure Free” Activities / “The Just Right Challenge”
  • Activities should provide some challenge so that participants are interested in what they’re doing and feel successful when they accomplish the task.
  • Activities should not be so challenging as to make the participant frustrated, feel like a failure, or quit without even trying.

• Consider how you can adapt familiar and motivating activities to match a person’s abilities

(Sheridan, 1997)
How to adapt an activity

• Change the way it’s presented: e.g. give only one item at a time instead of all the materials at once. Give one simple direction at a time.
• Change the environment: Minimize other distractions. Is there a better place to complete the task?
• Change positioning of the ptcp. Change your positioning
• Forwards or Backwards chaining
• Find an easier version of the same/similar task (think 24 pc puzzle, not 1000; rolling yarn into a ball instead of crocheting, baking cookies from a mix or refrigerated dough instead of from scratch)
• Provide better cues (more to come on this…)
• If all else fails, try again later or nix it altogether. Be flexible!

(Padilla, 2011)
How to Choose the “Right” Activity

• Look at the difference between a 24 piece board puzzle and a 1000 piece jigsaw puzzle!
Why Sensory Activities

- Participants in later stages of dementia experience their world through their senses.

- This means they avoid the noxious stimulus and seek the pleasant ones.

- What this looks like: They may carry their shoe around because their foot hurts. They may not eat because the food has no taste. They will enjoy exploring different kinds of interesting and pleasant sensations. They can easily become overstimulated by too much sensory input!

- Examples of sensory exploration: aromatherapy, baking cookies, exploring different textures and manipulatives, listening to music or nature sounds, “heavy work” or weighted objects, hand massage, fiber optics.

- For more info: Snoezelen
Therapy for the Senses
How to Choose the “Right” Activity

• Examples:
  • Gross motor activities: e.g. ball toss, golf, corn hole, balloon toss, general exercises and stretches, dance, etc.
  • Fine motor activities: nuts ‘n bolts, knitting, sorting/folding, activity apron/pillow
  • Games and puzzles: remember you can always change the rules. It’s not important that they play the game correctly, but that they engage and enjoy what they’re doing.
  • Reminiscing: don’t get bogged down trying to get participants to remember specific names or events. Try to elicit some sort of memory or conversation.
Examples of Activities at BR PACE

Puzzles
Music – favorite Pandora stations: Ray Charles, Big Band, Country Gospel Hymns, Blue Grass
Aromatherapy (Recommend lavender or chamomile for calming, orange for appetite stimulant)
Balls/Balloons/Bowling
Pool Noodles with Balloon toss
Sorting or stacking: towels, cards, shapes, blocks
Magazines, Catalogues, Books
Singing, Dancing
Coloring/Painting
Sanding block
Nuts ‘n Bolts
Manipulatives/Sensory Exploration (sand, putty, rain stick, activity apron, fabric swatches)
Cooking
Baby dolls
Pet therapy
Gardening/watering plants
Kinetic sand - $42.99 from ssww.com

Green Gel sensory maze $38.99 from ssww.com

Sensory Bead balls 15.99 from ssww.com

Soothing pat mat: 19.99 from ssww.com

Rain maker: 12.49 from ssww.com

Activity apron: $37.99 from ssww.com

Sensory soother ball: $12.99 from ssww.com
ENVIRONMENT
Environments we need to consider

• PACE Center
  • Entrance
  • Bathrooms
  • Dining Areas
  • Main Dayrooms/Memory Care Room

• Home
• Transportation
• Community
Environment

• What do you need to consider in each environment?
  • Sights including lighting
  • Sounds
  • Smells
  • Comfort
  • Safety
  • How to get in and get out of the space
  • Need for transitions

(Gitlin, et al., 2003)
Environment - Visual

- The room should be well lit for safety
- Try to avoid harsh fluorescent lighting and too much overhead lighting which can cause glare
- Try using task lights or natural light
- Create an environment that is visually interesting without being over stimulating
- Use contrasting colors (e.g. chairs should be different color than the floor, plates different color than the table, etc.)
- Don’t place items too high. The visual field in persons with dementia tends to be central and downward.
Environment – Olfactory and Auditory

• What do you smell in the environment?
  • Aromatherapy with lavender has been shown to decrease agitation in people with dementia – Aroma-acupressure was even more effective! (Yang, et al., 2015)
  • Are there smells to increase appetite? Orange? Baking Bread? Or to calm like lavender?
  • The sense of smell is often diminished in later stages of dementia. (Peabody, 2015)

• What do you hear?
  • People with dementia have a hard time filtering out extra noise. You may not notice the sound of the kitchen, hallway chatter, and the overhead lights, but your participants will!
  • Play music or sounds that are appropriate to the mood you want to set
  • *Keep the overall noise level low – it’s very easy to get overstimulated*
    
    (Gitlin, et al., 2003)
Environment - Transitions

- Transitions can be particularly challenging
- Consider how you can eliminate the need for some transitions
- Prepare participants when they do need to transition
- Keep a consistent routine. They will do better over time.
Environmental Safety

- Create a safe space for mobility
  - Clear walkways
  - No trip hazards (throw rugs, cords, clutter, bulky or extra furniture, etc.)
- Expect participants to be nosy! Have drawers or cabinets set up for them to safely explore. Have dangerous items locked away.
- Good lighting
  - Place nightlights in bathrooms and hallways within the home
  - Try to decrease glare, but maximize lighting by using task and natural light
- Bathroom safety equipment – only works if it makes sense to them
- Bed/chair/door alarms
- Disguise exits, but cautiously – remember your fire codes
  - This could include disguising the door, the handle, or using a black mat on the floor by the exit. Other ideas?

LOW TECH – LOW COST (i.e. free)! *Mostly* effective.
Exit doors at Riverside PACE in Hampton, Va
General Safety

• OT Home safety assessments are completed upon enrolling to PACE. These can be performed again as the person or environment changes.
• Lock up medications
• Lock up hazardous items (examples: knives, guns, cleaning products)
• Unplug the stove or use stove safety knobs covers
• Set the hot water heater to no higher than 120° as the person may not feel temperature very well and could burn themselves
• As noted above – keep the space well lit and clutter free

(Home Safety and Alzheimer’s, 2015)
Blue Ridge PACE

• Dogwood
  • The room is separate, “cozy” and calming
  • Sound panels dampen sound
  • Lighting has been adjusted to be less glaring with more natural light
  • Exit door is disguised
  • Artwork is simple with vibrant contrasting colors
  • Bathroom is signed, toilet has black seat, mirror is covered
  • There is a safe pathway for wandering
The room allows for group and individual activities, which are set up all over the room. Activities set up this day are: sorting activities, music playing, aromatherapy, sensory items out for exploration, sanding blocks, building blocks, magazines and books available. There is ample room for wandering safely.

Participants eat in this room, generally together but separated if needed/desired. The bathroom is also here. Both allow for easier transitions throughout the day. Furniture moves to meet the needs of the day and activities are varied to maximize engagement.
Bathroom door is signed. Toilet has black seat. Mirror is covered with white paper.
Blue Ridge PACE

• Schedule
  • We attempted to eliminate as many transitions as possible
  • The schedule remains the same each day (routine!) but flexible at the same time
  • As we’ve grown and expanded our hours open, it generally takes about 2 weeks for participants to adapt to a change in routine
  • Transitions story: AM
BR PACE

• Schedule
  • 10:30 – Transition to Dogwood. Toileting. Hydration.
  • 11:00 – 11:59 – 2-3 activities
  • 11:59 – Transition for lunch
  • 12:00 – 1:00 – lunch, quiet activities
  • 1:00 – 2:30 – group or individual activities, toileting, rest if needed
  • 2:30 – Snack
  • 3:00 – Transition back to the Dayroom

• Most participants arrive and leave the center within these times. This decreases the need to transition out of the Dogwood room and maximizes numbers from a staffing perspective.
WANDERING AND SAFE MOBILITY
Wandering

• Consider if they are wandering for a reason. Are they hungry, in pain, bored, overstimulated, do they need to use the bathroom?

• Consider when alarms are necessary to alert you when the person is wandering – this could be a chair alarm for when they stand up, a bed alarm for when they get up at night, or door alarms for when they leave the house. Is an alarm helpful or will it lead to agitation?

• Provide a safe environment for wandering

• Set up things to do along their wandering path

• Place door locks out of sight or up high so the person can’t get to them

• Project Lifesaver – available across the country [http://www.projectlifesaver.org/](http://www.projectlifesaver.org/)

  “The primary mission of Project Lifesaver is to provide timely response to save lives and reduce potential injury for adults and children who wander due to Alzheimer’s, autism, and other related conditions or disorders.”

(Peabody, 2015)
Mobility

• If someone’s gait is unsteady, have them see the PT/OT as early as possible for evaluation of safe mobility.
  • A person with dementia is very unlikely to learn how to use a new mobility device later than GDS stage 4. In other words, a person with moderate to severe dementia will not learn to use a walker if they didn’t use one previously.

• Safety and immobility vs. Mobility and independence
  • How do you find the right balance?

• Benefits of maintaining mobility: cardiovascular and musculoskeletal fitness, pulmonary hygiene, functional independence/participation, quality of life, skin integrity, maintaining ROM, minimizing agitation
Mobility - falls

• “Patients with dementia fall twice as often as elderly cognitively intact people and are at greater risk of injurious falls. Falls in older people with dementia cause higher rates of morbidity, mortality and institutionalization.” (Aizen, E., 2015)

• The one year mortality rate following hip fracture is reported to be between 12-37% with an estimated cost between “10.3 to 15.2 billion dollars per year in the United States” (Kiel, 2015)

• Typical fall prevention strategies may be less effective with this population – so what do we do?
Mobility - falls

• Strategies to decrease fall risk
  • Close supervision for all mobility
  • Allow for safe wandering
  • Ensure a safe environment
  • Look for nonverbal communication and address any needs before they become a problem
  • Provide caregiver training for how to assist with mobility. Remember the person with dementia won’t learn safety strategies.
  • EXERCISE! Regular exercise reduces fall risk in this population (Aizen, 2015)
  • ACTIVE ENGAGEMENT IN MEANINGFUL ACTIVITIES (Peabody, 2015)
ACTIVITIES OF DAILY LIVING
ADLs

• Strategies to maximize participation
  • Minimize distractions
    • Only have items out they will use at that time. Put everything else out of sight.
  • Provide clear and concise 1-step directions
  • Provide limited help first, then more assistance as needed
  • Keep a consistent routine
  • Be prepared before you start a task so as to minimize downtime
  • Do things “My Way”
  • Complete ADLs when the person is more alert (e.g. can they shower/dress after breakfast?)
Cuing for success

• Initiation and sequencing are often impaired with dementia
• Procedural memory tends to stick around longer than other forms of memory – so this is what you tap in to.
• To preserve and encourage function for as long as possible, it is important to
  1) set up the environment for success
  2) match the activity to the person’s abilities
  3) provide the right amount of cuing

Gitlin & Vause Earland, 2010
Cuing for success

• Start first with a verbal cue – it should be clear and concise. No more than 1 or 2 steps.
• If that doesn’t work, add a visual cue – this might include you pointing to the object they’re supposed to use or providing a visual demonstration for them
• If that doesn’t work, add a tactile cue – Hand-over-hand cuing can help tap into that procedural memory and assist them with initiation
• Don’t provide unnecessary cues
• **Give the person long enough to process the instructions**

Gitlin & Vause Earland, 2010
ADLs “My Way”

• Set up the task as the person would normally do it (Butler & Brizendine, 2005)
Toileting

• Why is this so important?
  • Dementia doesn’t cause incontinence until the very latest stages
  • It is so much more time consuming to change and launder someone’s clothes than to take them to the bathroom
  • Having to go contributes to agitation
  • Skin care and hygiene
  • Dignity and quality of life!

• If dementia doesn’t cause incontinence, then why are so many participants having problems with this?
  • They may lose the initiative to get up and go to the bathroom
  • They often don’t know where the bathroom is
  • They may struggle with the physical aspect of toileting
Toileting

• Strategies to improve independence
  • Place signs indicating where the bathroom is (even in the home)
  • Black toilet seats for visual contrast
  • Create an individualized schedule for each person and stick to it
  • Look for nonverbal cues indicating a need to go
  • When on the commode, give them at least 90 seconds to try
  • Help them to the sink afterward to wash hands. Many people will wash their own hands when in front of a sink. If they don’t start, place their hands in the water with soap to encourage them.

(Butler & Brizendine, 2005)
Toileting

• Voiding schedules
  • Often every 2-3 hours is sufficient and/or about 1 hour after mealtime.
  • Individualized is best.
  • Schedules aren’t appropriate for everyone.
  • Requires documentation, training, and staff adherence. *It is not effective if everyone doesn’t follow through.*
Showering

• Shower when the person is more alert

• Set up everything needed before starting so the person doesn’t have to wait or you have to leave in the middle of the shower to retrieve an item

• Keep the space warm

• Use familiar products – Shower “my way”

• Use bathroom safety equipment when needed (see your OT for help with this!)
Dressing

• Use easy on/easy off clothing
• Use familiar clothing – if they always dressed in a skirt and blouse or dress slacks and button-up shirt, let them keep wearing these types of clothing as they’ll be more comfortable
• Label drawers with items inside. Use pictures instead of words.
• If they insist on wearing only one type of clothing, don’t fight it. Buy multiples.
• Give them a choice when they are still able to make simple decisions (example: do you want to wear this blue shirt or this red shirt?)
• Set them up with one item at a time. Or set their clothes up Left to Right. Or top to bottom. Only help when needed.
• Dress in layers. Many people lose the ability to keep their bodies warm, so an extra sweater is often necessary.

(Butler & Brizendine, 2005)
Brushing Teeth

• Brushing teeth
  • Set them up with minimal distractions, provide minimal cuing then increase assistance as needed.
  • If they’re resistant, you could try distracting them by having them wash their hands at the sink while you brush. If they continue to resist, try again when they’re calm.
  • Keep regular dentist visits.
  • Talk with the dentist about strategies to help and to see if there are any special toothpastes or treatments you should use.
  • An electric toothbrush may help – it also may bother them! Worth a try.

• Keep an eye out for pain in the mouth or poor fitting dentures – this will lead to not eating!
Self-feeding

• Try using a plate with a color that contrasts with the food (example: Mashed potatoes and chicken will blend in when served on a white plate but will stand out on a blue plate)
• Highly seasoned and/or sweet foods may be more appealing
• Finger foods may be easier for independent self-feeding
• Remove any unnecessary items from the table
• Have the food already cut up
• Minimize distractions – TV and radio off
• Fiesta ware – Turquoise from Direct Supply $88.99 for 12 dinner plates

• Eatwellset.com
Mealtime Success

• Observations in Dogwood
  • Increased independence with self-feeding and utensil use
  • Increased intake overall
  • Increased variety of foods consumed
  • Able to eat with peers instead of needing to be isolated

• Key staff training points
  • Don’t put participants at the lunch table early. They won’t wait patiently.
  • Manners are no longer important
  • Dessert can be eaten first. Chocolate sauce can be put on anything.
  • Be flexible about where (and when) participants want to eat.
  • Expect mealtime to take a long time
  • Cue the right way – refocus and redirect participants before jumping in and feeding them
  • If intake is low, try providing smaller portions with increased frequency or one part of the meal at a time.
Swallow function related to dementia

• Maintaining adequate P.O. intake can be a challenge due to dysphagia, poor attention, executive function, and the ability to self feed.

• Decreased intake can lead to...
  • Malnutrition
  • Dehydration
  • Impaired skin integrity
• It is estimated that 45% of institutionalized dementia patients have dysphagia.
  
  • Easterling CS¹, Robbins E. (2008).
Stages of Swallowing

• Oral Prep:
  • Cognitive awareness of meal – visual, olfactory, gustatory
    • Initiation of meal / self feeding
  • Increased salivation

• Oral Phase:
  • Mastication
  • Bolus formation
  • Oral transit

• Pharyngeal Phase:
  • Involuntary - pharyngeal constriction, airway protection, peristalsis
Dementia Dysphagia and Aspiration Pneumonia

• In the LTC setting, aspiration pneumonia is the second most common cause of infection, hospital transfer, and mortality.
  • Oh E, Weintraub N, Dhanani S. 2005

• Prevention:
  • Proper Diet Consistencies
  • Setup / Cuing strategies
  • Positioning
  • ORAL HYGIENE
Dentition

• 25% of adults 60 years old and older no longer have any natural teeth
  • Vargas CM, Kramarow EA, Yellowitz JA. 2001

• All or None?
  • “Some” teeth that do not oppose on occlusive plane do not allow effective mastication.
Common Swallowing Issues in Dementia

• Impaired mastication – poorly fitting dentures / edentulous

• Overfilling oral cavity

• Refusing Intake

• Oral hold / Not swallowing
Simple Solutions

• Institute Swallow Screening on semi-annual / annual assessments and PRN with SLP
• Consider cognitive function / level of awareness of PTCP
• Consider the environment – Distractions???
• Initiation / Oral Prep?
  • Aroma therapy?
  • Gustatory Cues?
  • Tactile Cues?
• Task initiation?
• Textures – prolonged chewing leads to distraction / minimized attention to task
• Develop Denture policy for provision, repair, and replacement
• Visual stimulation:
  • does it look good?
  • Too much?
  • Can they see it?
Oral Hygiene

• Importance of oral hygiene -
  • After brushing, plaque begins redeveloping within 30 minutes reaching original concentrations within 24 hours.
    Marsh and Martin, 2009,
    Drinka, 2010

• Bacterial colonies in dental plaque are pathogenic!

• Oral hygiene reduced incidence of nosocomial pneumonia by an average of 40%
  Scannapieco et al., 2003.
These are symptoms of ...

- Falls
- Confusion
- Changes in levels of consciousness
- Muscle weakness
- Fatigue
DEHYDRATION
The battle to prevent dehydration

Dehydration was diagnosed in 6.7% of hospitalized patients age 65 and over, and 1.4% had dehydration as the principal diagnosis.

At risk for dehydration

• Fact: Older adults are at high risk for dehydration due to lack of thirst driven fluid intake

• Conditions that increase risk for dehydration
  • Dementia or cognitive impairment
  • Vomiting / Diarrhea
  • Dependence on staff for eating and drinking
  • Medications that cause dehydration
    • Antihistamines
    • Blood Pressure Medications
    • Chemotherapy
    • Diuretics
    • Laxatives

• Equation for fluid intake:
  • 1500 ml + 15 ml (weight in kg – 20) = daily fluid intake

  • Ex. 1500 ml + 15 ml (92-20) = 2580 ml = 10.9 cups per day (Geriatrics and Aging. 2007;10(9):590-596)
Symptoms of Dehydration

• Change in mental status
• Dry mucous membranes, skin, decreased saliva
• Elevated BUN (Blood Urea Nitrogen)
• Fever or UTI
• Hypotension
• Lightheadedness
• Nausea
Blue Ridge PACE Hydration program

• ID at risk PTCP’s
  • At risk diagnoses
  • Dehydration causing medications
  • Environmental factors

• Measure and document volume of drinking vessels
  • Ease of documentation
  • Staff awareness of intake per PTCP

• Offer fluids throughout the day
  • Unlike LTC / SNF – we do not have the luxury of med-pass fluid intake. We have, at most, 15 hours / week to offer hydration
What’s in a name?

• If all my possessions were taken away from me except one, I would choose to keep the power of communication, for in it I would soon regain all the rest

- Daniel Webster
Breakdown of Speech v Language

• Speech
  • Sound production
  • Usually impaired by dysarthria in this population

• Language
  • Comprehension and Expression of thoughts using speech, sign, picture communication systems
  • Usually impaired following CVA or progression of dementia
• Communication breakdown between care receiver and caregiver significantly contributes to the stress level and burden of caregivers (Small, Gutman, Saskia, & Hillhouse. 2003)
Communication

• Verbal skills: as dementia progresses, receptive and expressive language deteriorates due to deterioration of temporal lobe.
  
  • Clifford (1997)

• By GDS Stage VII, all verbal abilities are lost. Occasionally, automatic speech such as “thank you” or cursing will be produced. This is automatic, not volitional. So...
  
  • Try not to be offended when you get cursed at or someone is rude!

• How can I learn to understand non-verbal communication?
If they can’t speak to you, how do they communicate?

• Nonverbal behaviors
  • Gestures
  • Changes in mood
  • Pacing
  • Facial expressions
  • Fast breathing
  • Spitting, hitting, kicking
  • Nonsensical yelling

• Pay attention! Each person communicates differently.

• When someone is aggressive, they are trying to tell you something!
If they can’t speak to you, how do you know what they understand?

Functional Linguistic Communication Inventory

- Assessment of functional communication
  - Naming
  - Object/ Picture Matching
  - Comprehension of signs
  - Word reading / comprehension
  - Reminiscing
  - Pantomime
Identify what these communication attempts mean.

• Review ptcp’s history
  • Medical diagnoses and history
  • Medications – any recent changes?
  • Recent falls / injury contributing to pain?
  • Change in home environment – Respite at local facility?
  • PACE attendance / length of day
  • Identify Triggers – long periods of minimal stimulation causing agitation?
Track the behavior / communication

• Documenting behaviors, times, triggers and responses to intervention will help with management of these behaviors.
Communication Strategies training study results.

- **eliminate distractions** *
- approach the person slowly and from the front and establish and maintain eye contact
- use short, simple sentences
- speak slowly
- ask one question or give one instruction at a time
- use “yes/no” rather than “open-ended” questions
- repeat messages using the same wording
- paraphrase repeated messages
- avoid interrupting the person and allow plenty of time to respond
- encourage the person to “talk around” or describe the word he or she is searching for
- **Use materials such as books, pictures, magazines, and games, during communication interactions** *
  

- Do not depend on episodic memory – (ability to remember events and specifics about personal history. )
- Use Semantic memory – general fund of world knowledge / Concepts
Allow them to see you prior to Interacting

No Sneaking Up!
Staff interaction

• See – touch – talk
• Do not use a loud voice with participants unless you know they’re hard of hearing.
• Allow them to see you prior to interacting
• Easy and gentle touch on the shoulder may improve the interaction for some – but not for all.
• Speak in a slow, calm voice – loud sounds can be upsetting
• 90 second rule – it can take up to 90 seconds for some people to process what you’ve said and respond. Be slow. Be patient.
Assessments and Outcomes

• How are we doing?

• Subjective improvements ?????

• Must have an objective manner to track progress and changes in PTCP behavior
Assessments

• PAINAD –

• Cohen-Mansfield Agitation Inventory (CMAI)

• Functional Behavior Profile

• Agitated Behavior Scale

• Caregiver Strain Index
PAINAD

• 10 point / 5 item screening tool used to identify pain symptoms through non-verbal signals

Includes descriptors for each item to assist with scoring

http://www.geriatricpain.org/Content/Assessment/Impaired/Pages/PAIDADTool.aspx
## Pain Assessment in Advanced Dementia Scale (PAINAD)

**Instructions:** Observe the patient for five minutes before scoring his or her behaviors. Score the behaviors according to the following chart. Definitions of each item are provided on the following page. The patient can be observed under different conditions (e.g., at rest, during a pleasant activity, during caregiving, after the administration of pain medication).

<table>
<thead>
<tr>
<th>Behavior</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing</td>
<td>Normal</td>
<td>Occasional labored breathing</td>
<td>Short period of hyperventilation</td>
<td>Noisy labored breathing</td>
</tr>
<tr>
<td>Independent of vocalization</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative vocalization</td>
<td>None</td>
<td>Occasional moan or groan</td>
<td>Low-level speech with a negative or disappointing quality</td>
<td>Repeated troubled talking out</td>
</tr>
<tr>
<td>Face expression</td>
<td>Smiling or inexpressive</td>
<td>Sad</td>
<td>Frightened</td>
<td>Prawn</td>
</tr>
<tr>
<td>Body language</td>
<td>Relaxed</td>
<td>Tense</td>
<td>Distressed pacing</td>
<td>Fidgeting</td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to console</td>
<td>Distracted or measured by voice or touch</td>
<td>Unable to console, distract or require</td>
<td></td>
</tr>
</tbody>
</table>

**Scoring:**
The total score ranges from 0-10 points. A possible interpretation of the scores is: 0-2 = mild pain; 3-7 = moderate pain; 7-10 = severe pain. These ranges are based on a standard 0-10 scale of pain, but have not been substantiated in the literature for this tool.

**Sources:**
Cohen-Mansfield Agitation Inventory

- 29 items observation / scoring system for frequency of agitated behavior.

- Rates from “1-Never” to “7-Several times an Hour”
- Categories:
  - Physical/Aggressive
  - Physical/Non-Aggressive
  - Verbal/Aggressive
  - Verbal/Non-Aggressive

- Allows identification and tracking of type of agitation
- Highly Sensitive to changes in behavior
Name:          | Dates: From 2-1-15 To 2-17-15

Cohen-Mansfield Agitation Inventory (CMAI)\(^1\) - Short

**Instructions:** For each of the behaviors below, check the rating that indicates the average frequency of occurrence over the last 2 weeks.

### Physical/Aggressive

<table>
<thead>
<tr>
<th>#</th>
<th>Behaviors</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Hits (including self)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td>Kicking</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>Grabbing onto people</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>Pushing</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>Throwing things</td>
<td>1</td>
</tr>
<tr>
<td>6</td>
<td>Biting</td>
<td>1</td>
</tr>
<tr>
<td>7</td>
<td>Screaming</td>
<td>2</td>
</tr>
<tr>
<td>8</td>
<td>Setting</td>
<td>1</td>
</tr>
<tr>
<td>9</td>
<td>Hurting self or others</td>
<td>1</td>
</tr>
<tr>
<td>10</td>
<td>Throwing things or destroying property</td>
<td>1</td>
</tr>
<tr>
<td>11</td>
<td>Making physical sexual advances</td>
<td>1</td>
</tr>
</tbody>
</table>

### Physical/Non-Aggressive

<table>
<thead>
<tr>
<th>#</th>
<th>Behaviors</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>Pica, aimless wandering</td>
<td>1</td>
</tr>
<tr>
<td>13</td>
<td>Inappropriate dress or grooming</td>
<td>2</td>
</tr>
<tr>
<td>14</td>
<td>Tiring to get to a different place</td>
<td>2</td>
</tr>
<tr>
<td>15</td>
<td>Irritability</td>
<td>2</td>
</tr>
<tr>
<td>16</td>
<td>Eating/drinking inappropriate substances</td>
<td>2</td>
</tr>
<tr>
<td>17</td>
<td>Handing things inappropriately</td>
<td>2</td>
</tr>
<tr>
<td>18</td>
<td>Making physical sexual advances</td>
<td>2</td>
</tr>
<tr>
<td>19</td>
<td>General restlessness</td>
<td>2</td>
</tr>
</tbody>
</table>

### Verbal/Aggressive

<table>
<thead>
<tr>
<th>#</th>
<th>Behaviors</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td>Screaming</td>
<td>1</td>
</tr>
<tr>
<td>23</td>
<td>Making verbal sexual advances</td>
<td>1</td>
</tr>
<tr>
<td>24</td>
<td>Cursing or verbal aggression</td>
<td>1</td>
</tr>
</tbody>
</table>

### Verbal/Non-Aggressive

<table>
<thead>
<tr>
<th>#</th>
<th>Behaviors</th>
<th>Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>25</td>
<td>Repetitive sentences or questions</td>
<td>2</td>
</tr>
<tr>
<td>26</td>
<td>Strange noises (wet or laughter or crying)</td>
<td>2</td>
</tr>
<tr>
<td>27</td>
<td>Complaining</td>
<td>2</td>
</tr>
<tr>
<td>28</td>
<td>Negativism</td>
<td>1</td>
</tr>
<tr>
<td>29</td>
<td>Constant unwarranted request for attention or help</td>
<td>1</td>
</tr>
</tbody>
</table>

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\(^1\) The use of this tool is strictly for clinical assessment and educational purposes only and is restricted from use in any for-profit activities.

Developed by and shared with permission of Interior Health.
Agitated Behavior Scale

• Quick observation document for agitated behavior

• 14 item

• Scale from “1 = absent” to “4 = present to extreme degree”

AGITATED BEHAVIOR SCALE

Patient: A. M.  
Period of Observation: a.m. 2/12/15 to p.m. 2/12/15
Rating/Discl.  

At the end of the observation period indicate whether the behavior described in each item was present and, if so, to what degree: slight, moderate or extreme. Use the following numerical values and criteria for your ratings.

1 = absent: the behavior is not present.
2 = present to a slight degree: the behavior is present but does not prevent the conduct of other, contextually appropriate behavior. (The individual may redirect spontaneously, or the continuation of the agitated behavior does not disrupt appropriate behavior.)
3 = present to a moderate degree: the individual needs to be redirected from an agitated to an appropriate behavior, but benefits from such cueing.
4 = present to an extreme degree: the individual is not able to engage in appropriate behavior due to the interference of the agitated behavior, even when external cueing or redirection is provided.

DO NOT LEAVE BLANKS.

1. Short attention span, easy distractibility, inability to concentrate.  
2. Impulsive, impatient, low tolerance for pain or frustration.  
3. Uncooperative, resistant to care, demanding.  
4. Violent and or threatening violence toward people or property.  
5. Explosive and/or unpredictable anger.  
6. Rocking, rubbing, moaning or other self-stimulating behavior.  
7. Pulling at tubes, restraints, etc.  
8. Wandering from treatment areas.  
9. Restlessness, pacing, excessive movement.  
10. Repetitive behaviors, motor and/or verbal.  
11. Rapid, loud or excessive talking.  
12. Sudden changes of mood.  
13. Easily initiated or excessive crying and/or laughter.  
14. Self-abusiveness, physical and/or verbal.

Total Score: 17

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Functional Behavior Profile

- Details overall capacity of ptcp to engage in tasks, social interactions, and problem solving
- Scale 0 = <1min/ Never to 4 = >25min/Always
- Ideal for mild / moderate dementia

http://www.midss.org/content/functional-behavior-profile-fbp
The Functional Behavior Profile
Baum, C., Edwards, D. & Morrow-Howell, N.
Washington University, St. Louis Mo.

The FBP is designed to obtain from the primary caregiver the overall capacity for their loved one to engage in tasks, social interactions and problem solving. All of the questions relate to how their loved one performs in their daily activities. As a reference, the caregiver should respond based upon the person's behavior during the past week. (It can be administered in interview or self scored format).

My family member:
1. Is able to concentrate on a task for:
   - over 25 min. 5-15 min. 3-5 min. 1-3 min. <1 min.
   - Score

2. Finishes the tasks that have been started.
   - Always Usually Sometimes Rarely Never
   - (100%) (80%) (50%) (20%) (<10%)

3. Performs work that is neat.
   - Always Usually Sometimes Rarely Never
   - (100%) (80%) (50%) (20%) (<10%)

4. Can use tools or instruments in performing tasks (kitchen, hobby, repair).
   - Always Usually Sometimes Rarely Never
   - (100%) (80%) (50%) (20%) (<10%)

5. Can manipulate small items (hand work, buttoning, makeup).
   - Always Usually Sometimes Rarely Never
   - (100%) (80%) (50%) (20%) (<10%)

6. Activities are appropriate to the time of day (sleeps at night, alert during the day).
   - Always Usually Sometimes Rarely Never
   - (100%) (80%) (50%) (20%) (<10%)

7. Performs work that is accomplished within a reasonable time frame.
   - Always Usually Sometimes Rarely Never
   - (100%) (80%) (50%) (20%) (<10%)

8. Makes simple decisions independently like what to wear, what to eat, what to do around the house.
   - Always Usually Sometimes Rarely Never
   - (100%) (80%) (50%) (20%) (<10%)

The FBP is designed to obtain from the primary caregiver the overall capacity for their loved one to engage in tasks, social interactions and problem solving. All of the questions relate to how their loved one performs in their daily activities. As a reference, the caregiver should respond based upon the person's behavior during the past week. (It can be administered in interview or self scored format).

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Caregiver Strain Index

• Extremely valuable information

• Caregivers allow us to continue with home environment instead of LTC placement

• Offers insight into specific needs / concerns of the caregiver
  • Allows Social Work to identify needs to be addressed
The Caregiver Strain Index: I am going to read a list of things that other people have found to be difficult. Would you tell me if any of these apply to you? (Give examples)

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes=1</th>
<th>No=0</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep is disturbed (e.g., because ___ is in and out of bed or wanders around at night)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is confining (e.g., helping restricts free time or cannot go visiting)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been other demands on my time (e.g., from other family members)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been emotional adjustments (e.g., because of severe arguments)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some behavior is upsetting (e.g., because of incontinence; has trouble remembering things; or ___ accuses people of taking things)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is upsetting to find ___ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>There have been work adjustments (e.g., because of having to take time off)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>It is a financial strain</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling completely overwhelmed (e.g., because of worry about ___; concerns about how you will manage)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

TOTAL SCORE: (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)

Additional Testing

• Brief Cognitive Rating Scale (BCRS)
  • [http://www.zarcrom.com/users/alzheimers/4-cp8a.html](http://www.zarcrom.com/users/alzheimers/4-cp8a.html)

• St. Louis University Mental Status Examination (SLUMS)

• Global Deterioration Scale (GDS)
  • [http://geriatrictoolkit.missouri.edu/cog/Global-Deterioration-Scale.pdf](http://geriatrictoolkit.missouri.edu/cog/Global-Deterioration-Scale.pdf)
<table>
<thead>
<tr>
<th>Testing Date</th>
<th>Diagnosis</th>
<th>Caregiver Strain Index</th>
<th>Agitated Behavior Scale</th>
<th>PAINAD</th>
<th>Cohen-Mansfield Agitation Inventory</th>
<th>Functional Behavior Profile</th>
<th>SLUMS</th>
<th>BCRS</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.6.15</td>
<td>13</td>
<td>26/56</td>
<td>4</td>
<td>44/203</td>
<td>3/3/00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.24.15</td>
<td>13</td>
<td>29/56</td>
<td>5</td>
<td>49/203</td>
<td>3/3/00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.29.15</td>
<td>13</td>
<td>33/56</td>
<td>5</td>
<td>68/203</td>
<td>3/3/00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.19.15</td>
<td>7</td>
<td>19/56</td>
<td>1</td>
<td>38/203</td>
<td>18/18/4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.8.15</td>
<td>7</td>
<td>23/56</td>
<td>4</td>
<td>49/203</td>
<td>18/18/4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.6.15</td>
<td>7</td>
<td>33/56</td>
<td>5</td>
<td>68/203</td>
<td>18/18/4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.5.15</td>
<td>7</td>
<td>35/56</td>
<td>3</td>
<td>78/203</td>
<td>16/25/7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.3.15</td>
<td>9</td>
<td>21/56</td>
<td>2</td>
<td>62/203</td>
<td>15/15/2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.17.15</td>
<td>7</td>
<td>22/56</td>
<td>0</td>
<td>36/203</td>
<td>14/18/2</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Outcomes

• How is it going?
  • So far, we have seen:
    • Increased attention to task
    • Increased task performance
    • Increased interaction with environment
    • Increased socialization
    • Decreased wandering
    • Decreased agitation of ptcp’s in main social area
    • Increased PO intake
    • Increased hydration
    • Increased staff satisfaction
Outcomes

• Lucy states her mom's behavior at night is so improved. She isn't banging on the walls, is eating dinner, then laying in the bed watching TV. These are things that she hasn't done in years.
  • 6 months after enrollment

• Increased PO Intake = Weight stabilization
  • Only 1 ptcp with dietary supplement
• 5/7 PTCP’s maintained weight
• 1/7 Has begun trending weight loss (MM)
• 1/7 with significant decline in functional behavior has increased PO intake, self feeding, weight loss stopped with 2 lb. weight gain x1 month
How did we make this happen at Blue Ridge?
• Multi-disciplinary planning committee:
  • Recreation Therapist
  • Day Room Supervisor
    • UCP
    • Chaplain
    • Dietician
  • Facilities Manager
  • Social Workers
    • OT
    • SLP
  • Rep from the local Alzheimer’s Association
Committee meets at least monthly.

Agenda includes:
- current challenges and successes
- staffing
- “wish list” of supplies
- short- and long-term goals for the program.

“to-do” list assigned with completion dates
• Supplies
  • Prioritize items
  • Long-term budgetary planning
  • Explore low or no-cost activities (such as gardening, pet therapy)
• Staffing
  • higher ratios for our Dogwood participants than for our other participants. Managers are willing to help in a pinch
  • Consistency of staff is helpful
Problem list:

• Participants with dementia were not able to participate fully in the activities offered in the day center

• Large group activities were increasing behaviors such as agitation, aggression, wandering

• Participants with dementia were resistant to personal care attempts from UCP’s

• Family caregivers were reporting significant stress and difficulty with providing care at home.
Goals:

• Reduced caregiver stress and burden (PACE caregivers as well as family caregivers)
• Increased engagement with the environment and with ADL tasks
• Decreased anxiety and agitation
• Decreased utilization of hospital and nursing home services
Interventions:

• Dementia training initiated for all new staff (regardless of job title) and yearly re-training for direct care staff

• On the job mentoring provided to all direct care staff by SLP and OT

• UCP’s encouraged to assist with activity planning in the Dogwood Room

• Caregiver education and training was initiated both at the day center and in the home
Frequent Caregiver Concerns

• Inability to efficiently problem solve for loved one’s behavior
• Inability to communicate effectively with family members
• BURNOUT!!!
• Insufficient time to get everything done
• Physical and emotional strain of caring for loved one leading to injury and illness on the part of the caregiver
Caregivers

• One research group provided 6 hours of family training to 72 family caregivers over 3 weeks. Training addressed providing safe and effective assistance for BADLs. Caregivers demo’d improvements in knowledge of all areas of ADLs, communication, and nutrition. (DiZazzo-Miller, et al., 2014)

• Our caregiver training follows a similar practical skills based approach. We offer Lunch and Learn sessions
  • Education on dementia and learning how to effectively communicate
  • How to assist with ADLs
  • How to keep your loved one safe (focus on setting up the environment, keeping them engaged, and safe mobility)

• We also provide individual training within the home as needed
The most important aspect of our caregiver training may be in fostering relationships with each caregiver of a participant with dementia. This includes occasional phone calls, personal invites to caregiver support and training sessions, and encouraging the caregiver to reach out to us when they are having difficulty. This allows emerging problems to be addressed as they arise, and lets the caregiver see PACE as a partner; they’re not in this alone.
Importance of having a “project manager”:

“Of all the things I’ve done, the most vital is coordinating the talents of those who work for us and pointing them towards a certain goal”

-Walt Disney
“Even if you are on the right track, you will get run over of you just sit there”

-Will Rogers
References


References


