

Recognizing Pain in People with Dementia

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PRESIDENT: LIVING WELL WITH
DEMENTIA, LLC

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Objectives:

By the end of this program the participant will be able to:

- Summarize how dementia impacts pain perception and expression
- Identify tools that can be used to assess and document pain in people with dementia
- Utilize professional guidelines for treating pain with nonpharmacological approaches and medication management.

CMS Quality Measures for LTC

Both long term and short stay measures exist for pain

- Percentage who report moderate to severe pain
- The RAI User's Manual instructs the assessor to attempt the patient interviews for pain on all residents who are at least sometimes understood.

Percent of Residents Who Self-Report Moderate to Severe Pain

Residents with a selected target assessment with either/or of these two conditions:

- 1. Report of daily pain with at least 1 episode of moderate/severe pain
- 2. Report of very severe/horrible pain of any frequency

Exclusions

- No pain reported
- One or more items were not completed

Moderate to Severe Pain

Pain is subjective – it is whatever the person says it is and exists whenever he/she says it does*

Pain can cause suffering associated with:

- Inactivity, social withdrawal, depression
- Functional decline, interference with rehab

Most will need regularly dosed pain meds, and some will require additional PRN pain meds for breakthrough pain.

Pain Assessment Interview

J0300. Pain Presence

- Enter Code
- Ask resident: "**Have you had pain or hurting at any time in the last 5 days?**"
0. **No** → Skip to J1100, Shortness of Breath
 1. **Yes** → Continue to J0400, Pain Frequency
 9. **Unable to answer** → Skip to J0800, Indicators of Pain or Possible Pain

J0400. Pain Frequency

- Enter Code
- Ask resident: "**How much of the time have you experienced pain or hurting over the last 5 days?**"
1. **Almost constantly**
 2. **Frequently**
 3. **Occasionally**
 4. **Rarely**
 9. **Unable to answer**

J0500. Pain Effect on Function

- Enter Code
- A.** Ask resident: "**Over the past 5 days, has pain made it hard for you to sleep at night?**"
0. **No**
 1. **Yes**
 9. **Unable to answer**

- Enter Code
- B.** Ask resident: "**Over the past 5 days, have you limited your day-to-day activities because of pain?**"
0. **No**
 1. **Yes**
 9. **Unable to answer**

J0600. Pain Intensity - Administer **ONLY ONE** of the following pain intensity questions (A or B)

- Enter Rating
- A. Numeric Rating Scale (00-10)**
- Ask resident: "**Please rate your worst pain over the last 5 days on a zero to ten scale, with zero being no pain and ten as the worst pain you can imagine.**" (Show resident 00-10 pain scale)
- Enter two-digit response. Enter 99 if unable to answer.**

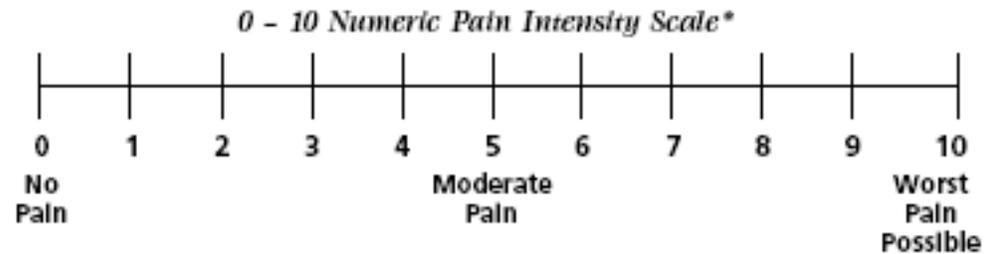
- Enter Code
- B. Verbal Descriptor Scale**
- Ask resident: "**Please rate the intensity of your worst pain over the last 5 days.**" (Show resident verbal scale)
1. **Mild**
 2. **Moderate**
 3. **Severe**
 4. **Very severe, horrible**
 9. **Unable to answer**

MDS Pain Assessment

Assessing Pain

Gold standard for cognitively intact adults

- Numeric Rating Scale



https://www.atrainceu.com/course-module-short-view/2270158-118_oregon-pain-module-07

Assisted Living Facilities

Regulations in 2800.4 Definitions

Specialist Cognitive Support Services

- Pain management and person centered care

What is pain?

Merriam-Webster defined pain as localized physical suffering associated with a noxious stimulus. Also acute mental or emotional distress.

Pain is subjective- exists entirely within that persons lived experience

Cultural- we know that there are cultural factors that impact pain expression and acceptance

Pain- Components

Sensory- Nociceptive

- Caused by activity in neural pathways in response to potentially tissue-damaging stimuli
 - Post-op pain
 - DJD
 - Cuts/Bruises

Sensory- Neuropathic

- Initiated from a primary lesion or dysfunction in the nervous system
 - Stroke
 - Neuropathy from DM
 - CRPS

Psychological (Hansen, 2005)

- Limbic system translates sensory signals into “feeling”
 - Attention
 - Anxiety
 - Memory/Learned pain
 - Coping

Pain- Components

Sensory- Nociceptive

- Localized
- Aching
- Annoying
- Throbbing

Sensory- Neuropathic

- Burning
- Electric
- Tingling
- Shooting/Stabbing

Pain in Cognitively Intact Older Adults

Considered to be under-recognized and underreported in older adults (BGS, 2007)

Over 50% of older adults report pain (BGS, 2007)

- As many as 83% of those in SNF report at least one current pain problem

Healthcare professionals consistently tend to underestimate pain compared to patients. (Seers, 2018)

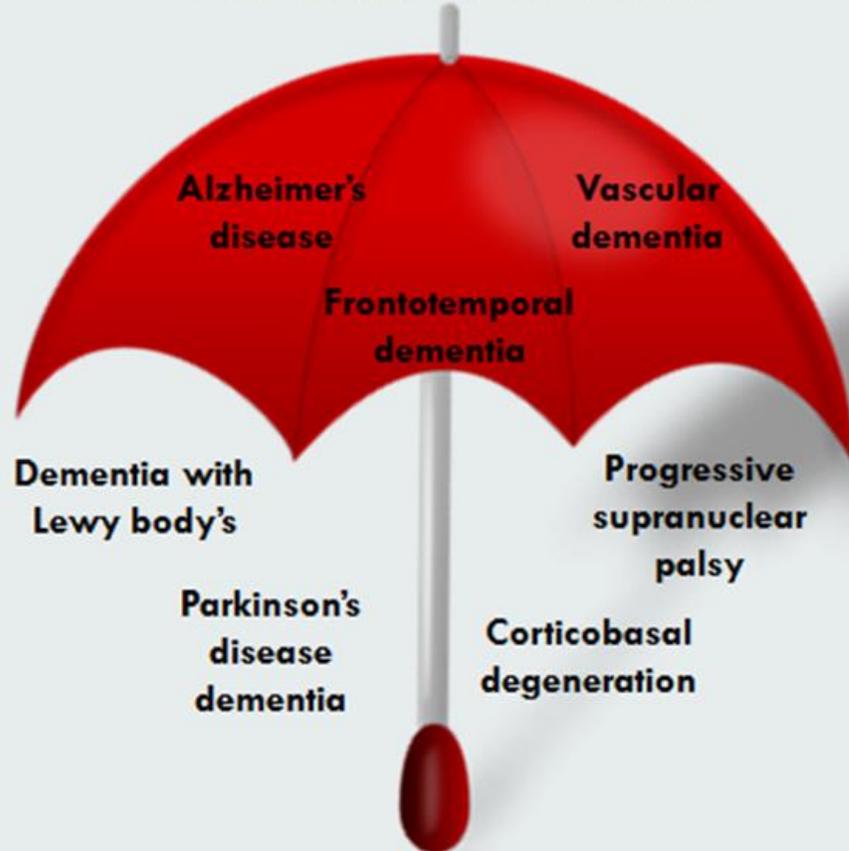
Pain for People With Dementia

Systematic Review of pain in people with dementia, estimates 46-56% of people with dementia have pain (van Kooten, 2016)

Widely accepted that people with dementia are under-recognized and under-treated for pain.

- Systematic Review of people with hip and pelvic fracture found 50% less use of medication for people with dementia than cognitively intact older adults (Moschinski, 2017)
- Systematic Review found people with dementia had worse oral health but were recognized as having oral pain less than cognitively intact older adults (Delwel, 2017)
 - Cohen Mansfield (2005) found 60% of people with dementia were identified as likely having oral pain by dentist assessment
- Systematic Review found nursing home residents with dementia are given less pain medication despite similar number of conditions. (Tan, 2015)

DEMENTIA: An umbrella term



Dementia Types

Cluster of symptoms that may include...

- Decline in memory
- Loss of thinking skills
- Disorientation to oneself, time, place
- Impaired judgment
- Impaired problem solving
- severe enough to limit their everyday activities

BUT:

- Different types represent different brain changes
- All people are unique

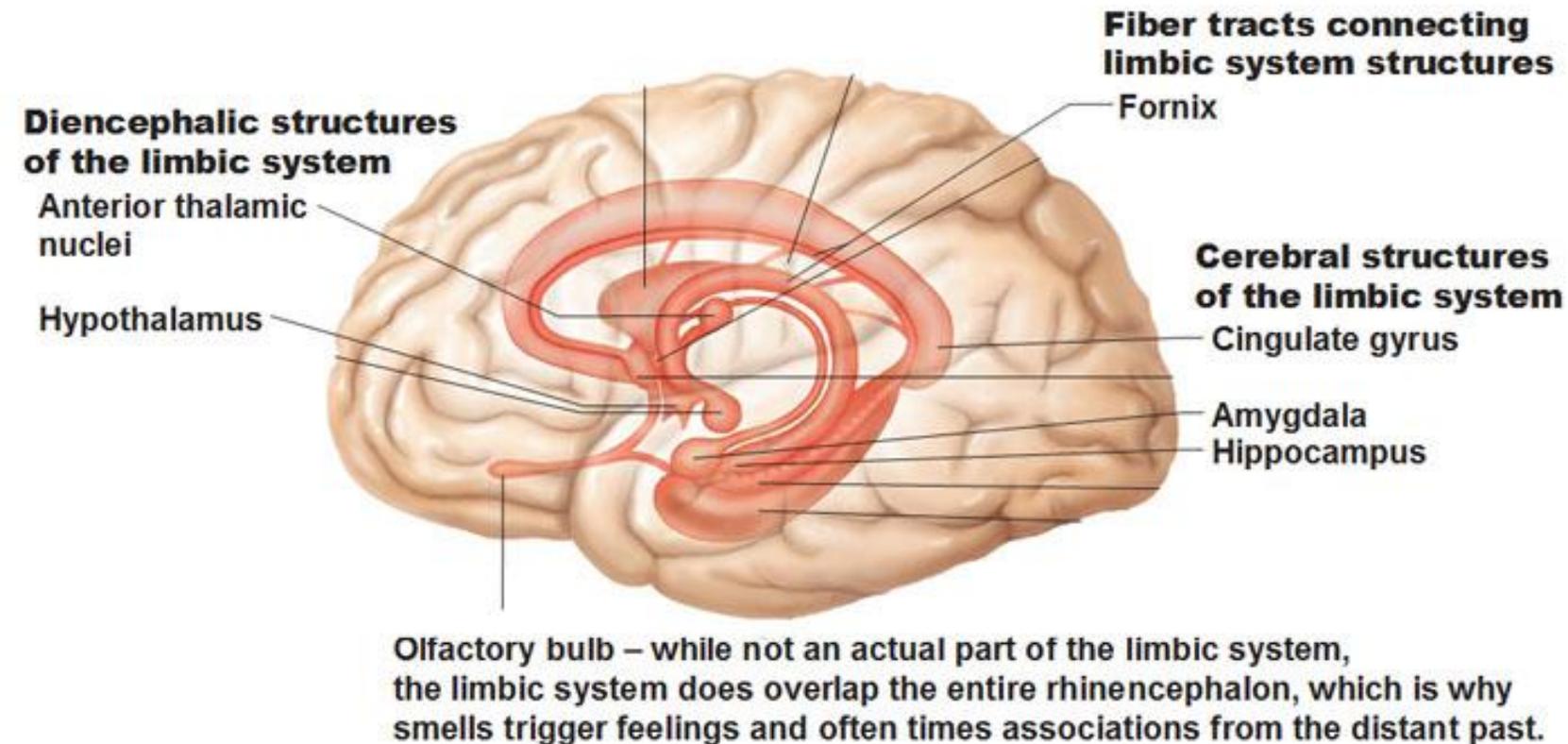
<http://neurowiki2014.wikidot.com/group:dementia>

Pain Experience

Dementia Type	Characteristics Include Impairment of	Pain (van Kooten, 2017)
Alzheimer's Disease	Executive function, memory, judgment and navigation	45.8%
Vascular	Specific to area of brain impacted	56.2%
Mixed	Alzheimer's and Vascular combined	53.9%
Lewy Body	Visual hallucination, disturbed sleep, gait changes	Unable to calculate
Frontotemporal	Personality changes, behavioral and risk taking	Unable to calculate

Limbic System

The Limbic System (the basics)



Limbic system is impacted in Alzheimer's Disease
Beyond storing new memories there is an associated change in mood regulation.

Pain/Alzheimer's Dementia (Achtreberg, 2013)

Believed that behavioral responses to pain are more significant in early/moderate dementia

- Hyperalgesia- response to chronic pain with increased sensitivity to painful stimuli
- Allodynia- painful response to nonpainful stimuli

Pain impact on behavioral expressions

Systematic Review and Meta-analysis (van Dalen-Kok, 2015) found some association between pain and:

- Agitation/aggression
- Anxiety
- Hallucinations and delusions
- Disruptive behavior
- Wandering
- Challenges with personal care

Question: how many people are being treated for anxiety or psychosis when they are really having pain?

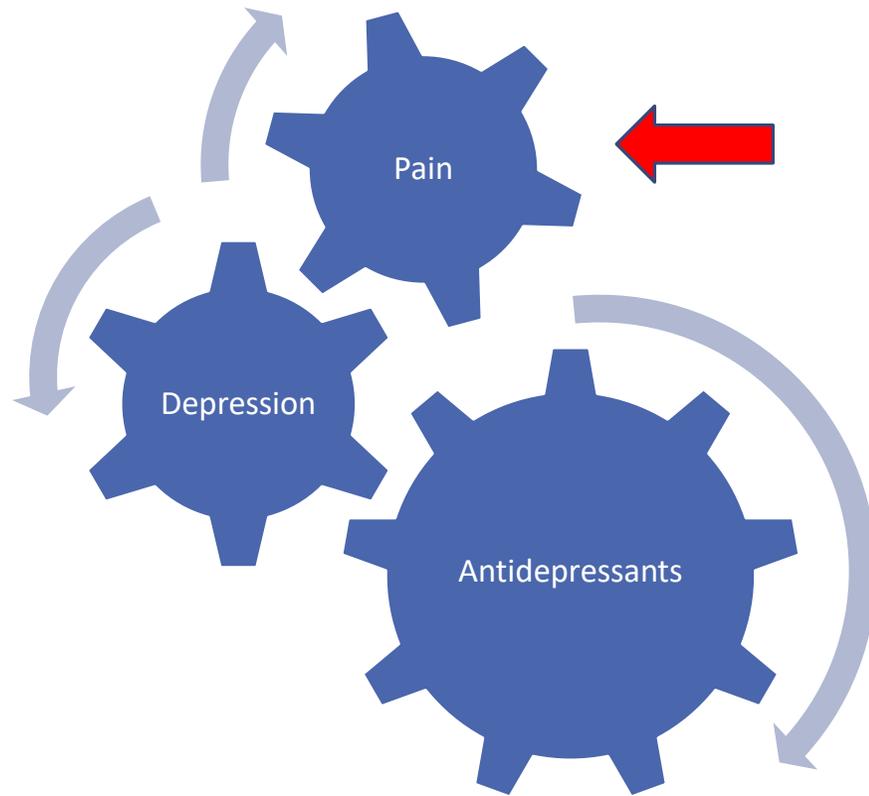
Pain relationship with depression

Norway study found correlation between pain levels and depression in people with dementia. Reducing pain was associated with less depression. (Erdal, 2017)

Systematic Review and Meta-analysis found cumulative odds ratio for pain and depression to be 1.84 (95% CI 1.23-2.80) (van Dalen-Kok, 2015)

Question: how many people are being treated for depression when they are really having pain?

Are we treating the right problem?



Is the pain causing depression and thus we see signs like weight loss or disengagement and treating it with antidepressants?

If we treated the pain appropriately could we avoid more costly treatments, psych referrals and secondary effects of medications.

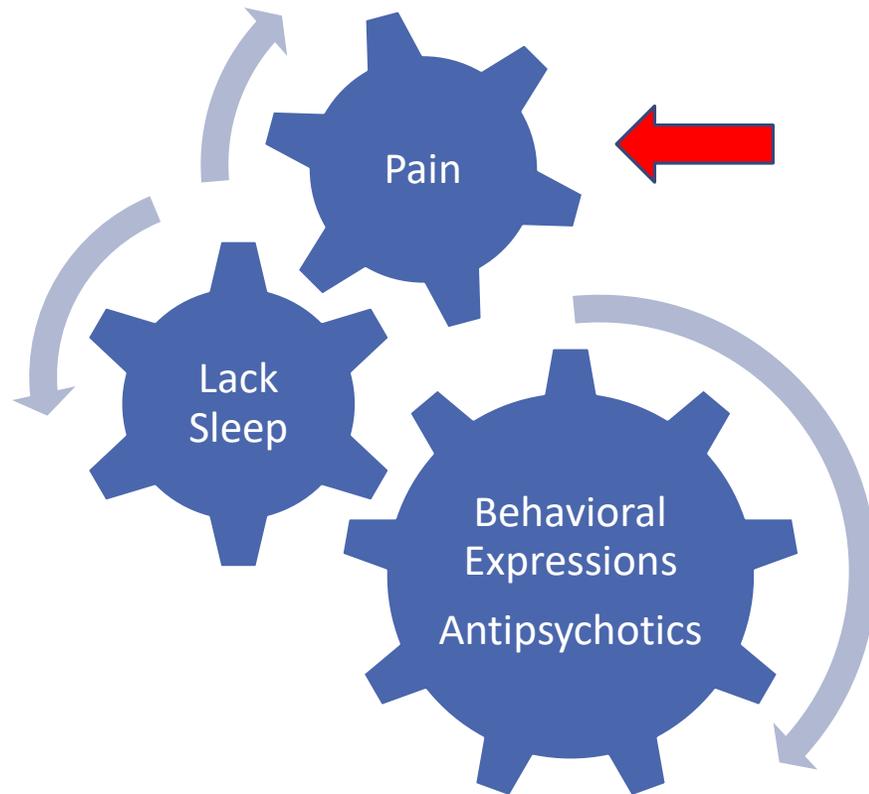
Pain impact on sleep

RCT in Norway of people with dementia use actigraphy to compare pain management vs control group and found that people treated for pain had improved (Blytt, 2017):

- Sleep efficiency
- Sleep onset latency
- Early morning awakening

Question: How many people would sleep better if we adequately treated their pain?

Are we treating the right problem?



Is pain disrupting their sleep and causing behavioral expressions?

Could we decrease antipsychotic use, medication expense, consultations if we adequately treated pain.

Pain in Dementia



Facial Expressions

- Grimacing, Frightened, Sad
- Rapid Blinking, Tightened eyes



Interpersonal Interactions

- Resisting care, aggressive, combative
- Socially inappropriate, withdrawn



Verbalizations

- Moaning, groaning, chanting
- Calling out, asking for help



Activity Patterns

- Appetite changes, refusing food
- Wandering, rest patterns



Body Movements

- Rigid, tense body postures
- Pacing, fidgeting, rocking



Mental Status Changes

- Crying, irritability, distress
- Increased confusion



My Experience

100s of chart reviews

Consistently see documentation of nursing assessment “are you in pain” to people with dementia

Response- no

Do you believe those are accurate responses?

Pain Assessment in Advanced Dementia (PAINAD) Scale

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation.	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respirations.	
Negative vocalization	None	Occasional moan or groan. Lowlevel speech with a negative or disapproving quality.	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial expression	Smiling or inexpressive	Sad. Frightened. Frown.	Facial grimacing.	
Body language	Relaxed	Tense. Distressed pacing. Fidgeting.	Rigid. Fists clenched. Knees pulled up. Pulling or pushing away. Striking out.	
Consolability	No need to console	Distracted or reassured by voice or touch.	Unable to console, distract or reassure.	
<p>* Five-item observational tool (see the description of each item below). ** Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0="no pain" to 10="severe pain").</p>				Total**

Pain Assessment In Advanced Dementia (PAINAD)
(Horgas, 2008)

Pain Assessment Checklist for Seniors with Limited Ability to Communicate-II (PACSLAC-II)

Facial Expressions

1. Grimacing
2. Tighter face
3. Pain expression
4. Increased eye movement
5. Wincing
6. Opening mouth
7. Creasing forehead
8. Lowered eyebrows or frowning
9. Raised cheeks, narrowing of the eyes or squinting
10. Wrinkled nose and raised upper lip
11. Eyes closing

Verbalizations and Vocalizations

12. Crying
13. A specific sound for pain (e.g., 'ow', 'ouch')
14. Moaning and groaning
15. Grunting
16. Gasping or breathing loudly

Mental Status Changes

31. Are there mental status changes that are due to pain and are not explained by another condition (e.g., delirium due to medication, etc.)?

Body Movements

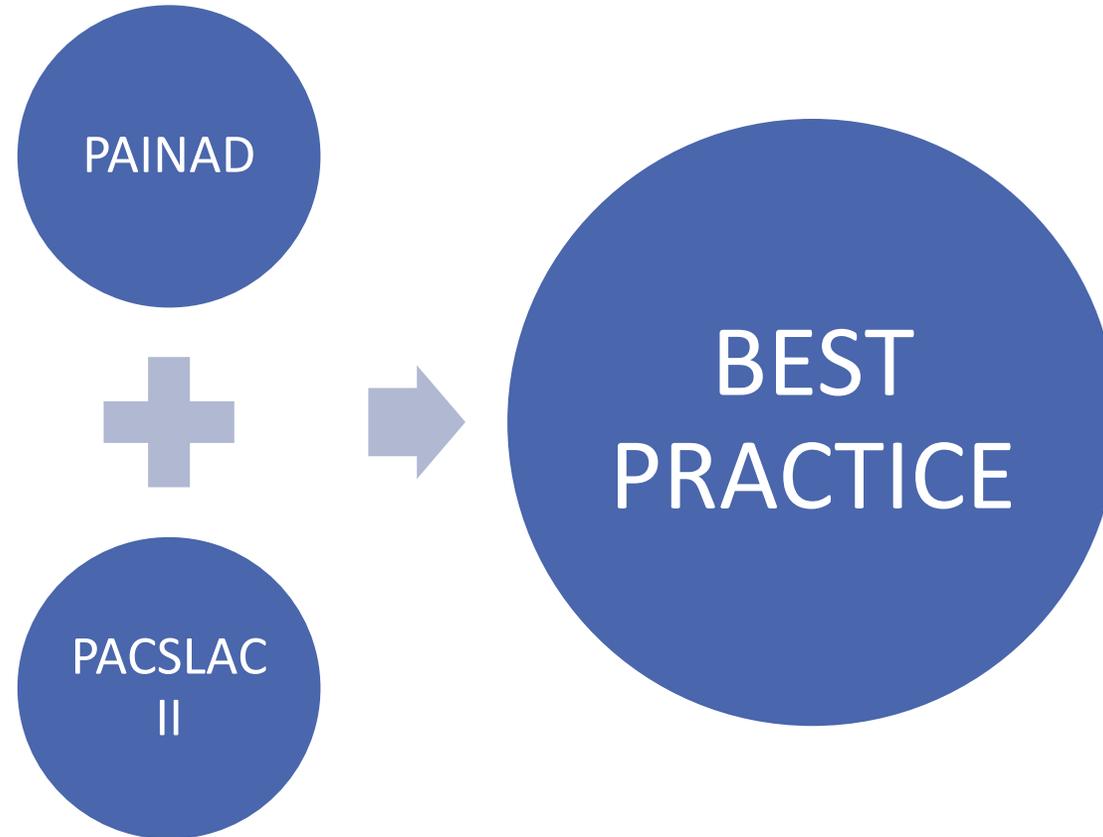
17. Flinching or pulling away
18. Thrashing
19. Refusing to move
20. Moving slow
21. Guarding sore area
22. Rubbing or holding sore area
23. Limping
24. Clenched fist
25. Going into foetal position
26. Stiff or rigid
27. Shaking or trembling

Changes in Interpersonal Interactions

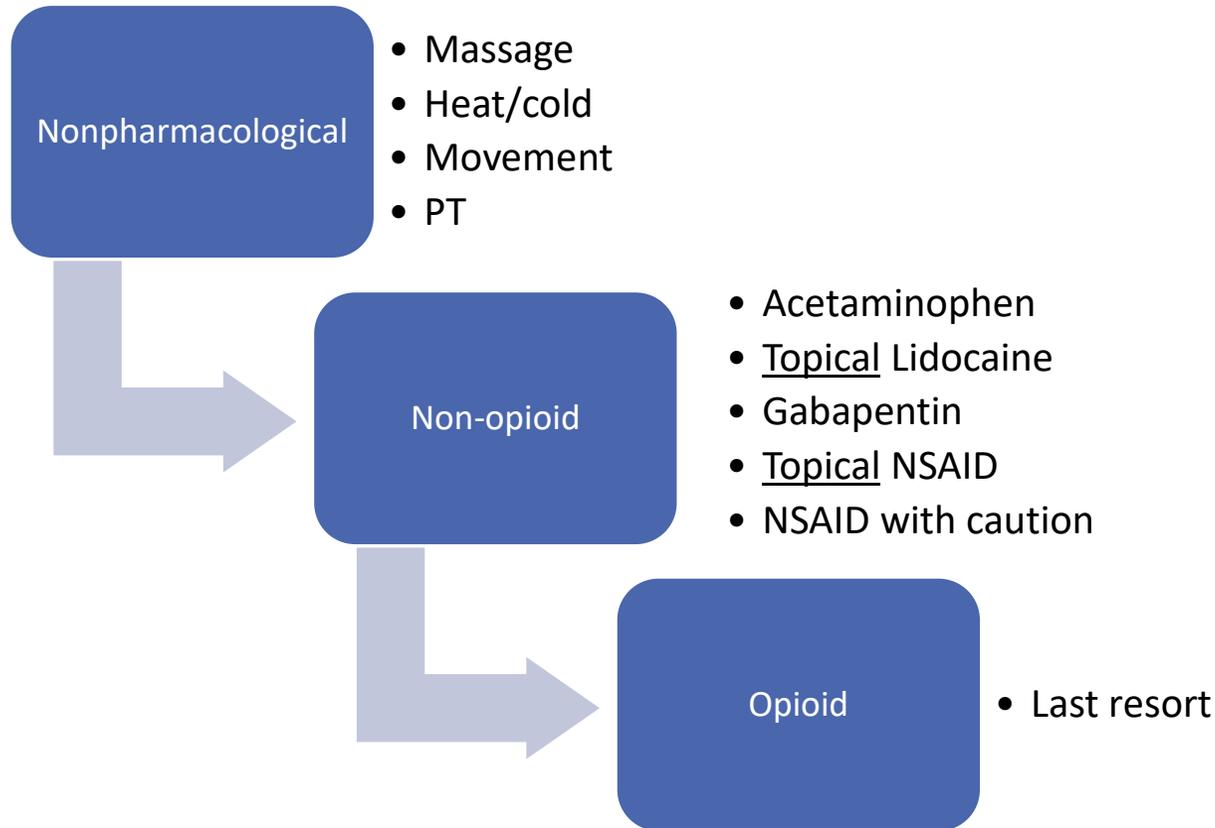
28. Not wanting to be touched
 29. Not allowing people near
- Changes in Activity Patterns or Routines
30. Decreased activity

PACSLAC II
(Hadjistravropoulos,
2010)

Nursing Study for Pain in Dementia (Herr, 2010)



Pain Treatment (AGS, 2009)



Complete pain assessments, medical exam and look for dx that can be contributing to pain (OA, post fall)
Start low, go slow
Assess effectiveness with pain tools
looking at pain expressions/changes
Monitor for side-effects

Literature Is Limited But Promising For People With Dementia

Manfredi studies 25 people with agitation with opioid analgesic- 13/25 showed improvement of agitation in 4 weeks. (Manfredi, 2003)

Study of 352 people with dementia in nursing homes (Husebo, 2014)

- Stepwise protocol on pain assessment and behavior
- Reduced pain
- Improved ADL function

Study of 195 residents in 6 Dementia Care Units- Better nonpharmacological management and pain medication use in facilities where nurses received pain education and pain protocol for assessment versus facilities with pain education alone. (Chen, 2016)

Take Home

People With Dementia
Feel and Express Pain
Differently
“Distress”

Pain Behavior
Assessment Tools Are
Key to Recognizing Pain

Behavioral Expressions
and Wellbeing May
Improve with Pain
Treatment



Questions? Thank You!

For more information please contact me:

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