Recognizing Pain in People with Dementia

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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.
Assessing Pain
Gold standard for cognitively intact adults
- Numeric Rating Scale


Assisted Living Facilities
Regulations in 2800.4 Definitions
Specialist Cognitive Support Services
- Pain management and person-centered care

https://commons.wikimedia.org/wiki/File:Amarna_House_Care_Home_York.jpg

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 person's lived experience

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

Pain Components

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. (Sears, 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 dental assessment
- Systematic Review found nursing home residents with dementia are given less pain medication despite similar number of conditions. (Tan, 2015)

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**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

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**Pain Experience**

<table>
<thead>
<tr>
<th>Dementia Type</th>
<th>Characteristics include impairment of</th>
<th>Pain (van Kooten, 2017)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Disease</td>
<td>Executive function, memory, judgment and navigation</td>
<td>65.8%</td>
</tr>
<tr>
<td>Vascular</td>
<td>Specific to area of brain impacted</td>
<td>56.2%</td>
</tr>
<tr>
<td>Mixed</td>
<td>Alzheimer’s and vascular combined</td>
<td>55.9%</td>
</tr>
<tr>
<td>Lewy Body</td>
<td>Visual hallucination, disturbed sleep, gait changes</td>
<td>Unable to calculate</td>
</tr>
<tr>
<td>Frontotemporal</td>
<td>Personality changes, behavioral and risk taking</td>
<td>Unable to calculate</td>
</tr>
</tbody>
</table>

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**Limbic System**

- Beyond storing new memories, there is an association change in mood regulation.

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**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

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**Pain/Alzheimer’s Dementia (Achterberg, 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

Allostomy - painful response to nonpainful stimuli

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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?

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?

Signs of Poor Sleep

- Difficulty concentrating
- Sleep changes
- Anxiety
- Suspiciousness
- Hallucinations
- Disorganized speech
- Depression
- Anxiety
- Difficulty functioning

Signs of Poor Sleep
Difficulty concentrating*
Sleep changes*
Anxiety*
Suspiciousness*
Hallucinations*
Disorganized speech*
Depression*
Anxiety*
Difficulty functioning*

*Is also a sign of psychosis

Are your residents experiencing “dementia with psychosis” or just side effect of sleep fragmentation?

Are we causing it?

Sleep Cycles
Full sleep cycle takes ~2 hours, 4-5 cycles/night
Stage 3 (Deep)
• physical healing
REM
• psychological healing
• longer phase in later cycles
Interuption = start over

https://upliftconnect.com/sleep-cycle/

Are we treating the right problem?
Is pain disrupting their sleep and causing behavioral expressions?

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 posture.
• 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

Pain Assessment in Advanced Dementia (PAINAD) (Horgas, 2008)
Pain Assessment Checklist for Seniors with Limited Ability to Communicate-II (PACSLAC-II)

**PACSLAC II**
(Hadjistravropoulos, 2010)

**BEST PRACTICE**

Nursing Study for Pain in Dementia
(Herr, 2010)

Literature Is Limited But Promising For People With Dementia

Manfredi studies 25 people with agitation with opioid analgesics- 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)

Survey Pathways

https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Nursing-Homes.html

Pain Treatment (AGS, 2009)

Nonpharmacological
- Massage
- Heat/cold
- Movement
- PT
- Nonopioid
- Acetaminophen
- Topical Lidocaine
- Gabapentin
- Topical NSAID
- NSAID with caution

Opioid
- Last resort

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

Survey Pathways

https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Nursing-Homes.html
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

References


Questions?

Thank You!

For more information please contact me:

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