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.
### Pain Assessment Interview

#### J0300. Pain Presence

<table>
<thead>
<tr>
<th>Enter Code</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><em>Have you had pain or hurting at any time in the last 5 days?</em></td>
</tr>
<tr>
<td>0. No</td>
<td>Skip to J1000, Shortness of Breath</td>
</tr>
<tr>
<td>1. Yes</td>
<td>Continue to J0400, Pain Frequency</td>
</tr>
<tr>
<td>9. Unable to answer</td>
<td>Skip to J0800, Indicators of Pain or Possible Pain</td>
</tr>
</tbody>
</table>

#### J0400. Pain Frequency

<table>
<thead>
<tr>
<th>Enter Code</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><em>How much of the time have you experienced pain or hurting over the last 5 days?</em></td>
</tr>
<tr>
<td>1. Almost constantly</td>
<td></td>
</tr>
<tr>
<td>2. Frequently</td>
<td></td>
</tr>
<tr>
<td>3. Occasionally</td>
<td></td>
</tr>
<tr>
<td>4. Rarely</td>
<td></td>
</tr>
<tr>
<td>9. Unable to answer</td>
<td></td>
</tr>
</tbody>
</table>

#### J0500. Pain Effect on Function

**A.** Ask resident: *“Over the past 5 days, has pain made it hard for you to sleep at night?”*

<table>
<thead>
<tr>
<th>Enter Code</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>0. No</td>
<td></td>
</tr>
<tr>
<td>1. Yes</td>
<td></td>
</tr>
<tr>
<td>9. Unable to answer</td>
<td></td>
</tr>
</tbody>
</table>

**B.** Ask resident: *“Over the past 5 days, have you limited your day-to-day activities because of pain?”*

<table>
<thead>
<tr>
<th>Enter Code</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>0. No</td>
<td></td>
</tr>
<tr>
<td>1. Yes</td>
<td></td>
</tr>
<tr>
<td>9. Unable to answer</td>
<td></td>
</tr>
</tbody>
</table>

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

**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.

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

(Hansen, 2005)
### Pain Components

<table>
<thead>
<tr>
<th>Sensory-Nociceptive</th>
<th>Sensory-Neuropathic</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Localized</td>
<td>• Burning</td>
</tr>
<tr>
<td>• Aching</td>
<td>• Electric</td>
</tr>
<tr>
<td>• Annoying</td>
<td>• Tingling</td>
</tr>
<tr>
<td>• Throbbing</td>
<td>• Shooting/Stabbing</td>
</tr>
</tbody>
</table>
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 fund nursing home residents with dementia are given less pain mediation despite similar number of conditions. (Tan, 2015)
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

<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>45.8%</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>53.9%</td>
</tr>
<tr>
<td>Lewy Body</td>
<td>Visual hallucination, disturbed sleep, gait changes</td>
<td>Unable to calculate</td>
</tr>
<tr>
<td>Fontotemporal</td>
<td>Personality changes, behavioral and risk taking</td>
<td>Unable to calculate</td>
</tr>
</tbody>
</table>
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.

Diencephalic structures of the limbic system
- Anterior thalamic nuclei
- Hypothalamus

Fiber tracts connecting limbic system structures
- Fornix

Cerebral structures of the limbic system
- Cingulate gyrus
- Amygdala
- Hippocampus

Olfactory bulb – while not an actual part of the limbic system, the limbic system does overlap the entire rhinencephalon, which is why smells trigger feelings and often times associations from the distant past.

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/agression
- 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

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

- **Body Movements**
  - Rigid, tense body postures
  - Pacing, fidgeting, rocking

- **Interpersonal Interactions**
  - Resisting care, aggressive, combative
  - Socially inappropriate, withdrawn

- **Activity Patterns**
  - Appetite changes, refusing food
  - Wandering, rest patterns

- **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

<table>
<thead>
<tr>
<th>Item</th>
<th>0</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>of vocalization</td>
<td>None</td>
<td>Occasional moan or groan. Low level speech with a negative or disapproving quality.</td>
<td>Repeated troubled calling out. Loud moaning or groaning. Crying.</td>
</tr>
<tr>
<td>Negative vocalization</td>
<td>None</td>
<td>Occasional moan or groan. Low level speech with a negative or disapproving quality.</td>
<td>Repeated troubled calling out. Loud moaning or groaning. Crying.</td>
</tr>
<tr>
<td>Consolability</td>
<td>No need to console</td>
<td>Distracted or reassured by voice or touch.</td>
<td>Unable to console, distract or reassure.</td>
</tr>
</tbody>
</table>

* 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").

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

**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

**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.)?

**Changes in Interpersonal Interactions**
28. Not wanting to be touched
29. Not allowing people near

**Changes in Activity Patterns or Routines**
30. Decreased activity
Nursing Study for Pain in Dementia (Herr, 2010)

- PAINAD
- PACSLAC II
- BEST PRACTICE
Pain Treatment (AGS, 2009)

Nonpharmacological
- Massage
- Heat/cold
- Movement
- PT

Non-opioid
- Acetaminophen
- Topical Lidocaine
- Gabapentin
- Topical NSAID
- NSAID with caution

Opioid
- Last resort

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)
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

Take Home
Questions?
Thank You!

For more information please contact me:
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302-753-9725
References


References


