Caring for Older Adults with Pain and Dementia: *Principles and Practice*

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GRECC Connect Program (GC) delivers virtual geriatric consultation with the aim to improve access to geriatric care for Veterans in rural areas. This project links geriatrics specialists from GRECCs (Geriatric Research, Education and Clinical Centers), located in urban tertiary medical centers, to providers and patients in rural areas. Clinical video telehealth, electronic consultation, and educational teleconferences bridge communication and access gaps that rural populations face.

Through this project, we aim to equip rural providers and staff with the knowledge and skills to care for older adults. GC supports staff at rural clinics.

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Learning Objectives:

• List 3 reasons, other than pain itself, that drive the older adult with dementia to report pain.
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• List 3 reasons, other than pain itself, that drive the older adult with dementia to report pain.
• Distinguish pain reporting from pain-related suffering.
• Describe 2 modifications to treatment that practitioners should consider for the older adult with dementia.
Number of Older Americans, 1960-2040 (in millions)

Ages
- 85+
- 65-84

Year
- 1960: 17
- 1980: 23
- 2000: 47
- 2020: 65
- 2040: 15

Top 10 Causes of Disability

1. Arthritis or rheumatism 8.6
2. Back or spine problems 7.6
3. Heart trouble 3.0
4. Mental or emotional problem 2.2
5. Lung or respiratory problem 2.2
6. Diabetes 2.0
7. Deafness or hearing problem 1.9
8. Stiffness or deformity of limbs/extremities 1.6
9. Blindness or vision problem 1.5
10. Stroke 1.1

Number (in millions) of 47.5 million U.S. adults with a disability
Alzheimer’s disease - 2022

Total: 6.5 Million

- 65-74 years: 1.75 million (27.0%)
- 75-84 years: 2.41 million (37.2%)
- 85+ years: 2.31 million (35.7%)
What happens when pain and dementia coexist?...
Dementia, Pain, and Pain Interference: NHATS Data

- National Health and Aging Trends Study 2011 wave
- 7,609 participants with complete cognitive function data
- 67.2% ≥ age 80
- 65% female, 67.9% white
- 802 with dementia

### NHATS Data (cont.)

<table>
<thead>
<tr>
<th></th>
<th>Pain Bothersome</th>
<th>Pain Limits Activity</th>
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<tbody>
<tr>
<td><strong>DEMENTIA</strong></td>
<td>63.5%</td>
<td>43.3%</td>
</tr>
<tr>
<td><strong>NO DEMENTIA</strong></td>
<td>54.5%</td>
<td>27.2%</td>
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In those with dementia:
- 49.7% proxy response

LBP-Related Changes in Physical Function

Weiner et al 2003; Pain Medicine 4: 311-20
PAIN ≠ DISABILITY

What are the treatment targets?
WEIGHING THE RISK OF DISABILITY

Social support
Affluence
Physical health
Brain health
Mobile
Pain-free
Socially isolated
Indigent
Physically ill
Brain unwell
Impaired mobility
Chronic pain
Case Presentation

ID/CC: 80 y.o., LBP/R leg pain X 2 yrs., SS on MRI

HPI: Forced to retire 2 years ago. Pain is worse with standing, walking, OK at night, better with heat, no constitutional symptoms. Increasing trouble with heavy housework, afraid to go on bus by self. Reports passive suicidal ideations. Frequent near falls at home. Failed PT trials.

PE: Poor balance, impaired clock-drawing test, kyphoscoliosis, SI/paraspinal/TFL pain, leg strength impaired from pain.
Medications:
- gabapentin
- oxycodone CR
- celecoxib
- tramadol/acetaminophen
- olanzapine
- escitalopram
- lorazepam

*Weiner, Pain in Older Persons; IASP Newsletter 12-07*
Socially isolated
Physically ill
Psychologically unwell
Demented
Impaired mobility
Chronic pain

Affluent
Rx: Short NH stay for detox. and balance/gait retraining. D/C’ed on tramadol + acetaminophen. Did very well while in NH.

Recommendation: Assisted Living

Family’s Decision: Patient to return home.
**Course**: Immediate deterioration at home with frequent calls, escalation of need for analgesics.

Her condition continued to deteriorate (eventual morphine pump trial), until she was admitted to an assisted living facility, where she did well.
Socially isolated
Physically ill
Psychologically unwell
Demented
Impaired mobility
Chronic pain

Affluence
Social Support
Socially isolated
Physically ill
Psychologically unwell
Demented
Impaired mobility
Chronic pain

Affluence
Fear & Pain Perseveration

Undermine dementia

Dementia & Social Isolation

Falsely escalate pain severity & impact

Fear = Rx Target
Basic Understanding of Pain Channels

- sensory-discriminative (nociceptive channel)
- motivational-affective
- cognitive processes
- descending modulatory influences
  +/− NE, 5-HT, glut, NMDA, GABA

- skin
- muscle
- joints
- viscera
- spinal cord

Slide used with permission from Gerald F. Gebhart, PhD, Director, PCPR
Basic Understanding of Pain Channels

Depression/Anxiety
Insomnia
Maladaptive Coping (fear avoidance beliefs, catastrophizing)
Low Self-Efficacy
Fibromyalgia
Dementia

descending modulatory influences

+/- NE, 5-HT, glut, NMDA, GABA

sensory-discriminative (nociceptive channel)

spinal cord

Slide used with permission from Gerald F. Gebhart, PhD, Director, PCPR
Is patient able to verbally report pain?
Is patient able to verbally report pain?

No

Behavioral Assessment
PAINAD
(Pain Assessment in Advanced Dementia)

0-10 scale
Summary score based on 5 items, 0-2 each

1. Breathing independent of vocalization
2. Negative vocalization
3. Facial expression
4. Body language
5. Consolability

Warden V et al 2003; J Am Med Dir Assoc 4:9
Is patient able to verbally report pain?

Yes
Dementia can impact...

• Pain reporting
  – Reliable for current pain intensity, ? validity
  – Historical inaccuracy

• Treatment compliance

• Pain coping
  – Fear avoidance

• Treatment expectancy

• Treatment response?
Dementia can impact...

- Pain reporting
  - Reliable for current pain intensity, ? validity
  - Historical inaccuracy
- Treatment compliance
- Pain coping
  - Fear avoidance
- Treatment expectancy
- Treatment response?
Kunz et al, Pain 2007; 133: 221-228
AD & Facial response to acute pain

General anxiety
Fear of needle sticks
Pre-venipuncture anxiety

Porter et al 1996; Pain 68, 413
IMPLICATIONS: Pain & Dementia

• While the behavioral manifestations of pain in those with dementia may indicate exaggerated suffering, the gold standard (self-report) defies this.
Dementia can impact...

• Pain reporting
  – Reliable for current pain intensity
  – Historical inaccuracy, ? validity

• **Treatment compliance**

• Pain coping
  – Fear avoidance

• Treatment expectancy

• Treatment response?
Dementia can impact...

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  – Fear avoidance
• Treatment expectancy
• Treatment response?
REAL-TIME OBSERVATION

An Essential Part of Assessing the Older Adult with Pain & Dementia
Real-Time Observation in LTC

• During activity is best, as most chronic pain is musculoskeletal
  – AM care
  – Physical therapy and other activity-based sessions
  – Other ideas??????
Is there a disconnect between reported pain and observed pain behaviors?
Case Presentation

**ID/CC:** 85 yo Veteran whose PCP notes, “Patient continues to report pain.”

**HPI:** Obtained from wife of 60 years (patient with advanced dementia).
- LBP X many years
- No red flags; no abnormal PE findings
- Mood, sleep, appetite good
- At PCP office, consistently reported pain “7.”
Case Presentation (cont.)

Pain Rx: acetaminophen
Case Presentation (cont.)

Pain Rx: acetaminophen → tramadol
Case Presentation (cont.)

Pain Rx: acetaminophen → tramadol → oxycodone
Pain Rx: acetaminophen → tramadol

↓

fentanyl 100 mcg/hr ← oxycodone
Case Presentation (cont.)

Pain Rx: acetaminophen → tramadol

fentanyl 100 mcg/hr ← oxycodone

Mental status changes/hospitalization
Case Presentation (cont.)

Pain Rx: acetaminophen → tramadol → fentanyl 100 mcg/hr ← oxycodone

Mental status changes/hospitalization

Pain Clinic referral – persistent 7 out of 10 pain
Case Presentation (cont.)

Pain Clinic Evaluation:
• Pleasant and cooperative, sitting in wheelchair
• No pain behaviors
• “Is he suffering from pain, or is he just talking about it?”…..”Just talking about it.”
Case Presentation (cont.)

Pain Clinic Evaluation:
- Pleasant and cooperative, sitting in wheelchair
- No pain behaviors
- “Is he suffering from pain, or is he just talking about it?”…..”Just talking about it.”

Pain Clinic Rx:
- Taper fentanyl off
- Adult day care referral
Pain Perseveration

Undermine dementia

Pain Severity assessment without Pain Interference assessment

Falsely escalate pain severity & impact

Perseveration = Rx Target
Dementia can impact…

• Pain reporting
  – Reliable for current pain intensity
  – Historical inaccuracy, ? validity

• Treatment compliance

• Pain coping
  – Fear avoidance

• **Treatment expectancy**

• Treatment response?
Dementia and Expectancy

- Participants: 28 older adults with Alzheimer’s disease and 16 healthy age/sex matched older adults
- Experimental pain: Venipuncture in dorsum of hand
- Pain rating: Before and after pain treatment (bandage with 1% lidocaine)
- Intervention assignment: Participants randomized to an OPEN or a HIDDEN paradigm

Benedetti et al 2006; Pain 121: 133
Dementia and Expectancy

• **OPEN** Paradigm: Participant told that they would be getting topical pain medication when needle removed

*Benedetti et al 2006; Pain 121: 133*
Dementia and Expectancy

- OPEN Paradigm: Participant told that they would be getting topical pain medication when needle removed

- HIDDEN Paradigm: Participant was not told, but received the same topical pain medication

Benedetti et al 2006; Pain 121: 133
Dementia and Expectancy

- **OPEN** Paradigm: Participant told that they would be getting topical pain medication

- **CLOSED** Paradigm: Participant was not told, but received the same topical pain medication

- **Difference** in pain control was evaluated.

  *Benedetti et al 2006; Pain 121: 133*
Results

• As dementia progressed (2 time points, 1 year apart), the difference in pain control using the open versus the hidden paradigm shrank....
Dementia can impact...

- Pain reporting
  - Reliable for current pain intensity
  - Historical inaccuracy, ? validity
- Treatment compliance
- Pain coping
  - Fear avoidance
- Treatment expectancy
- Treatment response?
What is the effect of placebo?

Analgesic → ↓ Pain
What is the effect of placebo?

Analgesic → Pharmacodynamic effect
What is the effect of placebo?

Analgesic ➔ Pharmacodynamic effect

Treatment Expectancy ➔ Hope ➔ ↓ Pain
What is the effect of placebo?

Analgesic → Pharmacodynamic effect

Treatment Expectancy → Hope → Placebo effect
What is the effect of placebo?

Analgesic → Pharmacodynamic effect

Treatment Expectancy → Hope - Placebo effect

Pharmacodynamic effect + Placebo effect
What is the effect of placebo?

Analgesic → Pharmacodynamic effect

Treatment Expectancy → Hope → Placebo effect

Pharmacodynamic effect → PAIN
Loss of expectation-related mechanisms in Alzheimer’s disease makes analgesic therapies less effective

Benedetti F, et al.
Pain 121 (2006) 133–144
Impact of Dementia on Rx Response?

• Because of reduced treatment expectancy, patients with advanced dementia may respond less robustly to treatment interventions.
Clinical Indicators of Possible Dementia

- Self or family-reported memory loss or functional decline
- Difficulty with information processing
- Inability to provide adequate historical details; “Head-Turning Sign”
- ≥ age 85
- Disconnect between reported pain level and observed pain behaviors
Clinical Indicators of Possible Dementia

• Self or family-reported memory loss or functional decline
• Difficulty with information processing
• Inability to provide adequate historical details; “Head-Turning Sign”
• ≥ age 85
• Disconnect between reported pain level and observed pain behaviors
Dementia Screening: The Mini-Cog

• “I am going to give you 3 words to remember….Now repeat them back to me.”
3-word examples

• Banana, sunrise, chair
• Leader, season, table
• Village, kitchen, baby
• River, nation, finger
• Captain, garden, picture
• Daughter, heaven, mountain
Dementia Screening: The Mini-Cog

- “I want you to remember the words. I will ask you to repeat them back to me in ~ 2 minutes.”
Dementia Screening: The Mini-Cog

• “I want you to remember the words. I will ask you to repeat them back to me in ~ 2 minutes.”

• “I want you to draw a clock with the hands pointing to 11:10.”
Dementia Screening: The Mini-Cog

- “I want you to remember the words. I will ask you to repeat them back to me in ~ 2 minutes.”
- “I want you to draw a clock with the hands pointing to 11:10.”
- “Can you repeat the 3 words back to me?”
Dementia SCREENING Algorithm

Scanlan & Borson 2001; Int J Geriatr Psych 16: 216
Modification of Rx Approach

- Contact PCP to communicate your observations.
- Involve caregiver in treatment sessions
- Teach more slowly
- Alter your expectations of rate of progress
- Reinforce, reinforce, reinforce
- Provide more support/ask for more feedback than you would ordinarily
- Validate self-report
Modification of Rx Approach

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What if you are the first healthcare provider to suspect dementia?

Getting Patient/Family Buy-In
Educational Messages

• Our brains are responsible for managing pain in our bodies. When our brains have a weakened ability to control pain (e.g., depression, anxiety, memory impairment, head trauma, PTSD), we may need to alter how we approach treatment.
Diagram of the brain with labels:
- Brain
- Feelings Center
- Thoughts Center
- Can open or close Gates
- Spinal Cord
- Gates
- Pain Signals

Used with permission from Dr. Beverly Thorn.
Educational Messages (cont.)

• Power of positive thinking; harm of negative thinking
Educational Messages (cont.)

- Power of positive thinking; harm of negative thinking
- **Reward positive behaviors**
- **Do not reinforce negative behaviors**
Educational Messages (cont.)

• Consider premedication prior to planned activity (for caregiver!) – They should speak with PCP about this.
Educational Messages (cont.)

• Goals:
  – Activity engagement in the face of some persistent pain
  – Regain confidence in mobility
  – Empower to gain control over pain
Your pain has you.

You have your pain.
Is patient able to verbally report pain?

Yes

Is patient able to verbally report pain?

Yes

Are there signs of physical or emotional suffering during REAL-TIME observation?
Is patient able to verbally report pain?

Yes

Are there signs of physical or emotional suffering during REAL-TIME observation?

No

1. Distraction
2. D/C asking about pain unless suffering
Is patient able to verbally report pain?

Yes

Are there signs of physical or emotional suffering during REAL-TIME observation?

No

1. Distraction
2. D/C asking about pain unless suffering

Yes

Evaluate patient:
1. Is there fear of pain?
2. Is there fear of movement?
3. Is pain causing suffering?
Key Point

1. Dementia can impact pain reporting (especially historical details), treatment compliance, pain coping, treatment expectancy and treatment response.
2. Pain self-management in the older adult with dementia should involve the caregiver(s). When treating the older adult with chronic pain and dementia, always encourage the caregiver to attend sessions as a way to optimize compliance and enhance patient/caregiver quality of life.
3. When treating the older adult with chronic pain and dementia, you may wish to consider a number of modifications such as slowing the pace of learning, providing extra support and time to accommodate fear, including extra learning reinforcement strategies....
Empowering Caregivers to Care for those with Chronic Pain and Dementia

ORH-Funded Project (FY23-FY25)
Goals

Teach caregivers:

1. Pain assessment
   – Pain reporting versus pain suffering
   – Real time observation

2. Adaptive pain coping strategies

3. Judicious use of pharmacological & non-pharmacological strategies

4. Self-care
Goal for Dissemination

FY25
If you want to participate…

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