

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

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VA



U.S. Department of Veterans Affairs

Veterans Health Administration

Geriatric Research, Education, and Clinical Centers

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GRECC CONNECT - CASE CONFERENCE SERIES

- ▶ **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.
- ▶ Funded by the VA Office of Rural Health (ORH)



DISCLAIMERS:

- ▶ The views expressed in this presentation are those of the author(s) and do not necessarily reflect the position or policy of the Department of Veterans Affairs or the United States Government.
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Learning Objectives:

- List 3 reasons, other than pain itself, that drive the older adult with dementia to report pain.

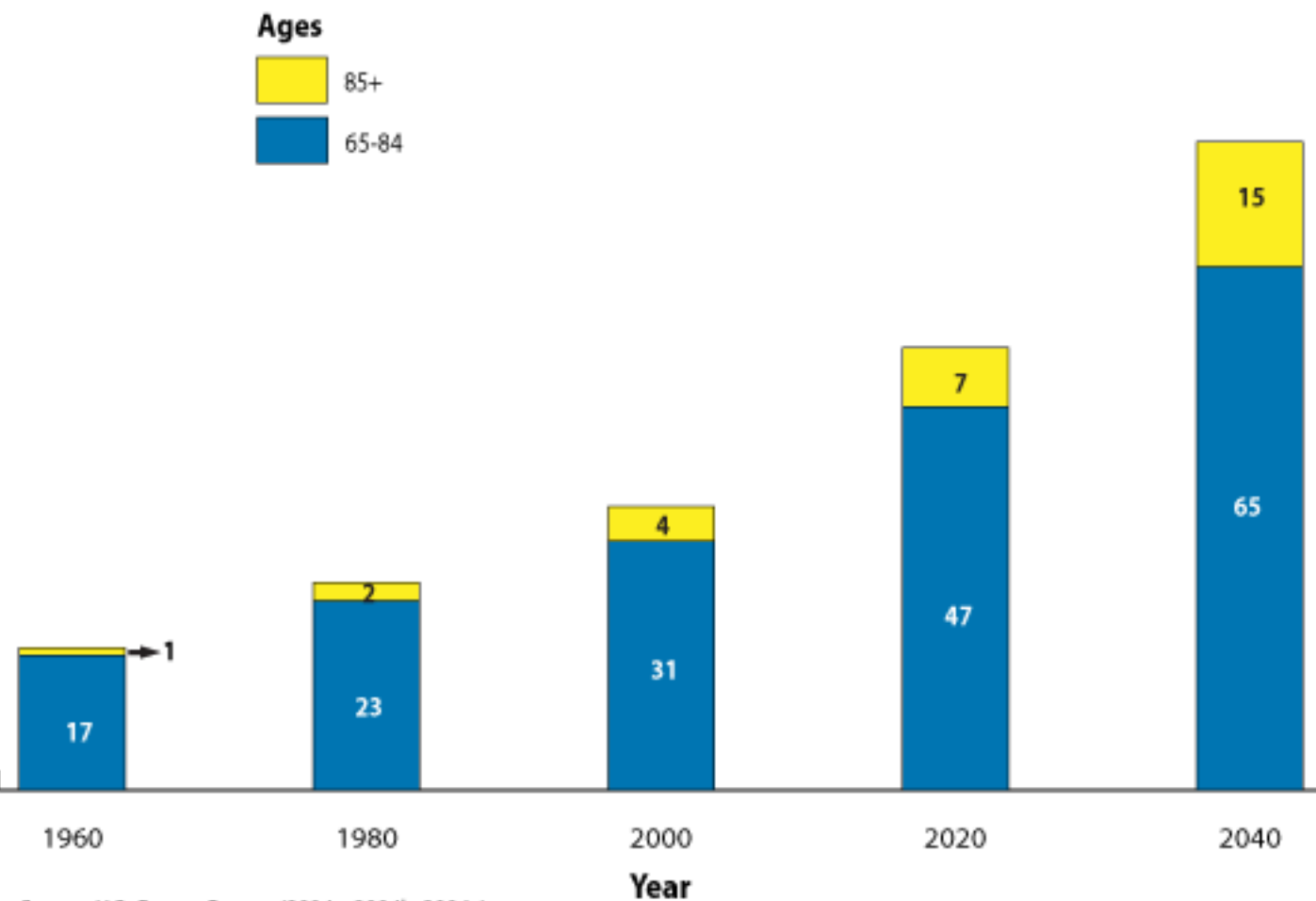
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- Distinguish pain reporting from pain-related suffering.

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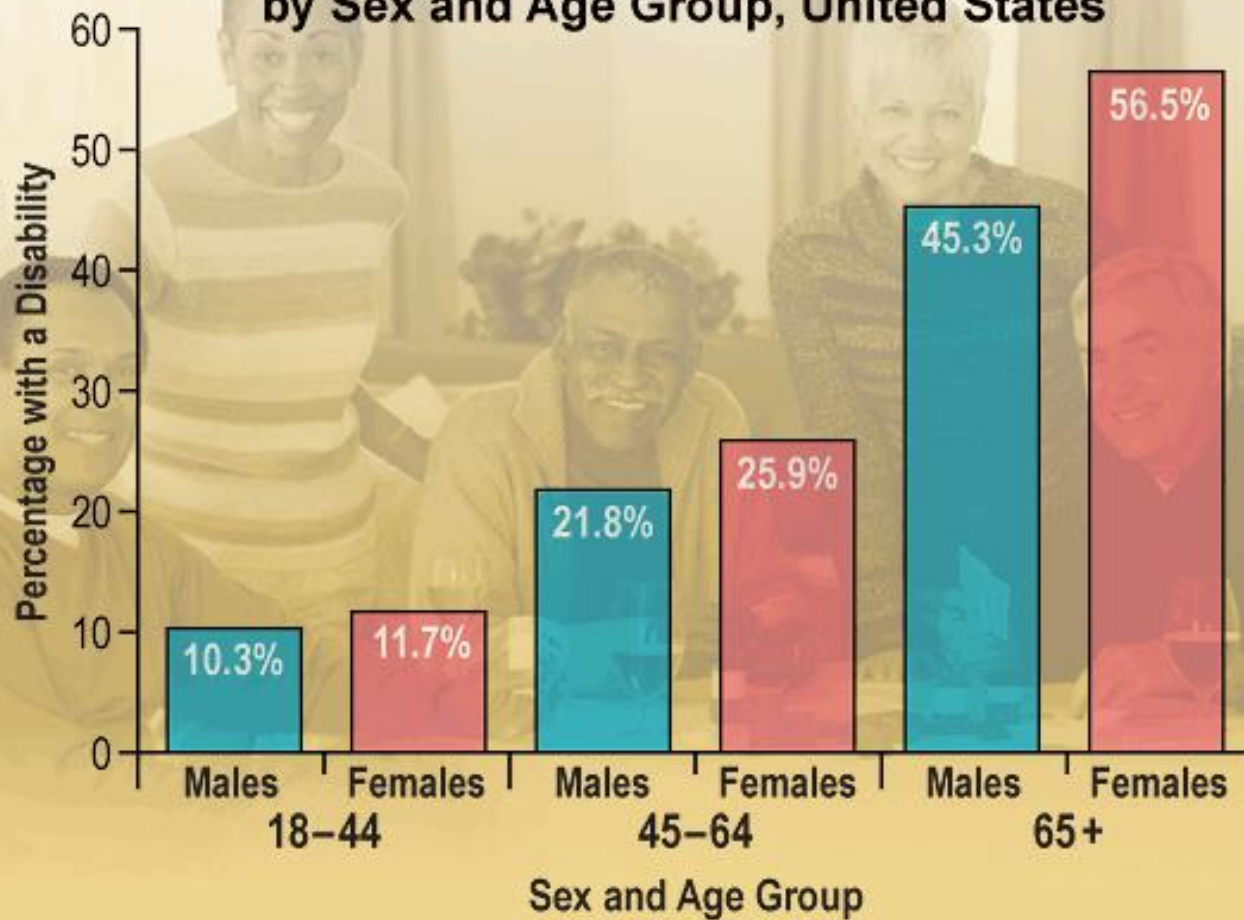
- List 3 reasons, other than pain itself, that drive the older adult with dementia to report pain.
- Distinguish pain reporting from pain-related suffering.
- Describe 2 modifications to treatment that practitioners should consider for the older adult with dementia.

Number of Older Americans, 1960-2040 (in millions)

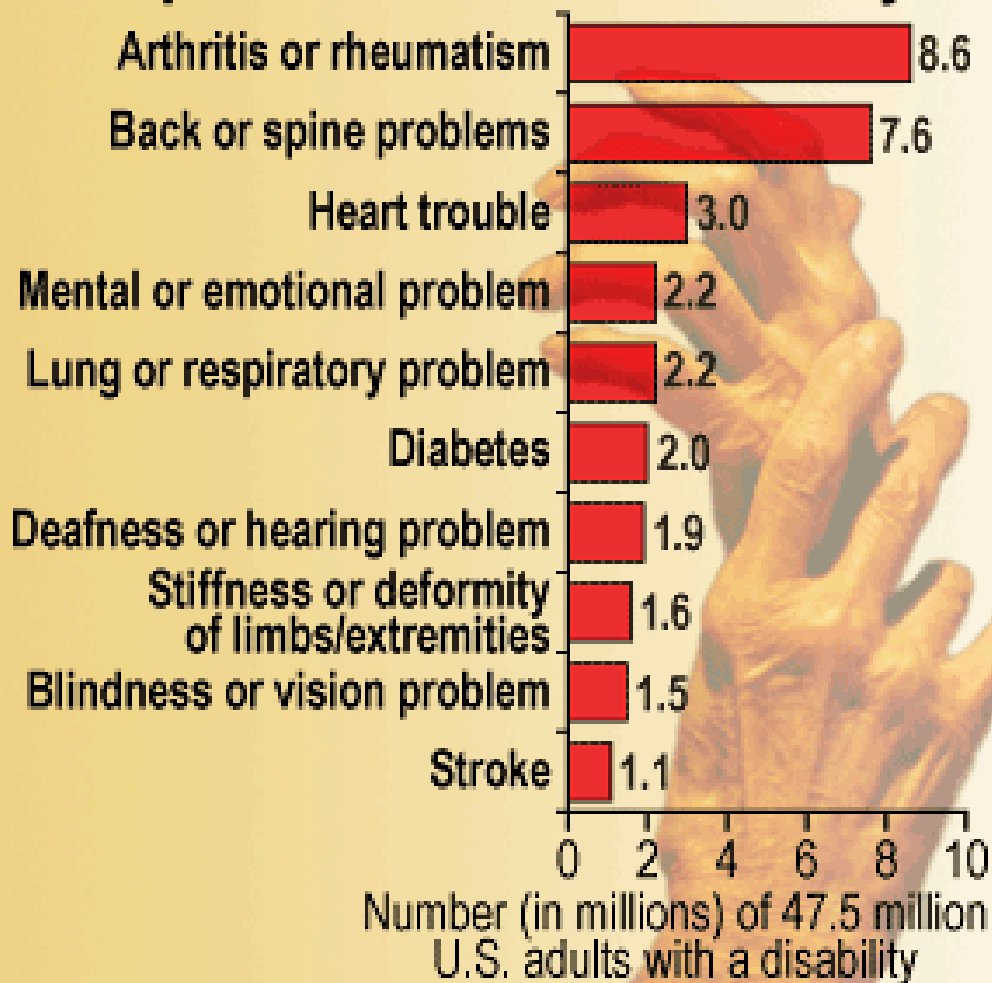


Source: U.S. Census Bureau (2004a, 2004b, 2004c).

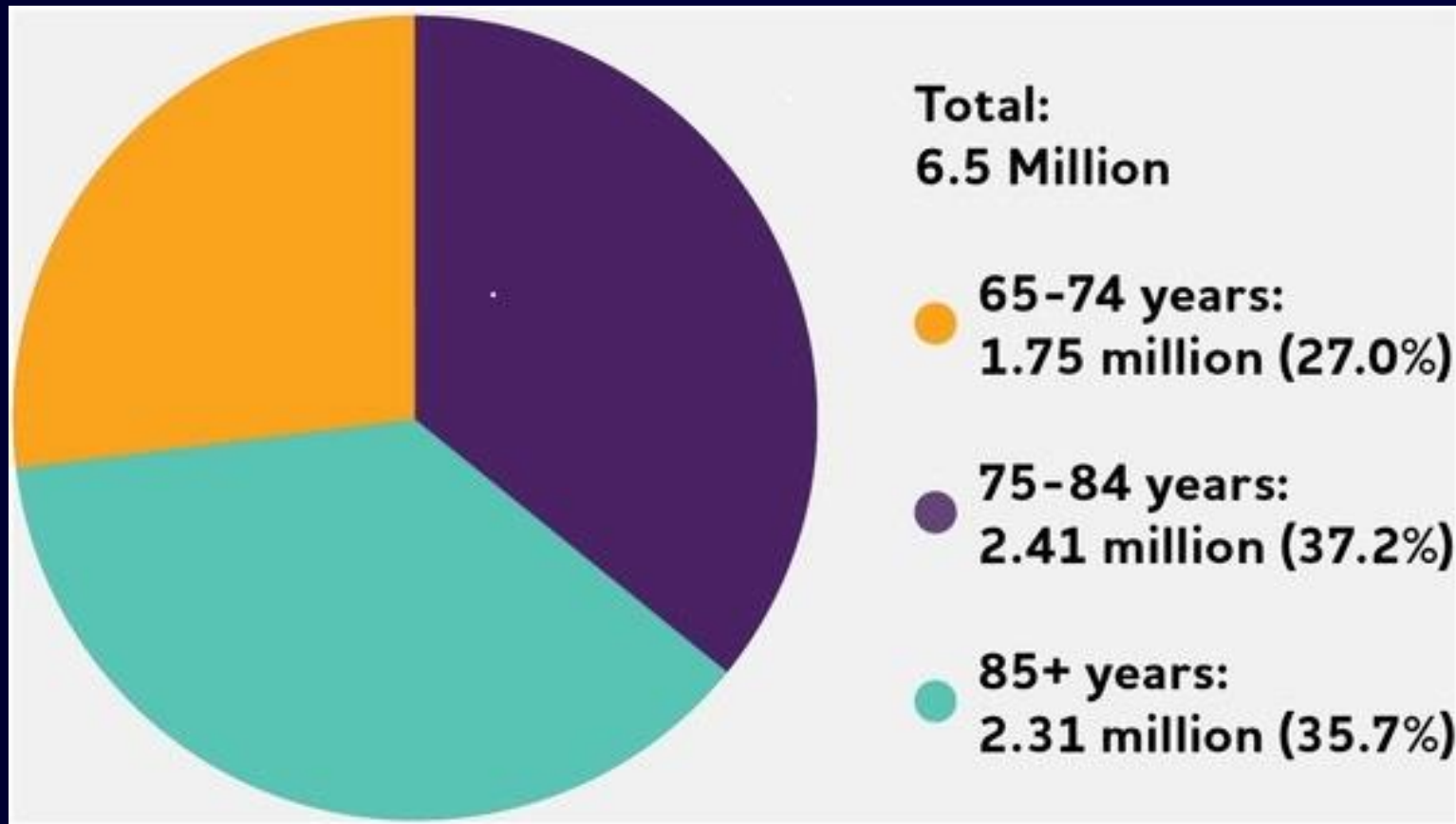
Adults Age 18 or Older Reporting Disability by Sex and Age Group, United States



Top 10 Causes of Disability



Alzheimer's disease - 2022



What happens when pain and dementia coexist?...

Dementia, Pain, and Pain Interference: NHATS Data

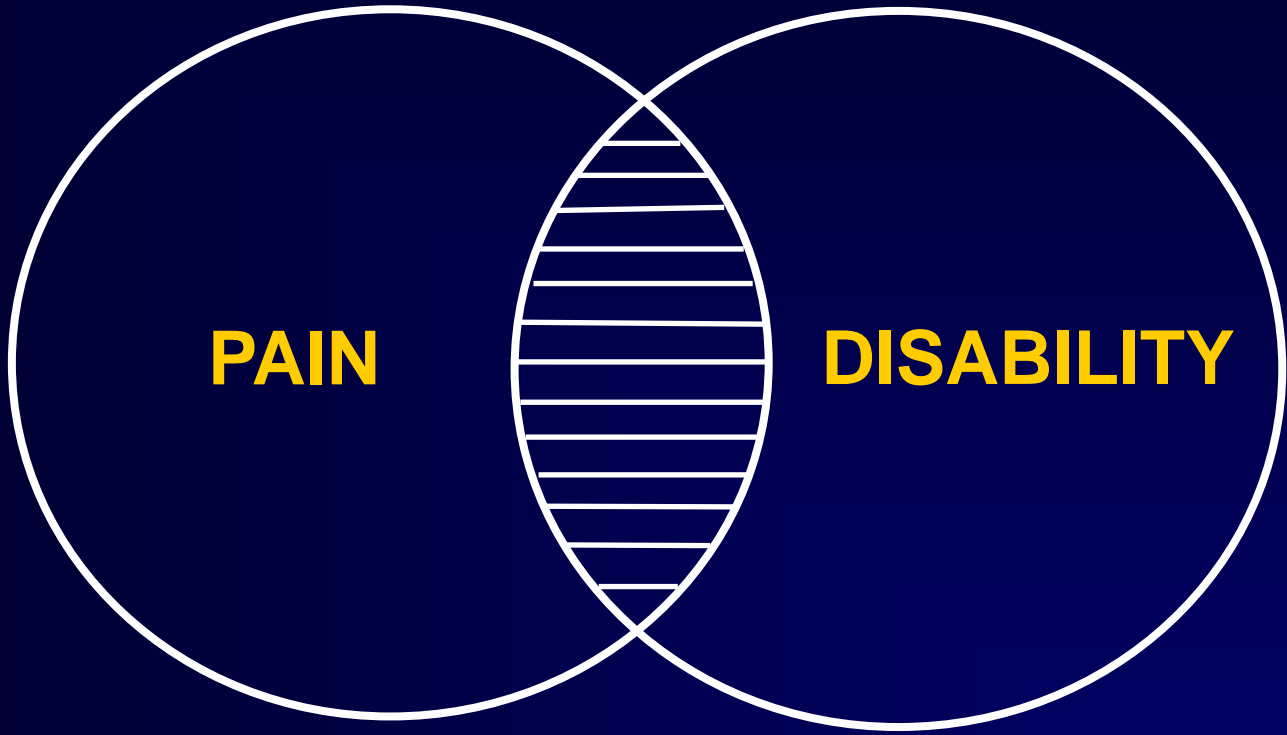
- National Health and Aging Trends Study
2011 wave
- 7,609 participants with complete cognitive
function data
- 67.2% \geq age 80
- 65% female, 67.9% white
- 802 with dementia

NHATS Data (cont.)

	Pain Bothersome	Pain Limits Activity
DEMENTIA	63.5%	43.3%
NO DEMENTIA	54.5%	27.2%

In those with dementia:

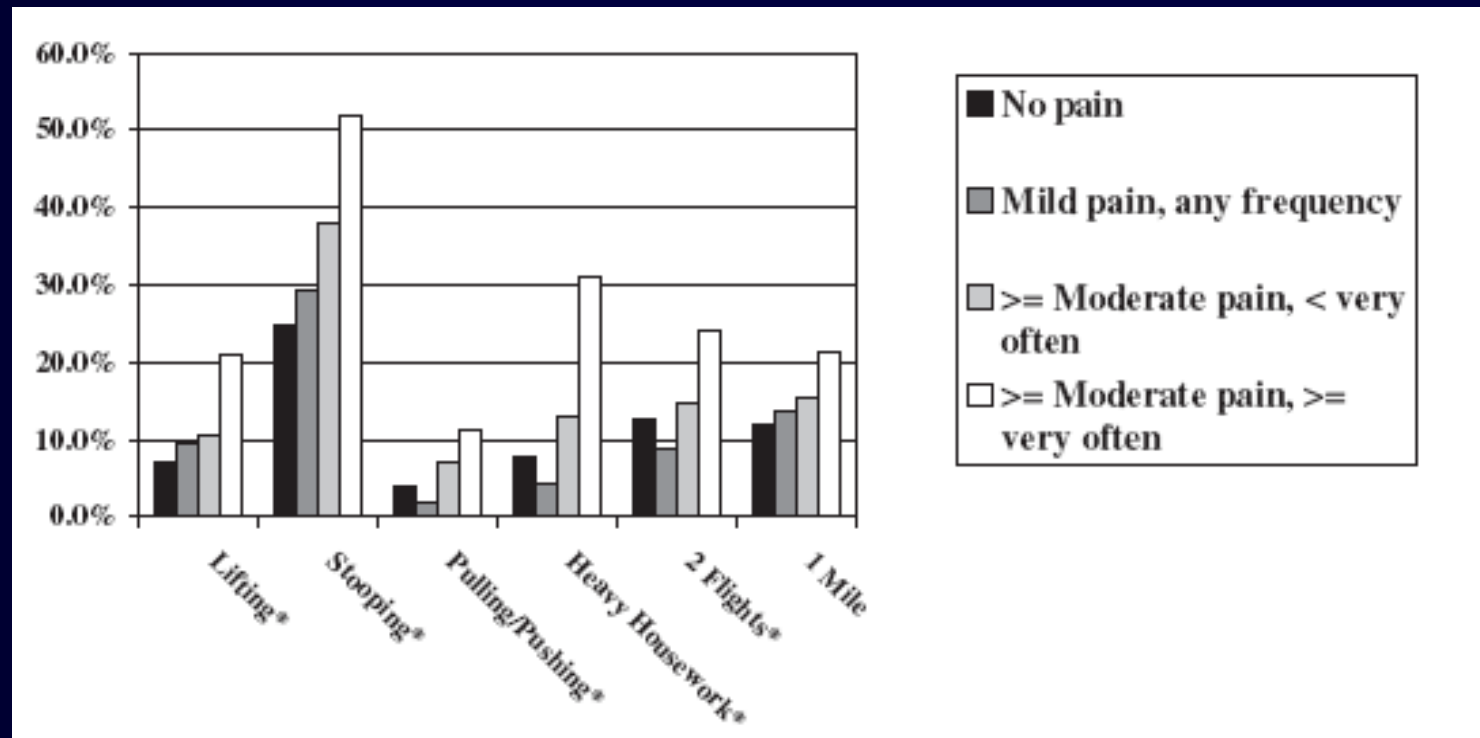
- 49.7% proxy response



PAIN

DISABILITY

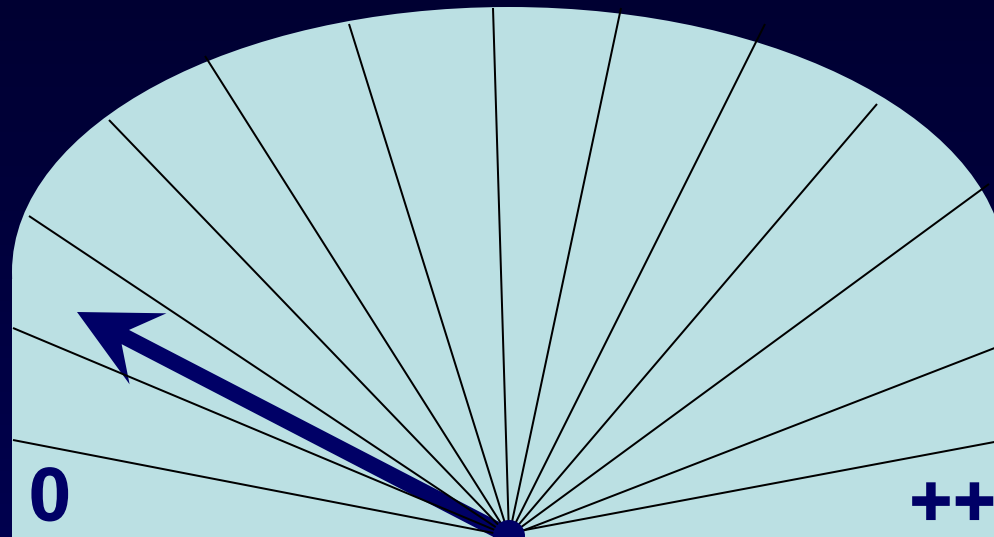
LBP-Related Changes in Physical Function



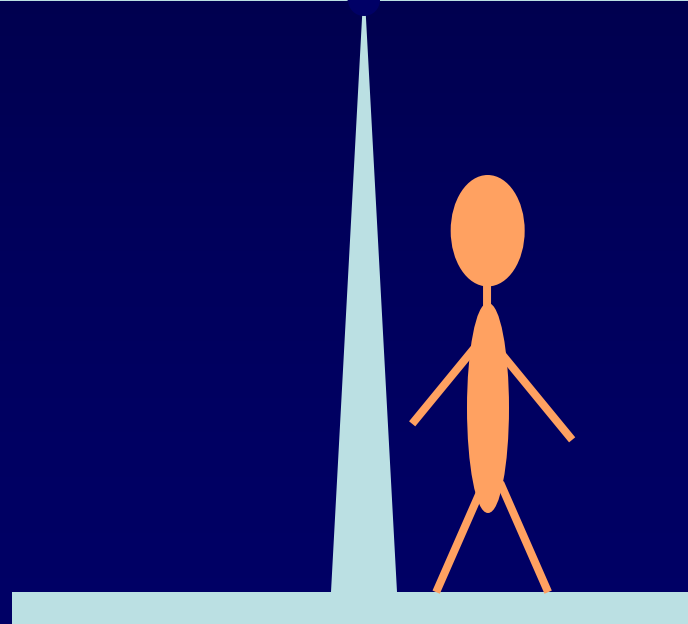
PAIN ≠ DISABILITY

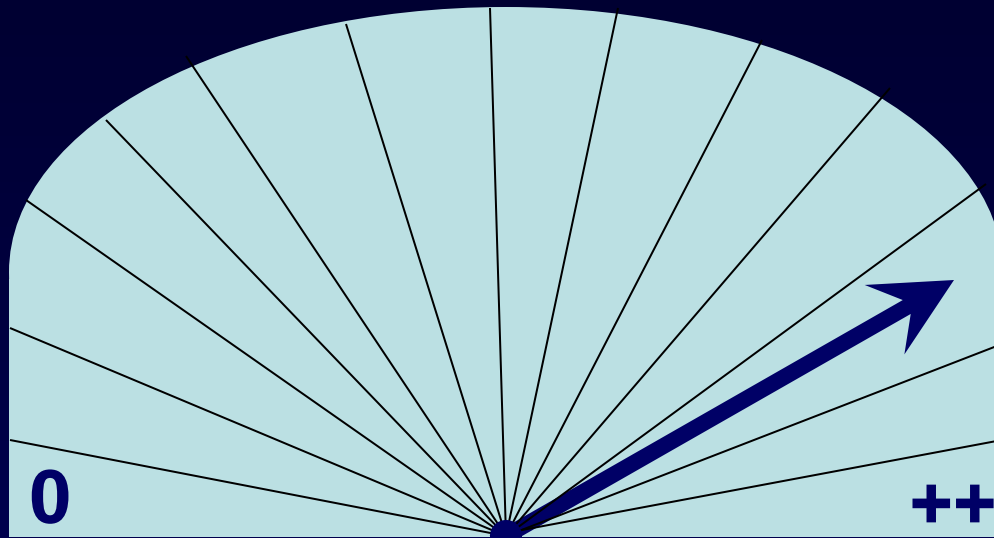
What are the treatment targets?

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

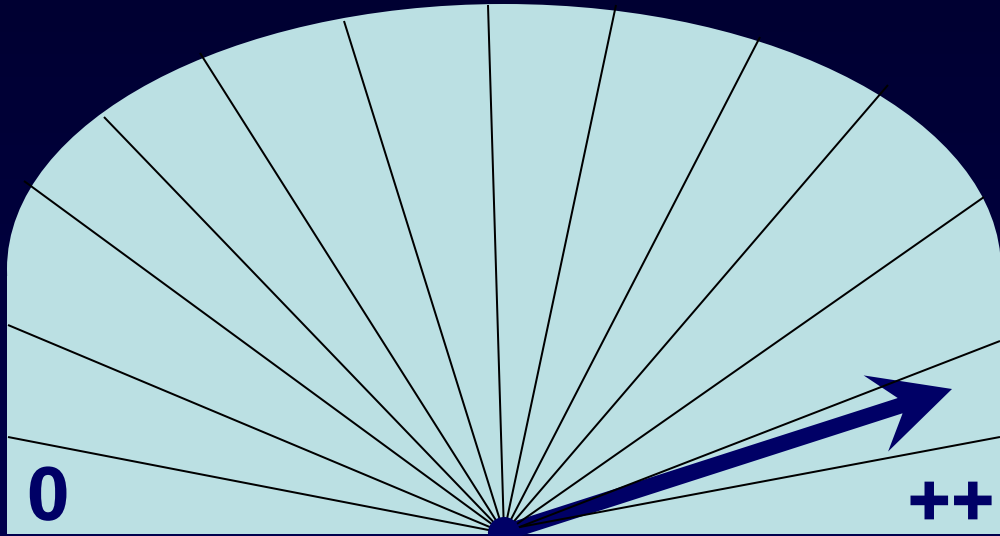
celecoxib

tramadol/acetaminophen

olanzapine

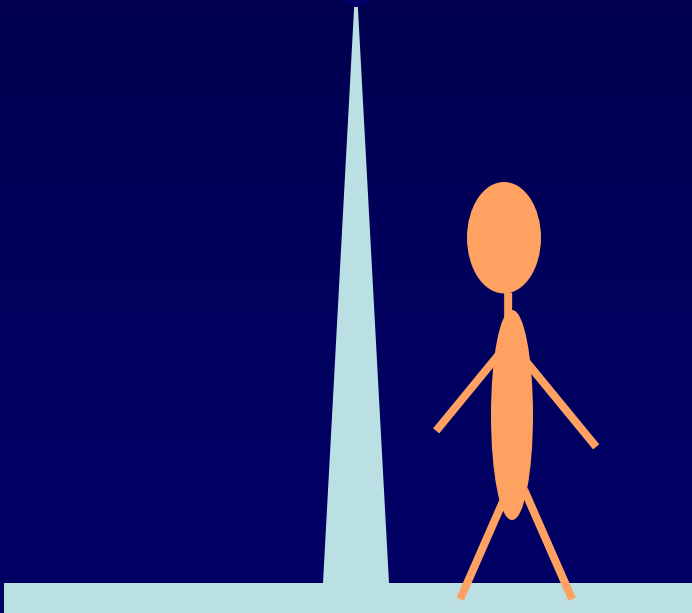
escitalopram

lorazepam



Affluent

- Socially isolated
- Physically ill
- Psychologically unwell
- Demented
- Impaired mobility
- Chronic pain



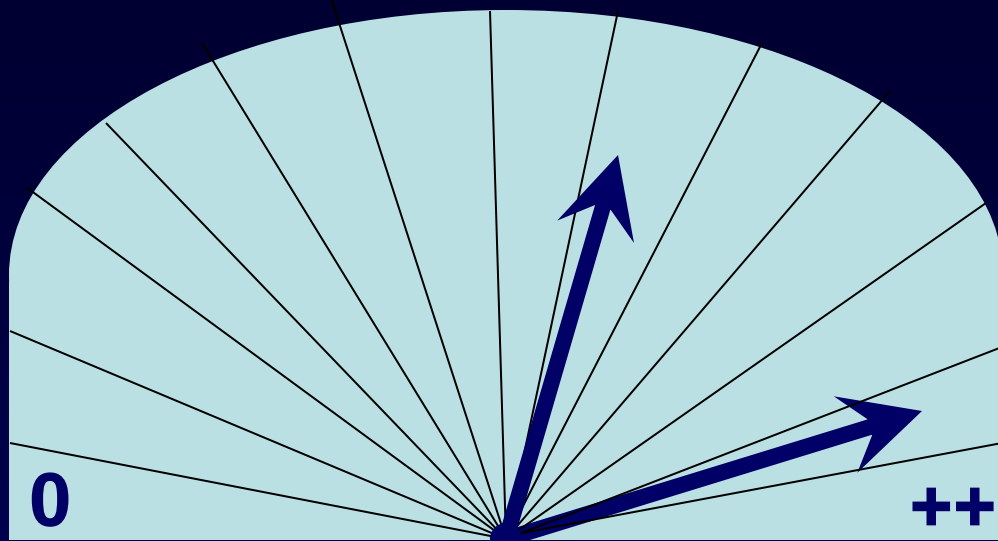
Rx: Short NH stay for detox. and balance/gait retraining. D/C'ed on tramadol + acetaminophen. Did very well while in NH.

Recommendation: Assisted Living

Family's Decision: Patient to return home.

Course: Immediate deterioration at home with frequent calls, escalation of need for analgesics.

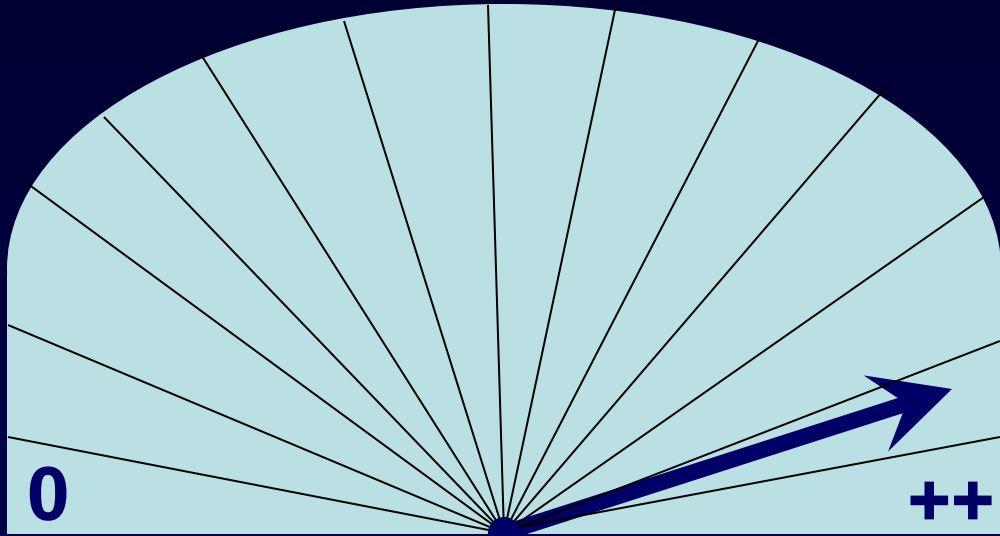
Her condition continued to deteriorate (eventual morphine pump trial), until she was admitted to an assisted living facility, where she did well.



Affluence
Social Support

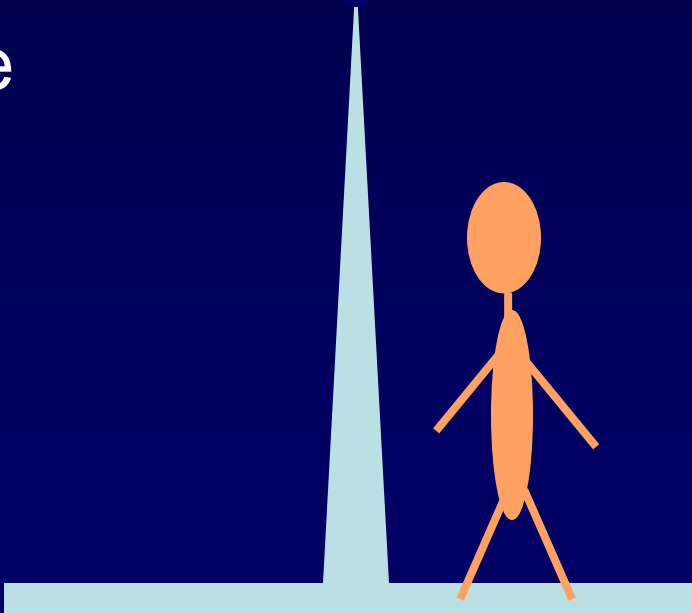
Socially isolated
Physically ill
Psychologically unwell
Demented
Impaired mobility
Chronic pain





Affluence

- Socially isolated
- Physically ill
- Psychologically unwell
- Demented
- Impaired mobility
- Chronic pain



Fear = Rx Target

Fear & Pain
Perseveration

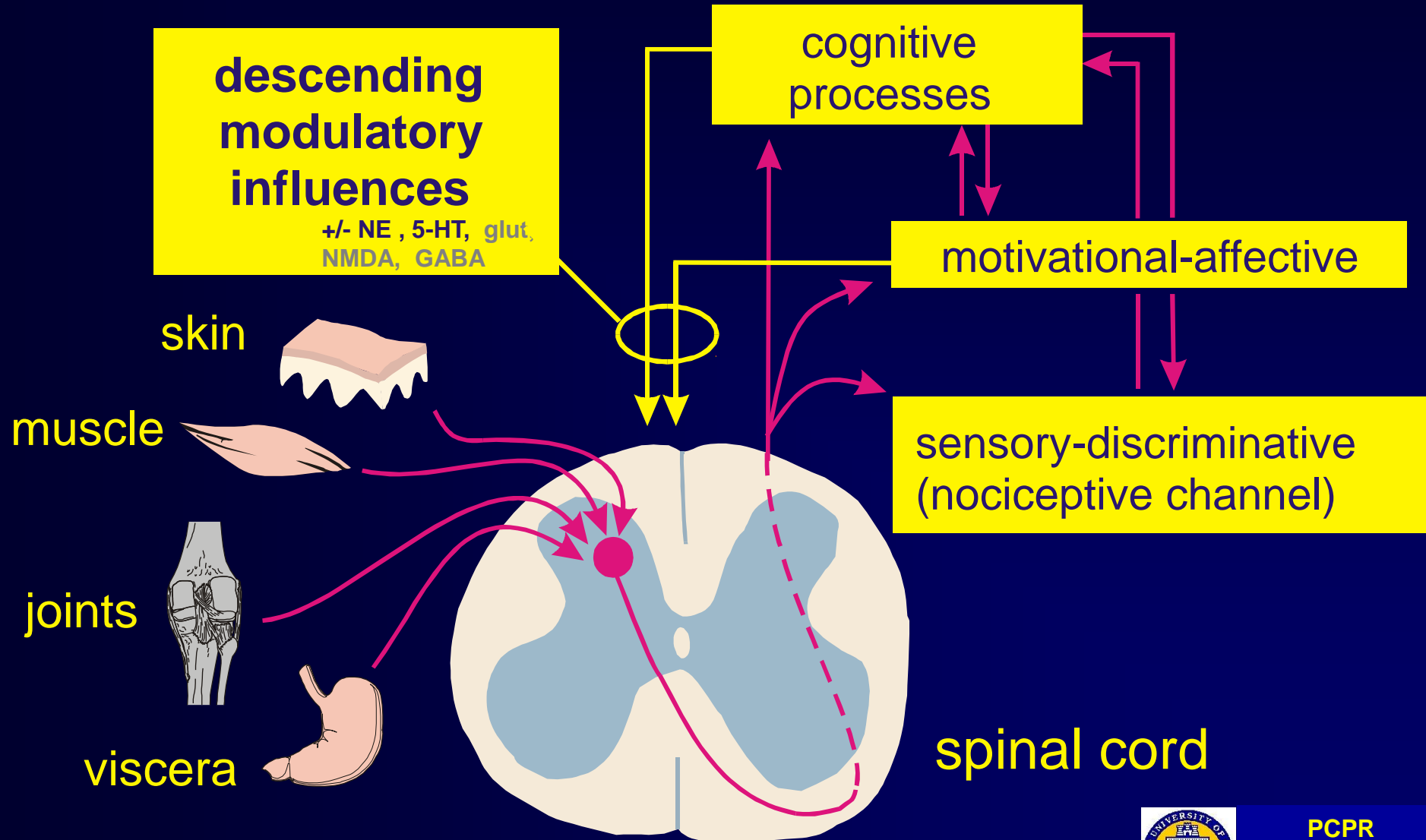
Undermine
dementia

Falsely escalate
pain severity &
impact

**Dementia &
Social Isolation**



Basic Understanding of Pain Channels



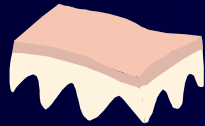
Basic Understanding of Pain Channels

**descending
modulatory
influences**

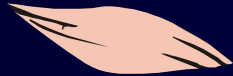
+/- NE, 5-HT, glut,
NMDA, GABA

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

skin



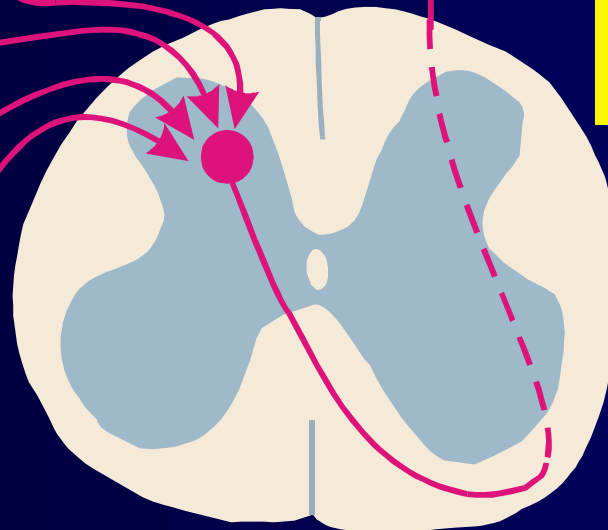
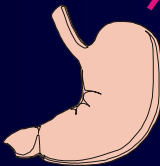
muscle



joints



viscera



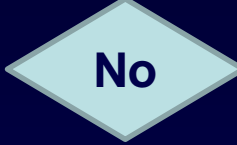
sensory-discriminative
(nociceptive channel)

spinal cord



Is patient able to verbally report pain?

Is patient able to verbally report pain?



Behavioral
Assessment

PAINAD

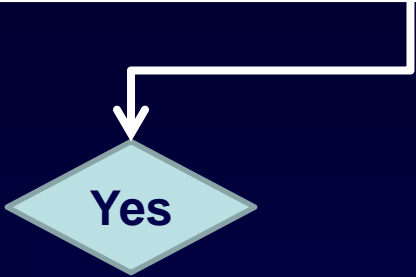
(Pain Assessment in Advanced Dementia)

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

Is patient able to verbally report pain?

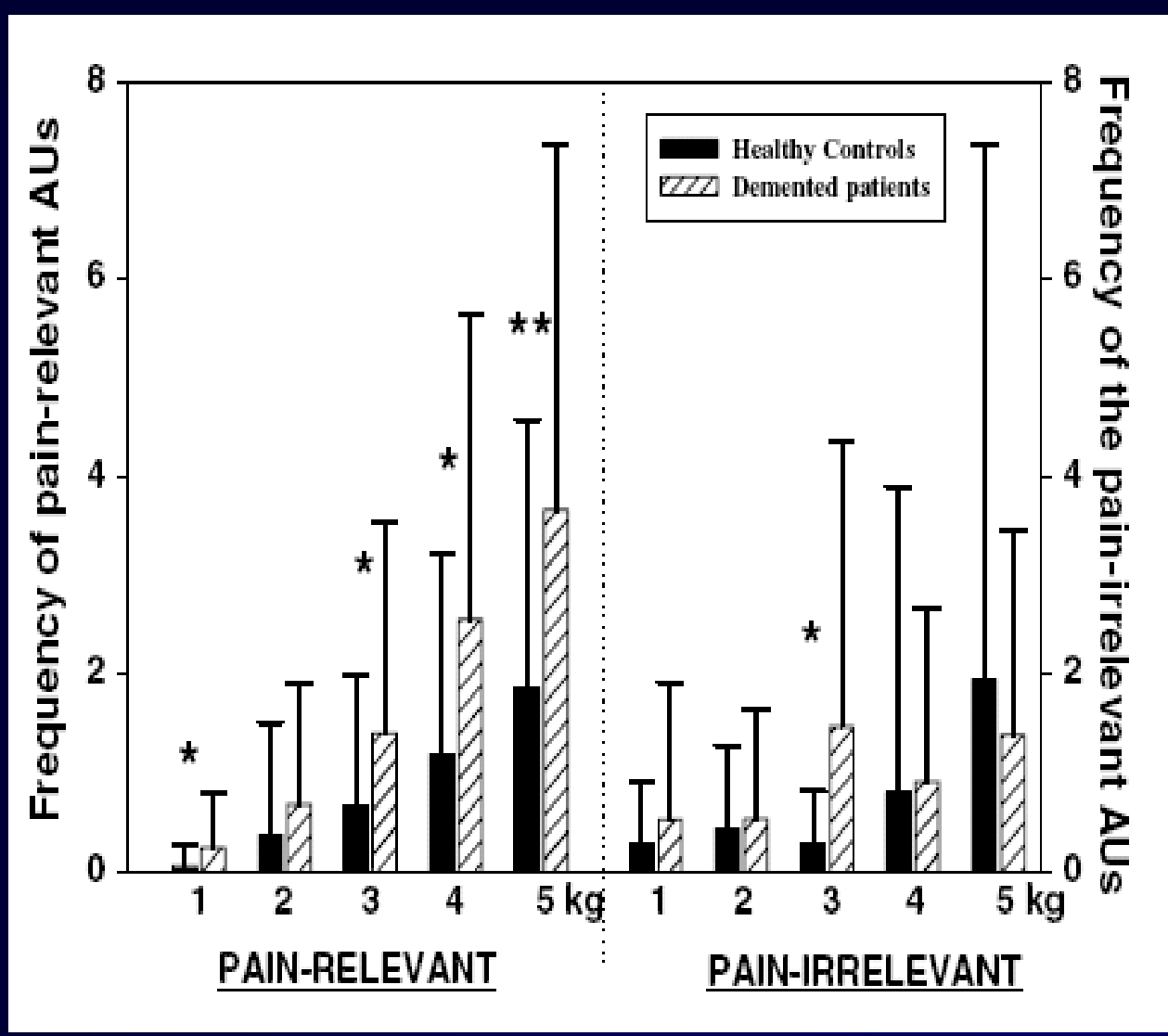


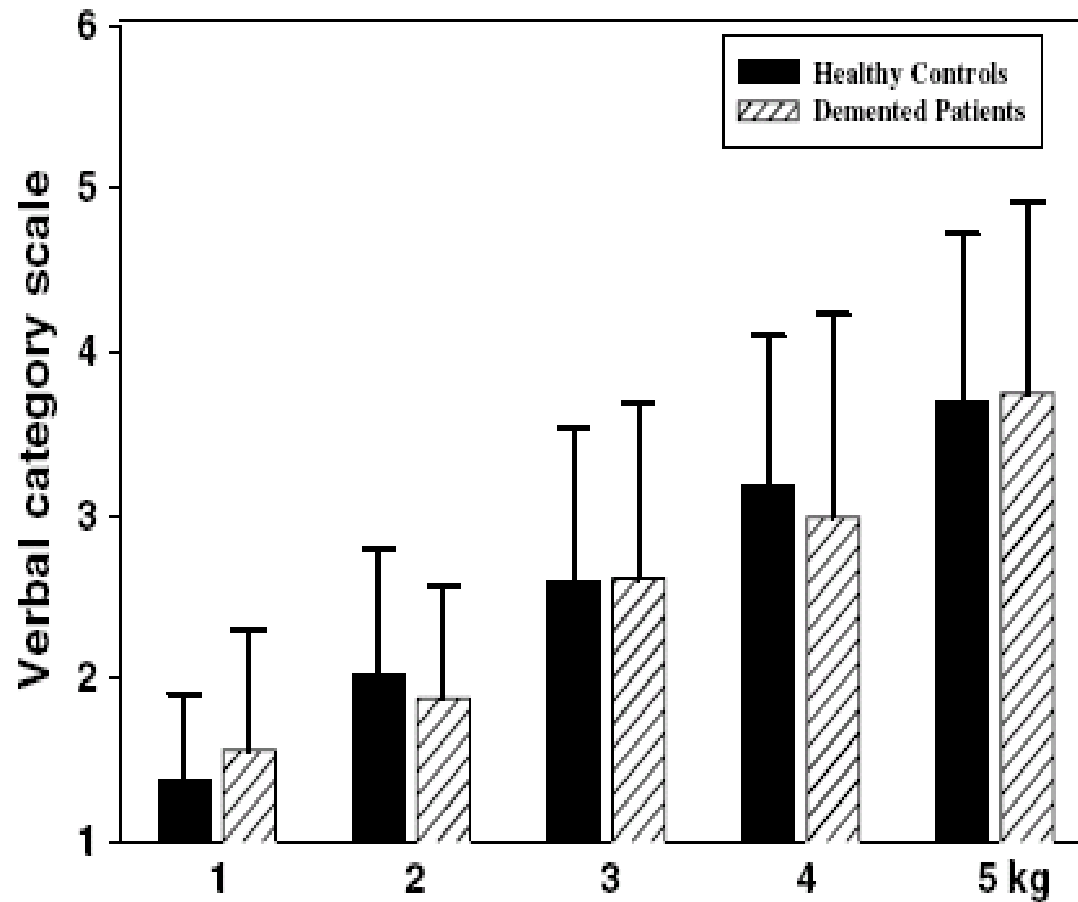
Dementia can impact...

- Pain reporting
 - Reliable for current pain intensity, ? validity
 - Historical inaccuracy
- Treatment compliance
- Pain coping
 - Fear avoidance
- Treatment expectancy
- Treatment response?

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AD & Facial response to acute pain



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
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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

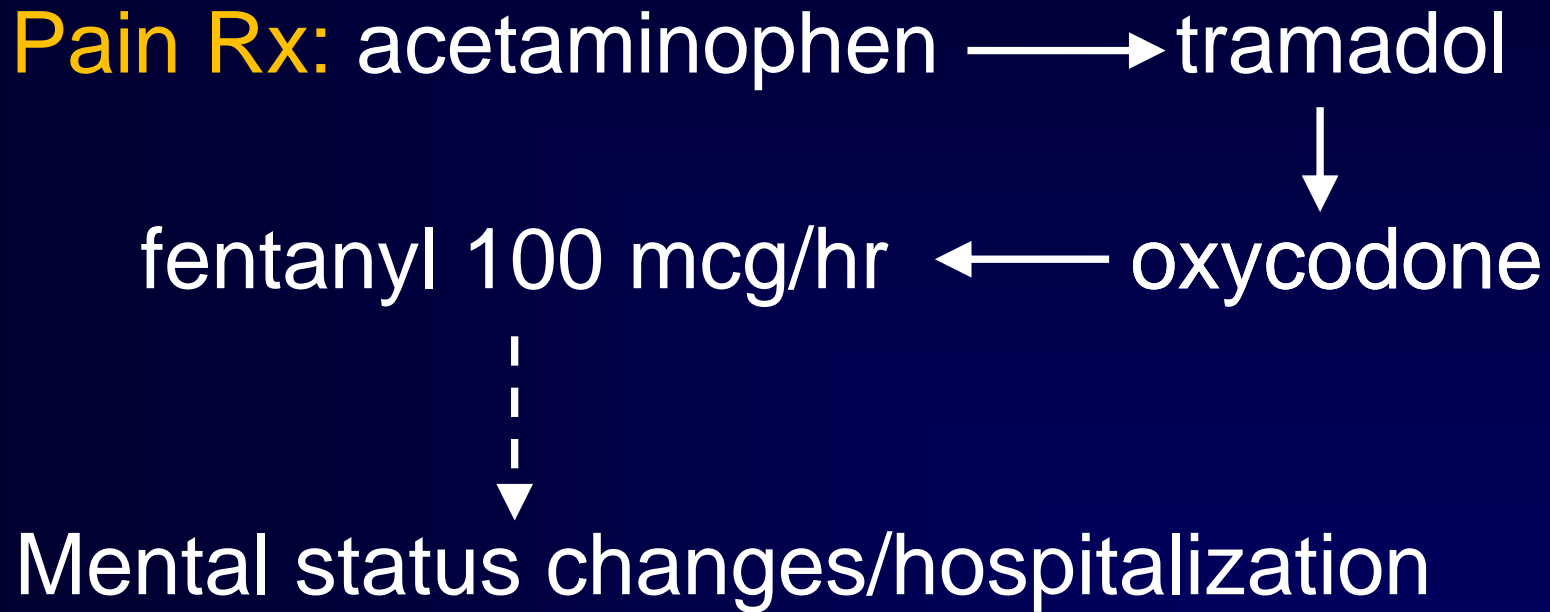
```
graph TD; A[acetaminophen] --> B[tramadol]; B --> C[oxycodone];
```


Case Presentation (cont.)

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

```
graph TD; A[acetaminophen] --> B[tramadol]; B --> C[oxycodone]; C --> D[fentanyl 100 mcg/hr];
```

Case Presentation (cont.)



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.”

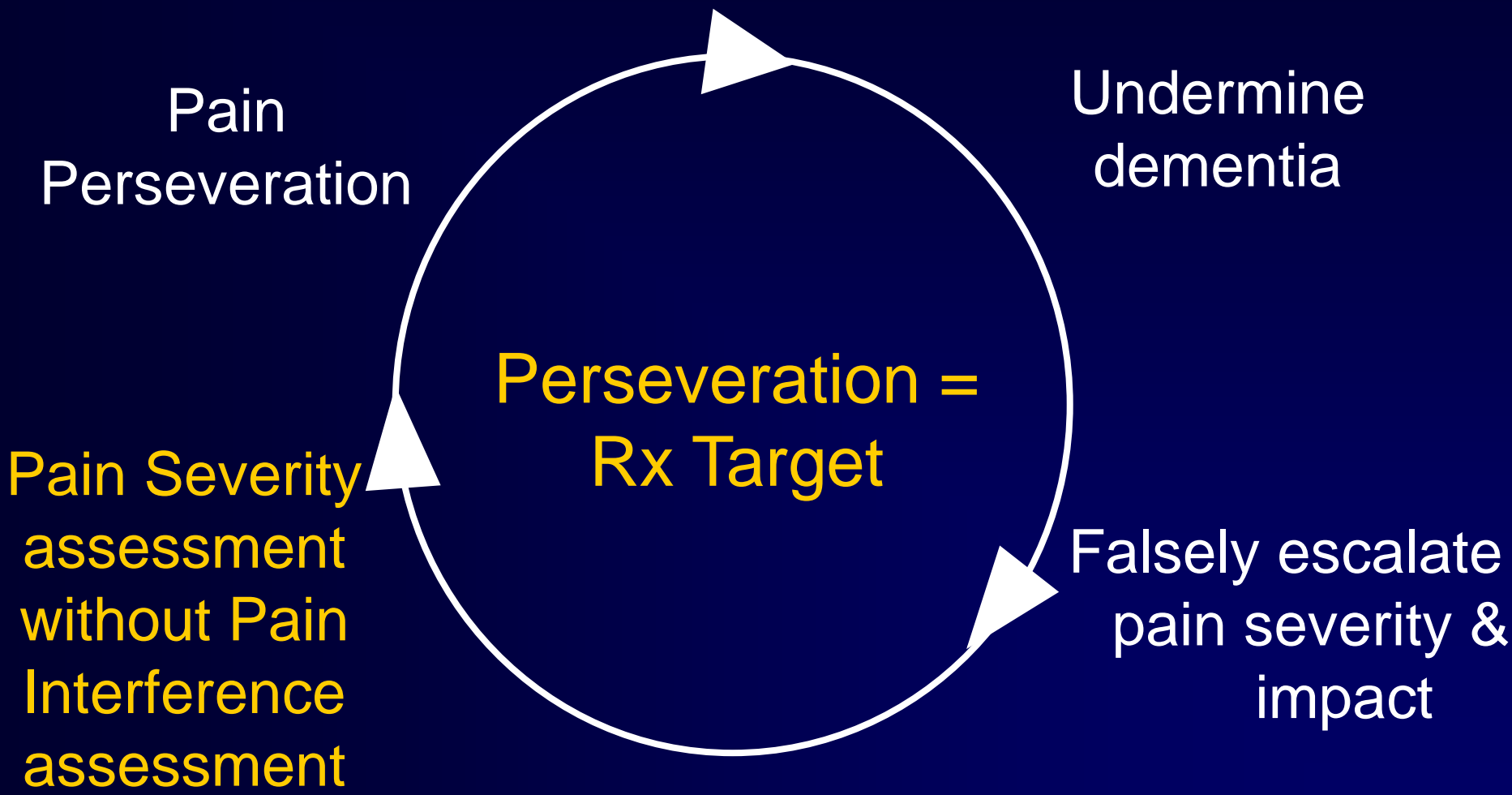
Case Presentation (cont.)

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



Perseveration =
Rx Target

Pain
Perseveration

Undermine
dementia

Pain Severity
assessment
without Pain
Interference
assessment

Falsely escalate
pain severity &
impact

Dementia can impact...

- Pain reporting
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 - 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

Dementia and Expectancy

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

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

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.

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 \longrightarrow \downarrow 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 \longrightarrow Pharmacodynamic effect

Treatment Expectancy \longrightarrow Hope - Placebo effect

Pharmacodynamic effect + Placebo effect

What is the effect of placebo?

Analgesic → Pharmacodynamic effect

Treatment Expectancy → Hope - Placebo effect



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”
- \geq age 85
- Disconnect between reported pain level and observed pain behaviors

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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.”

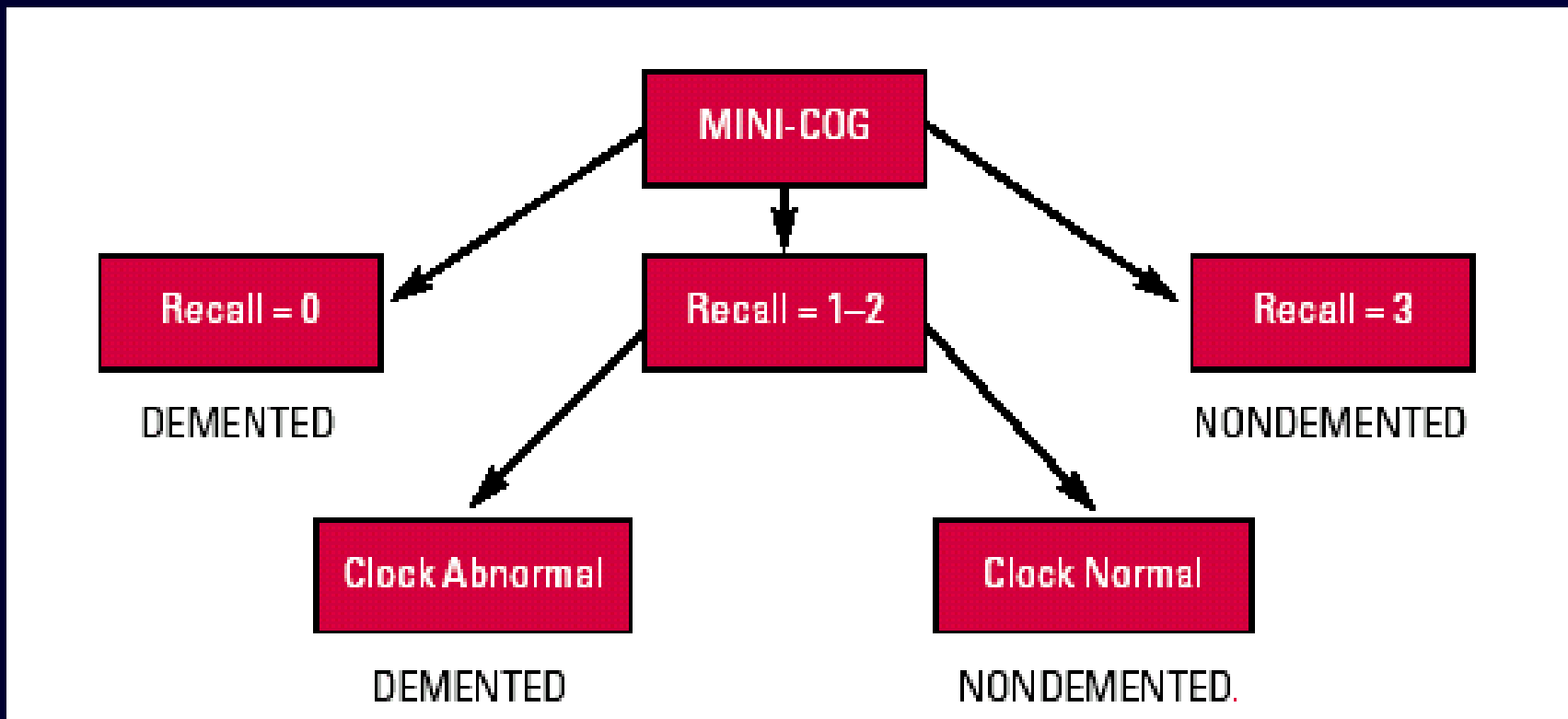
Dementia Screening: The Mini-Cog

- “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
Borson et al 2000; Int J Geriatr Psych 15: 1021

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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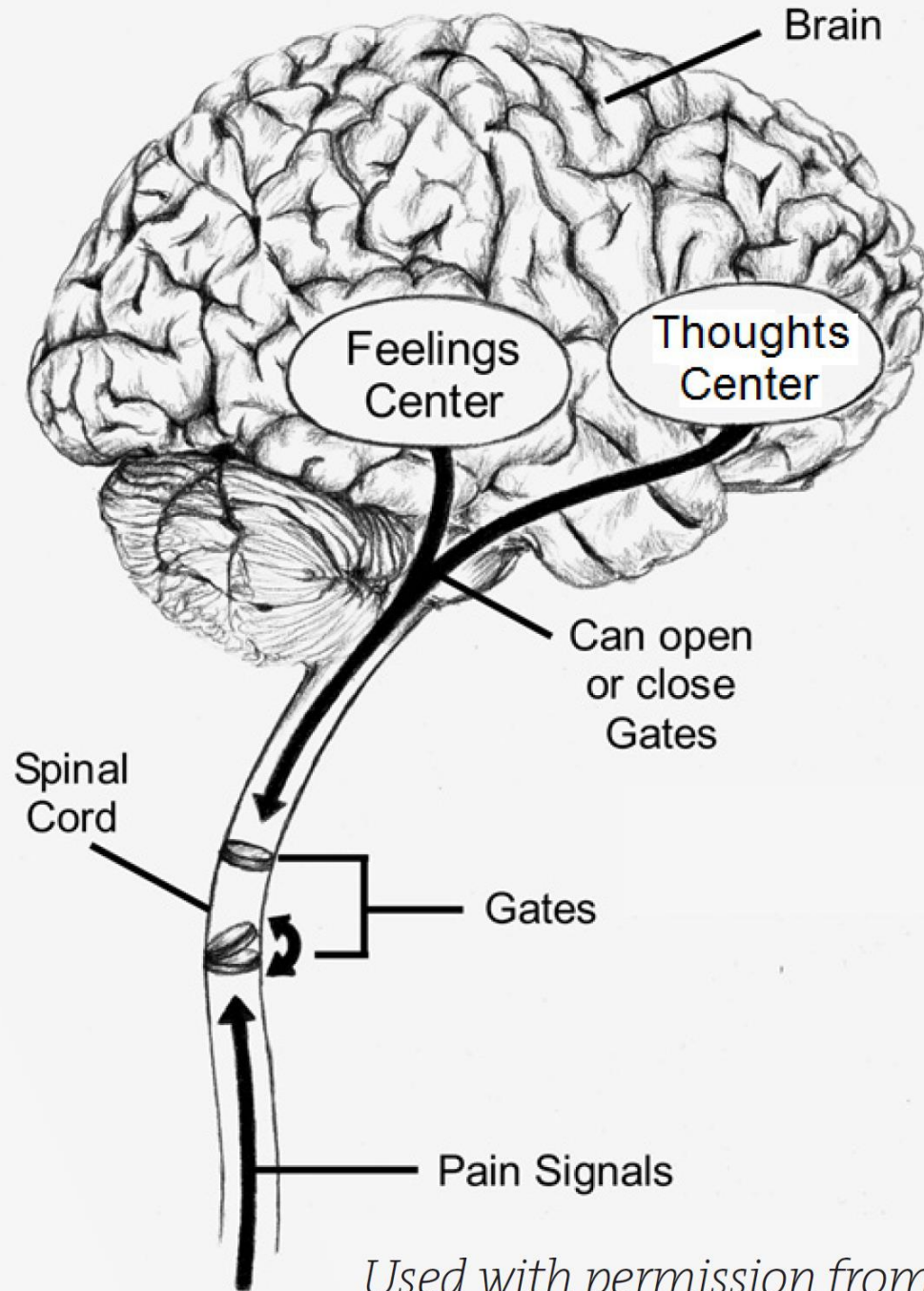
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- **Validate self-report**

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.



*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

NOW

YOUR PAIN

YOU

Your pain has you.



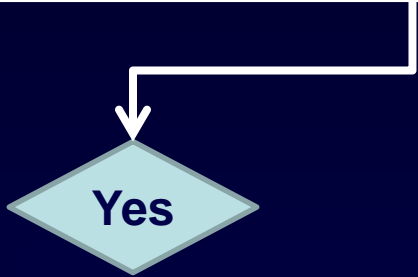
SOON

YOU

YOUR PAIN

You have your pain.

Is patient able to verbally report pain?



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.

Key Point

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.

Key Point

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...

Kimberly.Clemens@va.gov (Kimberly Clemens)

