# Recognizing Pain in Persons with Dementia

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# Objectives of the Presentation

- Describe the difficulties in determining whether persons with dementia are having pain
- Identify some ways to decide whether pain exists in persons who cannot remember or express themselves
- Explore how research has improved knowledge about understanding pain in persons with dementia
- Discuss applications to OEF/OIF

# Human Concern and Health Care Mandate

- Pain management is the standard of care for all persons
- VA: Pain is the 5th Vital Sign
- Joint Commission
  - assess, intervene, reassess
  - document, communicate
- American Geriatrics Society
  - comprehensive, disease-specific
  - individualized

# Do persons with dementia have pain?

## Challenges to determining pain

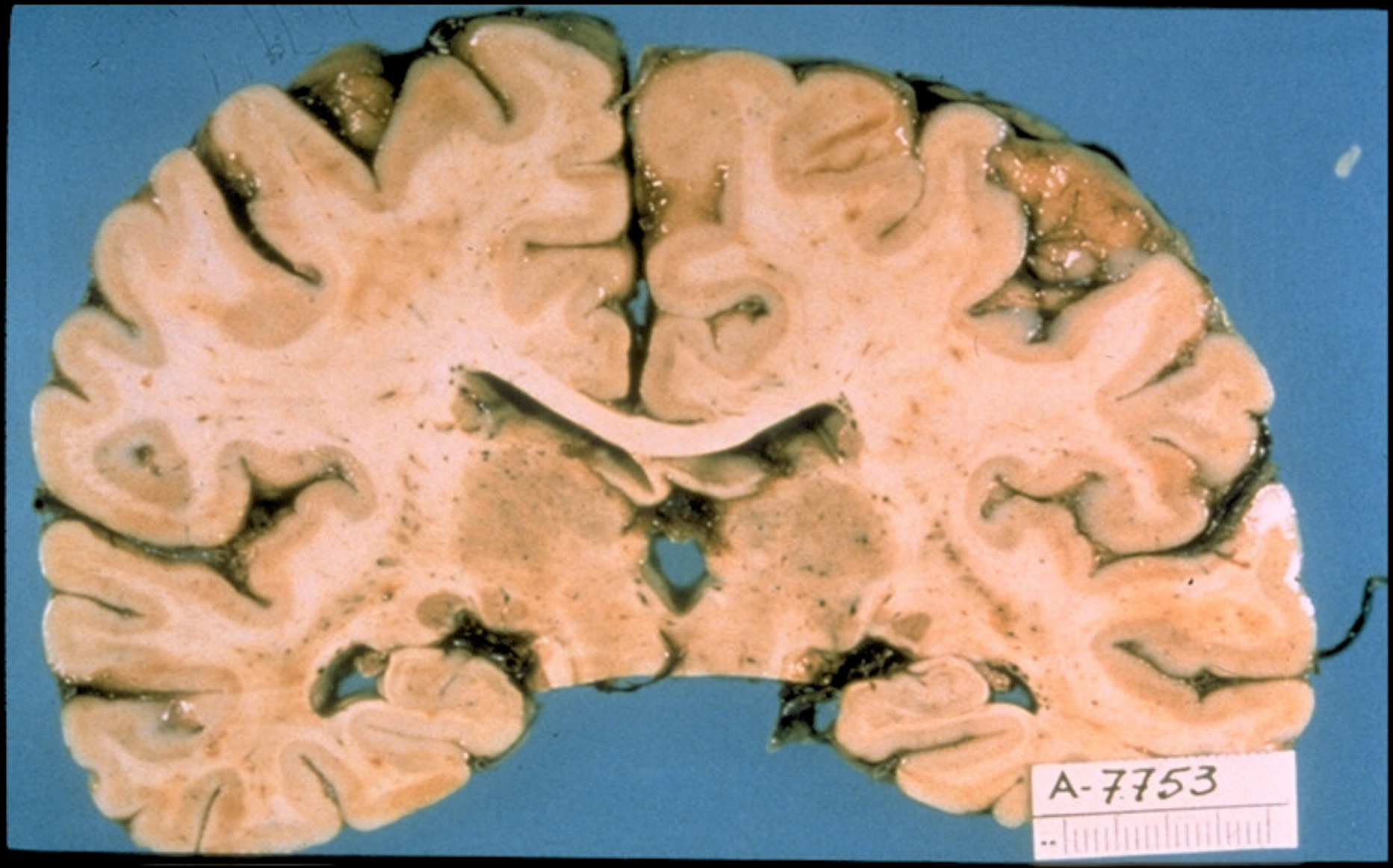
# Definition of Pain

- Pain=
  - verbal report
  - whatever the person says it is (McCaffery)
- Discomfort=
  - objective signs
  - behaviors
  - express negative emotional or physical state (Hurley et al)

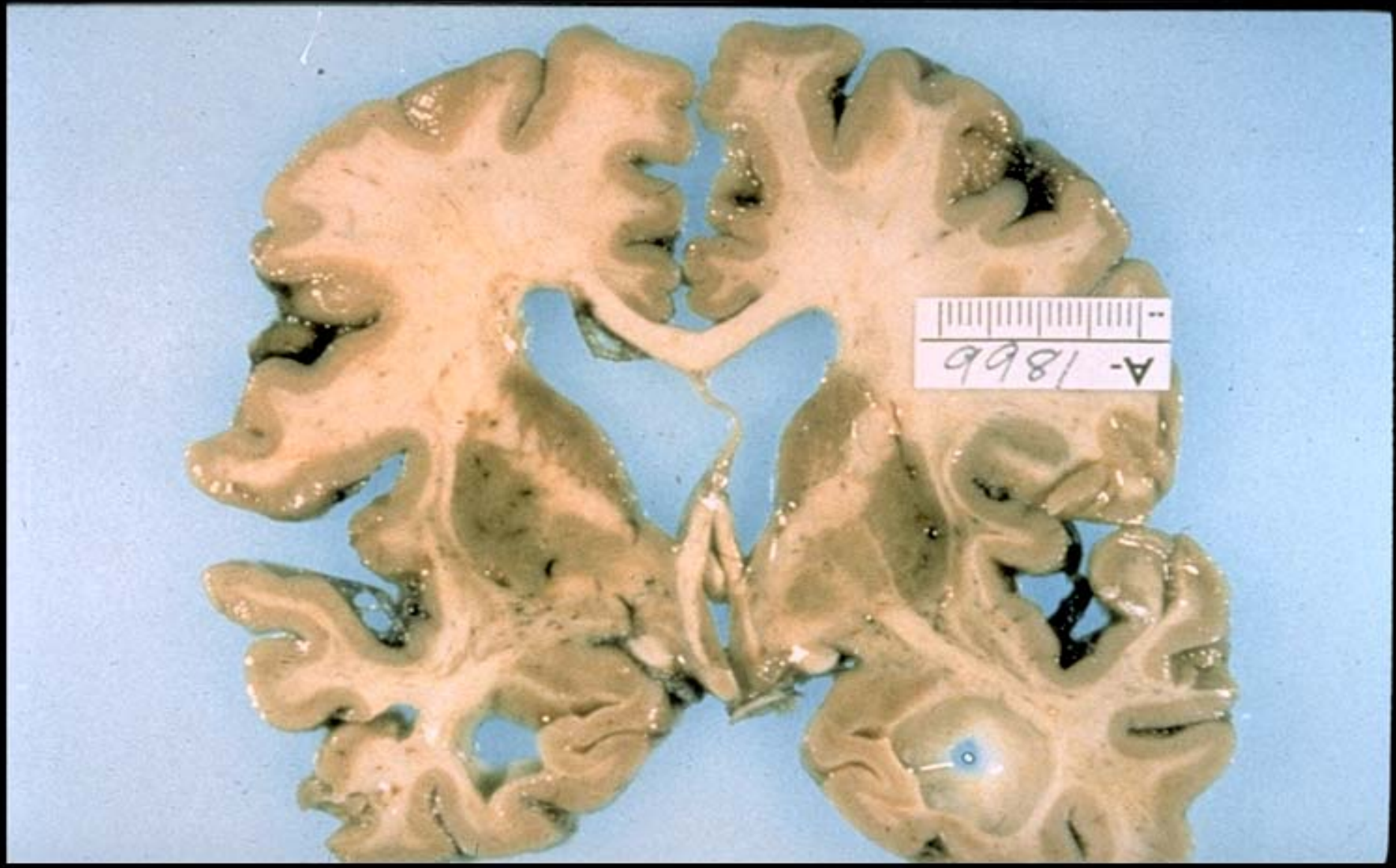
# Dementia

- Memory impairment
- Language disturbance
- Inability to recognize
- Impaired ability to plan, organize, abstract, conceptualize, sequence
- Difficulty carrying out tasks

# Normal Brain



# Alzheimer's Brain



# What happens to pain?

- What was person like?
  - Pain patterns
  - Analgesic use
  - Behaviors
- As dementia progresses
  - Verbal reports of pain?
  - Change in behavior?

# Pain in the Nursing Home

- Greater than 50% are cognitively impaired
- 80% have at least 1 pain complaint
- 47% have 3 or more pain complaints

(Parmelee et al., 1993)

- ↑cognitive impairment→
  ↓ pain complaints

(Miller et al., 1996; Parmelee et al., 1993)

# Potentially Painful Conditions

- Musculoskeletal
  - backaches, arthritis, fractures, falls, injuries
- Gastrointestinal
- Circulatory
  - cardiac, peripheral vascular pain
- Cancers / tumors
- Neurological
  - headaches
- Peripheral neuropathy

# Problems in Determining Pain

- No standard measure for *severely* demented
  - nonverbal patients cannot self-report
  - 0-10 doesn't work
- No request, recall, evaluation
- Do dementia patients have pain?
- Diseases common in elderly
- What is best way to assess pain?

# Family Caregivers

- Familiarity
- Understanding the person
  - Behaviors
  - Moods
  - Facial and bodily expressions
- Overwhelming?
  - Pain as a priority?

# Measuring Pain in Persons with Dementia

# American Geriatric Society Guideline Recommendations

- Facial expression
- Verbalization, vocalization
- Body movements
- Changes in interpersonal interactions
- Changes in activity patterns/ routines
- Mental status changes

# VHA Consensus

- Assess behavioral signs
- Describe visible signs of pain
- Document assessment
  - Do not use 99
  - Do not be the proxy by providing #
- Document intervention and effect

# Scales for Measuring Pain

Depends on verbal ability:

- Faces, Verbal, 0-10, Line

Observational:

- Checklist of Nonverbal Behaviors
- Discomfort Scale
- PainAD
- NOPPAIN
- Doloplus 2
- PACSLAC
- http://www.cityofhope.org/prc/elderly.asp

# Updated Findings

- Effectiveness of pain management should be included in assessment tools (Helme, 2007)
- PACSLAC and Doloplus 2 are the most sound psychometrically (Zwakhalen et al., 2006)
- All tools have been developed since 1992
- Most need more validity and reliability testing with larger samples

# Numeric Pain Scale (0-10)

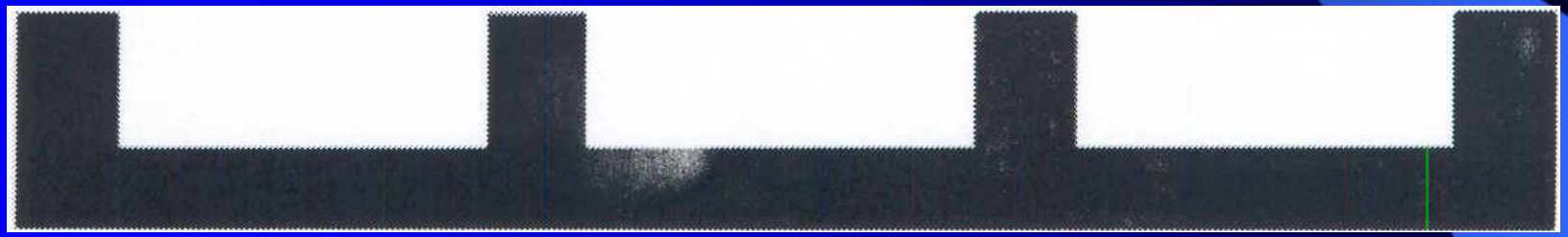
0 1 2 3 4 5 6 7 8 9 **10**

NO PAIN WORST PAIN

(McCaffery and Pasero, 1999)

# Verbal Pain Scale

NO PAIN MILD MODERATE SEVERE



# Checklist of Nonverbal Pain Indicators

(Feldt, 2000)

(Evaluate at rest and during movement)

- Vocal complaints: nonverbal (moans, groans, cries, sighs)
- Facial grimaces/winces (clenched teeth, furrowed brow)
- Bracing (holding onto side rails)
- Restlessness (shifting position, inability to keep still)
- Rubbing (massaging affected area)
- Vocal complaints: verbal ("ouch"; "that hurts"; cursing;"stop")

# Discomfort Scale
(Hurley et al, 1992)

- 9 observable behaviors:
  - noisy breathing, negative vocalization, sad or frightened facial expression, frown, tense body language, fidgeting
- Each observation is rated 1-3 according to:
  - intensity, duration, frequency
- Difficult to use, training required

## Pain AD
(Warden et al., 2003)

- 5 observable behaviors each rated 0-2
- Noisy breathing, negative vocalization, facial expression, body language, consolability
- Based on Discomfort Scale
- Score of 4 indicates pain treatment trial
- Easy to use, each behavior defined, little training required

# No Bodies in Pain (NOPPAIN)
(Snow, et al, 2004)

- Focuses on specific pain behaviors while doing common care tasks
- 4 sections
  - **Care conditions for observation**
    - **Bathing, dressing, transfers**
  - **Presence/absence of pain behaviors**
  - **Pain behavior intensity**
  - **Pain thermometer for overall rating**
- Excellent in clinical care
- Easy for caregivers to use, some training

## Doloplus 2 (Wary et al, 1999)

- 10 items
- Rated from 0 to 3 (intensity)
- 5 of 30 total = pain
- Total score reflects progression of experienced pain rather than pain at a particular moment
- Adapted from use with children
- French and English

# Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)
(Fuchs et al., 2004)

- 60 items with 4 subscales
  - Facial expressions
  - Activity/body movements
  - Social/ personality/mood
  - Physiological/eating/sleeping/vocal
- Scored as present or absent
- No interpretation of score available
- Created from interviews about recalled patients

# Other signs of pain: Information from observation and caregivers

- Family members know
- Watch during movement
- Other signs:
  - Poor appetite
  - Depressive symptoms
  - Poor sleep
  - Change in function
  - Agitation
  - Refuses care
  - Moans, groans, cries

# What does our research show?

# What is the relationship between pain, dementia, and agitation?

- 66 patients in VA NHCU
  - With painful diagnoses
  - With agitated behavior
- Significant and positive relationships:
  - Discomfort and agitation
  - Discomfort and dementia severity

(Buffum, Miaskowski, Sands, Brod., 2001)

# Does regular medication decrease discomfort better than as-needed medication?

- 42 patients in VA and non-VA nursing homes
  - With pain, agitation, severe dementia
  - Given regular acetaminophen 4 times/day for 2 weeks and then as needed for 2 weeks
- No difference in discomfort between regularly scheduled vs as-needed medication

(Buffum et al., 2004)

# Patients' Characteristics

Pain Sources (multiple):

- 84% have DJD
- 52% osteoporosis
- 38% fractures
- 15% back pain

Ability to report pain:

- 70% nonverbal; 30% inconsistent

# Behaviors

Agitated behaviors:

- Restlessness 46%
- Repetitive mannerisms 32%
- Repetitive speech 19%
- Strange noises 17%
- Trying to leave 12%
- Wandering 9%
- Screaming 7%

# Is the PAIN AD useful in other settings? With other patients?

- In 3 VA medical centers
  - (SF, LA, SD)
  - In ICU, nursing home, acute care
  - 110 patients
- Is the PAINAD useful in all 3 settings?
- Only with patients with severe dementia!

# What is the family role when patients move between settings?

- 34 family caregivers
- 66% unsure about staff recognition of pain
- 50% were asked about pain during admission
- Informal caregivers are an untapped resource for information
- Family caregivers are unsure how to discuss pain with providers

(Buffum and Haberfelde, in press)

# Caregiver Quotes

"Now she is not verbal. The staff is very kind and cares for her, but don't seem to think of pain as a cause of restlessness."

# Caregivers' Recommendations

"Family history told by caregiver, the patient themselves, and observations made by physicians and all persons involved. Caregivers probably have more information than anyone else involved."

"Watching body language. Being sensitive and asking frequently. It was very interesting (and a challenging experience) to see different nurses and doctors and family members' attitudes and understanding of pain issues."

# Caregivers' Recommendations

"Need better trained nursing assistants and more staff. I wish I had known some about pain management or even its existence. My mother also had a bed sore—I advocated but do not recall pain meds being administered."

"Training caregivers in use of appropriate scale for person and how to use it. Ongoing inservice or refresher courses for both staff, caregiver and family."

# Nursing Research in Progress

(Serial Trial Protocol: Kovach et al.)

- Rule out all possibilities
  - Pain, discomfort
  - Emotional expression: lonely, bored, sad
  - Physical need: hunger, thirst, fatigue, restless
- Try giving pain medication if think person has pain!
- If pain medicine works, try giving it routinely

# What does all of this research mean?

- Discomfort does not always mean pain
- Aggression, agitation, behavior change can be signs of discomfort or pain
- Existing scales probably work best for persons with dementia
- Most persons have only one or two of the behaviors on the observational scales
- Tylenol is not the drug of choice for all conditions
- Family caregivers need to be included

# In Sum

- Persons with dementia may have pain just like other people!
- Family caregivers and health care team members need education and communication about pain
- Persons with dementia need advocates
- Pain and discomfort should be treated in collaboration with ALL of the health care team

# Recommendations: Clinical Practice

- Find what works, be consistent
- Communicate what works and explore strategies with:
  - Family caregiver
  - Staff
  - Medical record
  - Other settings
- Continuously evaluate what works
  - If stops working = other need?

# Recommendations: Research

- Test the pain scales for other patients with problems expressing themselves (delirium, stroke, brain injury)
- Explore the role of family as part of the care team
- Empower family caregiver to learn how to identify and report pain

# Where we've been today

- Challenges to pain assessment
- Review of tools to evaluate pain
- Research findings that have guided practice
- Research that is needed to improve care to this vulnerable population

# Applications to OEF/OIF

- What is current practice?
- Pain assessment tools
  - Can any be adapted?
  - Testing of tools
- Types of pain
- Brain damage issues
- Behavioral, mood, personality issues
- Family and psychosocial issue
- Effectiveness of pain interventions
- Documentation issues