Pain and Behavior Problems In End-Stage Dementia: Evaluation And Management

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OBJECTIVES
Following this presentation, regarding patients with End-stage Dementia, the learner will be able to:
1. Describe the appropriate evaluation of behavior problems.
2. List the current non pharmacologic and pharmacologic management techniques and their evidence
3. Utilize evaluation tools for pain in end-stage dementia
4. Formulate and manage a highly effective pain management plan in conjunction with nursing home personnel
5. When to quit advocating for patients with dementia

Dementia and End-Of-Life Symptoms
• Pain…………………….. 50-85% 
• Depression………………25-50% 
• Apathy…………………50%
• Psychotic symptoms……..35-55%
• Delirium ………………..83%
However; due to perceptual and communication disabilities…………under treated

The Needs & the Care
For end-of-life health care needs Dementia same level of problems & discomfort as cancer patients;
However;
- Dementia pts experience sx longer
- EOL suboptimal care & inadequate palliation of symptoms

End-stage dementia & Nursing Homes
• QOL and quality of care at end-of-life----POOR
Due to:
-unsuitable physical environments
(e.g. lack of privacy, noise)
-inadequate staffing
(e.g. sub optimal, bathing, oral care, fluids & food intake, repositioning.)
Too much treatment:
-overuse systemic antibiotics, feeding tubes, inappropriate life-sustaining treatments & hospitalizations, etc.

Dying with Dementia
• ES Dementia – NH- 54.8% died/18 mo  N= 323
• Of the dead in the last 3 months of life
-40.7% received burdensome interventions
(hospitalizations, IVs, ER, TF)
and had uncontrolled sx; dyspnea, pain, PU, agitation,
-29.9% referred to hospice
-20% proxies aware < 6 mo to live
-18% of proxies received prognostic information.
-32.5% of proxies counseled re; ES dementia complications
Bottom Line: Hospice Partnering with NH can improve this
Difficulties Evaluating Symptoms

Pain
- In pain but less reporting by patient
Therefore; receive less analgesia

Solution
- Institute dementia specific pain scales
  examples: PainAD, CPNI (see end of handout)
- Assume behavioral outbursts secondary to
  pain, treat with analgesics and track
  frequency/severity of behaviors

Won A. et al. JAGS 1999; 47: 936-942
Curtis JR UNIPAC 9, pages 20-25

American Geriatrics Society
PAIN ASSESSMENT
Assess these behaviors as indicators of pain
- Facial expressions,
- Verbalizations & Vocalizations
- Body movements
- Changes in interpersonal interactions
- Changes in activity patterns or routines
- Mental status changes

Summary
End-stage dementia patients have:
- Just as much pain and discomfort as any Hospice patients
- Cannot express needs
- Often manifest pain or uncomfortable sx. as problem behaviors

Medical and delirium evaluation must be consistent with patient's goals of care
MEDICAL EVALUATION

Medical/Nursing interventions
a. Delirium evaluation as indicated (consistent with Goals Of Care)
b. Pain and general discomfort management (asssume behavior due to pain until proven otherwise)
c. Sensory enhancement
d. Removal restraints
e. Meeting physical needs
   food, hydration, dry*, dyspnea?, comfortable
temperature, etc)
   * Bowel, bladder, etc.

**Next Step**
Evaluation for Pain As a Cause of Behaviors
Usual pain evaluation plus:
- Painful source? (e.g., OA ~ 80% of elderly)
- Pain signature? (e.g., with movement what do they do?)
- Experienced nurses observation- highly valid
- Nurses and aids caring for pt long term – may be biased
- If pain is possible as cause of behavior............
   .................treat with analgesics and observe

PAIN MANAGEMENT

The three Guiding Principles of Pain Management in the Elderly

1) ALWAYS ATTEMPT TO INCORPORATE:
   • NONPHARMACOLOGIC TREATMENTS
     Why? Sensitive Brains, Lower SE

2) When adding PHARMACOLOGIC modalities:
   • USE SCHEDULED DOSE as much as possible
     Why? Reduce Decisions By NH staff, Less SE

3) When adding PHARMACOLOGIC modalities:
   • CHOOSE MEDICINES WITH THE LEAST SIDE EFFECTS

Pharmacologic: “Pain Relief Pyramid”

- narcotics
- Tylenol & Topicals
- NON PHARMACOLOGIC

Nonpharmacologic

Why? Comfort + low side effect risk

Temperature contrast:
- cold for acute (give scheduled & length of time)
- heat/cold for chronic
- e.g. -Warm moist packs 20 min tid-qid

Comfortable surfaces

Positioning

Physical therapy — employ early, shop for therapist’s strengths

Manipulation; massage — engage nursing, family

TENS unit

Alternative care practices
   (be inventive- next slide)

BATHING & HYGIENE

- Often issue of discomfort, fear and behavioral problems

ALTERNATIVE
- Person-centered towel bathing in bed.
- The Bathing of Older Adults with Dementia

AJN, American Journal of Nursing, April 2006

Pharmacologic: Pharmacologic: Pain Relief Pyramid

**1ST CHOICE --- ACETAMINOPHEN**
- lowest side effect, use as scheduled does for greatest effect
- NPO ---- suggest: 650 mg per rectum q.i.d
- P.O ------- 650-1000mg q.i.d or NEW! (XL 650mg two tid)
- Compatible with opiates.
- Total dose less than 4 gms/24 hours
- When on scheduled dose acetaminophen; AVOID acetaminophen/narcotic combinations as prn’s.

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**Pharmacologic: Acute Pain Pain Relief Pyramid**

**Next step:**
- Always add PRN narcotics
- Best choices:
  - Morphine sulfate
  - Oxycodone
  - Hydromorphone
  - Tramadol
  - Fentanyl

**Why Best choices?**
- Side effects well-known
- All have sustained release form except hydromorphone

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**“Oh by the way”**

**Constipation:**
- When prescribing narcotics in the elderly
- always add bowel hygiene
- e.g Senna 1-2 tablets q day ( max 6/day)

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**Pain and End-stage dementia**

- Set parameters NH personnel can understand
  - behaviors consistent with pain
  - get to scheduled dose quickly (take decision out of the hands staff who may be uncomfortable)
  - use pain scales to titrate drug

Remember; longtime caregivers may have bias…. Solution;=> Discover biases re-educate

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**Example of use of PainAD scale**

Example order;
1) For PAINAD scale 6-10 give morphine 5 mg buccal every one hour until PAINAD < 5
2) For PAINAD scale 3-5 give morphine 2.5 mg buccal every one hour until PAINAD < 3
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e. Meeting physical needs
   food, hydration, dry*, dyspnea?, comfortable temperature, etc
* Bowel, bladder, etc

Next Step

Sensory Enhancement

VISION
• Glasses
• Lighting- day time vs night time

HEARING
• Hearing aids
• Wax impaction
• Approach to speaking
• "Pocket Talker"

Removal of Restraints

• Nursing homes must be restraint free environment
• Hospice can help to meet requirements.
How?
By everything we were talking about in this lecture.

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Meeting physical needs

• Food,
• Hydration,
• Dry? (frequency of change)
• Dyspnea? (often overlooked)
• Comfortable temperature (who runs the thermostat?)
• Patient advocacy
• Diplomacy

BEHAVIORAL PROBLEMS in DEMENTIA

1. Understand and tailor behavior management plan
2. Medical evaluation & treatment (delirium)
3. Continue treatment & reassess
4. Improved
   - Improved
   - Not improved

5. Medical evaluation & treatment (dyspnea)
6. Behavior management plan:
   - Specific & characteristic behavior
   - Use specific "behaviors-based" nursing interventions
   - Comprehensive & holistic approach
   - Patient & family education
   - Evaluation & feedback

- Patient and family behavior management plan
- Educate caregivers

3/25/2011
Behavior management plan

- Most commonly overlooked by health care facilities.
- Provides consistent plan
- Teaches staff management techniques
- Addresses patient’s basic needs

Next step; Behavioral Management Plan

1. General approach devised with staff.
2. Review psychiatric and social history to understand current behavior.
3. Devise specialized activity when possible.

DATA WE NEED ABOUT THE BEHAVIOR

Specify & characterize behavior (use specific “behavior-based” terms)
- Provocative & palliative
- Historical & social perspective
- Establish baseline

Where can we get this data?
- Family, nursing baseline, PT/OT observations
- Family, nursing baseline, PT/OT observations
- Social work hx, family
- The Facility Staff

General Non-pharmacologic Interventions for BPSD

- Prevention
  - Does patient know who you are and why you are there?
  - Awareness/education/support
- Approach/Relationships/Trustbuilding
- Environment (Milieu Management)
- Safety/Reassurance
- KISS (Keep It Short and Simple)
- One Direction at a Time

Specific Intervention Examples

- Use of Printed Schedules/Care Plan for Hospice and NH Staff
  Should include:
  - Step-by-step approach initial approach
  - Interventions to deal with Sight, Hearing, or Physical Barriers

Care and Behavior Management Strategies

example strategies

Approach to Mr. B.
- always speak in his right ear
- deepen your voice and speak slowly
- identify yourself, what you are going to do, and remind him that he is safe and no harm will come to him.
- make sure that he knows when you are going to move him.
- remind him step by step, what you are going to do.
Depression in End-Stage Dementia

Symptoms
- difficult to be sure

Clues:
- Prior problems with depression
- Lost interest in previous activities
- Sleep pattern change
- Increased irritability and agitation

Consider depression if your efforts to reduce irritability and aggressiveness through all the previous algorithm fail—give trial antidepressant with dual benefit

When to use antipsychotics?

If:
1) All these are covered and met

If not reaching behavioral goals, next step:

Classify into dominant behavioral symptoms:
1) Hallucinations/paranoia/delusions (i.e. psychoses in dementia)
2) Aggressive, violent, or impulsive
3) Sexual orientated aggressive behavior
4) Anxiety or restlessness

Psychotic symptoms

Hallucinations/paranoia/delusions

<table>
<thead>
<tr>
<th>Choices</th>
<th>starting dose</th>
<th>max. dose</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haloperidol</td>
<td>0.5 mg q 30 min prn</td>
<td>behaviors that impair care (Haldol) then moved to scheduled dose</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>12.5-25 mg q.d. 50-100 mg bid (Seroquel)</td>
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<tr>
<td>Olanzapine</td>
<td>2.5 mg q.d. 10-15 mg q.d. (Zyprexa)</td>
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<tr>
<td>Risperidone</td>
<td>0.25 mg q.d. 1 mg q.d.</td>
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Remember; NH need documentation and justification to use antipsychotics
Aggressive, violent or impulsive behavior

- Aggressive, violent or impulsive behavior
- Starting dose: max.

1) Gabapentin 100 mg hs 300 mg tid
2) Valproic acid 125 mg bid 500 mg tid
3) Trazadone 25 mg 150 mg q d.

Pearl: Look for dual indications such as neuropathic pain (gabapentin).
Non-FDA approved for these uses

Sexual orientated aggressive behavior

- First: Add SSRI, (if not had trial for these symptoms, try med. again if previous use for depression)
- Estrogen (males) 1.25-2.5 mg q day
- Progesterone 100 - 200 mg IM q 2 wks

Non-FDA approved uses

Anxiety/restlessness

- Make sure all previous issues addressed (depression, pain, etc)
- If delirium (very likely)
  - Haldol
- If true anxiety
  - Lorazepam

THE END
# Pain Assessment IN Advanced Dementia (PAINAD)

<table>
<thead>
<tr>
<th>Behavior/Significant Vibration</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>Score</th>
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<tbody>
<tr>
<td>Breathing</td>
<td>Normal</td>
<td>Occasional labored breathing</td>
<td>Noisy labored breathing</td>
<td>Long period of ventilation</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Cheyne-Stokes respirations</td>
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<td>Vocalization</td>
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<tr>
<td>No</td>
<td>Occasional moan or grunts</td>
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<td></td>
<td>Low volume speech with a negative or plaintive tone</td>
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<td>Painful expression</td>
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<td>No</td>
<td>Sedated, frightened,</td>
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<td>Body Language</td>
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<td>No</td>
<td>Attentive</td>
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<tr>
<td></td>
<td>Distressed, pacing,</td>
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<td></td>
<td>Fidgeting</td>
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<td>Constipability</td>
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<tr>
<td>No</td>
<td>Distressed or restless by voice or touch</td>
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<td></td>
<td>Unable to monitor, distressed or restless</td>
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To download form: [http://www.healthcare.uiowa.edu/igi/tools/pain/PAINAD.pdf](http://www.healthcare.uiowa.edu/igi/tools/pain/PAINAD.pdf)

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# Checklist of Nonverbal Pain Indicators (CNPI)

**Instructions:** Observe the patient for the following behaviors both at rest and during movement.

<table>
<thead>
<tr>
<th>Nonverbal Pain Indicators</th>
<th>Yes</th>
<th>No</th>
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*Note: Score all if behavior was not observed. Some behaviors occurred only briefly during activity or rest. The total number of behaviors is based on the patient’s response to pain and comfort.*

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*References:*