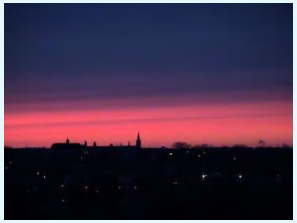
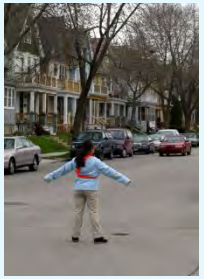






# UW-Milwaukee Campus

## Milwaukee, Wisconsin USA

College of Nursing

# The Ones who Can't Complain: Recognizing and Alleviating Pain in Persons with Dementia

Christine R. Kovach, PhD, RN, FAAN, FGSA
Distinguished Professor and Jewish Home and Care Center Research Professor in Aging
University of Wisconsin-Milwaukee

# BEHAVIORS ASSOCIATED WITH DEMENTIA

- Dementia-Biological Model
- Behavioral Models
- Environmental Vulnerability Models
- Unmet Needs Models

**FIGURE 1** C-NDB MODEL

Consequences of Need-Driven Dementia-Compromised Behaviors

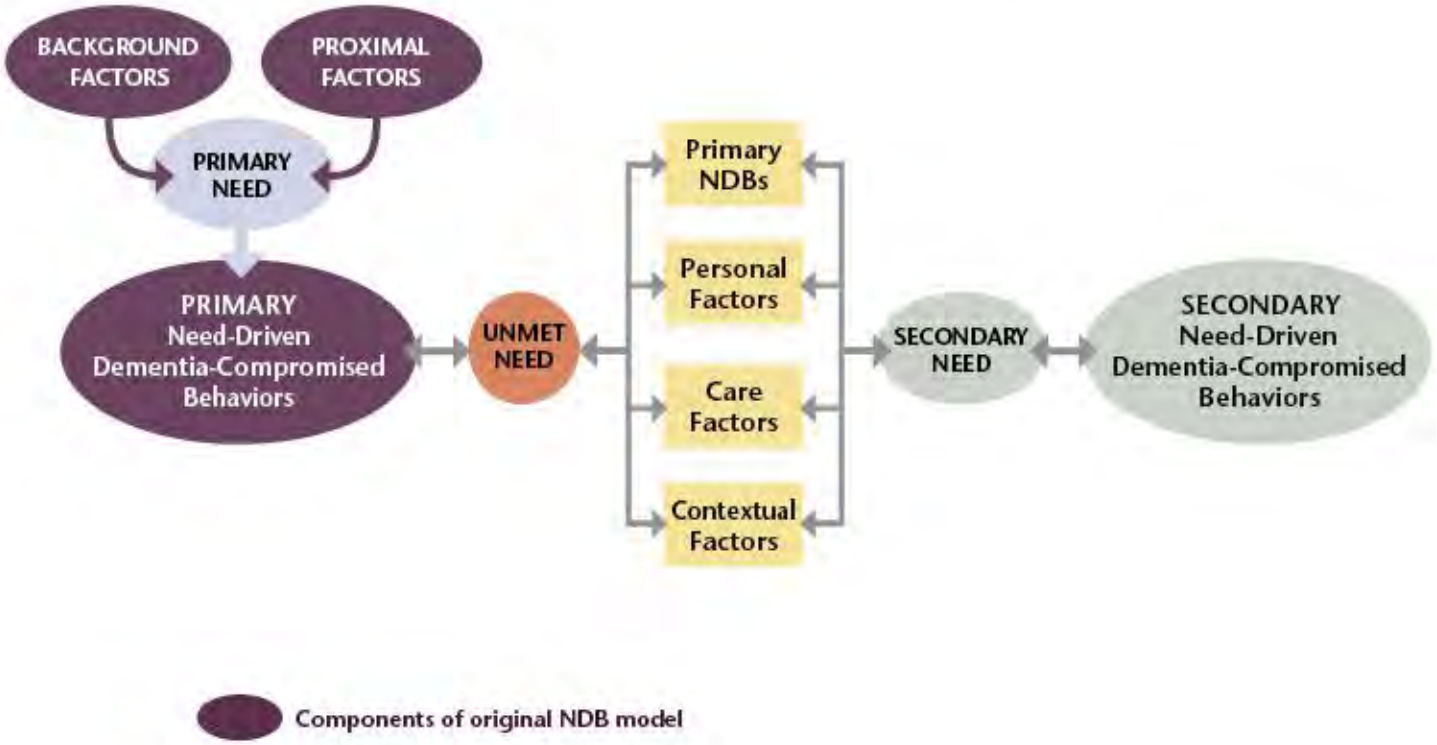


**TABLE 1A** The Cascade Effect

**EXAMPLE 1**

| PROXIMAL / BACKGROUND FACTOR | PRIMARY NEED | PRIMARY NDB | OUTCOME | SECONDARY NEED | SECONDARY NDB |
|---|---|---|---|---|---|
| THIRST | FLUIDS | Repetitive movement | Constipation & abdominal discomfort | Increased fiber & stool softener | Aggression |

## EXAMPLE 3 Cascading Effects

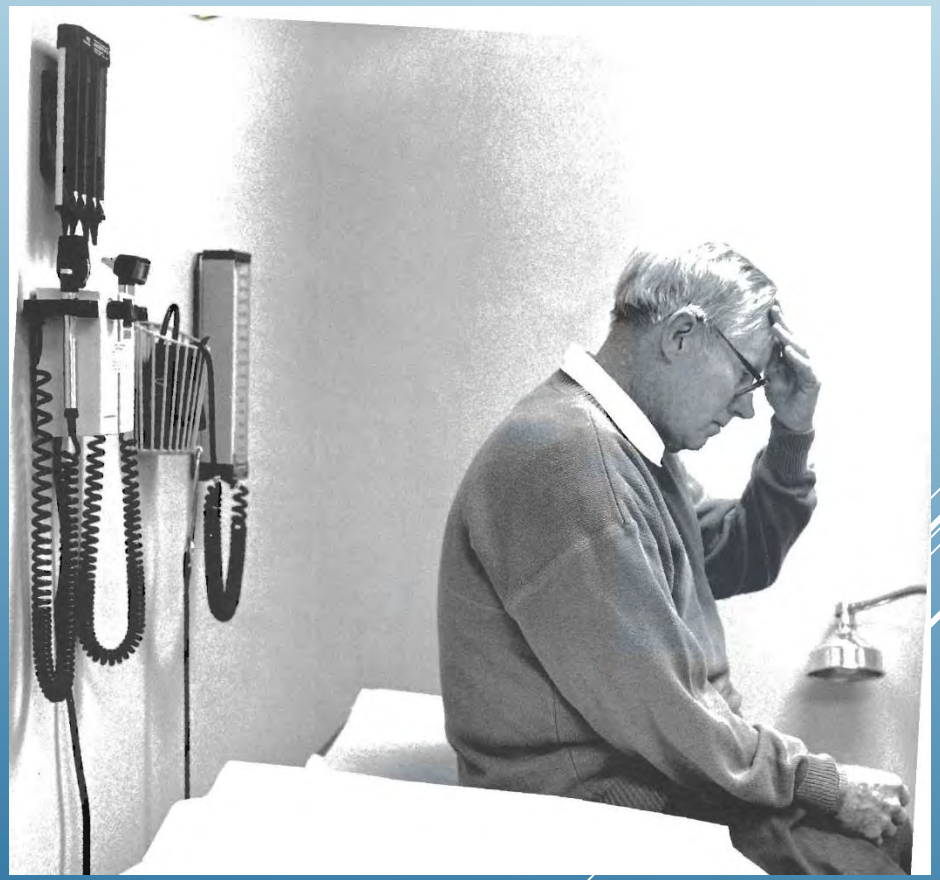
| PROXIMAL/ BACKGROUND FACTOR | PRIMARY NEED | PRIMARY NDB | OUTCOME | SECONDARY NEED | SECONDARY NDB |
|---|---|---|---|---|---|
| UNSTIMULATING DAILY SCHEDULE | THERAPEUTIC ACTIVITY | Pacing | Loneliness | Increased socialization | Withdrawal |
| | | | Depression | Antidepressant and/or counseling | |

## EXAMPLE 2 Cascading Effects

| PROXIMAL/ BACKGROUND FACTOR | PRIMARY NEED | PRIMARY NDB | OUTCOME | SECONDARY NEED | SECONDARY NDB |
|---|---|---|---|---|---|
| CIRCADIAN RHYTHM DISTURBANCE | PACE ACTIVITY & REST, LIGHT & DARKNESS throughout the day | Sundowning with calling out | Social ostracism | Increased socialization | Repeated apprehensive queries |

# BACKGROUND RESEARCH ON DEMENTIA

- Pain inadequately assessed
- Pain under treated
- Early and some moderate dementia can still accurately report pain symptoms.



## DECREASED REPORT OF PAIN

- Decreased ability to cognitively process painful sensations-to experience pain as threatening
- Emotional component of pain may be diminished but that the actual physical sensation of pain is not altered

## IMPLICATIONS

- Self-report scales will not accurately assess both components of pain
- Both self-report and observational scales be used to target both the sensory and affective aspects of pain

# COMMON PAIN BEHAVIORS

- Facial: grimacing, frightened, sad
- Vocalization: groaning, calling out
- Body: Rigid, tense, restless, guarding, resistiveness
- Activity: withdrawal, poor sleep, poor appetite, exiting behavior, crying, distressed

# 97-YEAR OLD NON-COMMUNICATIVE PWD YELLING OUT WITH MOVEMENT

- full ROM lower extremities, denies pain repeatedly
- bilateral knee pain controlled with scheduled Vicodin
- Hx anxiety, scheduled lorazepam
- "help me," "No, No No" or "ooh, ooh ooh,"
- resistive to care and looked frightened when approached

- Interpretation: anxiety

- Give care slowly
- Explain actions and the reason for the care
- Positive feedback every time she was

  "cooperative with cares"
- Reassured that "she will be all right and not fall" when transferred
- Day 13: when asked about pain, responded "yes" and touched her upper left leg
- Day 21: Vicodin and lorazepam 1 h before am care
- Day 22: right leg touched → she yells out
- Day 23: X-ray left intertrochanteric  FX

# 91-YEAR-OLD PLEASANT, PERSISTENTLY SMILING

- Verbally communicates her back pain regularly
- Well controlled scheduled acetaminophen, prn tramadol
- Day 8: c/o hemorrhoid pain → med and cushion
- Day 11: clear change in condition, smile, withdrawn, refused meals, spit out meds
- Day 12, 13: "spitting out yellow phlegm." VS normal, afebrile, lungs clear, no cough
- Day 14: fell
- Day 15: restless, spitting up larger

amounts of "yellow phlegm."

- Day 16, 17: smiling while grabbing staff

  Clothing and jabbing them
- Day 18, c/o fatigue, refused to open mouth, no c/o pain
  - nurse looked into her mouth, multiple "pus pockets"
  - Started on antibiotic → daughter orders hospice, all meds stopped
- Day 22: dentist DX acute abscess
  - antibiotic and opioid injections,
  - clonazepam orally disintegrating tablets and viscous lidocaine for the jawline
- Day 23: Much weaker
- Day 25: Died

# PHYSICAL PROBLEMS OVER 6 WEEKS (149 PROBLEMS IN 61 PARTICIPANTS)

| PROBLEM | f | % |
|---|---|---|
| **Musculoskeletal** | **35** | **23** |
| **Skin** | **17** | **11** |
| **Neurological**: | **17** | **11** |
| **Gastrointestinal** | **17** | **11** |
| **Genitourinary** | **16** | **10** |
| **Respiratory** | **15** | **10** |
| **Other** | **12** | **8** |
| **Eye, Ear, Nose and Throat**: | **11** | **7** |
| **Cardiovascular** | **9** | **6** |

# FREQUENCY OF BEHAVIORS ACCOMPANYING NEW INFECTIONS AND OTHER NEW PHYSICAL PROBLEMS N = 134 NEW PROBLEMS *

| New Problem | Resistive | | "Help Me" "Something is Wrong" | | Distressed Facial Expression | | Restlessness | |
|---|---|---|---|---|---|---|---|---|
| | f | % | f | % | f | % | f | % |
| Infection n = 36 | 17 | 47 | 14 | 39 | 9 | 25 | 7 | 19 |
| Other Physical n = 98 | 38 | 39 | 15 | 15 | 35 | 36 | 29 | 30 |

*Problems of severe psychosis and unresponsiveness were omitted from this analysis

# PREDICTORS OF TIME TO IDENTIFY NEW PROBLEMS

| Variable | Estimate | SE | t | CI |
|---|---|---|---|---|
| Assessment | -0.43 | 0.09 | -4.62* | (-0.62,-0.24) |
| Ratio of new to standard interventions | -1.35 | 0.40 | -3.38* | (-2.16,-0.54) |
| Specific physical symptoms | -0.82 | 0.30 | -2.78* | (-1.42,-0.22) |
| Length of Stay | 0.013 | 0.006 | 2.40* | (0.002,0.025) |

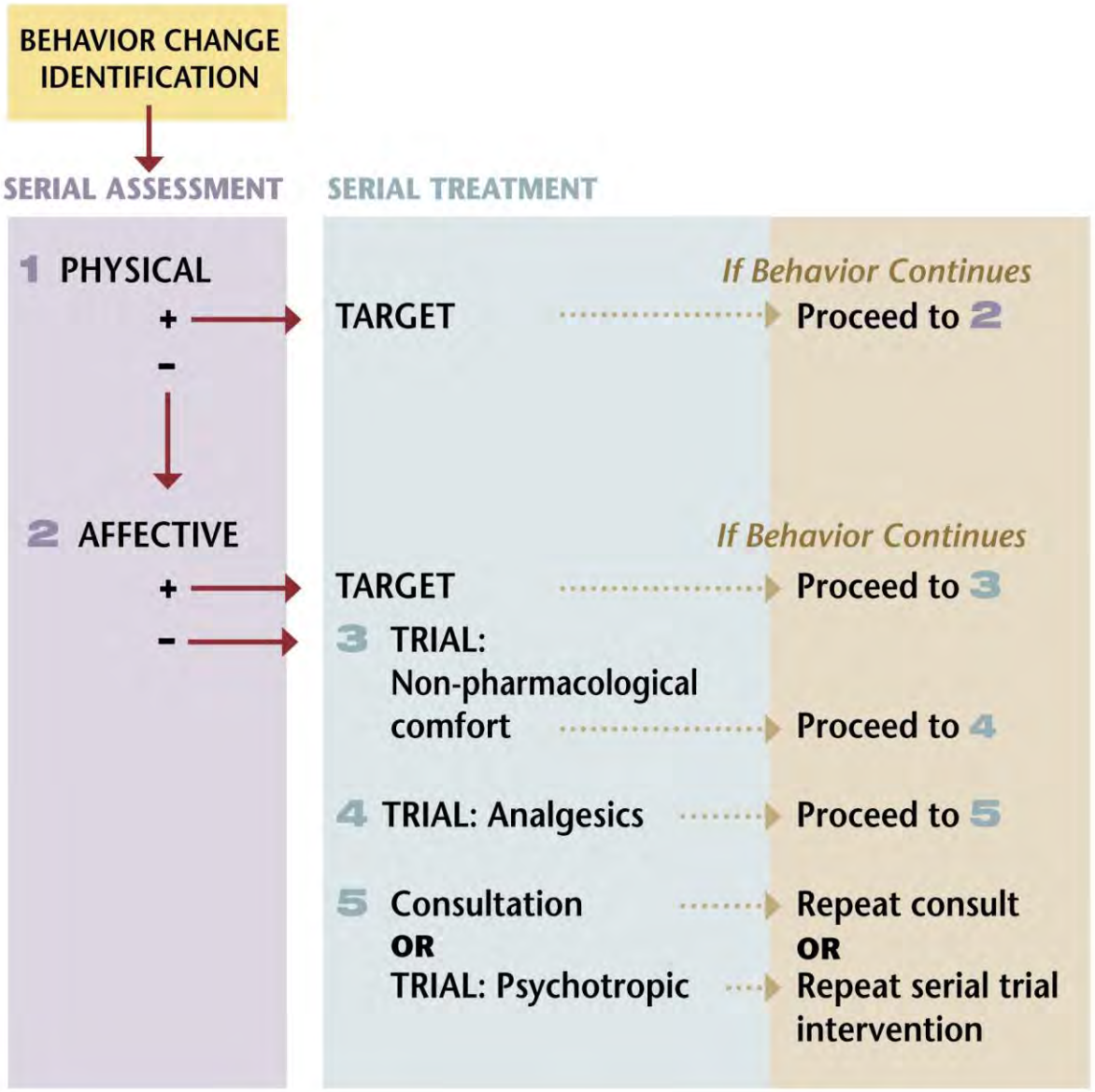
$p < .05$

# SUMMARY

- Staff nurses' skills in assessment of behavior and physical conditions may be  key factors in timely identification and treatment of new physical problems

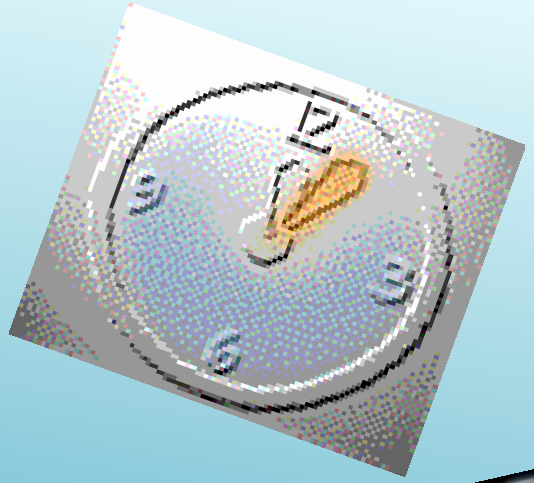
# Solution: Serial Trial Intervention

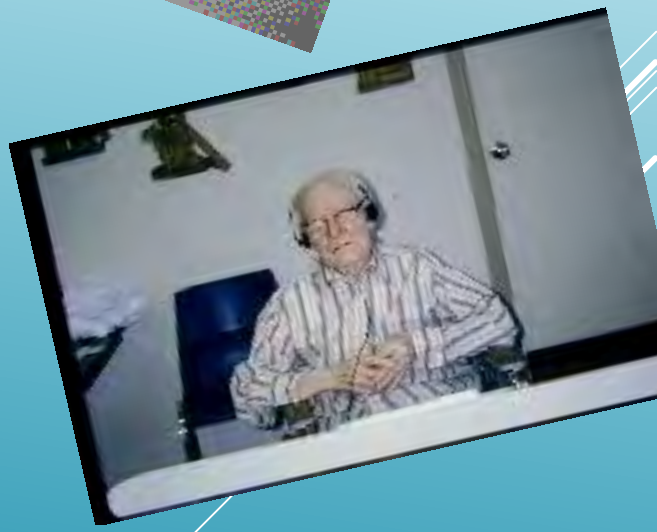
# SERIAL TRIAL INTERVENTION



# WHY USE THE STI?

1. Time: 5.7 to 201.5 minutes (mean = 23.1 minutes) to manage disruptive behavior.





# WHY USE THE STI?

2. Agitated behavior is contagious

# WHY USE THE STI?

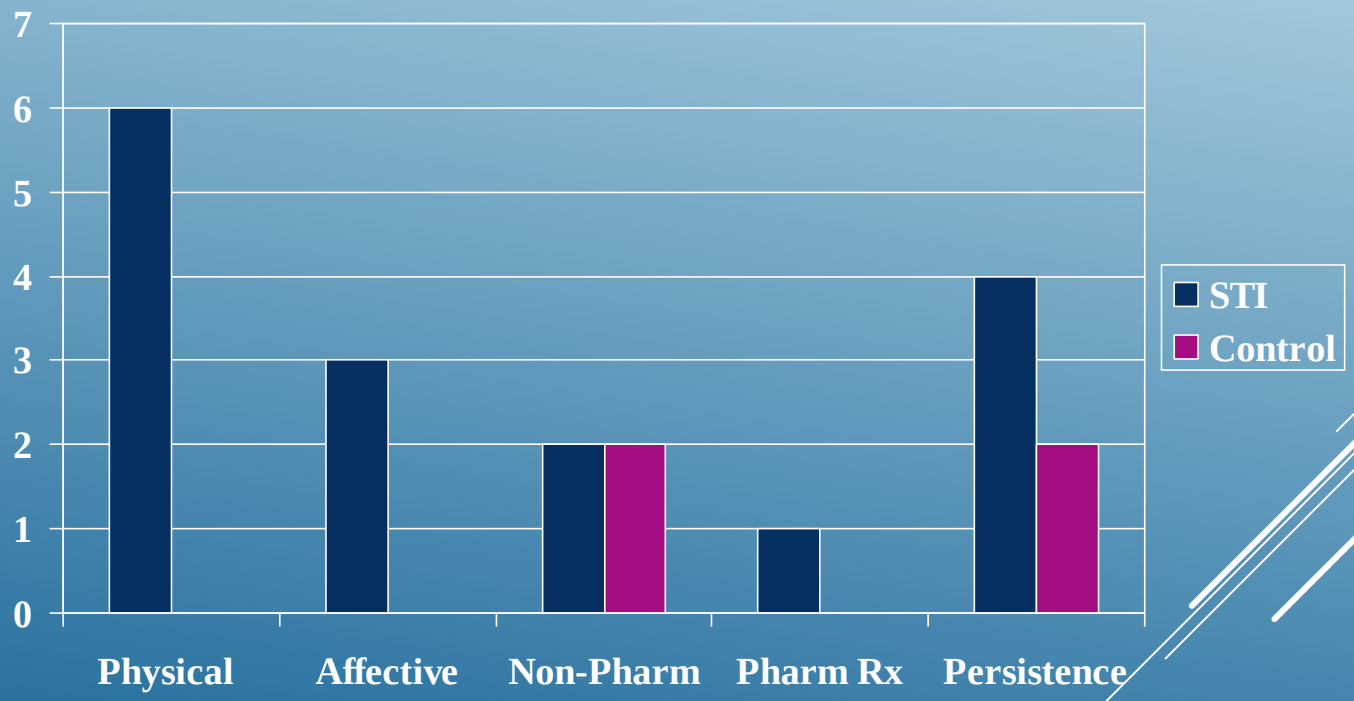
3. Satisfaction: Your competence, person's comfort

4. Primary reason for transfer out of home

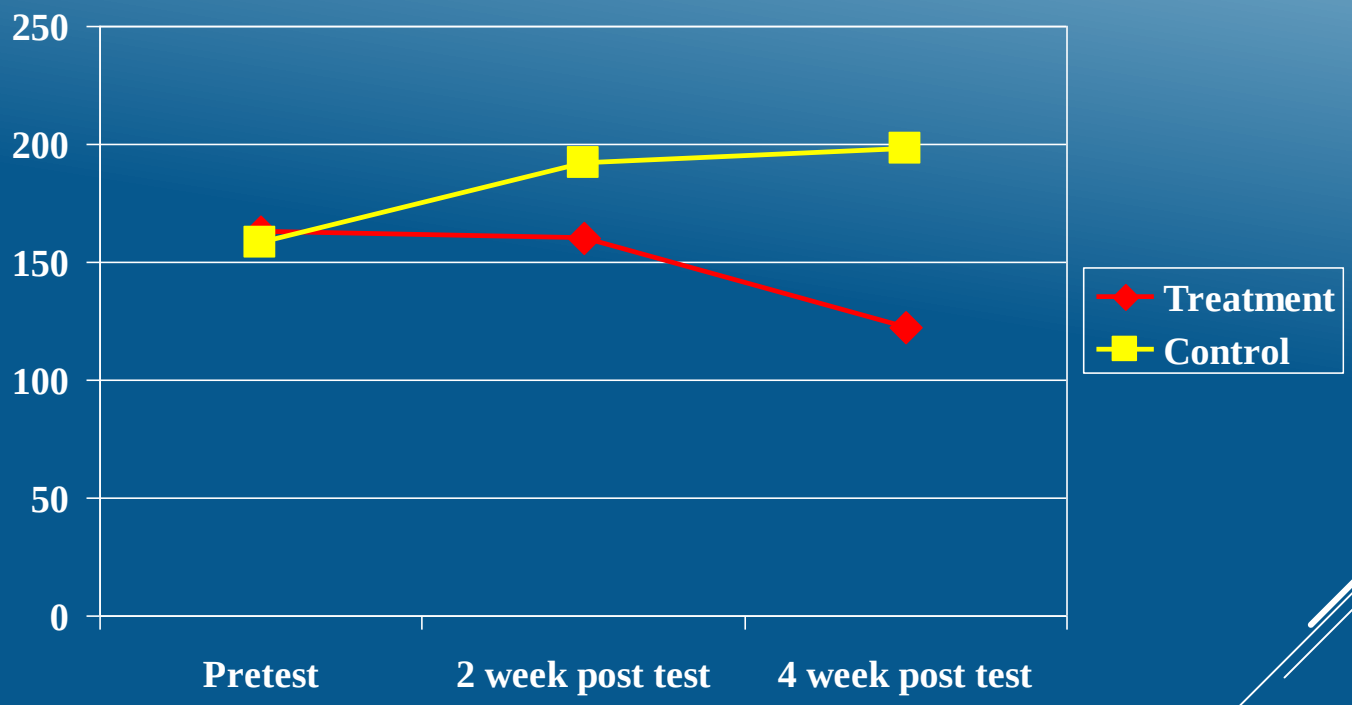
# TABLE 1. DESCRIPTION OF BEHAVIOR INITIATING STI (57 SUBJECTS HAD 98 BEHAVIORS)

| *Behavior* | *f* | % |
|---|---|---|
| Verbal: nonspecific vocalization | 23 | 40.35 |
| Combative/resistive | 16 | 28.07 |
| Restless Body Movement | 15 | 26.32 |
| Verbal: specific complaint/need | 9 | 15.79 |
| Crying/tears in eyes | 8 | 14.03 |
| General agitation | 7 | 12.28 |
| Exiting Behavior | 5 | 8.77 |
| Changes in appetite | 3 | 5.26 |
| Withdrawn/quiet | 3 | 5.26 |
| Rubbing/holding area | 2 | 3.51 |
| Facial grimacing | 2 | 3.51 |
| ↑ Confusion | 2 | 3.51 |
| Changes in sleep | 1 | 1.75 |
| General change in behavior | 1 | 1.75 |
| Change bowel elimination | 1 | 1.75 |

# DIFFERENCES IN PROCESS VARIABLES

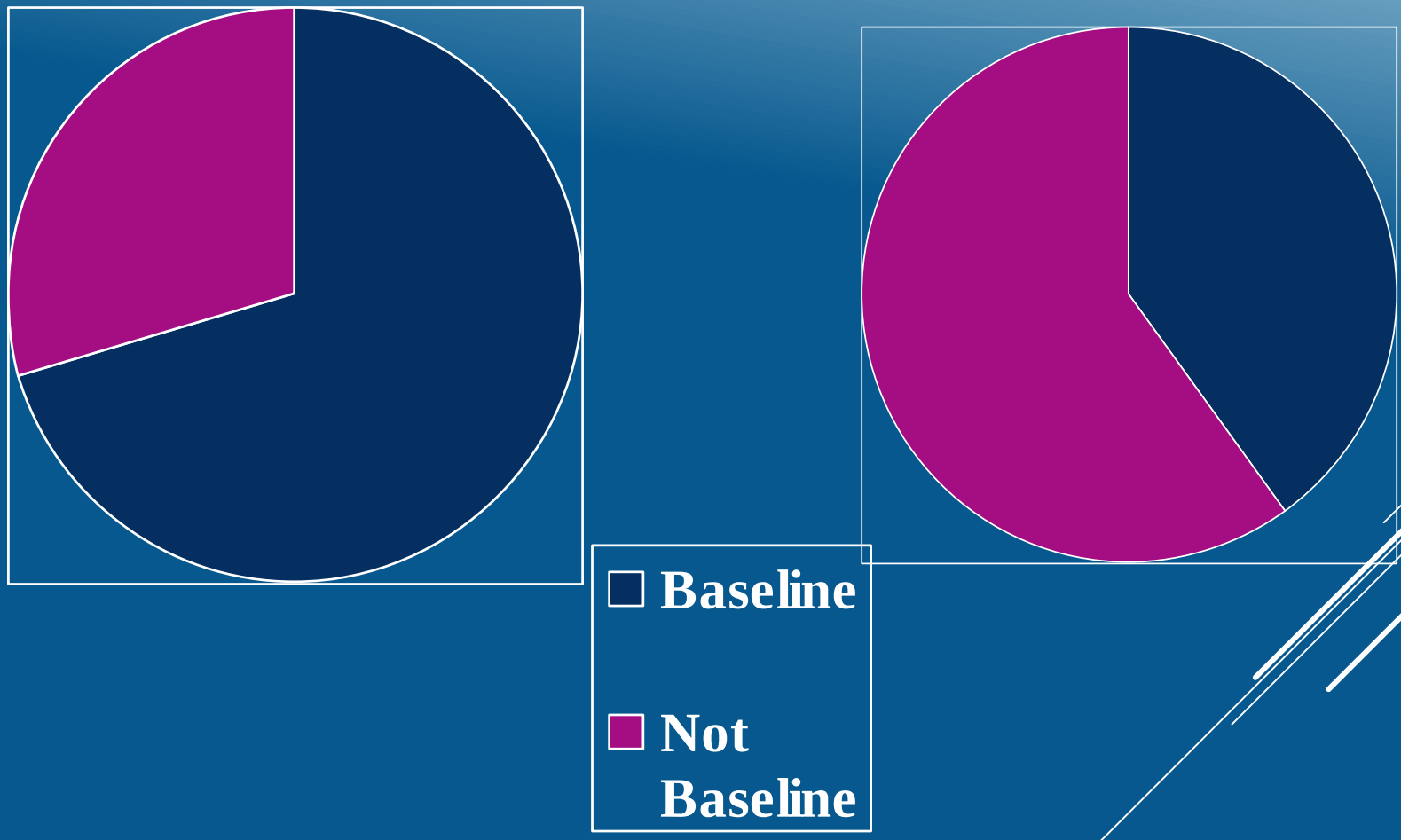


# DIFFERENCES IN DISCOMFORT BETWEEN TREATMENT AND CONTROL GROUPS



# RETURN OF BEHAVIORS TO BASELINE

STI CONTROL



# CHRONIC PAIN IS MOST COMMON

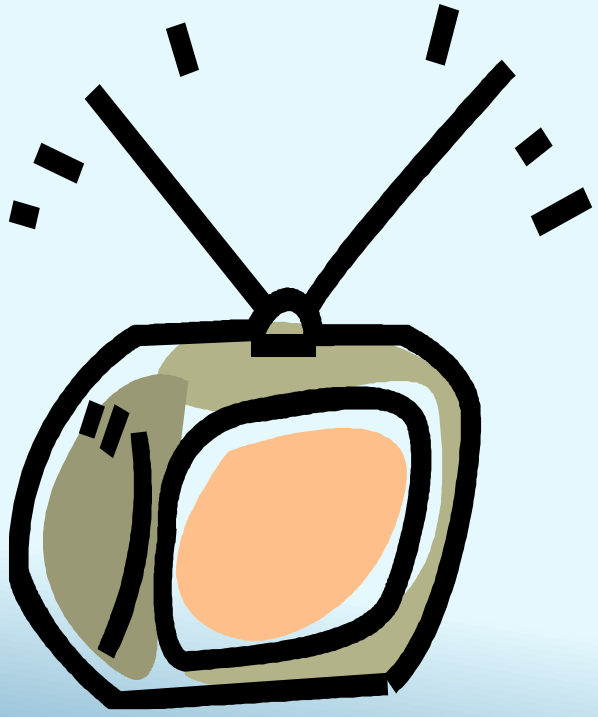
- **Arthritis (70%)**
- **Old fractures (13%)**
- **Neuropathies (10%)**
- **Malignancies (4%)**

# NEUROPATHIC PAIN ASSESSMENT

- Sensory adjectives used by patients: electric-shock, burning, tingling, cold, prickling, itching
- Evoked pain: either by a stimulus that does not usually evoke pain (allodynia) or increased response to a stimulus that is normally painful (hyperalgesia)

# Balancing Activity Controls Excesses

# WHY DO WE NEED BACE?



- Agitation and resistive behaviors are often caused by environmental factors which can be controlled.

# 1. DOES THE PERSON HAVE A BALANCE OF SENSORY STIMULATING AND SENSORY CALMING ACTIVITIES FOR THE DAY?

- Are there periods of sustained "up" or "down" activity in the person's day? Most people don't tolerate > 1.5 hours sustained "up" or "down" time.

# AFFECTIVE ASSESSMENT

Subject Code: _____

**BACE Assessment Form Worksheet**

Sustained Null Activity (↓) is highlighted in yellow. Sustained Mobile Aroused Activity (↑) is highlighted in pink.

| | Activity | Social Interaction | Environmental Press: Auditory, Visual, Tactile | Diagnostic Narrative: Activity Pacing, Environmental Press, Socialization |
|---|---|---|---|---|
| 7:30-7:59 | | | | |
| 8:00-8:29 | | | | |
| 8:30-8:59 | | | | |
| 9:00-9:29 | | | | |
| 9:30-9:59 | | | | |
| 10:00-10:29 | | | | |
| 10:30-10:59 | | | | |
| 11:00-11:29 | | | | |
| 11:30-11:59 | | | | |
| 12:00-12:29 | | | | |
| 12:30-12:59 | | | | |
| 1:00-1:29 | | | | |
| 1:30-1:59 | | | | |
| 2:00-2:29 | | | | |
| 2:30-2:59 | | | | |
| 3:00-3:29 | | | | |
| 3:30-3:59 | | | | |
| 4:00-4:29 | | | | |
| 4:30-4:59 | | | | |
| 5:00-5:29 | | | | |
| 5:30-5:59 | | | | |
| 6:00-6:29 | | | | |
| 6:30-6:59 | | | | |
| 7:00-7:29 | | | | |
| 7:30-8:00 | | | | |

# 2. DOES THE PERSON HAVE REGULAR MEANINGFUL HUMAN INTERACTION?

- Everyone needs meaningful human interaction – it provides feelings of comfort and safety.

- If necessary, order 10 minutes of 1:1 time two times/day as a nursing order.

# 3. HOW STRESSFUL IS THE PERSON'S ENVIRONMENT?

- When environmental stressors exceed the person's stress threshold, the result is stress. This may ↑ agitation.

# WHAT ARE ENVIRONMENTAL STRESSORS?

## Noise

- TV on all day
- Pounding pill crushers
- Background conversations
- Phones turned too loud
- Echoes in bathrooms or other tiled areas
- Public address systems

# WHAT ARE ENVIRONMENTAL STRESSORS?

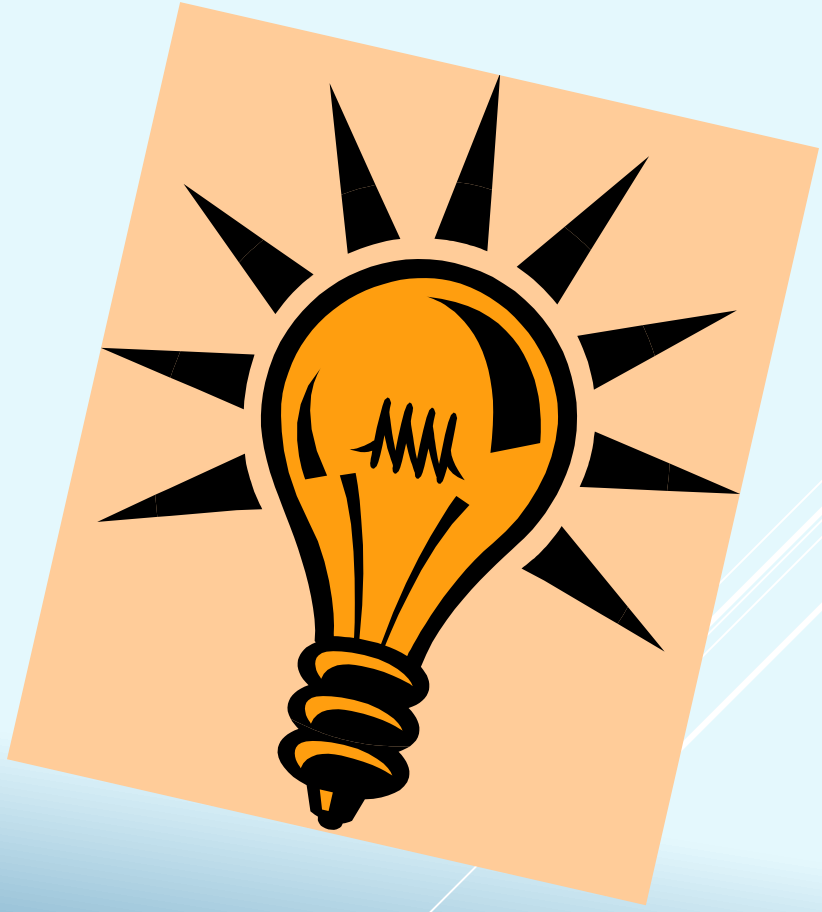
Tactile

- Itchy skin conditions
- Rough handling
- Room temperature too cold or too warm
- Vinyl furniture
- Hard, unpadded chairs
- Wrinkled bed linens or clothing
- Poorly fitted shoes or clothing

# WHAT ARE ENVIRONMENTAL STRESSORS?

Visual

- Glare from lights
- Shiny floors
- Clutter
- Spaces that are too big or too small
- Unfamiliar environments or people



# 4. ARE THERE ANY OTHER PSYCHOSOCIAL FACTORS THE NURSE FEELS MAY BE AFFECTING A PERSON'S BEHAVIOR?

# STEP 3
# NON-PHARMACOLOGICAL TREATMENT TRIAL

Please do this step if the behavior is still occurring, even if the assessment done in step 2 is negative.

# NON-PHARMACOLOGICAL TREATMENTS

- These treatments were found useful by nurses.
- Try 2-3 things in a row (do not move onto step 4 for 30-60 minutes).

# NON-PHARMACOLOGICAL INTERVENTIONS

- Therapeutic Communication
  - Calm approach
  - Use name often
  - Eye contact
- Quiet environment/quiet time
- Relaxation
- Change environment

# NON-PHARMACOLOGICAL INTERVENTIONS

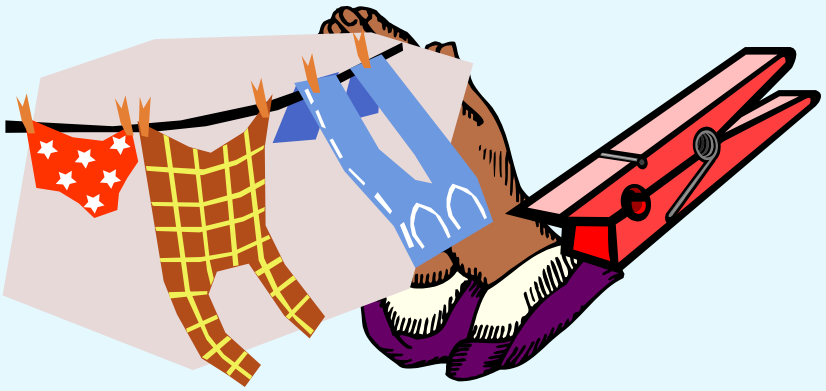
- Hugging
- Cueing/Redirecting
- Gentle touch
- Massage/warm foot soak
  - Provides distraction, relaxation, and increases superficial circulation

# NON-PHARMACOLOGICAL INTERVENTIONS

- Repositioning/movement
  - Exercise may improve circulation, reduce joint stiffness
  - Rummage boxes
  - *** No items small enough to choke on secondary to hyperorality ***
  - Handballs
  - Bean bags
  - Ambulating with staff
  - Up in wheelchair

# NON-PHARMACOLOGICAL INTERVENTIONS

- Normalization "work-based" activity
  - Folding laundry
  - Cooking
  - Scrubbing vegetables
- Cognitive activities
  - Reminiscence
  - Poetry readings
  - 1:1 visiting/therapeutic communication
- Spiritual intervention



- Which of these can you do now with the resources you have?
- Which could be done in under one minute?
- Which could be done in ten minutes or less?
- Which could you do if you had a few extra resources?

# NON-PHARMACOLOGICAL INTERVENTIONS

# AFFECTIVE ASSESSMENT

Subject Code: _____

**BACE Assessment Form Worksheet**

Sustained Null Activity (↓) is highlighted in yellow. Sustained Mobile Aroused Activity (↑) is highlighted in pink.

| | Activity | Social Interaction | Environmental Press: Auditory, Visual, Tactile | Diagnostic Narrative: Activity Pacing, Environmental Press, Socialization |
|---|---|---|---|---|
| 7:30-7:59 | | | | |
| 8:00-8:29 | | | | |
| 8:30-8:59 | | | | |
| 9:00-9:29 | | | | |
| 9:30-9:59 | | | | |
| 10:00-10:29 | | | | |
| 10:30-10:59 | | | | |
| 11:00-11:29 | | | | |
| 11:30-11:59 | | | | |
| 12:00-12:29 | | | | |
| 12:30-12:59 | | | | |
| 1:00-1:29 | | | | |
| 1:30-1:59 | | | | |
| 2:00-2:29 | | | | |
| 2:30-2:59 | | | | |
| 3:00-3:29 | | | | |
| 3:30-3:59 | | | | |
| 4:00-4:29 | | | | |
| 4:30-4:59 | | | | |
| 5:00-5:29 | | | | |
| 5:30-5:59 | | | | |
| 6:00-6:29 | | | | |
| 6:30-6:59 | | | | |
| 7:00-7:29 | | | | |
| 7:30-8:00 | | | | |

# BEGIN A TRIAL OF ANALGESICS…

- Start low and go slow

# ACETAMINOPHEN (APAP)

- For mild to moderate pain
- Routine dosing up to 2000 – 3000 mg/day maximum in older adults
- Avoid in hepatic compromise
- With renal disease, use

  q 6 h dosing rather than q 4h
- Be aware of "hidden" doses of APAP in combination products

# NSAIDS

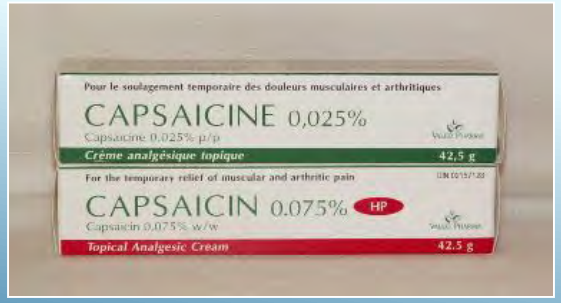
- Indicated for pain from acute inflammatory process (such as gout)
- Effective for mild to moderate pain
- Too many adverse effects

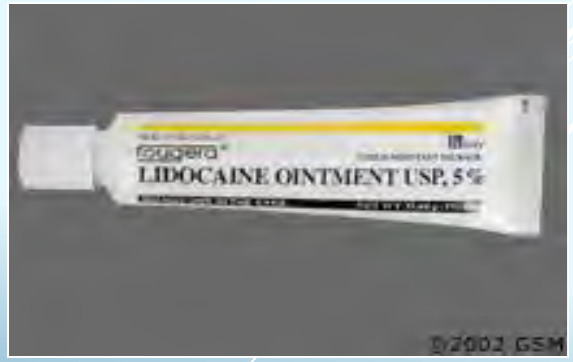
# ADJUVANTS

- Anticonvulsants: Gabapentin (Neurontin®), Lamotrigine (Lamictal®), Pregabalin (Lyrica® )
  - Adverse effects: unclear thinking, forgetfulness, and other CNS side effects
- Tricyclic Antidepressants
  - Adverse effects: anticholinergic effects (Desipramine and nortiptyline are preferred over amitriptyline or doxepin), morning grogginess, postural hypotension, can cause blood levels of other drugs to be much higher
  -
- Newer Antidepressants, expensive, duloxetine (Cymbalta®), venlafaxine (effexor®),
  - work better, fewer side effects

# TOPICAL AGENTS

- Local action with minimal systemic side effects
- Indicated for neuropathic pain but can be effective in musculoskeletal pain as well

# OPIOIDS

- Addiction-Tolerance-Physical Dependence
- Side effects:
  - Sedation (→ falls, ↓appetite)
  - Nausea, vomiting, dry mouth
  - Constipation
  - Urinary retention
  - Confusion
  - Dysphoria, hallucinations
  - Respiratory depression (rare)

# OPIOIDS: USE INFO

- Residents with regular recurring pain should have scheduled dosing rather than prn dosing
- Residents requiring multiple doses of short-acting combination or straight opioids  should be switched to long-acting opioids
- Always start on bowel regime

# COMBINATION DRUGS

- Acetaminophen With Codeine (constipation, nausea, not that effective)
- Oxycodone (Percocet) combination contains 325 mg acetaminophen
- Hydrocodone (Vicodin, Lortab) combination contains 500 mg acetaminophen
- Tramadol (Ultram)

- Inexpensive
- Widely available
- Short-acting
- Be aware of acetaminophen limits
- Which drug working or causing adverse effects?

# LONG ACTING OPIOIDS

- Morphine Sustained Release (MS Contin®, Kadian®, Avinza®)
- Oxycodone Sustained Release (Oxycontin®)
- Transdermal Fentanyl (Duragesic®)
- Methadone
- Tramadol (Ultram ER®)
- Oxymorphone (Opana ER®)

# PHYSICAL NON-DRUG TECHNIQUES

- Massage→↑ relaxation, ↑blood flow
- Cold→ numbs nerve endings (itch), ↓ inflammation, muscle spasm
- Heat → ↓ inflammation, soreness, sensitivity to pain, ↑blood flow
- Vibration → ↓ painful feeling ↑ pain threshold
- Positioning/movement → correct body alignment helps muscles, movements and fluid, blood flow

# NON-DRUG TECHNIQUES

## Pain → Stress → Pain

- Distraction
- Relaxation
- Music
- Comfort Foods
- Imagery
- Controlled Breathing

# WHAT IF ANALGESICS ARE INEFFECTIVE?

- Fork in the road

# NEXT STEP: CONSULTATION PSYCHOTROPIC ?

- Consult with the MD/DO/APNP
- Is a psychotropic drug indicated?
  - Antidepressants
  - Antipsychotics
  - Sedatives/hypnotics

# PROBLEM: TIME & INFORMATION OVERLOAD

- Decision Support Tools
- Efficient Use Assessment & Diagnostics