

## WHERE'S THE PAIN ANYWAY?

S.G. ZELENSKI, D.O., Ph.D.  
Clinical Assistant Professor of Psychiatry  
University of Wisconsin Medical School at Madison  
Developmental Neuropsychiatrist  
Central Wisconsin Center for the Developmentally Disabled  
Madison, WI 53704

ANNE HANSON, BS, RN, CDDN  
Coordinator of Health Education  
& Employee Health  
Lexington Center  
Gloversville, NY 12078

## Assessing & Treating Pain in People with Developmental Disabilities and Severe Cognitive Deficit

Focus on: Assisting Support Staff in Recognition of Pain & Discomfort in the MR/DD Individual

## Learning Objectives

- Discuss origins/classification/mechanisms of pain in normally cognitive individuals
- Discuss common myths and misconceptions about pain
- Discuss common pain behaviors
- Discuss how to assist our support staff in recognizing pain/discomfort
- Discuss strategies for assisting staff to alleviate pain and discomfort for our individuals

## BUT FIRST....

UNDERSTANDING PAIN IN PEOPLE WITHOUT PERMANENT NEUROLOGICAL IMPAIRMENT

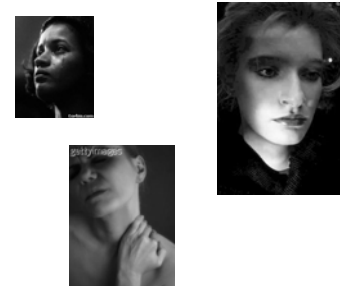
## THE MANY FACES OF PAIN

Obvious Physical Basis



## THE MANY FACES OF PAIN

Emotional Basis



## THE MANY FACES OF PAIN

Examples of the Pleasure-Pain Axis

Sado-masochism -  
Millennia of  
intuitive  
knowledge



Hicham El Guerrouj of Morocco winning the gold in men's 1500m final 2004

## THE MANY FACES OF PAIN

GETTING A PERSPECTIVE

- 43% of adults (83 million) report pain frequently affects their participation in life's activities
- 55% of senior citizens report suffering from pain on a daily basis
- Senior citizens report that severe or moderate pain often lasts over two years

## THE MANY FACES OF PAIN

Distribution of chronic pain in the cognitively-intact patient

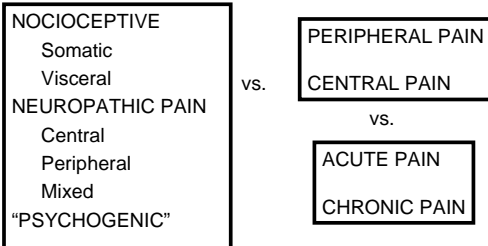
- Lower back pain (75%)
- Osteoarthritis (40%)
- Headaches (26%)
- Migraines (26%)
- Fibromyalgia (12%)

## PAIN DEFINITION

*"An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage"*\*

\*The International Association for the Study of Pain

## MANY WAYS OF CLASSIFICATION



Sensory, Adaptive, and Affective components

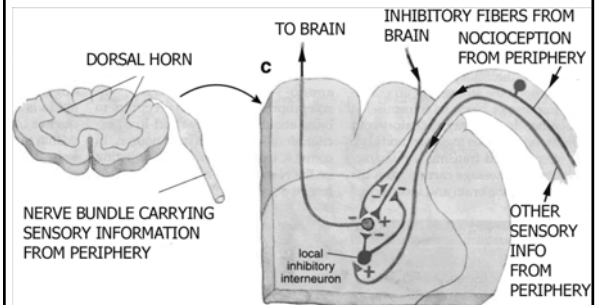
## ACUTE PAIN

## HISTORICAL CONCEPT OF PAIN



Descarte, "...an alarm bell ringing in a bell tower"

"Nociception is born in the dorsal horn, but we don't call it pain till it reaches the brain"\*

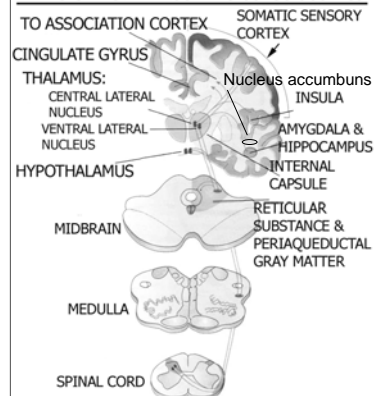


\*Casey, K. IASP Conference, Vancouver, August 1996

## FROM HURT TO PAIN

- Peripheral Nerve Sensitivity
- Dorsal Horn Transmission
- Dorsal Horn Pathophysiology
- Supraspinal Modulating Loops
- Descending Pain Modulating Pathways
- Spinocerebral Ascending Pathways
- Cortical Pain Center?

### PAIN SIGNALS AND ROUTE TO CONSCIOUSNESS



## MODULATION OF PAIN

## DOES SEX MATTER?

- Variations in women's estrogen levels -- like those that occur throughout the monthly menstrual cycle, or during pregnancy -- regulate the brain's natural ability to suppress pain.\*
- Women showed a tendency to rate the painful stimuli as more unpleasant and more intense than men. \*\*

\* Zubieta, Jon-Kar various publications

\*\* Sheffield D, Biles PL, Orom H, Maixner W, Sheps DS. Race and sex differences in cutaneous pain perception Psychosom Med. 2000 Jul-Aug;62(4):517-23.

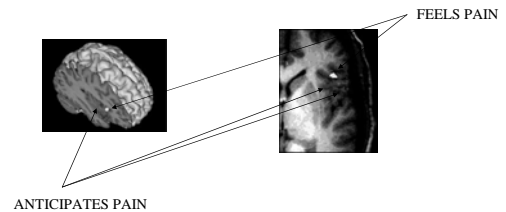
## DOES RACE MATTER?

- AFRICAN AMERICANS RATED A CUTANEOUS PAIN STIMULI AS MORE UNPLEASANT AND SHOWED A TENDANCY TO RATE IT AS MORE INTENSE THAN WHITES\*
- WHITE > BLACK > ASIAN\*\*

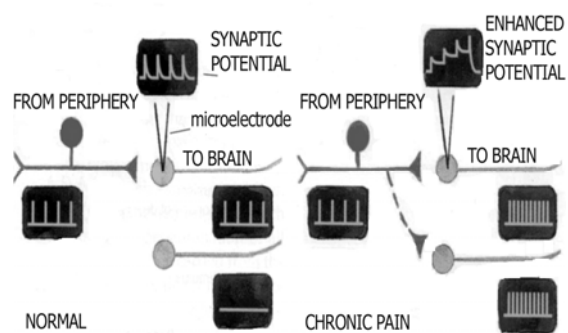
\* Sheffield, et al, 2000. Psychosomatic Medicine

\*\*Woodrow, et al. 1971. Psychosomatic Medicine

## ANTICIPATION OF PAIN VS. PERCEPTION



## ACUTE --> CHRONIC PAIN



## UNDERSTANDING THE STATE-DEPENDENT DIVERSITY OF PAIN

### ASPECTS OF PAIN IN INFANTS AND CHILDREN

- An infant's spinal sensory nerve cells are more excitable
- Individual sensory nerve cells in newborns are linked to much larger skin or receptive fields
- Newborns respond less selectively
- Less central dampening

### ASPECTS OF PAIN IN INDIVIDUALS WITH MENTAL ILLNESS

- Increased pain threshold in schizophrenics
- Increased pain threshold in relatives of schizophrenics

<http://www.psychlaws.org/generalresources/report-nevertreated.htm>

**IS THERE A SPECIAL PROBLEM  
ASSESSING AND TREATING  
PAIN IN INDIVIDUALS WITH  
SEVERE INTELLECTUAL  
DISABILITY?**

**SPECIAL PROBLEMS**

**ASSOCIATED WITH THE CARE SYSTEM**

- Myths/Beliefs
- Physicians trained to respond to verbal communication from the patient
  - “We’re going to still have to listen to a patient tell us what’s wrong, and why it’s wrong and what they’d like done about it and treat them as people with the best tools we have” (Paul Sieving, M.D., Ph.D.)

**ASSOCIATED WITH THE INDIVIDUAL**

- Communication
- Cognitive history and learning

**Support Staff Myths &  
Misconceptions.....**

- That pain sensitivity and perception of pain decrease with age
- That individuals with mental retardation and developmental disabilities cannot feel pain.
- That pain is normal and expected as we age

**Support Staff Myths &  
Misconceptions Continued**

- That individuals who do not complain of pain do not have pain
- That all individuals that have pain react in a predictable, usual manner to that pain
- That opioid and other pain medications have side effects that are too dangerous to allow use with the elderly and developmentally challenged.

**LEADS TO....**

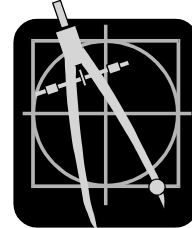
- Higher incidence of catastrophic mortality

**PAIN MANAGEMENT**

## COMPONENTS OF PAIN MANAGEMENT

- ASSESSMENT
- ALLEVIATION
- MONITORING

## PAIN ASSESSMENT



## ATTITUDE/EXPERIENCE OF CARE-GIVER

In one study, the commonly used pain signals from changes in VITAL signs, the use of AUGMENTATIVE communication devices, and standard BEHAVIORAL or FACIAL scales were not found to be particularly helpful in identifying the presence or location of the pain.

Anderson JB, et al. Beliefs about pain among professionals working with children with significant neurologic impairment *Developmental Med & Child Neuro* 43:136-140. 2001

In another study which compared localization of pain in cognitively intact individuals and cognitively impaired individuals, there was no significant difference found in the ability to localize.

Bromley J, Emerson E, Caine, A. "The development of a self-report measure to assess the location and intensity of pain in people with intellectual disabilities. *J. Intellectual Disability Research*. 1998 42(Pt 1):72-80

"It is important to use both self-report and nonverbal measures when assessing pain in the frail, elderly population, whether or not there is evidence of cognitive impairment."

Hadjistavropoulos T, LaChapelle DL, MacLeod FK, et al. *Clin J Pain*. 2000;16:54-63.

"The pain of people with severe ID appeared to be assessed differently from that of people with profound ID. Indicators belonging to the 'physiological' category scored relatively higher in the group of nurses specializing in profound disability. In contrast, indicators belonging to the 'social-emotional' category were scored relatively higher by nurses specializing in severe disability.

Zwakhaleh, et al. Pain assessment in intellectually disabled people: non-verbal indicators. 2004. Journal of Advanced Nursing 45(3), 236-245.

## DOMAINS OF PAIN ASSESSMENT NEED FOR MULTIDISCIPLINARY ASSESSMENT!

- SUBJECTIVE
- FUNCTION
- PRODUCTIVITY
- MEDICAL/DENTAL FINDINGS
- HEALTH RESOURCE UTILIZATION
- MENTAL HEALTH
- HEALTH PERCEPTION
- PATIENT SATISFACTION
- COST ANALYSIS

## STEP ONE

Realize that behavioral change is frequently the earliest sign of pain/discomfort in the person with severe or profound ID and that primary caregivers are more likely to recognize early behavioral change than early medical pathology.

## THE FIRST LOOK WHEN THERE ARE BEHAVIORAL CHANGES

- Head (eyes, ears, nose, throat, headache)
- Urine (entire urinary tract)
- Reflux (entire GI system)
- Thyroid
- Skeleton, Seizures

This acronym was developed based on the distribution of causality for behavioral admissions to a short-term assessment unit over a one year period

## DOLOPLUS-2

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>• SOMATIC REACTIONS           <ul style="list-style-type: none"> <li>- Somatic complaints</li> <li>- Protective body postures at rest</li> <li>- Protection of sore areas</li> <li>- Expression</li> <li>- Sleep pattern</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>• PSYCHOMOTOR REACTIONS           <ul style="list-style-type: none"> <li>- Washing &amp;/or dressing</li> <li>- Mobility</li> </ul> </li> <li>• PSYCHOSOCIAL RXNS           <ul style="list-style-type: none"> <li>- Communication</li> <li>- Social life</li> <li>- Dysfunctional behavior</li> </ul> </li> </ul> |
|--|---|

<http://www.Doloplus.com/versiongb/rubechelle/intro.htm>

## OTHER SCALES/METHODS

- Musculoskeletal evaluation
- Cognitively Impaired Geriatric
- Facial Action Coding System
- Pain Behavior Measurement

## ANOTHER APPROACH

### Progressive Intervention Protocol (PIP)

A linear progression of interventions individualized for a person and providing education, accountability, and data to allow the team to rule in or out a variety of causes for behavioral dysfunction

Measures are to be implemented after J is saying "I sorry" or "low" loudly, humming, and picking at his great toe for longer than 3 minutes. Staff are to monitor J throughout the interventions – if you cannot monitor, assign monitoring to another staff member.

**Measures:** Go through each step, waiting a few minutes to assess impact before moving onto the next step.

1. If J has missed a meal or snack or the current time is more than 5 minutes out from a meal or a snack, offer fluids (such as water or juice) or a small snack (1/2 peanut butter sandwich). <b>Wait 5 minutes</b> before moving to next step.	TIME:	<input type="checkbox"/> This step helped J calm OR <input type="checkbox"/> J refused this step OR <input type="checkbox"/> Behavior continued after this step <input type="checkbox"/> Food was not offered due to meal or snack due in 5 minutes or less.	Print staff name
2. Consult with Nursing about administering 15 cc of HPA as per MD order. Continue with Calming Approach as necessary. <b>Wait 15 minutes</b> before moving to next step. HPA given? YES NO	TIME:	<input type="checkbox"/> This step helped J calm OR <input type="checkbox"/> J refused this step OR <input type="checkbox"/> Behavior continued after this step	Print staff name
3. Follow Approach for Calming as in his Comprehensive Support Plan (CSP). Attempt for <b>15 minutes</b> before moving onto the next step.	TIME:	<input type="checkbox"/> This step helped Jon calm OR <input type="checkbox"/> J refused this step OR <input type="checkbox"/> Behavior continued after this step	Print staff name
4. Consult with Nursing about administering Vicodin as per MD order. Continue with Calming Approach as necessary. Wait <b>15 minutes</b> before moving to next step. Vicodin given? YES NO	TIME:	<input type="checkbox"/> This step helped Jon calm OR <input type="checkbox"/> J refused this step OR <input type="checkbox"/> Behavior continued after this step <input type="checkbox"/> Calming approach was continued during this step	Print staff name
5. If ongoing behavior presents an emergency or significant disruption, contact the attending MD for consideration of psychotropic medication or other approach.	TIME:	Suggested intervention is: _____	Print staff name

### Step One: What do staff need to monitor for?

- Behavioral or mood changes
- Changes in emotion/affect
- Audible expressions of pain: crying, moaning
- Verbal outbursts, screaming, asking for help
- Changes in physical movement/posture

### Other Changes for Staff to Monitor For

- Anxious pacing, aimless wandering
- Fidgeting, increased SIB, increased agitation
- Refusal to participate in usual activities
- Guarding, hitting parts of body, head banging
- Non-compliance
- Gait changes/changes in ADL's
- Striking out at staff or peers

### Additional Changes

- Social isolation
- Changes in relationships with peers/caregivers
- Appetite or sleep changes
- Medication/treatment refusals
- Insomnia, nightmares, night wandering

### Talking Points for Staff

- For all changes: consider a medical cause for changes.
- Don't assume that changes are a result of behavioral concerns, dementia, or aging.
- Sudden changes or severe changes are never normal, even with aging or disability.
- Look at the whole picture!
- Don't wait to report information!

Other thoughts.....



Staff must be taught to report changes in baseline

Pulse \*elevated or rapid

Respirations \*elevated or erratic

Blood pressure \*elevated about the persons normal range

\*\*\* be sure to report these signs, even in the absence of any other indications of illness!!!!!!

ALLEVIATING PAIN

PHARMACOLOGICAL INTERVENTIONS

WHO 3-step Ladder

- mild
- moderate
- severe

NON-OPIOIDS

- NON-STEROIDAL ANTI-INFLAMMATORY
  - PO (1st gen, COX-2 inhibitors)
  - INJECTABLE (ketorolac)
- ACETAMINOPHEN (<4 g/24 hrs)

## WEAK OPIOIDS

- CODEINE
- HYDROCODONE
- TRAMADOL
- PROPOXYPHENE

## OPIOID AGONIST/ANTAGONISTS (not recommended)

- BUTORPHANOL
- NALBUPHINE
- PENTAZOCINE

## STRONG OPIOIDS

- MORPHINE
- OXYCODONE
- METHADONE
- HYDROMORPHONE
- FENTANYL
- LEVORPHANOL
- MEPERIDINE

## EQUIANALGESIC DOSE CHART

MEDICATION	ORAL DOSE (MG)	PARENTERAL DOSE
Codeine	180	NA
Fentanyl patch	[1 ug of the patch is 2 mg/d of po morphine	equivalent to about
Hydrocodone	30	NA
Methadone	20	10
Morphine	30	10
Oxycodone	30	NA

## ADJUVANT ANALGESIC

- Antihistamine
- Anticonvulsant (Na<sup>+</sup>, Ca<sup>++</sup> channel blockers)
- Tricyclic antidepressant (NMDA receptor blockade)
- Muscle relaxant
- Corticosteroid
- Antipsychotic
- Calcitonin, Bisphosphonates
- Topical capsaicin

## DOSING CONSIDERATIONS FOR DD

- PRN VS SCHEDULED
- PROTOCOLS
- SUSTAINED RELEASE VS POINT DOSING
- ORAL VS PARENTERAL VS SKIN

## CAUTIONS

- Propoxyphen
  - No better than placebo
  - Toxic metabolite at high doses
- Meperidine
  - Poor oral absorption
  - Normeperidine toxic metabolite (renal failure)
  - Psychotomimetic
- Clearance concerns
  - Conjugated by liver
  - 90-95% excreted in urine
  - If oliguria or anuria STOP scheduled dosing of morphine, use prn

## Supporting Direct Care Staff During the Treatment Phase

How can we help to make our individuals more comfortable by supporting staff in their role?

## Keep Staff Informed During Treatment Phase

- Staff often think in a “quick fix” mode.
- Educate so that they can “buy into” a positive solution. Relate the positives to their roles.
- Don’t assume that staff will automatically know or understand why certain tests or appointments are being ordered. Break it down!
- Let staff know what to expect as follow up is being ordered; don’t leave them with ‘surprises’. They need time to plan for additional staffing, transportation, etc.

## Medication Education For Staff

- Review WHY we are giving ordered medications and treatments.
- Review when and how to give ordered medications or treatments.
- Review what side effects need to be monitored for and reported.

## Special Considerations in Supporting Staff with Narcotic Pain Medications

- Dispel myths: narcotic pain relievers can be very safe and effective in our population if the proper precautions are taken.
- Educate regarding the importance of following bowel protocols to address constipation issues.
- Education on proper dosing and special side effects to watch for.
- Address concerns over dependence or “addiction” to medication

## Key Topics to Cover with Staff.....

- Medicate BEFORE activity- most pain medications take 30-60 minutes to reach full effect (don’t assume staff will know this!)
- Don’t wait for the individual to be in significant pain before administering the medication- severe pain is much more difficult to get under control than when it begins.
- You may need to medicate around the clock, on a set schedule to get full relief. Consider setting a schedule for staff.

## Non-Pharmacologic Considerations for Staff

- Music therapy
- Relaxation therapy/ Biofeedback
- TENS
- Surgical
- Physical therapy

## Talking Points for Staff

- Educate staff about risks of untreated pain
- Add repositioning and physical comfort measures in wheelchair, recliner, bed.
- Gel pads, pressure relief mattresses, etc
- Soft music or silence
- Distraction or quiet based on preference and level of tolerance- it's all individual
- Heat/cold therapy or massage
- Warm bath, lotion therapy

## Continued.....

- Whirlpool
- Swimming
- Movement and range of motion
- Maintain fluid intake
- Maintain protein intake
- Relaxation techniques
- Fostering individual spirituality- remember that this is different for each person

## Key Points for Staff Education

- Remember to treat the root cause of the pain AND the environmental factors surrounding the experience of pain.
- Do all that you can to promote an environment that helps to alleviate discomfort.
- Medication is not always the solution to every pain concern. Educate staff to look toward a long term solution and not just a quick fix.

## Evaluate the effectiveness of pain relief measures....



## Continued Contact with Staff

- Has the pain been alleviated or lessened? Has any effect been noted?
- What side effects is the person experiencing, if at all?
- Is our treatment plan working? If not, re-evaluate and re-address until relief is met!
- Remember reasonable expectations- don't assume that they know what to look for in all circumstances. They will need continual contact and support.

## Additional information for staff support & teaching

- Be aware that pain can change over time and that treatment plans may need to change as well to obtain the same relief- staff need to know this up front.
- What works for one individual may not work for another!
- Tailor the treatment regimen for the individual, not for staff convenience ie: pain med dosing schedule

## Key Points for Staff Education

- Pain is.....whatever the person says it is, when it is, and where it is!
- Not all individuals indicate pain in the same manner
- Pain is real for the person experiencing it, regardless of how bad YOU perceive the person's pain to be!
- You have an ethical responsibility to provide adequate comfort measures and pain relief for individuals that you care for.

## Use Effective Educational Strategies for Staff

- Educate staff as you would a family member or someone with no medical knowledge. Start with the basics.
- Remember that many adults learn on a 5<sup>th</sup> – 8<sup>th</sup> grade reading level on average.
- “Need to know” information first.
- Visual and ‘hands-on’
- Small, digestible amounts at one time
- Encourage them to include the individual!
- **Staff cannot and will not think like nurses!**

## MONITORING

- REPEAT OBJECTIVE MEASURES
- EVALUATE FUNCTION
- MONITOR FOR AND CONTROL SIDE EFFECTS
- ADJUST DOSING BASED ON OUTCOME MEASURES

## SUMMARY

- NEVER STOP LOOKING FOR SOURCE
- ASSESSMENT
- ALLEVIATION
- MONITORING

Thank you for attending!

