Behavioral Changes
In Pain & Depression
• Further complication of an already complicated situation…
  • To tease out accurate feelings/sensations while in an intense affective state
  • Challenge: we don’t have agreed upon benchmarks for “sadness”…

How fair is our assessment?
• Pain and Depression can look so much alike!
• We may not be any good at making a definitive finding of depression or pain.

A Conundrum
• Examples of additional complications...
• What are the language skills?
• Are there cognitive/perceptual difficulties?
• What is the individual’s proprioceptive awareness of pain?

Complication of I/DD
• Even when a person has verbal language skills, observers have to be keyed into behavioral indicators.

• People with I/DD have learned that their ways of reporting their experience(s) may be disregarded.
• Case example:
  • Female, 40’s; deteriorating over months \( \rightarrow \) lots of medical evaluations = no etiology!
  • Learned she had specific physical findings
    • Embarrassed to reveal, “too personal” \{uterine\}
    • Didn’t think anyone would listen
  • Pain ever-present; Disregard ever-present; Anxiety and old ways of feeling.
• Pain and depression (in combination) move people toward regression
• Everyone has observations & has a voice
• Need to learn to articulate their observations about pain, depression, anxiety…
• Direct care staff – often have greatest opportunities for direct observations, and have the least confidence
• **Typical “behaviorist”**
  - Teaching residents of institution; some expressive language abilities, some receptive language capabilities.
  - Taught emotional states: happy-sad-afraid-angry.
  - What feel most of time? Sad = 80%.

• **Other behavioral consultant**
  - Same emotional state training, more contextual
  - What feel most of time? “mad” = 75%
• Pain interrupts concentration; attention
• Pseudo-dementia
• Decreased cognitive activity
• Decreased social interactions
• Withdrawal

Alteration in attention, energy
Activities change....
Changes in sleep

• May attempt to sleep more
  • Taking naps to deal with fatigue
  • Avoid situations that are painful, induce sadness
• Interrupted sleep patterns
  • Accompanied by increased irritability when awake
• Change in sleep position
  • Sitting more upright
- Areas vulnerable or hurting
- Prevent access
- “Splint” to prevent change/possible increase in pain
• A change from typical patterns is reason to start looking further

• Possible associations:
  • Hitting head ~ headache, earache
  • Avoiding lights/noise ~ migraine
  • Biting fist ~ GERD, stomach discomfort
  • Avoiding foods ~ throat problems, GI pain
  • Increase carbohydrates ~ depression, fatigue
Irritability = masquerader

- Can mask many symptoms/conditions
  - Increased anxiety
  - Despair
  - Chronic pain
  - “a good offense is your best defense”

Irritability = masquerader
• When have chronic, severe pain – perception of pain is altered and may be ignored
  • Once no longer acute, chronic pain can become the “new norm”
• If chronic pain is removed, what is this new state?...May not be recognized as pleasant.

Pain Disappears
• Withdrawal is a form of rejuvenation of energy and spirit
• Closeness to people who have died
• Honest awareness of losses
  • Hope for future engagement in living

Sadness may be ok
Feed-forward loops

- Depression
- Pain
• Importance of asking questions
• Everyone has experience
• Develop a way to learn what the patient/client means by their actions
  • “that’s how they’ve always been”
      --- DOESN’T CUT IT!!!