Pain in People With Developmental Disabilities

Dr. Eileen Trigoboff and Dr. Daniel Trigoboff
Module 1

The Mechanics of Pain
Outline
Module 1

- General Principles of Pain
- Individual Variables
- How Medications Sensitize People with DD to Pain
- Varieties of Chronic Pain Syndrome
Why is it Important to Focus on Pain?

- Pain negatively affects the quality of life by impairing
  - Daily functions
  - Social relationships
  - Sleep: 2014 study
  - Self worth
  - Emotional functioning
  - Medical condition
Why is it Important to Focus on Pain?

Unrelieved pain can have enormous physiological and psychological effects on the individual, their caregivers, & their loved ones.
General Principles of Pain
Pain & DD

Included in this group are people who have, to varying degrees of severity:

- Developmental disabilities
- Intellectual disabilities
- Autism
- Developmental delay
Health Care Provider Responsibilities Regarding Pain in Those with DD

- Ethical
- Medical
- Legal
Pain Symptoms

- Acute
  - Usually recent
  - Transient
  - Identifiable cause

- Chronic
  - Persistent
  - Lasts beyond acute cause
Acute & Chronic Pain in DD

- At higher risk for acute pain due to medical conditions, accidents
- At higher risk for chronic pain due to under-treatment including effects on neuropathic functioning
Chronic Pain in General

Nociceptive
  ▶ Tissue injury, disease

Neuropathic
  ▶ Damage to brain, spinal cord, peripheral nerves, or change in function

Functional
  ▶ Emotional, psychiatric, behavioral causes
Pain in DD Often Includes Several of These Factors

Nociceptive
  ▶ Higher incidence of physical problems

Neuropathic
  ▶ Change in function due to under-treatment

Functional
  ▶ Examples
Chronic Pain Exacerbation

- Increased pain in someone whose chronic pain syndrome had been well controlled
- Importance of ongoing assessment
Chronic Pain Exacerbation

- Change in underlying physical cause
- Change in emotional state
- Change in sensory function
- Interactional changes
- Psychiatric factors
Pain Is Complex

Pain perceptions are influenced by:

- Physiology
- Nervous system functioning
- Cognitive functioning
- Emotional state
- Behavioral factors
- Psychological distress
- Psychiatric factors
Mind/Body Duality and Pain
Medical
Environmental
Sensory
Interactional
Psychiatric
Pain & Intellectual/Developmental Disability

- Studies show pain in this population is improperly treated.
- This population often requires medical treatments/interventions that are painful.
- For equivalent surgical procedures, DD recipients are given lower levels of analgesics than non-DD recipients.
Under-Treatment

How do we know someone is in pain?
Pain & DD

- Reactions to pain
  - Vocal
  - Emotional
  - Facial
  - Protective reactions
  - Body movement
  - Physiological signs
Pain Impacts

■ Severe pain does more than just hurt
■ Pain can affect mood, appetite, ability to function
■ Pain can induce irritability and depression, anxiety, agitation, withdrawal, physical aggression
Knowing the Basics & the Intricacies

- Increase awareness about pain
  - Pain in someone with a developmental disability is expressed differently
- Consider all the components contributing to pain
- Conceptualize the process of short and long term pain, acute and chronic pain
- Nociceptive, neuropathic, functional pain, MESIP
Psychological Impacts of Pain

- Trauma often involves pain
- DD recipients, if traumatized, may have been hurt
- Trauma reactions include re-experiencing
- Can be triggered by (similar) pain
Psychological Impacts of Pain

Pain can be a trigger for psychological re-traumatization

- Pain in any area can evoke previous trauma reactions in another part of the body
- Pain can promote a feeling of helplessness and victimhood
- It can weaken someone’s resolve to move past the trauma
Psychological Impacts of Pain

- Pain can distract from coping with psychiatric symptoms. Feeling pain makes it difficult to manage symptoms of:
  - Hallucinations
  - Delusions
  - Depression
  - Mood instability
  - Obsessions &/or compulsions
  - Anger
  - Fear
  - Impulsivity
  - Behavioral problems
Psychological Impacts of Pain

- Pain detracts from the client’s efforts to cope with symptoms. Any problem will be magnified when in pain.
  - Arthritis
  - GI upset
  - GERD
  - Peripheral neuropathy
  - Respiratory distress
  - Seizures
  - Spasticity
Psychological Impacts of Pain

Psychiatric symptoms may not resolve with ongoing pain

- Pain can be an intermittent or a constant drain on the limited psychological resources of someone with DD

- Any psychiatric symptom can remain or worsen in the presence of pain
Pain is a Stressor

- Physical
- Psychological
- Behavioral
- Cognitive
Physiologic Impacts of Pain

Pain can worsen vital signs

- Hypertension is exacerbated by pain (even a normal BP can be heightened by pain)
- Breathing can be shallow and fast when people are in pain
- Heart rate changes
Physiologic Impacts of Pain

Pain can distract the client from coping with other physical problems

- If exercise, posture, certain movements are needed in order to treat, prevent an issue, or support a physical problem they may not be possible
- Pain could dislodge what is eaten, expenditure or conservation of energy, medication times
Physiologic Impacts of Pain

Pain can impair the efforts of the treatment team to evaluate the effectiveness of medical treatment

- Accuracy of assessments and evaluations could be reduced
- Reducing one pain problem may bring to the surface a different pain problem
Increase Awareness About Pain

Recognize the multitude of pain events possible

- When is pain experienced
  - With injury
  - Following injury
  - With debilitation
  - Only during use of debilitated body part/system
  - Anticipatory pain
  - Intermittent pain from muscle spasms or shifting of pressures/torque
  - Is adrenalin contributing to delay in pain
  - Is pain from another area masking different pain
  - Associated with a triggering experience
Increase Awareness About Pain

How is pain level determined

- Timing of event
- Severity of event
- Co-occurring events
- Prior events and subsequent events
- Individual pain threshold
- Gating
Personality and Pain
5-Factor Model

C=Conscientiousness
A=Agreeable
N=Neuroticism
O=Openness
E=Extraversion

These factors may affect experience/expression of pain
Personality Disorder Traits and Pain

■ Histrionic/Somatizing
■ Antisocial
■ Borderline
Increase Awareness About Pain

Structures involved in pain processes vary depending on the DD diagnosis

- Neurological
- Gastrointestinal
- Perceptual
- Respiratory
- Skin
- Joint
- Musculature
Pain & DD

Once someone who has DD experiences pain, the process can take variable paths:

- Feedback mechanisms
- Overstimulation challenges
- Reactions to pain
  - Impulsivity
  - Anger
  - Sadness
  - Fear
  - Confusion
Pain & DD

Consequences of these reactions—pain makes it worse

- Disruption of fragile psychological states
- Disruption of physical states
- Worsening of psychological problems
- Worsening of physical problems
- Interferes with interactions and communications
Consequences and Reactions

- Interferes with ADLs
- Interferes with maintenance of previous learning/achievements
- Can change rates of behavior
Caregivers’ attitudes and assumptions contribute to misdirected interventions. What do professionals think about pain and:

- Self injurious behavior
- Slow reaction time
- Under-reaction to pain routinely felt by others
- Cerebral palsy
Components Contributing to Pain

- Injury
- Chronic illness
  - Arthritis
  - Osteoporosis
  - Diabetes
  - Gastrointestinal problems
- Muscle spasticity
- Infection
Components Contributing to Pain

- Stress
- Change
- Surprises
- Expectations
- Boredom
- Sadness
- Hunger

- Fear
- Anger
- Excitement
- Disappointment
- Delays
- Reinforcement
Short Term Pain

Medical Procedures

- Medical professionals may not be sensitized to the needs and reaction times of DD recipients
Long Term Pain

Because DD recipients often cannot directly communicate about ongoing chronic pain, there is a risk that such pain will be undetected and untreated.
Individual Variables

Sensitivity

- Everyone has different pain sensitivities
- DD diagnoses further deepen those differences
- Psychiatric diagnoses in addition to DD diagnoses change pain sensitivity
- Changing over time
Individual Variables

Awareness

- Awareness of any internal process predicts pain awareness
- Incontinent individuals
- Spasticity
- Proprioception
Individual Variables

Reactivity

- How an individual reacts to any event with their bodies or in their lives can be applied to pain reactions
- Pain in different parts of the body has different psychological meanings to different people
Individual Variables

Resilience

■ How does a recipient handle difficulties
■ What is the recipient’s typical level of management of a negative outcome
■ Even those who take pain in stride need competent pain management
How Medications Sensitize People with DD to Pain

When a change takes place with a medication or substance, people with DD are more vulnerable to increases in pain symptoms.

The major categories of medications promoting problems are the following:

- Withdrawal from Substances of Abuse
- Changes in Pain Management Medications
How Medications Sensitize People with DD to Pain

Withdrawal from Substances of Abuse

- Alcohol
- Opioids
- Stimulants
- Sedatives
- Anti-anxiety
- Antidepressants
Withdrawal from Substances of Abuse

- Substance abuse issues with those who have DD is an important consideration.
- Reducing or removing the substance of abuse has more of an impact on those with DD than in the general population.
- Each substance of abuse has a different action on the body.
Withdrawal from Alcohol

- Removing alcohol can increase spasticity and thus increase pain
- Alcohol withdrawal has painful stages such as tremors
Withdrawal from Opioids

- Opioids create a sense of euphoria as well as pain management. Withdrawing the substance can cause a rebound of pain sensations, or a painful irritability and reactivity of the neurological systems of the recipient who did not have pain before.
Withdrawal from Stimulants

- Withdrawal from the artificial energy and excitement usually creates an emotional low that is a short-term depression.
- Resilience is low.
- Hopelessness may arise.
- Ability to tolerate another assault on the senses/body is greatly diminished.
- Pain is more acutely felt.
Withdrawal from Sedatives

- The removal of a calming, soothing compound can result in a heightened anxiety or irritability
- Insomnia is common
- Agitation makes pain less manageable
Withdrawal from Anti-Anxiety Medications

Whether it is a planned dose reduction, a scheduled discontinuation, or the cessation of a supply of a substance of abuse, anti-anxiety medications (anxiolytics) have withdrawal consequences.

- Rebound anxiety
- Rebound insomnia
- Irritability
- Decreased problem solving
Withdrawal from Anti-Anxiety Medications

- All consequences of withdrawal from anxiolytics exacerbate pain symptoms and can decrease the individual’s ability to communicate effectively.

- These difficulties can be misinterpreted as other problems which can interfere with the timely assessment and treatment of pain symptoms.
Withdrawal from Mood Stabilizers from Anticonvulsant class

- Any compound that stabilized the mood and is now reduced or removed will destabilize the mood
- Anticonvulsant class mood stabilizers have a neurological action that increases the risk of seizures once removed.
- The neurological calming also can have pain management features which will also dissipate, thus increasing pain sensations
Withdrawal from Antidepressants

- Some antidepressants have a pain management feature thus removal/withdrawal can exacerbate pain symptoms
- Any increase in depressive symptoms will increase pain symptoms
Changes in Pain Management Medications

- Schedule change
- Medication change
- Co-administration of medication changes
Changes in the Schedule of Pain Management Medications

- If medically feasible, the most effective pain management schedule is a regular dose
- The body accustoms itself to that schedule
- Shifting the schedule disrupts the response to the medication and recipient may need some time to adjust
Schedule & Reinforcement of Pain Complaints

prn schedules of pain medications can increase pain complaints directly
Schedule & Reinforcement of Pain Complaints

prn schedules can increase pain complaints indirectly through social reinforcement
Schedule & Reinforcement of Pain Complaints

DD recipients can become conditioned to increase their pain complaints prior to regularly scheduled dose.
Changes in the Type of Pain Management Medications

- Switching from one type of pain medication to another means different pathways are activated
- It may take time for the individual to feel the benefit of the switch
- In the meantime there may be increased pain symptoms
Changes in Administration of Other Medications While on Pain Management Medications

- Combining medications can be a delicate process
- A change in one med can influence the effectiveness of pain medication
- Changes in food and fluids can create the same pain symptoms
Varieties of Chronic Pain Syndrome

Interactions of

- Pain
- Psychological factors
- Behavior
Varieties of Chronic Pain Syndrome

- Pain affecting psychological state and behavior
- Psychological distress and behavior increasing experience of pain symptoms
Pain Affecting Psychological State & Behavior
Pain and Depression

- People in pain are more prone to a depressed mood.
- People who are depressed experience more pain from a given stimulus than people who are not depressed.
- Pain reduces positive reinforcement.
- Pain and depression can reinforce each other in a manner which creates a vicious cycle of increasing pain and depression symptoms.
Pain and Agitation

- When providers are not aware that a DD recipient is experiencing pain they may mistake pain-related behavior for psychiatric agitation.
- This can result in unnecessary psychiatric treatment while the pain goes untreated.
Pain and Social Withdrawal

- When DD recipients are in pain they may have trouble retaining and using previous levels of social skills
- This can lead to reduced and less effective social behavior
- This will result in less positive reinforcement for socialization and may lead to social withdrawal
Pain and Cognitive Functioning

Pain may interfere with the ability of the DD recipient to do the following:

- Orient to cognitive tasks
- Maintain task persistence
- Comprehend and learn new tasks or skills
- Retain previously learned material
- Pain and fight-or-flight response
Pain and Occupational Functioning

- Pain can reduce physical capacity for work tasks
- Pain can override the positive reinforcement the DD recipient may have experienced in their occupation, reducing their motivation for it
- Pain can reduce the quality of interactions with supervisors, co-workers, & customers leading to perceptions of poorer performance
Pain and ADLs

- Pain can interfere with range of motion and ability to perform effective and completely satisfactory ADLs
- Ineffective ADLs can lead to negative reactions from people in general
- Pain can reduce ability to perform ADLs effectively, thus presenting negative aspects to supervisors, co-workers, and customers
Training on Pain Issues Improves Care

Multidisciplinary training:

- Facilitates effective approaches for assessment, interventions, and outcome determination
- Improves the quality of life of those with DD