Pain in People With Developmental Disabilities

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and

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Module 2

Assessment of Pain
Outline - Module 2

- Pain Scale Options
- Proxy Reports
- Verbal & Vocal Indicators of Pain
- Under-Treatment of Pain Symptoms with Non-Verbal and Non-Vocal People with DD
- Behavioral & Physiological Indicators of Pain
- Syndrome-Specific Indicators of Pain Symptoms
- Co-Existing DD & Psychiatric Symptoms and Pain
- Staff Assessment Strategies
- Resilience
- Documentation of Pain Assessment
Pain Scale Options

FLACC

- Face
- Legs
- Activity
- Cry
- Consolability
Pain Scale Options

- Non-Communicating Adult Pain Checklist (NCAP)
  - 6 categories
  - 18 items

- Pain Behavior Scale
Pain Scale Options

- PainDETECT questionnaire (PD-Q)
- The Leeds Assessment of Neuropathic Symptoms and Signs (LANSS)
- A pain visual analog scale
VAS

No pain  Mild, annoying pain  Nagging, uncomfortable, troublesome pain  Distressing, miserable pain  Intense, dreadful, horrible pain  Worst possible, unbearable, excruciating pain
What If a Pain Scale Cannot Be Used?

If you cannot use an objective test or a scale, your remaining options are the following:

- Your clinical skills
- Your knowledge of your recipient
- Compare recipient to earlier behavior and function
Measures for Assessment

- Complete pain assessment
- Use a pain intensity scale to monitor pain
Measures for Assessment

Pain assessment components
- Location
- Intensity
- Timing
- What makes it worse
- What makes it better
- Response to treatments
Keep a record of experiences with pain, treatment for pain, and medications. Share this information to help manage pain most effectively.

<table>
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<tr>
<th>Date</th>
<th>Time</th>
<th>Pain Intensity*</th>
<th>Non-Med Treatment</th>
<th>Medicine Taken</th>
<th>What I was doing when pain began</th>
<th>Pain intensity 1 hour after</th>
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*Estimate pain intensity on a scale of 1 to 10 with 1 being mild and 10 being very severe. Adapted from U. S. Department of Health & Human Services: Agency for Health Care Policy and Research, 1994.
Proxy Reports

How to use information from others to formulate your assessment of a recipient’s pain

- Level
- Location
- Severity
Proxy Reports

Incorporate others’ information based on their descriptions of the following:

- Evidence of pain
  - What they see
  - How they interpret what they see
- Impact on function
- Impact on quality of life
Verbal Indicators of Pain

- Language
- Body Map
- Visual Analogue Color Scale to Rate Pain Intensity
- Responses to Photographs of Simulated Pain Experiences
Pain Scale

Agonizing | Horrible | Dreadful | Uncomfortable | Annoying | None

10 9 8 7 6 5 4 3 2 1 0

Unbearable Distress | No Distress

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2.18. Stabbing a toe
2.19. Having blood sample taken
2.20. Sitting in a wheelchair
2.21. Wasp sting
Vocal Indicators of Pain

- Utterances
- Moans/groans
- Screams
- Non-word sounds
Under-Treatment of Pain Symptoms

People who have any type of DD, especially those who are non-verbal and non-vocal, who have pain are typically undertreated for that symptom.
Non-Verbal and Non-Vocal People with DD who are in pain need special assessments

- Sensitivity to the cues given
- Interpret those cues effectively
- Respond to the cues
- Evaluate whether your response improved the pain symptom
Staff Attitudes Toward Pain Symptoms

Consider how these aspects affect staff reactions to pain:

- Is it OK to have pain?
- How should people behave when they have pain?
- How much expression of pain is allowed?
- How long is it OK to express being in pain?
Staff Attitudes Toward Pain Symptoms

What assumptions do staff make about pain in people who have DD:

- Their nervous systems are so different pain is not a problem
- Their intellectual disabilities mean they don’t understand and therefore don’t feel pain
- They don’t feel pain as intensely
Cultural Perspectives in the Assessment of Pain
Consider Culture in Assessment

- Generational cohort (i.e., Boomers era vs. GenX)
- Gender
- Ethnicity
- Family of origin attitudes towards pain (i.e., stoic vs. expressive)
Resilience

- How does the recipient handle distress and disappointment?
- What is the level of equanimity (low, moderate, high) when problems arise?
Personality and Pain Assessment: Using the 5-Factor Model

C  Conscientiousness
A  Agreeable
N  Neuroticism
O  Openness
E  Extraversion
Personality Disorder Traits and Pain Assessment

Histrionic/Somatizing
- Expressiveness
- Psychological Distress = Physical Sensations
- Antisocial
  - Instrumental use of pain complaints
Borderline
- Extreme emotional reactions
- SIB to generate pain
Behavioral Indicators of Pain

- Facial expression
  - Reliability
  - Validity

- Motor behavior
  - Reliability
  - Validity
Behavioral Indicators of Pain

- Sleep Disturbances
- Self Injurious Behavior (SIB)
  - Type
  - Location
  - Severity
  - Frequency
  - What occurred prior to SIB
  - What happens right after SIB
Behavioral Indicators of Pain

- Eating &/or Food Disturbances
- Trauma reactions
- Decreased/absent drive and motivation
- Decreased/absent task completion
Behavioral Indicators of Pain

- Problem behaviors
  - Interactional
  - Functional
  - Verbal
Pain and Occupational Functioning

- If task persistence, effectiveness, or attention are reduced this can be an indicator of pain symptoms.
- If the recipient’s enjoyment of occupational functioning decreases, this can be an indicator of pain symptoms.
- Ineffective, irritable, anxious, or sadness in interactions with co-workers or customers can indicate the presence of pain symptoms.
Pain and ADLs

- If observable standards of hygiene or dress are seen to decline, this can indicate the presence of pain symptoms.
- If physical abilities to perform tasks decline, this can be caused by pain symptoms.
- Decreased hygiene, poorer dress, and decreased task abilities can lead to negative reactions from other people.
Physiological Indicators of Pain

- Respiratory rate
- Heart rate
- Blood pressure
- Gait changes
- Postures
- Gastrointestinal
Pain Is Complex

Pain perceptions are influenced by the following:

- Physiology
- Nervous system functioning
- Cognitive functioning
- Emotional state
- Behavioral factors
- Psychological distress
- Psychiatric factors
Pain Is Complex

■ When assessing for pain, consider each variable.

■ Assessment is ongoing and conclusions change with the changes in each component.
Further Pain Assessment Components

Recipient’s character and history contribute information about experiencing and demonstrating pain symptoms

- Resilience
- Temperament
- Perspective
- Reaction to pain (nociceptive)
- Sense of humor
- Trauma
- Overall health
Further Pain Assessment Components

Co-morbidities create a platform for more pain, as well as more frequent and severe pain experiences for those with DD.

Co-morbid conditions contributing to pain often include the following:

- Spasticity
- Seizures
- Tobacco/alcohol use
- Diabetes
- Cardiac
- Osteoporosis
Further Pain Assessment Components

Pain is affected by more than physiology.
Excellent assessment of pain takes the form of the acronym (MESIP):

M
E
S
I
P
M  Medical
E  Environmental
S  Sensory
I  Interactional
P  Psychiatric
Syndrome-Specific Indicators of Pain Symptoms

- Level of Disability and Pain
- Down Syndrome
- Fragile X Syndrome
- Autism Spectrum Disorders
- Dementia
Syndrome-Specific Indicators of Pain Symptoms

- Down Syndrome – common cardiac problems
- Fragile X Syndrome – mitral valve prolapse is common creating hypoxia and what looks like anxiety, therefore assess for pain
- Autism Spectrum Disorders - sensitivity to textures such that cotton feels like sandpaper thus throwing off clothes could be pain from tactile hypersensitivity; pain is stressful which increases movement stereotypies
- Dementia – pain is stressful, stress worsens dementia symptoms, thus if dementia symptoms worsen look for underlying pain
Level of Disability and Pain

- Each functional level of disability will have a distinct reflection in the pain symptoms the person with DD experiences
- Overall categories include low, moderate, and severe DD
Issues in Assessment

Mild DD

- Greater cross-domain expression of pain symptoms
  - Verbal
  - Behavioral
  - Interactional

- Greater probability of reliable & valid self-report

- More opportunity to look at consistency among domains

- Are deficits variable or consistent?
Issues in Assessment

Moderate DD

- Often vocal rather than verbal
- Observational scales and reports more important
- Proxy reports more important
- Comparison with recipient’s own baseline and history more important
- Possibility that pain has contributed to a deterioration of function to this moderately impaired level
Issues in Assessment

Severe DD

- Cues may be subtle
- At best, vocal
- Observational reports and scales very important
- Proxy reports very important
- Any changes in types and rates of behavior including eating, drinking, sleeping, and observable physiological functions very important
Issues in Assessment

- Collateral information
  - Reliability
  - Validity
  - Variability
- Interpretation
Assessing pain in this population is

- Complex
- Diverse
- Requires examinations of different areas of functioning
- Requires frequent updating of assessments because functioning in any of the areas of assessment can change.
Issues in Assessment

- Mood
- Agitation/irritability
- Learned helplessness/ acquiescence
- Psychiatric status
- Overall interactions with assessor
Issues in Assessment

- Conditions and experiencing pain symptoms can change over time
  - Physical condition contributing to pain
  - Cognitive impairment due to pain
  - Cognitive impairment due to medical problem
Co-Existing DD & Pain with Psychiatric Symptoms
Mental Health Issues

- Psychosis
- Depression
- Bipolar Illness
- Dementias
- Behavioral problems
Psychosis

- Hallucinations
  - Delusions
  - Disorganization
Pain and Psychosis

Psychotic symptoms

■ May mask pain symptoms
■ May be worsened by pain symptoms
■ May interfere with communication about pain symptoms
■ Decrease ability to cope with pain
■ Disorganized cognitive processes may cause insensitivity or hypersensitivity to pain
Affective Disorder

- Major Depression
- Bipolar Illness
Major depression is diagnosed more commonly in the DD population than in the general population.

Episodes of depression can have strong impacts on people who have DD functioning.

Unfortunately, depression is often either undetected or detected only after long delays.
Communicating Depression

- Sometimes the non-verbal, observed changes are your 1st indication
- Sadness including crying
- Withdrawal
- Poor PO intake
- Disturbed sleep
- Irritability
- Anxiety
- Potential for mood congruent psychosis
Pain and Depression

Depressive symptoms

- May mask pain symptoms
- Increase the incidence of pain experiences
- Increase the intensity of pain
- Decrease ability to cope with pain
Bipolar Illness

- Bipolar illness has a 2- to 3-fold greater prevalence in the cognitively impaired than in the general population.
- Bipolar depression can require different treatment than major depression.
- Symptom topography and disease subtype can develop and change over time requiring tracking & adjustments of interventions.
Several Subtypes

■ I Manic and Depressed episodes

■ II Hypomanic and Depressed episodes
  Rapid Cyclers
  4+ episodes/year
  Mania can be accompanied by psychosis
Manic Symptoms

D  Distractibility
I  Insomnia
G  Grandiosity
F  Flight of Ideas
A  Agitation
S  Speech
T  Thoughtlessness (Impulsivity)
Pain and Bipolar Illness

Manic symptoms

- The high activity level may distract from pain symptoms
- May mask pain experiences
- Increase irritability & agitation
- Decrease the intensity of pain
- Decrease ability to cope with pain
Pain and Bipolar Illness

Depressive symptoms (same as in Depression)

- May mask pain symptoms
- Increase the incidence of pain experiences
- Increase the intensity of pain
- Decrease ability to cope with pain
Pain and Alzheimer’s Dementia

- Agitation
- Verbal outbursts or sustained yelling
- Mealtime issues
- Physical acting out
Pharmacological Treatment

Many medications treating dementia are acetylcholinesterase inhibitors (also called cholinesterase inhibitors)

■ Common GI side effects
  ► Nausea
  ► Pain

■ Hazards and Benefits
Environmental Impacts

Some problems unique to this population are environmental impacts. People with DD are more sensitive to the following:

- Ambient Environment
- Changes
- Health Impacts
- Functional Impacts
Substance Abuse Issues

- Longstanding substance use/abuse
- Self-medication
- Misunderstandings/misconceptions
- Inadvertent
Depression & Substance Abuse

- Alcohol is a depressant
- Self-medicating to treat a depression is very common
Complications that Arise from Combining Substance Abuse with DD

Clinical Issues

- Psychiatric Symptoms (or increased symptoms)
- Poor Treatment Compliance
- Increased Need for and Use of Emergency Health Care Services
- Poor Response to Medications
Clinical Issues

- Unstable Clinical Course
- Increased Hospitalization
- Chronic Threats to Health
- Increased Risk of Tardive Dyskinesia
Forensic Issues

- Behavioral Problems
- Suicide
- Homelessness
- Violence
Pain and Substance Abuse Issues

- Substance abuse may be self medication of pain
- DD recipients may seek pain meds as a substitute for whatever substance they were dependent upon (i.e., alcohol, marijuana)
- May more easily become addicted to analgesics because of limited cognitive abilities
- May see more pain complaints as an indicator of increased risk of substance abuse relapse
Understanding Treatment for DD, Psychiatric Symptoms & Pain

This unique population must have treatment for various problems in a way that

- Recognizes the consumer’s skill level
- Acknowledges the durable deficits
- Incorporates behavioral interventions
- Arranges care in a logical manner
- Allows for flexibility
Pain Can Signal These Physical Health Concerns

- Glucose dysregulation
- Hypoxia
- Infections
- Seizures
- Circulatory
- Hydration
- Metabolic encephalopathy
Pain Can Signal These Physical Health Concerns

- Neurological problems
- Incontinence
- Poor renal functioning
- Stomach problems
- Medication side effects
- Anticholinergic
Physiologic Impacts of Pain

- Persistence of pain of any particular type can result from simultaneous different problems.
- Therefore, if treating a diagnosed problem causing pain and the pain persists, we need to consider that another problem may be present as well.
Documentation of Pain Assessment

- Scale
- Observations
- Interpretations
- Examples of Effective and Ineffective Documentation