General Aging in Intellectual and Developmental Disabilities

Identifying and Assessing Pain

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Massachusetts Dept. of Developmental Services (DDS)

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Pain is Common

Estimates vary and research in general has a variety of common flaws/limitations

- General consensus:
- Pain in adults with IDD, both acute and chronic is:
 - Prevalent (commonly occurs)
 - Under-recognized
 - Undertreated





Framework: Pain Assessment in Nonverbal Patients

American Society for Pain Management Nursing (ASPMN), 2006

5 Key Principles:

- 1. Obtain a self-report of pain, if at all possible
- 2. Observe for behaviors that may indicate pain
- 3. Solicit a surrogate report from an observer or caregiver
- 4. Investigate for possible pathologies that could produce pain
- Consider the use of an analgesic (pain reliever) trial to evaluate whether pain management results in a reduction in the behavioral indicators thought to be related to pain







- Pain is subjective
- Self report is the gold standard, but it often limited, or nonexistent
- Inconsistencies in caregiver reporting
- Pain perception and the myth of "insensitivity to pain"
- Lack of reliable/practical gold standard for pain assessment





Identifying Pain

- Self report is often limited, or nonexistent
 - Some people can use modified pain scales (body map or visual analog color scale) to report pain
 - Be cautious: Scales often include abstract concepts, which may be beyond the grasp of many people, and may not be reliable
- Some pain assessment tools have been designed for children as well as adults with IDD
 - Even validated instruments are not easily adapted into clinical practice





Proxy Reporting

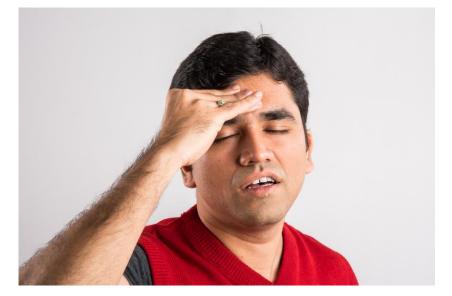
- Report via caregiver/parent
- In studies of children, parental reports are more valid than using non-verbal cues to measure pain
- Individuals with IDD often have their own identifiable characteristics for expressing pain, but you won't know unless you ask
- Obtain baseline information:
 - Does he/she express pain reliably?
 - In what ways are pain symptoms expressed?
 - Have you observed any signs of pain or discomfort?





Understanding Care Provider Observations

- Observations are often influenced by facial expression of the person in pain
- At baseline, people with IDD may show more or fewer facial expressions (for example, tics or lifelong facial abnormalities)
- Observers may apply their own beliefs and perceptions about the person or pain to their assessment, for better or for worse







Evaluation: Next Steps

- Use common sense and a multidisciplinary approach
- Consider patient's developmental age, temperament, personality, environmental factors, and previous pain experiences
- Be comprehensive in your medical/functional review
- Consider any syndrome-specific prevalent conditions
- Common things are common!
 - Osteoporosis
 - Arthritis
 - GERD



Dental



Gather the Evidence

In daily life and during personal care:

- Look for physical signs of pain and potential sources of pain
- High yield areas: musculoskeletal (bones/joints), spine/back, teeth, skin and soft tissue
- Observe walking, overall movement, range of motion
- Maintain a high index of suspicion, i.e.; give a fair benefit of the doubt that some degree of pain could be present
- □ If there are any doubts, consider getting a medical opinion





Additional Webinars on Aging with IDD

General Aging in Intellectual and Developmental Disabilities

- Understanding Age Related Changes
- □ The Role of Polypharmacy
- Identifying and Assessing Pain
- Behavior Related Changes and Aging in Adults with IDD
- Health Promotion and Aging in Adults with IDD
- Mobility and Aging in Adults with IDD
- Aging with Down Syndrome
- Aging and Cerebral Palsy

Dementia and Intellectual and Developmental Disabilities

- Introduction to Dementia and Aging with IDD
- Early Evaluation of Dementia and Alzheimer's Disease
- Stages of Alzheimer's Disease
- Applying the Knowledge to Dementia Caregiving and Caregiver Support
- Caregiving in Action: Case Studies and Practical Tips





Additional Aging with IDD Resources

Massachusetts Department of Developmental Services (DDS) www.mass.gov/eohhs/gov/departments/dds/aging-with-id.html

Center for Developmental Disabilities Evaluation & Research http://shriver.umassmed.edu/cdder/aging_idd_education





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