General Aging in Intellectual and Developmental Disabilities

Identifying and Assessing Pain

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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

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

5. 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

Challenges

❑ 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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