RECOGNIZING DEMENTIA IN PEOPLE WITH INTELLECTUAL DISABILITIES AND PLANNING APPROPRIATE HEALTH SERVICES

DDA Health Initiative
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Historical Perspective

• 1994 in Minneapolis, Minnesota, in conjunction with the 4th International Conference on Alzheimer's Disease and Related Disorders.

• AAMR/IASSID Practice Guidelines:
  – Recognize changes
  – Conduct assessments and evaluations
  – Institute medical and care management

• ADD Listening Forums in 2010

• National Task Group on Intellectual Disabilities and Dementia Practice – development of screening instrument
Dementia

• The progressive loss of brain function that occurs with certain neuropathological diseases or trauma and is often associated with aging.
• Marked by memory disorders, personality and behavioral changes, and impaired reasoning.
• Dementia is not a disease itself, but rather a group of symptoms that are caused by various degenerative brain diseases or conditions, such as Alzheimer’s disease, stroke, or other brain trauma.
• Progressive in nature
Incidence

- Persons with an intellectual disability are affected by dementia to the same degree as other adults in the general population.
- Some may be affected earlier and at a greater rate, i.e. adults with Down syndrome, most of who will be among approx. 200,000 adults in the general population affected under age 65.
- About 6% of adults with an intellectual disability will be affected by some form of dementia after the age of 60 (percentage increases with age).
- For adults with Down syndrome, at least 25% will be affected with dementia after age 40 and at least 50 to 70% will be affected with dementia after age 60.
- 33,000 adults with developmental disabilities and dementia currently live at home with older family caregivers and perhaps twice as many live in out-of-family-home settings.
NTG Recommendation #1

Conduct nationwide epidemiologic studies or surveys of adults with intellectual disabilities that establish the prevalence and incidence of mild cognitive impairment and dementia.
Risk Factors Specific to People with An intellectual disability

- Presence of Down syndrome
- Significant head injuries
- Obesity
- Limited cognitive reserve
- Poor cardiovascular health
NTG Recommendation #2

Conduct studies to identify and scientifically establish the risk factors associated with the occurrence of dementia among adults with an intellectual disability.
Edinburgh Principles

- Adopt an operational philosophy that promotes quality of life.
- Affirm that individual strengths guide decision-making.
- Involve the individual and family in all planning and services.
- Ensure availability of appropriate diagnostic and service resources.
- Plan and provide supports to optimize remaining in community.
- Ensure that people with an intellectual disability have access to same dementia services provided to others in population.
- Ensure that community dementia services’ planning also involves a focus on adults with an intellectual disability.
Identification, Screening, and Diagnosing

• Agencies need to adopt a strategy for the tracking of trajectories of functional and cognitive decline
• Screen all people with Down syndrome over the age of 40 and all others who show signs of cognitive decline
• Public health awareness
NTG Recommendation #3

Develop guidelines and instructional packages for use by families and caregivers in periodically screening for signs and symptoms of dementia.
NTG Recommendation #4

Encourage provider agencies in the United States to implement screenings of their older-age clientele with an intellectual disability who are at-risk of or affected by dementia.
Examine the utility of adopting an instrument such as an adapted Dementia Screening Questionnaire for Individuals with Intellectual Disabilities for use in preparation for the annual wellness visit.
NTG Recommendation #6

Conduct an evaluation of a workable scoring scheme for the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities that would help identify individuals in decline.
Diagnosis

Review of pre-morbid daily activities

Clinical observation for symptoms of mild cognitive impairment (MCI)
Symptoms of Mild Cognitive Impairment

- Forget important information that you would have previously remembered: conversations, recent events, appointments
- Ability to make sound decisions
- Ability to judge the time needed or sequence of steps to complete a task
- Visual perception problems
Medical Workup for MCI

- **Thorough history:** current symptoms, previous illnesses and medical conditions, and any family history of significant memory problems or dementia
- **Assessment of independent function and daily activities,** which focuses on any changes from a person's usual level of function.
- **Assessment of mental status** using brief tests designed to evaluate memory, planning, judgment, ability to understand visual information and other key thinking skills.
- **In-office neurological examination** to assess the function of nerves and reflexes, movement, coordination, balance and senses.
- **Evaluation of mood** to detect depression; symptoms may include problems with memory or feeling “foggy.” Depression is widespread and may be especially common in older adults.
- **Laboratory tests** including blood tests and imaging of the brain’s structure.
NTG Recommendation #8

Promote the exchange of information among clinicians regarding technical aspects of existing assessment and diagnostic instruments for confirming presence of dementia in people with an intellectual disability.
Health and Secondary Conditions Affecting Adults with Dementia

• After diagnosis, guard against attributing health and functional declines to dementia without appropriate differential diagnosis e.g. metabolic derangements, medication side effects, drug-drug interactions, cervical dysplasia etc.
Nursing Diagnoses and Dementia

- Anxiety
- Aspiration risk
- Fall risk
- Dysphagia
- Bowel and bladder incontinence
- Impaired comfort
- Impaired communication
- Chronic confusion
- Ineffective coping
- Impaired interpretation of environment
- Failure to thrive
- Fatigue
- Wandering
Dementia Management

- Include family members in the nursing process
- Identify usual patterns of behavior
- Determine baseline cognitive functioning
- Monitor cognitive functioning
- Determine behavioral expectations
- Provide low-stimulation environment
- Provide adequate, non-glare lighting
- Avoid frequent rotations of staff
- Provide rest periods

- Identify and remove potential environmental dangers
- Use ID bracelet
- Provide consistent physical environment and daily routine
- Interact with eye contact and touch as appropriate
- Avoid touch and proximity as appropriate
- Address person by name
- Give one simple direction at a time
- Speak in a clear, low, warm and respectful tone of voice
- Use distraction vs. confrontation
Dementia Management

• Monitor nutrition and weight
• Provide space for safe pacing and wandering
• Avoid frustrations
• Provide cues to assist orientation
• Allow to eat in small groups or alone if needed
• Provide finger foods if restlessness is present
• Decrease noise levels
• Select 1:1 or group activities based on abilities

• Label familiar photos
• In ISP development recognize the person may not be able to learn new material
• Limit choices
• Use symbols to help define boundaries and label rooms, drawers, etc.
• Monitor for physiological causes of confusion (constipation, UTI, infection, etc.)
• Remove or cover mirrors as needed
• Review home safety and interventions
• Carefully plan transitions
Case Study

• Ms. Sudette has Down syndrome and lived for many years with her family before moving to a small group home. After a few years, she decided to move to an apartment and got involved with many community activities. She had a group of friends and enjoyed spending time with her family. About three years after moving into her apartment, staff at her support services agency began to notice subtle changes in her function and behavior. The RN assigned to Ms. Sudette interviewed all of the support staff and completed a NTG Dementia Screening Questionnaire that she submitted to the primary care physician to review during a medical visit. The physician also noticed deterioration in function and suspected early dementia related to Alzheimer's disease.

• Within the year she showed further decline in skills and significant physical problems, such as incontinence. She began to have crying spells and became more emotionally unstable. Shortly afterwards, she moved back to a group home as she was having a very difficult time living alone. She began to have seizures and severe swings in her sleep patterns. Her behavior and functioning deteriorated even more. She was constantly agitated and was progressively more dependent on staff for everything.

1. What are Ms. Sudette's health risks?
2. What are appropriate outcomes for each risk, given that dementia is a progressive disease?
3. What interventions should be developed for each health risk?