GERIATRIC PATIENTS WITH INTELLECTUAL & DEVELOPMENTAL DISABILITIES

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OBJECTIVES/TALK OUTLINE

- Define intellectual disability & developmental disability, appreciate their differences, etiologies.
- Understand the common barriers to primary care.
- Know the different forms of long term care & services offered, including adult day health.

OBJECTIVES/TALK OUTLINE

- Know the common issues in the I/DD population: legal, risk of violence, financial exploitation, sexuality, healthcare disparity.

- Feel more confident in your approach to the comorbid conditions of your I/DD pts:
  - Cerebral palsy, seizures, spasticity, dysphagia, GI dysmotility, polypharmacy, behavior disorders, mood disorders, and dementia/cognitive decline.

DEFINITIONS

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Developmental Disability definition:

- Occurs before age 22, persists indefinitely.
- Chronic mental or physical impairment resulting in delay or failure to achieve normal developmental milestones.
- Causes significant functional impairment in areas such as independent living, self care, receptive and expressive language, learning, and economic self sufficiency.
- Encompasses intellectual disability but also includes physical disabilities.

DEFINITIONS

Intellectual Disability definition:

- Broad term that refers to mental capacity below normal.
- Limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior (covering many social & practical skills).
- Due to any cause, before age of 18.
- Replaces "Mental Retardation"

American Association on Intellectual and Developmental Disabilities (AAIDD)

ETIOLOGIES OF I/DD

- Etiologies of Developmental/Intellectual Disability:
  - Genetic abnormality
    - >500 genetic defects associated with I/DD
    - More associated with severe ID (IQ <50)
    - Majority due to Down Syndrome & Fragile X Syndrome
  - Brain injury
    - Prenatal (eg, fetal alcohol syndrome)
    - Perinatal (eg, infections, trauma)
    - In childhood (eg, metabolic abnormalities, infections, trauma)
    - More associated with mild ID
  - 1/3 of cases: no cause identified

BACKGROUND

- ID/DD affects 0.6-2.5% of the population
- Shorter life span (by 13-20 years) thought to be caused by an accelerated aging process.
- Higher rates of obesity, sedentary behaviors, poor nutritional habits, and dental disease.
- Living longer these days:
  - Including those with more severe or limiting disabilities
  - Down Syndrome patients living 2x as long as they did 25 years ago
- …more of these patients will be in the offices of primary care clinicians and geriatricians!

WHAT THE I/DD PATIENT FACES

- Huge risk for **diminished quality of life** from the combined forces of:
  - Changes of normal aging
  - Inadequate funding for health & social services
  - Healthcare system not designed for them
  - Discrimination and attitudes
  - Inadequate access to active lifestyle and appropriate nutrition
  - Caregivers burnt out, overburdened, inadequately trained, etc.
  - For many: progressive immobility, cognitive decline, increasing behaviors → world shrinks

BACKGROUND

- Questions you may ask yourself when approaching your patient with DD:
  - Preventive care and health screening?
  - Communication? With who?
  - Logistics of care in the clinic (or outside its walls)?
  - Maintain patient's comfort, dignity, preferences?
  - Protect from abuse, neglect, exploitation?
  - Determine goals of care, navigate end of life?
  - Others?

Barriers To Primary Care

- I/DD pts see PCPs less often compared with the general population.
  - Lack of PCPs knowledgeable/comfortable with I/DD pts
  - Behavioral issues that make examination, testing, treatments difficult.
  - Communication issues between provider, caregiver, and pt.
  - Physical challenges make leaving home difficult.
  - Clinic environment causing sensory challenges to the pt.
  - Caregiver burnout leading to missing appointments, etc.
  - Shortage of provider time needed to accommodate these pts' needs.

Case

- 74yo pt with I/DD and DM2, cognitive decline, OA, and AFib on coumadin. Has history of 2 falls in the past year and widely fluctuating INRs. Living in a "senior care facility" (?) for the past 5 years. With her last fall, she was found down by a friend after 8+ hours of long lie. Has been leaving her building less and less as she is fearful of falling and experiencing increasing arthritis pain.

UNDERSTAND THE LIVING SITUATION

- More living in the community vs institutions
- **Independently in private residence**
- **With parents [in younger years]**
  - Major transition as parents age, require care, and die.
- **Independent living retirement community**
  - Some with dining, laundry

ADULT FAMILY HOME (AFH)

- 2-6 residents in a community home
- Licensed by the state
- Nurse delegation/supervision by the state
  - Typically does not have frequent nursing involvement
- Room, meals, laundry, supervision, and varying levels of assistance with care.
- Specialized care offered by some

Assisted Living Facility (ALF)

- 7 or more residents, typically individual apartments
- Licensed by the state
- Varying level of services
- Memory/Dementia care is one specific type of ALF

Skilled Nursing Facility (SNF)

- 24-hour supervised nursing care, personal care, therapy, nutrition, activities, social services, room, board and laundry.
- Federal (CMS) oversight, State (DSHS) licensed
- Push now to avoid SNF for long term care and to instead place patients in community settings (AFH, ALF, etc).

Adult Day Health

- Half-day programs for pts to attend 1-5x/wk
- Individualized nursing care
- 1:1 & group rehab (OT or PT services)
- SW support
- Social programming, sense of community
- Group exercise
- Caregiver support & education
- Underutilized service
- Available to pts living at home, AFH, ALF, etc.

Back to our case…

- 74yo pt with I/DD and DM2, cognitive decline, OA, and AFib on coumadin. Has history of 2 falls in the past year and widely fluctuating INRs. Living in a "senior care facility" (?) for the past 5 years. With her last fall, she was found down by a friend after 8+ hours of long lie. Has been leaving her building less and less as she is fearful of falling and experiencing increasing arthritis pain.

BACK TO OUR CASE…

- Clarified: she is in independent living (IL) apartment / low income senior housing.
  - Common dining room, activities onsite, but no nursing care/monitoring/supervision.
- Asked her to bring in her pill bottles and explain what and when she is taking them: revealed impairments.
- Recommended she move to an assisted living apt or adult family home, where meds can be administered & a personal alert device is used.
- Recommended she begin attending adult day health for fall prevention exercises & nurse monitoring.

CAREGIVERS

- Family, hired individual, or from residential/institutional care setting.
- Caregiver's knowledge of the patient and ability to communicate issues is variable.
- Frequent disruptions in care and relocations are common.
  - Due to insurance, care needs, behaviors
  - Leads to fragmentation of care

FAMILY CAREGIVERS

- Demands increasing, population aging.
- Parents aging, suffering health decline.
- Ask about caregiver burden at every visit.
- Sleep disruptions/nighttime behaviors.
- Multidisciplinary support (SW) essential.

Patient Communication Ability

- Do not make assumptions about pt's abilities. Assess expressive & receptive/comprehension skills.
- Address the pt directly whenever possible.
- Always acknowledge the pt's right to consent.
- History is often from caregivers, can be vague & limited.

Patient Communication Ability

- Medical chart: big holes of info, broken chain
- Always worth the effort to seek out the caregiver(s) who best know the patient to get useful history!
- Nonverbal or severely limited pts are at greater risk for poor nutrition, overmedication, injury, and abuse.
- Look for undiagnosed hearing/vision impairment.
- Enlist the help of speech therapist for communication tools.

VALUE OF ROUTINE VISITS

- When pt unable to reliably communicate new symptoms or needs, important to have routine visits.
- Often require extra time due to underlying psychosocial issues.
- Half of the time will identify a new issue or diagnosis.

CASE

- 66yo M with Down Syndrome, dysphagia, and Alzheimer's Disease living in a SNF. Recently hospitalized for an aspiration pneumonia. Has had progressive cognitive decline in the past year. He has always been his own decision-maker, but recently he appears to have less of an understanding of his medical conditions. His POLST form from 5 years ago currently indicates he is full code with full interventions (intubation OK).

LEGAL ISSUES

- Clarify issues of Durable Power of Attorney for Healthcare and Guardianship early!
  - Many patients do have decisional capacity
  - Anticipate need for guardianship/DPOA-HC
  - Successor guardian for aging parent
- Medical providers often need to become patient advocate when there is controversy over the approach to care.
- Determining patient's goals, code status/POLST form should be done ideally *before* a life-limiting diagnosis or event occurs.

NOTE ON DECISIONAL CAPACITY

- Four elements:
  - The ability to communicate a choice.
  - The ability to understand the relevant information
  - The ability to appreciate a situation and its consequences
  - The ability to reason rationally.
- Have pt paraphrase back to you their understanding, reasoning.
- Decisional capacity is decision-specific!
  - May be able to assign a DPOA, choose where to live, but not decide between two different complicated surgery options, etc..
- Even if a patient lacks decisional capacity, medical decisions should still be discussed with them.

BACK TO OUR CASE…

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BACK TO OUR CASE…

- Asked pt if he can tell you what he knows about his recent hospitalization, and did his providers tell him pneumonia could happen again in the future [aspiration].
- Ask what he understands about intubation, ever known someone who was intubated/ventilated.
- → pt unable to describe his recent hospital stay or illness, confused breathing tubes and feeding tubes.
- → able to tell you who he would choose as decision-maker, consistent over time.
- → asked for SW help in assigning DPOA (friend).

SEXUALITY

- Overlooked
- Assumed that individuals with ID/DD (or simply geriatric) are not sexually active.
- Need to assess the individual's ability to consent.
  - Complex conversation with family
- Provide appropriate STD counseling.

VICTIM OF VIOLENCE RISK

- Increased risk of physical and sexual violence (by caregivers/staff or other patients).
- By meta-analysis of 3 studies, there was a 60 percent increased risk for experiencing violence among persons with ID compared with the general population.
- Individuals with ID had the highest rates of violence compared with individuals with other types of disability, including mental illness and physical or sensory impairments.

FINANCIAL ABUSE

FINANCIAL ABUSE

- One of the fastest growing forms of abuse targeting seniors and adults with disabilities
- Two general forms of financial abuse:
  - Financial Exploitation
    - perpetrated by someone who is known to the individual (family, caregiver, friend, etc)
  - Financial Scams
    - eg, home improvement and lottery schemes that target the elderly or disabled.

DISPARITY

- Due to the combination of the increased burden of disease, communication problems, and inadequately funded support services.
- I/DD pts less likely to receive adequate medical care than the general population, despite increased burden of chronic health problems.
- Decreased rates of recommended preventive health interventions.
- Deficiencies in the structure and funding of health services for this population.

COMMON COMORBID CONDITIONS/ISSUES

- Cerebral palsy (CP)
- Seizure disorders
- Muscle spasticity
- Gastrointestinal motility problems & dysphagia
- Pain
- Polypharmacy
- Behavioral disorders
- Dementia & cognitive decline

Common Comorbid Conditions: Cerebral Palsy (CP)

- Refers to the presence of a nonprogressive motor impairment and, like ID, is a nonspecific term.
  - Not all CP pts have ID
  - Up to 1/3 of all ID pts are affected by CP
  - Challenges of CP:
    - spasticity and immobility
    - strabismus and cerebral visual impairment
    - bowel and bladder dysfunction

Common Comorbid Conditions: Seizure Disorders

- More prevalent in patients with ID than the general population.
  - Especially among lowest IQ
  - ~50% of pts with CP have seizure disorders
  - Death rate is 3x higher for pts with epilepsy
- More than one agent often required to control seizures.
- Monitoring for toxicity and side effects
  - Osteoporosis screening important

CASE

- 69yo M with CP, RLE spasticity, wheelchair dependence. Having increased spasticity of the RLE causing increased pain and decreased ability to participate in transfers. Has been on methocarbamol for years, unclear if it's helping. Previously followed by a physiatrist, but lost to follow-up many years ago.

COMMON COMORBID CONDITIONS: SPASTICITY

- Difficult to manage in the elderly population
- Most antispasmodics have anticholinergic effects, increasing risk of falls, delirium, etc..
- Get help from a physiatrist!
- The basics are important: optimize positioning and seating, wheelchair fitting, etc.

SPASTICITY – MEDICAL MANAGEMENT

- **Diazepam**/other benzos: high risk of delirium, impaired cognition, falls
- **Tizanidine**: efficacious, but should avoid due to sedation
- **Dantrolene**: requires liver toxicity monitoring
- **Methocarbamol**: generally less effective, requires high doses that are not safe in the geriatric pop
- **Baclofen**: less sedating but effective, but associated with more muscle weakness
- Localized injections with **botox**: great if an option
- **Intrathecal pumps (baclofen)**: less CNS effects
- Bottom line: no preferred agent– balancing efficacy vs side effects

POINTERS ON WHEELCHAIRS

POINTERS ON WHEELCHAIRS

- Initial eval: should have a PT or OT involved!
  - Usually stuck with that chair for 5 years, important to get the fit, type, features right.
  - Important to determine if pt is safe to use a motorized WC
  - Alert PT/OT if progressive changes are anticipated
- WCs should be evaluated annually and as needed (vendor service or PT/OT)
  - Often broken parts, etc
  - Changes in weight, postural control
  - Fall from WC
  - Pressure injury, need for Roho cushion, etc

BACK TO OUR CASE…

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BACK TO OUR CASE…

- Slow cross-taper to baclofen
  - Start low and go slow (5mg TID)
- Asked PT to assess his wheelchair fit
- Modest benefit from baclofen → referred to rehab medicine → received botox injection with good effect

COMMON COMORBID CONDITIONS: DYSPHAGIA

- Prevalence of dysphagia in the geriatric population is at least 15-20% → rates will be much higher in the DD/ID geriatric population.
- Modified barium swallow evaluation is helpful
- Speech pathologist consultation for recs on food/liquid textures & feeding strategies.
- Gastrostomy tubes (G-tubes) & jejunostomy tubes (J-tubes):
  - provide adequate nutrition
  - ?prevent aspiration pneumonia – nope, probably not
  - not appropriate for patients with dementia

Common Comorbid Conditions: GI Dysmotility

- Upper GI dysmotility: leads to dysphagia, esophageal reflux, and gastroparesis.

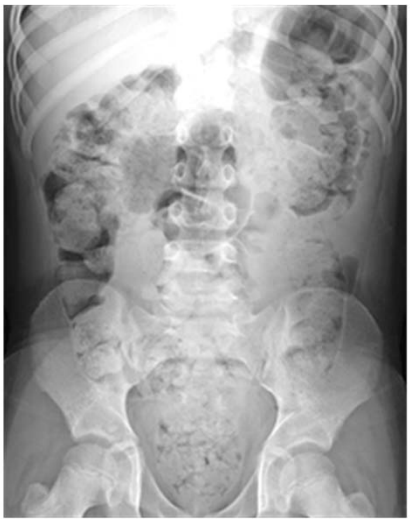
- Consequences:
  - dental erosion
  - esophagitis
  - anemia
  - feeding problems
  - aspiration pneumonia.

Common Comorbid Conditions: GI Dysmotility

- Lower GI dysmotility: Constipation
  - Up to 40% of ID pts
  - Most often due to:
    - immobility and lack of exercise
    - psychotropic, anticholinergic, opioid medications
  - Inadequate treatment/complicatons:
    - Fecal impaction, bowel obstruction
  - Constipation Dx is easy to miss, is common cause of pt distress
    - If history is limited, abdominal plain film can be helpful

- Bowel regimen, including hydration and activity is important

CONSTIPATION



OSTEOPOROSIS

- Increased risk due to:
  - Immobility/WC dependence
  - Nutritional deficiencies
  - Exposure to anticonvulsants
  - Hypovitaminosis D/more time indoors
- Routine Dexa screening important
- Replete vitamin D levels before initiating bisphosphonates
- Bisphosphonate is still first line
  - IV form if dysphagia
  - Address dental issues

POLYPHARMACY

- Very common
- Multiple prescribers
- Highest number of drugs taken by SNF dwellers
- Psychoactives for behavioral issues "left on the list," even when ineffective.
- Caregiver may not understand the medication's purpose.
- Review medications regularly, reduce or eliminate meds whenever possible.

PAIN

- Presentation of pain may be atypical
  - Often do not show usual signs of pain expression (facial grimace, verbalization, localization, crying, elevated BP or pulse, etc)
- Use the instincts and observations of caregivers/family.
- Ask about behaviors, activities, affect, mobility, sleep, etc..
- Even verbal pts may not be able to localize or describe pain.

PAIN

- Basics: heat, cold, stretching, etc
- Consider PT referral
- Consider tylenol (scheduled), avoid NSAIDs (GI & renal side effects) & muscle relaxants (delirium, fall risk).
- Gabapentin, pregabalin, venlafaxine, or duloxetine for neuropathy
  - Avoid tricyclics (anticholinergic– but nortriptyline less so than amitriptyline)
- Lowest effective dose of opioids
- Scheduled rather than PRN if pain presumed

CASE

- 74 yo woman with I/DD, dementia NOS, paranoia, living in AFH. You received a faxed note from the AFH operator that pt is agitated, striking out at staff and other residents for the past week. AFH operator is requesting a UA and prn ativan, as the pt is less redirectable.

BEHAVIORS

- Communication barriers make evaluation difficult.
  - Behaviors often an expression of pain, anxiety, need for attention.
- Any change from baseline behavior → look for:
  - Pain (constipation common)
  - Delirium
  - Evidence of abuse
  - Medication side-effect
  - Signs of anxiety, depression
- Please don't: get a UA without signs/symptoms of UTI
  - Asymptomatic bacteriuria commonly misdiagnosed as UTI!

BEHAVIORAL DISORDERS

- A careful physical exam to investigate:
  - Source of infection: respiratory, skin, urine
  - Source of pain: trauma, skin breakdown, constipation, GERD, dental issues, msk injury spasticity or fracture, kidney stone, testicular torsion, etc
- Studies:
  - Labs: metabolic abnormalities, thyroid dysfunction, anemia, etc

MANAGEMENT OF BEHAVIORS

- Look for patterns, stressors, triggers, interpersonal conflicts, disruptions in sleep.
- Multidisciplinary approach. Resist the temptation to respond initially with medication.
- Antipsychotics commonly used:
  - Reserve for resistant, serious behaviors
  - Wean to the lowest effective dose
  - Newer atypicals (quetiapine, olanzapine, clozapine): monitor for metabolic syndrome- weight gain, blood glucose, blood pressure, lipids.

BACK TO OUR CASE…

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BACK TO OUR CASE…

- → pt seen in clinic (or home visit done)
  - Learned PO intake decreasing due to increased paranoia.
  - No complaints of dysuria, frequency, no hematuria.
  - Dry oral mucosa on exam, passing very small hard stools
  - Abdomen protuberant, firm, tender. No suprapubic nor flank pain, no fever.
  - Diagnosis: constipation
  - Treated with increased bowel regimen, worked with pt and caregivers to increase & monitor oral hydration

MOOD DISORDERS

- Diagnosis and treatment of psychiatric disease often missed or delayed.
- ¾ of these patients are not seen by a subspecialist.
- Frequency of depression in institutional settings may be greater than community setting.
- Seizure disorders increase risk for depression.
- Behavioral issues often what draws attention to the psychiatric problem.
- Increased risk for abuse & PTSD

DEPRESSION

- Psychiatric symptom clusters of depression for the pt with ID/DD
  - **Psychological:** ↕anxiety, ↑morbid thoughts, ↓interest
  - **Behavioral:** ↑aggression, ↑self-injurious behaviors
  - **Neurovegetative:** ↓sleep, ↓appetite.

MOOD DISORDERS

- Mild-mod disability → psychological & neurovegetative symptoms.
- Profound disability → behavioral abnormalities: self-injurious behavior (SIB), aggression, psychomotor agitation.
- Both groups → weight loss, decreased activity, increased sense of pain.

CASE

- 54yo M with Down Syndrome, living in low-income senior housing (independent) and attends adult day health 3x/week. Pt presenting to clinic with his guardian, who states she is worried about the pt as he is losing weight. The ADH also notified you that pt has been attempting to exit-seek and is less engaged with activities. The ADH case manager performed a MoCA and his score was 10/30, down from 15/30 3 years ago.

DEMENTIA & COGNITIVE DECLINE

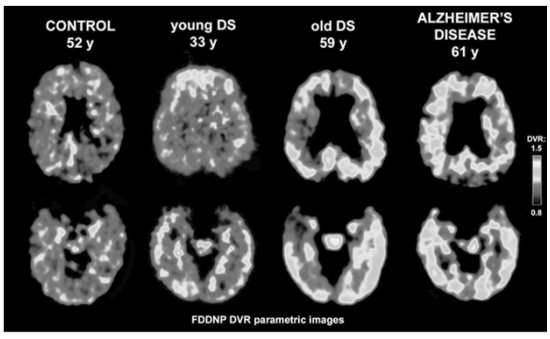
- In the DD/ID population, dementia involves a significant deficit in cognition that represents a *change* from a previous level of functioning.
  - Obtain history from family/caregiver
  - Ask: changes in ADL function, participation in hobbies, activities, etc..

Dementia & Cognitive Decline

- Can be difficult to diagnose dementia in DD/ID pts with underlying cognitive impairment.
- No generally accepted criteria for memory or cognitive assessment in adults with DD/ID.
  - Dementia Questionnaire for Persons with Mental Retardation
  - IBR Mental Status Examination
  - MoCA, MMSE: at least for baseline & follow-up

Dementia in Down Syndrome

- Down Syndrome:
  - Increased risk for Alzheimer's Dementia
  - Younger age of diagnosis
  - 20% of pts with Downs Syndrome >45yo have dementia



Dementia in Down Syndrome

- Alzheimer's dementia: neurofibrillary tangles & beta-amyloid plaques.
- Gene for beta-amyloid precursor protein (APP) is located on chromosome 21.
  - Trisomy 21 → excess APP production
- Also, superoxide dismutase (SOD-1) gene is located on chromosome 21.
  - Trisomy 21 → increased hydroxyl radicals, more neural damage.

Back to our case…

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BACK TO OUR CASE…

- Further questioning:
  - Pt unable to cook for himself now, apartment in disarray
  - Discussed moving to an assisted living apartment where meals are provided, more supervision.
  - Pt to continue to attend adult day health for social engagement, exercises, nursing care.
  - GPS wandering device monitor discussed
  - Cognitive testing done to compare to prior

TRUE / FALSE FUN!

- All individuals with a developmental disability also have an intellectual disability.
- Adult Family Homes & Assisted Living Facilities are pretty much the same thing.
- Nonverbal or severely limited pts are at greater risk for poor nutrition, overmedication, injury, and abuse.
- If a patient is deemed to lack decisional capacity regarding complex medical decisions, they should not participate in any decisions regarding their care.
- Healthcare disparity common due to increased burden of disease + communication problems + inadequately funded support services.

TRUE / FALSE FUN!

- All individuals with a developmental disability also have an intellectual disability. → **False**
- Adult Family Homes & Assisted Living Facilities are pretty much the same thing. → **False**
- Nonverbal or severely limited pts are at greater risk for poor nutrition, overmedication, injury, and abuse. → **True**
- If a patient is deemed to lack decisional capacity regarding complex medical decisions, they should not participate in any decisions regarding their care. → **False**
- Healthcare disparity common due to increased burden of disease + communication problems + inadequately funded support services. → **True**

MORE TRUE / FALSE FUN!

- All antispasmodics have similar efficacy and side effect profiles.
- For nonverbal patients, assess pain by measuring BP and pulse.
- It's a good idea to always obtain a UA when a patient presents with agitated behaviors.
- Profoundly disabled patients are more likely to present with behavioral symptoms in depression.
- 20% of pts with Downs Syndrome >45yo have dementia

MORE TRUE / FALSE FUN!

- All antispasmodics have similar efficacy and side effect profiles. → **False**
- For nonverbal patients, assess pain by measuring BP and pulse. → **False**
- It's a good idea to always obtain a UA when a patient presents with agitated behaviors. → **False**
- Profoundly disabled patients are more likely to present with behavioral symptoms in depression. → **True**
- 20% of pts with Downs Syndrome >45yo have dementia. → **True**

THANK YOU!

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