Intellectual Disabilities at Your Fingertips

25th Anniversary DDNA Annual Conference
Dallas, Texas
April 7, 2017
Carl Tyler MD, MSc, ABFP, CAQ Geriatrics
Director
Developmental Disabilities – Practice Based Research Network
Associate Professor
Cleveland Clinic Lerner College of Medicine
Case Western Reserve University

My Background

- Primary care of persons deinstitutionalized from developmental centers in Ohio in the late 1980s
- Student of the cumulative wisdom from persons with IDD, their families & caregivers, and disabilities professionals
- Education and training about health and health care in this population
  - Self-advocates, DSPs, QDDPs, DD nurses, medical students, resident physicians, practicing physicians
- Researcher: clinical care, practice-based research, health disparities, EMRs and large administrative datasets
- Medical consultant for state crisis prevention network
- Regional health system level approaches to improving CARE

Illinois Crisis Prevention Network

- Consultative services to adults with IDD with complex physical and mental health care needs
  - Recurrent hospitalization - medical &/or psychiatric
- Structure
  - Weekly interdisciplinary team distance conference calls
  - Record Review
    - Key medical, mental health, & service records
  - Electronic communication
  - Medical Consultation Report
    - Clinical Recommendations
    - Tracking worksheet
- Frequency
  - Average 1-2 consultations per week

Outline

- A Clinical Framework for Evaluating Healthcare
- Under-Recognized Physical Health Conditions
- Under-Recognized Mental Health Conditions
- Under-Recognized Adverse Drug Effects
- Assessing Declines in Adaptive Functioning
- Health Promotion/Disease Prevention

A Clinical Framework for Evaluating Healthcare

Focus Areas for Clinical Practice

- Focus #1: Consider common & medically serious conditions and risks that are often unrecognized.
- Focus #2: Review the adequacy of treatment of conditions that are often diagnosed but are frequently sub-optimally treated.
- Focus #3: Look for evidence of common mental health conditions that are often unrecognized and sub-optimally treated.
- Focus #4: Maintain constant vigilance for potential dangers and errors related to medications
- Focus #5: Observe for & promptly evaluate declines in adaptive functioning
- Focus #6: Be intentional about health promotion activities, emphasizing physical activity
Focus #1: Consider common & medically serious conditions & risks that are often unrecognized

- Spinal Cord Compression
- Recurrent Aspiration
- Coronary Heart Disease
- Seizures and "Pseudo-seizures"
- Urinary Retention

Consult #1:

- Presenting issues: 47-year-old female with recurrent psychiatric hospitalizations for self-injurious behavior; physical and verbal aggression; sudden decline in ADLs (mobility, self-feeding)
- Problem List:
  - Medical: Cervical spinal stenosis C4-5; Recurrent UTI; Iron-deficiency Anemia; Constipation with fecal impaction; Xerodermatitis; Dysphagia; Hypothyroidism; Rosacea
  - Neuro-behavioral: Severe intellectual disability; Epilepsy; Bipolar disorder; Psychosis NOS; Tardive dyskinesia; Neurodermatitis
- Changes in Adaptive Functioning: Used to walk independently, now requires wheelchair; Used to feed herself, now requiring full assistance with eating most days; cannot hold spoon

Spinal Cord Compression: Recognition

- Risk factors: Congenital defects of base of brain and spine anatomy; cerebral palsy; Down syndrome; degenerative arthritis of spine; scoliosis; osteoporosis; cancer
- Symptoms: Severe neck, back, or limb pain; weakness in arms or legs; loss of feeling in limbs; change in gait pattern; swallowing difficulty; (new) urinary or fecal incontinence
- Signs: Loss of strength in limbs; change in deep tendon reflexes; posturing of neck; loss of sensation; loss of adaptive functions
Spinal Cord Compression (SCC): Evaluation & Treatment

- **Evaluation:**
  - Thorough review of changes in strength, coordination, adaptive functioning
  - Adequate neurological examination
  - MRI imaging of spine (Plain X rays of spine not good enough!)

- **Treatment:**
  - Usually requires surgery
  - Sometimes "steroids" or radiation therapy (if cancer) may temporize the condition

Spinal Cord Compression (SCC): Take Home Messages

- Risk factors for and conditions causing compression of the spinal cord are common in this population
- Delayed recognition & treatment of SCC can lead to irreversible loss of function or death
- Clinicians often fail to appreciate the medical implications of loss of strength or significant changes in adaptive functioning
- Patients with alarming symptoms often receive an inadequate neurological examination & inadequate imaging of the spine.

Consult #2:

- 66-year-old with mild intellectual disability and schizophrenia; psychiatric condition stable for 15 years, with sudden decompensation requiring several hospitalizations for both medical and for psychiatric indications
- **Problem List:**
  - Medical: Myasthenia gravis; constipation; hypertriglyceridemia; hypothyroidism; osteoporosis; iron deficiency anemia; seizure disorder; sideroblastic anemia; macular degeneration; osteoarthritis; urinary incontinence
  - Neuro-behavioral: Paranoid schizophrenia; mild intellectual disability "with behavior problems"; depression
- **Medications:**
  - Psychoactive medications: Risperidone; Benztropine; Valproic Acid; Carbamazepine
  - Other medications: Levothyroxine; Pantoprazole; Miralax; Mestinon; Simvastatin; Bisacodyl; Alektronate; Os-cal; Cyanocobalamin; Darifenacin; Colace; Ferrous sulfate; Gemfibrozil; Osalc; Cyanocobalamin; Darifenacin; Colace; Ferrous sulfate; Gemfibrozil

Aspiration Events: Recognition

- Risk Factors: Dysphagia, dependency in feeding, quadriplegia, severe scoliosis, GERD, rumination, Medications: psychoactives, AEDs, muscle relaxants, antispasmodics, anticholinergics

Aspiration Events: Evaluation

- Observation
  - Mealtime behaviors
- Examination
  - General alertness, speech quality & clarity
  - Oral cavity (Clinicians don’t look carefully in the mouth!)
  - Bedside swallowing evaluation
  - Chest examination
- Review
  - Medications that dry up, alter consciousness, or slow reflexes
  - Previous studies (MBS, CXR, CT chest)
  - Hospitalizations related to infections or breathing problems

CT Chest ordered to R/O PE: "Bilateral patchy areas of groundglass opacity, greatest at left upper lobe. Course interstitial densities at the lung apices and lung bases, probably fibrotic in nature."
Aspiration Events: Take Home Messages

• Aspiration events are common & are often unrecognized, especially if they don’t lead to hospitalization
• Swallowing function is dynamic & can be transiently affected by acute illness & medications
• Clinicians are often falsely reassured by a single normal MBS
• Clinicians often ignore abnormalities of CXR or CT chest that indicate recurrent aspiration
• Recurrent aspiration can lead to irreversible changes in lung structure & function

Consult #3:

• Presenting issues: 66-year-old with mild intellectual disability and schizophrenia; psychiatric condition stable for 15 years, with sudden decompensation requiring several hospitalizations for both medical and for psychiatric indications
• Problem List:
  — Medical: Myasthenia gravis; constipation; hypertriglyceridemia; hypothyroidism; osteoporosis; iron deficiency anemia; seizure disorder; sideroblastic anemia; macular degeneration; osteoarthritis; urinary incontinence
  — Neuro-behavioral: Paranoid schizophrenia; mild intellectual disability “with behavior problems;” depression
• Seizure Disorder: New onset. MRI brain suggested chronic ischemic changes
• Family History of Heart Disease: Her father died of myocardial infarction age 56 with a history of several prior to the fatal one; mother died of myocardial infarction at age 64.

Coronary Heart Disease (CHD): Recognition

• Risk factors: Age, tobacco use, DM, HTN, OSA, HLD, physical inactivity, obesity, family history
• Signs & Symptoms: Change in exercise tolerance; dyspnea with exertion; chest, throat, arm, or abdominal pain; leg swelling; wheezing
  — With aging, CHD more commonly manifests as breathing-relating symptoms are more common than pain
  — CHD can be severe but asymptomatic in inactive persons
• CHD is the leading cause of death in middle-aged and older persons with IDD

Coronary Heart Disease (CHD): Evaluation

• Critical first step is recognizing that a sign or symptom could be heart-related
• “Ruling out a heart attack” ≠ “Ruling out CHD”
• Assessment begins with categorizing chest symptoms in context of coronary risk factors
• Physical examination is usually normal
• EKG is usually normal
• Cardiac function tests vary in their ability to detect coronary heart disease

How Chest Pain Is Categorized

Ask 3 questions:
1. Is chest pain substernal?
2. Is chest pain brought on by exertion?
3. Is chest pain relieved within 10 minutes by rest or nitroglycerin?
Total the number of “yes” answers to classify the symptom

<table>
<thead>
<tr>
<th>Total Score</th>
<th>Classification</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Asymptomatic</td>
</tr>
<tr>
<td>1</td>
<td>Non-anginal chest pain</td>
</tr>
<tr>
<td>2</td>
<td>Atypical Angina</td>
</tr>
<tr>
<td>3</td>
<td>Typical Angina</td>
</tr>
</tbody>
</table>

Estimating Risk of CAD

Stratified by Gender-Age-Risk Factors-Chest pain Category

<table>
<thead>
<tr>
<th>Risk Profile</th>
<th>Non-anginal CP</th>
<th>Atypical Angina</th>
<th>Angina</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male 35 y/o (-) DM-Tob-HLD</td>
<td>3%</td>
<td>8%</td>
<td>30%</td>
</tr>
<tr>
<td>Male 35 y/o (+) DM-Tob-HLD</td>
<td>35%</td>
<td>59%</td>
<td>88%</td>
</tr>
<tr>
<td>Male 45 y/o (-) DM-Tob-HLD</td>
<td>9%</td>
<td>21%</td>
<td>51%</td>
</tr>
<tr>
<td>Male 45 y/o (+) DM-Tob-HLD</td>
<td>47%</td>
<td>70%</td>
<td>92%</td>
</tr>
<tr>
<td>Male 55 y/o (-) DM-Tob-HLD</td>
<td>23%</td>
<td>45%</td>
<td>80%</td>
</tr>
<tr>
<td>Male 55 y/o (+) DM-Tob-HLD</td>
<td>59%</td>
<td>79%</td>
<td>95%</td>
</tr>
<tr>
<td>Male 65 y/o (-) DM-Tob-HLD</td>
<td>49%</td>
<td>71%</td>
<td>93%</td>
</tr>
<tr>
<td>Male 65 y/o (+) DM-Tob-HLD</td>
<td>69%</td>
<td>86%</td>
<td>97%</td>
</tr>
</tbody>
</table>
Estimating Risk of CAD
Stratified by Gender-Age-Risk Factors-Chest pain Category

<table>
<thead>
<tr>
<th>Risk Profile</th>
<th>Non-anginal CP</th>
<th>Atypical Angina</th>
<th>Angina</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female 35 y/o (-) DM-Tob-HLD</td>
<td>1%</td>
<td>2%</td>
<td>10%</td>
</tr>
<tr>
<td>Female 35 y/o (+) DM-Tob-HLD</td>
<td>19%</td>
<td>39%</td>
<td>78%</td>
</tr>
<tr>
<td>Female 45 y/o (-) DM-Tob-HLD</td>
<td>2%</td>
<td>5%</td>
<td>20%</td>
</tr>
<tr>
<td>Female 45 y/o (+) DM-Tob-HLD</td>
<td>22%</td>
<td>43%</td>
<td>79%</td>
</tr>
<tr>
<td>Female 55 y/o (-) DM-Tob-HLD</td>
<td>4%</td>
<td>10%</td>
<td>38%</td>
</tr>
<tr>
<td>Female 55 y/o (+) DM-Tob-HLD</td>
<td>25%</td>
<td>47%</td>
<td>82%</td>
</tr>
<tr>
<td>Female 65 y/o (-) DM-Tob-HLD</td>
<td>9%</td>
<td>20%</td>
<td>56%</td>
</tr>
<tr>
<td>Female 65 y/o (+) DM-Tob-HLD</td>
<td>29%</td>
<td>51%</td>
<td>84%</td>
</tr>
</tbody>
</table>

Predictive Models for CHD

- Not applied
- Mis-applied
  - Population & context for model development
    - Symptomatic vs. asymptomatic
    - Site of care - office, ED, hospital, NH
  - Predictive variables
- ASCVD Risk Estimator (ACC/AHA)

Coronary Heart Disease (CHD)
Take-Home Messages

- CHD is a common cause of death & under-recognized in this population
- Observe for changes in exercise tolerance and breathing difficulty rather than solely relying on complaint of chest pain
- Know your client’s 10-year risk estimate for CHD
- Educate patients and caregivers about value of accurately classifying chest pain as non-anginal, atypical, or anginal

Consult #4

- 61-year-old with profound intellectual disability and seizure disorder who is purportedly dying, but no clear diagnoses or explanation of prognosis. Longstanding behavioral issues with behaviors categorized as socially offensive, uncooperative, withdrawn/inattentive, disruptive, and hurting others. He has a history of ataxia which is worsening in severity.
- Problem List:
  - Medical: Constipation; Allergic Rhinitis; GERD; Gastroenteritis; Neurogenic bladder; Anemia; Hyperlipidemia; Chronic periodontitis; Osteoporosis
  - Neuro-behavioral: Epilepsy (Generalized tonic-clonic); Seizure disorder, Blind left eye; Pica
- Past Surgical History: ORIF humerus fracture; scaphoid fracture; enucleation left eye
- Past Medical History: Gastric ulcer; H pylori infection; Leukopenia
- Medications:
  - Medical: Benefiber; Calcium + D; Colace 100 mg; Folic acid 1 mg; (prazosin-HCl); Omeprazole; Simvastatin 40mg; Singulair 10 mg; Polyethylene glycol
  - Psychoactive: Divalproex 500 mg TID; Phenobarbital 45 mg Q AM and 90 mg QHS

Consult: Seizures

- Hospitalization May 26-June 2: Small bowel obstruction
- Hospitalization June 7-10: Small bowel obstruction
- Home - June 11: Holding stomach, making faces, attributed to severe constipation. Reportedly no bowel movement since June 5.
- Hospitalization June 18-21: Following unresponsive episode, presumed seizure, required mechanical ventilation for one day.

Epilepsy: Overview

- Prevalence of epilepsy in IDD ~ 20%
- Of those with IDD carrying a dx of epilepsy, about 20% have been misdiagnosed!
- Dx of episodic abnormal movements includes:
  - Stereotypies; drug-induced movements d/o; seizures; pseudoseizures; panic attacks, hallucinations, &/or PTSD; syncope
- Persons with IDD & epilepsy are at greater risk for fracture, accident, & hospitalization secondary to seizures
- Standard mortality ratio for IDD + epilepsy is about five times that of the general population
- Assessment should include behavioral and psychiatric components
Seizures: Recognition

- Risk Factors: Increasing severity of disability; specific syndromes (DS, TS, Fragile X, Angelman syndrome, Rett syndrome); ASD; CP
- Signs depend upon seizure type and concurrent antiepileptic therapy
- Seizures can be classified as motor, sensory, autonomic, emotional, or cognitive
- Signs of seizure can be subtle, such as eye deviation, rapid blinking, brief periods of altered consciousness
- Aura may include dizziness, lightheadedness, tightening of chest, sensation of time in slow-motion

Seizures: Evaluation

- Comprehensive history from a reliable witness
- Often EEG, sometimes neuroimaging
  - Sensitivity of single interictal EEG ~50%
  - Sensitivity of multiple interictal EEGs ~ 80-90%
  - Around 2-3% persons with epilepsy have repeatedly normal interictal surface EEGs
- Identify seizure type and syndrome in conjunction with etiologic diagnosis for IDD
- More than one seizure type may co-occur
- Bona-fide seizures AND pseudoseizures may co-occur

Seizures: Treatment

- Anti-epileptic drug therapies (AEDs)
  - Drug choice, time of administration, target control
  - Vagal nerve epilepsy & ineffective polypharmacy
- Vagal nerve stimulator (VNS)
- Epilepsy surgery
- Ketogenic diet

Urinary Retention

- Acute and chronic both under-recognized
- Predisposing factors:
  - Nervous system disease: Cerebral palsy; scoliosis; myelopathy; neuropathy
  - Syndromes: Down syndrome
  - Behavioral: Dysfunctional voiding habits
- Precipitating factors:
  - Medications: Anticholinergic; psychoactive; narcotics
  - Immobility
  - Constipation

Focus # 2: Review the adequacy of treatment of conditions that are often diagnosed but are frequently sub-optimally treated

- Constipation
- GERD
- Epilepsy
- Osteoporosis
- Obesity & its complications

Under-Treated Constipation

- Presenting issues: 39 year-old with cerebral palsy, quadriplegia, hydrocephalus and ventriculoperitoneal shunt, repeated hospitalizations for abdominal pain, dehydration; with onset over the past year of nightmares, insomnia, yelling, and swearing
  - Problem list:
    - Medical: Constipation; osteoporosis; degenerative joint disease right hip.
    - Pain complaints: abdomen; hip; eye
    - Neuro-behavioral: CP; quadriparesis; seizure disorder; visual impairment due to detached retinas; GAD; PD; depression; insomnia
  - Medications:
    - Medical: Alendronate; Miralax
    - Psychoactive: Quetiapine; Clonazepam; Lamotrigine; Baclofen; Trazodone; Alprazolam
    - She was hospitalized twice in one month with abdominal pain. Plain film studies and serial CT scans of the abdomen, as well as multiple physician reports all suggested constipation as the likely etiology, or at the very least contributory. During her second hospitalization, she improved with administration of (please redact) and but this apparently was not continued to the present. Her discharge laxative regimen was one packet of Miralax daily.
Constipation: Recognition

- Constipation can be defined as stools that are hard or infrequent enough to cause pain, decreased appetite, urinary incontinence, or behavioral problems.
- Recognition is difficult in persons independent in toileting.
- Constipation may be present even if there is daily passage of some amount of stool.
- Loose stools may occur with constipation as intestines attempt to bypass fecal blockage by liquifying stool.

Risk Factors:
- Cerebral palsy;
- Medications for seizures, mental health conditions, pain, bladder control, cardiovascular conditions, or spasticity;
- Immobility, hypotonia;
- More severe ID; DS, WS, Cri-du-chat.

Signs & Symptoms:
- Abdominal pain;
- Straining at defecation;
- Prolonged toileting;
- Hemorrhoids with bleeding;
- Poor appetite;
- Vomiting;
- Acid reflux;
- Weight loss;
- SIB;
- Irritability;
- Sleeplessness;
- Restlessness;
- Urinary incontinence;
- Fecal incontinence.

Constipation: Evaluation

- Constipation is poorly detected on physical examination.
  - Abdominal examination is an unreliable indicator.
  - Clinicians often misinterpret absence of stool in rectal vault as indication that constipation is absent.
- Radiologists often fail to comment about or grade severity of fecal accumulation evident on abdominal plain film X rays and abdominal CT scans.
- Clinicians often ignore radiology comments about fecal accumulation even when reported.
- Therapeutic response to laxatives is best indicator that constipation was problematic.

Constipation: Take-Home Messages

- Maintain a high index of suspicion for constipation causing or contributing to any behavioral, nutritional, or gastrointestinal complaint.
- Use therapeutic response to laxatives, not physical examination or bowel record, as most reliable indicator for symptomatic constipation.
- Clinicians tend to under-recognize constipation as a problem or they will give laxatives short-term without changing daily regimen.

Consult: Possible Gastroesophageal Reflux Disease (GERD)

- Presenting Issues: 21-year-old male with Down syndrome, severe intellectual disability, with frequent complaints of headaches, stomachaches, and ear aches, who engages in physical and verbal aggression, self-injurious behavior, and property destruction.
- Problem List:
  - Medical: Hypothyroidism; Hearing impairment; Constipation
  - Neuro-behavioral: Severe intellectual disability; Phonological disorder; ADHD; oppositional disorder.
- Past Social History: Reported abuse and neglect as a child; self-reported abuse with hot water and by confinement to locked room. History of foster care.
- Medications:
  - Medical: Levothyroxine 0.125 mg; Senna 8.6 mg QHS
  - Psychoactive: Benztropine mesylate 0.5 mg TD; Depakote sprinkles 1500 mg QHS; Risperidone 4 mg QHS;
GERD: Recognition

- Definition: “Troublesome” symptoms or complications caused by reflux of stomach contents into the esophagus (Montreal Consensus 2006)
  - Esophageal syndromes:
    - Symptoms: Typical reflux syndrome, reflux chest pain
    - Injuries: Reflux esophagitis, stricture, Barrett’s esophagus, adenocarcinoma.
  - Obesity is a risk factor for esophageal CA and GERD.
  - Extra-esophageal syndromes:
    - Reflux cough, laryngitis, asthma, dental erosions
    - Possible: Sinusitis, pulmonary fibrosis, pharyngitis, recurrent otitis media
    - Acid reflux may trigger angina in patients with CAD
- Prevalence:
  - General population: 14% overall, 10% nocturnal sx
  - IDD: 50% institutionalized populations

GERD: Evaluation

- Assessment for signs or symptoms suggestive of complications requiring more intensive investigations
  - Decision regarding empiric trial PPI vs. diagnostic testing
  - EGD identifies complications of stricture, Barrett’s esophagus, or adenocarcinoma
  - Most pts with GERD have normal EGD
  - Findings on EGD often do not correlate with symptom severity
- Common co-morbidities:
  - Impaired salivation
  - Dysphagia
  - Esophageal dysmotility
  - Gastroparesis
  - Duodenogastroesophageal (bile acid) reflux

GERD: Diagnostic Testing

- 24 hour pH probes or reflux scan can document reflux if EGD & manometry are normal but diagnosis still suspected and there is need to confirm it
- In tube-fed individuals, food dye coloring can be mixed with tube feeding and patient observed for appearance of dye-colored food in mouth
- Obtain CBC, iron studies, stool occult blood testing to screen for GI blood loss, determine need for colonoscopy in addition to EGD
- If co-morbid dysphagia/aspiration suspected, obtain clinical swallowing evaluation with modified barium swallow (MBS)
- If GERD unresponsive to standard therapies, consider esophageal manometry

GERD: Management

- Behavioral
  - Weight loss: if overweight or obese
  - Mealtime:
    - Timing: At least 3 hours before bedtime/lying down
    - Foods: Avoid caffeinated drinks, fatty foods, chocolate, peppermint, citrus. Promote high fiber, high protein foods.
    - Eating: Avoid overeating, rapid eating
  - Sleeping
    - Elevate head of bed at least 6 inches
  - Treatment-resistant:
    - Right-inclined, side-lying position during mealtimes
    - Thickening of liquid to pudding consistency
    - Separate times for food and liquid ingestion

GERD: Management-Medication

- Initial therapy:
  - Proton-pump inhibitors (PPIs) most effective RX
    - Lessor efficacy with H2RAs, antacids, prokinetic agents
    - All PPIs have similar efficacy at standard dosage
    - Administer 1 hour before meals
    - Twice-daily PPIs recommended if inadequate symptom control with once-daily PPI
  - Eradication of Helicobacter pylori no longer thought to improve or worsen GERD
- Maintenance Therapy:
  - PPIs maintain remission more than H2RAs
  - Addition of H2RA @HS to daily PPI decreased nocturnal acid
  - Less than daily dosing of PPIs not recommended as maintenance therapy in patients with history of erosive esophagitis
PPIs-Adverse Effects

- Fracture risk
- Enteric bacterial infection
  - Salmonella, Campylobacter, Clostridium difficile
- Atrophic gastritis, a precursor of gastric cancer
- Pneumonia - community-acquired
- Drug-drug interactions
  - Omprazole (Prilosec®) + Clopidogrel (Plavix)
- Nutritional Deficiencies

GERD: Take-Home Messages

- GERD is very common in persons with IDD
- Evaluation & treatment is complex in this population because
  - Management is typically driven by patient self-report
  - More PPI treatment failures
- Most of the time, EGDs will be normal and not correspond to symptom severity
- Administration of PPI prior to meals can greatly improve effectiveness
- Increasing awareness of adverse effects of long-term use, including pneumonia, fracture, bacterial intestinal infections, drug-drug and drug-disease interactions

Osteoporosis: Recognition

- Presentation
  - Fragility fracture, loss of height, back pain, aching in bones
- Definitions
  - Osteoporosis: loss of bone density and micro-structure causing increased risk for fracture
  - Osteomalacia: lack of vitamin D causing "soft" bones. Can co-occur with osteoporosis
- Risk Factors
  - Age; female; short stature
  - Medications (AEDs, steroids, anti-psychotics, Depo-Provera); Lack of estrogen (women), lack of testosterone (male)
  - Genetic conditions (ex: Down syndrome) and specific DD (NTDs)
  - Immobility; diet poor in vitamin D, calcium; malabsorption
  - Malnutrition, underweight

Osteoporosis: Key Information

- Key Information:
  - Record of all skeletal fractures
  - Menstrual history
  - Records of prior BMDs, X rays, CT scans, MRIs
  - Screening or diagnostic tests for celiac disease, malabsorption, kidney disease, parathyroid disease, hypogonadism, spinal stenosis
  - Documented change in height
  - Dietary history, especially avoidance of milk products
  - Medication history

Osteoporosis: Overview

- IDD itself is associated with low BMD, irrespective of other risk factors
- Secondary causes of OP, particularly hypogonadism & medication more common
- Sub-optimal vitamin D and calcium intake more common
- Optimum time for first BMD study unclear, but substantial percentage will be within osteoporotic range by mid 40s
- Role of biochemical markers of bone turnover unclear

Osteoporosis: Assessment

- DEXA of hip and spine most informative but may not be feasible
- CBC, CMP, TSH, free T4, T in men, 25-hydroxy vitamin D, iPTH
- Fall history and fall risk
- Seizure history
Osteoporosis: Treatment

• Assure 1,000-2,000 IU vitamin D3 daily and 1500 mg elemental calcium daily
  – Aim for 25-hydroxyvitamin D3 levels of 40-50 ng/mL
  – Wide individual variation in D3 doses required
  – Target dietary sources of calcium rather than supplements

• Bisphosphonates most effective Rx
  – Dysphagia, dysmotility, rumination not absolute contraindications
  – Alternative to oral bisphosphonates: IV zoledronic acid

• Non-bisphosphonates treatments
  – Teriparatide, Denosumab, Calcitonin
  – T replacement in men, raloxifene in women

Osteoporosis Management Program

• Primary prevention through calcium and vitamin D intake, medication management, weight-bearing exercise

• Monitor BMD, intervals between studies individualized

• Optimize seizure control and safety

• Fall risk reduction strategies

Obesity & Complications

• Obtain biophysical data

• Monitor and trend weight over time
  – Interventions driven by absolute weight & rate of weight gain

• Classify obesity severity
  – Class 1 (BMI 30 - 34.9 kg/m²)
  – Class 2 (BMI 35 - 39.9 kg/m²)
  – Class 3 (BMI >=40 kg/m²)

• Obesity hurts physically
  – DJD; spinal disease; plantar fasciitis/foot pain; GERD; gout

• Obesity hurts emotionally
  – Depression; social stigma

• Obesity kills
  – CHD; diabetes; atrial fibrillation; OSA/OHS; cancer

Focus #3: Look for evidence of these common mental health conditions that are often unrecognized and sub-optimally treated

• PTSD

• Mood D/O

• OCD

• Anxiety

• Dementia

Consults: Possible PTSD

• Presenting issues: 55-year-old female with profound intellectual disability and autism; recent series of hospitalisations for recurrent pancreatitis with weight loss. Longstanding behavioral issues of sleeplessness, physical aggression, and rectal digging. Recurrent hospitalisations for lethargy, alternating with persistent screaming and early morning awakenings with sleeplessness.

• Problems List:
  – Medical: Pancreatitis with pseudocyst; constipation; hypothyroidism; degenerative disease of cervical spine; hyperkalemia; dysphagia; osteopenia; periodontitis; seborrhea; bilateral cataracts with corneal opacity left eye
  – Neuro-behavioral: Profound intellectual disability, autism

• Medications:
  – Medical: Levothyroxine; Milk of Magnesia; Chlorhexidine rinse; Oyster shell with vitamin D; Triamcinolone 1% cream; Beclomethasone 0.05% cream; Fiber supplement; Polyethylene glycol; Albuterol nebulizer
  – Psychoactive: Lorazepam 3 mg TID

She was reportedly burned with cigarettes, and sustained a fractured arm, due to abuse.

Consults: Possible PTSD

• Presenting issues: Catatonic behaviors in 20-year-old with autism and severe-profound intellectual disability

• Problem List:
  – Medical: Hypothyroidism; hypertension; acne; seasonal allergies
  – Neuro-behavioral: Severe-profound intellectual disability, autism, impulse control disorder, psychotic disorder

• Family Medical History: Mood disorder in mother (post-partum depression). Both parents are deceased - causes of death not specified in documents

• Medications:
  – Medical: Levothyraxine; Loratadine; Minocycline; Clonidine; Metoprolol;
  – Psychoactive medications: Haldol decanoate; Haloperidol; Divalproex; Benztropine; Carbamazepine

Repeatedly verbalizes references to a belt and what sounds like history of physical abuse: "No belt," "Don't whoop me," and "I don't want belt off."
Consult: Possible PTSD

- Presenting Issues: 25-year-old with PDD; SIB; behaviors suspicious for pain and physical ailments; repeated self-removal of ileostomy bag
- Problem List:
  - Medical: Severe GI motility disorder requiring ileostomy; bladder distention
  - Neuro-behavioral: Profound intellectual disability; PDD; GAD; Depression
- Medications:
  - Medical: Seasonale

Social History: She was removed from her home secondary to sexual abuse.
Family History: Mother is alive with alcohol addiction history. Positive family history of schizophrenia.

Consults: Possible PTSD

- Presenting Issues: 36-year-old with Down syndrome with long-standing oppositional behavior; verbal and physical aggression, worsened severity since hospitalization for cellulitis of genital area
- Problem List:
  - Medical: Down syndrome; morbid obesity; obstructive sleep apnea; hypothyroidism; constipation; chronic leg edema; chronic blepharitis
  - Neuro-behavioral: Moderate intellectual disability; antisocial personality disorder; oppositional-defiant disorder; organic affective syndrome; pseudoseizures
- Past Surgical History: s/p repair congenital heart disease (partial AV canal); recurrent patellar dislocation right knee; hernia repair; urethral dilatation; cataract surgery
- Past Medical History: Possible seizure disorder; cellulitis legs; cellulitis genital area

Medications:  
- Medical: Docusate; furosemide; levothyroxine; Allegra.
- Psychoactive: Seroquel; Effexor; Clonazepam; Depakote

“In the past, he has inappropriate sexual issues, such as touching himself and/or others inappropriately. He also at times makes inappropriate sexual comments to others.”

“He has antisocial behaviors including stealing and lying; he has set a fire, vandalized, and held up a restaurant and had inappropriate sexual behaviors in the past.”

PTSD- Background

- Trauma-related anxiety disorder
- Often cyclical and progressive
- Compromise biological, psychological, social, spiritual functioning
- General population prevalence: 5-10%
- Prevalence in IDD population: unknown
  - More likely to experience sexual or physical abuse, negative life events
  - Lower threshold
  - Experience early separation from primary caregivers
  - (Ryan, 1994) 51/310 (16.5%) by retrospective analysis of routine initial psychiatric interview & record review by psychiatrist.
- No IDD-specific instruments to assess PTSD

PTSD- Diagnosis-Adapted Criteria

Criteria
- Traumatic event or threat
- Response-feel helplessness, horror
- Recollections
- Recurrent dream of event
- Re-experience of traumatic event
- Avoid activities, places, or people that arouse recollection

Adaptation to IDD
- Range of potential events
- Disorganized or agitated behavior, especially with severe/profound IDD
- Acting out or SIB
- Dreams w/s content
- Trauma-specific enactments appear psychotic
- May be interpreted as non-compliance

PTSD-Evaluation & Treatment

- Thorough medical evaluation because of high medical morbidity
- Investigate the nature, circumstances, contexts of trigger events
- Recognize co-existing mental health disorders
- Avoid inappropriate use of antipsychotic and other medications
- Change environment to eliminate frightening cues
- Training & support of caregivers to respond appropriately
- Cognitive-behavioral therapy
  - Exposure therapy
  - Imaginary rehearsal therapy
Consult: Possible Depression

- Presenting Issues: 66-year-old with mild intellectual disability and schizophrenia; psychiatric condition stable for 15 years, with sudden decompensation requiring several hospitalizations for both medical and psychiatric indications
- Problem List:
  - Medical: Myasthenia gravis; constipation; hypertriglyceridemia; hypothyroidism; osteoporosis; iron deficiency anemia; seizure disorder; sideroblastic anemia; macular degeneration; osteoarthritis; urinary incontinence
  - Neuro-behavioral: Paranoid schizophrenia, mild intellectual disability “with behavior problems”
- Medications: Levothyroxine; Pantoprazole; Miralax; Mestinon; Simvastatin; Bisacodyl; Alendronate; Osmac; Cyanocobalamin; Enablex; Colace; Ferrous sulfate; Gemfibrozil; Omeprazole
- Psychoactive medications: Risperidone; Benztropine; Depakote; carbamezapine
- Past Psychiatric History: Multiple suicide attempts
- Family Medical History: Depression and suicide.

Depression & IDD: Overview

- High co-existence of depression, anxiety disorders, and adjustment disorders
- Clinical recognition limited by ability of person to express verbally their internal mood states & subjective feelings such as lack of pleasure
- Prevalence of 9.1% in psychiatric outpatient clinic (Stavrakaki & Mintsioulis, 1997)
- More commonly diagnosed in women
- Higher prevalence in people with DS, PDD, FraX, FAS, WS
- Apparent higher frequency of stressful life events occurring 1-3 months prior to onset of depression — Sexual assault, physical assault, parental loss, parental separation
- Risk factors: Abuse, loss, lack of social support, daily hassles, negative social interactions

Major Depressive D/O vs. Dysthymia

<table>
<thead>
<tr>
<th>MDD</th>
<th>Dysthymia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration: 2 weeks</td>
<td>Duration: 2 years</td>
</tr>
<tr>
<td>Depressed mood/Anhedonia</td>
<td>Depressed mood</td>
</tr>
<tr>
<td>AND</td>
<td>AND</td>
</tr>
<tr>
<td>Weight change ↑↓</td>
<td>Appetite disturbances</td>
</tr>
<tr>
<td>Sleep disturbance ↑↓</td>
<td>Sleep disturbances</td>
</tr>
<tr>
<td>Fatigue or low energy</td>
<td>Fatigue or low energy</td>
</tr>
<tr>
<td>Feeling worthless</td>
<td>Low self-esteem</td>
</tr>
<tr>
<td>Ability to think or concentrate ↓</td>
<td>Poor concentration or indecisiveness</td>
</tr>
<tr>
<td>Recurrent thoughts of death</td>
<td></td>
</tr>
<tr>
<td>Psychomotor ↑↓</td>
<td></td>
</tr>
</tbody>
</table>

Symptom Presentation & Disability

Common symptoms:
- Depressed affect
- Sleep disturbance

Mild ID
- Tearfulness, diurnal mood variation, loss of energy, loss of interest, low self-esteem
Moderate ID
- Social isolation, weight loss, SIB
Severe/Profound ID
- Screaming, aggression, SIB

Depression-Treatment Principles

- Identify physical problems
- Identify co-morbid anxiety and adjustment problems
- Pharmacotherapies
  - Administer sufficient dose, but remember:
    - Increased susceptibility to adverse effects
    - Increased risk for paradoxical reactions
    - Increased risk for toxic reactions
- Cognitive-Behavioral Therapy
  - Mild ID (Lindsay, 1997)
- Staff Training

Focus #4: Maintain constant vigilance for potential danger and errors related to medications

- Serotonin Syndrome
- Psychoactive meds
- Appetite Stimulants
- Cognitive Enhancers
- Lactulose
- Anticholinergics
- Bladder Agents
- Nutritional Supplement Use
- Antiepileptic Drugs
- Co-administration Errors
Serotonin Syndrome

• Defined as a constellation of clinical findings attributed to excessive serotonin activity in the brain, typically induced by a combination of psychoactive medications that affect brain serotonin levels
• Clinical features
  – Mental status changes
    • Anxiety, agitated delirium, restlessness, disorientation, easily startled
  – Autonomic nervous system
    • Increased sweating, heart rate, temperature, vomiting, diarrhea
  – Neuromotor hyperactivity
    • Tremor, muscle rigidity, myoclonus, hyperreflexia, Babinski sign especially affecting legs

Consult: Psychoactive Medications

• Presenting Issues: 50-year-old with decline in adaptive functioning; physical agression towards staff
• Problem List:
  – Medical: Down syndrome; dysphagia causing aspiration pneumonia; urinary retention; GERD; hypothyroidism
  – Neuro-behavioral: Epilepsy; blindness; tremors; schizoaffective disorder
• Past Medical Hx: Esophageal stricture requiring dilatation; hypernatremia; aspiration pneumonia
• Past Surgical History: left corneal transplant
• Medical: Levothyroxine 112 mcg; Omeprazole 20 mg; Tamsulosin 0.4 mg
• Psychotropic: Risperidone 1 mg BID; Topiramate 50 mg BID; Trichlophenidyl 1 mg BID; Sinemet 25-100 two tabs TID; Olanzapine/Fluoxetine 6 mg/25 mg; Klonopin 0.5 mg; Trazodone 150 mg QHS; Baclofen 10 mg

Psychoactive Medications

He is prescribed a number of drugs which are high-risk for adverse drug effects, most notably Risperidone, Topiramate, Trichlophenidyl, Sinemet, Symbyax, Klonopin, Trazodone, and Baclofen. Using a standard drug interaction program there were 19 potential drug-drug interactions identified. Of these, the most important are:

  – Baclofen & Risperidone: additive anticholinergic effect, which can adversely affect mental functioning and mimic or worsen dementia
  – Risperidone & Sinemet: decrease the intended additive dopamine effect of Sinemet; increased risk of low blood pressure
  – Olanzapine/Fluoxetine & Sinemet: decrease the intended additive dopamine effect of Sinemet; increased risk for low blood pressure
  – Olanzapine/Fluoxetine & Trazodone: increased risk for serotonin syndrome and neuroleptic malignant syndrome
  – Olanzapine/Fluoxetine & Symbyax: increased risk for serotonin syndrome and neuroleptic malignant syndrome

Appetite Stimulants: Megestrol

• Synthetic hormone progestin
• Anti-neoplastic agent later used to stimulate appetite
  – Orphan use for HIV-associated cachexia
• Inappropriately used to treat weight loss without investigation for treatable causes
  – Psychiatric diseases, behavioral disorders & GI disorders affecting intake & absorption, endocrine or renal diseases, malignancies, systemic infections

Cyproheptadine

• Antihistamine used for allergies, sexual dysfunction, Cushing’s disease, headache anorexia nervosa
• Used to promote weight gain in adults without anorexia nervosa
• Anticholinergic effects: avoid in patients with asthma, glaucoma, hyperthyroidism; cardiovascular disease (including HTN)
• Increased risk of dizziness, sedation, and hypotension in geriatric patients
• Common adverse effects: Sedation, sleepiness, dizziness, disturbed coordination, restlessness, excitation
• Inappropriately used for weight loss without investigation for treatable causes
  – Psychiatric diseases, behavioral disorders & GI disorders affecting intake & absorption, endocrine or renal diseases, malignancies, systemic infections

Donepezil (Aricept)

• Reversible acetylcholinesterase inhibitor
• Palliative treatment of mild to moderate Alzheimer’s disease (AD)
  – Small benefits in cognition, ADLs, behavior
• Limitations:
  – Ineffective for treating agitation associated with AD
  – At 3 years, no differences in rate of institutionalization, progression of disability, behavioral & psychological sx, carer psychopathology, formal care costs, unpaid caregiver time, adverse events or deaths
  – No benefit in patients with mild cognitive impairment
  – No benefit in patients with delirium
• Inappropriately used to Rx persons without clear diagnosis of Dementia, or with MCI or with delirium
Donepezil: Adverse Effects

- Gen: Malaise, dizziness
- Resp: Asthma, COPD
- CV: Bradycardia, heart block, syncope
- GI: Diarrhea, nausea, vomiting, PUD (especially those with hx of PUD, NSAIDs)
- GU: Bladder outflow obstruction
- Neuro: Seizures, insomnia
- Psych: Aggression, agitation, abnormal dreams

Lactulose

- Synthetic derivative of lactose (milk sugar)
- Breakdown of lactulose to organic acids by bacteria in the colon, acidifies colon contents, increases the water content, & softens stool.
- Causes accumulation of hydrogen gas
- Caution in diabetics, may increase blood sugar
- Common adverse effects: gaseous distention, belching, flatulence, abdominal discomfort, cramping
- Poor choice of laxative in persons who cannot clearly express whether they are in pain

Anticholinergic Agents

- Anticholinergic drugs are used to treat:
  - Drug-induced movement disorders
  - Overactive bladder
  - Drooling
  - Insomnia
  - Irritable bowel syndrome
  - Parkinson’s disease

Anticholinergic Agents: Adverse Effects

- Constipation → bowel obstruction
- Sedation, orthostatic hypotension, impaired balance → falls
- Confusion, inattention → delirium, greater impairments in cognitive-behavioral function
- Dry mouth → poor food intake, dental caries
- Impaired bladder emptying → bladder obstruction

Anticholinergic Risk Scale (ARS)

- Ranked categorical list of commonly prescribed medications with anticholinergic potential
- Point score of 1, 2 or 3
- In elder populations, Anticholinergic Risk Score (ARS) correlated with Anticholinergic adverse effects:
  - Central
    - Falls
    - Dizziness
    - Confusion
  - Peripheral
    - Dry mouth
    - Dry eyes
    - Constipation

Highest Risk Anticholinergics: Score 3

- Amitriptyline
- Atropine
- Benztropine mesylate
- Carisoprodol
- Chlorpheniramine
- Chlorpromazine
- Cyproheptadine
- Dicyclomine
- Diphenhydramine
- Fluphenazine
- Hydroxyzine
- Hyoscyamine
- Imipramine
- Meclizine
- Oxybutinin
- Perphenazine
- Promethazine
- Thoridazine
- Thiothixene
- Tizanidine
- Trifluoperazine
Intermediate Risk Anticholinergics: Score 2
- Amantadine
- Baclofen
- Cetirizine
- Cimetidine
- Clonazapine
- Cyclobenzaprine
- Desipramine
- Loperamide
- Loratadine
- Nortriptyline
- Olanzapine
- Prochlorperazine
- Tolteradine
- Tripropidine

Low Risk Anticholinergics: Score 1
- Entacapone
- Haloperidol
- Levodopa-Carbidopa
- Methocarbaomol
- Metoclopramide
- Mirtazapine
- Paroxetine
- Pramipexole
- Quetiapine
- Ranitidine
- Risperidone
- Selegeline
- Trazodone
- Ziprasidone

Bladder Agents
- GU antispasmodic (GU smooth muscle relaxants)
- Used to treat urge urinary incontinence, urgency, and frequency
- Problem: Often used as first-line treatment without
  - Adequate evaluation (assure no impaired bladder emptying, UTI, tumor, stone, BPH, spinal cord disorder)
  - Recognition and treatment of fecal impaction or constipation
  - Initial trial of bio-behavioral strategies
    - Pelvic muscle exercises; fixed voiding schedule; bladder habit training

Bladder Agents: Adverse Effects
- (Nearly) All bladder antispasmodics are anticholinergic
  - Additive anticholinergic effects:
    - Falls, confusion, dizziness, dry mouth/dry eyes,constipation
  - Urinary retention
  - Gastric retention, decrease in GI motility
  - Glaucoma
  - Prolonged QT interval
  - Behavioral disturbance: Aggression, hyperactivity; inattention
  - Inappropriately used in combination with cholinesterase inhibitors (Donepezil, Rivastigmine, Galantamine)

Nutritional Supplement Use
- Iron
  - Initiated without adequate evaluation into cause of iron deficiency
  - Initiated for anemia without confirmation of iron deficiency as etiology
  - Inappropriately continued indefinitely
- Folic Acid
  - Risk for progressive neurologic complications if unrecognized & untreated co-morbid vitamin B12 deficiency
- Calcium supplementation
  - Risk of coronary heart disease
  - Role in osteoporosis prevention & treatment

Anti-Epileptic Drugs
- AEDs commonly affecting cognition
  - Primidone, Phenobarbital, Phenytoin, Topiramate
- AEDs commonly associated with weight gain
  - Valproate, Gabapentin, Pregabalin
- AEDs commonly associated with weight loss
  - Topiramate, Zonisamide
- AEDs associated with low bone mineral density
  - Phenytoin, Phenobarbital, Primidone, Carbamazepine, Valproate
Errors in Co-Administration

- Some drugs bind to other drugs and prevent their absorption from the stomach
  - Antacids (Maalox®, Alternagel®, Mylanta®, Gaviscon®)
  - Iron supplements
  - Magnesium supplements or laxatives
  - Calcium supplements
  - Bile acid binding resins – Cholestyramine (Questran®)
  - Sulfasalazine (Carafate®)
  - Orlistat (Xenical®, Alli®)
  - Sodium polystyrene sulfate (Kayexalate®)
  - Sevelamer® (Renagel®)

Focus #5: Observe For & Promptly Evaluate Declines in Adaptive Functioning

- Tracking adaptive functioning
  - Routine medical and nursing evaluations
  - Support needs: Ex: SIS
  - Health risk instruments: Ex: HRST
  - PT, OT Evaluations
  - Dementia screening instruments: Ex: DSQ-II
- Triggers for comprehensive assessment
  - Single domain vs multi-domain declines

Evaluating Decline in Adaptive Functioning

Decline noted in specific adaptive function
↓
Document extent and course of changes in adaptive functions
↓
Perform comprehensive clinical assessment as follows:
  (next slide)
↓
If above assessments are unrevealing, perform focused assessment for dementia

Focus #6: Be intentional about health promotion activities, emphasizing physical activity

- Chronic disease
- Opportunities for health behavior change
- Physical Activity
- Resources for promoting healthy lifestyle

Comprehensive Clinical Assessment
(Example: Individual with Down syndrome)

The Chronic Disease and Lifestyle Connection

- Chronic diseases cause 7 out of every 10 deaths
- Most people with major chronic diseases share multiple common lifestyle characteristics or behaviors, particularly smoking, poor diet, physical inactivity, and obesity.
- If the modifiable risk factors associated with chronic diseases could be eliminated, at least 80% of all heart disease, stroke and type-2 diabetes and 40% of cancer would be prevented.

Chronic Diseases and Spiraling Healthcare Costs

- Chronic diseases account for more than $3 of every $4 spent on healthcare in U.S. (83%)\(^1\)
- Average healthcare costs for an individual with one or more chronic conditions is 5 times greater than for someone without any chronic conditions\(^2\)

Opportunities for Intervention

- On average, 97% of adults need to change at least one behavior in order to maintain health
- These behaviors include:
  - Tobacco use
  - Diet
  - Weight
  - Physical activity

Health Promotion in the General Population

- Importance of physical activity
- Benefits of physical activity
- Recommended physical activity
- The HALE study
- Guidelines for physical activity counseling

Importance of Physical Activity

- Less than 50% of adult population engages in recommended physical activity (PA)
- Lack of adequate PA is the most common risk factor for heart disease in the US
  - More common risk factor than smoking, hypertension & hyperlipidemia

**Optimum PA associated with 25-35% reduction in all-cause mortality**

- Optimum PA associated with lower rates of cardiovascular disease, stroke, hypertension, Type 2 Diabetes, osteoporosis, obesity, colon cancer, breast cancer, anxiety and depression

What is Recommended PA?

- Moderate (aerobic) PA for 30 minutes on 5 days a week \or\
- Vigorous (aerobic) PA for 20 minutes on 3 days a week \or\n- Combination of above
- Muscle strengthening activity for 2 non-consecutive days a week

Physical Activity Benefits

- **Aerobic physical activity** is the most beneficial for reducing mortality and morbidity; most studies about benefits of exercise refer to this
- **Strength and flexibility** exercises are also beneficial in reducing falls and injuries, especially in the elderly
Muscle strengthening activity: Recommendations

- 8-10 strengthening exercises using major muscle groups on a minimum of 2 non-consecutive days a week
- Muscle strengthening activities include progressive weight training, weight bearing calisthenics, stair climbing, and similar resistance exercises

Muscle Strengthening: Benefits

- Slows bone loss and lowers risk of osteoporosis
- Reduces risk of falls in elderly
- Improves performance in Activities of Daily Living (ADL) and recreational activities
- Preserves lean body mass and helps maintain or lose weight

Specifics of Physical Activity

- Moderate aerobic activity can be done in several segments to total the recommended 30 minutes per day
  - Segments need to reach moderate level and last at least 10 minutes in duration
  - Short, low intensity walks do NOT count
- Even once weekly exercise provides measurable health benefit
- Weight loss requires diet and exercise up to 60-90 minutes/day; most weight loss is a function of caloric restriction
- Benefits of exercise are “dose related”, but too much exercise adds risk of injury

But You Don’t Have to Live Like a Spartan

- Vigorous exercise for 20 minutes 3 times a week reduced mortality by 32%
- Meeting both moderate and vigorous exercise requirements reduced mortality by 50%
- Findings held for overweight and smoking subgroups
- Even those with lower physical activity levels got benefit


Physical Activity: Take-Home Messages

- The bottom line for patients:
  - Any exercise is better than none
  - The greatest improvement in health occurs when people who are completely sedentary become slightly active
  - Even moderate intensity can reduce mortality
  - Even if you don’t lose weight with exercise, it is better to be fit and fat than unfit and thin — you will live longer

The Hale study

- Prospective study of 2339 elderly aged 70-90 years
- Followed for 10 years
- Healthy lifestyles (diet, exercise, smoking and alcohol)
- Outcome: Mortality

<table>
<thead>
<tr>
<th>Lifestyle Factor</th>
<th>Reduction in Mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mediterranean Diet</td>
<td>22%</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>37%</td>
</tr>
<tr>
<td>Non-smoking</td>
<td>35%</td>
</tr>
<tr>
<td>Moderate Alcohol</td>
<td>22%</td>
</tr>
</tbody>
</table>

Hale project: Knessel, et al. JAMA September 22, 2004
Combination of healthy behaviors

<table>
<thead>
<tr>
<th>Lifestyle Factor</th>
<th>Reduction in mortality</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 healthy factors</td>
<td>38%</td>
</tr>
<tr>
<td>3 healthy factors</td>
<td>55%</td>
</tr>
<tr>
<td>All 4 healthy factors</td>
<td>65%</td>
</tr>
</tbody>
</table>

Hale project: JAMA 2004

Assessment for Exercise Program

- Most sedentary, asymptomatic adults can start low-moderate intensity exercise without formal testing
- People with 2 or more CV risk factors starting vigorous exercise, need exercise stress testing (Family History sudden death, smoker, Hypertension, hyperlipidemia, men >45, women >55)

What Does it Take to Change Health Behavior?

- Median intensity interventions
  - Median of 5 contacts
  - Median duration 9 months
- High intensity interventions
  - Median of 16 contacts
  - Median duration 12 months
- Counseling interventions included
  - Didactic education
  - Individualized care plans
  - Problem solving skills
  - Audit and feedback

Counseling about Physical Activity 4 A’s

- Ask and Assess:
  - “Do you get any regular exercise?”
- Set the agenda
  - “Would you be interested in talking about increasing your physical activity?”

Counseling about Physical Activity

- Advise and Assist:
  - “Do you know the current recommendations for physical activity?”
  - TIP: Try giving patient goals and let them figure how to get there and monitor themselves with your help and coaching
  - Start with trying to get patient to start moderate aerobic exercise
  - Brainstorm with patient what they might enjoy and be able to do
  - Walking is simplest, cheapest form of aerobic exercise

Recommendations to Enhance Exercise Adherence

- Exercise with others
- Moderate exercise
- Emphasize variety
- Recruit support of family/friends
- Use logs, including on-line
- Include games
- Physician support and periodic fitness testing
Interventions to Promote Healthy Behaviors in Persons with DD

- Chronic disease risks
- Impacts of sedentary lifestyle
- Value of health screenings
- Characteristics of health promotion interventions
- Benefits of health promotion interventions

Health-Related Behaviors – DD

- Tobacco use  
  - Less likely to smoke than general population
- Overweight & Obesity  
  - 29% overweight; 35% obese
- Sedentary lifestyle  
  - 45% had NO physical activity in the past month  
  - Only 10% had engaged in PA three times per week
- Cancer screening

Obesity in Adults with DD

- Higher rates among women
- Increased prevalence among adults in community and family home settings
- Increased risk for cardiovascular disease
- Increased risk for hypertension

Consequences of Sedentary Lifestyle

- Higher BP
- Higher cholesterol
- Increased risk of diabetes
- Greater anxiety
- Greater hyperactivity

Types of Health Promotion Interventions

- Health care and screening interventions
- Fitness/exercise only
- Multi-component

Health Screenings

- Screen for conditions specific to patients’ predisposition
- Initial screening leads to more health care encounters in the future
- Other benefits:  
  ➢ Less pain
  ➢ Fewer falls
  ➢ Fewer emergency room visits
  ➢ Greater satisfaction


Outcomes for Fitness/Exercise Interventions

- Improved fitness (balance, endurance, strength)
- Lower BP
- Behavioral and psychological outcomes
  - Fewer maladaptive behaviors
  - Increased alertness
- Inconsistent impact on obesity reduction

Multi-component Interventions

- Healthy eating, physical activity & health self-care
- Additional components included:
  - Nutrition and exercise
  - Stress reduction
  - Home visits
- Positive physical, health behavior, and psychosocial outcomes
  - Reduced BMI

RESOURCES

- Books and videotapes at local libraries
- ACSM Fitness book
- Patient education materials
- Local rec centers, YMCA, Curves, etc.
- www.americanheart.org
- www.fitness.gov
- www.presidentschallenge.org
- http://www.nchpad.org/

Future Directions

- Community integration
- Web-based platforms
- Apps
- Interactive video games
- Health promotion and socialization
- Healthy environments for support persons and individuals with DD

Thank you

Carl V. Tyler Jr. MD, MSc
Cleveland Clinic
Case Western Reserve University
catyle@ccf.org