DOWN SYNDROME AND DEMENTIA

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The “Health Benefits” of Down Syndrome

Decreased Risk of:

● Coronary Artery Disease
  – Hypertension

● Solid tumors
Increase in Life Expectancy for people with Down syndrome
Mean and Median Life Expectancy

Dementia was associated with mortality in 70% of those with Down syndrome over 35 years old.
Take Home Point

- Dementia is the most significant issue facing adults with Down syndrome over the age of 40
Clinical Issues

- Proactive care
- Recognition
- Management
- Family Support
- Research
Proactive Care

- Hospitalizations
- Critical Illness
- Life Changes
Recognition

- Seizures
- Gait changes
- Balance disturbance
- Urinary incontinence
- Major personality changes
Why hard to diagnosis Dementia in DS

- Variable levels of baseline functioning
- Limited standardized assessment tools
- Some age-related deficits in functioning
- Often depends on caregiver report
- Change in functioning may be due to a range of other issues
Areas of early deficit

- Research suggests behavioral and psychological symptoms of AD may appear earliest
- Executive dysfunction also occurs early
- Memory loss follows
- Recommendation to establish a baseline level of functioning by age 35
Decline by Sex

- No significant difference in initial score
- No significant difference in rate of change per year

Free and Cued Recall

1 2 3 4 5 6 7 8
Female  Male
Decline by Mental Age (PPVT)

- Marked significant difference in initial score
- No significant difference in rate of decline by mental age at baseline

Free and Cued Recall

- 5 yrs
- 8 yrs
- 12 yrs
Cognitive Decline by β-Amyloid

Free & Cued Recall

Cued Recall Intrusions

PiB-

PiB+

+0.21

-0.93

+0.82

-0.11
Cognitive Decline by β-Amyloid

Block Design

- PiB-
- PiB+

-0.49
+0.10
Cognitive measures summary

- Decline starts in 40s (stable or increasing pattern in 30s), and becomes more marked in 50s
- Decline greater in following β-amyloid
- No differences in rate of decline by sex or mental age
- Episodic memory/working memory, executive functioning, and motor coordination and planning
Management

- Small group of caregivers
- Behavioral interventions
- Medications
Support

- Family resources
The Alzheimer’s Biomarkers Consortium- Down Syndrome Study
## ABC-DS Performance Sites

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<tr>
<th>Site</th>
<th>Location</th>
<th>Original Study</th>
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<tbody>
<tr>
<td>University of Pittsburgh*</td>
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<tr>
<td>Columbia University*</td>
<td>New York, NY</td>
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*Coordinating Site
Patient presentation: Evaluate for Alzheimer’s

- 44 year old male with ‘Seizure Disorder’
- Daily Events with Syncope and ‘Tremor’
- No response to anti-seizure meds