Alzheimer’s Dementia in Down Syndrome: A Clinicians Perspective

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For the past 25 years

* At the Chicago ADSC & Denver Adult Down Syndrome Centers
* We have seen close to 6000 people
* & Diagnosed over 450 people with Alzheimer’s Dementia
Clinical Sample ADSC, all over 40; (n=298)

Loss of function from a reversible disorders;  
\[ n=86 \ (29\%) \]

Loss of function from non reversible dementia;  
\[ n=42 \ (14\%) \]

No Loss of function;  
\[ n=170 \ (57\%) \]
Loss of function due to reversible and non-reversible disorders, all over 40; n=128

- Loss of function from a non-reversible dementia; n=42 (32.8%)
- Loss of function from a reversible disorders; n=86 (67.2%)
For older Adults with Down Syndrome (Older than 40)
Alzheimer’s is a Diagnosis of exclusion

- Loss of function is due to reversible causes in a majority of cases (@ 60%)
- Clinicians must find any and all possible health or psychosocial causes of a loss of function
- Before making a diagnosis of a non-reversible dementia
Change in Function:
Alzheimers. Dx of exclusion

Rule out

- Health conditions (Hypo-thyroid; sleep apnea; celiac; etc)
- Mental Health (depression, OCD, trauma, etc)
- Life stage changes & transitions: Loss of significant others etc.
- Environmental stressors (home, school, work)
Process of excluding other causes is not an easy task: Huge overlap Depression & Alzheimer’s

Symptoms of withdrawal, loss of interest and participation in activities

For example: Is he not brushing his teeth…?

- Depressed & does not care?
- Or cannot remember how (Memory?)
“Stubborn-Compulsive Behaviors “Grooves”

- Set patterns of behavior
- Can be very adaptive

- Under stress a ‘groove’ can become an ‘obsession or compulsion’
- Can be very odd and unusual
- Easily misinterpreted as alzheimer’s
- But Obsessions or compulsions are conduits For any stressors
- Health, mental health, Life change
All over the internet “In people with DS changes in overall function, personality and behavior...

- May be more common early signs of Alzheimer’s
- *Than memory loss or forgetfulness*

- “Behavior or Personality changes”,
- Are indicators
- *Of every other problem or issue*
- Those causes representing 60% of the loss of function
Cognitive Testing is also of limited value

- Results of Cognitive assessment tools
- Are normed on general population
- “Minimum value” floor effect” in the tests which affect most people with DS

For most people with DS

Results Do not distinguish differences in person’s ability below that minimal value/score.
But (in 27 years of practice ADSC) Found an interesting finding: People with DS have *Photographic visual memory*

- People remember past people, places and events in great detail
- And in living color
Best Diagnostic “Instrument” for Alzheimer’s Dementia in Persons with DS:

- Have an experienced clinician ask
- Person/s sharing the day to day life with person with DS
- About this “photographic memory”
Example Linda 57: Had excellent expressive & adaptive skills prior to onset of Alzheimer’s dementia

Linda’s unusual early memory changes

- Forgetfulness (lost keys, her lunch, glasses, etc)
Caregiver and Environmental Issues

- Growing sense of concern by people who really knew her
- The changes observed were highly unusual for her
- Because of her superb visual memory
- She never seemed to lose or forget anything

- Important early marker
- Example of the “here after”
Caregiver and Environmental Issues: Early Up and Down Course

- Some days on (focused, sharp, plugged in)
- Some days off (unfocused, confused)
- May lead many to believe the changes noted are behavioral (oppositional or willful)
- In fact: they are typical of AD course
Caregiver and Environmental Issues: Denial

- Very difficult for many significant others
- Safety issues may need to be stressed
- Wanderers (alarms needed on doors)
  - Close monitoring in public places
- One benefit/deficit of DS (compared to):
  Existing depth perception problems worsen (Less likely to wander; but also more difficulty getting in vans etc)
Most effective care: “Anchors”

- Small group of caregivers
- Providing one on one care

We found that:
- People maintained skills longer
- This greatly helps to minimized anxiety, fear & anger