DEMENTIA WITH LEWY BODIES (DLB)

A Summary Sheet of Information and Intervention Suggestions
With an Emphasis on Cognition

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AD refers to Alzheimer's Disease

CHARACTERISTICS

Brain Disorder
Most obvious symptoms: impairment in cognition, movement, behavior
Progression: increasing severity of symptoms over time (a progressive dementia)
Onset: age 50-70, usually around 55 or 65
Duration: shorter than ADand shorter life expectancy than AD
Cause unknown
Cure: no cure at this time, but there is treatment to reduce symptoms
Diagnosis verified at autopsy
Very common cause of dementia (20% of all dementia cases in United States; second most common)
About 66% of people with DLB also have cognitive symptoms of AD
Course: fluctuating (alternating periods of higher and lower functioning) with an overall decline over time, spontaneous improvement and decline, more rapid course than AD
Increased sensitivity to some medications
Named after F. H. Lewy, a German neurologist who in 1912 found the pathology (Lewy Bodies) in the brain stem
Other names: Lewy Body Dementia (LBD), Cortical Lewy Body Disease (CLBD)

NEUROPATHOLOGY

Lewy bodies inside brain cells
Acetylcholine reduction
Dopamine reduction
Neuritic plaques and neurofibrillary tangles (when AD present, as it frequently is)

LOCATION OF CORTICAL BRAIN CHANGES

Cortical refers to the cortex (i.e., the outer layer) of the brain
Changes (pathological abnormalities) occur in the cortex and in internal (subcortical) structures of the brain
Changes (pathological abnormalities) occur on both sides of the brain
Cortical brain structures affected:
- Parietal lobe
- Occipital lobe
- Temporal lobe

Subcortical changes disrupt frontal lobe functioning

Brain stem (subcortical): disrupted consciousness, REM sleep, and sleep behavior)
Limbic cortex (subcortical): disrupted emotions

COGNITIVE CHANGES

Fluctuations: good periods, then periods of more impairment, then good periods
Memory less affected than in AD (memory loss more evident in later stages)
Visuospatial: difficulty recognizing distance between objects and from self and difficulty arranging objects in space
Attention impairment (fluctuates)
Frontal-subcortical skills impaired
Logic based on wrong premise (paranoia with a detailed, perhaps plausible rationale)
Problem solving impaired early in course
More insight than in AD, often
Sensitivity to noise, sometimes
Disinhibition, sometimes
Inapproriate sexual behaviors, sometimes
Manipulation and controlling behaviors, sometimes
May sense or know hallucination isn't true, but is still emotionally engaged

EMOTIONAL CHANGES

Mood shifts: may be rapid;
Unexplained and unpredicted anger or aggression, sometimes
Depression is common

BEHAVIORAL CHANGES

Hallucinations: particularly visual, emotionally engaging; begin early in course; well formed, detailed
Parkinson symptoms: slowed movements (bradykinesia); balance impairment; coordination impairment; rigidity; stooped posture; shuffling walk; some people have a tremor
Falls
Paranoia
Delusions
Syncope
Transient loss of consciousness (unexplained)
REM Sleep disturbance: act out dreams (can begin years or decades before dementia symptoms appear; sleep gets better as dementia symptoms get worse)
Good days (weeks) bad days (weeks)
Most persons are not aggressive, but many persons with dementia who are aggressive have DLB. Non family caregivers often report particular fondness for the person between episodes.

INTERVENTIONS: Non-medicinal

- Use visuospatial interventions:
  - economy of movement (move minimally, gesture minimally, organize so most caregiver movement is out of sight of person)
  - watch for person's reaction and adjust caregiver response
  - reduce clutter and unnecessary objects
  - slow down
  - approach from front
- Maintain flexible and accurate expectations of person (expect fluctuations)
- Address unpredictability of cognition and behaviors
- Do difficult tasks (e.g., bathing) when person is in higher functioning period
- Don't argue
- Ask carefully (maybe indirectly) about hallucinations
- Counsel to find way of tactfully communicating when hallucination isn't true
- Counsel person using insight that may be intact until later stages
- Reduce noise
- Walk to keep legs from going numb and to reduce rigidity
- Prevent falls
- Soften environment to reduce risk of injury from falls
- Monitor nighttime sleeping behavior
- Monitor for mood shifts and unexpected aggression
- Constant 1:1 to prevent unpredictable aggression
- Treat depression
- Remember what is lovable about this person
- Support family/caregivers (guilt, doubt, frustration)
- May need to move to long-term care setting earlier than in AD (family fatigue, family not accurate in perception, family guilt)
- Address uncertainty and guilt of caregiver
- Educate/remind caregiver course is unpredictable
- Educate/remind caregiver DLB can look like it's not dementia, though it really is
- Tell families/caregivers:
  - Description of the course of DLB
  - Remember it is dementia even when person appears normal or unlike a person with AD (e.g., memory for details)
  - Fluctuations
  - Expectations can be too high (or too low some days)
  - Unpredictable behavior and cognition
  - Easy to feel guilty

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Summary Sheet

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MEDICAL TREATMENTS:

Cure unknown
Reduce loss of dopamine (Parkinson medications)
Reduce loss of acetylcholine (AD medications)
Anti-psychotic medications (neuroleptics) for hallucinations and delusions may cause severe rigidity or death (neuroleptics lower dopamine levels)
Unusually sensitive response to sedatives (extreme responses)
Medications that treat behaviors and hallucinations may make the Parkinsonian symptoms worse; medications that treat the Parkinsonian symptoms may make the behaviors and hallucinations worse. Dosages must constantly be monitored and adjusted.

COMMENTS

In 1996 consensus criteria for clinical and pathologic diagnosis created and have since been updated.
Kosak detected Lewy Bodies in cortex at autopsy in 1984 with new stain (dye)
Lewy bodies are pink abnormalities that darken over time, inside the cell
Often misdiagnosed as: Dementia with psychosis, with agitation, with hallucinations, or similar behaviors;
or, early in the course, as a mental illness

RESOURCES

http://www.ninds.nih.gov/disorders/dementiawithlewybodies/dementiawithlewybodies.htm (National Institute of Neurological Disorders and Stroke NINDS)
http://www.lewybodydementia.org (Lewy Body Dementia Association, Inc.)
http://www.alzheimers.org (Alzheimer's Disease Education and Referral Center ADEAR)
http://www.alz.org (Alzheimer's Association)
http://www.med.umich.edu/madrc/ (Michigan Alzheimer's Disease Research Center MADRC)

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