DEMENTIA CARE SERIES
Michigan Department of Health and Human Services
CARING SHEETS: THOUGHTS & SUGGESTIONS FOR CARING

Caring Sheet #12: Dementia with Lewy Bodies:

A Summary of Information and Intervention Suggestions with an Emphasis on Cognition

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Introduction

This caring sheet focuses on Dementia with Lewy Bodies, with an emphasis on cognition.

Caring sheets #11 and #13 summarize information and intervention suggestions regarding Alzheimer's Disease (caring sheet #11) and Frontotemporal Dementia (caring sheet #13). All three outline the brain changes in each type of dementia, the impact these changes have on cognition and behavior, and implications for effective intervention.

The three caring sheets (#11, #12, and #13) are written as companion pieces in outline form with virtually each line of one caring sheet corresponding with each line of the other two. The three can be laid out side by side, and compared almost line by line.

Other caring sheets describe the cognitive and behavioral changes and specific interventions for these dementias in more detail. Caring Sheet #2 in particular describes the characteristics of dementia, and the relationship between the brain changes and changes in cognition.

Dementia is a decline in a person's cognition. This decline occurs because of changes in the brain.

If the cognitive decline is caused by treatable disorders such as a urinary tract infection, vitamin deficiency, reactions to medications, or depression, it is likely **temporary** and **treatable** (e.g., delirium).

In other cases the brain changes and resulting cognitive decline are **irreversible** and **progressive** (i.e., increasingly severe). They are caused by disorders such as Alzheimer's Disease, vascular disorders (e.g., ministrokes), Creutzfeldt-Jakob Disease, Dementia with Lewy Bodies, or Frontotemporal disorders. There are over 80 different disorders that cause this type of progressive dementia. Dementia with Lewy Bodies is one of these disorders.

DEMENTIA WITH LEWY BODIES (DLB)

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 AD and 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
Inappropriate 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)
Good days (weeks) bad days (weeks)

REM Sleep disturbance: act out dreams (can begin years or decades before dementia symptoms appear; sleep gets better as dementia symptoms get worse)
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

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)

This caring sheet focuses on Dementia with Lewy Bodies (DLB). More details about the brain changes and resulting cognitive changes in dementia are in caring sheet #2.

Though these changes in behavior and cognition result from brain damage, they are often mistakenly viewed as intentional or manipulative.

In DLB two of the neuropathological changes to the brain are acetylcholine reduction and dopamine reduction. These refer to the reduction in neurotransmitters, the neurochemicals that are transferred from one nerve cell to another as a method of communication between nerve cells. This intercellular communication is essential to the brain's maintenance and functioning. There are many different kinds of neurotransmitters. Two that are particularly reduced in amount in DLB are acetylcholine and dopamine.

Other Dementias

See caring sheet #11 for more information about Alzheimer's Disease (AD) and caring sheet #13 for more information about Frontotemporal Dementia (FTD). AD is the most common cause of dementia. At the end of caring sheet #11, there is a brief description of vascular dementia, another common cause of dementia.

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All Caring Sheets are available online at the following websites: **http://www.michigan.gov/mdhhs/0,5885,7-339-71550_2941_4868_38495_38498---,00.html** (Michigan Department of Health and Human Services MDHHS), at **http://www.lcc.edu/mhap** (Mental Health and Aging Project (MHAP) of Michigan at Lansing Community College in Lansing, Michigan), and at **https://www.improvingmipractices.org/populations/older-adults** (Improving MI Practices website by MDHHS)

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