Beyond Alzheimer's Disease – Other Causes of Progressive Dementia in the Older Adult

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Geriatric-Competent Care: Beyond Alzheimer's Disease – Other Causes of Progressive Dementia in the Older Adult



Overview

- This is the second session of the "2017 Geriatric-Competent Care Webinar Series"
- Each session will be interactive (e.g., polls and interactive chat functions), with 60 minutes of presenter-led discussion, followed by 30 minutes of presenter and participant discussions
- Video replay and slide presentation are available after each session at: https://www.resourcesforintegratedcare.com

Beyond Alzheimer's Disease – Other Causes of Progressive Dementia in the Older Adult

- **Developed by:**
  - The American Geriatrics Society
  - The Lewin Group
  - Community Catalyst

- **Hosted by:**
  - The Medicare-Medicaid Coordination Office (MMCO) Resources for Integrated Care

Accreditation

- The American Geriatrics Society is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians, and by the National Association of Social Workers (NASW) to provide continuing education for social workers.

- The Centers for Medicare & Medicaid Services is accredited by the International Association for Continuing Education and Training (IACET). The Centers for Medicare & Medicaid Services complies with the ANSI/IACET Standard, which is recognized internationally as a standard of excellence in instructional practices. As a result of this accreditation, the Centers for Medicare & Medicaid Services is authorized to issue the IACET CEU.

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If You Are A:	Credit Options:	Requirements
Social Worker	The American Geriatrics Society designates this webinar for a maximum of 1 Continuing Education (CE) credit hour **Please note:** New York, Michigan, and West Virginia do not accept National CE Approval Programs for Social Work. New Jersey, Idaho, and Oregon do not recognize NASW National Approval.	- Complete the pre-test at the beginning of the webinar - Complete the post-test with a score of 80% or higher by midnight April 7, 2017
Physician (MD or DO)	The American Geriatrics Society designates this live educational activity for a maximum of 1 AMA PRA Category 1 CreditTM	- Complete the pre-test at the beginning of the webinar - Complete the post-test with a score of 70% or higher by midnight April 7, 2017
Other (social worker in non-NASW states, psychologist, PA, nurse (NP, APRN, RN, LPN), pharmacist, marriage and family counselor, etc.)	The Centers for Medicare & Medicaid Services (CMS) is authorized by IACET to offer CEUs. CEUs will be awarded to participants who meet all criteria for successful completion of this educational activity	- Complete the post-test through CMS' Learning Management System by midnight April 24, 2017

Support Statement

- This webinar is supported through the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare and Medicaid Services (CMS) to ensure beneficiaries enrolled in Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. To support providers in their efforts to deliver more integrated, coordinated care to Medicare-Medicaid enrollees, MMCO is developing technical assistance and actionable tools based on successful innovations and care models, such as this webinar.

- To learn more about current efforts and resources, visit Resources for Integrated Care at: **https://www.resourcesforintegratedcare.com**

Introductions

- **Melinda S. Lantz, MD**

  Chief of Geriatric Psychiatry; Program Director, Geriatric Psychiatry Fellowship Program; Director of Acute and Ambulatory Care, Mount Sinai Beth Israel Medical Center; Associate Professor of Psychiatry, Icahn School of Medicine at Mount Sinai

- **Geri R. Hall, PhD, ARNP, GCNS, FAAN**

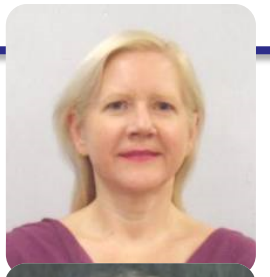
  Clinical Nurse Specialist, Banner Alzheimer's Institute

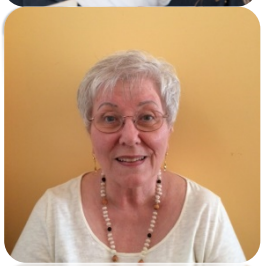
- **Rebekah Wilson, MSW**

  Aging Care Coach

- **Sharon Hall**

  Family Caregiver



Webinar Outline/Agenda

- Polls
- Key Diagnostic Features of Common Atypical Dementias
- Preventing and Managing Non-Cognitive Behaviors in Dementia
- Impact on the Individual/Family System
- Q&A
- Evaluation

Webinar Learning Objectives

Upon completion of this webinar, participants will be able to:

- Identify key distinguishing diagnostic features of the more common atypical dementias
- Demonstrate basic knowledge of key strategies for preventing or reducing difficult behaviors associated with Frontotemporal dementia or Lewy Body Dementia (LBD)
- Discuss the impact of these atypical dementias on adults and their families and how to address the resultant care challenges

Key Diagnostic Features of Common Atypical Dementias

Melinda Lantz, MD

Dementia
Major Neurocognitive Disorder (APA DSM5)

- Significant decline from a previous level of cognitive functioning
- Domains
  - Complex Attention
  - Executive Function
  - Learning and Memory, Language
  - Perceptual-motor
  - Social Cognition
- Based on collateral information including self-report, standardized neuropsychological testing or quantified clinical assessment
- Cognitive deficits interfere with everyday activities, social or occupational functioning

Mild Neurocognitive Disorder

(APA DSM5; Raskind 2004; NIA 2012)

- Subjective and objective in cognitive domain: memory, language or motor
- No significant impairment in:
  - Other cognitive domains
  - Activities of Daily living
  - Social or occupation functioning
- 10%-15% of patients with mild cognitive impairment progress to develop dementia each year
- “Precursor of dementia” versus spectrum of normal aging
- Patients with Mild Cognition Impairment (MCI) should be identified and monitored for cognitive and functional decline due to their increased risk for dementia
- There are no currently FDA approved medications for MCI

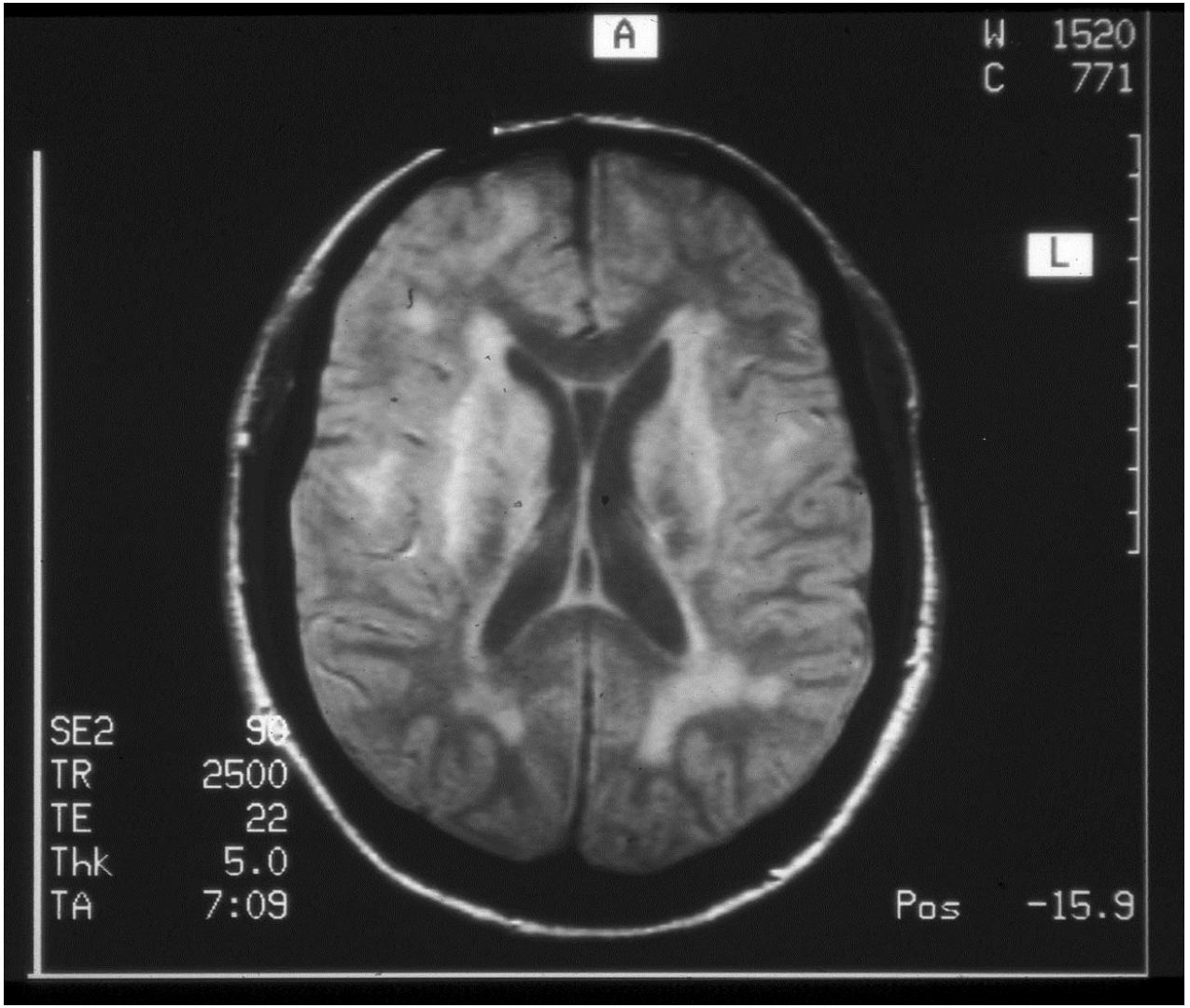
Vascular Dementia: Dementia Due to Cerebrovascular Disease

- Cognitive loss related to cerebrovascular disease
- Second most common cause in late-life
- Risk factors:
  - Hypertension
  - Diabetes
  - Hyperlipidemia
  - Smoking
  - TIAs
  - Stroke
- Decline may be abrupt due to a stroke or series of TIAs
- Cognitive loss may be focal, with more awareness of symptoms
- Disturbance of emotions and mood common

Vascular Dementia: Associated Features and Needs

- Care needs variable due to medical and physical conditions (hemiplegia due to stroke, multiple medical problems and medications)
- Decline may be more step-wise with plateaus in symptoms
- Patients may recover post-stroke but decline years later
- Mixed variants of Alzheimer's dementia are common
- More common in men than women

Diffuse and Severe Areas of Cerebral and Subcortical Infarction



Other Types of Vascular Dementia

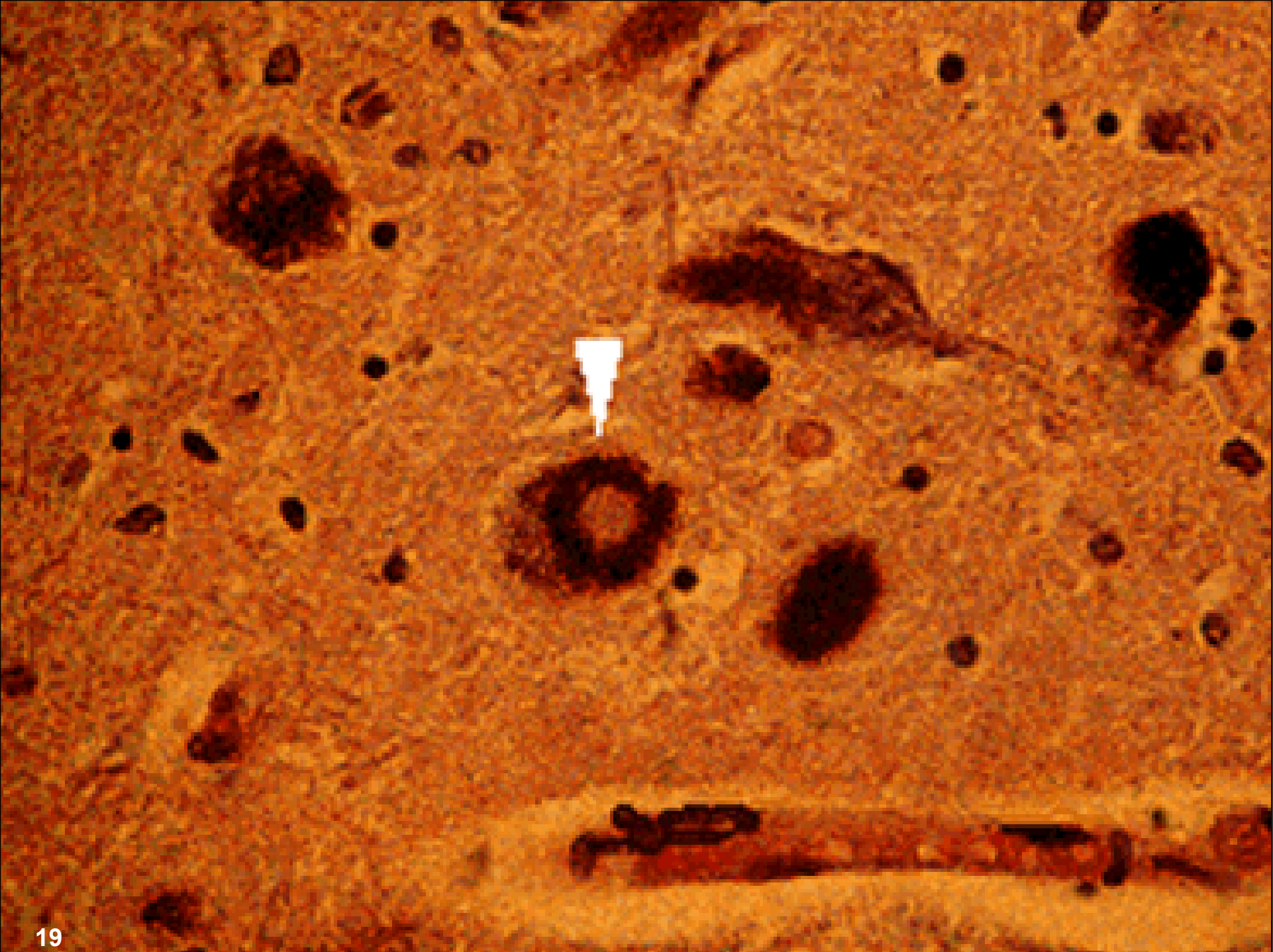
- CADASIL – Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarcts and Leucoencephalopathy, transient ischemic attacks (TIAs), strokes, mood changes, dementia, migraines with aura, onset in middle age, associated with NOTCH 3 mutation on Ch 19 p (APP)

- Binswanger's Type – multiple microvascular infarcts in the subcortical white matter of the brain with cumulative effects of memory, mood, motor skills and greatly increased risk of stroke

Lewy-body Dementia

(McKieth 2000)

- Memory loss and other cognitive deficits that often have a fluctuating and variable course, and relatively rapid onset
- Motor rigidity, Parkinsonian features
- Prominent hallucinations usually visual
- Unsteady gait, syncope, unexplained falls
- More rapidly deteriorating course
- Third most common type of Dementia
- Men > Women



Frontotemporal Dementia

(Perry RJ 2000;2001)

- Significantly earlier onset between 40 to 60 years of age
- Atrophy prominent in the Frontal and Temporal lobes of the brain
- Slow onset with early changes in personality, impulse control and language
- Memory, arithmetic, copying figures often preserved until later in the course
- Behavior often disinhibited, repetitive, socially inappropriate

Frontotemporal Dementia – Clinical Features

- Prominent personality change very early
- Early onset with very slow, progressive decline
- Memory impairment later in the course
- Behavioral changes: Disinhibition, impulsivity, apathy, depression, verbal outbursts
- Lack of recognition, agnosia often prominent
- Treatment is very symptom driven as there are no agents available for prevention or slowing progression

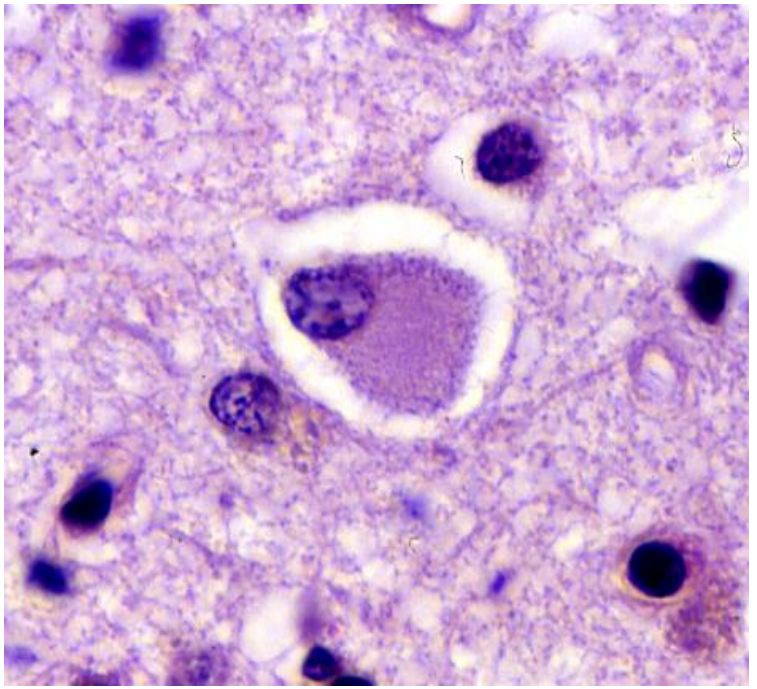
Frontotemporal Dementia subtypes

- **Pick's Disease**
  - A progressive dementia selective to the frontal (and to a lesser degree) temporal lobes characterized by significant aphasia and associated with Pick cells (ballooned shaped cells with inclusion bodies) at autopsy, a "tauopathy" dementia, early onset with strong genetic inheritance

- **Fronto-temporal Dementia with Parkinsonism**
  - Progressive dementia with prominent frontal and temporal lobe finding, aphasia and PD features, often associated with mutations in Ch 17 (tau gene), FPTD-17

Neuropathology of Frontotemporal Dementia

Pick's Disease is a type of FTD characterized by balloon shaped neurons damaged by Pick bodies, a characteristic abnormal collection of tau filaments that are deposited inside the cells.



Treatment of Cognitive Symptoms of Vascular and Lewy-body Dementia

- Cholinesterase Inhibitors: Donepezil, Galantamine, Rivastigmine, for mild to moderate AD, VasD, mixed the benefits relatively similar: +3 points ADAS-Cog, 4 to 6 Month delay in progression
- Individual response variable: 20% pts show “greater than average” response, 20% “some response”, but 30% to 50% show no response
- Greatest effect appears to be delay in need for nursing home placement of 6 to 8 Months
- NO ROLE for use in Frontotemporal Dementia, may worsen behavioral symptoms

Treatment of Cognitive Symptoms

- Rivastigmine may be more helpful in Lewy-body than the other available cholinesterase inhibitors
- Memantine is approved by the FDA for Dementia of the Alzheimer's type, but not enough evidence to show benefit for other types of dementia
- Cholinesterase inhibitors have no benefit in Frontotemporal dementia and may worsen mood and behavior
- Cholinesterase inhibitors may cause nausea, vomiting, weight loss and bradycardia

Pharmacologic Treatment
for targeted severe symptoms

- Psychosis (Hallucinations, Delusions) → Antipsychotic Agents (risperidone, olanzapine, quetiapine, aripiprazole)

- Depression
- Anxiety
- Irritability → SSRI (sertraline, citalopram) or bupropion, trazodone, mirtazapine

Pharmacologic Treatment
for Physical Aggression

- Severe Physical Aggression (also helpful for severe impulsivity and mood lability) ⇒ Mood Stabilizer (valproate, lithium, carbamazepine, gabapentin)
- Moderate Physical Aggression ⇒ Mood Stabilizer

Dosing Guidelines: Antidepressants

Drug	Initial/day	Maximum
Sertraline	25-50mg	100-150mg
Paroxetine	10-20mg	20-40mg
Trazodone	25-50mg	200-300mg
Citalopram	10-20mg	20-40mg
Escitalopram	5-10mg	10-20mg
Mirtazapine	7.5-15mg	30-45mg
Nortriptyline	10mg	50-75mg
Venlafaxine	37.5mg	75-150mg

Side Effects of Antidepressants

- Variable & Individual
  - Sedation
  - Orthostatic hypotension
  - Agitation/Irritability/Insomnia
  - Falls
  - GI Upset/Weight Loss
  - Confusion
  - Psychotic Symptoms

Dosing Guidelines: Mood Stabilizers

Drug	Initial/day	Maximum
Valproate	125-250mg	750-2000mg
Gabapentin	100-300mg	300-2400mg
Carbamazepine	100-200mg	400-800mg
Lithium	150-300mg	600-1200mg
Topiramate	25-50mg	200-400mg
Lamotrigine	25-50mg	100-200mg

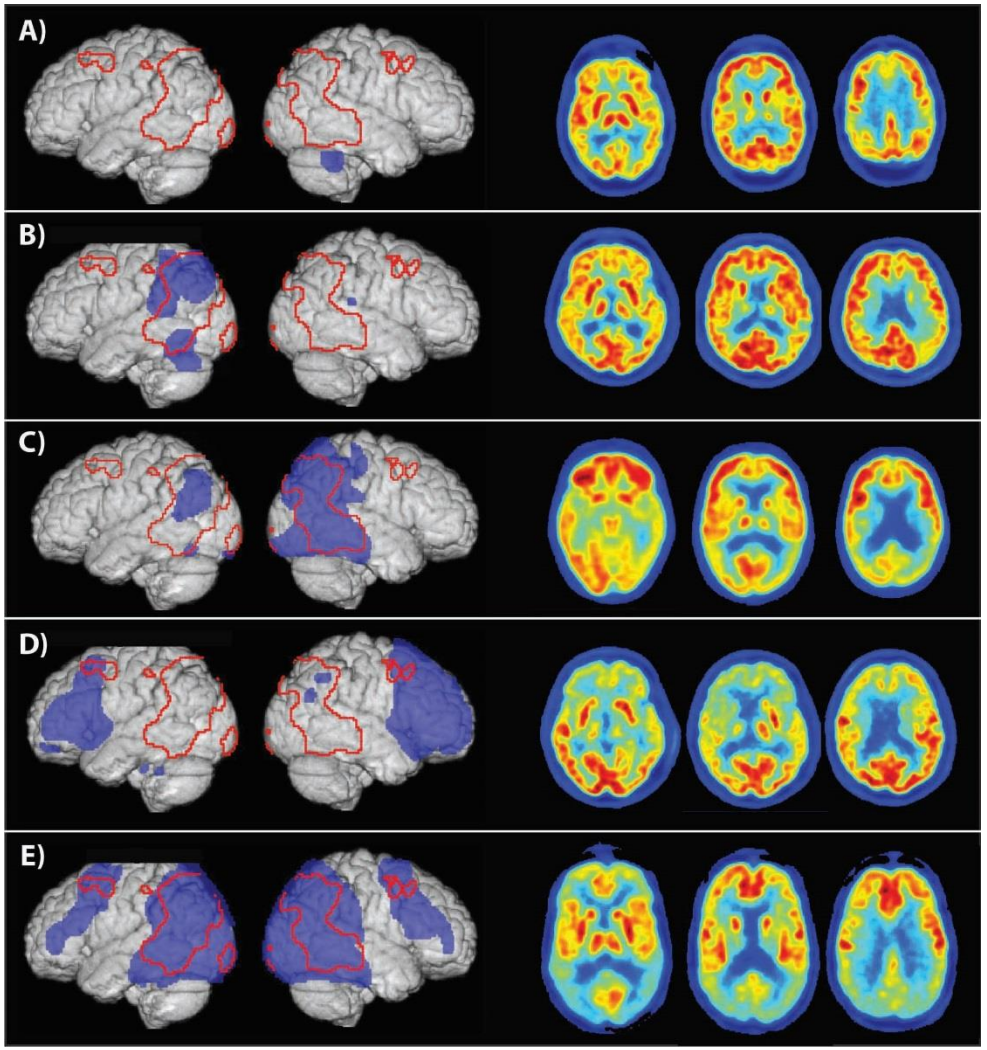
Preventing and Managing Non-Cognitive Behaviors in Dementia

Geri R. Hall, PhD, ARNP, GCNS, FAAN

Symptom Presentation in Dementia Depends on…

- Location of the degeneration: Location, location, location!
- Functions of that area
- Pathologic changes at the cellular level (e.g. presence of Lewy bodies)
- Comorbid conditions
- Environmental factors producing excess disability
- Premorbid personality

FDG PET to Distinguish Dementias



The Location of Damage is Different, Therefore so are Care Needs

- Due to time constraints we will examine two more common non-AD dementias:
  - Lewy Body Dementia (LBD)
  - Frontotemporal Lobar Degeneration (FTD or FTLD)

Lewy Body Dementia: Three Common Presentations

Regardless of the initial symptom, over time all three presentations of LBD will develop very similar cognitive, physical, sleep and behavioral features:

- Some individuals will start out with a movement disorder leading to the diagnosis of Parkinson's disease and later develop dementia. This is diagnosed as Parkinson's disease dementia
- Another group of individuals will start out with a cognitive/memory disorder that may be mistaken for AD, but over time two or more distinctive features become apparent leading to the diagnosis of 'dementia with Lewy bodies' (DLB)
- Lastly, a small group will first present with neuropsychiatric symptoms, which can include hallucinations, behavioral problems, and difficulty with complex mental activities, also leading to an initial diagnosis of DLB

(www.LBDA.org (2017). LBD, three common presentations. Lewy body Dementia Association, retrieved 2/2/2017)

Common Symptoms of Lewy Body Dementia

- Sleep Disorders
  - Acting out one's dreams while asleep
  - Excessive daytime sleepiness
  - Restless leg movement
- Impaired Thinking
  - Executive Function (planning, processing information)
  - Memory
  - Ability to understand visual information that fluctuates
- Problems with Movement
  - Tremors, stiffness, slowness and difficulty walking

(Lewy Body Disease Association (2017) www.LBDA.org ; National Institutes of Health (2013). Lewy Body Dementia: Information for patients, families, and professionals. Bethesda. MD

Common Symptoms of Lewy Body Dementia (Continued)

- Altered Sensory Perception
- Hallucinations
  - Often of animals or children
- Behavioral and Mood Symptoms
  - Depression, apathy, anxiety, agitation, delusions or paranoia
- Changes in Autonomic Body Functions
  - Blood pressure control, temperature regulation, postural control, bladder and bowel function
- Exquisite sensitivity to medications

Care of Lewy Body Dementia

- Similar to Alzheimer's-type dementia in terms of decreasing stimuli, increasing rest, promoting exercise (Big & Loud Programs) and balance
- Safety due to REM sleep disorders, fall precautions due to autonomic dysfunction, swallowing issues
- Supportive (self-care) activities of daily living (ADLs)
- Control of misleading environmental stimuli and medications that trigger hallucinations and delusions
- Prepare family for response to potential aggression
- LBD Association and support groups

Use of Therapies

- Physical therapy - Design a program and teach to patient/family focusing on postural stability, core strength
- Exercise Programs – Big and LOUD!!!
- Recreational Therapy
- Occupational therapy - ADLs
- Speech pathology – swallowing, spoken volume
- Pharmacist consultation – OTC's can be more problematic and interact

Lewy Body Dementia Support & Resources

- NIH (2013) Lewy Body Dementia: information for patients, families, and professionals. Washington, D.C. National Institute on Aging https://d2cauhfh6h4x0p.cloudfront.net/s3fs-public/lewy-body-dementia.pdf
- The Lewy Body Dementia Association: https://lbda.org
- Monthly support groups: for information contact Banner Alzheimer's Institute Family & Community Services www.banneralz.org/contact-us.aspx

Frontotemporal Dementia (FTD): It's Complicated!

- **Three common types**
  1. Progressive Behavior/Personality decline (Behavioral Variant Frontotemporal Degeneration (bvFTD)) (used to be called Pick's disease)
     - Apathy, reduced drive, loss of executive function, inappropriate & impulsive behaviors, loss of empathy, anosognosia
  2. Progressive Language Decline
     - Semantic Primary Progressive Aphasia (PPA) – Loss of meaning of words, Agrammatic PPA, Logopenic PPA
  3. Progressive Motor Decline
     - CBC, PSP, FTD with PD, FTD with ALS
- **Mixed dementias are common but are usually diagnosed at autopsy**
  - Memory is generally intact but can have AD with frontal lobe presentation. Characterized by impulsiveness, obsessive behaviors with memory loss

(NIA/NIH(2010), Frontotemporal Disorders: Information for patients, families, & caregivers, Bethesda, MD.)

Diagnosing Frontotemporal Dementia (FTD): Often Misdiagnosed

- Patients tend to be younger than Alzheimer's Disease
- Thought by many to be extremely rare
- Symptoms vary widely and appear in multiple DSM categories
- Often diagnosed as "late onset bipolar disorder"
- Many people with Behavioral Variant Frontotemporal Degeneration (bvFTD) have had very successful, highly driven, eccentric lifestyles

Progression of Symptoms

- People with Alzheimer's Disease have behavioral symptoms that worsen with progression
- One study reported people with FTD have initial severe behavioral problems that may remain stable or even improve with disease progression (3 years)
  - The study was compromised by high attrition, refusal rate, disinhibition, and heterogeneity in lesion progression
    - (Lavenu & Pasquier, 2005)

Predominant Characteristics

- Loss of insight (anosognosia) is a core diagnostic criterion
  - People with FTD show more problems with dominance, submissiveness, cold-heartedness, introversion & ingeniousness
  - FTD tends to exaggerate positive personality qualities and minimize negative
  - Were unable to update self-image after disease onset
    - (Rankin, Baldwin, Pace-Savitsky, Kramer, & Miller, 2005)

Staging Behavioral Variant Frontotemporal Degeneration (bvFTD)

Mild

- Marked behavioral changes
  - No insight!
  - Disinhibition
  - Apathy
  - Loss of sympathy/empathy
  - Inappropriate social behaviors
  - Social withdrawal, less interest in families
  - Increase in impulsive spending, gambling, hoarding
  - Loss of social manners
  - Breaks law
  - Preserved household function

Moderate

- Previous symptoms become more pronounced and disabling
  - Compulsive, obsessive behaviors
  - Binge eating, Pica
  - Repetitive behaviors and statements
- Increased signs of cognitive loss
  - Short term memory loss, coordination, learning

(Memory.UCSF.edu)

Community-based Interventions in Mild bvFTD

- Diagnostic evaluation at interdisciplinary setting including behavioral neurologist, advanced practice nurse (APN), social worker, speech pathologist, occupational (OT) and physical therapies (PT)
- Follow-up with social worker and APN for long term care management and strategies, coordination of family and community resources, and ongoing bvFTD specific education
- Psychiatric Assessment may be helpful for pharmacologic behavioral management, however, therapies at that time as people with behavioral variant do not experience depression due to a lack of insight and an inability to recognize changes in their own condition
- Guardianship and conservatorship empowers the family to make decisions on the patient's behalf and pay bills

Community-based Interventions in Mild bvFTD (continued)

- Manage patient's money creatively during the early phase (i.e., canceling credit cards and replacing with gift cards)
- Eliminate internet connection to stop patients from online shopping
- Take steps to block phone solicitors
- Apply for disability and SSDI
- Have the healthcare provider report the patient to the Department of Motor Vehicles and rescind the license and identify driving cessation measures
- Explore using companion services for activities if spouse/partner works

More Interventions

- A palliative approach
- Minimize medications to only essentials
- Family support group (see the AFTD website for locations)
- Association for Frontotemporal Degeneration (www.theaftd/org)
- Medic-Alert bracelet placed on the dominant hand, to reduce the ability to remove it. A GPS (Tile) tracking system can be placed in a pocket, in the car, etc.
- Behavioral approaches – avoid activities that trigger obsessions
- Violence precautions:
  - Remove all weapons without fanfare
  - Have an escape plan
  - Life Alert for caregiver

Obsessions

- Repetitive behaviors serve a valuable function in FTD. They reduce stress and help the person to remain calm and control mood
- These can be almost any behavior but motor activities are very common
- Caregivers often want the patient to stop and try distraction, etc. This results in agitation. If medicated you get a sleepy patient with an obsession
- It is best to facilitate if you can keep the person relatively safe

Staging bvFTD

- Advanced (average lifespan after dx 5-7 years)
  - Profound behavioral symptoms
    - Apathy
    - Lack of sympathy
    - Severe disinhibition
  - Language difficulties
  - Cognitive loss
  - Fully dependent in basic activities of daily living
  - May have spontaneous vocalizations

Post-admission Person-Centered Interventions

- Large dining rooms have too much stimulus and trigger agitation
- Monitor intake for stuffing mouth with food to avoid choking, stealing food from other residents' trays, and eating non-food items
- Structured but flexible routine. Intersperse high intensity activities with quieter ones
- Calorie-dense foods and snacks
- Obsessions help the patient manage stress, do not discourage unless unsafe
- Encourage activities but do not expect resident to respond to relationships.
- Focus on brief physical activities, such as exercising, walking, music, dancing, or painting
- Psychiatric assessment/treatment for disruptive social behaviors, manipulation, invasiveness, sexual gestures, and arguing.

Post-admission Person-Centered Interventions

- Staff education meet to educate staff on specific care needs and individual issues preferences and potential challenges. Include family in this meeting.
- Occupational therapy – personal care techniques re: bathing and grooming
- Physician assessment – poor appetite, behaviors, bowel movements
- Social work – people with behavioral variant of FTD rarely participate in or benefit from therapy
- Behavioral approaches – provide individual or small group activities; observe and positively intervene when arguing or violating privacy; provide snacks of choice with 1:1 attention; provide opportunities to make choices, (i.e. clothing, timing of personal care, food)

Terminal FTD is Similar for all Variants

- Bedbound or wheelchair bound
- Stiff, rigid, with joints becoming frozen
- Completely dependent
- Difficulty coordinating chewing and swallowing, aspirates
- No bowel or bladder control
- Spontaneous vocalizations
- Require 24/7 care

Post-admission Person-Centered Interventions for PPA

- Speech therapy consult - altered diet for chewing/swallowing issues and feeding techniques; non-verbal communication techniques, i.e. gestures, pictures.
- Jumpsuits to minimize handling own waste and daily bowel regiment to reduce the number of stools per day.
- Psychiatric assessment/treatment - wailing, hyper-sexuality, aggressiveness, compulsive eating behaviors, and possible depression (post-admission). Team meet with family, staff, management, and physician –time/place trending (increased monitoring at certain times of day)
- Staff education -Instructed on approaches when resident can neither produce nor understand language

Summary

- As diagnostic specificity improves, non-Alzheimer dementias will be diagnosed more frequently
- A “one size fits all” care program will not meet the needs of people with non-Alzheimer dementias. They differ in terms of symptom presentation, behavioral responses, and ability to tolerate medications
- Families and care providers are desperate for answers, ongoing support, and to seek out others suffering from similar conditions
- Interdisciplinary care and research is essential for humane approaches to these vexing conditions

Beyond Alzheimer's Disease: Impact on the Individual/Family System

Rebekah Wilson, MSW

Beyond Alzheimer's Disease
Impact on the Individual/Family System

- Challenges with diagnosis
- Symptoms generally less recognized/understood
- Caregiver burden
- Younger onset
- Community resources and considerations
  - Legal
  - Financial
  - Emotional support
  - Care options

Psychosocial Impact - Diagnosis

- Misdiagnoses common
- Rearview mirror clearer; consequences prior to diagnosis
- Sense of relief to get diagnosis
  - Negative experiences prior to diagnosis
  - Empowerment through learning about diagnosis
- Present and future support – limited beyond AD

Psychosocial Impact - Symptoms

- Less recognized – Alzheimer's disease as reference point
  - Memory may not be impacted
- Safety considerations due to brain changes
- Fluctuations in mental status misinterpreted
- Hallucinations/REM sleep disorder
- Impact of FTD symptoms
  - Legal
  - Financial
  - Employment
  - Social

Psychosocial Impact – Caregiver Burden

- Nature of symptoms
  - FTD – behavior/language
  - LBD - fluctuations
- High stress
- Isolation due to being a ‘rare’ diagnosis
- Age of onset impacts normalization
  - Expect memory and cognitive changes in older adults
  - Parents providing care for person with dementia (PWD)
  - Care for PWD while caring for kids in household
- Ambiguous loss

Psychosocial Impact – Young Onset

- Developmental stage of the family
  - Young kids at home
  - Aging parents
- Concerns about genetics
- Career and employment
- Financial implications
- Challenges finding services

Legal and Financial Considerations

- Legal planning documents
  - Power of Attorney for Healthcare
  - Power of Attorney for Finances
  - Living Will
- Employment Laws

Legal and Financial Planning Continued

- Early Onset diagnoses impact income and insurance
- Medicare
- Social Security Disability
- Social Security Compassionate Allowance
- Additional options for financing care

Compassionate Allowances

"The Compassionate Allowances (CAL) initiative is a way to expedite the processing of SSDI and SSI disability claims for applicants whose medical conditions are so severe that their conditions obviously meet Social Security's definition of disability. It is not a separate program from SSA's two disability programs, SSDI and SSI.

There is no special application or form that is unique to the CAL initiative. Individuals with a CAL condition apply for benefits using the standard SSA process for filing claims for SSDI, SSI, or both SSDI and SSI benefits. SSA will expedite the applications of those with a CAL condition. Applications for disability may be filed online, in the local field office, or by calling our toll-free number 1-800-772-1213. To learn how to apply for disability benefits please click How You Apply."

(https://www.ssa.gov/compassionateallowances/cal_faqs.ht)

Community Resources and Services

- Support groups
  - Caregiver
  - Person with the diagnosis
- Care models
- Limited experience and understanding if not AD

Care Planning

- Establishing the care team
- Determining goals for care
- Support for the person with the diagnosis
- Knowledge and Support for the care partners
  - Family/Friends
  - Professional

Challenges with Home & Community Based Care in Non-Alzheimer's Dementia

- Facility care for FTD
- Fluctuations as a challenge for care in LBD
- Hospice care & denials

Best Practices
Home & Community Based Care

- Recognize different than Alzheimer's
- Structure very important
- "Failure free," low demand engagement
- Group versus individual activities
- Recognize preferences may differ from other residents if younger
- Risky or impulsive behavior may increase safety concerns

Beyond Alzheimer's Disease: A Family Caregiver's Perspective

Sharon Hall

Questions

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