Frontotemporal degeneration: Anosognosia and other challenging symptoms

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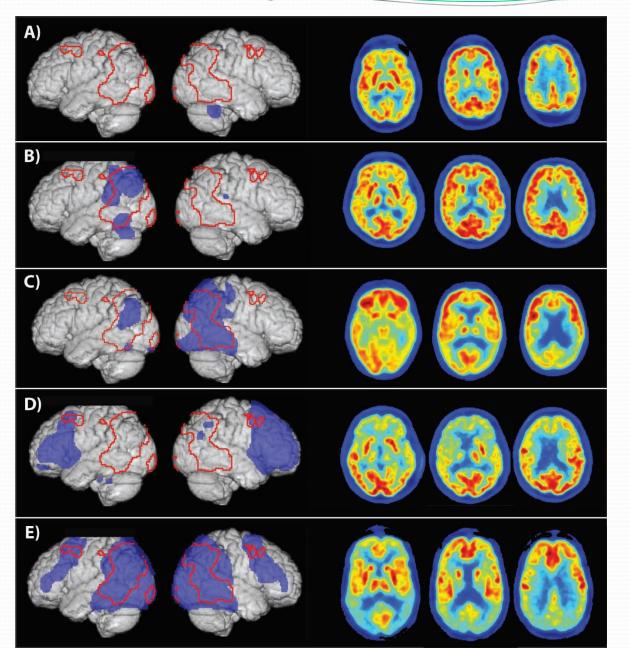
Anosognosia

- Purpose: To introduce caregivers and health professionals to symptoms of lack of awareness and other challenging behaviors
- Objectives: Following the discussion with participant should be able to do the following
 - Define "anosognosia" and describe what the symptom looks like
 - Describe two ways to manage "lack of awareness"
 - 3) Ask questions regarding common problems associated with bvFTD

Understanding dementia syndromes

- Dementia An umbrella term for a set of symptoms that occur when there is damage to the "thinking, doing, understanding, and perceiving areas of the brain
- Many diseases cause dementia. Symptoms vary by:
 - Size and location of the diseased area of the brain
 - Premorbid personality
 - Type of damage to the brain cells
 - Comorbid conditions
- FTD has a unique presentation on both scans and biopsy

FDG PET to distinguish Dementias



Anosognosia

- The inability to recognize/perceive one's limitations abilities, & illness aka "lack of insight," a hallmark symptom of FTD
 - "Lack of insight," is the single largest reason why people with FTD refuse medications, do not seek treatment and place previously capable individuals to demonstrate risky behavior
- Two primary types of anosognosia
 - Cognitive unawareness" factor, which loaded on items of memory, spatial and temporal orientation, calculation, abstract reasoning, and praxis (putting abstract ideas into practice)
 - the cognitive unawareness factor had more severe cognitive deficits, delusions, and apathy, but less depression
 - Decreased long-term memory
 - Associated with longer duration of illness
 - Correlates with declined cognitive test scores & language comprehension
 - "Behavioural unawareness" with factors of irritability, selfishness, inappropriate emotional display, and instinctive disinhibition.
 - Correlated significantly with higher mania and pathological laughing scores.

Anosognosia made visible



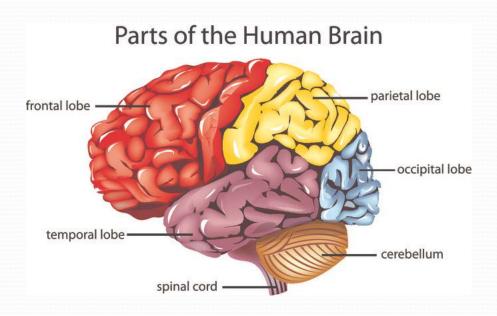
 $https://www.agingcare.com/articles/anosognosia-and-dementia-top-tips-from-caregivers-{\tt 210090}.htm$

Let's talk about loss of insight and awareness!

- How does loss of insight affect your person and yourself?
 - Person is not capable of know they have an illness and their abilities have changed
 - This is not "denial." it is due to a brain-based disorder
 - Damage to right parietal lobe and/or frontal lobe, the anterior cingulate and the orbitofrontal cortex.
 - Blind report they can see even describe elaborate scenes
 - Paralyzed people report they are fully mobile

Anosognosia

• Loss of awareness is a key symptom of FTD similar to "memory loss" is to Alzheimer's disease



Caregiver strategies

- Accept the loss is more than psychological "denial." You can not convince them they have a problem
- Therefore are often resistant to care and needs
- Combined with other losses this can be very frustrating for family, but person is relatively unconcerned
- Person will report they do activities they haven't done in years
- Person seems perfectly normal to others, including MDs
- Family may feel the person is "lying"
- Need an expert in FTD for diagnosis & care
- Routine dementia tests will be "normal"

Key strategies

- Acceptance
- Understand that explaining and reasoning are futile
- Patience
- Recognizing why you ask for certain things and asking yourself "Is this important?" Why?
- Developing alternative reasons to achieve a goal, ie fiblets, hiding things, etc
- Supervise for safety and inappropriate spending



More

- Have legal forms filed in advance
 - DPOA
 - May need guardianship & conservatorship for guardianship may need expert in FTD to testify
 - Difficult to obtain because person feels nothing is wrong
- Relationship issues
 - Anger: wanting divorce or to move out (may result in institutional
 - Sexual behaviors: porn, advances towards others, including family
 - Caregiver wants person to "admit" to the disease resulting in anger & power struggle

Plan for safety issues

- Recognize that risk of person harming others is constant and work to protect yourself
- Remove guns & potential weapons
- Have Medic-alert alarm system for caregiver to wear at all times and use it to summon help
- Don't be afraid/embarrassed to call 911
- Identify hiding places in home and lock yourself in
- Sleep in separate bedroom with door locked
- Driving cessation & hide keys
- Continually ask "Am I safe here?"
 - If you have to pause, get out of there. If more than two times, think hospitalization and/or placement

Making anosognosia worse

- Loss of empathy
- Narcissism
- Decreased attention/concentration
- Impulsivity
- Loss of language skills
- Loss of executive function (ability to plan, organize, and perform in order to reach a goal)

Anosognosia References

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