

# Tips to Disclosing a Cognitive Disorder Diagnosis



By: Ryan Townley, MD

UCNS Certified in Behavioral Neurology and Neuropsychiatry

Cognitive and Behavioral Neurology Fellowship Director

Co-Director of Research Education Core

Assistant Professor

KU Alzheimer's Disease Center

# Objectives

- A Future Outlook on Terminology
- Importance of disclosure
- How not to disclose a diagnosis
- Improving our disclosure process
- What comes after a diagnosis?

# The Title Changed? Where Did Dementia Go?

- Should we be using the word dementia?
  - Societal stigma
    - Barrier to discussing cognitive concerns with providers
  - Term creates confusion
    - Stages of cognitive changes before dementia severity
  - Never use the word demented – use person living with dementia
- Cancer is an umbrella term that encompasses lots of organ and genetic subtypes
  - We don't have a great term for this in neurodegenerative diseases
- Current DSM-V and ICD-10 coding:
  - Mild neurocognitive disorder vs. Major neurocognitive disorder

# Symptom Severity

- Does the patient have a neurocognitive disorder?
  - Umbrella term – NOT dementia, NOT Alzheimer's disease
  - Major = dementia equivalence
  - Mild = mild cognitive impairment
- What is the severity?
  - Daily Functional Impact: none, mild, moderate, severe
  - Behavioral changes: none, mild, moderate, severe
  - Cognitive changes: none, mild, moderate, severe
  - Motor and autonomic changes: none, mild, moderate, severe
- Clinical features:
  - Hallucinations, parkinsonism, visuospatial impairment, etc.

Clinical  
Syndrome

# Etiology of Cognitive Disorder?

- Biomarker evidence
  - Vascular pathology on MRI
  - Atrophy or FDG-PET hypometabolism pattern on brain scan
  - Amyloid/tau changes on spinal fluid or blood biomarkers
  - Alpha synuclein:
    - DaT scan, skin biopsy, spinal fluid test
  - Genetic mutations
- Autopsy will remain the gold standard

# Example diagnostic codes:

major neurocognitive disorder disease

ID	Name	ICD-10 Codes	ICD-9 Codes	HCC
2534939	Major neurocognitive disorder due to Alzheimer's disease (HCC)	G30.9, F02.80	331.0, 294.10	.346
1391757	Major neurocognitive disorder due to Alzheimer's disease, possible (HCC)	F01.50	331.0	.346
1391698	Major neurocognitive disorder due to Alzheimer's disease, probable, with behavioral disturbance (HCC)	F01.51	331.0, 294.9	.346
1391700	Major neurocognitive disorder due to Alzheimer's disease, probable, without behavioral disturbance (HCC)	F01.50	331.0, 294.10	.346
2535024	Major neurocognitive disorder due to Alzheimer's disease, with behavioral disturbance (HCC)	G30.9, F02.81	331.0, 294.11	.346
2534963	Major neurocognitive disorder due to Alzheimer's disease, without behavioral disturbance (HCC)	G30.9, F02.80	331.0, 294.10	.346
1884453	Major neurocognitive disorder due to Huntington's disease (HCC)	G10, F02.80	333.4, 294.10	.606
1391407	Major neurocognitive disorder due to Huntington's disease with behavioral disturbance (HCC)	G10, F02.81	333.4, 294.11	.606
1391408	Major neurocognitive disorder due to Huntington's disease without behavioral disturbance (HCC)	G10, F02.80	333.4, 294.10	.606
2548603	Major neurocognitive disorder due to Parkinson's disease (HCC)	G31.83, F02.80	332.0, 294.10	.346
2548600	Major neurocognitive disorder due to Parkinson's disease with behavioral disturbance (HCC)	G20, F02.81	332.0, 294.11	.606
2548598	Major neurocognitive disorder due to Parkinson's disease without behavioral disturbance (HCC)	G20, F02.80	332.0, 294.10	.606
1391722	Major neurocognitive disorder due to Parkinson's disease, possible (HCC)	G20, F02.80	332.0	.606
1391702	Major neurocognitive disorder due to Parkinson's disease, probable, with behavioral disturbance (HCC)	G20, F02.81	332.0, 294.11	.606
1391704	Major neurocognitive disorder due to Parkinson's disease, probable, without behavioral disturbance (HCC)	G20, F02.80	332.0, 294.10	.606
2533908	Major neurocognitive disorder due to possible Alzheimer's disease (HCC)	F01.50	331.0	.346
2533928	Major neurocognitive disorder due to possible Alzheimer's disease, with behavioral disturbance (HCC)	F01.51	331.0, 294.11	.346
2533929	Major neurocognitive disorder due to possible Alzheimer's disease, without behavioral disturbance (HCC)	F01.50	331.0, 294.10	.346
1884458	Major neurocognitive disorder due to prion disease (HCC)	A81.9, F02.80	046.79, 294.10	.346
1391413	Major neurocognitive disorder due to prion disease with behavioral disturbance (HCC)	A81.9, F02.81	046.79, 294.11	.346
1391414	Major neurocognitive disorder due to prion disease without behavioral disturbance (HCC)	A81.9, F02.80	046.79, 294.10	.346
2533906	Major neurocognitive disorder due to probable Alzheimer's disease, with behavioral disturbance (HCC)	F01.51	331.0, 294.9	.346
2533920	Major neurocognitive disorder due to probable Alzheimer's disease, without behavioral disturbance (HCC)	F01.50	331.0, 294.10	.346
2364896	Major neurocognitive disorder due to vascular disease, without behavioral disturbance, severe (HCC)	F01.50	459.9, 294.9	.346

# Importance of Early Diagnosis

- Evaluate
  - Potentially reversible or contributing conditions
- Family
  - Validates concerns, explains nature of problems.
  - Access to services
- Treatment
  - Importance of most appropriate treatment path
  - Removal of medications which contribute to cognitive impairment
  - Increases opportunities for research participation
- Plan for future
  - Reduce risks, proactive approach to transitions

# Importance of Disclosure

- 90 percent of Americans want to know if their memory symptoms are due to “Alzheimer’s disease”
  - Patients and caregivers get relief with an explanation for symptoms they are seeing - closure
- According to the Alzheimer’s Association – less than half of patients are told they have “dementia” by their provider
  - Even worse in other countries (28% in France)

# How Not to Disclose

- Not planning enough time
  - A life altering diagnosis cannot be rushed
- Not involving family members
  - 73% with dementia unable to explain their diagnosis shortly after disclosure
- Leading with the diagnosis
  - Delivering bad news 101
  - Must establish rapport and prepare the patient
- Being definitive without evidence
  - These are complex neurologic puzzles
  - If there is uncertainty – seek more tests

# Disclosure Tips

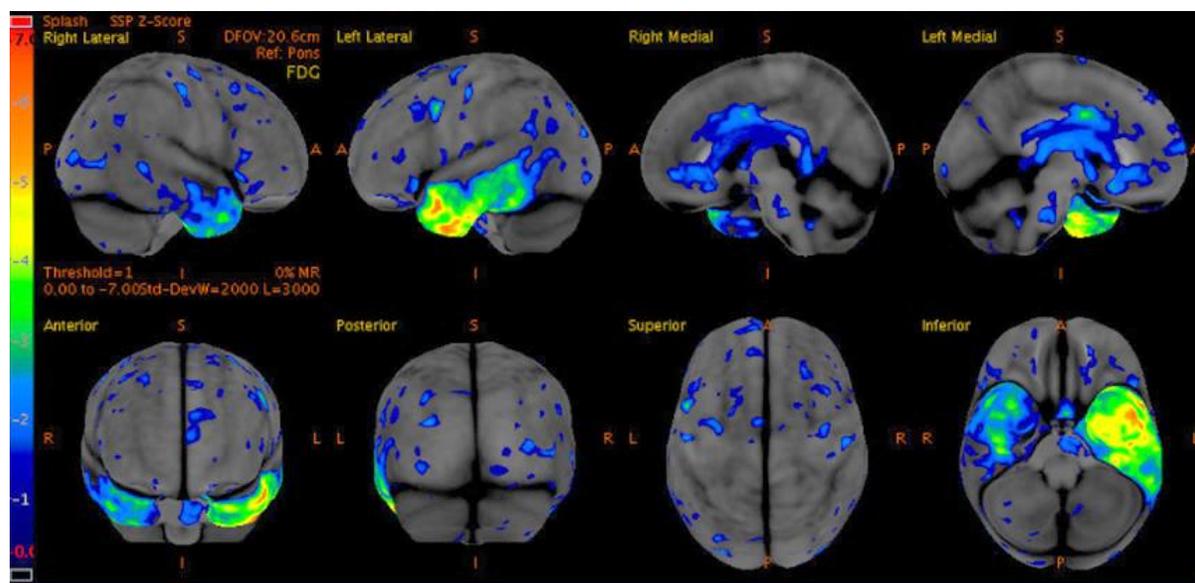
- Plan > 30 minutes for a diagnosis
  - There will be questions
- Ask care partners to accompany the patient
  - Care partners play important role of supervision/support
- Before you tell, ask - explore the patient's perspective of the problems
  - Is there denial, wishful thinking, unrealistic expectations?
  - Does the patient have lack of insight (anosognosia)?
    - This can be very tricky to deal with
- **Re-assure** family and the patient you have heard all their concerns

# Disclosure Tips

- Setting the stage
  - Acknowledge the changes, demonstrate understanding
    - Use terms like memory “concerns” “issues” or “inefficiencies” – mirror their language
      - Consider avoiding trigger words like memory “problems”
- Memory changes are very common
  - No single test makes the diagnosis
  - Review evaluation and purpose
    - MRI to rule out stroke, tumor, etc
    - Labs to rule out other causes
  - Review objective cognitive data
    - “Not doing as well as you would have 5 years ago”
- **Create confidence** in the process and the thorough evaluation
  - Build the case – MRI, cognitive testing, specialist report, etc
- Using terms: “working diagnosis” or “possible or “probable” is okay
  - Suggest further workup is needed if picture is not clear

# Neuroimaging Can Anecdotally Help

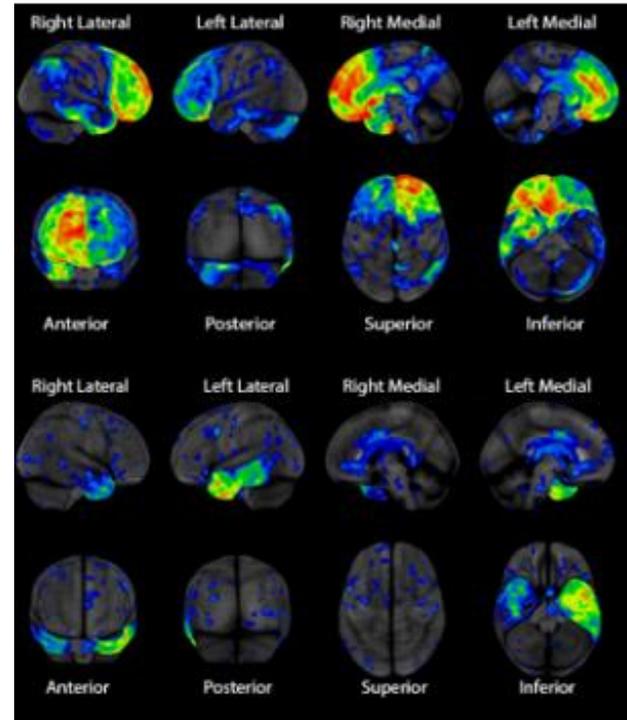
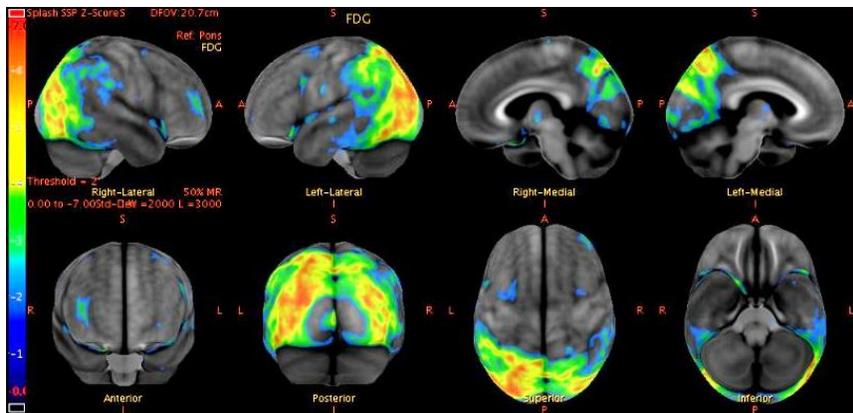
- Patients and caregivers can see the changes in the brain
  - I include images of their scans in their clinical notes
- There is a clear explanation why their loved one is struggling



“The anterior left temporal lobe is responsible for naming objects – this is why your loved one has been having problems with their words”

# FDG-PET with Cortex ID

- A good tool for memory specialists
- Pattern recognition
  - TDP-43 LATE pattern, Alzheimer's pattern, young onset AD pattern, DLB
  - Others: Posterior cortical atrophy



Behavioral variant FTD

Primary progressive aphasia – semantic dementia

# Disclosure Tips

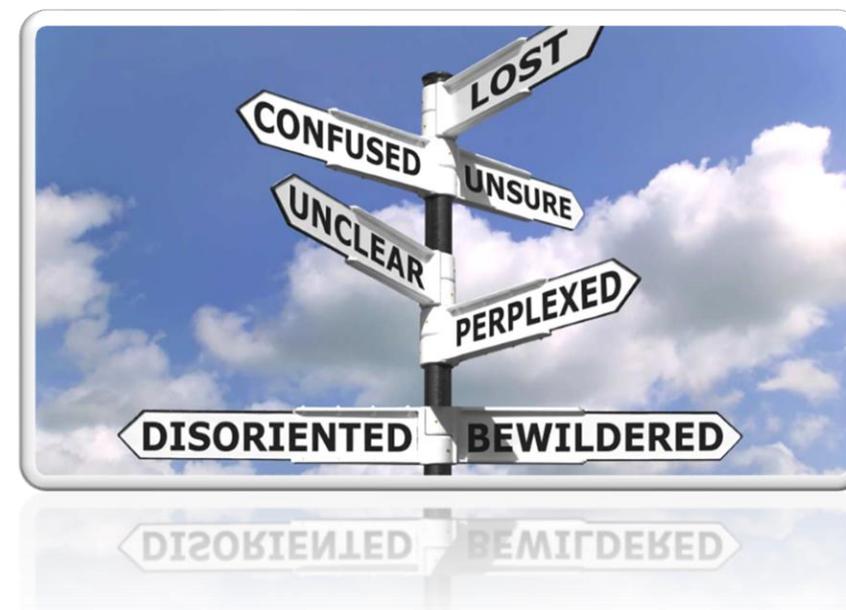
- Disclose the diagnosis directly to the patient
- Assess their understanding of the diagnosis
- Respond empathetically
- **Let's go after it**
  - Start meds (there are treatments)
  - Minimize contributing factors (sleep, depressive symptoms, etc)
  - Lifestyle: you can fight back
    - Exercise, eat right, stress reduction
  - MyAlliance and the Cognitive Care Network
  - Research opportunities available

# Improving our Diagnosis

- Patients with Lewy body disease see 3+ physicians in one year's time before getting a proper diagnosis
  - Lack of recognition
- Knowing where to find diagnostic criteria to help support a diagnosis
  - DLB: <https://www.lbda.org/go/new-diagnostic-criteria-published-dlb-0>
  - bvFTD: <https://www.theaftd.org/wp-content/uploads/2018/03/Table-3-International-consensus-criteria-for-behavioural-variant-FTD.pdf>
  - AD: <https://alz-journals.onlinelibrary.wiley.com/doi/abs/10.1016/j.jalz.2011.03.008>
  - MCI: <https://pubmed.ncbi.nlm.nih.gov/15324362/>

# What Happens After Diagnosis?

- This has been a major shortcoming in our field
  - Lack of resources
  - Lack of assistance/information with resources
  - Lack of communication
  - Lack of education on lifestyle changes
  - Lack of information on research studies
  - Lack of predictors of long-term outcomes



# Where do we go from here?

- Foster hope
  - Focus on quality of life, well being, health promotion
    - Take trips sooner than later in earlier stages
  - If they are interested, refer to KU ADC for research
    - Empowerment in research participation
- Plan follow up
  - A diagnosis is a process and does not end at that visit
- Planning for the future
  - Discuss support services
    - Cognitive Care Network Team
  - Be proactive rather than reactive

# Cognitive Care Network

## *Shifting the Point of Care*

MICHELLE NIEDENS LSCSW

- 913-945-7310
- [cniedens2@kumc.edu](mailto:cniedens2@kumc.edu)

**KU** ALZHEIMER'S  
DISEASE CENTER  
The University of Kansas Medical Center



# Goals



+

**Provide a collaborative system** to extend dementia specific resources in primary care.

+

Move the current crisis driven model of dementia care to an **empowerment model of support.**

+

**Extend function,** prevent neuropsychiatric crisis, reduce caregiver burden and decrease avoidable health care costs.

# Similar dementia support models have shown:



Improved physical, emotional and mental wellbeing for people with dementia and their care partners.



Improved identification and diagnosis of dementia.



Improved anticipation of deterioration and care coordination at end of life.



Reduced and delayed transitions into residential and nursing care.



Reduced inappropriate hospital admissions (both acute and mental health).

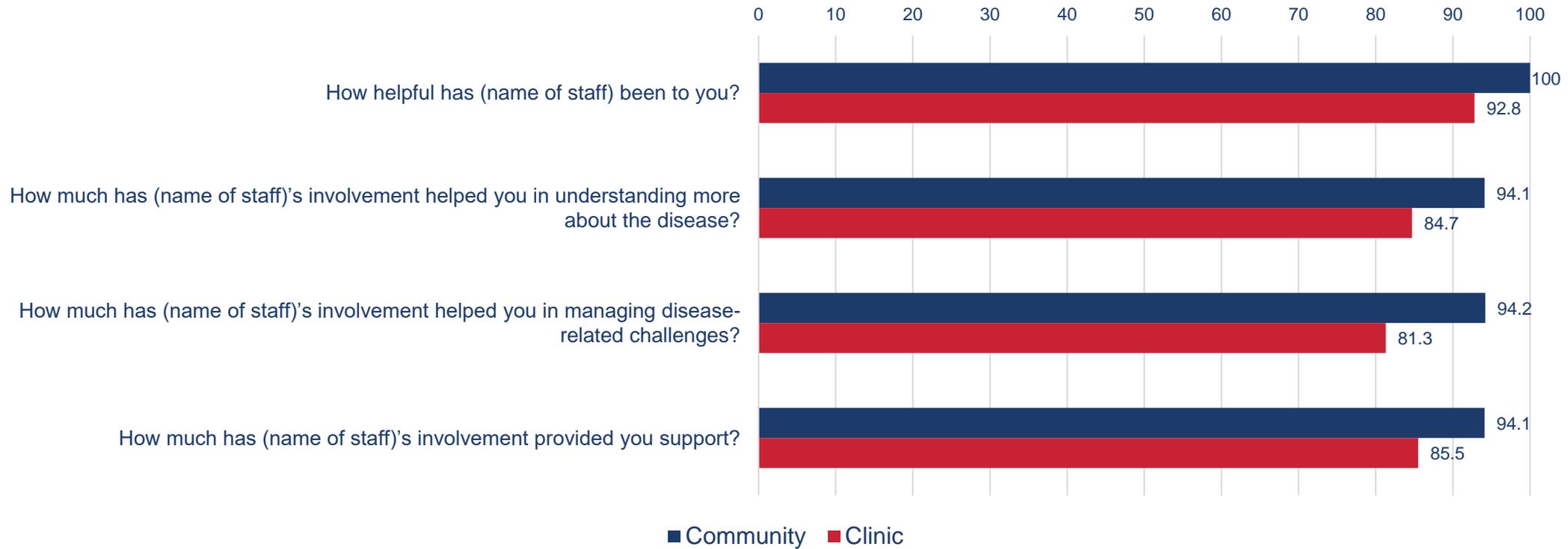


Improved communication between services.

# Impact Survey Results 2020

291 (231 clinic, 60 community)

## PERCENTAGE OF RESPONDENTS WHO ANSWERED MODERATELY OR VERY



# Summary Slide

- Previewed the future with terminology
  - Grappling with the terms Dementia and Alzheimer's Disease
- Discussed tips on disclosure
- Discussed our goals of what happens after a diagnosis
  - Cognitive care network team and MyAlliance