Tips to Disclosing a Cognitive Disorder Diagnosis

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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.
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:

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<th>ID</th>
<th>Name</th>
<th>ICD-10 Codes</th>
<th>ICD-9 Codes</th>
<th>HCC</th>
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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”
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• 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

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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

- How helpful has (name of staff) been to you?
  - Community: 92.8%
  - Clinic: 100%

- How much has (name of staff)'s involvement helped you in understanding more about the disease?
  - Community: 84.7%
  - Clinic: 94.1%

- How much has (name of staff)'s involvement helped you in managing disease-related challenges?
  - Community: 81.3%
  - Clinic: 94.2%

- How much has (name of staff)'s involvement provided you support?
  - Community: 85.5%
  - Clinic: 94.1%
• 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