Nomenclature

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Nomenclature Initiative

Progress on initiative

Asymptomatic people with biomarkers
Nomenclature Initiative

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Nomenclature
Words Matter

- Nomenclature issues very important
- Cut across all spheres of investigation
  - Science/Research
  - Clinical Care
  - Public Stakeholders
    - Government agencies
    - Advocacy groups
    - Research participants
    - Under-represented groups
Confusion in the field on terminology

- Alzheimer’s Disease
- Frontotemporal Degeneration
- Dementia with Lewy Bodies
- Vascular cognitive impairment-dementia
- Mixed dementias

Working Groups

Research:  Sandy Weintraub, PhD, NW University

Clinical:  Marwan Sabbagh, MD, Cleveland Clinic, Las Vegas

Public Stakeholders:  Jason Karlawish, MD, U of Pennsylvania

Facilitator:  RAND Corporation
Nomenclature Implications for Research

- **Science/Research:** Must be precise
- **Clinicians:** Must translate science to patients and vice versa
- **Public stakeholders:** Stigma, willingness to participate in research
  - Sensitivity in under-represented groups

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**NOMENCLATURE FRAMEWORK**

**Level 1:** Umbrella term for neurological disorders causing cognitive impairment and dementia

Each Working Group recommends an umbrella term

- e.g., Over/under 60, Mid-life, late-life, oldest old, Young onset, late onset

**Level 2:** Age of onset

- e.g., Over/under 60
- Mid-life, late-life, oldest old
- Young onset, late onset

**Level 3:** Continuum of cognitive impairment from none to severe (aka dementia)

- e.g., None, slight, mild, moderate severe
- Stage 0-5
- None, MCI, mild, moderate, severe dementia
- mid/major neurocognitive disorder

**Level 4:** Syndromic description

Descriptive, with cognitive and behavioral domains, underlying etiology not specified. May include adjectives (memory, language, executive, behavioral) and noun (disorder, spectrum, continuum) or combinations

- e.g., None, slight, mild, moderate severe
- Stage 0-5
- None, MCI, mild, moderate, severe dementia
- mid/major neurocognitive disorder

**Level 5:** Neuropathologies

- e.g., amyloid
- tau
- alpha synuclein
- TDP-43
- vascular
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Old Conception of Alzheimer’s Disease

Cognitively Normal

Dementia
Alzheimer’s Disease as a Clinical – Pathological Entity
Alzheimer’s Disease

1984
NINCDS-ADRDA Criteria
Clinical-Pathological definition

2011
NIA-AA Criteria
Clinical syndrome with biomarkers for amyloid and neurodegeneration

2018
NIA-AA Framework
Alzheimer’s disease as a biological entity defined by positive biomarkers for amyloid and tau
Clinical Spectra Independent

SEVERITY

CU          MCI          DEMENTIA

Memory  Executive  Language  Visuospatial  Behavior

Alzheimer’s Disease

AB  TAU  α Syn  TDP 43  CVD
Plans for Future

Work groups continue to meet
Research/Science
Clinical practice
Public stakeholders

Present research implications to NIH at workshop on February 16, 2021
Dementia Nomenclature Initiative
Winter 2021 Workshop

Goal: Update NIH and others on dementia nomenclature initiative progress; elicit feedback on working plan.

1. Challenges of Current Nomenclature for Research, Clinical Care, and Public Communication

2. Overview of the Dementia Nomenclature Initiative

3. Report from the Research Working Group

4. Working Group Updates: Clinical Care and Public Stakeholder

5. Panel Discussion: Through the Lens of Health Disparities

Thank you

Questions?