Dementia Nomenclature: Launching a National Discussion

Angela Taylor
Lewy Body Dementia Association
Decades of Evolution

• Age-associated memory loss, mild cognitive impairment, minor neurocognitive impairment

• Dementia, memory disorder, major neurocognitive impairment
  – Alzheimer’s disease, dementia due to Alzheimer’s disease
  – Dementia with Lewy bodies, Lewy body dementias
    • Lewy body disease, Lewy body disorders
  – Frontotemporal dementia, degeneration
    • behavioral variant FTD, Pick’s disease, primary progressive aphasia
    • progressive supranuclear palsy, corticobasal syndrome
    • motor neuron disease, amyotrophic lateral sclerosis
  – Vascular dementia, vascular contributions to cognitive impairment and dementia
  – Mixed dementia, mixed etiology dementia
2016 ADRD Summit Hot Topic

Is it time to...

Create a standardized bulls-eye model for public education and clinical care?

(While respecting the new DSM-V)
An Expanding Focus on Nomenclature

2016 ADRD Summit
• Hot Topic Session: Conceptual recommendations

2016 NAPA Advisory Council
• Recommendation by non-federal members

2017 Dementia Care & Services Summit
• Echoed by care experts and those living with dementia

2018 Working Group Formed
• NAPA Advisory Council charge

2019 ADRD Summit
• Draft procedural recommendations presented
Can Nomenclature be Improved?

• Any change = wide-ranging impact
  – Research, regulatory issues, clinical care, reimbursement issues and public health efforts

• Charge by the Advisory Council on Alzheimer’s Research, Care and Services to:
  – Design a transparent and inclusive process
  – Implement the process
  – Report on the results
    • May or may not include recommended changes to terminology
Focus Area 1: Dementia Nomenclature Working Groups

REC 1 – Priority 1. Form research, clinical practice and public stakeholder dementia nomenclature working groups (1-2 y).

Focus Area 2: Integration and Interoperability of Dementia Nomenclature

REC 2 – Priority 1. Integrate and refine recommendations from the Research, Clinical Practice, and Public Stakeholder Working Groups into standardized, acceptable and accurate nomenclature that works across the spectrum of stakeholders (2-4 y).
## Working Group Composition (Cross-Talk Required)

<table>
<thead>
<tr>
<th>Category</th>
<th>Members</th>
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</thead>
<tbody>
<tr>
<td>Research</td>
<td>- AD, LBD, FTD, vascular, mixed</td>
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<td></td>
<td>- Public health, regulatory agencies, etc.</td>
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<tr>
<td>Clinical</td>
<td>- Primary care and specialists</td>
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<td>- Payors, health systems, EMR vendors</td>
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<tr>
<td>Public</td>
<td>- People with dementia, caregivers, advocacy orgs</td>
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<tr>
<td></td>
<td>- Ethics, stigma, health disparities, communications</td>
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</tbody>
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Steering Committee

• Co-Chairs
  – Ronald Petersen, MD, PhD, Mayo Clinic
  – Angela Taylor, Lewy Body Dementia Association

• Working Group Chairs
  – Sandra Weintraub, PhD, Northwestern University
    • Research Working Group
  – Marwan Sabbagh, MD, Cleveland Clinic, Las Vegas
    • Clinical Practice Working Group
  – Jason Karlawish, MD, University of Pennsylvania
    • Public Stakeholder Working Group

• Additional Members
  – Charles Adler, MD, PhD, Mayo Clinic, Arizona
  – Paul Applebaum, MD, Columbia University
  – Peggye Dillworth-Anderson, PhD, University of North Carolina
  – Cynthia Huling-Hummel, DMin, Person Living with Dementia
Summary

• Changing terms would have a wide-ranging impact
• The recommendations establish a transparent and inclusive process, not an outcome.
• Stakeholder input and working group cross-talk is essential.
• Working groups will present and discuss recommendations at a nomenclature symposium.
• We will report out on opportunities and challenges to improving dementia nomenclature.