CLINICAL HETEROGENEITY OF DEMENTIA AND IMPACT ON RESEARCH PARTICIPATION

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RESEARCH SUMMIT ON DEMENTIA CARE
Building Evidence for Services and Supports

#DementiaCareSummit

CLINICAL DEMENTIA HETEROGENEITY

TYPES OF CLINICAL SYMPTOMS
- Insight
- Language
- Memory
- Attention
- Visuospatial
- Behavioral
- Motor

SOCIOECONOMIC FACTORS
- Access to Care
- Access to Resources

STAGE OF DISEASE
- Mild
- Moderate
- Severe
- Preclinical

PSYCHOSOCIAL FACTORS
- Support Network for Research Participation
- Study Partner
- Logistics

AGE AT ONSET
- Under 65
- Over 65
Clinical Heterogeneity: Symptoms

- Earliest symptom can occur in any brain function: memory, language, visuospatial perception, behavior, motor function
- Brain region affected corresponds to symptoms
- BUT symptoms can be caused by several diseases

<table>
<thead>
<tr>
<th>DEMENTIA SYNDROME NAME</th>
<th>MAIN EARLY SYMPTOMS</th>
<th>BRAIN REGIONS AFFECTED</th>
<th>NEUROPATHOLOGIC DISEASE</th>
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<tbody>
<tr>
<td>Dementia of the Alzheimer Type</td>
<td>Short Term Memory Loss (Amnestic Dementia)</td>
<td>80% AD 5-10% FTLD 5-10% LBD</td>
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<tr>
<td>Primary Progressive Aphasia</td>
<td>Word-finding; grammar errors; may not comprehend what others are saying (Aphasic Dementia)</td>
<td>30-40% AD 60-70% FTLD (Picks, TDP-43 proteinopathy, CBD, PSP)</td>
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<tr>
<td>Posterior Cortical Atrophy Dementia with Lewy Bodies</td>
<td>Visuospatial disorientation Perceptual deficits; may appear blind but acuity is normal (Visuospatial Dementia)</td>
<td>70% AD 30% Other (LBD, CBD)</td>
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<tr>
<td>Behavioral Variant Frontotemporal Dementia</td>
<td>Behavior/personality change; loss of judgment; socially inappropriate</td>
<td>80% FTLDFTLD (Picks, TDP-43 proteinopathy, CBD, PSP) 20% Other (AD, etc.)</td>
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Clinical Heterogeneity: Symptoms

- Differences in symptoms mean differences in the way you communicate with and treat and educate the person with dementia and caregivers: “One size does not fit all” (Morhardt, Weintraub, 2005)

- Symptoms have an impact on decision-making, communicating needs, validity and reliability of reported outcomes

Clinical Heterogeneity: Age of Onset

- Different forms of dementia have different typical age at onset

- Outcomes important to the research participants will differ based on age/stage of life.
Clinical Heterogeneity: Stage of Illness

- Symptoms are mild, localized initially but become worse and expand to other domains over the course of illness

- Need to consider the stage of illness—mild, moderate, severe

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<th>MAIN SYMPTOMS</th>
<th>IMPACT ON RESEARCH PARTICIPATION</th>
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<tr>
<td>Dementia of the Alzheimer Type</td>
<td>Short Term Memory Loss (Amnestic Dementia)</td>
<td>• Not aware of symptoms especially in later stages; may misreport</td>
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<td>• May forget why participating</td>
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<tr>
<td>Primary Progressive Aphasia</td>
<td>Word-finding; grammar errors; may not comprehend what others are saying (Aphasic Dementia)</td>
<td>• Aware of symptoms</td>
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<td>• Can report but may need to communicate with alternative methods</td>
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<td></td>
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<td>• May not understand words</td>
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<td>• Can report</td>
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<td>• May not be able to take tests that requiring visual perception or drawing</td>
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<tr>
<td>Behavioral Variant Frontotemporal Dementia</td>
<td>Behavior/personality change; loss of judgment; socially inappropriate</td>
<td>• Not aware of symptoms; may misreport</td>
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<td>• Judgment is not reliable</td>
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Engaging Affected Individuals
In Dementia Research: Recommendations

• Take specific symptoms, age at onset, stage of disease, and how symptoms are likely to influence outcome reporting into account
• Make adaptations to allow maximal participation: Surrogate decision makers, different types of explanations
• Educate patients and caregivers early in the illness to get input on wants and needs
• Public information about capacity to make decisions once dementia is more advanced
• Successful outcomes will differ depending on the individual patient’s specific problems
• Revise regulations for obtaining informed consent