CLINICAL HETEROGENEITY OF DEMENTIA AND IMPACT ON RESEARCH PARTICIPATION

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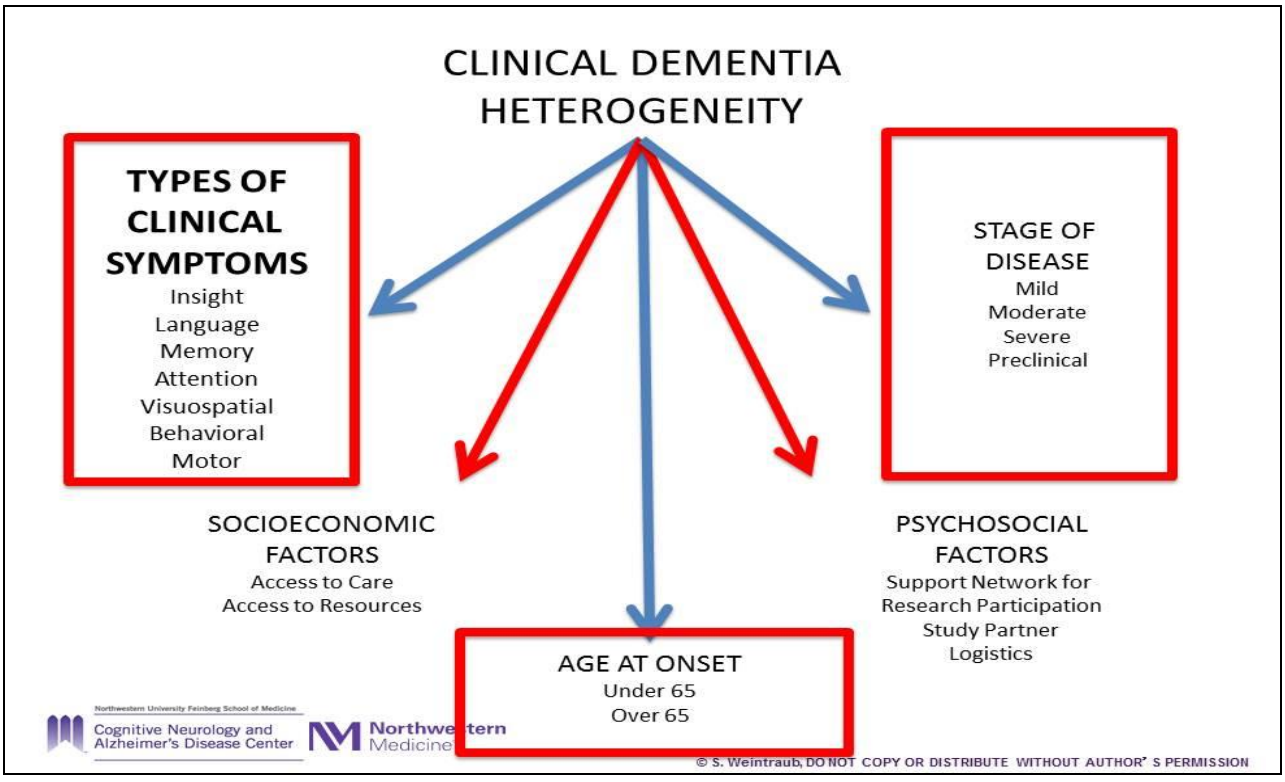
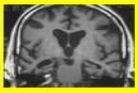
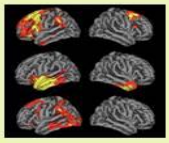
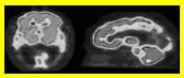
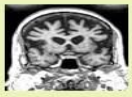
RESEARCH SUMMIT ON DEMENTIA CARE
Building Evidence for Services and Supports

#DementiaCareSummit



Clinical 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

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

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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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DEMENTIA SYNDROME NAME	MAIN SYMPTOMS	IMPACT ON RESEARCH PARTICIPATION
Dementia of the Alzheimer Type	Short Term Memory Loss (Amnestic Dementia)	• Not aware of symptoms especially in later stages; may misreport • May forget why participating
Primary Progressive Aphasia	Word-finding; grammar errors; may not comprehend what others are saying (Aphasic Dementia)	• Aware of symptoms • Can report but may need to communicate with alternative methods • May not understand words
Posterior Cortical Atrophy	Visuospatial disorientation Perceptual deficits; may appear blind but acuity is normal (Visuospatial Dementia)	• Aware of symptoms • Can report • May not be able to take tests that requiring visual perception or drawing
Behavioral Variant Frontotemporal Dementia	Behavior/personality change; loss of judgment; socially inappropriate	• Not aware of symptoms; may misreport • Judgment is not reliable

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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

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