Application of the life participation approach for individuals living with primary progressive aphasia

Authors: Becky Khayum, M.S.¹, Angela Roberts, Ph.D.², Aimee Mooney, M.S.³, Melanie Fried-Oken, Ph.D.³, Libby Rogers, M.A.¹, Marissa Esparza, B.S.¹, and Emily Rogalski, Ph.D.¹

Mesulam Center for Cognitive Neurology and Alzheimer's Disease, Northwestern University Feinberg School of Medicine, Chicago, IL1

Communication Sciences and Disorders Department, Northwestern University School of Communication, Evanston, IL²

Institute on Development and Disability, Oregon Health and Science University, Portland, OR³

Learning Outcomes:

- 1) Describe how living with a progressive aphasia may impact life participation differently compared to those living with stroke-induced aphasia.
- 2) Discuss why focusing only on PPA subtype for treatment planning may be detrimental to an LPAA approach to care.
- 3) Discuss how to select meaningful and motivating impairment-based and compensatory-based interventions jointly with individuals with PPA and their families as the disease progresses.

What is Primary Progressive Aphasia (PPA)?

PPA is a clinical dementia syndrome caused by neurodegenerative brain disease. PPA is defined by progressive difficulties with language processing (i.e., aphasia) that initially emerge in the absence of other cognitive or behavioral changes.

Limitations of subtyping:

The PPA subtype is based on the prominent aphasia profile. It is important to remember that many individuals do not neatly fit into one subtype, and may have symptoms from several different subtypes. Also, PPA is a moving target. As the disease spreads throughout the brain, symptoms from the various subtypes will emerge. It is important to look at the person's clinical presentation of language strengths and weaknesses when developing a plan of care. The described subtypes are:

- PPA-L (logopenic variant) is characterized by the absence of grammatical difficulties, preserved single word comprehension and hesitant speech with pauses for word-finding;
- PPA-G (agrammatic/nonfluent) is characterized by agrammatism in speech, writing and/or comprehension, and preserved single word comprehension;
- PPA-S (semantic) by impaired single word comprehension and naming and preserved grammar.

A Person-centered Holistic Approach

The complexity of these diagnoses require a holistic approach, with the following variables taken into account when considering treatment strategies: (1) Clinical profile of language strengths and weaknesses, (2) Severity of symptoms, (3) individual's hobbies, interests and communication needs, (4) individual's motivation, along with emotional well-being, and (5) caregiver and family dynamics & involvement/support. A unique combination of personalized home exercises, compensatory strategies, and environmental modifications may often be appropriate for each individual living with PPA. The recommended strategies may need to be frequently adjusted to meet a person's changing communication needs as the disease progresses.