

PREFACE

Person-Centered Approaches to Communication Participation and Engagement for Individuals with Primary Progressive Aphasia and Dementia

I recently evaluated a new patient with primary progressive aphasia (PPA) in our outpatient clinic. I walked into the waiting room and introduced myself to Dan and his wife, Lori. I invited them to join me in the clinic room. Lori asked, “Do you want me to come also?” I responded, “A person with PPA cannot communicate with himself. Conversational partners are critical to forming Dan’s treatment plan. Dan will use his new communication tools with you. In fact, you could consider yourself as much my patient as Dan. Yes, please join us.” By the end of our session together, Lori said, “I see now how important it is for you to understand our lifestyle so we can use all these new talking ideas and Dan can return to our active life.”

This issue of *Seminars in Speech and Language* is based on the premise that person-centered assessment and intervention must drive successful communication participation and engagement for our patients who present with dementia and PPA. Eight groups of authors have written about research projects, assessment methods, and treatment plans that maximize daily functioning with person-centered goals for social interaction. All of the articles address the need to personalize and optimize treatment for individuals with cognitive and communication impairments. Rogalski and Khayum even tell us to toss the treatment workbooks and start a conversation with our clients today.

There are three articles that address communication participation and engagement for adults with dementia. Hubbard, Mamo, and Hopper start us off with an important review of research evidence on hearing interventions for individuals with dementia. They provide recommendations for speech–language pathologists and audiologists to work together to ensure access to hearing health care and increase opportunities for meaningful life engagement for people with dementia and hearing loss. Lanzi, Wallace, and Bourgeois provide evidence that external memory aids are sustainable within community settings when skilled professionals use a person-centered approach and consider individuals’ unique needs, preferences, and experiences to develop strategies throughout the continuum of care. Douglas, Brush, and Bourgeois suggest practical strategies and a case example for guiding assessment, goal-writing, and treatment plans to meet the expectations of a person-centered approach to services for persons with dementia, using the Montessori approach as a clinical foundation.

The remaining five articles address a relatively new population that is screaming for clinical attention, adults with PPA. Since the onset of PPA usually occurs before the age of 65 years, this is a relatively young group of individuals who are actively managing careers, families, and finances. The speech–language pathologist has a unique opportunity to guide patients and

¹Oregon Health and Science University, Institute on Development and Disability, Portland, Oregon.

Address for correspondence: Melanie Fried-Oken, Ph.D., Oregon Health and Science University, 707 SW Gaines Street, CDRC Building, Portland, OR 97239 (e-mail: friedm@ohsu.edu).

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families toward participation and engagement as individuals progressively lose their language and cognitive abilities. Henry and Grasso take us through the evaluation process for PPA, describing the cognitive and language tools that will help establish the PPA diagnosis and clinical variant, determine appropriate interventions for patients and their families, and track progression of deficits over time. They remind us that the clinician should inquire about current functional communication needs and limitations to inform treatment planning. Croot reviews the research on lexical retrieval treatment in PPA from the earliest reports in the 1990s to early 2018 and considers the implications of this research for clinical practice.

The next three contributions examine participation and engagement of persons with PPA from three unique perspectives. Mooney, Beale, and Fried-Oken share a successful communication group treatment model that was implemented with five couples with PPA. Primary treatment goals were successfully implemented to provide education about PPA symptoms and progression; to increase practice and use of multimodal communication by people with PPA; and to establish an environment where

people with PPA and their partners could connect for training and support. Kim, Figeys, Hubbard, and Wilson then present a qualitative study about the experiences of one couple with PPA in an aphasia camp setting. They recommend considering personal factors of potential campers with PPA, and providing PPA-specific resources for programs such as aphasia camps that incorporate participants with mixed etiologies. Finally, Rogalski and Khayum discuss person-centered assessment and treatment for individuals with PPA within the Communication Bridge telehealth model for care, providing examples of what their clients said which led to goals that optimize change by addressing personal needs and strengths.

Person-centered care is a thread throughout these articles. Whether applying a Montessori-based approach, intervening with a telehealth model, or providing group intervention in an outpatient university clinic or aphasia camp, all come to the same conclusions: to increase participation, we must place the individual with communication impairments at the center of any treatment plans.

Melanie Fried-Oken, Ph.D., CCC-SLP¹