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Development of a Measure for Capturing Conversation Difficulties and their Social and Emotional Impacts for a Rare Dementia

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Inspiring Minds submission
Haylie Santos
PhD in Health and Rehabilitation Sciences

Title:

Development of a Measure for Capturing Conversation Difficulties and their Social and Emotional Impacts for a Rare Dementia

Abstract:

Primary Progressive Aphasia (PPA) is a rare dementia syndrome in which language (reading, writing, speaking, and understanding) is the primary impairment with minimal effects on other cognitive domains until later stages. Communication breakdowns create barriers that have devastating impacts on quality of life (QoL), relationship well-being, and family dynamics for persons with PPA and their loved ones. The impact of PPA is magnified by the fact that it is a younger onset dementia, often affecting people in their 50's and 60's. Despite this, there are few robust measures for evaluating communication changes in this disease. This has been a limiting factor in designing clinical trials for treating these devastating communication difficulties. My research study aims to evaluate the psychometric properties of a measure developed for persons with Alzheimer's dementia in PPA with the goal of optimizing the measure for use in PPA clinical trials.