Including People With Aphasia In Rehabilitation Research:
Examples From A Home Exercise Program Project

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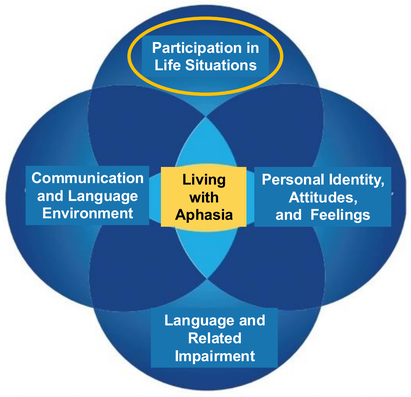
INTRODUCTION

- The **Life Participation Approach in Aphasia** (LPAA; Chapey et al., 2000) focuses on the broader consequences of aphasia, rather than aphasia solely as an impairment. Living with Aphasia: Framework for Outcome Measure (A-FROM) highlights the importance of participation (Kagan et al., 2008; Figure 1).
- **People with aphasia are frequently excluded** from rehabilitation research due to concerns about impaired understanding of intervention activities (Ali et al., 2014; Kersey et al., 2021; Wray et al., 2018).
- **People with aphasia may experience unique challenges in rehabilitation**, highlighting the importance of including their experiences and perspectives.
- In a rehabilitation study aimed at understanding acquired brain injury survivors' adherence to and experiences with Home Exercise Programs (HEPs), we implemented strategies to **facilitate participation of people with aphasia.**

Figure 1: Living with Aphasia: Framework for Outcome Measurement
[Adapted from Kagan et al., 2008]



METHODS

Participants
- 77 participants total
- Enrolled during admission to a regional Encompass rehabilitation hospital
  - Participants with aphasia:
    - Quantitative study: 10
    - Qualitative study: 6

Procedures
- Quantitative:
  - Weekly surveys via phone/email tracking HEP adherence
  - Surveys included scales described below
- Qualitative:
  - 1:1 semi-structured interviews 6 months post-discharge
  - Interviews were transcribed and coded by trained research assistants

To improve inclusion of people with aphasia in our research study, we used three techniques:

Multiple Screening Methods

- Cognitive screening to ensure participants had adequate memory skills for reliable self-report
- Two measures were used:
  - **Standard Tool:** Montreal Cognitive Assessment (MoCA; Nassredine et al., 2021)
    - Exclusion Criteria: < 21/30
  - **Aphasia-Friendly Alternative:** Cognitive-Linguistic Quick Test+ (Helms-Estabrooks, 2018) Design Memory Subtest
    - Non-linguistic tool for screening memory
    - Exclusion Criteria: < 4/6

Adaptation of Materials

- Multiple scales were used as part of data collection:
  - The modified Exercise Adherence Rating Scale (EARS; Newman-Beinart et al., 2017). We recorded auditory information to provide augmented input
  - The modified Self-Efficacy for Exercise Scale included visuals, a rating scale, and anchors (Figure 2)

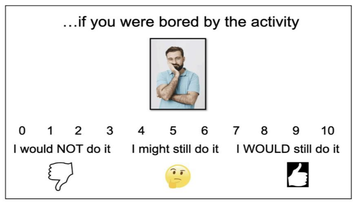


Figure 2: Example rating scale from the modified Self-Efficacy for Exercise Scale

Communication Strategies

- To ensure comprehension of study procedures and questions during the interview, researchers used aphasia-friendly communication strategies, including:
  - Response latency
  - Repetition
  - Simple language
  - Multiple choice
  - Recasting to confirm response
  - Acceptance of verbal and nonverbal communication
- Participants could complete interviews using phone or videoconferencing to facilitate communicative preference

OUTCOMES & DISCUSSON

- A team of multidisciplinary researchers successfully implemented aphasia-friendly modifications to a research protocol to determine the experiences and perspectives of people with aphasia within a sample of adults with ABI
  - **Improving attention to inclusive methods increased participation for people with aphasia while maintaining efficacy of the original research aim**

Quantitative Analysis (Donoso Brown et al., 2025)

- 63% of adults strongly agreed to understanding the exercises/activities assigned to them
  - 81% of adults understood the rationale for the exercises assigned to them
- The mean modified EARS score was 15.73 (*SD* = 4.35) out 24 total points
  - Participants had relatively high levels of self-reported adherence
- Participants reported an average of 0.82 barriers (*SD* = 1.08, Range = 0–6) per week
- Self-efficacy for exercise & reported number of barriers were predictive of self-reported adherence

Qualitative Analysis

- Participant responses focused on key themes and subthemes of their HEP experiences including:

HEP Experiences and Attitudes
- Understanding, Feasibility, Value, Change, Recommendations

HEP Adherence
- Status, Influencers, Changes to Adherence

Interconnectedness with Rehabilitation
- Funding, Health, Attitudes toward Therapists

APPRAISAL

- While several strategies were used to promote research participation in people with aphasia, there were limitations in the methodology:
  - Select decisions in the methodology (e.g., virtual communication) may have created barriers to participation in people with aphasia
  - Sample is not equipped for a balanced comparison of people with aphasia versus adults with ABI

FUTURE DIRECTIONS

- Determine effectiveness of inclusive research strategies on research participation in people with aphasia
  - Assess outcomes such as reported experience/satisfaction, sample size, and attrition
- Systematic review of inclusive research strategies which promote participation of adults with aphasia

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