

Do the Priorities of Research Funding Agencies Align with the People They Serve? Towards Building Evidence-Based Person-Centered Care in Aphasia



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INTRODUCTION

- High-quality speech-language therapy for stroke-survivors with aphasia (SSWA) is supported by strong scientific evidence and includes the participant's personal goals in intervention planning, reflecting a person-centered care approach^{1,2}.
- Building a strong evidence base requires large-scale clinical trial research projects, which are typically funded by federal sources in the US³. To have a strong impact, this research should involve intervention and outcome measures that align with that of the population they aim to serve⁴. However, it is not clear if the priorities of aphasia research in the US align with the priorities of SSWA.
- This potential disconnect may be a contributing factor to the established evidence-to-practice gap in aphasia⁵, leading to challenges in the implementation of high-quality speech-language therapy in clinical rehabilitation.

OBJECTIVES

- Aim 1:** Characterize the priorities of US federally-funded aphasia clinical trial research as operationalized by primary and secondary outcomes
- Aim 2:** Provide an overview of the rehabilitation priorities identified by US-based SSWA

METHODS

- Aim 1 Methods**
- Data pull of primary and secondary outcomes for stroke-induced aphasia clinical research trials
 - Database: ClinicalTrials.gov
 - Filters: date range 2014-2024, US federal funding source, excluded feasibility and observational studies
- Aim 2 Methods**
- Structured narrative review following methodological guidelines for systematic review to increase transparency and efficiency^{6,7}
 - Databases: PubMed, CINAHL
 - Search terms included:
 - "Aphasia" "goals" "goal setting" "priority" "priorities" "person centered" "patient centered" with filter for: English language

Data Classification
Priorities in both aims were classified as *impairment-* or *function-focused*, with a consideration for additional *contextual factors* as applied to the World Health Organization's International Classification of Functioning, Disability, and Health (WHO-ICF) model in aphasia^{8,9} (see Figure 1)

- Examples of Outcomes:
- Impairment-focused*: name pictured nouns, change in BOLD signal
 - Function-focused*: participate in conversation, write an email
 - Contextual factors*: reduce depression

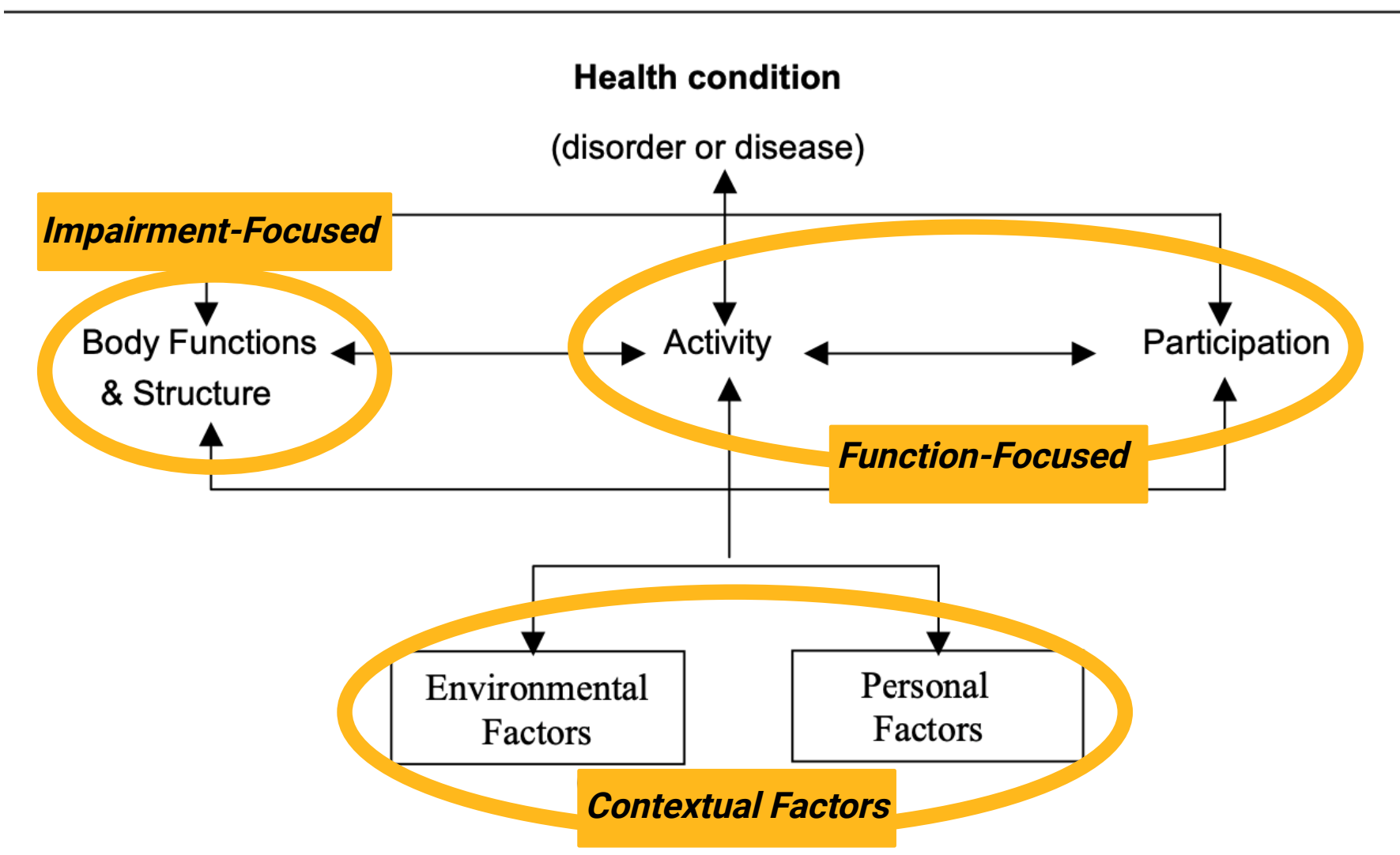
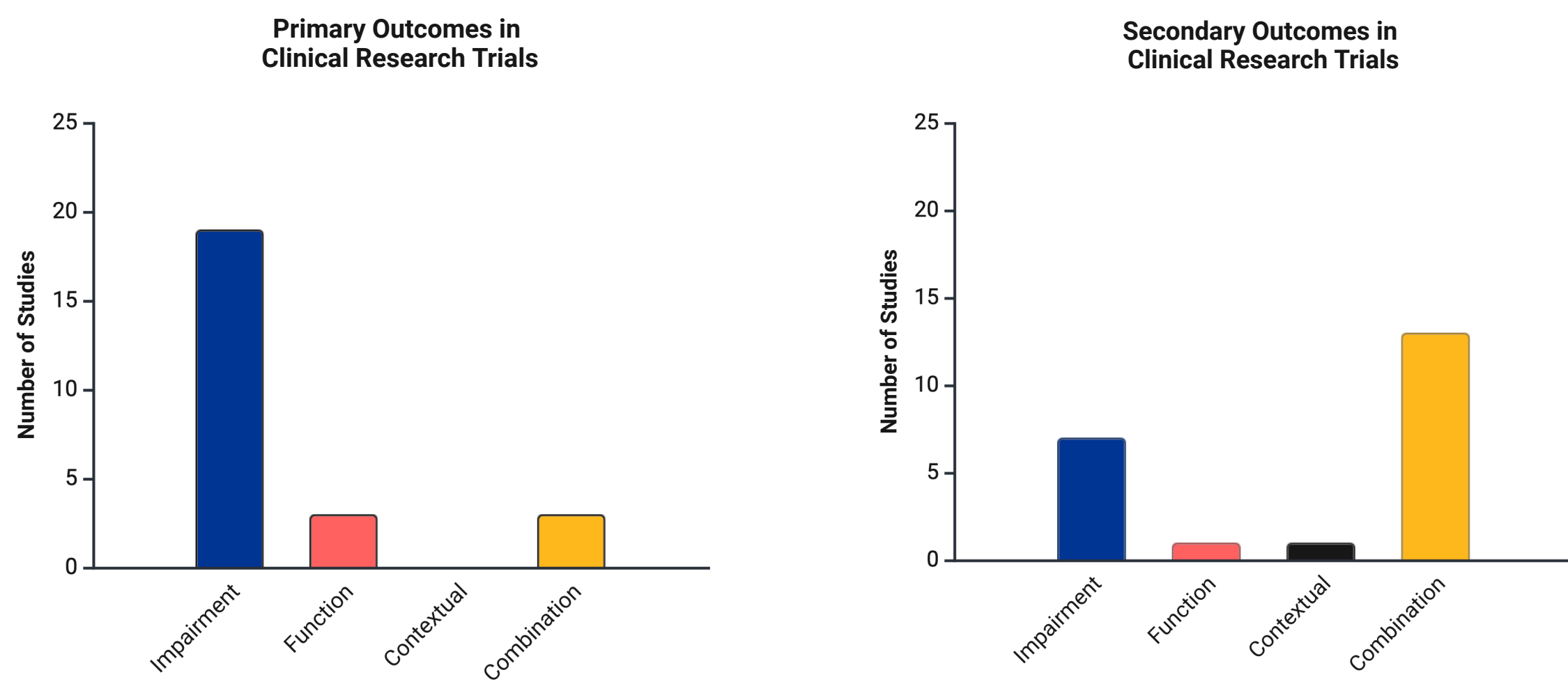


Figure 1: Classification of WHO-ICF domains into three priority categories as described by Simmons-Mackie and Kagan (2007)⁸. Image adapted from: World Health Organization (2002)⁹.

RESULTS

- Aim 1 Results**
A total of 25 US federally-funded interventional clinical trials in post-stroke aphasia were identified
- 76% of primary outcomes were impairment-focused**, with the remaining utilizing function-focused outcomes or a combination of both
 - 40% used a standardized impairment-focused assessment, most commonly the PNT¹²
 - 22 studies included secondary outcomes with the majority utilizing a combination of measures, typically impairment- and function-focused
 - 93% used a standardized impairment-focused assessment (ex: PNT¹², WAB¹³)
 - 79% used a standardized function-focused assessment (ex: ASHA FACS¹⁴, CETI¹⁵)



- Aim 2 Results**
After removing duplicates (n=176), unrelated articles (n=408), and non-US based articles (n= 8), there was a final total of 6 articles relating to rehabilitation goals as described by SSWA in the US
- Key Findings:**
 - No US-based publications directly aimed to outline rehabilitation priorities from the perspective of SSWA**
 - 1 international multi-site project by Wallace et al. included a small group from the US¹⁰
 - 5 indirectly described priorities in the context of larger studies (e.g. case studies within an article about improving collaborative goal setting in aphasia¹¹)
 - 67% of articles indicated a preference for function-focused goals and 33% indicated a combination of both function- and impairment-focused goals**

DISCUSSION

- The primary priorities of US federally-funded aphasia clinical trials do not appear to align with the priorities of US-based stroke survivors with aphasia.
 - Although research projects often include functional measures as secondary outcomes, these are typically addressed differently in analysis and data reporting in publications, reducing their impact on evidence-based practice.
 - This may be contributing to the challenges faced by clinicians in applying person-centered care practices into rehabilitation, as the impairment-focused evidence base may not match the function-focused goals of their clients.
- Future Directions:**
- Further research identifying the specific rehabilitation goals and priorities of stroke survivors with aphasia living in the United States is warranted.
 - Changes in clinical trial design including engaging end-users as partners in research may lead to improved prioritization and better translation of evidence to practice in aphasia rehabilitation⁴.

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