

## A One-item Quality of Life Measure for Aphasia: the "Wall Question"



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## DISCLOSURES

- **Financial**
  - Dr. Azios receives a salary from the University of Louisiana at Lafayette
  - Dr. Kim receives a salary from the University of Alberta
- **Non-Financial**
  - The Aphasia Institute is a research partner on this project
  - Drs. Azios and Kim are research associates of the Aphasia Institute
  - Drs. Azios and Kim are receiving an honoraria from the Aphasia Institute for this presentation
- **Course Content Disclosure**
  - This course will mainly discuss "The Wall Question" – a one-question quality-of-life measure for which research is ongoing

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## Aphasia can negatively impact quality of life

- *"After adjusting for age, sex, and other diagnoses, aphasia exhibited the largest negative relationship to the MDS-HSI followed by cancer and Alzheimer disease." (Lam & Wodchis, 2010)*
- *"Among the stroke patients, there were significant correlations between degree of aphasia and ... QoL at six months. Significant improvements in both aphasia and physical function were seen between the acute phase and six months, but this did not result in a perceived better QoL. ... This suggests that among aphasic stroke patients there are other facets than severity of aphasia that affects the perceived QoL." (Franzen-Dahlén et al., 2010)*
- *"Emotional distress, aphasia severity, communication and activity limitations, other medical problems, and social factors affect HRQL." (Hilari et al., 2012)*

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We need valid, reliable instruments to measure QoL in aphasia

	# of items / Domains	Time to administer	Comments
Stroke and Aphasia Quality of Life Scale (SAQOL-39)	39 items / Physical, Psychosocial, Communication, Energy	15 - 20 minutes	Comparison to pre-aphasia life 5 point scale
Quality of Communication Life Scale (QCL)	18 items / Socialization, leisure, communication, self-esteem	~15 minutes	Visual Analogue scale
Assessment for Living with Aphasia (ALA-2)	27 items / AFROM domains	15 - 30 minutes	Pictographic supports includes "Wall Question"

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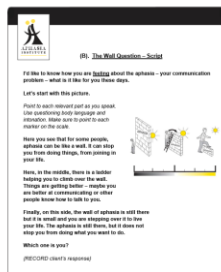
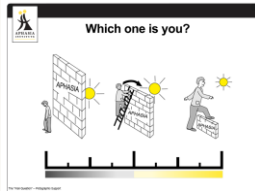
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"The Wall Question"

<https://www.aphasia.ca/health-care-providers/resources-and-tools/rating-scales/WALL>




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Research Questions

? Can a single-item assessment accurately capture quality of life for people with aphasia?

The "Wall Question" is an efficient tool to gather information about how aphasia impacts quality of life, but has not been investigated outside of the Assessment for Living with Aphasia for its psychometric properties.

1. What is the test-retest reliability of the Wall Question?
2. Does the Wall Question have concurrent validity?
3. How do people with aphasia conceptualize quality of life when answering the Wall Question?

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### Methods

- Design
  - Multiple methods study
  - Virtual data collection across multiple sites
- Participants
  - People with aphasia (any etiology, excluding PPA) recruited across Canada and the United States
    - At least 6 months post-onset
    - At least 18 years old
    - Access to computer/internet
    - Speak and understand English
  - Recruitment through aphasia groups and organizations using aphasia-friendly recruitment materials




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### Quantitative Methods

- RQ1: Test-retest reliability
  - Which one is post?
  - Which one is post?

Week 1      Week 2
- RQ2: Concurrent validity
  - VASES
  - SWLS

RQ1 Data Analysis: Intra class correlations for test-retest reliability

RQ2 Data Analysis: Pearson's R for concurrent validity

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### Qualitative Methods

- RQ1: Conceptualization of QoL via semi-structured interview
- RQ3 Data Analysis:
  - Deductive content analysis based upon PERMA Framework (Seligman, 2011, 2019)
  - Inductive content analysis to more richly describe patterns within each segment of PERMA

**PERMA Framework**

<b>P</b>	Positive affect
<b>E</b>	Engagement
<b>R</b>	Relationship
<b>M</b>	Meaning
<b>A</b>	Accomplishment

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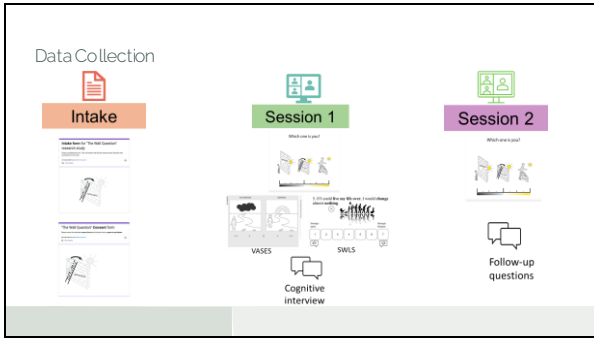
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### Assessment Fidelity (Spelt et al., 2020; Richardson et al., 2019)

- Assessors
  - Data collected from March 2024 – June 2025 across 4 separate sites by 19 different assessors: undergraduate students, graduate students, experienced clinicians and trained volunteers

Background Knowledge	Skill Development	Fidelity/Reliability
Review assessments (administered, scoring); Review Zoom features; Review manual	Complete role plays during SCA training with Zoom features; SLP supervisor observes and gives feedback	Complete checklist with review requirements for each participant
Complete SCA e-learning module	Review video of a assessment with PWA; Discussion	39% sessions reviewed for conciseness of delivery
SCA Modules I & II Training session	Practice session with partner (role play); partner discussion & feedback	Written reflections completed after each participant session
Review readings on qualitative interviewing; 2-hour training; Observes 2 or more interviews conducted by Research supervisor	Research supervisor observes minimum of 2 student interviews & provides feedback; Group discussions; Ongoing coachings required	Additional review of interviews; 1-1 coachings; retested; Ongoing ethics to interview guide for people with severe aphasia

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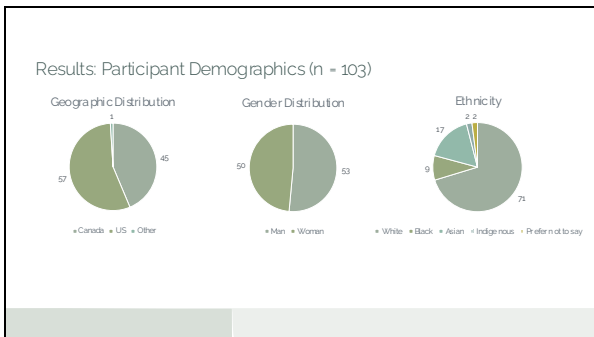
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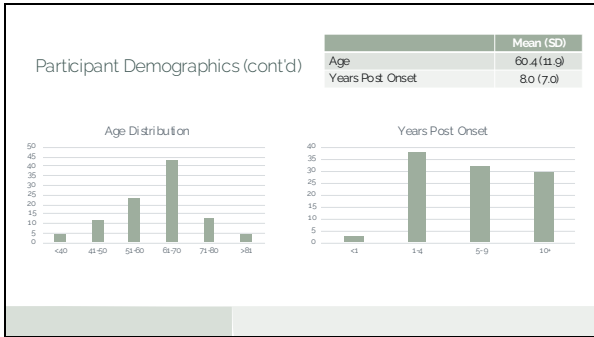
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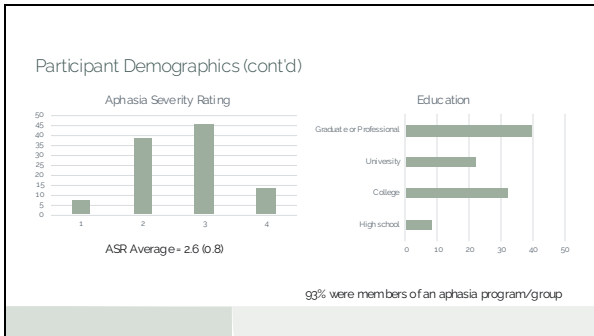
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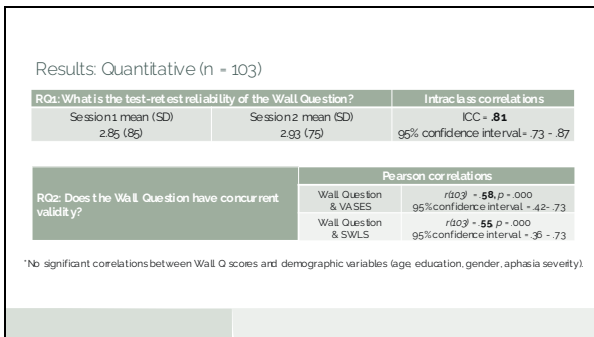
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Results: Qualitative (n = 72)

- Purposeful sampling resulted in 72 of 103 people with aphasia included in cognitive interview
  - **Age:** Range of 26 – 87 years; Mean = 59.8 years
  - **Gender:** 39 Women and 33 Men
  - **Ethnicity or Race:** Black, n=8; White, n=41; Asian, n=16; Indigenous, n=2; Arab, n=1; Latin American, n=2; Prefer not to say, n=2
  - **Severity of Aphasia:** ASR 1, n=5; ASR 2, n=28; ASR 3, n=30; ASR 4, n=9
  - **Level of education:** 44 had completed at least an undergrad, 25 completed some college or technical school, 3 completed high school only, 1 Prefer not to say
  - **Aphasia Center Participation:** 66 of the 72 had some participation

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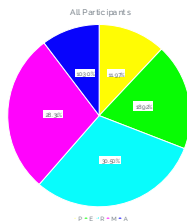
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Results: Qualitative

819 codes

PERMA Framework

- P** Positive affect
- E** Engagement
- R** Relationship
- M** Meaning
- A** Accomplishment




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Results: Positive Affect

Reciprocal relationship between emotion and communication

“And I worry about d- decre- uh decreasing the communication cause I have. It’s like this, I used to sleep-speak really well and now I don’t and sometimes it’s works or not there”



Frustration “Um before it’s frustrated. Yes. Uh and it’s I [...] can’t under I can’t I can’t I can’t improve”

Confidence and happiness important to expectation

“My expectation is is is – how do I say? Is excellent...because I am happy”

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Results: Engagement

Which one is you?



Flow state, getting in the zone, being in "my element"

"I can talk to those people because it's in my element I can talk about...what to do with uh presentations and proposals. I can, I can talk about all of that in the zone"

Aphasia diverts energy away during authentic activities

"You have to think before you open your mouth...and that kind of slows you down a little bit"

Authentic activities and hobbies

"I could take some pills. You know but but you know if I walk, if I get out and walk around...take my mind off"

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Results: Relationships

Which one is you?



Healthcare workers, especially SLPs!

"Or maybe I just keep moving. And and the one who had said that to me was the speech-language pathologist"

Families and friends

"Fiancé is another ring on the ladder"

Community workers as relationships

"Well because of my aphasia um they were they were very accomodating to me. And it was almost like I didn't even have aphasia."

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Results: Meaning

Which one is you?



Importance of pre-stroke and aphasia belief system to recovery

"I could always see the sun"

Self-advocacy and remaining "stubborn" and "persistent"

"Just because you interrupt me doesn't think that what what you have to say is more important than what I have to say"

Aphasia as a journey in identity renegotiation instead of an endpoint

"But then I stepping over – stepping over the wall so that I become who I am"

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Results: Accomplishment

Which one is you?

Having a goal is critical

"I've got to be the winner...I will not allow this cond... of aphasia to, I'm not going to say it doesn't change my life because it does, but it's not going to control my life"



Progress toward better language use in context

"Yes because I couldn't I couldn't utter a sound. When I started off. And now stepping over the wall"

Small skills leading to larger goals

"It's a um, it's a all computer. But I am growing in the uh...at I am getting better and better ev- every day. Because I wouldn't stop until I achieve my goal."

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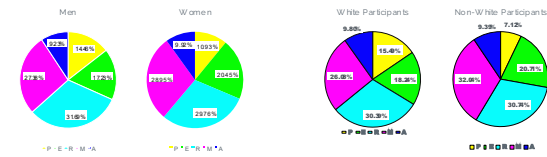
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**PERMA Framework**  
 P Positive affect  
 E Engagement  
 R Relationship  
 M Meaning  
 A Accomplishment

Distribution of Codes - Gender and Race




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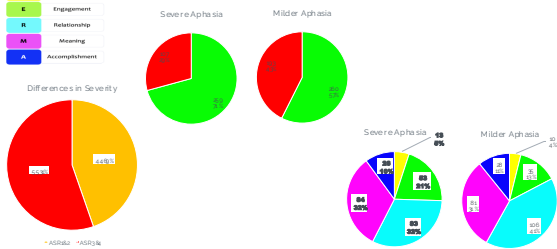
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**PERMA Framework**  
 P Positive affect  
 E Engagement  
 R Relationship  
 M Meaning  
 A Accomplishment

Distribution of Codes - Aphasia Severity




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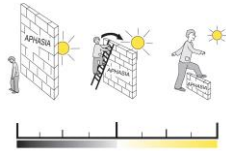
Clinical Implications

Advantages of the Wall Question:

- Efficient, easy to administer
- Rating scale and pictographs make it comprehensible, non-verbal means of capturing impact of aphasia

Wall Question can be used to drive discussions around quality of life, and support collaborative goal setting

Which one is you?




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Clinical Implications

Quality of Life in Aphasia

Checklist of Factors related to Well-Being

This checklist is based on the PERMA framework (Seligman, 2011) which suggests that well-being can be measured by the domains: Positive Emotions, Engagement in Life, Relationships, Meaning, and Accomplishments. In our work, we have found that people with aphasia are experiencing and struggling with all of these domains. The checklist below captures the most reported experiences of people with aphasia across the five domains and is used according to the PERMA framework. It is intended to be used by clinicians and the services they provide with the aim of providing support to help people with aphasia (Rogers et al., 2018) to facilitate person-centred care and as a support in collaborative goal setting conversations.

Client Name:	Date:
<b>Positive or Negative Emotions</b>	
Negative Emotions	Present <input type="checkbox"/> Therapy Priority
Contentment	
Excitement/interest	
Energy	
Engage	
Peace/harmony	
Other	
Positive Emotions	Present <input type="checkbox"/> Therapy Priority
Contentment	
Excitement/interest	
Energy	
Engage	
Peace/harmony	
Other	
<b>Engagement</b>	
Lack of engagement in life	Present <input type="checkbox"/> Therapy Priority
Not able to participate in meaningful activities	
Presently unable to engage	
Amount of effort/will to engage in activities low	
High	
Other	
Highly engaged in life	Present <input type="checkbox"/> Therapy Priority
able to participate in some meaningful activities	
able to find and/or flow state	
Presently unable to participate in activities	
Other	
<b>Relationships</b>	
Presence of Relationships	Present <input type="checkbox"/> Therapy Priority
Lack of Relationships	
Other relationships are positive	

Other people with aphasia		
Understanding of aphasia impacts/needs/signs (e.g. coaching, social communication)		
Openness to interaction with aphasia or grandchildren		
Other Relationships	Present <input type="checkbox"/> Therapy Priority	
Spouse or other family members		
Friends		
Other people with aphasia		
People through work or community members (e.g. neighbors, church or volunteer group members)		
Support participants or other healthcare workers		
Other		
<b>Meaning</b>		
Lack of Meaningful Purposes in Life	Present <input type="checkbox"/> Therapy Priority	
Significance to personal identity		
Loss of independence		
Other self-worth		
Other		
Purpose and Values in Life	Present <input type="checkbox"/> Therapy Priority	
Strong self-advocacy		
Empowerment		
Health outlook on life		
Other		
<b>Accomplishment</b>		
Health-Adhering Goals or Accomplishments	Present <input type="checkbox"/> Therapy Priority	
Lack of progress		
Difficulty with day to day tasks		
Other		
Prize or Goals or Accomplishments	Present <input type="checkbox"/> Therapy Priority	
Lack of ongoing progress or goals		
Important taking		
Parting not given		
Other		
<b>References:</b>		
Rogers, A., & Stephens-Peterson, N. & Kitchell, J. (2018). Assessment for Living with Aphasia (ALLA)-Second Edition. Aphasia Institute.		
Seligman, M. (2011). Flourish: A new understanding of happiness and well-being. Free Press.		

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Discussion

- The "Wall Question" is **valid and reliable** as a standalone measure of aphasia-related quality of life
- Qualitative analyses suggest people with aphasia consider many factors when reflecting on the impact of aphasia on their lives
  - Abstract and complex concepts** discussed in relation to pictograph (e.g. sun, ladder)
  - General structure and support while still allowing for **individual values and needs** to surface
- Limitations
  - Highly educated sample
  - Sample recruited through aphasia groups/centers
  - Interviewer skill and coding

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Acknowledgements – Wall Question Study Team

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  - Asia Donald
  - Dakha Kishuik
  - Mollie Zaleski

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Thank you!

Questions?

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