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# Patient Perspectives of an Intensive Comprehensive Aphasia Program for Stroke Survivors

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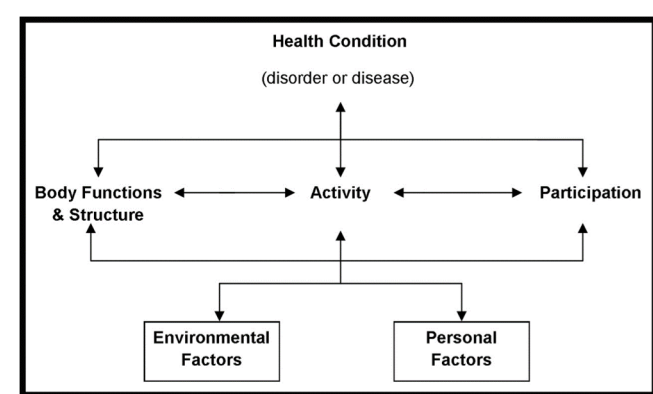
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## Background & Significance

### Stroke and Aphasia

- Aphasia is a **language disorder** that often occurs after stroke and can also occur after traumatic brain injury, brain tumor, or infection (Papathanassiou & Coppens, 2017).
- Persons with aphasia have varying degrees of difficulty with all/some of the following language-based skills: **speaking, writing, auditory-comprehension, and reading** (Papathanassiou & Coppens, 2017).
- The prevalence of **stroke** is high and increasing (CDC, 2018).
- The prevalence of **aphasia** is 2-4 million people in the US (Aphasia Access, 2018).
- Holistic, patient-centered care** is recommended (Robinson et al., 2008).



- The World Health Organization International Classification of Functioning, Disability, and Health (WHO-ICF) model provides a framework to implement holistic patient-centered care (Robinson et al., 2008).

- Principles of neuroplasticity (e.g., use it or lose it, use it and improve it, specificity, repetition matters, intensity matters, and salience) in the context of aphasia rehabilitation support that intensive, high dose therapy maximizes outcomes (Raymer, 2008).
- High intensity speech-language treatment is as effective, if not more effective than the current standard of care (Brady et al., 2016; Breitstein et al., 2017; Harnish et al., 2014; Pulvermuller et al., 2001).

### Intensive Comprehensive Aphasia Programs (ICAPs)

- Intensive Comprehensive Aphasia Programs (ICAPs) are a **service delivery model** of high intensity holistic, patient and family-centered rehabilitation (Hula, Cherney, & Worrall, 2013).
- ICAPs **must include**: at least 3 hours of treatment per day for 2 weeks, patient and family education, clear start and end dates, a cohort of participants (Rose et al., 2013).
- ICAPs **often include**: individual and group therapy, technology-based therapy, integration of alternative augmentative communication (AAC) devices, psychosocial support for patients and family caregivers (Off, et al., 2019), and additional rehabilitative services such as physical therapy, occupational therapy, music therapy, and/or recreational therapy (Hoover et al., 2017).

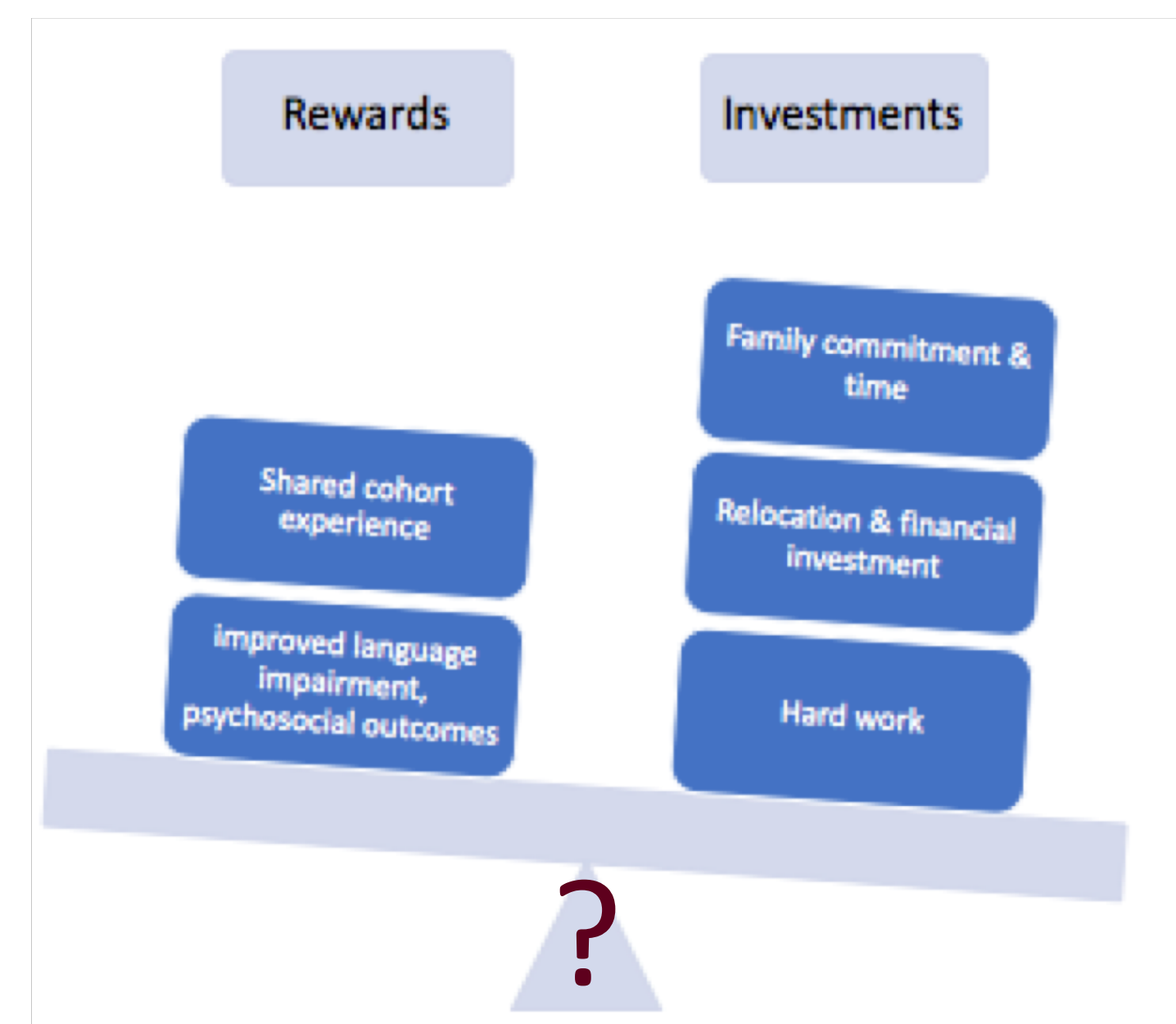
### ICAPs are Effective

- ICAPs have been shown to be effective for persons with aphasia (PWA) across many domains:
  - Neural change associated with improved language function (Baliki, Babbitt, & Cherney, 2018)
  - Impairment-based language outcomes (e.g., Code, Torney, Gildea-Howardine, & Wilmes, 2010; Dingam et al., 2015; Rodriguez et al., 2017).
  - Functional language outcomes (e.g., Hoover & Carney, 2014; Persad, Wozniak, & Kostopolos, 2013).
  - Psychosocial outcomes (Babbitt, Worrall, & Cherney, 2015; Dingam et al., 2015; Hoover & Carney, 2014; Rodriguez et al., 2017).
- Qualitative research suggests that speech-language pathologists (SLPs) believe ICAPs are worthy, but have room for improvement (Off, Griffin, Murray, & Milman, 2018).
- Qualitative research suggests that caregivers believe ICAP experiences are worthwhile (Babbitt, Worrall, & Cherney, 2013).
- No evidence has been provided about what it is like to be a PWA in an ICAP.

Study	Impairment-based outcomes	Functional communication outcomes	Psychosocial outcomes	Caregiver/SLP perspectives	Patient perspectives
Babbitt, Worrall, & Cherney, 2013					
Babbitt, Worrall, & Cherney, 2015	x		x		
Code, Torney, Gildea-Howardine, & Wilmes, 2010	x				
Off, Griffin, Murray, & Milman, 2018				x	
Dingam, et al., 2015		x	x		
Hinckley & Craig 1998	x				
Hoover & Carney, 2014	x	x	x		
Persad, Wozniak, & Kostopolos, 2013		x			
Rodriguez et al., 2017	x	x	x		
Rodriguez et al., 2013	x				
Rose, Cherney, & Worrall, 2013	x				
Wilmes-Mitnik et al., 2014	x				

## Research Question

What is it like to be a person with aphasia (PWA) in an intensive comprehensive aphasia program?



## Methods

### Research Design

Qualitative interpretive phenomenology was implemented to understand patient perspectives of the ICAP at the University of Montana. Interpretive phenomenology integrates lived experiences of participants with the researchers' interpretations of their lived experience (Creswell & Poth, 2018; Smith, Flower, & Larkin, 2009; Moustakas, 2004).

### Participants

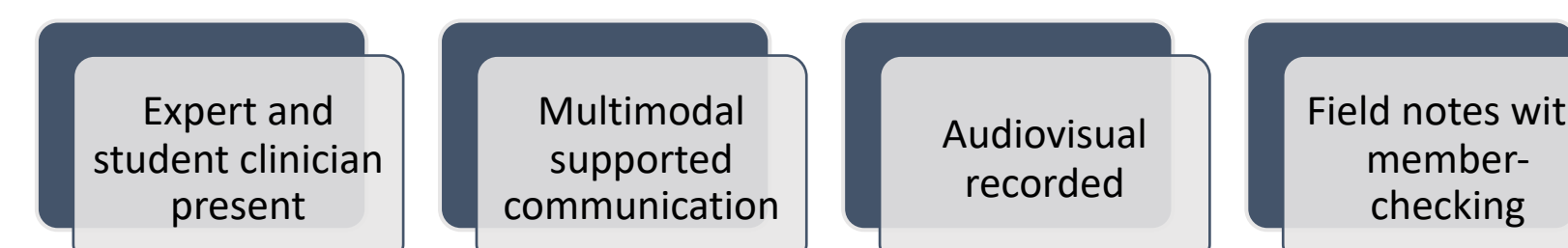
- 5 stroke survivors with chronic aphasia enrolled in the 2018 UM ICAP for 4.5 hours a day, 4 days per week, for 4 weeks
- All participants' dominant language was English, were 50 to 70 years of age, had a diagnosis of fluent or non-fluent aphasia with aphasia severity ranging from moderate to profound
- Language production of at least the short phrase level
- Capable of responding to questions through spoken production or message production through an AAC device with multi-modal support from SLP
- Capable of comprehending questions with multi-modal support from SLP

### Procedures

#### Measures

- Pre-treatment assessment battery (*Western Aphasia Battery-R, Boston Naming Test-2, Assessment of Living with Aphasia, Raven's Coloured Progressive Matrices, Scales of Language Rehabilitation, Aphasia Bank Discourse Protocol, Geriatric Depression Scale, Communicative Participation Item Bank, Communicative Confidence Rating Scale, & Communicative Effectiveness Index*)
- Structured interview within the first 14 days of therapy
- Post-treatment assessment battery
- Post-treatment structured interviews

### Interviews

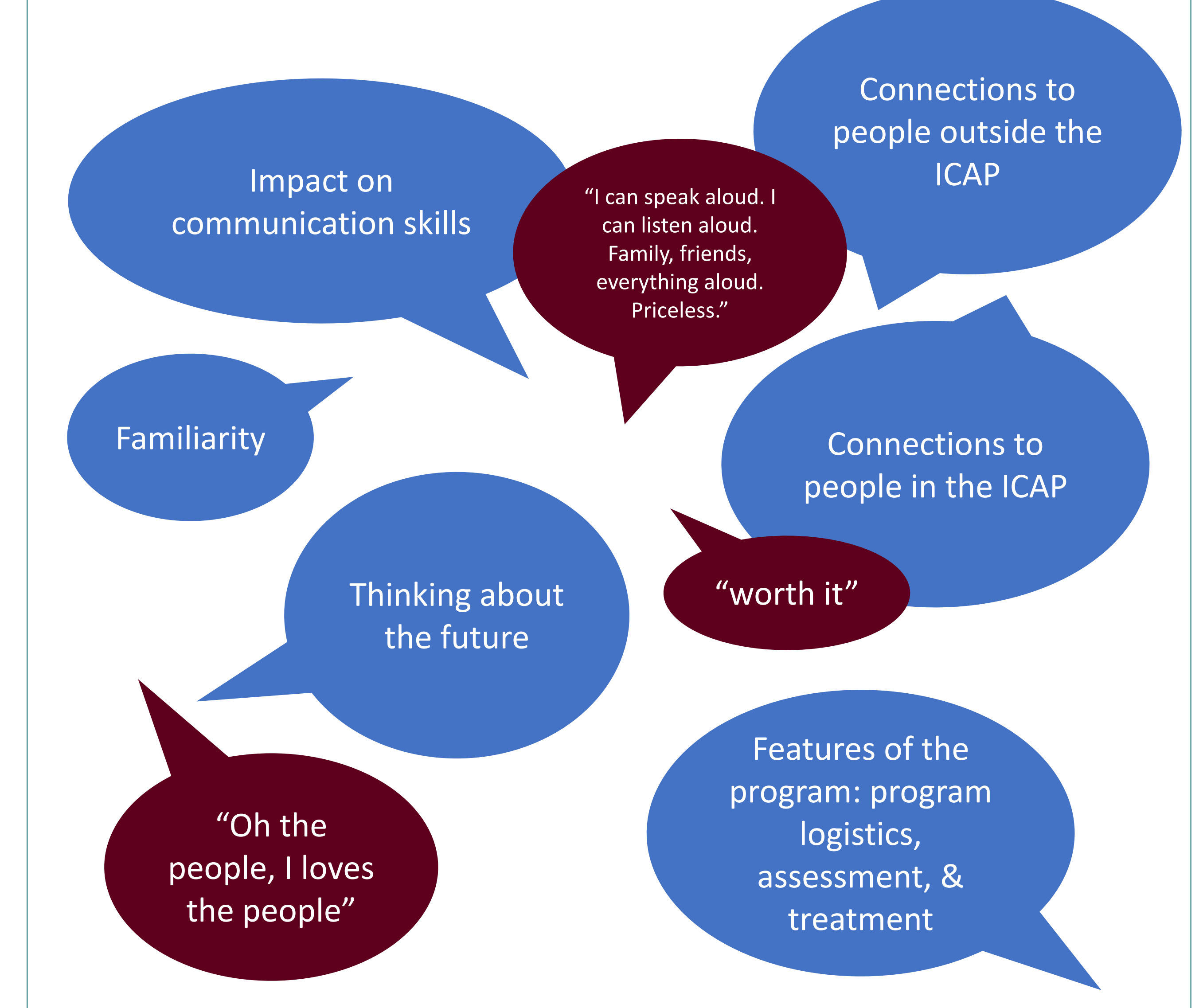


### Data Analysis

- Word-for-word discourse transcription of audiovisual recordings
- 20% transcribed by researchers unfamiliar with participants to increase trustworthiness of data and findings (Luck & Rose, 2007)
- Team coding process involving 3 researchers reading transcripts, developing key word phrases (i.e., codes) for significant ideas participants talked about, coming to consensus about themes arising from the codes
- Culminating analysis will tie together themes across participant experiences

## Results

### Emerging Themes Discussed by Participants



### Preliminary Conclusions

- PWA in the BSAP ICAP experience an impact on communication skills.
- BSAP ICAP patients' increased access to functional communication fosters connections with people in and outside the program, thereby contributing to the cost-benefit-utility of the program, making the substantial investments "worth it."
- PWA in the BSAP ICAP felt a sense of familiarity that made the experience comfortable.

### Limitations

- Convenience sample of PWA who self-selected to participate in an ICAP
- Bias is introduced in co-construction of PWA's messages and interviewers' familiarity with participants
- Limited sample size

### Implications and Future Directions

- ICAPs appear to be effective, but we do not yet know what it is like to be a PWA in an ICAP
- Interpretive phenomenological studies on ICAPs can include perspectives of PWA with a range of communication profiles (e.g., mild to profound severity of language deficit), which is crucial due to the heterogeneity typical of ICAP participants (Rose et al., 2013)
- Member-checking (i.e., following up with participants to verify they feel like their perspective is represented within the coded themes) will increase trustworthiness of continued studies on patient perspectives of ICAPs (Burns et al., 2015)