

Harmonizing Together

**Speech and Music Therapy and Support for Patients and
Partners With Primary Progressive Aphasia**

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Pilot Program for Therapy & Support:



- **Group Participants**
 - 8 PPA Patients
 - 8 Care Partners
- **Staff Members**
 - 2 SLPs, 3 SLP Graduate Students
 - 2 Music Therapists
 - 1 Community Resource Specialist
 - 1 Neurologist
- **Timeline**
 - Round I: 8 weekly sessions, 90 minutes each
 - Round II: 4 monthly sessions, 120 minutes each





Method



- **Pre Post Surveys**
- **Caregivers and Patients surveyed separately**
- **Caregiver Questionnaire**
 - Zarit Caregiver Burden Interview
 - Communication Effectiveness Index – Modified (CETTI-M)
- **Patient Questionnaire**
 - Chronic Disease Self-Efficacy Scales
 - Communication Effectiveness Index – Modified (CETTI-M)
 - La Trobe Communication Questionnaire



Areas Measured



Patients -

- Confidence
 - Hobbies and recreation
 - Contribution to family life
- Feelings/Emotions
 - Isolation
 - Guilt
 - Embarrassment
- Communication
 - Initiating conversations
 - Using empty words

Caregivers -

- Feelings/Emotions
 - Motivation
 - Self care
 - Stress
- Communication of partner
 - Partner's rate of speech
 - Partner's conversation tracking
 - Partner's word finding

Programmatic Goal

Improve Functional Communication



- 45 minutes per session of tailored speech-language therapy
 - Focus on acquisition of compensatory communication strategies
 - Opportunities for dyad utilization of acquired skills in group setting with therapeutic support
- Allowing time for patient and caregiver feedback about utilization of strategies at home

I felt this was very helpful and really appreciated the kindness and the depth of knowledge and commitment of the professionals. – Care Partner

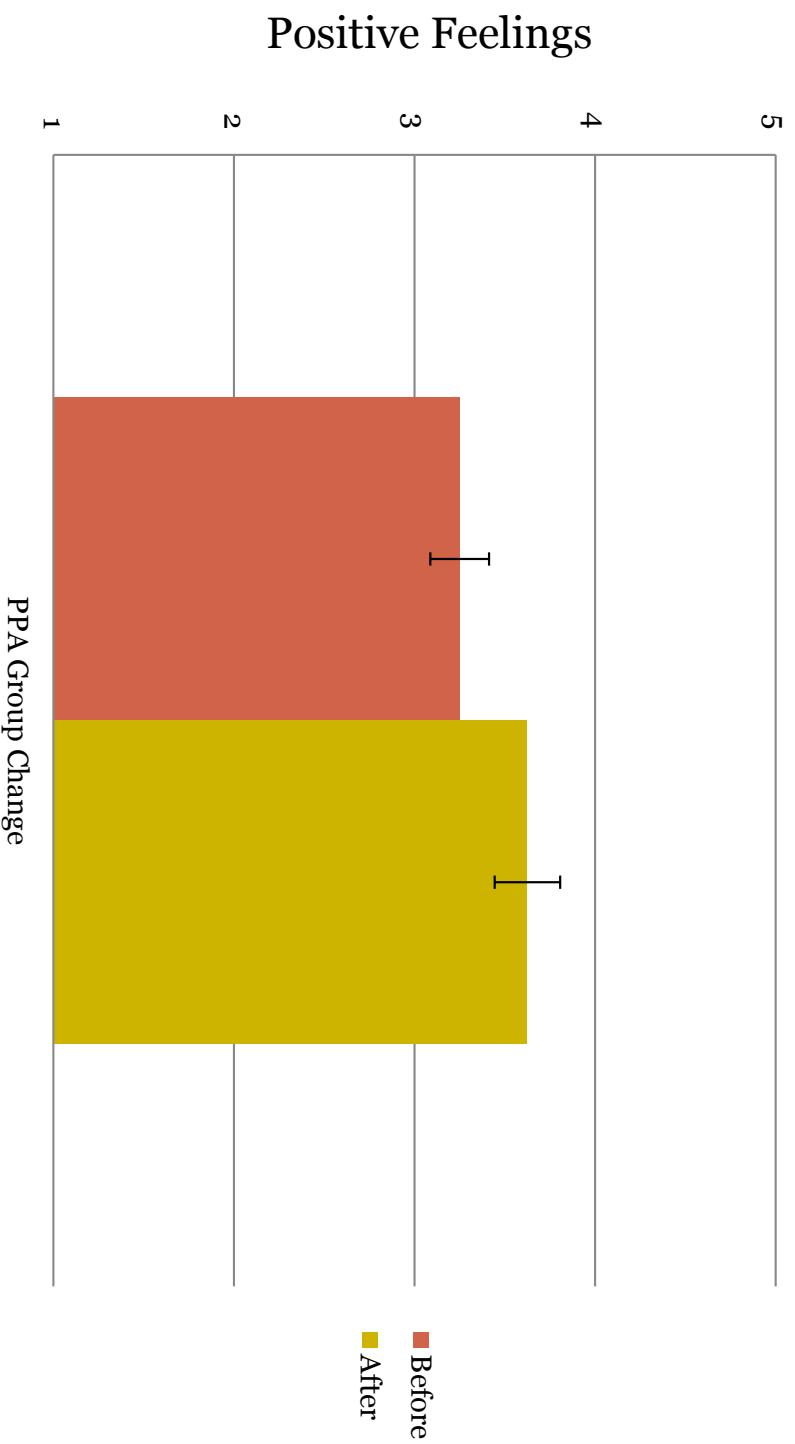




Measuring the Impact - Communication



I feel like I have developed successful strategies to compensate for my language impairment – Patient Response



1 Never 2 Hardly Ever 3 Sometimes 4 A lot of the time 5 Always

Programmatic Goal:

Learning about PPA and Current Research



- 90 minute session dedicated to a presentation for patients and caregivers from FTD unit director with opportunity for question and answer
- Handouts provided from The Association for Frontotemporal Degeneration and local community resources for support

“Dr. Dickerson’s meeting with the group was especially informative and hopeful, in that he is on the cutting edge of research in aphasia.”
– Care Partner



Programmatic Goal:

Utilizing Music Therapy to Enhance Communication & Connection



- 45 minutes per session dedicated to whole group music therapy by neurologically trained music therapist
- Music therapy sessions targeted the following:
 - Breathing exercises
 - Vocal strengthening
 - Utilization of Musical Instruments for Rhythm
 - Social & Emotional Connections

“I like the music therapy best. When I can't come up with the word, I sing.” – PPA Patient





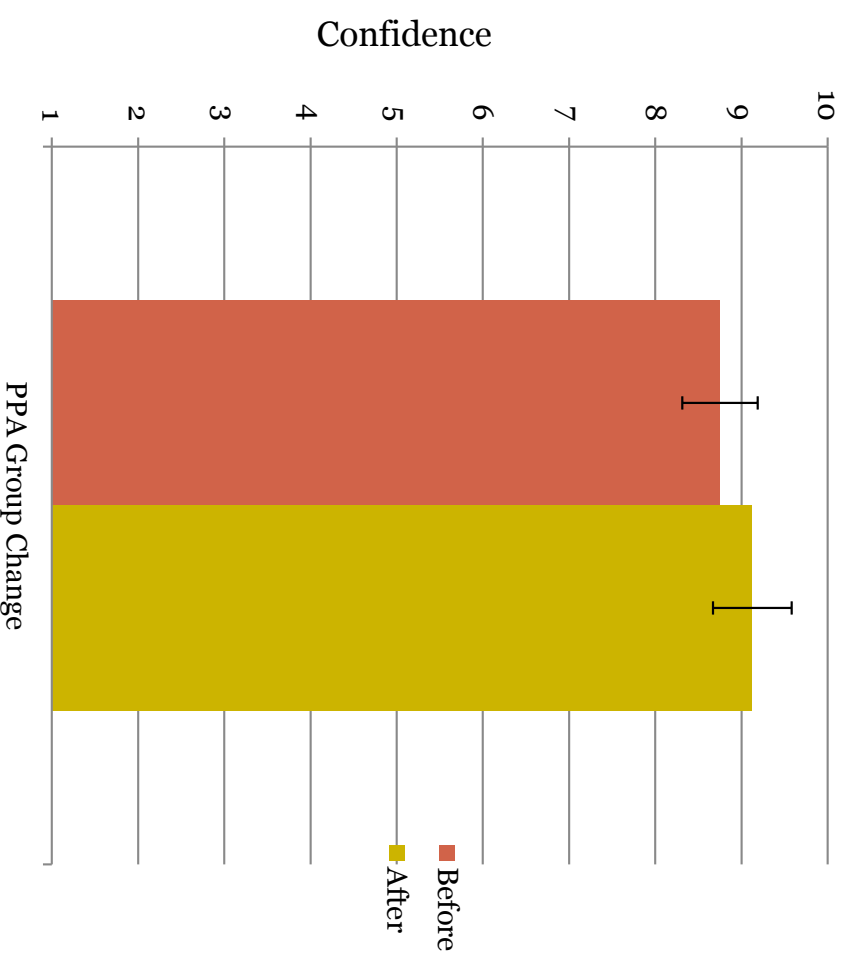
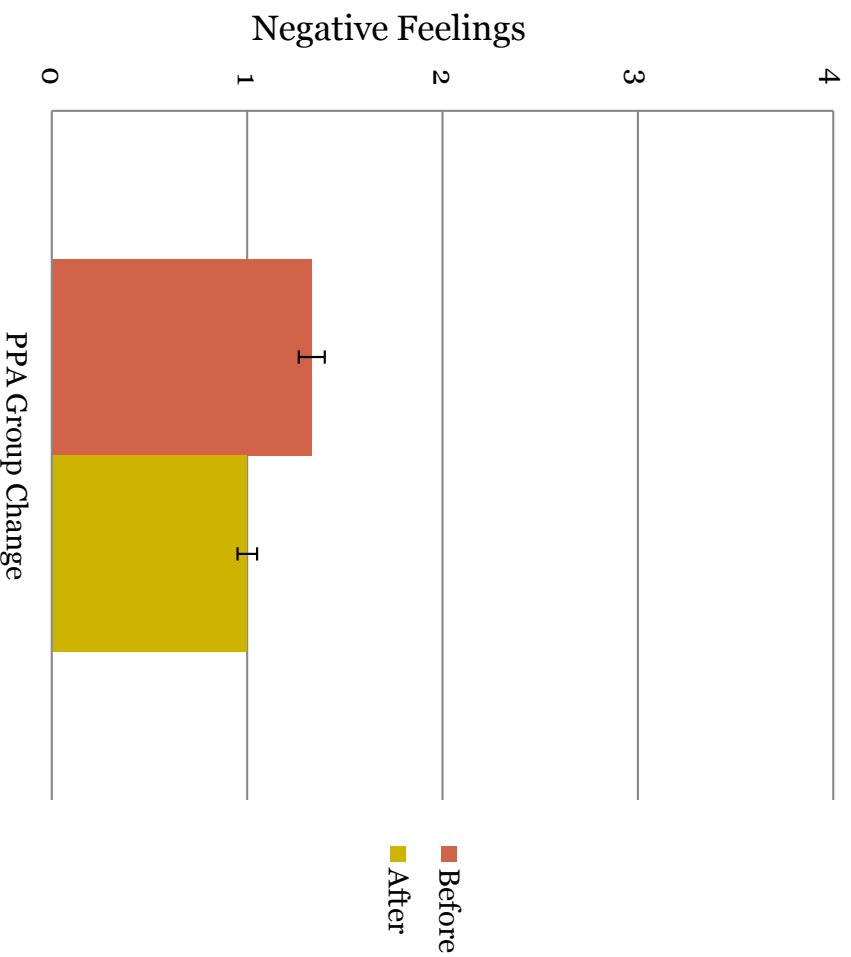
Measuring the Impact – Social

Do you feel that your social life has suffered because you are caring for your relative?

- Caregiver Response

Do you feel like you can participate in social visits and activities?

-Patient Response



Scale: 0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

Scale: 1 Not confident - 10 Completely Confident

Programmatic Goal:

Providing Emotional Support to Caregivers



- 45 minute session for caregivers with FTD unit community resource specialist
- Utilization of elements of Powerful Tools for Caregivers curriculum to promote caregiver resilience
- Handouts provided for local supports and community resources

“I feel that the group was very helpful to me and my wife. It gave me an opportunity to see other people in the same situation - both to talk to them and to find out how they are coping.”
– Care Partner Response

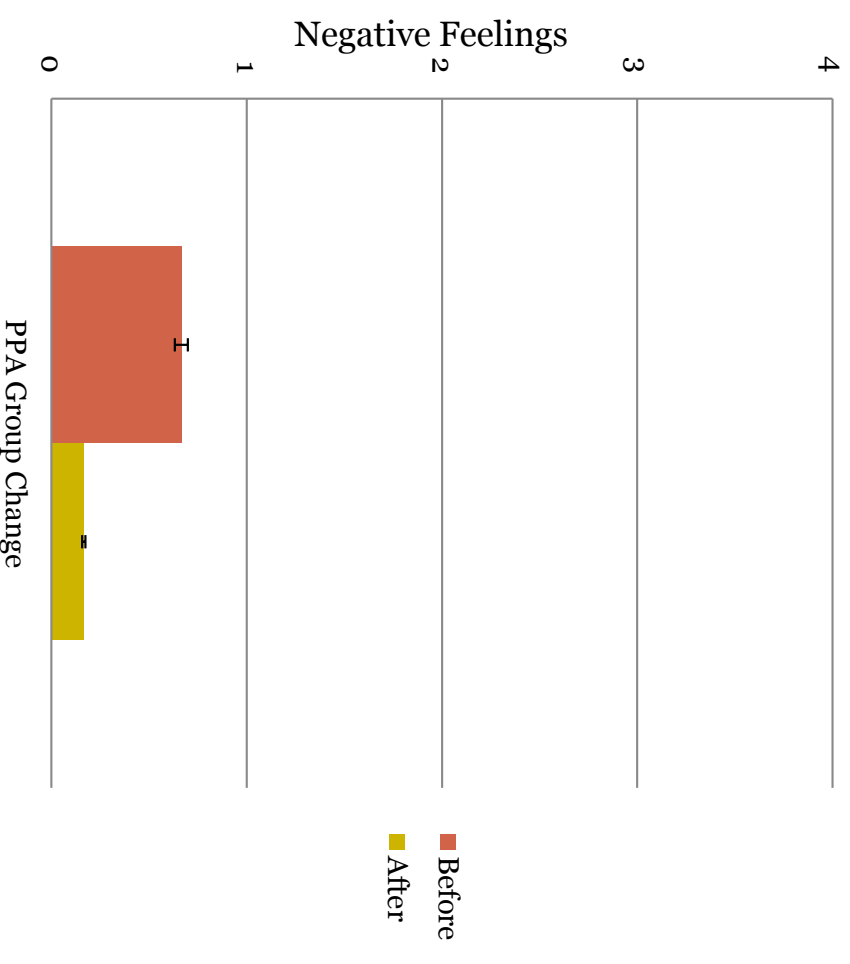
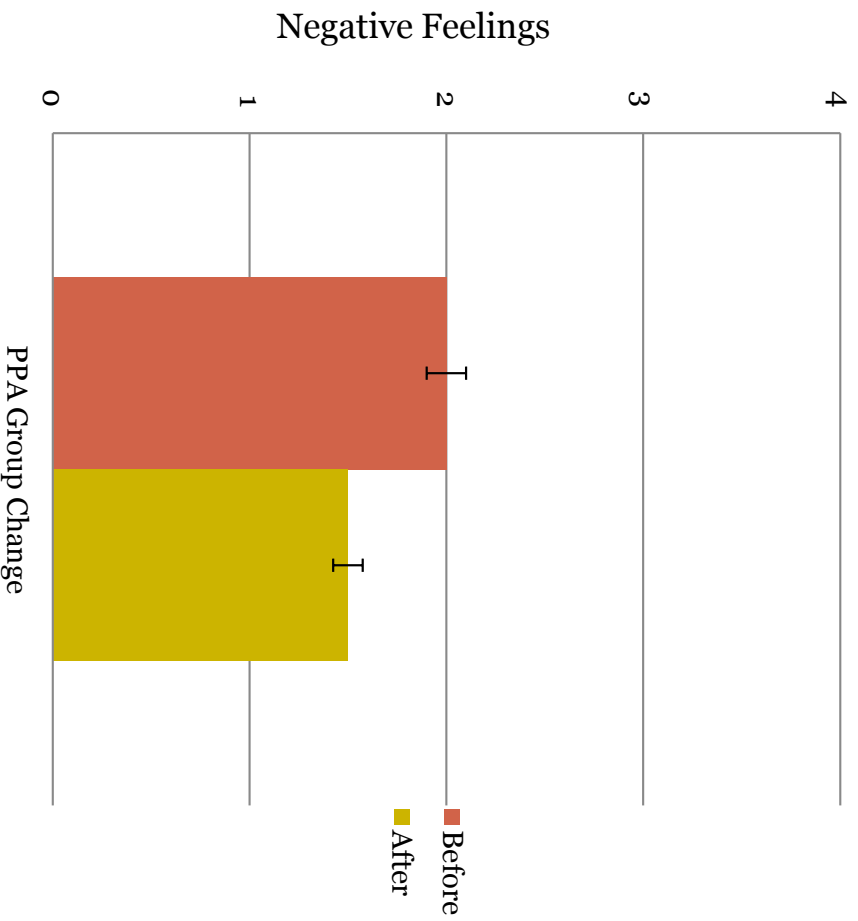




Measuring the Impact- Self Care

Do you feel the time spent being a care partner causes you to have less time for yourself?
– Care Partner Response

Do you feel your health has suffered because of your involvement with your relative?
- Care Partner Response



Scale: 0 Never 1 Rarely 2 Sometimes 3 Quite Frequently 4 Nearly Always

Programmatic Goal

Decrease Patient Isolation



- Facilitation of patients meeting and connecting with one another
- Creating opportunities for social engagement through group based speech-language and music therapy

“This is a wonderful group- So glad about the things we have done together- Also the fact that we have met other PPA people & the other part of their family. Of course the group is helping me and I would like to continue with them” - Patient Response





Measuring the Impact - Isolation

Do you Feel Isolated from

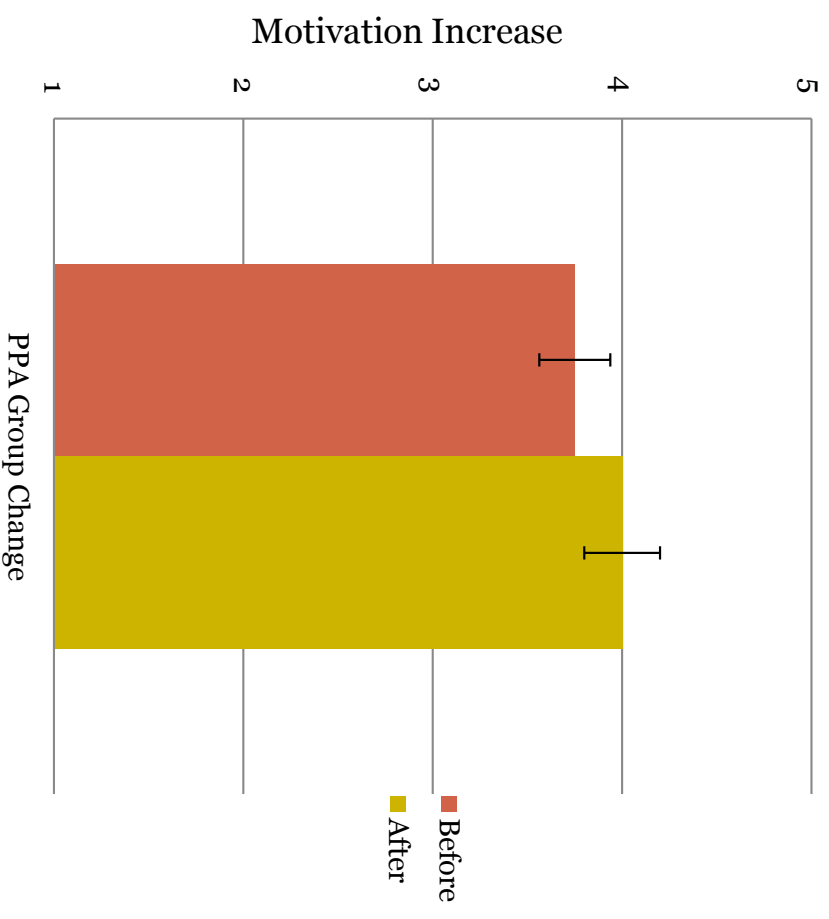
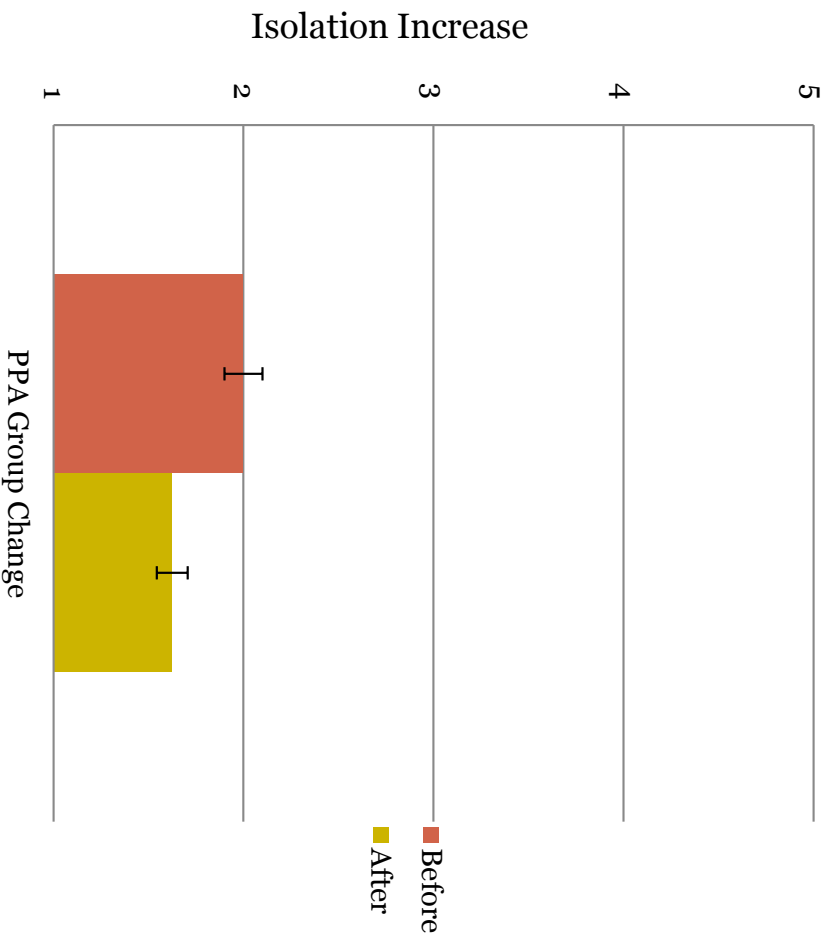
Family and Friends?

- Patient Response

I am still motivated to communicate with

people I encounter in the general public

- Patient Response



1 Never 2 Hardly Ever 3 Sometimes 4 A lot of the time 5 Always

Lessons Learned



OPPORTUNITIES FOR TREATMENT
MODIFICATION TO ENHANCE PATIENT AND
CAREGIVER OUTCOMES





Reasons for Negative Change

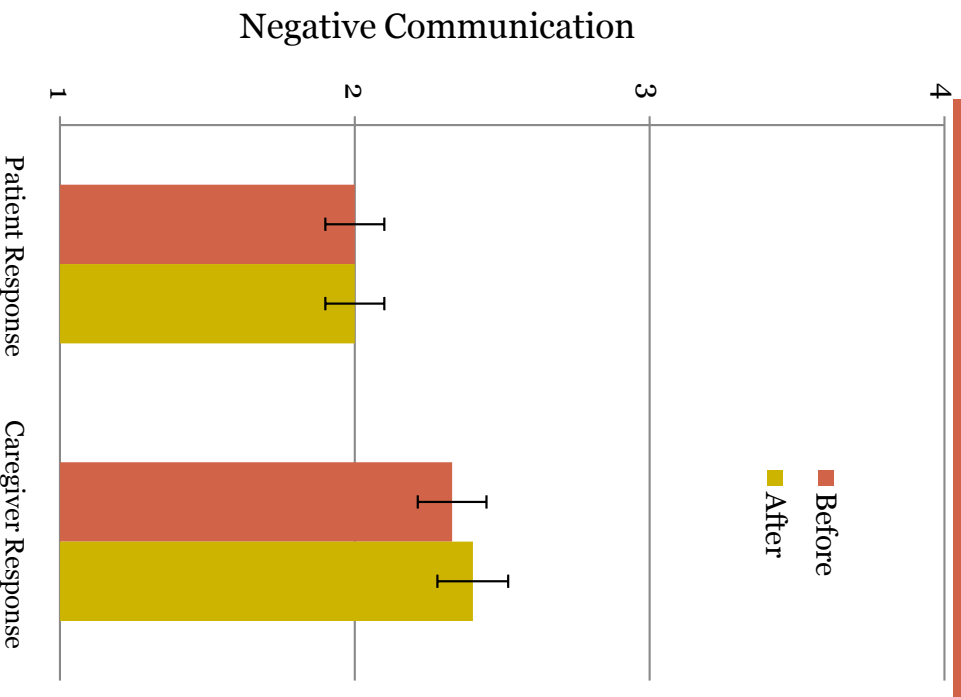


- **PPA is a progressive disorder**
 - Decline in language areas such as naming, fluency, auditory comprehension
- **Areas not specifically targeted in PPA Group**
 - Speech therapy focused on compensatory strategies
- **More information may lead to more awareness of PPA and the diagnosis**
 - This may explain increase in social isolation specifically guilt

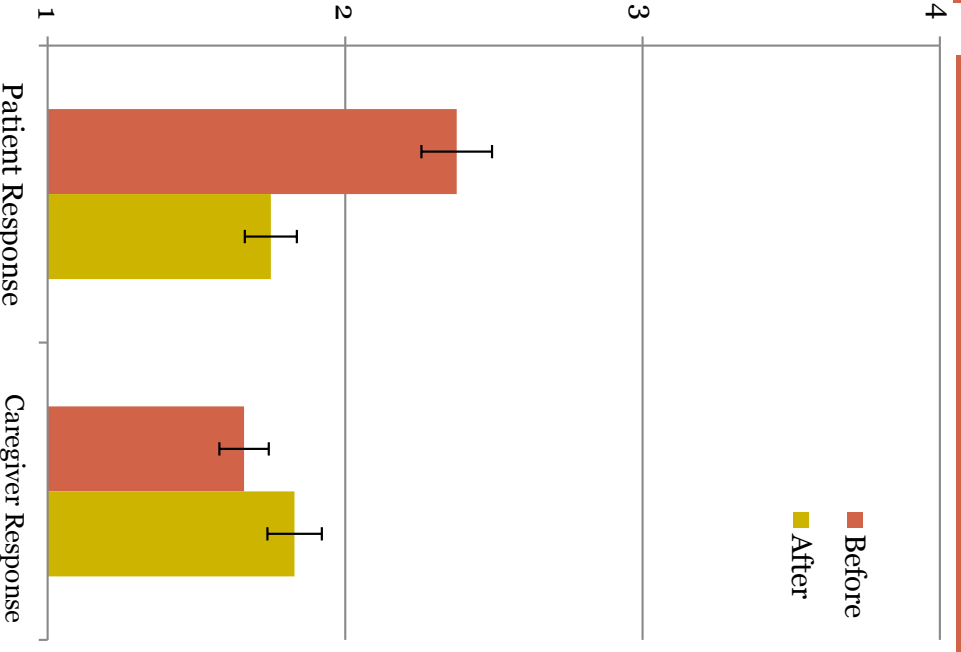


Lessons Learned - Communication Strategies

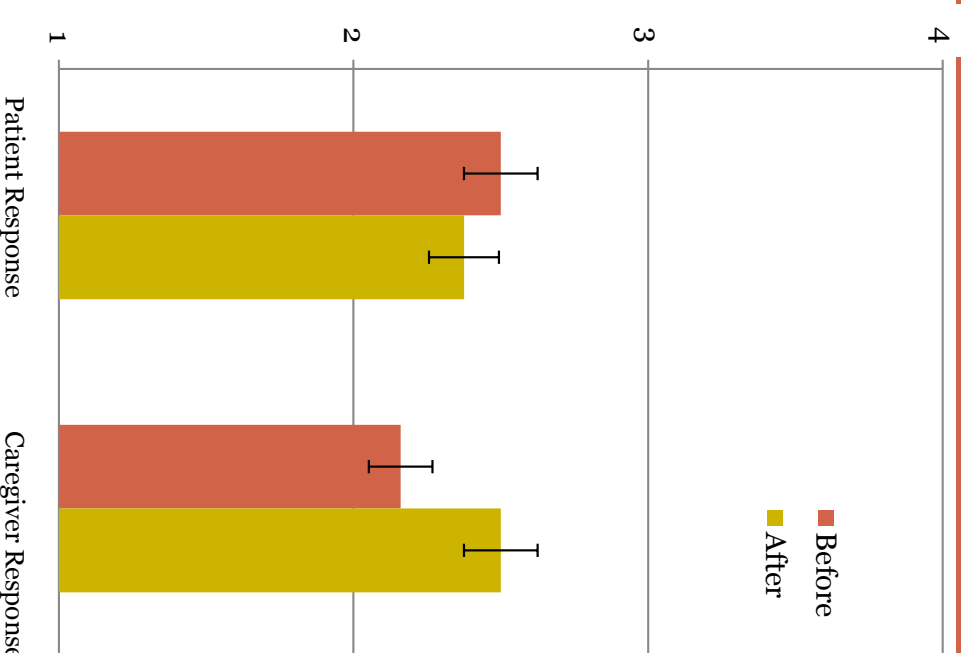
When talking do you leave out details?
- Patient & Caregiver Response



When talking do you speak too slowly?
- Patient & Caregiver Response



When talking do you hesitate/pause or repeat?
- Patient & Caregiver Response



1 Never 2 Sometimes 3 Often 4 Usually or Always

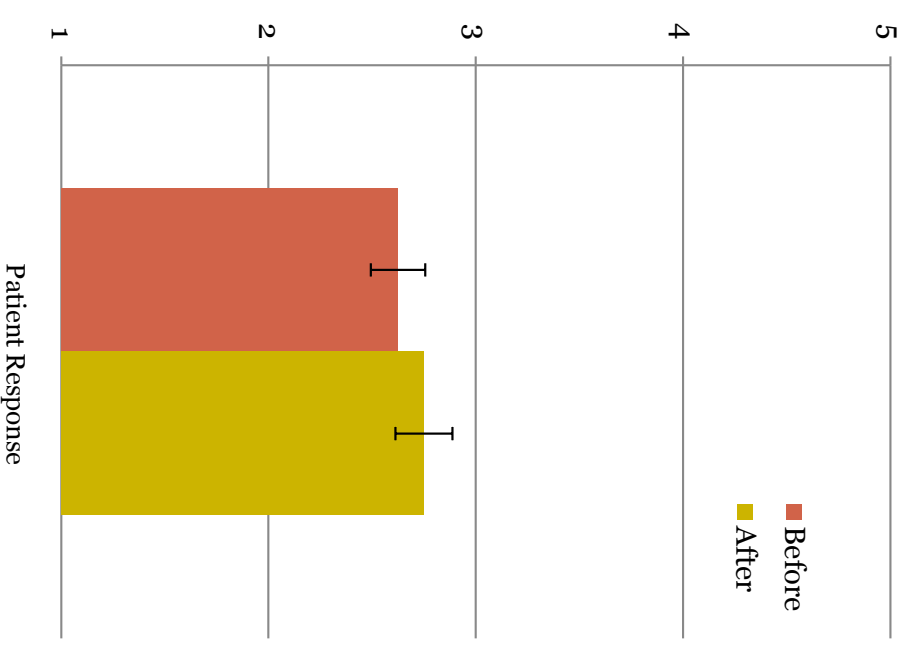
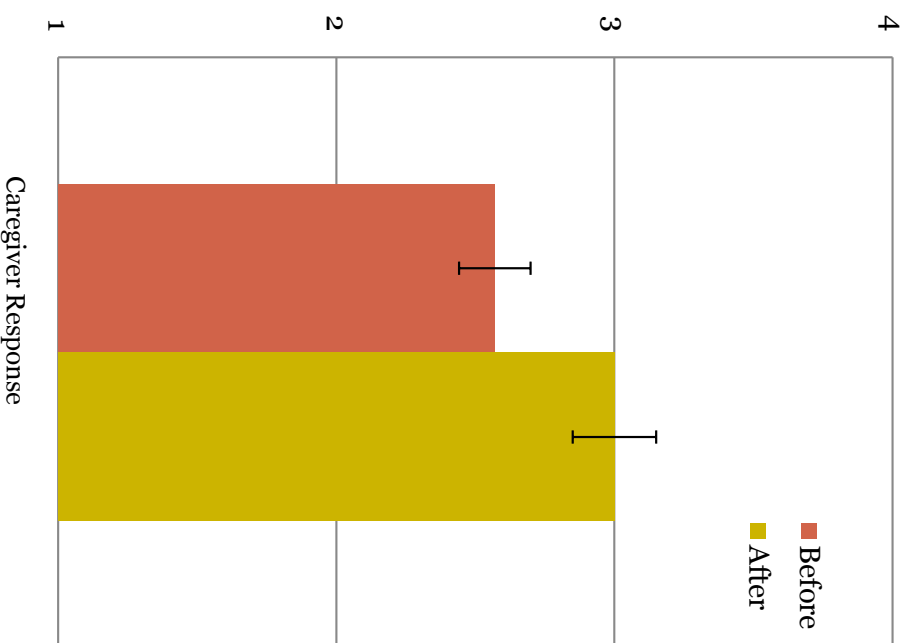
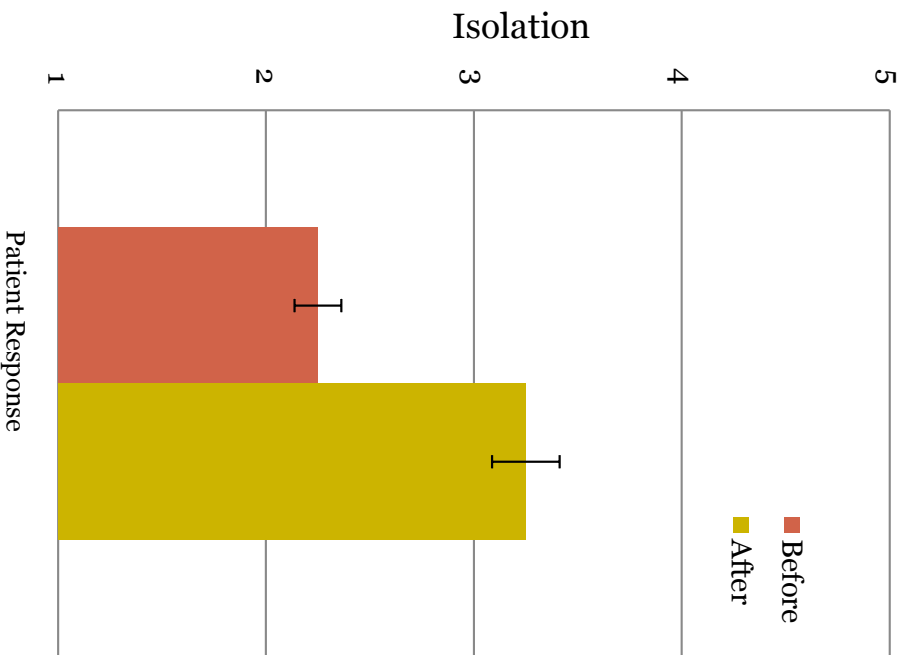


Lessons Learned - Social Isolation

Do you feel guilty about the time and effort your care partner spends helping you
– Patient Response

Are you afraid for the future?
-Caregiver Response

Do you feel isolated from the general public because of your language impairment?
– Patient Response





Thank You





Thank You



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- Caitlin Hyatt, Music Therapist
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Contact Us



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