2018
Caregiver Summit
Cumbre Para Cuidadores
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Disclosures

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“I just can’t follow what he is saying. It’s there but something is missing. The words and the way he communicates just isn’t him. Conversations don’t flow the same. I feel...alone” (Caregiver, 2010)

“It wasn’t my speech or movement but I would be in front of the class not able to find my words like ‘allomer’ that I have used for years teaching.” (M.L., 2013)

“By the time I put together what I want to say the conversation moved on so I just choose to sit quietly and not engage as much.” (J.V., 2009)
Conversations

Part of what make us human
- Interaction between at least two people
- Successes and failures lie at the intersection between people

Governed by a set of rules
- Universal across languages
- Learned implicitly over our lifetimes

When impaired...
- Negatively impact quality of life
- Increase sense of burden
- Make everyday activities more challenging
- Lead to social isolation and loss of relationships
If you want to go fast, go alone.

If you want to go far, go together.

-African proverb
How conversations work

Background on why conversations break down in PD

Raise awareness to the mutual responsibilities of conversation partners in good communication

Strategies you and your partner with PD can use to enhance conversations at home
“Honey, when you say we can’t communicate... what exactly do you mean?”
Successful turn

Body language, eye contact, gestures are clear

Topic/context is clear

Message/words are clear

Listener is focused and attentive

Speakers follow turn-taking rules

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Huh??
Conversation breakdown

What did you say??

Huh??


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Communication in Real-Life Contexts in PD

Roberts et al., 2014; 2016; Roberts et al., 2017; Roberts & Post, 2018

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Multiple Sources of Conversation Breakdowns

- Unclear speech/Quiet voice
- Hearing difficulties
- Word errors
- Sentences that are unclear or ambiguous
- Changing topics quickly
- Internal states: pain, distraction, impatience
- Unclear gestures or non-verbal signals
- Rushing/being in a hurry
- Noisy environments
- Memory problems and language problems
- Poor attention
- Emotional burden and relationship difficulties
- Starting in the middle of an idea/thought
Understanding complex sentences (e.g., Grossman, 2001)

Understanding action language (Garcia et al., 2018; Roberts et al., 2017)

Fewer grammatically correct sentences (Gutierrez et al., 2017)

Produce more filled pauses and revisions (Gutierrez et al., 2018)

Produce less information and omit meaningful main elements of the stories (Roberts & Post, 2018)
Causes of Conversation Breakdowns in PD Dyads

66% of breakdowns are unrelated to speech clarity and voice loudness issues
(Roberts et al., in prep; Griffiths, 2014; Branson et al., in prep; Rinne et al., in prep)

- Abnormally long pauses that create confusion in conversation turn-taking
- Unclear topic or topic not consistent with the current context
- Unclear non-verbal signals for turn taking
- Slowed processing of information
- Delays in initiating speaking turn or in responding to partner
- Use of incorrect or ambiguous words that cause confusion for conversation partners
- Talking over/interrupting the person with PD
Hearing loss and Cognition

• Common in aging, but more common in PD (Pisani et al., 2015; Vitale et al., 2012; Vitale et al., 2016)

• More cognitive resources required for listening and hearing less available for other functions/tasks

• Increases the frequency of conversation breakdowns in PD by more than a third (Griffiths, 2015)
Conversation breakdown

What did you say??

Huh??
Universal Rule: When a breakdown occurs, speakers attempt to repair it.
Conversation Repair Cycles

Signal of difficulty/misunderstanding

Repair
More missed opportunities for repair
– Less sensitive to signals of breakdown
– Person with PD is more likely to initiate the repair whether they or their partner is the source

Care partners are more likely to abandon repairs (not attempt or abandon before resolved)

More than a third of breakdowns go unresolved

Repairs take multiple attempts (complex repairs)
– More complex repairs than in Alzheimer’s dementia
– Less likely to be successful
– Lead to more misunderstandings

(Roberts et al., in prep; Griffiths, 2014; Branson et al., in prep; Rinne et al., in prep)
What did you say??

Huh??

Goal: Reduce conversation breakdowns
Goal: Increase the effectiveness and efficiency of repair cycles
Communication Enhancement Strategy Training  (Roberts, 2017)

Goals

• Reduce frequency and severity of conversation breakdowns
• Optimize strengths/Reveal competence of each partner
• Re-balance the conversation burden between partners
• Optimize effective strategies, reduce the use of unhelpful and harmful strategies

Treatment

• Person with PD and their conversation partner
• Learn personalized and systematic conversation strategies over 8-weeks
• Learn to identify signals of conversation difficulty and repairs
What did you say??

Huh??

Goal: Reduce conversation breakdowns
Being attuned to self, partner, environment

- Choose optimal times of day
- Medication times
- Fatigue

- Check-in on your own emotions
- Monitor your partners’ emotions/withdrawning
- Monitor signals of difficulty and adjust the conversation (pace, repair strategy)

- Conversation is for communicating, not testing
- Assess motivations that are driving the conversation
- Message does not have to be perfect in order to foster meaningful connections
Speech/Language-Centered

- Message/words are clear
- Body language, eye contact, gestures are clear
- Topic/context is clear
Early, targeted, and intensive voice training may potentially slow progression of voice impairments (Russell et al., 2010; Ciucci et al., 2015)

Intensive loudness training can change brain activity and muscle movement toward more normal patterns for voice/speech (Liotti et al., 2003; Narayana et al., 2009; Stathopoulos & Sapienza, 1997; Stathopoulos et al., 2014)
• Most researched program for voice treatment in PD
• High intensity voice exercise program – voice loudness
• Optimizes motor learning theories
  – Highly structured
  – Highly repetitive
  – Maximum effort
• 4 days (50 minute sessions)/week 4 weeks (16 sessions)
• Re-trains individuals in producing their maximum effort during speech
• ‘Think’ and ‘Be’ loud

(e.g., Sapir et al., 2011)
SpeechVive™

- Facilitates improvements in respiratory and speech muscles
- Device optimizes automatic reflex to increase voice loudness in noisy environments
- Practice occurs within everyday communication contexts
- Wear at home during normal communication activities. Settings adjusted based on client needs by SLP
- In some individuals it may reduce cognitive effort required to maintain voice loudness
- Increase loudness - automatic vs. focused effort

Jessica Huber – Purdue University and SpeechVive. Image used with permission. Do not reproduce.
Voice Amplifiers

- ChatterVox
- FM Systems
- Spokeman
- Voicette

- ADvox
- SoniVox

Andreeta & Adams (2013)
Turning up the volume may not be enough
Minimize Environment Distractions

- Turn off televisions, radios, running water and other sources of noise (visual and auditory)

- Reduce barriers by communicating face-to-face
  - Resist talking between rooms
  - Resist talking while walking away

- Provide alerting cues
Provide Additional Time

- Provide time to process information
- Present information in smaller ‘chunks’
- Listen patiently
- Provide additional time to formulate responses
- Avoid rushing or having important conversations during hurried moments
Topic Management

• Maintain topic until it is finished
• If necessary to change topics, alert your partner
• Return to the original topic when finished

• Avoid changing topics quickly

• Create context before introducing a new topic
Language Complexity
(more advanced disease, cognitive impairment)

• Reduce complexity of sentences
  – One idea per sentence
  – Put the main idea first
  – Reduce use of complex sentence structures and longer sentences

• Consider using familiar vs. less-familiar words

• Offer response choices or ask yes/no questions to help make responding easier
Conversation Repair Cycles

Signal of difficulty/misunderstanding

Repair
Repairing Conversations: What to do

• Monitor for signals of difficulty
• Verify that you understood the message
• Direct request for help
  – I don’t think I understood you correctly
  – Please repeat that again
  – Did you mean to say
• Repeat and simplify if needed
• Rephrase with added information
• Use gestures or show what you mean
• Stay calm. Avoid being critical.
Repairing Conversations: What not to do

• Raise your voice

• Provide non-specific clarifying prompts
  – What?, Huh?, Eh?

• Excessively reduce speech rate

• Demonstrate impatience

• Give-up or abandon the chance to clarify
  – If necessary then come back to the topic when everyone is settled and the time is optimal
Person-Centered

Negotiating Preferences

• Request permission to speak for or fill in information
• Discuss openly the type of help you both need and the way you want to receive it
• Decide jointly what to share with others

Facilitating Participation

• Create room in the conversation
• Arrange for smaller groups in less distracting environments
• Initiate topics of high interest
• Be a ‘ramp’ for helping the person with PD get into conversations
Person-Centered

Acknowledging & Revealing Competence

- Acknowledge conversation difficulties
- Acknowledge successes in getting messages across
- Acknowledge your partner’s expertise and perspective

Validating

- Validate the feelings of your conversation partner when failures occur
- Take responsibility for failures. Don’t blame

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• Conversations are the responsibility of both partners.

• Solution does not lie solely with ‘fixing’ the person with PD.

• Good conversation skills can be developed with practice.

• Meaningful and effective conversation require flexibility, empathy, and the ability to adjust over time.

• The payoff in preserving sense of self, emotional connections, and reducing burden of daily activities is worth it.

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-If you want to go far, go together.

-African proverb
New and Expanded: Speech, Communication, and Swallowing Booklet
Release: early 2019
1-800-4PD-INFO (473-4636)

On-line education program for advanced PD
Audience: Professional and Family Caregivers
Launch: November, 2018

Join via live broadcast from anywhere

https://parkinsonsociety.ca/
Research: We need your help!

- Individuals with Parkinson’s disease
- Adults without Parkinson’s disease

Currently recruiting:

- Understanding language processing differences in PD using eye tracking
- Understanding brain differences associated with speech changes in PD
- Wearable devices for remote monitoring cognitive and social interaction changes in PD
- Speech monitoring, error detection and their influence on everyday communication problems in PD
- Conversation Enhancement Training – Clinical Trial

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