“The puppy bit the tape”

(Measuring participation outcomes in speech-language pathology)

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Past and Present Funding Support

• NIH – Institute on Deafness and other Communication Disorders
  – R03 (PI: Baylor)
  – R01 (PI: Baylor)

• NCMRR Planning grant (PI: Yorkston)

• National Cancer Institute (PI: Eadie)

• UW Department of Rehabilitation Medicine
  – Departmental training grant
  – Stolov Award

• American Speech-Language-Hearing Foundation
  – Clinical Research Grant (PI: Baylor)

• NIH PROMIS (Patient Reported Outcomes Measurement Information Systems): (PI Amtmann)

• National Institute on Disability and Rehabilitation Research (NIDRR): National Rehabilitation Research and Training Center on Multiple Sclerosis: (PI Kraft)
He took a good book.
“Puh Tuh Kuh”
“We mow our lawn all year.”
“The puppy bit the tape.”
“I’m sitting in a job thinking should I really be doing this? It was hard for me on my own to figure out should I be teaching or shouldn’t I be teaching. I would have liked some sort of guidance. And I don’t know if just going in and reading five sentences—I’m thinking you don’t know what I’m going through. You’re not close to what I’m going through. I can read, ‘a puppy bit the tape’ or whatever but that’s not it.”

(Research participant with spasmodic dysphonia)
What is communicative participation?

• The communication that occurs
  – In real-life situations
  – As part of fulfilling required or discretionary life roles
    • Work
    • Education
    • Home
    • Leisure
    • Social
    • Community
Challenges with some ‘participation’ instruments in speech-language pathology

How difficult?
How often are there problems?
How effective?
Communicative Participation Item Bank (CPIB)

- Self-report instrument
- Community-dwelling adults
- Across communication disorders
- Situations in which people talk to each other
## The Communicative Participation Item Bank (CPIB)

<table>
<thead>
<tr>
<th>Does your condition interfere with...</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>...talking with people you know</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>...communicating when you need to say something quickly</td>
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<tr>
<td>...talking with people you do NOT know</td>
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<tr>
<td>...communicating in a small group of people</td>
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<tr>
<td>...getting your turn in a fast-moving conversation</td>
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<tr>
<td>...giving someone DETAILED information</td>
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<tr>
<td>...having a conversation while riding in car</td>
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<tr>
<td>...trying to persuade a family member or friend to see a different point of view</td>
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</tr>
</tbody>
</table>

46 items in the item bank / 10-item short form
Brief history of CPIB development

- **Qualitative Studies:** Experiences of Participation (MS, SD)
- **Construct Development / Item Drafting**
- **Rasch Analysis:** SD
- **Cognitive Interviews (SD)**
- **More Cognitive Interviews** (7 diagnoses)
- **IRT Analysis:** Item Bank Calibration (MS, PD, Cancer, ALS)
- **Publication of CPIB item bank and short form**
- **Sensitivity to change** (Voice, PD, Stroke – Motor speech)
- **Computerized Adaptive Testing**
- **Validation for aphasia; Other countries**
4 Questions for Today:

What is the essence of communicative participation?
4 Questions for Today:

What is the essence of communicative participation?

Can we untangle the knot?
4 Questions for Today:

What is the essence of communicative participation?

Can we untangle the knot?

Are people more alike than different?
4 Questions for Today:

What is the essence of communicative participation?

Can we untangle the knot?

Are people more alike than different?

Where do we go from here?
What is the essence of communicative participation?

“I go, but I don’t participate.”

--Research participant with spasmodic dysphonia
What makes you satisfied with your communication?

• Comfortable
  – It is easy
  – I feel confident

“I know I am satisfied because they (my friends) know me so well and it’s easy, I don’t have to explain things to them.”

Qualitative Interviews
8 adults with MS
Yorkston et al., 2007
What makes you satisfied with your communication?

• Successful
  – Function is achieved
  – Connection is made

  “I am satisfied with doing this because it helps me feel connected and like one of the gals. ..to me the satisfaction has a lot to do with staying connected, involved, and not being alone.”
What makes you satisfied with your communication?

• Personal meaning
  – Personal preferences
  – Comparison with the past (nothing has changed)
  – Thinking about your own communication (I don’t have to think about it)

“Doing my personal best is the measuring stick for just about everything I do.”
Two types of problems with communicative participation:

• Functional
  – “I have to do things differently because of my speech.”
  – Sometimes the “only way you can change a situation is to avoid it.”

• Emotional
  – I feel “like a bystander”
Capturing the essence of participation in the CPIB?

How satisfied are you... using the telephone?

Does your condition interfere with... using the telephone?
4 Ideas for Today:

Interference with feeling involved or connected; or getting the job done

Can we untangle the knot?
Why does this matter?
What influences communicative participation?
Qualitative Data

- Speech / Language Symptoms
- Participation
What influences communicative participation?
Qualitative Data

- Speech / Language Symptoms
- Health “soup”
  - Vision
  - Mobility
  - Fatigue

Participation
What influences communicative participation?

Qualitative Data

- Speech / Language Symptoms
- Health
- Social Environment
  - Communication Partners
  - Stigma

Participation
What influences communicative participation?

Qualitative Data

- Speech / Language Symptoms
- Health
- Social Environment
- Physical Environment
  - Noise
  - Telephone
- Participation
What influences communicative participation? Qualitative Data

- Speech / Language Symptoms
- Health
- Social Environment
- Physical Environment
- Situations
  - Groups
  - Fast
  - Detailed
What influences communicative participation?
Qualitative Data

- Personal Outlook
  - “I don’t let it stop me”
  - OR
  - “Holding back is a learned behavior”

- Speech / Language Symptoms
- Health
- Social Environment
- Physical Environment
- Situation

Participation
What influences communicative participation? Qualitative Data

- Speech / Language Symptoms
- Health
- Social Environment
- Physical Environment
- Situations
- Personal Outlook

Qualitative Interviews
44 adults across 7 disorders
Baylor et al., 2011
What influences communicative participation? 

Quantitative Data

**Significant Predictors** (strongest to weakest)

- Fatigue
- Slurred Speech
- Depression
- Problems Thinking
- Employment
- Social Support

\[ R^2 = .487 \]

**Non-significant Predictors**

- Pain
- Mobility
- Vision
- Age
- Education
- Gender
- MS Duration

Communicative Participation (CPIB)

Regression analysis
498 participants with MS
Baylor et al, 2010)
<table>
<thead>
<tr>
<th></th>
<th>MS</th>
<th>PD</th>
<th>Head and Neck Cancer</th>
<th>ALS</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>N = 216</td>
<td>N = 218</td>
<td>N = 197</td>
<td>N = 70</td>
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<tr>
<td>Speech Severity</td>
<td>*</td>
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<tr>
<td>Speaking demands</td>
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<td>Cognitive symptoms</td>
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<td>Emotional symptoms</td>
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<td>(anxiety / depression)</td>
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<tr>
<td>Ability to do physical</td>
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<tr>
<td>activities (mobility etc.)</td>
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<tr>
<td>Education</td>
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<tr>
<td>Age</td>
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<tr>
<td>Swallowing difficulties</td>
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<td></td>
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</table>
More variables to consider?

- Communication resilience?
- Self-efficacy?
- Beyond self-report?
- Speech / Language Symptoms
- Physical Environment
- Participation
- Health
- Social Environment
- Situations
- Personal Outlook
- Communication effort / fatigue?
- Communication Support?
- Stigma?
4 Ideas for Today:

- Interference with feeling involved or connected; or getting the job done
- Many influences on participation – understanding limited by available tools?
4 Ideas for Today:

Interference with feeling involved or connected; or getting the job done

Many influences on participation – understanding limited by available tools?

Are people more alike than different?
Why are we talking about a “cross-disorders” approach?
We are a profession of silos....
Avoiding situations

Sometimes the “only way you can change a situation is to avoid it.”

50 y.o. male, spasmodic dysphonia

“I go into the background and retreat,”

61 y.o. female, CVA

“Keep a low profile,”

67 y.o. female, Parkinson’s

“Drawing back”

66 y.o. female, spasmodic dysphonia
The emotional aspects of participation restrictions

I feel “like a bystander”
52 y.o. male, spasmodic dysphonia

I feel “out of the loop”
64 y.o. female, CVA

I feel like a “mop in the corner”
41 y.o. female, spasmodic dysphonia
The loss of expressiveness is a barrier

“It is hard to show you are angry if all you can do is whisper”

52 y.o. male, spasmodic dysphonia

“I had facts but no story telling aspects.”

56 y.o. male, CVA

“It’s like you are using a microphone and talking to someone in the front row.”

88 y.o. male, laryngectomy
Communication is easier with familiar people

People who know you well are willing to do “whatever it takes” to communicate with you.

52 y.o. male, spasmodic dysphonia

“There is no barrier if you know them well.”

41 y.o. female, Multiple Sclerosis

“People understand the problem and don’t let it get in the way.”

88 y.o. male, laryngectomy

69 y.o. male, Parkinson’s
The phone is a problem

The phone “trumps” all other problems

52 y.o. male, spasmodic dysphonia

The phone is a source of, “anticipation and anxiety.”

42 y.o. male, stuttering

I “hate the phone.”

60 y.o. female, laryngectomy
Is there quantitative support for the CPIB as a cross-disorder instrument?

- IRT analysis of Differential Item Function (DIF)
  - Item parameters same across disorders?
    - Item difficulty
    - Item discrimination

Diagnoses:
- PD
- MS
- HNCA
CPIB Scores across Diagnoses

Higher is better

$\text{p} = .092$

$\text{p} = .101$
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Participation:
Are people more alike than different?
We are a profession of silos....
Participation:
Are we more alike than different?
Are we a discipline of silos....?
4 Ideas for Today:

Interference with feeling involved or connected; or getting the job done

Many influences on participation – limited by available instruments

There are similarities in participation restrictions across disorders

Where do we go from here?
Measurement of Participation

• Current Projects
  – American Speech-Language-Hearing Foundation
    • DIF for aphasia
  – NIDCD R01
    • Meaningful change in CPIB with treatment
    • Contributors to change in communicative participation including clinician-judged measures of severity
    • Computerized Adaptive Testing (CAT)
    • Spasmodic dysphonia, vocal fold paralysis, PD, motor speech disorders due to stroke

• Future goals
  – Communication support?
  – Communication effort / fatigue?
Participation Focused Intervention

“...value should always be defined around the customer...”

(Porter, 2010)

• Typical speech-pathology goals:
  – Auditory comprehension
  – Word-finding
  – Grammatical utterances
  – Reading comprehension
  – Written expression

• What clients with aphasia wanted from speech therapy:
  – “Talking better”
  – “Getting out more and doing more”
  – “Having fun, enjoying life”
  – “Having self-esteem / confidence”
  – “Feeling in control”

(Kagan & Duchan, 2004)

(Worrall, 2006)
Participation-focused Intervention?

Impairment / activity-focused SLP tx + Facilitate awareness of other health and demographic influences + Environmental Accessibility
Making a meaningful difference in our clients’ lives...

“You do know what to do. But you don’t know me, and you don’t know my motivation and you don’t know my attitudes. Unless you really listen. Unless you really listen, then you may glean what’s it’s all about. But if you don’t listen and you’re on a roll of ‘this is what I want you to do’ ‘this is what you’re going to do’ ‘this is for your own good’. That’s maybe, absolutely true. But it doesn’t take care of me.”

(S.U. aphasia s/p CVA)

Runne, 2012 Thesis