A Functional Approach to Assessment in Dementia
**Some New Ideas**
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Disclosures
- Michelle Bourgeois’ Financial Disclosures:
  - Author for Health Professions Press, Memory and Communication Aids for People who have Dementia, for which she receives royalty payments.
  - Employed by the University of South Florida.
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State of the Art in Dementia
- 1980’s Bayles and Tomoeda developed first assessment tools
- 1990’s Interventions appear:
  - Memory books, Validation therapy, Reminiscence therapy, Caregiver-focused approaches
  - Spaced Retrieval
- 2000’s More approaches:
  - Montessori, Environmental Interventions
- 2014 Are we satisfied? Are our clients experiencing a quality life?
Which NH will YOU choose for your Mother or Father?

For YOU???

What’s possible:
A Meaningful, quality of life in a Nursing Home

https://www.youtube.com/watch?v=1LCRrcvXBE

ASHA Changing Health Care Landscape Summit (2012)

• The Affordable Health Care Act of 2012
• Critical need for patient-centered care that includes
  – measuring things that patients care about and notice, and
  – considering the patient’s perspective in determining the value of services.
• Patient-reported outcomes will be used
  – to measure functional improvement (or decline),
  – assess treatment effectiveness, and
  – investigate patients’ experiences of such phenomena as the burden of disability and quality of life.
How will we do this?

• Reconsider our usual approach to Rehab
  – Referral – Assess – Treat – Evaluate – Discharge
  – Clinician-focused approach

• Start at the End
  – Patient desires/discharge objectives – Treatments – Assess
  – Patient-centered approach

• Flip the rehab model

• FIRST,
  – Determine Patient opinions, desires, values
    • What do they want to be able to do?
    • What is meaningful to them?

• THEN,
  – Figure out what Assessments to use
    • to discover barriers to doing these desired things
    • to document baseline functioning
    • to measure progress or satisfaction

The WHO Model of Impairment, Activities, & Participation (WHO, 2001)
Living with Aphasia: Framework for Outcome Measurement (A-FROM)


Talking Mats

(Murphy, J. & Boa, S. (2012). Using the WHO-ICF with Talking Mats to Enable Adults with Long-term Communication Difficulties to Participate in Goal Setting. Augmentative and Alternative Communication, 28, 52-60.)
What is Meaningful; what is a Quality Life?

- Food and Shelter
- Someone to love, to talk to
  - Someone who loves you
- Something meaningful to do
  - A reason to get up in the morning
  - Enjoyable activities, interests
- Feeling useful and part of a community
  - Feeling appreciated for your contributions

How to determine goals?

- Interview the client
  - What will make your life here meaningful/pleasant?
  - What do you want to be able to do? What do you like to do?
- Interview the family
  - What was his/her usual routine and activities?
  - What would s/he want to be doing?
  - What would you like him/her to be doing?
- Interview the staff
  - What should s/he be able to do to function well here?
  - What is difficult for him/her to do independently?
- Evaluate the environment
Role of SLPs

- **Work in collaboration** with older adults to fill in the gaps of their abilities to allow them to spend their time doing what THEY choose to do (Brush, 2014)

- Use preserved abilities
- Modify the environment
- Continually educate and support staff
- Involve families

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**Participation Assessment Form**

**Name:**

**Date:**

- What are your interests?
- What did you do before?
- What would you like to do now?
- Who do you want to talk/interact with?
- What would make you feel useful?
- What could you contribute to this place?
- What is most meaningful to you?
- What would you like to do before it’s too late?

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**Evaluate the Environment**

- What’s available?
  - Someone to talk to (peers, staff, family, friends, pets)
  - Meaningful activities to do (book club, exercise group, walking the dog, setting the table, etc.)
  - Places to visit (chapel, beauty parlor, outside area, dining room, field trips, etc.)
- What are the barriers?
  - Facility-based: Auditory/visual barriers, lack of personnel, schedule
  - Person-based: Cognitive and physical limitations, familiarity, interests (likes/dislikes)
**Environment**

Barriers to communication and mealtime functioning
- Low light
- Poor contrast
- Small print

Facilitators to communication and mealtime functioning
- Wayfinding cues
- Large print labels
- High contrast

**Identify Environmental Barriers**

**Environment & Communication Assessment Toolkit for Dementia Care**

By Jennifer Brush, M.A., CCC/SLP; Margaret Calkins, Ph.D., CAPS, EDAC; Carrie Bruce, M.A., CCC/SLP, ATP, and Jon Sanford, M.Arch.

Includes:
- Sound level meter
- Light meter
- Personal Spaces Assessment Forms
- Public Spaces Assessment Forms

2011, Health Professions Press

www.dementiability.com
Personal Wants, Needs, & Safety Assessment Form
© Michelle S. Bourgeois, Ph.D.

Assessing the Wants, Needs, Safety of: ________________________

Environment:  Home   Hospital   Assisted Living    Nursing Home      (circle one)

Wants: The expression of personal preferences, likes and dislikes

Likes:   

Dislikes:  

Needs: The satisfaction of physical comforts and emotional needs

Physical: 

Pain:    

Emotional:

Safety: The prevention of harm to one’s self or others

Medication: 

Falls prevention:

Eating:

Personal hygiene:

Environmental constraints:

Emergency Contacts:

_________________________  __________________________
Functional Goals Screening Protocol: Community Clients with Dementia
© Michelle Bourgeois, Ph.D. CCC-SLP & Angela Halter Rozza, M.S. CCC-SLP

Name: __________________________________ Date of Screening: ________________

Medical Diagnosis:________________________________________________________

Date of Birth: _______________________  Age: ____________  Gender: _______________

PART 1:  CLIENT INTERVIEW

A.  Personal Information

<table>
<thead>
<tr>
<th>Family</th>
<th>Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lives with:</td>
<td>Hobbies</td>
</tr>
<tr>
<td>Friends</td>
<td>Activities</td>
</tr>
<tr>
<td>Preferences</td>
<td>Dislikes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Premorbid Basic Reading Ability</th>
<th>Yes</th>
<th>No</th>
<th>Unable to answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Premorbid Basic Writing Ability</td>
<td>Yes</td>
<td>No</td>
<td>Unable to answer</td>
</tr>
<tr>
<td>Wear Hearing Aid</td>
<td>Yes</td>
<td>No</td>
<td>Unable to answer</td>
</tr>
<tr>
<td>Wear glasses</td>
<td>Yes</td>
<td>No</td>
<td>Unable to answer</td>
</tr>
</tbody>
</table>

Other language spoken: ____________________________  Other:

B. NWEA Score:  ____________________________

Strength:  ____________________________

Weakness:  ____________________________
C. Conversational Sample:
Tell me about your family (or what you did for a living):

<table>
<thead>
<tr>
<th>Discourse Features</th>
<th>Present</th>
<th>Absent</th>
<th>No opportunity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Takes turns</td>
<td>______</td>
<td>______</td>
<td>______</td>
</tr>
<tr>
<td>Relinquishes turn</td>
<td>______</td>
<td>______</td>
<td>______</td>
</tr>
<tr>
<td>Maintains topic</td>
<td>______</td>
<td>______</td>
<td>______</td>
</tr>
<tr>
<td>Initiates new topic</td>
<td>______</td>
<td>______</td>
<td>______</td>
</tr>
<tr>
<td>Transitions from topic</td>
<td>______</td>
<td>______</td>
<td>______</td>
</tr>
<tr>
<td>Requests clarification</td>
<td>______</td>
<td>______</td>
<td>______</td>
</tr>
</tbody>
</table>

D. Orientation to Environment:

1. Show me where the bathroom is?
   - Able
   - Requires assistance (Mild, Mod, Max)
   - Not able

2. Show me where your telephone is?
   - Able
   - Requires assistance (Mild, Mod, Max)
   - Not able

3. Show me where I can get a glass of water?
   - Able
   - Requires assistance (Mild, Mod, Max)
   - Not able

E. Auditory and Tactile Behaviors:

1. Is attentive when others are talking?
   - Yes
   - No

2. Holds, squeezes, manipulates objects?
   - Yes
   - No

3. Is bothered by noises (radio, tv)?
   - Yes
   - No

4. Rubs, smooths, explores surface with hands?
   - Yes
   - No

5. Is attentive to or participates in music, singing?
   - Yes
   - No

6. Hits, bangs, slaps objects or surfaces?
   - Yes
   - No

F. Visual and Functional Reading Behaviors:

- Prompt client to "Tell me something interesting from this paper (magazine, mail, etc.)"
- Does client read aloud from the materials?
  - Yes
  - No
- Does client make comments about the topic?
  - Yes
  - No
- Complete form in Handout

Personally relevant End Goals (Kagan & Simmons-Mackie, 2007)
What the client hopes to accomplish at the end of treatment

- Food and Shelter
  - Client will eat without choking using a safe swallowing steps visual cue card
  - Client will find room using a visual cue (room number on wristband)

- Communication partners
  - Client will participate in mealtime conversation using visual cue cards
  - Client will talk on the phone with family members at scheduled times using a memo board calendar

- Meaningful activities
  - Client will participate in Book Club and Art Discussion groups
  - Client will set the table for meals using visual template

- Role in the community
  - Client will change the day/date on the community calendar
  - Client will offer and pour beverages for peers from rolling beverage cart

Example: Woman with PPA, living at home
(Thanks to Jennifer Brush, CCC-SLP)

- Client & Family identified desired activities:
  - Say blessing before meals (can’t remember blessing)
  - Empty dishwasher & put away dishes (can’t unload dishwasher in organized, sequenced fashion; takes excessive time)
  - Do laundry (difficulty sorting, organizing & folding clothing from dryer)

- Goals:
  - Client will read Blessing card before meals
  - Client will empty dishwasher, using labeled shelves/drawers and sequencing card
  - Client will follow visual checklist to wash laundry & templates for sorting/folding
What do we need to assess?

- To read Blessing
  - Oral reading ability; determine optimal size of font and complexity of text
- To empty dishwasher
  - Reading ability for checklist
  - Visual matching skills (labels – objects)
- To fold laundry
  - Reading ability for template
  - Visual matching skills (labels – objects)

So how do we assess and document...

- Pre-treatment
  - Oral reading ability?
  - Visual matching skills: words to objects?
  - Frequency of successful tasks (reading, unloading dishwasher, laundry)
- Post-treatment
  - Oral reading ability?
  - Visual matching skills?
  - Frequency of successful tasks
  - Client and Family satisfaction

Bourgeois Oral Reading Measure (1992)
(assessment of 2 font sizes)
I am fine.

How are you?

What a nice day.

Tired and true.

Live, laugh, and learn.

www.dementiability.com

Plate    Fork    Cup    Spoons    Knives

Create your own Match to Sample personalized assessments

Family-collected pre-treatment data:
Frequency of Desired Tasks

<table>
<thead>
<tr>
<th>Day</th>
<th>Says Blessing</th>
<th>% Success Unloading Dishwasher</th>
<th>% Success Sorting Laundry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tuesday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wednesday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thursday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saturday</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sunday</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Blessing before meals
Thank you, Lord, for this food – may it nourish us.
Thank you, Lord, for the people around this table – may they love and comfort each other.

Empty Dishwasher
Put away

Top Shelf
knives
forks
spoons

Middle Shelf
Glasses
Cups

Bottom Shelf
Plates
Bowls

Mine  Frank’s

↓
Socks  Socks

↓
Underwear  Underwear

↓
Shirt  Shirt

↓
Towels

But what about…??
• Expressive Language
• Receptive Language
• Memory
• Executive Functions
• Attention
• Visual-spatial/visual-perceptual skills
• Orientation
• Staging of Dementia
• ????????

And what about ….
Documentation!
- It drives the system
- Constrains us to specific coding categories and impairment-based measurement tools

Translating baseline data into NOMS scores
- Saying the Blessing
  - Memory: Level 2; requires maximal cues to recall blessing
  - Reading: Level 5; reads sentence-level material
- Unloading Dishwasher
  - Memory: Level 2; requires maximal cues for routine task
  - Attention: Level 2; unable to complete with maximal cueing
  - Problem Solving: Level 2; unable to complete with maximal cueing
- Sorting/folding laundry: Same as above

Standardized Measures Required?
- Comprehensive test batteries: too long
- Screening tests: denials from payers?
- Select subtests
  - Memory
  - Reading
  - Attention
  - Problem Solving
Commonly Used Comprehensive Assessment Tools

- **The Repeatable Battery for the Assessment of Neuropsychological Status** (RBANS; Randolph, 1998)
  - Includes 12 subtests yielding six indices, such as visuospatial, memory, attention, and language abilities

- **Ross Information Processing Assessment – Geriatric** (RIPA-G; Ross-Swain & Fogle, 1996)
  - Assesses attention, orientation, working/remote memory, verbal organization and reasoning, auditory and reading comprehension.

- **Communication Activities of Daily Living** (CADL-2; Holland, Fiattali, & Fromm, 1999)
  - Assesses orientation, attention, verbal and visual memory, confrontation naming, auditory comprehension, and executive functions.

- **Cognitive Linguistic Quick Test** (CLQT; Helm-Estabrooks, 2001)
  - Assesses orientation, attention, verbal and visual memory, confrontation naming, auditory comprehension, and executive functions.

**Brief Cognitive Assessment Tool (BCAT)** (Mansbach, MacDougall, & Rosenzweig, 2012)

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Orientation</td>
<td>Awareness of self, time, place, and situation</td>
</tr>
<tr>
<td>Immediate Verbal Recall</td>
<td>The ability to immediately recall a word list</td>
</tr>
<tr>
<td>Attention</td>
<td>The ability to accurately put names to objects</td>
</tr>
<tr>
<td>Abstraction</td>
<td>The ability to concentrate and focus</td>
</tr>
<tr>
<td>Auditory</td>
<td>The ability to determine how objects are similar to one another</td>
</tr>
<tr>
<td>Executive</td>
<td>The “command and control” cognitive abilities</td>
</tr>
<tr>
<td>Visuospatial</td>
<td>The ability to understand visual processes and relationships</td>
</tr>
<tr>
<td>Delayed Verbal Recall</td>
<td>The ability to recall previously presented words after a time delay</td>
</tr>
<tr>
<td>Immediate Story Recall</td>
<td>The ability to immediately recall elements of a story</td>
</tr>
<tr>
<td>Delayed Visual Memory</td>
<td>The ability to recall previously presented pictures</td>
</tr>
<tr>
<td>Delayed Story Recall</td>
<td>The ability to recall elements of a previously presented story after a time delay</td>
</tr>
<tr>
<td>Story Recognition</td>
<td>The ability to recall previously presented story elements after cuesing</td>
</tr>
</tbody>
</table>
Consists of ten subtests, each of which assesses a different functional activity:

1. telling time,
2. counting money,
3. addressing an envelope,
4. solving daily math problems,
5. writing a check/balancing a checkbook,
6. understanding medicine labels,
7. using a calendar,
8. reading instructions,
9. using the telephone, and
10. writing a phone message.
NINDS and NIH

- PROMIS: Patient reported outcomes measurement information system
  - www.nihpromis.org

- www.nihtoolbox.org
  - NIH Toolbox Cognition Battery: This battery, recommended for age 7+, consists of tests to assess Executive Function, Attention, Episodic Memory, Language, Processing Speed and Thinking Memory.

- www.neuroqol.org
  - Quality of Life Cognition Battery: Applied Cognition-General Concerns, Applied Cognition-Executive Function, Communication

---

### Applied Cognition - General Concerns

Please respond to each question or statement by marking one box per row.

<table>
<thead>
<tr>
<th>In the past 7 days...</th>
<th>Seldom</th>
<th>Rarely</th>
<th>Somewhat</th>
<th>Very often</th>
<th>Very often</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>I had to read something several times to understand it.</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>I had trouble keeping track of what I was doing if two people interrupted me.</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>I had difficulty doing more than one thing at a time.</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>I had trouble organizing my information, like phone numbers or simple instructions.</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>I had trouble thinking clearly.</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>My thinking was slow.</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>I had to work really hard to pay attention, or I would make a mistake.</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>I was mean to others.</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
</tbody>
</table>

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### Applied Cognition - Executive Function

Please respond to each question or statement by marking one box per row.

<table>
<thead>
<tr>
<th>How much DIFFICULTY do you currently have?</th>
<th>None</th>
<th>A little</th>
<th>Somewhat</th>
<th>A lot</th>
<th>Can't do</th>
</tr>
</thead>
<tbody>
<tr>
<td>checking the accuracy of financial documents, e.g., bills, checkbook, or tax statements</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>exerting the maximum amount of money when making purchases</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>reading and following complex instructions, e.g., directions for a new medication</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>planning for and keeping appointments that are not part of your weekly routine, e.g., a lunch with friends or a meeting with the doctor</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>managing your time to do most of your daily activities</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>taking care of complex tasks like managing a checking account or getting a prescription filled</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
<tr>
<td>keeping important personal items such as bills, insurance documents and tax forms organized</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
<td>1 1 1</td>
</tr>
</tbody>
</table>
Quality of Life Scales

- *ASHA Quality of Communication Life Scale (QCL; Paul-Brown et al., 2004)*

- *Dementia Quality of Life Scale (DQOL; Brod et al., 1999)*

- *Burden of stroke scale (BOSS; Doyle et al., 2004)*
Let’s take a break!

• When we return, let’s talk about
  – Interventions
  – Treatment approaches
• What is effective? What’s the evidence?