

Lessons Learned From Two Years of Family Workshops

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Abstract

Multi-hour, multi-day training is required in order to change the communication behaviors of primary communication partners of those with aphasia (Hinckley, Douglas, Goff & Nakano, 2013). For two years, we have been offering a two-day, 8-hour workshop at local hospitals and rehabilitation facilities. The purposes of this poster are to 1) report on immediate satisfaction reports of our attendees, 2) discuss longer term outcomes experienced by those who attended the workshop, and 3) to discuss the interesting challenges and questions that have arisen while delivering this workshop.

Program Participants

In the last two years, a total of 30 participants have attended the workshop. Each person with aphasia and his/her primary communication partner who attended were asked to complete survey at the end of the session, and a semi-structured phone interview between 6 and 24 months after workshop participation. This poster reports the immediate outcomes of 70% of the participants, and the long-term outcomes of 33% of the participants.

Long-Term Outcomes

Common themes emerged from our interviews:

Theme: Feelings of hope

"[The conference] gave us hope for continued progress."

Theme: We are not alone

"The big thing was, I saw other people had the same thing. It was an eye opener for me."

Theme: Communication tools

"[I learned] how to talk to my mom and how to ask her questions."

Program Description

Consistent with a recent review of the needs of relatives of people with aphasia (Hilton, Leenhouts, Webster & Morris, 2014), the purposes of the program are to: 1) provide people with aphasia and their families personalized information about successful communication techniques in a group setting 2) connect individuals and their families now living with aphasia with others in the community, and 3) provide local resources.

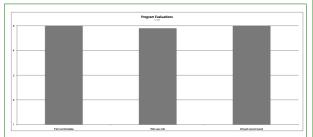
Day 1: "I have aphasia - what is it?"

Time	Topic	Activities	
10:00 - 11:00	Introductions What is aphasia?	1. Introductions 2. Complete NAA Knowledge quim 3. What is aphasia? -different types of aphasia -different modalities	
11:00 - 11:15	BREAK		
11:15 - 12:15	Starting to identify strategies: Break-Out sessions	People with aphasia: 1. What strategies do you use? 2. Complete self-advocacy card 3. What communication challenges do you experience?	Caregivers: 1. Enhancing empathy through aphasia simulations 2. What are your communication challenges?
12:15 - 1:00	LUNCH (included)		
1:00 - 2:00	Frustrations and resources	Share challenges identified before lunch Show/share self-advocacy strategy cards Demonstrate/practice strategies	

Day 2: "Now what?"

Time	Topic	Activities		
10:00 - 11:00	Supported	Define supported conversation for aphasia Demonstrate with video examples		
	Conversation for			
	Aphasia			
11:00 - 11:15		BREAK		
11:15 - 12:15	Strategy skill practice	Persons with aphasia: Practice	Caregivers: Use supported	
	and resources: Break	communication strategies with peers	conversation role plays to continue	
	out sessions	support and coaching	practice strategies	
12:15-1:00		LUNCH (included)		
1:00 - 2:00	Developing a personal	l 1. "It's Still Me" video (15 min) and discussion		
	plan	3. Share personal action plans		

Immediate Outcomes



Average ratings from 21 completed evaluations at the end of the 2-day program.

Selected Comments - Participants:

"I got so much out of it. I didn't know what to expect. It was like a college education in 2 days."

"Its very motivating."

"Even though it has been 11 years since [my husband's] stroke, we learned a lot!"

Selected Comments - Host facilities:

"We were really impressed!"

"I learned a lot, thinking about what I do in acute care..."

Lessons Learned

- •We expected education about aphasia to be the biggest impact; however, the surveys revealed feelings of hope and reassurance from others with the same experiences were the most common, lasting impacts.
- •The continued use of new communication tools learned during the workshop persisted, even 24 months after the workshop.
- •No matter how much we try to standardize the workshop, each instance is different based on the attendees.
- •We don't screen attendees in advance, except perhaps for a brief phone conversation. This keeps a very open door, but is also a clinical challenge.

A Few Challenges

- Caregivers breaking down
- Disruptive attendees
- Overdependence
- Attendees living with PPA