

# Telling the Stroke Story: AphasiaBank as a Teaching Tool

Margaret Forbes<sup>1</sup>, Davida Fromm<sup>1</sup>, Audrey Holland<sup>2</sup>, Brian MacWhinney<sup>1</sup>

<sup>1</sup>Carnegie Mellon University, <sup>2</sup>University of Arizona, Emerita

## Introduction

Each aphasic stroke survivor has a unique stroke story, although many have to struggle to them. Clinicians should learn to help people with aphasia (PWAs) communicate their stroke and recovery stories, and other stories, for several reasons, all relevant to the Life Participation Approach to aphasia.

1. **PWAs need people to communicate with them directly.** Lloyd et al. (2006) note that much qualitative research has effectively omitted people with communication difficulties, selecting articulate participants and interviewing caregivers rather than PWAs about their experience. They argue that it is essential to interview those who actually have language difficulties to respond effectively to their needs.

2. **PWAs need to tell stories, especially the story of their stroke, and clinicians need to hear them.**

"The self comes to terms with society through narrative identity." (McAdams, 2008)

"While speech-language pathologists focus on the recovery of functional communication, less attention has been given to the ability to project oneself to the world that can result from successfully communicating a stroke narrative, a type of illness narrative." (Ulatowska et al., 2011)

"For medical professionals to practise with humility, trustworthiness, and respect, they must first have an understanding of the reality of illness as lived by their patients." (Charon, 2006)

Illness narratives can help accomplish that goal.

"Clinical narratives are just as important as hard neuroscience." (Oliver Sacks, 1993)

3. **Clinicians need to facilitate stroke narratives and learn from them.** Each story furthers our understanding of what it feels like to have a stroke that compromises the easy communication that most of us take for granted. Each story also contains implicit or explicit clues about what might help the story-teller communicate the story more successfully.

## Objective

Describe one way to use AphasiaBank stroke stories as a teaching/learning tool for facilitating story-telling.

The Exercise: for a group, including students and instructors

Students prepare by reading about methods of conversational support, e.g. Garrett et al. (1992), Holland (1998), Kagan (1998), Simmons-Mackie (1998)

Students each choose and present a video, demographic and test data for one AphasiaBank participant and tell what kinds of support they would try and why. Group/instructors discuss.

No "right" or "wrong" answers, just thoughtful possibilities

Stories from a wide variety of PWAs are available, with video linked to transcriptions:

330 Stroke stories in AphasiaBank as of March 2015

Age range = 25 to 91 years old

Aphasia types, by Western Aphasia Battery (WAB) classification:

Anomic	106
Broca	76
Wernicke	25
Conduction	57
Global	4
Transcortical Sensory	2
Transcortical Motor	1
Normal Range	31
No WAB	19

WAB Aphasia Quotients range from 10.8 to 99.6.

## Examples



Story improves with help



co-constructing works

## Summary

Many fields, including speech-language pathology, are increasingly understanding the importance of telling personal narratives, including illness narratives.

"... the stories we construct to make sense of our lives are fundamentally about our struggle to reconcile who we imagine we were, are, and might be in our heads and bodies with who we were, are, and might be in the social contexts of family, community, the workplace, ethnicity, religion, gender, social class, and culture writ large." (McAdams, 2008)

## References

- Armstrong, E., Ulatowska, H. (2007). Making stories: Evaluative language and the aphasia experience, *Aphasiology*, 21, 6-8, 763-774.
- Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. New York: Oxford University Press.
- Garrett, K. L., Beukelman, D. R., & Yorkston, K. (1992). Augmentative communication approaches for persons with severe aphasia. *Augmentative communication in the medical setting*, 245-338.
- Holland, A. L. (1998). Why can't clinicians talk to aphasic adults? *Aphasiology*, 12(9), 844-847.
- Kagan, A. (1998). Supported conversation for adults with aphasia: Methods and resources for training conversation partners. *Aphasiology*, 12(9), 816-830.
- Lloyd, V., Gatherer, A., Kalsy, S. (2006). Conducting qualitative interview research with people with expressive language difficulties. *Qualitative Health Research*, 16(10), 1386-1404.
- McAdams, DP (2008). Personal narratives and the life story. In O. John, R. Robins, & L. Pervin (Eds.), *Handbook of personality: Theory and research* (3rd ed.). New York: Guilford Press.
- Sacks, O. (1993). Narrative and medicine. *Mount Sinai Journal of Medicine*, 60(2), 127-131.
- Simmons-Mackie, N. (1998). In support of supported conversation for adults with aphasia. *Aphasiology*, 12(9), 831-838.

AphasiaBank is funded by NIH-NIDCD grant R01-DC008524 (20012-2017). To join: macw@cmu.edu