



Aphasia Book Clubs: Lessons Learned Over the Past Twenty Years

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BACKGROUND

Book clubs are a popular social activity. However, individuals with aphasia often have difficulty participating. In 1999, the Aphasia Center of California created the Book Connection™ program in order to make book clubs accessible to people with aphasia. This poster includes clinical suggestions and program outcomes from the last twenty years.

Many everyday activities and hobbies require language skills, such as pleasure reading or sending an e-mail to a friend. Such participation is consistent with the World Health Organization's framework (LPAA Project Group, 2000, WHO, 2001) as well as the ASHA Scope of Practice (ASHA, 2016). The impaired ability to read for pleasure is frequently named as a significant loss for people with aphasia.

Book clubs have been around for hundreds of years. They have seen renewed interest since the late 1990s, due, in part, to increased media attention, most notably from Oprah Winfrey's book club (Hoffert, 2006). Oprah's book club encouraged television viewers to read a diverse array of books and to talk with one another about what they had read.

The "Oprah phenomenon" was a catalyst for the Aphasia Center of California's (ACC) shift from impairment based reading and writing classes to the Book Connection™, a book club specifically designed for people with aphasia. The Book Connection™ provides participants with the opportunity to affiliate with others as well as exchange thoughts, opinions, and feelings. Attending such classes can provide participants with an important sense of community (Elman, 1999, 2007a,b, 2016, 2018, 2019a,b; Elman & Bernstein-Ellis, 1995; Kagan & Gailey, 1993; Luterman, 2001; Ryff & Singer, 2000). In addition, research has demonstrated that aphasia groups can provide members with the needed support and confidence for reintegrating into the community at large (Elman & Bernstein-Ellis, 1999a,b).

CLINICAL METHODS



"Off the Shelf" Supports/Reading Ramps

Written Book and/or Unabridged Audiobook

- Choice of Large Print or Regular Print Book or e-reader
- Audiobook—choice of using their own e-reader or National Talking Books Library machine
- Maps and Internet information

Supports/Reading Ramps Created by the ACC

- **Chapter Highlights** (similar to CliffsNotes but with simplified vocabulary and grammar)
- **The Boy who Harnessed the Wind**
 - **William begins to put together his windmill. He burns holes in the plastic blades and attaches them to the fan. The blades of the windmill are over 8 ft across!**

Character Guides

Timelines and other Schematics

- **Worksheets A, B & C** are created for each chapter

Worksheet A = Multiple Choice or Ratings

A Dog's Purpose

Why does Bailey bark and cry when he is in the garage at night?
He is lonely He is happy He is tired

How much do you like Bailey?

Not at all	So-so							A lot!	
1	2	3	4	5	6	7	8	9	10

Worksheet B = Phrase & Sentence Writing

The Homecoming

Becky blames Pattie-Cake for the horse not talking.

What is supposed to happen in the barn at midnight? What does Olivia say to Becky? Has someone ever told you something that ruined your belief in something? Do you still believe in miracles? Why or why not?

Worksheet C= Drawn & Single Word Answers

Water for Elephants

What was your favorite part of the chapter? Use key words or draw a picture of this part.

Weekly Discussion Sessions facilitated by SLP

- Meets 1 hour week – up to 10 members
- Group members volunteer to summarize chapters and co-lead discussions
- Discussions focus on reactions to book and personal connections. Not focused on facts. Time allotted for clarification of the story.

"What surprised you about this chapter?"

"What do you think of character 'X'?"

"Who do you know that reminds you of character 'X'?"

"What would you do in 'X' situation?"

"How did you relate to 'X' s dilemma?"

"How would you describe 'X'?"

GOAL = maximize participation in the book club and **reading for pleasure** through the use of the various supports or "Reading Ramps."

Books are chosen using the following criteria:

- Length – 12 weeks or less to complete
- Uncomplicated narrative line
- Available in Large Print and Talking Book Library audiobook versions
- Genre of books varied over time

RESULTS

A total of **362** program satisfaction surveys have been completed since 1999. During this time period, materials for 35 age-appropriate books have been created. Weekly discussion sessions have been held with an average of 15 PwA enrolled across 2 weekly groups. The satisfaction survey included multiple choice and yes/no questions as well as questions requiring ratings (1 = "not at all"; 5 = "somewhat"; 10 = "a lot"). The questions focused on participant satisfaction of the content, format, and perceived outcomes following their participation in the Book Connection™ group. In addition to quantitative questions, an open-ended question was also provided, "What other feedback do you want to share about the Book Club?"

•362 ratings across 33 books

Enjoyed the weekly discussions: M = 8.83, SD = 1.53

Enjoyed the book: M = 8.27, SD = 2.01

91% said that they definitely wanted to enroll again

CONCLUSIONS

Reading for pleasure is frequently reported as a significant loss for many people living with aphasia. Adapted book clubs provide a way for people with aphasia to return to reading age-appropriate literature while providing an understanding environment that fosters communication through discussion and debate.

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