

Rebuilding Identity: A Book Group Experience

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Introduction

Aphasia book clubs offer PwA the opportunity to connect with literature and read for pleasure. A text about those problems and dilemmas shared by the readers may help to facilitate a deeper understanding and healing, a therapeutic approach referred to as bibliotherapy.

A recent publication, *Identity Theft: Rediscovering Ourselves After Stroke* chronicles the recovery of Dr. Meyerson, along with the stories of other stroke survivors and their carepartners. Meyerson describes how rehabilitation programs often leave survivors with a sense of "failure" if they don't regain all their capabilities. She proposes the need to reconstruct positive identities in the face of whatever disabilities remain, in order to rebuild rewarding lives.

The purpose of this preliminary study is to understand the perceived impact of reading this text in an aphasia book club for PwA.



Methods

Book Groups	Boston University ARC	Cal State East Bay ATP
Number of Groups	2	3
Number of Members	9-10	6-8
TPO range	8 months-22 years	6 months-20 years
Aphasia Severity	Mild to Moderate	Mild to Moderate-Severe
Age range (years)	25-89	32-75
Gender	10 male; 9 female	10 male; 11 female
Total Participants	19	21

Forty participants with chronic aphasia enrolled in one of five book clubs offered at two local university-based aphasia centers. Members self-selected to participate in the group.

The text was divided across 10 weeks and reading ramps were developed and provided to all participants to support comprehension of the text. Weekly 75 (BU) or 90 (CSUEB) minute conversation groups were facilitated by graduate students and under the supervision of experienced speech-language pathologists.

Participants discussed material from the weekly readings which included recovery frameworks, experiencing frustration and grief, stroke as a family illness, advocating, relationships, and fulfillment through growth.

Methods

Qualitative research methods were employed to learn what PwA perceive to be impactful about their book club experience.

Semi-structured qualitative interviews were conducted online at the conclusion of the book with 27 participants. Interviews lasted an average of 20 minutes and contained two conversational prompts exploring book club members' perception of the impact of :
1) reading a book about the emotional recovery and identity renegotiation after stroke and 2) reading this book within a book club setting.

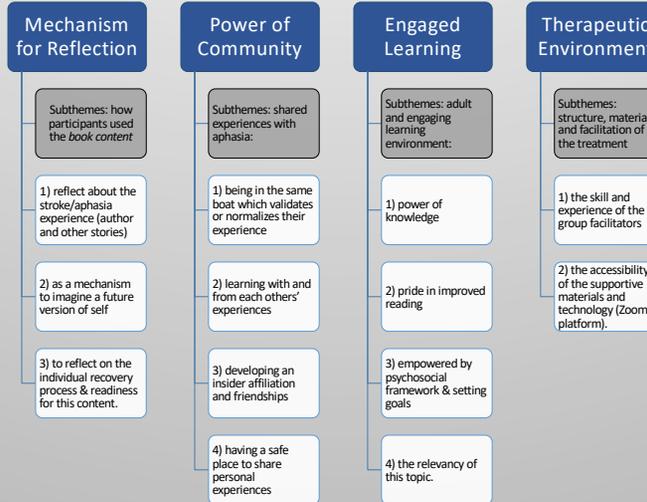
Conversations were facilitated with communication supports as necessary (gestures, drawings, and follow-up questions.) Transcripts of the interviews were analyzed using the six phases of reflexive thematic analysis outlined by Braun and Clarke. Two authors reviewed and coded the transcripts, meeting regularly to discuss coding differences and similarities across the data set. Themes, subthemes and thematic maps were developed collaboratively and recursively. This project received CSUEB IRB approval.



Braun and Clarke (2006; 2022)

Results

Themes and Subthemes



Results

And, but so I read it. I'm so lucky. I'm so lucky after reading this story. And some people have horrible times. And, and they get stronger and stronger and live with whatever is wrong with them. They become stronger and stronger, usually. And then, and so you need to be patient.

Everybody's journey is different of course, but when you read about a person you connect with certain things about that person's journey that is either the same or different that what you went through.

I did not laugh at anything for those first years. And as you know, now I can. Now, I can laugh at aphasia um...because it is not the end of me anymore. It thought it was the end of me, but it is not. The people use a term, they call it, it is your new normal...and that is okay, butmy point, is that it is not my new normal, this is me.

It didn't make me feel like a child- didn't talk down to me

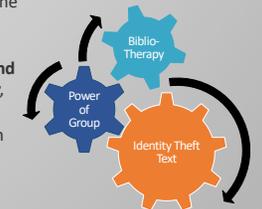
It's like the bible of, of uh uh identity....it's good to be able to have control over the identity I want going forward.

I feel like uh a lot of reading make me feel a lot of progress

When I talk to other people and got, and ittheir input, and I had the same input, then I then I got more out of it, out of the book than I did with only only um reading it myself.

Conclusions

These themes align positively with the outcomes identified by the bibliotherapy process by providing mechanisms of change, catharsis and positive development. Additionally, these findings support that reading literature about relatable stories can provide PwA an opportunity to process emotional reactions and develop coping mechanisms. One caveat: timing may be an important factor for some PwA. People may vary in their readiness to read this book. Given the high incidence of distress and depression and the lack of services that address post-stroke emotional recovery, reading this book may help support the renegotiating of a positive identity, a well-established critical issue for adjustment and recovery with aphasia.



Selected References

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