

Presentation Summary

Reading difficulties experienced by people with aphasia adversely impact their ability to access reading materials including novels, magazines, letters and health information (Brennan, Worrall, McKenna, 2005; Dietz, Ball & Griffith, in press). Connecting to family and friends through e-mail and Facebook is arduous, and leaves them with a sense of isolation in an “age of literacy.” Thus reading intervention is a critical component of aphasia rehabilitation.

A variety of restorative and supported reading interventions for PWA are available to help alleviate the challenges associated with reading (Brennan et. al., 2005; Cherney, 2005; Mayer & Murray, 2002; Orjada & Beeson, 2005; Rogalski & Edmonds, 2008). However, anecdotal information suggests that people with aphasia have limited awareness regarding the resources to help them navigate written material. Therefore, the purpose of this study was to explore the reading practices of PWA and to discover how PWA developed strategies to access written material.

Methods

Qualitative Approach

The researchers employed a phenomenological qualitative approach. Phenomenology assumes that people’s experiences are rooted in their relationships with other people, events, things, and situations as life events occur and that these experiences may be revealed through in-depth interviews. The in-depth semi-structured interviews of the person with aphasia and their caregiver, provided a window into their knowledge and access of restorative and supported reading interventions designed for people with aphasia.

Participants

The participants included 16 people. Eight participants were people with aphasia (PWA) who had a left cerebral vascular accident and were (a) right handed (b) were at least 12 months post stroke and medically stable, (c) native speakers of American English, and had at least a high school education. Table 1. displays the demographic information for the participants with aphasia. The remaining eight participants were caregivers (CGs), of the participant with aphasia.

Procedures

Each interview was video recorded and orthographically transcribed by a researcher and cross-checked for accuracy by a second researcher. Following transcription, the same researcher employed an inductive coding analysis to allow further understanding of specific domains regarding the reading practices of the person with aphasia.

Reliability

The researchers sampled 20% of the transcripts to determine reliability of the thematic coding. The inter-rater reliability for thematic coding was 95% for the PWA transcripts and 90% for the caregiver transcripts.

Results & Discussion

The researchers unveiled five major themes regarding the reading practices of PWA and how PWA developed strategies for navigating written materials. These themes include: (a) barriers to reading, (b) reading materials, (c) reading strategies, (d) reading comprehension, and (e) reading therapy delivery. Table 2. provides an operational definition of each theme with a numerical reference to the number of times each theme occurred throughout the transcripts.

Barriers to Reading

The following excerpts from the typological analysis highlight the barriers to reading that PWA often experience years after the stroke such as frustration and avoidance:

(Janet) "People think I'm dumb . . . because I can't read . . . but I don't tell them that I can't."

(John's CG) "He gets frustrated because he knows without his reading he can't return to work."

Reading Materials

In our computer driven society, both the PWA and their CG's understand the importance of accessing written material via the internet and reading e-mail correspondence as necessary skills for returning to previous employment or connecting to family and friends. The analyses revealed that although computer literacy permeates our everyday lives, PWA tend to struggle with this media. Janet's CG pointed out, *"She doesn't sit down and read email-nah, it doesn't happen"*. However, the findings suggest that some PWA find magazines to be motivating to read in the chronic stages of aphasia. Matt's CG comments, *"Once he started picking up things [reading] better, he started to order magazines again."*

Reading Strategies

With text-to-speech options becoming more readily available on the computer, a number of PWA and CG's are interested in using this technology as a strategy to augment their reading. *(John's CG) "He does have natural reader. He can highlight things and it will read it to him."* However, the findings suggest that all too often, in an effort to circumvent their frustration and enhance their understanding of the text, PWA turn to strategies such as having their caregiver read the text for them. John, the PWA, describes the following scenario for the researcher:

(John) "Brenda [wife] come here . . . reading, reading."

(Researcher) "So if you find something is hard to read you ask Brenda?"

(John) "Yes."

Reading Comprehension

The analyses illuminated the finding that both the PWA and their caregivers are sometimes skeptical regarding the extent to which PWAs comprehend written material. Most, however, are convinced that they are continually seeing improvement in their reading ability. Dan, a PWA, describes his perception of his reading comprehension to the researcher:

(Dan) "Reading, um, very good . . . but still. . . now but because of aphasia and everything . . . bad . . . a little bit . . . because now, um (reaches for book off shelf and opens it as though to read), maybe a little bit . . . but otherwise, no . . . really yet."

Reading Therapy Delivery

Additionally, the inductive analysis surprisingly revealed that as PWA silently struggle with their inability to read proficiently, they often turn to family members, not the SLP, for help in recapturing this skill. Kurt, a PWA, shares the following information with the researcher when describing his journey of reading recovery:

*(Researcher) "Who helped you learn how to read again?"
(Kurt) "Mom and dad."*

Clinical Implications

The results of this study support previous research that speaks to the reading challenges of people with chronic aphasia and their struggle to regain this highly valued life skill. The data revealed that PWA and their CGs have developed a variety of strategies for coping with their reading loss including the pursuit of strategies such as text-to-speech options with computer software or the reliance on their CGs to translate written information. Interestingly, very few of the participants mentioned that they sought the assistance of an SLP. In fact, one participant stated, "You (SLPs) work on reading?" These findings highlight the need for clinicians to address the reading needs of people with aphasia.

With rising health care costs and therapy visits at a premium, many PWA and their CGs are left adrift to manage their acquired reading difficulties. As PWA move into the chronic stages of aphasia following the stroke, they may be better prepared to tackle their reading challenges since that have likely established an effective communication system. Therefore, the findings of this study suggest that it is imperative that SLPs (1) educate the PWA and their CGs about available reading interventions, (2) develop personalized reading interventions based on current coping strategies, and to (3) collaborate with physicians to facilitate appropriate referrals for reading assessment in the chronic phases of follow up medical care (see Figure 1.).

References

- Brennan A., Worrall, L., McKenna K. (2005). The relationship between specific features of aphasia-friendly written material and comprehension of written material for people with aphasia: An exploratory study. *Aphasiology*, 19, 693-711.
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- Mayer J. F., & Murray, L. L (2002). Approaches to the treatment of alexia in chronic aphasia. *Aphasiology*, 16(7), 727-743.
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Table 1:

Demographic data for participants with aphasia.

| Name | Age | Educ. | MPO | WAB: AQ | Aphasia Type | Total RCBA | Caregiver Relation |
|-------|-----|-------|-----|------------|--------------------------|---------------|-----------------------|
| John | 40 | BA | 21 | 63.3 | Broca's | 84 | wife |
| Kurt | 55 | MA | 23 | 60.7 | Transcortical Sensory | 67 | sister |
| Sarah | 65 | MA | 120 | 52.1 | Broca's | 88 | husband |
| Matt | 57 | BS | 48 | 72.4 | Transcortical Motor | 92 | wife |
| Bob | 37 | BA | 60 | 76.6 | Anomic | 75 | girlfriend |
| Pam | 72 | AS | 252 | 61.1 | Broca's | 81 | husband |
| Janet | 56 | AS | 132 | 66.0 | Anomic | 75 | husband |
| Dan | 57 | BA | 48 | 61.8 | Broca's | ----- | wife |

Table 2:

Major themes, description, and number of occurrences.

| Major Theme | Description | Number of Occurrences |
|-----------------------|------------------------------------|-----------------------|
| Barriers to Reading | Frustration | PWA = 59 |
| | Avoidance | CG = 127 |
| | Independence | |
| | Motivation | |
| Reading Strategies | Caregiver | PWA = 54 |
| | Text-to-Speech | CG = 98 |
| | Computerized Software | |
| Reading Comprehension | Perception of Meaning from text | PWA = 46 CG = 49 |
| | Caregiver/Family Member | PWA = 19 CG = 16 |
| Reading Materials | Emails/Internet | PWA = 101 |
| | Magazines | CG = 117 |
| | Novels | |

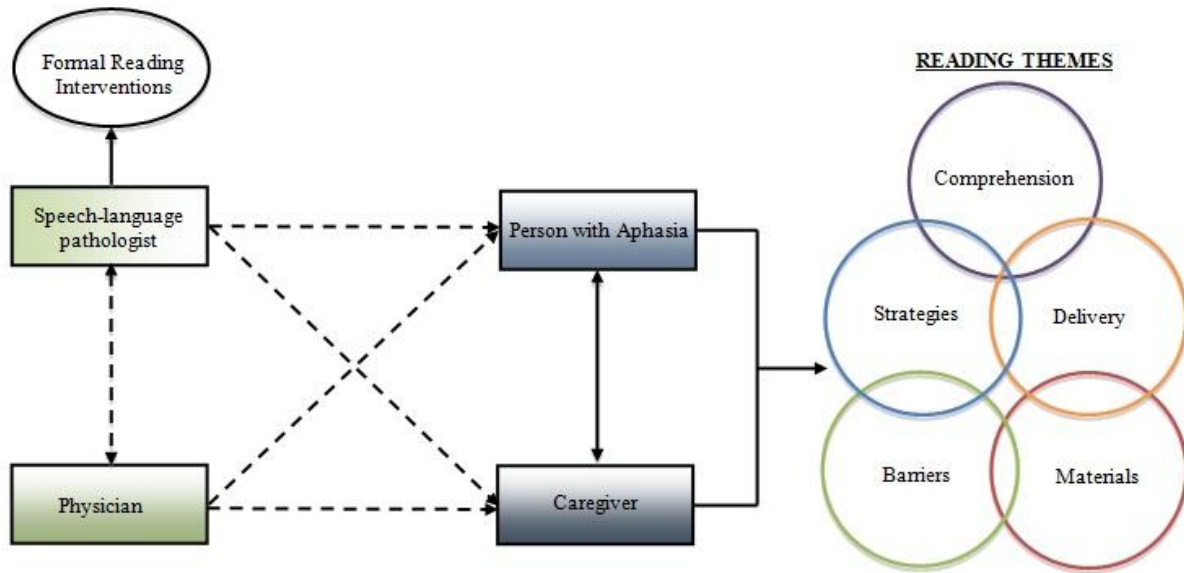


Figure 1. Relationship of major reading themes to the clinical management of reading challenges experienced by people with aphasia.