

## Moderate-severe, chronic aphasia: An exploration of the changes in social roles

People with aphasia chronic aphasia often encounter changes in their employment, reduced participation in leisure activities, and significant changes in family dynamics (Code & Herrmann, 2003; Michallet, Tetreault, & Le Dorze, 2003). Speech-language pathologists (SLPs) play an integral role in assisting people with aphasia regain these social roles or reestablish new social roles that are compatible with their current communication abilities. In order to develop appropriate intervention plans, especially with people who have moderate-severe aphasia, SLPs often collaborate with their family members or friends to assist with the development of treatment plans. This strategy is likely based on the assumption that those who spend lengthy amounts of time with people with aphasia, or those who had close relationships with them prior to their stroke, have a strong understanding of their current communicative priorities. As such, the purpose of this study was to explore the changes in social roles that people with living with moderate-severe, chronic aphasia experience, through the voices of their family and friends, then, validate the findings with people who have moderate-severe, chronic aphasia.

### *Methods*

#### *Qualitative approach*

The researchers employed a phenomenological qualitative approach to explore the experience of social role changes associated with chronic aphasia. The researchers used in-depth interviews as a tool to explore the lived experience of the changes in social roles caused by moderate-severe, chronic aphasia (Morse & Richards, 2002).

#### *Participants*

Clinical supervisors at several university speech-language and hearing clinics identified three people with moderate-severe, chronic aphasia and limited social roles secondary to their aphasia. Inclusion criteria required the participants to have a documented *Western Aphasia Battery* Aphasia Quotient (Kertesz, 1982) below 60, ability to answer accurately yes/no questions, and success communicating using augmented communication strategies. One of the researchers met with the participants with aphasia and their caregivers to explain the study and, at this time, requested the name second family member or friend to interview. The study included nine people, one person with moderate-severe, chronic aphasia and two family members or friends, which comprised three *interview sets*.

#### *In-depth Interviews*

Three researchers individually interviewed the family and friends. The themes from these interviews were used to formulate the questions for the interviews with the participants who had aphasia. Due to the severity of participants' aphasia, the researchers formatted the interview questions in an aphasia-friendly manner. Additionally, the researchers provided augmented input (Garret & Lasker, 2005) to clarify questions and verified communicative intent using the "speaking for" strategy (Simmons-Mackie, Kingston, Schultz, 2004; pp. 122), as necessary. These strategies also served as probes to assist the participants with aphasia in expanding their ideas following responses to yes/no and simple Likert scale questions. Each interview was recorded and orthographically transcribed by the interviewer and cross-checked for accuracy by another researcher.

### *Data Analyses*

Following transcription, the same researcher employed a typological coding analysis (Hatch, 2002) based upon previous research on social role changes following aphasia. The categories were defined as interpersonal relationships and activities (Code & Herrmann, 2003; Michallet et al., 2003). The researcher marked entries according to the established typologies. If entries formed a theme that did not fit within one of the abovementioned typologies, the researcher highlighted it for inductive analysis. A within transcript process was employed; that is, each participant's transcript was individually analyzed prior to analyzing the next participant's transcript. Next, an across transcripts method was used to compare and contrast the patterns, themes, and relationships, for each typology, across the three participants in each interview set (Hatch, 2002). For the inductive analysis, the researcher used the perspective of each participant as the frame of analysis. The researcher reread each transcript and identified relationship of the previously highlighted themes across all nine participants (Hatch, 2002). After the primary researcher completed the initial coding, a second researcher verified the findings using the same processes. The researchers discussed their findings and all discrepancies were recoded based upon the mutual agreement. This allowed validation of the findings via triangulation of the in-depth interviews, coding by two researchers, and prior research on social role changes.

### *Results*

The following excerpts from the typological analysis support previous reports of aphasia-related social role changes such as interpersonal relationships and activities:

*Jim's Wife:* "...whenever I'm in a room (with him and other people), he immediately looks to me to decipher for him and ...I find myself trying to remove myself from his vicinity because I know I'm a huge crutch for him."

*Paul:* "Yeah but I can't read so that's that yeah I can kind of kind of but I can't but..."

*Researcher:* "Newspaper?"

*Paul:* "Yeah, but, I can't read...I can kinda see it."

*Researcher:* "Do you read the headlines and pick the ones you want her to read? (Pause) Is that what you do at night?"

*Paul:* "Yeah, I can. I say here, here, here (pointing)."

The analyses also revealed differences in the perception of *how* these changes affect each person interviewed. Further analysis Jim's interview set (see above) regarding his socialization with friends illustrates how differently each participant perceived the impact of aphasia on the pre-stroke ability to socialize with friends. The mother responded with, "...it hasn't stopped them from going to a dance or a party." While Jim, the person with aphasia, and the researcher co-constructed following:

*Researcher:* "How is communication?" (while he is socializing)

*Jim:* "Repeat."

*Researcher:* "How is communication?"

*Jim:* "Repeat."

*Researcher: "How is....?"*

*Jim: "I know. Here. Question. Repeat. Repeat. Oh. Nice to meet you."*

*Researcher: "Oh. I thought you were telling me to repeat (what I said)...So you make people repeat?"*

*Jim: "Yeah!"*

Another spouse perceived role changes secondary to physical disabilities as more significant than the aphasia, "...most of the time...I know what she (Ruth) wants...I still got my roses she always had her flowers which she can't do now...Well she can't cook and she's a wonderful cook..." Meanwhile, the adult daughter appeared more affected than she, "...lost [her] best friend." Ruth, however, communicated that she was equally frustrated with both the physical and communicative disabilities caused by the stroke.

Additionally, the inductive analysis highlighted the participants' perspectives on the use of high- and low-technology augmentative and alternative communication (AAC) to facilitate communicative interactions. The following excerpts highlight experiences—or the lack thereof—with AAC:

*Jim's Wife: "...he...should have had a computer (AAC device) in his room (at the hospital)...I think they could very easily give patients...(a) portable computer..."*

*Paul's Friend: "Of course he's not able to verbalize a lot of things so sometimes you have to write things down ...on pieces of paper..."*

*Ruth: "What about your computer? (pause) Did you use that to tell her (the housekeeper) what to do (point to a picture of her AAC device)?"*

*Ruth: "Yes"*

*Researcher: "Does that help you tell her?"*

*Ruth: "Yes, yes."*

### *Implications*

The results of this study support previous research that aphasia adversely affects interpersonal relationships and activities. The data, however, also revealed that people with moderate-severe aphasia may perceive these changes differently than their family or friends and that AAC appears to play an important role in the rehabilitation process. These findings may guide SLPs' approach to the development of intervention goals for people with moderate-severe aphasia.

## References

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