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

Two purposes for this study
To explore the perceived changes in social roles of three people with living with moderate-severe, chronic aphasia through the voices of their family/friends.

To validate these findings, with the three people living with moderate-severe aphasia, through member-checking—using augmented input—as necessary.

METHODS

Qualitative Approach
The researchers employed a phenomenological qualitative approach. When people have aphasia, it impacts the entire family system. The subsequent social role changes are experienced not only by the people with aphasia, but also by their family/friends.

Phenomenology assumes a person’s experiences are rooted in their relationships with other people, events, things, and situations as life events occur. Thus, these experiences may be revealed through in-depth, semi-structured interviews. These interviews provided a window into the lived experiences of the changes in social roles due to severe, chronic aphasia.

Participants
• 3 adults with moderate-severe, chronic aphasia
• 2 adult friends and family members of 3 people with moderate-severe, chronic aphasia (total N = 6)
• Jim (42 y/o), spouse: Sally (40 y/o), friend: Katie (65 y/o)
• Paul (45 y/o), spouse: Jill (41 y/o), friend: Frank (45 y/o)
• Ruth (85 y/o), spouse: Robert (83 y/o), adult daughter: Catherine (50)
• WAB-AQ: 55.5, Broca’s Aphasia
• WAB-AQ: 65.7, Broca’s Aphasia
• WAB-AQ: 13, Global Aphasia

Interviews with Family and Friends
The authors took responsibility for one interview set (1 person with aphasia and 2 family/friends) and conducted individual, in-depth, semi-structured interviews.

Data Analysis of Family & Friends

Typological Coding
The original researcher employed a typological coding analysis based upon previous research on social role changes following aphasia and included the following categories:

(a) interpersonal relationships,
(b) activities,
(c) coping strategies.

Inductive Coding
This facilitated further understanding of specific domains regarding the lived experience of the social changes associated with moderate-severe, chronic aphasia, not addressed in the typological analysis. The frame of analysis used for the inductive analysis was the perspective of each participant.

RESULTS

Themes: Typological Analysis

The typological analysis supported previous reports of aphasia-related social role changes such as:

Interpersonal Relationships

Jim’s Wife: “You go from the role of having a partner to being a parent... in so many respects...”

Jim’s Mother: “I would say (that we are) closer.”

Jim: In response to the interviewer’s statement: “I feel my relationships have become better.” Jim: “Yeah. Normal... Finally.”

Paul’s Wife: “I would say... he’s more dependent on me (to communicate) than ever before.”

Paul’s Friend: “... his ability to verbalize has changed... so he’s a lot less to communicate... I think it’s still there, but his ability to... (speak) is difficult...”

Paul: “The group, football fans (at games), I can’t talk to them... so he (Frank) can talk to (them), but I can’t.”

Ruth’s Husband: “... she can’t talk and that is (probably) what hurts the most.”

Ruth’s Daughter: “… she doesn’t go outside (as often) when the neighbors come over... to sit... and visit.”

Ruth: When the Interviewer asked her if her: “Have your relationships changed since the stroke?” Ruth pointed to “YES.”

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.”

Jim’s Mother: “… it hasn’t stopped them from going to a dance or a party.”


Paul’s Wife: “He loves to read and that has probably been the hardest for him... now he can’t read.”

Paul’s Friend: did not emerge as a theme for Frank.

Paul: when communicating about getting help from Jill when reading the newspaper for stats on sporting events that he ‘picks’ to win.

Right, I can’t. Now I say, ‘Jill, 1 or 2?’ Yeah really frustrating.”

Ruth’s Husband: “She doesn’t like to go shopping very much anymore she like(d) shopping with her girls (before the stroke).”

Ruth’s Daughter: “… there’s so much going on in stores you... if there’s something over the speaker going and there’s people talking... there are so many things visually to absorb that she couldn’t absorb all that so (after the stroke) shopping wasn’t very pleasurable for her”

Ruth: Int: “... when you (are) shopping there are noises... (and) a lot of people. Is that overwhelming?” Ruth: “Sometimes”

DISCUSSION

Research & Clinical Implications

The results of this study support findings of previous research that aphasia affects interpersonal relationships and activities.

• This study also highlights the importance of considering the perspectives of people with moderate-severe, chronic aphasia during development of intervention goals due to:
  - Potential differences of opinion between friends, family, and people with aphasia.
  - Gender and age-related differences/preferences.