"I Don't Want to be a Burden": The Impact of Aphasia on Marriage Allie Reed, M.S. CCC-SLP & Jacqueline Hinckley, Ph.D. CCC-SLP

Background

Both the A-FROM and the LPAA models emphasize the importance of relationships for quality of life and rehabilitative success post-aphasia onset. Following the development of these models, there have been many studies on friendship relationships, however there continues to be a gap in literature on the impact that aphasia has on romantic relationships. In thinking about the importance of relationships on quality of life, how can the relationship that one has with a spouse be overlooked?

The limited work that has been completed on this topic has explored relationship satisfaction, communication, and intimacy, but has primarily focused on the

experience of the non-aphasic spouse. The purpose of this study is to better understand the broad impact that aphasia has on marriage by conducting interviews with both spouses.

Research Question

What is the impact of aphasia on marriage?

Methods

Five married couples, each including one spouse with aphasia, participated in **semi-structured interviews**. A process of **thematic analysis** was utilized to code and generate themes from the data collected. Two rounds of coding occurred by the two authors.

- Avg. age of spouse with aphasia: **59.6 years**
- Avg. age of spouse without aphasia: 56 years
- Avg. total length of relationship: **32 years**
- All couples were **heterosexual**.
- In **4/5** couples, the **husband** had aphasia.
- Cause of aphasia was **stroke** in all couples, averaging **5.4 years post-stroke**.

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Relationship Identity

'We've had to let go of...'this is what we do together' because it's not what we do together anymore."

> "Having aphasia really showed us that...life is short...we need to take the time that we have to love each other. and take care of each other."

"My relationship instantly was completely different.

"I'm still really sad about it. I still cry a lot about it. I just, I worry about him constantly. I'm always afraid he's goir to have another stroke.

Previous Roles

l guess, like... what I'm supposed to do... I guess to like, be a part of my family."

"It's like...

re-learning...

what you are,

"I cooked, I did all the finances, everything...He didn't know my password...He didn't know anything.

"I didn't want this. I wanted my life the way it was.

Identity Theft

Loss of

ability

"It's like a theft...I wanted to go back to my life and it just ripped everything from me..."

"Before the stroke I had my own life." Now I don't."

'I'm always worried about being poor, making more money... and when I stopped with stroke... I was very worried about this. Oh my God. I have to poor right now. Homeless. I was so worried about that. So depressed by that."

> "This is the opposite of how I wanted to be.'

"I'm a little more dependent than I used to be. A lot more."

year old daughter and a two-month yea ld son you know, and she's taking care of me...I'm helpless."

I know what he's doing and it's

Guilt

Experience of the Spouse with Aphasia

"Aphasia is the biggest thing we've

probably gone through.



"He's still my rock....he's still my person I'm gonna always go to.. here's nobody else I want to go to."

always been... the patient one in ur dynamic. I just **Responses to** leaned more into that role.

"I've

caregiving

Identity

Shift

Emotional

Burden

"I think I have more strength than I thought...But I guess when you don't have a choice, you have to do...what you have to do.' "It's totally changed my whole life. I mean, he used to take care of me."

"Now I have to make all the decisions."

've kind of...taken on the mom role."

have taken on all of the bill paying... it was pretty shared before... if anything he was doing more of that." "I don't want to talk to you and get you depressed

One of us depressed is enough "I might need to turn to somebody else...in ways that [he] was really

able to be there for me, he's no

"It was emotionally draining. I had to be positive for both of us."

had depression before all this started.. I had depression and anxiety and this iust all makes it worse."

"He can't answer questions on his of He constantly has me talk for him."

"He was the outgoing one. So if we got invited to a party… I had no

Communication Burden

Experience of the Spouse without Aphasia

2. Experience of the Spouse without Aphasia: Spouses without aphasia often indicated an involuntary shift in identity as they took on more of their spouse's roles and responsibilities. Responses to caregiving varied between participants and during different stages of recovery.

3. Relationship Identity: In addition to the individual identities, the relationship identities were characterized by relationship dynamic permanence, intentionality, and changes to communication.

4. Shared Stroke Experience: All couples discussed navigating the stroke and early recovery, often characterized by a shared trauma and empathy for each other, indicating a strengthening experience for couples.

5. Impact on Shared Interests/Activities: Aphasia often impacted previous shared interests and bonding activities, resulting in social isolation, grief, and an evolution of the relationship.

Results

Interview questions included topics of communication, intimacy, roles and responsibilities, and emotions. Five themes emerged from the data through thematic analysis:

1. Experience of the Spouse with Aphasia: Spouses with aphasia noted marked differences in their identity, characterized by a loss of their previous roles, subsequent depression, and feelings of guilt.

Conclusions

• Aphasia impacts marriage in multiple areas, including communication, identity, and emotions.

• Marital impact varies between couples and during different stages of recovery.

• Further research is needed to understand the **impact of aphasia** on relationships, how couples maintain their relationship through the aphasia journey, and the **SLP's role** in supporting couples.

