MARITAL SATISFACTION IN SPOUSES OF PATIENTS WITH CHRONIC APHASIA: QUALITATIVE FINDINGS

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Disclosure Statement

• I am employed by Loyola University MD
• I was a doctoral student at the University of MD Baltimore when this data was collected and analyzed in collaboration with my doctoral committee
• I am a certified ASHA member and Coordinator of ASHA Special Interest Group 15: Gerontology (I receive no compensation for this position)
• I have no relevant financial or nonfinancial relationship(s) within the products or services described, reviewed, evaluated or compared in this presentation.
Introduction

• Approximately 1 million people are currently living with aphasia in the U.S. (NIDCD, 2013)

• Aphasia
  • Acquired impairment of language that can affect a person’s ability to speak, write, understand, and/or read language
  • Most common cause is stroke

• Dearth of research directly examining and documenting the lived experience of chronic aphasia and its impact on the marital relationship and marital satisfaction

• Healthcare providers remain greatly uninformed about how aphasia impacts marriage and marital satisfaction.
Relevant Literature

• Only 2 published quantitative studies (Williams, 1993; Williams & Freer, 1986)
  • Decrease in marital satisfaction for the spouse of a person with aphasia when comparing retrospective pre-stroke and post-stroke marital satisfaction measures in both
  • Neither able to identify a significant factor that could have contributed to or predicted the decrease

• Only 1 qualitative study published (Lemieux, Cohen-Schneider, & Holzapfel, 2001)
  • 14 themes
  • Aphasia negatively affected sexuality
  • Improved communication skills would improve sexuality
  • Assuming the role of caregiver for one’s spouse decreased sexual desire for that spouse
PURPOSE & DESIGN
Purpose of original study

• To examine marital satisfaction in spouses of patients with chronic aphasia using a mixed methods approach

• Since empirical findings from purely quantitative or qualitative approaches have proven limited, the use of a mixed methods approach was warranted for continued exploration of this important research question

• Use of a sequential explanatory mixed-methods design allowed for collection of qualitative data to explain or build upon the quantitative findings
Sequential Explanatory Design

QUAN Data Collection

QUAN Data Analysis

Case Selection; Refine interview guide

Qual Data Collection

Qual Data Analysis

Integration of QUAN & Qual Results

Simon Schreck, ASHA 2014
Research Questions

• **Central Question:** How does chronic aphasia impact marital satisfaction in spouses of patients with aphasia?

• **Quantitative Question:** What are the relationships between the factors of aphasia severity, length of marriage, length of time post-aphasia onset, gender, and retrospectively reported changes in marital satisfaction?
  
  • **Hypothesis #1:** Post-aphasia marital satisfaction scores will be significantly lower than retrospective pre-aphasia onset marital satisfaction scores.
  
  • **Hypothesis #2:** There will be a relationship between post-aphasia marital satisfaction and the following variables: gender of non-aphasic spouse, length of marriage, aphasia severity, and time post-aphasia onset, with lower satisfaction seen in male spouses, in spouses who are married longer, in spouses married to persons with more severe aphasia, and in spouses with partners of more recent onset of aphasia.
Research Questions

• **Qualitative Question:** What are the lived experiences of spouses of patients with aphasia, particularly with regards to marital satisfaction?
  
  • **Qualitative Sub-questions:** While these sub-questions were later refined in relation to the quantitative findings, the following qualitative sub-questions were initially proposed. How can the findings of the quantitative phase be further explained? How does the lived experience of aphasia impact marital satisfaction in spouses of patients with aphasia? How do the lives of spouses of patients with aphasia change after its onset? What other factors might explain changes that occur?

• **Mixed Methods Research Question:** In what ways do the qualitative data obtained from interviews help to explain the quantitative findings?
PHASE I: QUANTITATIVE

Results
Hypothesis #1

Proposed that post-aphasia marital satisfaction scores would be significantly lower than pre-aphasia scores.

Using paired sample T-tests, this hypothesis was statistically supported for overall dyadic adjustment as well as for all 4 subscales.
Table 2

*Comparison of Pre-Aphasia and Post-Aphasia Dyadic Adjustment Scale Scores (DAS) for Non-Aphasic Spouses*

<table>
<thead>
<tr>
<th></th>
<th>DAS Raw Scores</th>
<th>DAS Clinical Profile T Scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-Stroke</td>
<td>Post-Stroke</td>
</tr>
<tr>
<td>Dyadic Adjustment (total)</td>
<td>120.43 (12.32)</td>
<td>97.19 (21.17)</td>
</tr>
<tr>
<td>Dyadic Consensus</td>
<td>53.24 (5.15)</td>
<td>41.33 (14.60)</td>
</tr>
<tr>
<td>Dyadic Satisfaction</td>
<td>39.33 (5.23)</td>
<td>34.90 (6.53)</td>
</tr>
<tr>
<td>Affectional Expression</td>
<td>9.62 (1.72)</td>
<td>7.95 (3.12)</td>
</tr>
<tr>
<td>Dyadic Cohesion</td>
<td>18.19 (3.36)</td>
<td>13.67 (4.67)</td>
</tr>
</tbody>
</table>

*Note.*  
* = p < .05, ** = p < .001. Standard Deviations appear in parentheses below means.
Hypothesis #2

Proposed that lower post-aphasia marital satisfaction would be related to non-aphasic spouses who were male, married longer, married to persons with more severe aphasia, and with more recent onset of aphasia

Explored using one variable regression with limited power due to small sample size

- Higher aphasia severity significantly correlated with lower post-aphasia marital satisfaction
- Lower physical recovery and greater aphasia severity were highly correlated
**Pearson Correlation Matrix among Non-Aphasic Spouse Gender, Aphasia Severity, Time Post-Onset of Aphasia, Length of Marriage, Caregiver Burden, and Post-Aphasia Dyadic Adjustment**

<table>
<thead>
<tr>
<th></th>
<th>Non-Aphasic Spouse Gender</th>
<th>Time Post-Onset of Aphasia Onset</th>
<th>Length of Marriage</th>
<th>Caregiver Burden (SIS-16 Scores)</th>
<th>Aphasia Severity (WAB scores)</th>
<th>Dyadic Adjustment Post-Aphasia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non-Aphasic Spouse Gender</td>
<td>1</td>
<td>-.275</td>
<td>-.016</td>
<td>.065</td>
<td>.037</td>
<td>-.287</td>
</tr>
<tr>
<td>Time Post-Onset of Aphasia Onset</td>
<td></td>
<td>.435*</td>
<td>.048</td>
<td>.072</td>
<td>.328</td>
<td></td>
</tr>
<tr>
<td>Length of Marriage</td>
<td></td>
<td>-.321</td>
<td>-.215</td>
<td>-.355</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Burden</td>
<td></td>
<td></td>
<td>.917**</td>
<td>.474*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(SIS-16 Scores)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aphasia Severity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.433*</td>
<td></td>
</tr>
<tr>
<td>(WAB scores)</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

*Note:* *= p < 0.05, ** = p < 0.001.*
Discussion

• Left many questions to be explored in qualitative phase
  • What is it about the experience of being married to someone with aphasia that decreases marital satisfaction in the non-aphasic spouse?
  • Does the relationship between aphasia severity and decreased marital satisfaction suggest that the decrease is related to breakdowns in communication and interpersonal processes?
  • How does the physical caregiver burden relate to marital satisfaction?
PHASE II

Qualitative Results
Sample

- 21 participants in Phase I were subsequently contacted for Phase II participation
- The final purposive sample was comprised of 11 non-aphasic spouses who had participated in Phase I
- Saturation was noted between 10th and 11th interview, so sample deemed to be of adequate size
- Demographics were similar to Phase I
Table 4  
Characteristics of Non-Aphasic Spouses in Qualitative Phase  
(n=11)

<table>
<thead>
<tr>
<th></th>
<th>N (%)</th>
<th>Mean (SD)</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spouse with Aphasia Age</td>
<td></td>
<td>65.27 (9.91)</td>
<td>44</td>
<td>77</td>
</tr>
<tr>
<td>Spouse without Aphasia Age</td>
<td></td>
<td>63.54 (5.97)</td>
<td>56</td>
<td>72</td>
</tr>
<tr>
<td>Length of marriage (years)</td>
<td></td>
<td>36.96 (13.47)</td>
<td>5.25</td>
<td>52.92</td>
</tr>
<tr>
<td>Time post-aphasia onset (years)</td>
<td></td>
<td>10.66 (9.57)</td>
<td>1.75</td>
<td>35.58</td>
</tr>
<tr>
<td>Severity of aphasia (AQ)</td>
<td></td>
<td>65.39 (37.53)</td>
<td>6</td>
<td>96</td>
</tr>
<tr>
<td>Male Spouse with Aphasia</td>
<td>10 (90.9%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moved Home</td>
<td>1 (9.1%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Modifications to Home</td>
<td>2 (18.2%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Children Moved into Home to Assist</td>
<td>1 (9.1%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family or Caregiver Moved into Home</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4 Continued  
Characteristics of Non-Aphasic Spouses in Qualitative Phase  
(n=11)

<table>
<thead>
<tr>
<th></th>
<th>N (%)</th>
<th>Mean (SD)</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hired Caregiver within Previous Year</td>
<td>1 (9.1%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Experienced Change in Household Employment</td>
<td>2 (18.2%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annual Household Income</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$21,000-$30,000</td>
<td>1 (9.1%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$41,000-$50,000</td>
<td>1 (9.1%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$51,000-$60,000</td>
<td>1 (9.1%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$61,000-$70,000</td>
<td>1 (9.1%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$71,000-$80,000</td>
<td>3 (27.3%)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>&gt;$80,000</td>
<td>4 (36.4%)</td>
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</table>
Qualitative methods

- Semi-structured interviews
- Verbatim transcription
- Analyzed using Atlas.ti
- Grounded Theory approach (Charmaz, 2006)
  - Field notes, memos
  - Open coding
  - Axial coding
  - In-vivo coding
- Qualitative validation
  - Member-checked with 3 participants
  - Coding of 4 random transcripts by a qualitative expert not related to the study with subsequent comparison of themes
Taxonomy of Categories

**Living with Loss**
- Loss of some aspect of spouse
- Loss of some aspect of self
- Loss of social support and friends
- Loss of partnership
  - Financial decision-making
  - Household responsibilities
  - Parent-child relationship
- Loss of intimacy
- Emotions that accompany loss
  - Anger and resentment
  - Guilt
  - Helplessness
  - Fear

**Creating a New Normal**
- Reaffirming the marital commitment
- Reframing the situation to identify the positive
- Cherishing the present
- Identifying self-care strategies
- Developing and nurturing social supports
- Acting as advocate
- Recognizing new skills and attributes
Loss of some aspect of spouse

“He’s totally different, yet he’s really the same.”

“So here was this young, super intelligent guy who had this great job and experienced such success in his career and he couldn’t even write his name. There was no way he was going back to his job and his career.”
Loss of some aspect of self

“It’s all about him.”

“Most of the time I’m thinking for two people. He needs two minds to take care of him.”

“It’s becoming increasingly hard over the years to keep carving out that time for myself.”

“I just feel exhausted, not so much burned out, but mentally and physically exhausted.”
Loss of social support and friends

“Well, now almost everyone that we knew as a couple has dropped off because it’s just one of us and it’s not fun for anyone. They are just uncomfortable.”

“Right, they made promises…’we’ll have lunch; we’ll go to the movies; I’ll take you to the golf course; we’ll do all this.’ Right. Did they call you? Because they must have lost our number.”
Loss of partnership

Financial decision-making: “I mean you don’t even have the conversations, you don’t have the talks about finances or what are you going to buy or what are you going to do, because he wouldn’t have a clue.”

Household responsibilities: “I think it’s just every once in a while, I would like him to try and help me a little bit more. He’s physically capable of helping. He just doesn’t think to do it anymore.”

Parent-child relationship: “It’s like having a child who doesn’t talk yet. You know, you’re talking to them, you’re interacting with them all day, but they’re not answering you and they’re not telling you...There’s no marriage aspect to it at all anymore, I don’t think.”
Loss of intimacy

“Probably the thing that I do miss about our marriage before is that we had that relationship, you know, one based on a lot of just talking about things of interest.”

“There was a real downward shift of intimacy at that point. And, I think in any marriage, well, I don’t want to say any marriage, but I think without sexual intimacy sometimes you’ve lost a very important piece. You become roommates, if you will.”
Emotions that accompany loss

**Anger and resentment:** “I really used to get angry about that. I’ve gone there. Could a healthier lifestyle...I take care of myself and now I have to take care of him.”

**Guilt:** “Sometimes I think, how can I say this about him? He didn’t choose this.”

**Helplessness:** “It was a feeling of helplessness because I physically couldn’t do anything for him and I didn’t feel like anybody was doing anything for him.”
Emotions that accompany loss

**Fear:** “All I wanted to know was will he get better. I mean, we had three small children. I needed to know that he could get well. But, no one could tell me.”

“Fear of the unknown…I think everyone who’s had a stroke has a big fear…what if it happens again?”

“The other big thing for me is not knowing what is coming down the road for us. What does happen to an aging brain that has damage? I don’t know what to expect. No one seems to know.”

“What if something happens to me? That scares me; that’s a burden.”

**Loneliness:** “In many ways, it’s just me running solo. He’s there, but he’s not.”
Reaffirming the marital commitment

“For better or for worse. So, in essence, it may not be what you signed up for. The younger generation would just pick up and run. But, my generation…you get married, you get married for life. That’s a promise that is sacred.”
Reframing the situation to identify the positive

“You either give up or you find a way to take something good from every day.”

“I look at it this way. We had a totally shitty thing happen to us. We could have let it destroy our family. But, it hasn’t devastated us. We have survived. We now know that we can be stronger than that.”
Cherishing the present

“I tell myself every day. I am so lucky. He is still here. He didn’t die.”

“He and I spend a lot of time together– a lot of time– and I have to look at it like I’m glad I didn’t have to wait until he was 70 to spend time with him. I feel lucky.”
Identifying self-care strategies

“I’m an avid reader and without being able to read I wouldn’t have lasted probably two years. I constantly read. The kids got me a Kindle, then I have a book everywhere we go. I have a book at the doctor. I have a book at the lab…When he watches these mindless TV shows over and over I read.”
Developing and nurturing social supports

“She’s definitely been a rock. I mean not only just to be there but to do anything…the sounding board thing, you know, the nonjudgmental listening, no matter how bad it gets. It is priceless to me.”

“But, when you meet somebody who has lived a similar lifestyle as you and you can talk about things that you really wouldn’t talk about with your other friends…what a comfort it is to know these folks get it and to not be afraid to cry in front of them or laugh at them like they would laugh or cry with you…these women have saved me, they really have.”
Acting as advocate

“They handed me this folder of pamphlets and there was one buried in there about communication after stroke. No one, until then, had ever said the word aphasia.”

“The doctors just want to fix it. But there’s a lot they don’t know but they won’t tell you they don’t know.”

“He got so lost in that system, not through entirely their fault... But, in a big setting like that it was just horrendous. First of all, he doesn’t talk well, so he doesn’t tell them what he wants. He’s like a small frightened child in there because he doesn’t understand. And so, he becomes combative, so nobody’s going to bat for him.”
Recognizing new skills and attributes

“I have found an inner strength that I never knew I had. I don’t think he (her husband) knew I had it either.”

“I used to be quiet and passive...unsure of myself around smart people. But, you can’t take a back seat when your husband is aphasic. Now, now I am confident of what I know and what I need and I will go for it.”
Discussion

• Various forms of loss described by participants help to explain the decrease in marital satisfaction illustrated in Phase I

• Subcategories associated with “loss” provided clear illustrations of how aphasia, and not just physical disability from stroke, can impact marital satisfaction

• Theme of the new normal could explain the inconsistencies found in previous studies when comparing aggregate marital satisfaction to individual item responses

• Fear about more rapid age-related decline in cognitive and physical function in spouse with aphasia is substantive
Limitations

• Design
  • Retrospective marital satisfaction evaluation could introduce recall bias
  • Lack of homogeneity of sample
  • Lack of comparison group

• Sample
  • Small N
  • Female non-aphasic spouses overrepresented
  • Affluent sample

• Measurement and analysis
  • Measures were not designed specifically for this study
Implications for practice

• Recommendations for healthcare providers
  • Recognition of grief
  • Greater need for provision of information (aphasia, sexual intimacy after stroke)
  • Assist spouses with developing strategies for requesting and obtaining formal and informal support

• Recommendations for speech-language pathologists
  • Incorporation of Life-Participation Approaches to Aphasia (Kagan, et al, 2001)
  • Supported conversation
  • Inclusion of spouse and focus on spousal communication as a therapy outcome
Future Research

- Incorporation of comparison groups (stroke with no aphasia)
- Exploration of marital satisfaction in spouses with aphasia
- Exploration of how aphasia impacts other familial relationships (e.g., between parents and children)
- Exploration of gender as a variable
- More intensive qualitative exploration of trajectory of these marriages over time
- Exploration of chronic aphasia in same-sex relationships and marriage
- Longitudinal exploration of disability, wellness, and functional outcomes of patients with aphasia and their spouses as they age.
References


References