# Examining the Relationship Between Resilience, Caregiving Burden, and Friendship Among Aphasia Caregivers

## Morgan Diener<sup>1</sup>, Lucinda Graven<sup>2</sup>, Christopher Constantino<sup>1</sup>, & Elizabeth B. Madden<sup>1</sup>

School of Communication Science and Disorders<sup>1</sup>, Florida State University College of Nursing<sup>2</sup>, Florida State University

School of Communication Science & Disorders
College of Communication & Information



## Introduction

- The importance of resilience (Hunting Pompon & Mach, 2022) and friendship (Azios et al., 2022) in aphasia recovery is emerging; however, there is little research in these areas focused on those caregiving for a loved one with aphasia.
- Becoming a caregiver is a major life event involving many new responsibilities, resulting in caregiving burden and limited time or energy for the caregivers' personal needs and social interactions (Haley et al., 2019; Madden et al., 2023; Shafer et al., 2019).
- For some, resilience can act as a protective factor against social isolation and promote good mental health (Palacio et al., 2020).

## Research Questions

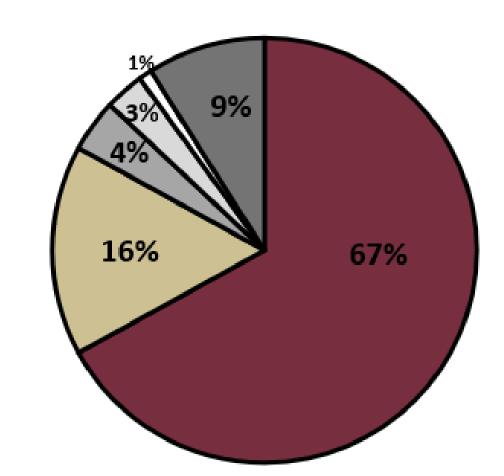
This study aimed to understand positive and negative influences on aphasia caregivers' friendship experiences. We asked how does:

- 1. Perceived resilience relate to friendship?
- 2. Perceived caregiving burden relate to friendship?
- 3. Age, time, health, and aphasia severity relate to friendship?

# Participants

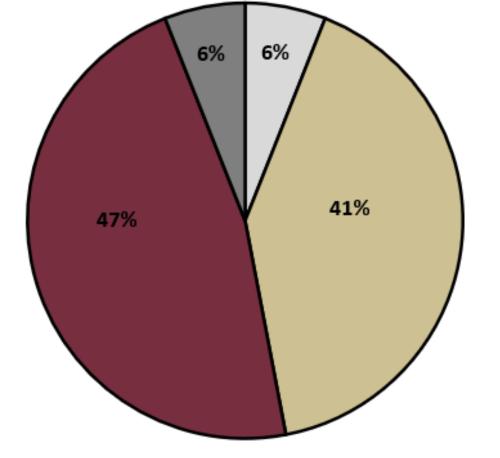
- 70 caregivers to individuals with stroke-induced aphasia
- Age: M = 59.89 years (SD = 12.86, range = 30-85)
- Gender: 57 women, 12 men, 1 non-binary person
- Race and Ethnicity: 61 White, 5 Black, 3 Asian, and 1 Latino
- Employment: 24 full time, 13 part-time, 27 not working
- Years Caregiving: M = 4.9 years (SD = 4.39, range = 0.5-23)

#### Caregiver's Relationship to Loved One



■Spouse ■Child ■Parent ■Sibling ■Nephew ■Friend

#### Caregiver's Perception of Loved One's Aphasia



☐ Mild ☐ Moderate ☐ Severe ☐ Very Severe

### Methods

Participants completed a Qualtrics survey composed of 4 sections:

- **About You**
- 2. About Your Loved One With Aphasia
- 3. Caregiving Experiences
- 4. Friendship Experiences

This analysis focused on a subset of the survey items, shown below:

#### UW Resilience Scale (Dagmar et al., 2018)

	Not at all	A little bit	Somewhat	Quite a bit	Very much
I maintain a positive outlook even in bad circumstances	0	0	0	0	0
When something happens that makes me feel stressed, I usually calm down quick.	0	0	0	0	0
When I experience a set-back, I keep moving forward.	0	0	0	0	0
Although I feel bad sometimes, I usually bounce right back.	0	0	0	0	0
During stressful times, I am usually calm and relaxed.	0	0	0	0	0
I do what is important to me, even when stressed.	0	0	0	0	0
When something stressful happens, I keep going.	0	0	0	0	0
When things go wrong in my life, I can pick myself up and start again.	0	0	0	0	0

# Hawthorne Friendship Scale (Hawthorne, 2006)

	Not at all	Occasionally	About half the time	Most of the time	Almost always
It has been easy to relate to others.	0	0	0	0	0
I felt isolated from other people.	0	0	0	0	0
I had someone to share my feelings with.	0	0	0	0	0
I found it easy to get in touch with others when I needed to.	0	0	0	0	0
When with other people, I felt separate from them.	0	0	0	0	0
I felt alone and friendless.	0	0	0	0	0

# Zarit Caregiving Burden Interview (Bedard et al., 2001)

	Never	Rarely	Sometimes	Quite frequently	Nearly Always
Do you feel that because of the time you spend with your loved one with aphasia that you don't have enough time for yourself?	0	0	0	0	0
Do you feel stressed between caring for your loved one with aphasia and trying to meet other responsibilities (work/family)?	0	0	0	0	0
Do you feel angry when you are around your loved one with aphasia?	0	0	0	0	0
Do you feel that your loved one with aphasia currently affects your relationship with family members or friends in a negative way?	0	0	0	0	0
Do you feel strained when you are around your loved one with aphasia?	0	0	0	0	0
Do you feel that your health has suffered because of your involvement with your loved one with aphasia?	0	0	0	0	0

# Interpersonal Support Evaluation List (Cohen et al., 1985)

	Definitely true	Probably true	1 Tobably Taloo	Definitely false
If I wanted to go on a trip for a day (e.g., to the mountains, beach, or country), I would have a hard time finding someone to go with me.	0	0	0	0
I feel that there is no one I can share my most private worries and fears with.	0	0	0	0
If I were sick, I could easily find someone to help me with my daily chores.	0	0	0	0
There is someone I can turn to for advice about handling problems with my family.	0	0	0	0
If I decide one afternoon that I would like to go to a movie that evening, I could easily find someone to go with me.	0	0	0	0
When I need suggestions on how to deal with a personal problem, I know someone I can turn to.	0	0	0	0
I don't often get invited to do things with others.	0	0	0	0

# Data Analysis

- Descriptive statistics (e.g., means, SD, ranges, %) were derived.
- Spearman's correlations were calculated for variables of interest.
- Based on statistically significant correlations, a standard multiple regression analysis with aphasia severity and scores on the UW Resilience Scale and Zarit Caregiving Burden Scale entered as predictors of the Hawthorne Friendship Scale score was conducted.

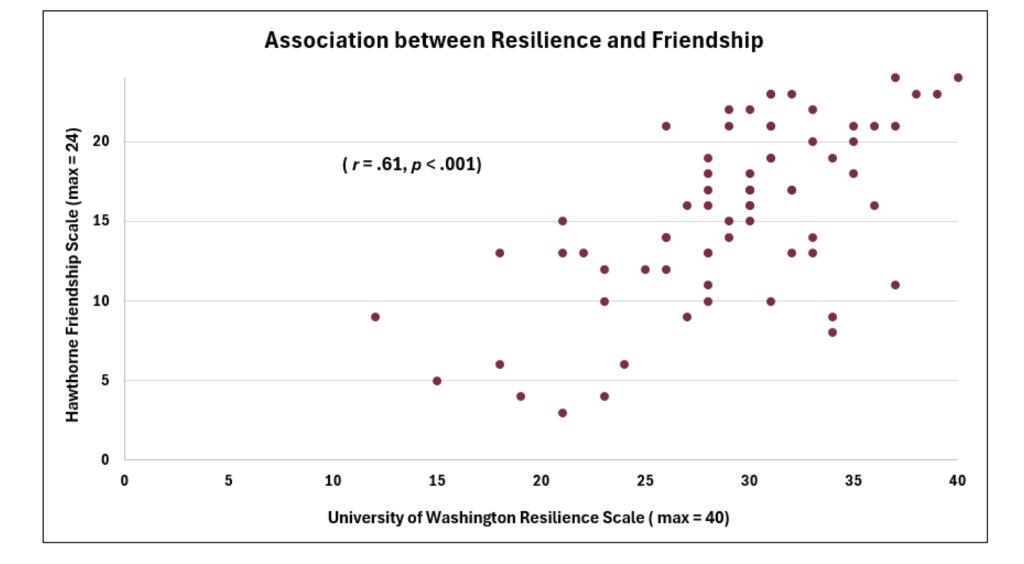
# Results

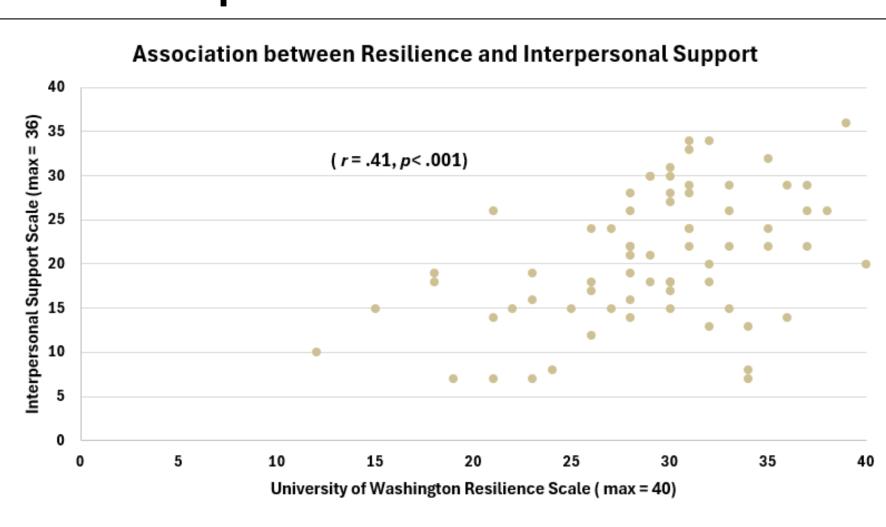
Associations between demographic factors and resilience, caregiving burden, and friendship

			Hawthorne	Interpersonal Support
	Resilience Scale	Caregiving Burden	Friendship	Evaluation
Caregiver's age	r= .043, p= .723	r=081, p= .511	r= .114, p= .350	r=081, p= .511
Years Caregiving	r =139, p = .262	r =015, p = .904	r = .042, p = .736	r =153, p = .217
Caregiver's Perceived				
Health Status	r =149, p = .220	r = .173, p = .162	r =180, p = .142	r =235, p = .053
Loved One's Perceived				
Health Status	r =200, p = .101	r = .331, p = .006	r =250, p = .040	r =159, p = .196
Severity of Loved One's				
Aphasia	r =093, p = .448	r = .365, p = .002	r =383, p = .001	r =329, p = .006

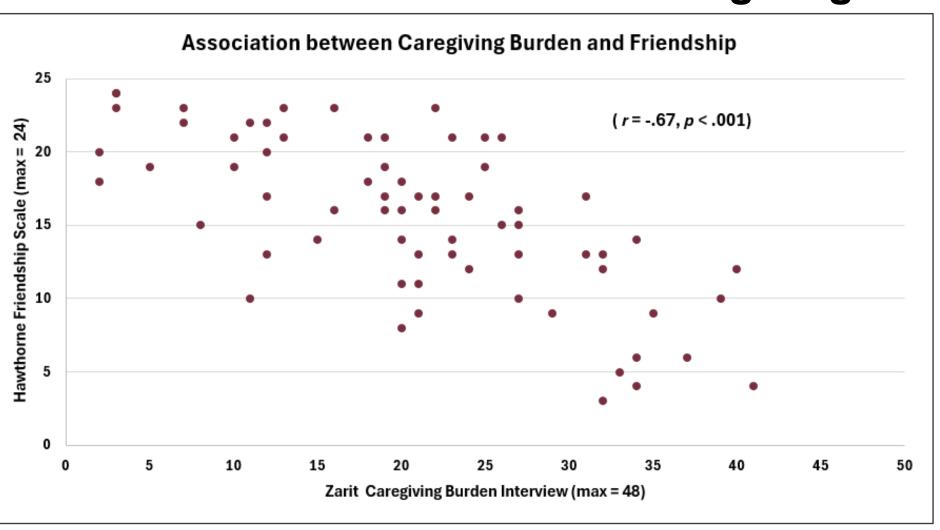
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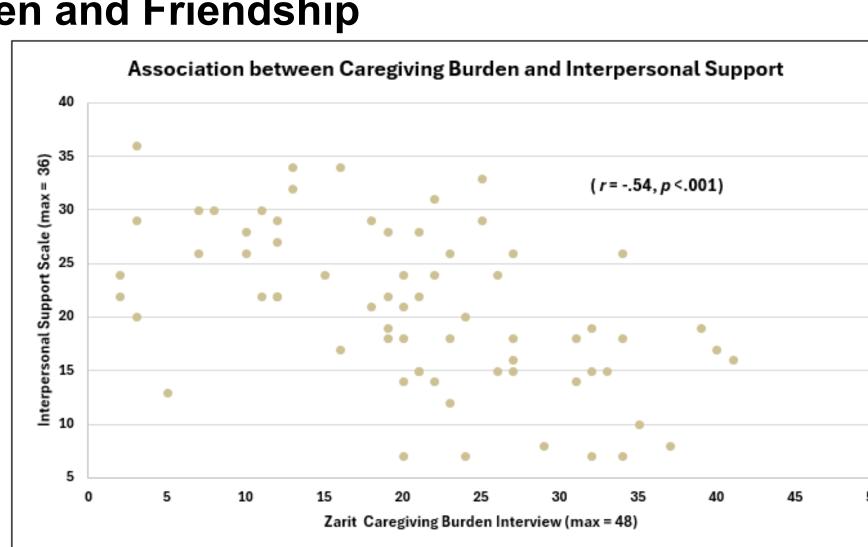
### Resilience and Friendship





### Caregiving Burden and Friendship





• Regression: Together, the three predictors (resilience, burden, and aphasia severity) statistically significantly predicted caregiver friendship, F(3, 67) = 28.23, p < .001, adjusted  $R^2 = .55$ . Resilience and caregiving burden uniquely added to the prediction, p = .003 and p < .001, respectively.

## Discussion

- Our results indicate that aphasia caregivers' friendships are influenced by their resilience, caregiving burden, and severity of loved one's aphasia.
- Resilience showed a positive relationship with friendship, while caregiving burden and aphasia severity were negatively related to friendship.
- The relationship between these variables, and related psychosocial factors, warrants further attention.
- In line with Hernandez and colleagues' (2024) call for aphasia caregiver programs that go beyond communication partner training, our findings support development of interventions aimed at increasing resilience and relieving burden to support caregivers' social well-being and health, and in turn, the well-being of their loved one with aphasia as well.

# References

- Azios, J., Strong, K.., Archer, B., Douglas, N. F., Simmons-Mackie, N., & Worrall, L. (2022). Friendship matters: A research agenda for aphasia. Aphasiology, 36(3), 317-336.
- Haley, K. L., Jacks, A., Morrison, B., & Richardson, J. D. (2020). Balance and preference in activity participation for informal caregivers of people with aphasia: A questionnaire study. *Aphasiology*, 34(9), 1182-1200
- Hernandez, N. J., Pettigrove, K., Mellahn, K., Isaksen, J. K., Pierce, J. E., & Rose, M. L. (2024). Carers in post-stroke aphasia: a scoping review of interventions and outcomes beyond communication partner training. *Disability and Rehabilitation*, 1-12.
- Hunting Pompon, R.., & Mach, H. (2022). Characterizations of resilience in poststroke aphasia: A scoping review and considerations for treatment and research. *Topics in Language Disorders*, 42(3), 236-251.
- Madden, E. B., Therrien, M., Bislick, L., Wallace, S. E., Goff-Albritton, R., Vilfort-Garces, A., Constantino, C., & Graven, L. (2023). Caregiving and friendship: Perspectives from care partners of people with aphasia. *Topics in Language Disorders*, 43(1), 57-75.
- Palacio G, ., Krikorian, A., Gómez-Romero, M. J., & Limonero, J. T. (2020). Resilience in caregivers: A systematic review. American Journal of Hospice and Palliative Medicine®, 37(8), 648-658.
- Shafer, J. S., Shafer, P. R., & Haley, K. L. (2019). Caregivers navigating rehabilitative care for people with aphasia after stroke: a multi-lens perspective. *International Journal of Language & Communication Disorders*, 54(4), 634-644.

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