Supporting Partners of People with Aphasia to Nurture Friendships

Aphasia Institute

Master Class Knowledge Exchange Series

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Introductions

FSU | SCHOOL OF COMMUNICATION SCIENCE & DISORDERS
COLLEGE OF COMMUNICATION & INFORMATION

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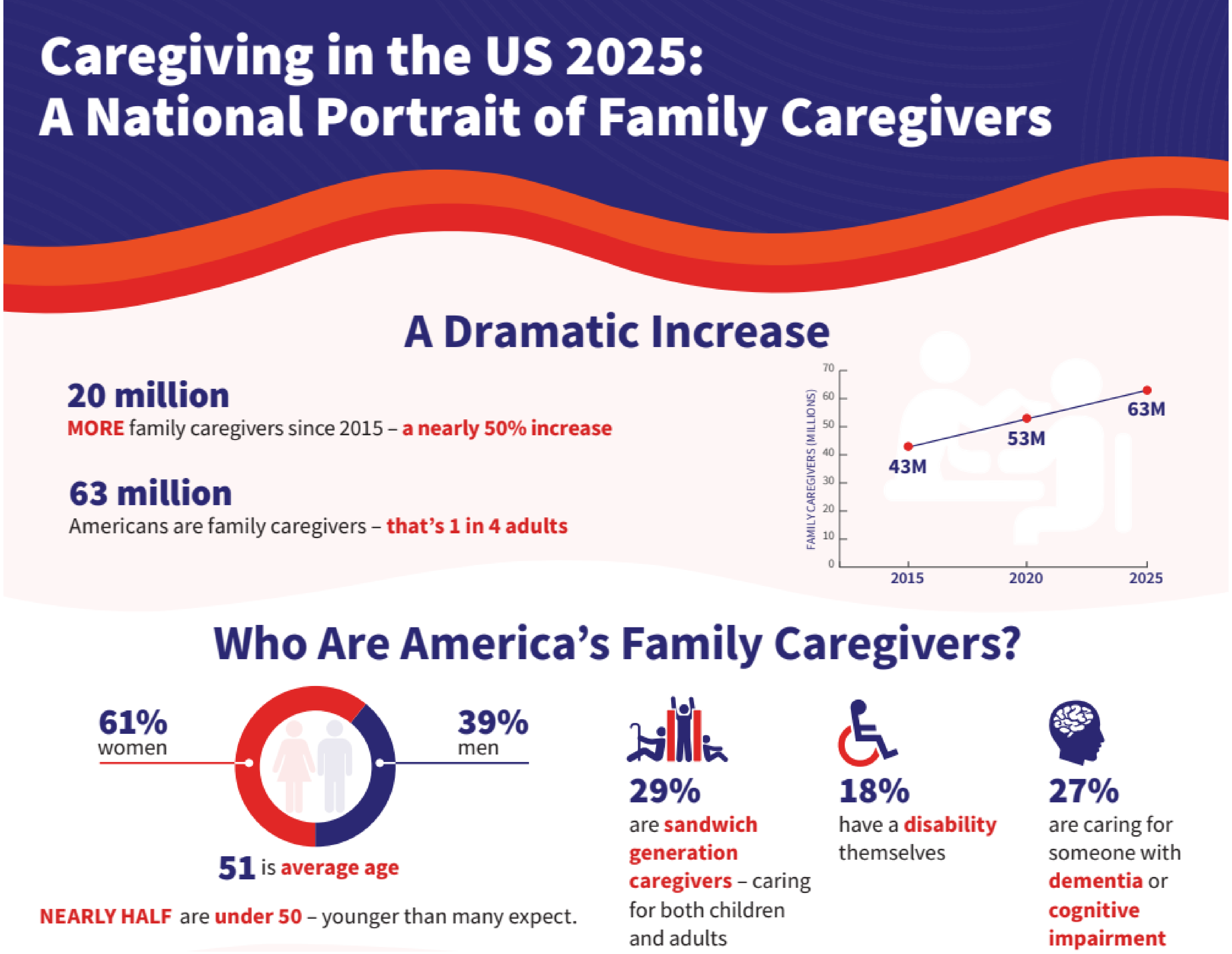
Financial Disclosures: I receive a salary from Florida State University. **Non-financial Disclosures:** I will receive an honorarium for this presentation.

Session Overview

- Caregiving Statistics
- Caregiving Interventions and Speech-Language Pathology
- Caregiving Interventions and Aphasia
- Friendship and Aphasia Caregiving
- Clinical Practice
- Q & A

National Alliance for Caregiving

https://www.aarp.org/pri/topics/ltss/family-caregiving/caregiving-in-the-us-2025/



Caregiving in the US 2025:
A National Portrait of Family Caregivers

A Dramatic Increase

20 million
MORE family caregivers since 2015 – **a nearly 50% increase**

63 million
Americans are family caregivers – **that's 1 in 4 adults**

Who Are America's Family Caregivers?

61% women

39% men

51 is **average age**

NEARLY HALF are **under 50** – younger than many expect.

29% are **sandwich generation caregivers** – caring for both children and adults

18% have a **disability** themselves

27% are caring for someone with **dementia** or **cognitive impairment**

Work and Financial Challenges

7 in **10** working-age family caregivers also work – **balancing dual responsibilities**

47% report at least one **negative financial impact**

1 in **5** can't afford basic needs like food and housing

1 in **4** family caregivers **feel alone**

Almost **4** in **10** report **emotional stress**

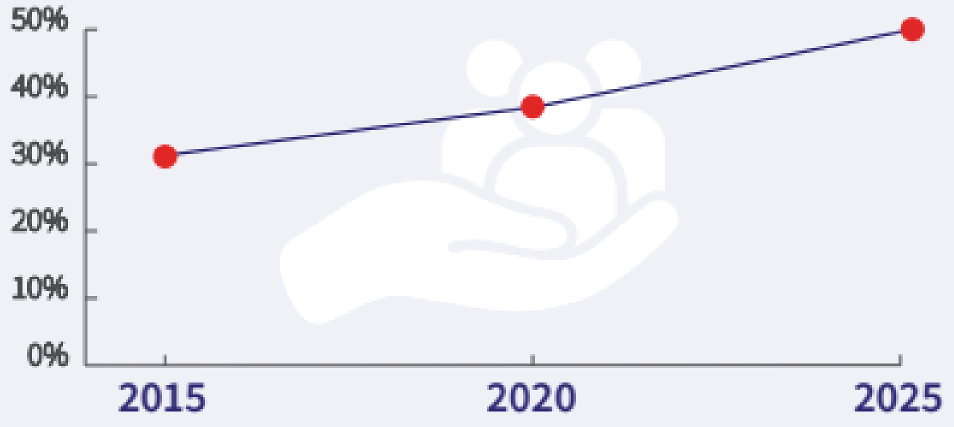
23% find it **difficult** to take care of their **own health**

Finding Hope & Solutions

51% of family caregivers **find purpose** in caregiving

Use of technology to support caregiving has **doubled** in 5 years

Caregivers' access to **paid family leave** has expanded over 10 years



https://doi.org/10.26419/ppi.00373.002

AARP®

NATIONAL ALLIANCE FOR CAREGIVING

Caregiving Interventions in Speech-Language Pathology

- Bedesha and colleagues (2002)'s review focused on how SLPs address caregiver burden
- Found only 11 caregiver burden intervention studies involving an SLP
- 6/11 studies included aphasia caregivers
- 9/11 included an SLP plus another professional
- Group therapy was most common intervention
- Concluded that SLPs can be effective at helping to reduce caregiver burden across the lifespan

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International Journal of Language & Communication Disorders

REVIEW

Caregiver burden interventions in speech–language pathology: A systematic review

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Scoping Review of Interventions for Carers of People with Post-Stroke Aphasia

(Hernandez et al., 2025)

- Scoping review focused on interventions for aphasia caregivers other than communication partner training
- Only 20 studies included with most focused on long-term phase of care
- Only 2/20 focused solely on the care partner
- Wide range of interventions and outcome measures used, yet most seemed to enhance carer well-being
- Advocating for change in healthcare model that views carer as a client too

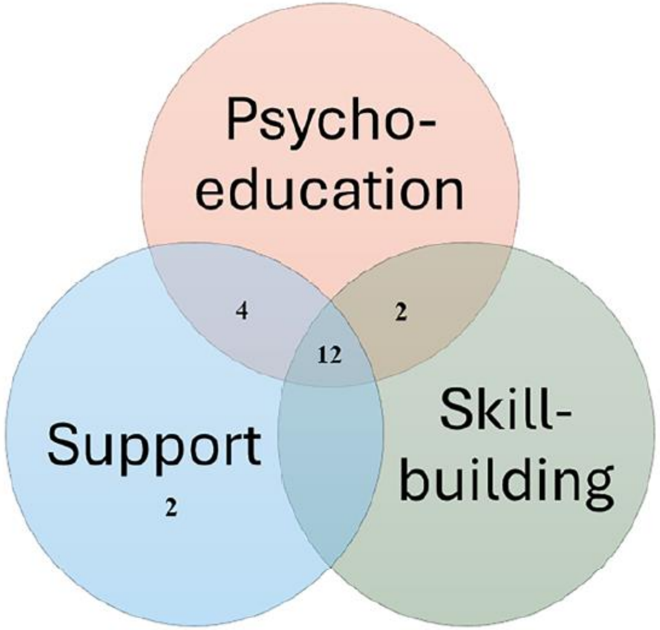


Figure 2. Venn diagram of number of studies with different intervention components.

SLP views of working with family members (Johansson et al., 2011)

- 758 Swedish SLPs completed the survey
- Discrepancy between reported importance of family involvement and actual practice due to restricted time and perceived limited skill

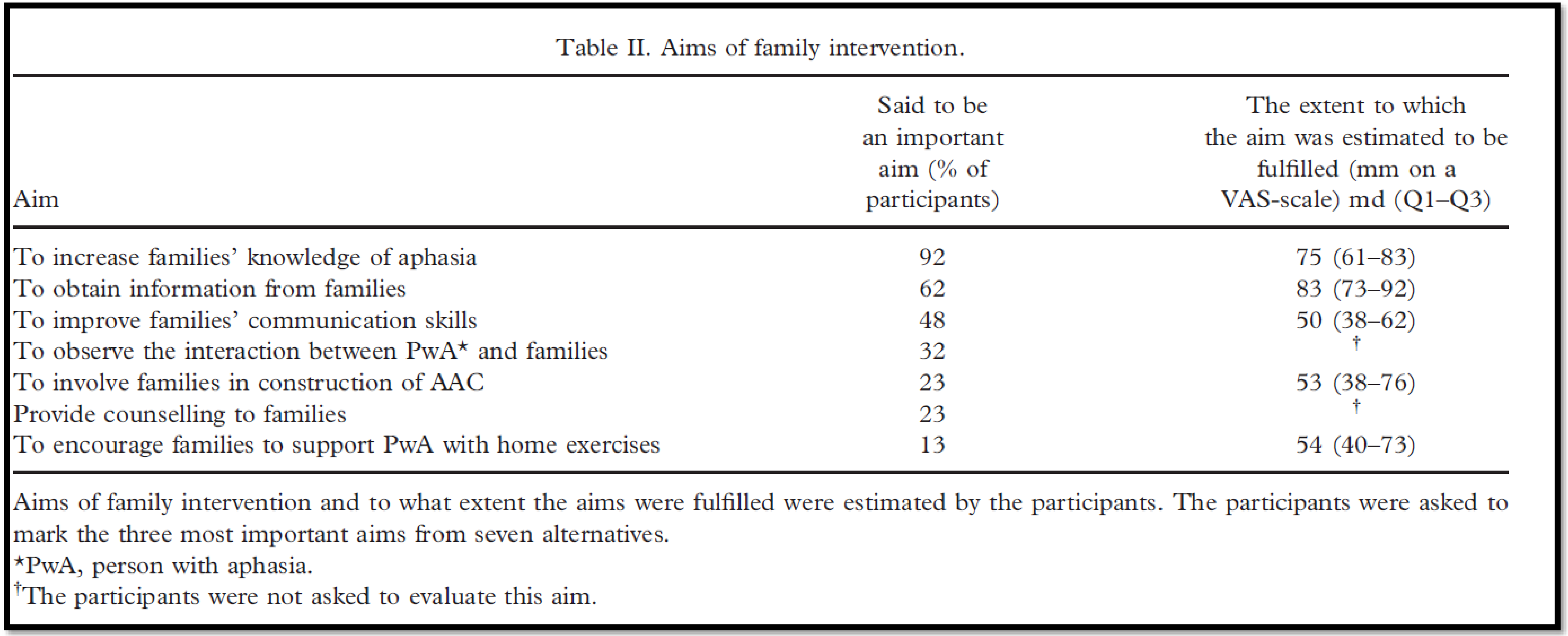


Table II. Aims of family intervention.

Aim	Said to be an important aim (% of participants)	The extent to which the aim was estimated to be fulfilled (mm on a VAS-scale) md (Q1–Q3)
To increase families' knowledge of aphasia	92	75 (61–83)
To obtain information from families	62	83 (73–92)
To improve families' communication skills	48	50 (38–62)
To observe the interaction between PwA* and families	32	†
To involve families in construction of AAC	23	53 (38–76)
Provide counselling to families	23	†
To encourage families to support PwA with home exercises	13	54 (40–73)

Aims of family intervention and to what extent the aims were fulfilled were estimated by the participants. The participants were asked to mark the three most important aims from seven alternatives.

*PwA, person with aphasia.

†The participants were not asked to evaluate this aim.

Where Does Friendship Fit In?

Good Friendship = Good Health

Friendships can improve:

- Well-being
- Physical Health
- Mental Health
- Self-esteem
- Quality of life
- Social engagement

(Davidson et al., 2008; Hilari & Northcott, 2006 ; Palmer et al., 2019; Therrien et al., 2021)

Friendships Change With Aphasia

- **Communication impairment can** strain social relationships
- Stroke survivors tend to have **smaller social networks** than adults with no stroke history
- **People with aphasia often have more trouble** with friendships than stroke survivors that do not have aphasia

(Azios et al., 2021; Hilari & Northcott, 2017 ; Madden et al., 2023; Palmer et al., 2019)

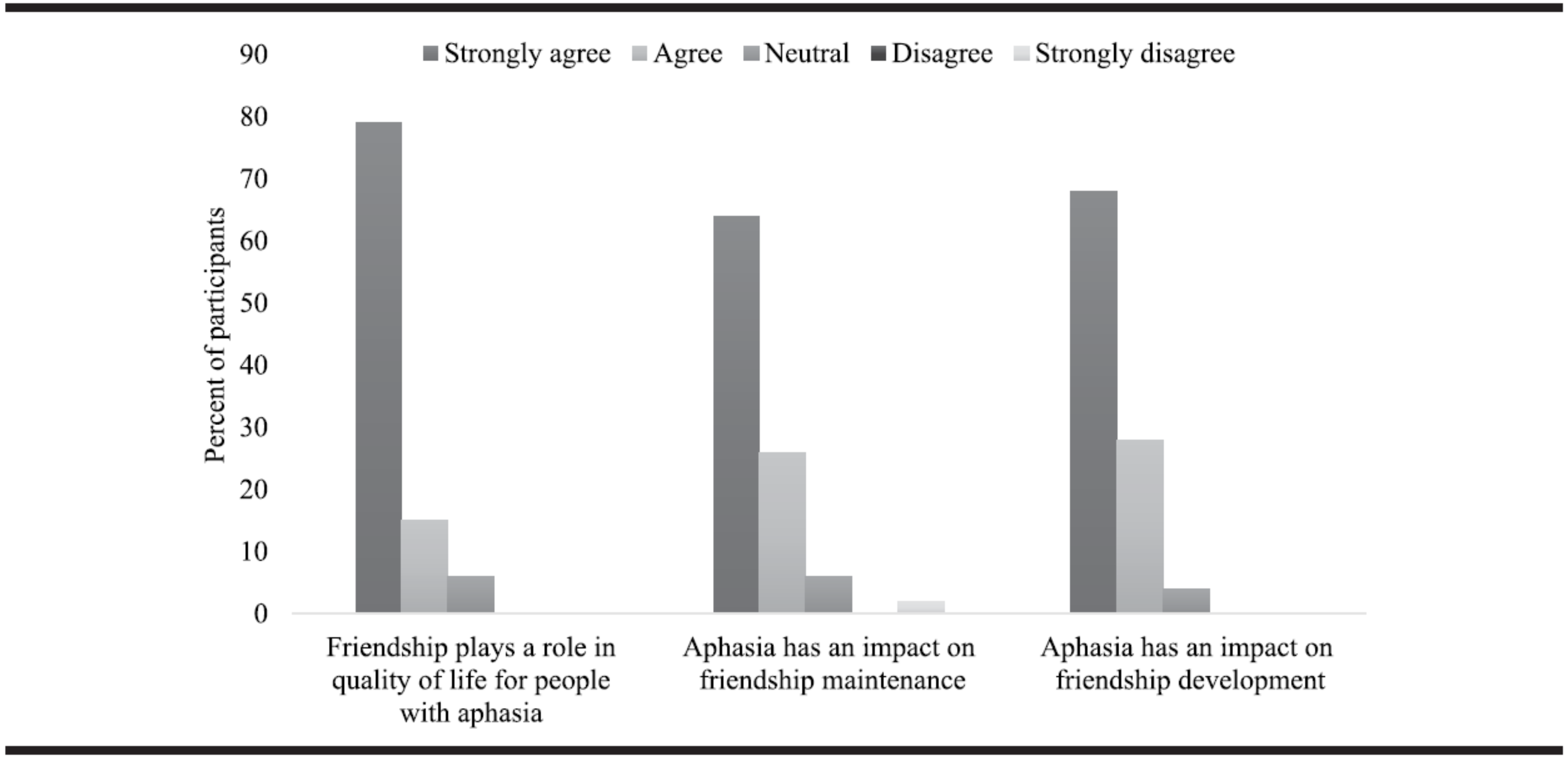
SLPs think addressing friendship is important (Therrien et al., 2021)

Purpose: Explore SLPs’ perspectives on the friendships of their clients with aphasia and on their role in supporting those friendships.

Participants:

- 47 SLPs who work with PWA
- Average of 11.51 years (SD = 11.31) working with PWA
- Many of the participating SLPs worked in multiple settings

Figure 1. Speech-language pathologists’ beliefs about friendship and aphasia.



Aphasia affects care partners’ friendships too

- Increased **caregiver burden** associated with **smaller social network**
- Caregivers are often stressed, tired, anxious, or depressed
- Suddenly taking on a lot more tasks and roles
- Less time for one’s self
- Third-party disability

(Hernandez et al., 2025; Rombough et al., 2006 and 2007; Shafer et al., 2019)

Share 3 Caregiving and Friendship Studies

STUDY 1: CHANGES IN FRIENDSHIP OVER TIME FOR APHASIA CARE PARTNERS

STUDY 2: INFLUENCE OF RESILIENCE AND CAREGIVING BURDEN ON FRIENDSHIP

STUDY 3: MODERATING ROLE OF FRIENDSHIP BETWEEN DEPRESSION AND CAREGIVING BURDEN

Team Work!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Study 1: Changes in Friendship Over Time

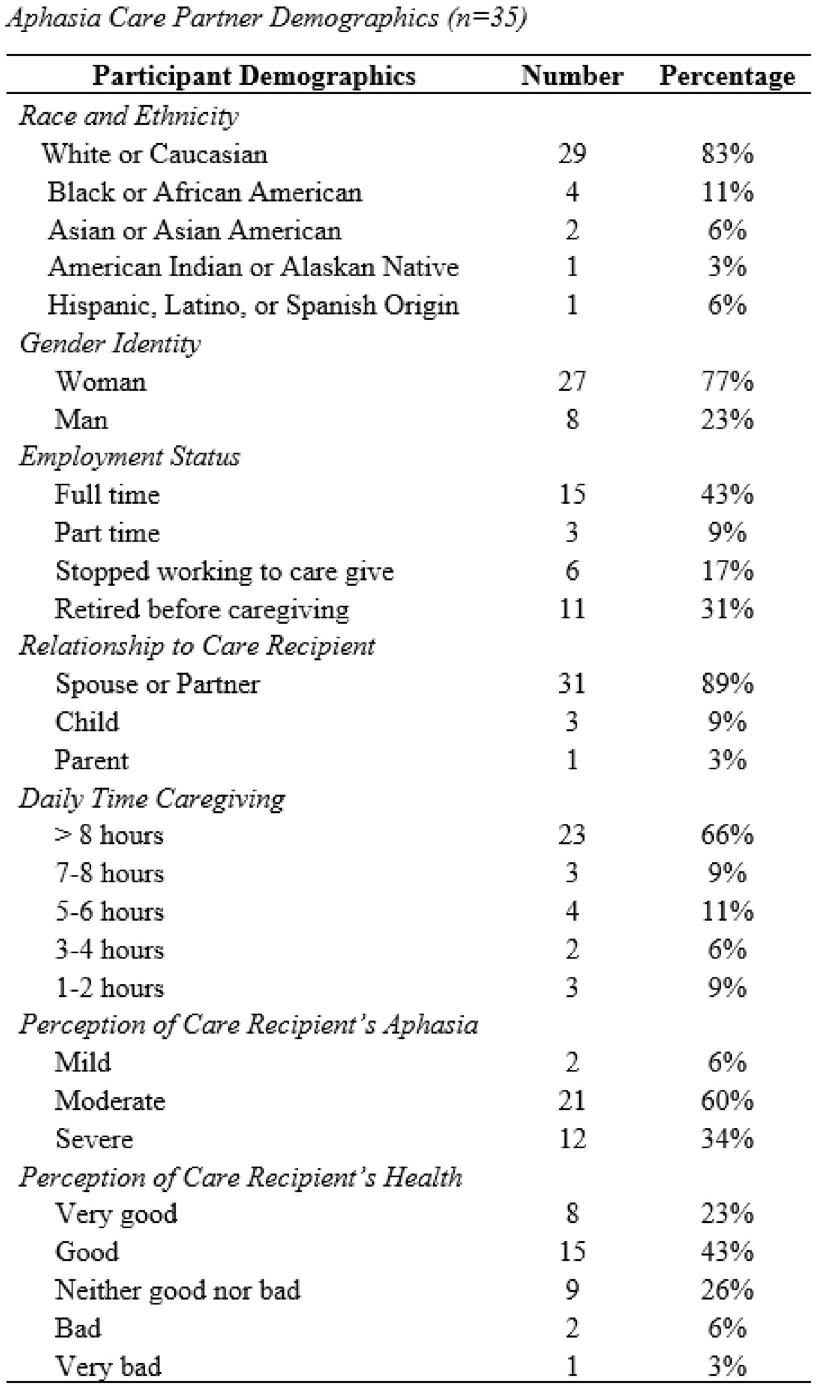
Purpose:

Examine how stroke and aphasia impact **friendships of care partners over time** from the perspective of care partners of individuals with aphasia.

Participants:

- 35 self-identified care partners
- Average age 59.26 (SD = 13.28, range 24-92)
- Average time caregiving 48.94 months (SD = 30.28, range 9 -120)

Madden et al. (2023)



Aphasia Care Partner Demographics (n=35)

Participant Demographics	Number	Percentage
Race and Ethnicity		
White or Caucasian	29	83%
Black or African American	4	11%
Asian or Asian American	2	6%
American Indian or Alaskan Native	1	3%
Hispanic, Latino, or Spanish Origin	1	6%
Gender Identity		
Woman	27	77%
Man	8	23%
Employment Status		
Full time	15	43%
Part time	3	9%
Stopped working to care give	6	17%
Retired before caregiving	11	31%
Relationship to Care Recipient		
Spouse or Partner	31	89%
Child	3	9%
Parent	1	3%
Daily Time Caregiving		
> 8 hours	23	66%
7-8 hours	3	9%
5-6 hours	4	11%
3-4 hours	2	6%
1-2 hours	3	9%
Perception of Care Recipient's Aphasia		
Mild	2	6%
Moderate	21	60%
Severe	12	34%
Perception of Care Recipient's Health		
Very good	8	23%
Good	15	43%
Neither good nor bad	9	26%
Bad	2	6%
Very bad	1	3%

Procedures

Participants completed an **online survey** comprised of **multiple choice and free-response** questions with **3** main parts**:**

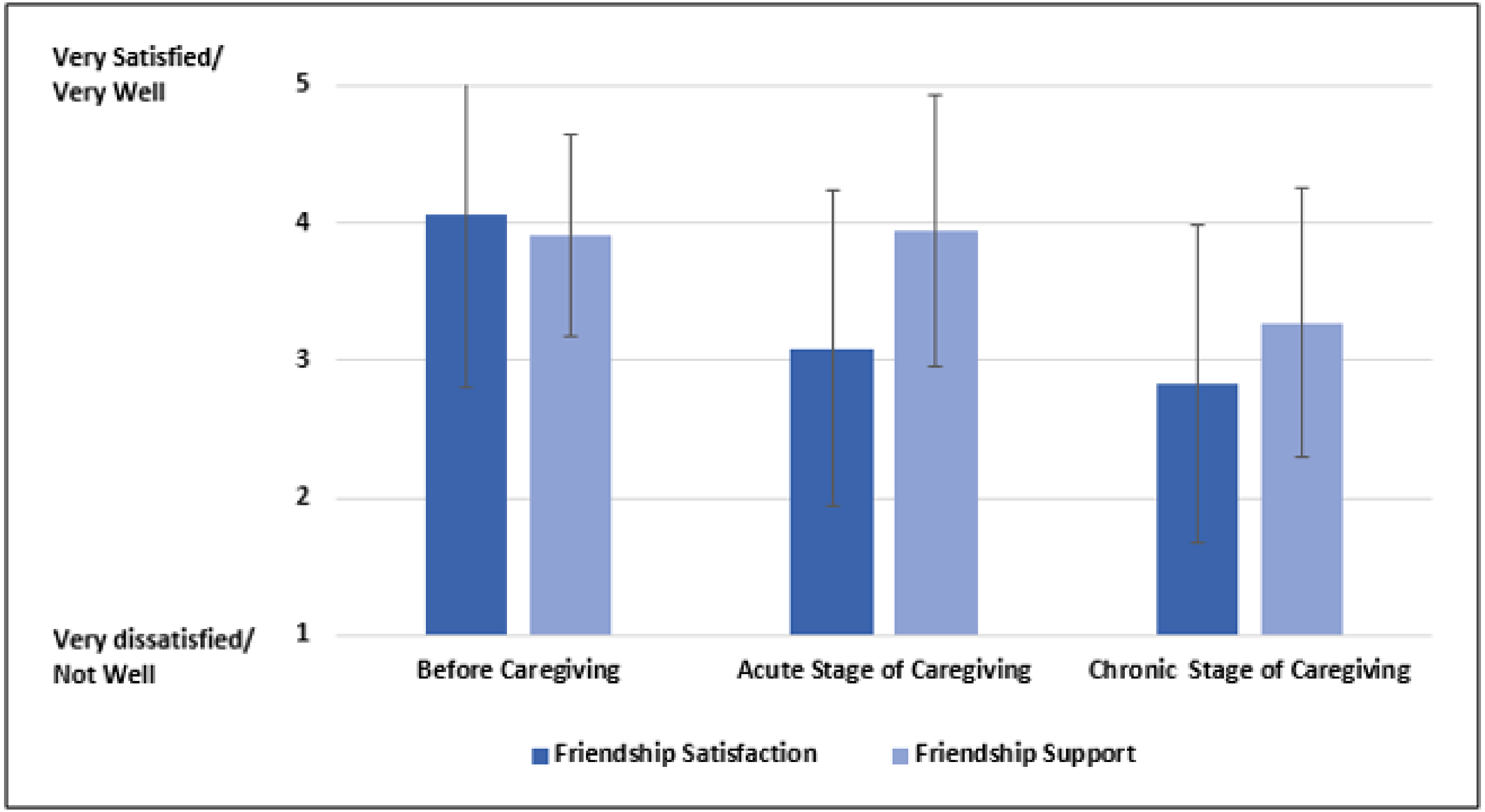
1. Questions about **caregiver demographics**
2. Questions about their **loved one's demographics**
3. Questions about **their own friendships** :
    - **Before onset** of loved one's aphasia
    - **First 6 months** of loved one's recovery
    - **Present time**

Results

Perceived Friendship Satisfaction and Support Over Time

Friendship satisfaction declined over time.

Friendship support was initially there in the acute stage but declined in the chronic stage of caregiving for most.

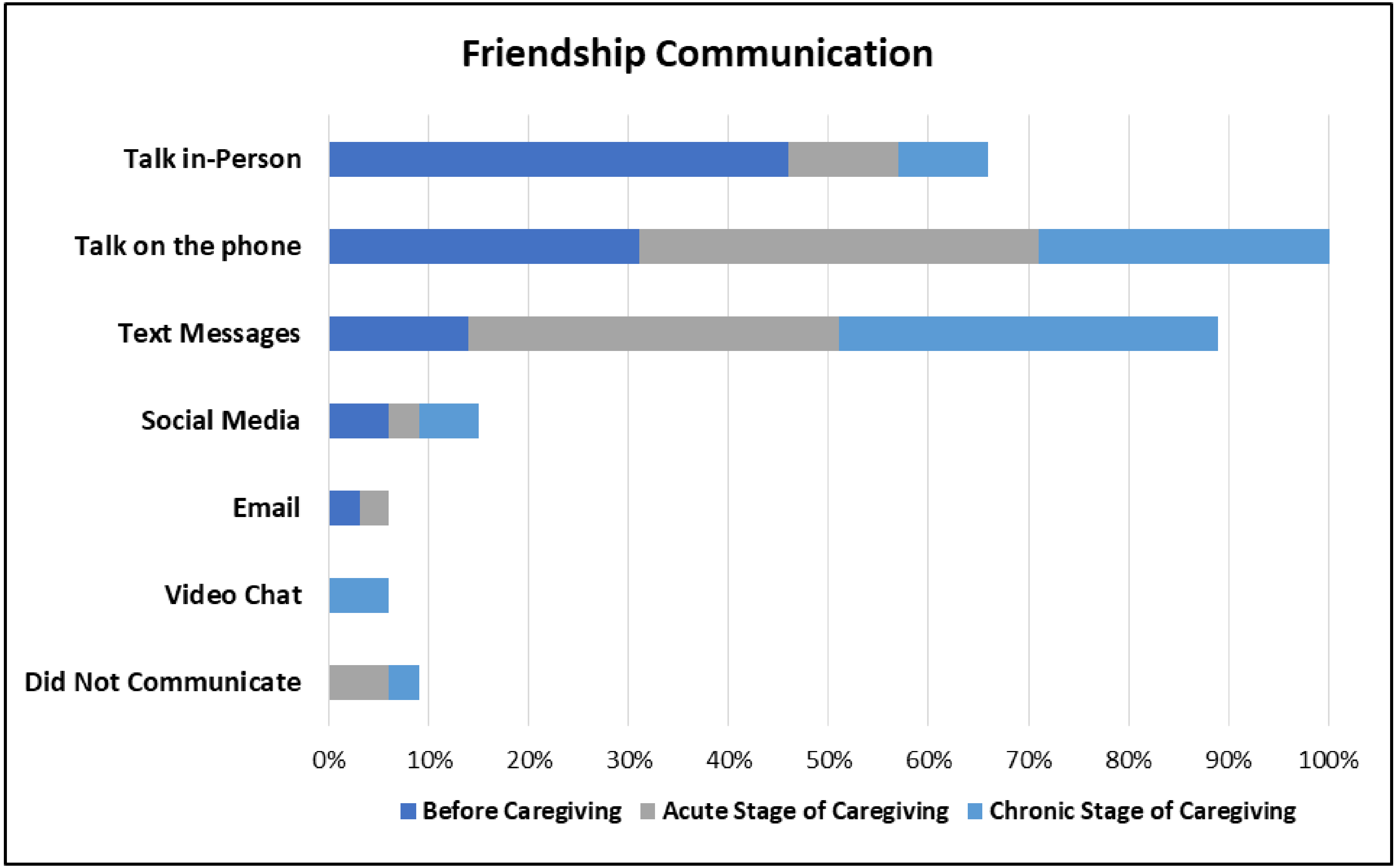


Results

Most Common Communication Methods with Friends Over Time

See a shift to communicating more often by phone or text.

A few care partners reported not communicating at all with friends

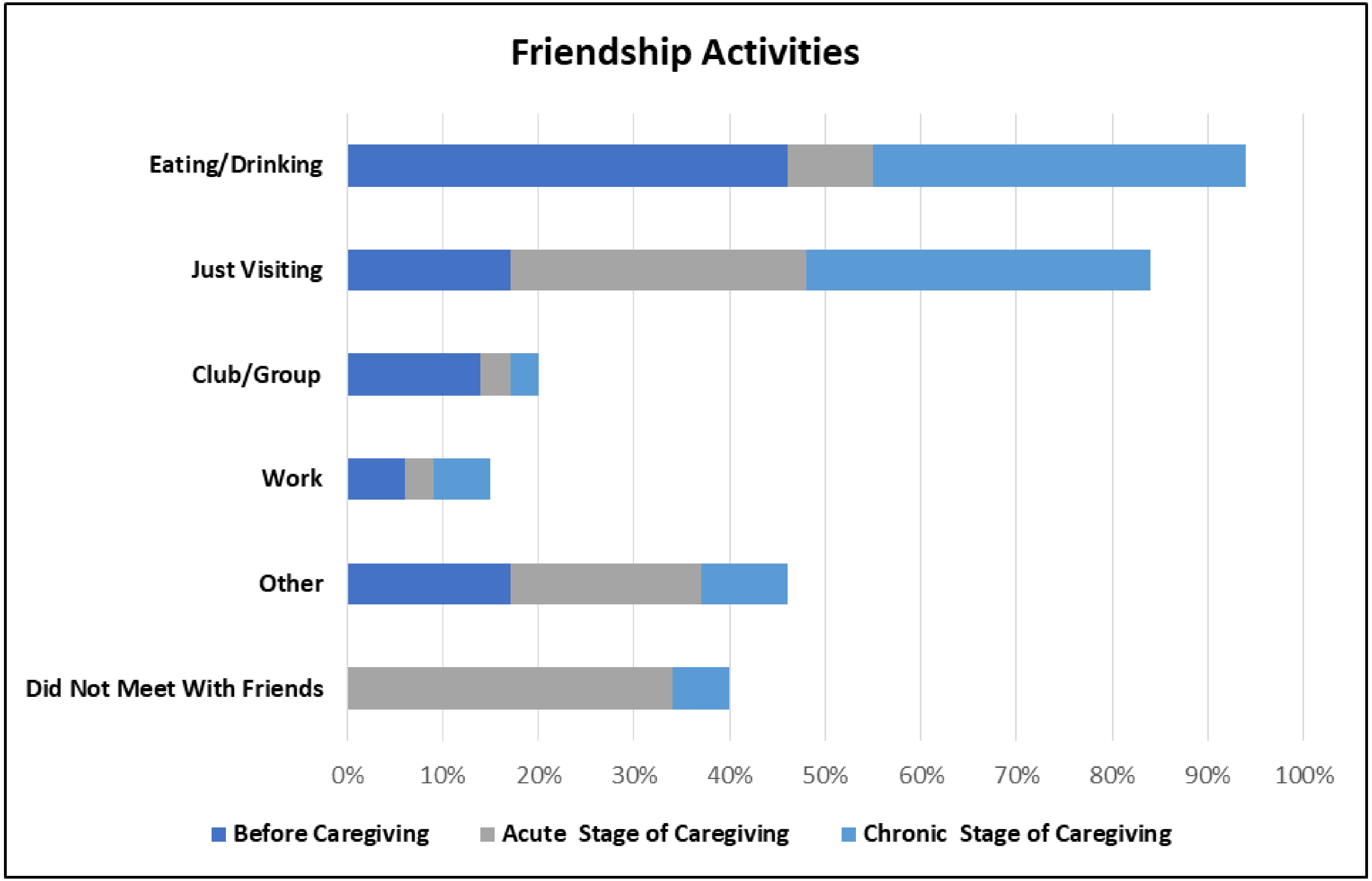


Results

Most Common Communication Methods with Friends Over Time

See a shift to "just visiting" for many.

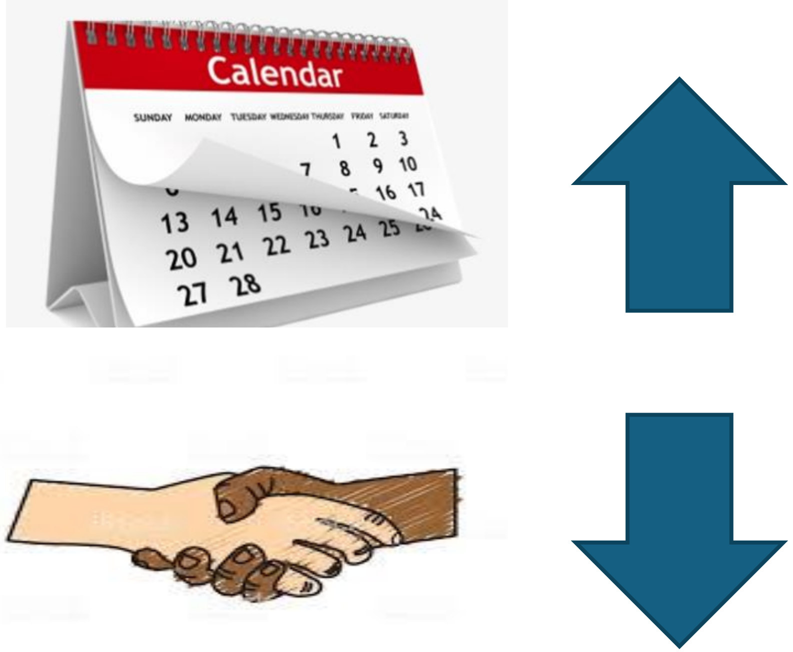
35% reported not meeting at all with friends in the acute stage and 5% do not currently meet with friends



Results

Relationship between demographic variables and friendship satisfaction

As months caregiving increased, friendship satisfaction decreased



(*r*=-0.39, *p*=0.02)

As perceived PWA health increased, friendship satisfaction increased

(r=0.40, p= 0.01)

Results

Qualitative Findings

Role Change

"There is no time to nurture any friendships when you are caring for someone 24/7."

Characteristics

"Their stick-to-itiveness because I don't have the energy now."

Initiation

"It's terrible and no one can really help. Every ask is a burden."

Interaction

"Those that were more social moved on because our lives were just too complicated and maybe hard to watch."

Outside Influences

"We can't do anything that they can because we had to declare bankruptcy and are still waiting on disability determination."

Study 2: Resilience, Caregiving Burden, and Friendship

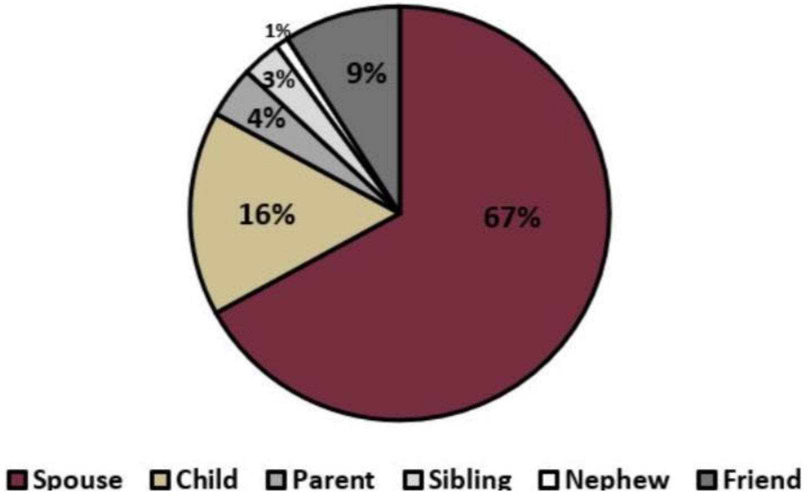
Purpose

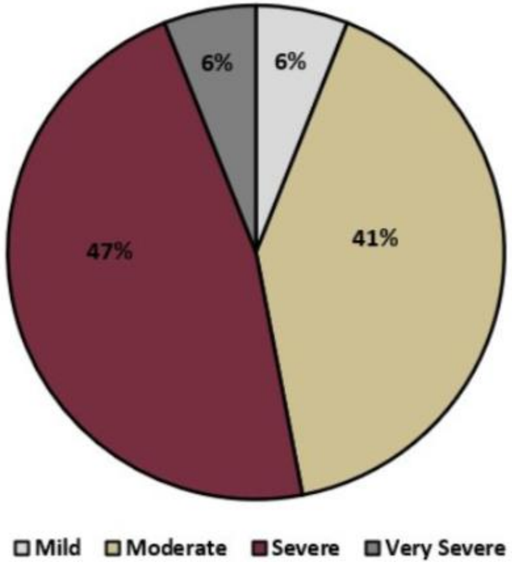
This study aimed **to understand positive and negative influences on aphasia caregivers' friendship experiences**. We asked how does:

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


Caregiver's Perception of Loved One's Aphasia

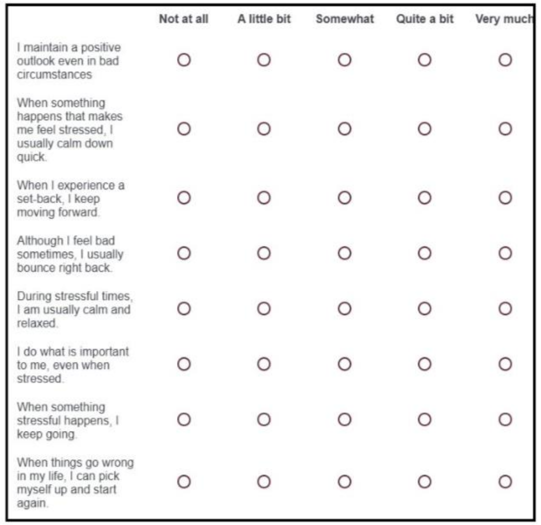
Procedure

Participants completed a Qualtrics survey composed of 4 sections:

1. **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)

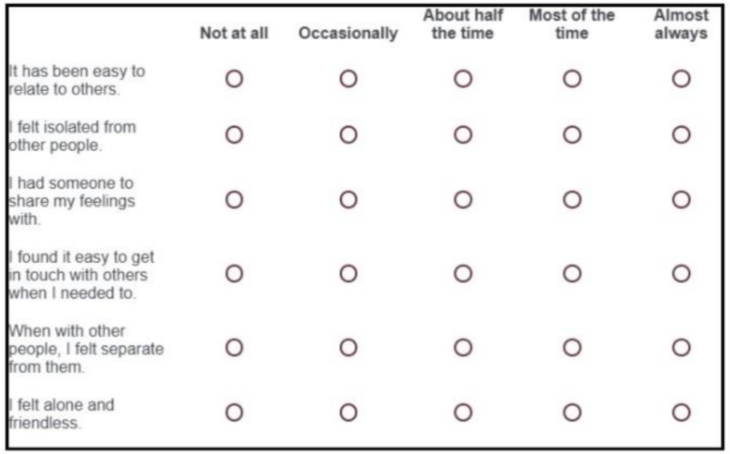


	Not at all	A little bit	Somewhat	Quite a bit	Very much
I maintain a positive outlook even in bad circumstances	○	○	○	○	○
When something happens that makes me feel stressed, I usually calm down quick.	○	○	○	○	○
When I experience a set-back, I keep moving forward.	○	○	○	○	○
Although I feel bad sometimes,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

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

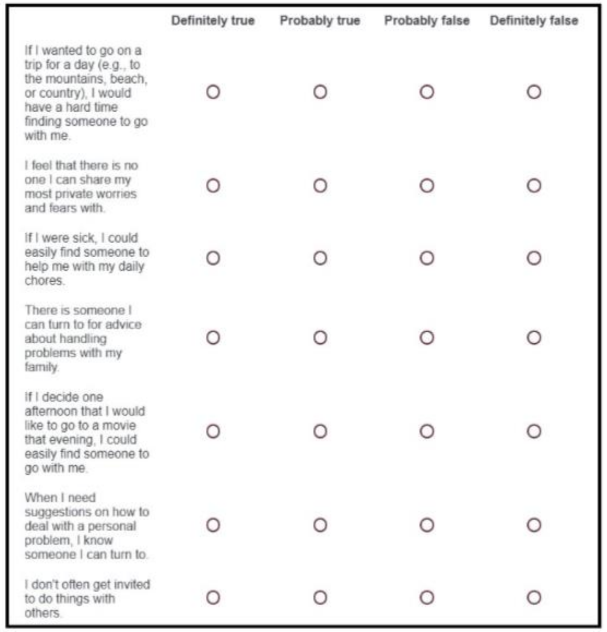
	Never	Rarely	Sometimes	Quite frequently	Nearly Always
Do you feel that because of the time you spend with your loved one with aphasia that you don't have enough time for yourself?	○	○	○	○	○
Do you feel stressed between caring for your loved one with aphasia and trying to meet other responsibilities (work/family)?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

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.	○	○	○	○	○
I felt isolated from other people.	○	○	○	○	○
I had someone to share my feelings with.	○	○	○	○	○
I found it easy to get in touch with others when I needed to.	○	○	○	○	○
When with other people, I felt separate from them.	○	○	○	○	○
I felt alone and friendless.	○	○	○	○	○

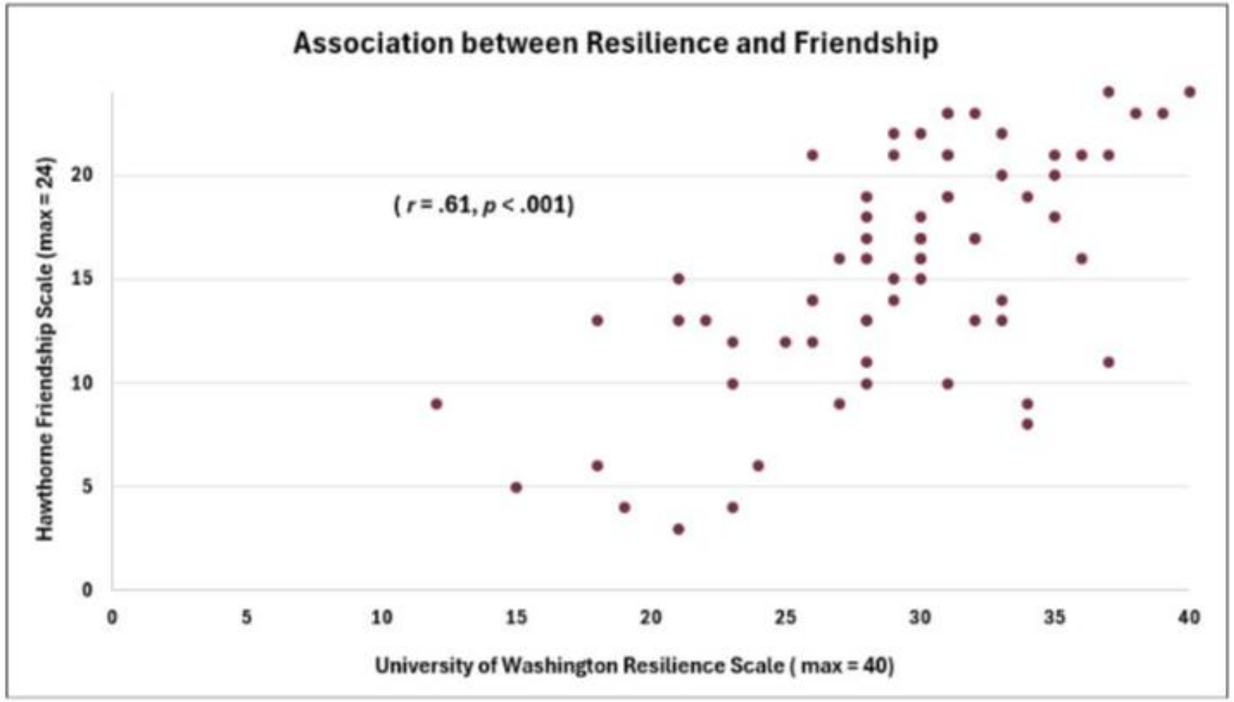
Interpersonal Support Evaluation List (Cohen et al., 1985)

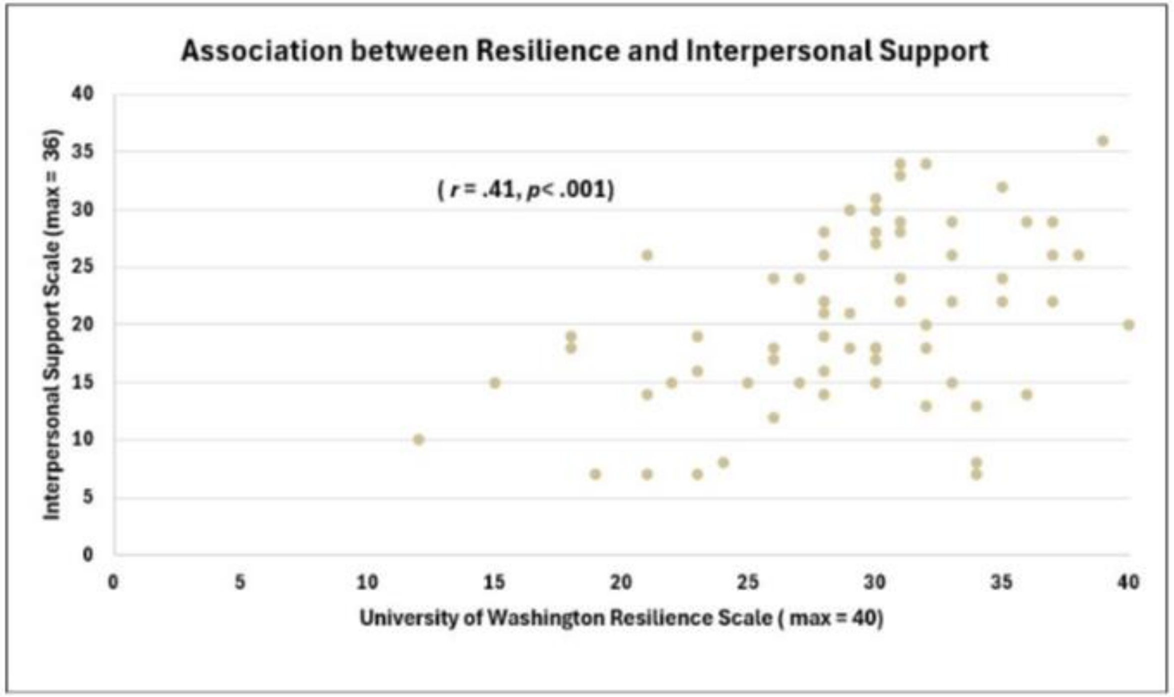


	Definitely true	Probably true	Probably false	Definitely false
If I wanted to go on a trip for a day (e.g., to the mountains, beach, or country), I would have a hard time finding someone to go with me.	○	○	○	○
I feel that there is no one I can share my most private worries and fears with.	○	○	○	○
If I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

Results

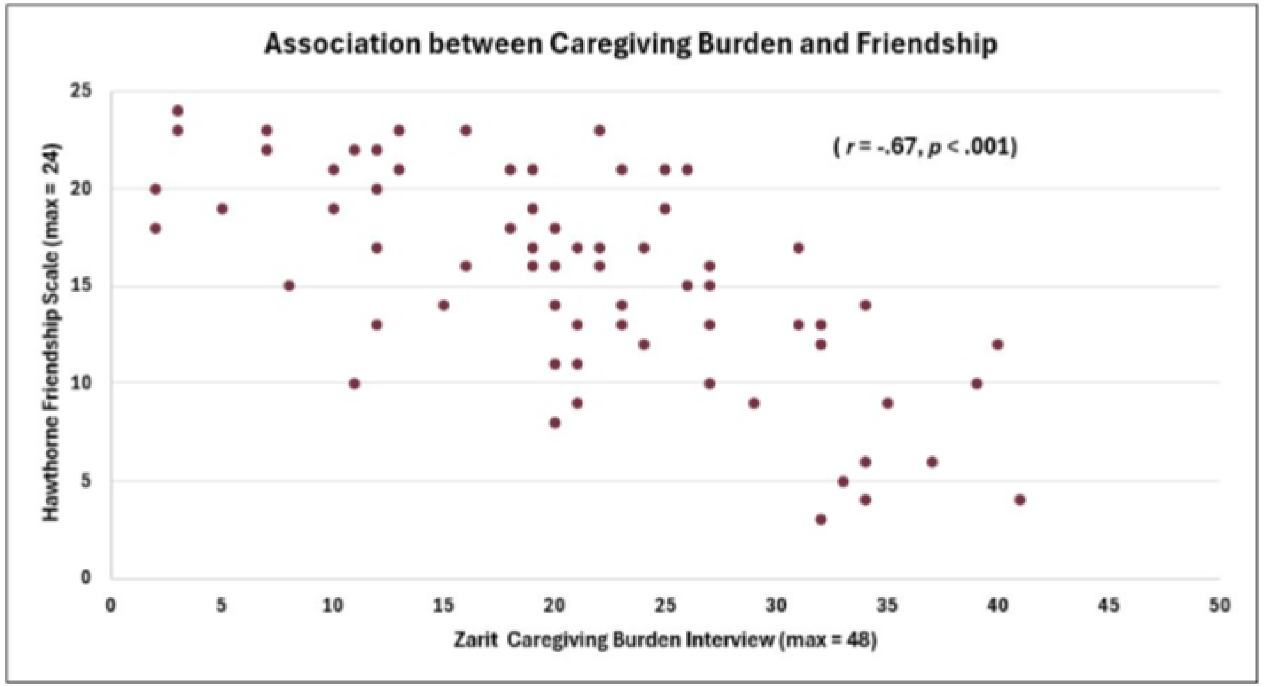
Resilience and Friendship

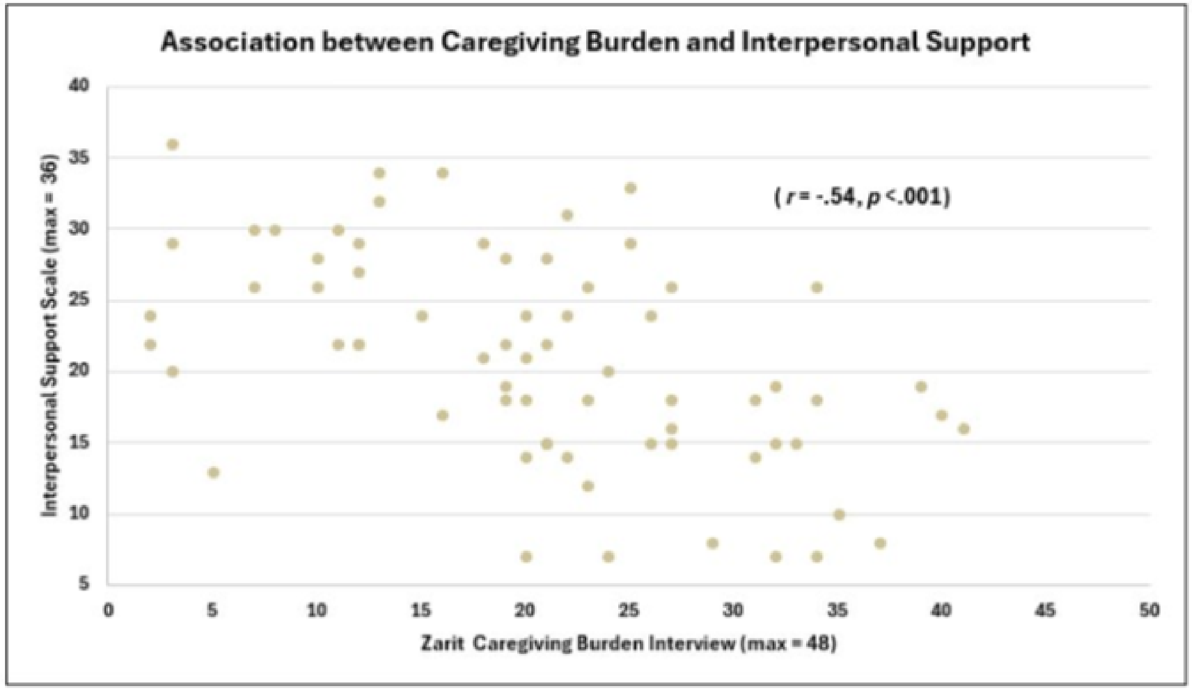




Results

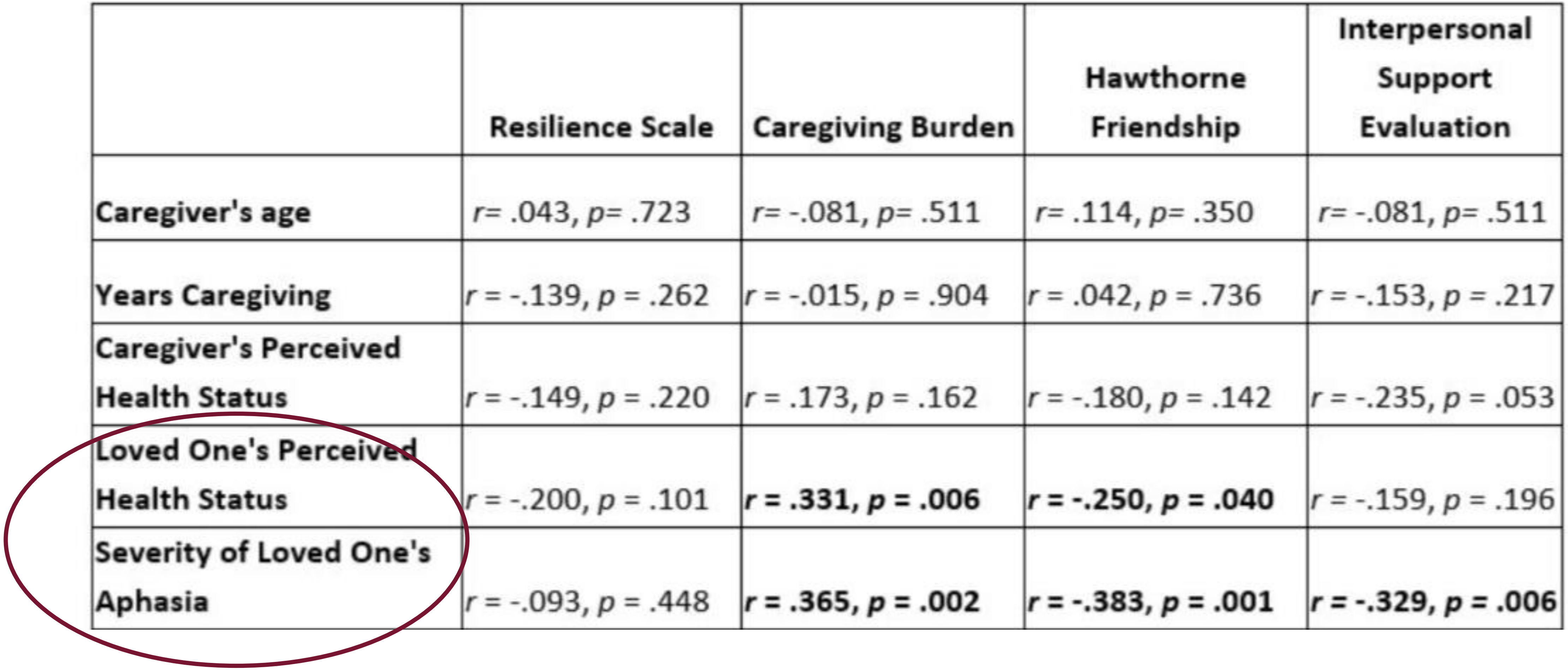
Caregiving Burden and Friendship


Association between Caregiving Burden and Friendship


Association between Caregiving Burden and Interpersonal Support

Results

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

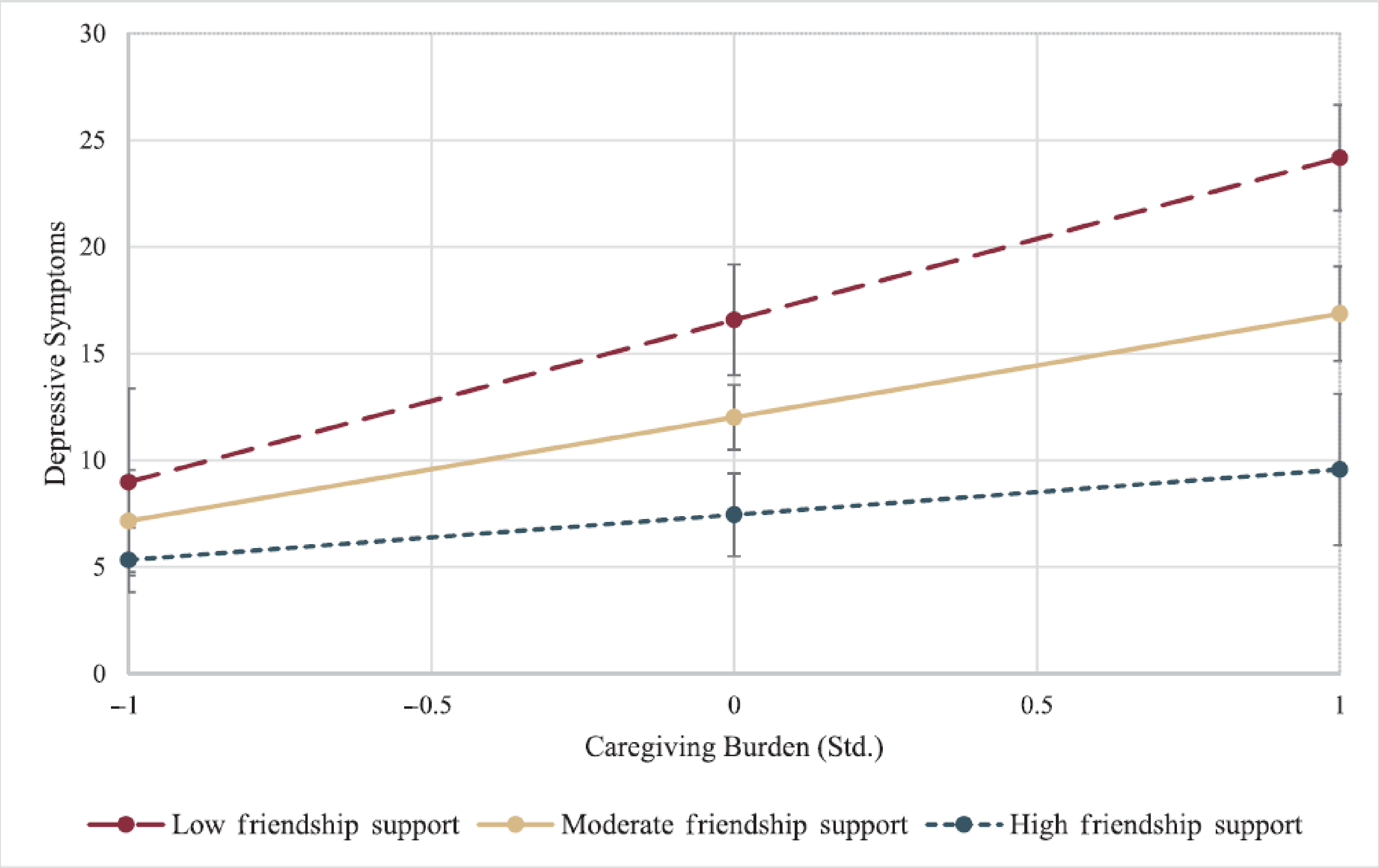


	Resilience Scale	Caregiving Burden	Hawthorne Friendship	Interpersonal Support Evaluation
Caregiver's age	*r*= .043, *p*= .723	*r*= -.081, *p*= .511	*r*= .114, *p*= .350	*r*= -.081, *p*= .511
Years Caregiving	*r* = -.139, *p* = .262	*r* = -.015, *p* = .904	*r* = .042, *p* = .736	*r* = -.153, *p* = .217
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**

Study 3: Moderating Role of Friendship

(Cao et al., 2025)

Figure 1. Marginal plot predicted depressive symptoms by caregiving burden, among people with high, moderate, and low friendship support. Note that 1 *SD* above the mean, the mean, and 1 *SD* below the mean of the Hawthorne Friendship Scale were graphed to present low, moderate, and high levels of friendship support, respectively. Nonoverlapping confidence intervals indicate significant differences in depressive symptoms across friendship support levels. Std. = standardized.



Next Big Step: Addressing Care Partners' Friendship in Clinical Practice

Two Examples

2-Day Residential Family-Based Intervention

(Fox et al., 2004)

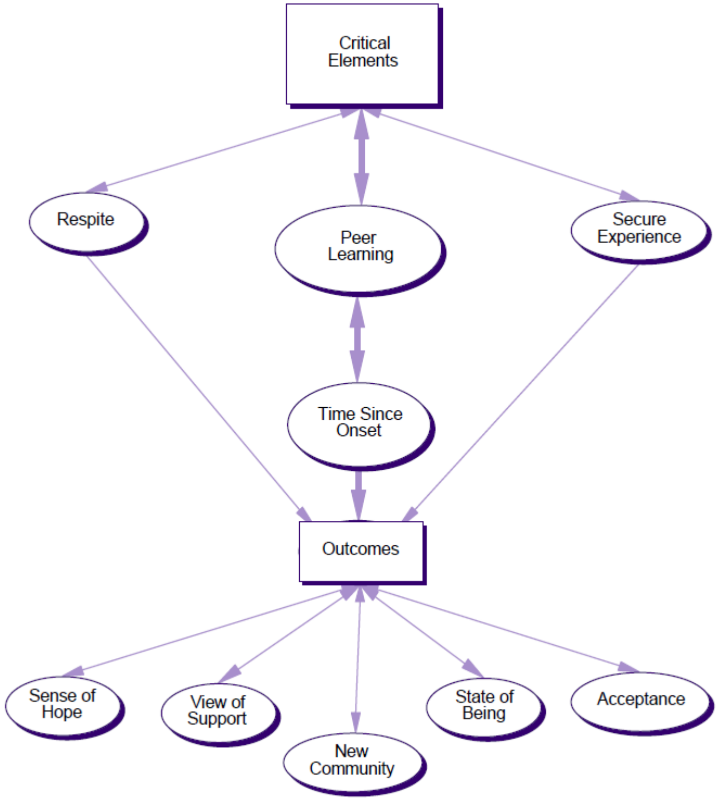


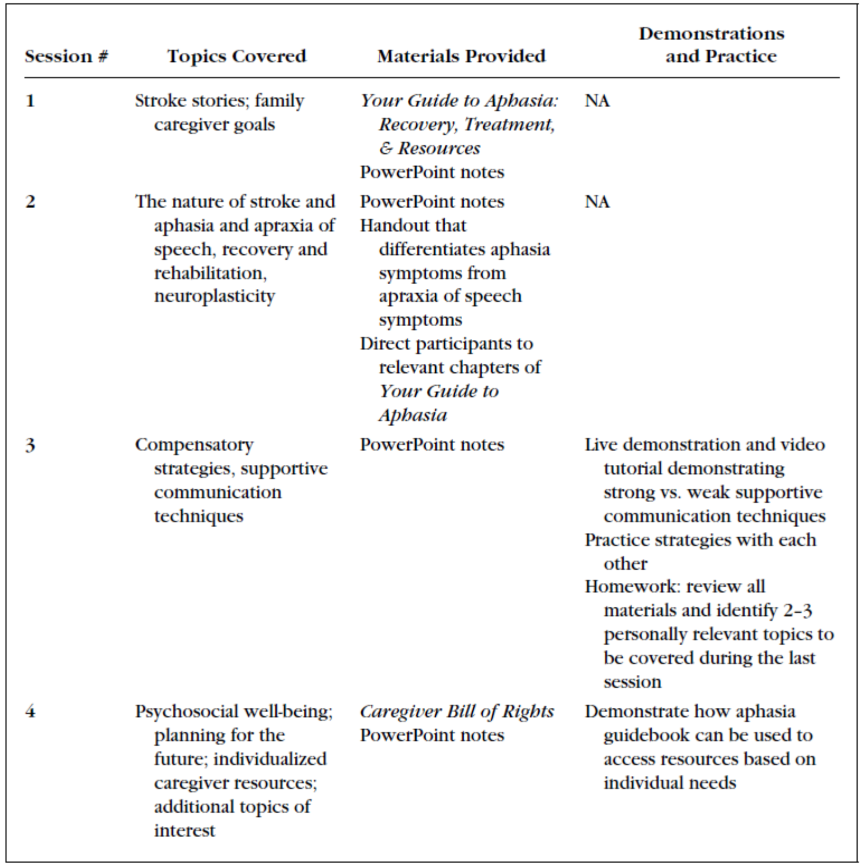
Figure 1. Model of thematic relationships: Web of influence between critical intervention elements and outcomes.

''*You asked what, what I might have taken back from the camp this year. I think this is the type of stuff that we take back each year, is getting information how to help us cope with brothers and sisters and friends and all. I seen people pull away from us when my wife had a stroke… But I think that I have learned how to react*'' (12C, year 3, focus group, lines 467–473).

Intensive Comprehensive Aphasia Program

(ICAP; Off et al., 2019)

Table 5. ICAP caregiver education sessions



Session #	Topics Covered	Materials Provided	Demonstrations and Practice
1	Stroke stories; family caregiver goals	*Your Guide to Aphasia: Recovery, Treatment, & Resources* PowerPoint notes	NA
2	The nature of stroke and aphasia and apraxia of speech, recovery and rehabilitation, neuroplasticity	PowerPoint notes Handout that differentiates aphasia symptoms from apraxia of speech symptoms Direct participants to relevant chapters of *Your Guide to Aphasia*	NA
3	Compensatory strategies, supportive communication techniques	PowerPoint notes	Live demonstration and video tutorial demonstrating strong vs. weak supportive communication techniques Practice strategies with each other Homework: review all materials and identify 2–3 personally relevant topics to be covered during the last session
4	Psychosocial well-being; planning for the future; individualized caregiver resources; additional topics of interest	*Caregiver Bill of Rights* PowerPoint notes	Demonstrate how aphasia guidebook can be used to access resources based on individual needs

"The fusion of equitable interprofessional collaboration, along with the cohort model of the ICAP, allows for acquisition of knowledge, communication strategies, and coping skills along with the **development of close, meaningful relationships with other caregivers** and persons with aphasia"

Share Your Ideas and Experiences?

Take Home Messages

- Caregivers are our clients too.
- Need more interventions focused solely on caregiver health.
- Limited evidence suggests that supportive friendships are related to lower caregiver burden and depressive symptoms and greater psychosocial well being.
- We should aim to measure and target friendship and related psychosocial variables.
- Better carer health helps the carer and the care recipient.

Anonymous proverb

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Thank You for Listening!

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