

Caregiving and Friendship Perspectives From Care Partners of People With Aphasia

**Elizabeth B. Madden, Michelle Therrien, Lauren Bislick,
Sarah E. Wallace, Rachel Goff-Albritton,
Ana Vilfort-Garces, Christopher Constantino,
and Lucinda Graven**

Friendship is an essential component of quality of life. The ongoing lifestyle changes and strain typically experienced by care partners of people with aphasia (PWA) can impact their social network, with friendships being particularly vulnerable to change. This study aimed to understand the impact of caregiving on care partners' friendships over time from the perspective of care partners of PWA. An online survey addressing care partners' demographics, care recipients' demographics, and care partners' perceptions of their friendships over time (before caregiving and during the acute and chronic stages of caregiving) was codesigned with three care partner stakeholders and then distributed to other individuals who care for a person with aphasia. Survey responses from 35 care partners of PWA who completed the survey were analyzed using quantitative and qualitative methods. Most participants reported their friendships were different in both the acute and chronic stages of caregiving compared with before caregiving. Overall, perceived friendship satisfaction and support decreased over time. Qualitative analysis revealed five main factors that could either facilitate or hinder care partner friendships, including role changes, personal characteristics, friendship initiation, friendship interactions, and outside influences. This work highlights that caring for a loved one with aphasia negatively impacts friendships for many care partners, and these friendship changes are often long-lasting. More resources for managing the impact of aphasia on care partners' social lives are needed, which, in turn, might improve the friendships and well-being of both the care partner and their loved one with aphasia. **Key words:** *aphasia, caregiving, care partner, friendship, stroke*

Author Affiliations: School of Communication Science and Disorders (Drs Madden, Therrien, and Constantino), College of Nursing (Dr Graven), and Office of Research Development (Dr Goff-Albritton), Florida State University, Tallahassee; School of Communication Sciences and Disorders, University of Central Florida, Orlando (Dr Bislick); Department of Communication Science and Disorders, University of Pittsburgh, Pittsburgh, Pennsylvania (Dr Wallace); and Brooks Center for Inpatient Rehabilitation, Halifax Medical Center, Daytona Beach, Florida (Ms Vilfort-Garces).

The authors thank the care partners who contributed to this study. The authors also thank Christine Lopez, Karina Hernandez, and Karen Uriostegui for their assistance analyzing the survey data. The authors acknowledge the use of tutorials from Laerd Statistics (<https://statistics.laerd.com/>) to inform and carry out the statistical analyses in this work.

FRIENDSHIPS are vital for good quality of life (Therrien et al., 2021). Unique from family relationships, the voluntary nature of friendships allows for people to establish committed relationships with individuals of their choosing whom they often identify with as equals and share common

The author and planners have disclosed no potential relevant financial relationships or otherwise. Author disclosures can be found at <http://links.lww.com/TLD/A104>.

Corresponding Author: Elizabeth B. Madden, PhD, School of Communication Science and Disorders, Florida State University, 201 W. Bloxham St, Tallahassee, FL 32306 (ebmadden@fsu.edu).

DOI: 10.1097/TLD.0000000000000301

interests (Patterson et al., 1993). Friendships are associated with many benefits, including increased life satisfaction (Patterson et al., 1993), greater happiness (Adams & Blieszner, 1995), higher morale and self-worth (Fiori et al., 2006), and better physical and mental health (Holt-Lunstad, 2016).

Major life events are known to affect a person's social network, with friendships being particularly vulnerable (Wrzus et al., 2013). Social convoy theory (Kahn & Antonucci, 1980) explains that a person travels through life with their convoy of social relationships, which change over time in response to life events. According to this theory, relationships with individuals in the center of someone's convoy, typically family and closest friends, should remain stable and weather the ups and downs of life, whereas relationships with people in the convoy periphery are less stable and are more likely to be negatively impacted by changes in the person's social role or other life situations. Nonkin relationships are typically the ones that dissolve more easily when life circumstances change, and this is especially true if the mutual benefit or reciprocity between friends becomes unbalanced (Wrzus et al., 2013). Moreover, non-normative life events (e.g., death of a relative or illness) tend to have a more negative impact on one's social networks and often result in a reduced social network as opposed to anticipated, normative life events (e.g., puberty, marriage), which often increase social network size (Wrzus et al., 2013).

Brain injury, and resulting aphasia, is a major, unexpected, non-normative life event that can impact the social network of both people with aphasia (PWA) and their care partners. Research shows that PWA are at risk for social isolation and typically participate in fewer social activities, experience friend loss, and often have more family-based social networks (Azios et al., 2021; Manning et al., 2019; Northcott et al., 2018). Research on the relationship between PWA and their care partners emphasizes the critical importance of this interpersonal relationship to both parties' well-being and highlights that

relationship struggles often occur because of both individuals adjusting to their new roles (McCarthy et al., 2020). There is less research, however, focused on care partners' other relationships, particularly friendships, which can be influenced by lifestyle changes inherent to caregiving (White et al., 2007).

Given the sudden onset of stroke/brain injury and resulting aphasia, care partners quickly adopt numerous roles, such as being their loved one's advocate, therapist, motivator, and guardian (Shafer et al., 2019). These unexpected roles are intensified after insurance-covered therapy sessions are exhausted, leaving the care partner as the primary individual to assist with the person's ongoing communication needs, as well as other possible needs, including assistance with grooming, meals, medication management, and mobility (White et al., 2006).

Caring for a loved one with aphasia not only can bring the care partner and the care recipient closer together and give the care partner a rewarding sense of purpose but also results in stress and strain for many (McPherson et al., 2011). The burden many care partners of stroke/brain injury survivors experience from intensive caregiving is typically long-lasting (Opara & Jaracz, 2010) and can worsen their own physical and mental health resulting in "third party disability" (Shafer et al., 2019). Navaie-Waliser et al. (2002) caution that care partners are at risk of becoming patients themselves due to the personal costs and sacrifices involved in dedicated caregiving. Unfortunately, it is common for care partners of stroke/brain injury survivors to experience decreased overall well-being and quality of life, as well as increased mood changes, depression, anxiety, loneliness, and social isolation (Loh et al., 2017; McPherson et al., 2011; White et al., 2006). These negative health consequences can be heightened for care partners who are caring for a loved one with greater needs or challenges, such as a person who has greater communication impairment, greater physical impairment, and/or declining abilities, such as the case with progressive

illnesses (Rombough et al., 2007; The National Alliance for Caregiving & American Association of Retired Persons, 2020; White et al., 2006). Disparities in stroke care (e.g., access to services, type and timing of treatment provided), which disproportionately affect racial minorities (Ikeme et al., 2022; Jacobs & Ellis, 2022), also can increase caregiving demands and negatively impact health outcomes for both the stroke/brain injury survivor and their care partner.

Haley et al. (2019) reported that care partners of PWA were less integrated in their communities and participated in fewer social and leisure activities than their age-matched controls. The reduced life participation experienced by care partners of PWA is likely a consequence of a substantial reduction of time with others (Johansson et al., 2022). Recent work by Graven et al. (2020) highlighted that social support acts as a coping resource for care partners of individuals with heart failure, a group that provides long-term care such as the care partners of PWA. Similarly, a “supportive social environment” was a desired facilitating factor to managing the role of caregiving identified by 14 care partners of stroke survivors in an interview study by White et al. (2007). Together, these findings suggest that positive social relationships, including friendships, have the potential to alleviate aspects of caregiving burden.

Rombough et al. (2006) explicitly stated that research dedicated to understanding the role of friend support for aphasia care partners is needed; however, this area of research remains mostly unexplored. Therefore, this study aimed to better understand caregiving and friendship dynamics among aphasia care partners. Specifically, the purpose of this study was to explore the impact of caregiving on friendship over time by gathering aphasia care partners’ perspectives about their own friendships before they started caregiving and during the acute and chronic phases of caregiving for their loved one with aphasia.

It is critical to note that the original idea and motivation for our research focused on care partners’ friendships originated from

small group discussions the first author facilitated at the “Team Friendship” table with four PWA and their five familial care partners at the 2018 Project Building Research Initiatives by Developing Group Effort (BRIDGE) conference (Hinckley et al., 2019). Therefore, this work focused on a personally meaningful issue that was organically inspired from aphasia care partners conversing with one another and their loved ones with aphasia at a conference focused on stakeholder-engaged research. Moreover, this work addressed two gaps in the research literature by concentrating on an often overlooked, yet important area of caregiving research, friendship, and by focusing on an often understudied, yet prominent population of caregivers, aphasia care partners. This research study aimed to provide information about the following:

1. How do friendships of care partners change over time, including the time before onset of their loved one’s aphasia and during the acute and chronic stages of caregiving?
2. How do care partner and care recipient demographic factors relate to care partners’ perceived friendship satisfaction?
3. What factors identified by care partners appear to facilitate or hinder the maintenance and development of their own friendships?

METHOD

This research was approved by the Florida State University (FSU) Institutional Review Board. An online survey focused on caregiving and friendship was created by the authors using Qualtrics survey software and was open for 2 months (December 2020 and January 2021). Care partners from the FSU Aphasia Registry and Repository were invited via email to participate. In addition, the survey link was emailed to several speech-language pathologists known to the authors who work with PWA and was shared with two aphasia centers to distribute directly to aphasia care partners.

Participants

In this study, a care partner is defined as a person who is not employed by an agency and provides voluntary assistance to a PWA in their home and/or community. Study participation required that participants (a) identify as a caregiver for a person with chronic aphasia, (b) have access to the internet, and (c) be able to read and respond to the survey in English.

Survey development

An advisory group consisting of speech-language pathology graduate student researchers ($n = 2$), speech-language pathologists who work with clients with aphasia ($n = 2$), communication sciences and disorders programs faculty researchers with a focus on aphasia, friendship, and/or survey work ($n = 3$), and three aphasia care partner stakeholders ($n = 3$) worked collectively to develop the friendship survey used in this study. The aphasia care partners in the advisory group were known to the first author. This group of care partners consisted of one man and two women who identified as White, ranged in age from 52 to 68 years, and were spouses of a PWA. A literature search using key words related to “caregiving,” “friendship,” “stroke,” and “aphasia” was completed to inform the survey questions. We generated potential survey questions based on the literature search findings and their experience working with aphasia care partners, as well as on a friendship survey we developed for PWA for a related project so that these two surveys shared common elements to allow for future comparison of perspectives and experiences among PWA and their care partners. To ensure that this survey adequately addressed aphasia care partner experiences with friendship, three care partners in the advisory group were invited to complete and critique the drafted survey. After viewing the survey online and taking notes containing their thoughts and impressions, two of the care partner stakeholders independently shared their input with one of the authors

via a phone conversation. Their feedback was manually transcribed during the conversation and read back to them before the conversation ended to confirm it was understood correctly. All the changes suggested by these two care partners were made, given their edits were feasible and the research team agreed they would improve the survey. Modifications were made to several questions to reflect the care partners’ observations and comments, such as providing more contextual information for the different sections and individual questions of the survey, as well as rewording survey questions care partners found critical or insensitive to be more inclusive and empathetic. For example, one stakeholder expressed that the survey made her feel sad about not making new friends, so a question was changed from “People often make new friends in . . .” to “On occasion, people have the opportunity to make new friends....” A third care partner completed the revised survey and shared via email with one of the authors that he did not have any suggested changes; therefore, no further changes were made to the survey. See Table 1 for more information regarding the contributions of care partner stakeholders in this study, illustrated by the Guidance for Reporting Involvement of Patients and the Public (GRIPP2-SF) checklist (Staniszewska et al., 2017).

The final survey took approximately 30–45 minutes to complete and consisted of 80 questions (71 closed-ended, nine open-ended) organized into three sections: a care partner demographics section (“About You”); a care recipient demographics section (“About Your Loved One with Aphasia”); and a friendship-specific questions section (“About Your Friendships”). At the start of the survey, care partners provided standard demographic information (age, race, gender identity, years of education, employment status, marital status). They also were asked caregiving-specific questions pertaining to time spent caregiving, relationship to the person with aphasia, caregiving activities, and caregiver support group attendance. In the second section, care partners reported on

Table 1. Aphasia care partner stakeholder engagement in this study using the GRIPP2-SF checklist

GRIPP2-SF Checklist	Illustration in Current Study
1: Aim	To involve aphasia care partner stakeholders in the development of research focused on their own friendships.
<i>Report aim of PPI in the study</i>	
2: Methods	Five care partners contributed to the initial idea and motivation for examining the impact of aphasia on care partners' friendships during small group discussions at the Project BRIDGE Conference in 2018. Three additional care partners were involved in the codesign and revision of the survey items used in this study.
<i>Provide description of PPI methods</i>	
3: Results	Survey items were substantially modified on the basis of feedback from care partner stakeholders, including providing more contextual information for the different sections and individual questions of the survey, as well as rewording survey questions that care partners found critical or insensitive to be more inclusive and empathetic.
<i>Report results of PPI in the study</i>	
4: Discussion	Care partner engagement in survey development allowed for their lived experience of caregiving to influence the survey content and better ensure that key questions were included and presented in a manner that was clear and sensitive to the feelings and needs of subsequent care partner participants completing the survey.
<i>Comment how PPI influenced the study</i>	
5: Reflections	Involving aphasia care partners in survey development was a positive experience. The stakeholders were eager to be a part of research development and contributed valuable input in a timely manner. This study would be improved by much greater engagement of aphasia care partners and other key stakeholders (PWA, friends) in all stages of the research process (formulating research questions, recruitment, data analysis, and manuscript writing).
<i>Comment critically on PPI in the study</i>	

Note. BRIDGE = Building Research Initiatives by Developing Group Effort; GRIPP2-SF = Guidance for Reporting Involvement of Patients and the Public-short form (Staniszewska et al., 2017); PPI = patient and public involvement; PWA = people with aphasia.

demographics pertaining to their care recipient, including the same demographic information they answered about themselves, as well as aphasia-specific questions (e.g., cause of aphasia, time since onset of aphasia, and care partner's perception of their loved one's aphasia severity—mild, moderate, severe, or not sure—and overall health—very bad, bad, neither good nor bad, good, or very good). In the final section, participants answered closed-ended questions about their friendship satisfaction, support, activities, and communication methods before onset of their loved one's aphasia, during the acute stage (i.e., first 6 months) of aphasia recovery and caregiving, and during the chronic, present time of caregiving. Open-ended questions addressing barriers and facilitators to friendship maintenance and development during both the acute and chronic stages of caregiving also were included. Participants were instructed not to consider their family relationships when answering the friendship-related survey questions. Given the survey occurred during the COVID-19 pandemic, questions pertaining to the pandemic's effect on friendships were included at the end of the survey. Prior to the questions asking about the chronic stage, participants were asked to consider the time pre-pandemic, to the extent possible.

Data analysis

Descriptive statistics (i.e., means, standard deviations, ranges, and frequencies) were calculated for the closed-ended survey questions. Spearman's rank-order correlations were conducted to examine how ordinal (aphasia severity, PWA health status) and continuous (age, months caregiving, months since aphasia onset) demographic variables related to the ordinal variable of interest, current friendship satisfaction ("very dissatisfied" to "very satisfied") in the chronic stage. For nominal data (race, gender identity, and employment status), chi-square tests of association were used to examine relationships with perceived friendship satisfaction. Wilcoxon signed rank tests were performed

to determine whether there was a statistically significant difference in the ratings of perceived friendship satisfaction and friendship support between different time points (before caregiving, acute stage of caregiving, and chronic stage of caregiving).

The open-ended survey questions addressing perceived barriers and facilitators to friendship were analyzed qualitatively. Codes and subcodes were identified to categorize participant responses and later applied to the data, after five authors independently read all responses and met to revise and reach agreement on all codes for all responses. The final codes were able to be applied to all the open-ended responses and there was not a need to code some responses as "other" or to create additional codes, indicating a saturation of responses among the participants. If a response did not address the posed question or was lacking information/clarity, then it was not categorized.

RESULTS

Participant characteristics

Forty-eight aphasia care partners accessed the survey; however, responses from 13 people were not included in the final analysis. Two care partners involved with survey design were excluded because of significant survey changes made after their participation. Two more care partners were excluded because they care for a loved one with primary progressive aphasia; these participants were excluded from the final data analysis, given their loved ones' abilities would be expected to decline over time, which can affect their caregiving experience differently from care partners of loved ones with chronic aphasia, who typically improve, to some extent, over time. Three participants were excluded because they answered "no" when asked if they identified as a caregiver, and six participants were excluded because of failure to complete 50% or more of the survey. After removing these data, 35 participant responses remained.

The average age of the 35 participants was 59.26 years ($SD = 13.28$, range = 24-92) and average completed years of education was 16.51 ($SD = 2.59$, range = 12-24). Participants reported caregiving for a loved one with aphasia for 48.94 months ($SD = 30.28$, range = 9-120) on average, 94% ($n = 33$) reported residing with their loved one with aphasia, and 11% ($n = 4$) reported attending a caregiver support group. See Table 2 for additional participant characteristics, including race, ethnicity, gender identity, employment status, relationship to care recipient, daily time spent caregiving, and care partners' perception of their loved one's aphasia severity and overall health status.

Changes in care partners' friendships over time

Maintenance and development of friendship

Fifty-seven percent ($n = 20$) reported friendships during the acute stage of caregiving differed from friendships before they started caregiving, and 66% ($n = 23$) reported friendships remained different during the chronic stage. Despite friendship changes, all participants reported some degree of friendship maintenance at the present time, with 29% ($n = 10$) being friends with "everyone," 20% ($n = 7$) being friends with "many," and 51% ($n = 18$) being friends with "some" friends from before caregiving.

Regarding friendship development, 29% ($n = 10$) of participants made new friends during the acute stage, and this increased to 80% ($n = 28$) reporting they made at least one new friend in the chronic stage. They met new friends at various places; however, many places were tied to caregiving responsibilities, including meeting a new friend in a medical setting, loved one's therapy session, or an aphasia group during the acute (37%; $n = 13$) and chronic stages (31%; $n = 11$). Eighteen participants (51%) said that at least one new friend also was a caregiver.

Table 2. Aphasia care partner demographics ($N = 35$)

Participant Demographics	<i>n</i>	%
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 give care	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 hr	23	66
7-8 hr	3	9
5-6 hr	4	11
3-4 hr	2	6
1-2 hr	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

Friendship satisfaction

Participants ranked their friendship satisfaction on the following scale: "very dissatisfied" (1), "dissatisfied" (2), "neither dissatisfied nor satisfied" (3), "satisfied" (4), or "very satisfied" (5). Their average response for the

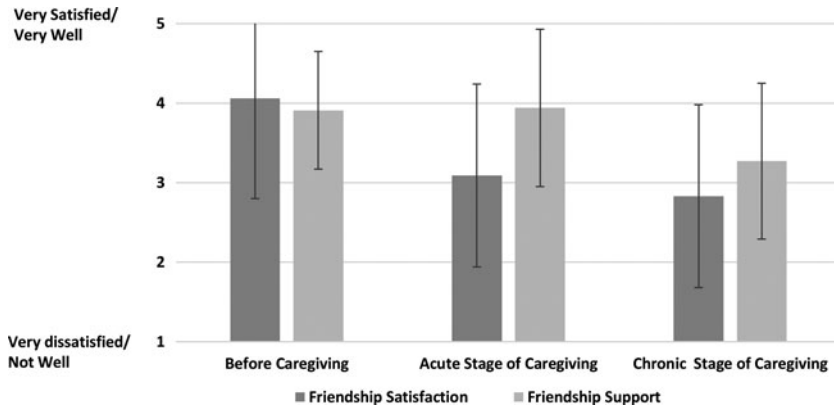


Figure 1. Aphasia care partners' ($N = 35$) perceived friendship satisfaction and support over time.

period before caregiving was 4.06 ($SD = 1.26$), and the most frequent response (49%; $n = 17$) was "very satisfied." During the acute stage, the most frequent response (49%; $n = 17$) changed to "neither satisfied nor dissatisfied" and the average was 3.09 ($SD = 1.15$). For the chronic stage, the average was 2.83 ($SD = 1.15$) and the most frequent response (34%; $n = 12$) was "dissatisfied." Wilcoxon signed rank tests determined there was a statistically significant decrease in perceived friendship satisfaction from before caregiving ($Mdn = 4.00$) to the acute stage of caregiving ($Mdn = 3.00$), $z = -3.28$, $p = .001$, and from the time before caregiving ($Mdn = 4.00$) to the chronic stage of caregiving ($Mdn = 3.0$), $z = -3.56$, $p < .001$. There was no statistically significant difference in perceived friendship satisfaction between the acute stage of caregiving ($Mdn = 3.0$) and the chronic stage of caregiving ($Mdn = 3.0$), $z = -1.21$, $p = .22$.

Friendship support

Participants reported the degree to which they felt supported by friends on the following scale: "not at all" (1), "not well" (2), "okay" (3), "well" (4), and "very well" (5). For the time before caregiving, the average response was 3.91 ($SD = 0.74$) and the most frequent response (46%; $n = 16$) was "well." During the acute stage, the most frequent response (40%; $n = 14$) changed to "very well" and the average was 3.94 ($SD = 0.99$). For the chronic stage, the average was 3.27 ($SD =$

0.98) and the most frequent response (43%; $n = 15$) was "okay" (see Figure 1). When asked whether they sensed a change in friend support ("more," "same," "less") during the COVID-19 pandemic, the majority (63%; $n = 22$) reported feeling equally supported. One person reported more friend support, and 11 people (31%) reported feeling less supported by friends during the pandemic. Wilcoxon signed rank tests determined there was a statistically significant decrease in perceived friendship support from before caregiving ($Mdn = 4.00$) to the chronic stage of caregiving ($Mdn = 3.00$), $z = -3.72$, $p < .001$, and from the acute ($Mdn = 4.00$) to chronic stages of caregiving ($Mdn = 3.0$), $z = -3.16$, $p = .002$. There was no statistically significant difference in perceived friendship support between the time before caregiving ($Mdn = 4.0$) and the acute stage of caregiving ($Mdn = 4.0$), $z = -0.19$, $p = .84$.

Friendship communication

Before caregiving, the most used method of communicating with friends was talking in person (46%; $n = 16$; see Figure 2). During the acute stage, talking by phone (40%; $n = 14$) and texting (37%; $n = 13$) became the two most common forms of communicating with friends, and these two methods remained the most used for 69% ($n = 24$) of people in the chronic stage. In addition to method of communication, care partners reported what they talked about most

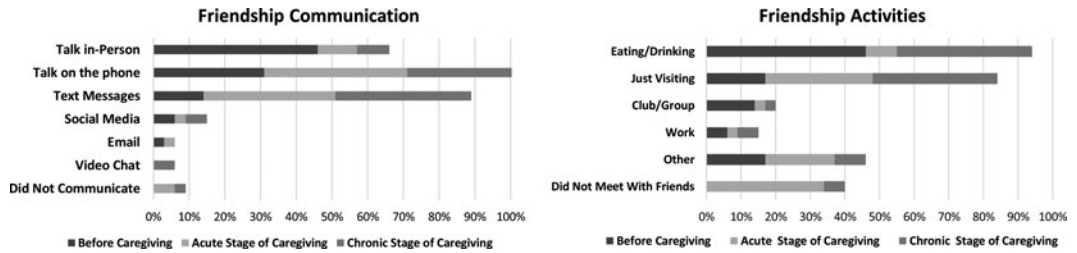


Figure 2. Aphasia care partners' ($N = 35$) most common communication methods and activities with friends over time.

often with friends. In the acute stage, the majority (74%; $n = 26$) talked about “aphasia/stroke/brain injury” and several (34%; $n = 12$) remained focused on this topic with friends in the chronic stage. Two people reported having no communication with friends during the acute stage, and one person did not communicate with friends in the chronic stage of caregiving.

Friendship activities

Before caregiving, the most common activity was “eating/drinking” with friends (46%; see Figure 2). During the acute stage, the most frequently reported activity was a lack of activity or “did not meet with friends” (34%; $n = 12$). “Just visiting” (31%; $n = 11$) was the most frequent activity to take place with friends during this time. In the chronic stage, “eating/drinking” (37%; $n = 13$) and “just visiting” (34%; $n = 12$) were the two most common friendship activities.

Friendship and COVID-19

When asked whether the COVID-19 pandemic affected their friendships (“yes” or “no”), 22 of the 35 care partners (63%) reported “yes” that the pandemic affected their friendships. When asked how often they interacted, in person or remotely, with friends (i.e., “more,” “less,” “the same”), the majority (57%; $n = 20$) reported interacting less often with their friends. Twelve care partners reported interacting the same amount as usual, and two people interacted more often with friends during the pandemic. Regarding perceived level of friend

support during the pandemic (i.e., “more,” “less,” or “same”), the majority (63%) felt equally supported by friends during the pandemic compared with before the pandemic occurred. One care partner felt more supported by friends, and 11 people reported feeling less supported by friends during the pandemic.

Relationships between demographic factors and friendship satisfaction

Age, race, gender identity, employment status, time after onset of aphasia, and the care partner’s perception of their loved one’s aphasia severity were not statistically significantly related to care partners’ friendship satisfaction. The total number of months caregiving showed a negative association with friendship satisfaction ($r = -.392, p = .020$) such that as the number of months caregiving increased, friendship satisfaction decreased. In addition, care partners’ perception of their loved one’s health status, rated on a scale from “very bad” to “very good,” showed a positive relationship with friendship satisfaction ($r = .396, p = .019$) such that better care recipient health was associated with better friendship satisfaction for the care partner.

Barriers and facilitators to friendship maintenance and development

Table 3 summarizes and provides examples of care partners’ responses to open-ended questions addressing barriers and facilitators to their own friendships. Responses were related to five main factors (i.e., role change, personal characteristics, friendship

Table 3. Aphasia care partners' perceptions of factors that influence their own friendships

Main Factor	What This Looks Like When It Facilitates Friendship	What This Looks Like When It Hinders Friendship
<p>Role change (Changes in roles and responsibilities of care partner, PWA, or friends)</p>	<ul style="list-style-type: none"> • Friends providing more material support <p><i>"[Friends] helped with transporting kids and giving kids support, providing meals and gift cards, spending time with my husband, helping me get a job."</i></p> <ul style="list-style-type: none"> • Friends learning about aphasia <p><i>"My friends have been very willing to learn about aphasia from different sources I have provided."</i></p>	<ul style="list-style-type: none"> • Caregiving taking all of the care partner's time and energy <p><i>"There is no time to nurture any friendships when you are caring for someone 24/7."</i></p> <ul style="list-style-type: none"> • Job loss because of caregiving requirements <p><i>"I had to quit my job, while most of my friends are still working. I really miss my coworker camaraderie."</i></p> <ul style="list-style-type: none"> • Caregiving causing unwanted separation from shared friends <p><i>"We miss our friends but we get that when their kids are having babies and getting new jobs, we are still doing PT/OT and Speech and progress is progress. That common theme of kids changes when you become a care giver . . . it's like a separation occurs that it's hard to build a bridge that will reach when your common interests are now so different."</i></p>
<p>Characteristics (Characteristics or personality traits of care partner, PWA, or friends)</p>	<ul style="list-style-type: none"> • Care partner with a positive outlook <p><i>"Difficulties in life, polishes and purifies us. we are not bitter if someone stopped communication but encouraged us to be stronger and more selective."</i></p> <ul style="list-style-type: none"> • Care partner and PWA being open <p><i>"Being open and sharing with people at a minimum that we had a medical situation. This allowed people to rally around us."</i></p>	<ul style="list-style-type: none"> • PWA not interested in spending time with friends <p><i>"After his stroke, my husband severed all contact, it was too painful for him to not be able to enjoy his old life."</i></p> <ul style="list-style-type: none"> • PWA unable to be left alone due to severity of disability <p><i>"I have never felt so isolated in my life. I could not leave him alone, even to go to the grocery store."</i></p> <ul style="list-style-type: none"> • Care partner feeling embarrassed about changes <p><i>"I'm embarrassed talking about my life because it was so fun and now it's so glub."</i></p>

(continues)

Table 3. Aphasia care partners' perceptions of factors that influence their own friendships (*Continued*)

Main Factor	What This Looks Like When It Facilitates Friendship	What This Looks Like When It Hinders Friendship
Initiation (Actions of care partners, PWA, or friends to make the first contact)	<ul style="list-style-type: none"> • Close friends who are committed and caring “Their stick-to-itiveness because I don't have the energy now.” • Friends who are comfortable with aphasia “The real friends don't mind that one of us can't talk the same as they used to.” • Friends who can relate to caregiving “...we had one family that had shared our journey before our health crisis. They were able to run interference for us and help us know what to expect. That was an immense gift.” • Being a friend to both care partner and PWA “The old friends who were both of our friends are the ones we continue to see socially.” 	<ul style="list-style-type: none"> • Care partner being hesitant to accept help “I should have accepted more help with food and such. I just was not hungry or home that much. It would have made my friends happy.” • Care partner feeling a lost sense of self “This is not self-pity. It was my reality. I felt I ceased to exist as a separate entity.” • Friends who do not understand aphasia and feel uncomfortable “Lost many friends who are uncomfortable with my wife's aphasia. Some were joint friends and they have drifted away. We are relatively isolated.”
<ul style="list-style-type: none"> • Care partner putting in effort to reach out “I sent daily text messages to friends and family. Helped me process things and keep people in touch.” • Friends putting in effort to reach out “Friends who cared and wouldn't let me go kept the old friendships—just showing up and surprising me or texting even when I didn't reach out.” 	<ul style="list-style-type: none"> • Care partner is hesitant to reach out “It's terrible and no one can really help. Every ask is a burden.” • Friends make no contact “Soon after the stroke, some of our friends became silent and stopped contacting.” 	<p>(continues)</p>

Table 3. Aphasia care partners' perceptions of factors that influence their own friendships (*Continued*)

Main Factor	What This Looks Like When It Facilitates Friendship	What This Looks Like When It Hinders Friendship
<p>Interaction (Types of friendship interactions or social activities involving care partner, PWA, or friends)</p>	<ul style="list-style-type: none"> • Keeping in touch using various methods <i>"There's really no time for anything outside of the house. Texting was huge lifesaver."</i> • Friends listening <i>"The best friends listened to us decompress over and over."</i> • Finding new activities to enjoy with friends <i>"We love to go out to brew pubs and breweries [now]. We have met all our new friends at those places."</i> • Care partner meeting friends without PWA <i>"I get to laugh and have fun and relax. I cannot do that at home because he doesn't like company or noise."</i> 	<ul style="list-style-type: none"> • Care partner finds it difficult to include PWA in social activities <i>"I have to carry on the conversation for both of us. I also have to be the one in charge of everything. Sometimes it's too much of a hassle."</i> • Superficial conversations lacking consideration for care partner <i>"No friends have ever asked how I'M doing—or never asked if they could help with my husband. It's beyond a sad & lonely life."</i> • Friends stop interacting with care partner and PWA <i>"Those that were more social moved on because our lives were just too complicated and maybe hard to watch."</i>
<p>Outside influences (Not directly related to care partner, PWA, or individual friendships)</p>	<ul style="list-style-type: none"> • Care partner belonging to a community group (e.g., church, school, clubs/groups) <i>"Our yacht club social group was like family, everyone stepped in to help us."</i> 	<ul style="list-style-type: none"> • Financial challenges prohibiting participation in activities <i>"We can't do anything that they can because we had to declare bankruptcy and are still waiting on disability determination."</i> • COVID-19 pandemic <i>"No one has time to socialize these days, and COVID has added to that."</i>

Note. Responses are presented as typed by participants. Spelling errors were corrected, however, when needed to improve clarity. PWA = people with aphasia.

initiation, friendship interactions, and outside influences) defined in Table 3. Within these factors, participant responses were identified as being related primarily to the care partner, person with aphasia, or friends.

DISCUSSION

Care partners' perspectives on friendship over time

This study highlights perspectives of care partners of PWA regarding the impact of caregiving on their friendships over the course of their caregiving experience. Most care partners felt their friendships differed in both the acute and chronic stages of caregiving compared with before they were caregiving, yet all 35 participants reported maintaining friendships with at least some friends. These findings align with predictions of social convoy theory (Wrzus et al., 2013) that social networks shift after a major life event, with close relationships in the middle of a person's convoy remaining intact, such as the enduring friendships reported by our participants.

Development of new friendships also occurred for most participants, although this was more likely to occur in the chronic versus acute stage of caregiving, with more than half of participants befriending a fellow care partner. This positive finding supports the socioemotional selectivity theory (Löckenhoff & Carstensen, 2004), which states people are motivated to emphasize relationships that will best meet their emotional needs. This preference for emotionally meaningful relationships is said to be more prevalent when people perceive their time is limited, which can occur for numerous reasons including times of illness or nearing the end of life. Socioemotional selectivity theory supports the idea that care partners with limited time due to caregiving responsibilities might be drawn to spending their available time with another care partner who can relate to their life situation and provide desired emotional support.

Despite the maintenance of old friendships and development of new friendships for

many care partners in this study, there was an overall decrease in perceived friendship satisfaction and support over time compared with the time before caregiving. Friendship satisfaction and support were perceived more favorably in the acute stage than the chronic stage of caregiving for some participants. The higher rating of friendship satisfaction and support during the acute stage might reflect friends initially being more available to support the care partner during their family medical emergency. Care partners are understandably preoccupied with their loved one and focused on their survival and recovery in the acute stage, likely leaving little time to be concerned with maintaining or developing their own friendships at that critical time. In the chronic stage of caregiving, however, care partners are likely more attuned to friendship changes that have occurred and may feel less satisfied and supported if friendship interactions have not resumed to precaregiving status or do not meet their current social support needs.

Perceived friend support is known to be a key variable to friendship success, even more so than a person's total number of friends or how often a person sees their friends (Patterson et al., 1993). Therefore, more work dedicated to addressing the decreased support that was reported in this study and others (White et al., 2006, 2007) is critically needed. White et al. (2006) found that "very few" care partners of stroke survivors reported using support services that would either help them care for their loved one (e.g., nursing, day center) or support themselves (e.g., mental health counseling or support groups). In fact, none of the 52 care partners in the White et al. (2006) study reported going to a caregiver support group, and only four of the 35 care partners in the current study reported attending a caregiver support group. These results are discouraging and demonstrate the need for more support resources, particularly caregiver support groups, given some care partners make meaningful friendships with fellow care partners. Northcott and Hilari (2018) emphasized the

key role that care partners play in supporting their loved one with aphasia and that more support options for care partners are needed to allow them to care for themselves and, in turn, their loved one with aphasia.

The reported changes in friendship communication methods and activities are likely a reflection of, or perhaps are contributing factors to, the decrease in friendship satisfaction and support observed in this sample of care partners. The demands of caregiving place limits on how a care partner can communicate with friends and what activities can be enjoyed with friends, especially during the acute stage when most individuals with aphasia need around-the-clock supervision; however, time-intensive care also can be required well beyond the acute stage of recovery. This time-consuming and typically long-lasting caregiving might contribute to most care partners in this study switching from primarily communicating in person with friends before caregiving to communicating most often by phone or text messaging in both acute and chronic stages of caregiving. Care partners also made noticeable changes to their friendship activities, illustrated by the finding that in the acute stage of caregiving, the most frequently reported activity was a lack of interaction or not meeting with friends at all. Participants who did meet with friends during the acute stage tended to “just visit” at this time compared with going out. These results represent the care partners’ primary or most frequent friendship activities and communication methods; however, they might not reflect their preferred ways of interacting with friends. Haley et al. (2019) found discrepancies between the social activities that 70 care partners of PWA were currently doing and what they wanted to be doing. “Having coffee/tea with friends” was a desired activity for more than 70% of their participants, demonstrating that many care partners want more leisure time with friends.

The findings surrounding changes in care partners’ most common methods of communicating and interacting with friends over time (see Figure 2) cannot be explained ex-

clusively by caregiving responsibilities and need to be discussed in the context of worldwide increased use of asynchronous communication and the possible effects of the pandemic. The common use of smartphones and texting among the general public likely contributed to changes in friendship interactions over time. However, an increase from 14% of care partners primarily communicating by texting before caregiving to 37% primarily communicating with friends via texting in the acute stage suggests new demands of caregiving contributed to their greater use of texting, which can occur anytime that is convenient for them. Similarly, a decrease from 46% of participants reporting that they talked in person as their primary communication method with friends before caregiving to only 11% primarily talking in person in the acute stage of caregiving indicates their new caregiving role negatively affected their ability to talk in person with friends. These changes in the acute stage of caregiving do not reflect pandemic effects because that period of time occurred before the pandemic onset for all our study participants except four people whose acute stage of caregiving overlapped with the beginning of the pandemic. In the chronic stage of caregiving, the continued low percentage (9%) of care partners talking in person as their most common way of communicating with friends might represent effects of a combination of caregiving demands, communication technology and options, and the pandemic. Participants were instructed to respond on the basis of activity prior to the pandemic; however, we discuss in the following text how that could be difficult for some people to accurately do.

It is critical to emphasize that some participants in our study reported that they did not communicate or meet with friends at all during the acute stage, and this remained true in the chronic stage for a few, when most care partners had resumed going out with friends. Care partners with severely limited interactions with friends are at risk for social isolation and likely have a greater need for social support resources. It is important

to keep in mind, however, that people have different preferences regarding social engagement. These differences are apparent in two participants who both reported they “never” interacted with friends in the chronic stage of caregiving. One of these care partners said they were “dissatisfied” with their current friendships, “not well” supported by friends, and only friends with “some” people they knew before caregiving. The other care partner who “never” interacted with friends said they were “neither satisfied nor dissatisfied” with their current friendships, felt “okay” friend support, and still friends with “everyone” they knew before caregiving. These two individuals appeared to respond differently to their lack of friendship interactions, with one having potentially more negative consequences for their social well-being. Future work should carefully examine social preferences, social isolation, and loneliness in care partners who identify as more introverted or extroverted and determine whether different interventions or resources are needed to support people’s varying needs for intensity and manner of social connection with others.

Demographic variables related to care partners’ friendship satisfaction

The more months a person had been caregiving, the more likely they were to report less satisfaction with their friendships. This result mirrors the finding that more time spent caregiving is associated with a lower quality of life for many care partners of stroke survivors (Rombough et al., 2007). Moreover, the negative association between caregiving time and friendship satisfaction might be intertwined with the typically persistent, or sometimes even increasing, caregiving strain that many care partners of stroke survivors experience over time (Opara & Jaracz, 2010; Vincent et al., 2009; White et al., 2006). This continued caregiving strain can result in burnout, leaving the care partner with reduced time, interest, or energy for friends. In addition, this negative relationship between time and friendship satisfaction might be explained by friends’ actions or lack thereof.

The longer a person has been caregiving, the greater the chance friends may stop reaching out. Care partners can feel forgotten or abandoned by friends and therefore friendship satisfaction can suffer after the initial period of their loved one’s stroke or brain injury when friends usually rally around to offer support (White et al., 2007).

Care partners’ perception of their loved one’s overall health also was related to care partner friendship satisfaction, with better care recipient health being associated with better care partner friendship satisfaction. Better health of a PWA may imply that the person can do more for themselves and that less caregiving is needed, which may lead to less caregiving burden. Fewer caregiving needs might allow more time for care partners’ friendships. Other research with care partners of stroke survivors reports a similar finding, in that care partners’ quality of life improved when care recipients had fewer behavioral or mood disturbances, had greater independence, and were more reintegrated into their communities (Rombough et al., 2007; White et al., 2006). A care partner in the White et al. (2007) study illustrated this relationship when she said, “He’s improving, so I’m improving.” These findings show that the health and social well-being of care partners and PWA can be highly interconnected.

Research suggests other demographic variables such as age, gender identity, and employment status are associated with care partner quality of life or perceived caregiver burden (Opara & Jaracz, 2010; Vincent et al., 2009). These factors were not related to participants’ perceived friendship satisfaction in this study. Perhaps, the variables related to quality of life and caregiver burden differ from those related to friendship satisfaction, and/or the small sample size and relatively homogeneous sample (e.g., predominately White, college-educated, middle-aged women of unknown income level who were spouses of the PWA and not working at the time of this study) of care partners in this study preclude these relationships from being adequately examined.

Factors identified by care partners that influence friendship success and challenges

Participants collectively wrote about many factors that influenced their friendships, and these were summarized into five main factors: role change, personal characteristics, friendship initiation, friendship interactions, and outside influences (see Table 3). Changes in roles (e.g., changes in activities and responsibilities) are known to strain relationships between care partners and stroke survivors (McCarthy et al., 2020), and almost all care partners in this study reported how their caregiving role also strained their friendships. Participants frequently described caregiving burden, during both the acute and chronic stages, with almost all emphasizing a lack of time or energy to socialize. Fortunately, care partners also shared some positive role changes, including friends assuming the responsibility of learning about aphasia or serving in new roles such as helping with childcare.

Regarding personal characteristics, care partners shared that their feelings of guilt, embarrassment, and a lost sense of self contributed to friendship difficulties. These common feelings of psychological distress among stroke caregivers are known to negatively influence quality of life (Rombough et al., 2006), and the current work shows their bearing on friendship as well. Care recipients' physical disability, aphasia, and lack of interest in being around others also were said to interfere with care partners' friendship opportunities. Interestingly, Northcott and Hilari (2011) identified the same factors as barriers to the friendships of PWA. Finally, care partners shared that their friendships suffered when friends felt uncomfortable and shied away. For some friends, this avoidance may reflect the relationship no longer feeling mutually beneficial (McPherson et al., 2011). Not surprisingly, being a caring friend who is comfortable with aphasia was identified by many participants to help their friendships, highlighting the importance of emotional support for successful friendships.

Many participants found friends initiating contact to be especially helpful to maintain their friendships. Care partners also identified the benefit of initiating interaction themselves. Successful friendship interactions focused on activities that not only could be enjoyed by both the person with aphasia and the care partner but also included time alone with friends. Unsuccessful interactions included friends fading away or the care partner finding the conversation trivial or not a good use of their time. Negative friendship interactions might be a result of social support burden, which often occurs when a care partner finds it burdensome to seek and receive support from others because of their intense caregiving lifestyle (Wittenberg-Lyles et al., 2014). This notion is further supported by our participants describing their hesitancy to reach out to friends or the immense effort required to do so.

Finally, participants described "outside influences" or factors not directly related to their individual friendships that either helped (e.g., belonging to a group) or hurt (e.g., financial challenges) their friendships. Overlapping with some of the "outside influences" discussed by our participants, White et al. (2006) noted that health and social support services (e.g., support groups, meal services, counseling) often are not used by caregivers of stroke survivors. Together, these findings illustrate the need for more outside resources for care partners and to identify specific services (e.g., financial assistance) that might help caregiver social well-being.

Limitations and future directions

Interpretation of this work is limited by the small and homogeneous group of care partners who participated in the study. Future work should further explore the impact of caregiving on care partners' friendships by sampling a larger, more diverse group of care partners and consider using different methodologies that might allow for a deeper understanding of caregiving and friendship dynamics. Longitudinal methods could be used to follow the same care partners over

time or, alternatively, experience sampling methods might be implemented, which would allow for a person's daily lived experience of friendship to be studied intensely over a few weeks. In addition, the use of focus groups and individual interviews might make it easier for participants to share more meaningful information and better allow researchers to confidently achieve saturation of responses than is typically possible in an online survey with a convenience sample. With future survey work, the use of cognitive interviews to assist with survey design and validation would strengthen the methods we employed and better represent the voices of care partners. Future research endeavors with larger samples can focus on important demographic variables that can influence a person's caregiving experience (e.g., age, race, gender identity, income level/socioeconomic status, language use, preferred recreational activities, health status of care partner, physical mobility status of loved one) in order to help determine why some care partners perceive their friendship experiences more positively than others and identify which care partners are most at risk for social isolation and loneliness. These future findings can lead to person-centered friendship and social support interventions.

Going forward, a diverse group of care partners should be invited to play a more integral role on the research team, with greater contributions to the study aims, design, and dissemination of findings. Our results demonstrate that social support resources and interventions for care partners of PWA are greatly needed, and future work should first look to care partners to guide the development of those social supports. The GRIPP2 checklist (Staniszewska et al., 2017) can facilitate enhanced stakeholder engagement in aphasia research.

Finally, it is important to acknowledge that the COVID-19 pandemic likely impacted participants' responses to questions regarding the chronic stage of caregiving. Participants were asked to think about their friendships pre-pandemic when answering those ques-

tions; however, it had been 9 or 10 months since the start of the pandemic when participants completed the survey, so results for the chronic stage were likely influenced by a combination of caregiving and pandemic effects on people's social lives. Most participants had been living in the chronic stage of caregiving for many years prior to the start of the pandemic, which allowed for numerous years of interacting with friends while in their role as a care partner. Therefore, most participants had ample pre-pandemic friendship experiences to reflect upon when answering questions regarding their friendships during the chronic stage of caregiving before the start of the pandemic. However, it is important to acknowledge that it is difficult for a person to accurately reflect back nearly a year and not have their current experience of the pandemic influence their memories or responses. Therefore, responses in the "chronic" stage of caregiving might be a recount of caregiving and friendship clouded by the first 9–10 months of living in the COVID-19 pandemic. It is interesting to note that when the participants were explicitly asked to think about the impact of the pandemic on their friendships, the majority, but not all, reported that "yes" their friendships were different, and not surprisingly many reported they interacted "less" often with friends. However, the majority felt the "same" level of friend support they felt before the pandemic began. These responses might very well be different if asked today, nearly 3 years into the pandemic. Implications of the pandemic and its lasting changes on how care partners currently interact with friends deserve further research.

CONCLUSION

Friendship is an essential component of quality of life, and this work highlights that caring for a loved one with aphasia often impacts the friendships and social life of the care partner. Negative changes in friendships put care partners at risk for reduced quality of life, loneliness, and other poor

health outcomes. The overall health and social well-being of care partners deserve greater attention and more available social support resources, including interventions aimed at improving care partner friendship maintenance and development. Care partners play an instrumental role in their loved one's aphasia recovery and reentry into their community. Better social support

for care partners likely equals better support for PWA, too (Rombough et al., 2006). Continued stakeholder-engaged research and clinical practice focused on the social impact of aphasia on PWA and their dedicated care partners, as well as their friends, are needed to assist all involved in aphasia recovery achieve better friendships and social well-being.

REFERENCES

- Adams, R. G., & Blieszner, R. (1995). Aging well with friends and family. *American Behavioral Scientist*, 39(2), 209-224. <https://doi.org/10.1177/0002764295039002008>
- Azios, J. H., Strong, K. A., Archer, B., Douglas, N. F., Simmons-Mackie, N., & Worrall, L. (2021). Friendship matters: Research agenda for aphasia. *Aphasiology*, 36(3), 317-336. <https://doi.org/10.1080/02687038.2021.1873908>
- Fiori, K. L., Antonucci, T. C., & Cortina, K. S. (2006). Social network typologies and mental health among older adults. *The Journals of Gerontology: Series B*, 61(1), P25-P32. <https://doi.org/10.1093/geronb/61.1.p25>
- Graven, L. J., Azuero, A., Abbott, L., & Grant, J. S. (2020). Psychosocial factors related to adverse outcomes in heart failure caregivers: A structural equation modeling analysis. *Journal of Cardiovascular Nursing*, 35(2), 137-148. <https://doi.org/10.1097/JCN.0000000000000634>
- Haley, K. L., Jacks, A., Morrison, B., & Richardson, J. D. (2019). Balance and preference in activity participation for informal caregivers of people with aphasia: A questionnaire study. *Aphasiology*, 34(9), 1182-1200. <https://doi.org/10.1080/02687038.2019.1659936>
- Hinckley, J., Brice, A., Bislick, L., Broussard, T., Caputo, M., Englehoven, A., Kurnal, J., Lenius, K., Madden, E. B., & Morgan, J. (2019, November). *Clinicians, researchers, & consumers collaborating: Project BRIDGE* [Paper presentation]. American Speech-Language-Hearing Association Annual Convention, Orlando, FL, United States.
- Holt-Lunstad, J. (2016). Friendship and health. In M. Hojjat & A. Moyer (Eds.), *The psychology of friendship* (pp. 233-248). Oxford University Press.
- Ikeme, S., Kottenmeier, E., Uzochukwu, G., & Brinjikji, W. (2022). Evidence-based disparities in stroke care metrics and outcomes in the United States: A systematic review. *Stroke*, 53(3), 670-679. <https://doi.org/10.1161/STROKEAHA.121.036263>
- Jacobs, M., & Ellis, C. (2022). Racial disparities in post-stroke aphasia: A need to look beyond the base analysis. *Journal of the National Medical Association*, 114(3), 258-264. <https://doi.org/10.1016/j.jnma.2022.01.009>
- Johansson, M. B., Carlsson, M., Östberg, P., & Sonnander, K. (2022). Self-reported changes in everyday life and health of significant others of people with aphasia: A quantitative approach. *Aphasiology*, 36(1), 76-94. <https://doi.org/10.1080/02687038.2020.1852166>
- Kahn, R. L., & Antonucci, T. C. (1980). Convoys over the life course: Attachment, roles, and social support. In P. B. Baltes & O. G. Brim Jr. (Eds.), *Life-span development and behavior* (Vol. 3, pp. 253-286). Academic Press.
- Löckenhoff, C. E., & Carstensen, L. L. (2004). Socioemotional selectivity theory, aging, and health: The increasingly delicate balance between regulating emotions and making tough choices. *Journal of Personality*, 72(6), 1395-1424. <https://doi.org/10.1111/j.1467-6494.2004.00301.x>
- Loh, A. Z., Tan, J. S., Zhang, M. W., & Ho, R. C. (2017). The global prevalence of anxiety and depressive symptoms among caregivers of stroke survivors. *Journal of the American Medical Directors Association*, 18(2), 111-116. <https://doi.org/10.1016/j.jamda.2016.08.014>
- Manning, M., MacFarlane, A., Hickey, A., & Franklin, S. (2019). Perspectives of people with aphasia post-stroke towards personal recovery and living successfully: A systematic review and thematic synthesis. *PLoS One*, 14(3), e0214200. <https://doi.org/10.1371/journal.pone.0214200>
- McCarthy, M. J., Lyons, K. S., Schellinger, J., Stapleton, K., & Bakas, T. (2020). Interpersonal relationship challenges among stroke survivors and family caregivers. *Social Work in Health Care*, 59(2), 91-107. <https://doi.org/10.1080/00981389.2020.1714827>
- McPherson, C. J., Wilson, K. G., Chyurlia, L., & Leclerc, C. (2011). The caregiving relationship and quality of life among partners of stroke survivors: A cross-sectional study. *Health and Quality of Life Outcomes*, 9, 29. <https://doi.org/10.1186/1477-7525-9-29>
- Navaie-Waliser, M., Feldman, P. H., Gould, D. A., Levine, C., Kuerbis, A. N., & Donelan, K. (2002). When the caregiver needs care: The plight of vulnerable caregivers. *American Journal of Public Health*, 92(3), 409-413. <https://doi.org/10.2105/ajph.92.3.409>

- Northcott, S., & Hilari, K. (2011). Why do people lose their friends after a stroke? *International Journal of Language & Communication Disorders*, 46(5), 524–534. <https://doi.org/10.1111/j.1460-6984.2011.00079.x>
- Northcott, S., & Hilari, K. (2018). “I’ve got somebody there, someone cares”: What support is most valued following a stroke? *Disability and Rehabilitation*, 40(20), 2439–2448. <https://doi.org/10.1080/09638288.2017.1337242>
- Northcott, S., Hirani, S. P., & Hilari, K. (2018). A typology to explain changing social networks post stroke. *The Gerontologist*, 58(3), 500–511. <https://doi.org/10.1093/geront/gnx011>
- Opara, J. A., & Jaracz, K. (2010). Quality of life of post-stroke patients and their caregivers. *Journal of Medicine and Life*, 3(3), 216–220.
- Patterson, B. R., Bettini, L., & Nussbaum, J. F. (1993). The meaning of friendship across the lifespan: Two studies. *Communication Quarterly*, 41(2), 145–160. <https://doi.org/10.1080/01463379309369875>
- Rombough, R. E., Howse, E. L., Bagg, S. D., & Bartfay, W. J. (2007). A comparison of studies on the quality of life of primary caregivers of stroke survivors: A systematic review of the literature. *Topics in Stroke Rehabilitation*, 14(3), 69–79. <https://doi.org/10.1310/tsr1403-69>
- Rombough, R. E., Howse, E. L., & Bartfay, W. J. (2006). Caregiver strain and caregiver burden of primary caregivers of stroke survivors with and without aphasia. *Rehabilitation Nursing*, 31(5), 199–209. <https://doi.org/10.1002/j.2048-7940.2006.tb00136.x>
- 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. <https://doi.org/10.1111/1460-6984.12467>
- Staniszewska, S., Brett, J., Simera, I., Seers, K., Mockford, C., Goodlad, S., Altman, D. G., Moher, D., Barber, R., Denegri, S., Entwistle, A., Littlejohns, P., Morris, C., Sueman, R., Thomas, V., & Tysall, C. (2017). GRIPP2 reporting checklists: Tools to improve reporting of patient and public involvement in research. *Research Involvement and Engagement*, 3, 13. <https://doi.org/10.1186/s40900-017-0062-2>
- The National Alliance for Caregiving & American Association of Retired Persons. (2020). *Caregiving in the U.S. 2020*. <https://www.caregiving.org/research/caregiving-in-the-us/caregiving-in-the-us-2020>
- Therrien, M. C. S., Madden, E. B., Bislick, L., & Wallace, S. E. (2021). Aphasia and friendship: The role and perspectives of speech-language pathologists. *American Journal of Speech-Language Pathology*, 30(5), 2228–2240. https://doi.org/10.1044/2021_AJSLP-20-00370
- Vincent, C., Desrosiers, J., Landreville, P., Demers, L., & BRAD Group. (2009). Burden of caregivers of people with stroke: Evolution and predictors. *Cerebrovascular Diseases*, 27(5), 456–464. <https://doi.org/10.1159/000210092>
- White, C. L., Korner-Bitensky, N., Rodrigue, N., Rosmus, C., Sourial, R., Lambert, S., & Wood-Dauphinee, S. (2007). Barriers and facilitators to caring for individuals with stroke in the community: The family’s experience. *Canadian Journal of Neuroscience Nursing*, 29(2), 5–12.
- White, C. L., Poissant, L., Coté-LeBlanc, G., & Wood-Dauphinee, S. (2006). Long-term caregiving after stroke: The impact on caregivers’ quality of life. *Journal of Neuroscience Nursing*, 38(5), 354–360.
- Wittenberg-Lyles, E., Washington, K., Demiris, G., Oliver, D. P., & Shaunfield, S. (2014). Understanding social support burden among family caregivers. *Health Communication*, 29(9), 901–910. <https://doi.org/10.1080/10410236.2013.815111>
- Wrzus, C., Hänel, M., Wagner, J., & Neyer, F. J. (2013). Social network changes and life events across the life span: A meta-analysis. *Psychological Bulletin*, 139(1), 53–80. <https://doi.org/10.1037/a0028601>