Stakeholder-Engaged Research

What Our Friendship in Aphasia Team Learned About Processes and Pitfalls

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There is a need for intervention to support friendship for people living with aphasia. The purpose of this article is to describe a stakeholder engagement process that involved researchers, clinicians, people living with aphasia, and care partners to inform such intervention. Through reflection and firsthand accounts of non–university-based researchers, people not typically represented in the research process, we share details of two main lessons learned throughout the stakeholder engagement journey: (1) accessible engagement and (2) team correspondence. Finally, we describe

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experiences with use of the Social Convoy Model to support discussion and engagement about friendship and aphasia. We argue that this tool be a consideration in future intervention research in this area to support people with aphasia communicating their friendship priorities and goals. Although the richness of multistakeholder research teams has been documented, we hope that this article provides detail that is not commonly shared thus illuminating the process. We also hope to provide a transparent account of the cost and time required to ensure equity across stakeholder groups. **Key words:** *aphasia*, *friendship*, *life participation*, *quality of life*, *social isolation*, *stakeholder-engaged research*

FRIENDSHIP is a critical component to life participation and has been identified as a priority area for research by people living with aphasia (Brown et al., 2013). Friendship is essential to social inclusion, contributes to quality of life and physical health, and is often viewed as a common source of joy (Argyle, 1987). Friendship has been identified as an important intervention target by people with aphasia (Simmons-Mackie, 2018); however, it is not regularly or directly targeted in speech–language therapy (Brown et al., 2013; Ford et al., 2018; Le Dorze et al., 2014; Northcott & Hilari, 2011). Having aphasia negatively impacts a person's ability to maintain friendships more so than any other stroke-related factor (Northcott et al., 2016b). In fact, at 6 months poststroke, one-fifth of people with aphasia report not having any friends (Northcott et al., 2016a). Developing interventions to address social connection and friendship may support the overall health and well-being of people living with aphasia, but research and clinical resources are needed in this area (Azios et al., 2021; Douglas et al., 2022).

Patterson et al. (1993) have found that strong and dependable relationships with friends impact well-being. A small number of high-quality friendships may be more beneficial than a large number of friends, indicating that the quality of relationships in a social network may be more influential to well-being than quantity of relationships (Patterson et al., 1993). Interestingly, interventions targeting increasing social networks have been recommended for people with aphasia (Northcott et al., 2016b). However, there are no known interventions targeting the quality of friendship of people with aphasia (Douglas et al., 2022).

Interventions such as peer befriending programs to target the acquisition of new friends for people with aphasia are emerging (Hilari et al., 2021). People with aphasia have noted that resources such as aphasia support groups and intensive aphasia programs allow them to establish new friends; however, they are often troubled by the loss of their friends prior to the onset of aphasia. Yet, there are no interventions that target the maintenance of friendships that existed prior to onset of stroke and aphasia (Douglas et al., 2022) leaving people with aphasia and speech–language pathologists (SLPs) with no tools to help prevent friendship loss and the potential resultant social isolation. As such, there is a need for intervention for friendship for people with aphasia who attend to both the quality and the maintenance of friendships.

A traditional response to addressing the need for a behavioral intervention is to establish the efficacy of that intervention. In traditional methods, this would involve studying the intervention within the context of a highly controlled setting with researchers taking the lead on developing research questions and priorities. An alternative approach is to partner with the individuals most impacted by the research (e.g., SLPs who work directly with people with aphasia to improve communication and people with aphasia themselves) to develop research questions and priorities. This alternative approach can be referred to as stakeholder engagement and can represent a range of levels of involvement (International Association for Public Participation [IAP2], 2018). For instance, the IAP2 Spectrum of Public Participation in Research notes that researchers can simply inform stakeholders about research, solicit consultative feedback from stakeholders about research, involve

stakeholders directly in the research process through considering the concerns and aspirations of stakeholders, collaborate in partnership with the research across every decision in the research process, or be empowered to make the final decisions about research aspects (IAP2, 2018).

The following article will describe a stakeholder engagement process that involved researchers, clinicians, people with aphasia, and care partners working together to inform intervention on friendship, the involvement level of engagement (IAP2, 2018). In an attempt to support researchers preparing to conduct stakeholder-engaged research in the area of aphasia, we will share our firsthand accounts and lessons learned of our journey. In addition, our experiences thus far warrant further exploration of the Social Convoy Model (SCM; Kahn & Antonucci, 1980) as a catalyst for friendship intervention for people with aphasia. A discussion of these experiences will conclude the article.

EVOLUTION OF OUR RESEARCH TEAM

In December of 2019, we formed our original research team with the aim of increasing social connection and supporting friendship in aphasia. Although a lofty goal, we had a tangible end product in mind to create and test an intervention that SLPs could implement to maintain quality preaphasia friendships. The original team was comprised of six university-based researchers. All researchers have backgrounds as practicing SLPs and study life participation approaches to live successfully with communication disorders. Four of the university-based researchers are employed full-time and two are semiretired. The research agenda was established by the university-based researchers. From the start, we knew that it was essential to have other stakeholder voices influence this work because recent work has demonstrated the benefits of partnering with stakeholders to create interventions (Cruice et al., 2022; Horton et al., 2021; Shiggins et al., 2022; Wray et al., 2021; Yarborough et al., 2013).

People with aphasia, care partners of people with aphasia, SLPs working in various settings, and researchers who had expertise in social networks and friendship would thus add critical input to any potential intervention. We wanted the concerns and aspirations of these stakeholders to be reflected in research activities and, ultimately, the intervention to support friendship for people with aphasia (IAP2, 2018).

In February of 2020, we began inviting stakeholders to join our team in an advisory capacity. The purpose of the stakeholder advisory group was to provide consultation on the research agenda (IAP2, 2018). We discussed the ideal size of the team and determined that we wanted no more than seven individuals so that when we met, the size of the group would facilitate communication rather than hinder it. We also discussed that different stakeholders may have different roles throughout the project. A list of individuals from each stakeholder group (e.g., person with aphasia, care partner, SLP, researcher with expertise in friendship and aphasia) was generated and we went about inviting each stakeholder to join our team. We purposefully sampled potential team members from personal contacts based on their lived experience, or if they provided service, or conducted research on aphasia and friendship. The initial stakeholder advisory group consisted of two stakeholders living with aphasia, two SLPs (one who was also a researcher), one care partner who was also an SLP and researcher, and two additional researchers with experience in friendship and aphasia. As the team developed, an additional care partner of a person with aphasia joined the team. Figure 1 displays the makeup of the entire research team, and Figure 2 presents the source of compensation for each stakeholder group of the research team.

We held our first consultative group meeting via videoconference on March 12, 2020, just before the world shutdown due to the COVID-19 pandemic. All team members were able to participate. At the time, virtual meetings were novel. To facilitate participation,
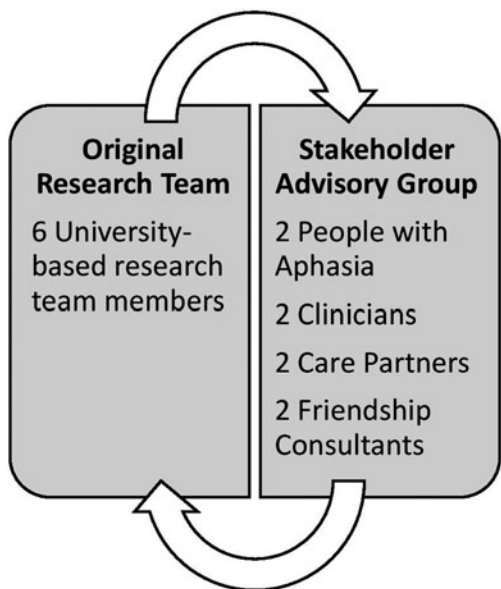
Figure 1. Research team members.

the stakeholders with aphasia and a known to them university-based researcher joined the meeting on the same computer. This also allowed for communication supports and to increase the comfort level of the persons with aphasia. The meeting was led by a university-based research team member and began with introductions and a reviewing of the purpose of the group, which was how to intervene in friendships early on in the aphasia recovery process to prevent these friendships from falling away.

An overview of the agenda, preset by the university-based researchers, was provided

Figure 2. Source of compensation for team member participation.

including (1) explain research agenda (Azios et al., 2021); (2) conduct a scoping review of literature of the nature of friendship intervention and prevention in older adults (Douglas et al., 2022); (3) learn about the impact of aphasia on friendship from people with aphasia, friends, care partners, and SLPs through qualitative interviews; and (4) develop and pilot a friendship maintenance program based on information learned from the previous phases. A meeting schedule was set for every 3 months with email correspondence more regularly as needed. This schedule was determined by the team in order to allow for enough contact to achieve team goals without being overly burdensome. Opportunities for clarification from team members were provided. As the stakeholders were from three different countries, all meetings were held virtually using videoconference software. Meeting agendas were set by the university-based researchers and minutes were taken during meetings. Emphasis was placed on cultivating an inclusive environment open to concerns and aspirations from all team members (IAP2, 2018). Although that was our intent, the following section conveys perspectives directly from stakeholders who are not university-based research team members that highlight lessons learned.

STAKEHOLDER PERSPECTIVES

Clinician, M.S., stakeholder perspective

The concept of the multistakeholder teams and research directives, while not new to our field, has evolved relative to the individual voices that have gained strength and confidence by merely being asked to participate. As a clinician–stakeholder, my perspective could be considered in terms of people with aphasia assessment and treatment preferences, intervention options, or logistical service issues. After all, it is the SLP who must focus on goal determination, measurements, treatment efficacy, and, for better or worse, reimbursement. Having worked along the

entire continuum of care and maintaining strong collaborations with community providers, I felt confident in my ability to contribute to these aspects of the research agenda. What was remarkable, and what clearly speaks to the evolution of these types of research teams, was that the input sought was not limited to my professional expertise, rather, I was encouraged to share personal narratives and views on creative management of real-life situations for people with aphasia. It was apparent from the conception of this effort that every voice mattered and that the only limitations on perspective-sharing were those that were self-imposed.

As a stakeholder on the team, I was encouraged to provide feedback on direction, status, and interpretation of the material collected. Much of the work, however, was completed by the main investigators, and I may have been underutilized in respect to the gathering of content, surveying of other providers, and analysis. It is important that those with the statistical and research backgrounds are responsible for the synthesis and ultimate presentation. However, I do believe that the work being done "in the trenches" may hold considerable value in collecting and truly determining what can be realistically offered to those we serve. Sparking creativity and encouraging out of the box thinking still feels like it has an inherent top-down structure. I imagine the possibilities with offering, encouraging, and even providing permission to contribute by people not perceived to be "at the top."

Participation on this dynamic stakeholder team was possible because of the virtual nature of the meetings and in so many ways, this too was a powerful catalyst for limitless discussions. The modality fostered the rich exchanges that would otherwise be limited by email drafts or a project management system. Communication was supported as much as it could be but clearly put those with verbal prowess at an advantage. In continuing to participate in these multistakeholder teams that include individuals with aphasia, I propose preparations and meeting modifications that could support the understanding and expression of all viewpoints. Specifically, we could prepare premeeting agendas that included Likert scales, choices, and pictographs, and provide an in-meeting cue window to display key words and material being discussed. It is with an understanding that the nature of these research studies, especially those built around relational (i.e. friendship) barriers and opportunities, will bring out emphatic dialogue and, undoubtedly, help us make transformational change in outcomes for people with aphasia. As such, we now offer the perspective of author R.J. a team member with severe expressive aphasia.

Person with aphasia, R.J., stakeholder perspective

Figure 3 shows a text message exchange between R.J., a person with aphasia, and K.S., a university-based researcher, regarding R.J.'s experience participating on the team midproject. R.J. communicated independently via text and emoji. R.J. and K.S. met virtually to discuss how to best showcase R.J.'s experiences in being a team member. It should be noted that R.J. took the lead in training K.S. on which emojis K.S. should use to pose each question. Throughout collaborative correspondence, R.J. stated that she not only enjoys being a part of the team but also feels underutilized and can do more. She notes challenges with correspondence (e.g., written communication), particularly with university payroll forms and complex emails.

M.S. and R.J.'s experiences compelled us to reflect more deeply about stakeholder engagement. Our team then identified two main engagement growth opportunities discussed here: accessible engagement and team correspondence. We share them as lessons in progress in the hopes that other teams can benefit from our experience.

LESSON IN PROGRESS 1: ACCESSIBLE ENGAGEMENT

One of our major growth opportunities was the need to empower all team member voices. Various supports were used during
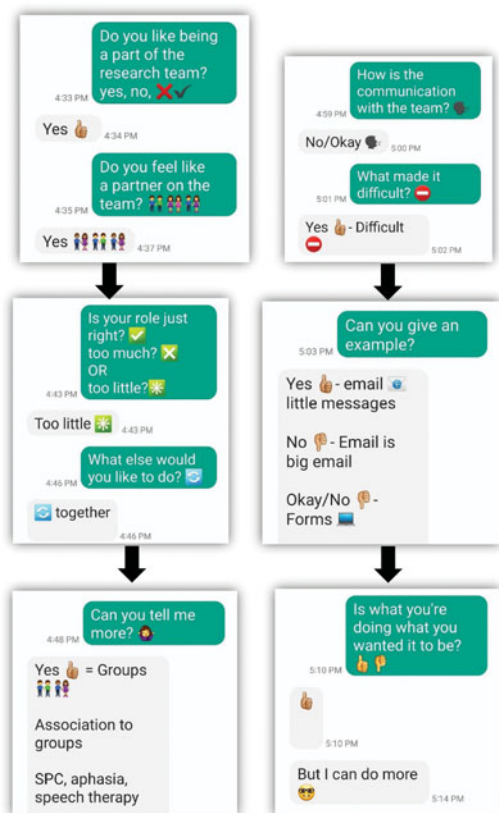
Figure 3. Text correspondence from stakeholder with aphasia about her experience on being a part of the team. SPC = autocorrect error for SLP (speech-language pathology). This figure is available in color online (www.topicsinlanguage disorders.com).

meetings to encourage contributions (e.g., casting turns, rewording questions, forced choice for agreement/disagreement of ideas and contributions, purposeful silence). Another way we did this was to train our team in stakeholder-engaged research. To increase our understanding of how we could better partner to pursue the aims of the friendship and aphasia project, we invited stakeholders from the advisory group and the original research team to join Project BRIDGE.

Project BRIDGE is a research incubator network in the United States designed to promote stakeholder-engaged research for people with communication disabilities (Hinckley et al., 2019). The aim of Project BRIDGE is to support people with aphasia, their families, SLPs, and researchers in working collaboratively on teams to plan, conduct, and disseminate research on topics important to people impacted by aphasia. Project BRIDGE provides training to prepare stakeholders to learn about research and how to contribute to a research team. Project BRIDGE also trains researchers how to lead a multistakeholder team and engage with all stakeholders. After completing the training, stakeholders are (1) paired with a guide from the same stakeholder group who is already trained and on a research team to provide support and instruction and (2) connected with a research team that aligns with their interests. The premise behind Project BRIDGE is that trained stakeholders will allow teams to be more effective in reaching their goals, ultimately allowing more meaningful research to reach the population faster.

Two team members with aphasia, two SLPs, and two university-based researchers completed the Project BRIDGE training. In addition, one university-based researcher was serving as a regional coordinator for Project BRIDGE and had previously undergone the training. This opportunity for colearning about the research process and how to engage various stakeholder voices into the project was valuable.

Engagement is not a "one size fits all" approach but rather it is about finding the right level of engagement for particular stakeholders (Wallerstein & Duran, 2010). As the aims of the friendship and aphasia project had been established before including other stakeholder voices, one of the challenges encountered was gauging the level of involvement of those who joined the team after the agenda was established. For some team members, the role of consultant was an adequate level of engagement. However, other team members wanted more engagement but perceived that they were not provided the opportunity. Other team members may have wanted to be more involved, but as this was new terrain to navigate, they were looking to team

leaders to provide specific direction. The level of stakeholder involvement is complex and is dependent on the research team and the project resources (Shiggins et al., 2022).

LESSON IN PROGRESS 2: TEAM CORRESPONDENCE

Communication can be challenging for any team; however, when team members have communication disabilities, such as aphasia, strategies for clear and concise communication are essential. The need for accessible information is a crucial factor in engaging stakeholders with aphasia in research (Pearl & Cruice, 2017). We want to highlight some of the barriers we encountered as well as how we grew in our capacity to address these barriers. Ensuring that communication for all team members was accessible (i.e., aphasia friendly; Stroke Association, 2012) was an initial challenge. One example of a communication challenge was that after our initial meeting with the entire team, a detailed email was drafted and sent to all team members except those with aphasia. The university-based researcher team member who drafted the email reached out to the university-based researcher who had the relationship with the stakeholders with aphasia prior to the project and asked her to send a separate email that communicated the message in an aphasia-friendly way. Although awkward, this was an opportunity for our team to understand that communication to the team should be in a format that is accessible to all team members. We worked together as a team of researchers to revise the email, so it was accessible to all team members. Figure 4 is an example of the original email and the transformation to an accessible message.

Another challenge in team correspondence was that consistent supports were needed to engage stakeholders with aphasia to ensure that they understood the content. From making written materials more accessible to sending texts or reaching out by phone call to confirm that email correspondence was received, engaging stakeholders with communication disabilities takes more time and effort. As an example of one such challenge, we offer the process of paying advisory team members.

We received grant funding for the interview phase of our research agenda. A subset of the research team was paid an honorarium for their work. Figure 2 outlines who received compensation for participation from the grant. Each member of this group needed to create a profile on a payment portal in order to receive payment from the university. The portal was text heavy and not accessible to people with communication disorders. In addition, the portal was not optimized for use on mobile devices. When setting up the profile, team members had to download and fill out a pdf, which was then emailed to them, and they had to reupload to the portal. Many Apple smartphones cannot open pdfs. Even when team members were able to download and open the pdfs, they were exceedingly difficult to fill out on a mobile device.

Completing the online forms for team members with aphasia was no small matter. To successfully complete the required documentation, numerous email messages, texts, phone calls, and multiple videoconference meetings were required over at least 8 weeks of time. Both team members with aphasia participated in a 90-min videoconferencing consultation for support with authors K.S. and B.A. Neither team member with aphasia managed to successfully set up their profiles by the conclusion of the consultation.

So, a second round of meetings was arranged. One team member with aphasia met for an additional 60-min virtual meeting with K.S. The other team member with aphasia and their spouse had to meet with K.S. in person. B.A. attended this meeting via videoconferencing. At one point during this in person meeting, four separate devices were being used by attendees to overcome the various technological challenges involved in setting up the profile. Eventually, both team members with aphasia set up profiles so that they could receive their honoraria.

Message sent to team members without aphasia

Hi all,

Thanks, again, for agreeing to be a part of our reference group for our strategic research plan on friendship in aphasia. It's been a long time since our last meeting with you all (3/12/20) and I apologize that I have not written sooner. This email is just to touch base with you and give you a quick update on the project since our last talk.

The COVID-19 pandemic did slow us down a bit, but did not stop us from continuing toward our goals. Our team has been thinking about the issues that you all raised in our first reference group meeting and including these ideas into our research plan. Our first major project is to complete an agenda paper that will provide a framework to guide friendship research in aphasia. That manuscript is currently being drafted and we have a plan to discuss the first version of that paper in a meeting on July 7. It is our goal to submit that paper for publication by the end of the summer. Thank you, again, for your insights into friendship in aphasia. Many of your ideas are already filtering into the framing of this paper, including the complexities of defining friendship and potentially creating an intervention for friends of people with aphasia. The second project is a scoping review of existing interventions that target friendship. We are working through the methodology on the scoping review right now, including playing around with search terms to better understand how broad or narrow our inclusion/exclusion criteria should be. We are also looking at potential funding options for this project. Once we learn more from these first two papers, we plan to conduct a few qualitative studies that would allow us to better understand the experiences of people with aphasia, family members, and friends.

When the team meets on July 7, we will have a better understanding of the next steps of these projects and will likely need input from you as we move forward. I'll be in touch after our meeting to propose some dates and times that we may be able to connect via Zoom.

I hope you are all safe and well. Thank you for serving on our reference group and I look forward to seeing you all again soon!

Message revised and inclusive to all team members

Friendship in Aphasia
Project Update

Hello Becca, Don, Sarah, Maura, Martha, and Barbara,

Thanks for helping us with our research on friendship in aphasia.

COVID slowed us down, but we are now picking back up.

Here is a project update.

We have 2 current goals for writing papers:

- Paper 1 is about our research agenda on friendship in aphasia
- Paper 2 is about what interventions already exist to increase friendships

We are making progress on goals. Our research writing team is meeting on July 7 to discuss progress.

We will be in touch soon to schedule another meeting with you to share our progress and ask for your input on this important topic.

Thanks for your ongoing support.

Figure 4. Examples of correspondence with stakeholders before and after changing style to be inclusive ("aphasia friendly") of all team members. This figure is available in color online (www.topicsinlanguage disorders.com).

The process of enrolling the team members with aphasia in the university's payment system required significant amount of time, resources, and effort on the part of the stakeholders with aphasia, their care partners, the university-researcher who was overseeing the grant (B.A.), and the university researcher who had the closest relationship with the stakeholders with aphasia (K.S.). The level of both frustration and patience by multiple stakeholders should not be underestimated. Finally, we will conclude this article with experiences warranting a further exploration of the Social Convoy Model (Kahn & Antonucci, 1980) as tool to support both quality and maintenance of friendship for people with aphasia.

SOCIAL CONVOY MODEL

One way to learn more about someone's friendships is through the SCM (Kahn & Antonucci, 1980). The SCM is typically used to predict social relations based on personal and situational characteristics over the life span. It has been used to quantify one's social networks and provide a visual depiction of levels of closeness. The SCM has been used to measure outcomes in friendship intervention programs targeting loneliness in older women such as the Friendship Enrichment Program (Stevens et al., 2006) and also in the study of later-life relationships (Fuller et al., 2020). Furthermore, the SCM has been used to quantify social networks inclusive of friends for people with mild to moderate aphasia (Cruice et al., 2006) and in determining living well with aphasia in the first year poststroke (Worrall et al., 2017).

The SCM assesses social networks through a hierarchical mapping process using three concentric circles with the word "you" at the center (Antonucci, 1986) and three levels of relationship closeness: close, closer, and closest (Antonucci et al., 2014). The person completing the SCM is asked to imagine themselves at the center of the circles and then identify their personal network or "convoy" of people in their life. The innermost circle has people who are closest, and life is difficult to imagine without them. The middle circle holds people who are not quite that close but who are still important. The outer circle is people who are important enough to mention but not in the inner or middle circles.

Adapting the SCM for people with aphasia

As part of our friendship and aphasia agenda, we conducted virtual interviews with 27 people with aphasia to understand how their friendships had changed since having aphasia and learn about their thoughts on what might be helpful in building an intervention that targeted maintaining friendships. We opted to use the SCM in order to increase the accessibility of the interview process for people with varying levels of aphasia type and severity. Findings from this interview project are undergoing analysis and will be published elsewhere.

Before conducting interviews, we piloted the interview process with two persons with aphasia who had severe aphasia to determine the feasibility of using the SCM in this manner. Specifically, we were interested in understanding the appropriateness for people with more severe forms of aphasia to access names of friends and described various characteristics of friendships while using the SCM as a support. The pilot was successful and both persons with aphasia were able to retrieve the names of friends or describe friendships using supported conversation techniques (e.g., encouraging multimodal communication, clarification with forced choice questions). Feedback from the pilot was incorporated into the process so that interviewers were trained on using the SCM. Specific changes from the pilot feedback included (1) simplifying the language of descriptions for each circle; (2) adding color to each ring based on further illustrating the differences among the circles (i.e., Yellow = Close Friends; Green = Friends; Purple = Distant Friends); and (3) using colors as a reference during the interviews to give
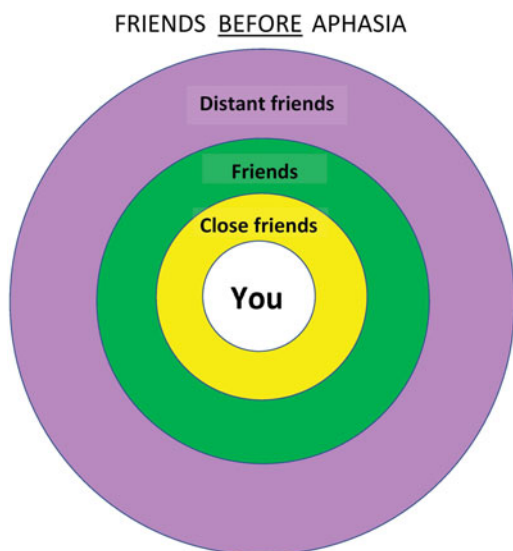
FRIENDS **BEFORE** APHASIA

Figure 5. Modifications to Social Convoy Model to increase accessibility for people with aphasia. This figure is available in color online (www.topicsinlanguagedisorders.com).

participants on option to map their friendships in list form versus writing directly on the circles (e.g., Yellow friends = Mary, Sue; Green Friends = John, Sally, Jan). Figure 5 highlights the changes made to make the SCM more accessible to people with aphasia.

Using the SCM to explore social networks and friendship experiences in people with aphasia

First, we introduced the SCM during the consent process. A video demonstrating how to complete the SCM for friendships before having aphasia was shared (see Supplemental Digital Content Materials, available at: http://links.lww.com/TLD/A100). Participants with aphasia completed the SCM on their own time prior to the scheduled interview and returned a photograph of their completed SCM to the project manager. During the interview, a screen share was used to display the SCM generated by the participant and used as a basis of discussion for how friendships changed since having aphasia. Then, during the interview, a second SCM was generated to represent current friendships of the person with aphasia. A discussion ensued about differences from the SCM before aphasia and the SCM after aphasia.

We would like to highlight two examples of SCMs from the interviews of Cathy and Alice. Pseudonyms have been used to maintain confidentiality. Both had communication that was rated as a score of 1 on the Aphasia Severity Rating by a team member who was a licensed SLP (Simmons-Mackie et al., 2018). A score of 1 represents that conversation is one-sided with the listener bearing a great deal of the conversational load. We selected these examples to highlight the possibility of using the SCM with individuals with severe aphasia. Figure 6 highlights the SCMs representing friends before aphasia and after aphasia.

Cathy was a 47-year-old woman who had been living with severe aphasia for 11 years. At Cathy's request, one of her family members participated in the interview to provide her support in expressing herself. Cathy's SCM before aphasia indicated one friend, Rita as well as friends from church that Cathy considered within her closest friend circle. Within the close friend circle, Cathy identified Susan and Melissa. And in the outer circle, friends who are not so close, Cathy identified three groupings of friends from her work, from her child's school, and from her child's sports teams.

Cathy's SCM after aphasia had some consistency in having Rita, Susie, and Melissa remain in their originally mapped areas. However, some changes in Cathy's friends after aphasia were observed. First, many of the friends before aphasia who were related to activities such as church, work, and her child's school and sports teams were not a part of Cathy's SCM after aphasia. In fact, she did not identify any friends in the outermost circle of her convoy. Second, Cathy has identified new friendships in Vicki along with other friends who also have aphasia whom she met through local and social media groups for people with aphasia.

As a second example, Alice's SCMs before and after aphasia are provided. Alice
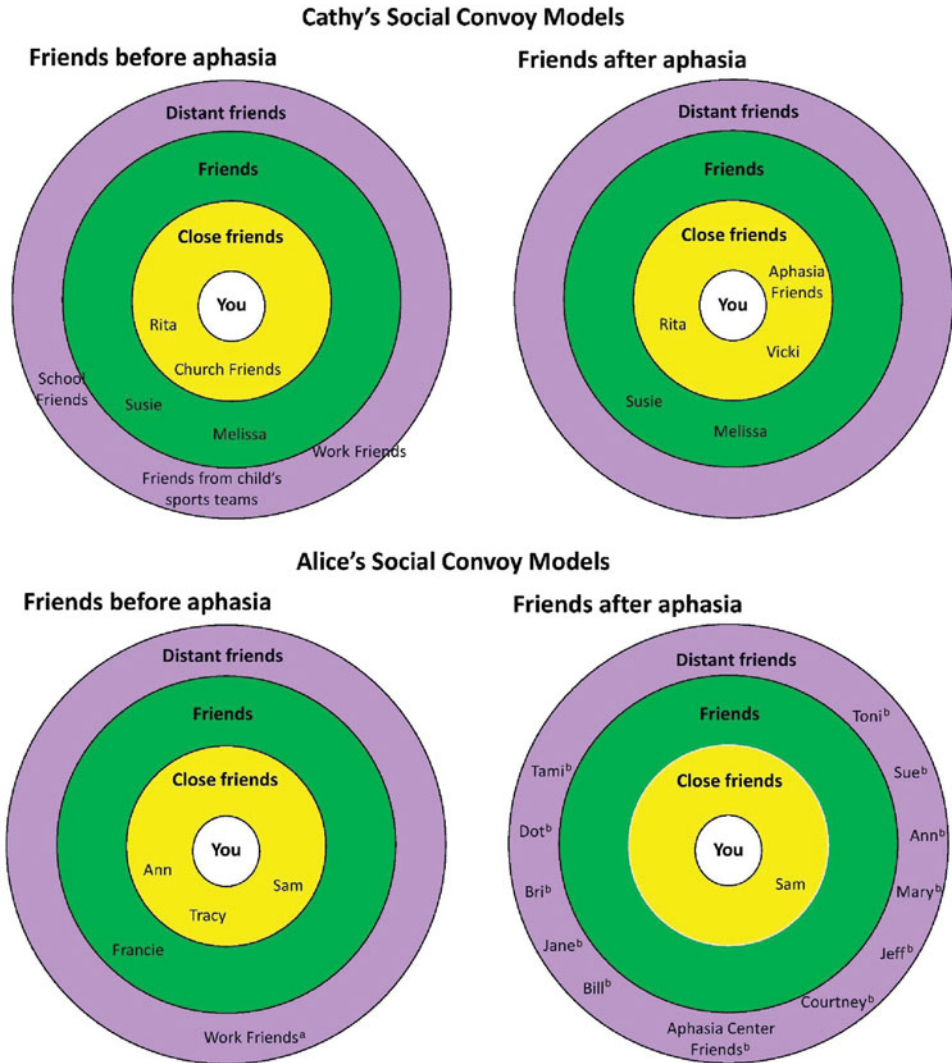
Figure 6. Case examples of Social Convoy Model used to map friendships before and after aphasia. Note: [a]Before aphasia, Alice had many acquaintances she was friendly with but would not consider friends. She also frequently traveled internationally and made social connections through this that were friendly, but she did not stay in touch and did not consider these people friends. [b]Friends from aphasia center Alice attends. This figure is available in color online (www.topicsinlanguagedisorders.com).

was a 53-year-old woman living with severe aphasia for 16 years. Alice's mother provided communication supports for Alice to complete the SCMs prior to and during the interview. Before aphasia, Alice had three friends, Ann, Tracy, and Sam, whom she identified as her closest friends, and one friend, Francie, identified as a close friend. Alice reported that she had many work friends who

were acquaintances but would not consider them friends. She made many social connections through international travel but did not stay in touch or consider these people friends.

In comparing Alice's SCM before and after aphasia, the one consistent friend is Sam, her closest friend. All other friends from before aphasia are no longer on the SCM. Alice

reported that a friend from before aphasia, who she did not name, would say that they were coming to visit but then never show. This happened a few times. Alice's work friends are not on the SCM after aphasia, but she has identified 11 friends from the aphasia center she attends whom she considers as friends who are not so close but in her network.

Although the SCM has been used in studies to measure outcomes of friendship intervention programs (Stevens et al., 2006), to quantify social networks (Cruice et al., 2006), and to live well poststroke (Worrall et al., 2017), we propose that it be used as a catalyst for aphasia friendship intervention. The nature of the tool was such that even people with severe aphasia were able to successfully reflect upon their friendships showing promise for future intervention that is informed directly from people with aphasia. It allowed a depth of discussion using visual cues that has potential for setting measurable goals for high-impact change. We need to investigate various aspects of the SCM before it is ready for widespread clinical use. However, we envision that at some point in the future, clinicians interested in selecting an intervention to increase the quantity and/or quality of social networks for people with aphasia could administer the SCM to assess intervention effects and goal attainment.

CONCLUSION

Throughout our journey involving people with aphasia, care partners, and clinicians directly in the research process to inform friendship intervention for people with aphasia, we identified key experiences that other researchers interested in this type of work should consider. First, although equity in voices heard is a priority, it can be difficult to utilize team members to their full potential and for members who are not university-based researchers to feel comfortable making

their concerns and aspirations known. It is important to check in frequently with team members, likely outside of larger team meetings, to ensure that they are benefiting from the research endeavor. Second, communication needs to be accessible for clinicians, people with aphasia, and care partners of people with aphasia. For people with aphasia, this means that supported conversation, communication modes other than verbal, and the involvement of care partners may be needed. This requires both time and relationships, resources that are not typically funded by the traditional research system. Shiggins et al. (2022) provide relevant details on accessibility, supported communication, and inclusion of stakeholders who have aphasia. Finally, we recommend that the SCM be employed in research endeavors attempting to address friendship in aphasia. In our experiences, the SCM allowed people with aphasia to communicate freely and openly about their friendships in ways that were not possible without those visual supports.

Engaging stakeholders with aphasia, care partners, and clinicians adds richness and depth to research questions, data collection and analysis, and findings. Genuine and perpetual engagement from all stakeholders requires time, effort, and skills not typically prioritized in research processes. Ideal engagement includes reciprocal relationships, colearning, trust, transparency, honesty, and partnership (Patient-Centered Outcomes Research Institute [PCORI], 2015). Project BRIDGE and other similar initiatives can provide important training to meet these goals and prepare multistakeholder teams to be successful. Although challenges such as those we experienced are likely to occur, work produced by stakeholder-engaged research teams has higher levels of credibility, transparency, implementation potential, and translation to clinical practice, the ultimate goal of our endeavors.

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