

The Narrative-Based Evolution of a Stakeholder-Engaged Research Team

Mining for Gems of Wisdom in Written Biographical Accounts of Life With Aphasia

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Millions of people worldwide have experienced abrupt and traumatic disruption in the flow of their personal life story as a result of stroke and the onset of aphasia. For each one who survives and embarks on the journey toward recovery, their unique and evolving narrative yields gems of wisdom borne of the experience. This wisdom is shared with others through interpersonal narrative exchange and engagement, which foster biographical coherence and provide sources of hope to others on the path toward a productive and fulfilling life. This case study illustrates how a biography-based approach to stakeholder-engaged research merges personal stories in three ways. First, the case illustrates how the personal and professional stories of the candidate research team members merged to form the team through networking over time. Second, the biography-based approach led the team to identify the written personal accounts of 259 people living with aphasia as the raw data set for their research, with the intended goal of mining gems of practical wisdom from these written biographical works. Third, the case illustrates how the biography-based approach draws on the personal stories of in-hospital experiences of research team members with aphasia to prospectively hone the initial research focus. Specifically, the team will tap the collective voice within the written accounts to evaluate the in-hospital experiences of people with aphasia. The ultimate goal will be to catalyze participatory action, in collaboration with transdisciplinary health care providers, to advance responsive, person-centered health care. The authors

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This project was partially supported by a Patient-Centered Outcomes Research Institute (PCORI) Eugene Washington PCORI Engagement Award (17449-NSU). Thomas G. Broussard Jr. receives royalties from self-published books, and speaking fees and honoraria for

presentations and seminars, associated with his ownership of Stroke Educator, Inc. Our sincere thanks to each author, biographically featured person, and interviewee with aphasia whose published accounts provide a wealth of insights into their lived experience.

All other authors and planners have disclosed no potential relevant financial relationships or otherwise. Author disclosures can be found at <http://links.lww.com/TLD/A107>.

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DOI: 10.1097/TLD.0000000000000318

address challenges and priorities in stakeholder-engaged research team development, the importance of honing a research focus, and the identification of research dissemination venues. Oral and written accounts of life with aphasia offer a timeless and potentially rich source of wisdom that can be tapped through the process of stakeholder-engaged research. **Key words:** *aphasia, in-hospital experiences, personal narrative, stakeholder-engaged research, written biography*

PEOPLE WHO HAVE experienced stroke and the onset of aphasia have described it as a life-shattering threat to one's identity (Meyerson & Zuckerman, 2019)—an abrupt and traumatic disruption in the flow of one's life story. Among the estimated 2.6 million people who have aphasia in North America (Simmons-Mackie, 2018), and among the millions more who live with aphasia worldwide, the lived experience of each person who has aphasia is unique to each, for "... each of us *is* a biography, a story. Each of us *is* a singular narrative ... historically, as narratives we are each of us unique" (Sacks, 1985, pp. 110-111). Thus, when conducting stakeholder-engaged research—research by, with, and for people who have aphasia, as integral, decision-making members of the research team—that engagement is naturally shaped by biography. The research team members who do not have aphasia seek perspectives of team members with aphasia: We listen closely to their life stories while remaining open to their impact on our own perspectives, and we listen in a way that will make the research relevant, actionable, and a source of hope for leading a productive and fulfilling life. Potential payoffs of the stakeholder-engaged research process include enhancement of the ecological validity, quality, and relevance of the research (Hinckley et al., 2019) as compared with more traditional aphasia research designs in which people with aphasia are minimally engaged as decision-makers, for example, as research participants.

Intended readership and purpose

This article is directed in particular toward people who are either contemplating involvement with or currently involved with a stakeholder-engaged research team: professional researchers, professional clinicians,

people who have aphasia from a variety of professional and life backgrounds, and co-surviving family and friends. There may be uncertainties inherent in the development of any stakeholder-engaged research team: uncertainties in finding team members and forming a team, uncertainties in defining motivations and roles of team members, uncertainties in identifying research questions, and uncertainties of access to a fitting data set for addressing those questions. The purpose of this case study was to illustrate how a stakeholder-engaged research group and its leadership might use a *biography-based framework* to navigate these uncertainties. Specifically, we provide a case study of how biographies of the team members of our stakeholder-engaged research team coalesced the group and focused our research topic, and how a set of written biographies of people living with aphasia are serving as our research data set.

Application of a biography-based framework

A biography-based framework, as applied to the development and research activities of a stakeholder-engaged research team, is conceptualized as a *merging together of life stories*. One may refer to biographical accounts of life events as sets of *life stories*, *personal accounts*, *personal stories*, or *personal narratives* (e.g., Olness & Ulatowska, 2011). These personal narratives are firsthand accounts that may include a variety of different protagonists, including the narrators themselves, who share the experience of any given life event or life activity together. Their identities and motivations are often reflected in their actions and reactions during those life events.

For the current case of development of a stakeholder-engaged research team, three

sets of biographies merge together: (a) the biographies of the research team members, whose identities, motivations, and shared history of working relationships support group formation; (b) written biographical accounts of people living with aphasia, which provide raw data representing the lived experiences and collective wisdom of people living with aphasia; and (c) the personal stories of research team members that hone the focus of our research. Thus, the current case account of development of a stakeholder-engaged research team and its activities is *the story of a merging of life stories*.

Merging of the biographies of the team members during team formation

Just as the perspective of the listener or reader contributes toward understanding and interpreting the personal narratives of people with aphasia, so, too, does each member of the narrative-based research team bring their own background and life story to the table. Thus, an essential element in the narrative-based research process is consideration of the life stories and priorities of each member of the stakeholder-engaged research team—people with aphasia, clinicians, professional researchers, and co-survivors—as they shape the research priorities, team member roles, and interpretations entailed in narrative-based research. Even as the narrator with aphasia brings their evolving identity with them as their stories unfold over time (Meyerson & Zuckerman, 2019), so also the members of the narrative-based, stakeholder-engaged research team bring their identities and their changing identities with them in defining their roles, making research decisions, and setting research priorities, as the research activities evolve over time.

Merging of written biographies of people with aphasia

The current account traces the evolution and growth of one stakeholder-engaged research team, *Team Gem*, which is centered in written personal stories of people living with aphasia. As we will see, many of these written

personal accounts are published book-length biographies. The metaphoric name of the research team alludes to its purpose: to mine for “gems” of wisdom in published life accounts written by and with people living with aphasia regarding their experiences. These gems of wisdom transcend time in their current relevance and applicability. Elsewhere, this process has been metaphorically conceptualized as “finding messages in bottles” (Hinckley, 2006).

Merging of personal stories of research team members to hone the focus of our research

Written biographies are often composed of sets of life events and personal stories. The research team is faced with the task of deciding which stories and content within these books will constitute the focus of the research. For example, given that many of the stories include the full timeline of events prior to, during, and after the onset of stroke and aphasia, how does the research team decide upon the points within that timeline where they will “dig” for the “gems of wisdom” they seek? What are the candidate topics that would be relevant and actionable? Again, as we will see, it is a biography-based approach that is used to hone the focus of the research. The current case describes how the life experiences of the research team members have led the team toward an initial focus on the in-hospital experience of people with aphasia, as a particularly relevant and actionable focus. This parallel narrative-based process has focused the initial research efforts of the team on mining gems of wisdom from published written accounts by and with people who have aphasia, regarding their in-hospital experiences specifically.

Summary

Team Gem serves as a model of *biography-based research* composed of a merging of personal and professional stories, identities, and motivations of each member of the research team with a large set of written biographical accounts of people who have

aphasia. The written accounts constitute the database for Team Gem's lines of research. This flowing together of life stories is exemplified in the current case study. Personal stories of in-hospital experiences of research team members with aphasia established the initial focus of Team Gem: to mine for gems of wisdom regarding in-hospital experiences in written accounts of other people living with aphasia. As we will see, this focus, in turn, leads us toward the ultimate actionable goal of this particular stakeholder-engaged research team: effecting positive change in transdisciplinary medical service delivery for and with people who have aphasia.

Models of narrative expression in context

Models of narrative expression in context guide our framing and mapping of the multiple biographies that merge together in the development and activities of a stakeholder-engaged research team, as highlighted in the current case study.

Narrative expression of reference versus evaluation

Personal narration fulfills two main functions in natural contexts of communication: the *referential function* (expression of the *who, what, where, and when*) and the *evaluative function* (expression of the *why* or *so what*, of the story, i.e., emphasis of the point that the story is making in the context of telling) (Olness & Ulatowska, 2011). The evaluative function goes by a variety of names, which fall under the umbrella concept of *stance* (Keisanen & Kärkkäinen, 2014), that is, the narrator's expression of their attitudes, opinions, and emotions about the narrated event. Notably, the very choice of which story to tell in a given context is itself an evaluative choice by the narrator, above and beyond the selective assignment of prominence to certain points within the story. The desire to make a point with a personal story may be the very reason a biographical account is narrated in the first place. In any biographical account, whether spoken or

written, we pay particular attention to *which* personal stories are selected for telling, and *how* and *why* certain points are highlighted by the narrator during the telling. Thus, in a biography-based approach to the development of a stakeholder-engaged research team, the team members should pay particular attention to (a) which stories team members and written biographers choose to relate; and (b) the points of emphasis that team members and written biographers are making through their personal accounts.

For the current case study, the evaluative function may be manifested as the selection of the life stories the members of the research team choose to tell to each other. These selected stories, especially those of the research team members with aphasia, may shape, in turn, the search for parallel stories selected by the authors with aphasia for inclusion in their written biographical accounts. Thus, the evaluative function of biographers with aphasia—both team members with aphasia and authors with aphasia—places focus on the topics and events that are the most *relevant* and *actionable* for the lives of people who have aphasia. This is a key priority of stakeholder-engaged research.

Constraints on narrative content in context of telling

Any life story, no matter how short or long its telling, is constrained in at least four ways (Linde, 1993). First, the events being related are assumed to be *meaningful to the teller*, as the teller remembers them, for their relevance to the context of telling. Second, the story is told to *affect the audience*: to evoke their understanding and potential alignment with the teller's stance (attitude, opinion, emotion) regarding the narrated events. Third, the story needs to be *organized* in a way that is predictable within the culture(s) represented by the teller and the audience, for example, including a beginning, middle, and end to the story, as is common in many cultures. Fourth, it is assumed the story is *coherent*, not only for the current audience but also for any other

audiences in the teller's network of relationships. Given these constraints, the researcher who listens to the stories of their research team members and who examines written accounts by and with people who have aphasia can be guided and reassured in the validity of the stories. The narrator is conveying a story that the narrator deems to be relevant to the listenership or readership, with the intent of sharing the journey and their perceptions of it with the readership-audience, and using the best of their ability to make the account an organized and coherent representation of the events and the narrator's perceptions of them.

Narratives expressed in spoken versus written language

Both spoken and written personal narratives can merge in biography-based development and activities of a research team. Spoken biographical accounts are shared among research team members during team meetings to guide roles and to coalesce the group in the work trajectory. Written biographical accounts of people with aphasia may constitute the data set for analysis. Written personal accounts of the team members may also be shared with each other for subsequent review by all team members. This exchange of stories, and careful attention to and evaluative interpretation of others' stories, is the essence of a biography-based approach to development of a stakeholder-engaged research team.

Notably, spoken and written language fills different functions (Halliday, 1989). Thus, the modality of expression of personal narratives may shape their relative advantages and disadvantages in biography-based research team development. Combining the use of narratives across both modalities may be advantageous to draw on the relative advantages of each modality.

For example, when written accounts constitute the data set, and when written personal narratives and correspondence are shared between and among team members, the written modality offers certain advantages

to team development and activities. The written modality offers maximal opportunity for the biographical writer to formulate, reread, and reformulate the structure, wording, and content of their accounts, over time, to achieve optimal pragmatic impact with the stories. This may circumvent in-the-moment linguistic difficulties associated with oral production of stories for narrators with aphasia. Written accounts also afford the research team member readership the opportunity to read and reread as they seek to understand. The fleeting and transitory nature of oral accounts may limit depth of audience interpretation and reinterpretation over time, if not recorded and transcribed into written form. The necessary transcription of oral narratives can be a time-consuming first step in analysis.

In contrast, spoken personal narratives that are told among the research team members to hone the research focus of the team provide certain advantages relative to written narratives. Spoken personal narratives can be told in the moment, when they are relevant to the topic of the discussion of the research team, to emphasize a point to the people in the immediate conversation. Written stories, however, cannot be tailored to fit the priorities of all readers who may access them over time, so they must be carefully searched by the reader for timeless "gems" that may be the most relevant to the reader. Another advantage of oral narratives is that no specific level of literacy is required to produce them. Written narratives may be skewed to represent only narrators who have attained a certain level of literacy. As a result, content of written samples of narratives in the written biographical literature may be less representative of the experiences of the population at large than is the content of oral samples of narratives. Another advantage of oral narrative may be the availability of paralinguistic channels such as prosody, gesture, and facial expression, which may enhance the evaluative function of language. Analogues in writing that may be used for selective emphasis—such as bolding, italics, and quotes—may not be as readily or successfully implemented.

Biography in the practice of narrative medicine

The goals of narrative-based research by and with people who have aphasia parallel those in the practice of narrative medicine (Charon, 2006). In clinical practice, the audience, that is, the clinician, carefully listens to or reads the personal illness narratives of the person with aphasia, which, in turn, enhances the clinician's understanding and deepens their empathy, with the goal of improving clinical service provision and promoting collaboration between the person with aphasia and the clinician in decision-making. As stated by Frank (1991), "(t)he mutual responsibilities of the ill to express and the healthy to hear meet in the recognition that our creativity depends on our frailty" (p. 128).¹ Notably, the intended audience for personal accounts written and published by and with people who have aphasia may include not only clinicians but also other people who have aphasia, their friends and family members, and the lay public.

Illness narratives include personal biographical accounts of stroke, associated aphasia, and their life sequelae. According to Frank (1995), any given illness narrative is composed of a changing kaleidoscope of three different narratives: *chaos*, *restitution*, and *quest*. These three narratives shift in their relative dominance across biographic accounts over time. The plot of the restitution has the "basic storyline: 'Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' (p. 77); the "active player" in restitution is the remedy (p. 115). Chaos, on the other hand, negates any expectation of one event leading to another, without any predictable event sequence (p. 97), and the "the voice of the teller has been lost" (p. 115). In comparison, we consider quest: "(T)he quest narrative speaks from the ill person's

perspective" as agent and "holds chaos at bay." Moreover, "both restitution and chaos remain background voices when the quest is foreground" (p. 115). Especially relevant to the written biographical accounts of people with aphasia that form the data set for Team Gem, "the quest narrative affords the ill their most distinctive voice, and *most published illness stories are quest stories*" (Frank, 1995, p. 115, italics added). Thus, quest, accompanied by high agency of the narrator, may dominate in the written biographical accounts that constitute the data set for Team Gem.

Narrative as product versus process

Narrative-based research and person-centered clinical practice alike benefit when we "distinguish the *product* (the actual story told) from the *process* (the experience of telling the story)," because "(t)he product, though important, is not as potentially transformative as the *process* of sharing a personal story" (Strong & Shadden, 2021, pp. 118-119, italics added). Likewise, Shadden and Hagstrom (2007) emphasize the importance of the narrative process within the Life Participation Approach to Aphasia (LPAA) to rebuild the coherence of one's life story by "target(ing) an individual's ability to participate in core social interactions that allow narrative exploration" of that life story (p. 330). Hersh (2015) advocates for this narrative-based, interactive process to extend into health care settings as well to train and support health care professionals to co-construct narrative feedback from their patients with aphasia toward development of person-centered care.

The *process* of sharing stories may be especially relevant and transformative for the development of the research team. The process of sharing personal stories may help define the roles of the research team members and may support development of the research agenda and research priorities. At the same time, the written biographical *products*, that is, the biographical publications

¹ Author G.S.O. acknowledges her research collaborator, Dr. Hanna Ulatowska, for sharing this quoted source.

of people who have aphasia, may provide a complementary stable source of data for the research team to examine for themes. Then, subsequently, the relevant stories extracted by the research team from the written biographical products may be used for another narrative *process*: sharing strategically selected written stories with others, such as health care service providers. This process amplifies the stories and voices from the written biographies for a given purpose, such as improvement of health care service provision.

BIOGRAPHY-BASED RESEARCH TEAM EVOLUTION: THE CASE OF *TEAM GEM*

Merging of the biographies of the team members during team formation

Overview

The evolution of a stakeholder-engaged, biography-based research team can be modeled as a merging of stories of the team members over time. Formal and informal networks of people, each reflecting their personal and professional stories, are guided to come together through shared mission and opportunity. The evolution of Team Gem follows this pattern of growth, typical of problem-focused, interdisciplinary research collaboration building.

The formation of Team Gem was grounded in the common experience of all team members, as participants in an initiative called Project BRIDGE (Building Research Initiatives by Developing Group Effort) (Hinckley et al., 2019), funded by PCORI (Patient-Centered Outcomes Research Institute, 2022). The mission of Project BRIDGE is to bring together people with aphasia, their families, aphasia clinicians, and researchers to learn how to collaborate and to integrate the perspectives of the stakeholders in the group to explore and develop a salient, novel research topic. Team Gem is one of the stakeholder-engaged research teams that emerged out of Project BRIDGE.

Team member identities and motivations

From a historical perspective, the context within which Team Gem has formed is grounded in background stories of its members. Specifically, the story of the development of Team Gem begins with the self-described identities of each Team Gem member, and their original motivations for joining Project BRIDGE, prior to the formation of Team Gem (Table 1). The data in this table were gathered in written form from each team member in response to a written prompt to provide each category of information. The team's meta-awareness of these data may be especially relevant for the identification of team member roles and distribution of research effort.

The clinical speech-language pathology members of the team (J.M.M., E.S.S., L.M.G., and C.C.A.) span career stages from early-career students to experienced clinicians. Their motivations for joining Project BRIDGE are various: to advance LPAA (Holland & Elman, 2021); to build on previously established friendships and professional relationships, as an opportunity to be part of a diverse stakeholder-engaged research team; and to extend pursuit of their interests in biography-based, life participation approaches in the design of intervention with people who have aphasia.

The team members with aphasia (T.G.B. and J.J.K.) self-identified on the basis of their professional career history, and their motivations for joining Project BRIDGE are tied into their career trajectory. For example, the identity of T.G.B. as an educator is related to his motivation to educate the wider public and health care community. Likewise, the identity of J.J.K. as a clinical faculty member and academic is related to her motivation to engage in the clinical research, technical writing, and professional presentations associated with her academic career; Project BRIDGE is a venue for her to regain and hone her skills as an academic. Interestingly, both of these team members who have aphasia have

Table 1. Team Gem members: Self-reported identity and motivation for joining Project BRIDGE

Team Member ^a	Self-Reported Identity	Self-Reported Motivation to Join Project BRIDGE	Joined Project BRIDGE
J.M.M.C	Manager and cofounder of an aphasia center. She describes herself in part as a “passionate and dedicated speech therapist” and works as a clinical professor and course instructor in higher education.	Whoheartedly believes in LPAA (Holland & Elman, 2021) and was elated when a PCORI grant for aphasia was awarded, stating that “involving people with aphasia is key to really moving mountains.”	2018/2019
T.G.B.A	An educator, who discovered this calling late in life: at first in his role educating shipbuilders as an engineer with the U.S. Navy and then via a career shift to higher education. Following the onset of his stroke-induced aphasia, he became an author-educator, advocate, and activist regarding educating the wider public about stroke, aphasia, recovery, and neuroplasticity.	In the hope that people with aphasia could learn from Project BRIDGE “to become educators ourselves, helping educate the wider public (as well as the health care community) about aphasia, recovery and plasticity, the foundation of all learning.” In the early phases of Project BRIDGE, he documented patterns of communication among early Project BRIDGE participants and shared this metadata during subsequent Project BRIDGE meetings, in support of Project BRIDGE development.	2018/2019
E.S.C	SLP clinical technology consultant at a medical device/software company that specializes in aphasia. Has extensive experience working with people with aphasia and co-survivors trialing AAC communication devices, working with aphasia support groups, and writing and presenting courses on topics in aphasia for CEUs of the profession.	Saw Project BRIDGE as a meaningful opportunity to recognize the expertise of all stakeholders and to collaborate with friends and colleagues who are aphasia researchers, clinicians, people with aphasia, co-survivors, and student clinicians to directly improve the lives of people impacted by aphasia.	2018/2019
J.J.K.A	Career sonographer, author, and clinical/faculty coordinator prior to the onset of her stroke-induced aphasia; an “educator in heart” who always loved academic pursuits.	Heard of the opportunity through the National Aphasia Association; drawn to Project BRIDGE as an opportunity to engage in clinical research, technical writing, and professional presentations, as she had been doing in her career. She sees involvement with Project BRIDGE as one way to regain and hone her skills as a researcher and technical writer, which is important to her as a person. In the early phases of Project BRIDGE, she prioritized lines of QOL research, conducted a literature review on QOL, and copresented at a national conference.	2018/2019

(continues)

Table 1. Team Gem members: Self-reported identity and motivation for joining Project BRIDGE (*Continued*)

Team Member ^a	Self-Reported Identity	Self-Reported Motivation to Join Project BRIDGE	Joined Project BRIDGE
G.S.O.R	An associate professor at a large public research university, teaching graduate and undergraduate courses grounded in impairment-level promotion of neuroplasticity and life participation approaches to intervention and support for and with people who have acquired neurogenic communication disorders, with a focus on serving people who have aphasia. She practiced several years as a certified speech-language pathologist.	Her research career has centered on narrative aphasiology and everyday communicative functionality of people living with aphasia. She has been listening to personal stories and readings, biographies of people with aphasia for more than two decades, based on a desire to better understand their lived experience. She was drawn to Project BRIDGE, in part, as an opportunity to build lines of stakeholder-engaged research in this area in order to lend focus of insiders with aphasia toward interpretation of these biographical accounts.	2020
L.M.G.C	Clinical SLP graduate student member of the research team who continued with the team after graduation as a certified speech-language pathologist.	Expressed research interest in biography-based, life participation approaches to aphasia intervention design that she had studied through graduate projects in coursework with G.S.O. (Olness & Campbell, 2020). She states that “(k)nowing about a situation and living through it provide starkly different perspectives. So how can we change [intervention and outcomes] without giving stakeholders a seat at the table?” She said she wanted to assist in finding solutions.	2021
C.C.A.C	Clinical SLP graduate student member of the research team who plans to continue with the team after graduation as a certified speech-language pathologist.	Expressed research interest in biography-based, life participation approaches to aphasia intervention design that she had studied through graduate projects in coursework with G.S.O. (Olness & Campbell, 2020). She states that “(when we) can understand what these individuals [with aphasia] experienced . . . (w)e are no longer restricted to the researcher’s lens but expanded in our view that is a result of the patient’s story.”	2022

Note. AAC = augmentative and alternative; CEU = continuing education unit; LPAA = the Life Participation Approach to Aphasia; PCORI = Patient-Centered Outcomes Research Institute; QOL = quality of life; SLP = speech-language pathology.

^aThree initials correspond with team member name. The subscript letter following the three initials identifies the role corresponding to their training module within Project BRIDGE: A = person with aphasia; C = SLP clinician; R = researcher.

a background in academia that predates their involvement with Project BRIDGE.

The team member who is a faculty-researcher (G.S.O.) is motivated by a long-standing desire to understand the lived experience of people who have aphasia through their personal stories and biographies. This has shaped her professional pursuits and provides the motivation for engaging with Project BRIDGE. She also worked for several years as a speech-language pathologist and incorporates principles of the LPAA, and the interpretation and clinical application of biographies, in her teaching.

Timeline of Team Gem evolution

As seen in Table 1, four of the current members of Team Gem (J.M.M., T.G.B., E.S.S., and J.J.K.) participated in one or both of the original Project BRIDGE meetings that took

place in person in 2018 and 2019. Some of the members of this subgroup had previously met each other through professional and clinical circles in central Florida that predated Project BRIDGE. An additional three members of Team Gem (G.S.O., L.M.G., and C.C.A.) joined Project BRIDGE in the early 2020s.

Figure 1 illustrates the growth and expansion of the biography-based Team Gem network over time. Much of this growth tapped into already established interpersonal networks. Each of the five indexed points in the timeline of Figure 1 is discussed here in the text:

Point 1 in the timeline. The originating members of the team, J.J.K. and G.S.O., were first placed in contact with each other by Project BRIDGE administrators in 2020

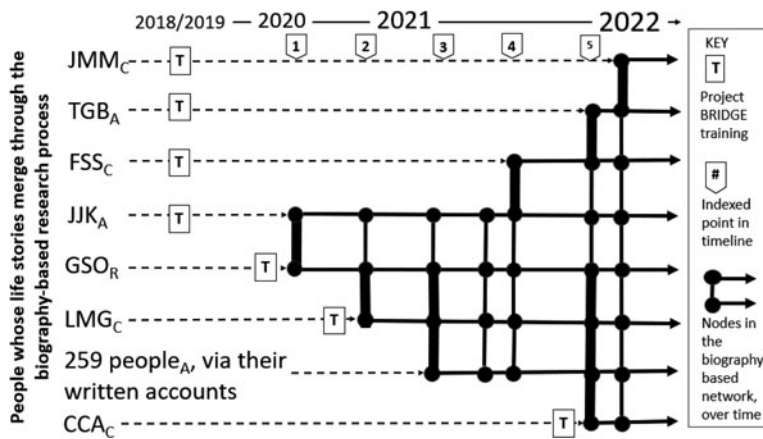


Figure 1. Growth and expansion of the biography-based Team Gem network over time. Horizontal axis represents time. Vertical axis represents biographies that contribute to the Team Gem network and its research: Seven members of Team Gem (three initials) and 259 people with aphasia whose biographies are found in published, written accounts. The subscript letters indicate the representative category of Team Gem members: A = person with aphasia; C = speech-language pathology clinician; R = researcher. The middle of the vertical axis and the left-most nodes in the timeline represent the earliest phases in development of Team Gem; the top/bottom extremes of the vertical axis and the right-most nodes in the timeline represent the latest phases in development of Team Gem. Thicker lines between nodes indicate the relatively greater weight of the established interpersonal connections that resulted in the addition of a new member to Team Gem. See text for discussion of indexed points in the timeline (1-5). *Note.* Once a node is added to the network, the relative two-dimensional distance between any two nodes, and the weight of the connections between nodes, is not indicative of the closeness or strength or of connections among team members or that of the team members to the written accounts. Given the early phase in development of the team, these interrelationships and relative roles are still being shaped and defined.

following review of their past participation in Project BRIDGE and their common expressed interest in quality-of-life issues. During initial meetings, they shared their backgrounds and stories with each other to define their research focus; they discovered a common interest in promotion of patient-centered, empathetic care in student clinical training.

Point 2 in the timeline. Graduate student member, L.M.G., joined the team in spring 2021. Following discussions between J.J.K. and G.S.O. as team coleaders, Team Gem was officially named and registered with Project BRIDGE in May 2021, with the stated intent to accomplish the following: “To research the content and main points (hidden gems) in memoirs of people living with aphasia. The goal is to educate, inform, and give hope to other people living with aphasia, co-survivors, health care providers, and society.”

Point 3 in the timeline. The written biographical accounts were incorporated as the data set for analysis by Team Gem. In essence, the lives featured in these biographical accounts, as the source of data for this research, constitute the participation of 259 additional “stakeholders” on the stakeholder-engaged research team. (See the later section, titled “Merging of Written Biographies of People With Aphasia,” and Table 2 for more details of the written biographical accounts of people who have aphasia.)

Point 4 in the timeline. The official registration of Team Gem with Project BRIDGE, in the middle of 2021, publicly invited other Project BRIDGE members to join the team, stating, “If you are passionate about quality of life after stroke, and if you want to help us dig for the gems of wisdom found in memoirs of people living with aphasia, please join us.” At this point in time, J.J.K. invited clinician member F.S.S. to join Team Gem; they had met at the first Project BRIDGE meeting in 2018. F.S.S. stated that the invitation to join Team Gem “reminded me of how much I love to work

on collaborative projects with and for people with aphasia.”

Point 5 in the timeline. In late 2021 and early 2022, the network continued to expand. F.S.S. invited a Project BRIDGE-affiliated friend with aphasia, T.G.B., who comments that, through joining Team Gem in early 2022, he has found “new pathways that would likely help both Team Gem, the PWA [person with aphasia] community and myself as well.” Notably, T.G.B. is a published author who has aphasia; his inclusion in the network as one of the 259 people with written accounts predated his personal, direct involvement with Team Gem. Subsequently, T.G.B. and one of the leaders on Project BRIDGE encouraged clinician member, J.M.M., to join as well, which she did in late 2021. This was based on her stated desire “to be involved in a [Project BRIDGE] group that directly touched and helped people with aphasia.” Interestingly, another Project BRIDGE team on which J.M.M. had previously participated was associated with therapeutic approaches for and with people who have aphasia, using autobiographical writing.

Graduate student team member, C.C.A., was also invited by her professor (G.S.O.) and a fellow graduate student (L.M.G.) to join the team during that same period of time. Both L.M.G. and C.C.A. each had previously designed an LPAA project, based on one of the biographies in the data set, in the graduate course that G.S.O. taught. C.C.A. states, “Since my interests lie in treating patients with aphasia . . . it became an opportunity to learn, hear the stories, and become an advocate for many.”

Merging of written biographies of people with aphasia

To date, a review of the literature using systematic database searches and snowball sampling for both short and book-length biographical accounts over a multiyear period have yielded written contributions by

and with 259 different people who have experienced aphasia (Table 2). Team member G.S.O. and colleagues have been assembling, reading, and examining the current set of biographical accounts over the course of several years, and rolling additions are incorporated into the data set over time.

For some of these 259 people impacted by aphasia, there is more than one written account available, for example, more than one book is available providing accounts of the life experience of Broussard and of de Mille. For others, there is only one written account available, for example, Armstrong and Bonadonna. For still others, they are featured as a biographical entry among a set of biographical entries within a single book. For example, there are life accounts of seven people in a book edited by Ott (2004), and there are featured life accounts of four different people who had participated in the same aphasia group in the book by McGregor (1999), in addition to his own personal account. Additional written accounts appear as featured cases in journal articles, short published essays, or featured contributions in anthologies (e.g., Edelman & Greenwood, 1992; Parr et al., 1997; Rolnick & Hoops, 1969).

Among the nonanonymous written accounts, 58 out of 121 (48%) appear as book-length accounts. Notably, with only a few exceptions, the authors of the books in the biographical data set wrote and published their works long after the onset of aphasia. The remaining nonanonymous written accounts appear as featured cases in interviews or journal articles, as short essays, or as featured contributions in anthologies. In contrast, 98% of the anonymous written accounts appear as featured cases in journal articles, as short essays, as featured contributions in anthologies, or as passing third-person anecdotes about other people with aphasia with whom the writer may have interacted with.

Authors of biographies (which include both biographies and autobiographies), featured cases, and authors of fiction and poetry who have aphasia represent a variety of

cultures; most are from the United States, representing a variety of backgrounds, and still others represent countries including Australia, Canada, France, Italy, New Zealand, Russia, Sweden, Switzerland, and the United Kingdom (England and Scotland). Graduate student team member, L.M.G., states that the transcultural representation within this literature is a key motivation for her. She states, "Aphasia does not discriminate against the lives it impacts, and I want to be sure that culturally and linguistically diverse communities are being taken into consideration."

Merging of personal stories of research team members to hone the focus of our research

The sheer breadth and depth of the biographical accounts—a set of 259 lives, with more than 50 of these whose stories are recounted nonanonymously through full-length books—presented the team with our first challenge: In which portions of the life stories of the people of people with aphasia would we mine for gems of wisdom first? What would be our initial focus?

Consistent with the biography-based approach of the research team, it was the personal stories of one team member with aphasia (J.J.K.), shared across a set of pivotal research team meetings, that guided us to our initial research focus. This focus is to mine gems of wisdom on the in-hospital experiences of people who have aphasia.

J.J.K. recounted multiple events associated with her hospital stay as a catalyst for this focus. When she was initially extubated and extremely thirsty, a tray of food was mistakenly brought to her before her swallow had been assessed. The tray was moved away from her when the mistake was discovered, yet was left in the room in her line of sight for two hours before the tray was fully removed from the room; it felt like torture; with aphasia and hemiparesis, she could not move it herself and she could not ask to have it removed. In another instance, she was excited and happy about relearning how to talk, but

Table 2. People impacted by aphasia for whom there are written accounts of their experience, categorized by degree of anonymity

Degree of Anonymity	Names of People Impacted by Aphasia ^a
Full name ^b	<p>Edwin Alexander; Shai Anbar; F. W. Andrewes; April Oursler Armstrong; Mark H. Ashcraft; Richard Bailey; Mrs. E. Barber; Ed Bas; Karine Bauzin; Ted W. Baxter; Paul E. Berger; Jean Beyer; Göran Biesert; Lawrence B. Bixby; Gianni Bonadonna; Dorothy K. Bonini; Thomas G. Broussard, Jr.; McKenzie Buck; Richard Butler; Edwin Collins and his partner; Grace Maxwell; Mrs. Corner; Judy Croll and her husband, Bill Croll; Richard G. Cuddihy; Charles Clay Dahlberg; Jean Paul Grandjean de Fouchy; Agnes de Mille; Colette Dobrott; Terry Dorsett; David Dow; Ingrid Tropp Erbladi; Leon Foreman; Emma Gee; Gabrielle Giffords and her husband, Mark Kelly; Dagoberto Gilb; Thomas T. Gilbert; Jennifer Gordon; John Graney; Christopher Green; Robert Greenwood; Sir John Hale and his wife, Sheila Hale; W. Alonzo Hall; Trish Hambridge; Malcolm G. Hampton; Whitney Hardy; Peter Heywood; Yvonne Honigsberg; Ed Hooper; Audrey Hope; M. Hopirott; Cliff Hopper and his wife, Rosemary Hopper; Kathy Howard; Ron Hudson; Jack Hughes; John Hughes; Kathy Hughes; Cleo Hutton; Charles Isted; Yvan Joliat; Samuel Johnson; Jaclyn Kalapos-Rios and her mother, Felicia Zera Kalapos; Leslie King; Dorothy Knox and husband, David R. Knox; Diana Law; Jacques Lordat; Mireille Louradour; Tom Lubbock and his spouse, Marion Coutis; J. E. Lyall; Carol M. Maloney; Sean Maloney; Lauren Marks; Ben McBride and his wife, Carmen McBride; Don McGregor; Debra E. Meyerson; Teresa Middleton; Randy Miller; Whitney Morse and his wife, Margaret Berger Morse; C. Scott Moss; Mr. D. Mott; Mary Mulqueen; Patricia Neal; Barbara Newborn; Charles Edward Noden; Eloise Northam; Michael Obel-Omia; Corinne Othenin-Girard; Thierry Ott; Paulina Perez; Marius Pope; Charles-Ferdinand Ramuz; Ruth Codier Resch; Lily Reid; Douglas Ritchie; David Roland; Robert H. Rose; Licy Rosenberg; Olivia Rueda; Sabadel; Carol Cline Schultz; Terry Scott; Peter Seidlitz; Lynn Lazarus Serper; Mary Sorrell; James Stephens; Jill Bolte Taylor; R. D. Thair; Thomas Tranströmer; Randy Travis; Mary Van Wyke; Kristensa Edny Viddal; Catherine Viret; Fergus Walker; Donald F. Weinstein; John Wells; Dorothea Wender; Arthur J. West; Paul West and his wife, Diane Ackerman; Guy Wint; D. C. Wordley; Helen Harlan Wulf; Lev Alexandrovich Zatsky; and Anita Zuppinge</p>
Anonymous ^c	<p><i>Anon.</i> and his wife, Christine Bayliss; Martin, and his wife, Doris Brett; Sara, and her husband, Timothy L. Culver; <i>Anon.</i> and her daughter, Kyle Ruffin; <i>Anon.</i> and his wife, Vera West; and 133 additional anonymous written accounts</p>

^aNames of related authors who are family members are also provided where relevant, following the name of the person with aphasia in the first position of the phrase.

^bIncludes two who use a public professional pseudonym or pen name.

^cAnonymous is defined as any reference that de-identifies the person with aphasia; this may include first-name only reference, reference with initials only, or any reference without name or initials.

then after one test, the speech therapist said, “Oh, you can’t talk.” And she thought to herself at that time, ‘I can’t talk just now? Or not learn to talk ever?’ Yet, she could not ask the question to find out due to her aphasia. Extremely upsetting. Hope is so important to recovery. In a third story, she recounted how she had just been provided with and taught how to use an augmentative communication system, but the speech therapist did not inform the nursing staff of the new system and the nurse moved the augmentative communication system out of her reach after the therapist left. She was left without a way to communicate. Finally, J.J.K. noted how no one in the hospital told her that she had aphasia, even though they were writing the diagnosis in her medical chart. It was not until years later, when she was reading the medical records from her hospital stay, that she realized she had aphasia, a communication disorder that she had known of from her years of clinical teaching, even though she was not directly told in the hospital that she herself had aphasia.

As noted by team member T.G.B., who also has experienced living with aphasia, our current research focus starts at the “beginning of the story” of living with aphasia. He himself tells the story of wanting to know more from the nurses, but “(t)here were no additional conversations with the speech pathologist. I wanted to know more, but I had been informed more than once: Physical injuries were treated at this hospital; the next hospital would treat any additional neurological issues” (Broussard, 2015, p. 7). How might he and the medical service provider have discussed the issue at the time? Might that discussion have been facilitated more thoughtfully by the provider in that moment?

After the research team had decided to focus on the biographical content related to the in-hospital experience, each team member was asked to write their perceptions of the value of the research focus on the in-hospital experience. See Table 3 for written quotes from Team Gem members for their unique perspectives on the value of these

lines of biographical research focused on the in-hospital experiences of people who have aphasia. Notably, these quotes include biographical accounts of team members, as well as evaluative content that highlights their motivation to work on this research.

Summary

A research team that was initially interested in quality of life with aphasia, in general, grew organically through networking and shared mutual interest as expressed through their biographies. An essential facilitator of this networked growth of the research team was mutual involvement of the team members with Project BRIDGE. A set of written biographical accounts of people with aphasia are serving as the research data set; the biographies represented in these written accounts of people with aphasia constitute an expansion of the stakeholder base involved in the research. The team members have tapped into the biographical roots of the research team membership in order to focus their biographical research lens on the very beginning of the road toward recovery—during the initial period of hospitalization when the person with aphasia may be at their most vulnerable.

CHALLENGES AND OPPORTUNITIES

Working with a diverse set of team members can be challenging, especially in early stages when team members do not know each other well. The importance of fostering group understanding of the backgrounds, priorities, motivating forces, specialized skills and interests, and additional commitments of each team member should not be underestimated. Open dialogue on these topics provides insights into division of labor across research activities, as do voluntary offers from group members to take on specific tasks. Allowing opportunity for team members to relate past and current events in their lives, as part of a biography-based approach to team development, builds this understanding and fosters trust and rapport. For a

Table 3. Written quotes from Team Gem members on the value of the research focus on the in-hospital experience

Team Member ^a	Quote
J.J.K.A	<i>I want to tell my stories of what TO DO & what NOT to do [in the hospital, by the medical team] I believe that digging out the “gems” in other stroke survivor stories may give light to common themes of great example & non-examples. Maybe our research will get the quality of life back to stroke survivors on a national level of the papers that patients get with their discharge higher quality and in more ways, like videos with captions, given our new differing abilities! Now that I’m a stroke survivor with aphasia, I want to get the word out about stroke & aphasia, though devastating, can give others HOPE!</i>
T.G.B.A	<i>Very few people have the opportunity to hear from stroke survivors who have gone through years of continued language activities and able to express what they couldn’t express before, who now reflect on their journey as recorded in various modalities for others to see, often for the first time. Team Gem is “mining” the thoughts and perspectives from patients who have experienced their health journey. It helps educate the disparate audiences in the health care community to better understand what their own patients had experienced at the start (in-hospital) but never knowing what their patients had been doing during their lifelong marathon towards recovery, until years of curating their experiences that started at the hospital. The research of Team Gem provides just those “gems” that can’t be found any other way.</i>
L.M.G.C	<i>Team Gem’s line of research can assist in the revolution to bring back compassion and empathy into the health care field. I believe having these experiences highlighted to medical professionals outside the scope of speech-language pathology can provide a better understanding of the diagnosis. A better understanding can improve not only the plan of care but the quality-of-life stakeholders. When individuals are confronted with the consequences of their words and actions. It brings to light a new line of self-awareness that may not have been there before. I once read that it takes 10–20 years for research to reach clinical practice. If this is true, what better time to push for this research than now.</i>
C.C.A.C	<i>I consider Team Gem vital to transforming the operations in the in-hospital setting. Acquiring aphasia after a stroke is life-changing, and the most crucial person in the scenario is the patient. Therefore, seeking to inform all disciplines involved is fundamental to the patient’s recovery and adaptation to their new life.</i>

(continues)

Table 3. Written quotes from Team Gem members on the value of the research focus on the in-hospital experience (*Continued*)

Team Member ^a	Quote
E.S.C	<p><i>As a clinician with experience in the acute care setting, I have worked with patients and their loved ones who were afraid and overwhelmed, looking for answers that they can process and hope that they can hold close. Learning from and with this team of people who are passionate about sharing their stories to inspire and improve the recovery experiences of others is a great beginning to the development of resources we can share to make an extensive, positive impact for people impacted by aphasia.</i></p>
J.M.M.C	<p><i>Working for a large non-profit hospital organization, we saw so many people who came to inpatient rehab with little or no knowledge of aphasia. They knew words were hard and their world had changed, but had not even educated on “aphasia” or ways to get help. That is so scary for those with aphasia. This team vows to help educate, empower and facilitate quality of care for those with aphasia.</i></p>
G.S.O.R	<p><i>I think of the feelings of isolation and social disconnection that my grandmothers must have been experiencing when they were hospitalized at the ends of their lives following strokes. At the time, I was young, and when our family visited them in the hospital, even a few words of guidance and reassurance in our broken communication with them would have meant so much to all of us. It was all so confusing, in such a confusing and chaotic time. I realize now as a researcher and clinician: Both of my grandmothers probably had aphasia. Each person with aphasia needs to be afforded the dignity of self-agency, and supported communication and engagement with loved ones, regardless of context. These are the foundations of quality of care, and quality of life, from the moment of initial hospitalization to the very last moment at the end of one's life, whenever that last moment may be.</i></p>

^aThree initials correspond with team member name. The subscript letter following the three initials identifies the role corresponding to their training module within Project BRIDGE: A = person with aphasia; C = speech-language pathology clinician; R = researcher.

narrative-based, stakeholder-engaged research team, such as Team Gem, this exchange of stories may have the added benefit of guiding the direction of the research; in this respect, the diversity of group perspectives is an advantage. There is a balance to strike between efficiency and depth of exchange among team members; whatever that balance, sufficient time must be afforded to each team member to formulate and express their ideas and to be heard by the group.

Another challenge is undertaking review and analysis of a large set of biographical works by members of a team that is composed of part-time volunteer researchers in a context where there is not (yet) any research funding to hire research assistants. Thus, the pace of the review and analysis, which is a labor-intensive process, is slow. A systematic search for funding support is essential to advance the research, not as an issue of prestige but rather as an issue of practicality. Yet, the pace is also steady, given the dedication of the research team to the topic. Specific review and analysis for in-hospital experiences of people with aphasia have begun for books including the following: Baxter (2018); Broussard (2015, 2016, 2018); Cummings (in press); Dow and Dow-Richards (2013); Kalapos (2018); Law and Paterson (1980); Marks (2017); and Meyerson and Zuckerman (2019). Notably, team member T.G.B. is the first person on the team to review and analyze his own publications. Team member J.J.K. is reviewing and analyzing Meyerson and Zuckerman (2019); she has spoken with Meyerson and hopes to gain admittance to an online class about the book to further her reading. Her analysis entails taking notes and typing them to organize the research process. In parallel, J.J.K. is currently in the process of authoring, firsthand, her personal stories of living with aphasia, even as she researches the stories of other authors who live with aphasia, as a member of Team Gem. Books currently under analysis and review by the more junior clinical team members (L.M.G. and C.C.A.) are those that they already had

in their personal libraries and had previously read. G.S.O. has made note of in-hospital accounts across multiple books, including two inclusions in works of fiction written by authors with aphasia (Gilb, 2011; Stephens, 2021). E.S.S. has included analysis of newly emerging publications that are under preparation or in press through direct contact with the authors. J.M.M. has begun review of key publications in the area of clinical practice and advocacy for and with people who have aphasia, including Holland and Elman (2021) and Simmons-Mackie (2018), for their comments on in-hospital experiences of people who have aphasia. To accelerate the pace of review and analysis of the biographical database, team members with university affiliations are seeking access to seed and leverage funding so that larger grant applications can be pursued to fund research assistants. In summer 2022, some seed funding from G.S.O.'s dean was obtained to temporarily hire C.C.A. into a part-time position, although the availability of these funds is limited, which slows the pace considerably. In the meantime, G.S.O. and C.C.A. are seeking data management and distribution solutions that minimize demands on the time of research personnel. One solution, in process, is pre-identification by G.S.O. and C.C.A. of the passages relevant to the in-hospital experience in each biographical work and subsequent electronic scanning of these passages to files that can then be posted to a centralized, password-protected, cloud-based location where each of the team members can directly access the raw data for analysis.

As results of the research emerge, an additional challenge will be to carefully and thoughtfully select the venues for dissemination of the work in order to reach the wide range of audiences who need to hear the life stories of people who have aphasia. Traditional academic dissemination venues, such as conference presentations and journal publications, are being strategically identified. However, the research team also recognizes that the topic of the in-hospital experiences of people with aphasia is ideally suited for

subsequent dialogue with transdisciplinary health care service providers to collaboratively develop and enhance the responsiveness of health care systems in person-centered, narrative-based support with and for people who have aphasia. Fitting venues for this stream of dissemination to transdisciplinary health care providers have been brainstormed by Team Gem and may include podcasts, meetings with stroke coordinators of hospitals, participation in medical grand rounds in divisions of physical medicine and rehabilitation, development of training materials, seeking access to televised venues or YouTube, media releases, and TED talks.

DISCUSSION

This case study gives account of the narrative-based process that has shaped the evolution of the stakeholder-engaged research group, Team Gem, and its research activities. The context of Project BRIDGE was a fertile ground that fostered group formation. The common, a priori commitment to stakeholder-engaged research among the team members was essential for group formation. As Team Gem has taken shape, grown, and evolved, it has been the “flowing together” of stories shared among us—told and understood from a variety of perspectives—that prepares us for the collaborative process of mining for gems of wisdom in the wealth of accounts written by and with people who have aphasia. The authors of those accounts themselves become stakeholder members of our team to effect potential change across broad medical, clinical, and societal contexts and to provide hope for other people with aphasia in their journey.

For people who experience uncertainties surrounding the formation and solidification of stakeholder-engaged research team, the current case study illustrates the advantages of a biography-based framework to team formation and development. These very uncertainties have been experienced by Team Gem members, so we speak from that very

experience. Adherence to a biography-based approach provides a stabilizing influence. One recommendation is to invest in sufficient time during meetings to carefully listen, read, and understand the background stories and motivations of the team members and to make this a steady practice. Our team meets only once a month, so meeting time is precious, and actual research activities must be relegated to periods between meetings. Even though we have all completed Project BRIDGE training, that is only a first step. We still need to make a considerable, concerted effort to regularly exchange personal stories and ideas and to build dedicated time for this exchange into our meetings. The research would not advance and the team could falter without this steady investment. It builds mutual understanding of the dynamic backgrounds, motivations, and collaborative ideas of each team member. This is the bedrock of distribution of effort in achieving the goals we set for ourselves. We seek to understand the “points” that team members make during storytelling and then to advance these points of emphasis into action.

Given Team Gem’s plan to address medical service providers as the first target audience who need to hear the voices of people with aphasia about their in-hospital experiences, we may be able to capitalize on the fact that a subset of the literature on the lived experience of aphasia is written by medical professionals who themselves have experienced stroke and have aphasia (Kapur, 1997). It is a poignant irony that, in the experience of Team Gem member J.J.K.—who herself has trained, worked, and trained others in the medical profession—the person-centered care that she taught to her students and fostered with her patients was not necessarily her experience in certain instances when she herself became the patient, even though she received good medical care overall. As a research team, we will need to plan and prepare for the necessary transition from an initial process of stakeholder-engaged research to the ultimate process: effecting change in health care practices in direct

collaboration with interdisciplinary medical teams and other people who have aphasia.

Another recommendation emerging out of a biography-based framework for advancing stakeholder-engaged research is to seek out the stories of people who have aphasia as the very data set to be analyzed by the research team. The current article has highlighted both the advantages and disadvantages of using written biographies as this database. With the relative advantages of written versus oral personal narratives as data held firmly in mind, Team Gem may be unique in its use of the extensive written biographical literature of people living with aphasia as our data set. For our team, the written stories of other people with aphasia provide a stable source of insights into the experience of living with aphasia. Use of these data essentially enlarges our group of research stakeholders by more than 200 people, which would be more difficult and labor-intensive if oral narratives were used for this purpose. The evaluative content of written narratives will help us highlight where relevant issues, problems, and solutions exist throughout the lived exper-

iences of people impacted by aphasia—with problems and opportunities surrounding the in-hospital experience as our initial focus. We next envision the change we want to see, and then we ultimately move that vision of compassionate, narrative-based, patient-centered care into evidence-based action (Trzeciak & Mazzarelli, 2019).

The written stories of people who have aphasia represent a flowing together of tributaries that may merge to form wider rivers of medical and societal change. Through writing, they provide permanent and timeless access to the life stories and experiences of people who have aphasia, a source of testimony that starts from the very beginning of their journey. The lessons they share, and the thirst for understanding that they quench, are wellsprings of deep resonance and hope for other people with aphasia who are on their own unique biographical journeys. As noted by Frank (1995), “(t)he quest narrative recognizes ill people as responsible moral agents whose primary action is witness; its stories are necessary to restore the moral agency that other stories sacrifice” (p. 134).

REFERENCES

- Baxter, T. W. (2018). *Relentless: How a massive stroke changed my life for the better*. Greenleaf.
- Broussard, T. G. Jr. (2015). *Stroke diary: A primer for aphasia therapy*. Thomas G. Broussard.
- Broussard, T. G. Jr. (2016). *Stroke diary II: The secret of aphasia recovery*. Stroke Educator Inc.
- Broussard, T. G. Jr. (2018). *Stroke diary III: Just so stories ... How aphasia got its language back*. Stroke Educator Inc.
- Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. Oxford University Press.
- Cummings, P. (in press). *The stroke didn't get the memo*. Fire Press.
- Dow, D., & Dow-Richards, C. (2013). *Brain attack: My journey of recovery from stroke and aphasia*. Speechless Publishing Group.
- Edelman, G., & Greenwood, R. (1992). *Jumbly words, and rights where wrongs should be: The experience of aphasia from the inside*. Far Communications Ltd.
- Frank, A. (1991). *At the will of the body: Reflections on illness*. Houghton Mifflin Company.
- Frank, A. (1995). *The wounded storyteller: Body, illness, and ethics*. The University of Chicago Press.
- Halliday, M. A. K. (1989). *Spoken and written language*. Oxford University Press.
- Hersh, D. (2015). “Hopeless, sorry, hopeless”: Co-constructing narratives of care with people who have aphasia post-stroke. *Topics in Language Disorders*, 35(3), 219–236. <https://doi.org/10.1097/TLD.0000000000000060>
- Hinckley, J. (2006). Finding messages in bottles: Living successfully with stroke and aphasia. *Topics in Stroke Rehabilitation*, 13(1), 25–36. <https://doi.org/10.1310/FLJ3-04DQ-MG8W-89EU>
- Hinckley, J., Brice, A. E., & Kong, A. P. H. (2019). *Project BRIDGE: Building Research Initiatives by Developing Group Effort* [Paper presentation]. Frontiers in Human Neuroscience Conference Abstract, Academy of Aphasia 57th Annual Meeting, Macau, SAR. <https://doi.org/10.3389/conf.fnhum.2019.01.00030>
- Holland, A. L., & Elman, R. J. (2021). *Neurogenic communication disorders and the life participation approach: The social imperative in supporting individuals and families*. Plural Publishing.
- Gilb, D. (2011). *Before the end, after the beginning*. Grove Press.

- Kalapos, F. Z. (2018). *Stroke through a mother's eyes: The first year*. Mill City Press.
- N. Kapur (Ed.). (1997). *Injured brains of medical minds: Views from within*. Oxford University Press.
- Keisanen, T., & Kärkkäinen, E. (2014). Stance. In K. P. Schneider & A. Barron (Eds.), *Pragmatics of discourse, Series: Handbooks of pragmatics, Vol. 3* (pp. 295–322). De Gruyter Mouton.
- Law, D., & Paterson, B. (1980). *Living after a stroke*. Souvenir Press.
- Linde, C. (1993). *Life stories: The creation of coherence*. Oxford University Press.
- Marks, L. (2017). *A stitch of time*. Simon & Schuster Paperbacks.
- McGregor, D. (1999). *One man's journey: An autobiography*. University of Texas at Dallas.
- Meyerson, D. E., & Zuckerman, D. (2019). *Identity theft: Rediscovering ourselves after stroke*. Andrews McMeel Publishing.
- Olness, G. S., & Campbell, R. (2020, April). *Integrating LPAA and narrative medicine in intervention planning: A pedagogical project for graduate-student professional training* [Poster presentation]. Fourth biennial Aphasia Access Leadership Summit. (Meeting was held virtually.)
- Olness, G. S., & Ulatowska, H. K. (2011). Personal narratives in aphasia: Coherence in the context of use. *Aphasiology (Special Issue—Discourse in Aphasia)*, 25(11), 1393–1413. <https://doi.org/10.1080/02687038.2011.599365>
- Ott, T. (2004). *Une fureur envie de vivre ... Témoignage recueilli par Thierry Ott [A passionate desire to live ... Testimony collected by Thierry Ott]*. Les Éditions d'Hébe.
- Parr, S., Byng, S., Gilpin, S., & Ireland, C. (1997). *Talking about aphasia: Living with loss of language after stroke*. Open University Press.
- Patient-Centered Outcomes Research Institute (PCORI). (2022, March 22). *About PCORI*. <https://www.pcori.org/about/about-pcori>
- Rolnick, M., & Hoops, H. R. (1969). Aphasia as seen by the aphasic. *Journal of Speech and Hearing Disorders*, 34(1), 48–53. <https://pubs.asha.org/doi/10.1044/jshd.3401.48>
- Sacks, O. (1985). *The man who mistook his wife for a hat, and other clinical tales*. Harper Perennial.
- Shadden, B., & Hagstrom, F. (2007). The role of narrative in the Life Participation Approach to Aphasia. *Topics in Language Disorders*, 27(4), 324–338. <https://doi.org/10.1097/01.TLD.0000299887.24241.39>
- Simmons-Mackie, N. (2018). *Aphasia in North America: Frequency, demographics, impact of aphasia, communication access, services, and service gaps*. Aphasia Access. <https://aphasiaaccess.org>
- Stephens, J. (2021). *The suspect speaker: The frustrations and the blessings of life with aphasia*. DMS Publishing.
- Strong, K. A., & Shadden, B. B. (2021). Stories at the heart of life participation: Both the telling and the listening matter. In A. L. Holland & R. J. Elman (Eds.), *Neurogenic communication disorders and the life participation approach: The social imperative in supporting individuals and families* (pp. 105–130). Plural Publishing.
- Trzeciak, S., & Mazzarelli, A. (2019). *Compassionomics: The revolutionary scientific evidence that caring makes a difference*. Studer Group.