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Caregivers navigating rehabilitative care for people with aphasia after stroke: a multi-lens perspective

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Abstract

Background: Up to 40% of stroke survivors acquire aphasia and require long-term caregiver assistance after discharge from the hospital. Caregivers assume multiple roles as they help people with aphasia to access outpatient rehabilitative care in an increasingly person-centered model of care. Examining caregiver roles and how different stakeholders in the rehabilitative journey perceive these roles may be the first step in providing more tailored support to caregivers and improving outcomes for both caregivers and people with aphasia.

Aims: The purpose of this study was to characterize the roles caregivers assume while navigating outpatient rehabilitative care for people with aphasia after stroke from the perspective of different stakeholders in the rehabilitative process.

Methods: Thirty-six people participated in the study, including seven caregivers, 22 stroke survivors with aphasia, and seven healthcare providers. Focus groups were conducted, and an iterative thematic analysis was used to identify themes.

Results: Results indicate that caregivers are perceived differently by varying stakeholders, and that caregivers adopt diverse roles as advocates, therapists, motivators, and guardians. They assume these roles in order to fill gaps in services or to otherwise facilitate the recovery journey for the person with aphasia.

Conclusions: Our study provides a valuable glimpse into how varying stakeholders view the role of the caregiver during rehabilitation for people with aphasia after stroke. Providing caregivers with the training and support they need throughout the recovery journey by treating them as partners in the process may mitigate the perception of caregivers as feeling compelled to adopt multiple roles.

Keywords

caregivers; aphasia; stroke; rehabilitative care

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Declaration of Interest
The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Background

There are an estimated 6.5 million stroke survivors currently in the United States, many of whom require caregiver assistance (Edwards and Segal-Gidan 2010). Of those survivors, as many as 25–40% acquire aphasia (Simmons-Mackie, 2018). Compared to people without aphasia, people with aphasia are less likely to receive information regarding their stroke and prognosis. This decreases overall satisfaction with the services they receive and exacerbates the burden on caregivers who are frequently attempting to navigate an already complex healthcare system with little to no preparation (Burns et al. 2015; Hinckley, Hasselkus, and Ganzfried 2013).

Caregivers are an integral part of the recovery process for people with aphasia, helping them to navigate outpatient rehabilitative care and reintegrate into the community after hospitalization. While services for people with aphasia are becoming more person-centered, support for caregivers remains lacking due in part to the specific focus on aphasia as an individual problem (Le Dorze and Signori 2010). In this paper, we seek to explore the many roles caregivers play as they help people with aphasia to navigate rehabilitative care after stroke. Moreover, we aim to examine how different stakeholders in the rehabilitative process —the caregiver, the person with aphasia, and the health care professional—perceive the roles that caregivers adopt.

Aphasia After Stroke: The Impact on Caregivers

The roles that caregivers assume evolve over time as both the caregiver and the person with aphasia adjust to life with a chronic disability. While the person with aphasia is in the hospital, caregivers may be so overwhelmed that they are unable to seek information regarding their new role effectively (Hinckley et al. 2013). Instead, the caregiver may focus on only the most immediate concerns, including how to handle significant medical costs and how best to interact with the healthcare team.

The loss of both shared and independent activities can sometimes lead to third party disability (Grawburg et al. 2013), wherein caregivers experience disability as a consequence of their loved one’s aphasia. According to McGurk and Kneebone (2013), disability for the caregiver includes poorer social adjustment, decreased social life and leisure activities, and relationship stress (especially if the caregiver is a spouse). The literature reports similar ramifications for caregivers of people with other acquired disabilities such as spinal cord injury and brain injury, who have also been found to be at greater risk for depression, anxiety, and decreased life satisfaction (LaVela et al 2015; Marwitt and Kaye 2006). Caregivers of adults with acquired disabilities do not typically anticipate having to provide long term care for their loved one with aphasia. Most often, they must assume the role without warning. This sudden shift in identity and responsibility leaves little time for psychological adjustment (Kim et al. 2006; Marwitt and Kaye 2006).

Frustration with the role change of becoming a caregiver is amplified by the presence of aphasia and, depending on the severity and type of aphasia, problems may actually worsen over time (McGurk and Kneebone 2013). The burden of communication is often thought to be the most difficult and distressing issue for caregivers of people with aphasia (Winkler et al. 2014). Certainly, the role shift from spouse, family member, or friend to caregiver requires active commitment, propensity for acquiring new skills, and ability to adjust the level of care during the recovery process (Agard et al. 2015). While some caregivers are able to reduce or leave the caregiver role gradually, as recovery progresses, caregivers of people with aphasia may never see such change.

Person-Centered Intervention and the Caregiver

During the past decade, several treatment approaches for people with aphasia have evolved toward a person-centered, social model of service delivery (Purdy and Hindenlang 2001). This is reflected most aptly in the Life Participation Approach to Aphasia (LPAA), a practice philosophy which encourages collaborative goal setting between the client and clinician (Chapey et al. 2000). One of the core values of LPAA is that caregivers of people with aphasia are entitled to services by virtue of being affected by the disorder. Additionally, they are often the ones communicating on behalf of the person with aphasia in situations related to navigating rehabilitative care. Caregivers want to be involved in the goal setting process for the person with aphasia (Howe et al. 2012). Simply educating caregivers about aphasia does not help to improve communication between the person with aphasia and the caregiver or between the caregiver and the healthcare professional (Purdy and Hindenlang 2001). If direct intervention is not provided, people with aphasia may be discharged from the hospital and sent home without ensuring that the caregiver is adequately prepared to handle not only typical caregiving tasks but also the role of communicator and navigator (Plank, Mazzoni, and Cavada 2012).

In the continual push to decrease length of inpatient stay and return patients to their communities, providers are placing more of a burden on caregivers to navigate a complicated healthcare system as the person with aphasia recovers. By focusing intervention goals solely on the person with aphasia, there is risk of missing a key link in ensuring that people with aphasia and their caregivers are able to successfully reintegrate into the community and receive appropriate outpatient rehabilitative care (Visser-Meily 2006).

This study emerged from a pilot investigation identifying access barriers to outpatient rehabilitive care after stroke. The purpose of the study described in this paper was to determine what roles caregivers assume in terms of facilitating access to outpatient rehabilitation care and navigating the recovery journey with the person with aphasia. Additionally, we were interested in how key stakeholders (people with aphasia, rehabilitation professionals, and the caregivers themselves) perceive the roles that caregivers adopt. We asked participants in each of these groups about access barriers to outpatient rehabilitative care and analyzed the data from the perspective of multiple caregiver roles. Our goal was to understand how rehabilitation healthcare providers may better support caregivers throughout all facets of the recovery journey.

Methods

Participants

Ethical approval for this study was obtained from the University of North Carolina at Chapel Hill Non-Biomedical Institutional Review Board. Participants were recruited via email from a nonprofit aphasia organization for people with aphasia and from a hospital rehabilitation service patient and family advisory board. A purposive sample was employed, targeting representation of the various stakeholders from the same local community. In addition to hearing from the caregivers themselves, we sought input from family members with aphasia who share their lives with them and presumably observe caregivers in varied roles. We also sought feedback from healthcare professionals, who routinely interact with caregivers and often call on their assistance during recovery. We enrolled all caregivers, people with aphasia, and healthcare professionals who responded to an invitation emailed via the aphasia program's listserv and the patient and family advisory board's listserv.

There were 36 participants, including seven caregivers, 22 stroke survivors with aphasia, and seven healthcare providers. Participants from the aphasia program were eligible if they were 18 years or older and had survived a stroke or were the primary caregiver of a stroke survivor. While information regarding aphasia type and severity were not formally collected as the study focused specifically on caregiver roles and was not limited to a specific type and severity of aphasia, participants had to have a diagnosis of aphasia in order to participate in the aphasia program. Eligible participants from the hospital patient and family advisory board were required to be current board members and report experience seeing patients as speech-language pathologists, occupational therapists, physical therapists, or nurses. Participant demographics are listed in Table 1.

Focus Groups

The clients and caregivers comprised four of the five focus groups (group 1, n=7; group 2, n=7; group 3, n =10; group 4, n =5), and these groups consisted of a mix of caregivers and people with aphasia. One focus group consisted of rehabilitation professionals and hospital administrators (n=7). The people with aphasia/caregiver focus groups were conducted at locations where the aphasia organization meetings typically take place (the organization's central office or a local outpatient rehabilitation center). Each group was held in a quiet meeting room, and only participants and study personnel were present during each group. The focus groups were conducted after normally scheduled groups whenever possible in order to minimize travel burden. The patient and family advisory board focus group occurred on the rehabilitation floor of the hospital in a private conference room and was scheduled at the end of the day to avoid conflict with patient appointments. The consent process began immediately after all participants had arrived. The first author, a certified rehabilitation counselor and doctoral student in Speech and Hearing Sciences, ensured participants with aphasia understood the consent process by using additional tools when needed (e.g. writing key phrases, explaining the consent form in short, clear sentences).

Focus group questions for the people with aphasia and caregivers were centered around characteristics of the stroke, immediate and long-term impairment (if applicable), and participants' experiences accessing outpatient rehabilitation care, including perceived barriers and facilitators (see Supplementary Material). Questions for the healthcare professionals addressed the mix of patients seen in the facility, perceived challenges in providing care, and suggestions for improving access to care. The questions were sent to stroke survivors and caregivers prior to the focus groups to allow adequate opportunity to prepare. The sessions were moderated by the first author and lasted approximately 60–90 minutes each. All focus groups were audio recorded and subsequently transcribed. Field notes were taken by a secondary facilitator, primarily to record gestures and other nonverbal communication.

Data Analysis

Focus group transcripts were examined by the first and third authors using thematic analysis focused on understanding caregivers' experience in navigating and accessing rehabilitative care (Halloway and Galvin 2016). We did not approach data analysis with a priori codes; rather, we used a dynamic process in which codes, code categories, and themes were the outcome of iterative reflection and summary (Freeman 2017; Saldana 2009).

The first and third authors read each transcript to become familiar and comfortable with the text and then identified and labelled codes individually. Codes consisted of short phases or labels and were selected to represent the fundamental meaning of the text. Some codes pertained to stroke characteristics or type (i.e. numbness resulting from the stroke or descriptions of ischemic or hemorrhagic stroke). For the purpose of the study, we discarded codes with this content, because the information did not pertain to the study purpose. After the initial pass, the coders worked jointly to combine codes that were similar in meaning (e.g. "caregiver support" and "family pushes and encourages" recoded as "family/caregiver as motivator").

The first author created a codebook based on the finalized codes and the first and third authors used this codebook to review and re-code all transcripts via ATLAS.ti (version 1.5.3). They discussed any new codes that arose via repeated re-readings of the text and updated the codebook accordingly. Next, clusters of similar codes were organized into subthemes, from which broader themes were identified. For example, numerous codes pertaining to caregivers combined to form the "Family/Caregiver" subtheme. Table 2 illustrates the relationship between codes and subthemes. To illustrate, a caregiver shared her experience dealing with outpatient therapy scheduling delays, explaining that she used her family to find someone willing to work with the person with aphasia until he was able to start outpatient speech-language therapy. In this example, initial codes were labeled, discussed and combined to form the final subtheme of "caregivers as advocates." The authors continued using this process until all codes had been grouped into subthemes and all themes had been identified.

Rigor

Rigor is established during qualitative analysis by attending to the tenets of credibility, dependability, and confirmability (Whittemore, Chase, and Mandle 2001). The first author maintained an audit trail throughout the analytic process that described in detail the development of codes, code categories, and resulting themes in order to adhere to these components of rigor. The initial codes were discussed by the authors, and decisions to keep, combine or discard specific codes were documented in the audit trail throughout the analytic process. Additionally, field notes (taken during each focus group by a trained research assistant and the second author) were used to document details that were not captured by the audio transcription, such as participant facial expressions and non-verbal gestures or actions. The first author referred to these field notes during data analysis to supplement understanding of participant interactions during each focus group. Any additional impressions garnered from the field notes were discussed with the third author and documented in the study audit trail.

A fundamental aspect of qualitative research is that coding progresses through experience-based filters (Saldana 2009) and that these filters can influence data interpretation. The professional background was different for the two coders, with the first author approaching the coding through the lens of a rehabilitation counselor, and the third author approaching it through the lens of a speech-language pathologist. To encourage validity and address researcher reflexivity, these coders met on a regular basis during data analysis to discuss interpretation, reactions, and any concerns relevant to the coding process. The second author, who attended four of the five focus groups, also reviewed the final codebook to provide a final code/theme check.

Results

Through thematic analysis of the focus group transcripts, we identified four themes related to caregivers assuming roles apart from simply facilitating access to outpatient rehabilitation for the person with aphasia. These themes were: caregivers as advocates, caregivers as therapists, caregivers as motivators, and caregivers as guardians. Further, we examined the results from the multi-lens perspective of the participating caregivers, people with aphasia, and healthcare professionals to identify how different stakeholders perceived these roles. These themes are listed and illustrated in Table 3. They are described in detail in the following.

Caregivers as Advocates

The most frequently occurring theme was that caregivers had to advocate for the person with aphasia during the process of accessing outpatient rehabilitative care. This advocacy included pushing for timely treatment and education regarding aphasia. The way in which caregivers acted as advocates evolved as the person with aphasia began to recover. First, caregivers--who were primarily unaware of aphasia prior to the person with aphasia's stroke-- educated themselves on the diagnosis and what they could expect during recovery. One caregiver indicated she had never heard of the word "aphasia" but understood after her husband's stroke that he was having word finding difficulties, which were initially overlooked by the medical team. She requested a diagnosis without being fully aware of what was wrong:

> "I just decided that something was really wrong and I didn't know what was wrong, so I saw his primary care doctor and said I'm having difficulty. [X] is not capable of

> getting a word out, and he knows the word, and she said ‘I really think he would really do well with some speech therapy.’”

A consistent message was that caregivers faced difficulties in educating themselves and that their need for education and information was largely overlooked by healthcare professionals. They often felt they did not receive as much information as they wanted and were somewhat disconnected from the healthcare providers. One caregiver shared her frustration with the lack of support she perceived after her husband’s diagnosis.

> “I had to educate myself. And it was a good thing because I was capable of doing it...But I didn’t know what I was doing.”

Her feedback points to a broader issue, which is the disconnect many caregivers felt from the healthcare system due to a perceived lack of guidance from healthcare professionals. While feedback regarding individual outpatient therapists was largely positive, many felt that they were provided little support as a whole throughout the recovery journey. Some caregivers felt abandoned by the system, and one described how discouraged she felt attempting to plot a path forward after her son’s stroke:

> “I think more of the focus that we felt frustration with was setting a direction because we had really good care...from the standpoint of the crisis that he went through and a couple of follow ups with neurologists after that to ensure there wasn’t anything that he could really, there wasn’t anything more they could do from their standpoint. The crisis was over. There was nothing to manage. Nothing to treat. But that was it.”

As caregivers began to research options for outpatient rehabilitative care, they felt that they had to advocate for getting the person with aphasia into the system in order to receive care in a timely manner. Not only did caregivers perceive little support in initiating outpatient rehabilitation, they also felt stymied by logistics such as scheduling and administrative hurdles. One caregiver said:

> “If I may, it took his ex-wife...many phone calls to check and call and see when is he starting, he should have been starting, when is he starting. If she hadn’t done anything, he probably wouldn’t be in there yet.”

Caregivers continued to strive for the best quality of care possible once the person with aphasia began receiving outpatient rehabilitative therapy, which one caregiver described as “leading the charge.” One caregiver of an older person with aphasia expressed frustration with the lack of therapist engagement she perceived during sessions, and other caregivers were displeased with the treatment team’s approach to therapy and management and even requested new therapists. Another caregiver recounted a particularly disturbing therapy session:

> “...So she was apparently doing things with his arm that you could tell he had pain in his face and he was wincing but she wasn’t even looking at him and she wasn’t talking to him because he couldn’t talk to her. I don’t care how good she was at her job. If he can’t talk to her that doesn’t give her any right to ignore him and just do the job and not see that he’s in pain. The other therapists need to understand aphasia and apraxia.”

Her quote illustrates a communicaton breakdown between the therapist and the person with aphasia that the caregiver recognizes needs to be addressed. She further advocates for the person with aphasia by stating that all members of the therapy team have the responsibility to learn about aphasia and apraxia of speech. Furthermore, the feedback reflects a theme that all pieces of the treatment team puzzle may not always be working together as a cohesive unit, which highlights another reason why caregivers feel the need to adopt multiple roles. The seven participating caregivers were most often the ones to view themselves through the lens of advocate.

Caregivers as Therapists

When scheduling issues prevented the person with aphasia from beginning outpatient therapy in a timely manner, caregivers often advocated for other ways to fill in the resulting gap between hospitalization and outpatient therapy. In some cases, the person with aphasia had to wait weeks before beginning outpatient therapy, and caregivers expressed the desire to facilitate recovery until formal therapy could begin. At other times, the person with aphasia began outpatient therapy a few days after discharge from the hospital, but the caregiver wanted to do more to encourage recovery in conjunction with formal therapy.

Here, the caregiver assumed dual roles--that of advocate and that of therapist. One caregiver further illustrated how difficult it was to delineate the two roles after her husband had to wait to begin speech-language therapy:

> “We were doing some stuff. We downloaded some apps, the aphasia apps that said A and B and 1, 2, 3 and sentences like, you know, just basic stuff, ‘I’m hungry,’ ‘I’m thirsty…’ Nobody said this is what you can do. We searched it on our own and got him started on stuff. I would write things and then I would let him copy it. We would talk about it but just basic stuff.”

Notably, caregivers appeared to take on the role of therapist without guidance, working on specific speech and language tasks as the caregiver became more educated about the aphasia diagnosis. One caregiver described her efforts to elicit word-finding practice from her husband:

> “I even went to the point and got coloring books that had pictures of stoves and refrigerators and apples and trees and had the coloring books and had [X] saying what they were, and then going to the refrigerator and the stove to get them.”

Caregivers also enlisted the help of other family members or friends, illustrating the caregiver acting as both advocate and therapist for the person with aphasia, as the caregiver sought out any available resources. One caregiver reported using a family friend to help act as a stand-in therapist for her husband as they pursued outpatient services:

> “A family friend who was a retired teacher all of the sudden felt inspired to go online and learn about aphasia and worked with him for about three months on her own.”

Taking on the role of therapist was often more about fulfilling a perceived need—the gap in services—than collaborating with the outpatient speech-language pathologist or helping the person with aphasia to complete therapy homework, though caregivers certainly also assisted with those tasks.

Sometimes, the caregiver felt more knowledgable about what would work for the person with aphasia than the speech-language pathologist. One caregiver questioned whether the outpatient speech-language pathologist was providing appropriate exercises and homework, given that the person with aphasia was unable to read or write adequately due to the type of aphasia he had. She described her efforts to engage him following what she perceived as ineffective homework tasks:

> "I could not tell if he had made any progress and they would send him home homework where he was supposed to write things and read things and it didn't make any sense. He couldn't read. He couldn't write. I mean he was supposed to practice words and stuff and we did that. I played games with him like match-up games, pictures, just to do something."

Other times, caregivers searched for ways to continue making progress after therapy ceased when the person with aphasia reached the cap on therapy services for the year. One caregiver described stopgap measures used to continue recovery progress in this case:

> "The speech therapy he's got a little iPad and he'll go to those apps and so he reads those things and then like she was saying, I write down and I make him copy things. The walking, the physical therapy, like I say, I've got a bad shoulder so I can't really manhandle the man so my son and my son-in-law and my daughter, they come in every day and make him walk."

Cognizant of their own limitations, caregivers acted in whatever capacity they could to push progress forward, even if that meant recruiting other family members to work with the person with aphasia. Again, participating caregivers were most likely to view themselves through the lens of therapist, which often coincided with caregivers taking on the active role of advocate, as well.

Caregivers as Motivators

Caregivers played an important role in motivating people with aphasia during the rehabilitative process, often spending hours encouraging them to complete therapy exercises or helping them to work through homework lessons. One focus group (n=7) consisted almost exclusively of people with aphasia, having only one caregiver present. Whereas caregivers in other focus groups described a variety of barriers they experienced in accessing outpatient rehabilitative care for the person with aphasia, the participants in this unique group denied encountering access barriers and provided an interesting perspective on caregivers as motivators, the lens through which these participating people with aphasia most often saw their caregivers. One participant, determined to return to work after her stroke, described working with both her therapist and her sister, as her sister encouraged her to practice her therapy homework for hours:

> "And so they were talking like okay every day let's try this sentence and do it again and do it again. And so I went two days therapy and my sister on Thursday, Friday

> -- not Friday, Saturday at my sister's house for two hours my sister would, you got it, you got it, and I do it now."

Focus group feedback pertained mostly to speech-language therapy, though the participants acknowledged that caregivers motivated them in all aspects of recovery. Often, speech-language homework was something that caregivers felt comfortable and confident to complete with the person with aphasia. Additionally, caregivers felt that encouraging the person with aphasia to press on, especially through bouts of frustration, was an important job. One caregiver described how she and her children would encourage her husband during his therapy sessions and after:

> "...We always pushed him, 'Okay, [X], you've got to do this. I mean they want you to do it.'"

At times, caregivers enlisted family and friends to help push the person beyond his or her comfort zone in order to motivate recovery and spread awareness about aphasia. Doing so was mutually beneficial to both the person with aphasia and the caregiver, as the person gained more confidence and the caregiver was not always responsible for educating people unfamiliar with the diagnosis, which could be fatiguing. One caregiver elaborated:

> "The lady, our family friend that's been helping him...she got a paper together and gave it to our pastor and said make copies for everybody in the church, and she made him give a 10-minute presentation on what aphasia and apraxia is so that our church members could understand that yes, [X] is all there."

Interestingly, while participating caregivers acknowledged the importance of being a motivator, they viewed their role primarily as advocate and therapist, feeling this assistance was necessary to aid the person with aphasia reintegrate into the community. Conversely, participants with aphasia described caregivers as motivators without commenting much on other roles.

Caregivers as Guardians

Just as the participants with aphasia described their caregivers as primarily being motivators, the healthcare providers that participated spoke frequently about caregivers as fulfilling the role of guardian. The healthcare provider focus group was comprised of rehabilitation providers and administrators, the majority of whom provide or have provided therapy services to stroke survivors. The providers appeared very aware that caregivers are often juggling multiple roles, yet feedback from this group focused mostly on caregivers navigating the functional issues pertaining to outpatient rehabilitation, such as dealing with scheduling, transportation, and insurance concerns while also balancing their previous responsibilities. While this appears to be the primary way healthcare providers interact with most caregivers during rehabilitation, it reaffirms the role that caregivers have been allotted within the healthcare system overall. From this perspective, it may be argued that caregivers are often viewed as fielding the practical consequences of stroke and aphasia without being acknowledged as partners in communicative rehabilitation.

In contrast to the other four focus groups, the group with almost all people with aphasia shared very few barriers to accessing outpatient rehabilitation services. In the context of the input from our other focus groups, we interpret this as indicating that the caregivers were bearing the burden of coordinating care and doing a good job of it. One person with aphasia acknowledged how fortunate he was to still have support from his parents:

> "I think—my parents are retired—but I think everybody's older and stuff like that, so I think it was less of an issue, versus people probably in their 60s where their parents are no longer alive, that's probably the people that would have more of an issue."

Alluding to a need to mask or downplay their challenges, caregivers asserted in other groups that they sometimes find it difficult to hide problems from the person with aphasia as issues arise. For example, one caregiver described her frustration at dealing with bills; she acknowledged that just because her husband is not able to talk about financial issues, it does not mean that he is unaware:

> "I mean he'll see me fretting over the bills and he'll ask me what's wrong and it's like you know what, I can't hide it from him. He knows what I'm talking about. I just try not to get into too much detail and all but I just let him know that we're going to be okay but he's not stupid. It's everything is there. It just isn't coming out."

Financial worries were a common theme among several caregivers, many of whom were new to assuming the role of head of the household but who also felt a strong desire to shield the person with aphasia from dealing with the accompanying issues. Yet, caregivers sometimes have little support themselves, as noted by one rehabilitation professional:

> "If you have a family and both were working and then one has a stroke, then you go down to one income which makes it even more difficult...And then that person as the caregiver is also trying to take care of the person that just had a stroke so it gets really hard for them and then they get sad and it goes on and on."

Another rehabilitation professional reiterated the difficult position caregivers find themselves in as the sole financial provider for the family as well as the caregiver, confirming that healthcare providers are well-aware of the struggle caregivers face:

> "Like they're trying to go back to work like what you mentioned earlier, you can't keep a job and take care of someone...If they need all this assistance and yeah you can hire caregivers but they don't show up, you miss work."

One caregiver became frustrated and tearful as she described how difficult it was to balance maintaining employment while also being present for her husband during his therapy appointments. She revealed that she felt criticized by her husband's therapist, because she had to miss appointments due to work. Her frustration stemmed from a lack of other options:

> "When you're down to one income, and it's mine not his, and I'm a temp. I'm not even permanent. I don't have insurance. I don't get paid holidays or anything. I have to work and I felt like she was criticizing me because she just wouldn't help me and it's like those people I thought were supposed to help and guide us through that process but they don't."

Caregivers sometimes endure criticism because the healthcare professional may perceive the caregiver as being disengaged or simply not present during rehabilitation. Feedback from the rehabilitation professionals group acknowledged the lack of support they are able to give, especially in terms of helping caregivers navigate the often confusing insurance system, an issue they frequently observed. In turn, caregivers highlighted the lack of resources provided by the healthcare professionals themselves. They observed that they were given insufficient resources to bridge the gap between when people with aphasia hit their therapy caps for the year and when they could resume services. This left them feeling frustrated and discarded by the healthcare system. One caregiver lamented:

> “I mean really, who wants to do this? Who wants to? I mean who wants to sponge the insurance? Who wants to take him to speech every day, three times a day for this and that, in and out?”

Both caregivers and rehabilitation professionals highlighted significant gaps in support services available to caregivers. However, it was also evident that there was disagreement between these stakeholders about who should be responsible for providing such services. The caregivers often looked to the therapist to provide guidance, especially bridging the gap between reaching the annual therapy cap and resuming services. In contrast, the healthcare providers acknowledged that disparities in support services were not something they could do much about, but rather a systemic issue that needs to be addressed on a policy level.

Discussion and Implications

Our findings illustrate the various roles caregivers assume throughout the recovery journey, from the acute event (e.g. stroke and inpatient hospital stay) to outpatient rehabilitation and community reintegration. Caregivers adopt the role of advocate, therapist, motivator, and guardian. These roles are diverse, but each helps facilitate rehabilitation for the person with aphasia. Feedback from the various stakeholders in the rehabilitation process—caregivers, people with aphasia, and healthcare providers—illustrates the many facets of being a caregiver for someone with aphasia.

The multi-lens perspective

The three participant categories provided valuable perspectives on the functions and responsibilities caregivers undertake. While our focus group design encompassed heterogeneous participants, each focus group was homogenous regarding shared experience (e.g. all participants shared the experience of navigating rehabilitation care or working in rehabilitation), which Liamputtong (2011) and Morgan (1997) state can help to foster differing perspectives on the study question—the aim of this project.

People with aphasia spoke mostly about caregivers being motivators, while healthcare providers frequently described them as guardians. The caregivers themselves helped to complete the bigger picture by describing the obligations they adopt as advocates and informal therapists. Our study provides a unique depiction of what it means to be a caregiver for someone with aphasia from the perspectives of the main stakeholders in the rehabilitative journey.

Sometimes, caregivers are forced into a particular role, such as having to advocate for additional services or communicating healthcare decisions for the person with aphasia. When caregivers act as advocates, much of their focus is about educating themselves on stroke and aphasia. On the other hand, caregivers sometimes assume a role not because they have to due to some failure in the healthcare system, but because they feel compelled to do so in order to facilitate recovery. This appears to occur when caregivers assume the role of therapist in an attempt to supplement the person with aphasia's scheduled services. Additionally, when caregivers spoke about acting as a therapist, it was nearly always in the context of speech and language. Feedback from caregivers indicates that they felt that finding various speech and language activities to do with the person with aphasia was something within their control.

Based on their feedback in this study, we know that many caregivers are resourceful and will take initiative to facilitate recovery wherever possible (Winkley et al. 2014). If they are not being provided with the specific communication strategies that will help them accomplish this goal, they may take the opportunity to teach themselves. Yet caregivers are not always included in person-centered rehabilitation. They may have reservations about requesting additional information from healthcare providers (Eames et al. 2010) and they may be overwhelmed or uncertain about what to ask. Halle et al. (2014) found that when speech-language pathologists invite caregivers to attend therapy sessions, they seldom use this time for specific communication strategies or training. In this respect, the therapist is missing a valuable opportunity to assess communication between the caregiver and the person with aphasia and to provide training and support as communication issues arise. The caregiver may then assume the role of therapist at home without adequate understanding of the best way to facilitate communication.

Caregivers must maintain a careful balance when acting as a therapist for people with aphasia. Gillepsie, Murphy, and Place (2010) interviewed caregivers and people with aphasia and found that caregivers often rated the person with aphasia as being more in favor of being spoken for than he or she actually was. Being included in therapy sessions as an active participant offers a teachable moment for the caregiver. For instance, the speech-language pathologist can use this opportunity to provide the strategies caregivers desire so they can conserve their relationship with the person with aphasia. Additionally, they can continue to encourage therapy progress at home while also respecting the person with aphasia's autonomy. An added benefit may be that the caregiver becomes a more collaborative partner with both the person with aphasia and the therapist, mitigating some of the burden caregivers feel at having to "lead the charge" during rehabilitation.

Notably, people with aphasia mostly described caregivers as motivators while the healthcare professionals focused more on how they dealt with the practical side of rehabilitation. Gillepsie et al. (2010) found that people with aphasia often rated themselves as being more independent than caregivers saw them, which parallels the theme of caregivers acting as guardians or motivators. If caregivers perceive people with aphasia as being less independent, this may also explain why they feel the need to assume the multiple roles they do. Because we did not specifically address this with caregivers, this requires further exploration and study.

The disparity in perspective between the healthcare professionals and the caregivers was especially interesting. The healthcare professionals often described caregivers as having to handle practical issues such as insurance, appointment scheduling and balancing work responsibilities. Perceiving caregivers as primarily dealing with the practical side of rehabilitation neglects to consider them as active partners in recovery (Creasy et al. 2013). Caregivers provide a vital economic benefit to the healthcare system by allowing stroke survivors to spend less time in the hospital and more time at home (Winkler et al. 2014). Still, neurorehabiliation in the United States has done little to address the needs of caregivers, who are often overwhelmed with such a sudden role shift. If the healthcare system provided more of what caregivers have repeatedly expressed they need and want such as training, education and support, it is possible that caregivers would feel less compelled to wear so many extra hats during the recovery process.

Limitations

The range of time post-stroke for people with aphasia who participated was 5–144 months, indicating that one limitation of our study is that all persons with aphasia (n=22) and caregivers (n=7) were in the chronic phase of recovery. This suggests that they were navigating longer-term adjustment to living with the person with aphasia. It is likely that the feedback would be different in other stages of the recovery journey. We know that caregivers adapt to each new stage as the person with aphasia recovers and each adjusts to life with the disorder (Cameron et al. 2013).

Feedback from caregivers and people with aphasia who do not currently participate in a support group would provide a valuable perspective on how caregiver roles may change in relation to outside support. Additional study is needed to determine how the roles caregivers adopt during recovery change depending on other factors such as relationship between the caregiver and the person with aphasia and the role each had prior to the aphasia diagnosis.

Moving forward

This paper describes how different stakeholders in the recovery process may perceive caregivers as they navigate rehabilitation for the person with aphasia. A better understanding of the many roles caregivers adopt throughout recovery, as well as the reasons they adopt them, are important first steps to improve rehabilitation outcomes for both people with aphasia and their caregivers. Providing education, communication training, and resources throughout the recovery process may help to improve quality of life for both the caregiver and the person with aphasia.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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What is already known:

Up to 40% of stroke survivors in the United States have chronic aphasia after stroke and require long-term caregiver assistance.

Caregivers assume diverse roles as they help people with aphasia access rehabilitation care and navigate the recovery journey.

What this study adds:

This study provides a unique depiction of caregivers navigating rehabilitation care for people with aphasia through the multi-lens perspective of healthcare professionals, people with aphasia, and caregivers themselves.

Examining caregiver roles and how different stakeholders in the rehabilitative journey perceive these roles may be the first step in providing more tailored support to caregivers and improving outcomes for both caregivers and people with aphasia.

Clinical implications:

Providing caregivers with the training and support they need throughout the recovery journey by treating them as partners in the process may mitigate the perception of caregivers as feeling compelled to adopt multiple roles, potentially reducing caregiver burden.

Table 1

Participant Demographics

	Stroke Survivor	**Caregiver**	**Healthcare Provider**
	(N=22)	**(N=7)**	**(N=7)**
Race			
White	13	6	7
Black	6	1	0
Asian	2	0	0
Other	1	0	0
Sex			
Male	14	1	1
Female	8	6	6
Age *(in years, mean and range)*	58 (43–92)	60 (45–83)	42 (32–55)
Time Since Stroke *(in months, mean, range)*	36 (5–144)	NA	NA
Highest Education			
High School	5	2	0
2-year Degree	1	1	1
4-year Degree	9	3	1
Adv. Degree	7	1	5

Table 2

Coding Process Examples

Quote	Initial Codes	Final Code	Theme
"Our family is widespread…They were able to find a couple of people that were willing to work with us until the outpatient therapy was able to get us in with their speech therapist."	Instrumental for advocacy, implementation, caregiving; caregivers as advocates	Caregivers as advocates	Family/Caregivers serve as advocates for stroke survivors with aphasia
"I want to work, I want to go to work again, I want this one. And so they were talking like okay every day let's try this sentence and do it again and do it again. And so I went two days therapy and my sister on Thursday, Friday -- not Friday, Saturday at my sister's house for two hours my sister would, you got it, you got it, and I do it now."	Family pushes and encourages; caregivers as cheerleaders; caregiver support	Family/caregiver as motivator	Family/Caregivers serve as motivators during the rehabilitative process

Table 3

Themes

Themes	Subthemes
Caregivers as advocates	Advocating for timely access to care
	Advocating for education regarding the stroke and diagnosis of aphasia
	Advocating for information regarding prognosis of recovery
	Advocating for guidance from the health care system
	Advocating for therapist engagement
Caregivers as therapists	Acting as therapist to mitigate gap in therapy services
	Acting as therapist to facilitate recovery
	Acting as therapist to encourage meaningful therapy tasks
	Acting as therapist to address dissatisfaction with formal therapy progress
Caregivers as motivators	Motivating people with aphasia to complete therapy homework
	Motivating people with aphasia to continue rehabilitation despite frustration
	Motivating people with aphasia to push past their comfort zones
	Motivating peole with aphasia to seek relevance in their therapy activities
Caregivers as guardians	Taking the burden of care coordination from people with aphasia
	Shielding people with aphasia from the stress of dealing with financial worries
	Allowing people with aphasia to focus their energy on therapy to facilitate rehabilitative progress