



# Perceptions of Communication and Mobility Recovery Among Stroke Survivors With and Without Aphasia

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**ABSTRACT:** Self-perceived recovery after stroke can substantially impact quality of life. Yet, a disability paradox exists whereby disability and perceived recovery do not align. This study explored stroke survivors' perceptions of their communication and mobility recovery, including perceived facilitators and barriers. Potential differences between the experiences of participants with aphasia (PWA) and participants without aphasia (PWOA) were also examined to explore the impact of communication disability on recovery experience. Semi-structured interviews were conducted with 17 adults with stroke 3 months after discharge from inpatient rehabilitation. Qualitative data in the form of interview transcripts were analyzed using thematic content analysis. Participants described their communication recovery primarily in terms of word-finding difficulty and slowed language formulation; they described their mobility recovery in terms of their ability to walk, their use of an assistive device, or their ability to participate in pre-stroke activities. Facilitators to recovery were described in the areas of (1) family involvement, (2) rehabilitation services and professionals, (3) personal factors, and (4) the need for self-reliance. Barriers were expressed in the domains of (1) physical difficulties, (2) communication difficulties, and (3) psychological difficulties. Key findings from this study include perceived needs for a high intensity of rehabilitation, earlier implementation of communication partner training for families of stroke survivors with communication impairments, and consideration of factors outside of stroke when tailoring intervention to the individual. Overall, these findings suggest a continued need for individualization rather than standardization of care, with an eye to both impairment and broader quality of life factors.

**KEYWORDS:** Stroke, aphasia, mobility, recovery perceptions

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## Introduction

It is widely accepted that the opinions of healthcare consumers are needed to evaluate whether interventions have had clinically important outcomes.<sup>1</sup> After stroke, patient perceptions of abilities and impairments may often not align with clinician ratings or measurements of function and impairment.<sup>2,3</sup> Indeed, previous research has found evidence of a “disability paradox,” where some stroke survivors with significant disability give a positive self-report of health while survivors with mild impairments report negative perceptions when self-reporting their health.<sup>4</sup> This is important because self-perceived recovery after stroke can substantially impact quality of life.

Self-perceptions of physical recovery<sup>3</sup> and overall recovery<sup>2</sup> can affect activity level and self-reported life role participation in adults 6 months post stroke. Further, poor perceived recovery is associated with lower adherence to home-based exercise programs, and contributes to depression, low self-esteem, frustration, lack of hope, and lack of motivation.<sup>5</sup> The potential for a substantial negative cascade of symptoms associated with poor perceived recovery warrants further investigation into factors that influence individuals' perceptions of their recovery following stroke.

Perceived recovery after stroke is often measured using the Stroke Impact Scale (SIS), which is a self-report 59-item questionnaire comprising 8 domains (strength, hand function, activities of daily living [ADL] including instrumental ADL,

mobility, communication, emotion, memory and thinking, and participation/role function). Overall perceived recovery on the SIS is evaluated using a visual analogue scale on a vertical line ranging from 0 (bottom, no recovery) to 100 (top, full recovery), which is frequently used to quantify patient-perceived recovery.<sup>2,6-9</sup> Despite its popularity, the SIS is limited in its ability to capture the nuances in the complex experience of stroke recovery. Thus, examining perceptions of recovery after stroke requires the investment of qualitative research that allows individuals to describe their experiences in their own words and in the context of their unique set of circumstances.

In the current study, perceived recovery was explored using semi-structured interviews. The semi-structured interview format centered stroke patients' voices while guiding them to reflect on and explain their experiences of recovery. The questions in the interview guide were designed to encourage participants to report their experiences of communication and mobility recovery using their own vocabulary for recovery and to share perspectives that may not be captured using surveys or quantitative self-reported measures such as the SIS.

In order to learn about the experiences of a diverse and inclusive population of stroke survivors, people with aphasia (PWA) and individuals with cognitive-linguistic deficits were included. PWA have often been excluded from stroke research due to assumptions that they cannot make decisions for themselves<sup>10</sup>; however, PWA can and should be permitted to



participate in self-report measures when given appropriate communication supports.<sup>11</sup>

The aims of this exploratory qualitative study were to (1) explore patient perceptions of recovery following stroke, including perceived facilitators and barriers, with a focus on mobility and communication domains of recovery, 3 months after inpatient rehabilitation discharge to home; and (2) compare patient perceptions of recovery for participants with and without aphasia, to explore the impact of communication on the recovery experience, 3 months after inpatient rehabilitation discharge to home.

## Methods

### *Design*

This was a longitudinal observational study that involved a comprehensive evaluation of cognitive-communication and mobility 1 to 3 days prior to discharge home the hospital, and a semi-structured interview 3 months after discharge from the hospital. Seventeen participants completed the 3-month follow-up interview, which was sufficient to achieve saturation of data. Ethical approval for the study was obtained from the local Institutional Review Board (IRB Approval #2020P003506). All participants provided written informed consent prior to enrollment in the study. Given that the study specifically included stroke survivors with aphasia and/or cognitive-linguistic deficits, both the patient and his or her family member(s) were invited to discuss the study with a certified speech-language pathologist with expertise in aphasia and cognitive-linguistic deficits. Extra care was taken to ensure that subjects understood the nature of the study. This included using written and verbal communication modalities and providing additional time for questions. Capacity for consent was assessed by demonstrated comprehension of the following: (a) that participation was voluntary; (b) the major study procedures; and (c) the risks of the study. Demonstrated comprehension included being able to verbally express key words or pointing to pictures and indicating agreement with study procedures using gesture or paired verbal and gestural communication. Individuals with aphasia are considered capable of making informed decisions and providing consent as indicated in the National Aphasia Association Bill of Rights.<sup>12</sup> Therefore, while family members were present when study procedures were explained, individuals with aphasia had the opportunity to provide or decline their informed consent. Potential participants were also informed that their participation was voluntary and that they could withdraw from the study at any time.

### *Participants*

Prospective participants were screened via the electronic health record and eligible participants were invited to participate. Eligible participants must have experienced a stroke (any type

in any brain region), have been admitted for inpatient rehabilitation for primary diagnosis of stroke and have had a discharge destination of home. Additional inclusion criteria were 18 years of age or older, able to understand verbal and written English, able to walk without constant physical assistance of another person to support body weight or advance the more affected limb (walking aid permitted), and able to follow single-step commands given verbally with or without visual cues in order to complete the study assessments. Participants were not excluded if they had experienced a prior stroke, provided there was no residual disability by self-report, caregiver report, or medical documentation. Participants were also required to report no pre-stroke disability related to other neurologic diagnoses or pre-stroke fall history, which was verified via health record review. Individuals with a diagnosis of dementia were not eligible.

### *Semi-structured interviews*

The semi-structured interviews were completed as close as possible to the participants' 3-month routine medical follow-up. If participants were unable to return in-person for their 3-month follow-up, they were given the option to participate in the interview remotely via institutional-supported secure virtual visit or for study staff to travel to the participants' homes. The interview guide included questions related to participants' perceived physical and cognitive-communication recovery (Table 1). The interviews lasted approximately 45 minutes and were audio-recorded. Interviews for participants with aphasia were completed by a certified SLP with expertise in aphasia and cognitive-communication deficits (the same study staff member who completed informed consent procedures for these participants). Study staff made field notes on non-verbal communication and other relevant information that did not appear in the audio recordings.

### *Data analysis*

Audio recordings were transcribed verbatim. Identifying statements and names were removed. The data were analyzed using thematic content analysis, drawing on analysis procedures described in Nowell et al<sup>13</sup> to ensure rigor. It should be noted that all interviewers were rehabilitation professionals and that many of the participant interviews took place at the inpatient rehabilitation hospital where all participants received their care.

All authors read the first 3 transcripts and met to discuss coding themes. Each subsequent transcript was read by at least 2 of the authors. The data were organized using a matrix to aid the authors in identifying themes.<sup>14</sup> An audit trail was constructed to provide evidence of the processes by which the researchers reached conclusions from the transcripts. All quotes presented in the results section are documented with the participant number from which the quote was taken.

**Table 1.** Structured interview guide.

STRUCTURED INTERVIEW GUIDE	
Recovery amount	How much do you feel you've recovered in your communication?
	How much do you feel you've recovered in your physical performance?
Change	What has changed that makes you feel you've recovered?
	What has not changed that you still want to improve?
Difficulty	What is most difficult for you in your communication?
	What is most difficult for you in your physical performance?
Recovery patterns	What has helped your recovery the most?
	What has made your recovery the most difficult?
Rehabilitation and recovery	What do you wish you had worked on during your inpatient rehabilitation stay that would help you at home?
	What would have to change for you to feel that you have recovered from your stroke?

Trustworthiness of the data have been ensured using the criteria of dependability, credibility, transferability, and confirmability, as described in Nowell et al<sup>13</sup> and Plummer<sup>15</sup> based on Lincoln and Guba's<sup>16</sup> original definitions. Dependability and confirmability were ensured with the audit trail discussed above, as the audit trail provides a method for other researchers or readers to follow the analysis and independently confirm conclusions drawn from the data.<sup>15</sup> Confirmability has been enhanced through disclosure of the authors' background (including identity, credentials, occupation, gender, experience, and training) to allow readers to determine for themselves how the authors' biases—conscious or unconscious—may affect the data analysis.<sup>15,17</sup> Credibility was addressed through the process of having multiple raters review and code the transcripts to ensure that the findings truly represent the views the participants expressed in the interviews. Finally, transferability has been addressed by providing rich descriptions of the data and the participant characteristics so that readers can draw conclusions about whether the study results can apply to other contexts relevant to the reader.<sup>13,15</sup>

## Results

### *Description of participants*

Participant characteristics are summarized in Table 2. Of the 17 total participants, 7 participants (41%) had a diagnosis of aphasia at discharge from inpatient rehabilitation. All participants with aphasia had experienced a left hemisphere stroke. Of those without aphasia, 6 had a right hemisphere stroke and 1 had a stroke involving both hemispheres. Of those remaining, 1 had a cerebellar stroke, 1 had a stroke involving the cerebellum and bilateral posterior cerebral arteries, and 1 had a brainstem (medullary) stroke. The mean age of study participants was 66 years (SD=16). There was no significant difference between average age of PWOA and PWA; however, the variance in age was much larger in PWOA (SD 20 years) than PWA (SD 8 years).

The average total hospital length of stay (LOS), including acute care and acute inpatient rehabilitation, was 27 days (SD=9). There was no significant difference between average LOS for PWA and PWOA. The median time from discharge to 3-month follow-up interview was 105 days (approximately 3.5 months). Eleven interviews were conducted in-person, 2 were conducted using teleconferencing software (1 PWA and 1 PWOA), and 4 were conducted over the phone (all PWOA).

### *Perceptions of communication recovery*

When considering the amount of communication recovery since discharge, many PWOA perceived that they had completely recovered in the communication domain, or that they never had experienced any communication deficits to begin with. For example,

*"My communication, I don't feel, was really that impaired to begin with." (PWOA05)*

*"100% [recovered] in communication" (PWOA09)*

Of the few PWOA who perceived some residual communication deficits, it was "remembering, mainly" (PWOA18) or difficulties expressing themselves, such as:

*"Sometimes I want to say something and it doesn't come out." (PWOA24)*

*"I have to think about what, what is the best word to describe (laughs) . . . So, uh, sometimes, sometimes I, I find it- it's not come out quite right." (PWOA08)*

Of note, 2 of these participants were under the age of 40 years. It is possible that these younger participants perceived more residual communication deficits than most others without aphasia because their expectations and requirements for communicating differed from older participants, especially after returning to full time employment.

Table 2. Participant characteristics and stroke information.

PARTICIPANT ID	AGE (YEARS)	SEX	TOTAL LOS (DAYS)	STROKE TYPE	STROKE REGION	SPEECH-LANGUAGE PATHOLOGY DISCHARGE DIAGNOSES			
						COGNITIVE-LINGUISTIC	APHASIA	MOTOR SPEECH	DYSPHAGIA
PWOA01	75	M	28	Hemorrhagic	Right frontal IPH	Mild	-	-	-
PWOA03	70	M	18	Thromboembolic	Right MCA	Mild	-	Mild flaccid dysarthria	Mild oropharyngeal dysphagia
PWOA05	76	F	22	Thromboembolic	Right internal capsule, lentiform nucleus, and corona radiata	Resolved, WFL Initially trace	-	-	-
PWOA08	61	F	21	Thromboembolic	Right cerebellar	Trace-mild	-	Trace ataxic dysarthria	-
PWOA09	75	F	32	Thromboembolic	Right MCA	Mild-moderate	-	-	Mild-moderate oropharyngeal dysphagia
PWOA11	67	M	20	Thromboembolic	Left medullary	Resolved, WFL Initially Trace	-	-	-
PWOA12	25	F	16	Hemorrhagic	Bilateral occipital IPH	Mild	-	-	-
PWOA18	92	F	24	Thromboembolic	Right cerebellar Left PCA, Right PCA	Moderate-severe	-	-	-
PWOA24	39	F	32	Thromboembolic	Right ACA	Mild-moderate	-	-	-
PWOA26	52	M	50	Hemorrhagic	Right basal ganglia hemorrhage	Mild	-	-	-
PWA06	74	M	28	Thromboembolic	Left MCA	Mild-moderate	Severe Broca's	Moderate verbal apraxia; Mild-moderate dysphonia	Mild oral dysphagia
PWA13	70	F	30	Thromboembolic with hemorrhagic transformation	Left MCA; hemorrhagic transformation with associated midline shift	-	Mild-moderate fluent	-	-
PWA15	82	M	18	Hemorrhagic	Left frontal IPH	-	Severe Broca's	Moderate verbal apraxia	Mild oropharyngeal dysphagia
PWA16	75	F	40	Thromboembolic	Left ACA/MCA	-	Moderate non-fluent	-	Mild oropharyngeal dysphagia
PWA17	56	M	18	Thromboembolic	Left MCA	-	Mild-moderate Broca's	-	-
PWA25	64	M	31	Thromboembolic with hemorrhagic transformation	Left MCA with subsequent SAH	-	Mild-moderate anomic	-	-
PWA27	73	M	25	Hemorrhagic	Left thalamic IPH	Mild-moderate	Mild-moderate anomic	-	-

Abbreviations: ACA, Anterior cerebral artery; IHP, Intraparenchymal hemorrhage; MCA, middle cerebral artery; PCA, posterior cerebral artery; SAH, Subarachnoid hemorrhage; WFL, within functional limits.

Not surprisingly, PWA perceived significant residual deficits in the communication domain, especially related to deficits in word-finding and verbal expression:

*“ . . . sometimes I get stuck on a word.” (PWA15)*

*“ . . . like now, I'm trying to get these words out. I can, I can see them and say them, but I just can't get them out.” (PWA25)*

Several PWA and PWOA also referenced needing more time than before their strokes to adequately express themselves verbally. As 1 PWOA described, *“Sometimes I, I feel a little bit st. . . uh, frustrated or, . . . it's a little bit difficult to express myself.” (PWOA08)*

Several PWA and PWOA also had diagnoses of dysarthria or apraxia of speech; however, it appeared that most participants considered speech and language together when thinking about communication, as their comments rarely differentiated between these areas.

### *Perceptions of physical recovery*

When considering the amount of physical recovery since discharge, many of the participants related the extent of their recovery to their ability to walk, some specifically mentioning the ability to negotiate stairs or their need, or lack thereof, for an assistive device. For example:

*“I'll give you 90 percent (recovered) because I can still walk.” (PWA06)*

*“I can walk around the world, but two flights of stairs, I'm done. I can't do two flights.” (PWA25)*

*“I mean, I have a cane in case I need it, but I don't need it. I can walk around without it, I can walk.” (PWOA09)*

Indeed, participants frequently described improvements in walking and balance since hospital discharge as 2 critical factors influencing perception of their physical recovery. As exemplified by these excerpts:

*“I can stand up without falling down. . . I can walk, uh, great distances, 'cause even when you got me walking with the walker (in the hospital), I always, I had a limited shelf life.” (PWOA11)*

*“I left the hospital with a walker. And now I don't use it.” (PWOA24)*

Others perceived their physical recovery related to everyday functional activities or their ability to participate in specific pre-stroke leisure or work activities:

*“I'm probably operating about 75 percent, really, 'cause, 'cause, I- I- I want to go back to playing pool, but I don't think I can right now, because I'm not balanced enough.” (PWA15)*

*“I couldn't do what I did before my stroke, like carrying my ladder that weighs like 25 pounds, and I would go up and up in the ladder and do my gutters.” (PWOA09)*

Others commented that recovery was related to “energy level” (PWA27), stamina, strength, and endurance, “gaining more independence” and “more confidence in myself” (PWOA12) and not struggling “with the most basic living, daily living activities” (PWOA26). For some, not yet being able to drive was a key gap in their present recovery:

*“I want to drive, and I can't drive right now.” (PWOA24)*

*“I cannot (drive). Yeah, if I can do the car, I think I'll be okay.” (PWA13)*

Very few participants mentioned upper limb function when considering their physical recovery.

### *Perceived facilitators to recovery*

Perceived facilitators to recovery included family involvement, rehabilitation services and professionals, personal factors, and the need to be independent with routine daily activities and household management (eg, for participants who lived alone post-discharge).

Participants frequently reported that spending time with or talking to family was a facilitator to recovery:

*“I would say, uh, getting home, uh, being- being back in the middle of my relationship [with my wife].” (PWOA01)*

*“Being with my family.” (PWOA09)*

*“And my grandchildren, the. . . I have two daughter, uh.....And they would stay with me and they. . . we'd talk all the time. And so it was good. So- So the family's pretty- pretty important.” (PWA15)*

In addition to spending time with family, participants expressed the importance of their family members' roles as caregivers as facilitators to recovery:

*“Uh, my wife don't let me eat a lot of things I used to eat. So that's, that's pretty good. And, um, and just keeps, keep me going and I'm fine, you know?” (PWA25)*

*“And so now my son is that's acting as my personal nurse at home. You know, he fix me food. He. . . when I go to the bathroom he watches me and he st- st- stand by the. . . by the door. You know, just making sure that I don't fall. . . You know, all the thing that the therapist used to do.” (PWA27)*

*“Like, the- the girls, they. . . I mean, they've been unbelievable.... They take me to this and that and do this and makes gravy then sends us food . . .” (PWA15)*

Many PWA and PWOA mentioned rehabilitation services as a facilitator to recovery. Several specifically mentioned their inpatient rehabilitation experiences:

*“I mean, the care that I received here (at the hospital) was fantastic. . .” (PWA27)*



*"I definitely think that my time at (the rehabilitation hospital) was pivotal to my ability to go back to work." (PWOA12)*

*"I think (the rehabilitation hospital) was, was wonderful. It was r-, it was really good, and they definitely, I definitely got stretched." (PWOA26)*

Ongoing rehabilitation provided via outpatient therapy services and home health services after discharge were also considered an important facilitator of recovery by many.

It was apparent that characteristics of the therapists were important facilitators of perceived recovery. In particular, participants appreciated being pushed to their limits by their therapy team, as 1 participant described, "(My OT) was kind of like a drill sergeant" (PWOA26). Another participant described her speech therapist as "tough cookies" and that she thought this was the "number 1" factor in her recovery (PWA16). Patience of the therapist was also highly valued. For example, when discussing re-learning to walk after her stroke, PWOA24 stated that she felt that "all the therapies I got" and "all the patience that they had too" were what helped her to recover her abilities more quickly. PWA17 also expressed that "Everybody's been wonderful and patient with, um, me."

Participants recognized that their own characteristics matter too. For example, several participants mentioned internal factors such as determination, a competitive nature, and trying their best as facilitators to recovery:

*"Um, and bless, I'm determined. From the very beginning, I was determined. . ." (PWOA05)*

*"Also the way I am, I'm, uh, I'm competitive and I s- I, I don't, like, um, one of the therapists said, um, some people will say, like, um, "I can't do that 'cause I had a stroke." That will never come out of my mouth. I'm right that I can't do that, but I'll keep trying until I can do it. . . That's the way I am, I push myself." (PWOA09)*

Less commonly expressed factors for facilitating recovery were religious faith and the need to be independent because they lived alone.

### *Perceived barriers to recovery*

Participants expressed a range of barriers to recovery. The most commonly mentioned barriers were communication difficulties, physical difficulties, and psychological difficulties. Several participants expressed perceiving no major barriers to their recovery.

It is worth noting that we observed that several participants appeared to have difficulty comprehending this question or expressing their response.

Several PWA and others with motor speech disorders reported that their largest or only barrier was their communication, particularly their expressive language or speech, saying things such as, "No barriers, just the speaking" (PWA15).

Several participants referenced physical difficulties as the most significant barriers to their recovery; however, the physical challenges they noted were not all directly related to their stroke. For example, 1 PWA stated that the largest barrier was "horrendous" pain in her hands and arms (PWA16), which predated her stroke and has prevented her from lifting "anything" and completing her ADLs independently. Another participant described injuring his "good hand" (PWOA26) due to a fall upon leaving the hospital, and that "not having 2 hands" was a "real drag" during his recovery.

Mental or psychological aspects of recovery were the largest barriers for others. For example:

*"I think, uh, the- the part that makes it difficult for me is that I don't understand, uh, what happened and why it happened. . . Why- why am I able to talk like this, and (wife's) dad had to struggle?" (PWOA01)*

*"Um, I don't think there's been any major barriers to success. I think a lot of it is just re-acclimating to this, like, new life that I have." (PWOA12)*

### *Additional thoughts on recovery*

Many participants acknowledged that recovery takes time:

*"I'm getting better. I'm getting better. It'll take some time." (PWOA03)*

*"It was a s- It was a slow recovery, but it was a good recovery" (PWA25)*

*"It's gonna be slow, probably slow, slower than you'd like." (PWOA05)*

And that it requires active effort on their part:

*"I mean, like exercise. I mean, you have to. . . it might not. . . it might not be, uh. . . I mean. . . I mean as fit as you, you want right away." (PWOA08)*

*"You got to keep yourself going 'cause you can't just sit around and work on it." (PWA25)*

Finally, a recurring idea amongst participants was the perspective of being fortunate to not be worse off, in comparing themselves to others who have experienced strokes or other injury. For example:

*"Well, there's hope. . . you know, you see a lot of things when you down the sports gym here (at the rehabilitation hospital). You know, you see people that got no legs, no arms, and they're doing everything. And I'm saying, 'Wow,' and I'm- I'm being a pain in the ass with a... with a stroke." (PWA15)*

## **Discussion**

This study explored patient perceptions of post-stroke recovery in the first 3 months after discharge home from inpatient rehabilitation, especially related to recovery of communication skills and mobility, in people with and without aphasia. We also

explored patient perceptions of the facilitators and barriers to their recovery. Perceptions of recovery in communication status, when applicable, were mostly related to word-finding and overall fluency of communication. The overwhelming factor considered by the participants in terms of physical recovery was the ability to walk, and whether they had progressed from being dependent on an assistive device for walking to walking independently. Returning to previous functional physical activities was also a common way by which participants evaluated their recovery.

In terms of key facilitators of recovery, participants perceived that being challenged, whether by external or internal motivators, was an important factor. Participants shared positive views of rehabilitation therapists who pushed them to work harder and to engage in therapy exercises. Participants also perceived that their own internal competitiveness, determination, and “trying their best” were facilitators to their recovery. These all suggest an idea of intense, effortful rehabilitation contributing to improved perceived recovery. These ideas are consistent with previous research that found determination or “willpower”<sup>5</sup> and “self-motivation” to be facilitators of improved outcomes.<sup>18</sup> In light of this, it has been suggested that rehabilitation approaches that include concepts of self-efficacy (belief in one’s abilities) and motivation may enhance patient autonomy and participation during the recovery process, thus optimizing patient outcomes post-stroke.<sup>19</sup> The results of the current study corroborate these findings about the impact of internal motivation on recovery, while also further suggesting that rehabilitation professionals should provide challenge and intensity in their intervention approaches. However, it is important to note that patience shown by rehabilitation providers was also highly valued. While the ideas of patience and challenge may co-exist, the comments regarding the value of patience by the treating therapists also reinforces the need to individualize one’s demeanor and level of rehabilitation intensity to a patient’s preferences. Thus, the findings from the current study support the idea of individualization of care while highlighting that many patients consider intensity and challenge to be a motivating and influential aspect of rehabilitation.

Another key facilitator was spending time with family and being cared for by family. This extent of involvement of family in participants’ recovery experiences reinforces the importance of including communication partner training (CPT) as a component of early rehabilitation. Family members are often the primary communication partners of stroke survivors who are discharged home after inpatient rehabilitation, suggesting that CPT should be implemented prior to inpatient discharge to lay the foundation for positive communication experiences for stroke survivors upon transitioning home. CPT for family members has been well-studied in stroke survivors with chronic aphasia, with positive outcomes reported across many studies<sup>20</sup>; however, further high-quality research is needed on the use of

CPT with families of stroke patients with acute aphasia (ie, earlier implementation of CPT), as well for patients with other communication deficits, including cognitive-communication deficits and motor speech deficits. Earlier implementation of CPT could also address the finding that participants with and without aphasia perceive expressive communication to take more time than it did pre-stroke. Implementing CPT consistently and earlier in rehabilitation would support patients’ communication partners in adapting to this change in their communication needs and approach post-stroke.

There were no major differences between PWA and PWOA regarding perceptions of recovery status or facilitators, but there were some differences—perhaps not unexpected—in perceived barriers to recovery based on speech and communication diagnosis at discharge. In particular, participants with motor-speech diagnoses, regardless of aphasia diagnosis, mentioned communication as a primary or sole barrier to recovery, whereas participants who had cognitive-linguistic diagnoses *without* any speech diagnosis did not mention communication challenges as a barrier to recovery. Recent studies have demonstrated the negative impact that post-stroke communication disability can have on quality of life and recovery from stroke. For example, Thayabaranathan et al<sup>21</sup> reported that stroke survivors who identified as having a communication disability more often reported moderate to severe problems in the domains of “anxiety or depression,” “pain or discomfort,” “self-care,” “usual activity,” and “mobility,” and experienced poorer cognition and lower social participation, as reported 3 to 6 months post-stroke.<sup>21</sup> Stroke survivors with aphasia have also been shown to have higher odds of death than people without aphasia, and overall greater disability.<sup>22</sup> The current study broadens the existing literature by highlighting that communication ability is not only a skill that patients seek to recover but may itself be a barrier to this recovery.

### Limitations

There were some challenges conducting semi-structured interviews with PWA.

Efforts were made to use multi-modal communication supports (eg, writing tools for patient and interviewer, gestures, and tablet) and to have a family member available during virtual interviews to further facilitate communication; however, interviews with PWA were found to be more limited in content than interviews with PWOA. To some extent, this limitation is inherent when including PWA in studies involving communication due to the nature of their language deficits; however, learning about the experiences of PWA to the best of researchers’ capabilities is essential. This limitation could be reduced in future studies by allowing for extended time to interview PWA, potentially across multiple sessions, as well as designing virtual communication supports or prioritizing in-person interviews with PWA. Recording interviews in a manner that captures the use of written output, drawings, and/or

other AAC methods should also be explored to maximize the contributions of PWA.

Although we have tried to discern thematic differences between PWA and PWOA, defining subgroups is complicated by the multifactorial nature of communication disability. Some PWOA had significant cognitive-linguistic deficits, and both PWA and PWOA additionally had motor speech and/or dysphagia diagnoses, thus the simple sub-group comparison between PWA and PWOA could not capture all nuances of the different experiences that participants may have had of their communication recovery and global recovery. Given the frequent coexistence of aphasia and speech diagnoses, it would be difficult to disentangle their effects on patients' perceived recovery; however, it could be fruitful in future work to examine the effects of language- and speech-related communication deficits in contrast to cognition-related communication deficits alone. Nonetheless, a major strength of this study was the inclusion of stroke survivors with and without aphasia.

## Conclusion

This study has reinforced the need to consider patient perspectives when developing rehabilitation programs across post-acute services, including from the individual provider's plan of care through systems-level shifts in policy and practice patterns. The perspectives that participants shared in this study support the use of patient-centered services. These services should consider patients' internal and external motivation sources, seek to improve communication with family and caregivers, and respect patients' whole selves.

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## Author Contributions

MES and PP conceptualized and designed the study, recruited and enrolled the participants, and shared responsibility for all study procedures. All authors contributed to the collection of clinical data, conducted participant interviews, and performed the qualitative analyses. RMS wrote the first draft of the manuscript. All authors provided editing and approved the submitted version of the manuscript.

## Data Availability

The data that support the findings of this study are available from the corresponding author on reasonable request.

## Ethical Committee Approval

Ethical approval was obtained from the Mass General Brigham (MGB) Institutional Review Board (IRB Approval #2020P003506). All participants provided written informed

consent prior to enrollment in the study. Given that the study specifically included stroke survivors with aphasia (a language impairment that may impact comprehension abilities) and/or cognitive-communication deficits, both the patient and his or her family member(s) were invited to discuss the study with a certified speech-language pathologist with expertise in aphasia and cognitive-communication deficits. Extra care was taken to ensure that subjects understood the nature of the study. This included using written and verbal communication modalities and providing additional time for questions. Capacity for consent was assessed by demonstrated comprehension of the following: (a) that participation was voluntary; (b) the major study procedures; and (c) the risks of the study. Demonstrated comprehension included being able to verbally express key words or pointing to pictures and indicating agreement with study procedures using gesture or paired verbal and gestural communication. Individuals with aphasia are considered capable of making informed decisions and providing consent as indicated in the National Aphasia Association Bill of Rights.<sup>12</sup> Therefore, while family members were present when study procedures were explained, individuals with aphasia had the opportunity to provide or decline their informed consent. Potential participants were also informed that their participation was voluntary and that they could withdraw from the study at any time.

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