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Research Report

‘Emotion is of the essence. ... Number one priority’: A nested qualitative study exploring psychosocial adjustment to stroke and aphasia

Becky Moss†, Sarah Northcott†‡, Nicholas Behn†, Katie Monnelly†, Jane Marshall†, Shirley Thomas§, Alan Simpson¶, Kimberley Goldsmith||, Sally McVicker†#, Chris Flood** and Katerina Hilari† 

†Centre for Language and Communication Science Research, School of Health Sciences, City, University of London, London, UK

‡School of Health Sciences, University of East Anglia, Norwich, UK

§Division of Rehabilitation and Ageing, School of Medicine, University of Nottingham, Nottingham, UK

¶Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care and Health Service and Population Research, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

||Biostatistics Department, Division of Psychology and Systems Sciences, Institute of Psychiatry, Psychology & Neuroscience, King's College London, London, UK

#Aphasia Re-Connect, London, UK

**School of Health and Social Care, London South Bank University, London, UK

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Abstract

Background: Stroke and aphasia can have a profound impact on people's lives, and depression is a common, frequently persistent consequence. Social networks also suffer, with poor social support associated with worse recovery. It is essential to support psychosocial well-being post-stroke, and examine which factors facilitate successful adjustment to living with aphasia.

Aims: In the context of a feasibility randomized controlled trial of peer-befriending (SUPERB), this qualitative study explores adjustment for people with aphasia in the post-acute phase of recovery, a phase often neglected in previous research.

Methods & Procedures: Semi-structured interviews were conducted with 20 people with aphasia and 10 significant others, who were purposively sampled from the wider group of 56 people with aphasia and 48 significant others. Interviews took place in participants' homes; they were analysed using framework analysis.

Outcomes & Results: Participants with aphasia were 10 women and 10 men; their median (interquartile range—IQR) age was 70 (57.5–77.0) years. Twelve participants had mild aphasia, eight moderate–severe aphasia. Significant others were six women and four men with a median (IQR) age of 70.5 (43–79) years. They identified a range of factors that influenced adjustment to aphasia post-stroke. Some were personal resources, including mood and emotions; identity/sense of self; attitude and outlook; faith and spirituality; and moving forward. Significant others also talked about the impact of becoming carers. Other factors were external sources of support, including familial and other relationships; doctors, nurses and hospital communication; life on the ward; therapies and therapists; psychological support, stroke groups; and community and socializing.

Conclusions & Implications: To promote adjustment in the acute phase, hospital staff should prioritize the humanizing aspects of care provision. In the post-acute phase, clinicians play an integral role in supporting adjustment and can help by focusing on relationship-centred care, monitoring mental health, promoting quality improvement across the continuum of care and supporting advocacy.

Keywords: aphasia, stroke, post-acute, psychosocial adjustment, qualitative interviews, SUPERB study.

Address correspondence to: Katerina Hilari, Centre for Language and Communication Science Research, School of Health Sciences, City, University of London, Northampton Square, London EC1V 0HB, UK; e-mail: k.hilari@city.ac.uk

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What this paper adds

What is already known on the subject

- Anxiety and depression are common consequences of stroke, with depression rates high at 33% at 1 year post-onset. There is evidence that the psychological needs of people with aphasia are even greater than those of the general stroke population. Social support and social networks are also negatively impacted. Few studies have examined adjustment when people are still in hospital or in the early stages of post-stroke life in the community (< 6 months). Further, many stroke studies exclude people with aphasia.

What this paper adds to existing knowledge

- Adjustment to living with stroke and aphasia begins in the early stages of recovery. While this partly depends on personal resources, many factors depend on external sources of help and support. These include doctors, nurses and hospital communication, their experience of life on the ward, and their therapists' person-centred care.

What are the potential or actual clinical implications of this work?

- Clinicians play an integral role in facilitating people with aphasia to utilize their personal resources and support systems to adjust to life after stroke. They can help by focusing on relationship-centred care, monitoring mental health, promoting quality improvement across the continuum of care and supporting advocacy.

Introduction

Stroke and aphasia can have a profound impact on people's lives. Anxiety and depression are common consequences of stroke, with depression rates remaining high at 33% 1 year post-onset (Hackett and Pickles 2014). Depression is associated with worse rehabilitation outcomes (Pohjasvaara *et al.* 2001), greater carer strain, increased healthcare utilization (Ghose *et al.* 2005) and higher mortality (Ayerbe *et al.* 2013). There is evidence that the psychological needs of people with aphasia are even greater than those of the general stroke population. One study reported a 62% rate of depression in this group 1 year post-stroke (Kauhanen *et al.* 2000). Social support and social networks are also affected (Winkler *et al.* 2014). People with stroke and aphasia are at risk of losing contact with their wider social network, with friendships at greater risk than family relationships (Northcott and Hilari 2011), yet friendships are a critical component of living successfully with aphasia (Brown *et al.* 2013). Furthermore, poor social support is associated with worse physical recovery (Boden-Albala *et al.* 2005) and increased likelihood of a second stroke (Lincoln *et al.* 2012). Thus, there are strong social and healthcare rationales for supporting psychological well-being post-stroke and aphasia, and examining which factors facilitate successful adjustment to living with aphasia after stroke.

Adjustment to chronic disease comprises cognitive, emotional and behavioural responses (Dekker and de Groot 2018). It is defined as the psychosocial accommodation of a life-altering event or transition

(Anderson *et al.* 2002). A range of potential influences on adjusting to stroke have been cited. In the long-term post-stroke (6–36 months), a longitudinal study of 55 people and 27 significant others identified five adjustment themes: shock, disruption and fear; making sense of what happened; needing to fit in with the services offered; finding what worked for them as an individual; and evolving a new normal, whilst managing ups and downs (Theadom *et al.* 2019). Early reactions to stroke that resonated and remained in the long-term included acute shock and the persistent nature of symptoms and disruption caused by the stroke event. Adjustment was not a linear process; rather, it was re-evaluated and re-negotiated over time in response to changes in recovery, health and wider circumstances. Mumby and Whitworth (2013) interviewed a subsample of participants (three with aphasia, three without) about psychosocial adjustment in a community-based intervention for people > 1 year post-stroke. They attributed adjustment to three stages in rationalization—looking back, around and forward—and transforming negative emotional reactions into positive outcomes. A common theme of both studies was that adjustment is an ongoing, evolving process which changes over time.

In the broader stroke literature, a systematic review of 40 qualitative studies explored adjustment from stroke survivors' and carers' perspectives (Sarre *et al.* 2014). Besides physical and communicative challenges, participants reported changes in identity, and negative changes in social relationships: reduced independence, less ability to care for others and diminished friendship

contact. They conceived adjustment as having three elements: recovery of function; finding practical ways of dealing with impairment; and psychosocial recovery despite continuing impairment. Influential factors were personal characteristics; practical and mental strategies; social support; and structural issues, including healthcare experiences, welfare practices and information provision. Again, a shifting pattern over time was identified.

Studies examining adjustment when people are still in hospital or in the early stages of post-stroke life in the community (< 6 months) are lacking, and many stroke studies exclude people with aphasia. While some of Sarre *et al.*'s (2014) participants reflected on the initial impact of stroke, individuals < 6 months post-onset were excluded. However, one longitudinal study (Grohn *et al.* 2014) interviewed people with aphasia and 3, 6, 9 and 12 months post-onset, and found that the overarching influence on adjustment was a sense of actively moving forward, including engaging in activities, receiving social support and maintaining positivity. Focusing specifically on the early stage (3 months), the most important themes for living well with aphasia were a need to do things in order to be actively engaged in recovery; the importance of social support; the value of rehabilitation; a need to make adaptations and adjustments; and having a positive outlook (Grohn *et al.* 2012). The current study seeks to further elucidate what promotes or hinders adjustment specifically in people with aphasia and their significant others in early recovery, exploring both their internal resources and external sources of care and support.

Methods

This qualitative study was nested within the Supporting well-being through PEER Befriending (SUPERB) study (ClinicalTrials.gov identifier NCT02947776). Reporting follows the CONSolidated criteria for REporting Qualitative research (COREQ, Tong *et al.* 2007) (see Supplementary file 1 in the supplemental data online).

SUPERB study design and methods

SUPERB was a single-blind, mixed-methods, parallel-group feasibility (phase II) randomized controlled trial (RCT) comparing usual care (USUAL) with usual care plus peer-befriending (PEER) for people with aphasia post-stroke who had low levels of psychological distress. The full trial methodology is reported in the SUPERB protocol (Hilari *et al.* 2021). A total of 56 participants were randomized, 28 in each arm. Of these 56, 48 also had a significant other taking part. All participants consented to a study on adjustment post-stroke with a com-

parison of different packages of care but no specifics regarding the intervention tested. Those randomized to the PEER arm were then provided with full details of the intervention and gave further consent. Participants were informed of the interviewer's role in the study and told she would not be involved in outcome assessments.

Setting and participants

Participants were recruited from North London hospitals, community services and/or GP practices (identified < 6 months post-stroke). Baseline assessments and randomization took place after discharge, and once intensive community rehabilitation had ended. All participants received usual stroke care in their borough. Those in the PEER arm also had six befriending visits between randomization and 4 months post-randomization. Clinical outcomes for the study were collected at 4 and 10 months post-randomization at participants' homes.

Inclusion criteria for participants were aged >18 years; fluent pre-morbid users of English (confirmed by relative or self-report); presence of aphasia due to most recent stroke; and low levels of emotional distress (score ≤ 2 on the Depression Intensity Scale Circles) (Turner-Stokes *et al.* 2005).

Each participant was invited to nominate one significant other, who was their closest confidant and > 18 years old. If participants lived alone, their significant other had to be someone they saw at least weekly. Consent was sought separately from significant others. Participants without a significant other were still eligible.

Exclusion criteria for participants and significant others, confirmed by medical notes or self/significant other report, were other diagnoses affecting cognition or mental health; severe uncorrected visual or hearing problems; or severe or potentially terminal comorbidities, on grounds of frailty. Participants were also excluded if they were discharged to a different geographical location from the recruiting hospital borough.

Nested qualitative study

The qualitative study used semi-structured interviews with a subsample of participants ($n = 20$) and significant others ($n = 10$) from both arms of the trial at 4 months post-randomization (figure 1) to explore the acceptability of trial procedures, experiences of care and the process of adjusting to life with aphasia after stroke. PEER participants were also interviewed at 10 months; these interviews focused largely on the befriending intervention and will be reported elsewhere. This article focuses on care experiences and adjustment for people

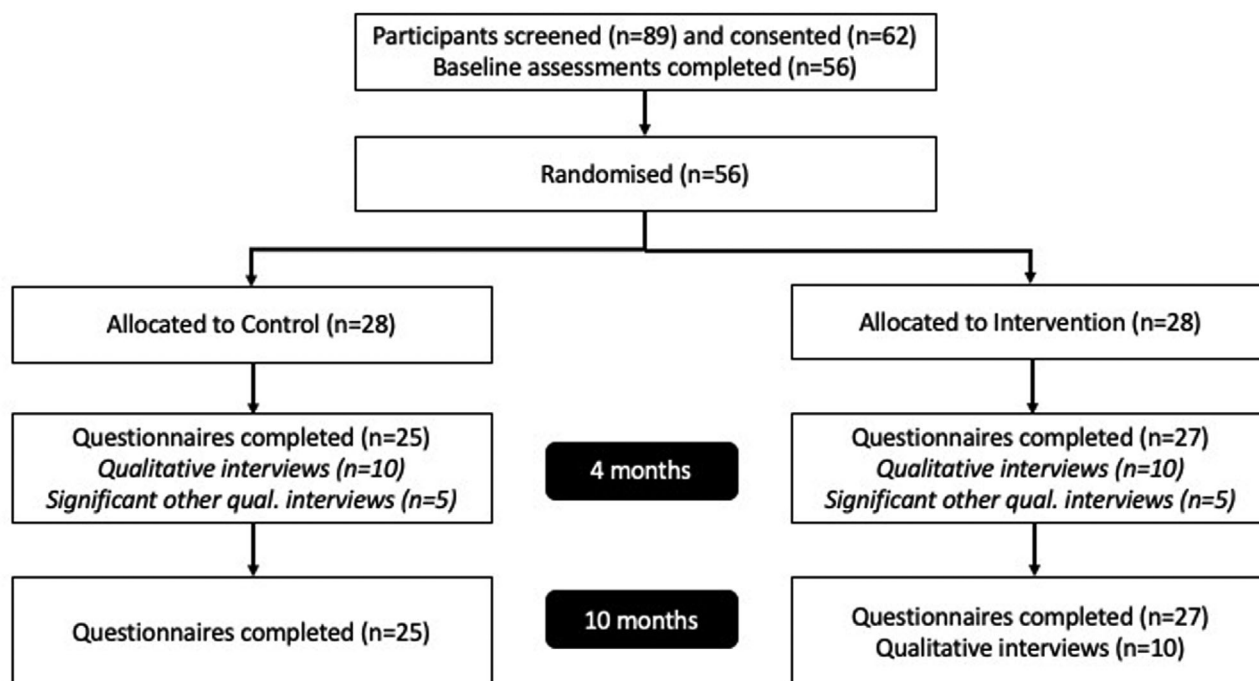


Figure 1. Participant flow in the study.

with aphasia, with contributions from significant other interviews.

Participants

All interviewed participants and significant others were selected purposively from the overall SUPERB sample. This was intended to capture a diversity of views and facilitate data saturation, the stage at which collection of data can safely be discontinued as no novel material is emerging (Faulkner and Trotter 2017). Key sampling criteria were severity of aphasia (mild versus moderate/severe), determined by the Western Aphasia Battery—Revised (Kertesz 2006) scores at initial assessment, and whether the person lived alone post-stroke. Secondary criteria were geographical area of residence, gender, mobility, ethnicity and mood (based on General Health Questionnaire-12—GHQ-12) scores: > 3 indicated low mood (Goldberg 1972). For significant others, sampling criteria included their relationship to the participant (partner/spouse or child/other), ethnicity, gender and GHQ-28 scores. Owing to this sampling strategy, on occasion a significant other was interviewed, but not the participant who nominated them.

Procedures

Interview topic guides were created by a senior qualitative researcher (SN) (see Supplementary files 2 and 3 in the supplemental data online), and refined through dis-

cussion with a user group of people with aphasia, who suggested minor word changes and a small number of additional questions, and the wider research team. Face-to-face interviews took place in participants' homes and were audio- and video-recorded with written consent. A research assistant (KM), a speech and language therapist with extensive experience of communicating with people with aphasia, conducted the semi-structured interviews. She was trained by a senior qualitative researcher (SN) who had extensive experience of adapting qualitative methodologies for people with aphasia. For example, pictures and photographs were used to support communication, and 'total communication' techniques such as gesture, drawing, facial expression and tone of voice were used to support speech. These techniques ensured that even people with severe aphasia were able to participate in interviews. The senior qualitative researcher viewed two videotaped initial interviews and gave feedback to ensure questioning was unbiased and led to a full exploration of topics. She also provided supervisory support throughout the trial. All interviews with participants were transcribed by the research assistant (KM). The main data analyst (BM) checked 25% of these for accuracy and no discrepancies were found. Significant other interviews were transcribed either by the research assistant or an external transcription service; all were checked for accuracy by the research assistant. The research assistant made occasional memos for logistics or personal reflection; these were not intended for analysis. At the beginning of the interview,

participants were informed of its purpose to explore adjustment and well-being, and that there were no right or wrong answers. Given their aphasia reading and writing impairments, participants did not review transcripts for comment, nor did they provide feedback on findings.

Analysis

Data were analysed using framework analysis (Ritchie and Lewis 2003), a type of thematic analysis. Initial themes and concepts were identified through reviewing the data. These were then used to construct a thematic index and assign an index label to each phrase or passage of the transcripts. The labelled raw data were summarized and synthesized into the thematic charts. This matrix-based method of analysis facilitates systematic exploration of the range of views, both between and within cases, to produce both descriptive and explanatory accounts of the data. The matrix format also promotes sharing data in a multidisciplinary team, and is regarded as being particularly suitable for interview data (Gale *et al.* 2013). Data were organized and analysed using NVivo v.12 (QSR International). Steps were taken to increase trustworthiness and minimize bias. The lead analyst (BM) conducted outcome assessments with some participants in the course of the wider study, but did not conduct any of the interviews. The thematic index was initially developed by the lead analyst, a clinical linguist with extensive experience of qualitative analysis, then further refined through discussion with the research team. Coding was conducted by the lead analyst. A second analyst (NB) read through four of the coded transcripts (13%), and also reviewed 25% of the charted material, reflecting with the lead analyst on merging themes, resulting in minor labelling amendments but no major thematic changes. A senior researcher (SN) oversaw all stages of analysis, and reviewed the material, for example, to reflect on how negative cases had been discussed, and whether the diversity of experiences was appropriately reported.

Results

No participants declined the interview. One participant was interviewed but discounted, in consultation with the senior research team, owing to an inability to stay alert and fully engage with the interview; an additional participant was therefore purposively sampled and interviewed. One significant other declined the interview, and a replacement was also purposively sampled and interviewed. Of the participants, 10 were male and 10 were female. Eight were wheelchair users. Ten were White, seven Black, two Asian and one mixed race. Twelve had mild aphasia, eight were moderate–severe. Their age ranged from 25 to 85 years, median

(interquartile range—IQR) = 70 (57.5–77) years. Four participants lived alone. In terms of their education background, five had not finished school, eight finished school, two went on to further education and five had a university degree. Five significant others were the spouse or partner of participants, and five were their child or other relative/friend. Seven were female and three male; and seven were White, two Black and one mixed race. Significant others were 26–83 years old with a median (IQR) age of 70.5 (43–79) years, and most ($n = 5$) held a university degree (two had a higher education qualification, two had finished school and one had not finished school). Individual participant characteristics for both groups are shown in Supplementary files 4 and 5 in the supplemental data online.

Interviews were mostly one to one; for two participants with severe aphasia, significant others stayed to support communication/clarify comments. For three significant other interviews, the participant with aphasia was present due to home environment or personal preference. Two of these participants with aphasia were not formally interviewed themselves, and their contributions do not feature. Interview length ranged from 15 to 82 min (median (IQR) = 54.5 (37.5–59.5) min) for participants, and from 22 to 64 min (median (IQR) = 42.5 (34–46) min) for significant others.

Four core themes emerged: hospital and rehabilitation, life changes since stroke, personal resources and external sources of help and support.

Hospital and rehabilitation

Doctors, nurses and hospital communication

A prevalent theme was feeling well cared for by individual doctors, nurses and other hospital staff. There was a sense they received emotional as well as physical care ('everything to comfort me'; Ivy); were responded to as individuals, for example, using humour; and treated with friendliness and kindness. This attendance to emotional support promoted adjustment to the unfamiliar setting of the acute stroke ward. There was variation in how effectively participants felt they could communicate with staff: some reporting difficulties in understanding and expressing themselves, despite otherwise adequate care provision. Likewise, bonding with staff members varied ('They were all OK, some were ... absolutely lovely'; Christine). Friendliness and successful communication could positively affect the hospital experience:

'I gave one of them feedback I said "Listen, if you wasn't in this stroke team I would have bust up." ... she was the only one I could have a conversation with, a friend, I needed to thank her' (Bashiir)

Staff status as stroke specialists was also important. Susan, who had been in hospital 'hundreds of times' for unrelated conditions, perceived specialism as a valuable difference:

'I think the staff actually thought about what they were doing. And how they speak to people. Rather than just doing things. Staff were brighter than normal. ... More intelligent.'

A main concern was miscommunication about health and treatment, such as lack of timely information regarding contracting methicillin-resistant *Staphylococcus aureus* (MRSA), or being informed of partial operative success in an apology letter 6 months later. Not being able to discuss treatment options with relevant personnel also caused distress. For example, Susan was unsure how serious her aneurysm was. When told she would receive a discharge letter rather than meeting a neurosurgeon, 'I just went mad. I said: "Someone's told me I've got something on my brain and you shrugging it off like you haven't got a cheese sandwich on the menu ... How dare you".'

A small subset of participants was dissatisfied with prognostic discussions and expectations of recovery. One participant, James, felt angry that a medic had implied he should simply feel lucky to be alive: his stroke was a 'frightening experience, terrifying', and this response left him feeling unsupported and impeded his ability to adjust to his changed circumstances.

Significant others reported mixed experiences in their own staff encounters, for example, Claire's husband said some were 'rough, sloppy', while others were 'angels ... God's gift to the nursing profession'. Effective communication was an important factor for family members ('They were telling us, like, every step of the way'; Bashir's sister), and it was problematic when staff workload meant this could not be prioritized. Though an isolated incident, Bashir's sister described their family's distress when paramedics suspected her brother was intoxicated or using drugs; she appeared to feel this had stereotyped him because he was a young black man.

The admission and discharge processes were difficult experiences for significant others. For example, on admission, Ivy was taken to the operating theatre before her daughter arrived, who felt she had needed more information to consent on the participant's behalf; while Elizabeth's daughter was frustrated when a nurse confused her mother with another patient. For some, discharge was perceived as sudden and unexpected, causing significant others to fear coping at home, yet to feel faced with little choice. Peter's wife described her worries about adjusting to caring for her husband at home:

I said: 'Coming home? The man can't walk, he can't speak. I'm crippled with arthritis. I've got heart failure. There's just me and him.' ... 'Well he either goes home

with you or he goes into a home.' I said: 'OK he comes home with me.'

Life on the ward

Despite positivity towards individual health professionals, issues were raised relating to life on the ward. There were specific concerns around mealtimes: displeasure at 'disgusting' food, which could be compounded by aphasia. For example, Peter was unable to explain that he needed something he could 'manage with one hand' and was given fish which he could not cut. A subset of participants were distressed at how toileting was handled on the stroke ward, such as not being accompanied in a timely way and being forced to use a commode.

The communal nature of the ward, and hospital rules and norms, could sometimes be challenging. Participants spoke about lack of privacy, and the sense that normality was on hold. This is illustrated by Bashir, in his 20s, saying: 'I have no one to talk to, you know what I mean?' Besides boredom and lack of entertainment, he struggled with protocol such as limited visitors, and rebelled against set bedtimes, saying:

I wanted to watch Match of the Day. I said '10 off, 10 o'clock is when the TV comes on yo. all of a sudden you think you're the boss of everybody. ... I'm a patient, and I have the rights to watch what the hell I wanna watch, yeah? I'm a young person. I don't go to sleep any time soon. So what do you want me to do, stare at the wall?

Conversely, attempts to maintain a sense of normality led to more positive experiences of life on the ward. This could be through supporting patient choice in what they wore, where they chose to eat and when they showered, sometimes assisted by having a private room. These factors are illustrated by Marilyn, who explained her nurse 'treated me like I was ordinary ... like I'm in a shop, she made light of it ... I don't think she realised how brilliant she was'. She never wore nightwear in the daytime when in hospital as she felt it immediately put her in 'patient mode', and the ward sister supported her, saying, 'No, she doesn't want to get undressed, she stays as she is.' She went to the morning room to eat her breakfast each day, explaining: 'It feels better to get up, go in and sit at a table.' Finally, Marilyn described developing friendships with some of the other patients—they would drop into one another's rooms, eat together and walk along the corridors for exercise. Retaining certain aspects of everyday life such as these, rather than curtailing patients' freedom of choice, appeared to be an important factor to their adjustment to life in hospital.

A subgroup of significant others also discussed life on the ward. One issue was feeling the need to advocate for their loved ones to ensure appropriate care, such as using the toilet rather than a commode, receiving the

correct meals and provision of laxatives. This was difficult when they could not always be present, and was compounded by a perceived need to preserve rapport with staff. However, unlike Bashiir, his sister was pleased by the structured routine: she wanted him to 'sleep early, to get more sleep and get relaxed'. Elizabeth's daughter also praised the friendly, humorous relationships that had developed among patients on the ward.

Therapies and therapists

Rapport was an important factor in how participants experienced therapy and its providers. Participants appreciated laughter, two-way conversations, and feeling the team were interested in them. Personalized therapy and goal-setting were seen as motivating, as were positivity and encouragement. For example, Marilyn described how her speech and language therapist had allowed her to choose her own reading material, and said of her physiotherapist: 'When she came to the door it was like a light had come on.' She appreciated the fact the physiotherapist had said, 'Nobody ever does [exercises]; let's go out.' They went to her local market; this reengagement with her community facilitated her adjustment and made her feel her situation was not 'all doom and gloom'.

Therapeutic exercises were sometimes perceived as hard or challenging, and therapists were thought to have 'meant business'; nonetheless, participants reported enjoying tasks or perceiving them as helpful. Many recalled practical examples of therapeutic tasks, such as fastening a bra one-handed. These were perceived to be specifically designed to enable them to adjust to their changed circumstances by promoting independence. Relatives praised therapists' willingness to involve them, which allowed them to offer additional practice and support.

Negative reports related to lack of, or limited, therapy; several participants would have liked a more intensive regime. For example, Sayid, who had very little speech, was discharged from speech and language therapy without explanation after only three sessions. His wife said this was 'absolutely rubbish': she felt his therapy package simply focused on physical mobility and ultimately discharge. Some significant others also described a hiatus between discharge and community therapy, which slowed down their adjustment to returning to the community.

Life changes since stroke

Mood and emotions

Participants described a new sense of vulnerability, loss of confidence and reduced independence, which low-

ered their mood. Several articulated that having a stroke had made them more aware of their mortality and left them feeling shocked. Susan said:

Of course I'm getting old, I wasn't unaware of that before, but you realise that the peak of your physical powers have gone, long gone. Doesn't make you feel good, but that's the human condition isn't it, we're all hurtling towards our end, mine just feels a bit closer than it did.

This sense of vulnerability left some feeling uneasy, insecure or afraid of being alone. Peter said that he had been reluctant to leave the house for the first time. He also reported sleeping on the sofa for 4 weeks after discharge because his stroke had occurred in the bedroom. This was related to fear of recurrence, also alluded to by several others, and exacerbated by a sense of disbelief that something so serious could have happened to them without warning. Several reported feeling: 'Why me?'

Diminished confidence was sometimes associated with social withdrawal. For example, Santiago stated he was previously a very chatty person, and aphasia had knocked his self-esteem, adding he 'want[ed] it back really, really bad'.

Participants described preferring to offer help than receive it, or a desire to play the caring roles they felt they had lost. Reliance on others could result in feelings of worthlessness or feeling 'sad and angry' (Ivy). Significant others also described the emotional impact of lost independence for participants: sadness, frustration and anger. For example, Claire's husband reported she 'hated every minute' of being dependent and often had 'tears in her eyes' or became infuriated and shouted at him. He perceived Claire's loss of independence as a major hindrance to her coming to terms with her stroke.

A sense of feeling unhappy, but less so than at onset, was common. Bashiir said it had taken him 6 months to talk openly about what happened, and thinking of it still made him tearful, but that it had also made him 'strong'. Several participants referred to being 'down-hearted' or emotionally labile in the early days and weeks post-stroke but had noted some improvement. Some also remarked that an increased sense of mortality had given them a sense they should live for the moment, making the most of life and not wasting time. Nonetheless, frustration or anxiety regarding recovery progress, and uncertainty over how much improvement they could expect, was a concern for a subset of participants who felt their prognosis had not been adequately discussed.

A minority of people felt having a stroke had little emotional impact. They described 'just sort of getting on with my day to day business really' (Katherine), or the importance of thinking positively. Alternatively, they raised their mood with distraction and support

from others. For example, despite being housebound, Kofi said his sons, friends and watching television kept him occupied and optimistic. This resilience appeared to relate more to individual disposition than the severity of impairments they experienced.

Identity/sense of self

Participants commonly described identity changes and an altered sense of self post-stroke. Some changes were negative such as no longer feeling 'charming' (Ivy), or feeling vulnerable 'like a wounded animal' (Marilyn). Others were more positive, such as reduced concern for others' opinions of them, or not worrying about trivial matters. Some experienced changes as a direct consequence of aphasia, as illustrated by James, who felt he had become more hot-tempered. Recounting an incident when a young woman blocked his way, he explained that, unable to speak, he waved his arms around and realized he had intimidated her, despite being 'the most harmless person you can imagine. ... I can't come across the way I want to so now I can't say anything'. This had upset him to the degree that he had stopped taking his daily walk to buy a newspaper.

Some significant others also commented on changes in their loved ones. A particular concern appeared to be participants' reduced independence, and resultant distress. They also described participants' increased lethargy and lowered self-esteem. Ivy's daughter spoke of taking steps to ensure her mother still felt worthy of self-care, paying for mood bolstering treats to boost her self-esteem and to connect her to her former self:

Maybe forty pounds once a while, say, 'mum, get this.' Sometimes I take her to go and do her hair. I want her to do her nails and feel like she used to feel, not to feel that she is not worth it anymore. She looked after herself ... it makes me feel relaxed and reassured, knowing that she feels okay, that she's got this stroke but she's still [mum].

For significant others, impact of becoming a carer

Many significant others described the burden of caring: for some this was a major issue ('someone's taking my life away from me'; Marcellino's daughter). The significant others described feeling 'drained' by responsibility, with lives 'transformed' or 'disrupted'; Elizabeth's daughter felt the roles had switched ('Mum is like the child now, you know?'). One response was to arrange respite or daily care to protect their own physical and mental health.

Fear and anxiety also affected significant others, particularly regarding stroke recurrence ('a sword of Damocles hanging over us'; Benjamin's wife). While many participants could not recall the stroke event, or men-

tioned it only briefly, significant others found it a traumatic experience, which had left them feeling 'scared', or 'helpless', some to the degree they had suppressed the memory. For some this trauma reduced their ability to put the stroke behind them. Echoing participants' shock at sudden onset of symptoms, Judy's husband said it was analogous to his previous car accident, both because it occurred without warning and because he was gradually more able to relax.

One significant other, Christine's granddaughter, had a markedly more positive experience than others:

I feel like this is part of my purpose in life. So even though it's been very challenging, it's also just a bit of a journey of life ... there's a lot to be grateful for... I'm in charge of my own emotions and I'm responsible for my own reactions to things.

Despite the detrimental impacts of caregiving, significant others spoke of positive consequences of the stroke, such as strengthened bonds, pride in participants' courage and relief that they had survived. Many were grateful for the opportunity to provide support, and this also appeared to have underscored appreciation for their loved ones. This was summed up by Ivy's daughter:

This has made us more stronger and bonded us, because I think that the worst could've happened, and she may not have been here by now, and we were really happy that she stayed. ... I think it's brought us much more together.

Personal resources

Attitude and outlook

Resilience, determination and optimism were frequently reported to impact adjustment. For example, Samson said, 'I have a philosophy called willpower. Even though the future's not predictable, I have confidence. Once I have my life, I think I have a future.'

Many acknowledged their own bravery ('I'm a tough little cookie. ... You can't crack a cookie like that'; Bashiir), and reconciling themselves to life's ups and downs ('Mountains, climb down sometimes fall. ... You have to know how to fall, go up again'; Betsy). Several older participants spoke of the importance of living in the moment: 'In a year's time I'll be eighty. ... I can't say well I'll do it in ten years' time, haven't got the opportunities to do that. ... Now or never. ... I wouldn't want, miss a day really' (James).

Faith

For a subset of participants, faith was highly important, helping them feel grateful, calm and resilient, and to

cope with and adjust to life's ebb and flow ('If you believe in God, if you fall down you don't bow'; Betsy). Some explicitly expressed their gratitude for survival in a religious context: Ivy said, 'I praise the Lord that I'm still alive, because what I went through, not many people would [be].' Communities of worship (relating to a church, mosque or temple) were also acknowledged for providing comfort and practical support. Susan said her spiritual beliefs were fluid—defining herself as 'more of a wishful thinker than a believer to be honest'—yet found solace in going to church and re-reading 'inspiring' gospels. Family members were also perceived to have a role in spiritual support: Jonathan was recently twice bereaved, and felt his brothers had 'died for me to live', while Santiago's sister often texted prayers. Finally, religion appeared to allow some to take a fatalistic approach, for example, Bashiir reported:

I believe in God and leave everything in his hand because he knows best. He got me out of hospital and he gave me the stroke. Even though you'd rather live, if you're a believer you can think I've lived, then I'll die. Nobody knows when it will be, age 6 or 56, death has no age limit. So when your time is written, your time [claps] up ... it doesn't matter if stroke, stabbed, shot.

Moving forward

Setting and moving toward targets despite setbacks was key to adjustment and maintaining a positive outlook for some participants. Participants described setting short-term tasks immediately post-onset, such as completing a word puzzle, and more long-term incentives to recovery, such as pre-booking a theatre ticket. Some said their confidence in achieving goals had increased rather than diminished: Susan had singlehandedly cooked for 25 fellow churchgoers, something she may 'not have had the nerve' to do pre-stroke. Bashiir summed up his preference for moving forward rather than looking back: 'Everything starting to look bright, forget the past, I want to move forward with my life. No time to think about what I went through and how it hurt me.'

Where progress was slow or variable, participants generally maintained optimism ('Just because I haven't been out, doesn't mean I haven't got the idea in my head. As long as I got life, there's a future'; Jonathan).

A subset of participants described undertaking activities they felt would benefit their recovery, such as walking around the hospital corridors to aid stamina, martial arts for balance, buying an exercise bike and handwriting practice to help with aphasia. This appeared mostly to be motivated by feeling responsible for their own health ('You should think "What can I do to stop it happening as much as I can?"'; Judy), although

for Peter it was driven by frustration with perceived inadequacies of formal therapy.

Reflecting on progress since their own early days prompted participants to consider strategies for others with aphasia. These included not becoming isolated, by 'gathering a team' (of loved ones) and prioritizing getting out of the house, focusing on the future and practising self-care ('Get your hair done. Pick out some nice clothes. Get dressed'; Susan).

External sources of help and support

Familial and other relationships

Participants were overwhelmingly positive about the central role of family in their recovery after stroke. For example, Samson described his brother as 'the pillar of my backbone, the kingpin'. Family members were described as providing emotional support, including encouragement, affection and reassurance, for example, Peter knew he could confide in his wife, and she would notice if he was feeling low. Many described small, thoughtful acts of kindness which had nurtured them, such as reassurances that medication-induced nightmares were false, or sending short-filmed messages. Family members also provided practical support. Participants described how family members had prioritized looking after them, sometimes reorganizing their own lives. For example, before her stroke Betsy was carer to her disabled adult son and also shared care of her grandchildren while her daughter worked; this role had reversed when her daughter resigned from her job to care for her. Participants described feeling grateful and acknowledged their loved ones' forbearance in the face of their own adjustment to being a carer ('You're a pain in the arse, aren't you? You know, anybody that's ill or incapacitated'; Katherine).

For many, both family and friends appeared vital for remaining connected to 'normality' and settling back into realities of their pre-stroke lives, such as discussing current affairs and politics. David described talking to friends as 'almost more helpful than speech and language therapy', enabling him to 'feel like I'm still in touch with life'. Maureen summed up her family's focus on including her, describing how her teenage grandson and his friends put on a firework display and brought her out to the garden bench when she was unable to go to their community event. Young family members seemed to offer a particular tonic and could have a more positive way of perceiving stroke-related difficulties, further motivating participants' recovery. For example, Susan said:

He just sees me in his own way, so he calls me granny with the flowers, because I always bring flowers for my daughter in law. So, it's granny with the flowers, it's not

granny with a stick. Oh, but he loves my stick. And he plays with it. I'm gonna buy him a little stick, walking stick for his for Christmas coz he loves it [both laugh]. He's enthralled with it.

Significant others also appeared to draw strength from relationships with others, with adult children in particular described as a source of support ('a great blessing'; Benjamin's wife).

For a small minority, the stroke was a catalyst for less positive change in their relationships. Sayid indicated that his relationship with his family had deteriorated greatly. Bashir's engagement had broken down, but he felt glad he realized his former partner was unsupportive, and was himself happy in a new relationship.

Psychological support

Participants described receiving informal psychological support from family, stroke groups, peer-befrienders and other ward patients. They also described therapeutic interactions with specific health care workers, such as a student doctor and an occupational therapist. Participants were rarely referred to a mental health professional for psychological support. An exception was Susan, whose physiotherapist referred her for cognitive behavioural therapy, and described its holistic approach to well-being as 'first rate'. A commonly held view was that formal psychological support would have been a beneficial option even if they did not personally require a referral. For example, Kofi said he thought counselling may have been an outlet to talk about his fatigue and comprehension difficulties. Perceptions around need could change over time: Ivy's daughter explained she initially wanted to complete a self-referral for Ivy to receive counselling, but then her mood improved once she began receiving befriender visits and attending a stroke group.

Psychological support was a theme for significant others as well, though most preferred informal support owing to time constraints and medical appointments. They stated they saw distress as a 'natural reaction', which also limited their desire for formal support. Most felt that relatives' support groups and/or counselling were good ideas in principle but felt they had other avenues for psychological help, such as their GP, colleagues and family support, and that adjustment would happen naturally over time.

Stroke groups

The majority of participants spoke about attending community stroke groups, and opinions of these varied. Reasons for choosing not to attend included preferring to manage problems privately ('It's not my style

... personal things, I'm on my own'; Santiago); avoiding others who 'reminded' them of their condition; finding others' experiences distressing or irrelevant; not liking just talking. This is illustrated by Peter who had been to a hospital group at which the nurse told them the 'idea is to get your feelings out', but said that people were 'kicking off, arguing' and he 'couldn't handle that ... just went back to bed'. By contrast, he greatly enjoyed his local post-stroke exercise group.

Others valued the 'lovely atmosphere', enjoying the companionship groups provided. These participants appreciated the sense of being part of a wider community with similar experiences, and felt they benefitted from seeing that they were on a spectrum of stroke effects.

Some significant others also made positive comments about stroke groups; Ivy's daughter explained: 'She's one of the more capable ones among them and that's really giving her hope to progress and recover fully.' Christine laughed as her grand-daughter recounted her initial reluctance: 'she was being a spoiled brat about it, I said "If you don't like it you don't need to go back." But she did'. She added that the participant had met a 'fancy man' who writes poetry at the group.

Community and socializing

Many participants had lived in the same tightknit communities for many years, and valued the social activities offered by their clubs, political parties and faith groups. Some expressed a preference for the company of familiar people. Santiago went out each day to increase his confidence by chatting to people he knew in the market or pub, but was not yet comfortable talking to strangers because of his aphasia. Others preferred to 'test' reacclimatizing socially without risking seeing acquaintances, such as visiting a different coffee shop than usual. They also described becoming 'more choosy' about where they went and with whom, due to fatigue and reduced mobility. Samson said recounting social activities to members of his stroke group was a useful incentive to keeping busy, so that he would have news to report.

However, there were some occasions where social activities made participants uncomfortable. Jonathan described one such instance. At a funeral, an acquaintance was 'carrying on' about his stroke, saying: 'Oh, how do you feel? How are you getting on?' He added, 'I said "I'm okay, I don't need help!". ... And I thought, why did I come here?'

Discussion

Participants and their significant others identified a wide range of factors which influenced their adjustment

to aphasia after stroke. Some of these were personal resources, including: mood and emotions; identity/sense of self; attitude and outlook; faith and spirituality; and moving forward. Significant others also talked about the impact of becoming carers. Other factors were external sources of help and support, including familial and other relationships; doctors, nurses and hospital communication; life on the ward; therapies and therapists; psychological support, stroke groups and community and socializing. These appeared similar to the adjustment themes identified by Theadom *et al.* (2019): participants described emotions including fear and said their lives had been disrupted, but had begun finding what worked for them as an individual to help them manage, including evolving a new normal and managing ups and downs.

Many, though not all, participants self-identified as being determined, optimistic, brave and resilient enough to deal with life's ups and downs. Similarly, Bright *et al.* (2020) observed that at 1 year post-onset, all four of their participants had a broad sense of hope for the future, and had recalibrated their early post-stroke hopes by reflecting on past progress, current function and future desirable outcomes. In particular, those with a strong sense of self appeared capable of tolerating uncertainty and maintaining optimism. The reflection they described is similar to the rationalization element of adjustment described by Mumby and Whitworth (2013) as looking back, around and forward. Our findings imply the foundations of this recalibrated outlook may begin to be laid in the post-acute phase, with some participants explicitly saying they preferred to live in the moment or look to the future, rather than look back at stroke onset, and describing setting themselves targets to move towards.

MacKenzie and Marsh (2019) point out that while spirituality has been discussed extensively in the general healthcare literature, it has received little attention in speech and language therapy research. They found that often patients' physical requirements took precedent over their spiritual needs, and cautioned that this lack of attention to what makes life 'meaningful' may render therapy superficial. Giaquinto *et al.* (2007) found that stronger faith beliefs were a potential protective factor against emotional distress post-stroke, and a significant subset of our participants spoke of the importance of their spirituality in adjusting to stroke and aphasia. This suggests a need for sensitivity and respect towards this aspect of patients' lives, both broadly from society, and specifically by clinical practitioners addressing it in therapy where indicated. Some participants may also have benefitted from a referral to the hospital chaplain from medical staff.

In line with the literature (Grohn *et al.* 2012; Northcott *et al.* 2016), participants regarded their so-

cial networks as essential to their adjustment to life after stroke, describing the pleasure they derived from being in their local communities, places of worship and retail and hospitality settings. Friends were seen as a way of being 'connected' to the world, providing opportunities for conversation and humour. Family members in particular were seen as central to participants' well-being, and both people with aphasia and their significant others spoke of their gratitude for one another. Nevertheless, significant others were negatively impacted by their loved ones' aphasia in a range of ways, similar to the 'third party disability' described by Grawburg *et al.* (2019). Significant others in Winkler *et al.*'s (2014) examination of carer blog-posts described taking on new roles and extra responsibilities, a finding consistent with the current study, with significant others feeling 'drained', and that their lives had been 'disrupted' or 'transformed'. Positive consequences were also identified, such as new closeness, new appreciation of life and pride in achievements, both in Winkler *et al.* and the current study. Interventions for significant others that help maximize these positive consequences are scarce, but much needed especially at the early stages of recovery post-stroke to prevent more significant problems in the longer term.

Reflecting on their care, participants with aphasia and their significant others felt that hospital communication, both verbal and written, regarding their condition, treatment and prognosis was not always clear or timely, which hindered their coming to terms with what had happened to them. Furthermore, some ward practices left participants feeling dehumanized. In their examination of practices which dehumanized stroke ward experiences, Pound and Randrup Jensen (2018) focused on communication needs and preferences of people with aphasia. However, nurses, as the most frequent communication partner for people with aphasia in hospital, rarely use communication repair or supported conversation strategies (Hersh *et al.* 2016). O'Halloran *et al.* (2012) distinguished between environmental factors related to the knowledge, communication skills, attitudes and characteristics of health care providers; and the stroke unit structure and processes including the physical environment and hospital systems. Our data suggest both factors influenced patients' experiences on the stroke ward.

Besides inadequate communication strategies, our study showed a wider pattern of behaviours, which served to homogenize patients, including environmental and recreational restrictions. However, there were also notable efforts made by staff to humanize patients' experiences. Many participants spoke of positive interactions with staff and therapists, which included humour, friendship and being treated as 'normal'. This is encouraging as it appears to contrast with Hersh *et al.*'s

(2016) observational study, which found that nursing staff engaged in little conversation with people with aphasia other than regarding their physical care. Similarly, some participants and their significant others felt ward staff facilitated bonding and mutual supportiveness among patients, for example, by allowing them to have meals together and take walks and exercise. This promoted adjustment by both fostering and maintaining social connections, and providing communication opportunities. Moreover, it is in line with recommendations that health professionals guard against fostering dependency on their expertise, instead promoting independence by facilitating patient knowledge, skills and confidence through quality interactions (Jones *et al.* 2016).

The young person in our study was an exception to this experience and felt there was little peer support available for him on the ward. In Kersten *et al.* (2002), younger people (aged 18–45 years) had significantly more unmet needs than older adults after stroke, including that of information provision. Issues for young adults and adolescents in medical care include dissatisfaction with low privacy levels, lack of communal spaces, poor technology access and differing sleep patterns (Albon and Vaughn 2014). Hospital staff need to be aware of the specific needs of younger people with stroke and consider how to accommodate them, for example, facilitate interaction among younger patients in the wider hospital where possible.

The sense of teamwork and involvement offered by therapists to family members was seen as a valuable way for them to model their own behaviour and facilitate home practice to supplement formal therapy. This is in line with best practice and with other studies' findings: Howe *et al.* (2012) observed significant others wanted to be included in rehabilitation, and also to be given information, support and coping strategies. In the current study, a sense of unpreparedness and fear was felt by some significant others at the prospect of transitions such as hospital discharge, and withdrawal of therapies, which hindered their own adjustment to life with a person with aphasia. A systematic review of early supported discharge had a similar finding, revealing mixed feelings whereby individuals longed to be discharged but simultaneously feared they may not cope (Brändal *et al.* 2019). Moreover, in our study, there was anxiety among both participants and their significant others relating specifically to chances of stroke recurrence, and uncertainty around prognosis and long-term progress. This is of concern for their adjustment considering evidence that for those fearful of experiencing a recurrent stroke in the acute phase after stroke, fear remained as strong years later (Theadom *et al.* 2019). Increased support seems to be needed at transition times to help people with stroke and their significant others adjust to changes

and their altered reality. This may take the form of more advance planning with better education about the effects of stroke and prognosis, and information about how to access support (Condon *et al.* 2019).

A notable exception in the literature to the dominant focus on psychological needs in chronic aphasia is a recent Australian study (Baker *et al.* 2020): of the 10 individuals interviewed regarding depression and stepped psychological care, seven were < 6 months post-onset. They observed three core themes: onset as a traumatic event leading to mood difficulties and depression; people with aphasia navigating these changes with limited psychological support services in stroke rehabilitation; and a need for positivity, supported communication and access to individually tailored therapy through stepped psychological care. In the current study, most participants did not feel they had personally required formal psychological intervention, but they felt it should be available if needed. This may be due to the inclusion criterion of low distress at the outset of the trial, or because formal psychological support is only seen as required when distress is in some way 'pathological' rather than a reasonable reaction to a distressing event. Nevertheless, interventions that promote positivity and help people navigate the changes they experience, such as solution focused brief therapy (Northcott *et al.* 2019), peer-befriending (Hilari *et al.* 2021) and Aphasia Action Success Knowledge (and providing strategies to manage mood and social networks; Worrall *et al.* 2016) may be acceptable and useful in promoting adjustment.

Some participants did not respond favourably to the idea of attending stroke groups, suggesting that a homogenized recommendation may not be useful. Lanyon *et al.* (2018) described factors influencing experience of group participation, including an open and non-hierarchical group environment, communication awareness amongst members, meaningful activity, structure and group leadership. Among our participants, groups which centred around meaningful activities, such as exercise classes for people with stroke, were also rated highly. Experiences were particularly positive when they had been introduced to the group by a peer-befriender, and a kind of buddy system could perhaps be employed more widely in order to facilitate a gentle introduction. A few participants felt that despite representing 'external' support, stroke groups became part of their social network, providing companionable activity, similar to the relationships with other patients that some developed while in hospital. Nevertheless, people with aphasia have a wide range of social needs and preferences; for some, a one-to-one intervention such as a buddy or befriending scheme may be more beneficial. The reciprocal relationship of befriending may also fulfil the desire expressed by some participants

to provide as well as to receive support, and maintain a caring role in some capacity.

Strengths and limitations

This study had a number of strengths. People with differing presentations of aphasia, including very severe aphasia, were enabled to participate. Perspectives of significant others were also captured and contrasted with those of participants with aphasia, and significant others were not always partners, but also included other relatives and friends. Purposive sampling ensured diverse viewpoints were included, for example those with low versus stable mood, living alone or with others, ethnic diversity, a wide age range and varied social backgrounds. The post-acute stage of the study meant that participants could provide reflections on being in hospital, the transition following discharge, and the subsequent ways in which they had rebuilt their lives post-stroke. Steps were taken to increase trustworthiness of the data through having two analysts at each stage of interpretation. The core research team included both speech and language therapists and a clinical linguist, with the broader research team also including mental health nursing specialists and a health psychologist.

There were also limitations. Participants were selected from a wider group of individuals who had already consented to participating in the SUPERB trial. The small number of significant others interviewed may have meant that data saturation was not reached for this group. It could also be argued that paired significant others and participants with aphasia should both have been interviewed. Owing to their aphasia, transcripts were not returned to participants for their approval, nor was their feedback sought. Finally, the study was based in London, UK, and it is possible the findings may not reflect issues from other settings or cultures.

Conclusions and implications

There are a wide range of personal and social factors that facilitate adjustment to aphasia after stroke. While people are still in hospital, the views of individuals with aphasia and their significant others described in the current study suggest that the humanizing aspects of care should be prioritized. This would help prevent a period of hospitalization from representing a hiatus from normal life, and facilitate it serving as a preliminary period of adjustment to a new normality, supported by hospital staff. In the post-acute phase, clinicians play an integral role in supporting adjustment. They should focus on relationship-centred care, monitoring mental health, promoting quality improvement across the continuum of care, providing a 'rope team', and supporting advocacy among other things, as recommended by Worrall

(2019). This way clinicians can help equip people with aphasia with practical strategies and support to navigate their changed circumstances and thus help them transition from hospital discharge to the community, and ultimately the end of therapy and reintegration into their new normal. Further research in interventions at the early stages of recovery that help people with aphasia and their significant others utilize their personal resources and effectively access external sources of support are much needed to maximize adjustment and minimize more significant long-term problems.

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Data sharing statement

The data that support the findings of this study are available from the corresponding author upon request. The data are not publicly available due to privacy or ethical restrictions.

Conflict of Interest

The authors declare that there is no conflict of interest.

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Supporting information