



# City Research Online

## City St George's, University of London

**Citation:** Northcott, S., Behn, N., Monnelly, K., Moss, B., Marshall, J., Thomas, S., Simpson, A., McVicker, S., Flood, C., Goldsmith, K. & et al (2022). "For them and for me": a qualitative exploration of peer befrienders' experiences supporting people with aphasia in the SUPERB feasibility trial. *Disability and Rehabilitation*, 44(18), pp. 5025-5037. doi: 10.1080/09638288.2021.1922520

This is the published version of the paper.

This version of the publication may differ from the final published version. To cite this item please consult the publisher's version.

**Permanent repository link:** <https://openaccess.city.ac.uk/id/eprint/26250/>

**Link to published version:** <https://doi.org/10.1080/09638288.2021.1922520>

**Copyright and Reuse:** Copyright and Moral Rights remain with the author(s) and/or copyright holders. Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge, unless otherwise indicated, provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way. For full details of reuse please refer to [City Research Online policy](#).



## “For them and for me”: a qualitative exploration of peer befrienders’ experiences supporting people with aphasia in the SUPERB feasibility trial

S. Northcott, N. Behn, K. Monnelly, B. Moss, J. Marshall, S. Thomas, A. Simpson, S. McVicker, C. Flood, K. Goldsmith & K. Hilari

To cite this article: S. Northcott, N. Behn, K. Monnelly, B. Moss, J. Marshall, S. Thomas, A. Simpson, S. McVicker, C. Flood, K. Goldsmith & K. Hilari (2021): “For them and for me”: a qualitative exploration of peer befrienders’ experiences supporting people with aphasia in the SUPERB feasibility trial, *Disability and Rehabilitation*, DOI: [10.1080/09638288.2021.1922520](https://doi.org/10.1080/09638288.2021.1922520)

To link to this article: <https://doi.org/10.1080/09638288.2021.1922520>



© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



Published online: 23 May 2021.



[Submit your article to this journal](#)



Article views: 263














[View related articles](#)



[View Crossmark data](#)

## “For them and for me”: a qualitative exploration of peer befrienders’ experiences supporting people with aphasia in the SUPERB feasibility trial

S. Northcott<sup>a,b</sup> , N. Behn<sup>a</sup> , K. Monnelly<sup>a</sup> , B. Moss<sup>a</sup> , J. Marshall<sup>a</sup> , S. Thomas<sup>c</sup> , A. Simpson<sup>d</sup> , S. McVicker<sup>a</sup> ,  
C. Flood<sup>e</sup> , K. Goldsmith<sup>f</sup>  and K. Hilari<sup>a</sup> 

<sup>a</sup>Centre for Language and Communication Science Research, School of Health Sciences, University of London, London, UK; <sup>b</sup>School of Health Sciences, University of East Anglia, Norwich, UK; <sup>c</sup>Division of Rehabilitation, Ageing and Wellbeing, School of Medicine, University of Nottingham, Nottingham, UK; <sup>d</sup>Health Service and Population Research and Florence Nightingale Faculty of Nursing, Midwifery & Palliative Care, King’s College London, London, UK; <sup>e</sup>Department of Mental Health and Learning Disabilities, School of Health and Social Care, London South Bank University, London, UK; <sup>f</sup>Department of Biostatistics and Health Informatics, King’s College London, London, UK

### ABSTRACT

**Purpose:** Peer-befriending, where support is offered by someone with shared lived experience, is an intervention that may facilitate successful adjustment in people experiencing post-stroke aphasia. This paper explores the experiences of the peer-befrienders.

**Materials and methods:** People with aphasia were recruited as peer-befrienders within the SUPERB trial investigating befriending for people with post-stroke aphasia. The intervention comprised six visits over three months. Peer-befrienders were matched with at least one befriender and received training and ongoing supervision. They were invited to participate in in-depth interviews which were analysed using framework analysis.

**Results:** All 10 befrienders participated in interviews, reporting on 19 matches. Seven main themes emerged: content of the sessions; befriender–befriender relationship; negotiating the visits; handling boundaries and endings; positive impact of the befriending for befrienders and befriendees; and beliefs about the nature and value of peer support. While befrienders described challenges, such as negotiating journeys and witnessing distress, the role was perceived as a “secure challenge” due to the support and training received.

**Conclusions:** Befrienders perceived the role as enjoyable and rewarding, and felt they were making a positive difference. They were unanimous in believing that people with aphasia can offer unique and valuable support to others with aphasia.

**Trial registration:** ClinicalTrials.gov identifier NCT02947776, registered 28th October 2016.

### ARTICLE HISTORY

Received 13 November 2020  
Revised 21 April 2021  
Accepted 23 April 2021

### KEYWORDS

Peer-befriending; aphasia; stroke; psychological wellbeing; qualitative; SUPERB trial

### ► IMPLICATIONS FOR REHABILITATION

- People with lived experience of stroke and aphasia were able to offer emotional and social peer support to others with aphasia within the SUPERB trial.
- Although there were challenges, peer befrienders perceived the role as rewarding and satisfying.
- Peer befrienders valued the training and ongoing supervision and support they received to deliver the intervention.
- It is recommended that rehabilitation professionals considering offering peer-befriending schemes provide training and ongoing supervision to support peer-befrienders fulfil their role, as well as practical support with, e.g., arranging visits.

## Introduction

Stroke is a leading cause of permanent disability in adults [1]. Having a stroke disrupts a person’s assumptions about themselves and their life. The process of adapting and coping with this “changed self” can be painful and challenge a person’s psychosocial wellbeing [2]. Prevalence of post-stroke depression is 29% up to 10 years after stroke, with the cumulative incidence within five years of stroke being between 39 and 52% [3]. Anxiety is also

common, estimated at 29.3% during the first year [4]. Around one-third of strokes result in aphasia, a communication disability than can affect speaking, understanding, reading, and writing [5]. People with aphasia are at higher risk of depression [6] and reduced social networks [7,8] than stroke survivors without aphasia. It is therefore concerning that people with aphasia are often excluded from stroke mental health research due to their language disability [9] and have reported difficulty in accessing

CONTACT K. Hilari  k.hilari@city.ac.uk  Language and Communication Science, City, University of London, Northampton Square, London EC1V0HB, UK

© 2021 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

mental health services [10,11]. There is currently limited evidence for effective psychological interventions for this group, particularly interventions aimed at preventing people from developing depression as they adjust to living with the stroke and aphasia [12]. One potential intervention is peer-befriending, which may benefit the wellbeing of both befriender and befriended [13–15]. The current paper investigates the experiences of people with post-stroke aphasia working as peer-befrienders.

Peer-befriending has been defined as social, emotional, and sometimes instrumental support provided by non-professionals who are recruited from the same client group as the individuals they are supporting [13]. As peer-befrienders have lived through similar experiences, they are able to offer unique understanding of the challenges an individual may be facing [13], offer authentic empathy and validation [16], and provide hope through positive self-disclosure and role modelling recovery and coping [17]. A review found people with severe mental illness who received peer-befriending improved on measures of hope, recovery, and empowerment [18]. Reported benefits for the person providing the befriending include a reduction in pain, disability, and depression for peer-befrienders with chronic pain [19]; and improvements in confidence, role functioning, and self-esteem for peer-befrienders with multiple sclerosis [20]. A meta-synthesis of peer support workers' experiences in healthcare settings found that working as a befriender enabled a positive reframing of the befriender's identity through giving them a sense of purpose and responsibility [13].

There is evidence that peer support within group settings for people with stroke and aphasia can lead to improved quality of life [21], reduced isolation and increased social connectedness [22]. There is also some evidence that taking on supportive, volunteer roles within groups can be a valued experience for people with aphasia [23]. Nonetheless, not everyone with aphasia wants to attend groups, and accessing them can be challenging [24]. One-to-one peer-befriending is an alternative way of providing and receiving peer support that may be more physically and emotionally accessible for some people post-stroke.

The current study explores the experiences of people with aphasia working as peer-befrienders, offering support to people with aphasia as part of a feasibility trial [25]. When evaluating peer-befriending programs, Dennis [26] argues that it is important to explore the views and experiences of the peer providers as the success of the intervention relies on their dedication and competence. It is a complex role, sitting in the "liminal space" between provider and recipient of healthcare services [27], suggesting that a sensitive exploration of any perceived challenges, as well as support received, may provide insights that would inform a definitive trial. The current study aimed to explore how peer-befrienders with aphasia conceptualised the role and their relationship with the befriended; their experiences of the training, supervision and support; and their perception of the challenges and benefits of taking on this role.

## Materials and methods

This qualitative study forms part of the Supporting wellbeing through Peer-befriending (SUPERB) trial [25]. The trial was a parallel group feasibility multicentre randomised controlled trial comparing peer-befriending plus usual care with usual care alone for people living with post-stroke aphasia who had low levels of psychological distress. It builds on an established community programme run by the aphasia charity Re-Connect, formerly Connect [28]. Fifty-six participants with aphasia were randomised, 28 in

each arm: their experiences are reported elsewhere [29]. This paper reports on the experiences of the peer-befrienders. Reporting adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) [30]. Ethical approval was granted by the NHS Health Research Authority London-Bloomsbury Research Ethics Committee (ref. 16/LO/2187), and local NHS Research and Development approvals were gained from participating sites. Peer-befrienders gave informed consent to be interviewed as part of the research project. Pseudonyms and replacement terms are used to preserve anonymity.

## Participants

All befrienders working in the trial were invited to take part in in-depth interviews. To be eligible, peer-befrienders were at least one year post stroke, aged over 18 years old, and had mild-moderate aphasia. The latter was determined using the Frenchay Aphasia Screening Test [31] on which befrienders needed to score a minimum of 5/10 for both auditory comprehension and verbal expression. Exclusion criteria were severe uncorrected visual or hearing problems; severe or potentially terminal co-morbidities on the grounds of frailty; diagnoses affecting cognition or mental health. These criteria were based on self-report. In addition, peer-befrienders were to be excluded if they scored  $\geq 3$  on the General Health Questionnaire-12 [32], indicating depressive symptoms. In fact, two potential befrienders scored 3 on GHQ. Following discussion, as they self-reported no mental health issues, had experience of offering peer-befriending, and were keen to take part, they were recruited into the trial, and their wellbeing monitored during regular supervision. Additional criteria for the role were developed in consultation with the project's consultants with aphasia ( $n=5$ ). These included good adjustment post stroke; to be confident, resilient, open and willing to talk with others; be able to concentrate for up to 3–4 h to enable them to manage the travel and visits; be able to use public transport or to drive. These additional criteria were assessed through self-disclosure, discussion, and the clinical judgement of the Trial Manager, NB, a qualified Speech and Language Therapist (SLT). After screening potential participants for eligibility, the Trial Manager consented them into the study. Nominations for potential peer-befrienders were received from the sites that were recruiting participants into the main trial (North London hospitals, community health services) as well as local services and voluntary organisations (e.g., The Stroke Association groups, Aphasia Re-Connect).

## Trial intervention and processes

### Peer-befriending intervention

The peer-befriending intervention was offered to adults who had recently had a stroke resulting in aphasia, and who had low levels of emotional distress, determined by scoring  $\leq 2$  on the Depression Intensity Scale Circles (DISCS) [25]. The befriending was offered following discharge from hospital and, where applicable, once intensive rehabilitation had ended. When matching befrienders with befriendeds, the following factors were considered: geographical location, journey time, as well as preferences around hobbies and interests, cultural factors, sex, and age. The befrienders visited people in their own home six times over a period of three months, with an optional further two visits within the next six months to support the transition to ending befriending. Visits included conversation and problem solving as well as activities such as looking at magazines together and trips out. It

was anticipated that visits would last around one hour. Further description of the intervention, including a TIDieR checklist, is provided in the published protocol [25]. Peer befrienders worked with no more than two befriendees at any time; they were paid per visit and for attending group supervision sessions.

### *Training and support*

Resources used in the SUPERB study are shared in the study website <https://blogs.city.ac.uk/superb/> and City Aphasia Lab's repository of research resources <https://cityaccess.org>. All befrienders received training based on an adapted version of a peer-befriending intervention manual [33]. This was adapted to reflect the SUPERB study protocol and sponsor requirements (e.g., monthly supervision, methods for check in/out, discussing goals of sessions, completion of record forms, City University's safeguarding, payments to befrienders). The training was run on three occasions as the befrienders were recruited into the study. The training lasted five to six hours across two to three days, led by two facilitators. Training was adapted to accommodate the number and abilities of befrienders in the group. It was delivered in a highly interactive format as a small group discussion. Discussion was stimulated through the use of worksheets and scenarios. Topics included the role of the befriender, dealing with challenging situations, health, and safety. Peer-befrienders received a peer-befriender handbook, containing key information in an aphasia-accessible format. In addition, peer-befrienders were offered monthly group supervision sessions, which they were encouraged to attend while actively befriending. They also received supplementary individual support as needed via the modality preferred by the befriender (e.g., telephone, email, face to face). Supervision and individual support were provided by the befriender supervisor (SMV), an SLT with expertise in setting up and running aphasia befriending schemes. Safe-guarding protocols for lone working were followed (e.g., texting in and out from visits). Further, the Trial Manager had visited all potential befriendees and assessed risk prior to visits commencing.

### *Data collection*

Befrienders were interviewed after completing two cycles of befriending, or one cycle where two cycles were not feasible. A topic guide was developed by the first author (SN) and further refined through discussion with the project's consultants with aphasia, as well as others in the qualitative research team (see Appendix 1). The order in which topics were covered varied as interviewer questions organically followed participant responses. The interviews explored befriender experiences of the visits, logistics, study procedures, training, and supervision. Participants were encouraged to reflect honestly on their experiences, with reassurances about confidentiality. The mean time taken to complete interviews was 62 min (range: 41–82 min). Interviews took place face-to-face either in the befriender's home or the university. No-one else was present during the interviews.

The interviewer, KM, was a female SLT who has worked with people with aphasia for nine years, including in research contexts. She received training in conducting in-depth interviews from SN, a senior qualitative researcher and SLT with experience of adapting qualitative interviews for people with aphasia. In addition to initial training, SN watched sections of video recordings to give feedback and facilitate reflection and was available to discuss issues as they arose. Steps were taken to facilitate the participation of people with aphasia, such as using visual supporting material and writing down key words. KM had met some of the

befrienders previously when assisting them to video-record a befriending session but was not otherwise involved in the befrienders' work. All interviews were video-recorded to ensure all types of communication used by befrienders was captured and transcribed verbatim, either by KM or by an external transcription company. Transcriptions were then checked for accuracy by KM and three student SLTs. KM made field notes for personal reflection: these were not included as part of the analysis.

### *Data analysis*

Data were analysed using the Framework method [34]. Initially, the data were reviewed to identify themes, thus themes emerged from the data rather than being pre-specified. This process resulted in a thematic index, developed by KM, which was further refined by discussion with SN. The thematic index was used to tag all the interview data. The labelled data were then synthesised in thematic matrices, with each main theme accorded a separate matrix. This method of organising the data were used to enable exploration of patterns within the data and systematic reporting of the range of views. An initial descriptive analysis was conducted by KM. SN independently read through all transcripts, revised all stages in the analytic process, and conducted the final analysis. This resulted in further refinements of themes, for example, foregrounding the perceived importance of relationship within befriending. Three student SLTs also independently analysed the data. These student analyses were inspected to provide reassurance that all main themes and diversity of experience were fairly represented. Data were managed using NVivo version 12.

## **Results**

### *Participant characteristics*

Of the 12 peer-befrienders that were screened and eligible, two withdrew consent for personal reasons before commencing befriending. The remaining 10 befrienders were matched with befriendees. There were 26 matches in total, with each befriender matched with between one and five befriendees, during the duration of the study. Of the 26 matches, two participants gave consent to receive befriending, were allocated a befriender, and subsequently changed their mind, declining visits. The remaining 24 matches completed at least two visits, and 21 matches completed all six visits. As interviews with befrienders took place after two successful cycles, befrienders were able to reflect on 19 matches, including three where <6 visits took place. Table 1 lists pseudonyms of befrienders matched with pseudonyms of befriendees and number of visits completed per match. Befriendee experiences are reported elsewhere, using the same pseudonyms [29].

Baseline participant characteristics are displayed in Table 2. There were eight female and two male befrienders; six were white, four were black; average age was 54 years old (range 42–72); average time post stroke was 10.5 years (range 2.8–19.8 years). Nine were working prior to their stroke; none were in paid employment when recruited into the trial although five were working as volunteers.

### *Main themes*

Seven main themes emerged from the data: content of the sessions; befriender–befriendee relationship; negotiating the visits; managing endings; training and support; impact of the befriending; and beliefs about the nature and value of peer support (Table 3).

**Table 1.** Befriender and befriended pseudonyms, characteristics, and visit information.

Befriender pseudonym	Befriender ethnicity and gender	Befriended pseudonym	Befriended ethnicity and gender	Number of visits	Visits within a residential care facility?	Befriended perspective reported in Moss et al. [29]?
Alice	F; White	Macey	F; Black	3	No	No
Yafeu	M; Black	Marilyn	F; White	6	No	Yes
		Ivy	F; Black	6	No	Yes + daughter's perspective
Louise	F; White	Santiago	M; Asian	0	No	No
		Marcellino	M; White	2	No	Daughter's perspective
		Max	M; White	2	No	No
Zainab	F; Black	Enid	F; White		No	Husband's perspective
		Samson	M; Black	6	No	Yes
Karen	F; Black	Trevor	M; White	6	Yes	Yes
		Jill	F; White	6	No	No
Joyce	F; White	Elizabeth	F; mixed race	6	Yes	Yes + daughter's perspective
		Rose	F; Black	6	No	Yes
Esther	F; Black	Beryl	F; White	6	Yes	No
		Graciela	F; Black	6	No	No
		Benjamin	M; White	6	No	Wife's perspective
Heather	F; White	David	M; White	6	No	Yes
Andy	M; White	James	M; White	6	No	Yes
		Gordon	M; Black	6	No	No
Mary	F; White	Lisa	F; Black	4 at time of interview (2 subsequent visits conducted)	No	No

F: female, M: male.

**Table 2.** Baseline characteristics of peer-befrienders.

Baseline characteristics	Peer befrienders in study, $n = 10$
Age (mean, S.D.)	54.2 years (8.4); range: 42–72
Sex	
Female	8
Male	2
Ethnicity	
Black	4
White	6
Marital status	
Single	3
Married	1
Has partner	5
Divorced	1
Employment	
Full-time or part-time paid work	0
Volunteer work	5
Retired prior to stroke	1
Retired because of stroke	1
Unemployed	3
Work prior to stroke	
Full-time paid work	7
Part-time paid work	2
Retired prior to stroke	1
Education	
Did not finish school	2
Finished school	2
Further education qualification (not university)	4
University degree	2
Able to drive	
No	6
Yes	4
Type of stroke	
Ischaemic	6
Haemorrhagic	4
Hemisphere of stroke	
Left	7
Right	3
Time post onset (mean, S.D.)	10.5 years (5.8); range: 2.8–19.8 years

## Content of sessions

### Sharing stroke experiences

It was common that befrienders both shared their own stroke stories and took an interest in hearing about the befriendeds' initial stroke experiences. They shared experiences of early days in hospital, their recovery, what they found helpful. Befrienders felt it was important that the befriended realised they were not alone. For example, Yafeu reflected that when he had a stroke, "you lose everything around you ... so you become alone." This influenced his belief that, "The whole befriending is share your experience with the others for them to know that they are not alone."

They noticed and encouraged befriendeds' achievements in their stroke recovery, for example, being able to hold a cup with one hand rather than two. Befrienders also shared strategies and tips, for example, how they handled speech mistakes, strategies for managing fatigue, poor memory, impaired sense of time or organisation. These conversations could help befriendeds make sense of what was happening to them.

He said he was still able to read, but he said, he said, after a while he said it's like I can't read it anymore. And I said, well, you know, by then, I said you gotta think about fatigue, overload, and he's like, oh, I said, yeah, yeah, I said well, you know, you can only fill up for so long, the bucket's only so big. (Heather)

Befrienders told befriendeds about local stroke groups, as well as other groups, such as exercise classes. They actively encouraged befriendeds to try out the groups, and in some cases were regular attenders themselves and could welcome them to the group. However, there was recognition that not all befriendeds wanted to attend groups or talk about the stroke. One befriender described value in talking about topics other than stroke:

First time I went to see her talking about um the stroke for one hour. But then after that we did other things you know. Because I think if it's, in the stroke, it's a little bit, uh, sad you know. (Louise)

### Conversation

The main activity within sessions was chatting. They discussed the interests of the befriended, such as cricket and football, hair and

Table 3. Main themes and subthemes emerging from interviews.

Themes	Subthemes
Content of the sessions	Sharing stroke experiences Conversation Activities
The befriender–befriendee relationship	Development of close bonds Challenging aspects Unsuccessful matches
Negotiating the visits	Negotiating journeys Scheduling appointments Managing the environment and unexpected incidents Managing anxiety Emotional reaction to befriender's situation
Boundaries and endings	
Training and support	Training Supervision sessions with peers One-to-one support
Impact of the befriending	Impact for befriender Impact for befriender
Beliefs about the nature and value of peer support	Providing a role perceived as valuable Using lived experience to share information and support Qualities needed in a peer befriender Overall evaluation

nails, music from different eras, movies or TV shows, travelling. They compared notes on common interests, such as having the same favourite football team, or spoke about their family. Some befrienders described how lighter conversations created intimacy (*"we spoke about things that never made any sense to anybody else but me and Elizabeth,"* Karen; *"silly stuff but meaningful,"* Alice).

It was common that befrienders observed a difference in how conversations worked when comparing befrienderes. For example, Esther explained that with her first match she talked about knitting and gardening, whereas in the second match they talked about geopolitical issues such as American aid to the Congo. To generate topics for conversation, befrienders described various strategies: they brought along magazines and newspapers; pointed to things in the room; shared photos on their phone. These strategies were particularly useful when the befriender had more severe aphasia: *"We used to look at people in the car park... she just seemed happy to look at the car park."* (Karen)

### Activities

Befrienders described going outside during visits, for example, going out for a coffee. Andy explained his motivation for going on outings. His first match rarely left the house or saw others. Andy remembered staying inside after his own stroke and felt others' encouragement to go out had helped his recovery. He therefore saw it as *"helpful, helpful"* for his befriender to leave his house: *"If it was a nice day we had a walk around, erm, chatting."* He encouraged him to speak to others in his neighbourhood on their walks, and also to go to a local stroke group. Befrienders also reported playing games such as dominoes and Ludo, listening to music, watching sports on TV, or knitting together.

### The befriender–befriender relationship

Of the 19 matches, 15 were perceived as successful, albeit sometimes challenging, while four matches were perceived as unsuccessful, including one which did not start.

### Matches where a close bond was developed

Befrienders described how they "clicked" with a befriender, and responded to their warmth, vibrancy, or friendliness. Ease of conversation was part of building rapport (*"Chat, chat, chat, chat,*

*chat, oh my God! Look at the time, that was really quick!"* Alice), as was having things in common, such as being from the same African country, or liking the same movies. Humour was bonding for many.

I laugh, I laugh then she laughed [laughs]. We bonded right from day one. (Esther)

It was common to describe the relationship as two-way and reciprocal (*"for them and for me,"* Andy), with befrienders sharing from their own lives, for example, reciprocally sharing photos. By the end of the six visits, some matches had built up real affection for one another. In some instances, befrienders described being inspired or influenced or learning from the befriender.

She's really kind lady, you know. And she's very um, warm, um. And I thought, I want to be like that. (Louise)

### Challenging aspects of matches

Severe aphasia was described as challenging. However, it was not a barrier to building a positive relationship, with befrienders expressing a commitment to find a way to connect. This is illustrated by Zainab. She visited her befriender in a nursing home and described him as having *"no speech"* which she found *"challenging."* Nonetheless, they bonded over listening to music and playing games. She described how when they played Ludo he would cheat: *"He just twist it and like that, and he get the six all the time, yeah, I said, Trevor! And he laugh, it funny. I think he enjoy, yeah."*

The befriender having a strong accent or being hard of hearing could also make communication more difficult. Further, it was concerning for the befriender if the befriender's health appeared to deteriorate. Conversations were also sometimes perceived as unequal. In some cases, befrienderes talked about themselves for long periods of time: *"He talked about 25 min. I couldn't talk. I was, I was sitting there and listening,"* (Esther). These challenges, however, were not perceived to threaten the overall success of a match. Befrienders saw it as part of their role to engage with someone with a communication and health disability. Their own stroke experiences appeared to give them empathy: *"But that's OK cos I do, 2003, all about me. I remember that, me, me, me, me, me. I dunno why, but you've gotta talk,"* (Alice).

### Unsuccessful matches

There was an expectation of understanding and reciprocity as befriender and befriended had both had a stroke. Where this did not occur, for example, because befriendeds were unfriendly, inconsiderate, or uncontactable, it could be hurtful. This is illustrated by Mary. She explained that *"I don't think she's very friendly... there was no interact between me and her."* The situation was compounded by the befriended not answering her door on several occasions after Mary had travelled across London to see her. Mary reflected: *"I've had a brain haemorrhage, I've had a stroke and everything else, that's quite a lot on me... it is tit for tat, isn't it, we've both had a stroke."* The impact on her was that *"It doesn't give me that I really enjoy."* She found the experience off putting and discouraging.

Severe memory difficulties and significant frailty could also threaten the success of a match. This is illustrated by Yafeu describing Marcellino: *"he couldn't remember anything... couldn't remember his past, it was difficult to get conversation from, you know ... even while we are talking he was, he was sleeping."* The visits had a negative impact on Yafeu: *"It's feel it's a challenge to you and as I said that make you feel more tired."*

### Negotiating the visits

#### Negotiating journeys

Managing complex journeys was a commonly reported challenge. Several participants described becoming lost and noted that their stroke meant finding their way was hard (*"me and direction is not that good,"* Zainab). The journey could also be tiring, requiring multiple modes of travel, and sometimes involving staircases. There were also unforeseen challenges, like finding the lift broken.

The thing is the step, two two storeys... I always tired when I reach there, I drink water. (Esther)

Journeys were made more manageable by the Trial Manager providing them with a map; and talking through difficulties with the befriender supervisor who provided real-time support (*"it's just anything, you ring,"* Alice). Less commonly befrienders did a trial run of the journey accompanied by a family member to build their confidence.

#### Scheduling appointments

Befrienders noted that both themselves and befriendeds sometimes found organising and remembering visits challenging due to their stroke. The befriender supervisor supported several befrienders in arranging visits. Despite the efforts made to fix visit times, befriendeds forgot on several occasions. Further, befriendeds had multiple health appointments, and in some cases busy lives, requiring rescheduling of visits. Befrienders described developing strategies such as phoning ahead to remind the befriended or in one case enlisting a befriended's brother to help. Despite this, there were still occasions when befrienders had wasted journeys.

He have appointment and he didn't tell me, and I show up at his home, one day, outside in the rain... it's a bit annoying but it's specially when you get wet. Nobody like to feel wet and miserable. (Zainab)

#### Managing the environment and unexpected incidents

Some environments were perceived as assets of the role: they enjoyed the views of the Olympic Park, the nice neighbourhood with cafes, the new carpet. However, accessing buildings was

sometimes fraught, for example, difficulties accessing blocks of flats. Another distraction was the TV being on in the background. Nursing homes could present particular challenges of noise and lack of privacy.

You cannot speak, erm, because Beryl is in a home, nothing's private ... one visit there was erm builder in here, I think there was a choir in there, and the noise was quite, really, really noisy, and that was a bit, yeah, very a bit hard work. (Joyce)

Befrienders also described managing unexpected incidents hard. For example, a befriender described how upset she became when a nursing home resident and manager were aggressive and hostile to her.

#### Managing anxiety

Several befrienders described feeling anxious: they worried about finding their way and how they would manage if they became lost, were anxious about going into people's homes, and worried about whether they would be accepted and liked. Although a subset described feeling confident about visiting strangers, first visits often provoked anxiety.

Obviously the first meeting you're always like oh my God, what they gonna be like, you know, am I gonna get on with them, are they gonna be really horrible, and I gonna find the place, am I gonna get lost? ... I think sometimes we overthink because of the stroke. (Heather)

#### Emotional reaction to befriended's situation

Witnessing another person's difficult situation sometimes provoked a strong emotional response in the befriender. They described feeling sad when they perceived their befriended was not visited by friends or family or had severe aphasia. They also felt sad to witness someone moving into a nursing home post stroke. This is illustrated by Zainab, who visited Trevor. Trevor had moved into a nursing home as a result of his stroke and received no visitors: *"my heart goes out to him, especially when he doesn't have a family around you. It is really sad, really, really sad."* It unsettled her as it reminded her of early days after her own stroke: *"I was there in the back of my head saying you were there ... Trevor kinda throw me back a bit, I just think about I was like him before."*

#### Boundaries and endings

It was common to describe the ending as challenging: the study protocol required a fixed maximum number of visits. It was difficult when they had bonded closely, or felt the visits were useful or valuable to the befriended. It contrasted with the ongoing nature of other stroke friends many had made. Yafeu described: *"we get close to the person so, and closer, then just disappear from the person's life again, you know, it's hard."* Befrienders described how they missed their befriended. The sadness was compounded if the befriender was themselves bored or alone.

Well it's hard ... it's a nice lady you know. And it's a shame because, like a coffee or something and a chat but no just, that's the rules so ... Because on my own way, you know, quite often I'm alone. (Alice)

It made the ending harder when the befriended had few or no other visitors and the befriender was concerned for them; when the befriended appeared upset that there were no further visits; or when the befriender thought they had further visits left to say goodbye. Some befrienders advocated a more flexible approach or suggested additional visits. However, there was also recognition of the benefits of having a fixed number of visits, as this

protected the befrienders from an open-ended commitment or becoming overly attached. Endings were easier when the befriender anticipated meeting the befriender again in a stroke group, when they knew the person had family or other support, when the befrienders retained awareness that the visits were time limited, when the ending was marked in some way (e.g., exchange of cards or gifts), or when the relationship was less good.

Where befriending ended prior to completing all six visits, this could negatively affect befrienders who found it disappointing if they had planned activities or anticipated positive benefits for the befriender. For example, Yafeu, reflecting on the match that never started, said he was *“disappointed,”* as he had hoped *“maybe I can help him to do thing, rather than staying home... pick up his life again.”* For one match, the befriender failed to cancel an arranged visit, was subsequently uncontactable, and never explained to the befriender why she had ended the visits, leaving the befriender *“angry and hurt”* (Alice).

## Training and support

### Training

Befrienders were positive about receiving training in a small group, describing the training as enjoyable, interesting, and useful. Following training they felt prepared and excited. It also allayed fears and underlined that they would be supported in their role.

This [training] was brilliant and the only thing I was worried about that someone's not gonna be behind me and... that's what I really liked cos I know I've got nothing to worry about... I couldn't wait to go. (Joyce)

A common theme, however, was that it was difficult to remember everything, and therefore it was helpful to have aspects of the training revised during ongoing supervision. For many befrienders there was a preference for training to be offered over several days in smaller chunks of time: *“it's heavy duty concentrating like half a day”* (Alice). Aphasia could also make it challenging to make notes or read hand-outs.

### Supervision sessions with peers

Befrienders liked being supervised in a small group. They were positive about their peers and perceived the group as supportive and encouraging: *“you need the crew”* (Joyce). They valued the fact that they had all had a stroke and were sometimes inspired by their peers. The groups were a chance to share stories, to hear how others were progressing, to give and receive advice and ideas. They also used the group to share disappointments and situations that upset or worried them, for example, handling requests for personal phone numbers. Although all participants described peers as supportive, an exception was when a befriender felt the group disapproved of her inclusion of a spouse within the befriending sessions, leaving her feeling cross.

The role of the supervisor was valued. She was perceived as highly supportive (*“support us all the time... is the top,”* Esther). She gave practical suggestions, resources to take to visits, as well as encouragement. She enabled group members to reflect on their conversational style, and to feel their contributions had been heard by the rest of the group:

I'm verbalising too slowly for it all to come out, so then I sort of think to myself what the hell am I actually trying to say. And she's very and [supervisor]'s very good at, like sort of deciphering it... she'll, she'll say well, well Heather's made a good point about and I think, oh blimey,

yeah, I did say that didn't I... so you feel like you've contributed. (Heather)

Most befrienders felt that having monthly hour-long sessions was an appropriate frequency, particularly when actively befriending. For befrienders with more extensive experience of peer support, they sometimes found the revisiting of key themes and topics less necessary. Travelling to and attending supervision necessarily took time and effort, so while appreciated, it was also noted that it sometimes took them away from other valued activities.

### One-to-one support

A common theme was that the personalised one-to-one support provided throughout the study was highly valued. They appreciated that the befriender supervisor was available to them for phone or video calls, helped them with paperwork or organisation, monitored their safety during visits, as well as listening to their concerns and providing reassurance. They felt confident she would be there for them in an emergency.

[Supervisor] will make you OK and can make you feel confident. (Esther)

Befrienders also appreciated that the Trial Manager had met all befrienders and was able to discuss both the journey and potential issues around the match so they could make an informed decision. He was also perceived to assist them with problems, for example, Joyce was struggling with a befriender's daughter who *“was there the whole time and I thought, God, this is too much.”* The Trial Manager phoned the daughter and resolved the situation, facilitating the success of the match.

## Impact of the befriending

### Impact for befriender

**Interesting and rewarding experience.** A common theme was that befriending was enjoyable and interesting. Befrienders liked meeting new people, learning about their lives, and building reciprocal connections, all of which made them *“really happy”* (Louise).

They're interesting people, and I enjoyed it... other people, what their jobs were, what they used to do. (Andy)

Befrienders reported how satisfying and rewarding they found it when they believed they had made a difference to someone else and witnessed the befriender respond to their encouragement and make progress. (*“You get good rewardings for it,”* Joyce). This is illustrated by Yafeu, who had encouraged his befriender to go out. In a later visit he relayed: *“she was telling me that, oh, I went out this morning, I went to the park here this morning... there's changes, yeah, it makes me feel excited, really happy, but yeah, at least somebody take your advice for once!”* He explained how this made him feel *“useful... at least we're helping people.”*

**Secure challenge.** Several befrienders saw it as an enjoyable challenge that was exciting. This sometimes linked to their pre-stroke identity. They liked the challenge of pushing themselves to use public transport and go into other people's houses. They perceived this as helpful to their post-stroke recovery. Given the support of the befriender supervisor, it was perceived as a relatively *“safe”* challenge.

I love it because also it benefits me, erm, it's a bit of a challenge... open the door and see who it is. I know I've got someone behind me... I feel secure in that way. (Joyce)

**Return of pre-stroke self.** The process of receiving training, going for supervision, and making a serious commitment resonated with pre-stroke work identities for some. This was perceived as exciting and valuable. It could validate that they had knowledge and skills and make them realise how much they knew. They also noticed and drew on their work skills within their peer-befriending role, e.g., ability to speak to people from different backgrounds as a former lawyer.

I think enjoyed the training because training reminded me of going to work... it made you feel more, like you're normal, because I'm not working any more. So getting up and going to training was really exciting. (Karen)

**Increased activity.** For some befrienders, it was a reason to leave the house. It provided a break from the boredom of being home alone. Several befrienders described how they combined visits with other activities, such as shopping or enjoying nice cafes in the befriender's neighbourhood, and made a day of it.

Getting out like an outing, that's the thing... so boredom, I'm bored, I can't work. (Alice)

**Improved speech.** The opportunity to have regular conversations was perceived by some as leading to improvements in their speech. It seemed to lead to improved confidence in their ability to hold conversations, including with strangers and acquaintances.

I talk too much, and then, I go I go to my dry cleaner I talk about anything, I go to my minicab, I talk about anything... my friends see me, they were shock [laughter] they said I could not, they could not believe it, I talked very much... I feel exceptional. (Esther)

**Comparison with positive impact.** Witnessing the difficult life situations of befriendees was sometimes distressing, as described above. However, it could also make befrienders feel grateful for aspects of their own life: for their own loving family, their own close friends, for their own level of post-stroke recovery, and that they had been able to return to their own homes after their stroke.

**'Still me': stability in befrienders' identity and situations.** No befriender reported a negative impact on their mood as a result of becoming a befriender. Nonetheless, a subset of befrienders described continuing difficulties, such as feeling alone and experiencing fluctuating mood (*"my mood's up and down, up and down... I'm stuck, no one to help me, so that's hard."* Alice). Another subset noted that befriending had not "changed" them, as they were always confident or bubbly, and that they would not want to change who they are. As such, befriending was a positive experience that augmented their life rather than transforming it.

I'm still me. I'm still me, I wouldn't change, it's only that I feel more alive again. (Zainab)

#### **Perceived impact for befriendees**

A common theme was that the visits were perceived to make the befriender laugh, smile, feel positive, more confident: *"She, mmm, stroke have made her not smile, I laugh. She look at me, and then she laughs."* (Esther) They also perceived that the visits had provided valued friendship and companionship. For more isolated befriendees, they felt that the befriender looked forward to being able to see someone regularly. The visits were also perceived to

encourage befriendees to go out more, for example, start going to stroke groups or to the park. Finally, befrienders described how the visits resulted in the befriender talking more, for example, a befriender with severe aphasia starting to say more words. The most successful matches were perceived to make a difference to the way the befriender had responded to their stroke and resulted in valued friendship. One befriender received a framed photograph with the following message:

Dear Alice, thank you for your friendship, thank you for your positive vibes, thank you for making me laugh, my very best wishes to you, love Marilyn. (Alice)

Where matches were perceived as unsuccessful, it was harder for befrienders to be sure what difference, if any, visits had made. This was underlined for Mary when in the fourth session, the befriender *"did ask me how I come for, why do I come to see her."* For one match, the befriender had a very mild stroke and active life. The befriender considered him *"really fine, absolutely,"* (Louise) and not needing six visits.

#### **Beliefs about the nature and value of peer support**

##### **Taking on befriender role as it is what they would have wanted**

One motivation for becoming a befriender was that they believed they would have benefitted from receiving a befriending service early in their own stroke journey. They reflected that after their stroke they had limited understanding about stroke and aphasia: *"two years I didn't know with aphasia."* (Louise). They had felt alone, did not know anyone who had a stroke or aphasia, and many described dark days when they felt *"it's the end of your life, it's all finished."* (Karen). They perceived it would have been useful to them if they had met someone with experience of stroke and aphasia, who could understand what they were going through, "normalise" their experience, and give them hope about what's possible after a stroke.

You're surrounded by people but all people that've never had stroke, did not really understand stroke... so it would've been nice to have someone come and say, well, I did have a stroke and now I'm able to, look, I'm able to even come to you. I would've appreciated that I think. (Karen)

##### **Unique ability of people with stroke to provide information and support**

All the befrienders believed that people with stroke are uniquely well placed to be offering support and information to others with stroke. The most common reason was that people living with aphasia brought understanding: they understood what it feels like to have a stroke and your world turned upside down, they had empathy for the person's struggles with language and other stroke related symptoms such as fatigue, they had *"been down the same road."* (Karen).

They understand you, you know, and you understand them... you make a mistake, they're not gonna laugh at you that you say something wrong, because they know that it can happen to them, you know, so yeah, that's the point. (Yafeu)

Befrienders noted that it could be hard for people to talk about their feelings after a stroke. It was sometimes difficult to talk about distress and frustration with family and friends. For some befrienders they felt that enabling a person with stroke to talk about their feelings was important, and that people found it more possible to confide in them because they had also had a stroke.

When you talk to someone that's had one they talk about word more about just stroke, how they feel, which no-one does. So this means quite a lot to that person. (Joyce)

Their stroke made some befrienders motivated to seek ways in to connect with people with severe aphasia. It also changed how they interacted, for example, made them more tolerant if a person appeared quiet or withdrawn. As Karen explained: *"I'm quite happy to sit with her Elizabeth because I remember when I couldn't speak and I think because you can understand because, because you've actually been there and you've been, I've been in Elizabeth's shoes, where it is a struggle to talk."*

There was a widespread conviction that they were also well placed to provide information, share strategies and tips from their own experience, and provide local knowledge about groups and activities. This is illustrated by Heather. She relayed her own experiences of being sent information packs which she could not read, or told about helplines which she found inaccessible: *"you can get an email or ring the helpline or, and it's like, well, it's not as simple as that when you've had a stroke, do need yeah, the personal touch of someone just who has been through it."*

Finally, some befrienders saw the value of being a role model, supporting others who were struggling with living with a stroke, and helping them to believe that there is hope. Yafeu spoke about wanting to give back to his community, through sharing his own story of recovery.

I mean I pick up myself and start to attempt to get myself better I think that's what people like about it ... they have their stroke, that's it, they told them, that's the end of their life. Like how I was thinking before, but that's not the end, maybe it's a new, beginning with a new chapter. (Yafeu)

### **Reflections on what is needed from a peer-befriender**

A common theme was that it was important to put the befriender first. This meant listening to them, being interested in them, being patient, and being aware that some of their problems might not be visible. There was also recognition that it was a commitment, and that it was important that potential befrienders needed to be *"at the right point in their own journey"* (Heather), for example, it was not felt appropriate to speak at length about their own current difficulties. Personal qualities such as having an open, positive outlook were considered helpful, as was having knowledge about stroke, and bringing their authentic selves into the role: *"just be all yourself."* (Yafeu)

### **Overall evaluation**

Befrienders in this project were pleased to have worked on the SUPERB trial. Only one befriender, Mary, had a more negative experience based on a single less successful match, although still believed in the potential value of peer support. Befrienders recommended the scheme should be incorporated into routine care. Peer-befriending was considered a worthwhile, enjoyable and satisfying experience with the potential to make a positive difference to both befriender and befriender.

The best thing is that I like happy and they satisfied with me that I've been there, they feel good about themselves, and I feel good about myself, yeah, that's the best thing. (Zainab)

## **Discussion**

This study explored the experiences of people with aphasia working as peer-befrienders within the SUPERB trial. Befrienders perceived the role as enjoyable and rewarding, and felt they were

making a positive difference in someone else's life. They experienced it as a secure challenge, which enabled them to reconnect with aspects of their pre-stroke identity. They all had a strong belief that people with aphasia can offer unique support to others post stroke as they can relate to the difficult emotions and offer practical suggestions. They described a number of challenges: negotiating complex journeys, scheduling appointments, challenging communication environments, managing unexpected incidents, witnessing befriender's distress. Where a match broke down, for example, repeated cancelled visits or a befriender not engaging, this was upsetting for befrienders. Training, group supervision and flexible one-to-one support was considered essential to enable them to handle these challenges.

People with aphasia may be able to provide a unique form of psychological support that is distinctive from therapy provided by a healthcare professional or volunteer without lived experience of aphasia. The befrienders in this study believed that their own experiences of the stroke enabled them to offer understanding and relate to the challenges of the befriender, matching what has been reported in other health studies [13,15,19], and also what was reported by the befrienders in the current study [25]. Peer-befrienders potentially have more time than health professionals, and the close, reciprocal relationship based on living through similar experiences may create trust [35], suggesting peer-befrienders may be well-placed to provide emotional support. In reviewing the mechanisms of peer support, Watson [17] found that the use of lived experiences underpinned beneficial outcomes for both befriender and befriender, enabling the befriender not only to empathise but also to role model recovery. Peer-befriending has also been used to help people navigate difficult transition periods such as from hospital to community [36]. Similarly, in the present project, befrienders were a role model for recovery, while supporting befrienders through the transition from hospital discharge to living with stroke in their communities, for example, encouraging them to leave their house for a coffee, or attend a stroke group for the first time, or listening and helping them make sense of their experiences.

Befrienders described the experience as valuable and rewarding. In common with other health befriending studies, making a difference to someone else was perceived to give befrienders a sense of purpose, and that they were accomplishing something useful [16,19]. In a study exploring what goals are meaningful to people with aphasia, a main theme was contribution: people with aphasia reported wanting to be able to help others [37]. Befriending offers this possibility. It potentially enables people with aphasia to reframe their own narrative, and *"transforms what has been most traumatic into that which is worthwhile"* [17], enabling a shift in identity whereby their illness, rather than being a source of shame or stigma, is a valuable asset. Within the present study, befrienders voiced their satisfaction in being able to use their own journeys to help others. No befriender referred to their aphasia as a barrier to delivering the role.

Befriending also enabled them to reconnect with aspects of their pre-stroke identity. A study exploring the experiences of peer support workers with chronic disease described how the role enabled them to regain confidence and skills they perceived they had lost through their illness, enabling them to take on a valued societal role [38]. Only 28.4% of working age people with aphasia return to work following their stroke, compared to 44.7% of people with stroke and no aphasia [39]. The majority of the befrienders in the present study were of working age: they described feeling excited to reconnect to former work identities and feel more *"normal."* For some, it also increased their

confidence talking, replicated in a study exploring the impact of volunteering for people with aphasia [23].

An achievement of the current project is the ability of peer-befrienders to connect with befriendedees who had severe aphasia. People with severe aphasia have worse quality of life than people with mild-moderate aphasia [40], underlining the importance of investigating effective ways to provide psychological care to this group. It is noticeable that in previous stroke research, peer support workers who did not have aphasia reported finding communicating with people with aphasia challenging, even though people with more severe aphasia were excluded in these studies [41,42]. While the befrienders in the present study found working with people with severe aphasia a challenge, they nonetheless perceived it as rewarding and feasible. The befrienders own aphasia appeared to give them motivation and understanding to reach out to people with severe language disability, and they perceived they had support in working out successful strategies. A review of peer support interventions investigated which strategies were effective in facilitating effective engagement with those that are "hard to reach," such as those with significant disability, or who are socially isolated [35]. All the key strategies were observed within the SUPERB trial: trust and respect, stemming from the befrienders having experience of the health condition; flexibility, such as home visits arranged around the needs of the befriendedee; user involvement in developing the programme; frequent contact during the intervention period; support for the befrienders; and content tailored to the individual befriendedee.

Although peer-befrienders were pleased to be involved in the trial, it was nonetheless a challenging intervention to deliver. Stroke-related disability, including less visible difficulties such as fatigue, and impaired time and organisational management, meant retaining information from training, negotiating journeys, and managing schedules were sometimes perceived as a challenge. People with aphasia have described fatigue as a major factor influencing their ability to take on voluntary roles [23]; and peer support workers with chronic health conditions have reported exhaustion, and managing administrative and organisational aspects of the role, as challenges [38]. In a Canadian stroke study peer support workers successfully met people with stroke in hospital, but struggled to provide the follow up calls: it was perceived as too effortful, requiring memory and organisational skills that were a challenge post stroke, such that this part of the role was mostly taken over by the scheme coordinator [42]. In that sense, the SUPERB trial befrienders were enabled, through training and supervision/support, to offer a more complex intervention successfully, involving travelling across a major city, managing appointments, and negotiating often challenging environments. Peer support workers have also voiced concerns over their own safety and vulnerability when visiting others in their own homes [36]. In the present study, befrienders had stroke-related disability and were arguably a vulnerable workforce, yet although they were sometimes anxious, they did not describe feeling unsafe. They appeared to have found it reassuring that the Trial Manager had met all potential befriendedees in their home environment, and that the supervisor provided real-time and reliable support, enabling them to feel safe.

In addition to the logistical challenges, there were also emotional challenges associated with the role. A common concern for peer-befrienders is witnessing other people's distress [42–44], worrying about becoming overly involved [19], concern or frustration that they do not have the skills to help someone in distress [19,42], and the concern that it may trigger relapse in their recovery [36]. SUPERB befrienders were upset to witness befriendedees'

sadness: this could make it harder to end the visits and could remind the befriender of former difficult episodes in their own life. Regular supervision, including one-to-one support as necessary, appeared to be essential in enabling the befrienders not to become overwhelmed by the role. Another emotional challenge was when the match was unsuccessful, which affected the befrienders, and could leave them feeling upset or angry. Other research has also found that peer-befrienders experience high levels of self-blame and distress if they perceive that the outcome is poor [13]. Unlike professional workers, it is the lived experience and personal identity that are central to peer-befrienders' work: as such, they bring their whole selves to the role [17], which may make client disengagement or rejection of the intervention more personal and therefore more upsetting for peer-befrienders than for professionals.

A strength of the current study was that all 10 befrienders agreed to participate in interviews, including the befriender with the most negative experiences, and their perspectives on 19 matches were captured. It is a strength of the trial that the befrienders reported feeling valued, and felt their expertise was respected, contrasting with a review of mental health peer support where a theme was peer support workers feeling their expertise and work was not recognised or acknowledged [43]. A number of steps were taken to increase trustworthiness of the findings, such as multiple analysts; however, the results were not member checked with the befrienders. The current study was located in London: it is unclear how the challenges would translate in a different geographical or cultural context. Further, caution should be taken in terms of extrapolating from befrienders' experiences: the befrienders were mostly women, were on average 10 years post stroke, and mostly had their stroke under the age of 50. They are not typical of the wider stroke population, and their experiences may not translate to those who are older when they had their stroke, or who are fewer years post onset. Indeed, the befrienders stressed that it was important that people with aphasia considering the role were at the "right" stage post stroke in terms of their own emotional recovery.

In terms of future directions, not all people post stroke will be drawn to, or suitable for the befriending role. Identifying what factors predict who will be successful in the role potentially merits further research. Further research could also explore who is an appropriate candidate to receive peer-befriending. There is a responsibility not only to the recipient of the intervention, but also the peer-befriender: clients who do not engage, for example, due to extreme frailty or disinterest, may have more of a negative impact on the morale of befrienders than would be the case with professionals. Further consideration could also be given to preparing befriendedees for their "role" in the dyad and supporting their understanding of how befriending differs from therapy delivered by healthcare professionals. There is also the issue of endings. Given the reciprocal friend-like nature of the peer relationship, endings were often found to be hard in this project, both for befrienders and also befriendedees [29]. Peer support workers in a mental health context similarly reported finding endings distressing, and felt underprepared for the depth of emotions experienced [45]. Careful thought is needed on how best to prepare and support befrienders in managing both the process and emotions of endings. Insights gained from this study have informed how to adjust aspects of the SUPERB peer-befriending scheme for a definitive trial and are reported with the feasibility trial results [46].

Research could also explore the issues that may emerge when befriending in aphasia is integrated into mainstream health

services. In the current project, all training and support was provided by study personnel with extensive experience of and commitment to aphasia befriending schemes. There is some evidence that when peer-befriending sits within mainstream health services there are additional challenges, such as healthcare professionals misunderstanding the scope of the role [36], peer support workers finding the administrative duties challenging, and not necessarily aligned with the more “relational” nature of their work [13]; and power structures being difficult to negotiate, particularly if befrienders have recently been patients themselves [15]. It is possible that certain structures, such as voluntary organisations, may more easily retain the unique flavour and values of peer support [47].

Successful peer-befriending relies on the capacity of the peer-befrienders to engage and commit to a challenging role. It asks them to deliver a complex intervention while handling their own fatigue and other post-stroke disability, and develop close relationships drawing from their own lived experience while also maintaining boundaries in a role that sits in the space between healthcare recipient and provider. The current study suggests that the role is indeed challenging, yet despite the challenges, as long as peer-befrienders are sensitively and carefully supported, this intervention is highly acceptable and rewarding to deliver. Peer-befriending appears to offer a unique form of support which can enable people to make sense of their aphasia and begin a journey to living well with their disability.

## Acknowledgements

We thank the recruitment sites and the participants in the study. We also thank Elinor Girdler, Helen Males, and Sylvia Toh who analysed the data for their student projects. KG's contributions represent independent research part funded by the NIHR Biomedical Research Centre (South London and Maudsley NHS Foundation Trust and King's College London) and the NIHR Applied Research Collaboration South London (King's College Hospital NHS Foundation Trust).











## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Funding

SUPERB was funded by The Stroke Association, Psychological Consequences of Stroke – Priority Programme Award [PPA2015-03].

## ORCID

S. Northcott  <http://orcid.org/0000-0001-8229-5452>  
 N. Behn  <http://orcid.org/0000-0001-9356-9957>  
 B. Moss  <http://orcid.org/0000-0003-0340-533X>  
 J. Marshall  <http://orcid.org/0000-0002-6589-221X>  
 S. Thomas  <http://orcid.org/0000-0003-0704-9387>  
 A. Simpson  <http://orcid.org/0000-0003-3286-9846>  
 S. McVicker  <http://orcid.org/0000-0002-4939-4210>  
 C. Flood  <http://orcid.org/0000-0001-5170-7792>  
 K. Goldsmith  <http://orcid.org/0000-0002-0620-7868>  
 K. Hilari  <http://orcid.org/0000-0003-2091-4849>

## References

- [1] Feigin VL, Norrving B, Mensah GA. Global burden of stroke. *Circ Res*. 2017;120(3):439–448.
- [2] Brumfitt S. Introduction. In: Brumfitt S, editor. *Psychological well-being and acquired communication impairments*. Chichester: Wiley-Blackwell; 2010.
- [3] Ayerbe L, Ayis S, Wolfe CD, et al. Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. *Br J Psychiatry*. 2013;202(1):14–21.
- [4] Rafsten L, Danielsson A, Sunnerhagen KS. Anxiety after stroke: a systematic review and meta-analysis. *J Rehabil Med*. 2018;50(9):769–778.
- [5] Flowers HL, Skoretz SA, Silver FL, et al. Poststroke aphasia frequency, recovery, and outcomes: a systematic review and meta-analysis. *Arch Phys Med Rehabil*. 2016;97(12):2188–2201.
- [6] Kauhanen ML, Korpelainen JT, Hiltunen P, et al. Aphasia, depression, and non-verbal cognitive impairment in ischaemic stroke. *Cerebrovasc Dis*. 2000;10(6):455–461.
- [7] Northcott S, Marshall J, Hilari K. What factors predict who will have a strong social network following a stroke? *J Speech Lang Hear Res*. 2016;59(4):772–783.
- [8] Hilari K, Northcott S. “Struggling to stay connected”: comparing the social relationships of healthy older people and people with stroke and aphasia. *Aphasiology*. 2017;31(6):674–687.
- [9] Townend E, Brady M, McLaughlan K. Exclusion and inclusion criteria for people with aphasia in studies of depression after stroke: a systematic review and future recommendations. *Neuroepidemiology*. 2007;29(1–2):1–17.
- [10] Northcott S, Simpson A, Moss B, et al. Supporting people with aphasia to ‘settle into a new way to be’: speech and language therapists’ views on providing psychosocial support. *Int J Lang Commun Disord*. 2018;53(1):16–29.
- [11] Baker C, Worrall L, Rose M, et al. Stroke health professionals’ management of depression after post-stroke aphasia: a qualitative study. *Disabil Rehabil*. 2021;43(2):217–228.
- [12] Baker C, Worrall L, Rose M, et al. A systematic review of rehabilitation interventions to prevent and treat depression in post-stroke aphasia. *Disabil Rehabil*. 2017;40(16):1870–1892.
- [13] MacLellan J, Surey J, Abubakar I, et al. Peer support workers in health: a qualitative metasynthesis of their experiences. *PLoS One*. 2015;10(10):e0141122.
- [14] Burke E, Pyle M, Machin K, et al. The effects of peer support on empowerment, self-efficacy, and internalized stigma: a narrative synthesis and meta-analysis. *Stigma Health*. 2019;4(3):337–356.
- [15] Repper J, Carter T. A review of the literature on peer support in mental health services. *J Ment Health*. 2011;20(4):392–411.
- [16] Biggs LJ, McLachlan HL, Shafiei T, et al. Peer supporters’ experiences on an Australian perinatal mental health helpline. *Health Promot Int*. 2019;34(3):479–489.
- [17] Watson E. The mechanisms underpinning peer support: a literature review. *J Ment Health*. 2019;28(6):677–688.
- [18] Lloyd-Evans B, Mayo-Wilson E, Harrison B, et al. A systematic review and meta-analysis of randomised controlled trials of peer support for people with severe mental illness. *BMC Psychiatry*. 2014;14(1):39.
- [19] Arnstein P, Vidal M, Wells-Federman C, et al. From chronic pain patient to peer: benefits and risks of volunteering. *Pain Manage Nurs*. 2002;3(3):94–103.

- [20] Schwartz CE, Sendor RM. Helping others helps oneself: response shift effects in peer support. *Soc Sci Med*. 1999; 48(11):1563–1575.
- [21] van der Gaag A, Smith L, Davis S, et al. Therapy and support services for people with long-term stroke and aphasia and their relatives: a six-month follow-up study. *Clin Rehabil*. 2005;19(4):372–380.
- [22] Vickers C. Social networks after the onset of aphasia: the impact of aphasia group attendance. *Aphasiology*. 2010; 24(6–8):902–913.
- [23] Pearl G, Sage K, Young A. Involvement in volunteering: an exploration of the personal experience of people with aphasia. *Disabil Rehabil*. 2011;33(19–20):1805–1821.
- [24] Lanyon L, Worrall L, Rose M. "It's not really worth my while": understanding contextual factors contributing to decisions to participate in community aphasia groups. *Disabil Rehabil*. 2019;41(9):1024–1036.
- [25] Hilari K, Behn N, Marshall J, et al. Adjustment with aphasia after stroke: study protocol for a pilot feasibility randomised controlled trial for Supporting wellbeing through PEER Befriending (SUPERB). *Pilot Feasibility Stud*. 2019;5(1):14.
- [26] Dennis C-L. Peer support for postpartum depression: volunteers' perceptions, recruitment strategies and training from a randomized controlled trial. *Health Promot Int*. 2013; 28(2):187–196.
- [27] Simpson A, Oster C, Muir-Cochrane E. Liminality in the occupational identity of mental health peer support workers: a qualitative study. *Int J Ment Health Nurs*. 2018;27(2): 662–671.
- [28] NHS Improvement. Psychological care after stroke: improving stroke services for people with cognitive and mood disorders; 2011. Available from: <http://www.nice.org.uk/>
- [29] Moss B, Behn N, Northcott S, et al. "He gave me advice, and hope": a qualitative exploration of outcomes and experiences of the SUPERB peer befriending scheme. *Disabil Rehabil*; 2021; submitted for publication.
- [30] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–357.
- [31] Enderby P, Wood V, Wade D. Frenchay aphasia screening test. Windsor (UK): NFEW-Nelson; 1987.
- [32] Goldberg D. The Detection of Psychiatric Illness by Questionnaire. London (UK): Oxford University Press; 1972.
- [33] McVicker S, Swinburn K. How to set up a befriending scheme: a guide for scheme organisers. UK: Connect Press; 2009.
- [34] Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess R, editors. *Analysing qualitative data*. London: Routledge; 1994.
- [35] Sokol R, Fisher E. Peer support for the hardly reached: a systematic review. *Am J Public Health*. 2016;106(7):e1–e8.
- [36] Forchuk C, Martin M-L, Sherman D, et al. An ethnographic study of the implementation of a transitional discharge model: peer supporters' perspectives. *Int J Ment Health Syst*. 2020;14(1):1–11.
- [37] Worrall L, Sherratt S, Rogers P, et al. What people with aphasia want: their goals according to the ICF. *Aphasiology*. 2011;25(3):309–322.
- [38] Barlow JH, Bancroft G, Turner AP. Volunteer, lay tutors' experiences of the chronic disease self-management course: being valued and adding value. *Health Educ Res*. 2005;20(2):128–136.
- [39] Graham JR, Pereira S, Teasell R. Aphasia and return to work in younger stroke survivors. *Aphasiology*. 2011;25(8): 952–960.
- [40] Hilari K, Byng S. Health-related quality of life in people with severe aphasia. *Int J Lang Commun Disord*. 2009; 44(2):193–205.
- [41] Morris R, Morris P. Participants' experiences of hospital-based peer support groups for stroke patients and carers. *Disabil Rehabil*. 2012;34(4):347–354.
- [42] Kessler D, Egan M, Kubina L-A. Peer support for stroke survivors: a case study. *BMC Health Serv Res*. 2014;14(1):1–9.
- [43] Shalaby RAH, Agyapong VI. Peer support in mental health: literature review. *JMIR Ment Health*. 2020;7(6):e15572.
- [44] Smith R, Drennan V, Mackenzie A, et al. Volunteer peer support and befriending for carers of people living with dementia: an exploration of volunteers' experiences. *Health Soc Care Commun*. 2018;26(2):158–166.
- [45] Simpson A, Quigley J, Henry SJ, et al. Evaluating the selection, training, and support of peer support workers in the United Kingdom. *J Psychosoc Nurs Ment Health Serv*. 2014; 52(1):31–40.
- [46] Hilari K, Behn N, James K, et al. Supporting wellbeing through peer-befriending (SUPERB) for people with aphasia: a feasibility randomised controlled trial. *Clin Rehabil*. 2021.
- [47] Faulkner A, Basset T. A long and honourable history. *J Ment Health Train*. 2012;7(2):53–59.

## Appendix 1.

### Topic guide

#### Objectives:

1. Explore their experiences of delivering peer befriending
2. Explore their experiences of training and supervision within the project
3. Explore the impact on their lives of taking part in the project

#### 1. Background information

- 1.1 How long ago had stroke
- 1.2 About their involvement with project: who they saw; where had supervision, etc.
- 1.3 Whether this project is their first experience of volunteering/working since the stroke

#### 2. Training and supervision

- 2.1 Training
  - how they found it
  - what they found useful/less useful
  - anything that was difficult/more challenging
  - how well prepared they felt prior to befriending
- 2.2 On-going supervision and support
  - elicit description of supervision process (how big was group; how did the supervision sessions work, etc.)
  - their experience of supervision (general, what was more useful/less useful; anything challenging/difficult)

- 2.3 Specific description of something they brought up at supervision session
- Consider a situation/case you discussed at supervision
  - Description of how handled by supervisor/group
  - What was helpful/less helpful
3. **Experience of befriending**
- 3.1 Map out: type of activities did together; befriender's interests and what they preferred to do with befriender, etc.
- 3.2 Logistics – how sessions were organised (any difficulties); how they negotiated timing of next visit; how they decided on what they would do together
- 3.3 Their experiences of being a befriender
- what worked well/less well;
  - anything challenging/difficult and how this was negotiated;
4. **Impact of befriending on their lives**
- Explain interested to know what difference it has made to be a befriender – to them, to their lives; what has changed for them since becoming involved with this project, if anything. [nb – make clear, acceptable to say, no change]*
- May help them to ask them to think back to how they were before the training.*
- Start with general question (e.g., “so, what difference has it made? If any?”)
- Possible prompts/areas to probe (in terms of change, and what has brought it about):

- Confidence
    - Feeling useful
    - Feeling part of a community
    - Feeling positive about oneself
5. **Study procedures (could come earlier in topic guide)**
- Experiences of being recruited/how knew about project
- Experiences of assessment protocol (length of assessments; asking the right questions; how assessment was organised, etc.)
- Experiences of fidelity checking processes
- Process of being “matched” – how they found it; how felt about introductory session; what should be considered in the “matching” process
- Ending
- \*\*\* suggestions for change (if any) \*\*\*
- Suggestions/overall comments
- 6.1 Final comments
- 6.2 How they would describe peer befriending to someone who has just had a stroke
- 6.3 What they would say to someone interested in becoming a befriender
- Provision of any relevant information
- Discuss with them what happens next
- Reassurances about confidentiality/what will happen with recording
- Thank yous!