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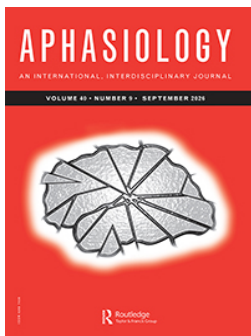
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What do people with aphasia talk about with other people with aphasia? A qualitative analysis of topics discussed in the SUPERB peer-befriending scheme

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ABSTRACT

Background and aims: Improved language function and participation in conversation are important to people with aphasia. While words to target in aphasia therapies have been explored in research, the topics that feature in real-life conversations of people with aphasia have not. Supporting wellbeing through PEER Befriending (SUPERB) was a feasibility trial that explored peer befriending for people with aphasia. As part of the trial, data were collected on the conversations that peer befrienders had with people with aphasia. The aim of the current study was to explore the topics discussed within these conversations.

Methods: People with aphasia were trained as peer befrienders ($n = 10$) and delivered a peer befriending intervention to people with aphasia recently discharged from hospital into the community ($n = 28$). Peer befrienders visited a person with aphasia up to six times over a 4-month period. For 20 dyads, one of the six visits was videorecorded. These 20 visits were transcribed verbatim and analysed using Framework Analysis to identify topics discussed.

Results and main contribution: Topics discussed covered five main areas: (1) stroke, aphasia and health; (2) shared stories; (3) friends and family; (4) within visit activities; (5) everyday activities and interests.

Conclusions and implications: Having a clearer understanding of the topics that are discussed by people with aphasia with peers may inform materials, tasks and discussion topics in aphasia therapies. Therapy can be focused on topics that are likely to facilitate participation in conversation, reflecting what people want from therapy post-stroke.

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Introduction

A stroke is a significant and life changing medical event and up to a third of stroke survivors will acquire a language disorder called aphasia (Flowers et al., 2016). People with aphasia experience poorer rehabilitation (Lazar & Boehme, 2017) and psychological outcomes when compared to stroke survivors without communication impairments (Flowers et al., 2016; Hilari, 2011; Kauhanen et al., 2000). Given the importance of communication in maintaining social connectedness with others, people with aphasia self-report feelings of loneliness (Nyström, 2006) and are at increased risk of anxiety and depression (Morris et al., 2017; Zanella et al., 2023), social isolation (Azios et al., 2022; Hilari & Northcott, 2017), and reduced participation in life (Dalemans et al., 2010). Thus, it is unsurprising that people with aphasia identify improved communication, life participation, and emotional wellbeing as areas of priority for their rehabilitation post injury (Wallace et al., 2017).

Despite emotional wellbeing being an area of priority for people with aphasia, there is limited evidence for effective psychological interventions for people with aphasia (Baker et al., 2018). In the UK, the James Lind Alliance Priority Setting Partnership consulted over 1,400 people affected by stroke on research priorities. The number one rehabilitation research priority was managing mood, specifically what interventions can best prevent psychological difficulties, support adjustment, and improve motivation, wellbeing and engagement. A potential psychological intervention that may meet these aims is peer-befriending, where people with lived experience of aphasia provide support to others with post-stroke aphasia. Peer befriending is intended to support adjustment, improve wellbeing and avert some of the long-term psychological consequences of stroke and aphasia. Peer befrienders can offer empathy, support, companionship, hope and share experiences about how to cope (Mead et al., 2010). The Supporting wellbeing through PEer-Befriending (SUPERB) randomised controlled trial, investigated the feasibility, acceptability and piloted the cost-effectiveness of a peer-befriending intervention (Hilari et al., 2019). In this trial, 56 people with aphasia were randomly assigned to usual care or usual care plus peer befriending (Hilari et al., 2021). The peer befrienders were people with lived experience of aphasia who had been trained to offer social support in six visits to the participants over a period of three months (Hilari et al., 2021). The intervention demonstrated potential to reduce depressive symptoms and to be a cost-effective approach to improving psycho-social outcomes for people with aphasia (Flood et al., 2022; Hilari et al., 2021). Not only was the intervention feasible but qualitative studies exploring the experiences of participants found that they held highly positive views of the intervention, they recommended peer-befriending should be offered as part of routine care, and they valued their interactions with their befrienders and opportunities for social connection (Moss et al., 2022; Northcott et al., 2022).

Fidelity for the peer befriending intervention was good (Behn et al., 2021), for all aspects of the intervention, including training and supervision of befrienders and befriending visits. A range of issues were raised and discussed when training and supervising peer befrienders. Issues addressed in training included the role of the befriender, dealing with challenging situations and health and safety. In supervision, the main issues discussed by peer befrienders included the logistics of arranging visits, ending the visits, providing disability resources and knowing how to communicate successfully with a person with aphasia, including identifying topics to discuss (Behn et al., 2021). People with aphasia who were befriended

described the importance of sharing experiences about stroke and aphasia, their families and past-life experiences (Moss et al., 2021). Despite this, little was known about the actual content of the visits and topics of discussion that may have led to positive change for participants. Developing a clear understanding of what people with aphasia talk about can help influence how interventions are designed, how befrienders are trained and in what topics, and how supervision can be structured to support befrienders discuss important topics within peer befriending visits.

Other studies have explored the specific words and topics of conversation considered most important to people with aphasia in therapy. In one study 100 people with aphasia identified 100 words they would like to address in therapy (Palmer et al., 2017). Of these 100 words, the top areas of priority included food and drink, people and gardening (Palmer et al., 2017). Other categories of importance included nature and gardening, entertainment, house, clothes, and travel (Palmer et al., 2017). A similar more recent study with a smaller sample of 12 participants with aphasia identified three overarching meaningful topics of conversation for speech therapy to target and these included family and friends, food and drink, and living with aphasia (Devane et al., 2024). While such studies highlight words considered most important to people with aphasia, they do not demonstrate the actual words used in conversation or therapy sessions.

Wilkinson et al. (2010) proposed analysing real conversational interactions of people with aphasia to identify patterns underlying successful conversations, as well as communication breakdowns. Observing first what people with aphasia like to discuss may assist with improving conversations by directing the content of speech therapy to be more meaningful and relevant to people with aphasia (Devane et al., 2024; Palmer et al., 2017). Such findings may also have implications for improving peer support services where important topics could then be used as guides for conversation. As a step towards enhancing peer support services and speech and language therapy content for people with aphasia, this study explored the exact nature of conversational topics discussed between people with aphasia in the context of the SUPERB trial.

Methods

This study is an ancillary study of the SUPERB trial (Hilari et al., 2021). The trial was a single-blind, mixed-methods, parallel-group feasibility multicentre randomised controlled trial comparing peer befriending plus usual care with usual care alone for people living with post-stroke aphasia with low levels of psychological distress. 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. In reporting qualitative findings, we have adhered to the Standards for Reporting Qualitative Research guidelines (O'Brien et al., 2014)(see supplementary file). Pseudonyms and group level descriptives have been used to preserve participant anonymity.

Participants

Participants with aphasia were recruited from North London hospitals, community services and GP practices. Randomisation took place after discharge from hospital once active rehabilitation had ended in the community. To be eligible for the trial, participants

had to: be over 18 years old; fluent pre-morbid users of English; present with aphasia (determined by multidisciplinary team notes, based on diagnosis from a speech and language therapist); and with low levels of emotional distress, determined by a score of ≤ 2 on the Depression Intensity Scale Circles (DISCS) (Turner-Stokes et al., 2005). Exclusion criteria were: a diagnosis of conditions affecting mental health or cognition; severe uncorrected visual or hearing problems; severe or potentially terminal co-morbidities; and discharged outside of the borough of the recruiting hospital, as this would have made it unfeasible for befrienders to visit those in the intervention arm. Fifty-six participants with aphasia were recruited, with 28 randomised to each arm of the trial.

Of the 28 participants with aphasia randomised to receive befriending, 26 consented and 24 received the intervention (two did not have time or did not want visitors in their home). Of these 24 (hereafter referred to as befriendees), 20 form part of this study. The remaining four pairs completed fewer than the six visits and were unable to have a visit recorded. There were 10 females and 10 males; 10 white and 10 black or of mixed race; age range was 47–92, median (IQR) 72.5 (61.0–81.8). Nine lived alone and five were wheelchair users. Time post-stroke ranged 1–6 months, median (IQR) 3.5 (2.0–5.8); all had a left hemisphere stroke; 14 had mild aphasia, two had moderate aphasia and four severe aphasia. Characteristics of participants with aphasia are shown in Table 1. All participants (Tables 1 and 2) have been given pseudonyms consistent with other qualitative papers reporting on the experiences of participants in this trial (Moss et al., 2021; Northcott et al., 2022). To protect anonymity of participants some information, e.g., age, marital status, time post-stroke, type of stroke, is not provided in the tables.

Befrienders were recruited from sites that were recruiting participants to the trial (North London hospitals, community health services) as well as local voluntary organisations. To be eligible, befrienders had to: be over 18 years old; at least one year post-stroke; and present with mild-moderate aphasia as determined using the Frenchay Aphasia

Table 1. Characteristics of participants with aphasia (befriendees; $n = 20$).

Name	Gender	Ethnicity	Severity of aphasia*	Lives alone	Wheelchair user
Samson	Male	Other ^a	Mild	No	No
Jill	Female	White	Mild	Yes	Yes
Graciela	Female	Other ^a	Mild	Yes	No
Marilyn	Female	White	Mild	No	No
Enid	Female	White	Mild	No	No
Ivy	Female	Other ^a	Mild	No	No
David	Male	White	Mild	Yes	No
Rose	Female	Other ^a	Mild	No	No
Emilia	Female	White	Mild	Yes	No
Elizabeth	Female	Other ^a	Moderate	No	Yes
Benjamin	Male	White	Mild	No	No
James	Male	White	Mild	Yes	No
Trevor	Male	White	Severe	No	Yes
Henry	Male	White	Mild	Yes	No
Beryl	Female	White	Severe	No	No
Betsy	Female	Other ^a	Severe	No	Yes
Gordon	Male	Other ^a	Severe	No	No
Simon	Male	Other ^a	Mild	Yes	No
Jonathon	Male	Other ^a	Moderate	Yes	Yes
Karl	Male	Other ^a	Mild	Yes	No

*Determined by Western Aphasia Battery- Revised Aphasia Quotient, where 0–50 = severe, 51–75 = moderate and 76 and above = mild.

^aOther = black or mixed race.

Table 2. Characteristics of befrienders ($n = 9$).

Name	Gender	Ethnicity	Befriender visited
Alice	Female	White	Marilyn and Henry
Yafeu	Male	Black	Ivy, Betsy and Simon
Louise	Female	White	Enid and Emilia
Zainab	Female	Black	Samson, Trevor, Jonathon
Karen	Female	Black	Jill, Elizabeth and Karl
Joyce	Female	White	Rose and Beryl
Esther	Female	Black	Graciela and Benjamin
Heather	Female	White	David
Andy	Male	White	James and Gordon

Screening Test (Enderby et al., 1986). Exclusion criteria were based on self-report and included: severe uncorrected visual or hearing problems; severe or potentially terminal co-morbidities on the grounds of frailty; diagnoses affecting cognition or mental health. Peer befrienders were also excluded if they scored ≥ 3 on the General Health Questionnaire-12 (Goldberg & Williams, 1988), indicating depressive symptoms. Other criteria included: good adjustment post-stroke; an ability to be confident, resilient, open and willing to talk with others; be able to concentrate for up to 3–4 hours to manage the visits; and be able to use public transportation or drive. These additional criteria were assessed by NB in discussion with the potential befriender. Ten befrienders were recruited to the trial.

There were 10 befrienders recruited of whom nine form part of this study. The tenth befriender supported a befriender but did not have any of their visits recorded and therefore did not provide data for this study. There were seven females and two males; four were black and five white; age range was 42–72, median (IQR) 55 (58–58). Time post-stroke range was 2.8–19 years, median (IQR) 8.5 (6.3–13.3); six had a left hemisphere stroke and three a right hemisphere stroke. Befrienders visited multiple befrienders across the trial. Characteristics of befrienders and who they visited are shown in Table 2.

This paper reports on *both* the participants in the intervention arm of the trial, who received the peer befriending intervention (befriendees) and the peer befrienders, who delivered the visits.

Procedure

The intervention comprised six befriending visits over a period of three months (each visit anticipated to last an hour), with an optional additional two visits within the next six months to support the transition to ending befriending. All visits were in-person in the befriender's home. Befrienders were matched with befriender, considering several variables including: geographical location, journey time, preferences around hobbies and interests, cultural factors and sex (Behn et al., 2021). The first visit aimed to build rapport and included a discussion of the nature and schedule of visits, as well as possible goals for the visits (e.g., befriender might highlight concerns to discuss or activities to pursue). Subsequent visits included, discussion of post-stroke challenges and how to adjust, and joint activities such as reading magazines or going out into the local community. Further details of the intervention, including a TIDieR checklist are provided in the published protocol paper (Hilari et al., 2019).

To support befrienders to conduct the visits, they were first trained. Befrienders received 4–6 hours of training in small groups ($n = 2-5$), delivered over 2–3 days by two facilitators. The first was a trained speech and language therapist with expertise in setting up and running aphasia befriending schemes (SM) and the second a clinical linguist, with extensive experience in working with people with aphasia (BM). Befrienders also attended monthly group supervision with facilitator one, the speech and language therapist (SM), who delivered the training. Individual support was provided as requested by the befriender. After each visit, befrienders completed a 12-question aphasia-friendly record form which included information about whether a visit was cancelled or not, topics discussed, activities completed and date and time of next visits. Resources for the SUPERB trial are shared on the study's website <https://blogs.city.ac.uk/superb/> and City Aphasia Lab's repository of research resources <https://cityaccess.org>. Detailed information about the visits, training and supervision of the befrienders is reported elsewhere (Behn et al., 2021).

Data collection

A visit was recorded for 20 of these pairs (reflecting 20 befriendees and nine befrienders). The visit recorded was chosen on practical grounds. Initially, it was intended for the befrienders to record a visit session independently, however, as some experienced difficulties with recording, a mutually convenient visit was chosen for a research assistant to set up the equipment, leave and return at the end of the visit to collect the equipment. The initial visit was not recorded as it was important for the pair to develop a rapport and shared understanding of each other without the potential pressure of being videotaped. Of the 20 visits recorded, four were the second visit, two were the third visit, seven were the fourth visit, six were the fifth and one was the sixth visit. The average length of the recorded visits was 53.9 minutes (range 20–67 minutes). After each visit, to check adherence to protocol,

befrienders completed an aphasia friendly, 12-question record form (including whether a visit was cancelled and reason why, topics discussed, activities undertaken and date and time of next visit). The data on “topics discussed” was used for triangulation in this study (see data analysis below). Fidelity of the visits including adherence is reported elsewhere (Behn et al., 2021).

Data analysis

Recordings of the visits were transcribed verbatim by one co-author (ASG) and one researcher, who were both speech and language therapists. A third researcher, also a speech and language therapist, translated and transcribed two visits that were spoken in English and a West African language.

Data were inductively analysed to identify conversational themes discussed by the befriendees and befrienders during the visit. Framework analysis was used with the aim of providing a descriptive rather than an in-depth explanatory account of the data (Ritchie et al., 2013). Framework analysis is a flexible and systematic approach that can facilitate descriptive accounts of the data, with a transparent process for developing the final themes from the raw data (Gale et al., 2013). Transcripts were imported into NVivo software Version 12. First, co-author ASG, who was a speech and language

therapist, familiarised herself with the data from the first eight visits, gaining an overview of the content and identifying topics. ASG had expertise in aphasia, was completing an MSc which included qualitative methodology, and was trained by senior qualitative researchers on the team on the analytic approach. Through this process of in-depth familiarisation with the data a thematic framework was developed, with a hierarchical arrangement of themes and sub-themes, to support initial organisation of the data. This initial framework was refined by discussion with three members of the co-author team, two senior research speech and language therapists (SN, NB), and (BM), the clinical linguist befriender-facilitator who is a senior qualitative researcher. Each had greater than 10 years' experience of qualitative data analysis including framework analysis. The thematic framework was then used to index all transcripts, with every phrase or chunk of data assigned to the most appropriate index category. This was completed by ASG, and co-authors TR and AH (student speech and language therapists trained in the analysis by BM and NB) and resulted in some further refinements to the thematic framework. The data were then synthesised into matrices, with each theme having its own matrix, and each participant becoming a row, while preserving the links back to the raw data. This process of data management enabled classifying and categorising the material within each sub-theme, as well as noting linkages across themes, and ensuring that the range of views and experiences were captured. This approach meant that all material was systematically considered and represented in a final descriptive account. Lastly, co-author REH (a clinical psychologist with more than five years' experience in qualitative research) independently reviewed all transcripts to provide reassurance that all themes were fairly reflected in the descriptive account.

Triangulation was provided by the open-text question, "topics discussed" in the record forms completed by befrienders after each visit. For the 20 visits analysed, the "topics discussed" question was completed on 16 record forms. This data was examined to ensure that the most discussed topics of conversation corresponded with what participants perceived as being discussed. The initial analysis was completed by the first author (NB) and then checked independently by SN. Any discrepancies were discussed and resolved through consensus. Examples of responses included, "family, stroke and general health" and "wishing for a full recovery" and "why it is important to socialise, being positive". The responses to this open-text question corresponded closely with the identified themes and no new themes were identified.

Results

Themes

Five themes were generated from the data. These included conversations about: (1) stroke, aphasia and health; (2) shared stories; and (3) family and friends; (4) within visit activities; and (5) everyday activities and interests.

Theme 1: stroke, aphasia and health

The experience of a person's stroke was a prominent theme within conversations. Many befrienders and befriendees highlighted the limited knowledge they each had of stroke

prior to their own experiences. They both told each other about their experiences of stroke and asked each other about its impact. Many spoke about the impact of the stroke on their mood including daily “ups and downs” (*Simon, befriender*) and being “quite cautious [now]” (*Marilyn, befriender*). One befriender asked their befriender about the stroke’s long-term impact, “... am I going to be miserable for the rest for the rest of my life?” (*Jonathon, befriender*). Many befrienders and befriendeds highlighted how the experience of stroke had affected their identity and sense of who they were (“new life, new me”, *Esther, befriender*).

Befrienders shared information about post-stroke support including, stroke groups (e.g., charity support groups, exercise classes, aphasia cafe) and gave advice and encouragement to befriendeds on local support available, including a variety of groups. Befrienders gave information leaflets, wrote out the details of the group and offered to contact group organisers. Attitudes and potential barriers to attending groups were discussed (e.g., befriender preference not to leave house, fatigue, travel), along with problem solving (e.g., helping plan out a travel route or discuss travel concessions or passes). Befrienders highlighted the value of socialising with others and meeting people with lived experience of stroke and aphasia, “It would be lovely if you could get some more group to come to [...] the more people you speak to, your speech will get better and better” (*Joyce, befriender*). One befriender spoke about the need to move home due to her stroke and waiting for a home to become available from the local council. Other befriendeds discussed transportation issues including, wheelchair access, transport options and using trains and taxis post-stroke to navigate their local community, or to travel abroad. These discussions provided further opportunities for befrienders to give advice and information, “I think you can get a taxi [to aphasia group] which, it’s it’s free [moving hands], you know ... so, so that could be good (*Louise, befriender*)”.

Befrienders showed concern, gave sympathy and encouragement for future progress. Befriendeds described how having befrienders share their experiences was helpful to moving forward with life, “Yeah, yeah, you’re in the same situation so you know what they’re going through and that counts to push forward” (*Benjamin, befriender*). Befrienders and befriendeds provided each other with reassurance and befrienders made comments to give a befriender hope and to make them feel less alone in their experience of having post-stroke aphasia, “you can do anything you put your mind to” (*Karen, befriender*).

All visits involved a shared discussion about aphasia and the range of resulting communication problems including speech, language, reading and writing difficulties. Some befriendeds reflected on what they did prior to their stroke compared to now (e.g., read more easily and quickly). Befriendeds reflected on post-stroke changes, and their frustration, for example, difficulties in word finding, “grrr just trying to say hello and they’ve gone, and I’m still fighting, it’s horrible” (*Jonathon, befriender*). Several befrienders were positive about the potential for changes in communication skills over time and offered strategies to help such as keeping passwords and important information in a notebook. They also commented on noticeable improvements in the skills of the befriender during the visits, “but it’s coming, if you think of how you were before to where you are now? Think in July ... you couldn’t say a word” (*Karen, befriender*).

Some befriendeds discussed their health including, medical and health appointments (e.g., general practice visits, blood tests, physiotherapy, hearing tests), co-morbid health issues (e.g., breathing difficulties, chest infections, diabetes, weight) or medications (e.g.,

what tablets people are taking and why, when they are taken). Some befriendees described the impact of non-communication post-stroke changes such as fatigue, weak or shaky limbs, difficulties standing, loss of smell or taste and dribbling. For some, symptoms had alleviated, for others they were an ongoing source of frustration. These discussions provided an opportunity for both befrienders and befriendees to share experiences.

Several befrienders and befriendees described their experiences with healthcare professionals, who were described as lovely and supportive, *“you couldn’t have had a more supportive organisation”* (Enid, befriender). However, a few befriendees described how some healthcare professionals may have made comments that were less positive or encouraging, or even demoralising:

Marilyn (befriender): And then she [therapy assistant], she said, “I’ve often wondered when you have a stroke would you rather your speak was affected or would you prefer to be in a wheelchair?” She said that to me and I could not, and this was in my room not in the main area

Alice (befriender): That’s an awful thing to say

Marilyn: I said, oh my, I said, “oh my god, how have you not got something nice to talk about or something uplifting?”

Professionals, such as physiotherapists and speech and language therapists were helpful in providing exercises (e.g., upper limb and tongue exercises) and scheduling appointments. On some visits, the befrienders suggested that the befriender attempted the exercises (e.g., hand and leg) during their time together. The experiences that befriendees had within hospital and in the community related to their stroke and aphasia and other health issues that arose following their stroke were a strong source of shared experience for both befriender and befriender.

Theme 2: shared stories

All befrienders and befriendees engaged in sharing stories, either from their past, events prior to their stroke, or related to important events. Pairs reminisced about their past relationships, their local community, upbringing in their home country (if different to the UK), their employment pre-stroke or what their parents did for work. Some befrienders and befriendees reminisced about their childhood, for example, of the local sweet shop or toys they used to play with. [Box 1](#) illustrates a case example of a childhood story.

Events prior to the stroke were discussed from childhood days out or family holidays to more recent, pre-stroke holidays, birthdays and special occasions. Reminiscing created opportunities for sharing reflections on self-identity and personal experiences related to family, religion, culture and sexuality. For one befriender following a conversation about her school-life, she described how she eloped with her husband and the reaction of her family, *“My father tell him I will kill you [laughing], you married my daughter”* (Graciela, befriender). Two befriendees spoke openly about their sexuality. One shared this information while reminiscing about his past work-life, *“I don’t know if, if, if I’ve told you that I’m gay, you know . . . I don’t see the need for immediately telling people”* (David, befriender). This led David to tell the story of his partner who he had been with for over twenty years and who had recently died. Both befriendees and befrienders reminisced and shared personal

Box 1. Shared stories: A case example

This case illustrates a story from one of the befriendees. The befriender, who had mild aphasia, described a childhood story to his befriender who also had mild aphasia. The story involved a childhood interaction with geese, and provided an opportunity for the pair to reminisce, share experiences and information about themselves and to laugh with one another.

David (befriender): I used to on my way home from school, I used to pass a piece of waste ground where there was a flock of geese

Heather (befriender): Oh goodness

David: I used to hate it because they all used to make for me

Heather: Yeah, they can sense it you know, they really can

David: And my father used to say, I used to complain to my father, "oh, the geese are chasing me", oh turn around and flap your arms they'll soon, they'll soon be frightened off [both laughing] I had a flock of geese chasing me.

Heather: Were you quite, were you sort of like seven or eight?

David: Yes, small

Heather: Well this is it, they are quite aggressive geese

David: Well, my father didn't think that, he was a grown man and I was just a child, they weren't taller than me but, erm

Heather: Well, when they stretch their necks and [gestures big]

David: Yes

Heather: Well, they would certainly knock you over

narratives. One befriender reminisced about past events he had attended in the local community:

It was really good enjoyment, it was really good enjoyment. When I see it the other day I was thinking I remember seeing that ... and it was like memory lane ... I think that might have been about the second or third concert I went to. (Yafeu, befriender)

Befriender Esther told stories about her religious background, her culture, the languages she spoke. She also gave a recount of how she learnt musical instruments growing up:

Right from three years old, I learn, and they pass violin and then the second one, the second one violin and flute, and then the third one violin and piano [laughing]. (Esther, befriender)

Yes, [laughs] she can accompany herself. (Benjamin, befriender)

[both laughing]

Both Esther and Benjamin laughed throughout this exchange. Humour was often used in stories in the form of jokes and anecdotes. This also included the use of humour by one befriender to cheer up a befriender who was visibly unwell when they recounted a humorous anecdote about a group of school children she had recently observed on local transport.

Theme 3: family and friends

Many befrienders and befriendees spoke specifically about family and friends during their visits. Sometimes this involved giving updates on the wellbeing of family members since their previous visit including birthdays, deaths, relatives who were expecting a child, careers of children and/or schooling achievements of grandchildren. Other befrienders and befriendees spoke of their pets as part of the family. One befriender talked about an upcoming wedding of her son while a befriender talked about the daily visits she receives from her daughters. Conversations about family were mainly positive, with one befriender describing how his family "have been a rock in my recovery" (James, befriender). Other

befrienders and befriendees described less positive experiences of relationships including opposing religious and political beliefs, painful break-ups and infidelity over the years. For one befriender, the stroke was considered a factor that may have led to the break-up, *“well maybe that had something to do with it. Maybe it was that or maybe she had planned to break up with me before”* (Yafeu, befriender).

Some discussions reflected the loss of family members and how they felt about not having family around them, *“But I’m not looking forward to it, because it’s going to be my first birthday without my mum”* (Louise, befriender). Some befrienders and befriendees spoke about friends they had met up with recently and/or upcoming social plans, *“actually my friend came from Canada the other day and she’s leaving today, we went out for dinner at a restaurant ... it was lovely”* (Zainab, befriender). Visits with friends were a source of enjoyment for some, although not all befriendees had friends following their stroke, *“and you said that was a problem that you had a lot, you didn’t have very many, erm friends”* (Andy, befriender). Those befriendees who had regular carer visits spoke of how the carers were a practical source of help.

Theme 4: within visit activities

Befrienders and befriendees spoke about activities carried out during their visits. These were opportunities for small talk between the pair. Several befrienders talked about practical tasks or activities they did during the visits including making a cup of tea, coffee or light refreshment, answering the front door, getting a pillow, calling a support group; or offered help in the future, including teaching a befriendee to swim or bringing objects to a future visit. Other discussions during visits included looking at magazines or leaflets and sharing thoughts and opinions about pictures of celebrities or world events, *“I like this dress. Could you tell me what you like there? [showing page of clothes in magazine]”* (Esther, befriender). Other participants had the television turned on and talked about what they were watching, including politics. Another activity within visits was sharing and discussing photographs, either on display in the home or on their mobile phone, *“Yes, oh here we go [referring to phone] here we go, there, right and then go that way [showing how to scroll photos]”* (Enid, befriendee) for example, when discussing a holiday a participant went on.

Theme 5: everyday activities and interests

Activities planned and/or completed were spoken about by a proportion of befrienders and befriendees in conversation. References were made to food and drink, and what they had for lunch or their favourite meals. Shopping for food, home delivery services, relying on family and carers to prepare food, and cooking skills post-stroke were all topics of conversation. Some befriendees spoke of their preferred shops and the logistical challenge of shopping independently:

So I have only been out once this week, we went down ... to Marks [type of supermarket], luckily we parked right outside so I can go inside and get a trolley and that hauls me around so that’s alright. (Enid, befriendee)

Some of these discussions led to conversations about food preferences, favourite places to eat, or cafes they liked to visit. Other conversations were about home, decoration style and renovations or adaptations completed or planned, some of which resulted from physical limitations due to their stroke. Special occasions were frequently discussed.

These discussions reflected the time of year. For instance, discussions about their plans for Christmas, gifts to buy and send to others, and decorations “... and the two round lights, big lights they changed colour, I got them from Mark’s [supermarket chain]” (Enid, befriender). Befrienders and befriendees also talked about their interests including favourite TV shows, sports and exercise, religion, reading, crafts and design, playing an instrument, birds, current affairs and politics. One befriender shared her enjoyment of travel and spoke about how she had started to travel independently again post-stroke, “I travel alone with, with stroke” (Esther, befriender).

Discussion

We identified five main themes for topics of discussion between people with aphasia. These included (1) experiences of their stroke, aphasia and health; (2) shared stories; (3) friends and family; (4) within visit activities; and (5) everyday activities and interests. A diverse range of conversational topics was generated, which offer valuable insights into the information shared between people with aphasia in the context of a peer befriending research project. While previous research has explored the conversational exchanges between individuals with aphasia and healthy controls (Davidson et al., 2003; Law et al., 2018), this study is among the first to specifically examine the nature of conversations between people with aphasia. These findings resonate with earlier work that categorised conversational themes involving individuals with aphasia (Davidson et al., 2003; Devane et al., 2024; Law et al., 2018).

A predominant topic discussed was the impact of stroke, aphasia and their health. This finding was expected. The visits provided a natural context for the pair to share their experiences of stroke and to discuss the impact of aphasia in their lives. Such exchanges offer individuals a space to relate to others with similar lived experiences, a core component of peer befriending (Mead et al., 2010). Research highlights that individuals with aphasia seek increased awareness and information about their condition (Wallace et al., 2017; Worrall et al., 2011), and these peer interactions provided opportunities to share practical advice and support about local services, community groups, and coping strategies. Additionally, befriendees received reassurance and encouragement, reinforcing hope and the notion that they are not alone in their journey. This forward-thinking perspective is often desired by people with aphasia in the early stages post-stroke (Grohn et al., 2014), and the opportunity to support others is equally valued by befrienders (Northcott et al., 2022; Worrall et al., 2011).

Sharing stories was an integral part of the visits, encompassing a wide range of personal stories about childhood, family, relationships, culture, sexuality, religion, work and holidays. Stories can help people with aphasia to build relationships and connection particularly in mitigating social isolation (D’Cruz et al., 2022). Law et al. (2018) noted that personal narratives comprised a large proportion of conversational topics among people with aphasia. While sharing stories was coded as a theme, it may also be considered as a mechanism for individuals to express their experiences about a range of topics, engage in meaningful conversations, and assert their identity, which is crucial for navigating post-stroke life (Brinkman et al., 2025; Corsten et al., 2015; Dipper & Cruice, 2018; Shadden & Hagstrom, 2007; Strong & Shadden, 2020;

Worrall et al., 2011). The importance of personal storytelling in aphasia has led to its use in discourse-level interventions aimed at enhancing communication skills (Dipper et al., 2024; Whitworth et al., 2015). Humour was a recurring element when telling stories, functioning as a tool for social engagement, relationship building, and coping with the emotional challenges of aphasia (Sherratt & Simmons-Mackie, 2016; Sherratt & Worrall, 2021). Sharing jokes was identified as a meaningful and valued aspect of conversation (Devane et al., 2024), reinforcing its potential role in enhancing social interaction and emotional well-being.

Family and friends were frequently discussed by participants. Similar findings have been found in other studies, whereby the people in a person's inner social network are focused on most (Davidson et al., 2003; Devane et al., 2024). Involvement of close family and friends can be important to early recovery. Befriendees described positive experiences of social contact which is encouraging given the risk of social isolation and the potential loss of friendships that are often seen over time for people with post-stroke (Northcott & Hilari, 2011). Encouraging conversations about close relationships may serve as a protective factor, helping individuals appreciate and maintain important social connections. Equally, connecting with others who share a lived experience of post-stroke aphasia may offer support, encouragement and empathy, helping the person with aphasia adjust to life after stroke and maintain a sense of connection (Moss et al., 2021; Northcott et al.,).

The activities undertaken during the visit were a regular topic of conversation. This ranged from making a drink at the start of the visit, to answering the door, looking at photographs or watching television. While other studies have not identified topics of conversation related to such activities, Davidson et al. (2003) observed that the conversations involving people with aphasia often focus on the here and now and their immediate surroundings. Furthermore, studies that have examined the words chosen by people with aphasia to target in therapy frequently highlight words related to food and drink (Hickin et al., 2023; Palmer et al., 2017). Many of these words were relevant to many visits (e.g., the drinks they made for one another) and the everyday activities participants discussed doing (e.g., favourite foods, food preferences). Other topics including entertainment and hobbies, nature and gardening, travel and arts, are not dissimilar to other studies that have explored words or topics important to people with aphasia (Devane et al., 2024; Hickin et al., 2023; Law et al., 2018; Palmer et al., 2017). This suggests that conversations involving people with aphasia need to balance the practical, day-to-day communication needs and the social topics that facilitate broader engagement.

We highlight the importance of social connection and of a caring relationship. People with aphasia post-stroke desire emotional support from someone who cares and who is concerned about their wellbeing (Northcott & Hilari, 2018). The visits provided an opportunity for people with aphasia to share their experiences, stories, interests and important life events. Befrienders were able to offer empathy and hope, and meaningful connections were made between participants, leading to a sense of friendship and companionship (Moss et al., 2022; Northcott et al., 2022). People with aphasia want hope for the future (Bright et al., 2020), and conversations and therapy should provide opportunities for people with aphasia to reflect on their progress and what may be possible in developing a sense of hope.

Importantly, there seems to be a difference between the broader conversational topics found in this study and other research that has explored the single words considered most salient for people with aphasia. For example, people with aphasia identified words related to food and drink as the most personally relevant and words related to places, people and travel less relevant (Palmer et al., 2017). However, all these words may occur in a range of topics, particularly when telling stories or discussing hobbies and interests. This suggests a functional difference between the use of single words to express basic needs and wants compared with the expression of deeper social and emotional needs through more expansive conversational topics. Therefore, when it comes to targeting the person with aphasia's participation in social communication, there needs to be a clearer alignment between targeting words people want to say to meet a need with those words that may help a person socially connect with others.

Implications

Our findings are drawn from the context (befriending visits) of a specific study. Future research could further explore what people with aphasia talk about with other people with aphasia, in different natural settings, through, for example, ethnographic observational methods. Nevertheless, knowing what people with aphasia talk about has significant implications for speech and language therapy interventions. For people who are early post-stroke with aphasia, previous research has shown that discussion about stroke symptoms, the impact of aphasia and services available is important (Wallace et al., 2017; Worrall et al., 2011). Existing research has also explored the utility of personally relevant narratives in discourse-based treatments (Dipper et al., 2024; Whitworth et al., 2015), while words related to food, hobbies, and travel have been targeted in word and sentence-level therapies (Devane et al., 2024; Hickin et al., 2023; Palmer et al., 2017).

For clinicians working in rehabilitation and community settings, the insights drawn from our findings can broaden and refocus conversational topics targeted in therapy and guide the focus of discourse treatments, communication partner training, the simulation of real-life scenarios and choice of meaningful topics to discuss in peer befriending, stroke or aphasia support groups. These results can help inform therapy approaches that are personalised to the individual. These topics may provide a meaningful starting point for early conversations with people with aphasia to clarify what matters most to them. Importantly, therapy should provide a space for people with aphasia to share their stories; of their past and who they are as individuals, to discuss their present post-stroke experiences and to describe their hopes for the future. Through clinicians listening to their personal stories and narratives, therapy may then be increasingly individualised and personalised by supporting people with aphasia to construct or co-construct their stories and share them with others (Corsten et al., 2015; Dipper et al., 2024; Strong & Shadden, 2020). In turn, this can facilitate linking intervention with goals of social participation and engagement (Wallace et al., 2017; Worrall et al., 2011). Thus, forming a foundation for people with aphasia early post-stroke to build meaningful relationships with others including, connecting with others who have a lived experience of aphasia, which can

positively influence emotional well-being (Hilari et al., 2021; Moss et al., 2021; Northcott et al.,).

Strengths and limitations

A strength of this study was a reasonable sample size of 20 dyads that allowed for a rich description of what different people with aphasia spoke about. While other studies have asked people with aphasia what words or topics are important to them (Devane et al., 2024; Palmer et al., 2017) this study captured real-life conversations people with aphasia have with other people with aphasia. Befrienders were not assigned to befriendees only based on practical considerations (such as location). We asked our participants with aphasia about their hobbies and interests, and any preferences they had in terms of which befriender to assign them to. For example, some of the befriendees were assigned befrienders of similar cultural and language background. This enabled several visits to be completed in languages other than English, of which two were translated and analysed in this study. It was also a strength that the visits were video recorded, which has been reported to be lacking in previous studies (Simmons-Mackie & Lynch, 2013). The presence of the video camera did not appear to interfere with the visit with a third of participants referring to the video camera and only one befriendee observed to avoid a personal topic while the camera was recording. There were multiple researchers involved in the analysis of the topics which increased the credibility of the results. There are, however, several limitations in this study. First, only a single visit (of six) from each pair was recorded which was chosen for practical reasons rather than through random selection, limiting the representativeness of the data. Furthermore, the study involved participants from a single geographical area, which may limit the generalizability of the findings to other regions or cultures. Although as mentioned earlier, the identified themes are consistent with those reported in studies from the UK and beyond, suggesting a degree of universality.

Conclusion

This study contributes to our understanding of the conversational interactions between people with aphasia, identifying key topics such as experiences of stroke, impact of aphasia, storytelling, family and friends and shared activities. This provides more information on what people with aphasia *want* and *need* to be able to say and *why*, including to build connections and relationships with others. It is critical that therapy focuses on the conversational topics that are meaningful for people to talk about. These findings underscore the importance of therapeutic interventions and support groups focusing on meaningful and personally relevant conversational topics. Furthermore, by incorporating these themes into goal setting and therapy planning, clinicians can ensure that interventions align with the lived experiences and social needs of individuals with aphasia, ultimately enhancing participation and quality of life post-stroke.

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