



City Research Online

City, University of London Institutional Repository

Citation: Devane, N., Buxton, S., Fox, C., Marshall, J., Staunton, D., Whiddett, J., Wilson, S. & Hilari, K. (2024). What Conversation Topics are Meaningful to People with Aphasia? A qualitative study. *Aphasiology*, pp. 1-18. doi: 10.1080/02687038.2024.2319364

This is the published version of the paper.

This version of the publication may differ from the final published version.

Permanent repository link: <https://openaccess.city.ac.uk/id/eprint/32395/>

Link to published version: <https://doi.org/10.1080/02687038.2024.2319364>

Copyright: City Research Online aims to make research outputs of City, University of London available to a wider audience. Copyright and Moral Rights remain with the author(s) and/or copyright holders. URLs from City Research Online may be freely distributed and linked to.



Reuse: Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. 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.

City Research Online:

<http://openaccess.city.ac.uk/>

publications@city.ac.uk

What Conversation Topics are Meaningful to People with Aphasia? A qualitative study

Niamh Devane ^a, Shannon Buxton^b, Chelsie Fox^c, Jane Marshall^a, Deirdre Staunton^c, Jennifer Whiddett^d, Stephanie Wilson^e and Katerina Hilari ^a

^aDepartment of Language and Communication Science, City, University of London, UK; ^bSpecialist Children & Young People's Services (SCYPS), East London NHS Foundation trust, London, UK; ^cChildren's Integrated Speech and Language Therapy Service for Hackney and the City, Homerton Healthcare NHS Foundation Trust, London, UK; ^dEast Kent Children's Therapies, Kent Community Health NHS Foundation Trust, Kent, UK; ^eCentre for Human Computer Interaction Design, City, University of London, UK

ABSTRACT

Background: Speech and language therapists apply word finding therapies for people with aphasia with good outcomes on treated words but limited evidence of generalisation to untreated words. As generalisation cannot be assumed, there is a need to select words for therapy that are meaningful to people with aphasia.

Aims: This study sought the views of people with aphasia to inform the stimuli for a word finding in conversation treatment. To this end, the research question was: What conversation topics do people with aphasia find most meaningful to talk about?

Methods & Procedures: This qualitative study used focus groups to identify meaningful conversation topics across a sample of 12 people with chronic aphasia (two groups of six). Participants were recruited from three community aphasia groups. The focus groups were videoed and transcribed. The transcription was analysed using framework analysis. A consensus decision process was then used by researchers to identify the themes with high agreement.

Outcomes & Results: Twenty conversation topics were generated. Consensus was that eight topics were meaningful. The three topics rated most meaningful were 1) family and friends, 2) food and drink, and 3) living with aphasia. Two topics reached consensus as not meaningful. Ten topics did not reach consensus.

Conclusions: The conversation topics, 'family and friends', 'food and drink' and 'living with aphasia' were most meaningful to this sample of people with aphasia. Using therapy stimuli from these conversation topics has the potential to create meaningful treatments.


ARTICLE HISTORY

Received 30 Jun 2023
Revised 08 Feb 2024
Accepted 09 Feb 2024

KEYWORDS

anomia; therapy stimuli;
topic selection; framework
analysis; focus groups

CONTACT Niamh Devane  Niamh.devane.2@city.ac.uk  Department of Language and Communication Science City, University of London, Northampton Square, EC1V 0HB, 020 7040 8821

 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/02687038.2024.2319364>.

© 2024 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. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

Introduction

For many people with aphasia, anomia is the most common feature of their aphasia (Goodglass & Wingfield, 1997). Speech and language therapists apply word finding therapies to address anomia with good outcomes on treated words but less evidence of generalisation to untreated words (Efstratiadou et al., 2018; Lavoie et al., 2017; Wisenburn & Mahoney, 2009). As generalisation cannot be assumed, one solution is to select words for therapy that people want to use. For example, if someone wants to talk about golf, select golfing vocabulary for anomia therapy. Involving people with aphasia in selecting treatment stimuli is therefore highly desirable. However, it poses a challenge, given that the anomia makes it difficult to propose treatment vocabulary.

This problem of stimuli selection has been reported in a few studies and addressed in different ways. Research has explored the stimuli for naming therapy based on what words are most *frequent* (Renvall et al., 2013a; Renvall et al., 2013b) or has prompted participants to choose words that are most *useful* (Palmer et al., 2017). When studies *observed* the topics people with aphasia talk about or explored in retrospect the topics people *chose* to practice in therapy, differences emerged. Observations showed a focus on the 'here and now' with less discussion about books, current events and politics (Davidson et al., 2003). When asked to choose topics, people made use of the therapy to describe their stroke story (Holland et al., 2010). This raises two points. Firstly, it is possible that what people with aphasia aspire to discuss is not what they are talking about day to day. Secondly, the research question asked determines the response to some degree.

It is difficult to determine how stimuli have been chosen in the past. Despite a high number of published papers addressing word finding treatments (Efstratiadou et al., 2018; Sze et al., 2020; Wisenburn & Mahoney, 2009), the methods for selecting treatment stimuli is not widely reported. A recent review looked at the important components of word finding therapies in detail (Sze et al., 2020) using a framework to explore Regime, Item, Technique and Application of technique (RITA). In the RITA framework, the 'I' explored the items used in therapy. Information extracted was number of items treated, number of times an item was named and grammatical class of the items, but not how or why particular items were selected.

To our knowledge two studies have described their methods for selecting a meaningful word list (Hickin et al., 2022; Law et al., 2018). Hickin et al. (2022) elicited a personally relevant word list through a total communication conversation about people, situations, and topics. Picture prompts were deliberately avoided to avoid a bias towards concrete stimuli. This method works well for individually tailored therapy. In another study, people with aphasia were prompted to talk about an important event in their life, their responses were coded, and the resulting topics were concluded as meaningful (Law et al., 2018).

This qualitative study took a different approach. It sought a list of topics that could be used across many people with aphasia so was searching for the universal rather than the personal. It also hoped to capture the topics and conversations people with aphasia aspire to have, rather than useful or actual conversations. Therefore, it asked about aspirations for conversations, what the conversations are that enrich our lives. In line with the Life Participation Approach to Aphasia this study has placed those with aphasia at the centre of the decision making (Chapey

et al., 2000). Twelve people with aphasia were invited to focus groups to discuss meaningful topics of conversation. A focus group methodology was chosen as it allowed participants to share their views, hear the views of others and adjust their contributions based on the new information (Acocella, 2012). This iterative process generates consensual data, representing the collective views of the group. These methods asked participants not only to share their own experience but also to reflect on the views and experiences of other people with aphasia they know. These methods (SWIM, Someone Who Isn't Me) have been used successfully with people with aphasia by this research team (Wilson et al., 2015). The resulting topics can guide word lists for naming therapy or provide topics for conversation groups. To this end, the focus groups addressed the question:

What topics do people with aphasia find most meaningful to talk about and why?

Materials and methods

Ethical approval was gained from the City, University of London Language and Communication Science Proportionate Review Research Ethics Committee (ETH1920-0148). The Standards for Reporting Qualitative Research were used as guidance in the reporting of this study (O'Brien et al., 2014).

Qualitative approach and research paradigm

Focus groups were used to identify the most meaningful topics. Focus groups were chosen as they can identify and clarify what topics are most important through discussion, and how a variety of opinions can be prioritised (Tausch & Menold, 2016 p.8). The researchers took a constructivist viewpoint, that knowledge is co-constructed through our interactions and experiences and not an external reality to be discovered (Given, 2008).

Researcher characteristics

Student researchers led the focus groups (authors SB, CF, DS & JW). The students were speech and language therapists in training. As such, they had some knowledge and clinical experience of aphasia. In each focus group one student researcher led the group, a second student researcher supported participant's communication. A specialist speech and language therapist experienced in qualitative research methods (author ND), was present in one of the two focus groups. This group included a participant with severe aphasia, so required additional facilitation to ensure that all views were captured. The student researchers received a two hour training session on how to run focus groups from ND. The training covered the nature of focus groups and focus group data, the stages of group discussion, the questions that elicit *breadth* or *depth* of a topic, and how to moderate the group e.g., the use of body language to include all participants, the use of neutral but encouraging responses (Ritchie & Lewis, 2003). In both focus groups two participants were known to two of the student researchers prior to the study, through a previous volunteering role. Otherwise, the student researchers had not met the participants prior to recruitment.

Context

Two focus groups were held on the same day in separate rooms in City, University of London in January 2020. Some participants were familiar with this venue as a community aphasia group was also held at this site.

Sampling

Participants were recruited from community aphasia groups in London, by speech and language therapy students (SB, CF, DS & JW), see [figure 1](#). Participants were invited to take part if they were >18 years old, had aphasia as a result of a stroke that occurred more than 4 months previously, and were a fluent English speaker pre-stroke. Participants were excluded if they had additional cognitive impairments or neurological diagnoses that impact on cognition.

The study was presented in the aphasia group and interested people were given the participant information sheet. Participants had a week to read the study information and had the option to ask questions before giving informed consent to take part. Study information was made accessible by following published guidance (Rose et al., 2012).

Data collection instruments

A topic guide was developed by student researchers with supervision from ND ([Appendix 1](#)). To ensure that both focus groups covered the same content, some sections of the topic guide were scripted e.g., the purpose of the groups. The focus groups began with introductions and group aims. Then group rules were agreed, and a warm-up activity was undertaken. The research aim of drawing out a discussion about meaningful conversations was achieved through a guided elicitation technique. Similar to the methods used in [Hickin \(2022\)](#), conversation topics

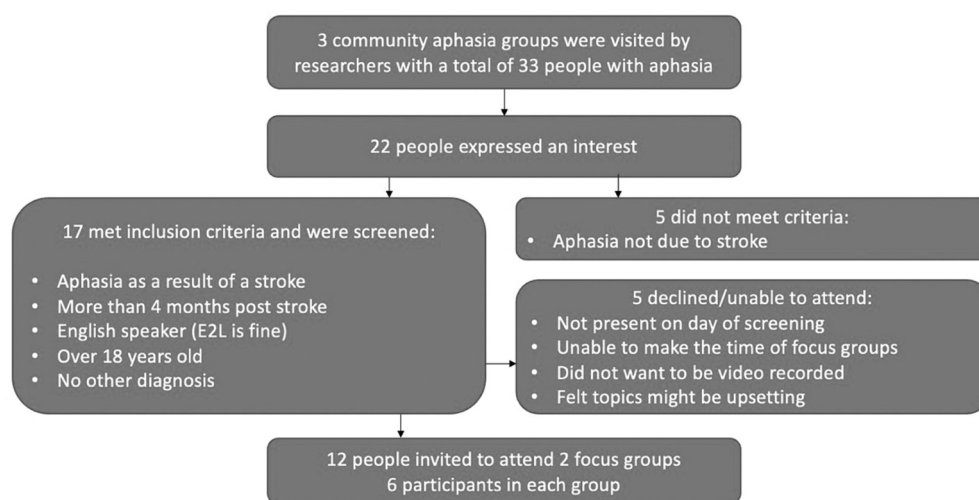


Figure 1: Recruitment flow chart

were first generated through a discussion about *who* people with aphasia communicate with, *where* they have these conversations, *what* the conversations are about and how those conversations made them *feel*. Answers from the group were recorded in a large grid with columns for *who*, *where*, *what* and *feel*. Participants were asked to write *what* the conversations were about on post-it notes. For those who needed support with writing the student researchers or therapists wrote the single word. This was an orienting task. It allowed the concept of meaningful conversations to be asked in the context of recent discussion about all the possible conversations that happen.

Then, the concept of meaningful conversations was introduced as “now we are going to start to think about what is most important . . . what is most meaningful for us to talk about?” (Student researcher). Meaningful topics were subsequently explored in two activities. First, participants placed written topics (the post-it notes) on a line on a piece of paper that represented a personal rating scale of least to most meaningful. Participants answered the question ‘what topics are meaningful and why’ for themselves, by physically manipulating the post-it note on the drawn line. Each participant used their own scale to map what they felt were meaningful for them personally, this was supported by gesture, writing down key words and drawing. Participants were supported in this task by the student researchers. For example, the students helped them to record their ideas, either in writing or through visual images. Some were also helped to rank topics on a low- to high-meaningfulness scale. Then, there was a group discussion about where topics should go on a single agreed sliding scale for the group. The session was closed by the group leader checking back the agreed topics from the single sliding scale with the group.

Units of study

The transcript of the conversation about topics and meaning was the data. The post-it notes on the rating scales were support materials for this conversation, not data.

Data Processing

The focus groups were video recorded, orthographically transcribed, and transcripts were uploaded to NVivo 12 software for coding. Video recording was used to capture non-verbal communication and gestures and facial expressions were documented in the transcription double parentheses (Beeke et al., 2013). Data was pseudonymised. Each participant was given an identifier (1-6) that indicated which focus group they had attended (A or B) e.g., P1A.

Data analysis

Framework Analysis (FA) was used to identify dominant topics, see [figure 2](#) for the stepped process (Richie and Spenser 1994). Student researchers analysed the data following FA training from the university and supervision from ND.

To establish whether there was consensus on what was meaningful, the researchers used a consensus decision process (Sirman et al., 2017). Using the themes in the framework, researchers cross checked by individual. If more than half the participants in a focus

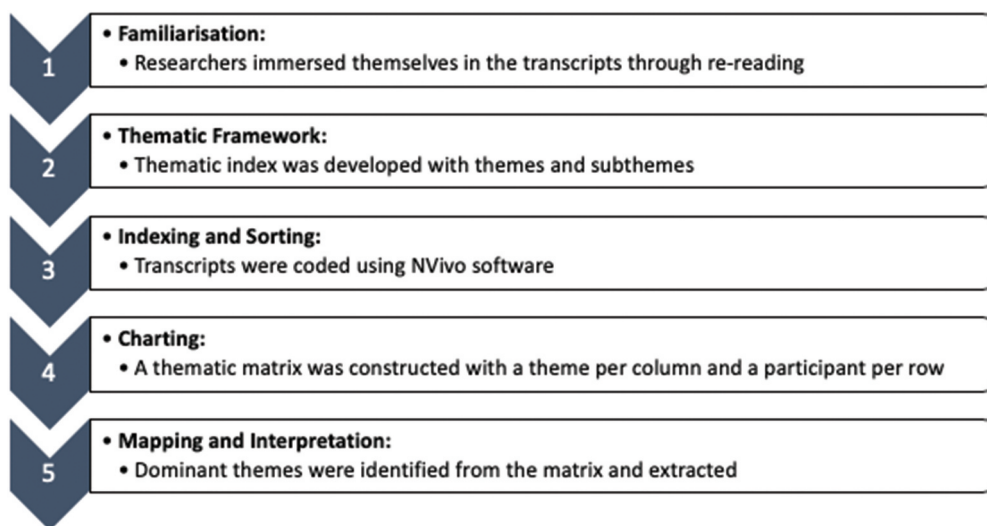


Figure 2: Framework analysis stepped process

group (>3) talked about a topic as having high, medium, low meaning it was stipulated that consensus was reached.

Techniques to enhance trustworthiness

Double coding was carried out on 10% of the coded focus group transcripts in NVivo, to check if there was agreement in the coding.

Results

Twelve participants with aphasia took part in the focus groups. The sample was predominantly white (10/12), male (10/12) and aged ≥ 60 years old (8/12); half were university educated, including one with a post graduate degree (6/12), see [table 1](#).

Table 1. Participant characteristics

		Focus Group 1 n = 6	Focus Group 2 n = 6	Total n = 12
Age Range (years)	40-49	2	1	3
	50-59	0	1	1
	60-69	3	3	6
	70+	1	1	2
Gender	Male	6	4	10
	Female	0	2	2
Ethnicity	White	6	4	10
	Black	0	2	2
	Asian	0	0	0
Highest Education	GCSE	2	1	3
	A-level	2	0	2
	Undergraduate	1	4	5
	Postgraduate	0	1	1

Table 2. Meaning rank and example quote for all topics that reached consensus

Meaning	Topic and example quote	Participants			
		FG1	FG2	Total	
High	Family and friends "Ummm well I would go nuts if I didn't talk to my sister once a week" (P3A) "But family are at the top" (P6A) "I'm quite proud of them and (.) so deep down it's important" (P3B)	6	5	11	
	Food and drink "It's good (.) for everybody" (P6B) "It's as important as any of them food is very important that's my opinion." (P5A)	5	4	9	
	Living with aphasia "Speaking about stroke and things are very important" (P3A) "But for me consistent ones are promoting aphasia, promoting [name of aphasia group]" (P3A)	6	2	8	
	The arts "Well, I would say as important as food and drink" (P1A) "It's more important and meaningful than food and drink" (P3A)	4	1	5	
	Sharing jokes and humour "I'd put it as one that's most meaningful" (P1A)	5	-	5	
	Holidays and travel "They are everywhere oh my god yeah" (P1B)	1	3	4	
	Life experiences "I'm very interested in um what people did before they had their stroke 'cos everybody has an interesting story to tell" (P5B)	-	4	4	
	News "Ok em how about talking about the news? Is that meaningful for you?" "Very very" (R4/P3B)	-	4	4	
	Medium	No topics reached consensus for a medium ranking	-	-	-
	Low	Religion "Against it" (800, P3B) "it's very personally" (personal) (P3A)	3	2	5
		Money "no one wants to talk about it!" (P1A)	4	-	4

FG = focus group

All participants had a mild/moderate aphasia except for one participant who had moderate/severe aphasia. All participants communicated predominantly through a verbal modality. This was determined through the clinical judgment of the therapist.

Twenty topics were generated by the twelve participants with aphasia across the two focus groups: stroke recovery journey; living with aphasia; medical; food and drink; nutrition; family and friends; work; holidays and travel; entertainment; sports; the arts; books; sharing jokes and humour; life experiences; daily events; sex; politics; news; money and religion. The number of topics highlights the range of views across the groups. The most popular topic (family and friends) was suggested by eleven participants, while two topics (sex, nutrition) were suggested by one person.

If more than half the participants in a focus group (>3) agreed, then consensus was considered established. Ten topics reached consensus. The three topics most participants thought meaningful were 1) family and friends, followed by 2) food and drink, and 3) living with aphasia. The other topics that reached consensus as meaningful were the arts, humour, travel, life experiences, and news. Two topics reached consensus as having low meaning. These were religion and money, see [table 2](#). Ten topics did not reach consensus.

Reliability of the double coding was almost perfect, kappa=0.92 (McHugh, 2012).

Highly meaningful topics

Family and friends

The people that are close to us, our family and friends, was the topic that almost all members of the focus groups (11/12) thought meaningful, that form a core part of participants identity *'they are the most – they are to you the most meaningful people that live'* (P1A). They described feelings of pride, *'I'm quite proud of them and, so deep down they its important, deep down'* (P3B). The importance of having a social network was also highlighted, *'we all need people, don't we'* (P5A), and losing social connections *'I used to be surrounded by people but no more'* (P5A).

Food and drink

Discussions about food and drink covered the basic human need for food, an interest in cooking and sharing new recipes, *'you've got to discuss a recipe'* (P2A) and going out to restaurants. The barriers following a stroke were discussed and being able to order for yourself in a restaurant was highlighted as important. Some participants associated food and drink with a sense of personal identity, such as P5A *'risotto'* who had previously lived in Italy.

Living with aphasia

Conversations about coming to terms with surviving a stroke were considered meaningful, *'speaking about stroke and things are very important'* (P3A). The impact of aphasia on conversations and wellbeing was mentioned *'I was frightened that I would never get my opinion across, and I think it's very important for people with aphasia to find ways of their opinions being meaningful and important'* (P5B). The difficulty saying the word 'aphasia' was discussed. The groups agreed there was a need to raise awareness of aphasia, *'it's imperative that people are aware of aphasia'* (P5A) as this was a common environmental barrier. An example was shared of a key person who did not know what aphasia was; *'I said to one of the barristers, what is aphasia, she didn't know!'* (P5A). Community aphasia groups were seen as spaces where aphasia was understood; *'because they understand, don't they'* (P5A).

The arts

This topic encompassed art, museums and theatre. It was considered important, described by one participant as more important than food and drink. Another described it as therapeutic, *'art is very therapeutic'* (P3A) and for another as connecting to something greater than themselves *'the spiritual side of me'* (P5B). The arts were seen as part of a pre-stroke self-identity that persisted post-stroke. Accessing arts activities post stroke as an indication of independence was important, *'when I went to my first art exhibition after I've had my stroke it was extremely important to me to get out . . . it meant a lot to me'* (P5B). A feeling of belonging to a cultural community was also expressed *'we also belong to the (name of a national art group)'* (PA3).

Sharing jokes and humour

The loss of the ability to be funny with aphasia was discussed, suggesting it had previously formed part of their identity, *'But umm umm before stroke me umm me humour*

amazing but now umm me jokes ((gestured gone)' (P4A). Telling jokes and understanding jokes was considered meaningful, *'I'd put it as one, that's most meaningful'* (P1A). One person suggested humour was a means of coping with difficult circumstances, *'Better laugh than cry'* (P5A).

Travel

Participants talked about the loss of ability to travel easily post stroke. The difficulty of seeing family who lived abroad was discussed, *'My son lives in Dubai, he said the first thing he said to me was can I fly after a stroke'* (P5A). The participants liked talking about holidays, *'if we are going on a holiday, you'd like to tell people you're going and where ya going and find out if they've been on holiday if they have, find out where'* (P2B). One person linked travel to the kind of person they were, *'I do that I go I go ((gesturing movement)) ... America anywhere! I just go ((gesturing))'* (P1B).

Life experiences

Participants talked about the importance of sharing events big and small, *'everything that's going on in life, whether it's to do with yourself to do with other people'* (P2B). They talked about laughing with friends about a shared past, *'the joint events that we shared in the past we sort of laugh about and remember'* (P3B). The stories of our lives are meaningful conversations, *'Everybody has an interesting story to tell and pre and poststroke so everybody! I enjoy talking stories'* (P5B).

Topics with low meaning

There were two conversation topics, religion and money, that the group felt were not meaningful to talk about. They agreed that religion was personal and therefore not meaningful to all. There was a reference to the taboo of talking about money, and there was consensus that it had low importance for conversations. However, participants also recognised that often money and benefits have to be discussed if you have someone supporting your financial management post-stroke, *'it would be nice if I could just take care of these things by myself'* (P1A). It was described as *'important'* (P3A) and necessary *'you've got to talk about it sometimes'* (P2A) but not a conversation topic people aspired to have *'Well of course money isn't worth talking about'* (P5A).

Topics that did not reach consensus

There were ten topics that did not reach consensus e.g., half the group or less agreed that they were meaningful. Some of these topics, such as work, elicited contrasting views, see [Table 3](#). Other topics, such as nutrition, daily events and sex, were proposed but did not gain enough agreement from the group to reach the consensus criteria.

Discussion

The participants generated twenty topics of conversation and reached a group consensus that eight of these conversation topics were meaningful. The three conversation topics

Table 3. Topics that did not reach consensus

Topic	Example quotes
Politics	Asked 'Where would you put it on here? would you say it's very important, not so important?' P1B points to P6B's scale and points to most meaningful (R5/ P1B) ((pushes his hand towards the 'not as meaningful')) (P2B)
Sports	P6A indicated on the scale that sports are very high up but not exactly at the top. "To some people it's very important to me it's not very important" (P5A)
Recovery	"It's meaningful to me" (P5B) "I never ever talk about that (.) never" (P3B)
Books	"... I couldn't live without books, and I was very lucky I could read immediately" (P5B) Asked 'is talking about books meaningful to the group?' "no" (P2B)
Medical	Researcher: So, one of the things that came up quite high on yours was medical conditions? "Yes yes" (P6B) "I think we don't talk about my medical condition except when it's relevant because we (.) I think they're very bored of it really" (P5B)
Nutrition	"you're very interested in healthy [eating] and the fact that (.) um eh as a nurse yes it's very you read all sorts of scientific journals" (P1B)
Work	"Yes, I have an interest in education and I keep in touch with my friends in school and um I'm always anxious to see the new developments you know" (former teacher, P5B) "I couldn't care less ((shakes head))" (P3B)
Entertainment	"Yeah, because I talk about those with my friends and TV programmes" (P3A) "I watch TV, but I don't talk about it" (P3B)
Daily events	"The joint chit chat" (P5B)
Sex	"Of course, it affects us all" (P5A)

considered important with the highest consensus were: family and friends, food and drink and living with aphasia. Ten conversation topics did not reach consensus.

This study builds on previous research into preferred treatment topics for word finding therapies. Synonyms for meaningful are 'important' and 'worthwhile' (Oxford University Press, 2023). The conversations where we share something of ourselves are often the conversations that feel important and give meaning to our lives. The agreement that family and friends are highly meaningful highlights the importance of a person's social network after their stroke. Social networks are at risk of shrinking in people with aphasia (Northcott et al., 2016) and are connected to a person's well-being. Community belonging is associated with better general and mental health (Michalski et al., 2020). The people you love and share your life with have been identified as a factor influencing quality of life (Cruice et al., 2006; Cruice et al., 2010) and living successfully with aphasia (Brown et al., 2010).

The importance of conversations about food and drink is highlighted across a number of studies. It is considered 'core' vocabulary for communication devices, such as voice output aids (Carter, 1987; Graves, 2000). Food and drink was the most frequent topic of conversation for both people with aphasia and healthy older people in an observational study (Davidson et al., 2003). This topic came joint first in the topics chosen in Hickin et al.'s study (2022). Equally, Palmer (2017), who asked people with aphasia to select the words they wanted to target in therapy, found most words selected belonged in the food and drink topic.

Living with aphasia is a core theme in aphasia research (Hilari et al., 2012). It is linked to the renegotiation of a sense of self that occurs post stroke (Shadden & Agan, 2004). The need to share your stroke journey is well documented (Corsten et al., 2015; Frank, 1995; Strong & Shadden, 2020) and targeting vocabulary in this topic and the topic of recovery may support a person to talk about, and therefore process, what has happened to them.

This sharing of personal stories, both the small stories of everyday and bigger illness narratives, is argued to be transformative (Strong & Shadden, 2020).

The small stories from your life, identified in the holidays and travel and life experiences topics, share something of who you are. Travel was the more frequently discussed topic when participants were asked to share a meaningful event in the Law study (Law et al. 2018). Personal narratives have a dual purpose; telling a story makes sense of events to the speaker, intra-personal, but also connects them to others through shared experience, inter-personal (Olness & Ulatowska, 2011). Conversations that allow you to reveal something of your identity, what has changed and what persists, can support adjustment to living with aphasia (Taubner et al., 2020). This data suggested that working on topics linked to self-identity can be personally validating.

The arts as a meaningful topic sits with literature that highlights satisfying activities and 'doing things' as factors that influence quality of life and living well with aphasia (Brown et al., 2010; Cruice et al., 2006; Cruice et al., 2010). Cultural activities, such as visiting museums and galleries, have known links to health and wellbeing (Camic & Chatterjee, 2013; Cuypers et al., 2012; Napier et al., 2014). They have been described as journeys of self-discovery (All-Party Parliamentary Group on Arts, Health and Wellbeing, 2017) and are reported to connect our personal beliefs to universal truths (Dodd et al., 2014), perhaps reminding us that we belong in something greater than ourselves. The agreement that arts activities were meaningful may have been influenced by the characteristics of the sample e.g., predominantly university graduates from London.

The most meaningful topics identified in this study differ in how they map onto potential therapy stimuli. The topic of 'family and friends' is perhaps most challenging, as most stimuli here would be proper nouns. Children and grandchildren were the third most frequent words in the Law et al. study (2018) and fifth in the Palmer et al. study (2017). Proper nouns have distinct properties (Yasuda et al., 2000). For example, they express unique entities rather than categorical meanings. As a result, they do not easily lend themselves to some therapy approaches, like semantic feature analysis. They are also highly personalised, so difficult to apply in a group programme. Although there are few published accounts of proper name treatments in aphasia, there is some evidence that they are amenable to word finding therapies, for example using word to picture matching and naming tasks (Robson et al., 2004). The importance ascribed to the topic of family and friends, at least within our participant group, suggests that we need to improve our understanding of how this word group is best treated. One possibility is that proper nouns become the focus of the associations within treatments like Semantic Feature Analysis e.g., events in our lives and the people we love can be discussed in relation to the location or personal association of the target word.

The topic of 'food and drink' is readily translated into therapy stimuli. Individual words within this topic are often concrete, familiar items with high naming agreement that make good targets in word finding treatments. Food and drink words link both to the mundane everyday items we consume and special occasions e.g., birthdays, holidays, celebrations.

The third topic of high importance, 'living with aphasia', potentially relates to a wide vocabulary. At least some of the relevant terms here are likely to be abstract, for example relating to feelings, attitudes and treatment ('despair'; 'hope'; 'change'; 'rehabilitation'). As with proper names, few studies have explored therapies for abstract terms. However, there is some evidence that word finding treatments can

be effective here and even promote generalisation to concrete vocabulary (Kiran et al., 2009; Sandberg & Kiran, 2014). Again, the priorities flagged by our participants suggest that we need to expand our therapy approaches, in this case so that abstract words can be accommodated.

Focus group methodology enabled consensus on what topics were meaningful to talk about across a range of individuals with aphasia. The age range of participants allowed us to gather both working age and retirement age perspectives. The use of written topics with a visual sliding scale for topics to be plotted on enabled the opinions of people with more severe aphasia to be collected.

A potential limitation of the study also relates to the sample, in that participants were predominantly male, urban and educated to university level. There is a concern, therefore, that they did not reflect the wider population of people with aphasia. Our lived experiences and perspective will influence what is important to us. The voices of women were underrepresented in this sample, as was diversity in ethnicity. There will be views not captured. The characteristics of the sample may have influenced some topic choices, such as 'the arts'. Although it is interesting that the priorities here were often consistent with previous studies in which the views of PWA have been consulted. Further investigations into priority treatment topics for PWA might employ purposive sampling to achieve a more balanced participant group.

Another limitation is that individual views can be lost in the group discussion. More in-depth exploration of meaningful conversations could be examined in individual interviews. This would allow for more probing about why these topics are important. The focus groups gave consensus on meaningful topics of conversation but not individual words within those topics.

Concepts such as 'meaningfulness' are abstract and therefore problematic for many people with aphasia. It is possible that we were not successful in conveying these concepts fully to the participants; for example, some may have thought about what brought meaning to their lives, rather than what topics of conversation are meaningful. However, in this sample of people with mostly mild-moderate aphasia it was evident that some participants knew the researchers were searching for a universally acknowledged list of topics. This was made clear by comments such as '*I did a lot of theatre (.) but most people are not interested in theatre*' (P5A) and '*[I would be happy to talk about] books um for an hour two hours but no I think It's difficult for (.) and not a lot of people have an interest in books, so you know*' (P5B).

Conclusion

Previous research into the potential vocabulary for aphasia therapy has used metrics such as frequency, familiarity and concreteness. Other studies tell us what people have chosen. This small qualitative study established consensus on meaningful topics for conversation from a sample of twelve people with aphasia. These topics provide another resource to guide word lists for naming therapy or provide topics for conversation groups. The topics identified as most meaningful in this study map onto a range of vocabulary types that go beyond the concrete words most often included in aphasic naming treatments. This suggests that new treatment approaches are needed, for example to target proper and abstract nouns.

Acknowledgments

Thank you to the participants with aphasia who took part in the study and to the community aphasia groups for supporting recruitment.

Declaration of interest statement

Authors declare no competing interests.

Disclosure statement

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

ORCID

Niamh Devane  <http://orcid.org/0000-0001-8448-1478>

Katerina Hilari  <http://orcid.org/0000-0003-2091-4849>

The study was funded by a doctoral studentship from the School of Health Sciences at City, University of London awarded to Niamh Devane in 2019.

References

- Acocella, I. (2012). The focus groups in social research: Advantages and disadvantages. *Quality & Quantity: International Journal of Methodology*, 46, 1125–1136. <https://doi.org/10.1007/s11135-011-9600-4>
- All-Party Parliamentary Group on Arts, Health and Wellbeing. (2017). *Creative Health: The arts for health and wellbeing*. <https://www.culturehealthandwellbeing.org.uk/appg-inquiry/>
- Beeke, S., Beckley, F., Best, W., Johnson, F., Edwards, S., & Maxim, J. (2013). Extended turn construction and test question sequences in the conversations of three speakers with agrammatic aphasia. *Clinical Linguistics & Phonetics*, 27(10–11), 784–804. <https://doi.org/10.3109/02699206.2013.808267>
- Brown, K., Worrall, L., Davidson, B., & Howe, T. (2010). Snapshots of success: An insider perspective on living successfully with aphasia. *Aphasiology*, 24(10), 1267–1295. <https://doi.org/10.1080/02687031003755429>
- Camic, P. M., & Chatterjee, H. J. (2013). Museums and art galleries as partners for public health interventions. *Perspectives in Public Health*, 133(1), 66–71. <https://doi.org/10.1177/1757913912468523>
- Carter, R. (1987). Is there a core vocabulary? Some implications for language teaching. *Applied Linguistics*, 8(2), 178–193. <https://doi.org/10.1093/applin/8.2.178>
- Chapey, R., Duchan, J. F., Elman, R. J., Garcia, L. J., Kagan, A., Lyon, J. G., & Simmons Mackie, N. (2000). Life Participation Approach to Aphasia: A statement of values for the future. *ASHA Leader*, 5(3), 4–6. <https://doi.org/10.01044/leader.FTR.05032000.4>
- Corsten, S., Schimpf, E. J., Konradi, J., Keilmann, A., & Hardering, F. (2015). The participants' perspective: How biographic–narrative intervention influences identity negotiation and quality of life in aphasia. *International Journal of Language & Communication Disorders*, 50(6), 788–800. <https://doi.org/10.1111/1460-6984.12173>
- Cruice, M., Hill, R., Worrall, L., & Hickson, L. (2010). Conceptualising quality of life for older people with aphasia. *Aphasiology*, 24(3), 327–347. <https://doi.org/10.1080/02687030802565849>
- Cruice, M., Worrall, L., & Hickson, L. (2006). Perspectives of quality of life by people with aphasia and their family: Suggestions for successful living. *Topics in Stroke Rehabilitation*, 13(1), 14–24. <https://doi.org/10.01310/4JW5-7VG8-G6X3-1QVJ>

- Cuypers, K., Krokstad, S., Holmen, T. L., Skjei Knudtsen, M., Bygren, L. O., & Holmen, J. (2012). Patterns of receptive and creative cultural activities and their association with perceived health, anxiety, depression and satisfaction with life among adults: The HUNT study, Norway. *Journal of Epidemiology and Community Health*, 66(8), 698–703. <https://doi.org/10.1136/jech.20https://doi.org/10.113571>
- Davidson, B., Worrall, L., & Hickson, L. (2003). Identifying the communication activities of older people with aphasia: Evidence from naturalistic observation. *Aphasiology*, 17(3), 243–264. <https://doi.org/10.1080/729255457>
- Dodd, J. T., Sandell, R. E., & Scott, C. A. (2014). Cultural value: User value of museums and galleries: A critical view of the literature. University of Leicester. Report: <https://hdl.handle.net/2381/37043>
- Efstratiadou, E. A., Papanthasiou, I., Holland, R., Archonti, A., & Hilari, K. (2018). A systematic review of Semantic Feature Analysis therapy studies for aphasia. *Journal of Speech, Language & Hearing Research*, 61(5), 1261–1278. https://doi.org/10.1044/2018_JSLHR-L-16-0330
- Frank, A. W. (1995). *The Wounded Storyteller: Body, illness and ethics*. University of Chicago Press.
- Given, L. M. (Ed.) (2008). *The SAGE encyclopedia of qualitative research methods*. (Vols. 1-0). SAGE Publications, Inc., <https://doi.org/10.04135/9781412963909>
- Goodglass, H. & Wingfield, A.(Eds.). (1997). *Anomia: Neuroanatomical and cognitive correlates*. Academic Press.
- Graves, J. (2000). Vocabulary needs in augmentative and alternative communication: A sample of conversational topics between staff providing services to adults with learning difficulties and their service users. *British Journal of Learning Disabilities*, 28(3), 113–119. <https://doi.org/10.1046/j.1468-3156.2000.00060.x>
- Hickin, J., Cruice, M. & Dipper, L. (2022). A feasibility study of a novel computer-based treatment for sentence production deficits in aphasia, delivered by a combination of clinician-led and self-managed treatment sessions. *Aphasiology*, 1–23. <https://doi.org/10.1080/02687038.2022.2116928>
- Hilari, K., Needle, J. J., & Harrison, K. L. (2012). What are the important factors in health-related quality of life for people with aphasia? A systematic review. *Archives of Physical Medicine and Rehabilitation*. 93(1 Suppl), S86–95. <https://doi.org/10.1016/j.apmr.2011.05.028>
- Holland, A. L., Halper, A. S., & Cherney, L. R. (2010). Tell me your story: analysis of script topics selected by persons with aphasia. *American Journal of Speech-Language Pathology*, 19(3), 198–203. [https://doi.org/10.1044/1058-0360\(2010/09-0095\)](https://doi.org/10.1044/1058-0360(2010/09-0095))
- Kiran, S., Sandberg, C., & Abbott, K. (2009). Treatment for lexical retrieval using abstract and concrete words in persons with aphasia: Effect of complexity. *Aphasiology*, 23, 835–853.
- Lavoie, M., Macoir, J., & Bier, N. (2017). Effectiveness of technologies in the treatment of post-stroke anomia: A systematic review. *Journal of Communication Disorders*, 65, 43–53. <https://doi.org/10.1016/j.jcomdis.2017.01.001>
- Law, S., Kong, A. P., & Lai, C. (2018). An analysis of topics and vocabulary in Chinese oral narratives by normal speakers and speakers with fluent aphasia. *Clinical Linguistics & Phonetics*, 32(1), 88–99. <https://doi.org/10.1080/02699206.2017.1334092>
- McHugh, M. L. (2012). Interrater reliability: The kappa statistic. *Biochemia Medica*, 22(3), 276–282. [biochem_med-22-3-276–4 \[pii\]](https://doi.org/10.1007/s12013-012-0000-0)
- Michalski, C. A., Diemert, L. M., Helliwell, J. F., Goel, V., & Rosella, L. C. (2020). Relationship between sense of community belonging and self-rated health across life stages. *SSM - Population Health*, 12, 100676. <https://doi.org/10.1016/j.ssmph.2020.100676>
- Napier, A. D., Ancarno, C., Butler, B., Calabrese, J., Chater, A., Chatterjee, H., Guesnet, F., Horne, R., Jacyna, S., & Jadhav, S. (2014). Culture and health. *The Lancet*, 384(9954), 1607–1639.
- Northcott, S., Marshall, J., & Hilari, K. (2016). What factors predict who will have a strong social network following a stroke? *Journal of Speech, Language, and Hearing Research*, 59(4), 772–783. https://doi.org/10.1044/2016_JSLHR-L-15-0201
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: A synthesis of recommendations. *Academic Medicine: Journal of the Association of American Medical Colleges*, 89(9), 1245–1251. <https://doi.org/10.1097/ACM.0000000000000388>

- Olness, G. S., & Ulatowska, H. K. (2011). Personal narratives in aphasia: Coherence in the context of use. *Aphasiology*, 25(11), 1393–1413. <https://doi.org/10.1080/02687038.2011.599365>
- Oxford University Press (2023). *Oxford English Dictionary*. Retrieved October 3, 2023, from <https://languages.oup.com/google-dictionary-en/>
- Palmer, R., Hughes, H., & Chater, T. (2017). What do people with aphasia want to be able to say? A content analysis of words identified as personally relevant by people with aphasia. *PLoS One*, 12(3), e0174065. <https://doi.org/10.1371/journal.pone.0174065>
- Renvall, K., Nickels, L., & Davidson, B. (2013a). Functionally relevant items in the treatment of aphasia (part I): Challenges for current practice. *Aphasiology*, 27(6), 636–650. <https://doi.org/10.1080/02687038.2013.786804>
- Renvall, K., Nickels, L., & Davidson, B. (2013b). Functionally relevant items in the treatment of aphasia (part II): Further perspectives and specific tools. *Aphasiology*, 27(6), 651–677. <https://doi.org/10.1080/02687038.2013.796507>
- Ritchie, J., & Lewis, J. (2003). *Qualitative Research Practice: A guide for social science students and researchers*. SAGE.
- Ritchie, J. & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. Burgess (Eds.), *Analyzing qualitative data* (pp. 173–194). Routledge.
- Robson, J., Marshall, J., Pring, T., Montagu, A. & Chiat, S. (2004). Processing proper nouns in aphasia: Evidence from assessment and therapy. *Aphasiology*, 18(10), 917–935. <https://doi.org/10.1080/02687030444000462>
- Rose, T. A., Worrall, L. E., Hickson, L. M., & Hoffmann, T. C. (2012). Guiding principles for printed education materials: Design preferences of people with aphasia. *International Journal of Speech-Language Pathology*, 14(1), 11–23. <https://doi.org/10.3109/17549507.2011.631583>
- Sandberg, C. & Kiran, S. (2014) How justice can affect jury: Training abstract words promotes generalisation to concrete words in patients with aphasia, *Neuropsychological Rehabilitation*, 24:5, 738–769.
- Shadden, B. B., & Agan, J. P. (2004). Renegotiation of identity: The social context of aphasia support groups. *Topics in Language Disorders*, 24(3), 174–186. <https://doi.org/10.1097/00011363-200407000-00005>
- Sirman, N., Beeke, S., & Cruice, M. (2017). Professionals' perspectives on delivering conversation therapy in clinical practice. *Aphasiology*, 31(4), 465–494.
- Strong, K. A., & Shadden, B. B. (2020). The power of story in identity renegotiation: Clinical approaches to supporting persons living with aphasia. *Perspectives of the ASHA Special Interest Groups*, 5(2), 371–383. https://doi.org/10.1044/2019_PERSP-19-00145
- Sze, W. P., Hameau, S., Warren, J., & Best, W. (2020). Identifying the components of a successful spoken naming therapy: A meta-analysis of word-finding interventions for adults with aphasia. *Aphasiology*, 1–40. <https://doi.org/10.1080/02687038.2020.1781419>
- Taubner, H., Hallén, M., & Wengelin, Å. (2020). Still the same? – Self-identity dilemmas when living with post-stroke aphasia in a digitalised society. *Aphasiology*, 34(3), 300–318. <https://doi.org/10.1080/02687038.2019.1594151>
- Tausch, A. P. & Menold, N.(2016). Methodological Aspects of Focus Groups in Health Research: Results of qualitative interviews with Focus Group Moderators. *Global Qualitative Nursing Research*, 3, 2333393616630466. <https://doi.org/10.1177/2333393616630466>
- Wilson, S., Roper, A., Marshall, J., Galliers, J., Devane, N., Booth, T., & Woolf, C. (2015). Codesign for people with aphasia through tangible design languages. *CoDesign*, 11(1), 21–34. <https://doi.org/10.1080/15710882.2014.997744>
- Wisernburn, B., & Mahoney, K. (2009). A meta-analysis of word-finding treatments for aphasia. *Aphasiology*, 23(11), 1338–1352. <https://doi.org/10.1080/02687030902732745>
- Yasuda, K., Beckmann, B., & Nakamura, T. (2000). Brain processing of proper names. *Aphasiology*, 14(11), 1067–1089. <https://doi.org/10.1080/02687030050174638>

Appendix 1: Focus Group Topic Guide

What conversation topics are meaningful for people with aphasia?

Introduction:

- Welcome
- Hi everyone, our names are X. We are speech and language therapy students at city university. We have seen a few of you already. So today we are here to find out from you 'what conversation topics are meaningful for people with aphasia'.
- We will start by: (write key words on board)
 - Saying some **rules**
 - Then we will do a **warm-up** activity
 - Then we will talk about **communication** in everyday life
 - Look at rating our own ideas in terms of **what is meaningful**
 - Have a short **break**
 - Then we will have a **group discussion**

And when we are finished, we just need to collect a little bit more information from each of you

Rules:

Ok so first let's go through some group rules

Throughout the group, please communicate however you feel comfortable, we have pens and paper if you want to write or draw

- We need to listen and wait for each other
- Everyone's thoughts are important
- There are no right or wrong answers
- And finally, whatever we say today stays within the group

Housekeeping – where the toilets are, not expecting a fire alarm

Warm-up:

First of all, we're just going to do a quick warm-up activity.

For this activity we are each going to pick a picture of a musical instrument and describe it using words, or gesture, or writing – or whatever way is easiest.

Communication:

Let's start by thinking about communication

Q1: Firstly, we want to ask: Who do you communicate with?

You can write them down if you'd like

You can have as many answers as you'd like

We will help you if needed.

Q2: Where do you communicate?

Does anyone have anything they want to share?... about where they communicate

So, it looks like we communicate in lots of places
Ok so the next question is...

Q3: What do you communicate about?

For this one you can put your ideas on the post-it notes in front of you
Ok so we have lots of ideas, we're going to think more about these conversations now and we'd like to ask

Q4: How do these conversations make you feel?

Does anyone have anything they want to share?
Ok so we have a few different ideas, now we are going to do something a little different

Q5: Looking at "what we communicate about" on the post-it notes, we want to know what is more meaningful to you

We have a scale, with "most meaningful" and "not as meaningful". We want you to stick your post-its on the line... What is most meaningful and not as meaningful to you.
We just want to take a moment to look at everyone's rating scales.

Does anyone want to share their "top topic?"

Can you give an example of when you spoke about X?

*Break – be back in the room in 20 minutes (time)
Discuss as a group when we come back.*

Ok so before the break we thought about the idea of communication and what we found 'most meaningful' to talk about.

Look at these ideas as a group

Using the same scale, can we decide as a group what is meaningful and not as meaningful to us.

Q6: Where do we think as a group this should go on the scale?

End: Palmer et al, 2017
We've come up with some really interesting topics today

There was a study in 2017, looking at what words people with aphasia wanted to be able to say.

The top 10 topic areas that people with aphasia talked about were:

- (1) *Food and Drink*
- (2) *Nature and Gardening*
- (3) *Entertainment*
- (4) *Places*
- (5) *People*
- (6) *House*
- (7) *Clothes*
- (8) *Travel*

(9) *Actions*

(10) *Money and numbers*

Q7: How do we feel about these?

They looked at what was **'useful'**, we looked at what is **'meaningful'** – write key words above.

Summary:

Ok so we have come up with lots of topic ideas

Let's have a look at all of our topics we have come up with

Q8: Looking at the scale, we've got x, y and z as the top topics.

Does this sound right?

Anything else?

End:

Thank you all for coming in today

We have gathered some interesting information from the group

We will hopefully have the results by June/July

We would love to come and share them with you

We can come to your groups and give you a summary of what we found