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Addressing the long-term impacts of aphasia: How far does the Conversation Partner Programme go?

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Abstract

Background

Approximately 176,000 new individuals in the United Kingdom and Ireland are diagnosed with stroke annually with up to one third experiencing aphasia. Qualitative research methods are increasingly used to capture the complexity of service users' experiences of health and illness; however, the voice of service users with aphasia continues to be limited in published healthcare literature. This participatory research study included people with aphasia as co-researchers in the exploration of aphasia and a Conversation Partner Programme (CPP).

Aims

To describe participants' insider (emic) experiences of (1) aphasia and 2) a CPP.

Methods and Procedures

Following a pilot study, the generation and analysis of qualitative data involved a Participatory Learning and Action (PLA) approach based on the interpretive paradigm. Using purposeful sampling, participants included people with aphasia ($n = 5$) who had experience of the CPP. Through ($n = 5$) 3-hour data generation sessions across 12 months using PLA techniques -Flexible Brainstorming and Card Sort - participants' unique perspectives of aphasia and the CPP were recorded. The principles of thematic analysis guided the co-analysis of data with participants. To explore transferability of findings, data generated in Ireland were presented to an international inter-stakeholder group in Connect UK.

Outcomes and Results

Participants identified eight themes describing the lived experience of

aphasia including (1) Back to Pre-School, (2) Tiredness, (3) It's Like in Prison, (4) Emotions, (5) Not able to talk the Words, (6) Escape, (7) Changing and Adapting, and (8) Family. Five additional themes were co-generated capturing the value of the CPP. It appeared that because the CPP training and programme acknowledged the expertise of individuals with aphasia and provided opportunities for conversations with unfamiliar people, the negative feelings of communicative incompetence described in "Back to Pre-School" and "Not able to talk the words" were minimised. Feelings of marginalisation captured in "Escape", "It's like in Prison" and "Emotions" were reported to be reduced through the social aspects of the Programme.

Conclusions

Aphasia changes communication situations and interpersonal relationships often resulting in psychosocial impacts and disempowerment. The CPP contributed to promoting successful communication and reducing social exclusion. Participants reported transformative experiences related to identity, independence, and confidence. These outcomes are encouraging as marginalisation and vulnerability to "secondary handicap" are recognised long term risks of aphasia. Findings will be of interest to those living and working with people with aphasia and to those designing, delivering and participating in CPPs.

Keywords

conversation approaches; impacts; emic; qualitative; participatory health research; insider

Introduction

Approximately 176,000 (Institute of Public Health (IPH) Stroke Briefing, 2012; Stroke Association, 2015) new individuals in the United Kingdom and Ireland are diagnosed with stroke annually with up to one third experiencing Aphasia (Code & Petheram, 2011). The voices of these people are frequently absent from the published stroke literature compared to other population groups (Carlsson, Paterson, Scott-Findlay, Ehnfors, & Ehrenberg, 2007). Through qualitative research the insider perspective or emic perspective (Creswell, 2013) of aphasia is emerging, and people with aphasia (PWA) are teaching us about the lived experience of aphasia

(Simmons-Mackie & Lynch, 2013). This emic perspective (Creswell, 2013), has taught us that adapting to life with aphasia and re-negotiating normal activities of daily living (e.g., finances, housework, work, social life, and leisure interests) is more difficult in the presence of a communication disability (Parr, Byng, & Gilpin, 1997; Pound, Parr, & Duchan, 2001). We know from previous research that family and friends can become anxious about communication, and attempts at normal conversation may result in feelings of fatigue, discouragement, and sadness (Le Dorze & Signori, 2010; Michallet, Tétreault, & Le Dorze, 2003). Others may perceive the person with aphasia differently, for example more difficult to talk to, less likable, less interested in achievement, less capable of endurance with less capacity to care for others (Croteau & Le Dorze, 2001). Partners often become the primary carers with additional responsibilities (Hammell, 2001) and new behaviours such as overprotectiveness and assuming the speaker role in conversation may develop thereby excluding the person with aphasia (Croteau, Vychytil, Larfeuil, & Le Dorze, 2004; Halle, Duhamel, & Le Dorze, 2011; Purves, 2009). Personal relationships and social networks may gradually decline for both the person with aphasia and family members resulting in increased isolation and disconnection (Cruice, Worrall, Hickson, & Murison, 2003; Northcott & Hilari, 2011).

Listening to the emic perspective (Creswell, 2013) has taught us that our efforts to understand aphasia must extend beyond the language and speaking problems to include the complex changing experiences and representations of all those negotiating life with aphasia (Barrow, 2008). Dealing with the uncertainty about the meaning of stroke and aphasia in terms of personal identity, relationships, professional and financial status are long term challenges (Dalemans, de Witte, Wade, & van den Heuvel, 2010; Pound et al., 2001). We need to co-design rehabilitation goals and develop interventions that help the person with aphasia and his/her family experience successful communication (Barrow, 2011). Conversation approaches are an increasingly popular intervention that emphasise communicative competence, reciprocity and life participation (McVicker, Parr, Pound, & Duchan, 2009).

Conversation partner training approaches

Aligned with the social model of disability, conversation approaches are

designed to increase communicative access and reduce the psychosocial consequences of aphasia (Byng & Duchan, 2005). According to Turner and Whitworth (2006) conversation training interventions centre on the belief that conversation partners can be trained to support and optimise communication with a person with aphasia and have traditionally targeted three primary groups including: (1) familiar partners - family or friends (Booth & Swabey, 1999; Lock, Wilkinson, & Bryan, 2001); (2) volunteers (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001; McVicker et al., 2009; Rayner & Marshall, 2003) and (3) healthcare professionals (Shale, 2004). Training interlocutors to become skilled conversation partners creates new expectations for the person with aphasia and the conversation partner. Conversation opportunities are increased as the competence of the person with aphasia is revealed and the risk of marginalisation is reduced (Turner & Whitworth, 2006). Supporters of conversation approaches recognise the therapeutic potential of conversation and value the expertise of the person with aphasia. Social interaction is prioritised above linguistic gains and positive communication experiences are promoted (Kagan, 1995; Kagan et al., 2001; McVicker et al., 2009). However the evidence on the impacts of conversation interventions for PWA is limited. The present study addresses this gap in knowledge by listening to the emic perspective of a small group of PWA with experiential knowledge of a Conversation Partner Programme (CPP).

Emerging evidence of the emic perspective (Pound, Duchan, Penman, Hewitt, & Parr, 2007) in published aphasia literature is regarded as a positive direction in the design of this study. However, the use of interviewing as the single predominant data collection method in qualitative studies is striking. As recommended by Simmons-Mackie and Lynch (2013), alternative research methods and data collection strategies should be considered. There is a growing body of literature reporting the use of participatory methods in the field of healthcare internationally (MacFarlane et al., 2009, 2012) with the suggestion that these methods are particularly useful to include marginalised groups typically excluded from the research process (MacFarlane, O' Reilly de-Brún, & de Brún, 2008). This study is innovative as we applied participatory research methods to include PWA as co-researchers in a three-phase research project. Here we report Phase I that involved an exploration of their emic experiences of (1) aphasia and (2)

a CPP. We are reporting this study on behalf of PWA who participated in this research as participants and co-researchers.

Methods

Study setting

The conversation intervention used is based on the CPP developed at Connect (the communication disability network, 2001), London in 2001. A detailed description of this programme is available elsewhere (McVicker et al., 2009). While the Connect conversation scheme originally focused on training volunteers as conversation partners, the network subsequently expanded to include universities across the United Kingdom and Ireland.

At the National University of Ireland (NUI), Galway, in the west of Ireland the CPP is an integral part of the the 4-year BSc in Speech and Language Therapy. The programme is run in collaboration with the local community Speech and Language Therapy service (Speech and Language Therapy Department Primary Community Continuing Care (PCCC) Health Services Executive (HSE) West, 2015). Community speech and language therapists (SLTs) refer approximately 5–20 new PWA into the programme annually. The majority of PWA choose to continue their participation across several iterations of the programme over a number of years.

For third-year students, CPP training and participation is a mandatory requirement. These students are trained as conversation partners, paired with a peer and matched with a person with aphasia based on interests and hobbies and geographical location. Students' weekly conversation visits to PWAs' homes or other locations provide unique opportunities to learn about aphasia and apply theory to practice in a relaxed environment which is different from the classroom or clinical settings. Weekly reflective logs, fortnightly tutorials, and assessment involving individual and group work facilitate students' reflective practice and learning throughout the programme (see Table 3.1 for detailed CPP information).

Table 4.1 Conversation Partner Programme Details

Conversation Partner	Speech and Language Therapists in training	People with aphasia
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Programme		
Participants	Third-year undergraduate students (25-30 students)	<p>People with aphasia living in the local community referred by community speech and language therapists working for the public health service.</p> <p>Partners include males and females aged between 21-90 years with an acquired brain injury resulting in aphasia. All participants have been discharged from acute health services and are living in the community e.g. family homes nursing homes</p>
Module content	<p>Students work in pairs and complete 10-12 visits with a person with aphasia.</p> <p>Students use supportive communication techniques to facilitate conversation</p>	<p>Visits take place in a variety of locations depending on conversation partners' preferences e.g. family home, coffee shop, restaurant, nursing home, Speech and Language Therapy office, University</p>
Monitoring	<p>Weekly reflective blogs</p> <p>Fortnightly class tutorials with academic staff</p>	<p>The PWA can contact the referring SLT and/or the CPP co-ordinator based at the university at any time during the programme</p>
Credits	<p>Students must pass all components of the module to complete the module.</p> <p>There is no compensation between components</p>	
Assessment	<p>Completion of conversation partner</p>	

	<p>training (1-day programme); participation in 10-12 visits with PWA; completion of weekly reflective blog; participation in fortnightly tutorials.</p> <p>Students work in small groups to prepare a poster presentation on aphasia-related themes</p>	
Duration	<p>1-2 Semesters</p> <p>7 Hours per week (1 day)</p>	<p>Visits take place over 10-14wks</p>

Study Design

This participatory study is designed following the principles of a Participatory Learning and Action (PLA) (O’ Reilly-de Brun & de Brún, 2010) approach based on the interpretive paradigm. PLA is an adaptive strategy developed from work by Chambers (1994) that enables diverse groups and individuals to learn, work, and act together in a co-operative manner, to share, enhance, and analyse their knowledge; and to plan together for positive action. PLA emphasises three key components:

1. **Participatory** research projects undertaken in rural and urban settings.
2. **Learning** is an essential part of the process – two-way or Multidirectional.
3. **Action** is about more than appraisal – it is about taking positive action.

Founded on the principles of (1) democracy, (2) equity, (3) liberation and (4) life enhancement (De Poy & Gitlin, 1998), this methodological approach promotes genuine participation and involvement of participants. The multidisciplinary backgrounds and PLA experience of the three authors supported the adaption of PLA techniques and materials for use with PWA. The first author is a SLT with over 15 years experience of working with

PWA and has coordinated the CPP at NUI, Galway for almost a decade. The second author is a psychologist with many years experience of working with people with intellectual disability and communication challenges. The third author is a social scientist and academic and has been involved in collaborative/partnered participatory research with a broad range of stakeholder groups nationally and internationally for over 10 years. All three authors are trained PLA facilitators¹ and through their combined clinical, PLA, and research expertise, they ensured the research process was communicatively accessible for the co-researchers with aphasia.

Pilot study

The research questions and PLA techniques were piloted with trained PLA experts ($n = 2$) and PWA ($n = 2$) to test relevance and understanding. As a result of the pilot several changes were made to improve the explanation and clarity of PLA techniques, timing, methods, materials, session facilitation and research questions.

Sampling and recruitment

The majority of studies that have included PWA have sampled on the basis of a general diagnosis, such as stroke, or with inclusion/exclusion criteria based on the person's communicative and/or cognitive ability. During recruitment we deliberately avoided exclusion criteria that may convey that some participants were not "good enough" for our study (Carlsson et al., 2007). We recognised that including PWA as co-researchers irrespective of the severity of their communication disability would contribute a unique perspective to the study that would not otherwise be achieved.

Purposive sampling (Creswell, 2013) was used to obtain the study sample. Using this sampling technique allowed us to select PWA living in the West of Ireland affiliated with NUI, Galway, CPP. A letter was sent to 10 PWA (five females and five males) of varying age ranges who had experience of the CPP. This letter invited PWA to participate in the research. In accordance with our ethical approval a maximum of five people could be recruited to this stakeholder group with up to three reminders about the study to each person. It was not ethical to contact potential younger and/or

¹ The authors were trained as PLA facilitators by the Centre for Participatory Strategies (CPS) Ross Wood Clonbur Co. Galway Ireland by Mary O'Reilly-de Brún and Tomas de Brún.

female participants a fourth time and from our recruitment drive four males and one female agreed to participate. There were no exclusion criteria, and participants were not screened for cognitive, hearing, and/or visual problems.

Participants

Four men and one woman with a mean age of 73 years agreed to participate in this study. Time elapsed since stroke ranged from 3 to 10 years with an average participation in 3 iterations of the CPP, that is, 30 conversation visits, 10 visits per annual iteration of the programme. Communication diagnoses and severity determinations were based on (1) the objective assessment reports from the referring SLTs documented in the speech and language therapy records, (2) the SLT researchers' confirmation of communication diagnoses with each referring SLT, and (3) informal observations of participants throughout the study. All participants had functional comprehension in conversation with either mild or mild to moderate comprehension difficulties. There was greater variability in expressive language ability, with a range of mild, moderate and moderate to severe disability. Similar to the Parr (2007) study, styles of communication varied as each person had adapted to communicating with aphasia in different ways, and had developed preferences for varied communication strategies. Most used gesture, intonation, facial expression, with occasional single written words or letters to supplement their speech. Nobody used drawing, word lists, or portable communication devices, and one person who presented with the most severe expressive disability did not spontaneously use any augmentative means to support communication. Table 2 shows some characteristics of the five participants with aphasia. Given the older age range of participants, we have also included details about the possibility of co-morbid dementia. All names in this table and throughout the paper have been changed to protect confidentiality.

Table 4.2 - Characteristics of People with Aphasia

Name, age and years since stroke	Sex	Participation in the CPP	Communication diagnosis (from (1) SLT records; (2) discussion with referring SLT; (3) SLT researcher's observations of participants)	Co-morbid dementia	Medical diagnosis	Employment	Domestic situation	Research sessions attended ($n = 8$)
David, 83 years and 3 years	M	3 times	Moderate expressive aphasia with moderate-severe literacy difficulties	No evidence in SLT records; on discussion with SLT or during data generation sessions.	Stroke	Retired	Home with family	$n = 6$
William, 85	M	4 times	Severe expressive	No evidence in SLT records;	Stroke	Retired	Home with family	$n = 5$

Name, age and years since stroke	Sex	Participation in the CPP	Communication diagnosis (from (1) SLT records; (2) discussion with referring SLT; (3) SLT researcher's observations of participants)	Co-morbid dementia	Medical diagnosis	Employment	Domestic situation	Research sessions attended (<i>n</i> = 8)
years and 10 years			aphasia	on discussion with SLT or during data generation sessions.				
Gary, 60 years and 4 years	M	3 times	Mild-moderate expressive aphasia and moderate-severe apraxia of speech	No evidence in SLT records; on discussion with SLT or during data	Stroke	Retired	Home with family	<i>n</i> = 8

Name, age and years since stroke	Sex	Participation in the CPP	Communication diagnosis (from (1) SLT records; (2) discussion with referring SLT; (3) SLT researcher's observations of participants)	Co-morbid dementia	Medical diagnosis	Employment	Domestic situation	Research sessions attended (<i>n</i> = 8)
				generation sessions.				
Neil, 69 years, and 6 years	M	4 times	Cognitive communication impairment affecting memory, planning, and organisation; some word finding difficulties	No evidence in SLT records; on discussion with SLT or during data generation sessions.	Stroke	Retired	Home with family	<i>n</i> = 7

Name, age and years since stroke	Sex	Participation in the CPP	Communication diagnosis (from (1) SLT records; (2) discussion with referring SLT; (3) SLT researcher's observations of participants	Co-morbid dementia	Medical diagnosis	Employment	Domestic situation	Research sessions attended (<i>n</i> = 8)
			and severe literacy difficulties					
Anne, 69 years and 4 years	F	3 times	Moderate aphasia with tangential speech and moderate literacy difficulties	No evidence in SLT records; on discussion with SLT or during data generation sessions.	Stroke	Retired	Home with family	<i>n</i> = 4

Consent

There are methodological issues related to obtaining informed consent when the participants being invited to consent have a communication disability. Some suggest that the complexities of providing informed consent to PWA might explain why the voice of this population group is limited in the literature (Carlsson et al., 2007). Strategies to address the ethical issues related to obtaining informed consent from people with communication disabilities have been reported e.g. (e.g., Parr, 2007; Philpin, Jordan, & Warring, 2005). In this study we aimed to facilitate participants' understanding of consent forms by presenting oral and written information in an aphasia-friendly format, for example, we adjusted language and used illustrated communication resources (Rose, Worrall, Hickson, & Hoffmann, 2012). We discussed the content of all consent forms with each individual as this strategy has been posited as the most effective way of improving participants' understanding of what informed consent involves (Flory & Emanuel, 2004; Penn, Frankel, Watermeyer, & Müller, 2009). Given that PWA with accompanying memory difficulties and/or co-morbid dementia may sign a consent form and then later forget what they had signed or even that they had given consent, we did not assume that participants' consent was long-standing. Rather we reviewed consent following each data generation session throughout the study (Usher & Arthur, 1998). All aphasia friendly consent forms including (1) project; (2) photo and (3) recording forms were approved by the NUI, Galway research ethics committee.

Data co-generation

A variety of PLA data generation techniques were used to create data with co-researchers, specifically the Flexible Brainstorming and Card Sort techniques. Importantly, and in recognition of their role as co-researchers, these two techniques were selected and agreed with co-researchers as part of the co-design process. Both PLA techniques have been used in international research settings (Chambers, 1994, 2004; O'Reilly-de Brún & de Brún, 2011). In the current study, these techniques were used to generate, organise, and display participants' data, and an accompanying "PLA interview" (O'Reilly-de Brún & de Brún, 2011) was used to explore, synthesise, and co-analyse the data. The key features of the selected techniques and materials are that they offered a mechanism for sharing,

discussing, and evaluating knowledge in a supported communication environment that was dynamic and could be adapted to suit individual communication needs and preferences. Through five data generation sessions of approximately 3 hours each across 12 months, participants' unique perspectives of aphasia and the CPP were co-generated and co-analysed. With participants' consent we took photographs during the data generation sessions. This had multiple purposes. First, it allowed us to visually record the co-selected PLA techniques, materials used, and active engagement of participants with the PLA techniques (see Figure 1). Second, the photographs provided a visual record of the data recorded on the Flexible Brainstorm and Card Sort charts, which was a valuable way of reminding participants about the data generated across sessions. In this way the photographs contributed to the qualitative analytic process with participants throughout the project. Finally for each session, we printed and displayed the photographs on blank charts and invited participants to choose any that they desired to take home as a personal keepsake and to share with others, for example, family and friends. The selected photographs were a tangible, visual reminder of the research work, and they acted as a ramp to communication with others about the activity during the data generation sessions. All sessions were taped with permission on a digital audio recorder.



Figure 4.1 Photographs from the data generation sessions. (left) examples of PLA materials used; (right) participants engaging with the PLA Flexible Brainstorm technique.

PLA Technique – Flexible Brainstorm

To answer the research question “How does aphasia affect me and my family?” co-researchers engaged in a PLA technique called “Flexible Brainstorm” (O’Reilly-de Brún & de Brún, 2011). A Flexible Brainstorm is a

fast way of using varied materials (large sheet of blank flip chart paper, coloured stickies, pictures, symbols, markers, pens, paper) to get information and ideas that can be arranged, re-arranged, connected, and discussed for different purposes (O'Reilly-de Brún & de Brún, 2011). The PLA materials were centred on the table, and participants selected materials to suit their individual communication preferences. Some chose to write single word(s) and talk about their idea(s), and others chose a picture to represent their intended meaning; the majority who had difficulty writing requested that the facilitators wrote on their behalf. Therefore on instruction from an individual, the facilitator wrote verbatim what the person wanted to record and checked that the intended meaning had been captured accurately before the PWA placed the stickie on the Flexible Brainstorm chart. There was no restriction on the number of ideas an individual could share; however in the interest of clarity the group agreed that they would only represent one idea on each stickie. Following review of the Flexible Brainstorm chart generated in response to Question 1 in Phase 1, the co-researchers suggested colour coding stickies for all subsequent research questions. Each participant chose a set of coloured stickies, which became "their colour" for the duration of the activity. The visual record of ideas on colour-coded stickies connected the person to the shared experience and enabled participants to identify "their stickies" quickly on the chart, for example, David could see that all of the orange stickies on the chart represented his ideas. Adopting colour coding as a strategy during data generation is a practical example of participants co-designing the research process.

Interviewing the technique

The process of sharing and recoding ideas continued until everyone had said all that they wanted to say in response to the research question. Sufficiency of data collected was determined by "interviewing" the emerging data. This means that the group reviewed the completed chart to identify potential gaps. They were encouraged by the facilitator to discuss anything surprising or striking about the experiences shared. If any additional information was generated co-researchers were invited to record the new ideas on their colour-coded stickies and place them on the chart. When the group agreed that there was nothing new to add, data saturation was reached and the Flexible Brainstorm was complete. The Flexible

Brainstorm technique was a foundation activity for the second PLA “Card Sort” technique (O’Reilly-de Brún & de Brún, 2011). Figure 4.2 shows Photo examples of the Flexible Brainstorm technique and co-created chart.



Figure 4.2: Photo examples of the Flexible Brainstorm technique and co-created chart.

PLA technique – card sort

A Card Sort is a variety of cards (or symbols) that participants sort, usually into bundles or categories. Card Sorts are a method of categorisation that facilitate participants to (1) organise and share large amounts of information,(2)move and connect information, and (3) “cross-check” information with each other (O’Reilly-de Brún & de Brún, 2011). Co-researchers reviewed the populated Flexible Brainstorm chart and engaged in a Card Sort process - sorting, organising, and analysing the data into meaningful groupings. The researcher asked co-researchers two questions: (1) “What stickies belong together?” and 2) “Why do these stickies belong together?” Reading individual stickies aloud supported the group to reflect on the data and group similar elements.

Data Co-Analysis

The principles of thematic analysis (Creswell, 2013; Silverman, 2013) guided the co-analysis of data. Through the PLA Card Sort (described earlier), co-researches identified, analysed and extracted patterns within the data generated during the PLA Flexible Brainstorm (described earlier) in response to the research questions. The group reviewed the individual elements on the Flexible Brainstorm chart and communicated their rationale for organising data to reflect patterns in semantic content (i.e.,

linked elements with a shared meaning/connection). They synthesised the data in a way that captured the key elements and represented the associations that connected the groupings together. When this was complete the co-researchers engaged in interpretative analysis (Smith, Bekker, & Cheater, 2011) by extracting descriptive categories that represented the groups' emic perspectives of aphasia and the CPP (i.e., co-researchers reviewed the co-generated meaningful groupings and agreed on categories of analysis). The group reviewed the individual elements generated during the Flexible Brainstorm, and through negotiation and debate the co-analysis of data progressed from description to interpretation resulting in co-created themes and emic patterns of meaning (Braun & Clarke, 2006).

The second stage of co-analysis provided an opportunity for co-researchers to move elements between categories if they "fitted better" in a different category. Category headings were also reviewed, discussed, and changed if desired in a democratic way with group agreement. Category headings did not have to comply with any syntactic rules or academic writing style and often included simple phrases or headings such as "Back to Pre-School"; "It's Like in Prison" (see Table 2). The categorisation process continued until all individual elements had been grouped under agreed themes. Arriving at consensus took time but similar to our experience in the Flexible Brainstorm technique, the colour-coded stickies provided a valuable visual connection to the individual personal experiences recorded, and this appeared to support decision making in the categorisation process and agreement of emergent themes.

Following the same process outlined above in "Interviewing the technique", the group determined data saturation and closed the "Card Sort". The completed Card Sort chart was a clear, commonly generated record of co-researchers agreed groupings and categorisation of diverse experiences from their emic perspectives. The PLA Flexible Brainstorm and Card Sort techniques were repeated for Question 2 "What difference does the CPP make to me?" (see Figure 4.3 for photo examples of the Card Sort technique and co-created chart below). Details of the co-created and co-analysed data in response to both research questions are presented in the "Results" section.



Figure 4.3: Photo examples of the Card Sort technique and co-created chart.

To explore transferability of findings, data generated in Ireland was presented to an international inter-stakeholder group (SLT ($n = 1$); PWA ($n = 2$) and trained conversation partner ($n = 1$)) at Connect (the communication disability network) in London, UK . This group was asked how the findings from the Irish study resonated with their experiences of Aphasia and the CPP in the United Kingdom.

Results

Study aim 1

To explore co-researchers' emic experiences of aphasia we asked: Q1 "How does aphasia affect me and my family?" The group generated 75 separate elements during the Flexible Brainstorm in response to this question. These elements were linked and categorised into eight different themes during the Card Sort technique² (see Table 3).

² The card sort categories are the emergent themes and are described in detail below

Table 4.3: Flexible Brainstorm and Card Sort chart co-generated in response to “How does aphasia affect me and my family?”

Back to Pre-school	Tiredness	It's Like in Prison	Emotions	Not able to Talk the Words	Escape	Changing and Adapting	Family
Lost all my talk, letters, writing, reading the whole lot	Physical tiredness affects ability to get words	Not able to converse	Frustrated	Putting ideas into words	Two talking over each other – I have to get out	Slowly and surely it's coming good	Good family and friends important
Know exactly in my mind when I write and I write rubbish. Second time correct what I've written	Reading the paper even if it is the most important thing if I'm tired I have to leave it and come back again	I was a go, go, go person – I will never be able to drive again	Angry Later (not when I got the stroke)	Crossroads related to getting the words out. Trying to get the word and sentence gets lost	Groups very difficult – cross over talking and noise	Crossing the road is difficult	Family support is very important
Slower speech very very slow	Meet students – grand for first 10 min but if I get tired that's it	Social life nil	Frustration	Very good in the mind but difficult to get words	Noise is difficult	Different ways of doing things. Realise we can do something else	Friends did not visit for a while
Used to do computer and	Very tired – words won't	You miss people –	Only getting half	It's all here (in mind). How	Have to get out when you	Other ways of doing things	Close family are

Back to Pre-school	Tiredness	It's Like in Prison	Emotions	Not able to Talk the Words	Escape	Changing and Adapting	Family
that sort of thing but since I had the stroke I wasn't able	come out	can't go out as you did before the stroke	way – e.g. shopping Get upset and Cross	much can you get out is the difficulty	are in a crowd – related to noise	– we know it without knowing it	the only ones who give you time
Re-learn everything like a baby	Tiredness related to effort put into language things (reading, writing, talking)	What is there for us to do? (related to loneliness and missing people)		Other things that can affect you getting the words out e.g., knee being very sore	Loneliness – in a crowd people wouldn't talk to you because of aphasia	We improve going along but not 100% - aphasia and doing things	
Not 100% writing	Different type of tiredness – not 100%	Haven't driven since stroke		Understand up here – mind – Frustrated	Feel invisible (linked to people talking over you)	Point to the bus or train timetable	
Spelling – cannot tell the difference between letters	I'll answer the phone but if it's evening I'm not able	Since stroke can't go to Mass every morning (related to getting out)		Like driving on the road – you come up to a traffic light and you have to stop but you weren't able to go again 'cause the sentence is	Cross talking difficult. It's the sound/noise – I have to give up	Getting a lot better (related to getting the words out)	

Back to Pre-school	Tiredness	It's Like in Prison	Emotions	Not able to Talk the Words	Escape	Changing and Adapting	Family
				gone			
Left with half – only get half things (related to reading, writing and speech)		Won't go out the way you used to – Afraid, crowds, people won't spend time seeing what you want		It's all hear (pointing to head) but how much can you get out (pointing to mouth)	People talking over you to your wife/partner – very annoying	Let someone else order food for you	
Reading very slow		What is there for us to do? (related to feeling down)		Know person-easier to get words	I love music but cannot listen to it	In the restaurant point to what you want	
Reading, writing, spelling, speaking, understanding – different levels				If it's face-to-face it's easier when you know somebody	Hate people telling me what I want to say	Perceptions of self – better than you think you are, e.g., going to Quest	
Reading – not able				Don't know person – more	They (people) won't give	Perceptions of others –	

Back to Pre-school	Tiredness	It's Like in Prison	Emotions	Not able to Talk the Words	Escape	Changing and Adapting	Family
				difficult	you time to say what you want to say	bus driver thinking we are "Loo-La"	
				The Phone – know the person - easier	Walk alone (in crowds) People talking to each other	Partners thinking that you are not able to do things, e.g., going to Quest	
				Same phrases for phone e.g. "Hello" "How are you" "Hold on there" – Can recognise voices			
				I don't answer the phone now			

Later we describe each theme separately but emphasise that there are inter-relationships between some themes, for example, the references to negative emotions in Themes 1, 4 and 5.

Theme 1a: Back to Pre-school

The elements grouped in this theme related to the linguistic impacts of aphasia. The degree of language impairment varied across participants, for example, “lost all my talk, letters, writing, reading the whole lot” (Gary). Anne described being “left with half – only get half things – reading, writing and speech” while other co-researchers focused on specific linguistic deficits: (1) speech, “slower speech very very slow” (William); (2) writing, “know exactly in my mind when I write and I write rubbish...” (David); (3) spelling, “spelling – cannot tell the difference between letters” (Neil); (4) reading, “Reading – not able” (David); (5) computer, “used to do computer and that sort of thing but since I had the stroke I wasn’t able” (Anne), and so on. The group co-generated the theme “Back to Pre-School” to capture the shared experience of communication challenges and the need to “re-learn everything like a baby” (Gary) from a very basic level.

Theme 2a: Tiredness

The elements grouped in this theme related to feelings of tiredness. Co-researchers explained that the experience of tiredness following stroke and aphasia is different from the normal tiredness of everyday life; “different type of tiredness – not 100%” (Anne). The majority agreed that tiredness whether physical or mental increases communication difficulties, for example, “Reading the paper even if it is the most important thing if I’m tired I have to leave it and come back again” (Anne); another co-researcher explained the effect of physical tiredness on word finding ability “very tired the words won’t come out” (Gary). Tiredness makes answering the telephone and meeting the conversation partners more challenging; “I’ll answer the phone but if it’s evening I’m not able and meet students – grand for first 10 min but if I get tired that’s it” (Anne). There was a shared belief amongst the majority of the group that the level of tiredness was directly connected to communication effort - “tiredness related to effort. Language things - reading, writing, talking” (Gary). One co-researcher reported that tiredness did not affect him in that way - “tiredness really doesn’t affect me that much ... although I go to bed early (since the stroke)” (Neil). Neil

reported that his challenges with word finding, reading and writing were always the same and his physical and/or mental tiredness did not make them worse.

Theme 3a: It's Like in Prison

The elements grouped in this theme related to the negative impact of aphasia on normal conversation. All co-researchers experienced difficulties communicating in groups “Not able to converse” (David). Consequently, social activities gradually reduced “Won’t go out the way you used to – afraid, crowds, people won’t spend time seeing what you want” (David). The reduction in social interaction created feelings of loneliness and isolation “You miss people – can’t go out as you did before the stroke” (Anne); “What is there for us to do?”(Anne). Daily activities that were part of life before stroke and aphasia are no longer possible, for example, “driving, going to Mass every day, socialising” (Anne). One co-researcher reported “Haven’t driven since the stroke” (Neil) and another said “I will never drive again” (Anne). Some co-researchers also perceived a change in personal identity, for example, “I used to be a go, go, go person...” (Anne) These experiences of not being able to converse and live life in the same way as before aphasia created a shared sense of being in prison.

Theme 4a: Emotions

The elements grouped in this theme related to the negative emotions experienced by the group following stroke and aphasia. All co-researchers were consistent in reports of “frustration”, “sadness”, “anger” (Gary, William, Neil, Anne, David), “upset and cross” (Anne) as a consequence of living with aphasia. Not being able to complete normal activities, for example, shopping “only getting half way” (Anne) resulted in feelings of weariness and annoyance.

Theme 5a: Not Able to Talk the Words

The elements in this theme related to co-researchers’ experiences of good cognitive ability but poor communication ability. The group shared the frustration of word-finding difficulties and communication breakdown, for example, “understand up here – mind – frustrated” (William). All agreed that they were “very good in the mind but difficult to get the words” (David). “It’s all here – in mind- how much you get out is the difficulty” (Gary). One co-

researcher explained that pausing to search for a word resulted in losing the whole sentence - "like driving on the road - you come up to a traffic light and you have to stop but you weren't able to go again 'cause the sentence is gone" (Gary). Gary's sharing triggered a memory of a similar experience for Neil "Crossroads - trying to get the word and sentence gets lost" (Neil). Participants reported that word-finding ability is affected by other situations and factors, for example, "other things that can affect you getting the words out e.g. knee being very sore" (Anne) or "tiredness" as discussed in Theme 2a. Talking appears to be easier with familiar people. Gary explained "Know the person – easier to get words".... "don't know person – more difficult" (Gary). The context and nature of the communication also appears to be an important factor in successful communication – "If it's face-to-face it's easier..." (William). Experiences of using the telephone varied, for example, "the phone know person easier" (Anne) while Neil shared "I don't answer the phone now." One co-researcher developed a strategy that involved using a set of memorised phrases to answer the phone, for example, "same phrases for phone 'Hello' 'How are you' 'Hold on there'" (William). This strategy enabled him to answer the phone successfully and allowed time for his partner to "take over" speaking.

Theme 6a: Escape

The elements in this theme related to co-researchers' experiences of trying to communicate in crowded environments. Co-researchers explained that group interactions are particularly challenging, for example, "groups very difficult – cross-talking and noise" (David). Gary shared "have to get out when you are in a crowd" and all agreed. Co-researchers reported making deliberate efforts to avoid groups/crowds for a variety of reasons, for example, feelings of (1) isolation - "loneliness in a crowd people wouldn't talk to you because of aphasia" (Anne), "feel invisible people talking over you" (David), "walk alone people talking to each other"(William); (2) annoyance - "Crowds of people also people talking over you to your wife/partner very annoying hate people telling me what I want to say" (David) {All agreed}. The noise levels, cross-talking and feelings of exclusion created a common desire to escape or avoid group situations.

Theme 7a: Changing and Adapting

The elements in this theme related to the ways that co-researchers have changed and adapted to life with aphasia. William explained that he felt “slowly and surely it’s {talking} coming good” and Neil shared that he feels he is “getting a lot better.” Anne felt that “we improve going along but not 100% - aphasia and doing things.” The group reported that everyday tasks are still challenging, for example, “Crossing the road is difficult” (Neil) but that they had developed some compensatory strategies - “other ways of doing things – we know it without knowing it” (Gary); “Point to the bus or train timetable ... bus driver thinking we are Loo-La” (Anne); “Let someone else order food for you” (David), “In the restaurant point to what you want” (Gary). Co-researchers explained that the way they perceive themselves and their ability are often different from the way that family members perceive them, for example, “better than you think you are” (Anne and Neil) while “partners thinking that you are not able to do things” (Anne). The group felt that living with aphasia necessitated new ways of coping with normal tasks.

Theme 8a: Family

The final theme in response to Question 1 related to co-researchers’ experiences of support after stroke. All agreed that “Family support is very important”. There was intensive discussion about the support received from family versus friends. The group shared that “good family and friends important” (David and all agreed) and “close family are the only ones who give you time” (Gary). Co-researchers described the decline in social networks following stroke and aphasia “friends did not visit for a while” (Gary and all agreed).

Study Aim 2

To explore co-researchers’ emic experiences of the CPP we asked: Q2 “*What difference does the Conversation Partner Programme make to me?*” The group generated 47 separate elements during the Flexible Brainstorm and categorised these elements into 5 different themes during the Card Sort technique. Data generated and co-analysed is set out in Table 4.

Table 4.4: Flexible Brainstorm and Card Sort chart co-generated in response to “What difference does the Conversation Partner Programme make to me?”

Preference of Location	Speak Easy	Confidence	Helping as Partners	Great Expectations
I think it is better at home (you have more time)	One to one and two to one. Both student should get a chance	I walked the talk	I feel proud if I help the students	I thought it would be therapy at first
We went for a drive in the beginning	One to one very easy. Easy to have conversation	Different talks, different conversations, different topics	It was good for me	When I realised it was not therapy I was very disappointed – waste of time
Brought me to a film “the King’s speech”	Easy conversation when the environment was quiet and company good	They (students) were very good. They gave me a chance to talk.	I was conscious to give each student a chance	I expected it would be therapy. It was not (disappointed)
In the office (speech therapy office) is the best	Able to have good conversation. Found it easier to talk	I got more brave with the talk	I wanted to please the student	When I realised it was not therapy I was fine. I never mentioned it again
The hotel and restaurant	Brought me out of my anti-social feeling	I was terrified – how will I talk to her?		The students were a type of therapist in their own right
I have to meet them in quiet places	It has got me more involved, something to do, it has got me out.	Not afraid of talking		I got on famously
I have met them in the coffee shop, in the restaurant, off the bus	They tried to find out my interests then we had a good conversation			One student was dominant (remained the same)
Speaking in the home is better	It was the first time I was left off on my own without family			They got better with experience

Preference of Location	Speak Easy	Confidence	Helping as Partners	Great Expectations
	They (students) brought me out of myself			The girls know what you are going through
	I looked forward to them (Students) coming out			I can talk to the girls like my own family
	One to one easier than in a crowd			They put me at ease. I had no problem
				Students + teachers (therapists) were excellent
				Student taught me card tricks (jogged my memory)
				(Students) nice girls were a waste of time
				They didn't do anything that was any good
				They talked nonsense
				They didn't help
				I wasn't happy about them

Later we describe each theme separately but, again, emphasise the connections with themes (1a-8a) generated in response to Q1. These connections show how the CPP addressed some of the challenges of aphasia, presented earlier, from the emic experiences of co-researchers.

Theme 1b: Preference of Location

The elements in this theme captured the variety of locations where co-researchers met their conversation partners, for example, “The hotel and restaurant” (William) “I have met them in the coffee shop, in the restaurant, off the bus” (Anne); the cinema “Brought me to a film –‘the King’s speech’” (David); and the car “We went for a drive in the beginning” (Gary). One person preferred to meet his conversation partner in the clinic “in the speech and language therapy office is the best” (William). The weekly meeting often involved “getting out” which resonates with the aforementioned theme 3a “It’s Like in Prison”. The location of the meeting influenced the communication – “I think it is better at home have more time....speaking in the home is better” (Anne), Gary shared “I have to meet them in quiet places”. The elements in this theme have strong connections with Themes 5a “Not able to Talk the Words” and 6a “Escape” described earlier.

Theme 2b: Speak Easy

The elements grouped in this theme related to the quality of conversation experienced during the programme. The majority of co-researchers agreed that they were “Able to have good conversation found it easier to talk” (David), “One to one very easy ... easy to have conversation” (William), “Easy conversation when environment quiet and company good” (Gary). The positive experiences of engaging with one or two conversation partners also relate to theme 6a “Escape”. It is noteworthy that while the student conversation partners were unfamiliar to the PWA the conversation experiences were mostly positive – “They tried to find out my interests then we had a good conversation” (David) (connected to Theme 5a “Not able to talk the Words”). Most co-researchers looked forward to their conversation partner visits and considered them a social experience – “I looked forward to them coming out” (David); “It has got me more involved, something to do, it has got me out” (Anne); “Brought me out of my anti-social feeling” (David); “They (students) brought me out of myself” (Gary). For the majority, participating in the CPP provided a new sense of independence – “It was the first time I was left off on my own without family” (Anne). Co-researchers focused beyond their personal communication challenges to the needs of their conversation partner, for example, “One to one and two to one - both student should get a

chance"... "I did say to her how I suppose it was hard for her as well" (Anne) and "tried to include the quieter one" (David). Four of the five co-researchers reported enjoyable, comfortable, conversations during the programme; however, one person reported no positive conversation experiences.

Theme 3b: Confidence

The elements in this theme captured a positive change in co-researchers' level of confidence with conversation overtime. At the beginning of the CPP Anne shared "I was terrified – how will I talk to her?" but as the programme progressed people grew in confidence "Not afraid of talking" (William), "I got more brave with the talk" (Gary), and 'I walked the talk' (Neil). The trained conversation partners contributed to this change "they were very good they gave me a chance to talk" (Gary). The experience of conversing with new people was challenging but enjoyable. As William explains "different talks, different conversations, different topics." The unfamiliarity of the conversation partners in the CPP resonates with theme 5a "Not able to talk the words".

Theme 4b: Helping as Partners

The elements in this theme related to the opportunity to help others through the CPP. Anne explained that "It was good for me....I feel proud if I help the students" (Anne). Rather than focusing on word-finding ability, co-researchers were conscious of their conversation partner, for example, "I was conscious to give each student a chance" (Anne) and "I wanted to please the student" (David). This theme has connections with theme 3a "It's Like in Prison" and theme 7a "Changing and Adapting".

Theme 5b: Great Expectations

The elements in this theme related to co-researchers' expectations of the CPP prior to and during participation. Some people thought the CPP would be speech therapy, for example, "I thought it would be therapy at first when I realised it was not therapy I was fine I never mentioned it again" (David). Gary felt that "students were a type of therapist in their own right". However Neil was disappointed that the CPP was not therapy – "When I realised it was not therapy I was very disappointed – waste of time" and as a result he felt that the CPP had no value for him "they didn't do anything that was any good, they didn't help....I wasn't happy about them." (Neil). The majority felt that the conversation partners were empathetic, for example, "The girls know what you are going through. ... I can talk to the girls like my

own family” (Gary), “I got on famously” (David) which resonates with Theme 5a ‘Not able to Talk the Words’. Some co-researchers developed new behaviours, for example, “Student taught me card tricks jogged my memory”... “Now I get audio books and its great, on top of the world” (David). These adaptations connected with Themes 1a “Back to Pre-school” and 7a “Changing and Adapting.” Some of the group believed that the student conversation partners also benefited from the programme “They got better with experience” (Gary) and “students were excellent” (William).

Discussion

PWA have a fundamental right to express their unique perspectives and show the competencies that are “masked” by aphasia (Kagan, 1995). This participatory research study did not exclude participants based on the severity of their aphasia but rather empowered one small group of people with varying communication abilities to share their emic perspectives of aphasia and the CPP resulting in important empirical data about conversation interventions. The detailed account shared by co-researchers of the complex nature of aphasia and the emic experiences of the CPP generated through PLA techniques provides a unique contribution to the existing literature base. Key findings include the positive value of the CPP in acknowledging the expertise of the individual with aphasia and providing opportunities for conversations with unfamiliar partners. The negative feelings of communicative incompetence described in “Back to Pre-School” and “Not Able to Talk the Words” appear to be reduced for some through participation in the programme. Impacts of aphasia related to feelings of marginalisation captured in “Escape”, “It’s Like in Prison” and “Emotions” may be partly addressed by the social aspects of the CPP.

These findings supported the existing literature in terms of aphasia and the value of conversation approaches. Participants shared the life changes following stroke and aphasia in their own words – “It’s Like in Prison,” “Tiredness,” “Not Able to Talk the Words,” “Escape,” “Emotions” and “Back to Pre-School.” The linguistic deficits described in “Back to Pre-School” and the psychosocial impacts spanning the other seven themes are well recognised in the literature (Chapey et al., 2008; Hersh, Worrall, Howe, Sherratt, & Davidson, 2012). The numerous and varied references to negative emotions, for example, you “feel invisible – people talking over you,” “frustration,” “anger,” “sadness,” “embarrassment” are reported across a range of studies (Barrow, 2008; Basso, 2010; Bright, Kayes, McCann, & McPherson, 2013). Interestingly, all participants in this study experienced isolation and disconnection when they were surrounded by other people “loneliness – in a crowd people wouldn’t talk to you because of aphasia.” Perhaps it is the lack of engagement of others and their poor communication skills and understanding of how to talk to PWA that transforms

communication difficulties into a disability (McVicker et al., 2009).

Conversation training supports family, healthcare professionals and friends to unmask the competence of the person with aphasia. The finding that participants valued the CPP in terms of enhanced social relationships, increased self-confidence, and positive identity changes reflects previous studies where improvements in psychosocial well-being were noted following participation in conversation interventions (Lyon et al., 1997; Penn, 1998; Savage, Donovan, & Hoffman, 2014) The fear of communication with unfamiliar partners reduced as the CPP progressed, for example, “I got more brave with the talk” and “Not afraid of talking” reflect findings that the number of conversational interactions and transactions increases following participation in a conversation programme with trained communication partners (Kagan et al., 2001; Rayner & Marshall, 2003). Other positive experiences included a sense of achievement, “I got on famously”; pride, “I feel proud if I help the students” and a belief that the CPP was valuable to both partners, “It was good for me,” and “they got better with experience” reflects important feelings of self-worth and connection when one considers the risk of secondary disability for people with chronic communication disability (Proctor, 2001). While the literature clearly acknowledges the impact of aphasia on family members and friends (Halle et al., 2011; Pound et al., 2001; Sorin-Peters & Patterson, 2014), it is noteworthy that the co-researchers in this study in response to the question “*How does aphasia affect me and my family?*” focused on the importance of family support in helping them adapt to life with aphasia - “family support is very important” rather than on how family members were affected by aphasia. In future studies to explore the impact of aphasia on family members from the emic perspective of the person with aphasia, co-designing a question related to the adaptation of family to “living with aphasia” (Pound et al., 2001) may stimulate the generation of more specific data.

The use of PLA is a novel and key feature of this research. Participants reported many benefits of working in a participatory way including: mutual support, peer acknowledgement, and understanding of the difficulties involved in communicating to a group, encouragement and reinforcement from others to persist with communication attempts, and to use supportive communication strategies. The group listened to each other’s perspectives which stimulated further sharing and enhanced learning around the stakeholder table. PLA techniques and materials were selected by participants to suit their communication preferences and the colour coded stickies gave participants a sense of continuity and identity throughout the data generation cycle, for example, “*I never thought I could say much ... so much*”. The positive experiences of acting as co-researchers in a participatory study resonate with findings from other studies using similar designs (MacFarlane et al., 2009) and are discussed further in

separate methodological paper.

Methodological critique

We used an innovative participatory approach to include five PWA as co-researchers to capture their lived experiences of aphasia and the CPP. We acknowledge that the small sample size of older, pre-dominantly male, retired participants with aphasia living at home in this study may impact the validity and generalisability of findings. However, sharing of data generated in Ireland with an inter-stakeholder group in the United Kingdom may contribute to the transferability of findings. The participants represented a select group of people with mixed aphasia interested in the CPP from a particular cohort. While a mixed receptive, expressive functional aphasia may reflect the majority of PWA, we recognise that the emic experiences and data generated by people with other types of aphasia (e.g., receptive only or expressive only) and ranges of severity (e.g., severe comprehension difficulties) may differ from the data generated by our co-researchers. Recruiting people with a pure receptive or expressive aphasia and a more gender balanced group with younger participants was beyond the scope of this study, and we acknowledge these limitations. Participants were all over 60 years with a high degree of motivation to discuss their experiences of the programme which was linked to a specific university site. While some older PWA may present with a co-morbid dementia, we did not experience this amongst our co-researchers; however, it is an important consideration for future studies. Despite their older age-range and data generation spanning 12 months, there was no attrition from the group nor did there appear to be any loss of connection with the data over time. The PLA charts and photographs co-created across the research phases served as valuable visual reminders of the co-generated data. As explained previously, we displayed and reviewed the PLA charts and photographs of co-researchers actively engaged in the research techniques at the beginning of each data generation session. This review process supported re-immersion with the data and visually re-connected co-researchers with their co-created charts. The colour coded stickies quickly linked individuals with their unique contributions and appeared to support memory recall. Finally, we acknowledge positionality issues - the first author was the co-ordinator of the CPP and involved in the study as a co-researcher and PLA facilitator. This required awareness of and movement between *insider/outsider* positions during the course of the work. The involvement of the second author as an “outsider” facilitator was an important feature to counter the effect of any bias the first author may have had on data generation, and multidisciplinary team meetings of all three authors for analysis stimulated reflexivity about the data and its meanings.

Conclusion

The co-researchers in this study were courageous, honest, and realistic in sharing their emic experience of coping with life with aphasia and exploring what difference the CPP made to them. The participatory research approach enabled participants to share their emerging and established experiences in their own words. While the findings are not generalisable, this emic perspective and use of participatory methods contributes new data to the evidence base. PLA methods require ingenuity, creativity, and emotional involvement on the part of the researcher and the co-researchers in all phases of the research process. Working within such ill-defined boundaries and surrendering control in the design and process of the study is different from other qualitative methodologies. These methods will not suit all researchers. We believe that proving the efficacy of the participatory approach to the research community is a challenging but worthwhile task. Future studies may want to explore the emic experiences of younger, working people with receptive aphasia or expressive aphasia or a group with mixed aphasia of varying severity levels. The perspectives of these groups in relation to the lived experience of aphasia and the CPP may differ from the co-researchers in this study. We encourage colleagues to consider the use of participatory research methods as a potentially empowering, transformative and innovative methodological approach to include PWA as co-researchers in health research studies.

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