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Understanding experiences, unmet needs and priorities related to post-stroke aphasia care: stage one of an experience-based co-design project

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ABSTRACT

Objective People with post-stroke aphasia (language/communication impairment) and their supporters report mixed satisfaction with stroke and aphasia care. To date, however, their journey of care and the key service interactions that shape their experience have not been comprehensively explored. We aimed to investigate the lived experience of post-stroke aphasia care, across the continuum of care and by geographical location, to establish priorities for service design.

Design This is the first stage of an experience-based co-design study. We purposively sampled people with aphasia (PWA) and significant others (SOs) across 21 hospital and health service sites, community groups and by self-referral. Participants shared experiences of care in online interviews and focus groups. Touchpoints (key moments that shape experience) and unmet needs were identified using qualitative thematic analysis. Priorities for service design were established using an adapted nominal group technique.

Setting Sites spanned remote, regional and metropolitan areas in Queensland, Australia.

Participants PWA (n=32; mild=56%; moderate=31%; severe=13%) and SOs (n=30) shared 124 experiences of acute, rehabilitation and community-based care in 23 focus groups and 13 interviews.

Results Both positive and negative healthcare experiences occurred most frequently in hospital settings. Negative experiences regularly related to communication with health professionals, while positive experiences related to the interpersonal qualities of healthcare providers (eg, providing hope) for PWA, or witnessing good rapport between a PWA and their health professional for SOs. To improve services, PWA prioritised communicatively accessible education and information and SOs prioritised access to psychological and peer support.

Conclusions We identified key aspects of post-stroke aphasia care that shape experience. The needs of PWA and SOs may be better met through health professional training in supported communication, increased service availability in regional and remote areas, communication-accessible hospital environments, increased access to psychological and peer support, and meaningful involvement of SOs in rehabilitation.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This comprehensive exploration of experiences provides novel insights into the unmet needs of people with aphasia and their significant others accessing aphasia services across the continuum of care and areas of geographical diversity.
- ⇒ The touchpoints and priorities identified provide a foundation for quality improvement, healthcare policy and new aphasia service design.
- ⇒ The participation of populations often excluded from aphasia research (eg, people with severe aphasia and those from culturally and linguistically diverse backgrounds) was supported through bespoke resource development and provision of additional support.
- ⇒ The representativeness of participants in this study may have been enhanced through additional recruitment of linguistically and culturally diverse participants.

INTRODUCTION

Aphasia is an acquired communication disorder experienced by 30–40% of all stroke survivors.[1] People with aphasia (PWA) have poor quality of life[2] and are almost twice as likely to experience depression when compared with stroke survivors without aphasia.[3] These poor outcomes are compounded by inequitable service access, a result of both geographical location[4] and inadequate communication support in healthcare settings.[5 6] PWA are often excluded from healthcare decision-making[6] and the presence of communication difficulties is associated with a threefold increase in preventable adverse events in hospital.[7] Lived experience underpins quality of care[8] and therefore understanding PWA's and significant others' (SOs) experiences of stroke and aphasia care is critical to addressing their unmet needs.

The WHO defines quality of care as the degree to which health services increase the likelihood of achieving desired health outcomes.[9] Health services should be effective, safe and person centred,[9] and understanding the experiences of service users is critical to achieving these outcomes. Engaging consumers is central to ensuring care planning and delivery, holding personal relevance to service users.[10] Furthermore, improved patient experience is positively associated with safety and health outcomes.[8] Service users (including those with aphasia and their SOs) have insights into their own experiences of care, knowledge of evolving symptoms and response to treatments. Such insights can highlight areas for improvement in healthcare services and even prevent diagnostic errors.[11] However, to date, exploration of the experiences and unmet needs of PWA and their SOs has focused on discrete service settings and time points in the stroke recovery journey.

While prior research[12–19] confirms gaps exist, how current services are not meeting needs across care pathways and geographically diverse service settings for those with post-stroke aphasia remains unclear. For example, Tomkins *et al*[20] conducted further analysis of data captured in 2011 (which asked PWA about their experience of aphasia, service experiences and rehabilitation goals at three specified time points), and explored satisfaction and dissatisfaction with healthcare received with participants from metropolitan settings. Similarly, van Rijssen *et al*[21] explored the experiences of PWA communicating with healthcare professionals unique to community-based care settings, and Wray and Clarke's[19] thematic synthesis of qualitative studies identified PWA's longer-term unmet community-based care needs. Prior research exploring specific needs also confirms gaps exist in discrete areas of practice such as access to aphasia information,[12] management of mood disorders,[13] communication partner training,[14] treatment goals[22] and more recently, communicating with healthcare professionals in an acute setting.[23] However, further research aiming to build on these findings is required to determine the relative importance of needs and priorities for change, able to guide service development with PWA and SOs (across the care continuum, geographical remoteness and service contexts). Therefore, we explored the experiences and unmet needs of PWA and SOs to establish priorities for aphasia service improvement. This paper reports the first stage of an experience-based co-design (EBCD) project[24] which aims to improve post-stroke aphasia services in partnership with PWA and SOs.

METHODS

Patient and public involvement

This research was co-produced with patient and public involvement, specifically the research was guided by a consumer advisory committee comprising PWA (n=3; authors KM, KD, BA), SOs (n=2; authors JD, PM) and a cultural capability officer (cultural capability officer support refers to the support provided to ensure behaviours, systems and processes are conducted in a way that is culturally respectful while engaging with the Aboriginal and Torres Strait Islander Peoples of Australia involved in this research. Aboriginal and Torres Strait Islander Peoples are the First Nations peoples of Australia.). They: (1) reviewed participant information; (2) co-developed interview and focus group procedures; (3) advised on recruitment strategies, co-developed a recruitment video and co-presented to potential participants; and (4) reviewed and contributed to publications. Author GB advised on culturally safe practices for Aboriginal and/or Torres Strait Islander participants. Plain English summaries and video summaries have been prepared with and for PWA and distributed across aphasia community groups (eg, https://shrs.uq.edu.au/research/research-centres-and-units/qarc/research).

Study design

This paper reports the initial stages of an EBCD study (figure 1). EBCD draws on qualitative and participatory methods to understand experiences, determine priorities and co-design solutions.[25] Detailed information about study design and sampling criteria is described in our published protocol.[24]

Participants

Participants were PWA and SOs (family member, close friend, main contact, that is, someone considered to know the PWA well) from Queensland, Australia. Eligible participants were adults (aged ≥18 years) with post-stroke (≥6 weeks) aphasia (as per Aphasia Severity Rating Scale (ASRS)[26]), who were able to participate in online interviews or focus groups. Exclusion criteria were aphasia due to non-stroke aetiology, or presence of neurodegenerative or neuropsychological disorder (self-report of clinical diagnoses). Participants were recruited through 21 hospital and healthcare sites, online advertisements and aphasia community groups, using maximum variation sampling.

Modifications to support inclusion

People with aphasia

Written project information was formatted to be communication accessible[27] and a speech pathologist supported the inclusion of PWA. Training sessions were held to support online participation and to identify individual communication support strategies. PWA could nominate a support person to attend sessions and had the option to participate in either interview or focus group formats. Supported communication strategies (eg, using multimodal communication techniques[28]) were used throughout. Access to an interpreter was provided for non-English speakers.

Regional and remote areas

Where needed, participants in regional and remote areas were provided with a device and internet connection to

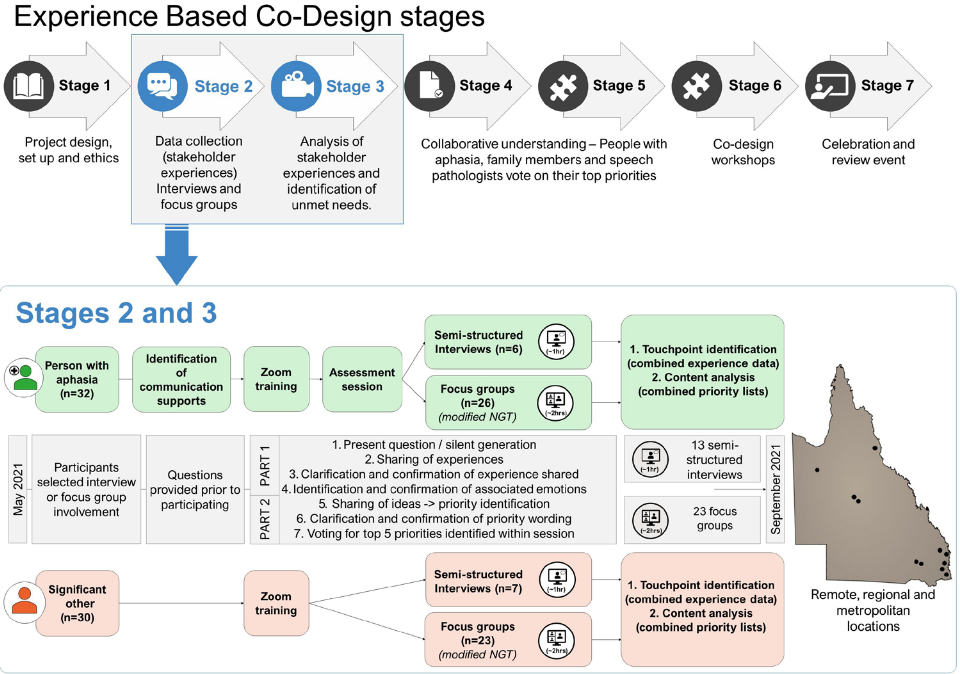


Figure 1 Experience-based co-design stage 2 procedures conducted with people with aphasia and significant others. NGT, Nominal Group Technique.

support online participation. Participants were mailed hardcopies of materials ahead of sessions.

Methodological approach

This is the first stage of a larger project using EBCD,[29] a form of participatory research.[25] The current study uses a qualitative descriptive approach incorporating elements of narrative enquiry (eg, patient stories about experiences of care), phenomenology (eg, exploring experiences to identify touchpoints or emotionally charged themes related to the journey of care) and participatory design, used to understand the who, what and where of post-stroke experiences.[30] Inductive thematic analysis[31] was used to understand participant experiences and the implication of those experiences for future service design.[32] Descriptive statistics were used to investigate patterns across data. Analysis was guided by a constructivist–interpretivist paradigm,[33] acknowledging that researchers are co-creators of knowledge.

Data collection

Data collection for the experience phase occurred between May and September 2021 using: (1) semistructured interviews and (2) focus groups. Interviews enabled a deeper, nuanced understanding of experiences, while focus groups provided a broader understanding of experiences from a wider participant group across geographically diverse regions. An adapted nominal group technique[34] was used in focus groups to establish priorities for service development. This technique uses a round-robin process of idea generation to ensure equal participation.[34] Separate focus groups were held with PWA and SOs and group size was capped at 3 and 5 participants, respectively. An interview/focus group guide was developed comprising open-ended questions to reflect the narrative focus of EBCD experience gathering[25] (see online supplemental table 1). Materials and procedures were piloted with PWA (n=1) and SOs (n=2), resulting in changes to wording of questions to improve clarity and processes to support online participation (eg, image supports and 'aphasia-friendly' formatting). Data collection occurred during the COVID-19 pandemic and was completed online using video-conferencing software,[35] considered an acceptable approach with this population.[36]

Procedures

An overview of procedures is provided in figure 1. Participants received interview and focus group questions prior to data collection (figure 1). Online sessions were held prior to involvement to provide training, establish communication needs and assess aphasia severity (lead author). Two researchers independently rated aphasia severity using the ASRS.[26] Interviews and focus groups (facilitated by the lead author) were video and audio recorded and followed the same format: (1) each participant shared one positive and negative experience of care and identified an emotion associated with that experience; (2) participants generated ideas for service improvement which were transcribed onto an online whiteboard. Participants selected their top five ideas and ordered them from one (highest priority) to five (lowest priority). Participants assigned 100 points across their top five priorities (higher number=greater significance) to indicate relative importance. During focus groups, breakout rooms were used to support the ranking process where needed (eg, to support participants with severe aphasia). Individual rankings were visible to other group participants (see online supplemental figure 1). Participants provided feedback on process, methods and experience of involvement (to be reported elsewhere).

Data analysis

Experiential data were transcribed and thematically analysed[31] to gain an understanding of PWA and SO experiences. Themes were further reviewed to identify touchpoints (key moments shaping experiences of care in positive or negative ways). Transcripts for PWA were annotated to reflect non-verbal communication.[37] The six-step thematic analysis[31] process was conducted by LA. A second author independently coded (BB) or reviewed (SJW) transcripts to ensure accuracy, comprehensiveness and interpretation of meanings. Variations in interpretations were discussed until a consensus was reached and a record of queries, disagreements and reflections maintained.

Themes of positive or negative experience (and associated emotions) were mapped to three phases of care: (1) *in-hospital*: hospital-based care; (2) *returning home*: care during transition (first few weeks preceding or post-return home or to the community) or transferring to alternative service; and (3) *long-term care*: care in the community (eg, day hospital appointments, in-home community-based rehabilitation). A themed understanding of unmet needs was developed based on factors contributing to negative experiences per touchpoint. Finally, each touchpoint and unmet need was reviewed against principles of person-centred care.[38] A detailed overview of analysis is available in online supplemental table 2. Priorities for service development were combined across interviews and focus groups using qualitative content analysis[39] (completed by LA, reviewed by SJW). Individual responses contributing to each themed priority were scored and summed.[40] Stakeholder experience maps were developed to provide a visual synthesis of healthcare experiences across the continuum of care.[41] These maps will be used in future EBCD stages.

Data quality, rigour and reflexivity

LA, SJW, DAC, and BB are qualified speech pathologists. LA completed this project as part of her doctoral studies. SJW and DAC are experienced researchers in the study population. SJW and VJP are experienced qualitative researchers and VJP an experienced participatory designer familiar with EBCD. Themes were reviewed and refined by LA, SJW and DAC. Final touchpoints and representative quotes were agreed by all authors. Transferability is reinforced by the diversity of participant sample which includes people often excluded from research (people in regional or remote areas without internet access, and people with severe aphasia). The research (where it follows standardised methods) is reported in alignment with the Consolidated criteria for Reporting Qualitative research guidelines for qualitative research studies[42] and the Guidance for Reporting Involvement of Patients and the Public[43] guidelines for reporting patient and public involvement.

RESULTS

PWA (n=32) and SOs (n=30) participated in 1 of 23 focus groups (duration 67–171 min, mean=105 min) or 13 interviews (duration 40–117 min, mean=68 min). Participant characteristics are provided in table 1. Participant experiences shared spanned the continuum of care, from point of stroke, up until participation in the research. Three focus groups involved participant dyads (ie, a PWA attending with an SO). Illustrative quotes are presented with participant codes and categories of geographical remoteness and aphasia severity. Presentation of touchpoints includes an overview of positive experiences; however, reporting focuses on highlighting negative touchpoints associated with identified gaps in care.

Positive touchpoints

Seven touchpoints were drawn from data captured in response to being asked to describe their best experience of stroke and aphasia care: (1) *coordination of care* (PWA, SO); (2) *communicating and connecting with others* (PWA), *inclusion in care* (SO); (3) *making progress* (PWA), *positive outcomes* (SO); (4) *mode of service delivery* (PWA, SO); (5) *healthcare service* (PWA, SO); (6) *access to care* (eg, availability/qualifying process) (PWA, SO); and (7) *therapy and care* (PWA, SO). Often the interpersonal qualities of the healthcare provider were seen to have a positive influence, 'It's like a real- hamp-hamster-wheel. And she [occupational therapist] made it different, […] a person's nature, gives you hope' (PWA-120-regional-mild). Table 2 provides an overview of themes with illustrative quotes.

Negative touchpoints

In response to being asked to describe an experience (of stroke or aphasia care) that did not go well, seven touchpoints were identified (table 3 and online supplemental figures 2 and 3).

Communication with healthcare providers in hospital was frequently associated with negative healthcare experiences by PWA. One PWA recalled a conversation in hospital with a medical professional, 'all I heard [understood was], 'You're going to die" (PWA-125-metropolitan-mild). Comprehension was influenced by the timing ('it was the middle of the night [woken at 8:30pm], because I've been asleep and I've got some aphasia'), amount of information ('too much information in one hit, you know, could have sort of done it in dribs and drabs' (PWA-103-metropolitan-mild)) or the type of information being communicated. Participants described challenges with wanting to ask what was happening, and not being able to, 'no one talked to me, so I didn't know really what was going on, and when I wanted to take up, I couldn't talk' (PWA-134-regional-moderate). Time pressures brought on by the mode of communication (eg, voice mail) also influenced the success of communication exchanges,

Table 1 Overview of participant characteristics

Participant characteristics (PWA)	Total no (n=32)	%	Participant characteristics (SOs)	Total no (n=30)	%
Geographical remoteness			Geographical remoteness		
Metropolitan	18	56	Metropolitan	14	47
Regional	11	34.5	Regional	13	43
Remote	3	9.5	Remote	3	10
Aphasia severity			Aphasia severity (of PWA)		
Mild	18	56	Mild	*9*	*30*
Moderate	10	31	Moderate	*10*	*33*
Severe	4	13	Severe	*11*	*37*
Time post-stroke			Time post-stroke (of PWA)		
6 weeks–5 months	5	16	6 weeks–5 months	*4*	*13*
6 months–2 years	11	34	6 months–2 years	*12*	*40*
2–5 years	6	19	2–5 years	*6*	*20*
5+ years	10	31	5+ years	*8*	*27*
Age			Age*		
18–54 years	8	25	18–54 years	10	45.5
55–70 years	17	53	55–70 years	10	45.5
70+ years	7	22	70+ years	2	9
Sex			Sex		
Female	10	31	Female	25	83
Male	22	69	Male	5	17
Cultural ethnicity (self-identified)†			Cultural ethnicity (self-identified)†		
Aboriginal and/or Torres Strait Islander	1		Aboriginal and/or Torres Strait Islander	0	
Maori	1		Maori	1	
American	1		American	0	
Dutch	1		Dutch	0	
Refugee	1		Refugee	1	
Country of birth			Country of birth		
Born in Australia	24	75	Born in Australia	24	80
Not born in Australia	8	25	Not born in Australia	6	20
Linguistic diversity			Linguistic diversity		
Non-English speaking	1	3	Non-English speaking	1	3
Speaks English (multilingual)	7	22	Speaks English (multilingual)	2	7
Speaks English (monolingual)	24	75	Speaks English (monolingual)	27	90
			Age (of SO with aphasia)		
			18–54 years	*3*	*10*
			55–70 years	*14*	*47*
			70+ years	*13*	*43*

Italic text represent characteristics of the signficiant other's, person with aphasia.
*Some SOs (n=8) chose not to report their age.
†Not all participants chose to nominate their cultural ethnicity.
PWA, people with aphasia; SOs, significant others.

Table 2 Key touchpoints associated with positive experiences of care with example quotations

Group	Example quotation
Touchpoint 1: coordination of care (PWA and SO)	
PWA	…the ex- entire experience was good for me because, um, they planned it for me. So, they assessed me, they planned it. I didn't have to do anything but recover. (PWA-120-regional-mild)
SO	…just knowing that there was someone there to help - that was it for me, because obviously it's a whole new kettle of fish, so it was just like, "Oh! That's fantastic!" That there's someone there to help us. (SO-135-regional-severe)
Touchpoint 2–2.1: communicating and connecting (PWA); 2.2: inclusion in care (SO)	
PWA	My actually best experience was meeting my- my speech therapist, [names therapist, (laughs)] because she was a bright spark in amongst this dreadful, [(G) shaking head] men in suits, and being sent to, um, do scans and- and stuff. (PWA-119-regional-mild)
SO	…they, um- they came and got me straight away, […] and we went through another process of explaining what had happened and what- what they did, and what- what- where she was going, and how she was. […] it helped me to reduce the fear factor. (SO-126-metropolitan-mild)
Touchpoint 3–3.1: making progress (PWA); 3.2: positive outcomes (SO)	
PWA	Yes, it made me think that I could get better. Uh, but- but I'm reading a lot now. I'm reading a lot, trying to, um, yeah. Just reading- I'm reading. (PWA-133-regional-moderate)
SO	Learning how to use an ATM, buying things from- from people or vendors, um, without having the language to do it, you know? (SO-051-metropolitan-moderate)
Touchpoint 4: mode of service delivery (PWA and SO)	
PWA	I was part of a aphasia slash OT, um, uh, group, […] I really valued it because there was speech pathology and there was OT [occupational therapy] (pause). But- amongst all of that, um, was probably just the- the sense of, um, uh - not inclusion, but as in like, we could, um- with a chance to meet and talk to people, […] there were things that were really, um, really relevant. (PWA-026-regional-mild)
SO	… he also did a, um- a 2 week [clinical aphasia research] trial, where he was- did speech [therapy] every day for 5 hours, for 2 weeks. (SO-114-metropolitan-severe) We didn't have to bother about, you know, getting out and getting dressed and getting out getting there on time. Just someone coming around to have a chat – it was nice. (SO-108-remote-mild)
Touchpoint 5: healthcare service (PWA and SO)	
PWA	Best experience was my- in my 3 months in re- in rehab at GARU was the speech therapy there because I had one main speech therapist all the way through. (PWA-079-metropolitan-moderate)
SO	There was- we could go and make him a coffee any time of day or night, um, and there was a lounge room there where we could go and sit up the front and we could open the windows and he could get the fresh air in, and that was really important for him. (SO-111-regional-moderate)
Touchpoint 6: access to care (PWA and SO)	
PWA	…both the speech, and also the psychological services were on par, um, because one of the things they don't make you aware of is the- the type of- of change and effects it has on you emotionally, um, and you're only able to deal with it when you can talk about it. (PWA-076-metropolitan-mild)
SO	Such a hard road and he also had access to a psychologist down there which, uh, proved immensely important, because when people have a stroke, they really go through some bad, bad times. (SO-088-metropolitan-moderate)
Touchpoint 7: therapy and care (PWA and SO)	
PWA	It's like a real- in hamp- hamster-wheel. And she [occupational therapist] made it different, […] a person's nature, um, gives you hope. (PWA-120-regional-mild)
SO	[Hearing] you know, there will be improvements. Um, and that can make a very big difference when you're in the first stages of, um, dealing with the shock and the grief. (SO-086-metropolitan-moderate)

ATM, automated teller machine; GARU, Geriatric and Rehabilitation Unit; PWA, people with aphasia; SO, significant other.

'the time pressure gets to your brain, and you can't think about the words' (PWA-120-regional-mild).

Challenges coordinating care were a negative experience and source of frustration for SOs. Participants expressed frustrations with scheduling appointments and described poor communication as a barrier for the involvement of PWA in this process. Participants described stress associated with understanding how to access community-based services when transitioning home, 'I had nothing- nothing in place. It

Table 3 Overview of negative touchpoints and identified unmet needs with example quotes

Touchpoint	Domain: subdomain of unmet need	Example of unmet need	Example quote
People with aphasia (PWA)			
1.1 Communication with healthcare providers	Healthcare provider: awareness of aphasia Individual: education and updates	▶ PWA not acknowledged when communicating needs ▶ Mode of communication is not suitable ▶ Amount, timing, type of information not communicatively accessible for PWA	*…all I heard* [understood]*, ‘You’re going to die’*. (PWA-125: metropolitan, mild) *…no one really spoke to me or anything, they just came in and just (pause). Changed me*. (PWA-134: regional, moderate)
2.1 Access to care	Healthcare provider: awareness of aphasia Context: service options Context: equitable access	▶ Lack of mental healthcare providers and reduced options for PWA ▶ Lack of specialists in remote areas	*You know I-[(G) pointing at chest] I made the process- I wanted to live, I wanted to live here, okay? Cause I- my cattle and all that are here.* (PWA-033: regional, severe)
3.1 Adjusting	Individual: education and updates Context: service options	▶ How to access mental health options ▶ Lack of providers to support connecting with community (chronic needs)	*I- that’s the one criticism I’d make, is they didn’t prepare you for the outside world.* (PWA-109: metropolitan, mild)
4.1 Healthcare provision	Healthcare provider: awareness of aphasia Healthcare provider: capability, knowledge and experience	▶ Healthcare worker knowledge of aphasia ▶ Supporting communication needs during care management ▶ Maintaining consistent care providers	*The first meeting* […] *there was a thick file of all my stuff and* [healthcare worker] *says, ‘Oh, I haven't read anything,’*[…] *I can’t read let alone speak, and you're asking me, to ask?* (PWA-079: metropolitan, moderate)
5.1 Service delays	Individual: education and updates Context: service options	▶ Clear explanations of transition process or delays ▶ Travel fatigue and delays in accessing care	*I felt like a number and had to wait for services. So, I felt like it was in the queue.* (PWA-120: regional, mild)
6.1 Hospital environment	Individual: education and updates Healthcare provider: awareness of aphasia Context: service environment	▶ Explanations of hospital procedures and processes ▶ Recognition of ability to consent for procedures recognised ▶ Suitable entertainment options, meaningful communication opportunities	*I stayed in a prison. […] because you’re, you know, locking doors and everything. I couldn’t- I wanted out!* (PWA-050: metropolitan, moderate) *…frustrated, um, stress because he was taking it* [blood] *when I was saying ‘don’t’.* (PWA-069: metropolitan, mild)
7.1 Emotional impact of aphasia	Healthcare provider: awareness of aphasia Healthcare provider: capability, knowledge and experience	▶ Healthcare worker knowledge/ understanding of aphasia ▶ Supporting communication needs during care management ▶ Preparing a person with aphasia to return to home	*…in one day, I became the patient and I’m, uh, powerless, um, helpless and I felt angry, uh, and stressed.* (PWA-089: metropolitan, mild)
Significant others (SOs)			
1.2 Challenges coordinating care	Individual: involvement of family Healthcare provider: awareness of aphasia Context: equitable access	▶ Timing of scheduled appointments ▶ Support completing paperwork, advocating for care ▶ Lack of specialists in remote areas	*If you’ve got an appointment at 10 o'clock, please turn up at 10 o'clock. […] you got people who are - are confused and not really understanding what’s - what’s going on.* (SO-126: metropolitan, mild)

Continued

Table 3 Continued

Touchpoint	Domain: subdomain of unmet need	Example of unmet need	Example quote
2.2 Exclusion from care	Individual: involvement of family Healthcare provider: awareness of aphasia	▶ Seeing therapy and involvement in planning of care ▶ Need for regular updates about care and progress	*…it doesn't excuse no communication. To tell me where is he, how's he going, what the hell is happening- for days! […] I didn't hear what- how- where he was. Was he- was he alive?!* (SO-035: metropolitan, mild)
3.2 Coping as carer	Individual: education and updates Context: service options	▶ Long-term negative effects of aphasia ▶ Respite or transport options for PWA	*Upset, because I just didn't know* (pause) *how I was going to cope and what I had to- what I had to do- because you're just literally left on your own.* (SO-116: regional, severe)
4.2 Therapy and care	Healthcare provider: awareness of aphasia Healthcare provider: capability, knowledge and experience	▶ Communication with treating teams ▶ Personalised and engaging therapy for PWA	*Don't make it because it's dollar signs, make a decision on 'do you know anything at all about this person; have you asked the family anything about this person?' […] there was no personalization of the patient at all.* (SO-062: metropolitan, severe)
5.2 Lack of information	Individual: education and updates	▶ Purpose of therapy/assessments, resources needed	*…we just sat there thinking, 'Oh, why are we doing all this stuff for?' Um, it kind of really wasn't explained up front.* (SO-108: remote, mild)
6.2 Geographical remoteness	Healthcare provider: awareness of aphasia Context: equitable access	▶ Awareness of impact of travel fatigue for PWA ▶ Lack of specialists in remote areas	*…once a fortnight's not gonna work. You know? That he needs - he needs more help.* (SO-116: regional, severe)
7.2 Poor awareness of aphasia	Healthcare provider: awareness of aphasia Context: service environment	▶ Systems need to allow family to support communication ▶ Increased risk and reduced safety for PWA in hospital	*The nursing staff. 'A.' They don't have the time. 'B.' They don't know enough about, um, aphasia.* (SO-059: metropolitan, severe)

actually- literally took weeks for him to get physio or speech' (SO-116-regional-severe).

Access to care was a particular challenge for people with severe aphasia and people living in regional and remote areas. Participants described not being able to access care when support was required to connect to services (eg, communication burden negotiating application processes (eg, National Disability Insurance Scheme)) or for those with chronic disability requiring ongoing speech therapy. PWA described long-term social isolation and an inability to access mental health providers as a key issue. Communication disability presented a barrier to verbal expression of feelings, and this was described by PWA as their 'biggest problem' (PWA-087-metropolitan-moderate) and an insurmountable barrier to accessing 'talk-based therapies', 'you're only able to deal with it when you can talk about it' (PWA-076-metropolitan-mild). One SO pointed out, 'when you think about it she wouldn't be able to just pick up the phone and ring lifeline [national mental health crisis call centre]' (SO-129-remote-severe).

Exclusion from care was a key negative experience for SOs, who expressed feeling dependent on healthcare provider teams for updates on progress. This was particularly pertinent for people with severe aphasia and in regional or remote areas where available services were far from local communities, 'he didn't know what the hell was happening to him and I didn't know what the hell was happening to him' (SO-035-metropolitan-mild).

Healthcare provision: PWA described feeling cut-off when therapy or support ended and needing a way to reconnect, 'I needed that follow up in like 18 months…. But then nothing! And then not starting again until 7 years' (PWA-069-metropolitan-mild). Lack of consistency in healthcare providers was also associated with negative experiences by people of all aphasia severity.

Therapy and care was a negative experience for SO when there was a lack of person-centred care or a perception of insufficient effort by healthcare providers to find out 'who' the PWA or their family were. One participant became distraught describing when *therapy and care* went wrong, 'I was just so, so upset when [names family-friend who found PWA confused on the side of the road in the early hours of the morning] brought him home [(G) starts to cry; visibly distressed] I just thought what am I gonna do!?' (SO-116-regional-severe).

The hospital environment was described by PWA as confusing and stressful, 'I stayed in a prison. […] because you're, you know, locking doors and everything' (PWA-050-metropolitan-moderate). Hospital environments were described as lacking meaningful activity or stimulation options, which meant a lack of distraction from grief associated with their stroke and their uncertainty over what life might be like moving forward. PWA expressed frustration, confusion and anger with experiences during their inpatient stay, and a lack of healthcare provider awareness of aphasia often featured in negative experiences. This extended to healthcare providers not acknowledging or recognising their consent for procedures, 'frustrated, stress because he was taking it [blood] when I was saying 'don't" (PWA-069-metropolitan-mild).

The emotional impact of aphasia was described by PWA across all geographical areas and severities of aphasia, particularly in interactions with healthcare professionals when needs and preferences could not be expressed, 'in one day, I became the patient and, powerless, helpless and I felt angry, and stressed' (PWA-089-metropolitan-mild). Participants commented on having things done to them, 'no one really spoke to me or anything, they just came in and just (pause). Changed me' (PWA-134-regional-moderate), and described negative interactions made worse for the individual due to their aphasia: 'nobody was telling me what's gonna happen to me, where I went-I had to go from a different place and I thinking, 'Oh, God!" (PWA-033-regional-severe).

Poor awareness of aphasia among healthcare providers was perceived to increase risk and reduce safety during inpatient stays, 'the nursing staff. 'A.' They don't have the time. 'B.' They don't know enough about, aphasia' (SO-059-metropolitan-severe). SOs expressed concern for patient safety while in hospital, 'I think we were very lucky that she didn't actually hurt herself while she was in there' (SO-138-regional-severe). SOs also described that a lack of aphasia awareness reduced their access to community support services, 'I tried three times, to get a carers allowance. I got nothing! […] was knocked-back three times, because they [national service centre] didn't understand […] what aphasia was all about' (SO-088-metropolitan-moderate).

Local site prioritisation and experience maps

PWA and SOs generated a total of 170 and 191 ideas for service development and improvement, respectively. Content analysis of combined stakeholder priority lists resulted in 34 (PWA) and 38 (SO) themed priorities, across the following domains: (1) therapy and service delivery; (2) support and help (to access, advocate and apply for services); (3) education and information; (4) emotional and peer support; (5) access to care and appointment scheduling; and (6) hospital environment and patient safety (SO only). Priorities by geographical remoteness and aphasia severity are available in online supplemental table 3. Experience maps are provided in figures 2 and 3.

Overview of unmet needs

Three domains of unmet needs were identified: (1) *individual*, (2) *healthcare provider* and (3) *context*. The interaction between touchpoints, domains of unmet needs and principles of person-centred care is available in online supplemental table 4.

Individual

Individual unmet needs were specific to the PWA and SOs. For PWA, this often related to communication support needs. Specifically, the timing, amount and type of information, as well as the mode of delivery, often presented a barrier to comprehension of critical health information and education. SOs also needed regular and often specific information and education (eg, purpose of therapy or resources needed in the home) throughout the continuum of care, to effectively support care processes and discharge planning. Family member unmet needs included not being informed or involved in care planning decisions (which often occurred outside of standard working hours). A lack of awareness of the emotional toll of aphasia complicated delivery and receipt of information for both PWA and SOs, specifically for PWA, when communication attempts are not acknowledged or effectively supported by healthcare providers during care interactions.

Healthcare provider

This domain captures unmet needs directly related to delivery of care. Reduced awareness of aphasia referred to unmet needs associated with care delivered, planned or managed by healthcare providers who had reduced awareness of aphasia or knowledge of how to support communication during service interactions. Healthcare providers lacked the experience or knowledge required to ensure the safety of PWA within hospitals (eg, ensuring there are suitable communication modes or supports available to facilitate asking for help when needed). Healthcare providers also lacked awareness of the time needed to support communication during service interactions or how to personalise care.

Context

The context domain related to the care setting. PWA face inequalities in their access care, particularly as geographical remoteness increased or severity of aphasia increased. PWA experienced reduced service options across geographically remote areas, and this led to unmet service needs, especially for PWA needing access to mental health or social work support. Service environment referred to unmet needs associated with hospital environments (eg, suitable entertainment/ward orientation materials to support patient safety, social connectedness

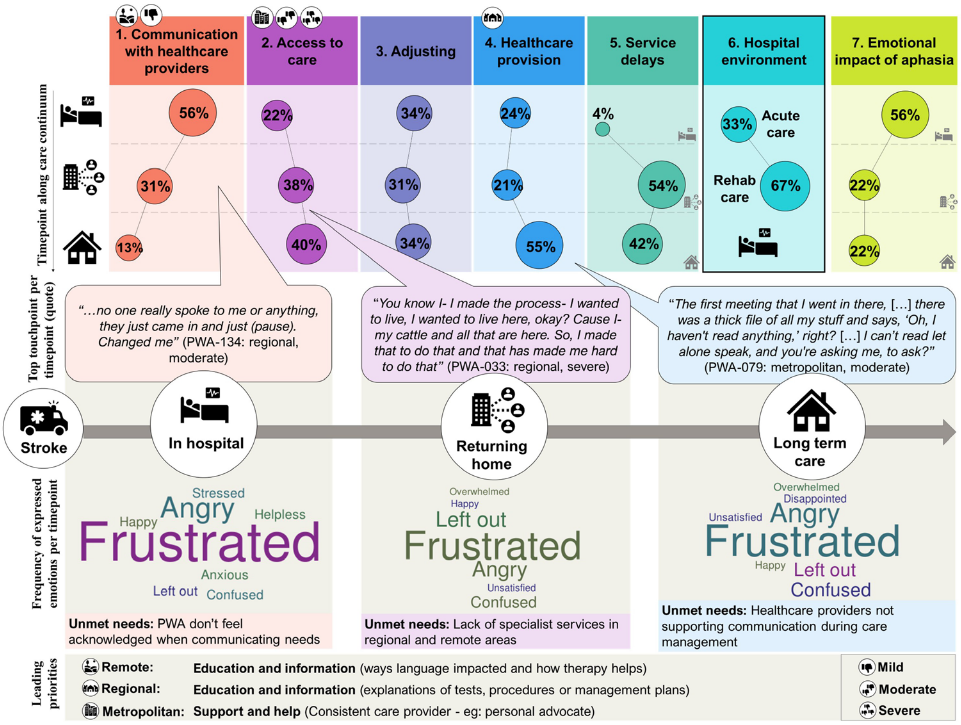


Figure 2 Experience map showing frequency of negative touchpoints (corresponding percentage of those reporting) per phase on the continuum of care for people with aphasia (PWA) (n=32). Unmet needs associated with the most commonly reported touchpoint and frequency of expressed emotions at each phase are shown. Frequency of words is illustrated by word size. Icons above each touchpoint illustrate most commonly identified touchpoint according to severity of aphasia (mild, moderate or severe) and geographical remoteness (remote, regional or metropolitan). Touchpoint 6 shows frequency of reporting during acute care or inpatient rehabilitation.

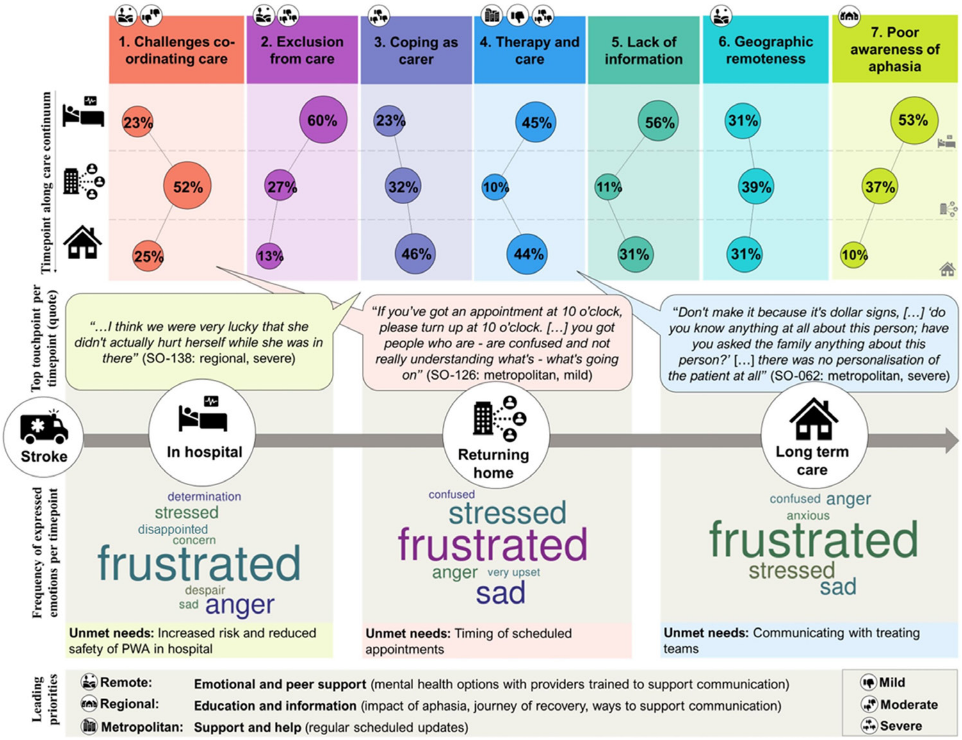
and emotional well-being during inpatient stays), accessible transport options or service models supporting flexible service delivery options.

DISCUSSION

This study aimed to explore experiences of post-stroke care from the perspectives of PWA and SOs, to understand their unmet service needs and priorities for improvement. Multiple areas of unmet needs across service contexts and geographical remoteness were identified. Both PWA and SOs shared positive experiences associated with therapy and care delivered in a hospital setting most often. This included providing hope (PWA/SOs) or witnessing good rapport between a PWA and their therapist (SO), and support for returning to paid employment (PWA). Additionally, PWA who recalled positive experiences once returning to the community, and reflected on the mode of service delivery (eg, group therapy, joint therapy sessions spanning different healthcare disciplines or engaging in research opportunities). Most negative experiences occurred in hospital settings and related to communication with healthcare providers. Such negative interactions were experienced across stakeholder groups, time post-onset, aphasia severity, geographical remoteness and cultural ethnicity, indicating that this is a key touchpoint for a diverse range of people who experience aphasia. Consistent with previous research,[5 13 44 45] unmet needs for PWA were often associated with a lack of access to mental health services, consistent care providers, equitable or longer-term speech therapy options and poor healthcare provider awareness of ways to support communication during service interactions. Likewise, unmet needs reported by SOs were consistent with prior research and often associated with: lack of education and information,[12] involvement of family in the planning of care,[46] access to local service providers[46] and poor healthcare provider awareness of aphasia.[5 44] Our findings build on this body of knowledge, demonstrating that SOs of a PWA need information and education about all areas of care (not just aphasia) and the importance of involving them in care planning (particularly where their PWA is unable to relay information or remote areas lacking locally available services) across the continuum of care. In the current study, SOs additionally described being responsible for care without knowledge or understanding of aphasia, prognosis or treatment plans, and having to teach themselves how to provide ongoing care. A discussion of how key experiences of care contribute to the three domains of unmet needs: (1) *individual*, (2) *healthcare provider* and (3) *context* for PWA is presented.

Individual: understanding person-centred care specific to PWA

PWA reported inequalities accessing post-stroke care,[47] exclusion from healthcare decision-making[6] and adverse



"…I think we were very lucky that she didn't actually hurt herself while she was in there" (SO-138: regional, severe)

"If you've got an appointment at 10 o'clock, please turn up at 10 o'clock. […] you got people who are - are confused and not really understanding what's - what's going on" (SO-126: metropolitan, mild)

"Don't make it because it's dollar signs, […] 'do you know anything at all about this person; have you asked the family anything about this person?' […] there was no personalisation of the patient at all" (SO-062: metropolitan, severe)

Unmet needs: Increased risk and reduced safety of PWA in hospital

Unmet needs: Timing of scheduled appointments

Unmet needs: Communicating with treating teams

Remote: **Emotional and peer support** (mental health options with providers trained to support communication)
Regional: **Education and information** (impact of aphasia, journey of recovery, ways to support communication)
Metropolitan: **Support and help** (regular scheduled updates)

Figure 3 Experience map showing frequency of negative touchpoints (corresponding percentage of those reporting) per phase on the continuum of care for significant others (SOs) (n=30). Unmet needs associated with the most commonly reported touchpoint and frequency of expressed emotions at each phase are shown. Frequency of words is illustrated by word size. Icons above each touchpoint illustrate the most commonly identified touchpoint according to severity of aphasia (mild, moderate or severe) and by geographical remoteness (remote, regional or metropolitan). PWA, people with aphasia.

events during hospital stays.[7 48] Research in other health fields (eg, covering a range of primary and secondary healthcare settings and disease conditions) has shown associations between improved patient experiences, clinical effectiveness and patient safety.[8] In a landmark study applying patient experience to hospital-based care, the Picker Institute identified eight principles of person-centred care: (1) *respect for the patient's values, preferences and expressed needs;* (2) *information and education;* (3) *access to care;* (4) *emotional support to relieve fear and anxiety;* (5) *involvement of family and friends;* (6) *continuity and secure transition between healthcare settings;* (7) *physical comfort;* (8) *coordination of care.*[38 49] In the current study, references to all eight principles were evident across responses. However, unique elements specific to PWA were identified. For PWA, two additional elements (principles) emerged: (1) *healthcare providers need* to *build competencies in how to support communication with PWA* and (2) *hospital environments need to be communicatively accessible with suitable engagement options for PWA.* Healthcare provider awareness of how to support communication was central to each of the eight previously identified principles. For example, *respect for the patient's values, preferences and expressed needs* was not maintained where healthcare providers did not acknowledge or support PWA's ability to express needs (eg, 'He didn't know how to even press the button- couldn't press the button [to call for help] (SO-059)), their rehabilitation goals or values (eg, 'nobody was telling me what's gonna happen to me, where I went- I had to go from a different place and I thinking, 'Oh, God!" (PWA-033)) or treatment preferences (including when consent is not supported) (eg, 'he was taking it [blood] when I was saying 'don't" (PWA-069)). The emotional distress and traumatic effect on the individual from not being able to express themselves have been highlighted elsewhere.[50] Indeed, prior research has shown that communicating with a trained communication partner can increase social participation and reduce risk of emotional distress for PWA.[51] The second element relating somewhat to 'physical comfort'[38 49] is for hospital environments to be safe, stimulating and engaging for PWA (see below).

Healthcare provider

PWA reported feeling afraid, frustrated, angry or misunderstood while attempting to communicate with those providing their care. This is concerning, given that PWA are known to experience greater emotional distress, develop depression, or suffer loneliness and social isolation,[3 52] and also experience reduced access to mental health services.[53] Furthermore, PWA reported being ignored, not spoken to or having things done *to* them (*in-hospital*). These findings are comparable with previous research reporting healthcare providers find communicating with PWA challenging and avoid communication attempts.[5] Reduced ability to communicate with or seek assistance from healthcare providers when needed potentially poses substantial risk for PWA, and may help to explain why they experience more complications during stroke admissions than other stroke survivors.[48] Internationally, training of healthcare providers in supported conversation techniques[54] and aphasia awareness[55] has been recommended as best practice.[54 56] The standardisation and implementation of communication partner training for all healthcare providers,[51] flexible service delivery options and improved communication between staff (to support greater consistency in care) may help to ensure awareness of effective communication strategies that reduce risk and optimise access to timely care.

Context: hospital environments for PWA

The importance of stimulating hospital environments and their influence on stroke recovery, particularly early stroke recovery, has previously been reported for all stroke survivors.[57] However, PWA have unique environmental needs and reported limited available stimulation opportunities outside of planned care. Given the increased risk of emotional distress[3 52] faced by PWA, the high proportion of time patients spend alone and inactive on stroke units,[58] and the toll boredom can take on engaging in therapy opportunities,[57] further exploration of suitable and engaging hospital environments specific to PWA is needed. In the current study, participants described entertainment options (eg, television programming/system navigation required complex language) as unsuitable or overstimulating and suggested simple music options or available (and quiet) green spaces. Recent studies in Australia and the UK have explored the feasibility of enriching hospital environments[59] and alternative ways to improve well-being for PWA.[60]

Implications for clinicians and policymakers

Limitations in health provider–patient communication could be addressed through implementation of existing supported communication partner training programmes, which have been shown to be effective.[51] This could also improve access to mental health services; however, more immediate impacts could be returned through implementation of speech pathology-led stepped psychological care.[61 62] Access to training in supported communication with PWA has been developed for a variety of cultural contexts, often with input from speech pathologists, PWA, SOs and neurologists.[51] The implementation of small, low-cost options like the systematic use of communication boards, suitable mobile music listening devices,[63] peer befriending models[60] or hospital-based volunteers able to support participation in everyday activities (eg, walks outside) warrants investigation.

Strengths and limitations

A strength of this study was the diversity of participants achieved through maximum variation sampling. Participants across the continuum of care, geographical remoteness areas and a range of service contexts were represented. The inclusion of populations often excluded from aphasia research (eg, people with severe aphasia, Aboriginal and/or Torres Strait Islander Peoples, and linguistically diverse people) was supported through the development of bespoke resources and support. Data were collected during the COVID-19 pandemic and it is acknowledged that this was a period where care may have differed from that typically provided. Additional limitations include the lack of observation of regional and remote contexts, which may have influenced interpretations of site contexts, and the lack of the wider stroke healthcare team, policymakers and PWA, resulting from an aetiology other than stroke. Aphasia-related impairments, and lack of access or familiarisation with communicating online may have discouraged some people from being involved, though research suggests there may be benefits to engaging online with people with communication impairments.[64–66]

Prompted by the lack of definitive explorations of need across service contexts (specific to aphasia care), this comprehensive examination adds to our understanding of post-stroke aphasia experiences and unmet care needs. Future aphasia service development should ensure these unmet needs are addressed in new policy and service-model designs, and further research consider the experiences and unmet needs of speech pathologists and those with aphasia caused by an aetiology other than stroke. Further research should also explore the perspectives and experiences of healthcare providers other than speech pathologists. The next stage of research will explore speech pathologists' experiences, unmet needs and service priorities.

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recruitment processes, analysis and dissemination. All authors have read and approved the final version.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and ethical approvals were granted by the Royal Brisbane and Women's Hospital (HREC/2020/QRBW/61368) and the University of Queensland (2020000965) Human Research Ethics Committees. Participants gave informed consent to participate in the study before taking part.

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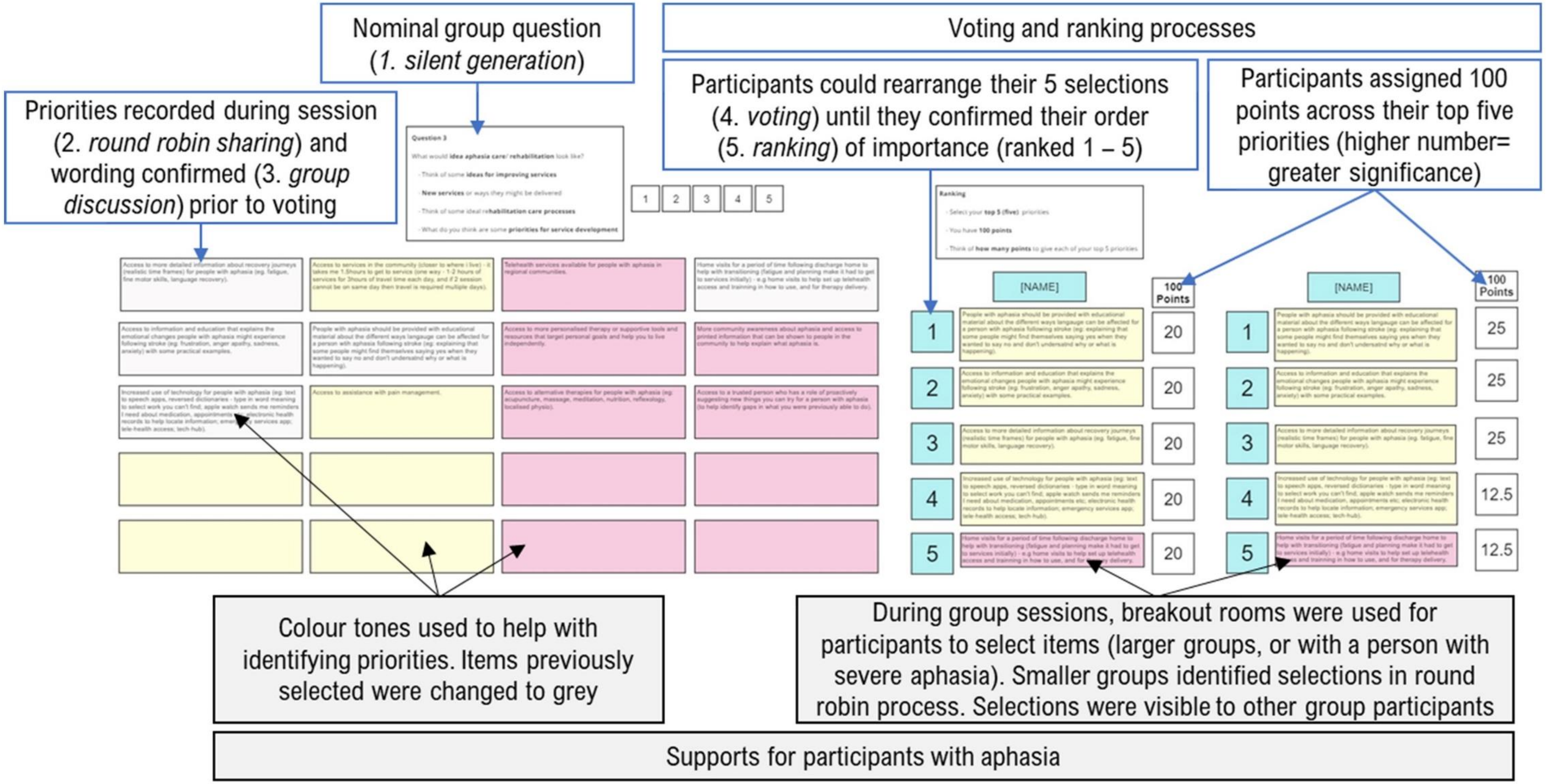
Supplementary table 1. *Focus group and interview guide*

Collection format	**Question guide**	**Purpose**
Online focus group and interview questions	Q1. What has been your best experience of receiving stroke or aphasia services? This might include a specific service, event, or person. *Please give 1 (one) example*. • *Select one (1) emotion most connected with your experience (*you can think of your own*)	Explore experience
	Q2. Describe an experience of receiving stroke or aphasia services that did not go so well? This might include a specific service, event or person. *Please give 1 (one) example*. • *Select one (1) emotion most connected with your experience (*you can think of your own*)	Explore experience
Nominal question (*online focus groups and interviews*)	Q3. What would ideal aphasia care look like? *Please share 1 (one) idea at a time.* You can think of: a. Ideas for improving services b. New aphasia services or ways they might be delivered c. Some ideal rehabilitation care processes d. Priorities for service development	Priority generation

*****Displayed options included**:** Happy, frustrated, anger, stressed, confused, sad, hopeful, left out, grateful, content, satisfied, included, and other. *Participants were able to identify their own emotion independent of the options provided*.

Note: Additional prompts used to explore experiences in more detail in interviews or to confirm details of experiences (e.g. hospital/community-based service, time post stroke, stage on continuum of care experience took place, healthcare personnel involved) during focus groups as needed:

- *Who was involved?*
- *When / where did it take place?*
- *How long after your stroke did this happen?*
- *Were there any thoughts that stood out to you?*
- *What do you think should have happened?*
- *Is there something that would have made a difference?*



Nominal group question (*1. silent generation*)

Voting and ranking processes

Priorities recorded during session (2. *round robin sharing*) and wording confirmed (3. *group discussion*) prior to voting

Participants could rearrange their 5 selections (4. *voting*) until they confirmed their order (5. *ranking*) of importance (ranked 1 – 5)

Participants assigned 100 points across their top five priorities (higher number= greater significance)

Question 3

What would **idea aphasia care/ rehabilitation** look like?

- Think of some **ideas for improving services**
- **New services** or ways they might be delivered
- Think of some ideal rehabilitation **care processes**
- What do you think are some **priorities for service development**

Access to more detailed information about recovery journeys (realistic time frames) for people with aphasia (eg. fatigue, fine motor skills, language recovery).	Access to services in the community (closer to where i live) - it takes me 1.5hours to get to service (one way - 1-2 hours of services for 3hours of travel time each day, and if 2 session cannot be on same day then travel is required multiple days).	Telehealth services available for people with aphasia in regional communities.	Home visits for a period of time following discharge home to help with transitioning (fatigue and planning make it had to get to services initially) - e.g home visits to help set up telehealth access and trainning in how to use, and for therapy delivery.
Access to information and education that explains the emotional changes people with aphasia might experience following stroke (eg: frustration, anger apathy, sadness, anxiety) with some practical examples.	People with aphasia should be provided with educational material about the different ways langauge can be affected for a person with aphasia following stroke (eg: explaining that some people might find themselves saying yes when they wanted to say no and don't undersatnd why or what is happening).	Access to more personalised therapy or supportive tools and resources that target personal goals and help you to live independently.	More community awareness about aphasia and access to printed information that can be shown to people in the community to help explain what aphasia is.
Increased use of technology for people with aphasia (eg: text to speech apps, reversed dictionaries - type in word meaning to select work you can't find; apple watch sends me reminders I need about medication, appointments etc; electronic health records to help locate information; emergency services app; tele-health access; tech hub).	Access to assistance with pain management.	Access to alternative therapies for people with aphasia (eg: acupuncture, massage, meditation, nutrition, reflexology, localised physio).	Access to a trusted person who has a role of proactively suggesting new things you can try for a person with aphasia (to help identify gaps in what you were previously able to do).

Ranking

- Select your **top 5 (five)** priorities
- You have **100 points**
- Think of **how many points** to give each of your top 5 priorities

	[NAME]	100 Points
1	People with aphasia should be provided with educational material about the different ways langauge can be affected for a person with aphasia following stroke (eg: explaining that some people might find themselves saying yes when they wanted to say no and don't undersatnd why or what is happening).	20
2	Access to information and education that explains the emotional changes people with aphasia might experience following stroke (eg: frustration, anger apathy, sadness, anxiety) with some practical examples.	20
3	Access to more detailed information about recovery journeys (realistic time frames) for people with aphasia (eg. fatigue, fine motor skills, language recovery).	20
4	Increased use of technology for people with aphasia (eg: text to speech apps, reversed dictionaries - type in word meaning to select work you can't find; apple watch sends me reminders I need about medication, appointments etc; electronic health records to help locate information; emergency services app; tele-health access; tech hub).	20
5	Home visits for a period of time following discharge home to help with transitioning (fatigue and planning make it had to get to services initially) - e.g home visits to help set up telehealth access and trainning in how to use, and for therapy delivery.	20

	[NAME]	100 Points
1	People with aphasia should be provided with educational material about the different ways langauge can be affected for a person with aphasia following stroke (eg: explaining that some people might find themselves saying yes when they wanted to say no and don't undersatnd why or what is happening).	25
2	Access to information and education that explains the emotional changes people with aphasia might experience following stroke (eg: frustration, anger apathy, sadness, anxiety) with some practical examples.	25
3	Access to more detailed information about recovery journeys (realistic time frames) for people with aphasia (eg. fatigue, fine motor skills, language recovery).	25
4	Increased use of technology for people with aphasia (eg: text to speech apps, reversed dictionaries - type in word meaning to select work you can't find; apple watch sends me reminders I need about medication, appointments etc; electronic health records to help locate information; emergency services app; tele-health access; tech hub).	12.5
5	Home visits for a period of time following discharge home to help with transitioning (fatigue and planning make it had to get to services initially) - e.g home visits to help set up telehealth access and trainning in how to use, and for therapy delivery.	12.5

Colour tones used to help with identifying priorities. Items previously selected were changed to grey

During group sessions, breakout rooms were used for participants to select items (larger groups, or with a person with severe aphasia). Smaller groups identified selections in round robin process. Selections were visible to other group participants

Supports for participants with aphasia

Supplementary figure 1. *Screen shot of miro board detailing voting processes used in interviews and focus groups to identify top priorities.*

Supplementary table 2. *Data analysis steps taken to identify positive and negative touchpoints and mapping of unmet needs*

Phase	Process description	Researcher
Familiarisation	Reviewing audio and video content alongside verbatim transcripts.	LA, BB
Coding	Open coding (inductive and deductive codes identified) for key units of meaning.	LA, BB, SW
Generating initial touchpoints (themes)	Grouping codes according to shared meanings and concepts reflecting positive or negative experiences of post-stroke care	LA
Developing touchpoints (themes and sub-themes)	Development of representative thematic maps. Touchpoints were identified and developed by considering the emotional and sensory connections described in experiences across the journey of care interactions.	LA, SW, DC
Refining touchpoints (and sub-themes)	Consensus was sought across multiple iterations of the representativeness of final touchpoints and sub-themes (touchpoints and experience maps were reviewed by participants in later stages of the EBCD process, to be reported elsewhere).	LA, SW, DC
Writing up	Identification of representative quotes to support understanding of positive and negative touchpoints Mapping each touchpoint (theme and sub-theme) by geographic remoteness and aphasia severity.	LA, SW, DC LA
Mapping touchpoints against journey of care	Assigning each code to one of three key timepoints along the continuum of care (according to experience excerpt) Mapping each touchpoint (theme and sub-theme) across the continuum of care.	LA, BB LA
Identifying unmet needs	Reviewing each negative touchpoint (theme, sub-theme and thematic map for PWA and SO) for key factors contributing to key instances eliciting an emotional response related to each touchpoint.	LA
Confirmation of unmet needs	Review and consensus of final interpretations of unmet needs per negative touchpoint for PWA and SO.	LA, SW, DC
Mapping touchpoints and unmet needs to principles of person-centred care	Reviewing each touchpoint and unmet need against each of the Picker Institutes eight principles of person-centred care[24]. Identification of elements of person-centred care not captured, specific to PWA. Review and confirmation of elements of person-centred care specific to PWA.	LA LA LA, DC, SW

Phases 1-6 incorporate the 6 steps outlined by Braun & Clarke (2006)[22]. Initial codes were generated in word documents and themes managed in excel. Changes to coding and themes were dated and saved as a new file. Regular peer debriefing of techniques and interpretations were conducted with supervisory team (SJW, DC, VJP). Member checking involved confirming a verbal summary of experiences and written representativeness of priority wording within sessions.

Notes: some participants (n=2) were known to the researcher (lead author) prior to data collection. One participant with aphasia (and their significant other) had previously participated in a clinical research trial where author LA collected assessment data and carried out the therapy intervention. Four authors are female and one author is male. Initial thematic analysis steps were completed to gain an understanding of key themes of experiences being reported prior to identifying touchpoints. Touchpoint development and refinement exist beyond this identification of themes and include a consideration of the critical moments shaping experiences (eliciting an emotional response) across their journey of care experiences. This involved a thorough understanding of experiences, where each experience took place across the continuum of care, service context, and the factors influencing their emotional responses described. Field notes were recorded following interviews and focus groups and reflections discussed during peer supervision. Codes were managed in word and themes, touchpoints, and unmet needs in excel.

PWA=Person with aphasia, SO=significant other of a person with aphasia

Supplementary figure 2. *Thematic map showing relationships between negative touchpoints (major themes and sub-themes) for people with aphasia*

Supplementary figure 3. *Thematic map showing relationships between negative touchpoints (major themes and sub-themes) for significant others*

Supplementary table 3. *Summary of leading local rankings identified by people with aphasia and significant others overall, by geographic remoteness area and aphasia severity*

People with aphasia		**Overall rank (NGT)**	**Geographic remoteness**			**Aphasia severity**		
Priority ID	**Theme domain** and (short priority label)		**REM**	**REG**	**MET**	**SEV**	**MOD**	**MILD**
Priority 18-E2	**Education and information** (ways language impacted and how therapy helps)	#1	#1	#2=		#1		#1
Priority 22-P2	**Emotional and peer support** (mental health services accessible to PWA)	#2			#2	#2=		#2
Priority 11-T1	**Therapy and service delivery** (Service delivery options - intensive speech therapy accessed from the community)	#3		#3			#1=	
Priority 24-P4	**Emotional and peer support** (social opportunities to connect and support group access)	#4						#3=
Priority 19-E3	**Education and information** (explanations of tests, procedures, or management plans)	#5		#1			#2	
Priority 6-H2	**Support and help** (Consistent care provider - e.g.: personal advocate)				#1		#3	
Priority 4-H1	**Support and help** (Involvement of primary caregivers in decisions about care)			#2=				
Priority 7-H5	**Support and help** (Support communicating with government services, banks, protection against scammers)					#2=		
Priority 8-H6	**Support and help** (Check-ins provided at regular time points following discharge)		#3=					
Priority 12-T2	**Therapy and service delivery** (Communication support - during transitions, self-management of care, service delays)						#1=	
Priority 16-T13	**Therapy and service delivery** (Service delivery options - frequent speech therapy of longer duration)			#2=				
Priority 23-P3	**Emotional and peer support** (hosted peer support groups and information sessions)		#2					
Priority 28-T6	**Therapy and service delivery** (therapy to use technology)		#3=					
Priority 33-H8	**Support and help** (additional funded services e.g.: intensive therapy, pharmacy, transport, therapy devices/apps)				#3	#3		#3=
Significant others								
Priority 1-H1	**Support and help** (regular scheduled updates)	#1		#2	#1	#2=	#1	#1
Priority 20-E4	**Education and information** (impact of aphasia, journey of recovery, ways to support communication)	#2	#2=	#1		#1	#2	#2
Priority 26-H6	**Support and help** (support co-ordinating access to care)	#3	#2=			#3=		
Priority 3-T1	**Therapy and service delivery** (intensive top-up therapy blocks)	#4			#3		#3=	
Priority 19-E3	**Education and information** (regular communication partner training for SO)	#5	#3=	#3		#3=		#3
Priority 23-A4	**Access to care / Appointment scheduling** (support for PWA co-ordinating care)				#2	#2=		
Priority 15-P1	**Emotional and peer support** (mental health options with providers trained to support communication)		#1					
Priority 5-T3	**Therapy and service delivery** (equitable speech pathology services in regional and remote areas)		#2=					
Priority 38-T7	**Therapy and service delivery** (care tailored to the individual)		#2=					
Priority 2-A1	**Access to care / Appointment scheduling** (considers personal circumstances - written / verbal information / SO aware)		#3=					
Priority 4-T2	**Therapy and service delivery** (longer-term needs-based therapy options)						#3=	
Priority 14-A2	**Access to care / Appointment scheduling** (transport options that support communication)					#3=		
Priority 25-H5	**Support and help** (support to advocate for services not available in regional/remote areas)		#3=					
Priority 32-H8	**Support and help** (emergency respite care for SO managing care)		#3=			#3=		
Priority 33-T6	**Therapy and service delivery** (technology to support recovery: devices and apps)		#3=				#3=	
Priority 35-E7	**Education and information** (technology that supports recovery)		#3=					
Priority 37-En6	**Hospital environment / patient safety** (personal details available at bedside – support communication /build rapport)						#3=	

NGT=Nominal group technique, REM=remote, REG=regional, MET=metropolitan, SEV=severe, MOD=moderate

Supplementary table 4. *Overview of unmet needs associated with touchpoints and corresponding principles of person-centred care for people with aphasia (PWA) and significant others (SO)*

Touchpoint	Unmet need	Domain of unmet need	Associated principles of person-centred care[25]
1.1 Communication with healthcare providers (PWA)	**Healthcare providers not:** • ensuring the volume, timing or type of information being communicated is communicatively accessible • providing communication supports or taking time to understand what they are attempting to communicate • acknowledging the individual even when they are able to communicate their needs • ensuring the mode of communication is suitable	🧑‍⚕️ 👤	• Respect for the patient's values, preferences, and expressed needs • Information and education • Access to care • Involvement of family and friends • Continuity and secure transition between health care settings • **Other:** *healthcare provider awareness of how to support communication with PWA*
1.2 Challenges co-ordinating care (SO)	**A lack of:** • communication from healthcare providers about when scheduled appointments will take place when they are delayed • support setting up and timely access to community-based services • support completing paperwork to access community-based care • access to timely service provision in remote areas (waiting 3 months to reschedule appointment)	🏥 🧑‍⚕️ 👤	
2.1 Access to care (PWA)	**Equitable or on-going access to:** • Funded, longer-term and intensive speech therapy in hospitals and/or private practice • specialist care across geographic remoteness and aphasia severities • mental health services • group therapy and peer support groups • social work services to facilitate access to community services and prepare individuals for returning to community	🏥 👤	• Information and education • Access to care • Emotional support to relieve fear and anxiety • Involvement of family and friends • Continuity and secure transition between health care settings • **Other:** *healthcare provider awareness of how to support communication with PWA*
2.2 Exclusion from care (SO)	**Healthcare providers not:** • providing regular updates (particularly for those with a moderate or severe aphasia, or when services are not local) • involving family in care or planning of care	👤 🧑‍⚕️	
3.1 Adjusting to life with aphasia (PWA)	**A lack of:** • ongoing mental health support • support connecting with community	🏥 👤	• Information and education • Access to care • Emotional support to relieve fear and anxiety • **Other:** *healthcare provider awareness of how to support communication with PWA*
3.2 Coping as carer (SO)	• respite options • transport options to support PWA to independently attend appointments • education about long-term impact of aphasia	🏥 👤	
4.1 Healthcare provision (PWA)	**A lack of:** • personalised and engaging speech therapy • healthcare knowledge of aphasia and how to ensure communication needs are considered in care management • knowledge of ways to re-connect with support services • consistency in care providers	🧑‍⚕️	• Information and education • Access to care • Emotional support to relieve fear and anxiety • Continuity and secure transition between health care settings (*consistent care*) • Co-ordination of care (*consistent care*) • **Other:** *healthcare provider awareness of how to support communication with PWA*
4.2 Therapy and care (SO)	• personalised and engaging speech therapy (PWA discontinuing, lacking person-centred care)	🧑‍⚕️	

	• communication with treating teams		
5.1 Service delays (PWA)	**A lack of:** • clear explanations of transition process • access to local service providers (regional and remote areas – travel is fatiguing) • communication with healthcare providers about service delays	👤 🏥	• Continuity and secure transition between health care settings • Access to care • Information and education • **Other:** *healthcare provider awareness of how to support communication with PWA*
5.2 Lack of information (SO)	**Healthcare providers not:** • providing education about aphasia or resources needed in the community • providing education or information about the purposes of therapy or assessments	👤	
6.1 Hospital environment (PWA)	**A lack of:** • access to intensive rehabilitation from home • suitable entertainment options in hospital • meaningful communication and stimulation on weekends • clear and accessible explanations of hospital procedures and processes	🏥 👤	• Respect for the patient's values, preferences, and expressed needs • Information and education • Access to care • Physical comfort • **Other:** *healthcare provider awareness of how to support communication with PWA* • **Other:** *communication accessible entertainment options in hospital environments*
6.2 Geographic remoteness (SO)	• local service providers in regional or remote areas • understanding the impact or accommodation of travel fatigue	🏥 👤 🩺	
7.1 Emotional impact of aphasia (PWA)	**Healthcare providers not:** • being aware and understanding aphasia • acknowledging communication competence and capacity to consent • knowing how to support communication • supporting or preparing a PWA to return home	🩺	• Respect for the patient's values, preferences, and expressed needs • Continuity and secure transition between health care settings • **Other:** *healthcare provider awareness of how to support communication with PWA*
7.2 Poor awareness of aphasia (SO)	**A lack of healthcare provider awareness of aphasia in:** • community service systems (not able to support needs) • hospital environments (increased risk and reduced safety) • community service systems (not aware of need for family to support communication)	🩺 🏥	

Domain of unmet need	**Sub-theme within domain**	**Principles of person-centred care associated with unmet needs for people with aphasia [25]**
Individual 👤	• Education and updates • Involvement of family	• Respect for the patient's values, preferences, and expressed needs • Information and education • Access to care • Emotional support to relieve fear and anxiety • Involvement of family and friends • Continuity and secure transition between health care settings • Physical comfort • Coordination of care • **Other:** *healthcare provider awareness of how to support communication with PWA* • **Other:** *communication accessible entertainment options in hospital environments*
Healthcare provider 🩺	• Awareness of aphasia • Capability, knowledge and experience	
Context 🏥	• Service options • Equitable access • Service environment	