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# **The relevance of stroke care for living well with post-stroke aphasia: a qualitative interview study with working-aged adults.**

## **Abstract**

**Purpose:** This study aimed to explore the perspectives of working-aged adults with post-stroke aphasia (PWA) towards what has or would help them in living well with aphasia (LWA). This paper reports the findings in relation to stroke care and its relevance for LWA.

**Materials and methods:** This qualitative study was designed with input from a Public & Patient Involvement advisory group. We conducted in-depth, semi-structured interviews with 14 PWA. Data were analysed following principles of reflexive thematic analysis.

**Results:** Support services and LWA spanned 5 themes: Inpatient care; Support in the community; Speech therapy; Mental health; and Aphasia education and training. Per the findings, all aspects of stroke care were affected and challenged by aphasia. Access to services and information was variable. PWA of working-age, their families and children need access to person-centred stroke care and information responsive to their changing needs at all stages of recovery. Healthcare workers must be equipped with aphasia competency.

**Conclusions:** The results highlight a need for equitable, transparent, responsive access to services, information and stroke liaison support. The findings extend knowledge of the importance of stroke care for supporting working-aged adults and their families to live well in the context of aphasia.

**Keywords**

Aphasia; health services research; language therapy; patient involvement; rehabilitation; stroke.

## **Implications for rehabilitation**

- There is a need for equitable, transparent access to a responsive integrated pathway of stroke care to support living well with aphasia.
- People with aphasia post-stroke and their families need access to person-centred stroke care and information responsive to their changing needs at all stages of recovery.
- This includes flexible access to mental healthcare and Speech and Language Therapy.
- In order to access relevant care, people with post-stroke aphasia need access to information and stroke liaison support.
- Training to improve aphasia competency is imperative for healthcare workers.

## **Introduction**

About one third of people with stroke are affected by aphasia, a communication impairment that “masks a person’s inherent competence, and most dramatically affects conversational interaction (talking and understanding), as well as the ability to read and write” [1, 2]. Compared to people with stroke and no aphasia, having post-stroke aphasia is associated with poorer outcomes and long-term residual difficulties including morbidity, hospital length of stay, quality of life, social networks and return to work [3-

8].

Exactly because of their communication difficulties, people with post-stroke aphasia (PWA) are systematically excluded from stroke research, including studies examining information provision, depression and self-management interventions post-stroke [9-13]. Such systematic exclusion leads to a relative lack of evidence on care delivery and questionable clinical validity of post-stroke interventions [10]. Responsive and relevant aphasia support must incorporate the perspectives of PWA and their significant others [14, 15].

In keeping with a policy shift towards person-centred care for living well with chronic conditions, including stroke [16-18], aphasia researchers are increasingly focused on understanding how to support wellbeing and life participation [19, 20]. There is a growing body of qualitative literature examining the insider perspectives of PWA on a range of inter-related topics including participation, community integration, life roles, coping, adjustment and quality of life [14, 21-33] as well as specific research in living successfully or living 'well' with aphasia (LWA) [34-39]. In a recent qualitative evidence synthesis exploring the perspectives of PWA towards topics relating to LWA, we found that LWA is promoted via: personal integration and acceptance of aphasia; flexible, responsive, long-term health and related support services for PWA; opportunities for community participation and contribution; support for, and from, family and friends; access to aphasia information; and healthcare workers who are knowledgeable about aphasia and supporting communication with PWA [40].

These findings were limited in two main ways. First, most of the included studies did not directly examine LWA. This pointed to a need for further research that had a

primary objective to ask PWA and other stakeholders specifically about LWA in order to validate and further explore the review findings. Just under half of participants (42%) in the included studies were clearly documented as being of working-age (under 66 years). However, it is particularly important to extend our understanding of how best to support working-aged adults and their families, in the context of increasing numbers of stroke in this age group [41-43], and recent evidence highlighting inconsistent access to post-acute stroke care for working-aged adults with stroke in Australia, the United Kingdom and South East Asia [44].

Second, the review process highlighted shortcomings in the quality of the existing evidence base. These include inadequate description of the steps taken to meaningfully include PWA in qualitative interviews and under-representation of the perspectives of people with severe aphasia.

We therefore aimed to address these two limitations by exploring the perspectives of PWA, including those with severe aphasia, towards what has or would help them to live well. We focused on the perspectives of PWA of working-age up to 65 years in order to extend our understanding of supporting this age group who will likely live with aphasia for a longer number of years than other age groups, and in the context of (un)employment and parenting. We designed a qualitative interview study with input from a Public and Patient Involvement (PPI) aphasia advisory group, which generated a rich data set about multiple aspects of LWA. This paper focuses on findings relating to stroke care and its relevance for LWA.

## **Methods**

### ***Qualitative approach and research paradigm***

This study is reported following the Standards for Reporting Qualitative Research (SRQR) [45] (Supplement 1). The design comprised qualitative, semi-structured in-depth interviews, underpinned by Critical Realism (CR) [46].

### ***Research team characteristics and reflexivity***

The team comprised: 2 SLT researchers (MM, SF), which brought knowledge of aphasia; a physiotherapist researcher with expertise in primary care research (RG); a social scientist with expertise in primary healthcare, PPI and participatory research (AM); a health psychologist with expertise in stroke and health services research (AH); and PPI Advisors including 3 women and 1 man of working-age living with post-stroke aphasia between 3- and 30-years post-stroke.

### ***Sampling strategy***

We purposefully sampled individuals with aphasia as a result of stroke (self-identified or by a member of the referring organisation), minimally one-year post-onset and of working-age (18-65 years). All eligible and interested individuals were recruited between February and June 2019. At this point, recruitment ended to ensure enough resources to complete the research within the project timeframe. Recruitment was limited to 1+ year post-stroke to increase the likelihood that participants had post-acute experience of living with aphasia and stroke care. We additionally wanted to obtain perspectives from people living with aphasia for a longer number of years (e.g. 10+ years) to learn how people

adapt and live well with aphasia over time.

We used maximal variation sampling to identify information rich participants and actively monitored diversity throughout recruitment [47]. The sampling parameters were age (18-65 years), gender, location in Ireland, severity of aphasia, recruitment source, living situation and time post-onset (1+ years). We additionally recorded information relating to marital status and employment status both at time of stroke and at time of interview. Each participant could invite a significant other in the main to help support communication [29]. We did not include people with serious cognitive and/or hearing impairment, not due to the methodological issues of including these groups, but because we wanted to focus on understanding the experience of PWA. People with similar lived experience of a phenomenon might be assumed to some extent to share some common meanings around it [48]. Therefore, excluding people with related and co-occurring severe cognitive and hearing impairment, would help focus specifically on the shared meanings attributed by PWA to the lived experience of aphasia and reduce confounders to understanding the experience of aphasia.

We recruited via third-sector support organisations: Acquired Brain Injury Ireland (ABII), Aphasia Ireland, Croí, Headway Ireland, Irish Heart Foundation (IHF) and the Limerick Stroke Support Club. We also recruited through the SLT service in the Health Service Executive (HSE) Mid-West. A description of the Irish health system is in Supplement 2. The first author contacted the above organisations and sent aphasia-friendly recruitment information by email. Gatekeepers in the organisations above identified and forwarded study information to potential participants. Informed consent was obtained at an initial meeting. The first author read the information sheet and consent



form aloud and participants were required to demonstrate that they had comprehended each element. We used a “participative” approach to member-checking [49] in which PWA decided to what extent they wanted to be involved in reviewing their data.

### *Ethical issues*

Approval for the study was obtained from the Research Ethics Committees of the University of Limerick Faculty of Education and Health Sciences (REC Ref: 2016\_09\_06\_EHS); University Hospital Limerick (REC Ref: 124/16); ABII; and Headway Ireland. Study approval was also obtained from Aphasia Ireland, Limerick Stroke Support Club, IHF and Croí.

### *Data collection methods*

All data were collected between March and July 2019. Except for 3 participants for whom fatigue was not an issue, the first author met each person twice, a minimum of 2 days apart. On Day 1, the researcher administered sub-tests of the Boston Diagnostic Aphasia Exam (BDAE) [50], the Western Aphasia Battery – Revised [51] and the Comprehensive Aphasia Test [52]. This was to assess severity of aphasia and possible need for supportive communication techniques [53]. Participants were also asked about the strategies that they found helpful during conversations [54]. We conducted qualitative in-depth, semi-structured interviews on Day 2. Interviews were in participant homes or third-sector support organisations. Average interview length was 96 minutes (range 50-128 minutes).

The topic guide (Supplement 3), underpinned by our earlier qualitative systematic review [55], was developed and piloted with our PPI advisory group in practice interviews

[56]. We used a semi-structured interview format with no fixed sequencing or wording. Participants were asked about: information about aphasia and services; support for and from family and friends; education for healthcare professionals; access to services; accepting aphasia; effects of aphasia; doing things; and public attitudes. Where possible, we asked non-directed, open questions, however responses were scaffolded using a hierarchy of supported questions and responses, including examples of what other PWA (e.g., interview participants and/or PPI advisory group members) had said, binary choice alternatives and yes/no questions. Additional detail of the strategies used to support PWA to meaningfully participate in the interviews is in Supplement 4. These were drawn from existing literature and suggestions from PPI collaborators.

### ***Participants***

Fourteen PWA (8 men, 6 women) took part in interviews. Participants were aged 33-62 years (mean age 51 years  $\pm$  8 years) and ranged from 14 months - 14years post-onset (mean 7 years  $\pm$  4 years). Half of these were in the Mid-West region of Ireland, 3 were in the East (Dublin / Kildare), 3 were in Galway and one was in the South-East of Ireland. Six had a severe aphasia and 3 had severe receptive aphasia. Two participants with aphasia were working at the time of interview; one of these was in a voluntary role. At the time of stroke 13 participants had been in employment. Eight had children at the time of stroke; two more had adult children at the time of stroke. Four PWA elected for their spouse to attend the interview as a source of communication support. Participant characteristics are reported in table 1.

Table 1. Participant characteristics.

Maximum variation sampling variable		Number of participants (N=14)
<b>Sex</b>	Male	8
	Female	6
<b>Time since stroke</b>	Mean (S.D.): 7 years (4 years); Range: 14 months – 14 years.	
	<2 years	2
	2 - 5 years	4
	6 - 10 years	5
	11+ years	3
<b>Age</b>	Mean (S.D.): 51 years old (8 years); Range: 33 – 62 years.	
	<i>[Age at stroke, Mean (S.D.):45 years old (10 years);</i>	
	<i>Range: 23 – 58 years].</i>	
<b>Aphasia severity</b>	Mild	3
	Moderate	5
	Severe	6

Maximum variation sampling variable		Number of participants (N=14)
<b>Location in Ireland</b>	Clare / Limerick	7
	Dublin / Kildare	3
	Galway	3
	Tipperary (South)	1
<b>Marital status</b>	Single (unmarried)	4
	Separated / Divorced	4
	Married	6
<b>Living situation</b>	Living alone	2
	Lives with at least one other person	12
<b>Referral source</b>	Acquired Brain Injury Ireland (ABII)	2
	Aphasia Ireland	1
	Croí	3
	Headway	6
	HSE	1
	Irish Heart Foundation (IHF)	1
<b>Currently employed</b>	Yes	2
	No	12

Maximum variation sampling variable		Number of participants (N=14)
<b>Employed at stroke</b>	Yes	13
	No	1

### *Data processing and analysis*

The first author transcribed the entire dataset. Consistent with CR, we viewed transcription as an imperfect, interpretive activity, involving decisions about what to include/omit from the transcript [57]. Transcripts were imported to NVivo 11 for reflexive thematic analysis [58-61]. We used a flexible deductive approach to initial coding [62]. We either applied codes generated in an earlier qualitative systematic review on living well with aphasia [55] if they fully captured the meaning (Supplement 5) or inductively created new ones. This process was iterative and involved multiple rounds of coding in order to counteract coding drift.

Next we applied axial coding looking for similarities and differences among the codes to create themes and noted how these might inter-relate [59]. Seven preliminary themes were presented to the PPI group for their interpretation and feedback. We then analysed the data and codes in each theme, visualised inter-relationships between themes and defined and named themes [59]. The final stage involved preparing a written

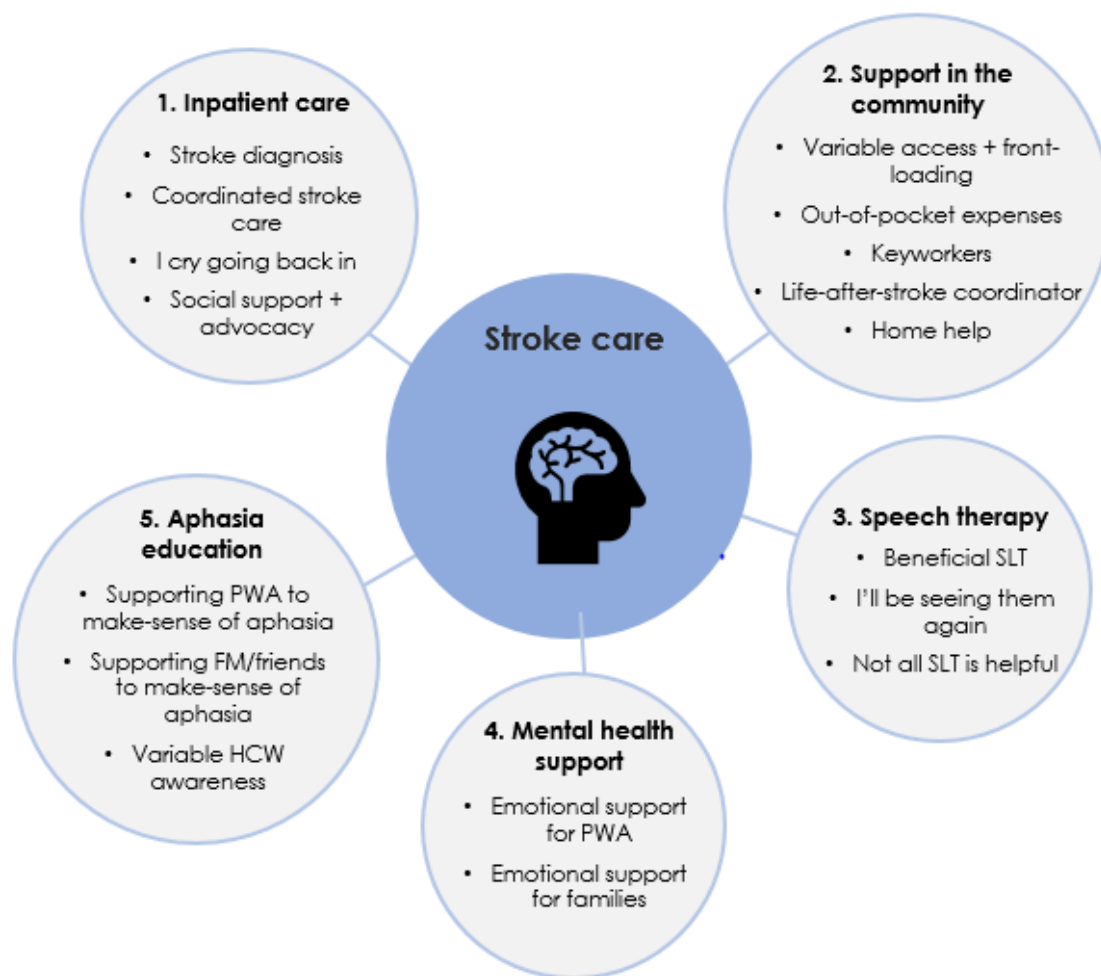
summary of the findings of the analysis that was grounded in participant data. This involved a final round of re-grouping and naming themes.

### ***Techniques to enhance trustworthiness***

In addition to working with the PPI contributors, we maintained a transparent audit trail via reflexive notes and clear documentation of all coding decisions. After initial coding of 4 transcripts, the first author met with the second and final authors to present and discuss analytical method. The researcher also met with the final author throughout the analytical process for in-depth discussion and interrogation of the analytical insights being generated.

### **Results**

The analysis generated 3 overarching meta-themes about living well with aphasia. These comprised stroke care, adapting to aphasia and social support and participation. This paper focuses solely on the findings relating to stroke care. Stroke care, as relevant for LWA, spanned 5 sub-themes: Inpatient care; Support in the community; Speech therapy (SLT); Mental health support; and Aphasia education and training (figure 1).



Each participant with aphasia was assigned a random identifier from P01-P14 (corresponding spouses are identified as S01 etc.). Quoted participants are further described as being above / below the mean age and time since stroke below.

### ***1 Inpatient care***

This sub-theme references participants' diverse inpatient experiences in acute and rehabilitation settings.

### *1.1 Stroke diagnosis*

P08 was the only participant to describe prompt hospital diagnosis and admission. Two participants recalled that they had not realised they were having strokes and therefore did not seek urgent care. Most participants (6) reported experiencing delayed stroke diagnosis and attention in the hospital Emergency Department (ED (A&E)). Communication difficulty appeared to be a relevant factor for some of these participants.

**P09** (*above mean age; below mean years since stroke*) The whole thing was a bit of a joke really...And then nurses coming up to me saying, "why are you here? What are you here for?" (laughs)

**I** Had you been triaged at this point or had anyone queried if it was a stroke?

**P09** No. No. In fact, one of the nurses...he said to me "what tablets are you on?" ... I couldn't answer.

**P04** (*above mean age; below mean years since stroke*) I was trying to tell everyone ... I eventually got it out that I think I was suffering from a stroke... I was passed from pillar to post ...they didn't offer me any medication ... I was a full day and a half a day waiting for a bed...

**I** ...you hadn't properly been seen by a doctor and you hadn't got a scan.

**P04** Yes. No no no no.

### *1.2 Coordinated stroke care*

Participants described the perceived benefits of coordinated stroke care in Stroke Units and Early Supported Discharge (ESD). P04 described how Early Supported Discharge (ESD) helped to prepare him for the pace of subsequent inpatient rehabilitation:

**P04** I was on the early supported discharge program and I had intensive speech & Language therapy that prepared me ... that all contributed to my recovery.



Stroke Units were perceived as facilitating better coordination of stroke care with oversight from an aphasia-aware stroke nurse, more therapy, rest periods and restricted visitor access.

**P09** It was better than the standard ward because you had a dedicated nurse there all the time...very cognisant of the way you were each day...and the difficulties that I had maybe expressing myself...and about ensuring that the speech therapist came down, occupational therapist came down, or whoever came down...or that I went wherever I'd to go...after lunch everyday there was a rest period... the relaxing thing was great because you might have been doing ...some kind of therapy...there was a lot of stress in that...it was great to be able to switch off.

Access to Stroke Units, when present in the treating hospital, was apparently inconsistent. P09 reported being admitted to a Stroke Unit on his 3<sup>rd</sup> stroke-related hospital admission only. Participants (S07, P08) also described a lack of coordination and communication between HCWs on general wards which they linked with less access to inpatient rehabilitation and therapy.

### *1.3 Social support and advocacy*

Many of the participants outlined a need for advocacy and social support in hospital due to perceived communication barriers, adverse events and/or a lack of care. Many described advocacy by family members (P04, P06, P07, P08) and P06 relied on support from other patients to order his meals. P09 described the benefit of his sister being present when he questioned multiple wards transfers.

**P09** So as my sister was sitting there, the ward sister person-in-charge comes in - I can still see her now - she came in like a tornado (laughs) ...And she caught the

curtain - she nearly pulled it off the rail... I was lucky my sister was there. So she was able to advocate for me... I probably wouldn't have been able to do it.

#### *1.4 I cry going back in*

While many PWA had positive inpatient experiences (P04, P05, P06, P08), some participants recounted negative emotions in response to time away from home and children:

**P13** (*above mean age; below mean years since stroke*) And that was in rehab, you know because I don't go home at weekends and I cry going back in cos I hated it, it was difficult now. Yeah. Very difficult.

P07 described how she had been unable to talk to her husband and daughter on the phone when in rehabilitation in a different part of the country due to her aphasia (P07). P06 reported that he had not been allowed to shower independently in rehabilitation despite having done so whilst in hospital.

## ***2 Support in the community***

This sub-theme references participants diverse experiences, needs and preferences around support in the community, perceived as inconsistently available.

### *2.1 Variable access and front-loading*

Access to post-acute support, both aphasia-specific and general rehabilitation, was seemingly variable and front-loaded.

**S01** I found the first year very difficult in that all the services were coming at you ...not remembering who was doing what ... he was tired as well as all of that and a

lot of unknown. ... if it was a little more phased it might have been better... but you don't want to knock something if it's being offered to you.

**P01** (*below mean age; above mean years since stroke*) Yeah yeah yeah yeah (agreeing).

Some blamed a lack of resources, funding or political will for a lack of SLT, stroke support groups and long-term support (P05, P09, P13). Discharge planning and onward referral were reported as being inconsistent. Some PWA reported being lost to services.

**P09** I had some speech therapy in hospital, particularly when I was in the stroke unit. And then when I came out of hospital after like my three different admissions, when I came out of hospital eventually, I had nothing ...I wasn't referred to any place ...I wasn't on the radar. I wasn't referred at all.

The reasons for this apparent variability in service provision weren't clear as illustrated by the examples of P02 and P06, of similar age, living near one another and who had their stroke in the same 2-year period in the last 4 years. Only P06 had inpatient rehabilitation and SLT. P08 highlighted apparent variation in the availability of SLT in different parts of the country when he experienced a stroke in another health area:

**P08** (*above mean age; below mean years since stroke*) I was afraid then that I was going to fall between the stools then...

Furthermore, an apparent lack of access to stroke care featured in the accounts of participants regardless of time post-onset. Some PWA accessed post-acute SLT and general rehabilitation with help from family or local politicians.

**S06** (*P06 is above mean age; below mean years since stroke*) He would have been lost ...There is help there if you look for it ... You have to be prepared to go out, sign forms ... if I didn't apply for him, he wouldn't know where to go.

Having information was perceived as important for being able to advocate for further support, however service-related information was reported as being inconsistently available (S01, S07, P07).

## *2.2 Out-of-pocket expenses*

Some participants had a medical card (means-assessed entitlement to free public health services). P13 recalled how she had been left out of pocket while she tried to navigate an apparently inaccessible, bureaucratic medical card re-application process. Others described paying out of pocket expenses for private SLT, Physiotherapy and GP care.

**P05** (*above mean age; above mean years since stroke*) It's choices ... there's only X amount... the costs of the doctor and the physio ... and the speech therapy... all those things cost money.

P11's friend paid for her to see a consultant privately. Others were unable to afford private support.

## *2.3 Keyworkers*

ABII Keyworkers were described as a much-valued, dependable source of support, companionship and conversation for participants for the 3 participants who had access to them (P02, P07, P11), who were otherwise relatively socially isolated. Keyworkers provided a listening ear and individualised support with exercising, reading, becoming more confident and independent, using money, shopping and getting out.

**P02** (*above mean age; below mean years since stroke*) I know it's only once a week for a couple of hours but gets me out of the house, visiting people and If I want to

go the doctors or anything he'll take me... If I have any bothers all I do is ask him you know and he'd always put me right, go this way, go that way.

**P07** (*below mean age; below mean years since stroke*) Cup of tea. Talking. Listening. Brilliant (stresses through hand gesture). Yeah.

**P11** (*above mean age; above mean years since stroke*) She's like my sister.

P11 described how she had regressed when her Keyworker support ended. She reported how her GP had helped her to get the Keyworker support re-instated.

#### *2.4 Home help*

Professional support in the home was valued, but access was reportedly variable. Daily home help supported P07 to maintain autonomy and S07 to return to work.

**S07** They had that in place you know to get her home or she wouldn't have been able to manage otherwise you see... it was either that or I had to give up my job and I've only one wage ... I'd no other choice.

Home help workers were a valued source of chat and companionship (P07, S07).

#### *2.5 Life-after-stroke coordinator*

Some wanted access to a life-after-stroke-coordinator for flexible emotional, informational and advocacy support, and help to direct people to relevant supports at different points in their lives.

**P05** Once a month. For an hour...even just "sit down and I want to take you through do that, do that, your head - you said you're ok, is health? ... But more importantly that you can ask questions and they can ask you questions ... And also emotional as well.

**P02** If there was somewhere or something put in place that you could ring, you could say that “I’m having problems this week with just going out” I suppose even saying that, if you could ring someone and tell them about this ...

For P09, the IHF Stroke Support Group Coordinator played a similar informational, liaison, counselling and advocacy role, but he reported that there was none in his area.

**P09** apart from coordinating activities ... they're also available there to meet... if I wanted... to access counselling or ... some kind of services, that they would help me in that regard ... they would help the carers who often don't know where to go.

### ***3 Speech therapy***

This sub-theme references participants’ diverse perspectives relating to SLT, when available.

#### ***3.1 Beneficial SLT***

At all recovery stages PWA described the many biopsychosocial benefits of SLT including improved language, reading and writing, information, therapeutic relationship and emotional support in confronting changed ability, developing confidence and managing negative emotions.

**I** So you feel relatively positive about it how?

**P01** Yeah yeah

**I** So what has helped...

**P01** Points at Speech and Language Therapist name

**I** Does the speech therapist help you to improve your aphasia?

**P01** Yes! Yes yes yes (emphatic)

**I** Does the speech therapist help you to be more confident in living with aphasia?

**P01** Yeah yes yes yes yes (emphatic)

**P09** I really clicked with the speech therapist because she was very supportive...I did very well because of her, I think.

**S06** You would have been lost without the Speech Therapists

**P06** You're right I would... you have to start from scratch. Really. You have to start from scratch.

### *3.2 I'll be seeing them again*

People valued access to SLT in the longer-term. However, this was reportedly not available to everyone who wanted it. Some described a need for more specialised support with communication and reading / writing than was apparently provided through third-sector brain-injury organisations.

**P10** (*below mean age; above mean years since stroke*) Headway were great. The only thing is they don't have aphasia links ...Why didn't they have anything for that?!...If they had a speech and language therapist ...I think that would be so much more better.

Where SLT was available in the long-term, this reportedly took the form of an 'open door policy'.

**P09** I feel the need to interact with them... even if it is occasionally, I like to have that kind of support there ... they have said to me like that at any stage that I could ring them... it's good to know that at some stage I'll be seeing them again ... That it's still available... that's a very important service for us.

Others, including P13, who had not accessed any SLT in the community, were no longer interested in it:

**P13** I think I'm gone up a level - I think I'm at that point now there's nothing that's going to change for me anymore ... But I really needed it in the beginning. I really needed it.

### *3.3 Not all SLT is helpful*

Some PWA described negative experiences of rehabilitation, poor therapeutic relationship and/or a sense that they themselves were better able to direct their own progress. For some, SLT goals were perceived as irrelevant and uninteresting.

**P05** Boring...I know you had to do it but Jesus Christ.

**I** What would good therapy have looked like ...

**P05** Like we're doing now, like now.

**I** Just chatting?

**P05** Yep!

**I** you feel that you're improving yourself?

**P03** (*above mean age; below mean years since stroke*) Yeah. Yes!

**I** ... as well as you would do in speech therapy?

**P03** As good, yeah! (nodding)... It's good! It's good! Some of them ... But some of them are awful! ...

**S03** He's had rows with some of them!... he was going to this girl and she had pictures ... he had to repeat the word after her and the next picture then was cot...he refused to say cot...this is a bed not a cot! ... And she said "oh please say the word 'cot'" - "no, no" - and this went on for half an hour ...

**P03** (laughing). ...

**I** ...something around the therapy not being relevant enough for your life?

**P03** Yes! Yes!

## ***4 Mental health support***

This sub-theme references the importance of mental health support for PWA and their families.



#### *4.1 Emotional support for PWA*

Some PWA reported accessing and benefitting from counselling (P10, P07). Others described how they had found counselling unhelpful or expressed disinterest (P08, P14, P06). At the same time, access to formal mental health support was reportedly unavailable to some who needed it:

**P13** It was horrendous, I jumped off a bus coming in [place], on the way home... I didn't understand panic attacks because I'd never had them! ... There is nothing out there now...there just isn't.

P11, a single mother now living alone, described a lack of support and alternative options for overcoming addiction to anxiety medication:

**P11** I went to the doctor and he just "take it again" ... And I'm doing the same story for 14 years ... And it's only Smarties to me ... I want to - down a bit, but I'm afraid if I go I'll only can really down down down! And that's no good for my kids to see those mental look of me ...Every time you go to the doctors it's a different one...I feel I'm trapped.

#### *4.2 Emotional support for families*

S01, a parent of young children, had benefitted from counselling:

**S01** The counselling would have helped... you have to keep yourself going. And you can't be not there for them. You are mammy and daddy.

S06 felt that counselling might have benefited her earlier on if available:

**S06** There was none in the [Rehabilitation Hospital] ... when we went to Headway... they put down our name, but that didn't happen then - only last week ... I just felt

that I didn't need it ...maybe at the start if I had got it, but I just felt that we done all our crying ... and we worked it out between us.

P09 highlighted apparently variable access to support for spouses and caregivers:

**P09** the carers are suffering in their own way... they're completely forgotten about.

Counselling for children and/or the family unit was reportedly not available to all as highlighted in the accounts of P01, P07 and P12, all parents to young children at the time of stroke.

**S01** But the support for the family - No not a lot really, now... The children were fine, didn't need any counselling ... but between the lines they were all affected too ...

**I** So is there anything that would have helped?

**S01** Perhaps counselling for them

**I** What do you think would have helped? ...

**P07** Counselling.

**P12** (*below mean age; above mean years since stroke*) [Child's name] ... Counselling... [Child's name] ... Me ... [Caregiver's name]

**I** For the three of you together?

**P12** Yes.

Not all children wanted counselling. P11 recounted how 1 of her 3 children attended counselling at ABII. At the same time, children's responses and support needs were dynamic and changed with time. This was illustrated by P12, a single mother who had experienced stroke shortly before the birth of her child.

**P12** Shout. Angry ... [Child's name]) ... Angry.

**I** At you?

**P12** Yes! ... Why?! (asking me).

**I** Has it always been the way?

**P12** No, no.

S07, who had himself attended counselling, felt that they did not (and could not) give exact information about the types of situation that the child might face:

**S07** Think of the good things – that’s all they’ll ever tell you. They never can tell you ... about how to deal with your condition. They can’t give you those answers. You have to live it to know it...

## ***5 Aphasia education and training***

This sub-theme references the relevance of aphasia education and training for LWA.

### ***5.1 Supporting PWA to make sense of aphasia***

Access to information about aphasia was apparently variable. Not everyone was satisfied with information received. Many described how they were told that language recovery would be time limited. All disagreed with this and believed that their language had continued to improve in the long-term. P08, now working full-time with his pre-stroke employer, wanted content relevant to younger PWA.

**P08** ...The US websites or one of the English websites about aphasia and what it might do to you...they did all tend to be older people. There probably was less information available as to back to work type information. Or maybe I just didn't look it up properly at the time.

Four PWA (P02, P06, P11, P13) did not appear to understand aphasia at the time of the interview. It is possible that some had received information but had difficulty

remembering it.

**P06** I'm sure someone told me what a stroke was, I'm sure a lot of people had said it to me, but it wasn't connecting.

Some reported having had no aphasia information on hospital discharge (P02, P06, P09).

P09 stressed the importance of such information for adjustment and recovery.

**P09** I would like to have it explained to me ... all I knew was that like I'd a speech difficulty...I just connected with the brain and you know but I didn't know about aphasia. Or the meaning of the word even... it's like anything...it's like stroke itself. It's like dementia...It's important to have the information on whatever illness... it's important that you know what you're dealing with. And that you've information about it.

On the other hand, P02, who did not appear to know about aphasia when we met, felt that this knowledge would not make any difference for him:

**P02** I don't know would it make any difference.

Some would have liked more aphasia information, particularly in the first few years (P01, P09, P06, P12, P13). On the other hand, P10 was grateful that her family had shielded her from the consequences of stroke in the early stages of recovery.

**P10** I think my parents and my sister ... wanted to protect me, so they didn't divulge what a stroke actually was...I don't know if that would have made me worse. ... I was walking with a stick after about like six to eight weeks and they were amazed... So maybe it was a good thing but I didn't know to the extent that my body had changed.

## *5.2 Supporting family members and friends to make sense of aphasia*

Aphasia information for family and friends was reportedly obtained in hospital, rehabilitation, SLT, stroke groups and brain injury organisations. People also sought information about aphasia and services on the internet. Access to aphasia information and training was apparently variable however, which was linked with reduced quality of conversations with family and friends (P02, P07) and ability to explain aphasia to family, friends and neighbours (P11, P07, S07, P06, P07, P12). Some participants described a lack of aphasia information for their children. This is illustrated in the accounts of P12 and P11, both single mothers.

**I** Did (son) get any support to understand your difficulties and your aphasia?

**P12** Aphasia. No.

**I** Nothing.

**P12** Nothing, nothing.

**P11** I look at my kids and they were kinda nervous.

**I** ... did they get any information or support at that time? ...

**P11** Well no. No there was no - you just "go" and nobody, say, "she'll be alright", you know, "the kids'll be alright" ... I think my kids should know, but they didn't know. They don't grasp it.

S07 and P07 valued ABII Keyworker advice in relation to supporting their daughter's emotional and informational needs. With support and information from Headway, S06 described becoming more confident in explaining aphasia to others and more supportive of P06's growing independence.

**S06** I felt people thought I was telling lies ...so then when I said it was aphasia I said well at least I have a name! ... they teach you to let him to be more independent... I had to realise now he's not my child he's the husband.

P02, who lived alone, believed that communication partner training would improve conversations with his sisters:

**P02** Yeah, I suppose that would be good alright... if they talk to you about it and explain to you that I might be talking away and if he gets stuck just leave him be.

Some participants believed their wider family would be reluctant to engage in Speech and Language Therapist aphasia training (S07, P10). P10 felt that aphasia awareness training might inadvertently increase peer stigma and rejection and should be limited to caregivers or family members. S07 felt that aphasia information paled in comparison to lived experience.

**S07** They can only tell you so much about it as regards what to look out for ... as you progress, they won't be able to tell you, you learn these things.

**P07** Yes.

### *5.3 Variable healthcare worker (HCW) awareness*

A lack of aphasia awareness was perceived as impacting on quality of care and communicative access in hospitals (S06, S09). For example, S06 reported how P06's aphasia was apparently interpreted as challenging behaviour and prevented him from being able to order meals. She believed that aphasia should be better communicated to all HCW's working with PWA.

**S06** More understanding with patients like him...when she came in now... I said to the girl "he's not ignoring you" ... I think if there was more understanding - if the

doctor had said to them maybe, "this is [P06's name]'s complaint" like "he can't understand".

**I** Do you think the doctor understands it?

**S06** Maybe he might only have been learning himself!

**P06** He might need some help! (laughing).

...**S06** Or even the people - the server like - the food ladies - he was there 4 and a half weeks - so I think a note should have been placed...For them to help him and for him to help them...I felt they felt he was kind of abusing them...Being difficult. So it would have been a lot easier.

**P06** Oh yeah - if someone knew! It should have been on your wall...

**I** Would a picture menu have helped?

**P06** I'm sure that would help. ... all strokes are different ... So you don't need that for everyone but you could maybe just ask them "are you ok?"

P10 believed that the use of medical jargon also restricted communication with doctors.

Her confidence developed after she had completed medical administration training:

**P10** If I had my training or my medical admin and stuff like that, I could interact with them more.

Some PWA recounted how their GP had supported them to express themselves in appointments, for example by scheduling longer sessions. Other PWA felt that their GP was ignorant both of their aphasia diagnosis and about aphasia more generally.

**I** Does the doctor know about aphasia?

**P03** Well I suppose so.

**S03** I don't know whether she does or not.

**P03** (laughs). They know very little!

**P03** Very little.

**S06** the doctor only writes down a stroke... And only about a month ago I said to Dr [GP name], "it's called aphasia" and he looked it up ... Now maybe he knew but he didn't say to me!

Some believed that their GP was unconcerned with the wider psychosocial consequences of stroke and aphasia:

**P13** they don't see your brain or your heart, well heart you would but the love of heart and stuff, they just look at the picture of your sickness.

## **Discussion**

We interviewed working-aged PWA, including those with severe aphasia, to explore what has or would help them to live well, thus addressing relative underrepresentation of these perspectives in the literature. This paper focuses on findings relating to stroke care and its relevance for LWA. The data illustrate how all aspects of services and support are affected and challenged by communication difficulties. Aphasia rendered people vulnerable to adverse events and substandard care, which were recounted vividly many years post-stroke. The data highlighted a need for equitable, consistent access to person-centred care and information for PWA, families and children in the long-term post-stroke and improved coordination and communication across care settings and professionals. Findings are discussed in relation to the existing literature under six headings.

### ***1 PWA have individual support needs which change over time***

The findings extend prior research documenting the highly complex and individual experience of aphasia for working-aged PWA [27] by illustrating how participants had diverse stroke care needs, preferences and experiences. Thus, relevant stroke care is



necessarily person-centred, flexible and responsive to individual needs and contexts in the long-term post-stroke. This is arguably especially important for working-aged PWA who are likely to live with aphasia for a longer number of years than other age groups, and in the context of (un)employment and parenting. The findings are in keeping with best practice statements for aphasia rehabilitation for adults of all ages [63], but highlight a specific knowledge gap and a need for inclusive, participatory research with working-aged PWA around stroke care and LWA.

### ***2 Families have individual support needs which change over time***

The findings from our sample of working-age PWA illustrate the individual psychosocial consequences for family members, including spouses and children in keeping with prior literature [14, 64, 65]. Best practice is for psychosocial support and information for families of PWA in the long-term [63, 66]. However, this was inconsistently available, in keeping with prior Irish and international research [67, 68]. Children's negative emotional responses often surfaced many years post-onset as children become older. This underscores a need for responsive, person-centred support in the long-term. The findings are important additions to the existing small body of literature that highlight consequences for children and parenting roles [27, 69] and highlight the importance of further research in this area to inform appropriate community based supports.

### ***3 There is a need for equitable, transparent access to a responsive, integrated pathway of care for LWA.***

Access to early stroke diagnosis, inpatient Stroke Units and ESD was apparently inconsistent despite these services being linked with a range of better outcomes [70, 71].

Access to community SLT, counselling and peer-networks was also reported as variable. Such support was often accessed through third-sector support organisations, echoing prior research findings [67, 68, 72-81]. The findings resonate with literature about the equitable distribution of stroke care across regions in Ireland and elsewhere for PWA [67, 68, 72-78, 82]. This has implications for improving equity of access, transparency, standardisation and responsiveness in stroke care in Ireland. A recent study highlighted inconsistent access to post-acute support and pathways of care across 668 working-aged adults with stroke in the UK, Australia and SE Asia [44]. This was despite high rates of depression, poor self-reported quality of life and a low rate of return to work at 12 months in this age group [44]. Additionally, participants with mild stroke and/or aged 18-45 years were reported as least likely to access post-acute rehabilitation. This was perhaps linked with “professionals’ expectations that younger survivors and those with mild stroke will spontaneously recover without services” (p.1). There is a need for further research examining whether younger people with stroke and/or aphasia are indeed more likely to be disadvantaged in accessing appropriate stroke care. Inequitable access to person-centred, responsive stroke care in the long-term post-stroke will likely have significant negative impact on the health, wellbeing and social participation of PWA of working-age and their families, who will live with the multidimensional and pervasive impacts of aphasia for many years post-stroke.

#### ***4 PWA need information and stroke liaison support to access relevant care.***

Some PWA in this study had been apparently lost to services, which highlighted a potential lack of communication across care settings. There was an apparent lack of

centralised information about stroke and aphasia care similar to other reports from Ireland and internationally [67, 68, 77, 83]. This made it more difficult for PWA and spouses to navigate, organise and collaborate in decisions about their care, mirroring previous findings [55]. The findings provide further evidence of the importance of supporting PWA through care transitions [63]. Some wanted access to a stroke liaison worker to provide dynamic, responsive and flexible psychological, informational, advocacy and liaison support. A Cochrane review examining effectiveness of stroke liaison workers reported improved satisfaction with aspects of service provision for patients with stroke (aphasia-status not reported) and caregivers [84]. Though there was evidence of reduced death and disability in patients with mild-moderate disability, improved outcomes were not evident across disability levels [84]. There is a need for research examining the effectiveness (and cost-effectiveness and potential impact on secondary care use) of stroke liaison support in the context of aphasia and ability to access quality stroke care.

### ***5 HCWs must be equipped with aphasia knowledge and competency.***

In this study, PWA perceived a lack of aphasia-awareness amongst HCWs across care transitions. PWA were sometimes vulnerable to adverse events and substandard care as a result. Similar barriers to patient-centred care have been reported previously [85-87]. Such reports include Hersh's vivid account of the experiences of 2 women of working-age with aphasia [88]. Best practice is for HCWs to be provided with aphasia awareness training [63, 66]. Hersh calls for better support and training for healthcare professionals to support PWA to give feedback on their experience of care: "the development of responsive, person-centred health care systems would be assisted by valuing such

narratives and giving a voice to a group of people so familiar with health care services but also so rarely heard” [88] (p.219). The findings of this study highlight a need to increase HCW knowledge of aphasia and supported conversation techniques in keeping with prior research [87, 89, 90]. This is particularly important given the potential longevity of clinical and care relationships for PWA of working-age and highlights a need for participatory research with PWA and clinicians to implement meaningful change.

### ***6 Make every contact count: PWA need repeated aphasia learning opportunities***

Participants had different experiences and preferences relating to aphasia information. Many had been told that their recovery would be limited to a specific timeframe. This mirrors recommendations for closer examination of prognostic information for PWA [91]. Access to information appeared inconsistent in this study. Several PWA did not appear to understand aphasia at the time of interview. Some PWA may benefit from repeated opportunities to discuss and refine their understanding of aphasia, as highlighted previously [92]. Each episode of care should present an opportunity to check-in about informational needs.

### ***Methodological critique and limitations***

This is the first study specifically seeking the perspectives of PWA around stroke care in Ireland. It is additionally the first study with a specific aim to explore what supports living well with aphasia, considering both individual and structural influences, including stroke care, informed by a rigorous qualitative systematic review. The study used a rigorous participatory approach working with PPI collaborators to design accessible, inclusive interviews to facilitate meaningful participation of PWA, including those with severe

aphasia, and to obtain rich, relevant information. The findings make a unique contribution in Irish and international contexts by extending our knowledge of the stroke care needs of working-aged PWA and their families at all stages of personally defined recovery.

This study is part of a larger mixed methodologies project examining how best to support working-aged adults with post-stroke aphasia to live well. Critical Realism (CR) influenced a broader conceptualisation of LWA, considering external and individual factors influencing LWA and ability to access and benefit from appropriate support [55]. Multiple methods and sources were triangulated in order to mitigate the fallibility of knowledge and its generation in CR, including research methods and designs, existing theory, data sources such as research participants and PPI group members. To address potential limitations in the representativeness of the small sample, sources were triangulated: (1) systematic review findings were extended and refined [55] with (2) input from the PPI advisory group using a participatory research approach and (3) qualitative interviews with PWA in the present study [93]. Flexible deductive initial coding facilitated transparent engagement with previous research findings consistent with a CR approach. Triangulating multiple methodologies permitted deeper exploration of the phenomena from different angles [93, 94]. Finally, the interdisciplinary team enhanced reflexivity [95] and exploration of issues for non-Speech and Language Therapists.

We did not aim for generalisability of the findings from this study. Through theoretical and maximal variation sampling, we aimed to maximise validity, representativeness and transferability of the findings, which may have relevance for other populations and vulnerable service users. The representativeness of the sample is limited in that the views of younger PWA (e.g. 18-30 years of age) are not included. This points

to a gap in the content relating to designing relevant stroke care for this age group. Furthermore, we purposefully recruited participants who differed according to the number of years that they had been living with aphasia. Although this introduces richness in terms of understanding how people might learn to adapt and live well with aphasia over time, with or without formal stroke care, the limitations of gathering participant perspectives regarding stroke care several years earlier must be acknowledged. At the same time, the reported variation in access to stroke care was a feature of participant accounts across the range of times post-onset, suggesting that apparent service provision issues might not be linked with the timing of participants' experiences. Similarly, these issues did not appear to be linked with participant age at time of interview and/or at time of stroke.

Potential methodological limitations included conducting interviews in a single sitting. Multiple short qualitative interviews may have been more productive [96]. Recruiting through third-sector support organisations and Speech and Language Therapists meant it was less likely to recruit PWA with negative experiences or those who were lost to formal support.

## **Conclusion**

We interviewed working-aged PWA, including those with severe aphasia, to explore what has or would help them to live well. This paper focuses on findings relating to stroke care and its relevance for LWA for working-aged PWA. The data illustrate how all aspects of support are affected and challenged by communication difficulties. There is a need for equitable, transparent access to a responsive integrated pathway of stroke

care for PWA, families and children, at all stages of recovery.

### **Acknowledgements**

We gratefully acknowledge the following supporters and enablers, without whom this project would not have been possible: our PPI aphasia advisory group; the referring Speech and Language Therapists and third-sector support organisations; and the interview participants.

### **Funding Statement**

Molly Manning is a PhD scholar funded by the Health Research Board (SPHeRE/2013/1). The funder had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

### **Interest Statement**

The authors declare no competing interests.

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