

## RESEARCH REPORT

# Regulating emotional responses to aphasia to re-engage in life: a qualitative interview study

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## Abstract

**Background:** People with post-stroke aphasia (PWA) are more likely to experience serious mood disorders compared with those without. Emotional regulation may be important for influencing life participation after stroke. Understanding emotional regulation in the context of aphasia is important for promoting personally defined recovery, psychological well-being and life participation.

**Aims:** To explore how individuals experience and regulate negative emotional responses to aphasia as part of re-engaging with life.

**Methods & Procedures:** In-depth semi-structured qualitative interviews with 14 PWA were conducted. The focus and design were developed with public and patient involvement contributors. Reflexive thematic analysis was applied.

**Outcomes & Results:** Analysis generated three themes, which captured inherent diversity across participants in terms of emotional experiences, responses and regulation strategies: (1) emotional upheaval at all stages of recovery; (2) regulating emotional upheaval; and (3) discerning possibilities for life participation. Emotional regulation occurred both within and without the context of formal support services.

**Conclusions & Implications:** Individuals may be differently (en)abled in responding positively, with implications for aphasia psychological support and self-management interventions. The findings may inform future interventions to optimize well-being and personally meaningful outcomes for PWA.

## KEYWORDS

aphasia, public and patient involvement, rehabilitation, stroke, qualitative research

## WHAT THIS PAPER ADDS

*What is already known on the subject*

- PWA experience significant psychosocial upheaval and are at risk of mood disorders. Emotional regulation may be important for influencing one's

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emotional state, social participation and relationships after stroke. There is a need to better understand the ways in which PWA experience and regulate their emotions to develop better support for personally defined recovery.

*What this paper adds to existing knowledge*

- PWA may experience significant and pervasive mood disorders in the long term after stroke. This may be compounded by worries for their children's well-being. Some, but not all, regulate emotions by drawing on positivity, determination, gratitude or stoicism. Having (supportive) opportunities to experience the impact of aphasia is important for discerning helpful strategies and participation opportunities.

*What are the potential or actual clinical implications of this work?*

- Confronting altered abilities requires supportive, responsive opportunities sensitive to emotional responses. Opportunities for peer support and/or meaningful emotional support and compassion from family and friends are important therapeutic targets. Therapeutic input should pay attention to any familial and parenting concerns that may be compounding low mood. Although emotional regulation and recovery may occur without formal support, mental health services must be organized in such a way that PWA can access as needed.

## INTRODUCTION

The present study is informed by prior stroke research examining the influence of emotional regulation on social interaction, participation and networks (Cooper et al., 2014; Scott et al., 2012). Emotional regulation encapsulates our ability, conscious or unconscious, to discern, monitor, regulate and influence our emotional experiences and responses and 'to produce desired emotional states and goals' (Scott et al., 2012).

People with post-stroke aphasia (PWA) are at high risk of psychological and mood problems at all stages of recovery (Kauhanen et al., 2000). Identifying processes of integrating negative emotional responses to re-engage in life participation is paramount for developing effective interventions, self-management support strategies and responsive psychological services promoting personally defined recovery and well-being in the context of aphasia. Within aphasiology, related concepts such as adjustment, living successfully and self-management have been explored from the perspectives of PWA (Grohn et al., 2014; Wray et al., 2019; Mumby & Whitworth, 2013).

Mumby and Whitworth (2013) explored *psychosocial adjustment* with three people with (and three without) aphasia who were interviewed at multiple time points.

Meaningful participation and increasing self-worth facilitated adjustment and enhanced quality of life. Overcoming reduced access to health services, societal ignorance of aphasia, communication impairment, negative emotional responses and social isolation were also important (Mumby & Whitworth, 2013). Processes of personal and emotional adjustment over time involved rationalizing one's current situation, finding new meaning and 'wholeness' following 'fragmentation' and upheaval. These were facilitated through reflection on pre- and post-stroke life, coming to terms with aphasia, engaging with peer support, comparison with other people's experiences, increasing confidence and independence, and exploring new pursuits (Mumby & Whitworth, 2013).

Separately, Brown et al. (2010) identified a range of biopsychosocial elements important for living successfully with aphasia through interviews with 25 PWA. These included doing things, cultivating meaningful relationships, striving for a positive way of life and communication. Later, Grohn et al. (2014) interviewed 15 PWA at various time points in the first year after stroke. Their research generated a number of psychosocial elements important for living successfully including actively moving forward, engaging in activities, accessing social support, maintaining positivity and perceived communication improvement.

More recently, Wray et al. (2019) examined the perspectives of 11 PWA (and five with other acquired communication impairments) in the first year after stroke. They described how participants enacted the following self-management strategies: testing out changed communication, exploring activities that required support or adaptation, maintaining hope for recovery and accessing healthcare.

These studies increased our understanding of strategies and processes that maximize psychosocial adjustment, living well and self-management from the perspectives of PWA, in both the first year and at later stages of recovery. Together, this research additionally contextualized individual support needs within a whole-systems context, that is, that psychosocial adjustment and self-management support must be implemented alongside improved access to healthcare, social support and the community.

The purpose of the present article was to generate insights around the emotional experience of aphasia after stroke, and the ways in which people regulate these emotional responses and discern what is still possible. The analysis draws on more extensive qualitative interview research exploring how best to promote personal recovery in the context of aphasia (Manning et al., 2019, 2020b, 2021). Personal recovery approaches, widely implemented internationally in mental health service models, emphasize how recovery is individually defined, and not linear (i.e., may positively and/or negatively change over time), and can take place within or without formal support services (Slade, 2009). Stages of personal recovery may be associated with different levels of support including direct interdisciplinary input and indirect interventions to dismantle adverse social determinants of health (Ragins, 2016). This model explicitly 'recognises both individual and structural influences on coping and living well' and 'is linked with empowering people to understand and manage their condition and symptoms and to fulfil life goals' (Manning et al., 2019: 22).

The conceptualization of personal recovery underpinning this study was refined in an earlier systematic review and thematic synthesis of the perspectives of 350 plus PWA across 31 articles (Manning et al., 2019). The review explicitly sought to refine, unite and extend a diverse range of phenomena examined in aphasia research (e.g., living successfully, social participation, adjustment, experiences of health services). This approach recognized that individuals are differently resourced and impacted by external societal, economic and political factors, including access to health and social support.

The findings emphasized how personal recovery is promoted and enabled through support from and for family members; having opportunities for meaningful contribution and participation in society; flexible access to respon-

sive health and social support services in the long-term after stroke; accessible, timely information about stroke and aphasia; and collaborative interactions with aphasia-aware health professionals (Manning et al., 2019).

The review process highlighted a need for further research that deliberately sought out perspectives on individual and structural influences on personal recovery. This was addressed through qualitative interviews with 14 PWA. This research provided a rich source of data; two of the major themes were *stroke care* and *social participation* (Manning et al., 2020b, 2021). These covered a wide range of elements highlighting a need for transparent and flexible access to a responsive aphasia pathway and aphasia-competent health professionals at all stages of recovery to address inequities and access barriers to mental healthcare, speech and language therapy, aphasia and self-management information, and support for families (Manning et al., 2020b). The unique support needs of working aged parents with aphasia were also highlighted, as was a need for individuals with aphasia to be meaningfully involved in research, policy and service development (Manning et al., 2021). Finally, the themes highlighted how personally meaningful social participation is necessarily individually defined, and so special considerations should be given to ensure that (working-aged) PWA have access to flexible and person-centred support to access opportunities for employment, training, peer support and social connection (Manning et al., 2021).

This research additionally generated a third major theme, which is the sole focus of the present article: to explore the ways in which people *emotionally integrate and regulate* negative psychological responses to aphasia.

## METHODS

### Research design

This qualitative semi-structured, in-depth interview study is reported in accordance with the Standards for Reporting Qualitative Research (O'Brien et al., 2014). This interview study was part of a wider mixed-methodologies research design that incorporated triangulation of methods and sources, including qualitative evidence synthesis (Manning et al., 2019), a quantitative clinician survey (Manning et al., 2020a) and public and patient involvement (PPI) contribution. This research design was underpinned by critical realist philosophy. This approach emphasizes the importance of incorporating multiple information sources and methodologies to mitigate the fallibility of human knowledge and inherent limitations in individual research methods and data sources (Bhaskar & Danermark, 2006).

## Researcher reflexivity

The multidisciplinary research team included two speech and language therapists with aphasia knowledge (M.M., S.F.), a physiotherapist and health services researcher (R.G.), a social scientist (A.M.) and a health psychologist (A.H.). The interviews contributed to the first author's doctorate. As such, the first author led on all study aspects including design, data collection and analysis, and reporting. The first author actively attended to potential influences of personal and professional experience, beliefs, motivations, emotions and training throughout the research process. This entailed, for example, regular reflexive writing, peer debriefing, and discussions with critical friends, PPI contributors and supervisors.

## Public and patient involvement (PPI)

In line with policies promoting PPI in health research (Health Research Board, 2016) and to enhance the methodological quality and relevance, four PPI contributors with post-stroke aphasia were consulted on aspects of the design, methods, analysis and dissemination. PPI meetings were held in the University of Limerick, facilitated by the first and last authors. We drew on the work of Mc Menamin et al. (2015b, 2015a) using participatory learning and action tools to create a collaborative and productive research space.

PPI contributors explored and commented on the findings of the qualitative evidence synthesis (Manning et al., 2019), and helped develop the content of a topic guide by prioritizing concepts to probe with interview participants. Contributors also took part in practice interviews and helped to identify strategies to ensure that interviews were communicatively accessible. For example, they gave ideas on how to ensure that spouses did not 'speak for' participants in the interviews (Dalemans et al., 2009; Croteau et al., 2004). These included posing questions to participants with aphasia first, using first names when asking questions, providing plenty of time to respond uninterrupted and checking back with the PWA to verify spouse contributions. Other strategies are described by Manning et al. (2020b). The contributors also provided ideas for accessible member-checking and dissemination. Following initial interview data analysis, preliminary themes were presented to contributors for comment and discussion prior to the final analysis.

## Ethical issues

Research ethics committee approval was obtained prior to recruiting participants and PPI contributors. This included

approval from: the University of Limerick Faculty of Education & Health Sciences (REC ref. 2016\_09\_06\_EHS); University Hospital Limerick (REC ref. 124/16); and third-sector support organizations.

## Sampling strategy

The sampling parameters were PWA of working age (18–65 years) a minimum of 1-year after stroke. People with severe cognitive and/or hearing impairment were excluded. A maximal variation strategy was implemented seeking perspectives of people who differed according to gender, location, severity, recruitment source, years post-stroke and living situation (Creswell, 2009). Diversity was actively monitored throughout the recruitment period (e.g., recruiting only women for the final six interviews to address a gender imbalance). For logistical reasons, a maximum of 14 participants were recruited. Each participant was permitted to include a significant other in the interview to support communication (Parr, 1994).

## Recruitment

Participants were recruited through third-sector support organizations and Health Services Executive speech and language therapists. The first author contacted these organizations and emailed aphasia-friendly study information for circulating to potential study participants. The first author obtained informed consent from participants by reading aloud the study information and consent form, confirming participants understood each element, giving the opportunity to ask questions and confirming continued consent on the day of interview.

## Interview participants

A total of 14 participants with aphasia (eight men and six women) were interviewed. Participants were aged 33–62 years and ranged from 14 months to 14 years post-stroke. They were from different parts of Ireland. Six had a severe aphasia; three of these had a severe receptive aphasia. Participant characteristics presented in order of age are shown in Table 1. Four with severe aphasia also opted for their spouse to participate. The role of the spouse was two-fold: to act as a communication support if helpful; and to provide additional information. This additional information would only be included for analysis if verified by the PWA.



TABLE 1 Interview participant characteristics

Maximum variation sampling variable		Number of participants (N = 14)
Sex	Male	8
	Female	6
Time since stroke	Mean (SD): 7 years (4 years); range: 14 months–14 years	
	< 2 years	2
	2–5 years	4
	6–10 years	5
	11+ years	3
Age (years)	Mean (SD): 51 years (8 years); range: 33–62 years	
	[Age at stroke, mean (SD): 45 years (10 years); range: 23–58 years]	
Aphasia severity	Mild	3
	Moderate	5
	Severe	6
Location in Ireland	Clare/Limerick	7
	Dublin/Kildare	3
	Galway	3
	Tipperary (South)	1
Marital status	Single (unmarried)	4
	Separated/divorced	4
	Married	6
Living situation	Living alone	2
	Lives with at least one other person	12
Referral source	Acquired Brain Injury Ireland (ABII)	2
	Aphasia Ireland	1
	Croi	3
	Headway	6
	HSE	1

## Data collection methods

Data were collected by the first author, a trained speech and language therapist. Most participants were seen twice, minimally 2 days apart, to minimize risk of fatigue. Three participants chose to meet on a single occasion. On the first meeting, informed consent was sought, a number of formal and informal language assessments (previously described) were administered (Manning et al., 2020b), and participants were asked about helpful communication strategies (Luck & Rose, 2007). These elements were used to support each participant to give rich, relevant information in the interviews. On the second meeting, participants were interviewed either at home or at the referring organization. Spouses, when present, additionally provided written informed consent. Interviews averaged 96 min (range = 50–128 min) and were audio and video recorded.

Rather than being overly prescriptive about the types of things that might be important, the topic guide was developed and piloted to be minimally directive. For example, the non-directive prompts below were used in the first instance.

- Tell me a little about yourself (e.g., living arrangements, day-to-day activities, interests)?
- What does a normal week for you look like?
- What is most important for you in your life?
- Is there anything else that is important for living well with aphasia?

The interviewer's main role was to listen actively and to respond in the moment to encourage participants to contribute expansively. If needed, the interviewer diverged from the standard qualitative interviewer role (Luck &



Rose, 2007) in using a hierarchy of increasingly directive interviewing techniques. This involved progressing from open questions to more scaffolded, supported questions and responses. The topic guide and hierarchy have been previously documented (Manning et al., 2020b).

Drawing on the in-depth collaborative work with the PPI contributors, the topic guide probed: information about aphasia and services, support for family and friends, support from family and friends, education for health professionals, access to services, doing things and public attitudes. Aspects of *accepting aphasia* and the *effects of aphasia* were also elicited using the following prompts, where necessary:

- Can you talk to me about your life since you had your stroke?
- Has living with aphasia changed over time?
- Can you talk to me about how you feel about your aphasia now?
- What helped/would have helped/would help?
- Can you talk to me about your life since you had your stroke?
- How is day-to-day life affected by aphasia/stroke?
- Is there anything you would change about your life?

## Data processing and analysis

The first author was responsible for transcription and importing transcripts to NVivo11. The analytical approach was informed by reflexive thematic analysis (Braun & Clarke, 2019). We used a flexible deductive coding process (Fletcher, 2017) to apply codes previously developed as part of the earlier qualitative evidence synthesis on personal recovery (Manning et al., 2019) and/or to inductively create new ones as required. Codes were scrutinized for similarities, differences and relationships to produce preliminary themes. Informed by discussions with PPI contributors, the data and codes in themes were explored and analysed further. In defining and labelling themes and visualizing interrelationships, we searched out negative cases and differences in participant data contributing to each theme. The final written report of the analysis involved regrouping and relabelling themes. Participants with aphasia were assigned a random identifier from P01-P14 (the four corresponding spouses are identified as S01 etc.).

## Techniques to enhance trustworthiness

The first author met with the second and final authors to present and discuss initial coding of four transcripts.

The first and final authors also met throughout the analytical process for in-depth interrogation of methods and emerging analytical insights. All analytical decisions and methods were transparently and reflexively recorded.

## RESULTS

We generated three themes to illustrate how participants experienced and regulated or integrated emotional upheaval as part of discerning possibilities for re-engaging in their lives (Figure 1).

The findings capture shared patterns across the data; however, the contribution of individual participant data was highly variable. Most, but not all, participants described past and/or present emotional upheaval. Some also had concerns for the well-being of their children (either currently and/or still dependent at the time of interview). Participants differed in the extent to which they regulated their negative emotions, and the ways in which this was achieved. For some participants, low mood persisted and/or emotional regulation was partial. Some responded with positivity, determination and hope; others responded with resignation and stoicism. Integrating and regulating emotions was linked with re-engaging in life. This entailed discovering altered ability and discerning and driving possibilities for life participation.

*Emotional upheaval* captures how emotional upheaval may be significant, pervasive, long-term, and mediated by participants' concerns for the well-being of their children.

*Regulating emotional upheaval* encapsulates a range of often positive, but partial, ways in which participants, with time, social support, rehabilitation, self-determined actions and caregiving/parenting duties, increase their confidence, positivity and determination, and emphasize hope, gratitude and stoicism.

*Discerning possibilities* elucidates how learning and implementing ways to do things differently necessitates supportive opportunities for being confronted with, and to some extent coming to terms with, altered abilities.

### 1 | Emotional upheaval at all stages of recovery

To varying degrees, aphasia and stroke brought significant negative emotions and/or mental health issues ranging from frustration and anger to anxiety, depression and suicidal ideation (1.1 *Negative emotions in the early years*). For some, but not all, the experience of aphasia remained overwhelmingly bleak (1.2 *Pervasive mood disorders*). Some

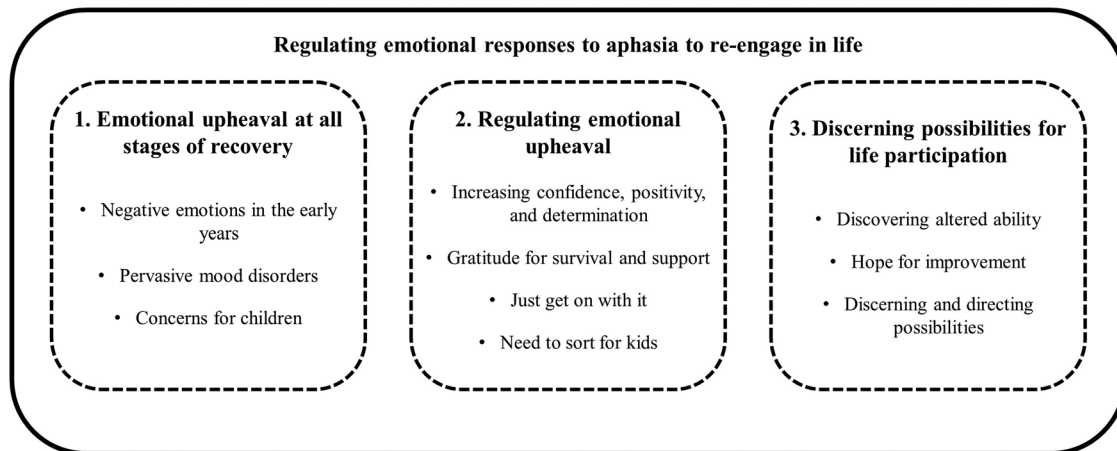


FIGURE 1 Regulating emotional responses to re-engage with life

participants' outlooks appeared to be influenced by perceived impact on their children (*1.3 Concerns for children*).

### 1.1 | Negative emotions in the early years

A range of negative emotions in the first 1.5 years after stroke were described by some participants. P07 experienced suicidal ideation in the first year.

**P07:** Myself, dead, 4 years ago, dead. Myself ... Dead. Box. Bye-bye.

P06, 19 months post-stroke, described the emotional impact of living a much-changed life:

**P06:** ... there's a little bit of it there every day ... I'm a little bit low ... because everything is different ... we're trying to do a different life ... trying to use something else.

P13 recounted experiencing anxiety and panic attacks as she became more independent and started to socialize in the early years post-stroke.

**P13:** ... there was a time where I couldn't come in here on my own ... The ground would come up with panic ... I couldn't come in here on my own. I couldn't! I couldn't get the bus ... The ground would come up with panic ... Because I'd start planning. Somebody will ask me. Or I have to get the money and then just. Aw!

### 1.2 | Pervasive mood disorders

Some (but not all) participants continued to experience significant low mood and mental health problems several years after stroke. This included participants who did not report any positive elements of living with aphasia. P02, who had a stroke 4 years previously and lived alone, appeared to be in low mood when we met. He recalled how he had experienced a change in his mood, which he found it hard to articulate. He felt that his previously sociable personality had changed.

**P02:** I feel something is changed alright. But it's getting the words to talk about it now ... Before ... I'd be chatting away with you and I'd be joking ... that has all calmed down. I wouldn't be as outgoing as I was.

Pervasive mood problems occurred even for participants who also described windows of improved mental health. P11, for example, who had lived with aphasia for 14 years, felt trapped because of persistent low mood and anxiety. Despite feeling numbed and tired on anti-anxiety medication, she was afraid that tapering would increase her depression.

**P11:** 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! ... But I would, if I take off the drugs, down, I'd be aware what I'm doing ... I feel I'm trapped. I do the same sentence, the same.



### 1.3 | Concerns for children

Children's negative emotional responses appeared to weigh heavily for some participants, although this was not universally applicable (e.g., P05, P08). This included participants who were many years after stroke, such as P12, who had experienced stroke during pregnancy. She was highly distressed that her child appeared to be increasingly negatively impacted as they approached adolescence.

**P12:** Shout. Angry. [son's name]...

**I:** At you?

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

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

**P12:** No, no.

**I:** Is it because he's nearly a teenager?

**P12:** Teenager.

**I:** ... did he used to be more affectionate when he was younger ....

**P12:** Affectionate ....

P07 too was visibly upset recounting, with the support of her husband, the emotional impact that aphasia had on her daughter.

**S07:** [Child's name] used to say to me ... roaring crying 'Dad, what am I going to do with mam? ... she can't talk, the way she's going to be, she can't move her hands, she can't do whatever- (crying)—my friends are there' she said, 'what am I going to tell me friends?!' (crying).

**P07:** Yeah

## 2 | Regulating emotional upheaval

For some, mental health and emotional upheaval appeared to improve to some extent over time. This recovery could be partial or fluctuating. Participants regulated their emotions in diverse ways. Many accounts suggested a sense of determination to maintain a positive outlook and to strive for improvement. Some participants drew on pre-existing strength and positivity (2.1 *Increasing confidence, positivity and determination*). Developing gratitude, focusing on the quality of care received, support from peers, family and friends, and/or perceiving better outcomes than other patients was important for some participants (2.2 *Gratitude for survival and support*). Others bore aphasia with a sense

of resignation, stoicism, and a sense that it was unchangeable and had to be tolerated (2.3 *Just get on with it*). Finally, for some, emotional regulation appeared to be influenced by parenting and familial responsibilities (2.4 *Need to sort for the kids*).

### 2.1 | Increasing confidence, positivity and determination

Despite continued low mood, many learned to live with increased confidence, positivity and determination. They enacted supportive strategies including exercise, yoga, walking and mindfulness, sometimes with support from their loved ones. Although P06 continued to experience low moods, he was developing confidence.

**P06:** I presume it's just I'm coming forward like, forward ... learning more ... Confidence and brought forward.

P08 also described how his attitude and confidence with aphasia had changed in the 18 months since his stroke.

**P08:** I know I still suffer from aphasia. The biggest improvement ... it doesn't bother me as much as it used to ... If I say, and I still do say something stupid, all the time ... But it doesn't bother me.

P13, 6 years post-stroke, described how she had become more confident and assertive. She recounted realizing that she was not 'stupid' and learning to accept her altered communication.

**P13:** It just hit me that I'm not stupid ... We're not different in a different way ... it took time ... I make jokes now ... when somebody would say 'oh your man (demonstrates word-finding difficulty)'—(laughs) 'welcome to my world' ... And they'd laugh at that!

It had been important for P13 to believe in the possibility of further recovery and healing in the early years.

**P13:** That's what I was saying—need it like, you know? If you think you've got a broken leg, it takes time for it heal, whereas I kept saying 'you'll heal you heal' ....

She had been determined not to let panic attacks restrict her socializing and had gradually increased her exposure to social situations:





**P13:** I just had to change it ... I met ... a group of friend ... in a pub and so the noise ... I was having a panic attack ... I just had to get out of there ... I made myself then go back ... I gave it 10 min ... the next time ... I'll go for 20 min, and I'd bring it back that way ... I was afraid that ... if I didn't do it, that I would never go! I wouldn't see my group.

Determination, striving to be hopeful and positive also featured in P04's account.

**P04:** It's always a barrier. But you don't let it be a barrier to yourself.

P14, 10 years post-stroke, felt in control of her life with aphasia. She denied any barriers to participation and well-being. She believed her positivity and strength, qualities she possessed prior to her stroke, had been important factors.

**I:** what gives you that control?

**P14:** Positive.

**I:** Just being positive?

**P14:** Ah Yeah... yeah (again suggesting 'sure why wouldn't I be') ... Strong. Strong ...

**I:** And you've always been strong and positive?

**P14:** Yeah!

## 2.2 | Gratitude for survival and support

Some described a sense of gratitude for surviving stroke, support received, improved language and that outcome had not been worse.

**P13:** I'm lucky that I did come back ... I know some people have felt 'poor me'—I've never felt that ... I'm not talking about what happened, I'm talking about 'I'm here!'.

P08 was grateful for support in hospital, and that his disabilities had been less severe than others in the stroke unit.

**P08:** I think I got very good support ... I was very very lucky ... other than my speech ... other people in the stroke unit, they had to be hoisted out of bed ... I didn't need a fraction of the services.

P06 valued support from peers at his local brain injury support organization.

**P06:** helping ourselves ... chatting ...

P05, 12 years post-stroke, also valued supportive relationships and friendships.

**P05:** I've some friends now ... he's who is a therapist ... I know I talk to him if I wanted to. If I need anything.

Since experiencing suicidal ideation in the first year after stroke, P07's mood had lifted somewhat in recent years, in part through support and conversations with her father.

**P07:** Thank you. One day. Gone.

**I:** ...your mood is a lot better in the last 2 years?

**P07:** Thank you. Yeah ...

**S07:** Her father pushes her as well

**P07:** Yeah... Listening, talking

## 2.3 | Just get on with it

Some participants appeared somewhat stoical, ambivalent or disenfranchised. Aphasia was something that could not be changed, and so they bore it with resignation. P03, who was 4 years post-stroke, appeared to be relatively accepting of stroke and aphasia, but did not emphasize hope or positivity.

**P03:** But you know—this fucking thing (laughs, pointing to right hand, arm)—there no good—(stands, points to right leg), in there no good (points to right leg), in there (right side generally)—but so what?! ... there's no point in finding things wrong with it.

P02, 3 years post-stroke, also resigned to aphasia, appeared to be in low spirits during the interview.

**P02:** Something you don't think about ... you have to get on with it. I got inflicted with this so. Grin and bear it ... There's no cure for it.

## 2.4 | Need to sort for the kids

For some participants, all the mothers in the sample, a concern for their children's well-being appeared to influence their motivation to regulate their emotions and to improve mental health, confidence and recovery. P13, a single mother of young children at the time of her stroke 6



years previously, described how parenting responsibilities motivated her in re-engaging with life.

**P13:** Part then when I was in the coma with kind of ‘wake up, wake up! ... I need to sort out for the kids’. So that’s what I did.

P11, also a single mother, was concerned that her dependence on anxiety medications was negatively impacting the wellbeing of her children.

**P11:** And that’s no good for my kids to see those mental look of me.

P07 described how concern for her child had pushed her to deny anti-depression medications and to try to improve her low mood.

**I:** what has helped to make that progress?

**P07:** [S07’s name], [child’s name], definitely ...

### 3 | Discerning possibilities for life participation

For some, being confronted with the impact of altered communication abilities on social participation, relationships and employment was linked with discerning possibilities for re-engaging in life participation. This process was often emotional and challenging (3.1 *Discovering altered ability*). Coming to terms with these changes was often partial and unresolved. Many participants continued to hope for, and work towards, improved communication (3.2 *Hope for improvement*). Some participants developed a sense of what was still possible, discovered retained abilities and/or devised and enacted compensatory strategies (3.3 *Discerning and driving possibilities*).

#### 3.1 | Discovering altered ability

Coming to terms with changed abilities required having opportunities for discovery. Encountering altered abilities featured in accounts of early acute, early post-acute and chronic phases of recovery. P08 illustrates how participants were often confronted with both altered and retained communication abilities in speech and language therapy sessions.

**P08:** when I walked out of [hospital] ... I thought I was ready for the world ... and

of course I wasn’t ... the very first phone call that I tried to make a doctor’s appointment and I bugged my way through it ... she put me back in my box then, she really really challenged me—and you know, she was probably doing it on purpose to say that ‘you know, there’s still more work to do’ right (laughs).

P06, 6 years post-stroke, had a similar experience. He had found this process highly emotional and challenging but valued his therapist’s sensitivity to his emotional needs in keeping pressure to a minimum.

**P09** You could have somebody trying to force you to do things ... if I couldn’t do something it was parked and ‘we’ll come back to it’ ... I couldn’t do things. It was making me very emotional ... if she pushed me, like, I would just have broken down ... she was able to encourage me ... it was a pleasure to be able to go into her.

#### 3.2 | Hope for improvement

Many participants were dissatisfied with their progress and wanted better conversation. Despite improved communication, P05 was keen for further progress.

**P05:** Even now I’m not happy, I need to get better better better.

P07 wanted to improve conversations with her husband and daughter.

**I:** But what do you want to work on?

**P07:** conversing... [S07’s name]. [Daughter’s name].

#### 3.3 | Discerning and directing possibilities

Re-engaging in life with aphasia took different forms. On their own initiative, some participants learned new ways to take part in previously enjoyed activities and/or incorporated compensatory strategies into their routines. Some enacted self-directed strategies for communication, memory and participation, often in absence of therapy. Enacting strategies entailed developing awareness of what helped in specific contexts, and confidence to implement in day-to-day life. P10, right-handed, taught herself to write using her

left hand against occupational therapy advice. She also prepared vocabulary and practised speaking confidently to her reduce anxiety around clothes shopping.

**P10** I couldn't say 't shirt' or 'clothes' ... I've changed my approach. I'll be all confident going up to somebody saying 'Can you get it for me or is there another shop where I can go to?' ... But I have to practice that.

P08 carefully edited emails before sending to colleagues.

**P08:** my writing was dreadful ... So, I'd have to spend a lot of time correcting myself before I could hit send ... that takes me a lot of time ....

P06 enacted strategies to improve reading.

**P06:** when I was doing my walking every day, I stop at all the signs ... I wait until I read it and then I go onto the next one. See little things like that. You're doing a walk. And you're learning at the same time!

P05 attributed recent language improvements, 12 years post-stroke, to attending eight weddings in the previous year. This had provided many high-stakes communication opportunities with unfamiliar people.

**P05:** I think it worked because it kind of had to do it.

Five years post-stroke, P04 was beginning to play the guitar and sing again. Although he could not perform his previous repertoire, he had discovered that it was possible for him to learn new songs instead.

**P04:** I tried to sing a couple of songs that I was familiar with ... there's a way around that ... I could learn songs that I never knew.

## DISCUSSION

The findings highlight several elements that influenced participants in processing and regulating negative emotional responses to post-stroke aphasia in such a way that supported discernment and driving possibilities for re-engaging in life participation. Although the data highlighted the very individual emotional experiences and recovery processes for the 14 participants, most partici-

pants had experienced significant negative emotions after stroke such as depression and anxiety. For some, this was compounded by concerns for their children's well-being. There were diverse examples of the ways in which participants regulated negative emotional responses. Many emphasized the importance of positivity, confidence and determination; others were more stoic and resigned to life with aphasia. Gratitude for surviving, for relatively better outcomes than others, and for emotional support from peers, family and friends, was also highlighted. Finally, for some, emotional regulation was to some extent linked with discerning possibilities for life participation. This entailed several elements including having opportunities for discovering changed abilities in a supportive, sensitive environment. This also entailed discerning and driving potential for participation opportunities including re-engaging with previous activities (or finding new ones) and identifying new strategies. This sometimes occurred alongside a deep-rooted desire for further communication improvement to improve participation and relationships.

## Connections with the literature

Regulating emotions and discerning possibilities for re-engaging in life with aphasia involved discerning both altered and retained abilities and discovering and enacting compensatory strategies. Oftentimes, these behaviours were initiated by PWA themselves. This supports prior research with PWA emphasizing the importance of being open to new ways of engaging, being proactive about socializing and participation, and how people discover altered capacity and confidence as part of engaging in activities (Manning et al., 2019).

For some, mood and confidence had improved to some extent in the years since stroke. Participants between 14 months and 14 years post-stroke alike emphasized positivity and hope in overcoming grief, depression and anxiety, and their accounts revealed a driving sense of determination and grit. This resonates with earlier research highlighting the role of striving for positivity and transforming negative emotions into positive ones (Brown et al., 2010; Grohn et al., 2014; Mumby & Whitworth, 2013); doing things (Brown et al., 2010); the interdependent relationship between increased participation and developing confidence (Pearl et al., 2011); actively moving forward (Mumby & Whitworth, 2013); and targeting taking control and actively moving forward with life as part of self-management support (Wray & Clarke, 2017).

For some, gratitude for support received and recovery in comparison with others was emphasized as part of posi-



tively responding to emotional upheaval. This mirrors and supports prior literature around providing opportunities for peer social support such as befriending (Northcott et al., 2021). The findings should be considered in the context of self-management support for aphasia, with attention to the opportunities and supports for people of different ages, and specific self-management interventions for occupational opportunities for people of working age.

However, the findings also highlighted how, for some participants, mental health problems prevailed. The accounts of these participants, who were between 3 and 12 years post-stroke, illustrated a sense of resignation, ambivalence, stoicism and disenfranchisement. The experience of significant grief several years post-stroke has been described in detail in Doughty Horn's (2016) case study.

Some participants continued to experience mood problems many years after stroke. This is in keeping with the individually defined and bi-directional (or non-linear) conceptualization of personal recovery in which the endpoint is not necessarily complete recovery. Additionally, emotional regulation and efforts to drive participation occurred both within and without the context of formal support services (Moss et al., 2021; Manning et al., 2019; Slade, 2009). To deepen understanding of how to support emotional well-being with aphasia requires us to contextualize mental health against broader social and structural determinants of health. This is particularly important given the documented shortcomings in access to psychological care for PWA (Manning et al., 2020a, 2020b) and the exclusion of PWA from post-stroke depression trials (Brady et al., 2014).

## Methodological critique and limitations

There are several potential limitations in the representativeness and richness of the sample. All participants were recruited through speech and language therapists and third-sector support organizations. Thus, the data may overly represent perspectives from people who are more inclined to positive self-management, and to enact health-seeking behaviours and adaptive strategies. Understanding the perspectives of people who have been lost to services and formal support is essential for developing targeted interventions for vulnerable and isolated PWA.

Additionally, the wide variation in time post-stroke might limit insights into emotional regulation at different stages of aphasia recovery. Most of the 14 participants had lived with aphasia for an extended period (i.e., 6 years and more,  $n = 8$ ). On average, 7 years had elapsed since the stroke and the interview time, and so these participants had perhaps benefitted from additional time to process,

regulate emotional responses and re-engage in life participation. At the same time, it was evident that debilitating low mood was pervasive for some participants many years after stroke. To better understand how time, and other factors, influence personal recovery, a mixed-methodology longitudinal research design examining diverse factors (including social and structural support and quantitative measures of health-related quality of life, depression and life participation) might better explicate bi-directional processes of emotionally integrating aphasia and discerning possibilities for life participation.

## CONCLUSIONS

PWA may experience significant and pervasive mood problems. Some people regulate emotional upheaval to some extent by emphasizing positivity, determination, gratitude and/or stoicism. Discerning possibilities for life participation entails being confronted with altered abilities, discovering and enacting supportive strategies, and identifying suitable occupations and activities. As a process of personal recovery, emotional regulation was linked with re-engaging in life, and could occur within or without formal support. However, individuals were differently (en)abled in overcoming pervasive low mood, and recovery did not always progress in a linear way. This highlights a need for psychological support to be appropriately matched with individual requirements and emotional distress. Self-directed strategies, opportunities for peer support and contribution and contextual factors including familial roles may also be therapeutically incorporated. The findings may have relevance for future research targeting psychological and self-management support.

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## CONFLICT OF INTEREST

The authors declare no conflict of interest.

## DATA AVAILABILITY STATEMENT

To maintain the anonymity of participants and research ethical approval requirements the interview data are not available.

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