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# **Supporting people with aphasia to ‘settle into a new way to be’: speech and language therapists’ views on providing psychosocial support**

Sarah Northcott<sup>1</sup>, Alan Simpson<sup>2</sup>, Becky Moss<sup>3</sup>, Nafiso Ahmed<sup>4</sup>, Katerina Hilari<sup>5</sup>

<sup>1, 3, 5</sup> Division of Language and Communication Science, School of Health Sciences, City University London

<sup>2, 4</sup> Centre for Mental Health Research, School of Health Sciences, City University London and East London NHS Foundation Trust

Running head: clinicians’ views on providing psychosocial care

Keywords: psychological well-being; social well-being; aphasia; clinical practice

## **Abstract**

**Background:** People with aphasia are at risk of becoming depressed and isolated. On-line surveys have found that the majority of Speech and Language Therapists (SLTs) lack confidence in addressing the psychological needs of people with aphasia.

**Aims:** To explore how SLTs conceptualise the scope of their role; barriers and facilitators to SLTs addressing psychosocial needs; and SLTs’ experiences of specialist training and support, and working with mental health professionals (MHPs).

**Methods and procedures:** Focus groups conducted in stroke healthcare settings. Purposive sampling was used in selecting sites so as to capture a range of experiences. Results were analysed using Framework Analysis.

**Outcomes and Results:** Twenty-three SLTs took part in six focus groups. Participants' psychosocial work included counselling-type interactions, psychoeducation, working with families, facilitating peer support, and training other healthcare professionals. There was a lack of consensus on the scope of the SLT role. Many expressed a sense of conflict, both perceiving it as valuable to spend time addressing psychological well-being, while simultaneously feeling uneasy if they deviated from 'direct SLT' work. Barriers to addressing psychosocial wellbeing were: emotionally challenging nature of this work, particularly for those who felt unsupported; caseload and time pressures; attitude of senior managers and commissioners; difficulties measuring and documenting more 'fluid' psychosocial work; and the complexity of needs and backgrounds of some patients. Enabling factors were: specialist on-going support; peer support from colleagues; experience; support of management; and personal belief. Specialist training was valued. It changed how participants viewed the therapist-client relationship (more client-led); the assessment and goal setting process; and gave them more confidence to acknowledge client emotions. However, many felt that there was a need for on-going specialist advice, and to be able to see approaches modelled for this client group. In terms of mental health professionals (MHPs), a subset of stroke specialist clinical psychologists worked directly with people with marked aphasia and families, as well as supporting the multidisciplinary team to provide holistic care. However, a main theme was that participants perceived many MHPs did not consider people with aphasia as 'appropriate candidates' for psychological input.

**Conclusions and Implications:** All participants cared about the emotional well-being of their clients; however, they identified a number of barriers to people with aphasia receiving appropriate psychological support. A cultural shift, whereby psychological care for people with aphasia is seen as valuable, feasible and necessary, delivered collaboratively by SLTs, MHPs and the wider team, may improve services.

## **What this paper adds**

### **What is already known**

Recent surveys have found that speech and language therapists (SLTs) lack confidence supporting the psychological needs of people with aphasia. We used focus groups to explore in detail how SLTs perceive barriers and facilitators, how they experience working with mental health professionals, and their experiences of specialist training and support.

### **What the study adds:**

SLTs described a number of barriers including: emotionally draining nature of the work, particularly where they felt unsupported or under-skilled, caseload and time pressures, and goal-orientated, outcome-driven services. Enablers included receiving training, particularly if modelled with this client-group, on-going specialist support (e.g. from a stroke specialist clinical psychologist), holistic multidisciplinary team ethos, and peer support from colleagues. There was wide variation in the extent to which mental health professionals (MHPs) were perceived to provide an aphasia-accessible service.

### **Clinical implications**

In order for people with aphasia to be able to access psychological support there is a strong case for collaborative working between SLTs and MHPs, and for services to value time spent addressing emotional well-being.

## **Introduction**

There has been increasing recognition of the importance of considering the mental health consequences of physical illness, particularly long-term health conditions (Department of Health, 2011). Guidelines for UK stroke services recommend that psychological well-being is considered as important as physical well-being (NHS Improvement, 2011). However, there is concern that the sub-group of people post stroke who have aphasia are receiving inadequate psychological support (Northcott, Simpson, Moss, Ahmed, & Hilari, 2016), despite being particularly at risk of adverse psychosocial outcomes (Hilari & Northcott, 2016; Kauhanen et al., 2000; Northcott, Marshall, & Hilari, 2016). The current project seeks to probe in detail how Speech and Language Therapists (SLTs) view their role in addressing the psychosocial well-being of people with aphasia, their experiences of delivering psychosocial support, and their views on working with mental health professionals (MHPs).

This present study builds on a recent on-line survey of UK Speech and Language Therapists (n=124) (Northcott, Simpson, et al., 2016). A main finding was that the most common barrier to referring to a MHP was that MHPs were seen as under-skilled in working with people with aphasia; similarly a main theme from the free text responses was that mental health services were often inaccessible to those with a moderate to severe communication disability. Yet this sub-group of the stroke population arguably have particular need for MHP support. Rates of depression at all stages post stroke are around 31% (Ayerbe, Ayis, Wolfe, & Rudd, 2013). This figure is higher for those with aphasia, estimated at around 62% in the longer term post stroke (Kauhanen et al., 2000), whilst at three months post stroke people with aphasia were significantly more likely to experience high distress (93%) than people with stroke without aphasia (50%) (Hilari et al., 2010). Expressive communication impairment has also been found to be a significant predictor of depression at both one and six months post stroke (Thomas & Lincoln, 2008). In integrating physical and mental health provision, there have

been calls for increased collaborative working (Joint Commissioning Panel for Mental Health, 2012). Joint working between SLTs and MHPs may be a feasible way of providing high quality, aphasia-accessible mental health services. To date, there has been little research probing how SLTs experience working collaboratively with MHPs.

There is also debate about the role of the SLT in providing psychological support themselves. The UK Royal College of Speech and Language Therapists (2005) state that an aim of aphasia rehabilitation should be to address ‘emotional health’. Similarly, the American Speech-Language-Hearing Association outline eight service delivery domains, one of which is counselling, where it is stated: ‘The role of the SLP [Speech Language Pathologist] in the counseling process includes interactions related to emotional reactions, thoughts, feelings, and behaviors that result from living with the communication disorder.’ (American Speech-Language-Hearing Association, 2016). In terms of the views of practising clinicians, recent survey results suggest that the majority of SLTs consider that their role includes addressing psychological well-being: 98% in an Australian SLT survey (n=111) (Sekhon, Douglas, & Rose, 2015); 93% in the UK survey (n=124) (Northcott, Simpson, et al., 2016). Further, counselling-type interactions appear to be a frequent SLT activity: 66% of respondents in an Australian survey (n=188) reported providing counselling frequently or very frequently (Rose, Ferguson, Power, Togher, & Worrall, 2014). However, there has also been research that has found that SLTs use a number of strategies to avoid addressing difficult emotions during sessions (Simmons-Mackie & Damico, 2011). A further aim of the present research was therefore to explore underlying reasons for any disconnect between SLT aspirations and actions, and more fully understand how SLTs view their role.

If best practice guidelines suggest that SLTs should ‘address negative emotional reactions’ through counselling skills (American Speech-Language-Hearing Association, 2016), a further

debate relates to what training and support SLTs should receive in order to deliver this.

Successive surveys (Northcott, Simpson, et al., 2016; Rose et al., 2014; Sekhon et al., 2015) have reported that the majority of SLTs lack confidence addressing psychological issues. In terms of the potential value of training, the Sekhon et al. (2015) survey found statistically significant correlations between SLTs attending counselling training and confidence in and satisfaction with managing psychological well-being in people with aphasia. Still, it has been little explored how SLTs experience receiving specialist training in this area, or how they view implementing new skills and knowledge within their work.

Closely linked to the psychological consequences are the social consequences of having a stroke: in a recent systematic review, poor social support was significantly associated with depression in 13/14 stroke studies (Northcott, Moss, Harrison, & Hilari, 2015). Language loss appears to present particular challenges in maintaining a diverse social network post stroke (Northcott, Marshall, et al., 2016), as well as profoundly impacting upon family dynamics (Fotiadou, Northcott, Chatzidaki, & Hilari, 2014; Winkler, Bedford, Northcott, & Hilari, 2014). Activity and participation goals which recognise the social context of communication are among people with aphasia's top priorities and have increasingly been incorporated into conceptions of SLT best practice (Royal College of Speech and Language Therapists, 2005; Wallace et al., 2016). A further aim was to explore how SLTs experience working towards social goals, and how they position remediating the language impairment within these broader psychosocial aims.

The focus groups aimed to explore the results of the companion on-line survey in depth, as well as probe contradictions or rationales behind opposing positions. For example, free text responses from the on-line survey exposed differing views on the SLT role in addressing psychological distress: focus groups gave us the opportunity to understand more fully the

reasoning behind these beliefs. Specific aims of this current research were to explore: how SLTs conceptualise their role in addressing psychological and social needs of people with aphasia; how SLTs experience barriers and facilitators; SLTs' views on receiving specialist training and support; and how SLTs perceive working with mental health professionals.

## **Methods**

This research was approved by the City University London School of Health Sciences Research Ethics Committee, as well as by the UK Health Research Authority. All individuals who agreed to take part in the study gave informed consent. In order to preserve anonymity, names and identifying details have been changed.

### **Participants and sampling procedure**

We aimed to recruit participants working in a range of SLT settings. A purposive sampling strategy was used to identify potential sites in order to capture a diversity of experience. Key sampling criteria included: whether the service was supported by a clinical psychologist embedded within the stroke MDT; stage post stroke (e.g. acute, early supported discharge, community); inner city or semi-rural. Finally, we were interested in exploring experiences of specialist training, and what impact this had on the care provided. We selected Solution Focused Brief Therapy as an exemplar psychotherapeutic approach and identified two sites where team members had received training in Solution Focused Brief Therapy (SFBT). SFBT explores a person's strengths and resilience in order to make small, meaningful changes in their everyday life. The strongest evidence for SFBT is in treating adults with depression (Gingerich & Peterson, 2012). It is more commonly used by SLTs working with people with aphasia than comparable approaches such as cognitive behavioural therapy or motivational interviewing (Northcott, Simpson, et al., 2016).

Participants were encouraged to speak freely about their current roles, and also previous roles in different NHS Trusts (health organisations). Participants were eligible to take part if they were qualified, practising SLTs who worked at least part of the time with clients who had post-stroke aphasia. Focus groups took place at each of the participating NHS sites: focus group members therefore knew each other prior to the study. To our knowledge, no-one who participated in a focus group also took part in the companion on-line survey (Northcott, Simpson, et al., 2016), although given the anonymous nature of the survey, this is a possibility.

### **Data collection**

The focus groups were facilitated by the first author (SN), and took on average 79 minutes (range: 66 minutes to 86 minutes). A topic guide was used (see on-line Appendix A): the areas to be covered were informed by the results of the companion on-line survey. Questions were not pre-specified, and the order in which topics were covered varied from group to group, emerging in an organic way through the group discussion. The facilitator stressed to participants that there were no right or wrong answers and that the aim was to hear a range of views rather than to reach a consensus. All efforts were made to include different group members within the discussion and to make the space sufficiently safe that participants could share controversial viewpoints, or describe challenging examples of clinical practice.

The social context of generating data within a focus group enables participants to listen to what others say, triggering further reflections on their own experiences. This process has been argued as useful in attitudinal research (for example, exploring the role of the SLT), as hearing other people's attitudes can assist people to 'better understand, describe and explain their own perspective against this backdrop.' (Lewis, 2003, p. 58). The group interaction is

also potentially useful ‘where what is required is creative thinking, or solutions and strategies’ (Lewis, 2003, p. 58), such as exploring concepts of an ‘ideal service’.

## **Data analysis**

All focus groups were transcribed verbatim. Data was then analysed using Framework Analysis, a matrix-based analytic method (Ritchie & Spencer, 1994). Following familiarisation with the material, a thematic framework was developed. This was generated inductively: thus it emerged from close readings of the data, rather than being pre-specified. The framework contained eight main themes (e.g. Theme 5: Barriers to SLTs delivering psychosocial support), under which more detailed subthemes were nested (e.g. Subtheme 5.2 Caseload/ time pressures). This framework was then used to ‘tag’ all the material, thus a decision was made about where it belonged within the framework. Thematic matrices were then constructed: each main theme was a separate matrix, and each subtheme a separate column. Every participant was assigned their own row, thus the contribution of each participant was analysed separately, while noting the group dynamics. The tagged data were summarised and synthesised, and placed in the appropriate cell in the matrices. This matrix-based system enabled systematic within case and cross case analysis, facilitating exploration of the range and diversity of experiences. Two researchers from different professional backgrounds (SN, speech and language therapy; and NA, mental health nursing) independently indexed the transcripts and analysed the charted material for emerging themes and concepts. Any disagreements were discussed until consensus was achieved.

## **Results**

Six sites were identified, and all six sites agreed to participate. Details of the sites are provided in Table 1. In total, 23 SLTs participated. The majority were female (22 of 23),

white British (87%), and had been working for at least six years as an SLT (63%). Participant details are provided in Table 2. The main themes from the focus groups are presented below: all 23 participants are represented in the selected quotes.

### **How SLTs address psychosocial needs**

Participants described a number of ways in which they supported the psychosocial well-being of clients. Many described counselling type interactions as forming part of their work, for example, giving someone space to explore their emotions, and acknowledging and validating what the client said.

‘[I] felt confident and comfortable enough to go with it and just go alongside her emotions with her and be there with her while she was expressing quite significant issues about death and severe disability.’ [Imogen, FG4L221]

Psychoeducation was also considered a core part of their work. Thus they saw it as their role to explain about the stroke and aphasia, and ‘what that means for them’ [Millie, FG6L409] and to recognise that this conversation may need to be revisited several times. There was also consensus that it was important to work with families, for example, helping family members to communicate successfully with the person with aphasia. Exceptionally, SLTs organised groups specifically for family members.

Running groups and providing clients with the opportunity to meet others with aphasia was another aspect of SLT psychosocial management. Some SLT-led groups were run with the explicit aim of helping people to adjust to living with aphasia as a long-term condition. One site also supported a peer-befriending scheme; more commonly participants were able to refer a PWA to a local stroke or aphasia group, although provision varied markedly between areas.

Peer supporters were seen as useful role models, and were a source of companionship and emotional support, including in the longer term.

‘[PWA] said going and meeting someone from the [local aphasia] group, and just sitting there and being normal was really... he just found it incredibly useful... I think that group is a real celebration of it, that there is life, life after stroke and life with aphasia, so I think that’s really positive and offers something that I can’t offer so I really rely on [it].’ [Belinda, FG2L576]

A subset of participants also trained other healthcare professionals such as nurses and rehabilitation workers in how to communicate with someone with aphasia.

### **The SLT role**

There was consensus that the SLT role encompassed addressing the social and participation needs of the PWA, and activity/ participation goals were commonly described. There was, however, debate amongst participants about the SLT role in addressing psychological well-being, in particular the boundary between SLT and MHP roles. Some aspects of role boundary were clear cut: there was consensus that if a PWA expressed suicidal thoughts this necessitated timely referral to a MHP. Participants described other circumstances when they would like to refer on or receive advice from an MHP including: when the PWA was not progressing in rehabilitation due to low mood/motivation; and when the SLT felt the issues were ‘too big’ [Diana, FG2L163] and they perceived that they did not have the necessary skills and competencies.

There was, however, recognition that it was not always clear cut when a referral was appropriate, and participants spoke about the ‘blurry edges’ [Chrissy, FG2L823] between SLT and MHP roles. In the absence of MHPs it was felt that often ‘your role is much bigger’

[Chrissy, FG2L178]. Given the limited MH service provision for this client group, it was agreed that in practice it was often SLTs who were the first, and in many cases only, professional to provide psychological support for a PWA. Rachel described her experiences on a specialist rehabilitation unit:

‘By the time they get to us [usually two to three months post stroke] they have had quite a long time of just not being able to, you know, having all these dreadful feelings and having no way of explaining it that then once it starts to come out with speech therapy often you are that person that is going to hear all this emotion and distress.’ [Rachel, FG5L722]

There were diverging views, however, on whether it was appropriate for SLTs to take on the role of providing psychological support. For many participants, communication was closely linked to identity and emotions, and it was not possible to progress with language goals without considering the psychological impact of aphasia. Participants also discussed that for many there was no ‘fix’ for the language impairment, so they viewed their role more as supporting their client to live with the aphasia and ‘settle into a new way to be’ [Chrissy, FG2L480]. In addition, without addressing low mood it was considered unlikely the PWA would engage with SLT therapy.

‘I think you can’t separate out those psychological support needs from the speech and language therapy needs... it’s just very fluid.’ [Kat, FG4L197]

By contrast, however, a subset of participants argued that the SLT role was to address emotional well-being indirectly via language and communication work, rather than directly, and they described sometimes being ‘quite strict’ in refocusing session time on SLT work. Tammi described a situation where she enabled a distressed PWA to articulate the key points

that were barriers to engaging in rehabilitation. Tammi saw it as her role to feed this information back to the MDT. She and her manager agreed it was not, however, her role to be 'going back and revisiting all of those issues and talking through them' with the PWA [Tammi, FG5L776].

In practice the contrast between these positions was not clear cut. Many participants appeared to have internalised both view points, and spoke of feeling conflicted: they felt bad if they spent a session listening to a PWA's distress rather than working on language goals, but equally, bad if they didn't.

'I'm writing my notes and I'm like, what have I done in terms of SLT outcomes? And it's the guilt of how much time you apportion to the psychosocial support when we know it's invaluable, but kind of, is that, as you say, the priority really?' [Diana, FG2L671]

The participants who did not experience this conflict were those with a high level of competence in psychotherapeutic approaches and departmental support: they placed their therapy, including impairment-based work, within a holistic framework, and did not recognise the division between 'direct SLT' work and addressing psychological well-being. This was exemplified by Una, working in an acute setting. Solution Focused Brief Therapy provided her with a person-centred structure within which to place SLT knowledge and skills: 'it's a way of thinking... it's that framework of how you will approach your client.' [FG2L839]. She did not view addressing emotional well-being as an optional extra to be bolted on, but rather as a core component of all her SLT work.

## **Factors which enabled SLTs to provide psychological support to PWA**

### *Specialist on-going support*

SLTs who felt well-supported by either a stroke-specialist clinical psychologist or an SLT with specialist skills were less anxious about addressing psychological well-being. The psychologist/ specialist SLT provided three key functions: [1] they talked through cases, facilitated reflection and gave strategies, advice, and information; [2] they provided emotional support to the MDT including managing anxiety and supporting MDT members through stressful situations; and [3] they provided the reassurance that if the SLT felt it was necessary, they would either arrange joint sessions or take over. As such, participants perceived that they had ‘back up’, which was highly valued.

Nina, working in a community stroke team, described the reflective sessions facilitated by the stroke-specialist clinical psychologists for the MDT: ‘They are fantastic... she just helps us all come up with ideas, and so often once they are put into practice you can see positive change. You have somebody you are really stuck with and then you have one of these sessions, and afterwards you can just see that, that it works and you’re like, wow!’

[FG6L290]

### *Peer support from colleagues*

Peer support from either an SLT or MDT colleague was highly valued. Participants described bouncing ideas off one another, talking through cases, and also shadowing colleagues.

Working jointly or knowing that others in the team knew a client well, meant shared responsibility, that it was ‘not just on my shoulders’ (Jenny, FG4L682). Peers provided reassurance, emotional support, and a chance to debrief.

A number of factors were described as enabling peer support. Participants spoke of needing a ‘very high level of trust’ [Valery, FG1L411] in a colleague to share uncertainty. Physical structures also facilitated peer support: sharing an office; working on the same ward; informal conversations in corridors or over lunch. Finally, a team culture of talking things over, and working closely together was helpful.

### *Support of management/ whole team approach*

Participants found it easier to address psychological well-being when working within a team where there was a strong holistic ethos. Managers or team leaders played an important role, for example, through enabling team members to access training.

### *Value of experience*

Day-to-day experience enabled participants to notice what worked and which techniques and approaches were a good ‘fit’ (Pam, FG5L545) with them and their clients. They also spoke of the need to put ‘skills into practice’ (Sam, FG5L492) in order to embed them. Experience gave them confidence to ask others for help, find creative solutions when there were competing demands on their time, assert their role within the MDT, and to acknowledge a PWA’s psychological needs.

For many participants experience had changed how they saw their role. As newly qualified SLTs they felt they had to ‘offer solutions’ [Georgia, FG3L409], or ‘provide all the answers’ [Kat, FG4L230]: however, as Georgia observed, ‘that’s not possible, not always actually what a person wants at all’ [FG3L409]. As such, their role had become less about ‘doing’ or ‘fixing’, and more about listening. Imogen explained that when visiting a client who wanted to talk through her diagnosis ‘my temptation was to go, oh my god, look at the time, actually the things I came down for I still haven’t done.’ However, with the ‘accumulation of

knowledge and experience' she described having 'the confidence to go with it and just listen to her.' [FG4L208]

### *Personal satisfaction*

Another facilitative factor was the emotional satisfaction participants gained from this aspect of their work. An example is Fran, who saw people in their homes once discharged from hospital. She described the intimacy of 'coming into their lives in quite a personal way', saying the psychosocial aspects of her role were the 'best part of the job' [Fran, FG3L354].

## **Barriers to SLTs delivering psychosocial support**

### *Emotionally challenging/ feeling under-skilled*

A main theme to emerge was that many participants found it emotionally demanding to hear the PWA's distress. They described how distressing it was to witness another person's tragedy, that it could feel 'mind blowing' and 'overwhelming'. The emotional demands were exacerbated when the SLT was not sure it was their role, when they felt unsupported by their manager, and when they felt they had no-one to turn to for specialist advice, emotional support or validation of the worth of this work. Hospital settings generally felt safer and less exposed than working in the community.

'A lot of active listening uncovered a whole depth of things that was way beyond my capabilities... I felt very out of my depth because I had no experience, I really needed... support' [Heather, FG4L652]

One response was for participants to avoid exploring emotional issues. There was concern that once they had 'opened up' these strong emotions, it would reveal areas which they

wouldn't have adequate support, experience or time to deal with, nor would they know how to close down the conversation.

'I don't think I would be very comfortable digging because I don't know what to do... with the information.' [Liza, FG6L188].

### *Caseload and time pressures*

Time was considered by many to be a barrier. Participants cited fixed pathways: knowing they had a set number of sessions meant family needs became 'lost a little bit' [Chrissy, FG2L613]; it also made them wary of starting psychosocial therapies which they perceived might take longer than they had.

There were particular pressures in the acute sector: a relatively common position was that participants felt their first priority was delivering recommendations on safe swallowing rather than communication or psychosocial work. As Millie observed, in her acute setting there was 'the prioritisation of dysphagia rather than counselling and delving into that.' [FG6L777]

Lack of time and busy caseloads also made it harder for participants to attend courses, reflect with colleagues and receive peer support, organise joint working, and initiate or maintain projects such as peer befriending schemes.

### *Attitude of senior managers and commissioners*

Some participants described feeling under pressure from managers to focus on language goals rather than psychosocial goals. More indirectly, participants perceived that managers did not facilitate their staff to go on relevant training.

‘I’ve been in teams where I’ve had to really strongly defend keeping someone on my caseload because they are very distressed to a manager, who wants me to discharge him because it’s not really direct speech therapy work I’m doing. And I’m saying, well, actually, I am supporting them, their life, their new life as a new communicator in this world.’ [Chrissy, FG2L684]

The way services were commissioned in the NHS was also seen to make it challenging to set up longer term psychosocial services. It was perceived that local commissioning groups viewed providing psychosocial support (e.g. peer befriending) as ‘the icing on the cake’ [Pat, FG5L370]. The one site that succeeded in running a peer-befriending scheme explained that it relied on the goodwill of volunteers and also local SLTs who offered their time (e.g. to supervise peer befrienders) on top of a full caseload.

There was also frustration at the way stroke pathways restricted SLTs’ ability to provide flexible patient-led care. For example, there was often pressure to provide intense rehabilitation in the first three months regardless of whether the PWA was ready. Participants also felt the current NHS climate emphasised efficiency, and audits tended to record tasks rather than emotional well-being.

#### *Goal-orientated, outcome driven services*

Almost all participants perceived that they worked in a goal orientated environment, and there was an expectation that they would be setting SMART (Specific, Measurable, Achievable, Realistic, Time-bound) goals with the PWA. Having agreed a SMART goal, most participants felt that session time should be spent working towards that goal, for example, through practising specific strategies. This was sometimes in conflict with responding to client emotions during a session.

‘It is quite a goal-oriented service, so, you know, not that I’m saying sitting and listening to somebody isn’t valuable, it is, but... I sometimes feel a little bit of pressure.’ [Fran, FG3L606]

Even in services which had fully embraced ‘participation’ goals, it appeared rare that SLTs selected feeling-state goals. Evelyn reflected on the impact of this: ‘we rarely incorporate emotional well-being goals... maybe that in itself is a barrier that we don’t think like that.’ [FG3L610]. Spending time with someone’s emotions was perceived as fluid, harder to plan, unlikely to be clearly time limited, and difficult to ‘outcome’. Liza observed: ‘there’s nothing to record, nothing to document, because you could be weeks just talking about how they’re feeling.’ [FG6L800].

Participants found some psychosocial outcome measures long and negative: they worried about spending an entire session administering one outcome measure when they only had a limited number of sessions. Furthermore, there was concern that psychosocial assessments may show the PWA ‘getting worse’ after receiving therapy, as they grieved for the life they had lost, or may not be sensitive enough to pick up meaningful change. This left the SLT vulnerable to criticism.

#### *PWA with complex needs or backgrounds*

A common barrier to providing psychosocial support was the severity of the aphasia (‘so severe that it is really almost impossible to access their inner world’ Nina, FG6L600).

Reduced cognition and insight was another barrier. A further challenge was the complexity of some people’s lives prior to the stroke, such as severe mental health disorders and traumatic pasts. The difficulty was compounded as the aphasia made it harder for the person to explain their background.

English as a second language and the need to rely on interpreters was also cited as a barrier. Interpreters were not always available, and potentially complicated the therapist-PWA relationship as the SLT was not clear how the interpreter had rephrased responses. Belinda observed that she sometimes ‘felt a bit of a spare part, or [interpreters] start giving their own advice’ [Belinda, FG2L650]

### *PWA preferences/ family preferences*

Participants described cultural health beliefs as a barrier to working on social participation goals. Some cultures were perceived to be ‘curing’ rather than ‘therapy’ cultures. The expectation from both family and the PWA was that either the SLT would cure the aphasia, or the PWA would persist in the sick role where it was the family’s duty to do everything for them. Participants also explored the complexity of negotiating activity/participation goals when the PWA wanted to focus all their SLT therapy time on ‘getting back to normal’ and expected session time to focus on impairment-based exercises.

## **Training in psychosocial approaches**

### *Training received*

The participants in this project varied greatly in how much training they had received in psychosocial approaches, from none to Diploma level training. In terms of pre-registration training, a small subset of participants had been inspired by a tutor or placement supervisor, who was expert in a particular approach (e.g. mindfulness). More commonly participants received a small amount of training at University in, for example, active listening skills, although this was typically regarded as inadequate preparation. Belinda described receiving ‘a token nod’ towards counselling skills at University. As a newly qualified clinician ‘it becomes real and you are in a room with someone who is not engaging, really emotional and

it's what you do with that. And I think I found I was so ill-equipped for it and I just felt way out of my comfort zone.' [Belinda, FG2L466]

Post-registration, it was relatively common that participants had been on a brief one or two day course. They described receiving training in counselling skills, SFBT, motivational interviewing, mindfulness, acceptance and commitment therapy, and strengths-based CBT.

How participants used the training in their work varied. Some participants spoke of collecting ideas, phrases and strategies from different courses. They adopted the aspects which they felt 'fitted' with their work. For example, Chrissy described taking 'bite sized bits' [FG2L383] from a number of different approaches, which she interleaved into sessions. Other participants internalised one approach which then underpinned all their work: Yvonne described how SFBT had become 'automatic', and that she couldn't 'not think it' [FG1L143].

### *Perceived Benefit for the SLT*

The most common experience was that participants found the training they had received a positive experience, using words such as 'invaluable', 'inspiring', 'incredibly useful'. A repeated theme was the satisfaction participants felt when they observed a particular approach working well for a client. An additional benefit was that approaches such as SFBT were perceived as time efficient. Focusing on self-efficacy and empowerment were also seen as helpful in managing the discharge process. These themes are illustrated by Imogen [FG4]. She described a PWA who she had been seeing for 'about a year'. They had focused on impairment therapy, and had 'struggled on for ages and ages and ages.' After receiving training in SFBT, she switched tack. Using SFBT, she observed 'what I noticed most was that he really, his face, his body language, he was just so engaged... I just got this sense of how he suddenly felt, gosh, at last, somebody is properly listening to me.' The focus of therapy

shifted to more functional goals, and ‘he self-discharged easily’. She remarked that this change ‘was lovely to see.’ [FG4L559].

### *Influence on SLT-PWA relationship*

Participants perceived that their work had become more client-centred as a result of attending training (e.g. in SFBT, mindfulness, counselling). The balance of the session was observed to change, and they were more likely to follow the client’s agenda and choices, rather than directing sessions. They noticed they used the client’s own words more, and aimed for the client to feel listened to rather than ‘done to’.

‘It [training in mindfulness] has had a positive impact on my relationship and rapport with clients. So rather than focusing on what I have to say to them, because I think that that would be beneficial for them, I focus on what they have to say to me, and what’s important to them.’ [Alex, FG2L368]

### *Changes to assessment and goal setting process*

Some psychotherapeutic approaches, such as SFBT, changed how SLTs viewed the process of assessment. Wendy, working in an acute setting, explained that she used to adopt a problem-based, therapist-led approach. Receiving training in SFBT changed her approach to assessment: ‘I feel strongly... that when you’ve got somebody in that psychological distress to do lots of [language] assessments that’s going to show up all the stuff they can’t do, I mean, it’s so counterproductive.’ Instead of starting with language assessments, she used solution-focused questions: ‘Focusing on how they are improving in these early stages is actually quite empowering.’ [FG1L131]

Participants found approaches such as SFBT and acceptance and commitment therapy helpful for enabling the PWA to explore what they wanted to work on. The emergent goals reflected

the PWA's priorities rather than the SLT's, and the PWA was observed to be more involved and engaged in the goal setting process.

### *Confidence in exploring emotions*

Following training, participants described feeling more confident to hear and acknowledge difficult emotions, and go alongside a client's distress rather than feeling they needed to 'fix' it. It gave them techniques which they observed made the PWA feel 'really listened to' [Imogen, FG4L545].

One participant, Olivia [FG6], attended a Psychology Level 1 course run by her NHS Trust. She described working with a lady with aphasia who was not engaging with rehabilitation on a stroke unit. The lady was seen repeatedly by the MDT who viewed her as uncooperative. Post training Olivia had the confidence to listen to the lady's distress, including hearing her despair and suicidal thoughts. As a result of this, she organised specialist MH input. She noted that without the training she would have avoided the conversation like the rest of the MDT.

### *Challenges and limitations of training*

Participants commented that generic courses did not necessarily prepare them well for using psychotherapeutic approaches with a PWA. They perceived there was a need to see it modelled, to be able to discuss cases and specific conversations in order to learn, to be able to experience and practice approaches in a supportive environment, and to have help in adapting approaches for their client group and setting. Without this, it was easy to become stuck, to forget core aspects of an approach, or become discouraged and revert to previous ways of working. Valery observed that with an approach such as SFBT 'unless you do it a lot I think

you can get quite bogged down.’ She was able to access an SLT with specialist skills for ongoing support, which she found ‘really helpful’ [FG1L792].

A relatively common theme was that approaches that looked exciting and inspiring when delivered by an expert on a training course were difficult to do in practice with a PWA. There was concern that without on-going specialist support it was easy to get them ‘wrong’, which could make the SLT feel inadequate, and potentially be detrimental.

It was also perceived by some as challenging combining psychosocial approaches with impairment based work. Further, a subset argued that it was beyond the SLT role to deliver psychological therapies, and as such SLTs became ‘unstuck’ by going on brief training courses. An additional concern was that in opening up holistic conversations after attending a brief training e.g. in SFBT, areas of client distress might be revealed which participants did not know how to deal with. This was particularly concerning for those without access to a supportive MHP/ specialist SLT.

## **MHPs addressing psychosocial well-being of PWA**

### *MHPs and aphasia*

There was variation in the extent to which SLTs perceived MHPs worked successfully with PWA. Some stroke-specialist clinical psychologists, and a specialist counsellor working in the voluntary sector, were observed to provide aphasia-accessible mental health services including one-to-one therapy and advice, even to those with more severe aphasia. Factors which enabled them to provide this service included: joint working with SLTs; team ethos where interdisciplinary working was the norm; and experience, where the MHP was able to build up specialist skills in aphasia.

‘[Our psychologists] are incredibly confident with people with aphasia and they may want one or two joint sessions just to get some strategies then they’re off doing it on their own and supporting their communication very well so that’s really good.’

[Nina, FG6L477]

A common experience, however, was that MH services considered PWA to be inappropriate or unsuitable for direct work. Alternatively, the PWA was seen for assessment and then advised further input was not possible. Medication was often all that was offered. There was consensus that knowledge around aphasia was lacking in mainstream MH services, and that generalist MHPs rarely managed the communication disability well. However, some stroke specialist psychologists were also perceived to struggle and be unable to adapt strategies and approaches which relied on talking.

‘The clinical psychologist arrived [on stroke unit]... I kind of outlined the strategies we were using quite successfully to communicate with her... at the end of the assessment I spoke to him, and he said “oh, she’s not a suitable candidate because she can’t communicate... she needs kind of medical treatment to address her depression”... and that was quite difficult because actually she could communicate quite well.’ [Jenny, FG4L132]

The situation was worst for those with moderate to severe aphasia, as observed by Evelyn [FG3L547]: ‘For people with more marked communication difficulty, I don’t think it really is a [MH] service if I’m being honest’.

### *Referral systems*

Participants found it easiest to refer a PWA to a MHP when there was a stroke-specialist clinical psychologist based in their team, particularly when the psychologist had a flexible

approach to accepting referrals, rather than only accepting referrals based on pre-specified criteria (e.g. attaining a certain score on a mood screen).

Participants experienced the referral process in the absence of a stroke specialist MHP as complex and time-consuming. It meant organising a hand over or joint session was challenging. Any service which required telephone self-referral (e.g. some community well-being services) excluded many with aphasia: ‘you know you’re on to a loser before you even start’ [Rachel, FG5L459].

### *Communication and collaborative working between SLTs and MHPs*

Communication between MHPs and SLTs was facilitated when the SLT and MHP were working in the same stroke MDT, particularly where the MHP was in the same office, had an ‘open door’ policy and proactively engaged with the team. Factors which enabled collaborative working were: SLTs perceiving that the psychologist valued their contribution (e.g. noticed what the SLT was adding, sought SLT opinion, and was open to SLT suggestions); and a perceived sense of equality, with both parties keen to learn from one another.

Poor communication between MHPs and SLTs was perceived to hinder MHPs’ ability to work with a PWA. Olivia, working on an acute stroke ward, described how the psychiatrist came onto the unit to see a lady with mild aphasia, made no attempt to talk to an SLT about facilitating communication, then wrote in the notes that it was not possible to communicate, leaving Olivia feeling ‘really angered’ [FG6L521]. Participants also noted instances of MHPs declining joint sessions, appearing to avoid joint working, or failing to turn up when a session had been arranged. Some participants had the perception that SLT input and expertise was not valued. Where a joint session was successfully arranged if SLT input was overridden this

also led to resentment. There was also sometimes a mismatch between SLT and MHP goals and approaches which was challenging to negotiate.

### *Limitations of MH service provision*

There was frustration that the focus of many MH services was seen to be assessment (e.g. of suicide risk) and report writing rather than engaging with the patient. Further, the purpose of some of the assessments was unclear to SLTs, for example, psychologists carrying out a high level language assessment, overlapping with work already done by the SLT. Provision of ‘talking therapy’ was perceived to be rare.

More generally, participants commented on limited MH services at all stages in the stroke pathway (acute, early supported discharge, community, long-term). The stage considered almost universally poor was the longer term, when the PWA was reliant on limited mainstream community MH services which were rarely aphasia-accessible, and sometimes required good mobility to access them. The consequence was that many with aphasia were perceived to ‘fall through the gaps’ with ‘lifetime implications and other long-term problems and potentially more hospital admissions, more use and reliance on other services.’ [Rachel, FG5L255]

### **The ideal service**

There was consensus that an ideal service would include a MHP who was skilled in working with people who have aphasia and who offered counselling and more in-depth support when necessary throughout the stroke pathway; alternatively, an SLT skilled in MH. Participants also discussed ways in which the PWA’s day-to-day communicative and physical environment could be made more enriching e.g. day rooms set up for interaction. There was consensus that ideally healthcare staff, including nurses, rehabilitation workers, and paid

home carers, should be trained in aphasia so that ‘every interaction that that individual [PWA] has [can] be the most fulfilling interaction it can be.’ [Rachel, FG5L915] Participants also spoke about the role of peer support, voluntary groups, and social activities for a PWA once at home in the community, made accessible even for those with poor mobility and without a pro-active carer.

Many participants felt that providing psychological care was the responsibility of all healthcare professionals not just MHPs. To facilitate this happening, they discussed the need for the whole team to take a holistic perspective, be given better support for delivering psychological care, and know they can handover or work jointly with a MHP if they feel out of their depth. Illustrating how expert support and a strong holistic MDT ethos translated into increased willingness to provide psychological care is the following quote from Nina:

‘Sometimes I think we think “Oh God, if we delve deeper or if I asked that question all this stuff is going to come out and what are we going to do with it?” But actually, it’s never really like a big horrible monster that you feel like you have to, I don’t know, that you can’t cope with and you just have to squash back in a box and if [pause]. I mean, I’m lucky, I guess, because I’ve got all those safety nets around me if it is like WAH!’ [Nina, FG6L783]

## **Discussion**

Twenty-three SLTs took part in six focus groups exploring experiences of addressing psychosocial well-being for people with aphasia. Main barriers identified included: feeling under-skilled, case-load and time pressures, the emphasis placed on achieving goals, and people with aphasia having complex needs. Facilitating factors included: training and on-

going specialist support, experience and personal belief, support of management and peer support from colleagues. There was wide variation in mental health service provision with many participants flagging up limitations in psychological support for this client group.

It was noticeable that the goal-driven nature of rehabilitation culture had the potential to steer SLTs away from addressing emotional needs. Spontaneous conversations exploring the emotional impact of aphasia were often neither pre-specified by a 'goal' nor particularly 'measurable'. An additional point was that while many participants spoke about routinely selecting participation goals, 'feelings' goals were rarely selected. Hersh et al. (2012) also found that aphasia clinicians were more likely to favour tangible 'objective' goals that they perceived as realistic, with the consequence that therapy time did not reflect the client's long-term social and emotional goals.

Another barrier described was the emotional discomfort SLTs experienced. This led some participants to avoid emotional issues. Other research has found that SLTs employ a variety of strategies to avoid engaging with client distress, such as focusing on 'facts' and objective therapy tasks, and deflecting distress with humour (Simmons-Mackie & Damico, 2011). It has been argued that these strategies enable the SLT to retain control, the sessions are easier to plan and manage, and the SLT is saved 'an uncomfortable and possibly frightening experience' (p345). What was striking in the current project was that SLTs who felt well-supported, particularly those who had received specialist training, did not describe this discomfort. This suggests that there is a need to reconsider the pre and post registration training SLTs receive. Of note was the finding that training was more useful if there was on-going specialist support. This has implications for how services are structured, potentially suggesting an expert (MHP or highly trained SLT) within teams to support less experienced members.

In research investigating which outcomes are important to people with aphasia, Wallace et al. (2016) noted the ‘synergistic relationship between the remediation of language impairment and communication in activities and everyday life.’ The interrelationship between communication, identity and emotional well-being has also been described (Brumfitt, 2010); more generally, post stroke depression is associated with less efficient use of rehabilitation services (Gillen, Tennen, McKee, Gernert-Dott, & Affleck, 2001) and worse rehabilitation outcomes (Pohjasvaara, Vataja, Leppavuori, Kaste, & Erkinjuntti, 2001). Given the close relationship between language and emotions, pigeon-holing therapy as targeting ‘psychosocial’ or ‘impairment’ goals in discrete blocks may not always be helpful. For a subset of participants in the present project, consideration of a person’s psychological and social needs were not discrete objectives, but rather framed all their interactions: these participants felt that this approach facilitated outcomes perceived as useful by people with aphasia. Specifically, they used approaches such as SFBT to open up holistic conversations about what was important to their clients, and then offered their SLT skills (e.g. knowledge of technology, impairment-based exercises, compensatory strategies, active listening) within this context. Their approach fitted with a philosophical perspective where SLTs worked collaboratively with people with aphasia and family members, who ‘need to be listened to, accepted as partners in seeking solutions’ (p341) (Holland, 2007). Support for this approach is provided by research investigating the factors that influence satisfaction with health care for people with aphasia. Two important factors were the rapport with healthcare professionals, and the manner of service delivery: people with aphasia wanted to feel included, involved, and recognised and accepted as an intelligent person (Tomkins, Siyambalapitiya, & Worrall, 2013). Arguably a core component of the therapeutic relationship is noticing the emotional well-being of the person with aphasia throughout the therapy process.

In terms of the role of MHPs, there was wide variation in services for people with aphasia. In part this reflects that psychology services in stroke are stretched: over half of stroke units in England still have no access to psychology services (Stroke Association, 2015). This project suggests a key role for stroke-specialist clinical psychologists, both supporting the MDT and also working with SLTs to ensure that people with aphasia are not denied access to specialist MH support when they are in need of it. It is to be welcomed that the most recent UK Stroke Clinical Guidelines assert that people with depression post stroke ‘should be offered brief psychological interventions ... (adapted if necessary for use with people with aphasia or cognitive problems) before considering antidepressant medication.’ (Intercollegiate Stroke Working Party, 2016, p. 77). As such, there needs to be a shift in the culture whereby it is no longer acceptable to view people with aphasia as ‘unsuitable candidates’ for psychological input.

### *Strengths and limitations*

This study explored the views and perspectives of SLTs at six different sites, and so represents a relatively small sample. It is possible that sites or SLTs with little interest in addressing psychosocial well-being may have been unlikely to participate. Furthermore, our decision to include managers in the focus groups, where requested, may have meant some participants were more circumspect in offering their perspectives.

In terms of researcher bias, the first author has a known interest in SFBT (Northcott, Burns, Simpson, & Hilari, 2015). As group facilitator, she aimed to adopt an unbiased stance and facilitate the expression of contrasting viewpoints, including on SFBT. Further, co-author BM (clinical linguist with experience of facilitating focus groups) attended two groups and listened to all audio recordings, providing feedback. Since we purposively selected two sites

with knowledge of SFBT, our results over-represent SFBT as an approach to delivering person-centred care.

It is a strength of the study that we included sites across the continuum of care, and sites both with and without dedicated psychology input. This enabled us to explore the positive impact of having a psychologist embedded within a stroke MDT compared to those without access to psychology services, but also to note the variation in how stroke-specialist psychologists appeared to view their role in this area.

It is also a strength that two analysts (SN and NA) were involved in all stages of the analytic process, providing some reassurance that the final framework fairly represented the raw material. Furthermore, the themes and results from the present project mirror those found in the on-line survey lending validity to the findings, while providing greater depth of understanding of the survey results.

#### *Future directions and implications*

Participants identified the value of training. It remains unclear, however, which models of training are most effective (e.g. the role of on-going learning and support), and which approaches fit best with the SLT role. There is also potential for further debate within the SLT profession as to the scope of the SLT role, both when working with people experiencing severe distress, but also in enabling those less severely distressed to cope better, and maintain or build social relationships and roles. In terms of MHPs and the wider MDT, further research could usefully evaluate how best to improve their skillset when working with people with aphasia, and how MHPs and the wider team view the barriers and enablers to addressing the psychosocial needs of people with aphasia.

In terms of clinical implications, there have been repeated calls for healthcare professionals to acknowledge the ‘whole’ person (Department of Health, 2013). According to both this project and the companion on-line survey, SLTs overwhelmingly wish to provide holistic, person-centred care. Yet it is unrealistic to expect them to do so without necessary support, and without this work being valued. The current pressure to achieve objective goals in an efficient manner may have the unintended consequence of devaluing time that is spent listening and considering the person’s social and emotional well-being. The humanising values framework has been suggested as one way of enabling healthcare professionals to provide person-centred care despite the pressure of the system , through placing value on the ‘things that make us feel more human’ (Galvin & Todres, 2012). The humanising values framework describes eight philosophically informed dimensions (e.g. ‘uniqueness vs homogenisation’; ‘sense making vs loss of meaning’; ‘agency vs passivity’; ‘togetherness vs isolation’), which it has been argued can inform nurse education (Scammell, Hemingway, & Heaslip, 2012) and understanding stroke care (Pound & Greenwood, 2016). Such a framework may also be useful in SLT education and practice, placing what it means to be human at the heart of all SLT interactions.

### *Conclusion*

People with aphasia are vulnerable to becoming depressed and isolated. This project found that SLTs aimed to consider the psychosocial well-being of clients, although faced a number of barriers. A successful model was MHPs and the wider team acquiring skills in aphasia, and SLTs receiving training on psychosocial support as well as ongoing support from a specialist, their peers and their manager.

**Table 1. Details of participating sites (NHS Trusts)**

<b>Site (each site one NHS Trust)</b>	<b>Stage post-stroke</b>	<b>Access to stroke-specialist clinical psychologist</b>	<b>Training in psychological therapies</b>	<b>Inner city or semi-rural</b>	<b>Manager/team leader present</b>
<b>Site 1</b>	Acute; outpatient	Acute: yes Outpatient: no	Yes. All participants highly trained in SFBT	Inner city	Yes
<b>Site 2</b>	ESD; community	Yes	No whole team training	Inner city	No
<b>Site 3</b>	ESD; community	ESD: Yes Community: No	2 days whole team training in MI	Semi-rural	Yes
<b>Site 4</b>	Acute; community	No	2 days whole team training in SFBT	Semi-rural	Yes
<b>Site 5</b>	Acute; general medical wards; specialist rehabilitation unit	Acute: Yes Rehab unit: Yes General medical wards: No	No whole team training	Inner city	Yes
<b>Site 6</b>	Two acute wards; ESD; two community teams	Varied between teams	No whole team training	Inner city	No

ESD: Early supported discharge; MI: motivational interviewing; SFBT: solution focused brief therapy

**Table 2. Participant details (n=23)**

<b>Characteristic</b>	<b>n (%)</b>
<b>Age</b>	
20-29	4 (17%)
30-39	12 (52%)
40-49	2 (9%)
50-59	2 (9%)
60 or older	3 (13%)
<b>Gender</b>	
Female	22 (96%)
Male	1 (4%)
<b>Ethnicity</b>	
White British	20 (87%)
White non-British	3 (13%)
<b>Number of years working as an SLT*</b>	
Under 1 year	2 (9%)
1-5 years	6 (27%)
6-10 years	6 (27%)
11-20 years	2 (9%)
20+ years	6 (27%)

\*missing data for one participant

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