

1 **Manuscript title:** “Living in a foreign country”: Experiences of staff-patient communication in
2 inpatient stroke settings for people with post stroke aphasia and those supporting them

3
4 **Running header:** Living in a foreign country

5
6 **Article category:** Research paper

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20

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7
8 **Abstract**

9
10 **Purpose:** Staff-patient communication in in-patient stroke settings is viewed as challenging for
11 stroke survivors with aphasia and those supporting them. This study sought to explore these
12 experiences from the perspectives of stroke survivors, their carers and healthcare professionals.

13 **Methods:** A qualitative study where stroke survivors with aphasia, carers and healthcare
14 professionals were interviewed (audio recorded) one-to-one or via focus group. Stroke survivors
15 were at least 6 months post-stroke and had a self-reported mild to moderate level of post-stroke
16 aphasia. Transcripts for each group were analysed separately using inductive thematic analysis;
17 followed by an integrative analysis.

18 **Results:** Six stroke survivors with aphasia, ten carers, and six healthcare professionals were
19 recruited. Three overarching themes were identified: ‘being in a foreign country’, ‘finding a voice’,
20 and ‘you’re just a number’. A dynamic model of communication is proposed offering a framework
21 for understanding the relationships between ‘the context’, ‘the people’ and ‘the interactions’.

22 **Conclusions:** Communication was viewed as important but challenging by all three groups. To
23 maximise staff-patient interactions in the future, attention needs to be paid to: the psychosocial
24 needs of stroke survivors and their carers, ongoing staff training and support for the healthcare
25 professionals supporting them, and the provision of an aphasia-friendly and a communicatively
26 stimulating ward environment.

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28
29 **Key words:** staff-patient communication, communication difficulties, stroke, healthcare
30 professional, carer, aphasia, qualitative

1 **Main text**

2 **Introduction**

3
4 Approximately 88% of stroke survivors are diagnosed with mild to severe communication
5 impairment [1], and a third acquire aphasia [2]. When stroke survivors are compared, people with
6 aphasia report reduced health quality of life, greater levels of emotional distress and depression,
7 and reduced participation in social activities [3,4]. Furthermore, people with aphasia report
8 challenges in engaging in deeper level conversations; most commonly manifested by a focus on
9 practical everyday issues and being positioned in a passive role. Communication partners' (both
10 carers' and healthcare professionals') lack of aphasia knowledge has been identified as a key
11 contributing factor to this challenge [5]. For example, nurse-patient interactions tend to be task-
12 focussed and nurse-controlled, and so may adversely impact on language recovery post-stroke [6,
13 7]. Indeed, the impact of staff-patient interactions within stroke rehabilitation are known to be
14 important because of their influence on engagement, not just with rehabilitation, but also with
15 person-centred goal setting and decision-making [8-11].

16
17 Engagement has been outlined as a multi-dimensional construct involving a co-constructed process
18 (between staff & patient) which means that the therapeutic dyad is therefore extremely important
19 [11]. In addition, the patient 'state', can be further compounded by inadequate communication
20 strategies employed by nursing staff, which also fail to account for the psychological and social
21 implications of living with aphasia [12]. Whilst staff recognise this as an issue, they experience
22 challenges, which include hospital-related environmental factors [13] when trying to identify,
23 address and represent the needs of people with aphasia [14,15].

1 Strategies for optimising staff-patient interactions in this setting have been outlined in a recent
2 meta-synthesis and include: increased time for communication, collaboration with the stroke
3 survivor's support network, staff education, and access to communication tools and service/policy
4 level initiatives [16]. The 'Supported Conversation for Adults with Aphasia' approach [17], is one
5 of the most widely adopted of such interventions to date. This approach is centred on enabling
6 communication via a set of verbal and non-verbal communicative techniques and resources.
7 Benefits have been reported when training for healthcare professionals has been fully or in-part
8 founded on this approach [18-21]. In particular, attention to non-verbal communication and
9 feedback loops between staff and persons with aphasia, have been identified as fundamental for
10 maximising understanding [14,20,22], providing explanations of treatment and linking to the
11 stroke survivor's goals [9]. One study collaborated with people with aphasia and in so doing,
12 refined their research processes to make participation in research more accessible for this group
13 [23]. An outcome of this refinement was that the people with aphasia who took part reported
14 increased confidence in communicating and felt stimulated and empowered to improve future
15 services for those with similar difficulties. However, although there have been some positive
16 outcomes [23], few study protocols and research include people with aphasia, despite the potential
17 patient and service gains [23,24]. Failure to include this population in stroke research poses the
18 question of the generalisability of research findings to stroke survivors with communication
19 difficulties.

20

21 This research aims to extend previous findings in several ways. First, by including stroke survivors
22 with aphasia as participants. Second, since most research to date has focussed on nurse-patient
23 interactions, it has failed to account for the remaining core healthcare professionals in a Stroke

1 Rehabilitation Team which may include: consultant physicians, physiotherapists, occupational
2 therapists, speech and language therapists, clinical psychologists, rehabilitation assistants, and
3 social workers [25]. Therefore, this study will explore the experiences of a range of healthcare
4 professionals. Third, this study will explore staff-patient interactions from the perspectives of
5 carers (close others), who play a key role in aiding the process of recovery, [16,26].

6
7 Triangulating the experiences and perceptions of these three stakeholder groups will provide
8 insight into the process of staff-patient communication in a way that previous research has not yet
9 done. Exploring the three stakeholder perspectives within the same study, using the same semi-
10 structured questions will enable the identification of shared and unique themes. By addressing this
11 gap the current research will explore the critical issues from the perspectives of the primary
12 stakeholders integral to improving services. Finally, the findings from this study will enable the
13 targeting and development of effective training to optimise staff-patient interactions. In short, the
14 study seeks insight into the experiences of stroke survivors with aphasia, carers and healthcare
15 professionals in four key areas:

- 16 • The experienced and preferred communication styles used by healthcare professionals and
17 stroke survivors with aphasia in stroke care settings;
- 18 • The perceived barriers and facilitators to effective communication in these settings;
- 19 • Experiences of communication roles during staff-patient interactions in these settings;
- 20 • The perceived impact of communication on patient engagement in stroke rehabilitation.

21

22 **Methods**

23 **Procedure**

1 This was a qualitative study which took a critical realist approach and used inductive thematic
2 analysis. A combination of one-to-one and focus group interviews were used to ascertain the
3 experiences of stroke survivors with aphasia, carers and healthcare professionals of staff-patient
4 communication within inpatient stroke settings. Interviews with stroke survivors with aphasia,
5 carers and healthcare professionals were based at various venues (home, support group venue and
6 hospital). Given patient participants' challenges with communication and carer participants'
7 responsibilities, persons with aphasia and carers were given the option of participating in either a
8 focus group or one-to-one interview. Due to shift patterns, the sensitive topics being discussed and
9 issues around disclosure and confidentiality, all healthcare professionals took part in one-to-one
10 interviews.

11
12 The first author conducted all interviews (which were recorded on a digital audio recorder).
13 Although the same flexible semi-structured questions (see supplementary material) were used for
14 all three participant populations; questions were adapted, repeated and prompts used to ensure
15 questions were tailored to the participant group. For example, persons with aphasia were given the
16 option of being supported by their central caregiver, the researcher regularly checked that both
17 they and the person with aphasia had the same understanding of what was being discussed,
18 sometimes this involved asking closed questions to confirm understanding and elicit information;
19 these strategies being in line with recommendations [see 17,27,28].

20
21 **Reflexivity:** Engaging in personal and epistemological reflexivity enabled the authors to
22 acknowledge how their past experiences and standpoints may have affected their interpretation of
23 the data. Author 1 is a white female Health Psychologist who is currently in practice in a National

1 Health Service teaching hospital in the North of England, supporting people with long term
2 conditions. She also has stroke and aphasia research and clinical experience and has personal
3 experience of a family member having had a stroke. Author 2 is a white female Associate Professor
4 in Health Psychology, who has not worked directly with people with post-stroke aphasia but has
5 researched people living with long term conditions. In order to maintain rigour, the interviewer
6 (LC) kept a reflexive research diary throughout the research process. During the analysis, both
7 authors were mindful of their experiences and background and continued to engage in reflexive
8 practice.

9

10 **Participants**

11 To inform sample size an advisor on qualitative methodologies was consulted as was literature in
12 the area, specifically the key texts of Braun and Clarke [29,30]. A sample size of 6-8 participants
13 per group was confirmed based on the type of question being asked (experiential), the methods of
14 data collection being used and the fact that the study accesses the experiences of three distinct
15 participant populations who were recruited via convenience and snowball sampling.

16 Recruitment of stroke survivors with aphasia and carers involved a brief presentation followed by
17 an opportunity for the audience to ask questions by the first author at local support groups for
18 stroke survivors and their carers. The presentation and participant information was developed in
19 line with the National Institute of Health Research [31] guidelines on optimizing participation in
20 research with individuals living with aphasia.

21 Inclusion criteria for stroke survivors with aphasia were: over 18 years of age; six months or more
22 post-stroke (a point when recovery has stabilized [32]); self-reported mild to moderate level of

1 post-stroke aphasia. Reliance on self-report was necessary because there was no access to a Speech
2 and Language Therapist to conduct a formal assessment.

3 Exclusion criteria for stroke survivors with aphasia were: inability to provide written or verbal
4 consent; unable to speak English (there was no access to a translator); severe aphasia (lack of
5 access to Speech and Language Therapist who could facilitate interviews meant that the decision
6 to exclude on this basis was taken, to limit any unnecessary distress to participants with aphasia).

7 For carers, any person providing a carer role to a person with post-stroke aphasia and whom had
8 observed staff-patient interactions during inpatient stroke rehabilitation could be included;
9 exclusion criteria matched that identified for people with aphasia. Carers were not required to be
10 a carer of a stroke survivor with aphasia who was participating in the study.

11
12 Two National Health Service hospital sites in the Yorkshire region in the United Kingdom were
13 identified for recruitment of healthcare professionals which involved email to primary contacts at
14 the sites (Stroke Nurse Researcher and Consultant Clinical Neuropsychologist), and face-to-face
15 contact on the ward with healthcare professionals to provide details on the study to those who were
16 available on the days visited by the first author. Inclusion criteria included any healthcare
17 professional working in inpatient stroke settings and who as part of their role supported stroke
18 patients with aphasia. There were no exclusion criteria.

19
20 Ethical approval for this study was granted by the [anonymised while being reviewed for
21 publication] University Ethics Committee and the National Health Service Health Research

1 Authority Ethics Board. All participants provided informed written consent to participate in the
2 study.

3

4 **Data Analysis**

5 Following verbatim transcription of the data during which all identifiable information was
6 removed and participants were given pseudonyms for anonymity, Thematic Analysis (TA) was
7 carried out independently by the first and second authors. The decision to use TA was centred on
8 its flexibility as an analytical approach [29,30], particularly given the diversity in data collection
9 methodologies and the range of research participant populations recruited.

10

11 The six-stage process of analysis outlined by Braun and Clarke (2013) [29,30] was adhered to.
12 This involved initially reading and re-reading through the data to increase familiarity and moving
13 back and forth through the stages as necessary. The two researchers used a semantic approach to
14 TA in which they progressed from describing to attempting to summarise and interpret patterns in
15 the data. The data sets generated from the three different populations were analysed separately
16 until coding was complete and themes identified for each data set, before then progressing onto
17 reviewing and reporting on the commonalities and differences between the populations. This
18 rigorous approach was used to minimise the analysis for each group from being influenced by data
19 from other groups; however, the authors were aware that exposure to other group data may have
20 in some way unintentionally shaped the analysis. Throughout all stages of the analysis, the authors
21 paid attention to Braun and Clarke's (2006) [29] 15-point checklist of criteria for good quality
22 thematic analysis. In a meeting to review the independent analyses there was strong agreement
23 between authors on the initial themes identified.

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A further integrative analysis was conducted by the first two authors (with input from the third author) to integrate and explore the experiences of the three groups. Authors then returned to the data to clarify and confirm themes. Representative quotes were used to name two of the themes; an author developed name staying close to the essence of the data was used for the ‘finding a voice’ theme.

Results

A total of 7 stroke survivors with aphasia (4 female/3 male) were recruited from support groups, but one male subsequently dropped out prior to data collection. Of the carers and stroke survivors with aphasia recruited, only one couple took part; Cath (stroke survivor with aphasia) was married to John (carer). Eight carer participants (focus group 2; 4 females/4 males) were recruited from the same support group; two carers from another. Four were caring for a husband, four for their wife and two for their mother. Failure to recruit from the first hospital site (due to departmental restructuring and relocating) meant that all healthcare professionals were recruited from the second site. Six healthcare professionals (3 females/3 males) were recruited from hospital-based stroke services (including acute and rehabilitation wards) and ranged in years of relevant experience from approximately 6 weeks to 20+ years. Three healthcare professionals were Physiotherapists (including a Consultant), two were Consultant Stroke Physicians and one was a Registered Nurse. Details on participant characteristics, link between participants and data collection methods used can be seen in table 1. All interviews were audio recorded and lasted between 15 and 54 minutes; ending when participants reached a point where they felt they had no further experiences to share.

1 *table 1 about here*

2

3 Three overarching themes were identified (see table 2). These spanned across all three groups;
4 'being in a foreign country', 'finding a voice' and 'you're just a number'.

5

6 *table 2 about here*

7

8 **Theme 1: Being in a foreign country**

9 All three groups acknowledged that the experience of, and recovery from, stroke was characterised
10 as a significant and life changing event. For stroke survivors with aphasia, this experience was
11 encapsulated by talk of uncertainty and confusion surrounding their condition and experienced in
12 the hospital environment that they now found themselves in, as well as the recognition that they
13 were dependent on others. The first shock was that of being ill; Sue (stroke survivor) had "*never*
14 *ever been ill in my life prior to this stroke*", similarly, Paul (stroke survivor) described the shock
15 of moving from someone who was "*fit...healthy*" who had worked for many years in a job with a
16 lot of responsibility; to someone who said: "*My brain weak though (laughs) '....' the erm brain (.)*
17 *muddle...muddle*", and his mouth as now "*weird*".

18

19 The sense of confusion about, and enormity of, being ill was exacerbated by the ward environment
20 itself. Stroke survivors with aphasia felt that it contributed to their sense of disruption and
21 confusion because it was a source of uncertainty and unfamiliarity; it was noisy, fast paced and
22 not considered conducive to effective staff-patient communication. Paul (stroke survivor)

1 described feeling “*overloaded*” at times. Sue (stroke survivor) noticed that procedures were being
2 done *to*, rather than *with*, persons with aphasia:

3
4 *And that was more frustrating because they were doing things and checking...blood*
5 *pressure and taking you for a scan and you had no idea what was happening because your*
6 *brain...your brain wasn't taking in what they were doing telling me ‘...’ I wasn't taking*
7 *that in and I'd no idea what was going on so I felt totally (.) at a loss*

8
9 The healthcare professionals also recognised that the hospital setting, with its own routine,
10 structure, environment and roles which impacted on staff-patient communication, was a place of
11 uncertainty and unfamiliarity; for example, Lisa, (a physiotherapist) recognised the sense of things
12 being done to the stroke survivors with aphasia when she said “*there's some strange people*
13 *(healthcare professional) trying to move them about (laughs)*”. In contrast, Alan (physiotherapist)
14 likened the hospital context to “*being in a foreign country*”, whereby aphasia (like being unable
15 to speak the language of another country) creates a barrier to the transfer of information, which in
16 turn heightens the sense of uncertainty and unfamiliarity experienced by persons with aphasia.
17 Healthcare professionals identified further sources of unfamiliarity caused by the ward setting,
18 including interruption in consistent care caused by shift changeover/use of temporary (agency)
19 staff; some of whom were either not being consistent in the communication style/techniques used
20 with stroke survivors with aphasia, or were failing to carry out techniques suggested by the Speech
21 and Language Therapist. For example, Pete (physician) noted that:

22

1 *sometimes we have bank staff on rather than our own staff...err (.) the bank staff will*
2 *inevitably concentrate more on just general nursing care rather than patient interactions*

3
4 Similarly, Karen (nurse) highlighted this as an issue; she believed that agency staff had limited
5 experience of working in stroke settings, specifically with aphasia. She expressed the view that
6 “*patients feel that bit of relief*” when regular staff take over after agency staff have covered a night
7 shift. Carers also noticed staffing and time constraints, poor transfer of information between staff
8 both during the shift and at handover. For example, Emma (carer) found it difficult to get consistent
9 information about her mother’s care:

10
11 *so and so’s been dealing with your mum but she’s now doing such a thing so...’ (.) its like*
12 *getting blood out of a stone getting information.*

13
14 Similarly, Ruth (carer) spoke of the challenges of ensuring information was appropriately and
15 effectively communicated:

16
17 *the information that’s needed is not passed on because every time I speak to somebody and*
18 *I say, ‘but he doesn’t do that’ and they go ‘really?’ and I think surely by now somebody on*
19 *this ward knows enough to say ‘by the way you need to take abit more time with [name of*
20 *husband]’*

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22 The need for consistent care was recognised as being important; Karen (nurse) felt it enabled her
23 to better identify and more quickly address the specific needs of her patients:

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if I look after a patient...like all week and I've got used to...like I said like that...where walking in the room...you kind of know what they already want, coz you know them well enough and you've looked after them long enough

However, she also acknowledged that time pressures and workload could hamper the ideal of consistent care, when she said: *“you might not go to them as often as you'd like to”*.

The experience of being in this foreign country was very emotional for both stroke survivors with aphasia and carers who both reported feeling frustration, denial, fear, panic and depression; Margaret (stroke survivor) summarised the patient focus group experience when she said: *“you get into an area of erm...because of this weepiness that you can easy get into a depression cycle”*.

Similarly, carers spoke of the shock they experienced; Emma (carer) spoke of how *“it hits like a car crash happening”* whilst Gill (carer) felt *“stunned”* and felt that she was *“just sat at the bedside waiting for her (mother) to die”*.

After the initial impact, carers also spoke about the burden they felt post-discharge, with the sudden and frightening realisation of the commitment they were making to care for their loved one, Sarah (carer) said: *“my God this is my responsibility”*. Carers' felt unprepared for the role and concerned about their ability to cope and provide support, with the parallel recognition that established roles were likely to change, Emma (carer) explained how *“she'd always been my mum...I'm now her mum”*. In addition, stroke survivors with aphasia and carers spoke of their need to make sense of what had happened, so that they could try to adjust to the situation that they now found themselves

1 in. This process was linked to ‘Finding a voice’ (Theme 2). Carers and stroke survivors with
2 aphasia wanted answers and more information about their loved one’s condition, treatment and
3 aftercare; they also wanted to feel involved in care and be better prepared for their loved one’s
4 discharge. However, the consensus was that this was not easy information to access; they felt that
5 they had had to battle (find their voice) for information and support, as exemplified by John (carer)
6 who describes

7
8 *there is so much information and knowledge available (.) but you’re never ever told about*
9 *it.*

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11 **Theme 2: Finding a voice**

12 The importance of the person with aphasia finding a voice was a strong theme across all three
13 groups. For the person with aphasia and their carers, finding their voice was central to their making
14 sense of what had happened and adjusting to stroke. Stroke survivors with aphasia had to find their
15 own voice or rely on that of their loved one. Carers were trying to interpret their loved one’s needs
16 (they were the voice of the person with aphasia), but also sought their own voice, so that healthcare
17 professionals could hear them, and involve them in their loved one’s treatment. Healthcare
18 professionals were also trying to find the voice of the person with aphasia and took pride in the
19 efforts they made to do so.

20

21 Stroke survivors with aphasia were helped to find their voice when healthcare professionals used
22 aphasia-friendly verbal and non-verbal communication. This included repetition, checking
23 understanding, speaking slowly and not giving lots of information at once, use of large font sizes,

1 as well as the use of lists and photographs. Both Margaret and Sue (stroke survivors) shared
2 positive experiences of feeling heard by a staff member and described the interaction as being
3 characterised by eye contact, checking understanding, being kind and helpful, and allowing time.
4 In contrast, being dependent on others meant that it could be difficult to get your voice heard. This
5 was challenging for the stroke survivor with aphasia who were dependent on others within the
6 hospital setting for a range of activities of daily living, pain management and access to information.
7 Support with toileting was an issue reported as especially frustrating and distressing; with requests
8 for assistance being overlooked or delayed. Cath (stroke survivor) requested support to go to the
9 toilet, but failed to get her request heard:

10

11 *I want a wee...I want a wee...no wait....ooooph ‘...’ waiting...waiting...waiting all the time*
12 *you’re just waiting.*

13

14 Not only was carer support in finding a voice deemed important by stroke survivor with aphasia
15 but also viewed as necessary by carers. However, whilst carers wished to represent their loved
16 one’s voice, at times, they too felt overlooked in the treatment process. Tom (carer) described
17 being treated like “*a bystander*”. This perceived lack of involvement in their loved one’s care led
18 them to worry about how their loved one was faring when they were not with them. Mark (carer)
19 spoke about this: “*you’re not there so you don’t know what’s gone on*”. This worry manifested in
20 concerns about treatment; Ruth (carer) felt that staff should have talked to her husband more
21 “*instead of just ignoring him because he can’t speak*”. Similarly, Gill (carer) felt “*they weren’t*
22 *trying to do anything with her (mother) it were just (.) basic needs sort of thing*”, and Mark (carer)
23 described mealtimes: “*I got the impression (.) if they hadn’t have been going in (daughters) and*

1 *feeding her she might not have got fed at all*". Emma (carer) outlined her concerns regarding the
2 lack of interaction on the ward:

3
4 *In my mum's case I think there were eight people in the ward (.) but (.) they didn't*
5 *communicate...they weren't encouraged to communicate with each other, my mum would*
6 *sit there all day and say nothing*

7
8 The carers also felt that since they knew the person with aphasia better than hospital staff, they
9 could be a valuable resource for staff; after all, they knew their loved one before their stroke;
10 his/her likes/dislikes and co-morbidities; and they also felt that they had "*got a better fix on what*
11 *that person is thinking and feeling '....' even though they can't communicate it*". For example,
12 Ruth (carer) noticed how her husband was feeling and asked him:

13
14 *Are you sorry you survived this? and he just nodded his head...and, and in that time it was*
15 *really dark for him.*

16
17 In contrast, the healthcare professionals felt that sometimes carers could block effective
18 communication; this is exemplified by Karen (nurse) stating that "*sometimes relatives can be a*
19 *barrier [. . .] assuming what they're [the patient] wanting*". As such, both carers and healthcare
20 professionals felt that they knew what the person with aphasia wanted, the carers because they felt
21 they knew their loved one's the best, and the healthcare professionals because they were trained
22 to work with people with aphasia, and felt they had greater insight.

23

1 However, supporting the stroke survivor with aphasia to find a voice was also a priority for the
2 healthcare professionals, indeed, all staff talked about the importance of, and need for, patient-
3 centred individualised care, with communication being fundamental to this. There was shared
4 acknowledgement that “*every single person’s different and individual*” (Lisa, physiotherapist),
5 and that “*there are loads of different ways and it just depends on the individual person...what*
6 *works for them*” (Jo, physiotherapist). It was acknowledged that healthcare professionals needed
7 to work through a range of strategies to find those which best matched the needs of the person with
8 aphasia. For example, Alan (physiotherapist) noted:

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10 *if you’re not 100% sure if they’ve understood try and ask them in a different way see if you*
11 *can get the consistent response.*

12
13 Whilst effective communication was of central importance to patient-centred care, achieving this
14 was challenging for both stroke survivor with aphasia and healthcare professional. By way of
15 example, Pete (physician) stated that sometimes you must “*accept that there are some things you*
16 *can’t explain*” and that some patients won’t engage “*no matter what you do*”. Where patients were
17 able to engage, there were still barriers. For example, Lisa (physiotherapist) talked about how the
18 communication ability of a person with aphasia can be “*variable*”, whilst Karen (nurse)
19 recognised “*how each person hears things differently*”. Sometimes communication aids
20 themselves could become a barrier, due to lack of time, lack of access, and in some cases, because
21 they were viewed negatively by people with aphasia. In addition, persons with aphasia sometimes
22 used the aids as a means of communicating by pointing, rather than the aid acting as a prompt for
23 words. For example, Jo (physiotherapist) said:

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sometimes (.) they hinder them because they're trying to point at the thing that they want to say but they don't try and (.) actually verbally communicate.

Furthermore, the healthcare professionals outlined how they felt that sometimes there were situations where despite their best efforts they were unable to help the patient articulate their needs and therefore *“in some instances you have to go with [what you assume are] their best interests”* (Alan, physiotherapist). Not being able to interpret the needs of a stroke survivor with aphasia was outlined as *“sad”* (Lisa, a physiotherapist), *“quite upsetting”* (Jo, a physiotherapist), *“it's awful”* (Alan, a physiotherapist), and *“you feel awful, coz you feel like you're not doing [enough] for them”* (Karen, a nurse).

The healthcare professionals felt that multidisciplinary team working was incredibly valuable. Working with other professions, sharing advice and understanding was important. Healthcare professionals particularly valued input from the speech and language therapists, as a means of helping the person with aphasia find and use their voice. However, there were challenges in accessing such support. When face-to-face contact with other members of the multidisciplinary team was not possible, there was a reliance on the medical notes. However, these were not always easy for staff to interpret; Karen (a nurse) found the speech and language therapists used *“jargon”* which made the notes inaccessible *“I don't understand any of that”*.

Theme 3: You're just a number

1 Stroke survivors with aphasia and carers both felt that people with aphasia were sometimes seen
2 as ‘just a number’ in the healthcare system, rather than as a person with unique individual needs,
3 preferences and co-morbidities. For example, Margaret (stroke survivor) explained that she felt
4 she had been treated like “*a blanket case*”, whereas Sue (stroke survivor) felt that rehabilitation
5 had not taken her needs into account:

6
7 *I kept saying to them ‘but I’m left handed’...’well use your right hand Mrs [surname]’ and*
8 *I kept saying ‘what is the point I need to be able to use me left hand I’m left handed ‘....’*
9 *and the whole kitchen was set out for a right handed person*

10

11 The consensus from carers and stroke survivors with aphasia was that the physical effects of stroke
12 were focused upon, at the expense of improving communication. For example, Neil (stroke
13 survivor) felt healthcare professionals were more concerned about his physical condition as
14 opposed to “*making things easier for me to understand*”. Similarly, for carers, Gill (carer)
15 explained how “*they just met her (mother’s) physical needs when they had to and then moved on*”.
16 Likewise, John (carer) explained how “*their only concern...only concern really was the physical*
17 *side, it was NOT the speech side...at all*”, a view shared by Carol (carer) “*they’d assessed that he*
18 *didn’t need anything because like he was talking rubbish so he could talk*”. Ruth (carer) reported
19 on her husband being “*expected to follow the programme*”, which was pre-determined and staff
20 led.

21

22 Given this perception, carers talked about staff needing to invest more time and effort into
23 communicating with stroke survivors with aphasia by trying different modes of verbal and non-

1 verbal communication to maximise interactions and engagement. There was a view articulated by
2 Ruth (carer), shared by members of the carer focus group, of how ineffective staff-patient
3 communication could cause a person with aphasia to “*withdraw*”. Ruth (carer) felt this had been
4 caused by repeated encounters with a healthcare professional who did not modify their
5 communication style to match the needs of her husband. This approach experienced as infantilizing
6 and depersonalising and had a disempowering effect. For example, Sue (stroke survivor) reflected
7 how:

8
9 *you try and do it yourself and then they shout at you for trying to get out of bed (....) you*
10 *think ‘well what choice do I have? I really need the loo’.*

11
12 Others spoke of being told what, and when to do tasks, being told off, and feeling that they had
13 been made to wait. Similarly, carers felt that healthcare professionals had communicated with their
14 loved one like “*a child*” or “*a bit like babies*”; particularly related to the tone of voice. This was
15 reinforced for some by rehabilitation related tasks which did not use age appropriate tools: “*they*
16 *had like you know like babies’ toys*” (Gill, carer). Others reported that the way in which stroke
17 survivors with aphasia were monitored could feel inappropriate, for example Sarah (carer) said:
18 “*occasionally they’d hire one of these bank staff just to stand in that bay and watch four people*
19 *and make sure they didn’t get out of bed*”, or they would communicate with the carer instead of
20 the person with aphasia. Some healthcare professionals recognised this form of interaction as
21 indicating a power imbalance. Alan (physiotherapist) suggested that:

22

1 *perhaps he's compliant because he's been in the patient role for a while [. . .] well I*
2 *suppose traditionally in a healthcare setting...and particularly sort of for older patients*
3 *they tend to see the person who's got the role of the healthcare clinician as to be the person*
4 *who's sort of in charge of the interaction [. . .] so people tend to sort of say 'yes' pretty*
5 *much to whatever you suggest and...and if you're aware of that I suppose you have to be a*
6 *little bit careful*

7
8 Similarly, Pete (physician) made reference to the 'sick role' explaining how some stroke survivors
9 *"aren't quite comfortable with being looked after"* and talked about patients delaying or avoiding
10 asking for help as they *"think that they're wasting (.) your time"* (Karen, nurse).

11
12 The power imbalance was also manifest in institutionalisation in the hospital setting. Jo
13 (physiotherapist) makes reference to this explaining how stroke survivors:

14
15 *give up a little bit of their control, they have to do the routine of the hospital, and if they*
16 *don't understand what's going on (.) it can become a very frustrating place*

17
18 Carers reflected on patients being *"told off"* when they did not appear to be adhering to the rules
19 and regulations of the setting. Furthermore, several carers themselves described being told off;
20 John (carer) describes *"on numerous occasions we were chastised for err getting in too early and*
21 *things of that nature"*. The healthcare professionals also mentioned the issue of infantilization
22 exemplified by inappropriate communication. Tim (physician) had seen healthcare professionals
23 *"talking to a carer or relative across the dysphasic person"*, whilst Pete (physician) noted the use

1 of communication which is “hurried” and involves “shouting ‘...’ raising their voice”. Both
2 physicians linked this behaviour to a lack of knowledge of aphasia combined with a lack of
3 confidence in supporting people with aphasia, and healthcare professionals feeling stressed.

4
5 In contrast, creative attempts by staff to stimulate communication on the ward were positively
6 viewed. For example, Greg (carer) recounted the time when his wife and a fellow patient were
7 given a game of snakes and ladders to play and although “they got the number wrong every time
8 and they didn’t know whether to go up ladders and down stairs (laughs) ‘...’ it made them laugh”.

9 10 **A model of the barriers and facilitators to communication**

11 In exploring the experiences of the three participant populations, and the subsequent three
12 overarching themes from the integrative analysis, the authors identified three complex interrelating
13 areas impacting on staff-patient interactions (within which the themes are embedded). To depict
14 this a preliminary model was developed (see figure 1) proposing a framework for understanding
15 the relationships between ‘the context’, ‘the people’ and ‘the interactions’, therefore offering
16 targets for interventions for optimising staff-patient interactions.

17
18 *Insert figure 1 about here*

19
20 The dynamic model presents how ‘the people’ and ‘the context’ mediate ‘the interactions’; ‘the
21 interactions’ then directly impact on ‘the people’ and ‘the context’. Indeed, interactions can
22 influence future interactions. Therefore, all three areas can pose as both barriers and facilitators to
23 communication in the context of stroke rehabilitation and post stroke aphasia. By way of example,

1 some stroke survivors with aphasia reported that they felt their ability to communicate effectively
2 had been impacted not just by the stroke and aphasia, but also by the noisy and fast paced ward
3 environment and the limited knowledge/use of aphasia-friendly communication strategies by staff.
4 This could reduce the person’s confidence and motivation to engage in future interactions, and
5 therefore rehabilitation.

6

7

Discussion

8

9 This qualitative study explored the experiences of staff-patient communication by stroke survivors
10 with aphasia, carers and healthcare professionals; paying attention to the initial research questions
11 relating to: the experienced and preferred communication styles, barriers and facilitators to
12 communication, roles in communication, and the impact of communication on patient engagement
13 in stroke rehabilitation. In doing so, the authors confirm and extend past research in the area; and
14 offer a model of communication to provide a framework for understanding and targeting
15 interventions for optimising staff-patient interactions with stroke survivors with aphasia. This
16 model will be used as a basis for discussing the present findings, making links to the initial research
17 aims and the literature base in the area.

18

The people

20 The current findings highlight the need to recognise ‘the people’ as individuals with unique
21 characteristics and experiences, influencing and being influenced by the stroke rehabilitation
22 process and the hospital context. In line with past research, the current findings support evidence
23 of the emotional impact of post stroke aphasia on stroke survivors [3,4], and that of staff

1 (particularly sadness and frustration) in trying to understand and represent the needs of stroke
2 survivors with aphasia [14]. However, this study extends on this by further highlighting the
3 emotional impact experienced by all three stakeholders, including carers. The current study
4 suggests that stroke survivors and carers alike experience a ‘biographical disruption’ [33]
5 (captured in the ‘being in a foreign country’ theme) denoting changes in the way in which they see
6 themselves and the world they live; and the need to make sense of their new reality. Implicit within
7 this is a felt need by the person with aphasia and carers for the carer to adopt the role of an
8 advocator to safeguard and represent the voice of the person with aphasia, given the
9 communication impairment. The issues outlined here have similarly been reported by informal
10 carers of patients with a range of long term conditions [34]; however the communication
11 difficulties inherent in post stroke aphasia mean that there seems to be a heightened sense of
12 responsibility for carers of people with aphasia to advocate on behalf of their loved one. Further
13 research is needed to explore how such a biographical disruption impacts upon how the carer
14 adjusts to and evaluates their role in recovery post stroke.

15
16 The findings suggest how ‘the interactions’ and ‘the context’ could help or hinder the process of
17 sense making (for the person with aphasia and those supporting them), the emotional burden, and
18 how the person with aphasia and their loved one engages in the rehabilitation process. The presence
19 of severe cognitive impairments of the person with aphasia is identified as a further barrier to
20 communication. This study highlights how communication is inextricably linked to psychosocial
21 wellbeing, and therefore how in order to improve staff-patient communication there is a need to
22 assess for, and support, people with aphasia and those supporting them, through the biographical
23 disruption. For healthcare professionals, this may involve: bearing witness to these experiences,

1 more training on supporting people with communication difficulties and aphasia friendly
2 communication; as well as education on psychosocial adjustment to stroke, and particularly
3 aphasia (for the stroke survivor with aphasia and their loved one). Access to Psychology Services
4 for specialist input may also be required. Clinical supervision is also necessary to facilitate
5 knowledge/skills development, in addition to providing a space for healthcare professionals to
6 share the emotional impact of their work. This could serve to counteract the issue of staff-
7 disengagement in response to the emotional burden and self-critical appraisal of professional
8 competence in this context; found to have an adverse effect on patient experience of and access to
9 care [11].

10

11 **The context**

12 The ward environment was recognised as a place of uncertainty and unfamiliarity for stroke
13 survivors with aphasia; one which has its own routine, structures and roles, which should be
14 conformed to, but which could be communicatively limiting and further magnify the biographical
15 disruption. The busy and changing workforce and inconsistent use of communication strategies
16 were observed as contributing to perceptions of uncertainty and unfamiliarity. The current study
17 supports and elaborates on past research on the influence of stroke unit structure and processes on
18 communication [13]. Carers were found to be useful, indeed necessary in helping the person with
19 aphasia navigate this system in the present study. The present study also recognises the tension
20 between healthcare system goals versus patient goals. Across all three groups there was reference
21 to there being a physical focus to stroke care contributing to lack of attention to the psychosocial
22 needs and goals of the stroke survivor with aphasia; this being in conflict with the priority for many
23 of the stroke survivors with aphasia interviewed on improving communication. This supports past

1 findings [10] on activity and participation level goals being particularly important to stroke
2 survivors with aphasia. This focus on the physical was reflected in the provision of services and a
3 need for greater access to speech and language therapy, staff with understanding of and skills in
4 supporting people with aphasia, and psychological support.

5
6 There was reference to ‘learned non-use’ of language [7] on the stroke ward due to lack of language
7 stimulation; stroke survivors with aphasia and carers expressed a view of there being a need to
8 provide a communicatively richer environment for people with aphasia, with a suggestion by some
9 carers for a role for volunteers on stroke wards to provide opportunity for interactions and
10 stimulation with people with aphasia. Patient to patient support was also identified as providing
11 needed stimulation and encouragement on the ward.

12
13 **The interactions**

14 This study expands on the literature by acknowledging the role, interest and influence of all three
15 stakeholders (stroke survivors with aphasia, carers and a range of healthcare professionals) in
16 optimizing staff-patient communication. Although there were unique experiences across the three
17 groups, there was a common view of patient-centred communication and care being important but
18 this being at times challenging to achieve. Common factors associated with this included: patient
19 and carer adjustment to stroke and post stroke aphasia, the hospital setting and roles, knowledge
20 and use of aphasia-friendly communication, staffing and time constraints, transfer of information
21 and type of aphasia. The current study supports past research highlighting the issue of staff-patient-
22 carer interactions being task-focussed and staff-led [6,7] and the impact of poor staff-patient-carer
23 communication on patient engagement, meaningful goal setting and decision-making [8-10]. The

1 findings highlight the issue of socially constructed versus mutually agreed roles in stroke care, and
2 how communication could shape and reinforce ‘roles’ in stroke care settings (e.g. patient in the
3 ‘sick role’ and being a recipient of instead of joint decision maker on care, healthcare professional
4 as ‘the expert’). Moreover, although the issue and effects of infantilization on older people by care
5 services/institutions has been widely reported [35,36]; this study suggests how aphasia makes
6 stroke survivors particularly susceptible to this form of communication.

7

8 The findings corroborate past findings [16] of the strategies for optimising staff-patient
9 interactions, namely the need for increased time for communication, collaboration with the support
10 network of stroke survivors with aphasia, and staff education. Despite the expressed need in the
11 present study for carers to adopt an ‘advocator role’, carers felt excluded from patient care. Carers
12 made the suggestion of the development of an interactive comments book for carers and healthcare
13 professionals within which comments and questions could be shared and monitored. Furthermore,
14 the current findings highlight incongruity between reports from healthcare professionals of their
15 use of a range of strategies to optimise interactions with stroke survivors with aphasia, and how
16 interactions are experienced by people with aphasia and their carers observing them. Future
17 research could be helpful in exploring if and how the use of strategies (such as picture boards) to
18 optimise communication are communicated to stroke survivors with aphasia and their carers; and
19 the impact of this on how they are experienced.

20

21 **Limitations**

22 In relation to study limitations, it is important to note that the stroke survivors with aphasia and
23 carer participants were recruited from a different geographical region to the healthcare professional

1 which needs to be considered when interpreting these findings given that stroke care and
2 experiences will likely differ across regions. Future research would benefit from an examination
3 of stroke survivors with aphasia and healthcare professionals working in the same environment
4 and taking a case study approach to explore the same interactions, from different perspectives.
5 Additionally, video-recording interviews would also be useful with stroke survivors with aphasia
6 to capture the non-verbal modes of communication which would further strengthen the analysis.
7 Furthermore, many of the healthcare professionals within this study made reference to having
8 attended in-house training to further their aphasia knowledge; such training may not be as
9 accessible in other services and would likely affect the level of aphasia knowledge and skills in
10 communicating with people with aphasia. Additionally, although it was our aim to recruit a
11 representative sample of the range of healthcare professionals working in inpatient stroke services
12 this was not possible in the current study.

13

14 Future research would benefit from recruiting a broader and larger sample of healthcare
15 professionals to explore whether these views are representative across different professions;
16 furthermore, to make a greater distinction between staff-patient communication in acute and
17 rehabilitation settings to better understand the unique challenges and target interventions for these
18 settings and those accessing/working within them. Finally, access to a Speech and Language
19 Therapist in the planning, recruitment and data collection process would have allowed for a formal
20 assessment of aphasia severity type and for people with more severe and complex aphasia
21 presentations to be recruited and interviewed at different stages of the recovery process; not
22 possible in the current study.

23

1 **Clinical implications & future directions**

2

3 The findings of the present study highlight a range of clinical implications for stroke care settings.

4 Firstly, the need for greater access to Speech and Language Therapists and Psychology Services

5 for stroke survivors with aphasia and their carers who are playing a vital role in supporting them.

6 For healthcare professionals, this study supports the need for mandatory training for all members

7 of the multidisciplinary team (including some training for bank staff), in supporting people with

8 communication difficulties, both communicatively and in recognising any psychosocial needs of

9 stroke survivors with aphasia and their carers. Furthermore, healthcare professionals should have

10 access to clinical supervision to facilitate professional development in this area, but also to provide

11 a space to share the challenges of working in this context. Attention must be paid to maintaining

12 consistency of care across teams, in relation to the use of communication strategies identified as

13 helpful to each person with aphasia; effective transfer of information on the ward and during shift

14 handover being integral to this. The importance and influence of carers during inpatient stroke

15 rehabilitation must also be recognized and incorporated into care plans.

16

17 Interventional studies to assess the usefulness of volunteers on the ward to provide a richer

18 communicative environment for people with aphasia are also warranted; as are studies exploring

19 the benefits of increased opportunities for patient to patient interaction. The development and trial

20 of an interactive communication booklet for each stroke survivor with aphasia to support the

21 transfer of information and questions between people with aphasia, their carers and healthcare

22 professionals supporting them is also suggested.

23

1 **Conclusion and Recommendations for Rehabilitation**

2 The current study has extended the literature in further highlighting the complexity of staff-patient
3 interactions and the key contributing factors which can be a facilitator or barrier to this, as
4 experienced by staff, stroke survivors with aphasia and their carers. The preliminary model
5 proposed offers a dynamic framework for understanding the three primary interrelating factors
6 influencing staff-patient interactions within a hospital context and therefore offering targets for
7 interventions to optimise these interactions and the provision of aphasia-friendly services. This
8 study promotes the need for greater attention to an individual's (patient and carer) unique
9 experience of and adjustment to stroke, training and support for staff working within stroke
10 settings; and for the provision of an aphasia-friendly and a communicatively stimulating ward
11 environment.

12
13
14
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16
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21
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23
24 The authors report no declarations of interest.

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Figure 1: Model of communication

Table 1: Table of participant characteristics

| Participant¹ | Details | Data collection method |
|--------------------------------|---|-------------------------------|
| Stroke Patient | | |
| - Sue | Aged 68. 'Mild' aphasia; significant improvements since stroke. Time since stroke not recorded but minimum of 3yrs plus. | Focus Group 1 |
| - Margaret | Aged 61. 'Mild' aphasia; significant improvements since stroke. Time since stroke not recorded but minimum of 3yrs plus. | |
| - Joyce | Aged 68. 'Mild' aphasia; reported as 'severe' at time of stroke. Time since stroke not recorded but minimum of 3yrs plus. | |
| - Paul | Aged 55. 'Moderate' aphasia. Stroke 9 years ago. | One to One |
| - Neil | Aged 65. 'Moderate' aphasia. First stroke in 2003; further suspected stroke over past year. | One to One |
| - Cath | Missing data for age. 'Moderate' aphasia. Stroke 6 years ago. Husband (carer – 'John') also participated in study. | One to One |
| Carers | | |
| - Ruth | Missing data for age. Carer for husband. Carer for 5years. | One to One |
| - Gill | Aged 61. Carer for mum. Years being a carer not known but a minimum of 2-3 years+. Mum since passed away. | One to One |
| - John | Aged 81. Carer for wife 'Cath'. Carer for 6years. | One to One & Focus Group 2 |
| - Carol | Aged 76. Carer for husband. Years being a carer not known but a minimum of 1-2years+. | Focus Group 2 |
| - Greg | Aged 74. Carer for wife. Years being a carer not known but a minimum of 1-2years+. | |
| - Tom | Aged 77. Carer for wife. Years being a carer not known but a minimum of 1-2years+. | |
| - Sarah | Aged 63. Carer for husband. Years being a carer not known but a minimum of 1-2years+. | |
| - Jean | Aged 85. Carer for husband. Years being a carer not known but a minimum of 1-2years+. Husband since passed away. | |
| - Emma | Aged 66. Carer for mum. Years being a carer not known but a minimum of 1-2years+. | |
| - Mark | Aged 72. Carer for wife. Years being a carer not known but a minimum of 1-2years+. | |
| Healthcare Professional | | |
| - Alan | Aged 47. Consultant Physiotherapist. Many years experience working across stroke settings | One to One |
| - Lisa | Aged 28. Physiotherapist. New to working in stroke settings, currently based in acute stroke settings. | One to One |
| - Jo | Aged 36. Physiotherapist. Several years experience working across of stroke settings, currently based in acute. | One to One |
| - Tim | Aged 57. Consultant Stroke Physician. Many years experience working across stroke settings. | One to One |
| - Karen | Aged 35. Registered Nurse/soon to be Sister. Four years experience in stroke settings. | One to One |
| - Pete | Aged 57. Consultant Physician. Many years experience across stroke settings. | One to One |

¹All names reported in table are pseudonyms.

Table 2: Development of research themes

| | Independent Analysis | Integrative Analysis |
|--|---|--|
| Stroke survivors with aphasia | Theme 1: A Biographical Disruption The ward environment: an alien place / Emotional impact | Being in a foreign country |
| | Theme 2: Power and the Powerless Not being heard / Being dependent on others / Being treated like a blanket case / Focus on the physical / Infantilization | Finding a voice & you're just a number |
| | Theme 3: Finding a Voice Family support / Keeping it simple | Finding a voice |
| | | |
| Carers | Theme 1: A Biographical Disruption Carer emotions / Carer burden and coping post discharge / Needing to make sense of it | Being in a foreign country |
| | Theme 2: Needing to be the Patient's Voice but Being Treated Like a Bystander Carer concerns / Staff need more education on aphasia / We know them best | Finding a voice |
| | Theme 3: You're Just a Number Focussed on the physical / Care needs to be tailored / Infantilization | You're just a number |
| | Theme 4: An Inflexible Healthcare System Focussed on the physical / Urgency to discharge / Staff need more education on aphasia / Institutionalisation / Hospital roles and power imbalances / Staffing and time constraints | Being in a foreign country & you're just a number |
| | | |
| Healthcare professionals | Theme 1: Patient-Centred Care Using a range of verbal and non-verbal communication strategies | Finding a voice |
| | Theme 2: Communication as Challenging Communication aids: facilitators v barriers / Complicating factors / Emotional impact / We all need support | Finding a voice |
| | Theme 3: Living in a Foreign Country Uncertainty and unfamiliarity / Benefits of consistency and familiarity in patient care | Being in a foreign country |
| | Theme 4: The Hospital Setting and Roles A physical focus / Time pressures and workload / Infantilization | Being in a foreign country & you're just a number |
| | | |
| Outcome of Integrative Analysis was the identification of three overarching themes: | | |
| Theme 1 | Being in a foreign Country: All three groups acknowledged that the experience of, and recovery from, stroke was characterised as a significant and life changing event. This theme demonstrates how the stroke impacted differently on stroke survivors and their carers, and the efforts (with differing levels of success) that healthcare professionals made to try and understand. | |
| Theme 2 | Finding a Voice: This was a strong theme across all three groups. For the stroke survivors and their carers, finding their voice was central to their making sense of what had happened and adjusting to stroke. Stroke survivors with aphasia had to find their own voice or rely on that of their loved one. Carers were trying to interpret their loved one's needs (they were the voice of the person with aphasia), but also sought their own voice, so that healthcare professionals could hear them, and involve them in their loved one's treatment. Healthcare professionals were also trying to find the voice of the person with aphasia and took pride in the efforts they made to do so; patient and carer accounts suggest these efforts by healthcare professionals are not always perceived as such. | |
| Theme 3 | You're just a number: This theme captures the patient and care experiences of being infantilised and depersonalised, by both the hospital context and staff communication styles. There was a perception that staff focused on physical rehabilitation rather than on the patient as a whole. In particular, communication was considered to be largely neglected. | |