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

Running header: Living in a foreign country

Article category: Research paper

Authors: Dr Louise Clancy¹,², Dr Rachel Povey¹, Professor Karen Rodham¹

¹Staffordshire Centre for Psychological Research, Staffordshire University, Stoke-on-Trent, United Kingdom.
²Clinical Health Psychology Service, Bradford Teaching Hospitals NHS Foundation Trust, St. Luke’s Hospital, Bradford, United Kingdom

Corresponding author: Dr Louise Clancy, Clinical Health Psychology Service, St. Luke’s Hospital, Little Horton Lane, Bradford, BD5 0NA. (+44) 1274 365176, Louise.Clancy@bthft.nhs.uk

Declaration of interest: The authors report no declaration of interest.
Title: “Living in a foreign country”: Experiences of staff-patient communication in inpatient stroke settings for people with post stroke aphasia and those supporting them”

Running header: Living in a foreign country

Article category: Research paper

Abstract

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

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

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

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

Key words: staff-patient communication, communication difficulties, stroke, healthcare professional, carer, aphasia, qualitative
Introduction

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

Engagement has been outlined as a multi-dimensional construct involving a co-constructed process (between staff & patient) which means that the therapeutic dyad is therefore extremely important [11]. In addition, the patient ‘state’, can be further compounded by inadequate communication strategies employed by nursing staff, which also fail to account for the psychological and social implications of living with aphasia [12]. Whilst staff recognise this as an issue, they experience challenges, which include hospital-related environmental factors [13] when trying to identify, address and represent the needs of people with aphasia [14,15].
Strategies for optimising staff-patient interactions in this setting have been outlined in a recent meta-synthesis and include: increased time for communication, collaboration with the stroke survivor’s support network, staff education, and access to communication tools and service/policy level initiatives [16]. The ‘Supported Conversation for Adults with Aphasia’ approach [17], is one of the most widely adopted of such interventions to date. This approach is centred on enabling communication via a set of verbal and non-verbal communicative techniques and resources. Benefits have been reported when training for healthcare professionals has been fully or in-part founded on this approach [18-21]. In particular, attention to non-verbal communication and feedback loops between staff and persons with aphasia, have been identified as fundamental for maximising understanding [14,20,22], providing explanations of treatment and linking to the stroke survivor’s goals [9]. One study collaborated with people with aphasia and in so doing, refined their research processes to make participation in research more accessible for this group [23]. An outcome of this refinement was that the people with aphasia who took part reported increased confidence in communicating and felt stimulated and empowered to improve future services for those with similar difficulties. However, although there have been some positive outcomes [23], few study protocols and research include people with aphasia, despite the potential patient and service gains [23,24]. Failure to include this population in stroke research poses the question of the generalisability of research findings to stroke survivors with communication difficulties.

This research aims to extend previous findings in several ways. First, by including stroke survivors with aphasia as participants. Second, since most research to date has focussed on nurse-patient interactions, it has failed to account for the remaining core healthcare professionals in a Stroke
Rehabilitation Team which may include: consultant physicians, physiotherapists, occupational therapists, speech and language therapists, clinical psychologists, rehabilitation assistants, and social workers [25]. Therefore, this study will explore the experiences of a range of healthcare professionals. Third, this study will explore staff-patient interactions from the perspectives of carers (close others), who play a key role in aiding the process of recovery, [16,26].

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

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

**Methods**

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

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

**Reflexivity:** Engaging in personal and epistemological reflexivity enabled the authors to acknowledge how their past experiences and standpoints may have affected their interpretation of the data. Author 1 is a white female Health Psychologist who is currently in practice in a National...
Health Service teaching hospital in the North of England, supporting people with long term conditions. She also has stroke and aphasia research and clinical experience and has personal experience of a family member having had a stroke. Author 2 is a white female Associate Professor in Health Psychology, who has not worked directly with people with post-stroke aphasia but has researched people living with long term conditions. In order to maintain rigour, the interviewer (LC) kept a reflexive research diary throughout the research process. During the analysis, both authors were mindful of their experiences and background and continued to engage in reflexive practice.

Participants

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

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

Inclusion criteria for stroke survivors with aphasia were: over 18 years of age; six months or more post-stroke (a point when recovery has stabilized [32]); self-reported mild to moderate level of
post-stroke aphasia. Reliance on self-report was necessary because there was no access to a Speech and Language Therapist to conduct a formal assessment.

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

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

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

Ethical approval for this study was granted by the [anonymised while being reviewed for publication] University Ethics Committee and the National Health Service Health Research
Authority Ethics Board. All participants provided informed written consent to participate in the study.

Data Analysis

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

The six-stage process of analysis outlined by Braun and Clarke (2013) [29,30] was adhered to. This involved initially reading and re-reading through the data to increase familiarity and moving back and forth through the stages as necessary. The two researchers used a semantic approach to TA in which they progressed from describing to attempting to summarise and interpret patterns in the data. The data sets generated from the three different populations were analysed separately until coding was complete and themes identified for each data set, before then progressing onto reviewing and reporting on the commonalities and differences between the populations. This rigorous approach was used to minimise the analysis for each group from being influenced by data from other groups; however, the authors were aware that exposure to other group data may have in some way unintentionally shaped the analysis. Throughout all stages of the analysis, the authors paid attention to Braun and Clarke’s (2006) [29] 15-point checklist of criteria for good quality thematic analysis. In a meeting to review the independent analyses there was strong agreement between authors on the initial themes identified.
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.
Three overarching themes were identified (see table 2). These spanned across all three groups; ‘being in a foreign country’, ‘finding a voice’ and ‘you’re just a number’.

**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. For stroke survivors with aphasia, this experience was encapsulated by talk of uncertainty and confusion surrounding their condition and experienced in the hospital environment that they now found themselves in, as well as the recognition that they were dependent on others. The first shock was that of being ill; Sue (stroke survivor) had “never ever been ill in my life prior to this stroke”, similarly, Paul (stroke survivor) described the shock of moving from someone who was “fit...healthy” who had worked for many years in a job with a lot of responsibility; to someone who said: “My brain weak though (laughs) ‘....’ the erm brain (.) muddle...muddle”, and his mouth as now “weird”.

The sense of confusion about, and enormity of, being ill was exacerbated by the ward environment itself. Stroke survivors with aphasia felt that it contributed to their sense of disruption and confusion because it was a source of uncertainty and unfamiliarity; it was noisy, fast paced and not considered conducive to effective staff-patient communication. Paul (stroke survivor)
described feeling “overloaded” at times. Sue (stroke survivor) noticed that procedures were being done to, rather than with, persons with aphasia:

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

The healthcare professionals also recognised that the hospital setting, with its own routine, structure, environment and roles which impacted on staff-patient communication, was a place of uncertainty and unfamiliarity; for example, Lisa, (a physiotherapist) recognised the sense of things being done to the stroke survivors with aphasia when she said “there’s some strange people (healthcare professional) trying to move them about (laughs)”. In contrast, Alan (physiotherapist) likened the hospital context to “being in a foreign country”, whereby aphasia (like being unable to speak the language of another country) creates a barrier to the transfer of information, which in turn heightens the sense of uncertainty and unfamiliarity experienced by persons with aphasia.

Healthcare professionals identified further sources of unfamiliarity caused by the ward setting, including interruption in consistent care caused by shift changeover/use of temporary (agency) staff; some of whom were either not being consistent in the communication style/techniques used with stroke survivors with aphasia, or were failing to carry out techniques suggested by the Speech and Language Therapist. For example, Pete (physician) noted that:
sometimes we have bank staff on rather than our own staff...err (.) the bank staff will
inevitably concentrate more on just general nursing care rather than patient interactions

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

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

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

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

The need for consistent care was recognised as being important; Karen (nurse) felt it enabled her
to better identify and more quickly address the specific needs of her patients:
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
This process was linked to ‘Finding a voice’ (Theme 2). Carers and stroke survivors with aphasia wanted answers and more information about their loved one’s condition, treatment and aftercare; they also wanted to feel involved in care and be better prepared for their loved one’s discharge. However, the consensus was that this was not easy information to access; they felt that they had had to battle (find their voice) for information and support, as exemplified by John (carer) who describes

\[
\text{there is so much information and knowledge available (.) but you’re never ever told about it.}
\]

**Theme 2: Finding a voice**

The importance of the person with aphasia finding a voice was a strong theme across all three groups. For the person with aphasia 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.

Stroke survivors with aphasia were helped to find their voice when healthcare professionals used aphasia-friendly verbal and non-verbal communication. This included repetition, checking understanding, speaking slowly and not giving lots of information at once, use of large font sizes,
as well as the use of lists and photographs. Both Margaret and Sue (stroke survivors) shared positive experiences of feeling heard by a staff member and described the interaction as being characterised by eye contact, checking understanding, being kind and helpful, and allowing time. In contrast, being dependent on others meant that it could be difficult to get your voice heard. This was challenging for the stroke survivor with aphasia who were dependent on others within the hospital setting for a range of activities of daily living, pain management and access to information. Support with toileting was an issue reported as especially frustrating and distressing; with requests for assistance being overlooked or delayed. Cath (stroke survivor) requested support to go to the toilet, but failed to get her request heard:

_I want a wee...I want a wee...no wait....ooooph ‘...’ waiting...waiting...waiting all the time you’re just waiting._

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

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

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

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

In contrast, the healthcare professionals felt that sometimes carers could block effective communication; this is exemplified by Karen (nurse) stating that “sometimes relatives can be a barrier [. . .] assuming what they’re [the patient] wanting”. As such, both carers and healthcare professionals felt that they knew what the person with aphasia wanted, the carers because they felt they knew their loved one’s the best, and the healthcare professionals because they were trained to work with people with aphasia, and felt they had greater insight.
However, supporting the stroke survivor with aphasia to find a voice was also a priority for the healthcare professionals, indeed, all staff talked about the importance of, and need for, patient-centred individualised care, with communication being fundamental to this. There was shared acknowledgement that “every single person’s different and individual” (Lisa, physiotherapist), and that “there are loads of different ways and it just depends on the individual person...what works for them” (Jo, physiotherapist). It was acknowledged that healthcare professionals needed to work through a range of strategies to find those which best matched the needs of the person with aphasia. For example, Alan (physiotherapist) noted:

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

Whilst effective communication was of central importance to patient-centred care, achieving this was challenging for both stroke survivor with aphasia and healthcare professional. By way of example, Pete (physician) stated that sometimes you must “accept that there are some things you can’t explain” and that some patients won’t engage “no matter what you do”. Where patients were able to engage, there were still barriers. For example, Lisa (physiotherapist) talked about how the communication ability of a person with aphasia can be “variable”, whilst Karen (nurse) recognised “how each person hears things differently”. Sometimes communication aids themselves could become a barrier, due to lack of time, lack of access, and in some cases, because they were viewed negatively by people with aphasia. In addition, persons with aphasia sometimes used the aids as a means of communicating by pointing, rather than the aid acting as a prompt for words. For example, Jo (physiotherapist) said:
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
Stroke survivors with aphasia and carers both felt that people with aphasia were sometimes seen as ‘just a number’ in the healthcare system, rather than as a person with unique individual needs, preferences and co-morbidities. For example, Margaret (stroke survivor) explained that she felt she had been treated like “a blanket case”, whereas Sue (stroke survivor) felt that rehabilitation had not taken her needs into account:

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

The consensus from carers and stroke survivors with aphasia was that the physical effects of stroke were focused upon, at the expense of improving communication. For example, Neil (stroke survivor) felt healthcare professionals were more concerned about his physical condition as opposed to “making things easier for me to understand”. Similarly, for carers, Gill (carer) explained how “they just met her (mother’s) physical needs when they had to and then moved on”.

Likewise, John (carer) explained how “their only concern... only concern really was the physical side, it was NOT the speech side... at all”, a view shared by Carol (carer) “they’d assessed that he didn’t need anything because like he was talking rubbish so he could talk”. Ruth (carer) reported on her husband being “expected to follow the programme”, which was pre-determined and staff led.

Given this perception, carers talked about staff needing to invest more time and effort into communicating with stroke survivors with aphasia by trying different modes of verbal and non-
verbal communication to maximise interactions and engagement. There was a view articulated by Ruth (carer), shared by members of the carer focus group, of how ineffective staff-patient communication could cause a person with aphasia to “withdraw”. Ruth (carer) felt this had been caused by repeated encounters with a healthcare professional who did not modify their communication style to match the needs of her husband. This approach experienced as infantilizing and depersonalising and had a disempowering effect. For example, Sue (stroke survivor) reflected how:

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

Others spoke of being told what, and when to do tasks, being told off, and feeling that they had been made to wait. Similarly, carers felt that healthcare professionals had communicated with their loved one like “a child” or “a bit like babies”; particularly related to the tone of voice. This was reinforced for some by rehabilitation related tasks which did not use age appropriate tools: “they had like you know like babies’ toys” (Gill, carer). Others reported that the way in which stroke survivors with aphasia were monitored could feel inappropriate, for example Sarah (carer) said: “occasionally they’d hire one of these bank staff just to stand in that bay and watch four people and make sure they didn’t get out of bed”, or they would communicate with the carer instead of the person with aphasia. Some healthcare professionals recognised this form of interaction as indicating a power imbalance. Alan (physiotherapist) suggested that:
perhaps he’s compliant because he’s been in the patient role for a while [...] well I suppose traditionally in a healthcare setting...and particularly sort of for older patients they tend to see the person who’s got the role of the healthcare clinician as to be the person who’s sort of in charge of the interaction [...] so people tend to sort of say ‘yes’ pretty much to whatever you suggest and...and if you’re aware of that I suppose you have to be a little bit careful

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

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

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

Carers reflected on patients being “told off” when they did not appear to be adhering to the rules and regulations of the setting. Furthermore, several carers themselves described being told off; John (carer) describes “on numerous occasions we were chastised for err getting in too early and things of that nature”. The healthcare professionals also mentioned the issue of infantilization exemplified by inappropriate communication. Tim (physician) had seen healthcare professionals “talking to a carer or relative across the dysphasic person”, whilst Pete (physician) noted the use
of communication which is “*hurried*” and involves “*shouting ‘...’ raising their voice*”. Both physicians linked this behaviour to a lack of knowledge of aphasia combined with a lack of confidence in supporting people with aphasia, and healthcare professionals feeling stressed.

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

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

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

The dynamic model presents how ‘the people’ and ‘the context’ mediate ‘the interactions’; ‘the interactions’ then directly impact on ‘the people’ and ‘the context’. Indeed, interactions can influence future interactions. Therefore, all three areas can pose as both barriers and facilitators to communication in the context of stroke rehabilitation and post stroke aphasia. By way of example,
some stroke survivors with aphasia reported that they felt their ability to communicate effectively had been impacted not just by the stroke and aphasia, but also by the noisy and fast paced ward environment and the limited knowledge/use of aphasia-friendly communication strategies by staff. This could reduce the person’s confidence and motivation to engage in future interactions, and therefore rehabilitation.

Discussion

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

The people

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

The findings suggest how ‘the interactions’ and ‘the context’ could help or hinder the process of sense making (for the person with aphasia and those supporting them), the emotional burden, and how the person with aphasia and their loved one engages in the rehabilitation process. The presence of severe cognitive impairments of the person with aphasia is identified as a further barrier to communication. This study highlights how communication is inextricably linked to psychosocial wellbeing, and therefore how in order to improve staff-patient communication there is a need to assess for, and support, people with aphasia and those supporting them, through the biographical disruption. For healthcare professionals, this may involve: bearing witness to these experiences,
more training on supporting people with communication difficulties and aphasia friendly
communication; as well as education on psychosocial adjustment to stroke, and particularly
aphasia (for the stroke survivor with aphasia and their loved one). Access to Psychology Services
for specialist input may also be required. Clinical supervision is also necessary to facilitate
knowledge/skills development, in addition to providing a space for healthcare professionals to
share the emotional impact of their work. This could serve to counteract the issue of staff-
disengagement in response to the emotional burden and self-critical appraisal of professional
competence in this context; found to have an adverse effect on patient experience of and access to

The context
The ward environment was recognised as a place of uncertainty and unfamiliarity for stroke
survivors with aphasia; one which has its own routine, structures and roles, which should be
conformed to, but which could be communicatively limiting and further magnify the biographical
disruption. The busy and changing workforce and inconsistent use of communication strategies
were observed as contributing to perceptions of uncertainty and unfamiliarity. The current study
supports and elaborates on past research on the influence of stroke unit structure and processes on
communication [13]. Carers were found to be useful, indeed necessary in helping the person with
aphasia navigate this system in the present study. The present study also recognises the tension
between healthcare system goals versus patient goals. Across all three groups there was reference
to there being a physical focus to stroke care contributing to lack of attention to the psychosocial
needs and goals of the stroke survivor with aphasia; this being in conflict with the priority for many
of the stroke survivors with aphasia interviewed on improving communication. This supports past
findings [10] on activity and participation level goals being particularly important to stroke survivors with aphasia. This focus on the physical was reflected in the provision of services and a need for greater access to speech and language therapy, staff with understanding of and skills in supporting people with aphasia, and psychological support.

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

The interactions

This study expands on the literature by acknowledging the role, interest and influence of all three stakeholders (stroke survivors with aphasia, carers and a range of healthcare professionals) in optimizing staff-patient communication. Although there were unique experiences across the three groups, there was a common view of patient-centred communication and care being important but this being at times challenging to achieve. Common factors associated with this included: patient and carer adjustment to stroke and post stroke aphasia, the hospital setting and roles, knowledge and use of aphasia-friendly communication, staffing and time constraints, transfer of information and type of aphasia. The current study supports past research highlighting the issue of staff-patient-carer interactions being task-focussed and staff-led [6,7] and the impact of poor staff-patient-carer communication on patient engagement, meaningful goal setting and decision-making [8-10].
findings highlight the issue of socially constructed versus mutually agreed roles in stroke care, and how communication could shape and reinforce ‘roles’ in stroke care settings (e.g. patient in the ‘sick role’ and being a recipient of instead of joint decision maker on care, healthcare professional as ‘the expert’). Moreover, although the issue and effects of infantilization on older people by care services/institutions has been widely reported [35,36]; this study suggests how aphasia makes stroke survivors particularly susceptible to this form of communication.

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

Limitations

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

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

The findings of the present study highlight a range of clinical implications for stroke care settings. Firstly, the need for greater access to Speech and Language Therapists and Psychology Services for stroke survivors with aphasia and their carers who are playing a vital role in supporting them. For healthcare professionals, this study supports the need for mandatory training for all members of the multidisciplinary team (including some training for bank staff), in supporting people with communication difficulties, both communicatively and in recognising any psychosocial needs of stroke survivors with aphasia and their carers. Furthermore, healthcare professionals should have access to clinical supervision to facilitate professional development in this area, but also to provide a space to share the challenges of working in this context. Attention must be paid to maintaining consistency of care across teams, in relation to the use of communication strategies identified as helpful to each person with aphasia; effective transfer of information on the ward and during shift handover being integral to this. The importance and influence of carers during inpatient stroke rehabilitation must also be recognized and incorporated into care plans.

Interventional studies to assess the usefulness of volunteers on the ward to provide a richer communicative environment for people with aphasia are also warranted; as are studies exploring the benefits of increased opportunities for patient to patient interaction. The development and trial of an interactive communication booklet for each stroke survivor with aphasia to support the transfer of information and questions between people with aphasia, their carers and healthcare professionals supporting them is also suggested.
Conclusion and Recommendations for Rehabilitation

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

Acknowledgements

The authors would like to greatly thank all of the participants for sharing their experiences and therefore enabling important voices to be heard and those who supported recruitment for the study. We would also like to thank the support of the lecturing team at [anonymised until publication], in particular [anonymised until publication] for her invaluable feedback and guidance.

Declaration of interest statement

The authors report no declarations of interest.
References


8. O'Halloran R, Hickson L, Worrall L. Environmental factors that influence communication between people with communication disability and their healthcare providers in hospital: a review.


Figure 1: Model of communication
**Table 1**: Table of participant characteristics

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

*All names reported in table are pseudonyms.*
<table>
<thead>
<tr>
<th>Stroke survivors with aphasia</th>
<th>Independent Analysis</th>
<th>Integrative Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme 1: A Biographical Disruption</strong></td>
<td>The ward environment: an alien place / Emotional impact</td>
<td>Being in a foreign country</td>
</tr>
<tr>
<td><strong>Theme 2: Power and the Powerless</strong></td>
<td>Not being heard / Being dependent on others / Being treated like a blanket case / Focus on the physical / Infantilization</td>
<td>Finding a voice &amp; you’re just a number</td>
</tr>
<tr>
<td><strong>Theme 3: Finding a Voice</strong></td>
<td>Family support / Keeping it simple</td>
<td>Finding a voice</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carers</th>
<th>Independent Analysis</th>
<th>Integrative Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme 1: A Biographical Disruption</strong></td>
<td>Carer emotions / Carer burden and coping post discharge / Needing to make sense of it</td>
<td>Being in a foreign country</td>
</tr>
<tr>
<td><strong>Theme 2: Needing to be the Patient’s Voice but Being Treated Like a Bystander</strong></td>
<td>Carer concerns / Staff need more education on aphasia / We know them best</td>
<td>Finding a voice</td>
</tr>
<tr>
<td><strong>Theme 3: You’re Just a Number</strong></td>
<td>Focussed on the physical / Care needs to be tailored / Infantilization</td>
<td>You’re just a number</td>
</tr>
<tr>
<td><strong>Theme 4: An Inflexible Healthcare System</strong></td>
<td>Focussed on the physical / Urgency to discharge / Staff need more education on aphasia / Institutionatisation / Hospital roles and power imbalances / Staffing and time constraints</td>
<td>Being in a foreign country &amp; you’re just a number</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Healthcare professionals</th>
<th>Independent Analysis</th>
<th>Integrative Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Theme 1: Patient-Centred Care</strong></td>
<td>Using a range of verbal and non-verbal communication strategies</td>
<td>Finding a voice</td>
</tr>
<tr>
<td><strong>Theme 2: Communication as Challenging</strong></td>
<td>Communication aids: facilitators v barriers / Complicating factors / Emotional impact / We all need support</td>
<td>Finding a voice</td>
</tr>
<tr>
<td><strong>Theme 3: Living in a Foreign Country</strong></td>
<td>Uncertainty and unfamiliarity / Benefits of consistency and familiarity in patient care</td>
<td>Being in a foreign country</td>
</tr>
<tr>
<td><strong>Theme 4: The Hospital Setting and Roles</strong></td>
<td>A physical focus / Time pressures and workload / Infantilization</td>
<td>Being in a foreign country &amp; you’re just a number</td>
</tr>
</tbody>
</table>

**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.