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**A Qualitative Exploration of Communication Impairment following Stroke**

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## Statement of Word Count

Thesis Sections	Main Text	Appendices (including tables, figures, and references)	Total
Thesis Abstract	298	-	298
Systematic Literature Review	7999	9263	17262
Empirical Paper	7998	13056	21054
Critical Appraisal	3967	881	4848
Ethics Documentation	3291	8456	11747
Total	23553	31656	55209

## **Thesis Abstract**

Section one presents a systematic literature review exploring the barriers and facilitators to accessing rehabilitation interventions for stroke survivors with communication impairments. Four databases were systematically searched, and 16 papers were reviewed using a meta-ethnographic approach. Findings highlight the importance of collaborative multi-disciplinary team (MDT) working across disciplines within services where training for all professionals is prioritised and expertise are shared. Stroke survivors with communication impairments are at risk of being excluded from or feeling unable to engage with rehabilitation interventions without this approach to care. In particular, the psychosocial wellbeing of these patients was often not prioritised or identified as a concern within rehabilitation. Clinical implications are discussed.

Section two details an empirical exploration of the lived experiences of stroke survivors who have dysarthria in relation to their personal and social identity. Seven participants engaged in remote semi-structured interviews and data was analysed utilising interpretative phenomenological analysis (IPA). Four themes were identified: (1) a sense of distance and disconnection from other people; (2) navigating the reactions of others; (3) changes in self-perception; and (4) adjusting and coming to terms with dysarthria. Findings indicate that dysarthric stroke survivors can experience several challenges which impact upon how they feel about themselves. However, for many of the participants, they experienced a shift in their level of acceptance of their altered speech over time, finding ways to come to terms with it. Clinical implications are discussed, particularly relating to the role of clinical psychology within stroke rehabilitation.

Section three includes a critical appraisal, which highlights some of the practical, methodological, and ethical issues encountered during the development of the empirical paper. The paper also provides some reflections and insights into the process of undertaking

an IPA investigation within this field, particularly with individuals who have communication impairments following stroke.

## **Declaration**

This thesis was completed in partial fulfilment of the Doctorate in Clinical Psychology at Lancaster University, submitted in April 2022. The research has not been submitted for any other academic award. The work submitted is the authors own and does not contain the work of any other authors, except where due reference is made.

Sophie Cochrane

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**Section One: Systematic Literature Review**

Exploring barriers and facilitators to accessing rehabilitation interventions for stroke survivors with communication impairments: A qualitative meta-synthesis

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### Abstract

**Purpose:** To produce a synthesised understanding from the research literature of the challenges that stroke survivors with communication difficulties face in relation to accessing appropriate rehabilitation interventions. To identify what further considerations can facilitate these individuals accessing effective rehabilitation.

**Materials and methods:** A qualitative meta-synthesis was conducted utilising four electronic databases; Academic Search Ultimate, CINAHL, MEDLINE, and Psycinfo. Sixteen papers met the inclusion and exclusion criteria and were included in the review. Quality appraisals were completed, and a meta-ethnographic approach was used to synthesise the key themes and concepts of included papers.

**Results:** Four overarching themes were identified from the synthesis. (1) patient and family related barriers and facilitators; factors relating to the stroke survivor themselves (as a result of the communication impairment), or the influence of their families/carers (2) staff related barriers and facilitators; how healthcare professionals can help or hinder access to rehabilitation (3) service-level barriers and facilitators; factors present on a higher, systemic level and (4) multi-disciplinary working related barriers and facilitators; factors relating to collaborative working between disciplines.

**Conclusions:** Findings indicate the importance of collaborative MDT working across disciplines within a service where expertise are shared, and training is prioritised. Without this approach to care, these patients are at risk of being excluded from or feeling unable to engage with person-centred interventions, which could contribute to a more successful recovery. Findings indicate that, in particular, patients' psychosocial wellbeing is often not prioritised or even identified as a concern within rehabilitation.

*Keywords: stroke, communication impairment, rehabilitation, meta-synthesis, qualitative*

### **Implications for Rehabilitation**

- Collaborative working between members of different health professions; particularly Speech and Language Therapists (SLT) and psychologists is essential to meet the psychological needs of stroke survivors with communication impairments. Specifically, this could improve patient understanding of and engagement with rehabilitation interventions, as well as psychological adjustment to their impairment/s.
- Training should be prioritised across disciplines to ensure that all professionals feel knowledgeable and competent in supporting these patients. SLTs should share their expertise regarding communicating with patients effectively and psychologists should increase awareness/understanding of the psychosocial impact of communication impairments.

### **Introduction**

Cerebrovascular accident (stroke), occurs when blood supply to the brain is interrupted and part/s of the brain become damaged or die [1]. Over 100,000 individuals experience a stroke in the United Kingdom (UK) and over 795,000 in the United States of America (USA) each year [2,3]. Stroke is the second leading cause of death and the third leading cause of disability-adjusted life years (DALYs) globally [4]. However, advancements in the recognition and treatment of stroke have resulted in a significant decline in worldwide stroke mortality over time [5-7]. Subsequently, the number of stroke survivors in Europe is predicted to increase by 34% by 2035 [8] and an increase of 50% by 2050 is predicted for the USA [9]. Stroke has historically been considered “a disease of the developed world”, however the burden is predicted to increase substantially in the developing world due to ongoing demographic changes and ageing populations [10,p.4].

Stroke is the largest cause of complex disability in adults and causes a greater range of disabilities than other conditions [11]. Disabilities following stroke are grouped into five categories; paralysis/muscle weakness/motor control problems, sensory disturbances (including pain), language impairments, cognitive impairments, and emotional disturbances [12]. These difficulties can leave individuals grieving for the life and identity they have lost, particularly due to its sudden onset [13]. Managing the effects of stroke can become a complex process as symptoms can vary significantly between individuals based on the type, severity, location, and the number of strokes experienced [14]. As survival rates have improved, there is a continued national and global focus on how individuals can be supported with the consequences, through rehabilitation [15,16].

Generally, rehabilitation is defined as “a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions in interaction with their environment” [17,p.1]. Stroke rehabilitation is defined as “a multidimensional process [...], designed to facilitate restoration of, or adaption to the loss of, physiological and psychological function when reversal of the underlying pathological process is incomplete” [18,p.6]. The aim of rehabilitation is to enable stroke survivors to regain independence and improve quality of life [19]. Rehabilitation priorities include improving patients’ ability to complete activities of daily living (ADLs) as well as identifying the cognitive and emotional impact, identifying interventions to help overcome them, and developing resilience to possible permanent lifestyle changes [20]. The importance of access to a well-led and skilled multi-disciplinary team for the holistic care of stroke survivors is recognised [21-23]. This includes specialists in medicine, nursing, physiotherapy, dietetics, occupational therapy, speech and language therapy (SLT)<sup>1</sup>, clinical psychology, orthoptics, and social work. The

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<sup>1</sup> There are varying terms used for Speech and Language Therapy/Speech and Language Therapists within papers included in the review. For simplicity, these will be shorted to ‘SLT’ unless direct quotations are being used.

importance of stroke survivors being involved in decision making regarding rehabilitation is highlighted in relation to getting their healthcare needs met [24].

Despite the development of, and emphasis upon, post-stroke rehabilitation, there are some stroke survivors who face challenges in relation to accessing interventions. Individuals who cannot be easily matched up to an implicit template of the “ideal service user” could be at risk of not receiving some aspects of care; one example being those with communication difficulties [25,p.355]. A previous literature review identified that interactions between nurses and those with communication impairments tend to be task-focused, nurse-controlled, and predominantly focused upon physical needs [26]. Recent studies have found similar results, recognising that this reduces stroke survivors’ autonomy [27,28].

A diagnosed language impairment has been found to lead patients and healthcare professionals to focus only on SLT and neglect other important aspects of rehabilitation [29]. Time constraints have resulted in nurses avoiding speaking with patients with complex communication needs, instead focusing their conversation on family or carers [30]. In addition, stroke survivors with communication impairments often have a tendency towards social isolation [31,32], which could impact upon their level of engagement with services.

Impairments in expressive and receptive communication are common following a stroke; approximately one third of stroke survivors experience communication difficulties (aphasia, dysarthria, and apraxia of speech) [33-35]. Dysarthria and AOS mostly cause difficulties with motor execution of language [36,37], whereas aphasia can also affect word-finding ability and comprehension of speech [38]. It is widely acknowledged that experiencing a stroke can have a significant impact on emotional wellbeing, with or without communication difficulties [39-41]. However, problems with communication are directly associated with heightened levels of emotional distress [31,42]. Communication impairments can limit range of affective expression, meaning that emotional distress may not always be

apparent [43]. Emotional difficulties can be overshadowed by communication or physical impairments, which are often prioritised in the acute stage of rehabilitation [44]. National clinical guidelines acknowledge how cognitive and communication impairments after stroke compound difficulties by compromising ability to participate in standard evidence-based psychological therapies [18].

Numerous systematic reviews and meta-analyses have evaluated the effectiveness of stroke rehabilitation e.g., [45-48], focusing primarily on functional outcomes. Quantitative research has measured the effectiveness of a variety of treatments/rehabilitation interventions for stroke survivors with communication impairments [49-51]. These reviews compared functional outcomes focusing on communication ability. Some quantitative studies have measured alternative outcomes for those with communication problems such as quality of life [52-54] or depression [55]. Quantitative research remains the dominant paradigm in health research [56]; providing useful, large-scale, generalisable findings, which focus on improving the effectiveness of stroke rehabilitation over time.

Although making a valuable contribution to the field, one limitation of quantitative research is the use of standardised measures/questionnaires. Such measures rely on pre-determined questions, which presume the areas being measured are of most importance to the individual [57]. Using this model of outcome assessment places the healthcare professional, as opposed to the stroke survivor, as the expert [58]. One way to address this is through the use of qualitative methods, which can help elucidate the underlying reasons for the findings of quantitative research (the *why* and *how* factors) [59]. Therefore, to gain a more detailed, holistic understanding of the factors which may help or hinder these stroke survivors accessing rehabilitation, qualitative findings will be reviewed. This will include research that prioritises the experiences of those receiving rehabilitation interventions and those supporting with them.

Previous reviews of qualitative literature on related topics have provided useful insights. Two reviews explored the perspectives of stroke survivors with communication difficulties in terms of longer-term needs and how they can live well [60,61]. Other reviews have focused on communication between these individuals and healthcare professionals: on stroke survivors specifically [62-64] and patients with communication disabilities as a result of a range of conditions [26,65-67]. The focus of many of these reviews has been the impact of environmental factors on such communication with professionals [64,66,67]. However, one review focused specifically on the impact of communication impairment on the therapeutic relationship [62]; this highlighted that clinicians' communication patterns can influence a patients' sense of self by situating them as either valued or invalid communicators. Another review concentrated solely on goal setting [63]; a model was developed to increase accessibility of goal setting for these patients, with a focus on supportive conversation strategies and a supportive physical environment. It is also important to note that one review used a narrative approach (including qualitative and quantitative literature) [63], one was a scoping review [66], and one only included three studies conducted by the same research team [64].

Collectively, these reviews provide useful insights into difficulties faced by these individuals, particularly in relation to how they communicate with professionals. However, focusing on the impact communication impairments may have on stroke survivors' ability to receive appropriate and recommended care would be a useful addition to the literature. Therefore, this review aims (a) to produce a synthesised understanding of the challenges that stroke survivors with communication difficulties face in relation to accessing appropriate rehabilitation interventions and (b) to identify what further considerations can facilitate these individuals accessing effective rehabilitation. This review will take a polyvocal approach, which involves the inclusion of multiple voices, opinions, or perspectives. In this instance,



this will include the perspectives of stroke survivors, their families, and staff members who support them.

## **Method**

### **Review Design**

This qualitative meta-synthesis, was conducted utilising the meta-ethnographic approach [68]. This aims to produce third-order interpretations of experiences in which the reviewer re-interprets the conceptual data created by authors of the primary study (second-order constructs), which is in turn based on original participant data (first-order constructs) [69]. This process allows for the emergence of higher order interpretations across the data through constant comparison, whilst preserving the original context of participants' accounts and experiences [68,70]. The aim of meta-synthesis is to produce a new and integrative interpretation of findings that is more substantive than those resulting from individual studies [71]. Single qualitative studies often do not report on generalisability; however, the nature of meta-synthesis allows more scope for tentative generalisable ideas to be made [72], which can more readily be used in clinical practice [73].

### **Systematic Search and Selection of Studies**

A systematic search was completed in November 2021 using four electronic databases covering varying disciplines relevant to stroke rehabilitation; Academic Search Ultimate, Cumulative Index to Nursing and Allied Health Literature (CINAHL), MEDLINE, and Psycinfo. Two specialist librarians from Lancaster University were consulted regarding the search strategy. They advised the inclusion of Academic Search Ultimate over Embase (originally selected) due to Embase and Medline covering similar areas. The search was organised around four distinct concepts: stroke, communication difficulties, rehabilitation, and qualitative methods. With regards to the second concept, a broad search on

“communication difficulties” and synonyms was completed as well as specific diagnoses (aphasia/dysphasia, dysarthria, and apraxia of speech). Relevant subject headings were identified using database thesaurus functions where possible. (See Appendix B for complete search terms). Within concept terms were searched in titles and abstracts and combined using the Boolean operator ‘OR’. All four concepts were then combined using the Boolean operator ‘AND’. Figure 1 details the search process.

[INSERT FIGURE 1]

### **Inclusion and Exclusion Criteria**

Studies were included in the review if: (a) the study was published in a peer-reviewed journal (to ensure a minimum level of quality appraisal), (b) the study was written in English, (c) the study used inductive qualitative methodology (or mixed methods where qualitative data met these criteria), (d) the analysis focused on experience and was derived from first-person accounts, (e) the study focused on stroke rehabilitation interventions including some element of barriers and/or facilitators which could be synthesised, (f) the study included findings relevant to stroke survivors with communication difficulties. The participant sample was not required to be stroke survivors; studies were also included if they explored the perspectives of others (e.g., staff members, family, or carers).

Studies were excluded if: (a) it was not possible to identify findings specific to those with post-stroke communication impairments, (b) there was a focus only on the acute phase of stroke care (studies which included acute and longer-term rehabilitation were included), (c) the study was not original peer-reviewed research (e.g., literature review). The included studies were synthesised with the relevance of clinical psychology within stroke rehabilitation in mind.

The search retrieved a total of 1,089 results. The articles were collated into a referencing software (EndNote), before being screened by title and abstract to assess eligibility for inclusion. Where relevance could not be ascertained by title and abstract, the full text was retrieved. The reference lists of included studies were also scanned to identify any additional articles; one further study was included as a result.

### **Characteristics of Studies**

Sixteen studies were included in the meta-synthesis. One of these [74] was not returned in the original search strategy but met criteria and was subsequently identified using Google Scholar. The paper was identified when searching for the prevalence of perspectives of psychologists on the topic. It was likely not identified with the original search as the first concept (stroke) was not written in the title or abstract, only within the main body of text. All papers were published between 2016 and 2021 and drew on 15 different samples. Two studies [75,76] used the same sample, however both were included as they had different aims and reported different aspects of the data when identifying themes. Seven papers used samples in Australia, four in the UK, one in the USA, one in Norway, one in Austria, one in the Netherlands, and one across Netherlands and Belgium. Sample sizes ranged from six to 58. The studies included the perspectives of a variety of stakeholders; six included the views of healthcare professionals, six focused on SLTs specifically, one included only mental health providers, one focused on the views of stroke survivors, and two reviews included a combination of perspectives (stroke survivors, professionals, and carers). In terms of data collection, eight papers used one-to-one interviews, six used focus groups, and the remaining two used a combination of both approaches. Studies employed various types of analysis; thematic analysis (7), interpretive description (3), interpretative phenomenological analysis (1), framework analysis (1), grounded theory (1), systematic text condensation (1), and

unspecified qualitative description methods (2). Table 1 provides a summary of the included studies' characteristics.

[INSERT TABLE 1]

### **Appraisal of Study Quality**

There are differing opinions on the necessity and criteria of critical appraisal of articles in qualitative meta-syntheses [77,78]. For this review, the Critical Appraisal Skills Programme (CASP) was selected [79], which is widely used within qualitative reviews. Using structured approaches such as the CASP tool can be valuable when appraising the quality of qualitative research, so long as they are applied appropriately [80]. This tool uses two screening questions and eight subsequent questions to evaluate various aspects of the research (e.g., suitability of research design and recruitment method, rigor of the analysis, and value of the research).

The scoring system developed by Duggleby et al [81] was utilised to assess study quality using the CASP. Within this system, scores ranging from one to three are assigned to articles. A score of one indicates a weak score, where little to no justification is offered for an issue, two indicates a moderate score where issues are addressed but not fully elaborated, and three indicates a strong score where issues are extensively justified and explained. The maximum possible score using this system is 24; scores from this review ranged from 12 to 22 (Appendix C). To add rigour to this process, four papers were appraised by an external peer rater (trainee clinical psychologist). Comparisons were made between ratings, differences discussed, and a final score agreed upon.

The exact meaning of "quality" and "reliability" is contested, particularly within the appraisal of qualitative research [82]. Due to variations in conceptions of what is "good quality" research [83], the CASP scores were not used to exclude any studies from this

review. It is argued that few grounds exist for the exclusion of data due to low methodological quality as useful contributions could be missed [84]. Instead, the checklist was used to reflect on studies and subsequently have an awareness of the weight given to each study within the analysis. Although areas of weakness were identified in some papers, all themes within this review are predicated on papers with varying scores, and therefore not reliant upon weaker-scoring studies.

### **Analysis and Synthesis of Studies**

The identified studies were synthesised using the seven-step process outlined within the meta-ethnographic approach [68]. Firstly, included studies were read several times to ensure familiarity with the data, whilst notes were made on emerging concepts or themes. Relationships between the studies were identified which were relevant to the research question and involved some element/s of either barriers or facilitators to accessing rehabilitation. Britten et al [70] describe the first and second order constructs which were useful to draw upon during this process; first order constructs are the participants' own experiences/interpretations, and second order constructs are the authors' interpretations of these experiences. This then allowed for further comparison between studies to produce third order constructs, which are themes that emerge from the current researcher's own interpretations. Table 2 illustrates how each paper contributed to the final themes of the review.

[INSERT TABLE 2]

### **Results**

The analysis led to generation of four overarching themes, which will each be discussed in relation to barriers and facilitators.

#### **Patient and Family Related Barriers and Facilitators**

This theme encompasses the factors present relating to the stroke survivor themselves or the influence of their families/carers. Fourteen papers contributed to the analysis.

### ***Barriers***

Communication impairment directly contributed to the difficulties that stroke survivors had in getting their rehabilitation needs met [74,85-88]. These types of impairments cause difficulty with word finding, speaking clearly, understanding language, and reading and writing. Accessing interventions to improve psychosocial wellbeing was particularly challenging: “It’s really hard to do counselling work with somebody who doesn’t have any language” [74] (p.6). Understandably, mood difficulties were hard to detect when patients couldn’t express their feelings [87], or relevant information about themselves [86], and misinterpretations were described as inevitable during such conversations [88]:

... it’s just hidden, it doesn’t come on to someone’s radar, they just think they’re withdrawn because they can’t communicate... So, it’s like it might be there but it doesn’t get highlighted to anyone because it’s hidden underneath the communication issues [87] (p.785).

The interaction between communication impairments and mood difficulties was emphasised in terms of how this can impact motivation to engage with rehabilitation [76,89-91]. Stroke survivors in one study described refusing to talk, avoiding social interaction, and having no direction in rehabilitation: “didn’t wanna do anything, learn anything. Just go away and leave me alone” [89] (p.30). The role of adjustment/acceptance was highlighted in terms of engagement; when stroke survivors held unrealistic expectations regarding their recovery (i.e. wanting to regain “normal” speech), they were less able to engage with SLT [91].

Some studies focused more specifically on the challenges of goal setting. It was acknowledged that engaging in some therapies (e.g., counselling or SLT, especially early on in the process) might not be consistent with stroke survivors’ rehabilitation priorities [74,92]

and guiding them to “see the point” of participating was sometimes challenging due to their level of impairment [90]. The more severe the communication impairment, the more likely it was that SLTs perceived they were the decision maker for identifying goals; in these situations, the best that could be hoped for was that the patient agreed with their suggestions:

I have to admit that with some of the ones with severe aphasia, well some might have goals that they are able to express... but many don't and I have to admit that sometimes I just do what I think is best and we might agree that this is what we will do, but it's not like we really negotiate [93] (p.875).

When identifying rehabilitation goals, it was recognised that family members/carers being present was not always beneficial if they were not aligned with the patient in their identified goals [92,93]. “Sometimes relatives can be a barrier... assuming what they're [the patient] wanting” [94] (p.329). Family members were also found to present challenges relating to engagement when they had not yet themselves come to terms with longer-term implications of the impairment and responsibilities required of them [91].

### ***Facilitators***

Including stroke survivors' family members/carers in conversations with professionals was seen to facilitate access to and engagement with rehabilitation. This included general conversations with rehabilitation nurses [76], goal setting discussions, [93,95] and therapies to target mood [75]. Healthcare professionals and carers recognised that this collaboration was important as relatives and carers had a better understanding of the patient's pre-stroke personality and could be a useful resource to facilitate communication [88,92-94]. Carers felt they had: “got a better fix on what that person is thinking and feeling... even though they can't communicate it” [94] (p.329). However, staff members conveyed that they strove to ensure that the stroke survivor's perspective was not lost [92].

Collaboration with family members was also identified as beneficial for building patient rapport, especially if interactions were particularly challenging: “If it’s more severe then I tend to chat to their family members, and you know find out what they love... so that I can interact with them using those, that information” [92] (p.1399). The importance of informing and educating relatives about the rehabilitation process was emphasised to achieve good cooperation: “It is practically impossible to pursue a goal which the partner didn’t find important” [95] (p.3633). Observing patients in their home environment was identified as a useful strategy to gain insight into their personality to better engage them in the rehabilitation process [88,92]: “I think it is not just about asking people, but you need a broad view, a broad observation to complete the puzzle” [88] (p.480).

There were also more naturally occurring, patient related factors recognised to impact upon stroke survivors’ ability to engage with rehabilitation. With time, patients felt more able to re-engage with tasks and activities [89]. Strong bonds with “stroke peers” and interactions with others who had communication impairments encouraged stroke survivors to keep trying [76,89].

### **Staff Related Barriers and Facilitators**

This theme explores how healthcare professionals could help or hinder access to rehabilitation for these stroke survivors. Thirteen papers were included within this theme.

#### ***Barriers***

Healthcare professionals supporting these patients generally felt under-skilled and lacking in the confidence they felt was needed to communicate with them [75,76,85,89,94,96,97]. This caused professionals to have negative feelings either towards themselves or towards communicating with these individuals; feelings of helplessness, foolishness, discomfort, and even dread were described [76,85,97]: “If I know they’ve got aphasia, then I know this is going to be a difficult conversation” [85] (p.3007). Such negative



feelings and experiences of unsuccessful interactions led staff members to avoid encouraging communication [96], or to try and maintain a sense of control by limiting conversations to their specific discipline [85]. Professionals anticipated the interaction might be more challenging if the topic was more complex or open-ended, such as discussing discharges: “That’s such an ambiguous and non-concrete thing to talk about and then anticipating that gets harder” [85] (p.3008).

Professionals reported feeling they didn’t have enough knowledge of or experience in utilising supportive communication strategies to facilitate these conversations [85,96,97]: “I feel like I don’t know where else to go... maybe there’s things out there that I don’t know about that would help us to communicate with these patients” [96] (p.6). In some circumstances, this was even the case for SLTs who expressed uncertainty around using tools to encourage participation in goal setting [93]. For some staff members, using communication strategies was associated with higher cognitive burden, therefore they would revert to their usual practice [85].

Ineffective communication with professionals not only impacted upon stroke survivors’ access to rehabilitation, but it was experienced by them as patronising, infantilising, and disempowering [88,94]: “They treated me like a little boy” [89] (p.31). As a result, they withdrew and were less inclined to participate with rehabilitation [94]. This demonstrates the significant impact that staff-patient communication can have upon stroke survivors’ experience of rehabilitation.

### ***Facilitators***

Several staff related behaviours and strategies were described which could facilitate access to rehabilitation for stroke survivors. Firstly, the use of practical strategies to facilitate mutual understanding [89,92,94,95,97]. These included; simplifying language, breaking

down information, using repetition, and paraphrasing to confirm understanding: “One quickly thinks that one has understood, but maybe one is interpreting... always be very careful” [95] (p.3632). The benefit of healthcare professionals being patient to allow more time for interactions [95,97] and feeling comfortable enough to intuitively modify communication was highlighted [92]. Engagement in rehabilitation could be promoted by developing rapport if such interactions and interventions were person-centred and tailored towards the needs/interests of the individual [75,76,89,90,95]: “It’s trial and error... we know quite quickly if we hit the nail on the head or not” [76] (p.224).

The importance of staff members building rapport and establishing trusting relationships with patients was acknowledged [92,95,96]. Specifically, it was identified that using humour could be beneficial when verbal communication was limited to mitigate embarrassment and provide light relief in challenging therapy sessions; the “lubricant of therapy” [90,92]. “He’d get really frustrated, and then we’d kind of just, I guess using laughter and humour as almost a way of releasing tension I think” [92] (p.1400).

Studies included discussion regarding goal setting with these stroke survivors and how engagement with this process could be encouraged [90,92,93,95]. Particularly in relation to SLT, therapists attempted to strike a balance between patient goals and their own goals; aiming to balance realistic expectations with hope to promote engagement [90,92,93]. “Client participation is not easy, especially when it comes to dealing with unrealistic goals and expectations. Then you need to be aware of what client participation and self-determination is and you need to find a balance” [93] (p.873).

Another key role professionals played in encouraging engagement (particularly with psychological interventions) was reducing stigma and normalising difficulties [74,75,87,89,95]. This was done by educating stroke survivors about the potential impact of

communication impairments on mood [87,89], informing them that referrals to psychology were routine practise [75], and giving examples of others in similar situations [95]:

I think a lot of it is in the pitch in some ways. So rather than saying, ‘We think you've got a problem, we think you're depressed’ where you might get more resistance, I tend to crack the door open and talk about the fact that generally anyone that comes in and has such a big change in their life might benefit from talking to someone, is that something you would be open to? [87] (p.786).

As demonstrated in this example, changing the way that difficulties are addressed can create a more welcoming environment, which can in turn facilitate engagement with rehabilitation.

### **Service-Level Barriers and Facilitators**

Included within this theme are factors which were present on a higher, systemic level within rehabilitation services. Ten papers contributed to the analysis.

#### ***Barriers***

Professionals, stroke survivors, and carers identified challenges which were more systemic and related to the rehabilitation service as a whole. Working or being treated within a medical model framework was recognised as problematic when physical functioning goals were prioritised at the expense of improving communication or managing mood [75,76,94]. One carer expressed: “Their only concern... only concern really was the physical side, it was NOT the speech side... at all” [94] (p.330). This was attributed to the desire to expedite discharge and reduce overall length of stay [75,76]: “There’s very much a focus on getting to walk and getting out of the hospital” [76] (p.223). Even when greater significance was placed upon communication goals, there were times where this was “in competition” with the lesser prioritised psychosocial interventions [76,86]:

I’ve been in teams where I’ve had to really strongly defend keeping someone on my caseload because they are very distressed to a manager, who wants to me to discharge

him because it's not really direct speech therapy work I'm doing. And I'm saying, well, actually, I am supporting them, their life, their new life as a new communicator in this world [86] (p.22).

It was acknowledged that medical teams may lack understanding of the impact communication impairments can have upon stroke survivors and their families [76].

There were also reports of service-level policies and pathways creating challenges to working holistically with these patients due to pressures to focus on SMART (Specific, Measurable Achievable, Realistic, Time-bound) goals [86,90]. SLTs reflected that pressure to “do therapy” and meet such targets was often in conflict with developing a therapeutic relationship and responding to patient emotions, as this was seen as more fluid and harder to outcome: “There's nothing to record, nothing to document, because you could be weeks just talking about how they're feeling” [86] (p.23). Such external expectations sometimes led to goals and plans being implemented which were not in line with stroke survivor's wishes [93].

The way in which services were commissioned was noted to restrict flexibility with the number of sessions and type of support SLTs could offer in the long-term [86,91] (e.g. intensive therapy in the first three months, even if patients were not ready). SLTs in Northcott et al [86] highlighted that training in identifying and managing psychosocial difficulties was not facilitated by management. In one American study, the additional barrier of insurance to cover the cost of mental health treatment was highlighted when these patients were often unable to work [74]. As a result of such restrictions, it seems that challenges in providing psychosocial support for stroke survivors appeared to continue throughout their rehabilitation pathway.

### ***Facilitators***

Within all papers, there was an absence of service-level facilitators identified as already present within the services participants worked or were treated in. However,

suggestions were offered by professionals regarding what they believed could facilitate communication and engagement with rehabilitation for these patients.

The most prominent factor identified was the importance of management ensuring that training is made available for staff members [74-76,86,97]. Training to increase knowledge and awareness of communication difficulties [74] and the impact they can have upon relationships and psychological adjustment was noted, especially for medical teams [75,76,97]: “but aphasia is often misunderstood. If a person cannot talk, many people believe this person doesn’t understand either... In an ideal world, everyone who works in this healthcare centre receives education on what it means to have aphasia” [97] (p.5). Additionally, training and education in supportive communication techniques [76,97] and mood assessment/intervention with these patients [75,76] was highlighted.

Also identified was the importance of the service facilitating access to a stroke specialist clinical psychologist to support with management of mood difficulties [75,76,86]. Another suggestion offered by professionals was increased access to supportive communication strategies and tools [96,97]. It was acknowledged that skills and even motivation could improve if staff members knew where to find and how to use them effectively.

### **Multi-Disciplinary Working Related Barriers and Facilitators**

This theme encompasses factors relating to collaborative working between disciplines within stroke rehabilitation. Nine papers were included in this theme.

#### ***Barriers***

Difficulties were identified regarding meeting the needs of patients in relation to their mood when there was a lack of clarity or blurred boundaries within MDT roles [76,86-88]. In general, SLTs felt the management of mood difficulties often fell to them, either due to lack

of access to specialist psychological support [87,91], or other professionals having limited knowledge, skills, or confidence in communicating [76,87]: “The psychologist couldn’t understand what she was talking about and she was so embarrassed she left” [87] (p.786). This was commensurate with views of mental health providers: “You’re trained to sit and listen to the patient and get them to talk about their problems but a patient with aphasia can’t do that” [74] (p.8).

However, some SLTs felt ill-equipped to influence motivational readiness for rehabilitation [90] or just to have conversations with these individuals about psychological difficulties [91]:

...there’s not been any formal training in terms of how you might approach certain things with people... or how you might guide them to talk about certain things. We haven’t had anything like that but that would certainly be something that would be extremely valuable... we haven’t got access to psychology or counselling that easily, we are doing an awful lot of it, a lot of the time [91] (p.421).

SLTs struggled with the emotionally demanding nature of these conversations, especially when they were unsure if it was part of their role, or they felt unsupported by the wider MDT [86]. This led to avoidance of exploring emotional difficulties: “I don’t think I would be very comfortable digging because I don’t know what to do... with the information” [86] (p.22).

In terms of the provision of mental health services, it was identified that often individuals with communication impairments were perceived as unsuitable for direct therapeutic work [74], resulting in medication being the more commonly offered intervention [86,87]:

So even though the clinical psychologist will go and see them it wouldn't be uncommon for them to come back out of the session and say there's not really anything that I can do because they can't communicate at that level [87] (p.785).

This resulted in a 'catch-22' at times as communication therapy was seen to be hindered by mood difficulties, but psychological therapies were perceived as not possible in the absence of a certain level of communication ability [87].

### ***Facilitators***

Some professionals recognised the impact that communication could have upon self-identity, roles, overall mood, and subsequently engagement with rehabilitation, and therefore took a more holistic approach to managing concomitant communication and mood difficulties [74,76,87,88]. Specifically, SLTs identified their sessions with patients as; a quiet time to discuss feelings [76], a way to indirectly target mood by preparing patients for later participation in psychological interventions [87], or a way to at least identify difficulties with mood to signal to other professionals [74,88]. "During other treatments, communication is less prominent, so when I think of the rehabilitation setting, we [the SLTs] are the first persons to offer patients a chance to talk about it" [88] (p.479).

Understandably, it was acknowledged that a holistic approach (to mood management specifically, but also to general rehabilitation) was only possible when professionals from other disciplines were available to work collaboratively. The benefit of collaborative MDT working was emphasised [74,76,86,88,92,94]. A collaborative relationship between SLT and psychology led to an increase in referrals for mental health services: "The SLP would often walk the patient down the hall and say 'there's someone I want you to meet who maybe you could talk to about some of this stuff'" [74] (p.7).

Such collaborative working was noted to include; shared clinical decision making/problem solving, joint sessions, informal peer support, and opportunities for reflection, which subsequently resulted in reduced anxiety for SLTs in addressing mood and increased awareness/knowledge about communicating for psychologists [74,76,86]. “Working jointly or knowing that others in the team know a client well, meant shared responsibility, that it was ‘not just on my shoulders’” [86] (p.21). Joint working in this way was helpful to support patients’ wellbeing [74,76,88], particularly when there was a perceived sense of equality between professions with both disciplines being keen to learn from one another [86].

### **Discussion**

This meta-synthesis drew from data across a range of literature to enable new insights to be generated from the perspectives of stroke survivors with communication impairments, their carers, and healthcare professionals. The literature varies according to sample, country, methodology, and stakeholder perspective, however, converges in highlighting factors which can help or hinder these individuals in accessing rehabilitation.

The findings indicated that stroke survivors with communication impairments often found their needs were unmet during rehabilitation. This was highlighted as particularly relevant to psychological wellbeing, due to patients’ inability to effectively express their feelings. It has been acknowledged that communication impairments sometimes mask depressive symptoms and subsequently hinder identification of them [43,98]. However, these were not the only difficulties identified regarding psychological support.

The review builds on existing literature highlighting the complexities present within collaborative MDT working in stroke rehabilitation. SLTs often felt they were lacking in the knowledge and confidence to support patients with their psychological wellbeing, as



acknowledged within previous research [99-101]. Similarly, the sense that mental health services were inaccessible or that professionals were not equipped with the skills to communicate with patients is supported by existing literature [100]. However, the current review provided a comprehensive analysis of relevant literature, offering a more detailed explanation of the interplay between these MDT roles. For example, the challenges faced by SLTs with managing mood goes further than the practicality of not knowing what to say; they were also affected by the emotionally demanding nature of the conversations, which created more anxiety.

When a holistic approach was not taken regarding concomitant mood and communication difficulties, patients were often considered unsuitable for therapeutic intervention and were more commonly offered medication [86,87]. The benefit of collaborative working between SLTs and psychologists has previously been acknowledged [99-101]. The current findings extend this understanding by identifying how this reduced anxiety for SLTs, meaning they were able to utilise their sessions; to begin discussions with patients about their feelings and as a stepping-stone to prepare them for later engagement in psychological therapies. The importance of each discipline being willing to learning from the other and perceiving each other as equal was highlighted. This echoes previous findings which recognised that all members of the rehabilitation team need a desire to collaborate for MDT working to be effective [102].

The findings emphasised challenges that concomitant communication and mood difficulties can pose in relation to stroke survivors' motivation to engage with rehabilitation. It is perhaps unsurprising that these patients might struggle with engaging, given that participation with life more generally has been indicated as challenging [103-105]. Goal setting with stroke survivors is recognised as encouraging engagement when individuals are actively involved and when goals were based on mutual understanding [106]. However, the

review details the complex nature of goal setting with stroke survivors who have communication impairments, and how this can be challenging for clinicians to navigate. The communication impairment itself was recognised as a barrier to involving patients in this process, reducing their level of autonomy. Another barrier was the mismatch between patient and therapist goals. This echoes findings from a previous meta-synthesis, which recognised this to be a major barrier for stroke survivors, even in the absence of communication difficulties [107]. The current review builds on this understanding by acknowledging the navigation required by therapists (usually SLTs) in terms of balancing realistic expectations with hope to promote engagement. The importance of fostering hope through a process of clinicians knowing when and how much to push/challenge patients has been identified [62].

Although a focus on SMART goals is often recommended within rehabilitation [108], the review identified that this placed heightened pressures upon clinicians, which conflicted with developing a therapeutic relationship and offering person-centred care. The prioritisation of physical functioning goals over communication or emotional goals was recognised, which has been acknowledged previously [44]. This understanding is extended by the current findings as this was attributed to the aim of expediting discharge and reducing overall length of stay.

In previous reviews, family member involvement was problematic when they provided staff members with inaccurate information about the patient [64], or were perceived as speaking for the patient, [63,64] which could then result in professionals doing the same [63,65]. The current review builds on this, finding that family members also provided challenges when they were not aligned with the patient in their goals, when they made assumptions about the patient's desires, or when they had not yet adjusted to longer-term implications of the impairment. Despite this, family members/carers involvement was

identified as helpful at times as they often knew the patient best and could provide relevant information and assistance [64,65].

Other reviews identified interactions between nurses and these patients as task-focused, nurse-controlled, and associated mainly with physical needs [26,64]. The current review found these behaviours were not specific to nurses and that other healthcare professionals would sometimes avoid interactions or limit their conversations to basic, discipline-specific topics. Such behaviours were identified as a way of professionals attempting to maintain a sense of control over interactions which they felt under-skilled or lacking in confidence to be part of.

### **Clinical Implications**

An interesting observation was the absence of facilitators identified by participants at a wider, organisational level. This suggests that professionals perceived there to be problems with the support offered by services to facilitate access to rehabilitation for these patients. However, they did offer several suggestions for improvements, including increased access to and provision of training.

As previously stated, a wide range of professionals work into stroke rehabilitation [21-23] and it seems sensible for each discipline to share knowledge relating to their specific expertise with the wider team. This could then result in increased confidence within all disciplines. Based on the findings, training within the following areas should be prioritised. SLTs sharing their knowledge about specific communication impairments, what they know about each individual, and what supportive communication strategies they would recommend. Previous research has identified the important role leadership also hold regarding this to ensure that SLT guidelines and recommendations are being implemented [109]. Another focus of training should be for psychologists to increase awareness of

communication impairments and the profound psychosocial impact they can have upon stroke survivors and their families, as well as guidance regarding addressing these concerns with them. One study included in the review highlighted that ‘generic training’ on addressing psychological needs without follow up was not useful and difficult to apply in practise [85]. SLTs in the study instead suggested that being able to see this modelled by psychologists and having opportunities to discuss specific cases would be valued.

Clinical guidelines state that provision of psychological care within stroke rehabilitation should be commissioned with the same emphasis as physical care [110] and that this is best delivered in a service with full access to clinical psychology. Although the findings of the review support these recommendations, they also highlight that, for patients with communication impairments, such guidelines are not consistently applied. A holistic approach to intervention within a culture of collaborative MDT working (particularly between SLT and psychology) is crucial to meeting the needs of these individuals. The findings of the review indicate that such collaborative working could improve patient engagement with the interventions being offered to them, as well as psychological adjustment to their impairment/s.

Although direct therapeutic work with stroke survivors with communication impairments is often possible when the appropriate adaptations and training are provided, the importance of indirect work should also be emphasised. Clinical psychologists hold a variety of skills which could be applied effectively to help overcome some of the barriers identified in the review [111]. This includes providing clinical supervision/consultation to other professionals to normalise reactions to working with these individuals as well as supporting caregivers to develop psychological formulations.

A final consideration should be the role of family members/carers within the rehabilitation process. It is important that patients and families are provided with accessible

information regarding the nature of the communication impairment, the potential psychosocial impact, and the types of rehabilitation interventions they can expect. This should better prepare these individuals for goal setting and engaging with rehabilitation. The impact of Covid-19 related restrictions on family/carer involvement cannot be ignored [112] and recommendations are made regarding increased virtual access and support in the future.

### **Strengths, Limitations, and Future Research**

The present review draws upon up-to-date and relevant research; all papers included were published within the past seven years, with 12 of the studies published during or after 2020. This indicates that findings and recommendations identified are relevant to the current state of stroke rehabilitation. The polyvocal approach of this review can be considered a strength as it enabled the voices of a variety of stakeholders to be included. However, it should be acknowledged that in taking this approach, a greater proportion of studies focusing on the perspectives of certain stakeholders were included, meaning that there was an uneven representation of perspectives overall.

Firstly, the perspectives of stroke survivors and their families/cares were outweighed by the perspectives of professionals, with only three papers including patients with aphasia and only one paper including carers. Of the stroke survivor participants, none were experiencing communication impairments other than aphasia and 12 of the included studies also specified aphasia as the condition they were researching. Therefore, it is possible that the findings are not representative of stroke survivors experiencing dysarthria or apraxia of speech. Interestingly, despite the predominance of the psychosocial impact of communication impairment within the themes of the review, there was only one paper included which had a sole focus upon the perspective of mental health professionals. Six papers included perspectives of various healthcare professionals, three of which included psychologists. However, this is minimal in comparison to the prevalence of SLT participants (10 papers

overall, six featuring SLTs only). Additionally, although studies included recruited participants from a range of countries, these remain biased towards Western countries. This limits the geographical applications of findings.

As indicated above, further efforts are required to address the discrepancies noted in perspectives of stakeholders contributing to this field. It is important that voices of stroke survivors with communication impairments and their families/carers contribute more to this literature. It is recognised that these individuals can often be excluded from research as they are perceived as impossible to interview [113]. However, it has been demonstrated that this is not the case when appropriate adaptations are made to make the process more accessible [114,115]. Specifically, the perspectives of stroke survivors with communication impairments other than aphasia should be sought.

In terms of professionals, further research focused upon perspectives of mental health professionals, specifically clinical psychologists who specialise in stroke rehabilitation would be useful. This would allow more detailed comparison between these perspectives and SLTs/other professionals. It would be interesting to consider how the findings of this review (specifically relating to MDT working and psychological care) would change with a higher representation of mental health professionals' perspectives.

## **Conclusion**

This meta-synthesis highlights a multitude of factors which can either help or hinder stroke survivors with communication difficulties in accessing appropriate rehabilitation interventions, from the perspectives of healthcare professionals, stroke survivors, and carers. Findings add to current understanding by emphasising the importance of collaborative MDT working across disciplines within a service where expertise are shared, and training is prioritised. Without this approach to care, these patients are at risk of being excluded from or

feeling unable to engage with person-centred interventions. In the absence of effective collaborative working and appropriate training, professionals often feel lacking in the confidence and/or knowledge to be able to communicate with and support these individuals effectively. This is especially the case in terms of detection and treatment of psychosocial difficulties for these patients, which present particular challenges in terms of collaborative working.

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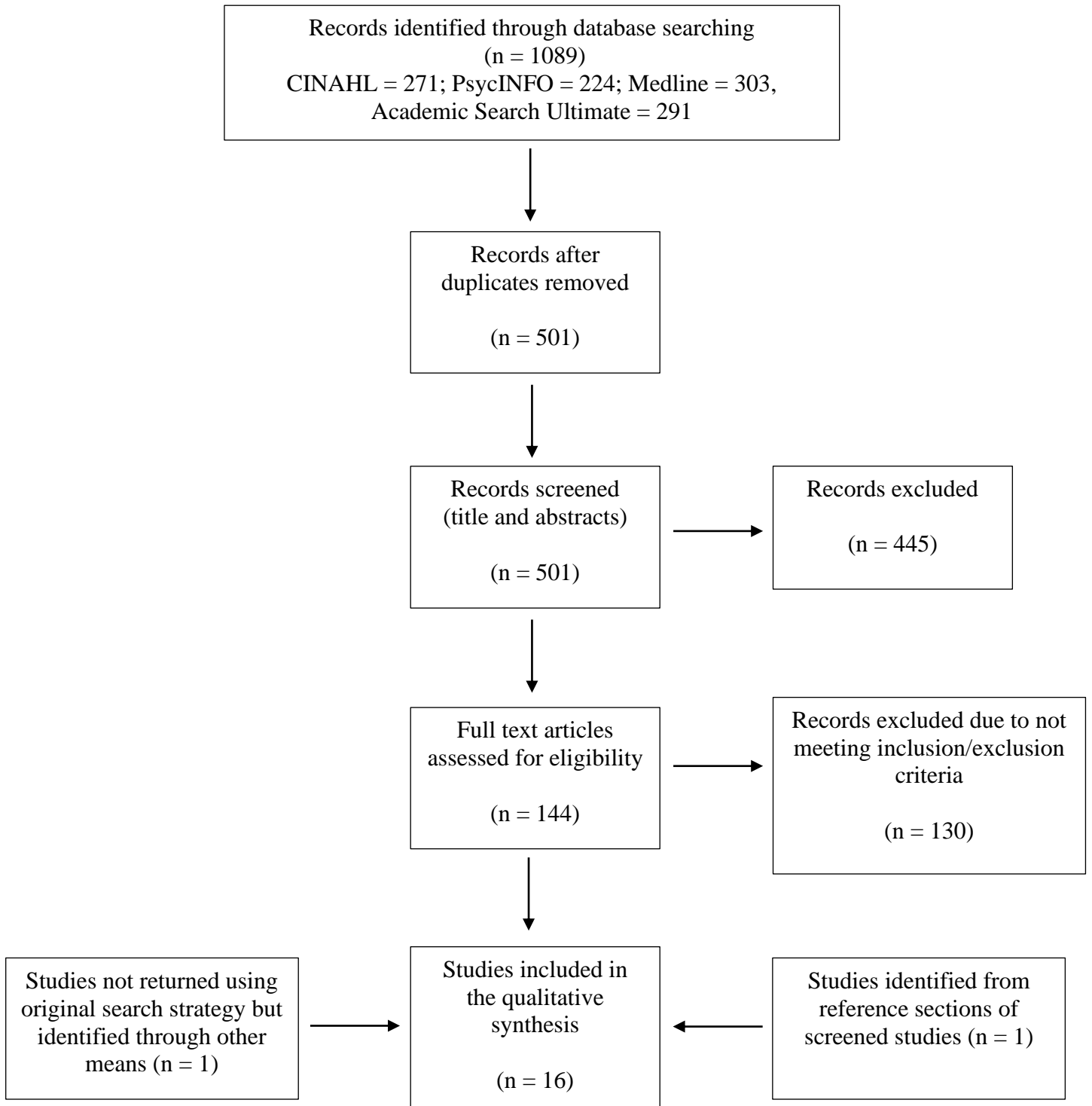
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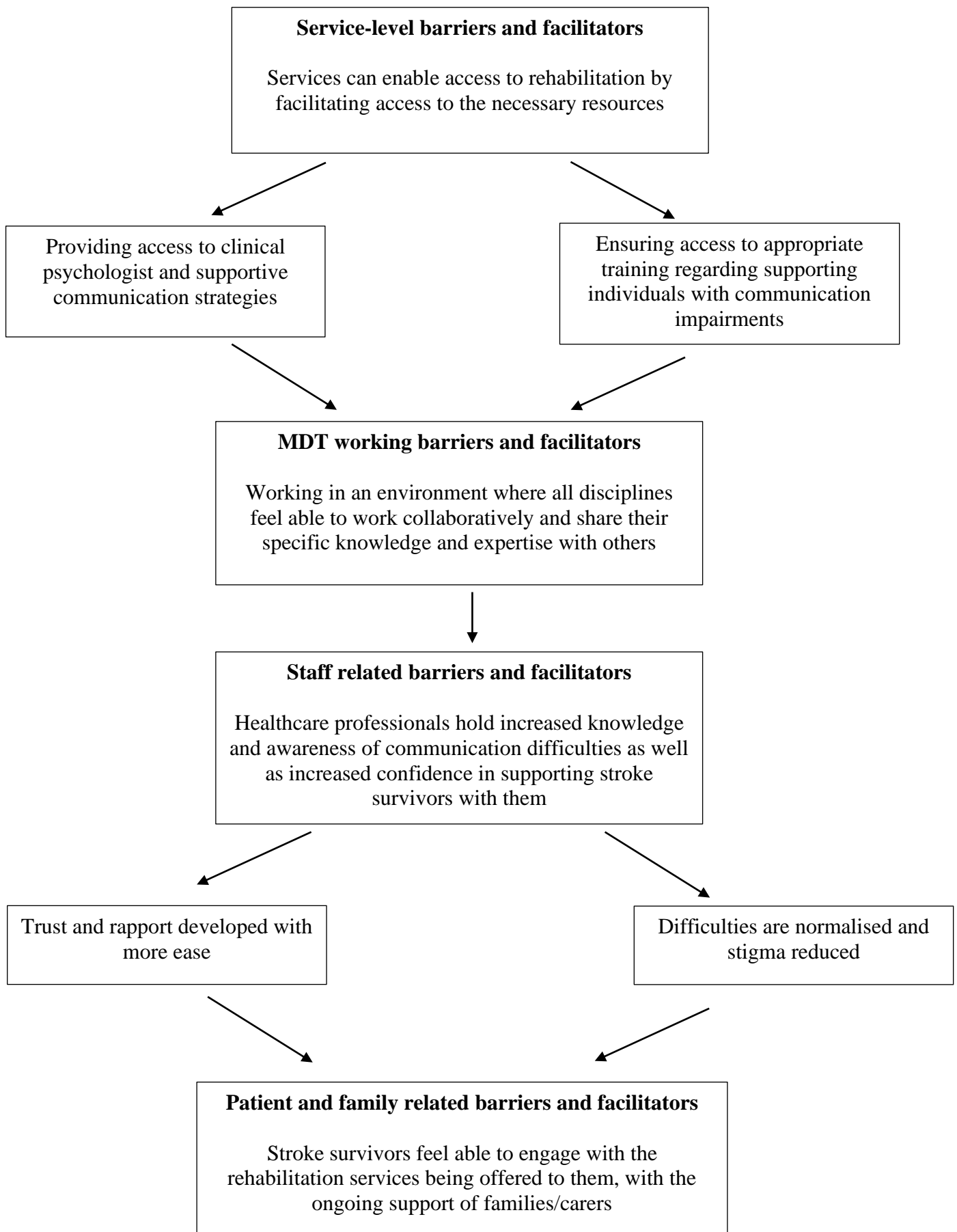
**Figure 1**

*Flow diagram of the systematic search process*



**Figure 2**

*Visual representation of themes*



**Table 1***Summary of the included papers*

Authors	Research question/Aim	Participants	Data Collection	Methodology	Location
Baker et al (75)	To identify, from the perspective of stroke health professionals, the barriers and facilitators to implementing stepped psychological care for depression after post-stroke aphasia.	39 stroke health professionals	Semi-structured focus groups	Interpretive Description	Australia
Baker et al (89)	To describe, from the perspective of people with aphasia: a) the experience of mood changes, depression, and current practice after post-stroke aphasia, and b) preferences within a stepped psychological care approach	10 stroke survivors with aphasia	Two semi-structured interviews within a period of 1-2 weeks (using supportive communication strategies)	Interpretive Description	Australia
Baker et al (75)	To explore current practice for managing depression after post-stroke aphasia from the perspective of stroke health professionals.	39 stroke health professionals	Semi-structured focus groups	Interpretive Description	Australia
Berg et al (93)	To investigate how speech pathologists experienced client participation during the process of goal-setting and clinical decision making for people with aphasia.	20 speech pathologists	Semi-structured focus groups	Systematic Text Condensation	Norway



Carragher et al (85)	To explore the experiences of the acute and subacute multidisciplinary stroke team with regards to healthcare communication with patients with aphasia.	16 healthcare professionals	Semi-structured focus groups	Inductive, semantic thematic analysis	Australia
Clancy et al (94)	To seek insight into the experiences of stroke survivors with aphasia, carers and healthcare professionals in four key areas: (1) the experienced and preferred communication styles used by healthcare professionals and stroke survivors with aphasia in stroke care settings; (2) the perceived barriers and facilitators to effective communication in these settings; (3) experiences of communication roles during staff–patient interactions in these settings; (4) the perceived impact of communication on patient engagement in stroke rehabilitation.	6 stroke survivors with aphasia, 10 carers, 6 healthcare professionals	Combination of one-to-one and focus group interviews	Thematic analysis	United Kingdom
D’Souza et al (97)	To explore barriers and facilitators to patient communication in an acute and rehabilitation ward setting from the perspectives of hospital staff,	51 healthcare professionals, 7 stroke survivors (3 with aphasia)	Semi-structured focus groups and interviews	Qualitative description approach	Australia

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	volunteers and patients following stroke.				
Dörfler & Kulnik (95)	To explore strategies that are used in rehabilitation to involve stroke survivors with communication and/or cognitive impairment in person-centred goal-setting.	11 stroke rehabilitation professionals	Semi-structured interviews	Thematic analysis	Austria
Lawton et al (90)	To explore speech and language therapists' perceptions and experiences of developing and maintaining therapeutic alliances in aphasia rehabilitation post-stroke.	22 SLTs	Semi-structured interviews	Inductive thematic analysis	United Kingdom
Northcott et al (86)	To explore how SLTs conceptualise the scope of their role; barriers and facilitators to SLTs addressing psychosocial needs; and SLTs' experiences of specialist training and support, and working with mental health professionals (MHPs).	23 SLTs	Focus groups	Framework analysis	United Kingdom
Ryan et al (87)	To investigate SLPs' perspectives on how they currently support help-seeking for mood problems in people with aphasia and factors they perceive to be impacting service uptake.	18 SLPs	Semi-structured interviews	Inductive thematic analysis	Australia

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Stagg et al (92)	To gain an understanding of the practices and processes used by allied health clinicians to establish and maintain working alliances with people with stroke-related communication impairment in rehabilitation.	11 allied health clinicians	Interviews	Grounded theory	Australia
Strong & Randolph (74)	To explore the experiences of mental health care providers who provide services to people living with aphasia.	6 mental health providers	Semi-structured interviews	Interpretative Phenomenological Analysis (IPA)	United States of America
van Ewijk et al (88)	To describe how Dutch SLTs, working with people with aphasia in a private practice or a healthcare setting, address patient's subjective wellbeing (SWB) during diagnosis and treatment, and to identify barriers and facilitators they experience when addressing SWB.	8 SLTs	Interviews and focus groups	Phenomenological approach	Netherlands
van Rijssen et al (97)	To explore and describe the experiences of healthcare professionals in communicating with people with aphasia and their needs and wishes for the content in communication partner training.	17 healthcare professionals	Semi-structured interviews	Thematic analysis	Netherlands and Belgium
Wray et al (91)	To explore UK SLTs views of “self-management” as an approach in stroke rehabilitation including its application	18 SLTs	Semi-structured interviews	Inductive thematic analysis	United Kingdom

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in practice with stroke survivors with  
aphasia.

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**Table 2***Contribution of each study to meta-synthesis themes*

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
<b>Patient and family related barriers</b>		x	x	x	x	x			x	x	x	x	x	x		x
<b>Patient and family related facilitators</b>	x	x	x	x		x		x				x		x		
<b>Staff related barriers</b>	x	x	x	x	x	x	x									x
<b>Staff related facilitators</b>	x	x	x	x		x		x	x		x	x	x			x
<b>Service-level barriers</b>	x		x	x		x			x	x			x			x
<b>Service-level facilitators</b>	x		x				x			x			x			x
<b>Multi-disciplinary working barriers</b>			x						x	x	x		x	x		x
<b>Multi-disciplinary working facilitators</b>			x			x				x	x	x	x	x		

## Appendix A - Search Strategy

Search terms (combined with AND)	Stroke	Rehabilitation	Communication difficulties	Qualitative
	"cerebrovascular accident*" OR "cerebrovascular apoplexy" OR cva OR stroke	rehabilitation OR therap* OR treatment* OR intervention*	(communication OR speech) N5 (difficult* OR problem* OR challenge* OR impair* OR disorder*) OR aphasia OR dysarthria OR "apraxia of speech"	qualitative OR "thematic analysis" OR "interpretative phenomenological analysis" OR ipa OR "grounded theory" OR "narrative analysis" OR interview* OR "focus group*" OR "mixed method*" OR mixed-method* OR survey*
<b>Subject headings by database</b>				
CINAHL	MH "Stroke+"	MH "Rehabilitation" OR MH "Occupational Therapy" OR MH "Physical Therapy" OR MH "Speech-Language Pathology"	MH "Aphasia+" OR MH "Dysarthria+" OR MH "Apraxia of Speech (Acquired)"	MH "Qualitative Studies+"
Academic Search Ultimate	DE "STROKE" OR DE "HEMORRHAGIC STROKE" OR DE "ISCHEMIC STROKE" OR DE "LACUNAR STROKE"	DE "REHABILITATION" OR DE "NEUROPSYCHOLOGICAL rehabilitation" OR DE "VOCATIONAL rehabilitation"	DE "APHASIA" OR DE "DYSARTHRIA" OR DE "SPEECH apraxia"	DE "QUALITATIVE research" OR DE "FOCUS groups" OR DE "INTERVIEWING" OR DE "THEMATIC ANALYSIS" OR DE "GROUNDED theory"
MEDLINE	MH "Stroke+"	MH "Rehabilitation" OR MH "Rehabilitation, Vocational" OR MH "Recreation Therapy" OR MH "Occupational	MH "Aphasia+" OR MH "Dysarthria"	MH "Qualitative Research" OR MH "Grounded Theory"

PsycINFO	DE "Cerebrovascular Accidents"	Therapy" OR MH "Neurological Rehabilitation" OR MH "Stroke Rehabilitation" OR MH Rehabilitation of Speech and Language Disorders" DE "Rehabilitation" OR DE "Cognitive Rehabilitation" OR DE "Neuropsychological Rehabilitation" OR DE "Occupational Therapy" OR DE "Physical Therapy" OR DE "Psychosocial Rehabilitation"	DE "Aphasia" OR DE "Dysphasia" OR DE "Dysarthria"	DE "Qualitative Methods" OR DE "Focus Group" OR DE "Grounded Theory" OR DE "Interpretative Phenomenological Analysis" OR DE "Narrative Analysis" OR DE "Thematic Analysis"
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**Appendix B - CASP Scores for Included Studies**

Study	Research design	Recruitment strategy	Data collection	Reflexivity	Ethical issues	Data analysis	Findings	Value of research	Overall
Baker at al (75)	3	3	3	2	1	2	3	2	19
Baker et al (89)	3	2	3	1	3	2	3	2	19
Baker et al (76)	3	3	3	2	1	3	3	2	19
Berg et al (93)	3	2	2	3	2	2	2	2	18
Carragher et al (85)	3	2	2	2	2	3	3	2	19
Clancy et al (94)	2	2	2	3	2	2	2	2	17
D'Souza et al (96)	1	1	1	2	2	1	2	2	12
Dörfler & Kulnik (94)	1	3	2	2	3	1	2	2	16
Lawton et al (90)	3	3	2	3	2	3	3	3	22



SYSTEMATIC LITERATURE REVIEW

Northcott et al (86)	2	2	3	2	2	2	2	3	18
Ryan et al (87)	2	2	3	2	2	1	2	2	16
Stagg et al (92)	2	2	2	2	1	1	2	2	14
Strong & Randolph (74)	1	2	2	1	1	2	2	2	13
van Ewijk et al (88)	1	1	2	1	2	3	2	2	14
van Rijssen et al (97)	2	2	2	2	1	2	2	2	15
Wray et al (91)	2	3	3	2	2	3	2	2	19

**Appendix C - Theme Extraction**

Authors	Theme Extraction
Baker et al (75)	<p>Core theme 1: Knowledge, skills, and attitudes have the most impact of implementing stepped psychological care</p> <ul style="list-style-type: none"> <li>• Barriers: stroke health professionals' lack of knowledge, skills, and negative attitudes</li> <li>• Facilitators: stroke health professionals' improving skills, knowledge, and attitudes</li> <li>• Barriers related to people with aphasia and their significant others</li> <li>• Facilitators for people with aphasia and significant others: understanding aphasia, mood difficulties and depression after stroke</li> </ul> <p>Core theme 2: The physical environment impacts on managing depression and communication disability for people with aphasia</p> <ul style="list-style-type: none"> <li>• Barriers: lack of quiet areas for counselling, social hubs for interaction and resources</li> <li>• Facilitators: modification of physical environment to enhance mood and communication access</li> </ul> <p>Core theme 3: the support and leadership of the health organisation influence change in any implementation of a stepped psychological care approach</p> <ul style="list-style-type: none"> <li>• Barriers: lack of leadership and resources such as funding and staff</li> <li>• Facilitators: Strong leadership and resources such as psychologists</li> </ul>
Baker et al (89)	<p>Core theme 1: The onset of stroke and aphasia is a traumatic event resulting in mood difficulties and depression</p> <ul style="list-style-type: none"> <li>• Concomitant aphasia and depression result in disengagement in stroke rehab and social activities</li> </ul> <p>Core theme 2: People with aphasia are trying to work through communication and mood difficulties with limited psychological support and services in stroke rehabilitation</p>

- Low mood and depression are infrequently addressed in stroke rehabilitation
- Stroke health professionals sometimes lack a full understanding of the history and communication needs of the person with aphasia to effectively address low mood and depression
- People with aphasia are not always supported to communicate, be independent or make decisions in stroke rehabilitation which impacts on mood

Core theme 3: Positivity, supported communication and access to individually tailored therapy through stepped psychological care would be essential to people with aphasia

- Communication support with positive attitudes are needed to address low mood and depression in stroke rehabilitation
- People with aphasia need information and choice of tailored therapy to manage low mood and depression
- Relationships with family, friends and stroke peers are very important in managing low mood and depression
- Improving awareness of psychologists' role and access to services are required

Baker et al (76)

Core theme 1: concomitant aphasia and depression after stroke is a challenging area of rehabilitation

- Aphasia is a specialty with lack of clarity in multidisciplinary roles for managing depression
- Seeking ways to support each other due to the emotionally challenging work
- Acknowledging training needs
- Depression impacts on engagement in stroke rehabilitation

Core theme 2: Mood difficulties and depression are not always a high stroke rehabilitation priority

- Priority differs across care settings
- Focus on other impairments and functions

Core theme 4: Stroke health professionals are trying to bridge the gap between clients' psychological care needs and limited services

- Finding what works
- Building and maintaining relationships with family members
- Seeking external help

Berg et al (93)

Theme 1: Client-oriented participation

Theme 2: Next of kin-oriented participation

Theme 3: Professional-oriented participation

Carragher et al (85)

Major theme 1: Health professionals find communicating with patients with aphasia to be a negative experience

- It is time consuming to communicate with patients with aphasia
- It is really hard to communicate with patients with aphasia
- Negative perceptions about communicating with patients with aphasia

Major theme 2: Health professionals do not know how to help

- Inadequate skills to communicate with patients with aphasia
- Strategies are not always effective

Major theme 3: Health professionals limit their conversations with patients with aphasia

Clancy et al (94)

Theme 1: Being in a foreign country

Theme 2: Finding a voice

Theme 3: You're just a number

D'Souza et al (97)

Major theme 1: Barriers to communication

- Subtheme b: Staff-related barriers

Major theme 2: Facilitators to communication

- Subtheme b: Staff-related factors

Dörfler & Kulnik (95)

Theme 1: Flexibility

Theme 2: Trusting relationships

Theme 3: Enabling empowerment

Theme 4: Techniques for one-to-one interaction

Theme 5: Involving relatives

Lawton et al (90)

Theme 1: Laying the groundwork

- Sharing expectations
- Activating ownership

Theme 2: Augmenting cohesion

- Being responsive
- Resolving conflict

Theme 3: Contextual shapers

Northcott et al (86)

Theme 3: Factors that enabled SLTs to provide psychological support to people with aphasia

- Specialist ongoing support
- Support of management/whole team approach
- Value of experience

Theme 4: Barriers to SLT delivering psychosocial support

- Emotionally challenging/feeling under-skilled
- Caseload and time pressures

- Attitude of senior managers and commissioners
- Goal-orientated, outcome driven services
- People with aphasia with complex needs or backgrounds

Theme 5: Training in psychosocial approaches

- Training received
- Confidence in exploring emotions
- Challenges and limitations to training

Theme 6: Mental health professionals addressing the psychosocial wellbeing of people with aphasia

- MHPs and aphasia
- Referral systems
- Communicative and collaborative working between SLTs and MHPs
- Limitations of MH service provisions

Ryan et al (87)

Theme 1: SLP's understanding of barriers and facilitators to people with aphasia seeking help

- Barriers and facilitators specific to people with aphasia

Theme 2: SLPs as skilled helpers for mood management

- Normalising the need for the patient to seek help
- Referral and advocacy
- The complexity of role boundaries

Theme 3: Competing priorities between patient mood intervention and stroke rehabilitation intervention

- What takes precedence: mood or communication?

Stagg et al (92)

Theme 1: Enabling interaction

Theme 2: Being responsive

Theme 3: Building relational capital

Theme 4: Building credibility

Strong & Randolph (74)

Theme 1: Barriers

- Subtheme 1.A: Training
- Subtheme 1.B: Stigma
- Subtheme 1.C: Accessibility of services

Theme 2: Interprofessional collaboration

- Subtheme 2.A: Referrals
- Subtheme 2.B: Increased knowledge and awareness

Theme 3: Therapy looks different

- Subtheme 3.A: A new approach
- Subtheme 3.B: Challenges

van Ewijk et al (88)

Theme 2: SLTs experience more responsibility for patients' subjective wellbeing than their profession allows

Theme 3: Collaboration between SLTs and patients, patients' network, and other healthcare professionals is required to address subjective wellbeing during diagnosis and treatment

Theme 4: Misinterpretations are inevitable when SLTs or patients' networks address patients' subjective wellbeing

van Rijssen (97)

Theme 1: Communication difficulties impede healthcare activities

Theme 2: Improving communication through organisational changes

Theme 3: Improving communication by changing the roles of SLTs

Theme 4: Improving communication by increasing knowledge and skills of HCP

Wray et al (91)

Theme 2: Barriers to enabling self-management

- Lack of resources for SLT in the community setting
  - Stroke survivors' "readiness" to engage in self-management
  - Difficulties involving family members in rehabilitation
  - Lack of availability of other services to support self-management
-



## **Appendix D - Author Guidelines for *Disability and Rehabilitation***

### **Instructions for authors**

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements.

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*Updated 12-11-2021*

**Section Two: Research Paper**

The experience of identity and dysarthria following stroke: An interpretative  
phenomenological analysis

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### Abstract

**Purpose:** Although dysarthria is a common consequence of stroke, there is a paucity of research focused upon this topic. This study aimed to explore the experiences of stroke survivors who have dysarthria in relation to their identity, or how they feel about themselves.

**Materials and Methods:** Data was collected through semi-structured interviews with seven dysarthric stroke-survivors and analysed using interpretative phenomenological analysis (IPA).

**Results:** The following four themes were generated from the analysis: (1) a sense of distance and disconnection from other people; (2) navigating the reactions of others; (3) changes in self-perception; and (4) adjusting and coming to terms with dysarthria.

**Conclusions:** The findings suggest that stroke survivors with dysarthria can experience several challenges which can impact upon how they feel about themselves. They can often feel disconnected from other people and have concerns about how they are perceived due to their speech. These difficulties along with changes to their abilities and groups they feel a part of can result in shifts in identity. However, for many of the participants, they experienced an increased level of acceptance of their dysarthric speech over time and found ways to come to terms with it. Suggestions are made for ways in which clinical psychologists working within stroke services can utilise therapeutic approaches in order to encourage a positive self-concept in relation to speech.

*Keywords: stroke, dysarthria, identity, communication impairment, ipa, qualitative*

### **Implications for rehabilitation**

- Clinical psychologists should promote the use of Acceptance and Commitment Therapy (ACT) principles within the MDT to facilitate the development of a positive self-concept in relation to speech
- Professionals should aim to increase awareness of dysarthria and provide links to relevant support groups and communities for dysarthric patients

### **Introduction**

Stroke is a leading cause of acquired, long-term disability in adults worldwide [1,2]. Globally, one in four adults over 25 will suffer a stroke in their lifetime and it is estimated that 116 million years of healthy life is lost each year as a result of stroke-related death and disability [3]. Up to 50% of stroke survivors are chronically disabled [4]. Stroke is also associated with more individual domains of disability compared with other conditions [5]. The disabilities which most commonly occur are; cognitive difficulties, communication impairments, visual problems, limb weakness, sensory issues (including pain), bowel/bladder control, and swallowing difficulties [6].

Although the consequences of stroke can vary greatly between individuals, the condition often results in a profound impact upon emotional wellbeing [7]. The unpredictable nature of consequences are associated with high levels of social embarrassment and psychosocial burden, which can result in increased emotional distress [8]. Over 50% of stroke survivors will experience anxiety at some point within ten years of their stroke [9] and approximately 30% will experience depression [10].

A dominant theme found within qualitative stroke literature is the impact of post-stroke impairments upon stroke survivors' identity [11]. The term "identity" is defined by the American Psychological Association [Internet] [12,p.1] as "an individual's sense of self

defined by (a) a set of physical, psychological, and interpersonal characteristics that is not wholly shared with any other person and (b) a range of affiliations and social roles". It is widely acknowledged that individuals with disabilities can face stigma and/or discrimination, which could negatively impact upon their identity and subsequently emotional wellbeing [13,14].

A meta-synthesis conducted on the experience of living with stroke reported that the concept of an ongoing process of re-interpretation of the self and a sense of estrangement from the person they had been prior to the stroke was found in most studies [15]. Similarly, Crowe et al [16] identified a dominant theme of "loss of self" for stroke survivors where participants described lamenting their pre-stroke self and rejecting their post-stroke self. Haslam et al [17] highlighted the importance of stroke survivors being able to maintain multiple group memberships to preserve their wellbeing post-stroke; they recommended that an individual's social identity should be prioritised during rehabilitation. A recent meta-ethnography recognised the identity of stroke survivors as an essential aspect of perceived recovery; by restoring a sense of control and self-sufficiency, individuals feel able to rebuild and integrate their lives [18]. This was highlighted as a central need which should be acknowledged by clinicians, prioritising stroke survivors' self-efficacy within the rehabilitation process [18].

Human language and the way we communicate with others has been acknowledged as playing a significant role in how we make sense of who we are and how we construct our identity [19,20]. It is highlighted that for individuals with disabilities, language is an important resource available to mitigate or explain differences, but for those with communication impairments, that resource is not available [21].

Approximately one third of stroke survivors experience communication impairments [22,23]. However, this number is significantly increased in the acute/inpatient phase of

rehabilitation (with numbers ranging up to 64%) [24,25]. These include aphasia, dysarthria, and apraxia of speech (AOS) [26]; impairments which encompass problems with expressive and receptive communication. Literature conducted on communication impairments post-stroke has a predominant focus on aphasia over other speech difficulties [27]. Cochrane reviews of interventions for these impairments identified 57 randomised controlled trials for aphasia [28] compared to only five randomised controlled trials for dysarthria [29]. Aphasia has been described by Shadden [30 p211] as “identity theft”. It is acknowledged that individuals with aphasia are “robbed” of the ability to project themselves effectively whilst being assigned a pathological identity of incompetence by others [31]. People with post-stroke aphasia describe language and communication as central to their identity [32]. Marginalising interactions with others can also result in a negative externally constructed identity (e.g., experiences of being treated as intellectually incompetent or childlike) [33].

Aphasia and dysarthria affect production of speech, dysarthria mostly causes difficulty with motor execution of language, whereas aphasia can also affect word-finding ability and speech comprehension [34]. The wider impact of post-stroke dysarthria is not as well elaborated. Although the presence of dysarthria following stroke is well documented, it tends not to receive focused attention within research [35]. Dysarthria is caused by an impairment in the ability to control facial muscles and this can impact upon the speed, strength, range, timing, or accuracy of speech [36]. There are variations reported regarding the prevalence of dysarthria within the stroke population [37-40]. Flowers et al [37] identified an estimated incidence of 42% for patients who had suffered a first acute ischemic stroke. A similar figure (44%) was found more recently in first ischemic stroke patients by De Cock et al [38]. Analysis of pooled stroke clinical trial data indicated that 70% of patients had dysarthria at the acute stage and at three months, 27% of stroke survivors remained dysarthric [39]. Prevalence has also been found to range from 5% to 85% depending on the type of



stroke suffered [40]. Despite these disparities, it is clear (from the above studies) that dysarthria is a common consequence of stroke.

There is a paucity of research exploring stroke survivors' experiences of dysarthria. While some pertinent quantitative studies are available (e.g., using self-report questionnaires/scales) [41-43], this form of data collection can place the healthcare professional, as opposed to the stroke survivor, as the "expert" by using pre-determined questions presumed to be important to them [15]. To overcome these limitations, health and disability researchers often utilise qualitative methods to explore the meaning of ill health from the perspective of those concerned [44]. The qualitative literature exploring the impact of post-stroke dysarthria is limited: Walshe and Miller [45] explored the experience of living with dysarthria, but included individuals with dysarthria from mixed aetiologies, not specifically focusing on stroke. A group of researchers explored stroke survivors' perspectives of dysarthria within three studies. They investigated patients' experiences of disruptions associated with dysarthria [46], patients' perspectives on management and rehabilitation [47], and the impact of dysarthria on social participation [48].

Each study has some relevance to how dysarthria can impact upon stroke survivors' identity. In particular, Dickson et al [46] identified one of the major themes from their analysis as psychosocial consequences, which included issues relating to identity, relationships, social and emotional disruptions, and stigma. More than half of participants experienced negative changes in self-identity, with responses being framed around the concept of "normality" and dysarthria being seen as "abnormal". The impact of dysarthria was found to be disproportionate to physiological severity.

Researchers conducting qualitative meta-syntheses have noted there is generally a lack of studies involving stroke survivors with communication impairments [49,50]. Therefore, although there is substantial literature which details the changes in identity

experienced by stroke survivors, this has principally focused upon those whose expressive language abilities are intact [15-18].

The current research aims to contribute a more detailed understanding of how dysarthria can impact upon stroke survivors' personal and social identity, by making this the sole focus of the study. Findings will help increase the voice of dysarthric stroke survivors, who currently have reduced opportunities to share experiences of their disability and how it affects them. In addition, it is anticipated that findings will be used to make recommendations regarding effective and targeted psychological support specifically aimed towards those with dysarthria. This is reflective of the recommendation that all elements of stroke rehabilitation (including psychological support) should be person-centered and designed around the specific needs of the individual [51].

## **Method**

### **Design**

Research design and materials were developed through discussions between the authors and two Speech and Language Therapists (SLTs) experienced in stroke; their insight was particularly helpful regarding the recruitment process, study materials, and interview schedule. As the aim of the study was to obtain the first-hand experiences of dysarthric stroke survivors, a qualitative, inductive, idiographic approach was deemed the most appropriate. The use of semi-structured interviews allows researchers to explore participants' thoughts, feelings, and beliefs about a particular topic and to delve deeply into personal and sometimes sensitive issues [52]; therefore this method was used to gather first-person accounts of participants' experiences. Interpretative Phenomenological Analysis (IPA) was utilised to analyse the data. This approach aims to explore personal lived experience of a phenomenon and how individuals perceive and make sense of that experience [53,54]. The analysis used is

often described as a “double hermeneutic” process; it draws out how participants make meaning of their own world, and the researcher then draws upon their own meanings and understandings to interpret [55].

### **Sampling and Participants**

Within IPA, it is recommended to aim for a fairly homogenous sample and sample sizes tend to be small due to the detailed analysis involved [56]. IPA aims to find a well-defined group for whom the research question will be significant through purposive sampling [55]. The study initially aimed to recruit six to 12 participants to allow for analysis within and between specific cases. Participation was not limited by gender or age; it was thought that, despite the broad age criteria, participants would represent a fairly homogenous sample due to them sharing a common characteristic of being dysarthric stroke survivors.

The criteria for inclusion were individuals currently experiencing dysarthria following a stroke they experienced at least six months ago (when recovery is said to have mostly stabilised) [57]. This was based on self-report due to the way participants were recruited to the study (social media). Due to funding restrictions regarding using a translator, participants were required to communicate in English, however this was not restricted to verbal communication. Individuals could also participate if they could communicate in written format. Despite this, all participants opted for a spoken interview. It was acknowledged that some participants may have comorbid diagnoses of dyspraxia or aphasia, however without formal Speech and Language Therapy (SLT) assessments, these would have been difficult to accurately distinguish between. Therefore, these factors were not an exclusion criterion, however the interview schedule was devised to specifically explore the impact of dysarthria upon participants’ identity.

The study was advertised via posters through a charitable organisation and social media platforms. All participants were recruited via social media, the majority from online

stroke support groups. Participants were recruited via Twitter and closed Facebook groups; recruitment took place over five months. Twenty people expressed initial interest in the study. However, eight did not meet the inclusion criteria and five changed their mind during the recruitment process and decided not to participate. Therefore, seven people participated in the study. Five participants were female and two were male. Six resided in the United Kingdom (UK) and one resided in the United States of America (USA). The length of time passed since participants' strokes ranged from one year, two months to 24 years, 11 months (M = six years, nine months). See Table 1 for full details of participant demographics.

[INSERT TABLE 1]

### **Procedure**

Individuals who expressed initial interest were contacted by the researcher twice before interviews took place. The first contact was used to confirm that participants met the inclusion criteria, using an eligibility checklist. They were then sent a participant information sheet, opt-in form, and consent form via email. Easy-read versions of these forms were available and sent to participants who confirmed that they had cognitive impairments or other communication difficulties which affected their reading ability. The Colours and Symbols (CAS) [58] supported communication tool for people with aphasia was used within these forms to make them more accessible and easier to understand. The researcher contacted participants again seven days later, providing enough time to read over the information. At this point, verbal consent was obtained. Participants were asked whether they felt more comfortable taking part in a phone call, video call, or typed interview. All participants agreed to participate with a video call. Please refer to Appendices A-I of the ethics section for participant documents.

**Ethics**

Ethical approval for the research was gained through the Lancaster University Faculty of Health Medicine Research Ethics Committee (FHMREC) (project number FHMREC20065) prior to recruitment. Guidelines were followed regarding conducting research with individuals who may not have capacity to consent to participation (due to cognitive impairments after stroke) [59]. Following initial conversations, the researcher had no concerns about participants' capacity to consent. Refer to sections three and four of thesis for details regarding how this was managed.

Protocols were developed regarding risk issues and the potential of interviews leading to emotional distress. An information sheet including sources for further support was devised and shared with participants upon completion of interviews; additional sources were sought for one participant from the USA.

**Data Collection**

Given that participants experienced communication difficulties, options were provided to communicate responses in written format or to have a relative/carer there to support them. All participants confirmed they were comfortable with a spoken interview and only one participant asked for support from their partner during the interview. It was made clear that it was the stroke survivor's views being explored and support provided was only to assist communication.

Data for the study was collected through video call interviews (using Microsoft Teams) ranging from 48 to 73 minutes (M = 56 minutes); this was to reduce risk for participants/researcher in relation to Covid-19 and to allow for international recruitment. A semi-structured interview schedule was generated by the researcher; this was informed by previous research [46] and received input from research supervisors. Attempts were made to collect feedback from experts by experience (through a stroke charity), however no responses

were received within the allotted timeframe. The interview schedule allowed for some commonality between participants but also allowed space for each individual to lead the conversation based on what felt most important to them and their personal experiences. Some example questions include: “How has your speech/ability to communicate with others been affected?”, “Would you say your speech has had any impact on how you feel about yourself?”. Refer to Appendix I of ethics section for full interview schedule.

### **Data Analysis**

Interviews were video recorded using the Microsoft Teams online conferencing software and transcribed verbatim by the researcher. Participant data was anonymised, and pseudonyms were used when transcribing. The researcher analysed the data using IPA [60]. Transcripts were read and recordings listened to several times; this was in order to help the researcher become immersed in the data and to help generate new insights [54]. Transcripts were analysed one at a time. Initial codes were generated for each transcript (example in Appendix B) which aimed to remain as close to the experience and sense-making of the participant as possible. An iterative process was then used to place codes into discrete groups to represent various thematic threads from the transcript. Following this, an interpretative narrative summary was written for each cluster of codes to capture what each theme encompassed, and a title given to each theme to encapsulate the summary. Once the process was complete for each participant, themes were examined across participants to explore convergences and divergences of the data. A synthesised narrative summary was then produced for each group of themes and quotes from participants added to illustrate the points made, resulting in the identification of final themes capturing a more general understanding of participants’ experiences.

### **Quality in Qualitative Research**

The merits of qualitative research remain an ongoing issue of debate and investigation; researchers therefore aim to demonstrate the trustworthiness of their research outcomes [61]. Throughout the research process, guidelines were followed to improve the validity of the research [62]. A reflective journal was kept throughout which enabled the researcher to note down any thoughts, feelings, or actions which may have influenced the data collected, before and after each interview. The writing of a journal has been shown to improve validity by keeping an audit trail whilst also reflectively prompting the process of learning, interpretation, and bracketing, therefore evidencing transparency [63]. For example, following the first interview, the researcher reflected that the participant described some positive consequences she felt had resulted from her dysarthria. This was not included within the original interview schedule and following discussion with the research supervisor it was agreed that this felt an important addition to include within subsequent interviews.

Research and peer supervision were also utilised to enhance the trustworthiness of the data; collaboration with the research supervisor was central to improving the quality and rigor of the analysis. Coding excerpts from anonymised transcripts were shared with the research supervisor following analysis of the first transcript and feedback was provided. An audit trail (example - Appendix B) relating to the analysis of each participant was also completed, which is a strategy proposed to increase the trustworthiness of data [64].

### **Results**

The following four themes were generated from the analysis: (1) a sense of distance and disconnection from other people; exploring how dysarthria created barriers to connection in relationships; (2) navigating the reactions of others; how participants managed other people responding to them differently; (3) changes in self-perception; shifts in the way

participants viewed themselves and (4) adjusting and coming to terms with dysarthria; exploring the varying levels of acceptance participants held regarding their changed speech. Table 2 demonstrates the individual participant themes, which contributed to each of these final themes.

[INSERT TABLE 2]

### **A Sense of Distance and Disconnection from Other People**

This theme represents how, for all participants, dysarthria resulted in barriers to feeling connected within relationships and a sense of distance from others. This seemed to manifest in a variety of ways for participants, although there were commonalities within descriptions.

Most participants referred to feeling more introverted since their stroke. They experienced reduced confidence in their ability to communicate, and relayed how they spoke much less, avoided contact with other people (most prominently new people) where possible, and spent more time engaging in solitary activities.

Martin described avoiding conversations: “I would avoid that situation if possible. Only talk when cornered, which is what happens a lot at the bowls club... you’re around other people so you have to talk quite a bit”, only initiating conversations in situations where he felt it would seem ‘weird’ if he didn’t. Other than this, Martin relied heavily on his wife to aid his communication with others or to do this completely on his behalf. He reflected: “I don’t engage as much as I did. Self-absorbed I think the word to use is”, it seems that Martin felt he came across this way as he felt he was not fully present in most relationships. Similarly, Holly explained: “Everything feels so much more effortful, including maintaining relationships. So, I’m a little less invested”, describing the significant amount of effort it takes for her to speak. There was also an association for Holly between the effort of communicating and levels of post-stroke fatigue.



Paul and Sue made several references to the struggles of joining in with group conversations. They described how it was hard to keep up due to their speech, but also how they were self-conscious about how they sounded and that what they had to say was not of enough value to express: “You just sit quiet and listen to people ‘cause you think ‘Well, is what I’m gonna say worth anything? Is it gonna be important? Are they gonna laugh at what I say?’” (Sue). Subsequently, both participants would then take a backseat and instead observe in such situations, although this then caused them to worry about being judged for remaining silent: “They’d think ‘What’s the matter with him, there’s something wrong with him, he don’t really speak’ or ‘his speech comes out funny’”. (Paul).

Despite facing such challenges, Ada and Gabriella both reflected on how they reframed the consequences of dysarthria more positively. Ada described thinking “What’s the point?” regarding speaking to new people, however when reflecting on being more introverted she said: “Oh I like it! It’s nice... I’m alone more and I’m learning to like my own company”. Gabriella also made reference to feeling distant from friends/family and that her speech made conversation seem more robotic and less natural. Despite this, she found ways of managing this distance over time: “I can contact my friends now, through Facebook” and actually had more confidence in herself than she did prior to the stroke. This will be discussed further within the final theme, as the way in which Gabriella managed this distance contributes to her level of acceptance of her speech.

Finally, Nicola also spoke of experiences whereby she felt disconnected from others: “People would rather talk to someone next to you or they’ll cut the conversation short ‘cause they’re uncomfortable”. However, specific to Nicola’s account was the sense that she was able to maintain most of her existing relationships with ease: “I’ve been very fortunate that I don’t feel I’ve lost any friends since this”. It seems relevant to acknowledge that Nicola’s

self-rating of her dysarthria was the lowest of the participants and her slurred speech was observed to be milder in comparison to others.

### **Navigating the Reactions of Others**

All participants, except for Martin, gave descriptions of how their slurred speech affected how other people responded to them. It is likely that, for Martin, his increased reliance upon his wife to communicate for him may have protected him from having to navigate these reactions to the same extent as others. Indeed, Martin was the only participant who invited somebody else (his wife) into a portion of the interview.

For all other participants, there was a shared experience of people making assumptions that there was something “wrong” with them because of the dysarthria. This was predominantly people assuming that participants had cognitive impairments or additional learning needs: “I’m afraid that my speech implies that I also have cognitive deficits” (Holly), “Now people treat you like you’ve got no intelligence... people treat me like I’ve got special needs” (Sue). However, there were also descriptions of people believing that some participants were drunk and for Gabriella, that she was deaf or even a child (when communicating over the phone). Most participants discussed how people would then respond to them differently; by speaking slower, directing conversation to the person they are with, or cutting conversations short: “They treated me like I was backwards or ask ‘Is she alright?’” (Gabriella).

These reactions caused many participants to have more worries or reservations about interacting with others. Holly and Paul both described feeling self-conscious about how they were perceived by other people. Additionally, Holly reflected: “With other people I don’t know that they understand the neurological fatigue and speaking fatigue as well”.

For some participants, experiencing such reactions to their speech impacted upon how they viewed themselves. Gabriella reflected: “I feel disabled. Less of a person. People don’t

see me, they see my disabilities”. An important factor in shaping this identity appeared to be that Gabriella had never met anybody else with dysarthria. Within Sue’s interview, she talked about the importance of feeling accepted by others: “You just want to be accepted for who you are, more so than anything” and she described many relationships where she felt this was no longer the case for her as a result of her slurred speech. This included those she was not close to: “The next-door neighbour, he looks at me like I’m loopy”, as well as people in her closest circles, e.g., her daughter: “She still saw me, but she didn’t accept me as I was, she wanted me back as I was before”.

For Nicola, there was a sense of feeling overprotected. She described how her family encouraged her to take a rest when she sounded more slurred: “I might sound like I’ve got worse in that conversation, but it doesn’t mean that I can’t carry on”. This caused Nicola to feel frustrated as she had a strong desire to remain independent: “Don’t wrap me in cotton wool, ‘cause that’s the worst thing you can do”.

Most participants expressed a desire for general increased understanding/awareness of the condition. Ada, Nicola, and Gabriella all described how people they spoke to often appeared uncomfortable and unsure of how to act around them: “I don’t feel embarrassed but embarrassed for the other person, because they don’t know what to say” (Gabriella). Ada and Nicola both expressed empathy for these people, acknowledging that if they have not had a personal experience of something, then it is difficult to understand:

People don’t really understand the condition. They don’t. They have to get sensitised. But you know, humans are like, if we don’t experience it, then we don’t know, so, we don’t think about it... It’s like disability, we don’t think about it (Ada).

All participants referred to increasing awareness being the motivation for their participation, which seems important to consider, particularly for individuals who have a tendency to avoid speaking to new people.

### **Changes in Self-Perception**

This theme represents how, for some participants, the changes in their speech and subsequent changes to their perceived abilities and personalities shaped how they subsequently viewed and felt about themselves. As previously mentioned, most participants experienced themselves as more introverted and less confident than they were prior to the stroke. However, for some participants changes in identity extended beyond this. For Holly, this seemed to relate specifically to her identity at work:

I always kind of thought of myself as more of a thought leader, idea producer at work. And I'm much quieter now. I really only contribute as necessary rather than volunteering, so I feel like that's a weakness, that I'm less likely to volunteer and I'm so busy trying to talk that I have less energy to think about and contribute in more higher level ways.

With speaking taking up so much more energy, she explained how she was just "trying to survive" rather than going "above and beyond".

For other participants, a more general shift in identity was described. Ada had a strong sense of who she was prior to her stroke, describing herself as 'not mainstream' and 'an anomaly'. However, as a result of her dysarthria she reflected: "I don't know how I feel about me, my confidence, you know. I was really outgoing, so with the stroke, and the slurred speech, everything is like mmm, yes, I don't feel like I was before", describing how she seemed to have lost a sense of who she was. It was apparent from Ada's interview that her perceived inability to fulfil roles or do the things she used to enjoy before the stroke (e.g. working as a performance poet, mentoring others, and engaging in debates) were significant contributing factors to her perceived loss of identity.

Sue also described how she saw herself before the stroke; including being outgoing and able to make people laugh. As previously mentioned, following the stroke, Sue found it

very difficult to join in with conversations and felt much more anxious about communicating. She reflected that she now perceives herself as more of a listener and how this can result in her feeling overlooked and as though she's not really present when around other people despite being physically there: "Less of a person, I think in some ways. Less visible. Sometimes invisible actually... It's not just about your speech, it's about you as a whole person".

For Gabriella, it appears that she had been on more of a journey with regards to how she viewed herself. It seems important to acknowledge that 25 years had passed since Gabriella's stroke, much longer than any other participant included in the study. Initially, Gabriella described a desire to return to 'normal' speech: "I was stupid 'cause I thought I was going to talk normal... I didn't realise it was permanent". She also described feeling very negative about herself: "In the early days, I felt degraded. It made me feel like I was just a thing". However, over time, she had come to recognise her strength in tolerating the challenges she faced and how this changed her personality: "I'm confident, I'm not shy, I'm happy, content. I'm fearless", "I will say anything to anyone, and I don't say 'I can't do that, I say 'How can I do that?'".

It is clear that acquiring dysarthria resulted in a variety of changes in how participants viewed themselves. This was often in relation to previously held roles they were unable to fulfil or qualities they no longer saw themselves as having.

### **Adjusting and Coming to Terms with Dysarthria**

During their interviews, most participants spent time discussing how they felt about their dysarthria and whether they felt they had been able to accept or at least come to terms with the way they speak. Paul, Martin, Holly, and Gabriella all described how they experienced a shift in mindset over time and subsequently felt more accepting of their slurred speech as part of their identity.

Martin expressed how, over time, he became used to speaking slower and even found positives in being forced to think more about what he was going to say, rather than letting his mouth “run away” with him: “Well it hit quite hard initially, but now that I have mastered talking slowly and thinking about it, I’m getting there really”. Holly was also able to recognise some positives in going at a slower pace with her speech, particularly in relation to her work; she acknowledged that work no longer seeps into her personal hours so she can spend time doing other things she enjoys:

Initially I felt bad about it but, you know I have less stress and that’s one of the positives of having these limits, is when I’m at work, I’m focused on work and then when I’m done, I don’t really think about it or worry about it. I do what I can do and that’s okay, so that’s new.

Both Martin and Paul reflected that joining online stroke support groups played a helpful role in them becoming more accepting of their speech, particularly when they were able to interact with other stroke survivors who they perceived to be worse off than them: “It actually helps me realise how lucky I was” (Martin). In these situations, both participants seemed to compare their dysarthria not only to other stroke survivors’ speech, but also to the other varying consequences of stroke:

So, my speech is shit and I can’t get on with people as I used to and I can’t drive and I’ll get tired, but that’s it. You know what I mean, that’s it. He’s got it worse than me so when I feel bad I just think ‘I am lucky really’ (Paul).

Shared in both Paul and Gabriella’s accounts was the sense that they were able to feel more accepting of their speech when they made the realisation that, physically, there was nothing they could do to change or improve it any further: “I don’t think I’d ever get that back, it’s horrible innit, but that’s life, what can you do? The cards you’re dealt you have to deal with don’t you?” (Paul). “This is me and I can’t change. I’ve tried my hardest to speak normal and

I can't, my soft palette is paralysed, so there's nothing I can do about it" (Gabriella). For both Paul and Gabriella, having this level of acceptance enabled them to feel less affected by the reactions of others and even feel confident enough to use humour during these interactions: "They will talk [demonstrated talking slowly and clearly] 'Hello, my name is...' and I say 'I can hear you! You look stupider than me'" [laughs] (Gabriella).

For Nicola, she expressed some conflicting feelings towards her speech and her level of acceptance of how it has changed. She described feeling 'kind of' happy with where she was at with her speech and reflected: "I still haven't accepted it but part of me doesn't want to accept it because I feel that if you accept something, you might not then progress any further".

### **Discussion**

The purpose of this study was to explore the experience of living with dysarthria following a stroke in relation to personal and social identity. Through the process of IPA, using semi-structured interviews with seven participants, four themes were derived. The themes will be discussed in relation to existing literature, significant findings highlighted, and clinical implications offered.

The findings indicated that, because of their dysarthria, participants experienced a variety of challenges which led to them becoming more isolated from others. Given that elevated levels of social isolation post-stroke have been indicated even in the absence of communication difficulties [65-67], this finding is unsurprising. However, this study expands on existing literature by recognising that dysarthric stroke survivors might be more likely to reduce levels of interaction with others due to the significant effort it takes for them to communicate. Another barrier to connectedness was the avoidance of communication, either by taking an observer role during conversations or generally avoiding contact with others. This echoes findings of Walshe and Miller [45] who highlighted that avoidance behaviours

and attempts to conceal communication impairments are common for individuals with dysarthria. Within the current study, participants attributed avoidance to reduced confidence when communicating and difficulties in keeping up with conversations. Similar difficulties were also described in previous studies on post-stroke dysarthria [46,48].

Concerns regarding how participants were perceived by others and how this affected their own perceptions of themselves was a predominant focus within the interviews. This is understandable when considered through the lens of the social model of disability [68], which situates disability in the context of wider societal responses rather than as a direct consequence of an individual's impairments. The findings suggest that dysarthric stroke survivors may be treated differently by others as they are perceived to have cognitive deficits. Perceived or actual stigmatisation by others has also been highlighted in previous research on dysarthria [45,46,48].

It is interesting to consider the motivations of individuals who often avoid speaking to participate in this study. The desire to increase awareness of dysarthria appeared to outweigh reservations participants may have had about engaging in an interview with somebody they had never met. This highlights the significance of stigmatisation and how it can affect the lives of those experiencing dysarthria. The findings also indicated how being treated differently by others could impact upon how dysarthric stroke survivors view themselves. Anderson and Whitfield [11] discuss how, after any life-changing event, people's sense of self becomes fluid; individuals are at risk of losing their social position, which in turn impairs their ability to maintain a positive identity. This reflects research focused on individuals with aphasia, which acknowledged how marginalising interactions with others can lead to a negative externally constructed identity [33] due to the pathological identity of incompetence they have been assigned by others [31].



The findings also indicated that participants experienced a shift in their identity due to changes in their abilities (or perceived abilities) to fulfil certain roles and complete activities they previously enjoyed. Walshe and Miller [45] identified that individuals with dysarthria may experience changes in employment and family roles. For participants in the current study, there were descriptions of changes to employment, leisure, and relational roles. As a result of this, participants not only had to adjust to a shift in their abilities, but they also experienced changes to the groups which they identified as being a part of. Social identity theory [69] can be a useful tool to understand the implications these changes may have upon participants' sense of self. This theory proposes that groups in which people view themselves as being a part of provide an important sense of belonging to the social world [69]; this then leads to stereotyping, whereby we may exaggerate the differences between groups and the similarities within them. It seems understandable then, that some participants may have experienced confusion regarding their own identities as they lost previously held group memberships and were assigned membership into a new group of individuals with communication impairments.

A significant finding within previous research on post-stroke dysarthria was that participants were continually striving to get their speech back to "normal"; to how they sounded prior to the stroke [46]. Although there were references made in the current study to this (specifically for Gabriella), it was not a prominent theme. A novel finding within this study is the sense that, over time, participants experienced an increased level of acceptance of their dysarthric speech. Although participants' relationship with acceptance is recognised to be a complex one, it seems that for many, despite the challenges they faced due to their dysarthria, over time, they found ways of coming to terms with their speech. This seems important, particularly as non-acceptance of disabilities post-stroke has been found to be associated with levels of depression [70].

This does not appear to be an inevitable shift applicable to all dysarthric stroke survivors after a certain amount of time, especially considering the large range in years passed since their stroke. Additionally, this shift in acceptance does not necessarily translate to the development of a positive disability identity relating to dysarthria, particularly as participants continue to experience stigmatising interactions with others. It has been recognised that if affirmation of a positive disability identity can be achieved, this could promote satisfaction with life and protect wellbeing [71].

### **Clinical Implications**

The primary aim of post-stroke rehabilitation is to support stroke survivors to relearn skills which have been lost because of the stroke in order to regain independence and improve quality of life [72]. For those with dysarthria, that usually includes SLT which aims to improve ability to communicate and provide effective strategies to compensate for impairments [26]. Although it is important to encourage stroke survivors to regain communication skills where possible, the findings have also highlighted the importance of interventions which can help promote a positive disability identity and encourage a shift to self-acceptance of impairments, as detailed below.

The impact of social isolation upon wellbeing and identity should be acknowledged by all professionals. The benefits of psychosocial interventions, such as providing community-based provisions and personally relevant meaningful activities, have previously been highlighted for stroke survivors with aphasia [73,74]. Examples of such activities from the current study include both in-person and online stroke support groups that many participants attended, as well as Martin's bowls club; this demonstrates that participants did not attend/were not aware of many alternative community-based provisions. Although exploring support networks was not the focus of the study, most participants referred to stroke support groups they found helpful, all of which they discovered independently.

Healthcare providers recommending relevant support groups as well as improved co-ordination between healthcare services and third sector organisations could help dysarthric stroke survivors feel part of a new community at an earlier stage. These should include dysarthria specific support groups where possible, although general stroke support groups were also valued by participants. Such support systems could be validating and provide space for stories to be shared [75]. The importance of connection with other people with disabilities has been recognised in relation to developing a positive disability identity [71].

Much of the previous research on post-stroke dysarthria has been conducted within the SLT field; subsequently most clinical recommendations have been targeted towards these professionals. However, the importance of multidisciplinary teams (MDT) including the expertise and input of a clinical psychologist has been acknowledged for stroke survivors with communication difficulties [76,77].

To encourage a greater emphasis upon the promotion of a positive identity for dysarthric stroke survivors, the role of a clinical psychologist in teams should include supporting patients to identify and work towards realistic and achievable goals. Having support to adjust and redefine originally set goals can facilitate understanding and acceptance of limitations for stroke survivors [78]. It is thought that clinical psychologists are best placed to not only provide this support directly, but also to indirectly promote a focus upon identity and self-concept within the wider MDT, drawing upon their skills of formulation and consultation.

The findings from the study are useful in terms of providing contextual information to clinical psychologists regarding what is likely to contribute to increased emotional distress for these stroke survivors. Highlighting the significance of stigma and how people with dysarthria are perceived by the public could result in psychologists holding a more socially informed understanding of distress for these individuals. This has previously been

recommended to bridge the gap between clinical psychology and disability studies generally [79].

Clinical psychologists can provide therapeutic intervention based on a wide range of models [80]. Specifically, drawing on principles of Acceptance and Commitment Therapy (ACT) both within clinical sessions and MDT discussions could be useful. ACT, unlike other therapeutic modalities, is not focused upon symptom reduction; instead, it focuses upon creating a rich, meaningful life while accepting the inevitable pain that accompanies it [81]. It has been identified that ACT could be an effective psychological intervention for long-term health conditions [82]. Specifically, ACT has been recognised as a suitable model for stroke survivors as its emphasis on acceptance can support those living with the enduring consequences of stroke to “accept a changed reality” [83,84].

Although many participants in the current study found ways of coming to terms with their dysarthric speech over time, this is likely to have been a smoother process if they had access to such interventions initially. Whether this is in the form of direct psychological intervention, or through conversations with professionals who are aware of and promote the principles of ACT. Specifically, the mechanisms within ACT which appear most relevant based on the current findings are acceptance of unwanted private experiences [81] (such as self-critical thoughts) and connecting with values [81]; identifying what participants find most important and finding new ways of connecting with them.

Guidelines recommend that stroke services should provide access to specialist clinical psychologists throughout the pathway [85], however this is not always the case [86,87]. Whilst this remains a barrier, there are suggestions made for how clinical psychology can still offer support; providing specialist stroke support within other general mental health services [86], identifying these gaps within services, and potentially providing consultation support even when based in separate services within an organisation [87].

Participants expressed how important it was to them to promote awareness/understanding of dysarthria. Professionals working in this area should support this (e.g., by creating information leaflets and sharing resources), especially as dysarthria can often be overshadowed by the emphasis placed upon post-stroke aphasia [27-29]. Increasing the focus on dysarthria could help to make the condition feel more “valid”, which could also facilitate acceptance of the condition.

### **Strengths and Limitations**

Due to the recruitment methods utilised, no standardised measures were used to measure the severity of dysarthria; instead, information was gathered regarding participants’ own perceptions of severity. There were varying levels of slurred speech observed during interviews, however due to the subjective nature of participant self-ratings and researcher observations, no inferences were made regarding the impact of dysarthria based on severity. It is acknowledged that this has been done in previous research [45,46,48]. It is possible that this may have excluded stroke survivors who would be categorised as having “severe” dysarthria, especially as these individuals may feel less able to participate in a semi-structured interview.

Similarly, as most participants were recruited through social media support groups, this may also mean that the experiences of dysarthric stroke survivors who have not drawn upon this type of support have been excluded. This may also mean that the views represented in the study favour such groups more highly than the general stroke survivor population. It is also acknowledged that males were underrepresented within the sample, indicating that the results may not be fully representative of this group.

Individuals with communication difficulties are often excluded from participation in qualitative research [88]. It has been suggested that researchers can judge them as impossible to interview and therefore, choose to interview participants who are articulate, reflective, and

expressive [88]. However, it has been demonstrated that although conducting research with these individuals can present more challenges, it is achievable when appropriate adaptations are made [89,90]. Within the current study, participants were provided with options and adaptations to ensure the interview process was comfortable for them and able to encourage detailed descriptions of their experiences (refer to section three of thesis for more detail).

### **Future research**

Firstly, research to explore the experiences of those potentially excluded in this study is important. So, studies focusing on dysarthric stroke survivors who might not utilise online support groups and may subsequently have different experiences in relation to their identity. Also, research to explore the experiences of stroke survivors who have been diagnosed as having severe dysarthria to identify any variations specific to their lives. Of course, adaptations would possibly be required, to make research accessible to this group.

Emphasis on male stroke survivors' experiences of dysarthria would also be useful, not only as they were underrepresented within the study, but also due to differences identified in some of their responses when compared with female participants. Interestingly, the two male stroke survivors who participated in the study did not contribute to theme three as they did not make direct reflections about their sense of self. Both male participants expressed that they were not used to discussing their experiences in such detail and it was observed they may have found the prospect of reflecting on their identity more uncomfortable than their female counterparts. Previous literature has identified a lack of emotional expression or tendency towards laconic responses in male participants as a significant challenge to qualitative research [91]; alternative methods to explore emotionally sensitive topics are recommended, which might be useful to draw upon here.

**Conclusions**

The findings suggest that stroke survivors with dysarthria can experience numerous challenges which can impact upon how they feel about themselves. They can often feel disconnected from other people and have concerns about how they are perceived due to their speech. These difficulties along with changes to their abilities and groups they feel a part of can result in shifts in identity. However, for many of the participants, they experienced an increased level of acceptance of their speech over time and found ways to come to terms with it. This is, of course, a very individual experience, however suggestions are made for ways in which clinical psychologists working within stroke services can utilise therapeutic models such as ACT to encourage a positive self-concept in relation to speech.

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**Table 1***Participant demographics*

Participant (pseudonym)	Gender	Age	Time passed since stroke	Employment status	Other consequences of stroke (excluding dysarthria)	Self-rating of dysarthria severity (1-10)
Ada	F	49	2 years 5 months	Unemployed	Attention, memory, fatigue, muscle weakness, balance, bowel/bladder control	5
Gabriella	M	45	2 years 7 months	Unemployed	Aphasia, concentration, fatigue, balance, pins and needles in right hand	5
Holly	F	38	1 year 2 months	Part-time	Fatigue, muscle weakness, balance, numb skin/pins and needles	6
Martin	M	61	7 years 11 months	Retired	Memory, swallowing, fatigue, muscle weakness in left side, pain in shoulders and neck	9
Nicola	F	46	2 years 5 months	Part-time	Balance, spatial awareness, attention, fatigue, muscle weakness and pain – left hand and shoulder	4
Paul	F	47	24 years 11 months	Unemployed	Aphasia, memory, fatigue, balance, muscle weakness and pain – right arm, blind to the right hand side, pins and needles in arm	8
Sue	F	57	5 years 11 months	Unemployed	Aphasia, memory, fatigue, swallowing, muscle weakness – right sided, spatial awareness, eye droop and blind spot, pins and needles in feet	7

**Table 2***Final themes and individual participant themes*

Final theme	Participant themes
<b>Theme 1:</b> A sense of distance and disconnection from other people	<p data-bbox="1133 405 2029 485"><b>Ada</b> - A shift to an introverted identity: ‘I’m learning to like my own company’</p> <p data-bbox="1133 517 1951 596"><b>Paul</b> – Living a more solitary life: ‘I don’t really speak to many people these days’</p> <p data-bbox="1133 628 1973 708"><b>Paul</b> – ‘I can’t really join in conversations like I used to’: Feeling self-conscious and frustrated about speech</p> <p data-bbox="1133 740 2029 820"><b>Holly</b> – Identifying as more of an introvert: ‘I’m much more prepared or I participate less’</p> <p data-bbox="1133 852 2007 932"><b>Holly</b> – The effort of communicating and maintaining relationships: ‘It’s so effortful and slow, it’s not always worth it’</p> <p data-bbox="1133 963 1973 1043"><b>Martin</b> – Reduced confidence and increased reliance on others to communicate: ‘I don’t look people in the eye anymore’</p> <p data-bbox="1133 1075 1995 1155"><b>Martin</b> – Avoiding communication and interactions with others: ‘I have become introverted... only talk when cornered’</p> <p data-bbox="1133 1187 2029 1264"><b>Sue</b> – The impact of reduced confidence: Difficulties with connection and self-sufficiency</p>

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**Theme 2:** Navigating the reactions of others

**Sue** – The importance of being able to join in and feel included: ‘I do sometimes see myself as invisible’

**Gabriella** – Acknowledging and finding ways to manage feelings of distance from other people

**Nicola** – Feeling overprotected: ‘Don’t wrap me in cotton wool cause that’s the worst thing you can do’

**Nicola** – A desire for increased understanding and awareness: ‘If someone deems you as different, they don’t know how to deal with it’

**Holly** – The importance of the perception of others: ‘I’m less self-conscious with stroke survivors’

**Sue** – Navigating the reactions of others: ‘You just want to be accepted for who you are, more so than anything’

**Ada** – The uncertainty of responses from others/feeling misunderstood: ‘People don’t really understand the condition’

**Gabriella** – ‘What’s wrong with her?’: Being seen as different

**Gabriella** – Responses of others shaping a disabled identity: ‘People don’t see me, they see my disabilities’

**Theme 3:** Changes in self-perception

**Ada** – Losing your sense of self: ‘I don’t feel like I was before’

**Sue** – Changes in self-perception: ‘I think speech affects everything really... you as a person’

**Theme 4:** Adjusting and coming to terms with dysarthria

**Sue** – The importance of being able to join in and feel included: ‘I do sometimes see myself as invisible’

**Gabriella** – Managing and being ‘normal’: ‘I felt I couldn’t be me’

**Gabriella** – Responses of others shaping a disabled identity: ‘People don’t see me, they see my disabilities’

**Holly** – A shift in work identity: Acknowledging the benefits of slowing down

**Paul** – Developing a sense of self-acceptance over time: ‘The cards your dealt with you have to deal with, don’t you’

**Gabriella** – A shift to self-acceptance: ‘This is me and I can’t change’

**Gabriella** – Acknowledging and finding ways to manage feelings of distance from other people

**Nicola** – A complicated relationship with acceptance: ‘I’m happy with where I’m at, kind of’

**Nicola** – Making adaptations for limitations: ‘It’s still living life, just in a different way’

**Martin** – Feeling frustrated but coming to terms with a shift in abilities

**Holly** – A shift in work identity: Acknowledging the benefits of slowing down

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### **Appendix A - Biographical Sketches of Participants**

Holly is 38 years old. She is married, lives in the USA with her husband, and has a PhD in literature. Before the stroke, Holly was working full-time as an acquiring book editor and described herself as very analytical and logical. Holly experienced her stroke one year and two months prior to the interview. Since the stroke, she has continued in the same role however now works part-time. The most prominent difficulties Holly described as a result of her stroke were dysarthria and fatigue.

Ada is 49 years old and experienced her stroke two years and five months prior to the interview. Prior to the stroke she was a performance poet, a promotor, and a workshop facilitator for teenagers and women. She described herself as 'an anomaly' and unique. Ada enjoyed travelling and was in Uganda at the time of her stroke. Since her stroke, she has been unable to return to work. Ada lives independently with the support of carers at various points throughout the day. She has four children (aged 24, 21, 20, and 16). The most prominent difficulties Ada described as a result of her stroke were speech impairments, muscle weakness, and problems with memory.

Nicola is 46 years old and lives with her partner (who she met following the stroke) and her two sons. She experienced her stroke two years and five months prior to the interview. Before this, she had a livery and training yard with horses and taught horse riding. She described herself as spontaneous and outgoing. Nicola decided to sell the yard when she split with her sons' father; she moved to a small village and lived there for

two years before she had her stroke. There she began working as a support worker for people with learning disabilities. She continues to work in this role part-time. The most prominent difficulties Nicola described as a result of her stroke were muscle weakness, memory problems, and speech difficulties, although she rated her dysarthria as lower severity than other participants.

Sue is 57 years old and lives with her partner. She has two adult daughters (aged 29 and 31); she divorced from their father prior to her stroke. Sue described herself as bubbly and somebody who likes caring for others; she also worked as a carer prior to her stroke. Sue experienced her stroke five years and 11 months prior to the interview, and she has been unable to return to work since then. Sue's stroke resulted in a number of speech impairments; dysarthria and aphasia (which she continues to experience) and foreign accent syndrome (which has now resolved). Other prominent difficulties she described were memory problems, fatigue, and right sided weakness.

Martin is 61 years old and experienced his stroke seven years and 11 months prior to the interview. He lives with his wife and two dogs and is now retired. He has two sons and two daughters. Prior to his stroke, Martin served in the armed forces and following this worked as an IT manager; he spent his working week away from home and returned on weekends. He experienced his stroke as a result of complications from surgery he was having to treat cancer. Martin initially returned to work after the stroke but was unable to fulfil his role. The most prominent difficulties Martin described as a result of his stroke were dysarthria, swallowing difficulties, left sided weakness, and memory problems.



Gabriella is 47 years old and experienced her stroke 24 years and 11 months prior to the interview. She described herself as a 'punk' prior to the stroke and that she hid behind her tattoos as she was not very confident. She was training to be a hairdresser and then worked in a factory.

Gabriella gave birth to her son six weeks before having her stroke and subsequently moved back in with her parents for support. Gabriella has not returned to work since her stroke and currently lives with her partner (who has also had a stroke; they met through an online stroke support group). Dysarthria, fatigue, memory difficulties, and right sided weakness are the most prominent impairments Gabriella described.

Paul is 45 years old and lives with his partner. He experienced his stroke two years and seven months prior to the interview. Before the stroke, Paul worked in plant hire and he described the job as very busy. Outside of work, Paul would spend much of his time socialising with his friends in the pub and he described that he drank alcohol and used drugs to excess. He described himself as not very nice as he was mostly motivated by alcohol. Following the stroke, Paul returned to work and driving, however experienced an epileptic seizure and subsequently stopped working and had his license revoked. He is currently unemployed. Dysarthria, fatigue, and memory difficulties were the most prominent impairments Paul described following his stroke.

## Appendix B- Audit Trail Example 'Gabriella'

*Theme 1: 'What's wrong with her?': Being seen as different*

Initial Codes	Narrative Summary	Participant Quotes
<ul style="list-style-type: none"> <li>• Others thinking there is something wrong with her due to her speech 434</li> <li>• Experiences of people thinking she is deaf due to her speech and changing how they communicate with her 188</li> <li>• Being treated by others as though she had cognitive difficulties 210</li> <li>• Communicating on the phone is even harder - experience of others thinking she is a child and asking for her mum 343</li> <li>• Strangers perceiving there to be something 'wrong with her' and curious about her condition 297</li> <li>• Not overly concerned about the curiosity as long as it is directed to her and not about her to someone else 299</li> <li>• Experiences of other people talking to the person she is with about her, rather than with her directly 190</li> </ul>	<p>This theme reflects how Gabriella feels she is viewed differently and subsequently treated differently by others as a result of her dysarthria. Gabriella described how other people often think that there is 'something wrong' with her due to her speech. This included people believing that she is deaf, that she has cognitive difficulties, or that she is a child (when communicating over the phone). This then leads people to change how they speak to her, either by slowing down their own speech or by directing their conversation to the person she is with instead.</p> <p>Gabriella has had many experiences of being ignored when she is with her mum and explained that other people ask her mum about her condition rather than asking her directly. Gabriella described meeting new people who are curious about her speech all the time. She is not particularly bothered by the curiosity</p>	<ul style="list-style-type: none"> <li>• 'What's wrong with her?'</li> <li>• But a lot of people think I'm deaf. They will talk [demonstrates talking slowly and clearly] 'Hello, my name is...'. And I say 'I can hear you!' [Laughs]. You look stupider than me.</li> <li>• No. They treated me like I was backwards or... ask 'Is she alright?'. And I couldn't speak in those days.</li> <li>• Yeah, the phone's the worst. If people phone me, strangers, they say 'Is your mum in?'. I'm 47, she's not here!</li> <li>• They'd say 'Well, what's wrong with her?'. Curious, all the time.</li> <li>• I'd rather them say 'What's wrong with you? What's happened to you?'. In the early days, I was only 22. They'd say</li> </ul>

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- Family facilitating conversation – directing people to talk to her directly 212
  - Varying experiences depending on the age of others – ‘young people are brilliant’ and old people ask ‘what’s wrong with you’ 220
  - Older people speaking to the person she is with rather than directly with her 222
  - Has noticed an improvement in responses from others, but still acknowledged different between ‘old’ and ‘young’ people 305
  - Experience of others not knowing what the term ‘dysarthria’ means and having to explain 331
  - Sense of embarrassment for the people she is speaking to due to the dysarthria 373
  - Wanting to avoid having negative feelings towards others when they make comments 460
  - Worries about what other children would say about his mum that might make him embarrassed - Worries that other children would say his mum is ‘thick’ due to speech 186

displayed by others but would understandably prefer the questions to be asked directly to her. Gabriella has noticed that older people are often more likely to be more direct and less polite in the way they ask about her condition, whereas younger people seem to be more understanding and less likely to highlight the difference between them and her.

When people are curious, Gabriella will tell them about her condition. However, she explained that often people don’t have knowledge of what the word ‘dysarthria’ means so she has to explain to them. Gabriella described feeling a sense of embarrassment, not for herself, but for the person she is communicating with when she observes them to be uncomfortable or not know what to say in response to her.

Gabriella also discussed such responses from others in terms of her relationship with her son. Gabriella had her stroke six weeks after her son was born. She was concerned that when he was a child, his friends might make comments about his mum due to her speech. Although Gabriella has the confidence to respond to people who make comments or ask about her dysarthria, she had worries that her son might be embarrassed

‘What’s wrong with her? She’s young’.

- Oh yes, a lot. Or they will talk to my mum – ‘How is she?’. And I’ll say ‘I’m fine!’.
  - No, I’d just look at my mum and my mum would say ‘She’s fine, talk to her!’.
  - Yeah. Young people are brilliant. Young people always see me and smile and they’re lovely. It’s the old people who are like ‘What’s wrong with you?’.
  - Yeah, but some people are better now. It’s normally old people. And I’ll say ‘I’m here!’.
  - Yeah, because when I say dysarthria, people say ‘What’s that?’ and I say ‘Slurred speech’.
  - Yeah. A lot, a lot. I don’t feel embarrassed but embarrassed for the other person. Because they don’t know what to say. So, I feel embarrassed for them, not embarrassed for me.
  - I would hate the person, but I don’t want to have to.
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| <ul style="list-style-type: none"> <li>• Not wanting son to be embarrassed of her because of speech, although she felt confident to speak up about things (son told her he wasn't embarrassed) 180</li> </ul> | <p>of her, although he reassured her that he wasn't. It seems that although Gabriella does not appear to feel too embarrassed on her own behalf, she worries about how other people will feel as a result of her dysarthria.</p> | <ul style="list-style-type: none"> <li>• Yeah, cause children can be cruel and I didn't want them to say your mum's thick or...</li> <li>• Well, me and my son are quite close, but it was hard. I didn't want him to be embarrassed because of me... cause I was confident, I wasn't afraid of saying that.</li> </ul> |
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*Theme 2: Responses of others shaping a disabled identity: 'People don't see me, they see my disabilities'*

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<b>Initial Codes</b>	<b>Narrative Summary</b>	<b>Participant Quotes</b>
<ul style="list-style-type: none"> <li>• Experience of struggling to even communicate what has happened to her and why her speech is different 369</li> <li>• Feeling of frustration at not being able to express self 389</li> <li>• Describing self as 'disabled' as it is easier to say than the word 'stroke' 371</li> <li>• How participant feels when she starts to speak – 'I feel disabled. Less of a person. People don't see me, they see my disabilities.' 430</li> </ul>	<p>Gabriella mentioned various ways in which her dysarthria and how people respond to the condition has changed the way she views herself. She described feeling frustrated when she is unable to express herself and explained that she even has difficulty trying to explain to people why her speech is different as she is unable to say the word 'stroke' clearly. As an alternative to struggling with that word, Gabriella will use the word 'disabled' to describe herself instead. However, it seems that this is not only due to the word being easier to</p>	<ul style="list-style-type: none"> <li>• I kept it to as minimal as possible. I don't talk... I mean the hardest bit for me is saying 'stroke'. I can't say 'stroke'. STR, I can't say STR.</li> <li>• Yeah, it's very frustrating.</li> <li>• Yeah! 'So what's wrong with you?'. 'Erm... I'm... disabled'.</li> <li>• Yeah, I feel disabled. Less of a person. People don't see me, they see my disabilities.</li> </ul>

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- Describes self as having ‘loads’ of disabilities 118
- Lots of nerves prior to meeting someone new because of her speech 329
- Experience of feeling embarrassed speaking to neighbour for the first time 383
- Feeling upset if people just nod along 134
- Wanting to be heard and listened to, even if that means repeating self ‘a million times’ 136
- Feeling ‘degraded’ – ‘It made me feel like I was just a thing’ 208
- Never meeting anyone else with the same condition/speech difficulties as her 440
- The sense of feeling different and ‘odd’ due to not meeting others similar to her 446
- Feeling that she could be lonely, but she has the support of family 402

pronounce, but this is part of how Gabriella views herself now. She described that when she begins to speak, she feels disabled and as though she is less of a person. Gabriella feels that when she is talking to others it is easier for them to focus on her speech being different rather than being able to view her for the person she is. This can understandably leave Gabriella feeling very nervous prior to meeting somebody new.

When speaking with others, Gabriella has described feeling upset if people don’t take the time to really listen to her. Gabriella often experiences people nod along as if they have heard her, rather than asking her to repeat herself when she is unclear. She expressed a strong desire to be heard and listened to, even if that means repeating herself a ‘million times’. As a result of the responses she has experienced from others (detailed in theme 1), Gabriella described feeling degraded. Again, there was the sense that Gabriella feels as though she is less of a person at these times.

It also seemed very significant to Gabriella that she has never met anybody else with dysarthria. Although Gabriella has met a large number of stroke survivors who have communication

- Yeah. And he has no disabilities whereas I’ve got loads.
- Oh, I was so nervous. Really nervous. I was worried about my speech, and he said ‘Well, speak slowly! I’ll take you as you are’.
- And I felt embarrassed speaking to her. I said ‘Thank you’ [speaking slowly]. Cause I couldn’t say I have a speech problem at first.
- Yeah. Cause a few times I’ve seen them do it [nods] and people have said that and it upsets me.
- Yeah! If I have to say it a million times, I’d be happy you’d listened to me.
- In the early days I felt... Degraded. It made me feel like I was just a thing.
- I was young when I had my stroke and I’ve met no one with dysarthria. I’ve met thousands of people with speech therapists and no one with dysarthria.
- I want to say unique but erm, odd. Because most people meet people

problems (aphasia), it seems important that she cannot fully relate to these individuals as they do not have slurred speech. This has resulted in Gabriella feeling odd and different. There was a sense that this could have made Gabriella feel lonely, if not for the strong family support she has.

who have the same problem as them but I haven't.

- No, because I have my family

*Theme 3: Managing and being 'normal': 'I felt I couldn't be me'*

Initial Codes	Narrative Summary	Participant Quotes
<ul style="list-style-type: none"> <li>• Desire to return to 'normal' speech after the stroke and believing that this was achievable – 'I didn't realise it was permanent' 154</li> <li>• Support from a vocal coach helping participant to communicate more effectively 160</li> <li>• Feeling naïve due to the belief speech would return to 'normal' 156</li> <li>• Sense of being perceived as 'normal' until she speaks 420</li> <li>• Seeming 'normal' to others externally, until she walks or talks and the</li> </ul>	<p>Throughout the interview, Gabriella made numerous references to the idea of 'normality' and her desire to want to feel more 'normal'. Initially following her stroke, Gabriella described having a strong desire to want her speech to return to the normal speech she had prior to her stroke. She thought that this would be achievable with time and had the support of a vocal coach to support her with this. Although Gabriella described how this support helped her to communicate more effectively, she now views her past self as naïve for believing that her</p>	<ul style="list-style-type: none"> <li>• Well, I was stupid cause I thought I was going to talk normal. I thought I was talking normal with speech therapy, I thought I'd be talking normal. I didn't realise it was permanent.</li> <li>• He was a vocal coach. And he taught me how to breathe from my diaphragm... deep in my belly, breathing. I was breathing fast [demonstrates fast breathing], I couldn't breathe and he taught me how to breathe from my</li> </ul>

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experience of them responding differently to her when she does 218

- The desire to be seen as ‘normal’, but feeling as though she can’t be herself as although she looks normal, she feels she isn’t normal 418
- Had more of an impact on sense of self in early days after stroke 307
- Trying to maintain ‘normality’ by speaking less 424
- Having to spend time planning conversations and what she will say before she speaks – identifying the words which are easier to say 426
- Being a mother helped participant to feel more ‘normal’ and helped her to get on with things ‘I’d take him to school and go to the shops with him’ 138
- Son and his friends have ‘only ever known me as this’, so don’t have a pre-stroke comparison 138

speech could possibly return to how it was before.

As previously discussed, Gabriella often feels different when communicating with others and therefore there is a continued desire to be seen as more normal by others. It seems that Gabriella is able to feel normal in terms of her external appearance, however when she begins to speak, this sense of normality seems to dissolve. There is also an acknowledgement, that not only to others, but in terms of her own identity, she does not view herself as normal as she feels unable to be herself. However, Gabriella described how being a mother allowed her to feel more normal as she had no choice but to do the tasks and activities that were required for her son. She also reflected that her son and his friends had never heard her speech prior to the stroke so did not have anything to compare it to.

It seems that as time has passed since the stroke, the impact that Gabriella’s speech has on her sense of self has decreased (discussed in theme 4). Despite this, she continues to make attempts to be perceived as more normal within conversations. She achieves this by generally

diaphragm. It made a hell of a difference.

- I’d get back to normal. I was naïve.
  - Yeah, now. I want to be seen as normal. And I am, until I open my mouth.
  - It’s hard because people see me as normal until I walk or talk and they go ‘woah!’. It’s weird, you know what I mean. Like if I was sitting in the shops and someone asks ‘Is anyone sitting there?’ I’d say ‘No’ and they’d look [pulls funny look]. Or ‘Can you look after my bag?’ and I’d say ‘Yeah, no problem’ and [pulls face again].
  - I felt, erm... I couldn’t be me. Because people would see me as normal but I’m not normal, you know what I mean? And I want to be seen as normal. So, it’s confusing.
  - It did in the early days. But now I say... ‘You can think what you want’.
  - Yeah, and nodding my head.
-

speaking less to others and spending time planning out conversations before she speaks.

- Every conversation I have to everyone, I think about what I'm going to say in my head first and what words I can say and what's hard, you know what I mean, the words I can't say. So, I play the scenario in my head. And work around words that are hard to say.
- My son helped me a lot though. When he was at walking age, I'd take him to school and go to the shops with him... I'm normal to him.
- I'd have his friends to the house; I'd cook them meals. Him and his friends have only ever known me as this.

*Theme 4: A shift to self-acceptance: 'This is me and I can't change'*

Initial Codes	Narrative Summary	Participant Quotes
<ul style="list-style-type: none"> <li>• Change in mindset from wanting 'normal' speech back to 'this is me' - acceptance 168</li> </ul>	<p>It was acknowledged in theme 3 that Gabriella struggled to achieve a sense of normality due to her dysarthric speech. However, she also</p>	<ul style="list-style-type: none"> <li>• Yes, but then I thought, 'this is me, I have to deal with it! I'm not gonna change so this is me'.</li> </ul>



- Initially, after the stroke, when living with parents, ‘I was very in myself’ 138
- ‘I’m more confident now, I don’t fear my speech, I don’t fear my disabilities’ – sense of a change of mindset over time 124
- Feeling more confident as a result of the dysarthria 456
- Taking a long time to change that mindset 172
- ‘There’s nothing I can do about it’ 170
- Acknowledgement of the physicality of condition and knowing it won’t change ‘my soft palette is paralysed, so there’s nothing I can do about it 458
- Descriptions of self now – ‘Confident. I’m not shy and erm... happy, content. I’m fearless. I’m normal’ 216
- ‘This is me’ attitude, she can’t change how she communicates so ‘it’s their problem, not mine’ 230
- Now, has changed mindset and feels less of an impact from others’ comments 309
- Not feeling embarrassed for self as she has a sense of self-acceptance – ‘there’s nothing I can do, I can’t change’ 373

described how she experienced a shift in her mindset over time. It seems that she went from wanting to return to her pre-stroke ‘normal’ self to realising that ‘this is me’, there is nothing she can do to change her speech, so she has been able to accept herself as she is now.

Gabriella has described how she feels more confident now, even more so than she was prior to the stroke. Gabriella described how she was never that confident before her stroke and would hide behind her punk style and tattoos. However, it seems that she now holds a feeling of fearlessness as a result of experiencing the stroke and dysarthria. Gabriella explained that this change in mindset took her a long time to achieve following the stroke but being able to acknowledge the physicality of her condition and that this will not change appears to have played a significant role in this.

Gabriella described how having this new-found acceptance of herself enabled her to feel less affected by the responses of others. She is now able to feel confident enough to use humour to respond to people who treat her differently or speak up when people direct their conversation to her mum rather than her.

- Definitely. I was very erm, because I was at my mum and dads, I was very in myself.
- For 12 years I think I was still living with my mum and dad. Since moving here I’ve been happier... I’m more confident now, I don’t fear my speech, I don’t fear my disabilities.
- I suppose my dysarthria made me more confident.
- I would say at least 10 years.
- Yeah, cause there’s nothing I can do about it.
- Because this is me and I can’t change. I’ve tried my hardest to speak normal and I can’t. My soft palette is paralysed, so there’s nothing I can do about it.
- Confident. I’m not shy and erm... I’m happy, content. I’m fearless. I’m normal.
- It’s their problem, not mine... Yeah, I’m being me.
- But now I say... ‘You can think what you want’. It’s their problem, not mine.

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- Description from friends as being crazy, confident and unafraid to speak up, despite the slurred speech 281
  - Using humour to respond to these reactions 188
  - Having the confidence to say something to them in these situations 192
  - Responding to these reactions to her speech by telling people her age 347
  - Mindset to tackle problems rather than accept that she is unable to do things 291
  - Identifying her disabilities as a weakness but the strength she has had to manage them 317
  - Recognising strength in self 315
  - Recognising own strength in having this confidence 287

Gabriella does not feel embarrassed about her speech now as she is aware that there is nothing she can do about it. However, despite being able to accept her speech, this does not mean that she has give in to her disabilities; she described how she will think about how to tackle problems rather than accept that she cannot face them.

Although Gabriella continues to view her disabilities as a weakness, she is also able to acknowledge the strength she has in order to cope with them. She has recognised the strength she possesses in order to respond to others and see herself in the way she does now.

- I don't feel embarrassed but embarrassed for the other person. Because they don't know what to say. So, I feel embarrassed for them, not embarrassed for me cause there's nothing I can do, I can't change.
  - Crazy. I'm confident and will say anything to anyone and if someone says something I'll say 'What?'.
  - They will talk [demonstrates talking slowly and clearly] 'Hello, my name is...'. And I say 'I can hear you!' [Laughs]. You look stupider than me.
  - Yeah, and I say 'I'm here!'.
  - I'll say 'I'm 47!', they'll say 'Oh, I'm sorry'.
  - Another thing. I don't say 'I can't do that', I say 'How can I do that?'.
  - Disabilities. I can't move my arm. So that's my weakness. I can't do the things I want to and my strength is me.
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*Theme 5: Acknowledging and finding ways to manage a feeling of distance from other people*

Initial Codes	Narrative Summary	Participant Quotes
<ul style="list-style-type: none"> <li>• Low mood attributed to losing friends after the stroke - Being unable to speak or communicate with friends as she normally would, meaning that she lost those friendships 146</li> <li>• Being physically distant from my friends and having no other way of communicating 148</li> <li>• Change in friendship group/s – describes losing friends and connecting with family members or others through social media 275</li> <li>• Experience of a family member who is embarrassed when she speaks and won't listen 468</li> <li>• Feeling of distance within relationship with brother due to speech 478</li> <li>• Brother feeling protective over her due to her speech 474</li> <li>• Sense of determination to maintain communication with brother, even when he struggles 476</li> </ul>	<p>This theme represents the feeling of distance that Gabriella described within many of her relationships, which she feels is as a result of her dysarthria. This feeling of distance seems to prevail across existing relationships as well as within potential new relationships. Gabriella expressed that, understandably, she felt depressed immediately after the stroke and she attributed this mostly to losing many of her friends. She was physically distant from them at the time whilst living with her parents and felt she had no other way of communicating with them as she could not talk over the phone. Gabriella acknowledged that social media did not exist then but explained that more recently she has been able to use social media to connect with family members and new friends.</p> <p>There also seems to be a feeling of distance between Gabriella and her brother, particularly when compared with before her stroke. She described how he seems to be embarrassed when she speaks and does not always listen to</p>	<ul style="list-style-type: none"> <li>• I went through depression and had Prozac... I lost all my friends.</li> <li>• I couldn't phone them or go round their house or speak to them.</li> <li>• No because most of my friends were where I used to live, I lost contact. In my early days, there was no Facebook.</li> <li>• I lost most of them. I have a few off Facebook now. My closest friend or my support group is my cousins. She's a bit younger than me and we've been friends through life.</li> <li>• My relationship with my brother. My brother doesn't listen to my speech. He gets embarrassed. And when I can't say things, he doesn't say 'What?' he just [nods].</li> </ul>

- The sense that the dysarthria means she is unable to meet new people and start new relationships 416
- Keeping conversation to ‘as minimal as possible’ when speaking with new people 369
- Keeping conversation minimal with people she doesn’t know well (neighbours) 387
- Experience of even having difficulty telling people her name due to the dysarthria 339
- When speaking with someone new, slowing down speech and saying each word at a time to aid communication 333
- Sense that this feels ‘robotic’ and ‘strained’ – unnatural way of communicating 335
- Will choose to ignore calls if she does not know who is calling 351
- Speaking in a slow, ‘robotic’ way when initiating phone calls 355
- Speech affecting ability to have phone calls 381
- Experience of being approached by men who are attracted to her physical

her. However, she also seems to have a sense of determination to maintain communication with her brother, even when he struggles.

There are also ways in which Gabriella seems to remain distanced from new people, or from the potential of developing any new relationships. She described keeping conversation to as minimal as possible with people she does not know well, even having difficulty pronouncing her name in order to be able to introduce herself. When she does speak with new people, Gabriella will often adapt how she speaks by slowing down and making more effort to pronounce each word. However, she reflected that this can make conversation feel robotic and subsequently less natural. Speaking on the phone is particularly hard for Gabriella and so she will often choose not to answer if she does not recognise the number.

In terms of romantic relationships, Gabriella described the experience of men approaching her who are attracted to her physical appearance, but that she feels unable to respond to them due to her speech and so will remain silent. Gabriella met her current partner online through a stroke support group and she reflected that she would still be single now if it wasn’t for

- It’s hard because we were close growing up and we’re not as close as we were. I used to go to him but I don’t do that now.
- Yeah, but he’s more protective now. Cause my brother’s a bouncer, so he’s quite a big person, you know what I mean? He tries to protect me.
- Yeah, but I will try every time.
- I kept it to as minimal as possible. I don’t talk... I mean the hardest bit for me is saying ‘stroke’. I can’t say ‘stroke’. STR, I can’t say STR.
- I still don’t talk much to them. Just ‘hello’ and move on.
- Yeah, everyone, new people. And I can’t say my name. They’ll say ‘What’s your name?’ and I say [Name] and they say ‘What?!’.
- When I first spoke to him, I very slow and I spoke each word at a time [demonstrating]. I’d concentrate on each word.

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appearance, but that she feels unable to respond and remains silent 404

- Wearing a wedding ring to avoid being approached by men so that she doesn't have to speak to them 406
- 'I'd still be single now if I hadn't met my partner' – through social media 412

this way of meeting. Prior to this, Gabriella would wear a wedding ring in order to avoid having to speak to new men.

Despite the feeling of distance described within relationships, Gabriella did highlight various ways in which she feels more comfortable either in initiating relationships or with the relationships she has. She mentioned some practical strategies she has tried, such as writing things down, asking others for help, and putting more effort into the words and sounds she finds more difficult. However, as previously mentioned, these strategies can serve to make Gabriella feel more different or make conversation feel less natural.

There was a sense within our conversation that Gabriella has no desire to initiate new relationships with people who do not make the effort to ask her to repeat herself when she is unclear. Understandably, Gabriella wants to be heard and therefore has a strong desire for people to admit that they cannot understand her, rather than pretending. It seems that Gabriella has become comfortable with the idea of not meeting new people if this is how they respond to her. Gabriella did identify that she finds it helpful when the new people she is meeting

- I found it robotic. Yeah, and it was strained because I was talking like that [demonstrating].
  - Well, the fact that I have a phone where it tells you who's phoning, whether it's mum, dad, sister. Say if it's a strange number, I think 'answer machine'.
  - I could. I've phoned a few places like the doctors, dentist and stuff. And then I talk very robotic [demonstrating] 'Do you have an appointment?'.
  - Well, a few times I've been out with my cousin before I met my partner and men approached me because I look normal. They like my appearance. I have big boobs and stuff like that. And they're like, 'How are you, can I buy you a drink?' and I'd be like... [silent].
  - I'd normally say I'm married and I'd wear a wedding ring. Because my nan gave me her wedding ring. So I'd wear that and say 'I'm married'.
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already have an awareness of her disability, so that there is less pressure on her to have to explain.

Gabriella described having a strong family support system. Within her family relationships it seems that Gabriella really values the recognition of her progress since the stroke, as well as having people who know her well enough that they can understand her speech with ease. One part of her support system is her new partner, who she met through an online stroke support group. Being able to communicate with people online where she can type initially seems to be significant in Gabriella initiating new relationships.

- I'd still be single now if I hadn't met my partner.
  - No, I'd ask my mum. When I couldn't speak, I wrote it down cause I'm left-handed.
  - Yeah. I couldn't say 'Dad' for 15 years. I couldn't say 'D'. And I find 'K' hard, I have to really push them out. You know what I mean.
  - Well, my nephew was married a few months ago and I went to his wedding. And his partner's family said 'Hello, how are you?'. And I was like 'I'm [name], I'm his aunty' [speaking slowly]. And they said, 'It's alright, we know you're disabled'. So, that was helpful.
  - If you don't understand me, say 'what', don't say mmm and nod.
  - Since having my stroke, I know if people don't say 'what did you say?', they're not worth talking to.
  - Yeah, fine. Sometimes... my son's the best. Sometimes when
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I'm on my period or when I'm tired, my speech is terrible. And sometimes I can't understand what I'm saying. I'll mumble stuff and he'll say 'Yes mam'. And I'm like 'How the hell did you understand that?!'. [Laughs].

- A lot of my family would say amazing. Cause I've come through all this and still where I am.
  - My sister's... married with two sons. Cause she says if she had my stroke, she wouldn't... have wanted to live. And my brother says the same, says how you've done this is amazing.
  - We only met this year because he's from down South. But erm, it was the best experience ever. We just gelled and had things in common. We'd both had strokes. We both had hypermobility. And I'm just me.
  - Yeah, he runs it. We spoke a few times then we started phoning and using messenger.
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- Yeah, I can contact my friends now, through Facebook.
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### Appendix C - Summary Table of Individual Participant Themes

Participant	Themes
Holly	<p>Theme 1. The effort of communicating and maintaining relationships: 'It's so effortful and slow, it's not always worth it'</p> <p>Theme 2. Identifying as more of an introvert: 'I'm much more prepared or I participate less'</p> <p>Theme 3. The importance of the perception of others: 'I'm less self-conscious with stroke survivors'</p> <p>Theme 4.: A shift in work identity: Acknowledging the benefits of slowing down</p>
Ada	<p>Theme 1. A shift to an introverted identity: 'I'm learning to like my own company'</p> <p>Theme 2. Losing your sense of self: 'I don't feel like I was before'</p> <p>Theme 3. The uncertainty of responses from others/feeling misunderstood: 'People don't really understand the condition'</p>

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Nicola

Theme 1. A complicated relationships with acceptance: 'I'm happy with where I'm at, kind of'

Theme 2. Making adaptations for limitations: 'It's still living life, just in a different way'

Theme 3. Desire for increased understanding and awareness: 'If someone deems you different, they don't know how to deal with it'

Theme 4: Feeling overprotected: 'Don't wrap me in cotton wool cause that's the worst thing you can do'

Sue

Theme 1. The impact of reduced confidence: Difficulties with connection and self-sufficiency

Theme 2. The importance of being able to join in and feel included: 'I do sometimes see myself as invisible'

Theme 3. A significant change in self-identity: 'I think speech affects everything really... you as a person'

Theme 4. Navigating the reactions of others: 'You just want to be accepted for who you are, more so than anything'

Martin

Theme 1. Avoiding communication and interaction with others: I have become introverted... only talk when cornered'

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Gabriella

Theme 2. Reduced confidence and increased reliance on others

Theme 3. Feeling frustrated but coming to terms with a shift in abilities

Theme 1. ‘What’s wrong with her?’: Being seen as different

Theme 2. Responses of others shaping a disabled identity: ‘People don’t see me, they see my disabilities’

Theme 3. Managing and being ‘normal’: ‘I felt I couldn’t be me’

Theme 4. A shift to self-acceptance: ‘This is me and I can’t change’

Theme 5: Acknowledging and finding ways to manage a feeling of distance from other people

Paul

Theme 1. ‘I can’t really join in conversations like I used to’: Feeling self-conscious and frustrated about speech

Theme 2. Living a more solitary life: ‘I don’t really speak to many people these days’

Theme 3. Developing a sense of self-acceptance over time: ‘The cards your dealt with you have to deal with, don’t you?’

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## **Appendix D - Author Guidelines for *Disability and Rehabilitation***

### **Instructions for authors**

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- Reconstructive surgery is a technique available to this group.
- In a relatively small sample this study shows participation and social functioning improved after surgery.

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  - People with MS have complex reasons for choosing to exercise or not.
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### **Section Three: Critical Appraisal**

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### **Critical Appraisal**

This paper aims to complement sections one and two of the thesis as it provides opportunity for more detailed, in-depth considerations regarding the research process. I will firstly provide a summary of the findings of the systematic literature review (SLR) and empirical paper in relation to each other. I will also offer a critical reflection of the research process more broadly, although specific strengths and limitations have been highlighted in the main report. This information will be presented in chronological order, reflecting upon issues/challenges as they arose. In doing so, it is hoped that the thesis is contextualised for the reader and that reflections offered can provide insight into the process of conducting research within this field, particularly with individuals who have communication impairments.

#### **Summary of Findings**

The SLR aimed to explore the barriers and facilitators faced by stroke survivors with communication impairments in relation to accessing appropriate rehabilitation interventions from the perspectives of healthcare professionals, stroke survivors, and their carers. Four themes were identified through a meta-synthesis of 16 studies. Barriers and facilitators were discussed in relation to the patient, their families, healthcare professionals, the interaction between disciplines, as well as higher-level, systemic factors. The relevance of collaborative multi-disciplinary team (MDT) working (particularly between Speech and Language Therapists (SLT) and psychologists) was highlighted within a service where expertise are shared and training is prioritised. The findings suggest that a holistic approach could facilitate access to rehabilitation for these individuals by: increasing understanding and awareness of communication difficulties and their potential impact upon wellbeing, reducing levels of uncertainty/anxiety for healthcare professionals in supporting them, and promoting patient engagement with the rehabilitation process by addressing their psychological needs more effectively.



The research paper aimed to explore the experiences of stroke survivors who have dysarthria in relation to their identity. Seven participants took part in semi-structured interviews and using Interpretative Phenomenological Analysis (IPA) four themes were derived: (1) a sense of distance and disconnection from other people; (2) navigating the reactions of others; (3) changes in self-perception; and (4) adjusting to and coming to terms with dysarthria. The findings indicate that dysarthria can impact upon stroke survivors' perceptions of themselves in several ways. Participants described feeling disconnected from others and subsequently seeing themselves as more introverted. Participants also noticed being perceived differently by others and described changes in their relationships and groups they felt they belonged to. All of these factors resulted in changes in participants' self-identity. However, for many of the participants, they experienced a shift in their level of acceptance of their speech over time and found ways to come to terms with it. Suggestions were made for ways in which clinical psychologists working within stroke services could draw upon psychological approaches to facilitate the process of acceptance and encourage a positive self-concept in relation to speech.

Although the two sections of the thesis differed in their focus and target population, it is interesting to consider the similarities within the respective findings. Firstly, there was a sense of reluctance apparent within both papers regarding the approaches of other people when interacting with these stroke survivors. Although the responses of the public described in the research paper were more blunt and overt than those of professionals in the SLR, it is still important to consider the impact these responses can have upon stroke survivors' wellbeing and sense of identity. The importance of an assumption of competence and realisation of mutual respect has been previously recognised in terms of enhancing the identity of individuals with aphasia [1,2]. This is unlikely to be guaranteed for these patients when professionals feel uncertain about their ability to communicate with them. This

supports the recommendations made for training of all healthcare professionals in communicating with these individuals to ensure a level of comfort when interacting.

Interestingly, the role of adjustment/acceptance was emphasised within both papers. Most participants from the research paper described how, over time, they found ways of coming to terms with their altered speech and its impact on their lives. In the SLR, such acceptance was recognised to be beneficial for goal setting and engagement with rehabilitation. It has been previously recognised that acceptance can play a significant role in emotional adjustment for stroke survivors and is an important area to be considered during rehabilitation [3]. This further highlights the potential benefits of utilising Acceptance and Commitment Therapy (ACT) [4] principles within rehabilitation.

Another commonality between the two papers was the finding that stroke survivors with communication impairments had a tendency towards social isolation; there were descriptions of individuals in both papers speaking less and avoiding interactions with others. It is interesting to note that although most of the papers within the SLR were focused upon aphasia and the research paper explored dysarthria, these similarities were present across conditions.

Based on the findings of the two papers, there are various ways indicated in which clinical psychology could offer support to both stroke survivors and healthcare professionals. Firstly, clinical psychologists are able to offer a space for the wider MDT to reflect on challenges they may face when supporting these individuals, the impact it may have on them/their work, and to provide containment and validation [5,6,7]. The hope would be that this results in staff members feeling less alone and less likely to blame themselves for the difficulties they have experienced; it could serve as a form of cognitive restructuring [8]. Clinical psychologists can also offer support drawing upon principles of behavioural activation [9] to support stroke survivors to engage once more in enjoyable activities and

reduce the likelihood of social isolation. The importance of identifying personally relevant, community-based provisions is important here, as highlighted within the SLR. Providing psychoeducation [10] regarding the role of avoidance in relation to patients' communication impairment could also be beneficial.

### **Choosing a Research Topic**

My interest within this field was sparked during my clinical work as an assistant psychologist before commencing the Lancaster DCLinPsy programme. I worked for six years within a rehabilitation setting for individuals with acquired brain injuries, which included many stroke survivors. During this time, I developed a keen interest in neuropsychology and the unique and often devastating impact these injuries/conditions can have upon the lives of patients and their families. During my training within this service, it was emphasised that acquiring a brain injury could feel to patients as if they had become a whole new person [11]. This was something I was mindful of when interacting with all patients, however, there were a couple of stroke survivors I supported whose stories always stuck with me, both of whom were experiencing communication difficulties. I was struck by how significant the changes were that they experienced within their social, relational, and occupational roles/abilities. For example, one of these individuals owned his own business (where effective communication was essential) and was the sole breadwinner for his family, his wife had given birth to their first child weeks before he experienced his stroke. Clearly, the sudden impact of being unable to communicate in the same way was substantial for this stroke survivor and his family.

Upon commencing the DCLinPsy programme, I had the opportunity to choose a topic to conduct a literature review on in my first year. I decided to explore the general psychological impact of communication impairments following a stroke. Findings from this review confirmed that what I had observed clinically regarding changes to identity was also present in the relevant literature. The findings also highlighted the paucity of research on

dysarthria following stroke in comparison to aphasia, despite its recognised prevalence [12,13]. This provided the basis for the selection of this topic.

### **Choosing a Methodology**

When deciding which methodology to use, it was important for me to first consider my own epistemological standpoint for the research to be meaningful [14]. Following further research, I decided that critical realism [15] best represents my view of knowledge and how it is obtained. Critical realists subscribe to the idea that “truth” exists independently from our perceptions and beliefs, but that our knowledge of truth will always be provisional and influenced by social context [16]. Critical realism asserts that the ‘real’ world cannot be observed and exists independent of human perceptions; therefore, unobservable structures are recognised to cause observable events and the social world can only be understood if people understand what these structures are [17].

IPA was identified as an appropriate methodology to utilise for the study as it is theoretically rooted within a realist framework [18]. IPA is primarily focused on giving voice to and making sense of participants’ personal lived experiences [19]. For this reason, IPA has proved to have particular relevance in the field of health psychology; IPA provides opportunity for increased understanding of patients’ perceptions of their bodily experiences and the meanings which they assign to them [20]. IPA has also been recognised as valuable when exploring topics which are complex and emotionally laden due to the attention it gives to enabling participants to give as full an account as possible of their experience [21]. Despite this, I did have some reservations about utilising IPA with individuals who have difficulty communicating: “Some worries/concerns about having enough data to analyse when it might be likely that participants use short answers” (10th May 2021).

The process of IPA involves “detailed examination of participants’ lifeworld” [22 p53] which relies on in-depth discussion through semi-structured interviews. Therefore,

concerns have previously been highlighted regarding the suitability of such an approach when focusing on individuals with communication impairments [23]. However, existing literature has successfully utilised IPA with individuals with aphasia [24] and intellectual disabilities [25]. Within the current study, although participants' responses were shorter than might be expected from a typical IPA study, enough rich, meaningful data was obtained to complete a detailed analysis.

### **Homogeneity**

Within IPA, it is recommended to aim for a fairly homogenous sample [22]; samples are selectively chosen to find a well-defined group for whom the research question will be relevant. This was something I considered carefully when deciding on inclusion/exclusion criteria. I realised that I needed to strike a balance between defining criteria to ensure the sample would be homogenous, whilst avoiding making criteria so restrictive that I would struggle to recruit.

Specifically, the factors which I considered were the length of time passed since participants had experienced their stroke and the wide variation in other consequences they might be experiencing (e.g. communication, physical, sensory impairments etc). Smith and Osborn [22] assert that the specificity of a sample will depend on the study and that, in some cases, the topic under investigation may itself be rare and define the boundaries of the relevant sample. Therefore, it was decided that participants sharing the common characteristic of being dysarthric stroke survivors would result in a fairly homogenous sample without requiring more restrictions. Upon reflection, I think including stroke survivors who were at varying points within their recovery led to useful insights which may otherwise have been overlooked. An interesting finding from the study was relating to participants' shift in acceptance regarding their dysarthria over time, which may not have been as apparent if restrictions were placed upon how long ago they had experienced their

stroke. The challenge of participants experiencing a range of concurrent impairments was managed at the data collection stage, described later.

### **Ethical Challenges**

Whilst planning the research, there were several ethical considerations which needed to be taken into account. Firstly, ensuring that informed consent was obtained from all participants, whilst recognising the challenges within this process when individuals may not have the capacity to give consent [26]. Due to the complex nature of the condition, stroke survivors usually experience a range of consequences, which can include cognitive impairment [27]. This was the case for several participants in the study (mostly memory difficulties). I had anticipated that participants may experience these difficulties and acknowledged that this might have impaired their capacity to consent to participate. Guidance from the British Psychological Society (BPS) [28] on “Conducting research with people not having the capacity to consent to their participation” was followed. This states that the researcher should always presume the participant has capacity to consent or refuse to participate, based on the first principle of the Mental Capacity Act (MCA) [29]. Following initial conversations with participants, I had no concerns regarding their capacity to consent. There were no problems identified with any participant’s ability to; understand the research/consequences of participating, retain the information provided (between conversations), weigh up the relevant information to make a decision, or to communicate their decision.

However, when preparing materials for the study, I knew that making information accessible to participants who may have difficulty reading, processing, or understanding complex information would be important. Guidance suggests that practical support (such as amending research materials) could enable participants to make their own decision about their involvement [28], based on the second principle of the MCA. Therefore, following

consultation with two SLTs experienced in stroke, adapted, easy-read versions of the participant information sheet and consent form were developed (see section four of thesis). The Colours and Symbols (CAS) [30] supported communication tool was utilised within these documents. During initial conversations with participants, I explained that there were two versions of the forms and asked them which they felt would be more suitable. There was a mixture of responses and, upon reflection, I feel that having these options and providing participants with the choice worked well to meet their varying needs and abilities.

I was also keen to consult with stroke survivors during the development process; involvement of stroke survivors in research proposals has been described as vital to ensure the right research is being undertaken to effectively meet their needs [31]. I contacted the Stroke Association regarding service user consultation on the development of the recruitment process, materials, and interview schedule. Unfortunately, a response was not received. This is a key area of learning I have taken from the research process. The significance of obtaining input from service users regarding research which aims to support them is clear and I aim to allow time for this within future projects.

### **Recruitment**

There were some challenges faced regarding recruitment. Initially the plan was to share posters via the Stroke Association and social media. However, upon contacting the Stroke Association, although they were able to advertise the study on their forum, other routes they usually offered were unavailable due to Covid-19 restrictions. Unfortunately, no interest was expressed via the forum. The poster was also advertised via Twitter and one participant was recruited as a result. Most participants were recruited through closed Facebook stroke support groups. Having had such a slow start to the recruitment process, I was overwhelmed by the responses and support received through these groups. Lots of people appeared keen to share their stories, however unfortunately many did not meet the

inclusion criteria. Although I felt uncomfortable explaining to these individuals that they would not be able to participate, nobody seemed to respond negatively to this. It seemed that some participants had experienced this process before with previous research being shared in the groups. The advertisement was shared several times over the period of a few months to gain enough participants who met the inclusion criteria. Although the number of participants recruited was at the lower end of the aimed sample size (6-12), it is recognised that IPA studies usually benefit from a concentrated focus on a small number of cases due to the detailed account of individual experiences sought [32].

### **Data Collection**

Semi-structured interviews are noted to be the exemplary method for IPA studies [22]. The use of remote interviews was agreed upon to maintain the safety of all parties during the Covid-19 pandemic. However, preparing to conduct these interviews remotely presented some concerns. I was mindful that this might hinder the development of rapport, which increased my anxieties. Video-call interviews can present challenges in terms of the inability to read body language/nonverbal cues and a loss of personal connection and intimacy [33]. However, this study also suggests recommendations to help overcome these obstacles; confirming a stable internet connection, ensuring a quiet setting with minimal distractions, slowing down, and paying close attention to facial expressions. Weller [34] also highlighted that physical separation in remote interviews can facilitate greater connection due to an increased sense of ease with the setting.

For my research, I took several steps to manage these concerns. The initial phone conversations I had with participants were a useful way of beginning to develop rapport. In particular, the opt-in forms were a valuable means of starting conversation and inviting participants to provide more details about the stroke and its impact. However, I also made sure to spend time having more casual conversations to hopefully alleviate pressures on



participants and help them to feel more at ease before talking about themselves. We discussed practical challenges before interviews; having a quiet space to talk and what we would do if there was an unstable connection. I also thought it was important to acknowledge with participants that taking part in a remote interview might feel different/unnatural at times and that there would probably be occasions where we missed cues or talked over one another. I think this effectively set the scene for the interviews so that when these challenges arose, they felt less uncomfortable. All participants reflected positively upon the interview process and some of them expressed that they felt more able to speak openly via video than they would have in person.

As previously mentioned, participants in the study were experiencing a variety of concurrent difficulties following the stroke as well as dysarthria. Ensuring that dysarthria was maintained as the focus of interviews was a challenge which I reflected on throughout the data collection process. Although the interview schedule was devised to maintain this focus, I acknowledged that this was only a guide and to allow participants to speak openly, I would need to prepare for how I might manage this in the moment. An extract from my reflective journal read:

Need to remain mindful of the numerous consequences of participant's stroke. Don't want to minimise these or leave her feeling dismissed when discussing them but need the focus of the interview to be dysarthria. To address this – will discuss with her at the beginning and let her know the areas we aim to cover can be flexible. Might help to name it if I feel the focus drifting and want to pull it back (26th May 2021).

Understandably, preparing to conduct interviews with dysarthric participants presented its own concerns/anxieties. Having interacted with stroke survivors with dysarthria previously, I was aware that I may have difficulty in fully understanding what they were saying (particularly without having established a relationship with them). It has been argued that

there is a greater risk of researchers imposing their own perceptions onto the accounts of participants when they are less verbally articulate, or responses are difficult to comprehend [35]. I wanted to ensure that I was fully able to comprehend what participants were describing to avoid this. I used strategies such as asking participants to repeat anything that was unclear and repeating what they had said to ensure that I understood. I was also mindful of transcribing interviews as soon as possible to avoid any misinterpretations when I listened to the recordings. Despite this, there were a small number of specific phrases I was unable to comprehend when transcribing; I marked these as 'inaudible' to avoid my own interpretations filling the gaps when analysing. Below is an excerpt from my journal:

I was aware of me speaking more during this interview, but I think it worked well having the strategy of asking her to repeat herself. Interesting that this felt uncomfortable for me when I needed to ask multiple times, but she said "If I have to say it a million times, I'd be happy you'd listened to me." Discomfort sat with me rather than her (12th August 2021).

### **Reflection on my Roles**

Throughout the research process, it was important for me to maintain an awareness of my position, perspective, and presence as a researcher and how this could influence data collection and analysis [36], particularly given my previous clinical experience. Bracketing such preconceptions can create tension within IPA work; the researchers' experiences/understandings are required in order to make sense of the data, however I needed to ensure I did not impose my own understanding upon the experiences of participants [37].

The use of supervision and a reflective journal were central to this process, following guidelines presented by Yardley [38]. Utilising the journal provided opportunities for me to record my thoughts before and after each interview, which helped me to bring my own

assumptions into conscious awareness and bracket them before interacting with participants.

The following journal excerpt is an example of this process prior to the first interview:

I feel I need to acknowledge how interactions in interviews are likely to be different from types of interactions I'm used to with this population. Previous conversations with people with dysarthria have been in a clinical setting with a focus on developing a therapeutic relationship to help manage distress. I hope I'm able to transfer my skills (e.g., validating and managing distress), but I don't want to assume that will be the case, or that participants will even be experiencing the same struggles as patients I worked with. Need to ensure the research is maintained as the focus, whilst handling any distress with care (10th May 2021).

This excerpt represents some of the challenges I experienced in relation to my varying roles of trainee clinical psychologist and researcher. Another excerpt prior to an interview read:

“This participant has rated his dysarthria as the most severe and I noticed this during our previous conversation. Don't want to make presumptions about the impact this might have had – be open to hear his story” (14th June 2021).

Undertaking this research and conducting interviews during my clinical training was an interesting experience. Holding the roles of researcher and trainee clinical psychologist simultaneously was useful in terms of feeling more comfortable in my ability to manage any potential distress for participants. However, I also found myself having to carefully navigate these roles during interviews to maintain focus on the research whilst remaining responsive to participants' needs and not minimising their distress. An excerpt from my journal after one interview read:

I noticed a pull to help formulate/'do therapy' more during this interview when we were discussing her difficult experiences, especially when she opened up more about her family. It's an interesting position to be in and I had to consciously pull back a

little from how I would usually respond to this to ensure we focused on the research aim (8th June 2021).

Even in the absence of conflicting roles, individuals conducting qualitative health research have acknowledged the conflict of being perceived as a therapist by participants [39].

Interestingly, when reflecting on one interview with a participant, she expressed: “You sound like a bit of a therapist, you do listen and that’s important” (26th May 2021). Although navigating these roles felt difficult at times, I think this quote demonstrates how the skills of a trainee clinical psychologist can be transferable to qualitative research to help participants feel heard.

### **Conclusion**

It is hoped this critical appraisal has highlighted some of the practical, methodological, and ethical issues encountered during the development of the research paper and described ways in which they were addressed. The paper has also aimed to provide useful reflections/insights into the process of completing this type of research within this field and with this population of participants. It has hopefully demonstrated that IPA is not only possible, but an effective method of exploring the views of individuals with communication impairments when the process of doing this is carefully considered.

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**Section Four: Ethics Section**

The experience of identity and dysarthria following stroke: An interpretative  
phenomenological analysis

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**Faculty of Health and Medicine Research Ethics Committee (FHMREC)  
Lancaster University**

**Application for Ethical Approval for Research**

*for additional advice on completing this form, hover cursor over 'guidance'.*

**Guidance on completing this form is also available as a word document**

**Title of Project:** The experience of identity and dysarthria following stroke: An interpretative phenomenological analysis

**Name of applicant/researcher:** Sophie Cochrane

**ACP ID number (if applicable)\*:**

**Funding source (if applicable)**

**Grant code (if applicable):**

**\*If your project has *not* been costed on ACP, you will also need to complete the Governance Checklist [\[link\]](#).**

**Type of study**

Involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants. **Complete sections one, two and four of this form**

Includes *direct* involvement by human subjects. **Complete sections one, three and four of this form**

**SECTION ONE**

**1. Appointment/position held by applicant and Division within FHM** Trainee Clinical Psychologist

**2. Contact information for applicant:**

**E-mail:** s.cochrane@lancaster.ac.uk      **Telephone:** 07852270655 (please give a number on which you can be contacted at short notice)

**Address:** Health Innovation One, Sir John Fisher Drive, Lancaster University, Lancaster, LA1 4AT

**3. Names and appointments of all members of the research team (including degree where applicable)**

Sophie Cochrane (Principal Researcher)  
 Dr Craig Murray (Research Supervisor)  
 Dr Karen Quinn (Field Supervisor)

**3. If this is a student project, please indicate what type of project** by marking the relevant box/deleting as appropriate: (please note that UG and taught masters projects should complete **FHMREC form UG-tPG**, following the procedures set out on the [FHMREC website](#))

PG Diploma     Masters by research     PhD Thesis     PhD Pall. Care   
 PhD Pub. Health     PhD Org. Health & Well Being     PhD Mental Health     MD   
 DClInPsy SRP  [if SRP Service Evaluation, please also indicate here: ]    DClInPsy Thesis

**4. Project supervisor(s), if different from applicant:** Dr Craig Murray, Dr Karen Quinn

**5. Appointment held by supervisor(s) and institution(s) where based (if applicable):** Dr Craig Murray (Senior Lecturer, Lancaster University), Dr Karen Quinn (Clinical Neuropsychologist, Airedale General Hospital)

## SECTION TWO

**Complete this section if your project involves existing documents/data only, or the evaluation of an existing project with no direct contact with human participants**

1. Anticipated project dates (month and year)

Start date: \_\_\_\_\_ End date: \_\_\_\_\_

2. Please state the aims and objectives of the project (no more than 150 words, in lay-person's language):

### Data Management

*For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: [rdm@lancaster.ac.uk](mailto:rdm@lancaster.ac.uk)*

3. Please describe briefly the data or records to be studied, or the evaluation to be undertaken.

4a. How will any data or records be obtained?

4b. Will you be gathering data from websites, discussion forums and on-line 'chat-rooms'  no

4c. If yes, where relevant has permission / agreement been secured from the website moderator?  no

4d. If you are only using those sites that are open access and do not require registration, have you made your intentions clear to other site users?  no

4e. If no, please give your reasons

5. What plans are in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

6a. Is the secondary data you will be using in the public domain?

6b. If NO, please indicate the original purpose for which the data was collected, and comment on whether consent was gathered for additional later use of the data.

Please answer the following question *only* if you have not completed a Data Management Plan for an external funder

7a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

7b. Are there any restrictions on sharing your data?

### 8. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?

b. How will the confidentiality and anonymity of participants who provided the original data be maintained?

9. What are the plans for dissemination of findings from the research?

10. What other ethical considerations (if any), not previously noted on this application, do you think there are in the proposed study? How will these issues be addressed?

## SECTION THREE

**Complete this section if your project includes *direct* involvement by human subjects**

1. Summary of research protocol in lay terms (indicative maximum length 150 words):

Many stroke survivors experience communication problems. Dysarthria is one example of this; it causes weakness of muscles that are used to speak. This can result in slurred, strained, quiet, or slow speech which others may find hard to understand.

This can understandably cause high levels of emotional distress for stroke survivors. Experiencing such communication difficulties can lead to individuals feeling 'different' or 'left out'. This can result in individuals withdrawing from social activities and isolating themselves. It is likely that these experiences impact upon how stroke survivors view themselves as individuals and as parts of wider social groups (personal and social identity).

This study aims to explore how dysarthria can impact upon stroke survivors' personal and social identity through the use of online interviews. A qualitative approach will be used; participants for the study will be identified through charity organisations and will be invited to take part in online interviews.

**2. Anticipated project dates (month and year only)**

Start date: November 2020

End date: May 2022

**Data Collection and Management**

For additional guidance on data management, please go to [Research Data Management](#) webpage, or email the RDM support email: [rdm@lancaster.ac.uk](mailto:rdm@lancaster.ac.uk)

3. Please describe the sample of participants to be studied (including maximum & minimum number, age, gender):

Within Interpretative Phenomenological Analysis (IPA), it is recommended to aim for a fairly homogenous sample and sample sizes tend to be small due to the detailed analysis involved [1]. This study aims to recruit 6-12 participants to allow for investigation within and between specific cases.

Inclusion criteria:

- Participant has experienced a stroke at least six months ago; when recovery has mostly stabilised [2].
- Participant is experiencing dysarthria as a result of their stroke (self-report).
- Participant has the ability to communicate their responses in some way, either verbally or in written format.
- Participant will be able to communicate in English so that a translator is not required to conduct the interview.
- Participation will not be limited by gender or age; it is hoped that, despite the broad age criteria, participants will represent a fairly homogeneous sample due to them sharing a common characteristic of being dysarthric stroke survivors.

**Note on inclusion:**

It is possible that some participants may have comorbid diagnoses of dyspraxia or aphasia, however it will be difficult to accurately distinguish between these impairments without formal Speech and Language Therapy (SLT) assessments. Many participants will also likely be experiencing other physical impairments as a result of their stroke. Therefore, these factors will not be an exclusion criterion, but this will be important to acknowledge when devising an interview schedule to specifically explore the impact of dysarthria upon participants' identity.

4. How will participants be recruited and from where? Be as specific as possible. Ensure that you provide the *full versions* of all recruitment materials you intend to use with this application (eg adverts, flyers, posters).

Participants will be recruited via posters (Appendix B) which will be distributed online through social media (Twitter and Facebook) as well as with the support of charitable organisations for stroke survivors and those with communication difficulties. These organisations will provide links to potential participants through online forums or clubs/groups.

Due to the remote means by which interviews will be conducted, these advertisements will not restrict recruitment to a specific geographical area.

Within the advertisement, participants will be asked to contact the lead researcher to express interest in taking part via telephone or email. The lead researcher will use this contact to confirm that participants meet the inclusion criteria, using the eligibility checklist (Appendix C). If the participant confirms that they meet all criteria, they will be sent a participant information sheet, opt-

in form, and consent form (Appendix D, E, and F respectively) either via email or post (whichever they prefer).

It is possible that participants may have cognitive impairments or other communication difficulties (e.g. aphasia) as a result of their stroke, which could impact on their level of understanding of these materials. As long as participants do not have severe impairments which would impact on their capacity to consent (discussed later), they will not be excluded. Therefore, during the first contact, they will be informed that adapted, easy-read versions of the participant information sheet and consent form are available (Appendix G and H respectively).

During this contact, the lead researcher will also request permission to contact participants again seven days after the documents have been sent. This should provide them with time to read over all the information and to verbally consent to participating. This contact will also allow them to decline the invitation to participate if they wish. The opt-in form will be completed over the phone at this point to help with any difficulties participants may have.

The opt-in form will be useful if the number of participants interested in the study exceeds the maximum sample size (12). The information provided within this form will allow for recruitment of a sample that is as homogenous as possible, which is required when using IPA [1]. Any participants who are not recruited for the study as a result of this, will be informed that no more data is required and thanked for expressing interest. They will also be offered a summary of the research findings.

In addition to this, a snowball sampling technique will be utilised; participants will be asked if they know of anybody else who may meet the inclusion criteria and would be interested, willing, and able to take part. If so, they will be asked to pass an information sheet to them or alternatively direct them to the advertisement.

Participants will be recruited to the study once the forms are received. Interviews will then be arranged at a time and date convenient for both the participant and researcher.

5. Briefly describe your data collection and analysis methods, and the rationale for their use.

Semi-structured interviews will be used in order to gather rich, detailed, first-person accounts of participants' experiences. These will be informed by an interview schedule (Appendix I), however this will not necessarily be followed exactly and instead used as a guide. This should allow for some commonality between participants but should also provide space for each individual to lead the conversation based on what feels most important or relevant for them and their experiences. Interview schedules from existing literature on the topic were referred to when developing the schedule for this study.

Interviews will be conducted using remote means; this is both to reduce risk for participants/researcher in relation to Covid-19 but also to allow for worldwide recruitment. Participants will be given the option to complete their interview either by video call or voice call. A voice call could be conducted using an online platform or using telephone if this is preferred by participants. Microsoft Teams is the University's method of choice for video interviews; therefore, this will be the first choice of software for the study. Participants will be given the option to use other platforms (such as Skype or Zoom) particularly if they are more comfortable with them, however they will be informed that these might not be as secure.

Given the sample population and the communication difficulties they will have, participants may not feel comfortable participating with a spoken interview. There could also be difficulties ensuring that

communication is clear enough for analysis for this reason. This will be addressed by giving participants the option to communicate their responses in written format, either using a chat function on Microsoft Teams or another online platform. Provision will also be made for relatives/carers to support them if required. It will be made clear that it is the stroke survivor's views being explored, and any support given will be documented and reflected upon within the research.

The researcher will make use of a reflective diary to note any impact it is perceived that using these different mediums may have upon the interviews and subsequent results.

Interviews which are not typed will be transcribed verbatim by the lead researcher. Each transcript will then be analysed individually.

Interpretative Phenomenological Analysis (IPA) will be utilised to analyse the data. This approach aims to explore personal lived experience of a phenomenon and how individuals perceive and make sense of that experience [3]. It allows investigation of the group of participants as a whole as well as of the individual differences between each of their experiences, therefore it seems appropriate for this study.

6. What plan is in place for the storage, back-up, security and documentation of data (electronic, digital, paper, etc.)? Note who will be responsible for deleting the data at the end of the storage period. Please ensure that your plans comply with General Data Protection Regulation (GDPR) and the (UK) Data Protection Act 2018.

Interviews will be transcribed using pseudonyms and these will be referred to in place of real names throughout reports. These electronic files will be stored on the University approved secure cloud storage where the research supervisor will also be able to access them as part of the analysis process.

Files containing participant demographic information or email addresses will be stored separately from transcripts on the University secure network using the unique participant code number rather than names. Any physical copies received from participants will be scanned and uploaded on this system before being destroyed.

The lead researcher and research supervisor will have access to the data during the study and the lead researcher will have guardianship of the stored data. This data will be retained on the secure University server for 10 years.

7. Will audio or video recording take place?  no  audio  video

a. Please confirm that portable devices (laptop, USB drive etc) will be encrypted where they are used for identifiable data. If it is not possible to encrypt your portable devices, please comment on the steps you will take to protect the data.

Interviews will be either audio or video recorded depending upon the type of interview chosen by the participant (other than typed). This will either be done using the record function of the online platform or using a pick-up device to record phone calls. Immediately after each interview, the recording will be downloaded/uploaded on to the lead researcher's password protected computer and then saved on to University approved secure cloud storage. This will be under a uniquely assigned participant code number. The files will then be deleted from the computer.



b What arrangements have been made for audio/video data storage? At what point in the research will tapes/digital recordings/files be destroyed?

Audio/video files will be deleted from the laptop as soon as they have been uploaded on to the University secure network. They will be retained on the university network until the doctoral thesis has been submitted.

Please answer the following questions *only* if you have not completed a Data Management Plan for an external funder

8a. How will you share and preserve the data underpinning your publications for at least 10 years e.g. PURE?

Following completion of the thesis, data will be transferred to a member of the DClInPsy administrative team using an electronically secure method and retained on the University network. The data will then be preserved according to Lancaster University's Data Policy for 10 years.

8b. Are there any restrictions on sharing your data ?

Data will only be accessible to the lead researcher and research supervisor, who are bound by the same terms of confidentiality. Participants will have been made aware of this via the participant information sheet. Data will only be shared upon request. Access will be granted on a case by case basis by the research team for purposes of verifying data collection and secondary analysis leading to publication.

9. Consent

a. Will you take all necessary steps to obtain the voluntary and informed consent of the prospective participant(s) or, in the case of individual(s) not capable of giving informed consent, the permission of a legally authorised representative in accordance with applicable law?  yes

b. Detail the procedure you will use for obtaining consent?

As previously described, at the point where participants have expressed interest in taking part and it has been confirmed that they meet all of the inclusion criteria, they will be sent a participant information sheet, opt-in form, and consent form (via email or post).

At this point the lead researcher will also request permission to contact them again seven days after this documentation has been sent. The seven days should allow sufficient time for participants to read over the relevant information and decide whether they would like to take part. During this second contact, each item on the consent form (Appendix F) will be read out and participants asked to verbally provide consent to participate. This contact will also allow them to decline the invitation to participate if they wish.

It is possible that participants will have acquired cognitive deficits subsequent to their stroke which may impair their capacity to consent to take part. The researcher will ensure to be mindful of this throughout the data collection process. The researcher will ensure that guidance from the British Psychological Society (BPS) [4] on 'Conducting research with people not having the capacity to consent to their participation' is followed. This states that the researcher should always presume that the participant has capacity to consent or refuse to participate, based on the first principle of the Mental Capacity Act (2005) [5].

If the researcher has any concerns about a participant's capacity to consent, practicable steps will first be taken to facilitate capacity, which is again in line with principles of the Mental Capacity Act (2005) [5]. This will include reviewing the participant information sheet and consent form again verbally whilst also referring them to the written copy of these that they will also have. Participants will also be reminded of their right to withdraw consent up to two weeks after the interview.

If, following this assistance, a participant is deemed to lack the capacity to consent by the researcher, the interview will not be undertaken. This decision will be based on an individual being deemed to not meet any of the following criteria; if they do not understand the research project/consequences of taking part or refusing, if they are unable to retain information provided about the project, if they are unable to weigh up the relevant information in order to make a decision, and if they are unable to communicate their decision in some way. In this circumstance, this decision will be communicated sensitively to the participant and they will be thanked for expressing interest.

10. What discomfort (including psychological eg distressing or sensitive topics), inconvenience or danger could be caused by participation in the project? Please indicate plans to address these potential risks. State the timescales within which participants may withdraw from the study, noting your reasons.

Due to the topics being addressed within the interview and participants being asked to talk about their personal experiences, there is potential for this to lead to some emotional discomfort. In the event that a participant is observed to become upset or distressed during an interview, the lead researcher will attempt to manage the situation as delicately as possible. Participants will be offered space to speak about the emotive issues or alternatively offered a break from the interview, whichever feels most comfortable to them. Participants will also be reminded that they can choose not to answer any questions they do not wish to. The lead researcher will use their clinical judgement to decide whether to bring the interview to an end if a participant appears too distressed to continue.

In addition to this, prior to commencing with interviews, participants will have been made aware of the aims of the research via the participant information sheet. They will also have opportunity to ask any questions they may have and will be reminded of their right to withdraw consent at any time before or during the interview as well as up to two weeks after.

Upon completion of the interview, each participant will be debriefed and have the chance to talk through the experience of taking part with the interview. At this point, they will also be provided with contacts for further support (Appendix J).

11. What potential risks may exist for the researcher(s)? Please indicate plans to address such risks (for example, noting the support available to you; counselling considerations arising from the sensitive or distressing nature of the research/topic; details of the lone worker plan you will follow, and the steps you will take).

As interviews will be conducted remotely, it is likely that potential risks to the researcher will be minimised. However, the possibility remains that the researcher could find the experience of conducting interviews emotive or upsetting. Should this be the case, the researcher will utilise supervision with the project supervisors to talk through these difficulties.

Email correspondence will only go through a University account and Microsoft Teams interviews will also be conducted using a University account. The mobile number given out to participants will be that from a University sim card.

12. Whilst we do not generally expect direct benefits to participants as a result of this research, please state here any that result from completion of the study.

There may be no direct benefit to participation in this study. However, it is hoped that the interviews may provide participants with the opportunity to share their experiences of dysarthria in more detail than they may generally be provided day to day. It is hoped that this will be perceived by participants as a positive experience.

It is also anticipated that findings from the study can allow for recommendations to be identified in relation to psychological support within stroke aftercare and rehabilitation for those experiencing dysarthria.

13. Details of any incentives/payments (including out-of-pocket expenses) made to participants:

There will be no incentives for participation made to participants.

14. Confidentiality and Anonymity

a. Will you take the necessary steps to assure the anonymity of subjects, including in subsequent publications?  yes

b. Please include details of how the confidentiality and anonymity of participants will be ensured, and the limits to confidentiality.

Participant data will be anonymised, and pseudonyms will be used when transcribing interviews. A unique participant code number will be used when storing any demographic data and this will be stored separately from transcripts. Only the lead researcher will have access to the original data; the research supervisor will have access to the anonymised transcripts. Participants will have been made aware of this via the participant information sheet. The pseudonyms will be referred to in place of real names throughout reports.

As direct quotations may be used within the write up of the study, confidentiality cannot be maintained, however participants can be assured of anonymity. However, quotations containing any easily identifiable information will not be included.

Confidentiality and any limits to this will be included within the participant information sheet and discussed fully with participants prior to interviews. Limits to confidentiality refer to anything which concerns the lead researcher that anybody is at significant risk of harm. In these circumstances, confidentiality will be broken in order to maintain the safety of anybody at risk. It will be communicated to the participants, where possible, that confidentiality is being broken. These concerns will be shared with the project supervisors in order to decide the best course of action for the specific situation.

15. If relevant, describe the involvement of your target participant group in the *design and conduct* of your research.

The Stroke Association was contacted regarding consulting on the development of the recruitment process, recruitment materials, and interview schedule. Unfortunately, a response was not received within the timeframe available to complete the work needed for the thesis.

However, two Speech and Language Therapists (SLT) experienced in the area of stroke were contacted and asked to provide feedback on the study materials. They recommended that the adapted, more accessible versions of the consent form and information sheet be developed. These were generated and they both expressed that these would be helpful to use for participants with concurrent cognitive or other language difficulties (e.g. aphasia), as well as dysarthria.

The Colours and Symbols (CAS) (Banfield, 2014) [6] supported communication tool for people with aphasia was used within these forms to make them more accessible and easier to understand.

16. What are the plans for dissemination of findings from the research? If you are a student, include here your thesis.

The research will be submitted as a requirement of the DClinPsy programme as a doctoral thesis. It may also be written for publication in an academic peer reviewed journal.

Results will be presented to trainees and staff members of the DClinPsy programme in the summer of 2022.

Participants will also be asked if they would like a copy of the report or a shorter summary once it has been submitted.

17. What particular ethical considerations, not previously noted on this application, do you think there are in the proposed study? Are there any matters about which you wish to seek guidance from the FHMREC?

Other than ethical considerations already mentioned within this application, the use of online platforms or telephone to undertake interviews and the potential impact this may have upon the experience generally should also be considered. The rationale for choosing remote interviews has been highlighted in terms of ultimately maintaining the safety of participants and the researcher in relation to Covid-19. However, it needs to be acknowledged that this may have an impact upon how the interviews are experienced by all of those involved, specifically in terms of developing rapport. Specifically, when asking more personal questions, Seitz [7] found that video calls can result in the loss of personal connection and intimacy. However, it has also been identified that the physical separation between participant and researcher can actually facilitate a greater connection due to an increased sense of ease with the setting [8]. In order to address this, steps will be taken to ensure participants feel as comfortable as possible with engaging; providing all relevant information beforehand, naming that this may feel different to a 'normal' conversation and giving space to ask any questions, more frequent check-ins, and allowing time for general conversation to put participants at ease before commencing with interview questions.

Additionally, it should be acknowledged that using video calls for interviews also has implications in relation to participants having the equipment necessary to take part and being able to utilise it. However, as the recruitment process is also online, it is thought that individuals who express an interest to participate will have the means and ability to do so. The option of telephone interview will also be offered. Although this is not an entirely inclusive process (e.g. considering those who may not have this equipment), this has been weighed up against the potential risks to health amidst the ongoing pandemic.

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**SECTION FOUR: signature**Applicant electronic signature: 

Date:

18.11.2020

Student applicants: please tick to confirm that your supervisor has reviewed your application, and that they are happy for the application to proceed to ethical review

Project Supervisor name (if applicable): Date application discussed: **Submission Guidance**

**1. Submit your FHMREC application by email to Becky Case ([fhmresearchsupport@lancaster.ac.uk](mailto:fhmresearchsupport@lancaster.ac.uk)) as two separate documents:**

**i. FHMREC application form.**

Before submitting, ensure all guidance comments are hidden by going into 'Review' in the menu above then choosing *show markup>balloons>show all revisions in line*.

**ii. Supporting materials.**

Collate the **following materials for your study, if relevant, into a single word document:**

- a. **Your full research proposal (background, literature review, methodology/methods, ethical considerations).**
- b. Advertising materials (posters, e-mails)
- c. Letters/emails of invitation to participate
- d. Participant information sheets
- e. Consent forms
- f. Questionnaires, surveys, demographic sheets
- g. Interview schedules, interview question guides, focus group scripts
- h. Debriefing sheets, resource lists

**Please note that you DO NOT need to submit pre-existing measures or handbooks which support your work, but which cannot be amended following ethical review. These should simply be referred to in your application form.**

**2. Submission deadlines:**

- i. Projects including direct involvement of human subjects [**section 3 of the form was completed**]. The *electronic* version of your application should be submitted to [Becky Case](#) **by the committee deadline date**. Committee meeting dates and application submission dates are listed on the [FHMREC website](#). Prior to the FHMREC meeting you may be contacted by the lead reviewer for further clarification of your application. Please ensure you are available to attend the committee meeting (either in person or via telephone) on the day that your application is considered, if required to do so.
- ii. The following projects will normally be dealt with via chair's action, and may be submitted at any time. [**Section 3 of the form has not been completed, and is not required**]. Those involving:
  - a. existing documents/data only;

- b. the evaluation of an existing project with no direct contact with human participants;
  - c. service evaluations.
3. **You must submit this application from your Lancaster University email address, and copy your supervisor in to the email in which you submit this application**

**Appendix A - Research Protocol**

Study title: The experience of identity and dysarthria following stroke: An interpretative phenomenological analysis

Researcher details:

<b>Name</b>	<b>Contact Details</b>
Trainee name: Sophie Cochrane	Address: Clinical Psychology, Div. Of Health Research,  Lancaster University, Lancaster, LA1 4YG  Phone: 01524 592754  Email: s.cochrane@lancaster.ac.uk
Research/programme supervisor name: Dr Craig Murray	Address: Clinical Psychology, Div. Of Health Research,  Lancaster University, Lancaster, LA1 4YG  Phone: 01524 592754  Email: c.murray@lancaster.ac.uk
Field supervisor name: Dr Karen Quinn	Address: Medical Psychology, Building 14, Airedale  General Hospital, Skipton Rd, Keighley, BD20  6TD  Phone: 01535 292842  Email: karen.quinn@anhst.nhs.uk



## Introduction

Cerebrovascular accident, also known as stroke, is a leading cause of disability in the UK; almost two thirds of stroke survivors leave the hospital with a disability [1]. There are more than 100,000 strokes in the UK each year [2]. The disabilities which most commonly occur as a result of a stroke are; cognitive difficulties, visual problems, upper and lower limb weakness, sensory issues (including pain), bowel/bladder control, swallowing difficulties, and problems with communication [3]. Communication problems can vary depending upon the area/s of the brain affected. Approximately one third of the stroke survivor population experience communication difficulties [4,5]. There are different types of impairments which encompass problems within both expressive and receptive communication; aphasia (or dysphasia), dysarthria, and apraxia of speech (AOS)[1].

It has been widely reported that experiencing a stroke can have a profound effect on emotional wellbeing. Over half of patients will experience anxiety within ten years of having stroke [6] and approximately 30% of patients will experience depression following a stroke [7]. There are a variety of factors found to be associated with psychological distress, including; isolation, fear of recurrence of stroke, dependence in activities of daily living, lack of self-compassion, and loss of self [8,9].

More specifically, research has indicated that communication difficulties following stroke can impact significantly upon emotional wellbeing, for stroke survivors, their families, and/or carers. It has been reported that patients with aphasia are more likely to experience depression than other stroke survivors [10]. When considering what factors may be associated with depression; frustration, anxiety, and an inability to communicate with family have been identified [11]. Stroke survivors have also reported feeling helpless, scared, embarrassed, angry, and upset in relation to being unintelligible, the reactions of others, and feeling the need to repeat themselves [12]. However, such emotional difficulties can often be

overshadowed by physical/communication impairments associated with the stroke, as these are often prioritised at the acute stage of rehabilitation [11,13].

Understandably, there are a range of psychosocial factors which have been indicated to play a role within this level of emotional distress. It has been shown that communication difficulties can lead to a loss of confidence and motivation to participate in social activities, which can result in individuals withdrawing and isolating themselves [14]. When comparing perspectives of patients, family members, and professionals in relation to the impact of aphasia following stroke; consequences within activities and participation in community and social life were common to all three groups [15]. Perceived stigmatisation is another psychosocial factor which can contribute to psychological distress. Stroke survivors with communication difficulties have described feeling left out, abnormal, and different when unable to keep up with conversation, as well as feeling worried about appearing drunk when communicating [12]. Difficulties within relationships, such as lack of conversation, irritation, loss of interest in communicating, and role changes have also been identified as a prevalent concern [16].

All of these experiences can impact upon stroke survivors' perceptions of themselves both personally and within a social world. Therefore, it seems important to explore the impact of such communication difficulties upon patients' personal and social identity. This could be beneficial to identify further implications for clinical practice and specifically how clinical psychologists can most effectively contribute to stroke aftercare for those with communication impairments.

Current national guidelines recommend routine assessment and management of mood after a stroke [17]. It is noted that post-stroke psychological care is optimal when provided by a service with access to clinical psychology, however it is acknowledged that this kind of care is multifaceted and that significant improvements can be observed within the stroke

survivor population when psychological support is considered by a multidisciplinary team (MDT) [17]. A stepped (hierarchical) care approach is recommended in relation to psychological interventions which aims to offer more simple interventions initially and more complex interventions only if and when required. Level one (sub-threshold problems) is noted to be support provided by stroke specialist staff or peers for general coping problems. Level two includes support by staff members supervised by clinical psychologists for any 'mood disorders' which interfere with rehabilitation. Level three is noted to require intervention by clinical psychology specialising in stroke, neuropsychology and/or psychiatry; this is defined as 'severe and persistent mood disorders'. It is highlighted that patients may not always progress through the model in a sequential manner but may need support at different levels throughout their recovery [17].

It is interesting to consider whether stroke survivors with communication difficulties would "fit" within this model or whether these individuals can access psychological support in the same way. It has been identified that Speech and Language Therapists (SLTs) perceive there to be a lack of accessible mental health services for stroke survivors with communication impairments, including psychological or counselling professionals who are trained in supportive communication approaches [18]. Supportive Communication (SC) techniques have been found to have notable benefits for staff members communicating with aphasic patients and it is reported that this approach could create a culture of inclusion and access for all stroke survivors [19]. It has also been highlighted that joint sessions with an SLT and psychologist could be effective and empowering when working with these individuals [11]. The importance of support from an MDT including clinical psychologists has been emphasised for these individuals, not only to promote the wellbeing of the patients, but also to empower the professionals providing care [15,20].

It has been highlighted that the majority of research on this population is focused upon individuals with aphasia and it seems that those with other communication problems may get overlooked. Dysarthria is caused by an impairment in the ability to control facial muscles and this can impact upon the speed, strength, range, timing, or accuracy of speech [21]. Research indicates that, although the presence of dysarthria following stroke is well documented, it tends not to receive specific attention within published texts [22]. There are variations reported within the literature regarding the prevalence of dysarthria within the stroke population. Flowers et al [5] identified an estimated incidence of 42% within patients who had suffered a first acute ischemic stroke. Prevalence has also been found to range from 5% to 85% depending on the type of stroke suffered [23]. Despite these disparities, the presence of dysarthria is frequently reported in both acute and three-month post-stroke clinical trial data [24].

Therefore, it appears that dysarthria is a common impairment experienced by stroke survivors but there seems to be a paucity of research on the topic. This study will attempt to use Interpretative Phenomenological Analysis (IPA) to explore how these individuals experience their difficulties with communication, particularly in relation to their personal and social identity. This could help to provide insight into how those with dysarthria perceive the disorder to have impacted on their sense of self and their connection with others, as well as to explore their ideas in relation to the support they feel would be beneficial for their emotional wellbeing. This should then allow for recommendations to be made in relation to how the provision of psychology aftercare can be tailored to be accessible and inclusive to those with dysarthria throughout the course of their rehabilitation/recovery.

## Method

### Participants

Within Interpretative Phenomenological Analysis (IPA), it is recommended to aim for a fairly homogenous sample and sample sizes tend to be small due to the detailed analysis involved [25]. This study aims to recruit 6-12 participants to allow for investigation within and between specific cases.

Inclusion criteria:

- Participant has experienced a stroke at least six months ago; this is when recovery is said to have mostly stabilised [17].
- Participant is experiencing dysarthria as a result of their stroke (self-report).
- Participant has the ability to communicate their responses in some way, either verbally or in written format.
- Participant is able to communicate in English so that a translator is not required to conduct the interview.
- Participation will not be limited by gender or age; it is hoped that, despite the broad age criteria, participants will represent a fairly homogeneous sample due to them sharing a common characteristic of being dysarthric stroke survivors.

Note on inclusion:

It is possible that some participants may have comorbid diagnoses of dyspraxia or aphasia, however it will be difficult to accurately distinguish between these impairments without formal Speech and Language Therapy (SLT) assessments. Many participants will also likely be experiencing other physical impairments as a result of their stroke. Therefore, these factors will not be an exclusion criterion, but this will be important to acknowledge when devising an interview schedule to specifically explore the impact of dysarthria upon participants' identity.

**Recruitment**

Participants will be recruited via posters (Appendix B) which will be distributed online through both social media (Twitter and Facebook) as well as with the support of charitable organisations for stroke survivors and those with communication difficulties. These organisations will provide links to potential participants through online forums or clubs/groups. Permission will be sought from the research department of these organisations to make contact with potential participants. Due to the remote means by which interviews will be conducted, these advertisements will not restrict recruitment to a specific geographical area of the UK.

Within the advertisement, participants will be asked to contact the lead researcher to express interest in taking part via telephone or email. The lead researcher will use this contact to confirm that participants meet the inclusion criteria, using the eligibility checklist (Appendix B). If the participant confirms that they meet all criteria, they will be sent a participant information sheet, opt-in form, and consent form (Appendix D, E, and F respectively) either via email or post (whichever they prefer).

It is possible that participants may have cognitive impairments or other communication difficulties (e.g. aphasia) as a result of their stroke, which could impact on their level of understanding of these materials. As long as participants do not have severe impairments which would impact on their capacity to consent (discussed later), they will not be excluded. Therefore, during the first contact, they will be informed that adapted, easy-read versions of the participant information sheet and consent form are available (Appendix G and H respectively).

During this contact, the lead researcher will also request permission to contact participants again seven days after the documents have been sent. This should provide them with time to read over all of the information and to verbally consent to participating. This

contact will also allow them to decline the invitation to participate if they wish. The opt-in form will also be completed over the phone at this point.

The opt-in form will be useful if the number of participants interested in the study exceeds the maximum sample size (12). The information provided within this form will allow for recruitment of a sample that is as homogenous as possible, which is required when using IPA [25]. Any participants who are not recruited for the study as a result of this, will be informed that no more data is required and thanked for expressing interest. They will also be offered a summary of the research findings.

In addition to this, a snowball sampling technique will be utilised; participants will be asked if they know of anybody else who may meet the inclusion criteria and would be interested, willing, and able to take part. If so, they will be asked to pass an information sheet to them or alternatively direct them to the advertisement.

Participants will be recruited to the study once the forms are received. Interviews will then be arranged at a time and date convenient for both the participant and researcher.

### **Materials**

Posters will be used to recruit participants to the study (Appendix B). Once interest has been shown, the eligibility checklist (Appendix C) will be used by the researcher. If participants meet the inclusion criteria, they will be sent an information sheet, opt-in form, and consent form (Appendix D, E, and F respectively). Adapted versions of the information sheet (Appendix G) and consent form (Appendix H) will also be sent which are more accessible for individuals with any cognitive or communication difficulties. Semi-structured interviews will be conducted using an interview schedule as a guide (Appendix I). Following the interview, participants will be debriefed and provided with contacts for further support (Appendix J).

### **Procedure**

Semi-structured interviews will be used in order to gather rich, detailed, first-person accounts of participants' experiences. These will be informed by an interview schedule (Appendix H), however this will not necessarily be followed exactly and instead used as a guide. This should allow for some commonality between participants but should also provide space for each individual to lead the conversation based on what feels most important or relevant for them and their experiences. Interview schedules from existing literature on the topic were referred to when developing the schedule for this study.

Interviews will be conducted using remote means; this is both to reduce risk for participants/researcher in relation to Covid-19 but also to allow for nationwide recruitment. Participants will be given the option to complete their interview either by video call or voice call. A voice call could be conducted using an online platform or using telephone if this is preferred by participants. Microsoft Teams is the University's method of choice for video interviews; therefore, this will be the first choice of software for the study. Participants will be given the option to use other platforms (such as Skype or Zoom) particularly if they are more comfortable with them, however they will be informed that these might not be as secure.

Given the sample population and the communication difficulties they will have, participants may not feel comfortable participating with a spoken interview. There could also be difficulties ensuring that communication is clear enough for analysis for this reason. This will be addressed by giving participants the option to communicate their responses in written format, either using a chat function on Microsoft Teams or another online platform. Provision will also be made for relatives/carers to support them if required. It will be made clear that it is the stroke survivor's views being explored, and any support given will be documented and reflected upon within the research. The researcher will make use of a reflective diary to note any impact it is perceived that using these different mediums may have upon the interviews



and subsequent results. Participants will also be asked how they have found using whichever platform they choose at the end of the interview.

Interviews which are not typed will be transcribed verbatim by the lead researcher. Each transcript will then be analysed individually.

### **Consent**

As previously described, at the point where participants have expressed interest in taking part and it has been confirmed that they meet all of the inclusion criteria, they will be sent a participant information sheet, opt-in form, and consent form (via email or post).

At this point the lead researcher will also request permission to contact them again seven days after this documentation has been sent. The seven days should allow sufficient time for participants to read over the relevant information and decide whether they would like to take part. During this second contact, each item on the consent form (Appendix F) will be read out and participants asked to verbally provide consent to participate. This contact will also allow them to decline the invitation to participate if they wish.

It is possible that participants will have acquired cognitive deficits subsequent to their stroke which may impair their capacity to consent to take part. The researcher will ensure to be mindful of this throughout the data collection process. The researcher will ensure that guidance from the British Psychological Society (BPS) [26] on “Conducting research with people not having the capacity to consent to their participation” is followed. This states that the researcher should always presume that the participant has capacity to consent or refuse to participate, based on the first principle of the Mental Capacity Act [27].

If the researcher has any concerns about a participant’s capacity to consent, practicable steps will first be taken to facilitate capacity, which is again in line with principles of the Mental Capacity Act [27]. This will include reviewing the participant information sheet and consent form again verbally whilst also referring them to the written copy of these

that they will also have. Participants will also be reminded of their right to withdraw consent up to two weeks after the interview.

If, following this assistance, a participant is deemed to lack the capacity to consent by the researcher, the interview will not be undertaken. This decision will be based on an individual being deemed to not meet any of the following criteria; if they do not understand the research project/consequences of taking part or refusing, if they are unable to retain information provided about the project, if they are unable to weigh up the relevant information in order to make a decision, and if they are unable to communicate their decision in some way. In this circumstance, this decision will be communicated sensitively to the participant and they will be thanked for expressing interest.

### **Proposed Analysis**

Interpretative Phenomenological Analysis (IPA) will be utilised to analyse the data. This approach aims to explore personal lived experience of a phenomenon and how individuals perceive and make sense of that experience [28]. It allows investigation of the group of participants as a whole as well as of the individual differences between each of their experiences. Therefore, IPA has been identified as appropriate for this study in order to gain a better understanding of stroke survivors' experience of dysarthria and how they perceive it to impact upon their identity.

Interviews (which are not typed) will be transcribed verbatim and analysed individually before comparisons between the experiences of participants are considered. It is recommended that transcripts should be read, and recordings listened to a number of times to help researchers immerse themselves in the data as well as to generate new insights [29]. Initial notes and observations will be made on each transcript, which will contribute to emerging themes. Connections can then be identified between emerging themes; they will be grouped together according to conceptual similarities and each group given a descriptive

label. Final themes will be identified, and salient quotes selected to represent each. The research supervisor will also be involved in the analysis process.

### **Practical Issues**

Conducting interviews remotely will minimise the amount of practical issues that need to be considered for the research. In order to receive calls from potential participants, the University will provide the researcher with a mobile phone. All photocopying, postage, and printing costs will also be covered by the University.

### **Service User/Stakeholder Involvement**

The Stroke Association was contacted regarding consulting on the development of the recruitment process, recruitment materials, and interview schedule. Unfortunately, a response was not received within the timeframe available to complete the work needed for the thesis.

However, two Speech and Language Therapists (SLT) experienced in the area of stroke were contacted and asked to provide feedback on the recruitment process, study materials, and interview schedule. We discussed the importance of having adapted, more accessible versions of the consent form and participant information sheet. These were generated and they both expressed that these would be helpful to use for participants with concurrent cognitive or language difficulties (e.g. aphasia), as well as dysarthria. The Colours and Symbols (CAS) [30] supported communication tool for people with aphasia was used within these forms to make them more accessible and easier to understand.

## **Ethical issues**

### **Confidentiality**

Participant data will be anonymised, and pseudonyms will be used when transcribing interviews. A unique participant code number will be used when storing any demographic data and this will be stored separately from transcripts. Only the lead researcher will have access to the original data; the research supervisor will have access to the anonymised

transcripts. Participants will have been made aware of this via the participant information sheet. The pseudonyms will be referred to in place of real names throughout reports.

As direct quotations may be used within the write up of the study, confidentiality cannot be maintained, however participants can be assured of anonymity. However, quotations containing any easily identifiable information will not be included.

Confidentiality and any limits to this will be included within the participant information sheet and discussed fully with participants prior to interviews. Limits to confidentiality refer to anything which concerns the lead researcher that anybody is at significant risk of harm. In these circumstances, confidentiality will be broken in order to maintain the safety of anybody at risk. It will be communicated to the participants, where possible, that confidentiality is being broken. These concerns will be shared with the project supervisors in order to decide the best course of action for the specific situation.

### **Potential Distress**

Due to the topics being addressed within the interview and participants being asked to talk about their personal experiences, there is potential for this to lead to some emotional discomfort. In the event that a participant is observed to become upset or distressed during an interview, the lead researcher will attempt to manage the situation as delicately as possible. Participants will be offered space to speak about the emotive issues or alternatively offered a break from the interview, whichever feels most comfortable to them. Participants will also be reminded that they can choose not to answer any questions they do not wish to. The lead researcher will use their clinical judgement to decide whether to bring the interview to an end if a participant appears too distressed to continue.

In addition to this, prior to commencing with interviews, participants will have been made aware of the aims of the research via the participant information sheet. They will also

have opportunity to ask any questions they may have and will be reminded of their right to withdraw consent at any time before or during the interview as well as up to two weeks after. Upon completion of the interview, each participant will be debriefed and have the chance to talk through the experience of taking part with the interview. At this point, they will also be provided with contacts for further support (Appendix I).

### **Other Ethical Considerations**

Other than ethical considerations already mentioned previously, the use of online platforms to undertake interviews and the potential impact this may have upon the experience generally should also be considered. The rationale for choosing remote interviews has been highlighted in terms of ultimately maintaining the safety of participants and the researcher in relation to Covid-19. However, it needs to be acknowledged that this may have an impact upon how the interviews are experienced by all of those involved, specifically in terms of developing rapport. Specifically, when asking more personal questions, Seitz [31] found that video calls can result in the loss of personal connection and intimacy. However, it has also been identified that the physical separation between participant and researcher can actually facilitate a greater connection due to an increased sense of ease with the setting [32]. In order to address this, steps will be taken to ensure participants feel as comfortable as possible with engaging; providing all relevant information beforehand, naming that this may feel different to a 'normal' conversation and giving space to ask any questions, more frequent check-ins, and allowing time for general conversation to put participants at ease before commencing with interview questions.

Additionally, it should be acknowledged that using video calls for interviews also has implications in relation to participants having the equipment necessary to take part and being able to utilise it. However, as the recruitment process is also online, it is thought that individuals who express an interest to participate will have the means and ability to do so.

Telephone calls will also be offered as an alternative. Although this is not an entirely inclusive process (e.g. considering those who may not have this equipment), this has been weighed up against the potential risks to health amidst the ongoing pandemic.

### **Timescale**

Ethical approval will be sought in November 2020 and data collection should be completed by September 2021. The project end date is May 2022; the research is required to be submitted at this point as part of the DClinPsy programme. Participants who have requested feedback will be provided with this following submission. Required amendments will be completed and if the research will be submitted for publication, this is likely to be in September 2022.

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## APPENDIX B

Invitation to take part in:

# A study of stroke survivors' experience of dysarthria



- Have you had a stroke at least six months ago?
- Do you have dysarthria (slurred speech) as a result of your stroke?
- Would you like to take part in a research study to share your experience?

If all of the above apply to you, please read on:

We are looking at exploring the experience of having dysarthria following a stroke in relation to personal and social identity (how it makes people feel about themselves).

The study involves taking part in an online/phone interview lasting around one hour.

If you are interested in taking part and would like more information, please contact:

**Researcher** Sophie Cochrane, Trainee Clinical Psychologist

**Telephone** 07508 406 297

**Email** [s.cochrane@lancaster.ac.uk](mailto:s.cochrane@lancaster.ac.uk)

**APPENDIX C**

**Checklist for eligibility**

**Study Title:**            **The experience of identity and dysarthria following stroke: An interpretative phenomenological analysis**

**Please use the following checklist in order to screen participants' eligibility for receipt of study invitation.**

*The stroke survivor must meet ALL of the following criteria to take part:*

Experienced a stroke at least six months ago

Experiences dysarthric speech as a result of their stroke

Has the ability to communicate their responses either verbally or in written format

Has the capacity and is willing to take part

If all the criteria are met, pass on study invitation information.

## APPENDIX D

### Participant Information Sheet

**Study Title:**           **The experience of identity and dysarthria following stroke: An interpretative phenomenological analysis**

My name is Sophie Cochrane and I am conducting this research as a Clinical Psychology Doctorate student at Lancaster University. The study is being supervised by Dr Craig Murray and Dr Karen Quinn. Thank you for taking the time to read this information sheet. Once you have read the information, if you would like to take part or would like further information, please don't hesitate to contact me at [s.cochrane@lancaster.ac.uk](mailto:s.cochrane@lancaster.ac.uk).

#### **What is the study about?**

The aim of the study is to explore the experiences of individuals who experience dysarthria as a result of a stroke. Specifically, it will be exploring the impact that dysarthria can have upon how stroke survivors view themselves as individuals and as parts of wider social groups. Although dysarthria is fairly common in stroke survivors, there does not seem to be much research exploring how this is experienced. This study aims to address this gap and to provide recommendations in relation to psychological support within stroke aftercare and rehabilitation.

#### **Why have I been approached?**

You are being invited to take part in this study as you experience dysarthric speech as a result of having a stroke at least six months ago. Prior to receiving this information sheet, you will also have had a conversation (via email or phone) to confirm your eligibility for the study based on a checklist of criteria, which will have been discussed with you.

#### **Do I have to take part?**

No, it is entirely up to you whether you choose to take part. As we agreed, I will contact you seven days after sending this information to give you time to decide. During this call, you will have the opportunity to ask any questions you may have about the research. If you decide not to take part, you will not hear from me again. If you do, you are still able to withdraw from the study up to two weeks following the interview if you wish to. Whatever your decision, this will not have any effect upon any services you receive.

#### **What will I be asked to do if I take part?**

The researcher will contact you and go through the documents you have been sent. The items on the consent form will be read out and you will be asked to give verbal consent if you wish to take part. The opt-in form will also be completed over the phone.

You will be asked to take part in an interview with the researcher at a time that suits you both, which will last approximately one hour. This will take place either via Microsoft

Teams, another online platform if you are more accustomed to using them or phone call and you will have a choice regarding how you would want this to be carried out. There are the options of either a video call or a voice call, whichever feels more comfortable to you. Alternatively, if you don't feel comfortable participating with a spoken interview, there will be an option of a typed interview. You can also request for someone you know (family member, friend, carer etc) to assist with the process if this would feel helpful; please indicate your preferences within the relevant section of the opt-in form.

You will again have chance to ask any questions you may have prior to the interview and time to speak with the researcher informally before commencing with the questions. During the interview, you will be asked some questions about your experience of having dysarthria since your stroke. The interview will be recorded and then transcribed, analysed, and written up.

### **Will my data be identifiable?**

The information you provide during the interview will be transcribed by the researcher. Once the project has been submitted, the recordings will be destroyed. Electronic copies of the transcripts and electronic copies of the forms you return will be kept for 10 years within the University's secure storage.

As direct quotes may be used in the final report, your information will not be completely confidential. However, the transcript will be anonymised using a pseudonym and only this name will be referred to within reports. All of your personal details (e.g. name, age, address) will be stored separately to the transcript under a unique participant code number. Only the lead researcher and the research supervisor (Dr Craig Murray) will have access to the information you provide.

### **What will happen to the results of the study?**

The information obtained from all participants will be summarised together in order to produce a final report which will be submitted to Lancaster University as part of the researcher's doctoral thesis. It is also intended that the research will be submitted to an academic or professional journal for publication. There is the opportunity for you to be sent a brief summary of the report once the study has been submitted, if you are interested in this.

### **Are there any risks associated with taking part?**

There are no risks anticipated for participants in this study. However, some people may find talking about their experiences upsetting. If you do experience any distress either within or following the interview, we would advise you to inform the researcher. You will also be provided with some contacts for further support.

### **Are there any benefits to taking part?**

There are no direct benefits associated with taking part in the study, although you may find participating interesting. It is also hoped that findings from the study may contribute to recommendations for psychological support within stroke aftercare for those with dysarthria.

**Who has reviewed the project?**

The study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee (FHM REC) at Lancaster University.

**Where can I obtain further information about the study if I need it?**

As we have agreed, I will contact you seven days after this information has been sent. You will have opportunity within this call to ask any questions you may have about the study. You can also contact me via email or telephone before or after this time if you have questions using the below details.

Email: [s.cochrane@lancaster.ac.uk](mailto:s.cochrane@lancaster.ac.uk) Telephone: 07508 406 297

**What do I do if I have a concern or complaint relating to this project?**

If you wish to make a complaint or raise concerns about any aspect of the study and do not wish to speak to the researcher, you can contact:

Dr Craig Murray

Research Supervisor for the project

Email: [c.murray@lancaster.ac.uk](mailto:c.murray@lancaster.ac.uk)

Professor Bill Sellwood

Programme Director

Email: [b.sellwood@lancaster.ac.uk](mailto:b.sellwood@lancaster.ac.uk)

Telephone: 01524 593998

If you wish to speak to someone outside of the Clinical Psychology Doctorate Programme, you may also contact:

Dr Laura Machin

Chair of FHM REC

Email: [l.machin@lancaster.ac.uk](mailto:l.machin@lancaster.ac.uk)

Telephone: 01524 594973

**Thank you for taking the time to read this information sheet.**

## APPENDIX E

## Opt-in form

**Study Title: The experience of identity and dysarthria following stroke: An interpretative phenomenological analysis**

If you would like to take part in the study following reading through the information sheet, this form will be completed with you over the phone.

<b>Name:</b>	
<b>Contact number:</b>	
<b>Email address:</b>	
<b>Gender (<i>please tick</i>):</b>	Male <input type="checkbox"/> / Female <input type="checkbox"/> / Prefer to self-describe (please state) <input type="checkbox"/> _____ / Prefer not to say <input type="checkbox"/>
<b>Age:</b>	
<b>Current employment status (<i>please tick</i>):</b>	Employed full time <input type="checkbox"/> / Employed part time <input type="checkbox"/> / Unemployed <input type="checkbox"/> / Student <input type="checkbox"/>
<b>Brief information regarding current impact of the stroke as well as dysarthria (<i>please tick</i>):</b>	<b>Please say tick if you experience problems with the following:</b> Speech (aphasia/apraxia) <input type="checkbox"/> / cognition (e.g. memory, attention) <input type="checkbox"/> / fatigue <input type="checkbox"/> / swallowing <input type="checkbox"/> / muscle weakness <input type="checkbox"/> / balance <input type="checkbox"/> / vision <input type="checkbox"/> / bowel or bladder control <input type="checkbox"/> / pain <input type="checkbox"/> / numb skin <input type="checkbox"/> / pins and needles <input type="checkbox"/> / other <input type="checkbox"/> (please state)
<b>Length of time passed since stroke:</b>	<b>Years:</b> _____ <b>Months:</b> _____
<b>How would you rate the severity of your dysarthria on a scale of 1-10 (1 = lowest, 10 = highest) (<i>please tick</i>)?</b>	1 <input type="checkbox"/> / 2 <input type="checkbox"/> / 3 <input type="checkbox"/> / 4 <input type="checkbox"/> / 5 <input type="checkbox"/> / 6 <input type="checkbox"/> / 7 <input type="checkbox"/> / 8 <input type="checkbox"/> / 9 <input type="checkbox"/> / 10 <input type="checkbox"/>
<b>Who would you prefer me to contact to arrange the interview (<i>please tick</i>):</b>	Me <input type="checkbox"/> / Partner <input type="checkbox"/> / Family member <input type="checkbox"/> / Other (please state) <input type="checkbox"/>
<b>Name and number of person to be contacted (<i>if required</i>):</b>	
<b>Preferred means of completing interview (<i>please tick</i>):</b>	Video call <input type="checkbox"/> / Voice call <input type="checkbox"/>
<b>Please indicate if you would feel more comfortable taking part with a typed interview or with the support of someone you know (<i>please tick</i>):</b>	Typed interview <input type="checkbox"/> / Support <input type="checkbox"/> / Not applicable <input type="checkbox"/>



**APPENDIX F****Consent Form**

**Study Title:** The experience of identity and dysarthria following stroke: An interpretative phenomenological analysis

**Researcher:** Sophie Cochrane, Trainee Clinical Psychologist

1. I confirm that I have read and understood the information sheet for the above study and had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, up until two weeks following the interview.
3. I understand that my interview will be audio/video recorded and then made into an anonymised written transcript. I understand that the recording will only be kept until the research project has been examined.
4. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project.
5. I understand that once my data has been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of submission.
6. I consent to anonymised quotations from my interview being used in reports and academic journal articles.
7. I understand that the researcher will discuss data with the project supervisors, as needed.
8. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or

others, in which case the lead researcher will need to share this information with their research supervisor.



9. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.

10. I understand the above information and consent to take part in the study.

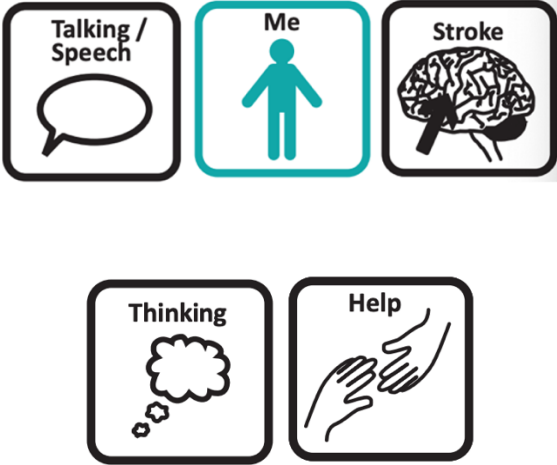
Each item of this form will be read out over the phone and you will be asked to provide verbal consent if you wish to take part.

APPENDIX G




Participant Information Sheet

 <p>Lancaster University </p>	<p><b>Researcher:</b> Sophie Cochrane Lancaster University</p> <p><b>Supervisors:</b> Dr Craig Murray Dr Karen Quinn</p>
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What is the research?

 <p>Talking / Speech</p> <p>Me</p> <p>Stroke</p> <p>Thinking</p> <p>Help</p>	<p>I am doing some <b>research</b></p> <p>It is about <b>dysarthria (slurred speech)</b> after <b>stroke</b> and how it makes people <b>feel about themselves</b></p> <p><b>Research</b> helps us <b>learn</b></p> <p>We need to know more about <b>how to help</b></p>
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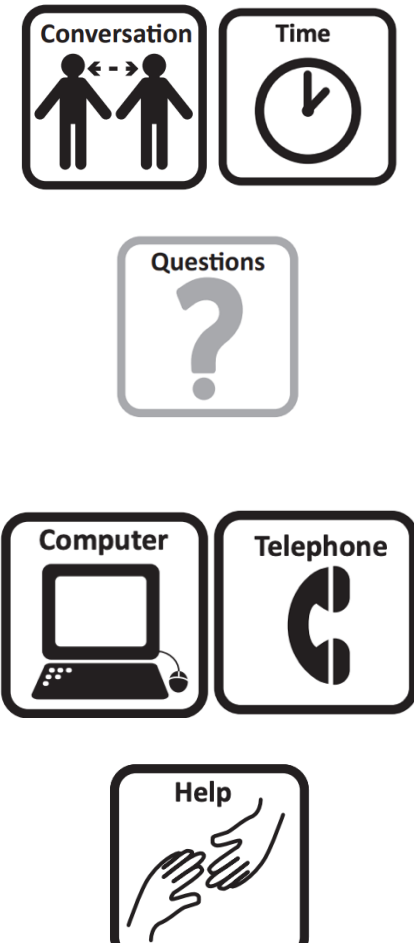
**Why me?**

 <p>Stroke</p>  <p>Talking / Speech</p>  <p>Conversation</p>	<p>You have had a <b>stroke</b></p> <p>You have <b>dysarthria (slurred speech)</b></p> <p>You have already <b>spoken to the researcher</b> about the study</p>
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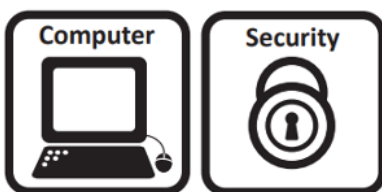
**Do I have to take part?**


 <p>Choice / Decision</p>  <p>Time</p>  <p>Thinking</p>  <p><b>STOP</b></p>	<p>You can <b>decide</b></p> <p>You <b>don't</b> have to</p> <p>You can <b>take time</b> and <b>think</b> about it</p> <p>You can <b>stop at any time</b></p> <p>You <b>don't</b> have to <b>give a reason</b></p> <p>You can ask for your data to be taken out up to <b>two weeks after the interview</b></p>
---	--

**What will I have to do?**

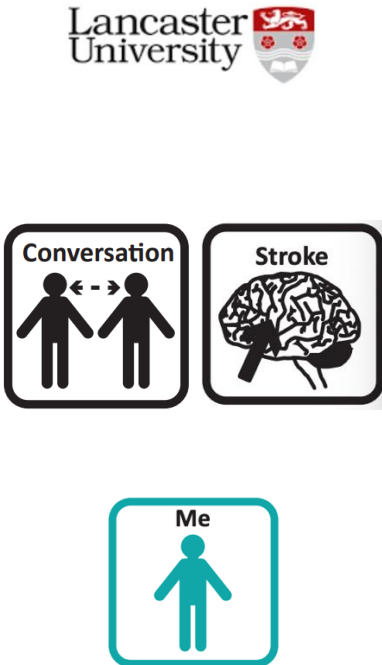
 <p>Conversation</p> <p>Time</p> <p>Questions</p> <p>Computer</p> <p>Telephone</p> <p>Help</p>	<p>You will have an <b>interview</b></p> <p>It will last around <b>one hour – more time</b> if needed</p> <p>You will be asked <b>questions</b> about your <b>dysarthria (slurred speech)</b></p> <p>This will be <b>online</b> or on the <b>phone</b></p> <p>If this feels hard, it can be a <b>typed interview</b></p> <p>You can ask for a <b>friend or family member</b> to <b>help</b></p>
--	---

**Who will see the information about me?**


 <p>Computer</p> <p>Security</p>	<p>We will keep the <b>information</b> about you <b>safe on a computer</b></p> <p>Only the <b>researchers</b> will see the <b>information</b></p> <p><b>Quotes</b> from the <b>interview</b> may be used</p>
---	--


	<p>We will take your <b>name and personal details out</b> of the <b>results</b></p>
---	---

**What will happen to the results?**


	<p>We will <b>share this research</b> with <b>Lancaster University</b></p> <p>The <b>university</b> will keep the information for <b>up to 10 years</b></p> <p>It will be <b>shared</b> with <b>other researchers</b></p> <p>This will <b>help</b> with other <b>research about stroke</b></p> <p>We will give <b>you</b> the <b>results</b></p>
--	--

**What might be good about taking part?**


	<p>You may <b>enjoy</b> taking part</p> <p>You may find it <b>interesting</b></p>
---	---



	<p>You will <b>help</b> us to <b>learn</b></p> <p>This might <b>support</b> people with <b>strokes</b> in the <b>future</b></p>
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**What might be difficult about taking part?**





	<p>We <b>don't</b> think it's <b>dangerous</b></p> <p>But you may find it <b>upsetting</b></p> <p>You may find it <b>tiring</b></p> <p>It will take up some <b>time</b></p>
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**Is the research safe?**

	<p>A <b>group of people</b> look at the <b>research</b></p> <p>This is the <b>ethics committee</b></p> <p>They say that this <b>research can happen</b></p>
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 	<p>They say it is <b>safe</b></p> <p>They say it has been <b>planned properly</b></p>
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**What next?**

   	<p>I will <b>call</b> you <b>seven days</b> after sending this <b>information</b></p> <p>We can have a <b>conversation</b></p> <p>You can ask any <b>questions</b> you have</p> <p>Let me know if you <b>want to take part</b></p> <p>We will go through the <b>forms</b> over the <b>phone</b></p> <p>You may want <b>more information</b></p> <p>Contact me:</p> <p>Email: <a href="mailto:s.cochrane@lancaster.ac.uk">s.cochrane@lancaster.ac.uk</a>          Telephone: [Insert research mobile number]</p>
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**What if I have a concern or complaint?**






 	<p>If you have any concerns</p> <p>Please contact:</p> <p>Dr Craig Murray Research Supervisor for the project Email: <a href="mailto:c.murray@lancaster.ac.uk">c.murray@lancaster.ac.uk</a></p> <p>Or</p> <p>Professor Bill Sellwood Programme Director Email: <a href="mailto:b.sellwood@lancaster.ac.uk">b.sellwood@lancaster.ac.uk</a> Telephone: 01524 593998</p> <p>Or, someone outside of the university programme</p> <p>Dr Laura Machin Chair of FHM REC Email: <a href="mailto:l.machin@lancaster.ac.uk">l.machin@lancaster.ac.uk</a> Telephone: 01524 594973</p>
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**Thank you for taking the time to read this information sheet.**

APPENDIX H

Consent Form

	<p>Taking part in <b>research</b> about <b>speech</b> and <b>how I see myself</b> following <b>stroke</b></p>	<p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p>
	<p>I have been given <b>information</b> about <b>taking part</b> in the <b>research</b></p>	<p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p>
	<p>I <b>understand</b> the information given to me</p>	<p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p>
	<p>I am <b>happy</b> with the <b>answers</b> given to my questions</p>	<p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p>
	<p>I understand I may <b>stop</b> taking part at any time <b>without giving a reason</b></p>	<p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p>
	<p>I understand that my <b>information</b> will <b>not be shared</b> with anyone outside of the research</p>	<p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p>
	<p>The <b>only</b> time my <b>information</b> may be shared is if I or someone else is at <b>risk of harm</b></p>	<p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p>

       	<p>I understand that my <b>answers</b> from the interview will be <b>recorded</b> and <b>kept safe</b> on a <b>computer</b></p> <p>I understand that the research <b>results</b> will be <b>shared</b> but I will <b>not be named</b></p> <p>I am happy for <b>Lancaster University</b> to keep my <b>information</b> for <b>up to 10 years</b></p> <p>I <b>agree to take part</b> in the research</p>	<p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p> <p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p> <p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p> <p>YES ✓ NO X  <input type="checkbox"/> <input type="checkbox"/></p>
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We will talk through this form over the phone when we speak

You will be asked to answer each question if you want to take part

**APPENDIX I****Interview schedule**

The following questions will be used as a guide for interviews, but the researcher will be flexible and will allow space for each participant to lead the conversation based on what feels most important/relevant to them and their experiences.

Interviews will aim to cover the following areas:

- Life prior to the stroke – specifically relating to perception of self
- How dysarthria affects perception of self
- How dysarthria affects interaction and connection with others
- Debrief and opportunity to ask questions

Can you tell me about what life was like prior to the stroke?

How would you describe yourself prior to the stroke?

How do you think others (family, friends etc) would have described you then?

What were your hobbies/interests prior to the stroke?

What were your strengths/weaknesses/values?

How has life changed since your stroke?

How has your speech/ability to communicate with others been affected?

How would you describe yourself now?

Would you say that your speech has had any impact on how you feel about yourself?

How do you think others (family, friends, strangers etc) would describe you now?

Has your speech impacted on your strengths/weaknesses/values in any way?

Does your speech affect your ability to complete any tasks?

Does your speech impact on your ability to initiate or maintain relationships with others?

If so, can you describe the consequences your speech has on different relationships?

Does your speech affect your ability to engage with enjoyable activities/hobbies/interests?

How have you found the interview process today and using this platform? (video/phone etc)

Is there anything you would like to mention that I have not asked about?

Do you have any other questions?

**APPENDIX J****Sources for further support****The Stroke Association****Helpline: 0303 3033 100**

- Monday, Thursday and Friday: 9am – 5pm
- Tuesday and Wednesday: 8am – 6pm
- Saturday: 10am – 1pm
- Sunday: Closed

**Website: [www.stroke.org.uk](http://www.stroke.org.uk)****Email: [helpline@stroke.org.uk](mailto:helpline@stroke.org.uk)****Online support tool: [www.mystrokeguide.com](http://www.mystrokeguide.com)****Different Strokes**

(Stroke charity helping younger stroke survivors)

**Information line: 01908 317618 or 0345 130 7172****Website: [www.differentstrokes.co.uk](http://www.differentstrokes.co.uk)****Email: [info@differentstrokes.co.uk](mailto:info@differentstrokes.co.uk)****Headway**

(Charity aiming to help improve life after brain injury)

**Helpline: 0808 800 2244**

- Monday to Friday: 9am to 5pm (Option to leave voicemail at any time)

**Email: [helpline@headway.org.uk](mailto:helpline@headway.org.uk)****Samaritans**

(24/7 support)

**Helpline: 116 123****Website: [www.samaritans.org](http://www.samaritans.org)****Email: [jo@samaritans.org](mailto:jo@samaritans.org)**

**Should you experience significant distress, you are strongly advised to contact your GP for further support and advice.**

## APPENDIX K



Applicant: Sophie Cochrane  
Supervisor: Dr Craig Murray, Dr Karen Quinn  
Department: Division of Health Research  
FHMREC Reference: FHMREC20065

14 December 2020

**Re: FHMREC20065**

**The experience of having dysarthria following a stroke in relation to personal and social identity**

Dear Sophie,

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: [fhmresearchsupport@lancaster.ac.uk](mailto:fhmresearchsupport@lancaster.ac.uk)

Yours sincerely,

A handwritten signature in black ink, appearing to read "ABeap".

Annie Beauchamp,  
Research Ethics Officer, Secretary to FHMREC.

**From:** FHM Research Ethics <[fhmresearchsupport@lancaster.ac.uk](mailto:fhmresearchsupport@lancaster.ac.uk)>  
**Sent:** 04 December 2020 09:40  
**To:** Cochrane, Sophie (Student) <[s.cochrane@lancaster.ac.uk](mailto:s.cochrane@lancaster.ac.uk)>  
**Cc:** FHM Research Ethics <[fhmresearchsupport@lancaster.ac.uk](mailto:fhmresearchsupport@lancaster.ac.uk)>  
**Subject:** Application feedback

**Application reference: FHMREC20065**  
**Reviewed by FHM REC on 03/12/20**

Dear Sophie,

Thank you for submitting your application to the Faculty of Health & Medicine Research Ethics Committee. Your application has been reviewed and the following feedback provided:

- 1) In terms of information being collected, tick boxes could be used instead of text entry to make it easier for participants to provide their information.

Please implement the requested amendments and return the updated application to this email address, ensuring that the amendments are highlighted in **yellow** for ease of reference. This helps to speed up the re-review process and move your application along more quickly.

If you have any questions, please don't hesitate to get in touch via this email address.

Best wishes,  
Annie

**Annie Beauchamp | Research Ethics Officer (FST/FHM)**  
Research and Enterprise Services | Lancaster University  
[Contact me on Microsoft Teams](#)

Pronouns: She/Her

[Click here to hear my surname](#)

[www.lancaster.ac.uk](http://www.lancaster.ac.uk)



**From:** Cochrane, Sophie (Student) <[s.cochrane@lancaster.ac.uk](mailto:s.cochrane@lancaster.ac.uk)>  
**Sent:** 07 December 2020 11:09  
**To:** FHM Research **Ethics** <[fhmresearchsupport@lancaster.ac.uk](mailto:fhmresearchsupport@lancaster.ac.uk)>  
**Cc:** Murray, Craig <[c.murray@lancaster.ac.uk](mailto:c.murray@lancaster.ac.uk)>  
**Subject:** Re: Application feedback

Hi Annie,

Please find attached my **ethics** documents with the requested amendments.

I have included tick boxes on the opt-in form which are highlighted in yellow. This is in Appendix D of the protocol.

Best wishes,  
Sophie

FHM Research **Ethics**

Mon 14/12/2020 16:06

To:

- Cochrane, Sophie (Student) <s.cochrane@lancaster.ac.uk>

Cc:

- FHM Research Ethics

FHMREC20065 Sophie Cochrane **Ethics** Approval.pdf

131 KB



**Approval of a new application**

**Subject: **Ethics** approval FHMREC ref: FHMREC20065**

Dear Sophie,

Thank you for submitting your research **ethics** application for the above project for review. The application has been reviewed by members of the FHM Research **Ethics** Committee and I can confirm that approval has been granted for this project.

I have attached a copy of your approval letter for your records. Please read it carefully and contact me on fhmresearchsupport@lancaster.ac.uk if you have any queries or require further information.

Best wishes,  
Annie

**Annie Beauchamp | Research **Ethics** Officer (FST/FHM)**

Research and Enterprise Services | Lancaster University

[Contact me on Microsoft Teams](#)

*I work flexibly so may send or respond to emails outside of standard office hours. There is no expectation for you to respond outside of your working hours.*

Pronouns: She/Her

[Click here to hear my surname](#)

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