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RESEARCH REPORT

How do stroke survivors with communication difficulties manage life after stroke in the first year? A qualitative study.[1]

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Running Head: Managing life after stroke in the first year

Keywords: Aphasia, Dysarthria, Apraxia of Speech, Stroke, Self-Management, Qualitative

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DECLARATION OF INTEREST

None

RESEARCH REPORT

ABSTRACT

Background: Interest in how stroke survivors might be better supported to manage life after stroke has grown rapidly in recent years, with a particular emphasis on enabling ‘self-management’. Post-stroke communication difficulties may pose a unique barrier to longer-term adaptation and adjustment. It is important to understand how stroke survivors with communication difficulties manage life after stroke and what support may be needed to facilitate this process.

Aim: To explore how stroke survivors with communication difficulties manage life after stroke in the first year.

Methods & Procedures: Cross-sectional qualitative study involving in-depth semi-structured interviews with stroke survivors with communication difficulties (aphasia, dysarthria or apraxia of speech) and/or their family members at single time points during the first year post-stroke. A total of 21 participants (14 stroke survivors and seven family members) took part in interviews for the study. Interview data were analysed using thematic analysis.

Outcome & Results: A total of six themes were identified: 1) Strategies to manage changes to communication, 2) Testing communication outside of the home, 3) Balancing support and independence, 4) Hope for recovery, 5) Obtaining support from healthcare professionals, 6) Adapting activities and keeping busy. Stroke survivors with communication difficulties and their family members undertook significant work (practical, relational, emotional) to manage their condition. Adaptation and adjustment was often facilitated by ‘doing’; testing out which activities could be managed independently and which required additional support. Some stroke survivors and their family members demonstrated considerable resourcefulness and creativity in developing strategies to manage their communication difficulties. Despite the work undertaken, many expressed a lack of confidence in their ability and feelings of powerlessness and abandonment at the point of discharge from community services.

Conclusions & Implications: Stroke survivors and their family members develop personally meaningful and context specific strategies to adjust to and manage life after stroke.Future interventions should recognise, support and build upon the active work already undertaken by stroke survivors with communication difficulties and their families. Further support prior to and around the point of discharge from community services may be needed to help build confidence and skills to manage in the longer-term. The benefit of a supported self-management approach for stroke survivors with communication difficulties should be further investigated.

WHAT THIS PAPER ADDS

What is already known on this subject?

Few qualitative studies have explored how stroke survivors with communication difficulties and their family members manage life after stroke in the first year. Considering the poor longer-term outcomes experienced by this population, it is important to understand how stroke survivors with communication difficulties manage during this time and what support might be needed to facilitate the transition to longer-term adaptation, adjustment and condition management.

What this study adds

Findings highlight the resourcefulness and creativity with which some stroke survivors with communication difficulties and their family members managed the challenges they faced. Yet despite the active work undertaken, many expressed a lack of confidence in their ability and feelings of powerlessness and abandonment at the point of discharge from community services.

Clinical implications of the study

Further support prior to and around the point of discharge from community services may be needed to help build confidence and skills to manage in the longer-term. To facilitate condition management, future interventions should recognise and build upon the active work already undertaken by stroke survivors with communication difficulties and their families.

BACKGROUND

Interest in how stroke survivors might be better supported to manage life after stroke has grown rapidly in recent years. Stroke survivors with communication difficulties (aphasia, dysarthria or apraxia of speech) represent approximately one third of the stroke survivor population (Donkervoort et al., 2000, Melo et al., 1992, Arboix et al., 1990, Flowers et al., 2016) and have particularly poor longer-term outcomes. For example, stroke survivors with aphasia have reduced quality of life (Hilari, 2011), reduced social participation (Cruice et al., 2006) and are also at increased risk of depression (Hilari et al., 2012). Qualitative studies also highlight the persistent difficulties faced by this population in adjusting to and managing life with a communication difficulty (Wray and Clarke, 2017). This is not limited to the immediate aftermath of stroke; those who are several years post-stroke also express significant challenges, for example, in maintaining their social networks and participating in meaningful activity (Wray and Clarke, 2017).

One promising means by which to improve longer-term outcomes is ‘self-management’; an approach which aims to enable survivors to adapt to and manage the physical and psychosocial consequences of their condition (Fryer et al., 2016, Lorig and Holman, 2003, Barlow et al., 2002). In the UK, the National Clinical Guideline for Stroke (Intercollegiate Stroke Working Party, 2016) and the National Stroke Strategy (Department of Health, 2007) recommend that all stroke survivors should be offered the opportunity to learn self-management skills. A recent Cochrane review by Fryer et al. (2016) suggested that stroke self-management interventions may improve quality of life and self-efficacy. However, a systematic review by Wray et al. (2017) found that 46% of existing randomised controlled trials (RCTs) of stroke self-management interventions reported the total or partial exclusion of stroke survivors with aphasia, and, in a further 38% of studies it was unclear whether stroke survivors with aphasia were included or excluded.

Given the underrepresentation of stroke survivors with aphasia in RCTs to date, and the unique challenges to participation posed by post-stroke communication difficulties, it is important to consider how stroke survivors with communication difficulties may be better supported to adjust to and manage their condition in the longer-term. A systematic review by Wray and Clarke (2017), exploring the views and experiences of stroke survivors with communication difficulties following hospital discharge, found few qualitative studies in the first year post-stroke (Grohn et al., 2012, Grohn et al., 2014, Pringle et al., 2010, Brady et al., 2011). Grohn et al. (2012, 2014) explored the meaning of living successfully with aphasia in the first year post-stroke; Pringle et al. (2010) the experience of coming home from hospital for stroke survivors with aphasia, and Brady et al. (2011) explored the impact of post-stroke dysarthria upon social participation. Although it may be possible to draw some inferences about the management of post-stroke communication difficulties from the findings of these studies, none explicitly investigated condition management and the meaning of this from the participant's perspective exclusively in the first year post-stroke.

The first year post-stroke is likely to be an important time for adaptation and adjustment for stroke survivors with communication difficulties given the transition from hospital to home, and likely discharge from community services during this time period. By exploring the way in which stroke survivors and their family members manage during this time period, we hoped to gain insight into the complex experience of managing a post-stroke communication difficulty, and to investigate the support which might be needed as part of a supported self-management intervention.

Aim

To explore how stroke survivors with communication difficulties and their family members manage life after stroke in the first year including:

- The process of adaptation and adjustment to post-stroke life
- Strategies used to facilitate participation in post-stroke life
- The needs of this population in relation to self-management support

METHOD

Qualitative research represents a diverse assortment of traditions and methods capturing rich, in-depth accounts or explanations of social phenomena (Denzin and Lincoln, 2011). Many traditional approaches are rooted in sociology or anthropology where philosophical underpinnings influence the choice of methodology, interpretation of data and presentation of findings (Giacomini, 2011, Reeves et al., 2008). This study adopts a pragmatic approach, consistent with the applied health research being undertaken which seeks to “discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved” (Merriam, 1988) (p.11). A key facet of pragmatism is the centrality of the research question and the resulting value of the research in its contribution to knowledge (Bryman, 2006). Methods are seen as an assortment of tools used to answer a research question and are judged in terms of their appropriateness for doing so (Bryman, 2006, Chamberlain, 2000). Qualitative methods fitting the aims of the project were carefully considered including methods of data analysis which were consistent with the pragmatic approach. The research design was a cross-sectional qualitative study based on semi-structured interviews with stroke survivors and family members at single time points during the first year post-stroke. Steps to ensure rigour throughout data collection and analysis were undertaken and are described in further detail in this section.

Ethical approval

Ethical approval was granted by the Leeds West Research Ethics Committee, Leeds, UK (Ref:16/YH/0002) in February 2016. To protect the anonymity of participants, pseudonyms have been used and references to people or places have been anonymised.

Participants

A purposive sampling strategy was used in this study. We aimed to sample stroke survivors and/or their family member to reflect a range of communication difficulties (aphasia, dysarthria and apraxia of speech), severity of communication difficulties (mild, moderate, severe), and time post-stroke (less than 6 months and 6-12 months).

Stroke survivors and their family members were identified through five hospital based and community based speech and language therapy services by speech and language therapists. Stroke survivors were eligible for inclusion if they were aged 18 or over, within 12 months post stroke, had communication difficulties following stroke including one or more of: aphasia, dysarthria or apraxia of speech (as diagnosed by the treating speech and language therapy service) and had the capacity to provide fully informed consent. Stroke survivors were excluded if they were residents in nursing or care homes, or were receiving palliative care. Family members were considered for inclusion in an interview if they were aged 18 or over, were able to provide informed consent and were an informal carer to a stroke survivor with a communication difficulty (informal carer as opposed to a paid or voluntary carer), defined as someone who provides help and support (practical and/or emotional) to the stroke survivor at least once a week. A speech and language therapist from within the service made the initial approach to the stroke survivor and/or their family member and explained the study to them. If interested, a ‘consent to contact’ form was returned using a freepost envelope to the first author, who contacted the person indicated to discuss the study and arrange a visit. Informed consent was gained from all participants prior to data collection. The Consent

Support Tool (Jayes and Palmer, 2014) was used to assist this process as necessary. Severity was evaluated via informal assessment taking into consideration discussions with the treating speech and language therapist and results of the Consent Support Tool (Jayes and Palmer, 2014) assessment.

Data collection

Semi-structured interviews were conducted in participants own homes between June 2016 and January 2017. All interviews were conducted by the first author who is a Psychology graduate with training in supported conversation techniques. Supported conversation techniques (for example, speaking in short sentences using high frequency words, using repetition to aid comprehension and paraphrasing responses to check understanding) were used as required throughout the interviews (Dalemans et al., 2009, Luck and Rose, 2007). Stroke survivors and their family members chose whether they wished to be interviewed together or separately for the project and the researcher followed their wishes.

Informed by reviewing previous literature (Wray and Clarke, 2017), a topic guide was devised with questions designed to explore how life post-stroke was managed (including challenges or support to manage) and unmet needs in relation to condition management (see supplementary file). The topic guide was used flexibly and questions re-phased or simplified depending upon the severity of the communication impairment. Talking Mats™ was used as an ice-breaker task and as a prompt for relevant questions from the topic guide. Stroke survivors were asked to sort health and wellbeing cards using the Talking Mats™ system and discuss areas they were managing well with and areas they were not managing well with. Initially Talking Mats™ had been intended for use with participants with more moderate to severe communication impairments. However, this developed as more interviews were completed to become an important ‘ice-breaker’ task, and helped take the pressure off communication for participants who were anxious about speaking (including participants with milder impairments). The other ‘ice-breaker’ questions were removed from the topic guide and replaced by this task.

Interviews were audio recorded and digitally transcribed. The resource to videotape interviews was not available. To mitigate the potential limitations of audio recording (Luck and Rose, 2007) as far as possible, the researcher repeated unclear phrases for the benefit of the recording and described non-verbal communication throughout; for example, ‘I see you are pointing to the card about understanding’ or ‘you are giving me the thumbs up about this’ or ‘you are shaking your head about that’. Fieldnotes were made during and immediately after the interviews detailing interruptions or distractions and impressions of the key topics discussed.

Data analysis

Thematic analysis (Braun and Clarke, 2006) was used to analyse the interview data and NVivo software version 10 (QSR International, 2012) was used to aid this process. The six phases of thematic analysis outlined by Braun and Clarke (2006) provided a framework for the analysis of data in this study. In phase one, transcripts were read and re-read and initial impressions of the data stored as memos within NVivo. In phase two, initial coding of the transcripts was done line by line. Segments of data interpreted as relevant to understanding how stroke survivors with communication difficulties manage life after stroke were coded inductively using terms which were close to the original data. In phase three, segments of data coded in phase two were organised into groups and labelled based upon the data contained. The process of line by line coding and organising data into labels was completed within each individual interview transcript before looking for themes across transcripts (phase four). Data which was relevant to the aims of the project was actively selected, which included interpreting the ‘keyness’ of the theme in its contribution to the topic in question (Braun and Clarke, 2006). The creation of themes was not necessarily dependent upon the prevalence or recurrence of a concept within the data but rather its ability to inform the research. In some cases themes may be recurrent in the majority of participants experiences and in other cases less so but this is stated explicitly within the findings.

In phase four and five potential themes were reviewed in relation to the aims of the project and checked to ensure that the data reflected the theme described. The names of the themes were also carefully considered to ensure that they best represented the concepts being described. Writing up (phase six) constituted the final stage of analysis as links between the themes were considered and in some cases themes were re-organised to present a clearer picture. In writing up the findings, the abbreviations ‘I:’ and ‘P:’ are used to denote interviewer and participant. In supporting quotations, ‘…’ indicates the omission of irrelevant content which does not add to the meaning of the experience described. Phases four to six were non-linear and a considerable amount of back and forth between transcript data and theme organisation was undertaken before the themes were finalised. The analysis was primarily undertaken by the first author; however, the themes were also discussed with second and third authors and at a PhD group held within the academic unit. This method of debriefing ensured that the first author clarified and refined her interpretation of the data, and considered other perspectives upon the themes which had been developed.

Rigour

There is no consensus about the best criteria by which to judge rigour in qualitative research (Long and Godfrey, 2004). Lincoln and Guba’s ‘trustworthiness’ criteria are commonly used and include credibility, transferability, dependability and confirmability (Guba, 1981, Lincoln and Guba, 1985, Schwandt et al., 2007). In this study, credibility (the extent to which an interpretation of data is representative of the experiences of participants) was enhanced through purposive sampling (to ensure that a range of views were available to create rich data for interpretation) and peer debriefing (discussion of themes and data interpretation with peers at the academic unit). To facilitate judgements about transferability (the extent to which findings might be applied or generalised to other participants in similar contexts), relevant contextual information about participants was reported in the findings. Dependability (the extent to which a researcher's interpretation of data would be consistent if repeated) was enhanced through the use of NVivo software which facilitated a clear audit trail of the decisions about analysis from initial coding to final themes. Confirmability (the extent to which the findings of the study are free from bias) was maximised through line-by-line coding of the data (which helped the researcher to stay 'close' to participants experiences) and active exploration of negative (or atypical) cases during the analysis. The researcher also kept a reflexive log to consider their influence on the collection and interpretation of the data.

FINDINGS

Overview of interview participants

A total of 21 participants (14 stroke survivors and seven family members) took part in interviews for the project. The majority of stroke survivor and family member dyads (six out of seven) chose to be interviewed together; one dyad chose to be interviewed separately. 15 separate interviews were conducted in total. The length of interviews ranged from 42 to 85 minutes; the mean interview length was 62.27 minutes (SD 13.60). Participants were assigned pseudonyms following the interviews. Table 1 shows an overview of participant characteristics.

[TABLE 1: Participant characteristics]

Stroke survivor's ages ranged from 44 to 87 years old and time post-stroke from one month to 12 months. The majority of stroke survivors (11 out of 14) lived with a family member; three lived alone. As highlighted by an asterisk (*) in the table, we were unable to obtain informed consent for one stroke survivor to participate in an interview. Carol's husband Stan wished to take part in an interview and for Carol to be present. Consultee declaration was therefore obtained on behalf of Carol.

Themes

A total of six themes were developed from the interview data.

1) Strategies to manage changes to communication

The sudden loss of speech and language was described by stroke survivors as a shocking and unexpected consequence of stroke. Since stroke the act of speaking or understanding language was effortful and frustrating. Changes to communication were not only related to the physical difficulties of speaking, but also to the consequences of communication difficulties upon the stroke survivor's ability to freely project their character and sense of self. Notably stroke survivors felt they had lost control over their ability to express their sense of humour or contribute to conversations on more than a basic level.

Stroke survivors used a number of strategies to manage their altered level of communication. Some withdrew from conversation or actively avoided activities which would involve speaking or understanding language, commonly those outside of the home environment or those which involved speaking to strangers.

> *"Anxiety I think…*and me speech, I wouldn't go on a bus or anything like that on me own 'cos if I'm thinking about it, when I get to the bus I will

> *come out with something completely silly!” (Susan,* age 59, aphasia, 12 months post-stroke)

In contrast, some stroke survivors developed proactive strategies to aid their communication. Some strategies had been obtained through speech and language therapy, for example, Alfred (age 73, dysarthria, 3 months post-stroke) described how the speech and language therapist advised slowing down his speech as a strategy, and, Gregory (age 87, apraxia of speech, 7 months post-stroke) described how the speech and language therapist had advised him to break longer words down into syllables to help with his communication. Other strategies included those which were associated with the character of the stroke survivor, for example, the importance of having a sense of humour in managing changes to communication.

> *“Well when I get started telling somethi*ng and then it goes all wrong, I *can’t find the right words to explain myself but I laugh at meself and it’s better than embarrassing meself…” (Gregory,* age 87, apraxia of speech, 7 months post-stroke)

Paul’s mother Sarah spoke about how he struggled with spontaneous conversation and so used his own novel strategies to start conversation with people. For example, if going to a comic book event, Paul would purposely wear a t-shirt with a comic book character on to start conversation or would prompt conversation through pointing at something of interest. At the local stroke group he attended, he noticed another member was wearing a rugby shirt, which helped to facilitate conversation:

> *“…because he would wear the t*-shirt*…so I’m wearing this t*-shirt, talk to me about it, that that type of thing. You know, and one of the guys had a stroke, he was wearing a rugby shirt and he went up to him, and he just *pointed, and he went, “England, England,” like that, “Oh do y*ou like *rugby?”…” (Sarah,* age 66, mother to Paul)

The most common strategy stroke survivors used in order to manage difficulties with communication was to obtain support from friends and family. Family members often played a significant role in supporting the management of post-stroke communication difficulties. Sometimes this involved mediating conversation directly; for example, helping to convey the stroke survivor's message, or, providing support for them to do so. Family members acted as a source of reassurance for stroke survivors, so that even if they did not play a part in a conversational exchange, stroke survivors valued them 'being there' to step in if needed. For example, Simon describes feeling more comfortable having his daughter present when shopping.

> *"P: ... Morrison's, Asda, bit tricky when I'm on me own, particularly a person behind me, I get a feeling that something's not right, probably just* me, yeah.
>
> *I: Do you feel like you're sort of a bit rushed if someone's behind you?*
>
> P: Yeah, yes. With me [Name of daughter], alright, yeah, on me own, *yeah." (Simon,* age 49, aphasia, 5 months post-stroke)

Having a family member present provided reassurance to stroke survivors, who feared the embarrassment of becoming 'stuck' with their communication in a public place.

2) Testing communication outside of the home

Managing communication outside of the home was an important aspect of managing life after stroke. Stroke survivors varied in the extent to which their communication difficulties had restricted their activities outside of the home. Stroke survivors who were less than six months post-stroke generally engaged in fewer activities outside of their home environment which involved speech. During this time period, daily life was taken over by an influx of healthcare professionals and a focus upon engaging in therapy, and, adapting and adjusting to being in the home environment physically. For example, Isobella felt she had not had time to go out and see friends since her stroke:

> *"…not since I've been back home because it's been so busy that's* honestly true when we go out we go visit a few friends then. I hope that *we will go on Tuesday I hope we'll go then. So yes I think that's imp*ortant *if you can…" (Isobella,* age 83, aphasia, 3 months post-stroke)

Once support from rehabilitation services came to an end (usually between two and six months post-stroke), stroke survivors either took tentative steps towards adapting or adjusting to their communication problems, or, they continued to restrict themselves to activities which did not involve communication (generally those in the home environment).

> *“I clean me girls, clean me girls, feed me girls, me chickens, yeah, they don't care what I talk like!” (Susan,* age 59, aphasia, 12 months post-stroke)

Some stroke survivors tested the boundaries that their communication difficulties imposed, and figured out the situations in which they were able to cope, and the situations where they needed more assistance. This process generally occurred towards the end of formal rehabilitation or once the stroke survivor had been discharged from speech and language therapy. For example, in spite of his limited expressive language, Paul had recently resumed his hobbies of going to the cinema and collecting comics. A facilitator to this was familiarity, as the staff in the cinema and comic shop knew him and were able to assist with communication.

> *“Yes, but I was making sure that the cinema, the staff there, are right,* they know me. Yes? And the [Name of comic shop], they know me. So, *and then that’s basically it. Yeah.” (Paul*, age 44, aphasia, 7 months post-stroke)

Paul felt he was able to manage in some situations with the limited expressive language he had:

> *“I: How confident do you feel about your speech, when you’re out?*
>
> P: As you say, hello, goodbye, yes, thank you, y*eah…” (Paul,* age 44 aphasia, 7 months post-stroke)

However, Paul encountered difficulties if he needed to express himself outside of the language he felt comfortable with i.e. hello, goodbye, yes, thank-you (“…I can’t get it out.”). Paul was developing knowledge about the situations in which he was able to manage his communication. This was an ongoing process and Paul was continuing to test the boundaries. Testing communication outside of the home in this way was only achieved by a minority of stroke survivors within the sample. With the exception of Paul, those who had resumed activities which involved communicating outside of the home independently tended to have milder difficulties with their communication, or obtained support from family and friends in these situations. Paul had previously had a stroke and this may have impacted upon his experience.

3) Balancing support and independence

In their accounts of managing post-stroke communication difficulties, stroke survivors spoke about the need to retain a sense of autonomy within their lives whilst receiving support from healthcare professionals, friends or family members. Although stroke survivors accepted that support was sometimes needed, they wished to maintain independence wherever possible.

> *"…and they tend* to want to go to the bar and I mean they want for me to sit there*…they're meaning well, but I want to do it myself." (Alfred,* age 73, dysarthria, 3 months post-stroke)

Survivors talked about the way in which their sense of independence was either restricted or maintained in their post-stroke lives. Difficulties with speech and language were often perceived to cause restrictions to independence:

> *"…I can't go gallivanting off alright now and speech has got a lot* to do *with it, yeah." (Simon,* age 49, aphasia, 5 months post-stroke)

Simon felt restricted in the activities he could do outside of the home due to the difficulties he experienced with accessing public transport and talking to strangers. In spite of difficulties with communication, a sense of independence could still be expressed by stroke survivors in relation to other aspects of their lives. For example, it was important to Gregory that he was able to manage his self-care independently, and he gained a sense of accomplishment from doing so. Reliance on others was not desirable for some stroke survivors in terms of their own feelings of independence, but also in terms of the perceived burden it may place upon the others.

> *“Yes, and we have good friends that will pick us up and take us anywhere but don’t like to rely on them too much.” (Gregory,* age 87, apraxia of speech, 7 months post-stroke)

> *“I’m lucky because I have help two daughters but I really can’t have them for too long because that’s too fair for them to do that…” (Isobella,* age 83, aphasia, 3 months post-stroke)

Isobella had been discharged from hospital shortly before the interview had taken place. Although the hospital team had been satisfied that she would be able to manage independently, Isobella’s daughters had raised concerns about her safety and ability to manage (physically and cognitively) since she had returned home. However, Isobella held ambivalent views about the need for additional support. On the one hand it was becoming apparent to her since she had been home that things had changed (“I’m learning now to sense how things are changing”) but on the other hand Isobella did not want “too much” support which stifled her sense of independence. For Isobella there seemed to be a balance to be struck between having enough help and having “too much” help.

The extent to which stroke survivors were able to get the balance of having enough support, but not feeling restricted in their sense of independence varied. Some stroke survivors accepted the fact that additional support was necessary and this was not a threat to their sense of independence. Others expressed difficulties in relying upon others for support. For example, Susan felt unhappy about the extent to which she relied upon her daughter Kerry:

> *“P*: *…*Kerry more or less does everything*…* I get all words wrong if I want to go on the telephone so I can't make an appointment*…* for the doctor's*…*she's not a, oh God, what's the word... not a [laughs] sorry, not a crook! No, sorry I don't know what the word is.
>
> *I: …A crutch?*
>
> P: Tha*t's the word! Oh gosh, yeah”* (Susan, age 59, aphasia, 12 months post- stroke)

Susan recognised that she relied heavily on her daughter for support, and felt that a lack of confidence in her speech and language held her back from attempting to do things on her own. However, Susan wished for independence within her own community.

> *“Erm... go on a bus on me own I think, yeah, just to go somewhere on me* own, you know, close, I don't want to go miles but yeah, that'd be nice, *that.” (Susan,* age 59, aphasia, 12 months post- stroke)

4) Hope for recovery

Maintaining a sense of hope and progression towards recovery was discussed by a significant proportion of interview participants as an important contributor to managing life after stroke. A commonly held hope was the wish or desire to get back to ‘normal’ with normal representing the survivor’s level of speech and language prior to stroke. Stroke survivors often perceived that the rapid physical improvements they had experienced in hospital would continue in the community setting. Some stroke survivors were confident in the likelihood of their speech and language returning. For example, Robbie talked about aphasia as a “mind blockage” but was certain that he would recover from this:

> *“It’s just the little hiccup regarding my speech, and once that’s sorted out I’ll be back to how I was before...” (Robbie,* age 62, aphasia, 1 month post-stroke)

Other stroke survivors expressed uncertainty about the extent to which normality could be recovered. For example, on one hand Simon was hopeful for improvements to his speech and language and had set a goal to be ‘back to normal’ by the Christmas following his stroke, however, Simon had not progressed as quickly as he had hoped. In this extract the interviewer asks Simon if he would like any further information about his stroke and he replies:

> *“Why it’s taking me so long. I don’t know about you feel that it’s just a bit too soon and I know, I just want to know how it’s taking me so long that five months don’t seem an awful long* time for somebody because I got aphasia,*…I just want to know how it’s doing….” (Simon,* age 49, aphasia, 5 months post-stroke)

Simon’s frustration appears to be related to the level of uncertainty about his recovery and the length of time this will take. Without an understanding of what the future may hold, stroke survivors may face a decision about whether to accept their communication difficulties and adapt or continue to wait for improvements to occur. In hoping for recovery some stroke survivors and family members delayed resuming pre-stroke activities and roles with the hope that improvements would occur.

Some stroke survivors accepted that their speech and language may never recover to the level it was prior to stroke. For example, James spoke about getting back to normal but commented: “you know, as back as we were, there’s no chance now, no chance, no.” (James, age 58, aphasia, 5 months post-stroke). Although James appeared to have come to terms with the fact that his speech and language might not fully recover, it was still important for James to work towards improvements and to come as close to recovering his speech and language as possible:

> *“James: Talking as well, at the end of the day it is possible, as much as* we can back to work as we were and carrying on as we were, but like we *said with everything else, you know…*
>
> *Sylvia: Just to get back to what you did before really is what he’s saying really, as close to…*
>
> *James: What we can, yeah.” (James,* age 58, aphasia, 5 months post-stroke)

5) Obtaining support from healthcare professionals

Obtaining support from healthcare professionals to manage activities of daily living and to continue rehabilitation was a priority for stroke survivors and their families. The time post-stroke was associated with the level of support participants were receiving; those who were less than 6 months post-stroke were generally under the care of a multidisciplinary stroke team, and those who were 6-12 months post-stroke had generally been discharged from these services. Participant’s experiences of support from healthcare professionals during the transition from hospital to home varied. All stroke survivors spoke of their relief and happiness to be discharged from hospital, however, for some family members this was a time of worry and apprehension as they took on the responsibility for caring for the stroke survivor. Where transitions were smooth, the support received from healthcare professionals was highly valued and helped to alleviate some of the family member’s apprehensions.

> *“…*I was worried about him being down here when I went up to bed, but*…it got easier with time didn’t it?...Just figuring it [out], just getting into* a routine, I think was the thing, and then because the two, they came in and, , the first morning helping him to get washed and dressed just, , and you would see how they would do it and I would be there as well*…*you picked up *how to…” (Sylvia,* age 55, wife to James)

However, the transition from hospital to home was not always smooth and for some obtaining support was effortful and associated with delays and uncertainties. Due to sickness, the physiotherapist working with Daniel (stroke survivor) became unavailable shortly after he was discharged. Daniel’s wife Elizabeth explains how they had sought support from a private physiotherapist in the absence of support from NHS services:

> *“…and it was four weeks before we got any of the physio. We went private then, you know…we went private for physio because we’d been* told how important it was for the *first six and twelve weeks….” (Elizabeth,* age 62, wife to Daniel)

Some families were uncertain about who they should contact with questions following hospital discharge. For example, stroke survivor Hideo had experienced headaches since being home from hospital and his wife Mai was unsure who she should contact.

> *“P: But I don’t know…we have never had a medical team to visit him. So* it might be that it will be good because he or needs to arrange the doctor, *GP, I don’t know.*
>
> I: Oh okay, so you are not quite sure who to contact about that?
>
> *P: Or to contact direct to the hospital…maybe he needs an x*-ray to be *sure this is okay or not.” (Mai,* age 68, wife to Hideo)

Access to speech and language therapy in the community was time limited and concerns were often raised when discharge from speech and language therapy in the community was imminent. The prospect of discharge was emotional:

> *"Yeah, it's sad really, because it's all come to the end, but referring me to* [Name of hospital], specially [Name of speech and language therapist], *yeah." (Simon,* age 49, aphasia, 5 months post-stroke)

> *"…we don't know if that might be coming to an end really, just by the way they were talking yesterday…but they're talking about reducing the care down… we don't want to just stop …" (Sylvia,* age 55, wife to James)

For stroke survivors and their family members the process of adjustment and adaptation had not ended at the point of discharge from rehabilitation services; many of those interviewed at this timepoint had only just begun to venture outside of their home environment and few had resumed their previous roles or meaningful activities. Stroke survivors and their family members generally negotiated this stage of adjustment without support from healthcare professionals. Sarah (family member) felt dissatisfied with support her son Paul (stroke survivor) had received from speech and language therapists in the community. Sarah felt that an insufficient number of speech and language therapy sessions had been provided and the service lacked continuity if members of staff were on holiday or off sick.

> *"…I felt that the poor relation was the speech therapy, I said, "I think there should be more for him," and I don't think once a week, once a* fortnight was sufficient. And if people were *off ill or they're on holiday then we didn't get any visits at all." (Sarah,* age 66, mother to Paul)

In addition to the perceived lack of speech and language therapy sessions, Sarah felt uninvolved in the speech and language therapy sessions which did take place. This was difficult for Sarah as she was keen to understand how she could help her son Paul to progress with his speech.

> *"…involve the carers as I say, this is what's happening, try this, try that,* and listen, have ti*me for the carers, saying, "Well I'm doing this, is that alright, is there anything else I can be doing, should I be doing this?"…"* (Sarah, age 66, mother to Paul)

Sarah was unique in her explicit dissatisfaction with the amount and type of speech and language therapy input available to her son Paul. Although other families did not express dissatisfaction with the type or amount of speech and language therapy which was provided in the community, some experienced a sense of abandonment when rehabilitation services were withdrawn:

> *"… and the worst thing about our situation was, as you get signed off by different people, when you get a letter saying, 'well you don't need this anymore'… you always feel as though, a bit abandoned when people say, '*well, *we don't need to come anymore,' or, 'you don't need to* have any *more of this or that.' But we have so many things now." (Elizabeth,* age 62, wife to Daniel)

Although Elizabeth felt a sense of abandonment when Daniel had been discharged from various rehabilitation services, over time she felt they had replaced their support with other activities ("but we have so many things now") for example, attending a stroke group and volunteering. Elizabeth's account of discharge portrays a sense of powerlessness. This was an experience common to the stroke survivors and families who took part in the interviews who expressed feeling lost at the point of discharge. Families were left to navigate sources of ongoing support on their own or simply coped alone:

> *"So it's a struggle, it's an uphill struggle, but we're not giving up y*et are *we?"* (Clara, age 74, wife to Nico)

Those who had found ongoing support, sometimes expressed an element of chance in the way in which support had been obtained suggesting a lack of coordinated approach:

> *"…it does make you wonder that if we hadn't gone down certain routes and been lucky that somebody told us that one, that's made a big difference to us." (Elizabeth,* age 62, wife to Daniel)

It is important to note that some stroke survivors and family members did accept the end of speech and language rehabilitation without concern; either accepting the time limitations of the service or feeling that they had made sufficient progress and were ready to manage.

Satisfaction was generally high in stroke survivors with milder difficulties who were happy with the progress they felt they had made.

6) Adapting activities and keeping busy

Some stroke survivors and their family members spoke about how their day to day activities had been significantly disrupted in comparison to pre-stroke life. The extent to which stroke survivors were able to manage the changes to their circumstances, and participate in activities which were meaningful to them varied. Some had not managed to resume any of the pre-stroke activities they valued (or the amount of activity was highly restricted) and were left with a sense of loss and monotony in their lives. Those who reported successful resumption of participation in meaningful activity tended to be more than six months post-stroke or have milder impairments which they perceived had not presented a substantial barrier to participation. Nico struggled to participate in any meaningful activity since his stroke and spoke of significant loss in this respect. When completing the Talking Mats™ activity Nico indicated the activities he used to enjoy including driving, walking his dogs, cooking, looking after his grandchildren and doing DIY. However, since his stroke Nico had been unable to participate in these activities and even self-care tasks (for example, washing and dressing) which had previously been taken for granted were effortful. Nico indicated that prior to stroke many of the items discussed in the Talking Mats™ activity would have been placed under the ‘managing well’ category, however, these were now in the ‘not managing well’ category. Nico had become virtually housebound since his stroke and struggled take part in daily activities within his home.

> *“I: So what do you do during the day?*
>
> P*: Not a lot [laughs].” (Nico,* age 77, aphasia, 8 months post-stroke)

On the other hand, some stroke survivors had either successfully continued with their pre-stroke activities or had made adaptations in order to participate. For example, Gregory had previously enjoyed bowling but due to mobility problems had been unable to play since his stroke. As an alternative to playing in the matches, Gregory watched the matches and was therefore still able to enjoy the social aspect of his previous hobby.

> *“For green bowling and some of the members* still pick me up to go and *watch… for instance, there’s a league game tonight and one chap he’s been very good.” (Gregory,* age 87, apraxia of speech, 7 months post-stroke)

Some stroke survivors who adapted their activities appeared to have reached a level of acceptance about the changes to their routine which had occurred since hospital discharge. Although they recognised the changes which had occurred, they were driven to make the best out of the situation:

> *“Hmm, I’d like to be able to do a lot of things but I can’t turn the clock back so I’ve got to be satisfied with what I can do.” (Gregory,* age 87, apraxia of speech, 7 months post-stroke)
>
> *“I just wouldn't happen, wish it hadn't happened, but it did, so you put up with it.* That's all you can isn't it r*eally?” (Albert,* age 87, aphasia, 9 months post-stroke)

Gregory and Albert were the two oldest participants in the sample. Age may be a facilitator to accepting changes to activities post-stroke as both participants alluded to restrictions in activity being an expected consequence of the ageing process. For example, Albert states in response to participating in leisure activities outside of the home: “I don't really have it, I stay here now, 87…”. This quote suggests that Albert anticipates taking part in less activity outside of the home due to his age, however, Albert is still satisfied with activities he is able to take part in at home (“I'm quite happy with things I do…”).

Those stroke survivors who were able to participate in meaningful activity recognised the importance of keeping busy. This was often linked to the stroke survivor’s sense of mental wellbeing:

> *“I mean if I move about outside and things like that I’m okay, you know, like take me mind off different things… I think you ought to keep bu*sy, keep busy and *activated don’t you?” (Teddy,* age 83, dysarthria, 4 months post-stroke)

Family members also facilitated aspects of keeping busy and believed this helped to protect the stroke survivor against feelings of depression.

> *“So that’s why when th*e weather is good, I take him out, just to find something he can enjoy and away from his illness, otherwise always *thinking and sometimes thinking too much… I think with stroke patients, if* they can walk, better to go out and to get the fresh air if the weather is *good. Better not to stay home all the time, that makes people depressed.”* (Mai, age 68, wife to Hideo)

A particularly problematic adjustment for working-age stroke survivors was returning to their previous occupations. None of the stroke survivors who had previously been employed had returned to work at the point of interview. Whilst the severity of the communication difficulty played a key role in the stroke survivor’s ability to return to work, the organisations understanding of the difficulties faced by stroke survivors was also important and acted as a facilitator to returning to work.

DISCUSSION

Summary and interpretation of findings

The interview findings suggest that managing life after stroke is a complex process; from the initial navigation of the transition to the home environment, to the tentative steps taken towards regaining previously valued roles, responsibilities and activities. Stroke survivors varied in the extent to which they were able to successfully work through the problems they encountered. This process was often influenced by individual and contextual factors e.g. time post-stroke, personality, severity of communication difficulty, availability of family support, age. The relationships between these factors and the management of life post-stroke were complex. For example, level of participation was often associated with the severity of the impairment, however; some participants developed strategies to participate in spite of limited expressive language. Time post-stroke also influenced levels of participation; with participants less than six months post stroke involved in fewer activities involving communication outside of the home environment in comparison to those more than six months post-stroke. However, this was not the case for all participants. Another factor influencing participation was the meaning and consequences of the stroke upon participant's lives (termed 'biographical disruption' by Bury (1982)). For some (in particular older participants, those with pre-existing health conditions), stroke and communication difficulties did not cause catastrophic disruption to their lives but were perceived as a difficulty which could be accommodated within their journey (Hawkins et al., 2017). These participants appeared to resume participation sooner than stroke survivors who were younger or who had worked previously (who experienced greater levels of disruption).

A significant finding was the active 'work' participants undertook to manage the consequences of stroke and living with a communication difficulty (Corbin and Strauss, 1991, Corbin and Strauss, 1988, Corbin and Strauss, 1985). In particular, the trial and error process of 'figuring out' which activities could be managed and which would require further support. This appeared particularly important in cases where stroke survivors and their families had developed strategies to manage their communication difficulties. Other qualitative studies also suggest the importance of family support and 'doing' in relation to successful adaptation, adjustment and condition management following stroke (Kubina et al., 2013, Satink et al., 2015a, Satink et al., 2016) and, in living successfully with post-stroke aphasia (Grohn et al., 2012, Grohn et al., 2014). Yet, despite the resourcefulness and creativity with which some stroke survivors with communication difficulties and their family members managed the challenges they faced, many still expressed feelings of powerlessness and abandonment at the point of discharge from community services. This appeared to be a key turning point for many, when concerns and uncertainties about managing in the future were brought to the forefront.

Implications for practice

Introduction of self-management techniques in the rehabilitation process may be useful in order to smooth the transition to longer-term adaptation and adjustment. The findings of this study suggest that a key aspect of any self-management approach must be to build confidence and strategies to manage the impact of post-stroke communication difficulties in daily life. In particular, being supported to test out communication in different situations, and develop their own ways of managing, may be a fundamental aspect of such an approach for stroke survivors with communication difficulties.

Such an approach is in line with the general trend away from traditional approaches to self-management which, arguably, have been more educationally focused in teaching a set number of skills in a set order (Foster et al., 2007, Lorig et al., 1999). Given the complexity of difficulties faced post-stroke and in particular, the complexity of post-stroke communication difficulties there may be no ‘right’ or ‘wrong’ way for stroke survivors with communication difficulties to manage life after stroke (Jones et al., 2017). However, support during the process of developing strategies, and ways of managing which are specific to the particular context of the stroke survivor with communication difficulties and their family, may be crucial for building feelings of confidence in ability to manage in the longer-term. By considering self-management as a concept which is highly context specific, and which might require more or less input from family members, stroke survivors with more severe communication difficulties may be included in self-management interventions. Satink et al. (2015b) suggest that self-management should be considered as a continuum upon which stroke survivors and their family members should be supported to manage as far as possible.

Whilst this research has illuminated the possible role of a self-management intervention for stroke survivors with communication difficulties, questions still remain about where such an approach may ‘fit’ with or ‘add’ to existing rehabilitation practices. Some may argue that existing approaches in speech and language therapy are designed to build strategies and confidence in ability to manage post-stroke communication difficulties. For example, alternative and augmentative communication strategies (Jacobs et al., 2004), conversation therapy (Sirman et al., 2017) or communication partner training (Simmons-Mackie et al., 2016). On the other hand, these approaches have not been designed to specifically to facilitate self-management which has a particular emphasis on supporting people to take the lead in managing their condition moving forwards (Mudge et al., 2015). Principles of self-management (e.g. problem solving, self-discovery, activity planning) may be integrated with existing therapeutic approaches to support this process (Jones et al., 2016).

Another important element of self-management is the management of the broader psychosocial consequences of living with a long-term condition (Fryer et al., 2016, Lorig and Holman, 2003, Barlow et al., 2002) . Research suggests variation in speech and language therapists practice when it comes to addressing psychosocial issues as part of speech and language therapy (Northcott et al., 2017, Northcott et al., 2018, Sirman et al., 2017). A number of factors may account for this variation including variation in confidence, training and the amount of resources available for speech and language therapy in the community setting (Northcott et al., 2017, Northcott et al., 2018, Sirman et al., 2017). Overcoming organisational barriers to implementing self-management approaches may be particularly challenging. Research suggests that this type of therapeutic work may be perceived to be a less ‘justifiable’ element of therapy in the context of organisations with lengthy waiting lists and high caseloads (Norris and Kilbride, 2014, Northcott et al., 2018).

Sample limitations

Participants in this study were recruited from NHS services and were therefore often (although not always) in receipt of support from speech and language therapists or had recently been discharged from speech and language therapy services. This may create a bias in the type of stroke survivor who took part in the study as those who were not in receipt of support from NHS services were not approached to participate. Although we recruited from multiple NHS services, the services were located in one geographical region of the UK and so may not be fully representative of other areas of the country or other countries outside of the UK. The sample may also be limited in terms of the number of stroke survivors with dysarthria and apraxia of speech included. These conditions were less well represented within the sample and this is a limitation of the research. Finally, the limitations of recruiting participants at a single time point post-stroke must also be acknowledged. Those at earlier time points post-stroke may have been more limited in the experiences they had to share regarding condition management.

CONCLUSION

Stroke survivors with communication difficulties and their families undertook significant work to adjust, adapt and manage life after stroke in the first year. Despite the resourcefulness and creativity demonstrated, some expressed a lack of confidence in their ability and feelings of powerlessness and abandonment at the point of discharge from community services. A self-management approach may be useful to smooth this difficult transition, however, such an approach must recognise, support and build upon the active work which is already undertaken by stroke survivors with communication difficulties and their families. Supporting stroke survivors and their families to engage in a trial and error process of practising communication in meaningful contexts may aid the development of unique and context specific strategies to manage the impact of communication difficulties in daily life (Satink et al., 2016, Kubina et al., 2013). Understanding the experiences of stroke survivors with communication difficulties and their families is vital for ensuring that interventions are designed to address the specific needs of this population.

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Table 1: Participant characteristics

Stroke survivor (Pseudonym)	Age	Communication difficulty	Time post-stroke	Living circumstances	Severity^	Interviewed with carer?	Carer (Pseudonym)	Age	Relation to stroke survivor
Albert	87	Aphasia	9 months	Lives alone	Mild	No	--	--	--
Alfred	73	Dysarthria	3 months	Lives with wife	Mild	No	--	--	--
Carol*	75	Aphasia	2 months	Lives with husband	Severe	Yes	Stan	89	Husband
Daniel	62	Aphasia	12 months	Lives with wife	Moderate	Yes	Elizabeth	62	Wife
Gregory	87	Apraxia of speech	7 months	Lives with wife	Mild	No	--	--	--
Hideo	72	Aphasia	3 months	Lives with wife	Moderate	Yes	Mai	68	Wife
Isobella	83	Aphasia	2 months	Lives alone	Mild	No	--	--	--
James	58	Aphasia	5 months	Lives with wife	Moderate	Yes	Sylvia	55	Wife
Nico	77	Aphasia	8 months	Lives with wife	Severe	Yes	Clara	74	Wife
Paul	44	Aphasia	7 months	Lives with father	Moderate	No	Sarah	66	Mother
Robbie	62	Aphasia	1 month	Lives with wife	Mild	No	--	--	--
Simon	49	Aphasia	5 months	Lives with daughter	Moderate	No	--	--	--
Susan	59	Aphasia	12 months	Lives with daughter	Mild	Yes	Kerry	39	Daughter
Teddy	83	Dysarthria	4 months	Lives alone	Mild	No	--	--	--

* Consultee declaration obtained ^Severity evaluated via informal assessment taking into consideration discussions with the treating speech and language therapist and results of the Consent Support Tool (Jayes and Palmer, 2014) assessment