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“Guiding them to take responsibility”: Exploring UK speech and language therapists’ views of supporting self-management of aphasia[1]

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ABSTRACT

Background: Self-management approaches are increasingly recommended after stroke with the aim of supporting longer-term adaptation, adjustment and condition management. Stroke survivors with aphasia (SSWA) have particularly poor longer-term outcomes; however, the suitability of self-management for SSWA is unclear. Speech and language therapists (SLTs) play a key role in the provision of care for this group of stroke survivors; however, UK SLTs views of self-management have not been explored.

Aims: To explore UK SLTs views of 'self-management' as an approach in stroke rehabilitation including its application in practice with SSWA.

Methods & Procedures: In depth, semi-structured qualitative interviews were conducted with SLTs from five NHS speech and language therapy services. Interview data were analysed using thematic analysis.

Outcomes & Results: Eighteen SLTs participated in interviews. Many SLTs were not familiar with the term 'self-management'. However, SLTs were positive about the connotations of this term which aligned closely with the values they held about their role and the desired outcomes of rehabilitation. SLTs described multiple aspects of their existing practice which they associated with enabling 'self-management' (e.g., self-directed practice of therapy tasks, encouraging SSWA to take responsibility for their own rehabilitation, involving family members in therapy). However, some SLTs identified difficulties involving SSWA as active participants in the rehabilitation process and in facilitating 'readiness' to take responsibility for managing in the longer-term. Other barriers to enabling self-management were identified including limited session time for speech and language therapy in the community setting, difficulties involving family members in rehabilitation and a lack of access to other services to support self-management (including specialist psychological support).

Conclusions: Making the transition to longer-term adaptation, adjustment and condition management is a complex and challenging task which is likely to require tailored support for many SSWA and their families. Supported self-management may help to facilitate this process; however, SLTs require a structured and clearly defined approach and training to assist implementation in practice. Organisational 'buy-in' and support for self-management as a therapeutic approach within speech and language rehabilitation will also be required for successful implementation.

Keywords: Stroke, Aphasia, Qualitative, Speech and language therapists, Self-management

BACKGROUND

Aphasia is a debilitating condition affecting approximately one third of stroke survivors (Flowers et al., 2016). In the short term, aphasia is associated with a number of negative outcomes including longer hospital stays, increased risk of mortality and greater levels of disability at one month post-stroke (Ellis, Simpson, Bonilha, Mauldin, & Simpson, 2012; Flowers et al., 2016). In the longer-term (the months and years following hospital discharge) stroke survivors with aphasia (SSWA) continue to experience poor outcomes including; reduced quality of life (Hilari, 2011), reduced social participation (Cruice, Worrall, & Hickson, 2006) and an increased risk of depression (Kauhanen et al., 2000).

The importance of supporting stroke survivors in the longer-term is increasingly being recognised as evidenced by recommendations for longer-term care in clinical guidelines (Intercollegiate Stroke Working Party, 2016; NICE, 2013) and service improvement plans (e.g., UK National Stroke Strategy) (Department of Health, 2007). A wide array of unmet care needs have been reported up to five years post-stroke, including problems related to; mobility, fatigue, falls, pain, incontinence, emotional problems, speech and language problems or problems with vision (McKevitt et al., 2011). The number and complexity of longer-term needs experienced by stroke survivors and their families makes the development of a suitable and evidence based pathway (which comprehensively identifies and addresses longer-term needs) particularly challenging (Forster et al., 2015; Forster et al., 2009; McKevitt et al., 2011; NICE, 2013).

One promising approach which may help to improve longer-term care for stroke survivors is ‘self-management’. Self-management aims to empower patients with the knowledge and skills that they need to adjust to and manage the consequences of living with a long-term condition (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Fryer, Luker, McDonnell, &

Hillier, 2016; Lorig & Holman, 2003). Self-management interventions are multicomponent approaches which typically include education, goal-setting, problem solving, action planning and decision making. Such components are theorised to build skills, confidence and self-efficacy for long-term condition management (Barlow et al., 2002; Fryer et al., 2016; Lorig & Holman, 2003). Self-management approaches also challenge the traditional clinician-patient relationship by promoting and valuing the patient's role and expertise in managing their condition (Mudge, Kayes, & McPherson, 2015).

Self-management interventions have been delivered by various means including group-based, telephone-based, and individually delivered approaches (Taylor et al., 2014). Facilitators of self-management approaches (who have typically received specialised training in self-management) also vary and include medical doctors, nurses, allied health professionals, psychologists and lay people (Taylor et al., 2014). Although there is no consensus upon who should provide self-management interventions and how (including which modes of delivery are most likely to be effective), there is robust evidence that self-management interventions can improve outcomes and reduce healthcare utilisation in clinical populations (e.g., people with diabetes, asthma, chronic obstructive pulmonary disease) (Deakin, McShane, Cade, & Williams, 2005; Gibson et al., 2002; Zwerink et al., 2014).

Approaches designed to support self-management after stroke are increasingly being developed and tested. A Cochrane review suggested benefits of stroke self-management interventions upon quality of life and self-efficacy (Fryer et al., 2016). This approach is recommended as part of longer-term care for stroke in a number of countries including the UK (Department of Health, 2007; Intercollegiate Stroke Working Party, 2016), USA (Winstein et al., 2016), Canada (Hebert et al., 2016) and Australia (Stroke Foundation, 2017).

However, a recent systematic review suggests that SSWA may be underrepresented in existing randomised controlled trials testing stroke self-management interventions (Wray, Clarke, & Forster, 2017). The effectiveness of this approach for SSWA is, therefore, unclear. Furthermore, given that typical components of self-management approaches (e.g., education, decision making, action planning, problem solving) are mediated through language; the accessibility of existing self-management approaches for SSWA should also be considered (Wray et al., 2017).

A recent scoping review by Nichol et al. (2019) suggested that the term ‘self-management’ is not used widely in the aphasia literature. Uncertainties remain about the role of this concept in relation to aphasia rehabilitation, including, when and how self-management approaches might be introduced in the care pathway (Nichol et al., 2019; Wray et al., 2017). There are parallels between the broader psychological, social and quality of life outcomes often targeted by self-management interventions (Fryer et al., 2016; Taylor et al., 2014; Wray et al., 2017) and existing approaches within aphasia rehabilitation. For example; the Life Participation Approach (Chapey et al., 2008; Simmons-Mackie, 2009), Aphasia centres (Elman, 2016) and the Life Coaching approach (Holland, 2007; Worrall et al., 2010). It is unclear where and how self-management may ‘fit’ with or ‘add to’ existing aphasia rehabilitation practices.

Nonetheless, there is increasing interest in this concept. Self-management is recommended as part of the Australian Rehabilitation Pathway (Australian Aphasia Rehabilitation Pathway, 2014) and there is ongoing work being undertaken by an Australian research group to explore speech and language therapists views of aphasia self-management (Nichol, Hill, Wallace, Pitt, & Rodriguez, 2018). Speech and language therapists (SLTs) play a key role in the provision of care for SSWA and it is therefore important to explore SLTs views of this approach to aid the development of suitable self-management approaches. In this study, we explore UK SLTs views of ‘self-management’ as an approach in stroke rehabilitation, including, its application in practice with SSWA.

AIM

To explore UK SLTs views of ‘self-management’ as an approach in stroke rehabilitation including;

- Understandings of the term ‘self-management’ in relation to stroke rehabilitation
- Whether and how self-management is used in existing practice with SSWA
- How self-management could be used in SLTs practice in the future

METHODS & PROCEDURES

The research design is a cross-sectional qualitative study based on in-depth, semi-structured interviews with SLTs based in the UK. This study formed part of a broader qualitative project which explored perspectives of self-management with stakeholders including; stroke survivors with communication difficulties (aphasia, dysarthria or apraxia of speech), their family members, and SLTs. This paper reports upon findings in relation to SLTs views of self-management, focusing in particular upon applications in practice with SSWA.

Ethical approval

Ethical approval was granted by the Leeds West Research Ethics Committee, Leeds, UK (Ref:16/YH/0002) in February 2016.

Participants

SLTs were recruited through five National Health Service (NHS) speech and language therapy services. Prior to recruitment, the first author attended a team meeting with each service to explain the study and answer any questions. The researcher was not known to participants prior to the study. During the meeting the researchers background (as a Psychology graduate and applied health researcher) and motivations for doing the study (as part of a doctoral project) were discussed. The invitation to take part in an interview was extended to all SLTs within the service and contact details were provided for interested SLTs to get in touch. Data on the number of participants who chose not to participate was not collected. SLTs were purposively sampled to reflect a range of experience and services (hospital [acute/rehabilitation wards], early supported discharged [ESD] and community services). ESD services allow for care received in the inpatient setting to be continued at home. It is expected that ESD services provide rehabilitation therapy at the same intensity as the inpatient service, and, with input from a multidisciplinary team with the same level of expertise as the inpatient service (NICE, 2013). Inclusion criteria required SLTs to be 1) employed as a SLT within a recruiting trust and, 2) Have a caseload including adults with post-stroke communication difficulties (aphasia, dysarthria, apraxia of speech).

Data collection

After providing written informed consent, in-depth, semi-structured interviews were undertaken with eligible SLTs. Informed by previous literature reviews (Wray & Clarke, 2017; Wray et al., 2017), a topic guide (see supplementary file) was devised for the interviews which focused upon four areas:

1) The needs of stroke survivors with communication difficulties (including SSWA), the challenges faced by this group and the additional support which may be needed.

2) The role of speech and language therapists in providing support to stroke survivors with communication difficulties (including SSWA) and barriers to fulfilling the role.
3) SLTs understanding of self-management (in relation to stroke rehabilitation) and whether this approach was used in their own practice (including with SSWA).
4) The future of care for stroke survivors with communication difficulties (including SSWA), improvements to care and where and how support should be provided.

The topic guide was not pilot tested, however, was refined on an ongoing basis. For example, further prompts were added in relation to self-management as it became apparent that some SLTs were unfamiliar with this term. To explore SLTs own views of self-management (and its application in practice), no additional information about self-management was given prior to or during the interviews. At the beginning of the interview, we reminded SLTs that we were interested in communication difficulties which included aphasia, dysarthria or apraxia of speech. Where there was ambiguity during the interviews, we sought to clarify if SLTs views were specific to a particular communication difficulty (e.g., aphasia) or if their views were applicable across communication difficulties. Recruitment continued until there was significant overlap in the codes generated and it was felt that there was sufficient data to meet the aims of the study (Saunders et al., 2018).

Interviews were undertaken in a quiet room at the service where SLTs were based and took place between June 2016 and January 2017. Each participant was interviewed on one occasion by the first author alone (no other members of the research team were present). Interviews were audio recorded and digitally transcribed. Transcripts were not returned to participants for comment or correction. Once transcribed, pseudonyms were used to protect the anonymity of interviewees. References to people, places and NHS services were also anonymised. Fieldnotes were made during and immediately after the interviews detailing interruptions or distractions and impressions of the key topics discussed. Fieldnotes were stored as memos in NVivo and provided contextual data to inform the coding and interpretation of the transcripts.

Data Analysis

Interview data were analysed using Thematic Analysis (Braun & Clarke, 2006). In line with this approach, the analysis was conducted in six phases (Table One).

[Table One: Phases of Thematic Analysis]

Codes and themes were developed inductively from the data. Codes were grouped in to five labels and fifteen sub-labels prior to theme development: 1) Meaning of self-management; 2) Examples in practice [Sub-labels: a) joint approach or decision making, b) family involvement, c) therapy tasks, d) other]; 3) Organisational barriers to enabling self-management [Sub-labels: a) session time b) hospital environment, c) waiting lists, d) lack of psychological support]; 4) Individual (stroke survivor) factors influencing self-management [Sub-labels: a) acceptance b) expectations of recovery c) family involvement d) stroke survivor characteristics]; 5) Support for self-management following discharge [Sub-labels: a) Lack of support b) Support groups c) Other sources of support].

The process of analysis was non-linear and a considerable amount of back and forth between transcript data and theme organisation was undertaken before the themes were finalised. There was active selection and extraction of data based on its relevance to the research question which included interpretation of the ‘keyness’ of themes in illuminating SLTs views of self-management. In this paper, we focus upon data where views were reported to be related to SSWA specifically or reported to be applicable across the different types of communication difficulties. 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 topic. 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. Coding was undertaken on an ongoing basis.

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. Coding and 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. Findings were also presented back to participants locally at team meetings. Feedback from participants was not included formally in the process of analysis, however, meetings provided general confirmation of the relevance of the findings to participants’ experiences.

Rigour

Steps to ensure rigour were incorporated throughout the process of analysis. These are described in Table Two with reference to Lincoln and Guba’s trustworthiness criteria (credibility, transferability, dependability and confirmability) which are commonly used to judge rigour in qualitative research (Guba, 1981; Lincoln & Guba, 1985; Schwandt, Lincoln, & Guba, 2007).

[Table Two: Description of steps to promote rigour]

RESULTS

A total of 18 SLTs took part in interviews. All participants who consented took part in an interview and no participants subsequently dropped out from the study. Interviews length ranged from 42 to 77 minutes; with a mean of 57.14 minutes (SD 10.21). Participant characteristics are reported in Table Three.

[Table Three: Overview of interview participants]

Description of sites

The recruited sites included hospital based and community based teams in the north of England. At Hospital 'A' and 'B' SLTs were based exclusively in the hospital setting and did not see SSWA in the community. Hospital sites had both acute and rehabilitation-based inpatient wards which were staffed by members of the SLT team. Hospital 'C' provided an inpatient, ESD and community based SLT service. Community Team 'D' were a stroke community rehabilitation team with SLTs working as part of a larger multidisciplinary stroke team. Community Team 'E' were a standalone adult community speech and language therapy team responsible for SSWA who were discharged from the local hospital. There was no ESD service for SSWA in this site at the time of interview.

Themes

A total of two themes (and four sub-themes) were developed inductively from the data.

1) Understandings of 'self-management'

SLTs were asked directly about their understanding of ‘self-management’ during the interviews and their views about how this may apply to their practice. Many had not come across the term before, or if they had, it was not understood in a context related to stroke or speech and language rehabilitation.

> *“Well I've probably heard it more in respect to other conditions, so I've kind of heard it more as, oh I don't know, like smoking cessation or like weight management or something like that…” (Holly, Band 6, Community Team ‘D’, community service)*

> *“Well I can guess what it is but I don't know.” (Alice, Band 6, Hospital ‘C’, inpatient/ESD/community services)*

Although this term was unfamiliar, most SLTs thought that enabling ‘self-management’ was an integral part of their practice or an integral aim of speech and language rehabilitation more generally. ‘Self-management’ was associated with efforts to reduce the impact of language and communication difficulties as far as possible by maximising language recovery and also by fostering confidence and longer-term independence.

> *I: “Do you think that's [self-management] something that applies to your practice as a speech and language therapist?”*
>
> *P: “Yes, because the majority of the time I tell people my job is to get myself unemployed, so once they don't need me anymore then they're doing well!” (Alice, Band 6, Hospital ‘C’, inpatient/ESD/community services)*

Some SLTs also associated ‘self-management’ with the ‘handing over’ of responsibility to the stroke survivor to manage their condition. Some described how this required a joint approach within the therapeutic relationship. For example, Ruby suggests the SLT should take the role of a facilitator, working with the stroke survivor using their clinical expertise to guide them.

> *“…the role is more… guiding and facilitating them to take that responsibility and then almost just kind of shaping it a little bit, “Try this, do this,” so using your clinical knowledge or your expertise but…we can’t fix that problem, we can only guide them*

> *and say, try this and there'll be a lot that we can do in one session…but it is not anything compared to all the hours that a week contains …so it's very much about them doing the work themselves or having somebody to do the work with…." (Ruby, Band 7/8, Community Team 'E', community service)*

The need to 'hand over' responsibility was most prominent in the experiences of community based SLTs. Some hospital based SLTs suggested that the hospital environment may limit opportunities to promote self-management:

> *"You're very much on the hospital's schedule so you'll go to the toilet when the hospital says you can, you'll have your meals when the hospital says you can and I can only imagine how much of a change that is once you go home." (Lily, Band 5, Hospital 'A', inpatient service)*

Jessica suggested that there may be different stages of self-management with stroke survivors able to take more responsibility over time as their knowledge about their condition (and how best to manage it) develops.

> *"I think sometimes in an acute hospital when something's just happened to you, it's in quite a different stage of self-management to somebody who's six months or six years down the line" (Jessica, Band 7/8, Hospital 'B', inpatient service)*

SLTs often exemplified their understanding of 'self-management' with illustrations from their own practice. SLTs gave a wide range of examples of how this term may be applied to their day-to-day work with SSWA. Some associated self-management with completing impairment (language) focused therapy tasks between sessions with minimal supervision.

> *"…things like iPads and computers have got programmes on them that give you feedback as you're doing the therapy task and give you a score at the end of it, so I guess that is self-managing your therapy then." (Katie, Band 6, Hospital 'B', inpatient service)*

Others spoke about encouraging the practice of communication (or compensatory strategies) outside of session time. Goal setting was also related to promoting self-management by facilitating a sense of ownership and control within therapy. Lastly, the involvement of family members was a common interpretation of the application of self-management in practice.

SLTs reported that families could be involved in three ways; firstly, by supporting the SSWA to complete therapy tasks between sessions; secondly, by facilitating the integration of communication strategies learnt in speech and language therapy to daily life and; thirdly, by taking on board strategies to support their family member's communication. SLTs highlighted family involvement as being particularly important in cases where severe aphasia or cognitive difficulties presented an additional barrier to engagement in therapy. In this case SLTs work became focused upon altering the environment to benefit the stroke survivors' quality of life. In this context 'self' management was extended to encompass supporting the family to support the SSWA.

> *"…and it might be at that point that we say, "These are the strategies, they're at a point where they're not making any progress, there's no carry-over in therapy because of the cognitive difficulties"…and that's when you kind of hand it over to the family, and to other people, to support it." (Amy, Band 5, Hospital 'A', inpatient service)*

2) Barriers to enabling self-management

Although many SLTs endorsed the idea of supporting and encouraging 'self-management', they also identified a number of barriers to achieving this in practice. Four sub-themes were generated within the theme 'barriers to enabling self-management'. Each sub-theme is discussed in turn below:

a) Lack of resources for speech and language therapy in the community setting

In the community setting, SLTs identified constraints on the number of sessions they were able to offer as a barrier to supporting SSWA and their families to manage in the longer-term.

> *"…ideally we would be seeing them five days a week and at most we are seeing our high priority ones, who would need and benefit from five times*

> *a week, possibly once or twice." (Lucy, Band 6, Community Team 'D', community service)*

SLTs described how limited time impacted delivery of therapy which was perceived to be important in relation to self-management. For example, building confidence in communication was perceived to be an important role in relation to self-management. One aspect of building confidence was practising in real life situations, for example, going to a coffee shop or on the bus with a stroke survivor in order to practise communication itself or the use of alternative strategies. However, this was not always possible as part of speech and language therapy. Lucy (Band 6, Community Team 'D', community service) described going to a coffee morning with a SSWA and acknowledges "But we don't get to do that as often as we probably should do…". Charlotte also echoes how the amount of resources impacts upon opportunities to support self-management within therapy.

> *"…I think it's very easy to slip into, "I've done it once with a rehab assistant, now I've got to do it on my own I'm not going to bother, it's too scary", or, "I'm worried I can't communicate to get myself back home", or, "what am I going to do if I get stuck", I had one lady who just wanted some help at the bank, she wanted to do it on her own but she wanted someone to stand just behind her just in case she got really stuck and I just think things like that, if you could do it over a couple of weeks would be amazing because I think that would build confidence and independence and things but I think as a team, a community team, they don't have the resources to support that." (Charlotte, Band 6, Hospital 'A', inpatient service)*

However, it is important to note that some services did have the time and flexibility to deliver this kind of approach:

> *"I'm very much I think more 'let's get out there and do something weird and wonderful and a bit more kind of 'well, if this is what you used to do, let's have a go at doing it'', you know! So, you know, I've done everything from being taught how to play Bridge to discussing stamp collecting, yeah, anything and everything, going to shops, yeah, going to the hairdressers with people, yeah, rather than 'here's a worksheet on how*

> *you name this many items'…." (Alice, Band 6, Hospital 'C', inpatient/ESD/community services)*

However, limited resources were a clear source of frustration for many SLTs who described feeling restricted in the level of support which they could offer SSWA.

> *"…and a lot of the work that you do do with those clients often is just kind of being there for them and supporting them but at the minute when you haven't got the staff, you can't, we can't really justify why there is a speech therapist involved…" (Ruby, Band 7/8, Community Team 'E', community service)*

Ruby's experience suggests that 'being there' or 'supporting' may be perceived to be a less legitimate therapeutic activity from an organisational perspective. Sally also described organisational requirements to 'justify' use of session time:

> *"…and if we wanted to provide more sessions for that we'd have to have a very good rationale for doing so, we'd have to be able to prove that they would be able to benefit from it, just because of obviously capacity and demand and all those things." (Sally, Band 5, Hospital 'C', inpatient/ESD/community services)*

b) Stroke survivors 'readiness' to engage in self-management

In addition to resource limitations, SLTs also identified individual (stroke survivor) characteristics which influenced engagement with aspects of therapy perceived to facilitate self-management. SLTs in hospital and community settings reported that stroke was a sudden, shocking and life-changing event and this necessitated psychological adjustment or the stroke survivor 'coming to terms' with the sudden loss of speech and language which had previously been taken for granted. However, difficulties arose when a lack of adjustment (often termed 'acceptance') affected the stroke survivor's ability to engage in therapy. Struggles to adjust were often associated with stroke survivors having unrealistic expectations of recovery and the role speech and language therapy could play in recovery. SLTs reported that a common perception was that SSWA expected to regain 'normal' speech and language following therapy or that therapy would 'fix' their communication difficulties. In this circumstance, SLTs suggested that some acceptance of living long-term with communication disability was needed in order for SSWA to utilise strategies which might aid their transition to longer-term adaptation, adjustment and self-management.

> *"…people obviously want to be back to normal, that's their goal and that's very rarely how things will pan out in stroke, and it takes a long time for them to accept that fact, and also to accept the changes to their role, to their lifestyle, to their communication, you know, to all these different things, and as soon as they've, kind of, reached that acceptance stage, that's when they're able to, to do a lot more, in a sense I suppose." (Sally, Band 5, Hospital 'C', inpatient/ESD/community services)*

Difficulties with psychological adjustment (or acceptance) were often perceived to be related to low mood and lack of motivation. These factors were again highlighted by SLTs as those which influenced stroke survivors' ability to engage with strategies which might enable longer-term condition management. Within hospital and community settings, SLTs reported managing difficulties with low mood and motivation as well as they could with the skills they possessed. However, some SLTs identified a training need to feel better equipped to have conversations with SSWA about psychological problems.

> *"…there's not been any formal training in terms of how you might approach certain things with people or how might, kind of what phrases you might say, 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." (Lucy, Band 6, Community Team 'D', community service)*

Many SLTs also reported a lack of access to specialist psychological care for SSWA (see 'availability of other services to support self-management' sub-theme)

c) Difficulties involving family members in rehabilitation

As described in the ‘understandings of self-management theme’, SLTs highlighted the important role family members could play in supporting self-management. Although the benefits of involving family members were recognised, barriers to involving family members were also reported. In particular, some SLTs described struggles to actively involve family members in the rehabilitation process;

> *“…it's the family who's going to be with the patient, it’s 24/7 that you need to help that patient communicate, to help improve. If I'm just going out for an hour or two or if the ESD are involved, say, a maximum of five hours a week, that's a drop in the ocean, there's no, you almost wonder what the point is to that if nobody else is doing anything…” (Jasmine, Band 7/8, Hospital ‘C’, inpatient/ESD/community services)*
>
> *“…it’s putting the responsibility in the environment as well, on the carers and the family members or the friends or, you know, actually they have to be active participants in this process of rehabilitation. Not easy at all though and sometimes we will have to discharge people where there’s low motivation, you know, or they don’t have that support really because there’s little that we can do and at the minute we haven’t got the capacity to provide more than one session a week.” (Ruby, Band 7/8, Community Team ‘E’, community service)*

Practical barriers to involvement were identified including whether or not the family member was available to be involved in the therapy session. Some SLTs also suggested that some family members may have certain expectations about the role of a SLT which subsequently influenced their level of involvement;

> *“…I think at first it's very much like 'well the speech therapist is here, they're going to fix it', and then with time people start to realise that it's more about the kind of what can they do to support as well.” (Holly, Band 6, Community Team ‘D’, community service)*

Family members' expectations about their involvement were also reported to be related to 'readiness' to accept the potentially longer-term implications of living with aphasia.

> *"…it's that kind of reality…essentially the two of you will be at home, just the two of you, and this is how your conversations, how you'll need to support each other, and not just being able to rely on words anymore…yeah, it can be quite a difficult realisation for people…" (Elizabeth, Band 6, Hospital 'B', inpatient service)*

One SLT, Kerry, questioned whether assumptions that families will be able to cope or were able to take on the extra responsibility were made too readily.

> *"… I think we have quite high expectations of partners, carers in terms of them taking on this new responsibility, we don't know the state of somebody's relationship that existed before the stroke…I think we do make assumptions that other people are going to step up." (Kerry, Band 6, Community Team 'E', community service)*

d) Lack of availability of other services to support self-management

SLTs identified the limitations of community services in terms of the amount of therapy which could be offered with the resources available. In this respect, the therapy offered by SLTs was perceived to be one aspect of the support needed to enable and sustain self-management. However, difficulties were also identified in accessing further support to SSWA and their family members following discharge from community services.

> *"I feel like they sometimes just leave here and they get a bit of speech therapy when they're home maybe but then there's nothing, once that finishes I think it feels like a bit of a black hole, like oh you know, my speech therapy's come to an end, what's next, and often it's nothing." (Charlotte, Band 6, Hospital 'A', inpatient service)*

Further support was often described by SLTs to be needed to address the longer-term, psychosocial implications of living with a communication difficulty. This generally focused upon being supported to apply the skills which had been learned in therapy to everyday and personally meaningful situations.

> *"…you know, going with somebody back to work on their, for the first month of their job to support in working with bosses, whatever it would be…really typical things that we do day-to-day that therapists don't have the time, in a sense, to do under their services or the facility to do but actually is where the interest is." (Jessica, Band 7/8, Hospital 'B', inpatient service)*

At the time of the interviews, SLTs reported that the majority of support available to SSWA post-discharge was in the form of peer support groups run by charitable organisations. Support groups were either specific aphasia groups or general groups for all stroke survivors. The perceived benefits of support groups were that they gave stroke survivors an opportunity to practise their communication and meet others in a similar position. However, SLTs identified a number of barriers to attending support groups including transport (either arranging transport or the financial cost of transport), mobility problems and the need for toileting assistance which could not be provided at the group. Other barriers to attending groups included personality factors (not being a 'group person'), a lack of confidence, and younger stroke survivors feeling as though they did not fit in at groups with stroke survivors who were older than them.

> *"…if it's somebody that's younger they think, 'Oh it's going to be full of older people. I don't want to be part of that.'…." (Sally, Band 5, Hospital 'C', inpatient/ESD/community services)*

Due to charities changing provision, SLTs were often uncertain about what they were offering or perceived that the support they could offer had reduced. For example, Holly described how previously a charity provided one to one support for SSWA to help with mail or bills, or to build up confidence by going out to a cafe or shop. However, this service was no longer available.

> *"…the [Name of charity] they used to do a lot more one-to-one stuff, so there used to be some kind of one-to-one support from them and that's not there at the moment, so*

> *if that came back then that would be helpful…" (Holly, Band 6, Community Team 'D', community service)*

SLTs perceived that longer-term support was often necessary but expressed a number of barriers to SSWA accessing services to meet their needs. Some SLTs suggested that those who lived alone or lacked social support were in particular need of ongoing support:

> *"…it can be quite isolating really… if they're lucky they might be living with a partner or husband or wife and they've got quite a bit of family support, but particularly if you've got someone who lives alone and they've got communication problems it might be that their social opportunities are quite limited anyway and then if they've got reduced confidence around their communication difficulties then that might be even less so…." (Holly, Band 6, Community Team 'D', community service)*

Difficulties were also identified by SLTs in accessing specialist psychological support across the care pathway. As discussed previously, difficulties with low mood or adjustment were highlighted by SLTs as a factor which influenced stroke survivors' ability to engage with strategies which might enable longer-term condition management. The lack of availability of timely, accessible and appropriate psychological services for SSWA was a clear source of frustration for many SLTs.

> *"…if someone has low mood and they can't engage or they're not motivated, then that's a big problem and unfortunately we don't have anywhere to send those people…" (Ruby, Band 7/8, Community Team 'E', community service)*

At each of the participating sites, SLTs described a lack of specialist input from psychologists for SSWA. None of sites had dedicated input from a clinical or neuropsychologist and many described lengthy waiting lists to access such services. Barriers were also reported to accessing Increasing Access to Psychological Therapy (IAPT) services in the community setting; with IAPT criteria precluding referral of SSWA with moderate to severe aphasia.

DISCUSSION

Summary and interpretation of findings

The term ‘self-management’ was unfamiliar to many SLTs who participated in this study. However, SLTs were positive about the connotations of this term which aligned closely with the values they held about their role and the desired outcomes of rehabilitation. SLTs described a number of elements of their existing practice which they associated with enabling ‘self-management’ (e.g., self-directed practice of therapy tasks, encouraging SSWA to take responsibility for their own rehabilitation, involving family members in therapy). On the other hand, SLTs also identified a number of barriers to enabling and sustaining self-management. In particular, SLTs acknowledged difficulties involving SSWA as active participants in the rehabilitation process and in facilitating ‘readiness’ to take responsibility for managing in the longer-term. Other barriers to supporting SSWA and their family members to manage their condition were also identified including limited resources for speech and language therapy in the community setting, difficulties involving family members in rehabilitation and a lack of other services to support self-management (including specialist psychological support).

SLTs unfamiliarity with the term ‘self-management’ and lack of consensus about its application to existing practice is in line with the lack of clear direction about precisely when and how self-management should be supported in the stroke pathway (Fryer et al., 2016; Wray et al., 2017). It is also perhaps unsurprising given that this term is used infrequently and inconsistently in the aphasia literature (Nichol et al., 2019). Echoing the findings of this study, a scoping review by Nichol et al. (2019) found that this term had been associated with a number of interventions in aphasia rehabilitation. These included technology based treatment (e.g., self-managed computer therapy), group and community based treatment (e.g., group aphasia therapy) and communication partner training. Existing aphasia rehabilitation practices may be underpinned by values (e.g., promoting independence) or include some components (e.g., goal setting) which relate to self-management. However, it is important to recognise that they were not designed specifically to address this concept and a specific self-management framework may be necessary to ensure the comprehensive and consistent delivery of a self-management approach in practice (Nichol et al., 2019). Under recognised areas may include the provision of education about self-management for SSWA and their family members or targeted intervention to aid the development of self-efficacy or self-management skills such as problem solving, action planning or decision making (Nichol et al., 2019).

Furthermore, it is important for any aphasia specific framework to consider the barriers SLTs raised to enabling self-management. For example, some SLTs identified difficulties 'handing over' responsibility to SSWA and their family members and their 'readiness' to take on this role. An integral part of self-management is the collaborative and empowered relationship between the patient and the facilitator of the approach (de Silva, 2011; Lorig & Holman, 2003). Whilst collaboration is routinely strived for in the rehabilitation setting (e.g., via collaborative goal setting), taking a self-management approach also has a strong focus upon patient empowerment. This requires a progressive shift in the level of 'control' within a therapeutic relationship so that SSWA and their families not only have a balanced input (sharing the 'control'), but ultimately go on to take the lead in managing the condition (Mudge et al., 2015).

How best to facilitate this novel role reversal (whereby SSWA and their families are empowered to become the 'experts' in managing the condition) is an important question to be addressed in relation to self-management of post-stroke aphasia. Other studies in stroke suggest that successful implementation of self-management approaches requires ongoing support for healthcare professionals to overcome the challenges associated with supporting the patient to take the lead within the therapeutic relationship (Jones, Livingstone, & Hawkes, 2013; Norris & Kilbride, 2014). Role expectations in relation to self-management may also need to be considered and clearly communicated across the care pathway (for example, SLTs suggested that some family members may not expect to play an 'active' role in the rehabilitation process). In this study there also appeared to be an expectation that SSWA and their families take a more 'active' role in managing their condition in the community setting compared to the hospital setting. Whether and how opportunities to support self-management could be promoted within the hospital environment should be considered. Endorsing and supporting self-management across the care pathway will be necessary for successful implementation of this approach.

The findings also highlight potential organisational barriers to supporting self-management; in particular, the limited resources available for speech and language therapy in the community setting. Although the value of enabling 'self-management' was recognised, SLTs also described the challenges of delivering some elements of therapy to support this consistently (e.g., practising communication in real life situations). Within resource constrained organisations, therapeutic activities such as these may be more difficult to 'justify' to service managers. The benefits of such work may be less easy to measure or less sensitive to change within the restricted number of sessions available. For successful implementation, self-management must have organisational 'buy-in' and be perceived as an equally valuable and 'justifiable' use of session time as part of speech and language rehabilitation (Kennedy et al., 2014; Norris & Kilbride, 2014).

Implications for research and practice

There is a robust evidence base to support to the use of self-management to improve outcomes for patients with long-term conditions (Deakin et al., 2005; Gibson et al., 2002; Zwerink et al., 2014). SLTs could play a key role in supporting self-management as part of aphasia rehabilitation. This term aligns with the core values held by many SLTs about their role in fostering longer-term independence for SSWA and their families. However, it is important to recognise the challenges of implementing such an approach. At the sites in this study, there was no structured or clearly defined approach to assist SLTs to support self-management. Some SLTs identified difficulties involving SSWA and their family members as active participants in the rehabilitation process. A supported self-management approach may help to facilitate this process and assist SSWA and their families in feeling confident to take the lead in managing moving forwards. The process of actively moving forwards has been identified as being a key concept in living successfully with aphasia by SSWA and their family members (Brown, Worrall, Davidson, & Howe, 2011; Grohn, Worrall, Simmons-Mackie, & Brown, 2012; Grohn, Worrall, Simmons-Mackie, & Hudson, 2014). Self-management may provide a structured and clearly defined approach to support active participation as part of aphasia rehabilitation.

However, further research is needed to fully define and evaluate the benefits of supported self-management for SSWA and their families (Wray et al., 2017). Stakeholder input from SSWA, their family members and SLTs will be crucial to translate general components of self-management (e.g., education, problem solving, decision making and action planning) (Fryer et al., 2016; Wray et al., 2017) in to an approach which is accessible and appropriate, and can be integrated with existing practice. An individually tailored approach is likely to be appropriate, with more or less input from family members, depending upon the severity of aphasia and presence of cognitive impairments. Appropriate training for SLTs may also be necessary to assist the implementation of the approach.

The availability of other (non-SLT) services to support self-management is also an important consideration. SLTs who participated in this study expressed considerable frustration at the lack of specialist psychological services to provide support for SSWA. Joint working with psychological services to support SLTs working with SSWA experiencing significant difficulties with low mood or adjustment may be useful, but is not routine within many rehabilitation services in the UK (Northcott, Simpson, Moss, Ahmed, & Hilari, 2017, 2018). The limited session time available within many rehabilitation services may also necessitate exploration of the role third sector organisations could take in providing continuing self-management support. For successful implementation, a ‘whole systems’ approach to self-management is needed which engages patients, clinicians and services across the care pathway (Kennedy, Rogers, & Bower, 2007).

Limitations

SLTs who participated in this study were from one geographical region in the UK. Their practices, views and experiences may not be representative of other services across the country or speech and language therapy provision in other countries. Similarly, those SLTs who chose to participate in this study may have had different practices, views or experiences to those who did not. It is also important to acknowledge that SLTs were asked about communication difficulties more broadly as part of the interviews. Where there was ambiguity, we sought to clarify whether views were specific to a particular type of communication difficulty (e.g. aphasia) or applicable across the different types of communication difficulties. However, different responses may have been generated if the topic guide had focused solely on aphasia. A further limitation is that we did not collect information about SLT’s years of experience working with SSWA. The NHS banding reported for each SLT is indicative of level of overall experience, however, we recognise that this may not correlate directly with years of experience working with SSWA.

Conclusion

Making the transition to longer-term adaptation, adjustment and condition management is a complex and challenging task which is likely to require tailored support for SSWA and their families. Taking a self-management approach may help to facilitate this process and SLTs could play a key role in delivering such an intervention. The term ‘self-management’ was perceived to align well with SLTs existing values about their role and the desired outcomes of rehabilitation. However, a structured and clearly defined approach is needed to assist SLTs to support self-management in practice. A key focus of such an approach should be upon education and self-management skills (e.g., problem solving, action planning, decision making) (Fryer et al., 2016; Wray et al., 2017) to facilitate ‘active’ participation in the rehabilitation process and the empowerment of SSWA and their families to take the lead in managing moving forwards. Furthermore, self-management should be supported by all organisations involved in the care of SSWA and their families. A whole-systems approach is required which works to engage SSWA and their families, SLTs, and which is actively supported by organisations across the care pathway.

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DECLARATION OF INTEREST STATEMENT

None.

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Table One: Phases of thematic analysis (adapted from Braun and Clarke, 2006, p.87)

Phase One: Familiarizing yourself with the data	Transcripts were read and re-read and initial impressions of the data stored as memos within NVivo.
Phase Two: Generating initial codes	Initial coding of the transcripts was conducted line by line. Segments of data interpreted as being relevant to understanding views of ‘self-management’ were coded inductively using terms which were close to the original data. Data segments were then organised in to groups and labelled based upon the data contained. The process of line by line coding and organising data in to labels was completed within each individual interview transcript.
Phase Three: Searching for themes	Potential themes were identified by reviewing labels across transcripts. Labels were grouped together by content and draft names for the themes were generated based upon the labels within each group.
Phase Four: Reviewing themes	The original data extracts within each theme were reviewed to check for relevance to the theme and the appropriateness of the theme as a category for the data contained. Mind maps were used to organise the themes and data represented within them.
Phase Five: Defining and naming themes	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 carefully considered to ensure that they best represented the concepts being described.
Phase Six: Producing the report	Writing up constituted the final stage of analysis as links between the themes were considered. Themes were re-organised iteratively to present a clearer picture.

Table Two: Description of steps to promote rigour

Criteria	Definition	Description of steps taken in this study
Credibility	The extent to which an interpretation of data is representative of the experiences of participants	-Purposive sampling was used to ensure that a range of experiences were available to create rich data for interpretation. -Peer debriefing (discussion of data and themes with co-authors and peers at the academic unit) and presentation of findings to participants was used to check that interpretations were representative of experiences.
Transferability	The extent to which findings might be applied or generalised to other participants in similar contexts	-Relevant contextual information about sites and participants is included in the findings to facilitate judgements about transferability.
Dependability	The extent to which a researcher's interpretation of data would be consistent if repeated	-NVivo software used to facilitate 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	-Line-by-line coding of the data was undertaken so that the researcher stayed 'close' to participant's experiences. -Active exploration of negative (or atypical) cases was undertaken during the analysis to refine interpretations. -A reflexive log was kept by the researcher to consider their influence on data collection and analysis (a reflexive statement is contained within the supplementary file).

Table Three: Overview of interview participants

Pseudonym	**NHS banding (Experience level)***	**Site**
Amy	5	Hospital ‘A’
Charlotte	6	Hospital ‘A’
Danielle	5	Hospital ‘A’
Helen	7/8	Hospital ‘A’
Lily	5	Hospital ‘A’
Elizabeth	6	Hospital ‘B’
Jessica	7/8	Hospital ‘B’
Katie	6	Hospital ‘B’
Sophie	6	Hospital ‘B’
Alice	6	Hospital ‘C’
Jasmine	6	Hospital ‘C’
Sally	5	Hospital ‘C’
Holly	6	Community Team ‘D’
Lucy	6	Community Team ‘D’
Emily	5	Community Team ‘E’
Kerry	6	Community Team ‘E’
Kimberley	7/8	Community Team ‘E’
Ruby	7/8	Community Team ‘E’

(* Note: NHS bandings usually denote the following level of experience: Band 5 qualified junior therapist, Band 6 experienced therapist, Band 7/8 senior therapist/manager)