

Designing a self-management
intervention for stroke survivors with
communication difficulties

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The candidate confirms that the work submitted is her own, except where work which has formed part of jointly authored publications has been included. The contribution of the candidate and the other authors to this work has been explicitly indicated below. The candidate confirms that appropriate credit has been given within the thesis where reference has been made to the work of others.

The work in Chapter One of this thesis has appeared in publication as follows:

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I was responsible for the design, conduct, analysis and write-up of the systematic review. Co-authors David Clarke and Anne Forster provided guidance on the design and conduct of the review and provided feedback upon the manuscript prior to submission.

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I was responsible for the design, conduct, analysis and write-up of the systematic review. Co-author David Clarke provided guidance on the design and conduct of the review and provided feedback upon the manuscript prior to submission.

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Abstract

Background: Stroke survivors with communication difficulties have poor outcome in the longer-term and may benefit from the support typically offered by self-management approaches.

Aim: To critically examine the suitability of self-management as an approach for stroke survivors with communication difficulties and to use this knowledge to design an intervention to support stroke survivors with communication difficulties in the longer-term.

Methods: Medical Research Council guidance for the development of complex interventions provided a framework for designing the intervention (MRC, 2008). In line with this guidance the intervention was designed iteratively using a staged approach. The design of the intervention was informed by a mixed methods systematic literature review and qualitative fieldwork undertaken with key stakeholders (stroke survivors with communication difficulties, carers and speech and language therapists). The Behaviour Change Wheel (BCW) provided a theoretical framework to identify which behaviours the intervention should target and appropriate behaviour change techniques. A Delphi survey was conducted to gain an expert consensus on the design of the intervention.

Results: Stroke survivors with communication difficulties need further support to manage the consequences of their condition in the longer-term. Self-management may provide a structured and clearly defined intervention to support this group of stroke survivors with the challenges they face. However, existing self-management interventions do not address the needs of stroke survivors with communication difficulties and a condition specific self-management intervention is required. A novel self-management intervention for stroke survivors with communication difficulties was designed using the BCW as a theoretical framework. Feedback from an expert panel was used to refine the design of the intervention.

Discussion: To the authors knowledge this is the first theoretically informed self-management intervention designed specifically for stroke survivors with communication difficulties. Further research is needed to develop the intervention. Future plans for feasibility testing and large-scale evaluation of the approach are discussed.

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Background

This thesis makes recommendations for the design of a self-management intervention to support stroke survivors with communication difficulties in the longer-term. This chapter presents a context to the thesis; outlining the rationale for the study and providing an overview of the chapters to follow.

Self-management: History and policy context

As the population ages, there is increasing concern about the rising prevalence of long-term conditions such as diabetes, heart disease, arthritis and stroke (Murray et al., 2012; Salomon et al., 2012). It is predicted that by 2030 long-term conditions will be the leading cause of death and disability in the world (Mathers and Loncar, 2006) and this poses a significant challenge to healthcare services to cope with the increasing demand and escalating costs associated with managing these conditions (Epping-Jordan et al., 2001).

Approximately 15 million people in England are living with a long-term condition and this figure is expected to rise by one third over the next 10 years (Department of Health., 2015). Providing care comes at a substantial cost to the NHS as those with long-term conditions are the most frequent users of health care accounting for 50% of GP appointments and 70% of inpatient bed days (Department of Health., 2012). In response to this challenge, some have advocated a shift away from traditional paternalistic models in which patients are treated as passive recipients of care (Wade and Halligan, 2004). Instead it is argued that patients should be treated as active partners in the care process and should be encouraged and supported to manage their own health wherever possible (Holman and Lorig, 2000). It is proposed that this will not only benefit patients' quality of life but will also save cost to the NHS by reducing healthcare utilisation (Foot et al., 2014).

Empowering patients to take an active role in the management of their condition is often known as self-management (Lorig and Holman, 2003). Self-management is

increasingly advocated as a core component of care for long-term conditions (Taylor et al., 2014) and is defined by Barlow et al. (2002) as:

“The individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition.” (p.178).

Successful self-management of a long-term condition may require the patient to take responsibility for their health on a day to day basis, for example, adhering to medication, changing their lifestyle or monitoring symptoms (Newman et al., 2004). However, low adherence to medication regimes and the reduced quality of life seen in patients with long-term conditions indicates that many may struggle to manage their condition effectively without education and support (Sprangers et al., 2000; Kripalani et al., 2007).

A number of self-management interventions have been devised in order to empower patients to become actively involved in the management of their condition (Taylor et al., 2014). Early work in this area was conducted by Kate Lorig and team at Stanford University (Lorig et al., 1999a; Lorig et al., 2001; Lorig and Holman, 2003). Based on the work of Corbin and Strauss (1988), Lorig and Holman (2003) propose three self-management tasks are needed to manage a long-term condition; medical management, role management and emotional management. Medical management requires the patient to adhere to medical advice, for example, by taking medication, losing weight or changing diet. Role management involves the creation or maintenance of alternative roles; for example, a patient may be unable to clean the whole house but may be able to wipe down kitchen surfaces. Finally, emotional management involves the patient coming to terms with the emotional consequences of having a long-term condition that impacts upon daily life.

In order to successfully manage these tasks, Lorig and Holman (2003) propose that patients must be skilled in the following areas; problem solving, decision making, finding and utilising healthcare resources, action planning, self-tailoring and forming an effective relationship with their healthcare provider. The Chronic Disease Self-Management Programme (CDSMP) devised by Lorig and team educates patients in the skills and competencies needed to facilitate the tasks outlined above and enable effective self-management. The CDSMP is a seven week, group based intervention, designed for patients with a range of long-term conditions including heart disease, lung disease, arthritis and stroke. Trained lay leaders with experience of long-term

conditions delivered the intervention; focusing upon a different self-management topic each week with a corresponding workbook. In a randomised controlled trial (RCT), the intervention significantly improved participants' health outcomes and reduced healthcare utilisation at one year follow-up (Lorig et al., 2001).

Lorig and Holman (2003) acknowledge that the development of the CDSMP was largely atheoretical and based mostly upon their clinical experience and intuition. Through qualitative work exploring the mechanisms of change associated with the CDSMP, the authors noted that participants felt more 'in control' of their health since participating in self-management programmes and the CDSMP was later linked to self-efficacy theory (Bandura, 1977). Self-efficacy is the extent to which a person believes they have the ability to perform a certain task or behaviour (Bandura, 1997). Lorig et al. (1999b) found that increased self-efficacy was related to improved health outcomes and suggest that enhancing self-efficacy is a key aspect of their self-management programme (Lorig and Holman, 2003). The CDSMP utilises a number of behaviour change techniques to increase self-efficacy that include performance mastery, modelling, interpretation of symptoms and social persuasion (Bandura, 1977).

The success of the CDSMP led to a surge of research in this field (Deakin et al., 2005; Foster et al., 2007; Gibson et al., 2002; Zwerink et al., 2014). However, the evidence base to support self-management is mixed. A Cochrane review conducted by Foster et al. (2007) found only small, short term benefits to group self-management education programmes delivered by lay leaders like the CDSMP. No benefits were found in terms of increased psychological wellbeing or quality of life or reduced healthcare utilisation. On the other hand, such principles have been adapted and applied to develop disease specific self-management interventions that have proven effective. For example, in diabetes care, a Cochrane review found that self-management interventions were effective in helping patients to control glycated haemoglobin up to two years after the intervention (Deakin et al., 2005). Patients who had received such interventions also had reduced body weight and were less likely to need diabetes medication. Another Cochrane review in chronic obstructive pulmonary disease (COPD) found that self-management increased health related quality of life and reduced respiratory related hospital admissions (Zwerink et al., 2014). Similarly positive results associated with self-management (improvements to quality of life and reductions in healthcare utilisation) have also been shown in a Cochrane review of asthma care (Gibson et al., 2002).

A recent rapid review and synthesis of the evidence for self-management interventions in long-term conditions found benefits to disease specific approaches and advocated individually tailored self-management interventions (Taylor et al., 2014). However, like many self-management reviews, the authors found significant variation in the interventions identified. It is important to note, that there is no gold standard definition of self-management (Barlow et al., 2002). Most definitions conform to the notion of the patient being empowered to manage the medical, social or emotional consequences of their condition (Department of Health, 2001; Barlow et al., 2002; Lorig and Holman, 2003; Taylor et al., 2014), however, there is notable variation. For example, in their definition Deakin et al. (2005) refer to “group-based educational programmes” (p.6) whereas Gibson et al. (2002) suggest that self-management must include “self-monitoring”, “regular review” and an “individualised written plan” (p.3). Some definitions include exclusively lay-led interventions (Foster et al., 2007) and others propose that self-management requires “an iterative process of interaction between participant and healthcare provider” (Zwerink et al., 2014 p.8). This variation highlights the ongoing evolution of self-management approaches and the continuous emergence of new evidence in this field (Taylor et al., 2014). Recent literature suggests a shift away from providing mass educational-based interventions like the CDSMP towards individually tailored and disease specific approaches (Taylor et al., 2014). As core components of self-management interventions may vary from condition to condition, it may be impossible to create a ‘one size fits all’ definition of self-management.

Another challenge in this area of research is the implementation of self-management approaches in practice. As highlighted previously, a diverse range of self-management interventions have been developed, however, little research has explored how these might be translated into practice (Taylor et al., 2014). Lessons about the implementation of self-management approaches may be learnt from the UK implementation of an approach equivalent to the CDSMP known as the Expert Patient Programme (EPP) (Rogers et al., 2006; Kennedy et al., 2005). The EPP had mixed success; uptake was poor in some regions and the courses failed in many cases to recruit socially disadvantaged groups, in particular those from ethnic minorities. Through qualitative interviewing Rogers et al. (2006) reported that clinicians felt that referral to self-management courses was not a priority for their practice. In line with these findings, Taylor et al.’s (2014) review highlighted the need for self-management approaches to be fully integrated into current practice as opposed to being seen as an add-on to routine care. Barriers to implementation may include a lack of clarity about

which patients should be targeted, who should deliver this type of care and how (Foot et al., 2014).

In spite of the challenges outlined above, self-management is a major focus of health policy and is fervently promoted by organisations such as the Kings Fund (Naylor et al., 2015) and the Health Foundation (de Longh et al., 2015). Self-management is also at the core of a number of health policy initiatives for example, the House of Care model (NHS England, 2017), the Self-Care Forum (Self-Care Forum, 2017) and ‘Guan Yersel’ (Long Term Conditions Alliance and the Scottish Government, 2008). Furthermore, NHS commissioning boards have been mandated by the Department of Health to ensure that patients with long-term conditions are supported and encouraged to manage their own health and are educated in necessary skills and competencies to do so (Department of Health, 2013). Incorporating this approach is a key item on the agenda for NHS reform; however, in practice, evidence regarding the optimum way to deliver this type of care is still emerging and may vary from condition to condition.

Self-management after stroke

Stroke is defined by the World Health Organisation as:

“Rapidly developing clinical signs of focal (at times global) disturbance of cerebral function, lasting more than 24h or leading to death with no apparent cause other than that of vascular origin” (Hatano, 1976) (p.541).

In the past, stroke has been viewed as an acute event as opposed to a long-term condition (O'Neill et al., 2008) and much research has concentrated upon developing evidence based care pathways for acute onset (Department of Health, 2007; National Collaborating Centre for Chronic Conditions, 2008). Although this has successfully improved care, interest is increasingly turning to the provision of care for stroke survivors following hospital discharge.

Data from the National Audit Office suggests that 300 000 people are living in England with moderate to severe disability following stroke (Department of Health, 2007). The disabilities stroke survivors face are complex and many report unmet care requirements. McKeivitt et al. (2011) found that approximately half of all stroke survivors

report unmet need one to five years following stroke including difficulties with mobility, fatigue, falls, pain, incontinence, emotional problems, speech and language problems and problems with vision. Qualitative research also highlights the difficulties stroke survivors face in adjusting to life following stroke (McKevitt et al., 2004; Salter et al., 2008; Satink et al., 2013; Walsh et al., 2015). For example, patients describe the transition to community care as discontinuous and abrupt, even when early supported discharge (ESD) is provided (Cobley et al., 2013). Many stroke survivors report feeling unsupported and abandoned in the longer-term (Ellis-Hill et al., 2009; O'Connell et al., 2001).

The term 'longer-term' is often poorly defined in the literature and in policy documents (Department of Health, 2007; NICE, 2013). In this thesis 'longer-term' is defined as the time following hospital discharge (Murray et al., 2003). The importance of supporting stroke survivors in the longer-term has been recognised by policymakers, however, the precise format and content of such support has yet to be established (Department of Health, 2007; NICE, 2013). Despite the high prevalence and diversity of the difficulties reported, services to address longer-term problems are generally patchy, uncoordinated or completely lacking (Stroke Association, 2015). Establishing an evidence-based pathway for longer-term care remains an ongoing challenge. For example, current recommendations for a structured six month re-assessment (Department of Health, 2007; Intercollegiate Stroke Working Party, 2016) were shown to have no clinically significant benefit in a RCT comparing this approach to usual care (Forster et al., 2009). A system of longer-term care based upon a structured needs assessment conducted by stroke coordinators also found no evidence of clinical or cost effectiveness (Forster et al., 2015).

Teaching stroke survivors self-management skills has been suggested as one possible solution to improve longer-term outcomes (Jones, 2006). Support for this approach has been bolstered by the growing body of research in other long-term conditions to suggest that self-management interventions can be beneficial (Deakin et al., 2005; Foster et al., 2007; Gibson et al., 2002; Zwerink et al., 2014; Taylor et al., 2014). Incorporating this approach has recently been recommended in the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2016) and as part of the National Stroke Strategy (Department of Health, 2007); however, evidence regarding the efficacy of self-management interventions in stroke is still emerging (Lennon et al., 2013). Stroke falls behind many other long-term conditions with regards to the

development and testing of self-management interventions which are comparatively uncommon (Jones et al., 2013).

In view of the heterogeneity of difficulties faced by stroke survivors, questions also remain about the feasibility of delivering a ‘one size fits all’ approach to self-management for this population (Jones et al., 2013). In developing interventions for stroke, it is important to consider the failure of some self-management programmes to recruit representative samples (Foster et al., 2007; Rogers et al., 2006), and, the shift towards providing individually tailored self-management approaches (Taylor et al., 2014). There is concern that current self-management programmes may not be accessible to or meet the needs of certain sub-groups of stroke survivors (Jones et al., 2013). This concern is also reflected in the National Stroke Strategy which advises that:

“Careful planning of the support systems required to enable people with stroke to participate in managing their own care is needed, especially to enable the inclusion of people with communication and cognitive difficulties.” (p.39) (Department of Health, 2007).

This thesis focuses upon the use of self-management for stroke survivors who experience communication difficulties (Stroke Association, 2012a). Approximately one third of stroke survivors will experience communication difficulties including aphasia (prevalence 21-38%), dysarthria (20-30%) and apraxia of speech (30%) (Arboix et al., 1990; Donkervoort et al., 2000; Engelter et al., 2006; Melo et al., 1992). A description of the aetiology and clinical presentation associated with each condition is provided below:

Aphasia

Aphasia is commonly acquired as a result of stroke and is a neurological impairment which impedes language function. (Royal College of Speech and Language Therapists, 2005). The term aphasia is often used interchangeably with the term dysphasia, although the term aphasia is most commonly used in recent literature (Worrall et al., 2016a). Language is defined as a complex and multimodal communication system made up of words and symbols (included in speaking, reading, writing, signing) which are governed by rules and used to convey and understand meaning (Papathanasiou, Coppens and Davidson, 2017; Harley, 2014), Aphasia may affect both the

comprehension and expression of language across one or all modalities for example, speaking, reading, writing, signing. Different components of language may be affected as a result of aphasia; these include, phonology (word sounds), morphology (word structures and relationships), syntax (the arrangement of words to form sentences), semantics (the meaning of language) or pragmatics (the way in which context contributes to meaning). Aphasia is associated with damage to the language centres of the brain which are typically located in the left hemisphere (Potagas, Kasselimis and Evdokimidis, 2017). Several areas of the brain have been implicated in supporting linguistic processes including Broca's area, Wernicke's area, the arcuate fasciculus, angular gyrus and the supramarginal gyrus. Although some areas of the brain are associated more strongly with language processing than others, lesion and imaging studies show that neural systems involved in language are variable and diffuse (Ardila, Bernal and Roselli, 2016; Hickok, 2009). Nevertheless different classifications of aphasia have been suggested based upon symptom presentation and typical lesion location (Potagas, Kasselimis and Evdokimidis, 2017). These include;

Broca's aphasia

Broca's aphasia is typically characterised by non-fluent, effortful and agrammatical speech. People with Broca's aphasia typically communicate using mainly nouns and verbs and small function words such as prepositions are generally absent. Repetition of words, naming, reading aloud and writing are also affected. Comprehension is relatively preserved although there may be some difficulty in understanding syntactically complex sentences. Broca's aphasia is associated with damage to Broca's area which is located in the posterior inferior frontal gyrus, the insula and the frontal operculum (Potagas, Kasselimis and Evdokimidis, 2017).

Transcortical motor aphasia

Patients experiencing transcortical motor aphasia have similar symptoms to people with Broca's aphasia; comprehension is relatively preserved, speech is non-fluent and reading aloud and writing is impaired. However, in contrast to Broca's aphasia, repetition skills are strongly preserved and naming is also relatively spared (Potagas, Kasselimis and Evdokimidis, 2017). Transcortical motor aphasia is typically associated with multiple infarcts or diffuse lesions in a number of different areas including the frontal operculum, deep white matter in the frontal lobe or the left supplementary presupplementary motor area (Crosson, Bohsali and Raymer, 2018).

Global aphasia

Global aphasia is characterised by severe impairments in all aspects of language; including production, comprehension, naming, repetition, reading and writing. Utterances are non-fluent; however, automated verbal sequences such as counting or reciting the days of the week may be preserved. Global aphasia is typically associated with larger lesions of the perisylvian region including Broca's and Wernicke's area (Potagas, Kasselimis and Evdokimidis, 2017).

Wernicke's aphasia

Patients experiencing Wernicke's aphasia typically have poorer comprehension. They are able to produce fluent verbal output but which is characterised by phonemic paraphasias (using a different sound in part of a word), semantic paraphasias (producing a semantically related word in place of the target word), neologisms (word sounds which are severely disturbed resulting in a new and sometimes meaningless word) or completely empty or meaningless speech (Potagas, Kasselimis and Evdokimidis, 2017). Due to comprehension deficits people with Wernicke's aphasia may be unable to monitor their own verbal output and therefore may be unaware of their impairments. Impairments are also seen in repetition, naming, reading aloud and writing. Wernicke's aphasia is associated with damage to Wernicke's area which is located in the posterior superior temporal cortex (Potagas, Kasselimis and Evdokimidis, 2017).

Transcortical sensory aphasia

Transcortical sensory aphasia is characterised by fluent but meaningless speech output (similar to Wernicke's aphasia) which includes semantic and phonemic paraphasias and neologisms. Comprehension of verbal and written language, naming and writing are typically poor, however, the ability to repeat words and sentences is strongly preserved (Potagas, Kasselimis and Evdokimidis, 2017). Transcortical sensory aphasia is typically associated with lesions posterior to the perisylvian region including the temporal occipital cortex or the inferior parietal cortex. However, lesions in a number of other areas of the brain including anterior perisylvian regions have also been linked to this type of aphasia (Berthier, 2001).

Conduction aphasia

Those experiencing conduction aphasia have fluent speech with milder word finding difficulties and verbal output which includes phonemic paraphasias. People experiencing conduction aphasia are aware of their errors and may successively try to correct their mispronunciations producing many phonemic variations of the target word (often referred to as a *conduite d'approche*) (Potagas, Kasselimis and Evdokimidis, 2017; Bernal and Ardila, 2009) Comprehension is usually relatively well preserved although some difficulties with understanding syntactically complex sentences may be observed (Basso, 2003). Impairments in naming, writing and reading aloud may be seen. Phonemic and semantic paralexias (akin to paraphasias) may be observed when reading aloud. Conduction aphasia is typically associated with damage to the arcuate fasciculus which is thought to play a role in transmitting information between Wernicke's and Broca's area (Damasio and Damasio, 1980).

Anomic aphasia

Anomic aphasia is characterised by significant impairments in naming ability (Potagas, Kasselimis and Evdokimidis, 2017). Verbal utterances may be halted by word finding difficulties and circumlocutions (describing the features of the person or object but without being able to name the target itself) but is otherwise fluent. Auditory comprehension, reading and repetition ability are not impaired. Anomic aphasia has been associated with lesions in the angular gyrus or posterior middle or inferior temporal cortex (Potagas, Kasselimis and Evdokimidis, 2017). However, as word finding ability is sensitive to damage in many types of aphasia (and is often a residual difficulty during recovery from other types of aphasia) and so can be associated with damage to a diffuse range of lesion sites in the perisylvian region (Swanberg et al., 2007).

The descriptions above demonstrate the heterogeneous language and communication difficulties faced by stroke survivors with aphasia. Many symptoms of aphasia may not fit neatly within the classifications outlined above and may be labelled as 'unclassified' (Potagas, Kasselimis and Evdokimidis, 2017). Although broad classifications may be useful, speech and language therapists often focus upon gaining a detailed understanding of specific deficits experienced by each individual (Byng, 1993). Models of normal language processing developed by cognitive neuropsychologists and neurolinguists have been informed by the impairments seen in patients with aphasia

and can be used to provide hypotheses about the level of linguistic processing which may have been affected by a lesion (Martin, 2017). For example, a detailed analysis of error types in word production (established through a variety of word tasks and assessments) can help to determine whether the word retrieval deficit is a breakdown in processing at the word selection level (lexical retrieval) or the phonological encoding level (retrieval of sounds for articulation). This then impacts upon the type of therapy which may be provided to promote reactivation of the impaired linguistic modality or re-organisation of the language system to compensate for the impairment (Martin, 2017; Byng, 1993).

Although aphasia is primarily classified as a disorder of language; language is also a part of cognition and the neural networks supporting language processing have active ties to other aspects of cognition; for example, memory, attention and executive functioning (e.g. reasoning, planning, self-regulation, monitoring, cognitive flexibility) (Murray and Myer, 2017). These aspects of cognition have been shown to play a vital role supporting aspects of linguistic processing; for example, working memory is required for maintaining and manipulating linguistic representations (Martin et al., 2012) and attention is thought to play a role in almost every aspect of language processing including word retrieval, word identification and grammatical processing (Murray and Myer, 2017; Kok et al., 2007). Martin and Reilly (2012) describe these cognitive processes as the 'supporting cast' which mediate access to and maintenance and retrieval of linguistic representations. Disruption to these aspects of cognition may contribute to disruption in linguistic processing which manifests as a difficulty with communication. A breakdown in language may, therefore, be a result of cognitive as opposed to language impairment. Cognitive impairment may either underlie or exacerbate symptoms of aphasia and may also impact upon the ability to engage in speech and language therapy or learn as part of this process (Murray and Myer, 2017). In particular, the ability to maximise the use of residual language and the use of compensatory strategies depend significantly upon cognitive ability (Cherney and Small, 2015). The severity of aphasia is not always related to cognitive ability in that patients may have similar aphasia severity but different levels of cognitive impairment (Helm-Estabrooks, 2002; Murray, 2012; Lambon Ralph et al., 2010). People with aphasia commonly present with some degree of cognitive impairment and the importance of assessing cognition and accounting for this within rehabilitation is well recognised (Visch-Brink et al., 1993).

Dysarthria

Dysarthria and apraxia of speech are motor speech disorders which result from damage to the neurological systems and processes necessary for speech production (Lowit and Kent, 2017; Enderby, 2014). Speech is defined as the action used to produce the sounds of spoken language. Dysarthria results from damage to the sensorimotor processes involved in speech production (Lowit and Kent, 2017; Enderby, 2015). Dysarthria is typically associated with a weakness or disturbance of tone in the muscles used for speech production (Royal College of Speech and Language Therapists, 2005) which results in speech becoming unclear, slurred or slow (Stroke Association, 2012a). The disruption to speech may range from mild with a slight distortion of speech to a severe impairment in speech production. However, dysarthria does not affect a person's ability to understand language unless it co-occurs with another disorder such as aphasia.

Apraxia of speech

Apraxia of speech affects the stroke survivors' ability to co-ordinate the muscles needed for speech production (Ogar et al., 2005). The muscles may have no weakness but the person may struggle to produce the sounds needed for speech, experience dysprosody and/or take several attempts to pronounce a word when asked (Stroke Association, 2012a). Like dysarthria, apraxia of speech does not affect a person's ability to understand language unless it co-occurs with another disorder such as aphasia.

The preceding paragraphs highlight the diversity and complexity of speech and language difficulties which may affect stroke survivors. In this thesis, 'communication difficulty' is used as an umbrella term to refer to stroke survivors with aphasia, dysarthria or apraxia of speech. This term is used to capture and be inclusive of the range of difficulties with speech and language which impact stroke survivors' ability to receive or convey information and meaning (Stroke Association, 2012a). Evidence suggests that people with post-stroke communication problems have particularly poor longer-term outcome (Laska et al., 2001). For example, stroke survivors with aphasia living in the community have reduced quality of life compared to those without and participate in fewer activities of daily living (Hilari, 2011). This sub-group of stroke survivors is also more likely to suffer from depression (Kauhanen et al., 2000) and have reduced social interactions (Cruice et al., 2006a). Less research has been conducted

regarding outcomes for stroke survivors with dysarthria and apraxia of speech. However, qualitative research suggests a negative impact of these conditions upon quality of life; in particular loss of friendship and reduced social participation (Baylor et al., 2011; Brady et al., 2011a; Dickson et al., 2008).

Traditional speech and language therapy approaches have typically been restoration based; focusing upon returning or improving natural speech and language (Fried-Oken et al., 2012). However, given the negative impact of communication difficulties upon quality of life, there have been calls for speech and language therapy to broaden its focus and to actively support stroke survivors to manage the wider social and psychological consequences of their communication difficulties in the longer-term (Worrall et al., 2010; Simmons-Mackie, 2009; Holland, 2007; Chapey et al., 2008). This is particularly relevant for stroke survivors with chronic communication difficulties where a return to pre-morbid speech and language is not expected (Fried-Oken et al., 2012). Researchers in the field have called for a more holistic approach to speech and language therapy to be considered. Examples include 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). Common to these approaches is the notion that stroke survivors with communication difficulties should be supported and actively encouraged to participate in activities that are meaningful to them and be supported to engage in a rich and fulfilling life in spite of their communication difficulties. Although stating the aims of such approaches is valuable, there is a lack of structured interventions to address these aims directly in practice and a lack of evidence of effectiveness. It is important to recognise that the diversity and complexity of communication difficulties experienced post-stroke is also likely to pose a significant challenge to intervention developers. Nevertheless, there is a paucity of research into interventions to support stroke survivors with communication difficulties to manage the consequences of their condition in the longer-term and a lack of RCTs to robustly evaluate such interventions (Worrall et al., 2016b). However, interest and research in this field is growing rapidly (Thomas et al., 2016; Ryan et al., 2017; Hoffstrom and Laine, 2016; Patterson et al., 2015).

Self-management may be a possible candidate for providing a structured and clearly defined approach to support stroke survivors with communication difficulties to manage the consequences of their condition in the longer-term. There is a clear policy drive towards incorporating self-management in stroke rehabilitation and as noted previously

self-management has been recommended as an approach that should be offered to all stroke survivors in the UK (Intercollegiate Stroke Working Party, 2016; Department of Health, 2007). Self-management has also been advocated within the Australian Aphasia Rehabilitation Pathway as part of a series of best practice statements (Power et al., 2015). However, it is unclear how applicable the evidence to support the introduction of self-management approaches is to stroke survivors with communication difficulties. For example, it is unclear how many RCTs of self-management have included stroke survivors with communication difficulties. Stroke survivors with communication difficulties have previously been excluded from many RCTs in stroke research (Brady et al., 2013; Townend et al., 2007) and this is a cause for concern with regards to the efficacy, appropriateness and acceptability of self-management in this population.

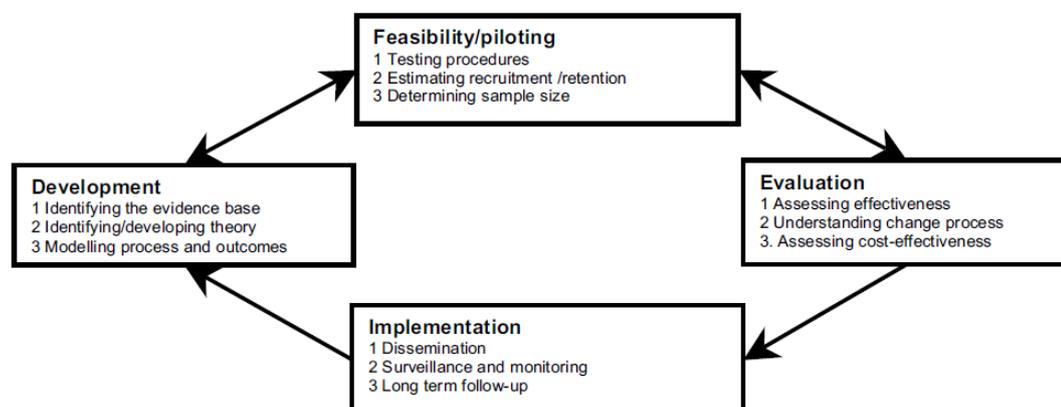
In summary, despite evidence suggesting poor longer-term outcomes there is a lack of clearly defined and robustly tested interventions to help stroke survivors with communication difficulties to manage the consequences of their condition in the longer-term. One potential candidate for longer-term support is self-management; however, at the outset of this thesis uncertainties remained about whether this approach was suitable for stroke survivors with communication difficulties. This PhD study explores the suitability of self-management and uses this knowledge to design a self-management intervention for stroke survivors with communication difficulties. It is important to note that no *a priori* assumptions were made about the suitability of self-management for stroke survivors with communication difficulties at the outset of the project. The original aim of the PhD was to design an intervention to support stroke survivors with communication difficulties in the longer-term. Self-management was identified as a potential candidate for an intervention following scoping searches of the literature. As the research progressed, a rationale for taking a self-management approach developed and this informed the design of a self-management intervention for stroke survivors with communication difficulties.

Complex intervention development

Complex interventions are usually defined as those that are multi-component in nature; but such interventions may also be complex due to the number of organisational levels, the number of outcomes targeted, the complexity of the target population or the level of

tailoring within the intervention (Craig et al., 2008). In this thesis self-management is defined as a complex behaviour change intervention (Craig et al., 2008; Michie et al., 2011). Self-management is complex as the intervention comprises more than one component and is targeted at a complex population (Craig et al., 2008). Self-management is also a behaviour change intervention as it seeks to alter health behaviour patterns in order to facilitate effective management of a long-term condition (Michie et al., 2011; Lorig and Holman, 2003; Barlow et al., 2002). Designing a successful complex intervention requires careful consideration of the approach, its suitability for the target population and the potential for the intervention to be implemented as a routine part of practice (MRC, 2008). No consensus currently exists about the best method to develop a complex intervention and new approaches are constantly evolving, particularly with regards to the development of complex behaviour change interventions. In this field a number of frameworks exist to help develop interventions for example 'MINDSPACE' (Institute for Government, 2010), 'Intervention Mapping' (Bartholomew et al., 1998) or Population Services International (PSI) behaviour change framework 'bubbles' (PSI, 2004). Guidance from NICE (2007) recommends that interventions should be developed in stages using an established approach. This thesis uses guidance from the Medical Research Council (MRC) as a framework to design the intervention (MRC, 2008). MRC guidance is well established and brings together elements of best practice to structure and facilitate the development of robust interventions from the early stages of development to final implementation. MRC guidance states that the development of a complex intervention is an iterative process involving four main stages: Development, Feasibility/Piloting, Evaluation and Implementation. An overview of the stages of intervention development suggested by the MRC guidance is shown in Figure 1.

Figure 1: MRC framework for the development of a complex intervention (MRC, 2008)

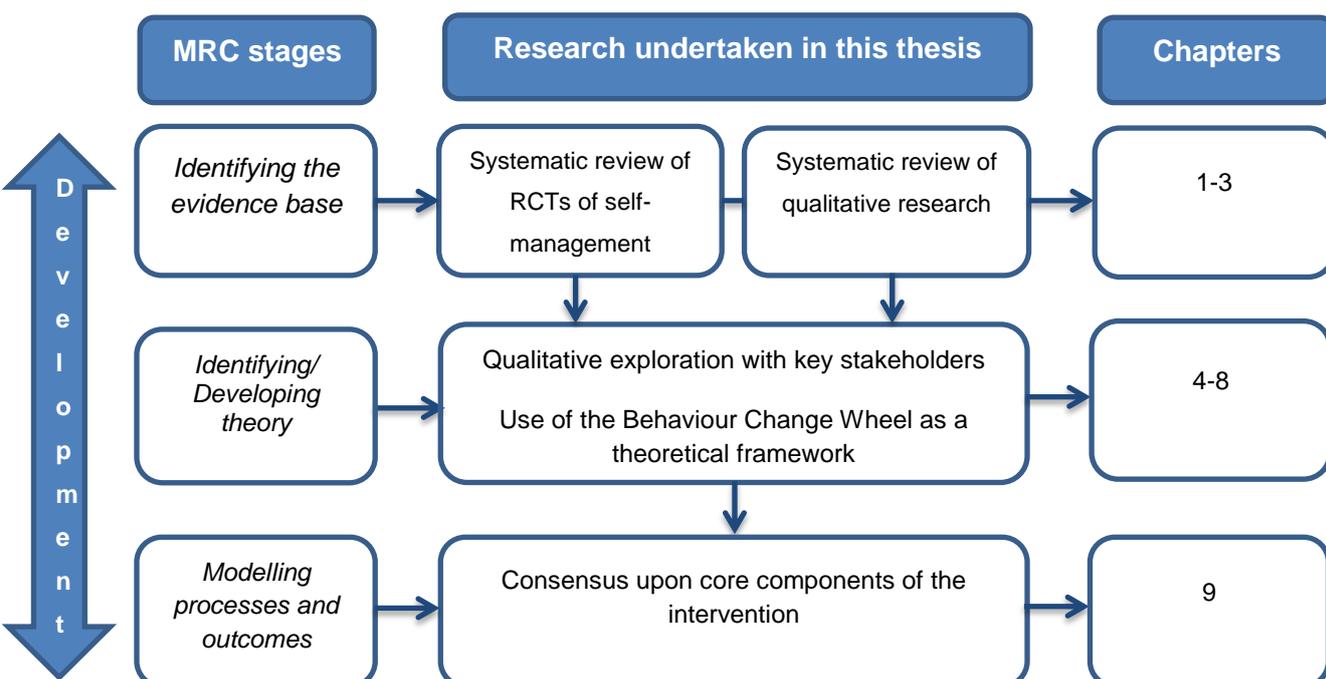


This thesis focuses upon the development stage that has three sub-components: 1) identifying the evidence base, 2) identifying/developing appropriate theory, and 3) modelling processes and outcomes. Firstly, in order to understand if the planned intervention is likely to be effective in the target population, researchers are guided to identify the evidence base by conducting and maintaining a systematic review. Next, the guidance advocates that researchers develop a theoretical understanding of why an intervention is expected to work and how. Theoretical understanding may be developed from existing evidence or through new research e.g. engaging with stakeholders. The final stage of the development phase is modelling how the proposed intervention will work in practice; identifying the potential barriers and facilitators to implementation. An overview of this thesis in relation to MRC (2008) guidance is presented in the next section.

Overview of thesis

In line with MRC (2008) guidance, the intervention is designed iteratively using a staged approach. In Figure 2 the research undertaken in this PhD study is mapped to each of the development stages outlined by MRC (2008).

Figure 2: Designing a self-management intervention for stroke survivors with communication difficulties: Thesis overview



1) Identifying the evidence base

The project began with a mixed methods systematic review (Chapters One, Two and Three). The reviews aimed to understand whether existing self-management interventions meet the requirements of stroke survivors with communication and considering this, whether such interventions are likely to be an effective means of supporting this population in the longer-term.

2) Identifying/developing theory

Findings from the literature reviews suggested that further research was needed to explore the requirements of stroke survivors with communication difficulties in relation to longer-term care. Qualitative exploration with key stakeholders (stroke survivors with communication difficulties, carers and speech and language therapists) was undertaken to address these aims (Chapters Four, Five, Six). This knowledge was used to develop a rationale for taking a self-management approach and to inform an adapted model of self-management (Chapter Seven). The Behaviour Change Wheel provided a theoretical framework to identify which behaviours the intervention should target and what needed to change in order for the behaviours to occur (Michie et al., 2014; Michie et al., 2011) (Chapter Eight). The Behaviour Change Wheel was used to guide the design of the intervention including the identification of appropriate behaviour change techniques (Michie et al., 2008).

3) Modelling processes and outcomes

At the modelling stage, it is recommended that researchers begin to design the intervention in practice (MRC, 2008). An expert panel was used to reach a consensus upon the behaviours to be targeted by the intervention, the behaviour change techniques to be used as part of the intervention and to gain feedback upon how the intervention might be delivered in practice (when, where and facilitated by whom) (Chapter Nine). The design of the intervention was refined using feedback from the expert panel. Recommendations for the design of the intervention are proposed in Chapter Nine.

Thesis aims and objectives

Aims

1. To critically examine the suitability of self-management as an approach for stroke survivors with communication difficulties.
2. To use this knowledge to design an intervention to support stroke survivors with communication difficulties in the longer-term.

Objectives

1. To explore whether existing self-management interventions are suitable for stroke survivors with communication difficulties (Chapters One, Two and Three).
2. To develop an in-depth understanding of the requirements for longer-term care for stroke survivors with communication difficulties (Chapters Four, Five and Six). This knowledge is used to develop a rationale for taking a self-management approach and to inform an adapted model of self-management (Chapter Seven).
3. To design a self-management intervention informed by a theoretical framework of behaviour change (Chapter Eight).
4. To gain an expert consensus about the key components of the intervention and how this might be delivered in practice and to use this knowledge to refine the design of the self-management intervention for stroke survivors with communication difficulties (Chapter Nine).
5. To draw together the information obtained through objectives 1-5 in order to make recommendations for the future development of the intervention (Chapter Ten).

Section One:

Literature Reviews

Overview of the approach

The Background Chapter identified uncertainties about the suitability of existing self-management interventions for stroke survivors with communication difficulties. In line with MRC (2008) guidance, prior to designing an intervention, a comprehensive review of existing evidence was undertaken to explore if such an intervention was likely to be suitable for stroke survivors with communication difficulties. A systematic review is a valuable methodology designed to collate all empirical evidence in order to address a pre-defined research question (CRD, 2009; Higgins and Green, 2011). The strength of this approach is its attempt to minimise bias both at the review level (by using pre-defined inclusion and exclusion criteria, comprehensive, transparent and replicable searches) and, at the study inclusion level (by assessing methodological quality) (CRD, 2009; Higgins and Green, 2011). Traditionally, systematic reviews have been based upon evidence from RCTs only with a focus upon answering narrow effectiveness questions, for example, is treatment 'A' more effective than treatment 'B' (Higgins and Green, 2011). However, there is increasing recognition of the need to incorporate other study types in reviews, particularly where there is a lack of evidence from RCTs or where there is uncertainty in the results of the RCTs identified. Researchers have begun to recognise the merit of understanding why interventions may work in some populations, and not others, in order to aid policy recommendations and future intervention development (CRD, 2009; Pawson and Tilley, 1997).

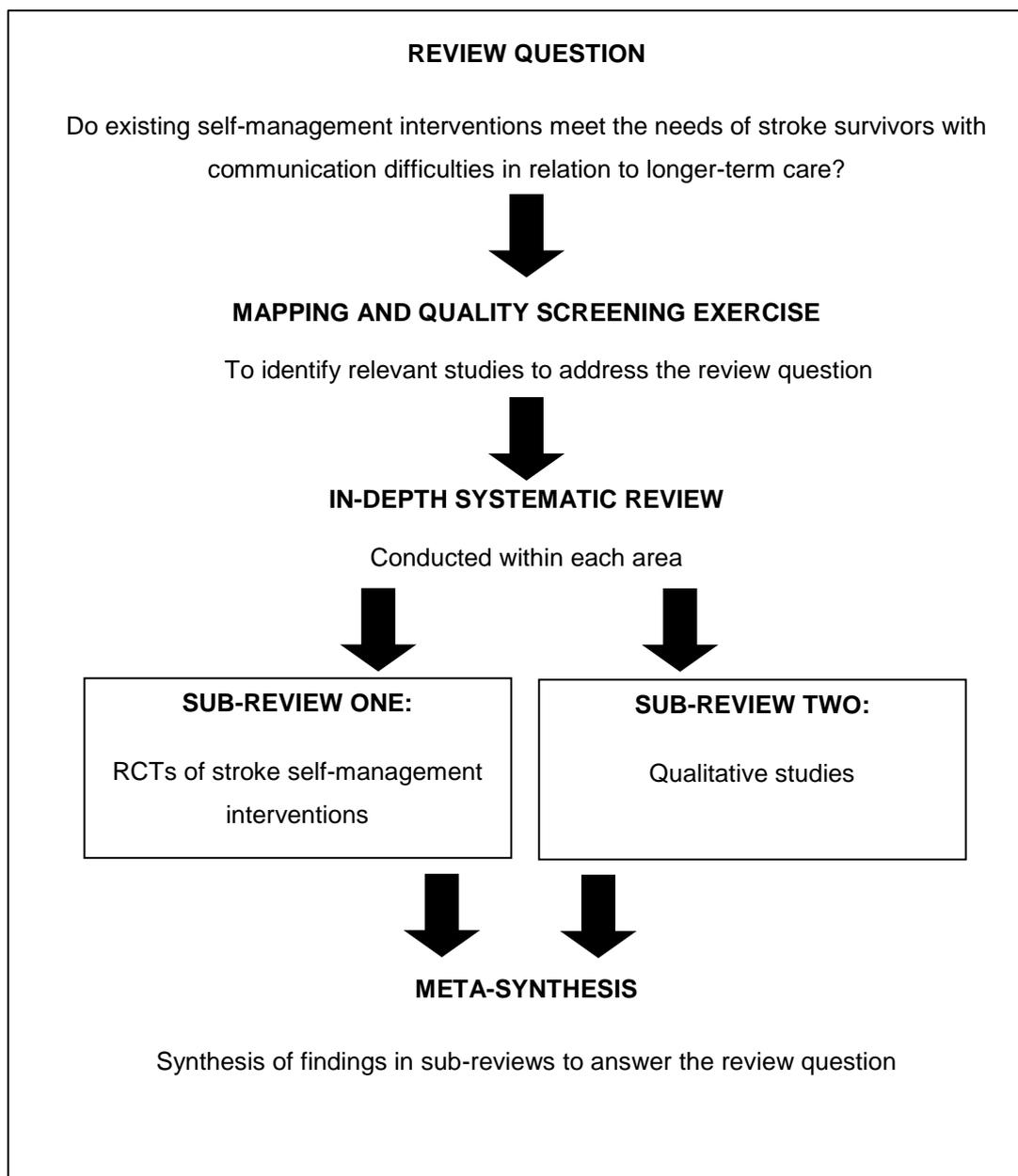
In order to systematically explore the suitability of existing self-management interventions for stroke survivors with communication difficulties, it was important not only to draw upon RCTs of existing self-management interventions in stroke care, but also, to draw upon qualitative literature in order to understand the requirements of stroke survivors with communication difficulties in relation to longer-term care. The requirements for longer-term care were conceptualised as 'needs' and a definition of this term is provided later in this section of the thesis. The overarching aim of the literature reviews was to develop a greater understanding of whether existing self-management interventions address the needs of stroke survivors with communication difficulties and considering this, whether such interventions are likely to be an effective means of supporting this population in the longer-term. An overarching review question was formulated:

- Do existing self-management interventions meet the needs of stroke survivors with communication difficulties in relation to longer-term care?

This question was addressed using The Evidence for Policy and Practice Information and Coordinating (EPPI) centre method for mixed methods reviews (Gough et al., 2012; Oliver et al., 2005). It is important to note that there is no universally agreed method for including 'qualitative' and 'quantitative' data in systematic reviews (CRD, 2009; Higgins and Green, 2011). However, the EPPI approach is one of the first to set out a structured, rigorous and transparent approach to mixed methods reviewing with published examples (Brunton et al., 2005; Rees et al., 2004; Thomas et al., 2004). Using this approach, an overall review question is posed and separate but parallel systematic reviews (sub-reviews) are undertaken. Information from the sub-reviews is then combined in a 'meta-synthesis' to address the overall review question. The meta-synthesis of information allows the researcher to go beyond a traditional effectiveness review by drawing information together from different research areas. Meta-synthesis provides a novel interpretation and integration of the data that would not be achieved if the reviews were completed separately. It is acknowledged that, although one of the most established methods for mixed methods reviewing, development of the EPPI approach is ongoing (Gough et al., 2012) and this may be considered a limitation. However, this approach is one of the most established and adheres strongly to systematic review methodology, considered the most rigorous form of literature review (Higgins and Green, 2011).

In this section of the thesis, two parallel sub-reviews are presented. The first identifies and synthesises RCTs of existing self-management interventions in stroke to establish if they have included stroke survivors with communication difficulties and, if so, their effectiveness in this population (Chapter One). The second systematic review synthesises qualitative studies concerning the longer-term needs of stroke survivors with communication difficulties (Chapter Two). The meta-synthesis will draw together information from each of the sub-reviews to understand the extent to which existing self-management interventions meet the needs of stroke survivors with communication difficulties in relation to longer-term care (Chapter Three). A review protocol was developed prior to undertaking the review that outlined inclusion/exclusion criteria and search strategies. The review protocol was not registered or published. An outline of the approach is shown in Figure 3.

Figure 3: Stages of an EPPI centre mixed methods review (Adapted from Oliver et al., 2005)



Chapter One: Sub-review one (RCTs of self-management)

This chapter reports upon the first systematic review undertaken as part of the EPPI centre mixed methods approach; A systematic review of RCTs of stroke self-management interventions.

1.1. Introduction

At the outset of this PhD study, the efficacy of self-management interventions in stroke was uncertain. The most recent systematic review had been conducted by Lennon et al. (2013) and the authors of this study identified nine RCTs in this area. Six out of the nine trials found significant results in favour of self-management (Allen et al., 2002; Allen et al., 2009; Damush et al., 2010; Harwood et al., 2007; Johnston et al., 2007; Kendall et al., 2007); however, the wide variation in format and outcomes measured precluded the use of meta-analysis. In addition, the methodological quality of some of the included trials was questionable. For example, in two studies (Allen et al., 2002; Marsden et al., 2010) it was unclear if the researcher conducted follow-up assessments blind to treatment allocation, and in six studies (Allen et al., 2002; Allen et al., 2009; Cadilhac et al., 2011; Frank et al., 2000; Kendall et al., 2007; Marsden et al., 2010) there was a high drop-out rate exceeding 20%. The authors were therefore unable to reach firm conclusions about the efficacy of self-management for stroke survivors. The Lennon et al. (2013) review also highlighted wide variation in the format, content and delivery of the self-management interventions identified. The authors proposed that it was unclear precisely where in the stroke pathway self-management approaches should be offered, by whom and in what format and whether such an approach is appropriate for all stroke survivors. Since the searches for this review were undertaken, a Cochrane review of self-management has also been published (Fryer et al., 2016). The Cochrane review found a positive effect of self-management upon quality of life and self-efficacy. However, the diversity of the self-management interventions and outcomes were problematic and the authors could not draw conclusions about the key features of effective self-management interventions to inform future research. In addition, neither the Lennon et al. (2013) review nor the Fryer et al. (2016) review examined the inclusion or exclusion of stroke survivors with communication difficulties in the trials identified.

Stroke survivors with communication difficulties have previously been excluded from many RCTs in stroke research (Brady et al., 2013; Townend et al., 2007) and this raises questions about their inclusion in RCTs of self-management. The systematic exclusion of stroke survivors with communication difficulties from research may stem from the assumption that this population lack the capacity to consent to research procedures, however, the view that all stroke survivors with communication difficulties lack capacity is outdated (Brady et al., 2013). Novel methods have been developed to facilitate the inclusion of stroke survivors with communication difficulties in research (Jayes and Palmer, 2014); however, it is unclear whether this has translated to the more frequent inclusion of this population. The systematic exclusion of this sub-group of stroke survivors from research examining the efficacy and suitability of these approaches is a cause for concern. This issue is of particular importance given recent recommendations that self-management is offered to all stroke survivors as a key component of longer-term care (Intercollegiate Stroke Working Party, 2016; National Stroke Strategy, 2007).

Due to the rapid growth of research in this field (Taylor et al., 2014), it was considered timely to update Lennon et al.'s (2013) review in this thesis. The author was aware of the ongoing Cochrane review (Fryer et al., 2013) and so decided to focus upon the effectiveness of self-management interventions specifically for stroke survivors with communication difficulties. Sub-review one had three objectives that are outlined below.

1.2. Review objectives

- 1) To identify and describe RCTs of self-management interventions in stroke care.
- 2) To explore the inclusion or exclusion of stroke survivors with communication difficulties.
- 3) To review the efficacy of self-management interventions for stroke survivors with communication difficulties in relation to any health outcome (including quality of life, measures of physical disability or measures of mental health).

1.3. Methods

Eligibility criteria

Study design:

RCTs published in English.

Population:

Stroke survivors aged 18+, in any setting (for example, hospital, home, community-based) and at any time point post stroke.

Intervention:

Scoping searches indicated that the term 'self-management' was not used consistently (Taylor et al., 2014), and thus a broader definition of this concept was used by incorporating components of self-management identified as being important by a previous review (Lennon et al., 2013), and by scoping the literature. Given the uncertainties in definition identified and to be inclusive of all possible iterations of self-management, the definition used did not specify the precise content of the intervention i.e. group-based or lay-led and was purposely broad to gain an understanding of all possible self-management interventions in stroke care. Interventions were eligible for inclusion if they were defined by the authors of papers as 'self-management' or similar terminology such as 'self care', or if they comprised some aspect of planning, goal-setting or problem solving to facilitate behaviour change and improve participants' quality of life. Self-management interventions solely including stroke survivors with communication difficulties were eligible for inclusion. Interventions could be compared to any control condition.

Comparator:

Any control condition.

Outcomes:

Quality of life measures, measures of physical disability or measures of mental health.

Search terms

The development of the search terms was an iterative process that included scoping searches and repeated piloting. A full list of search terms is available in Appendix A. Search terms were developed with the help of an information specialist and included a

strategy to identify stroke studies developed by the Cochrane Stroke Group. Apart from terms related to stroke, search terms included 'self-management' and synonyms such as 'self-care' and 'self-led'. Other search terms relating to components of self-management for example, 'goal-setting', 'problem solving' and 'decision making' were also included. The search terms were initially trialled in the Medline database using the Ovid interface and then adapted according to the capabilities of each database.

Information sources

The following databases of published literature relevant to stroke were searched: MEDLINE, EMBASE, PsycINFO, CINAHL, The Cochrane Library and IBSS. To limit publication bias, the following grey literature sources were searched: Index to Theses (UK dissertations and Theses), Proquest (international dissertations and theses) and Web of Science conference proceedings. Databases were searched 2-6th February 2015 (Week 5, 2015). All databases searched from inception.

To make the search as comprehensive as possible, the following strategies were also used:

- Hand searching the reference lists of studies meeting inclusion criteria.
- Reverse citation search of all studies meeting inclusion criteria
- Checking the reference lists of other known reviews in this area (Jones and Riazi, 2011; Lennon et al., 2013).
- Searches of databases containing on-going research including:
 - Health Services Research Projects in Progress (HSRProj)
 - UKCRN Portfolio
- Searches of clinical trials registers including:
 - U.S. National Institutes of Health. ClinicalTrials.gov
 - World Health Organization. International clinical trials registry search portal (ICTRP)
 - Current Controlled Trials

Study selection

All citations identified were exported to Endnote X7 bibliographic management software (Clarivate Analytics, 2013) where duplicates were removed. Screening for eligible papers was a two step process: firstly involving title and abstract review and secondly

involving full text review. An eligibility form was created to help with the screening process. Screening was performed independently by the author and another researcher for all citations. Discrepancies were resolved by consensus with the author's supervisors. Once agreement on study selection was reached, data extraction was performed.

Data extraction

Data extraction was performed independently by the author and another researcher for all of the included studies. Data were extracted using a template and included participant characteristics (sample size, country, setting, age, gender, time post-stroke, % of participants with communication difficulties), methods (aim of study, inclusion/exclusion criteria, design of study, unit of allocation), description of the intervention/control, outcome measures and follow-up time points. Efficacy data were extracted for relevant outcomes (including means and standard deviations for continuous outcomes and event counts for dichotomous outcomes) where RCTs included $\geq 20\%$ of stroke survivors with communication difficulties.

Risk of bias

The methodological quality of studies was assessed using the Cochrane Risk of Bias tool (Higgins and Green, 2011). The tool covers six biases that may arise in RCT design. Reviewers are asked to judge if a trial is at 'high', 'low' or 'unclear' risk of bias in these areas. Quality assessment was not used to exclude studies; however, it highlighted potential limitations of the research. It was also planned for use in sensitivity analyses; however, insufficient studies were found to conduct such analyses.

Data synthesis

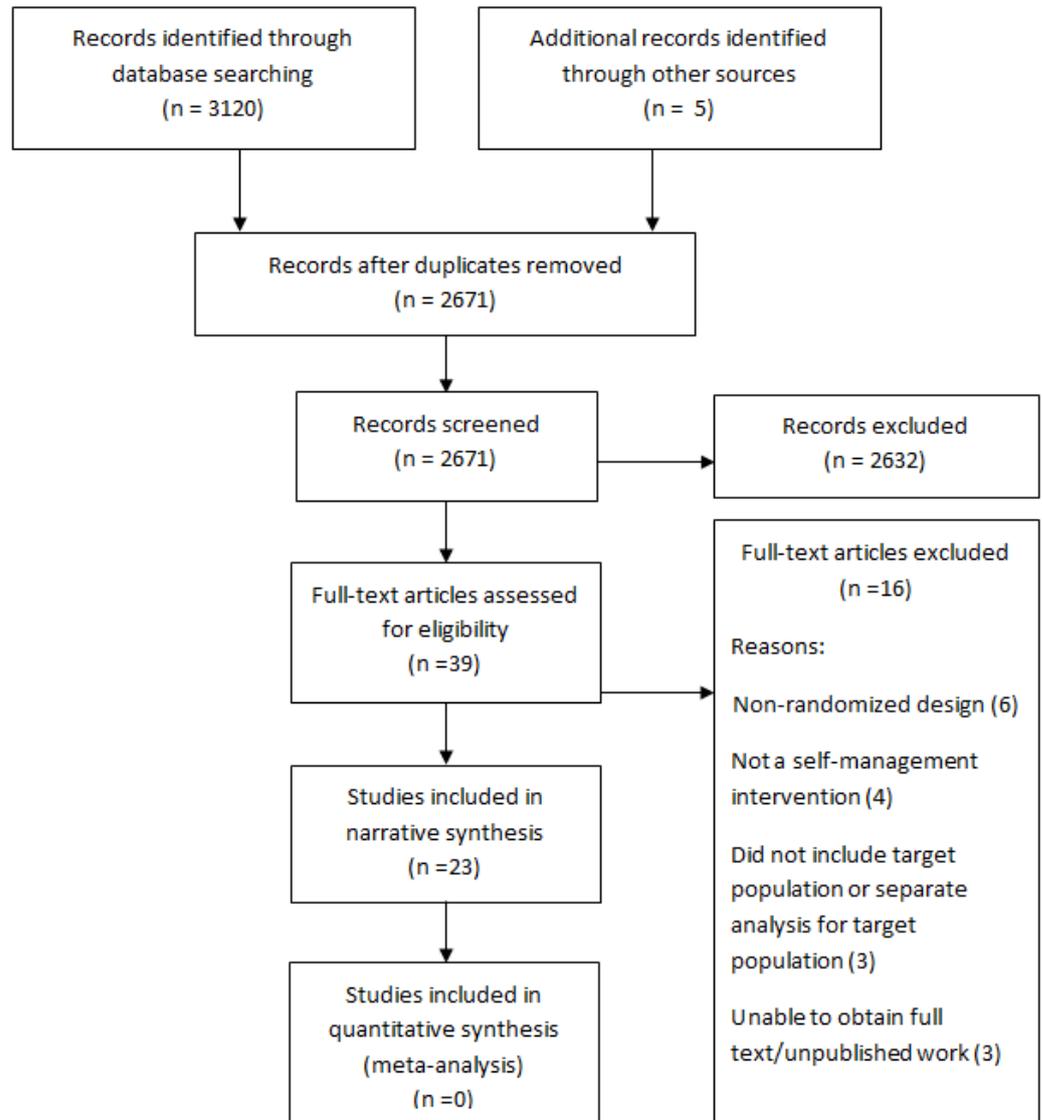
Where sufficiently similar studies are identified results can be combined in a statistical meta-analysis (Higgins and Green, 2011; CRD, 2009). Pooling data allows for more precise and powerful estimation of interventions effectiveness. Plans for statistical pooling of data were pre-specified in the review protocol, including sub-group and sensitivity analyses. However, due to clinical heterogeneity and a lack of comparable outcome measures, the data in this sub-review was summarised using a narrative approach (Higgins and Green, 2011; CRD, 2009), including information from the trials relating to the inclusion of stroke survivors with communication difficulties.

1.4. Results

Study selection

Once duplicates had been removed, 2671 references were screened for eligibility. Full text was obtained for 39 articles of which 16 were excluded. Reasons for exclusion included; six studies did not use a randomised design (Battersby et al., 2009; Huijbregts et al., 2008; Jaglal et al., 2013; Jones, 2005; Jones et al., 2009; Neubert et al., 2011); four studies did not include a self-management intervention (Corr et al., 2004; Forducey et al., 2012; Hoffmann et al., 2007; Yeung, 2012); three studies did not include a stroke survivor population (Dongbo et al., 2003; Hadidi et al., 2012; Ownsworth et al., 2008) and, for three studies, the author was unable to obtain full text or the work was ongoing and had yet to be published (Huijbregts et al., 2010; Lo et al., 2014; Theben, 2006). Twenty three citations comprising 20 independent samples (studies) were eligible for inclusion in the review. The PRISMA flow diagram of study selection is shown in Figure 4.

Figure 4: PRISMA flow diagram (sub-review one) (adapted from Moher et al. 2009)



Study characteristics

The characteristics of the included studies are shown in Table 1. Studies are combined within the table where two citations have reported upon the same sample. The table is organised alphabetically by study author.

Table 1: Characteristics of included studies (sub-review one)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age (Mean and SD)	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Aben et al. (2013) and Aben et al. (2014)	153	11.11% with aphasia	Netherlands	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	58 (9.7)	45.1	Mean 54 months	-Memory self-efficacy intervention - Peer support group	- Metamemory-In-Adulthood questionnaire - CES-D -Quality of life-EQ-5D, WhoQol Bref -Memory capacity-Auditory Verbal Learning Test and story recall from the Riverhead Behavioural Memory Test	10 days after the intervention 6 months 12 months	N
Allen et al. (2002)	96	?	USA	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Control: 72 (SD not reported) Intervention : 69 (SD not reported)	55.9	Not stated, however, enrolled in to study approximately 48 hours prior to discharge	-Enhanced post discharge care with self-management component -Usual care	-NIHSS -Barthel Index -Stroke Adapted 30-item Sickness Impact Profile -Blood pressure -Appropriate anticoagulation -Stroke Knowledge	3 months	?
Allen et al. (2009)	380	?	USA	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Control: 69 (SD not reported) Intervention : 68 (SD not reported)	50	Not stated, however, enrolled in acute unit following confirmation of diagnosis. Intervention participants contacted within 1 week of discharge	-Enhanced post discharge care with self-management component -Usual care	-NIHSS -Timed up and go test -Days hospitalized and death -SSQOL -Blood pressure - CES-D -Medication appropriateness Self-reported falls and incontinence -Stroke Knowledge	6 months	N

Table 1: Characteristics of included studies (sub-review one) (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Cadilhac et al. (2011)	143	34.27% with aphasia	Australia	<u>Design:</u> 3 arm, parallel group <u>Unit:</u> Individual randomisation	69 (11)	59	To be included ≥ 3 months post-stroke (70% of sample were >12 months post-stroke)	-Chronic condition Self Management programme and standard care -Stroke Self Management Programme and standard care - Standard Care Only	-Health Education Impact Questionnaire - Assessment of Quality of Life -Irritability, depression and anxiety scales -Health resource utilisation	3 and 6 months	Y
Chumbler et al. (2012) and Chumbler et al. (2015) Supplementary information obtained from published protocol Chumbler et al. (2010)	52	?	USA	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Control: 67.7 (10.0) Intervention : 67.1 (9.5)	2.1%	?	-Multifaceted stroke telerehabilitation (STeLeR) - Usual care	-The motor subscale of the Telephone Version of the Functional Independence Measure -The Overall Function Component of the Late-Life Function and Disability Instrument (LLFDI) -Secondary outcomes included the 3 subscales of the LLFDI Function Component: upper extremity function, basic lower extremity function, advanced lower extremity function -LLFDI Disability Component, which evaluates social roles (e.g. visiting friends) and personal roles (e.g. meal preparation), and evaluates difficulty with task performance and frequency of performance	3 and 6 months	N

Table 1: Characteristics of included studies (sub-review one) (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Damush et al. (2010)	63	?	USA	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Control: 64(8.4) Intervention : 67.3 (12.4)	1.6	1 month	- Stroke self-management programme -Placebo telephone call	- SS-QOL -Self-Management behaviour frequency -Self-efficacy	3 and 6 months	Y
Fido (2010)	29	?	UK	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Overall: 69 (12.30) Control: 67.93 (12.24) Intervention : 70.13 (12.69)	55.17	?	-Diary Plan - No diary plan	-Diary completion - NEADL -Psychological Wellbeing-HADS -Prospective and Retrospective Memory Questionnaire -Motivation for diary keeping	2 weeks	N
Frank (2000)	39	Excluded people with aphasia	UK	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Control: 64.35 (14.30) Intervention :63.58 (12.09)	48.7	Workbook group: mean weeks since stroke- 41.42(SD 24.53) Control group: mean weeks since stroke- 37.95 (SD 27.53)	-Workbook based intervention -Wait list control	-Functional limitations Profile -Sickness Impact Profile - HADS -Recovery Locus of Control Scale -Perceived Health Competencies Scale	1 month	Y
Glass et al. (2004)	291	?	USA	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Control: 70.4 (11.0) Intervention : 69.3 (11.0)	49.3	Aim to recruit participants within 1 month post-stroke	-Psychosocial Intervention -Usual Care	-Barthel Index -Mini Mental State Exam - CES-D -Barrera's Inventory of Social Supported Behaviours -Recovery Efficacy	3 and 6 months	N

Table 1: Characteristics of included studies (sub-review one) (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Guidetti et al. (2010) And Guidetti and Ytterberg (2011)	40	42.5%	Sweden	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Control: 69 (15) Intervention : 66 (14)	57.5	Recruited 3-5 days post-stroke	-Client centred self-care intervention (CCSCI) -Usual Care	-Barthel Index -FIM -Frenchay Activities Index -Stroke Impact Scale -Life Satisfaction Scale -Occupational Gaps questionnaire - Caregiver Burden Scale	3 , 6, and 12 months	Y
Harwood et al. (2012)	172	?	New Zealand	<u>Design:</u> 2x2 parallel factorial <u>Unit:</u> Individual randomisation	61.4 (13.6)	52.3	Randomised up to 3 months post-stroke	-Inspirational DVD -Take Charge session -Inspirational DVD and Take Charge session -Control (written information)	- SF-36 -Barthel Index -Frenchay Activities Index -Carer Strain Index -Modified Rankin Score	12 months	N
Johnston et al. (2007)	203	?	UK	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Control: 68.79 (12.02) Intervention : 68.96 (12.64)	38.9	Baseline interview within 2 weeks of discharge following hospital	-Workbook based intervention -Usual Care	-Barthel Index -Observer Assessed Disability -HADS -Satisfaction -Recovery Locus of Control Scale -Confidence in recovery -Physical functioning SF-36	8 weeks, 6 months	N
Kendall et al. (2007)	100	?	Australia	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	65.96 (10.67)	33	Eligible for inclusion if stroke sustained in the past 'few months'	-Chronic Disease Self-Management course plus stroke specific information session -Usual Care	- SSQOL -Self-efficacy scale	3, 6, 9 and 12 months	N

Table 1: Characteristics of included studies (sub-review one) (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age	Gender (% female)	Time post-stroke	Intervention(s)/ Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Marsden et al. (2010)	25	?	Australia	<u>Design:</u> 2arm cross-over RCT <u>Unit:</u> Individual randomisation	Control: 73.1 (9.3) Intervention: 70.0 (9.0)	24	Intervention group mean time post stroke: 37.2 (26.7) months Control group: 39.0 (23.6) months	-‘Community Living After Stroke for Survivors and Carers’ (CLASSIC) -Wait list control (received intervention after study completed)	-Quality of life: Stroke Impact Scale and Health Impact Scale -Modified Rankin Scale -Mini mental state examination -Six minute walk test -Timed Up and Go - Caregiver Strain Index	week 9, week 17, week 21	Y
McKenna et al. (2015)	25	?	UK	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Control: 67.38 (10.60) Intervention: 62.18 (13.57)	44	Intervention-mean weeks post-stroke 7.0 (SD 4.45) Control-mean weeks post-stroke 11.38 (SD 12.70)	-Bridges Supported Self-Management Programme -Usual care	-Health related quality of life (EuroQol and SSQOL) -Self efficacy (SES and SSEQ) -Functional independence (Barthel Index, NEADL, mood-GHQ-28, community integration SIPSO)	3 months	Y
Polatajko et al. (2012)	20	?	USA	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	60.4 (SD not reported)	57.9	? (At least 6 months post-stroke)	-Cognitive Orientation to daily Occupational Performance (CO-OP) -Standard occupational therapy	-Performance Quality Rating Scale -Canadian Occupational Performance Measurement	Not stated (‘after intervention’)	Y
Robinson et al. (2008)	176	?	USA	<u>Design:</u> 3 arm, parallel group <u>Unit:</u> Individual randomisation	Medication (Escitalopram)- 61.3(13.7) Problem-Solving Therapy-67.3 (11.2) Placebo-63.9 (13.3)	40.34	Within 3 months	-Medication (Escitalopram) -Problem-solving therapy - Placebo	-Structured Clinical Interview for DSM-IV -Hamilton-17 Depression Rating Scale -Hamilton Anxiety Rating Scale -FIM -The Social Functioning Exam	3, 6, 9 and 12 months	N

Table 1: Characteristics of included studies (sub-review one) (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Sabariego et al. (2013)	213	?	Germany	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Individual randomisation	Control: 59.31 (12.67) Intervention : 55.31 (12.56)	46	Mean days post-stroke for both groups: 150.36 (SD 519.69)	-ICF based patient education programme -Attention placebo control consisting of standardised lectures with information about stroke	-Liverpool self-efficacy scale -WHOQOL -Stroke Impact Scale - EQ-5D - HADS	1 week and 6 months	N
Sackley et al. (2006)	118	?	UK	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Cluster randomisation	Control: 86.3 (8.8) Intervention : 88.6 (6.5)	82.2	?	-Occupational therapy intervention -Usual Care	-Barthel Index -Rivermead Mobility Index -Short Orientation-Memory-Concentration Test	3 and 6 months	Y
Taylor et al. (2012)	41	Excluded people with aphasia	New Zealand	<u>Design:</u> 2 arm, parallel group <u>Unit:</u> Cluster randomisation	Control: 63.5 (16.6) Intervention : 58.5 (15.9)	36.7	Intervention group- mean time since stroke (days) 28.1 (SD 25.2) Control group-mean time since stroke (days) 13.2 (SD 5.0)	-Structured goal-setting using Canadian Occupational Performance Measure -Usual Care	-SEIQOL-DW -SF-36 - FIM -Patient Perception of rehabilitation	48 hours and 12 weeks	Y

Key: [? : Insufficient information] [CES-D: Center for Epidemiologic Studies Depression Scale] [FIM: Functional Independence Measure] [General Health Questionnaire-28: GHQ-28] [HADS: Hospital Anxiety and Depression Scale] [NEADL: Nottingham Extended Activities of -Daily Living Scale] [NIHSS: National Institute for Health Stroke Score] [SEIQOL-DW: Schedule for the Evaluation of Individual Quality of Life] [SSQOL: Stroke Specific Quality of Life scale] [SES: Self-efficacy scale] [SIPSO: Subjective Index of Physical and Social Outcome] [SSEQ: Stroke self-efficacy Questionnaire]

In total, 2379 participants participated in the included studies with a mean age ranging from 58 (Aben et al., 2013; Aben et al., 2014) to 87.5 years (Sackley et al., 2006). 44.9% of participants were female. Time post-stroke ranged from 3 days (Guidetti et al., 2010; Guidetti and Ytterberg, 2011) to 10 years (Marsden et al., 2010). Over half the interventions recruited participants within the first year post-stroke (12 out of 20) (Allen et al., 2002; Allen et al., 2009; Damush et al., 2011; Glass et al., 2004; Guidetti et al., 2010; Guidetti and Ytterberg, 2011; Harwood et al., 2012; Johnston et al., 2011; Kendall et al., 2007; McKenna et al., 2015; Robinson et al., 2008; Sabariego et al., 2013; Taylor et al., 2012). Fifteen studies included community dwelling participants (Aben et al., 2013; Aben et al., 2014; Allen et al., 2002; Allen et al., 2009; Cadilhac et al., 2011; Chumbler et al., 2012; Chumbler et al., 2015; Damush et al., 2011; Fido, 2010; Frank et al., 2000; Glass et al., 2004; Harwood et al., 2012; Johnston et al., 2007; Kendall et al., 2007; Marsden et al., 2010; McKenna et al., 2015; Polatajko et al., 2012). Sample sizes ranged from 20 (Polatajko et al., 2012) to 380 (Allen et al., 2009). Just under half of trials (nine) were pilot or feasibility studies (Cadilhac et al., 2011; Damush et al., 2011; Frank et al., 2000; Guidetti et al., 2010; Guidetti and Ytterberg, 2011; Marsden et al., 2010; McKenna et al., 2015; Polatajko et al., 2012; Sackley et al., 2006; Taylor et al., 2012).

Fifty nine different outcome measures were used in total. Broadly, they included measures of physical disability (e.g. the Barthel Index, Nottingham Extended Activities of -Daily Living Scale), measures of quality of life (e.g. Stroke Specific Quality of Life scale, SF-36) and measures of mental health (e.g. Hospital Anxiety and Depression Scale, Center for Epidemiologic Studies Depression Scale). Sixteen out of 20 studies explicitly stated a primary outcome measure. Six studies chose a quality of life measure for their primary outcome (Damush et al., 2011; Harwood et al., 2012; Kendall et al., 2007; Marsden et al., 2010; Taylor et al., 2012; McKenna et al., 2015). Five studies chose measures of physical disability as their primary outcome measure (Chumbler et al., 2012; Chumbler et al., 2015; Glass et al., 2004; Johnston et al., 2007; Polatajko et al., 2012; Sackley et al., 2006). Two studies chose measures of self-efficacy as their primary outcome measure (Aben et al., 2013; Aben et al., 2014; Sabariego et al., 2013) and one study chose a measure of depression (Robinson et al., 2008).

Intervention characteristics

A descriptive summary of the design, theoretical rationale and content of the self-management interventions is provided in Table 2. The table is organised alphabetically by study author.

Table 2: Characteristics of self-management interventions (sub-review one)

Authors	Theoretical Rationale	Mode of delivery	Facilitators	Title and Content of intervention (s)	Location of the intervention	Duration of the intervention
Aben et al. (2013) and Aben et al. (2014)*	Memory self-efficacy	Group format	Trained psychologist	<p><u>Title:</u> Memory self-efficacy intervention</p> <p><u>Content:</u>1) A general introduction on memory and stroke, including the consequences of actual memory deficits and how to cope with these 2) Training in internal and external memory strategies to improve compensating abilities (e.g. visualisation, diary use, taking notes) 3) Psychoeducation on the influence of beliefs, anxiety, memory-related worries, and motivation on memory performance; and 4) Realistic goal-setting regarding memory-demanding tasks, using cognitive behavioural therapeutic aspects Patients received a training booklet with information about the sessions, and homework assignments were handed out after each session</p>	Rehabilitation clinic (participants living in the community)	9 twice weekly group sessions of 1 hour
Allen et al. (2002)	Wagner's chronic care model	Individual home visits and telephone follow-up.	Advanced practice nurse care manager/interdisciplinary post stroke consultation team	<p><u>Title:</u> Enhanced case-management and review plus self-management component</p> <p><u>Content:</u> goal-setting, problem solving, care planning, educational resources, skills training, access to community resources.</p>	Community	6 months (contact varied upon level of need but contacted at least once a week by telephone for the first month and monthly thereafter until 6 months)
Allen et al. (2009) (Supplementary information obtained from Allen et al. (2004))	As above	As above	As above	As above	As above	As above
Cadilhac et al. (2011)*(supplementary information from Battersby et al. (2009))	Social Cognitive Theory of Self-Efficacy	Group format	Trained stroke educator and peer facilitator	<p><u>Title:</u> Stroke Self-Management programme</p> <p><u>Content:</u> Stroke specific information provision, problem solving, identifying and accessing local resources, healthy lifestyle behaviour change</p>	Community	2 ½ hours once a week for 8 weeks

Table 2: Characteristics of self-management interventions (sub-review one) (continued)

Authors	Theoretical Rationale	Mode of delivery	Facilitators	Title and Content of intervention (s)	Location of the intervention	Duration of the intervention
Chumbler et al. (2012) and Chumbler et al. (2015) (Supplementary information obtained from published protocol Chumbler et al. (2010)	Self-efficacy	Individual home visits and telephone calls	Occupational and physiotherapists	<u>Title:</u> Multifaceted stroke telerehabilitation (STeleR) <u>Content:</u> Goal-setting, review, treatment planning, physical exercise, adaptive strategies	Community (home-based)	3 months (three one-hour home visits, daily participant use of an in-home messaging device that is monitored weekly by the teletherapist, five telephone intervention calls between the teletherapist and the participant)
Damush et al. (2011)	Social Cognitive Theory of Self-Efficacy	Individual telephone calls	Trained facilitators (nurse, physician assistant, masters level social scientist)	<u>Title:</u> Stroke self-management programme <u>Content:</u> Facilitated goal-setting and problem solving	Community (home-based)	Six 20 minute bi-weekly telephone calls
Fido (2010)	Theory of planned behaviour	Face to face visit and diary keeping	Researcher	<u>Title:</u> Diary Plan <u>Content:</u> Diary keeping to facilitate participation in meaningful activities- included aspects of planning and behavioural goal-setting. Intervention group were also helped to form 'implementation intentions' with regard to diary keeping	Community (home-based)	1 home visit with a researcher to administer instructions for keeping the diary. Participants were required to keep the diary daily for 2 weeks
Frank et al. (2000)	Control cognitions theory	Face to face visits and telephone calls	Researcher	<u>Title:</u> Workbook based intervention <u>Content:</u> Information provision, enhancing coping resources, rehearsing planning, problem-solving skills, recovery plan.	Community (home-based)	2 home visits and 3 telephone calls over 5 weeks

Table 2: Characteristics of self-management interventions (sub-review one)(continued)

Authors	Theoretical Rationale	Mode of delivery	Facilitators	Title and Content of intervention (s)	Location of the intervention	Duration of the intervention
Glass et al. (2004)	Psychosocial Model	Individual	Psychologist or social worker trained in Cognitive Behavioural Therapy	<u>Title:</u> Psychosocial intervention <u>Content:</u> Assessment of social assets, coping strategies, goal-setting, planning, behavioural strategies	Community (home-based)	16 meetings over 6 months
Guidetti et al. (2010) And Guidetti and Ytterberg (2011)*	?	Individual	Occupational therapist	<u>Title:</u> Client centred self-care intervention <u>Content:</u> 'Goal, plan, do' strategy, supportive goal-setting planning and review. Training diary to assume responsibility for goals and self-care.	Rehabilitation clinic	?
Harwood et al. (2012)	Social Cognitive Theory of Self-Efficacy	Individual	Trained research assistants	<u>Title of intervention 1:</u> Inspirational DVD: <u>Content:</u> Coping, encouraging meaningful activity and participation <u>Title of intervention 2:</u> Take Charge session: <u>Content:</u> Goal-setting, information provision on individual risk factor, planning	Community	1 x 80 minute session
Johnston et al. (2007)	Control cognitions theory	Face to face visits and telephone calls	Workbook implementer	<u>Title:</u> Workbook based intervention <u>Content:</u> Coping skills, self-management instruction, goal-setting, relaxation and breathing exercises	Community (home-based)	3 home visits and 2 telephone calls over a 5 week period
Kendall et al. (2007)	Social Cognitive Theory of Self-Efficacy	Group format	Trained health professionals	<u>Title:</u> Chronic Disease Self-Management course plus stroke specific information session <u>Content:</u> Information provision (health, wellbeing, exercise, relaxation) problem solving, goal-setting, communication with healthcare team and family	Community	2 hours per week for 6 weeks

Table 2: Characteristics of self-management interventions (sub-review one)(continued)

Authors	Theoretical Rationale	Mode of delivery	Facilitators	Content of intervention (s)	Location	Duration
Marsden et al. (2010)	?	Group format	Stroke multidisciplinary team (Physiotherapist, social worker, dietician, nurse, speech pathologist and occupational therapist)	<u>Title:</u> Community Living After Stroke for Survivors and Carers <u>Content:</u> Education, physical activity, self-management principles (goal-setting, risk factors and prevention, fatigue management, stress and relaxation, community participation and accessing resources)	Hospital (with community based stroke survivors)	2 ½ hours per week for 7 weeks
McKenna et al. (2015)	Self-efficacy	Individual	Members of the community stroke team who had previously undergone training in the program	<u>Title:</u> Bridges Supported Self-Management Programme <u>Content:</u> Goal-setting, problem-solving, progress review, stroke workbook to record goals and achievements	Community	One session of up to one hour per week over 6 weeks
Polatajko et al. (2012)	Meichenbaums problem-solving strategy	Individual	Occupational therapist	<u>Title:</u> Cognitive Orientation to daily Occupational Performance <u>Content:</u> Goal-setting, cognitive problem solving, strategy identification, skill acquisition, supported goal achievement.	Community	10 x 1 hour treatment sessions
Robinson et al. (2008)	?	Individual	Problem-solving therapy-'trained therapist'	<u>Title:</u> Problem-solving therapy <u>Content:</u> patients selects a problem and then goes through 7 steps to arrive at a course of action	?	Problem-solving therapy-consisted of 6 treatment sessions over the first 12weeks (weeks 1, 2, 3, 4, 6,and 10) and 6 reinforcement sessions (months 4, 5, 6, 8, 10, and 12)

Table 2: Characteristics of self-management interventions (sub-review one)(continued)

Authors	Theoretical Rationale	Mode of delivery	Facilitators	Content of intervention (s)	Location	Duration
Sabariego et al. (2013)	Social Cognitive Theory of Self-Efficacy	Group format	Psychologist	Title: ICF based patient education programme Content: Problem identification, problem solving, planning, cognitive representation	Inpatient rehabilitation	1 hour sessions over 5 days
Sackley et al. (2006)	?	Individual	Occupational therapist	Title: Occupational therapy intervention Content: Goal-setting, skills training, progress review, carer and care home education	Care home	3 month period but frequency and duration dependent upon agreed goals
Taylor et al. (2012)	?	Individual	Occupational therapist	Title: Structured goal-setting using Canadian Occupational Performance Measure Content: Facilitated goal-setting, Feedback on goals to clinical team	Inpatient rehabilitation	One administration

Key: [? : Insufficient information][*Studies reporting the inclusion of stroke survivors with aphasia]

The most common theoretical rationale for interventions was self-efficacy theory which was cited in eight studies (Aben et al., 2013; Aben et al., 2014; Cadilhac et al., 2011; Chumbler et al., 2012; Chumbler et al., 2015; Damush et al., 2011; Harwood et al., 2012; Kendall et al., 2007; McKenna et al., 2015; Sabariego et al., 2013). Three of the eight studies were explicitly based upon the Stanford model of self-management (Cadilhac et al., 2011; Damush et al., 2011; Kendall et al., 2007). Other theoretical rationales included control cognitions theory (two studies) (Frank et al., 2000; Johnston et al., 2007), Wagner's chronic care model (two studies) (Allen et al., 2002; Allen et al., 2009) and the psychosocial model (one study) (Glass et al., 2004). Five studies did not state any theoretical rationale for their intervention (Guidetti et al., 2010; Guidetti and Ytterberg, 2011; Marsden et al., 2010; Robinson et al., 2008; Sackley et al., 2006; Taylor et al., 2012).

The content of the interventions varied; however, they could be broadly arranged into three categories based on their content: 'general self-management', 'occupational self-management' and 'other'. The majority of studies (11 out of 20) delivered general self-management interventions that focused upon teaching stroke survivors skills such as coping, planning and goal-setting to improve quality of life (Cadilhac et al., 2011; Damush et al., 2011; Fido, 2012; Frank et al., 2000; Glass et al., 2004; Harwood et al., 2012; Johnston et al., 2007; Kendall et al., 2007; Marsden et al., 2010; McKenna et al., 2015; Sabariego et al., 2013). Five of the 20 self-management interventions identified were occupational therapy-based interventions that focused upon stroke survivors regaining the skills to perform activities of daily living (ADL) (Chumbler et al., 2012, Chumbler et al., 2015; Guidetti et al., 2010, Guidetti and Ytterberg, 2011; Polatajko et al., 2012; Sackley et al., 2006; Taylor et al., 2012). These studies met the criteria for 'self-management' as they used aspects of planning, goal-setting or problem solving as part of the intervention. However, they were distinguished from other types of self-management interventions, as the focus was upon regaining the physical skills needed for self-care, as opposed to the broader quality of life outcomes addressed by general self-management interventions. All were facilitated by occupational therapists or physiotherapists. Of the 'other' interventions, one study was specifically targeted towards improving memory (Aben et al., 2013; Aben et al., 2014) and one other targeted the prevention of post-stroke depression (Robinson et al., 2008). Again, these studies met the criteria for 'self-management' as they included aspects of problem-solving, planning and goal-setting. However, they were distinguished from general self-management interventions due to their specific focus upon a single aspect of stroke rehabilitation. The final intervention was distinguished from the others as it was part of

a wider care strategy that involved enhanced-case management and review plus a self-management component (Allen et al., 2002; Allen et al., 2009).

Risk of bias

The results of the risk of bias assessment are provided in Table 3. The table is organised alphabetically by study author. Figure 5 shows the proportion of studies with high, low or unclear risk of bias.

Figure 5: Proportion of studies with high, low or unclear risk of bias (sub-review one)

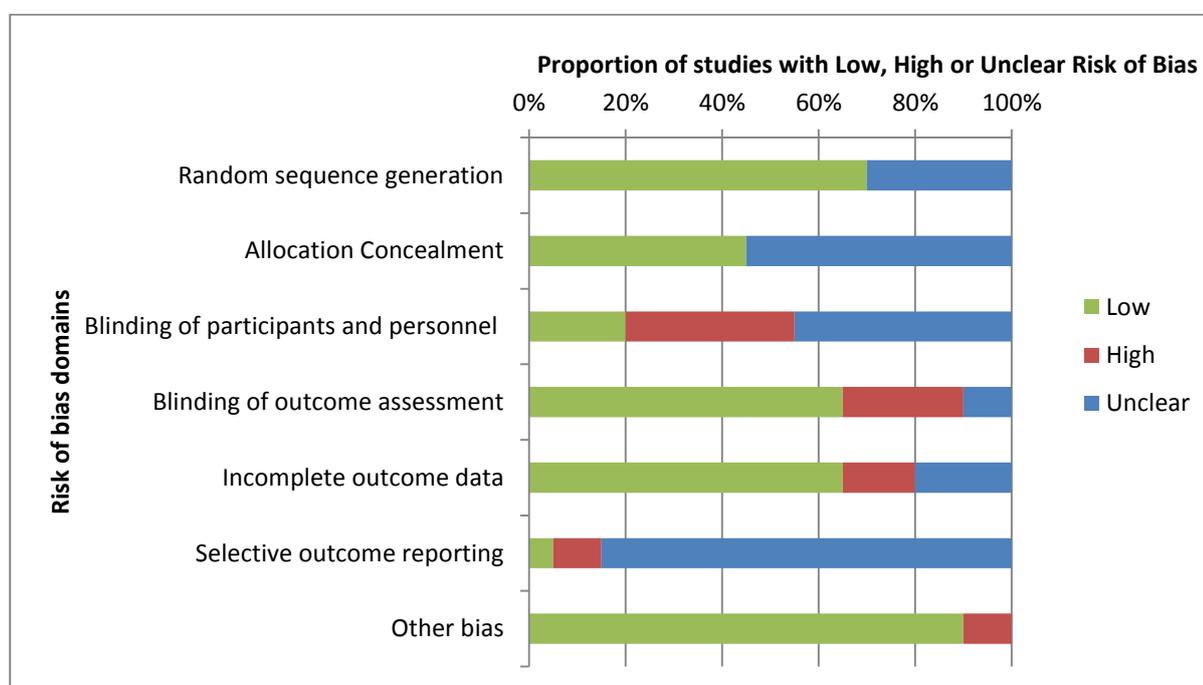


Table 3: Assessment of risk of bias (sub-review one)

Authors	Selection Bias		Performance Bias	Detection bias	Attrition Bias	Reporting Bias	Other bias
	Random sequence generation	Allocation Concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective outcome reporting?	
Aben et al. (2013) and Aben et al. (2014)*	Low	Low	Low	Low	Low	Unclear	Low
Allen et al. (2002)	Unclear	Unclear	High	High	Unclear	Unclear	Low
Allen et al. (2009)	Low	Unclear	Unclear	Low	Low	Unclear	Low
Cadilhac et al. (2011)*(Supplementary information obtained from published protocol by Battersby et al., 2009)	Low	Low	Low	Low	Low	Low	Low
Chumbler et al. (2012) and Chumbler et al. (2015) (Supplementary information obtained from published protocol Chumbler et al. (2010))	Low	Low	High	Low	Low	High	Low
Damush et al. (2011)	Unclear	Unclear	Unclear	Low	Unclear	Unclear	Low
Fido (2010)	Low	Low	High	Low	High	Unclear	Low
Frank et al. (2000)	Unclear	Unclear	High	High	Low	Unclear	Low
Glass et al. (2004)	Low	Unclear	Low	Low	Low	Unclear	Low

Table 3: Assessment of risk of bias (sub-review one) (continued)

Authors	Selection Bias		Performance Bias	Detection bias	Attrition Bias	Reporting Bias	Other bias
	Random sequence generation	Allocation Concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective outcome reporting	
Guidetti et al. (2010) and Guidetti and Ytterberg (2011)*	Low	Low	Unclear	Low	Low	Unclear	Low
Harwood et al. (2012)	Low	Unclear	Unclear	Low	Low	High	Low
Johnston et al. (2007)	Unclear	Unclear	Unclear	Low	Low	Unclear	Low
Kendall et al. (2007)	Low	Unclear	Unclear	Unclear	Unclear	Unclear	High
Marsden et al. (2010)	Low	Low	Unclear	High	Low	Unclear	Low
McKenna et al. (2015)	Unclear	Unclear	High	Low	Low	Unclear	Low
Polatajko et al. (2012)	Unclear	Unclear	High	High	High	Unclear	Low
Robinson et al. (2008)	Low	Low	High	High	Low	Unclear	Low
Sabariego et al. (2013)	Low	Unclear	Low	Unclear	High	Unclear	Low
Sackley et al. (2006)	Low	Low	Unclear	Low	Unclear	Unclear	Low
Taylor et al. (2012)	Low	Low	Unclear	Low	Low	Unclear	High

Key: [* Studies reporting the inclusion of stroke survivors with aphasia]

One out of 20 studies was judged to have low risk of bias across all domains (Cadilhac et al., 2011). Twelve out of 20 studies scored high risk of bias in at least one domain (Allen et al., 2002; Chumbler et al., 2012; Chumbler et al., 2015; Fido, 2010; Frank et al., 2000; Harwood et al., 2012; Kendall et al., 2007; Marsden et al., 2010; McKenna et al., 2015; Polatajko et al., 2012; Robinson et al., 2008; Sabariego et al., 2013; Taylor et al., 2012).

No studies were judged to be at high risk of bias in the random sequence generation domain. In the blinding of outcome assessment domain, five studies (25%) were at high risk of bias, reporting that the assessor was not blind to the allocation of the participant in the outcome assessment (Allen et al., 2002; Chumbler et al., 2012; Chumbler et al., 2015; Fido, 2010; Frank et al., 2000; McKenna et al., 2015; Polatajko et al., 2012; Robinson et al., 2008). In the incomplete outcome data domain, three studies (15%) were judged to be at high risk of bias (Fido, 2010; Polatajko et al., 2012; Sabariego et al., 2013). Two of the studies reported substantial losses at follow-up and conducted 'as treated' analysis (Fido, 2010; Polatajko et al., 2012), and the remaining study reported substantial losses in the intervention arm in comparison to the control arm (Sabariego et al., 2013). In the selective outcome reporting domain, 17 studies (85%) were at an unclear risk of bias (Aben et al., 2013; Aben et al., 2014; Allen et al., 2002; Allen et al., 2009; Damush et al., 2011; Fido, 2010; Frank et al., 2000; Glass et al., 2004; Guidetti et al., 2010; Guidetti and Ytterberg, 2011; Johnston et al., 2007; Kendall et al., 2007; Marsden et al., 2010; McKenna et al., 2015; Polatajko et al., 2012; Robinson et al., 2008; Sabariego et al., 2013; Sackley et al., 2006; Taylor et al., 2012). These studies did not reference a study protocol or trial registration that pre-specified outcome measures, therefore, they were judged to be at unclear risk of bias. Two studies (10%) were at high risk of bias in this domain due to discrepancies between measures planned in the protocol and those reported in the publication (Chumbler et al., 2012; Chumbler et al., 2015; Harwood et al., 2012). In the other bias domain, two studies were judged to be at high risk of bias; one due to potential recruitment bias as a result of the cluster design (Taylor et al., 2012) and one due to baseline imbalances between study arms (Kendall et al., 2007). The implications of the risk of bias assessment upon the evidence generated by this review will be discussed in further detail later in this chapter (see discussion Section 1.5).

Evidence synthesis

Inclusion of stroke survivors with communication difficulties

A review of inclusion and exclusion criteria showed that eight out of twenty studies (40%) reported total or partial exclusion of stroke survivors with communication difficulties. In nine studies (45%), it was unclear whether stroke survivors with communication difficulties had been included or excluded (Allen et al., 2002; Allen et al., 2009; Chumbler et al., 2012; Chumbler et al., 2015; Fido, 2010; Harwood et al., 2012; Johnston et al., 2007; Marsden et al., 2010; McKenna et al., 2015; Sackley et al., 2006). Two studies (10%) explicitly excluded all participants with aphasia (Frank et al., 2000; Taylor et al., 2012). Six studies (30%) reported the partial exclusion of stroke survivors with communication difficulties (Damush et al., 2011; Glass et al., 2004; Kendall et al., 2007; Polatajko et al., 2012; Robinson et al., 2008; Sabariego et al., 2013). Partial exclusion refers to studies where a proportion of stroke survivors with communication difficulties were excluded. Where partial exclusions were reported, three studies reported the use of a standardised screening tool (Damush et al., 2011; Glass et al., 2004; Robinson et al., 2008), one used the judgement of the treating speech and language therapist (Kendall et al., 2007), one the judgement of a physician (Sabariego et al., 2013). In the remaining study, it was unclear how the exclusion criterion of 'no more than minimal aphasia' was determined (Polatajko et al., 2012). In four out of six studies, partial exclusions appeared to be related to those with severe language deficits (Damush et al., 2011; Glass et al., 2004; Robinson et al., 2008; Sabariego et al., 2013); the inclusion criteria of remaining two studies were less clear about the level of impairment; 'no more than minimal aphasia' (Polatajko et al., 2012) and 'sufficient expressive/receptive English language skills to take part in interviews and the intervention, as determined by the treating speech pathologist' (Kendall et al., 2007). None of the studies with partial exclusion criteria reported the number of stroke survivors with communication difficulties who did participate.

Three out of 20 studies (15%) reported the number of stroke survivors with aphasia included. Aben et al.'s sample (Aben et al., 2012; Aben et al., 2014) included 11.1% of participants with aphasia, Cadilhac et al.'s (2011) sample included 34.27% of participants with aphasia and Guidetti et al.'s sample (Guidetti et al., 2010; Guidetti and Ytterberg, 2011) included 42.5% of stroke survivors with aphasia. Although Aben et al.'s inclusion and exclusion criteria did not appear to exclude participants with communication difficulties, and the number of participants with aphasia was reported,

the authors of the paper describe in their results section the exclusion of three participants due to a 'severe language disorder' suggesting that this population were partially excluded. The authors of the 15 remaining studies that did not report the number of participants with communication difficulties were contacted by email (where available). No further data were obtained following email communication. The rationale for the inclusion or exclusion of stroke survivors with communication difficulties was not reported in any of the included studies.

Efficacy of self-management interventions for stroke survivors with communication difficulties

Two studies met the pre-specified criteria for meta-analysis by including $\geq 20\%$ of stroke survivors with communication difficulties (Cadilhac et al., 2011; Guidetti et al., 2010; Guidetti and Ytterberg, 2011). However, meta-analysis was not performed for two reasons. The first was clinical heterogeneity; Cadilhac et al.'s intervention had previously been categorised as a 'general self-management intervention' and Guidetti et al.'s intervention was categorised as an 'occupational self-management intervention'. It was, therefore, inappropriate to pool results from two heterogeneous types of self-management interventions. The second reason meta-analysis was not performed was due to a lack of comparable outcome measures. Cadilhac et al.'s outcome measures were related to health education and quality of life and Guidetti et al. measured ADL, life satisfaction and caregiver burden. The results of these studies are therefore synthesised narratively below:

Cadilhac et al.'s (2011) study was a pilot study and therefore was not adequately powered to detect efficacy. No statistically significant differences were found between the intervention and control groups; however, the authors concluded that their self-management intervention was safe and feasible to deliver in practice. Guidetti et al.'s study was also a pilot study and again was not adequately powered to detect differences between the intervention and control group (Guidetti et al., 2010; Guidetti and Ytterberg, 2011). The authors found no statistically significant differences between the intervention and control group in terms of ADL, life satisfaction or caregiver burden at 3, 6 and 12 months post-stroke.

1.5. Discussion

Summary of main results

This systematic review identified 20 RCTs of self-management in stroke involving 2379 participants. The theoretical rationales, delivery and content of the self-management interventions identified varied widely as did the outcome measures used to determine effectiveness. Just under half of the interventions identified were pilot or feasibility studies. Only three out of 20 (15%) self-management trials identified reported the number of stroke survivors with communication difficulties included. Eight out of 20 (40%) self-management trials reported total or partial exclusion of stroke survivors with communication difficulties in their inclusion/exclusion criteria. In nine out of 20 (45%) self-management trials, it was unclear whether stroke survivors with communication difficulties were included or excluded. The efficacy of self-management interventions for stroke survivors with communication difficulties could not be established for two reasons; firstly, due to the low number of trials reporting the number of stroke survivors with communication difficulties who were included and secondly, due to clinical heterogeneity and lack of comparable outcome measures in the two trials that included the pre-specified number of stroke survivors with communication difficulties.

This review adds to the findings of previous systematic reviews of self-management in stroke (Fryer et al., 2016; Lennon et al., 2013) by highlighting the exclusion of stroke survivors with communication difficulties and, the lack of evidence of the effectiveness of this approach for this population. Caution must be applied when interpreting the positive effects of self-management interventions suggested by Fryer et al. (2016), as stroke survivors with communication difficulties may be underrepresented in RCTs of this approach.

Methodological quality of included studies

The methodological quality of the included studies was mixed. Twelve out of 20 of the trials identified were judged to be at high risk of bias in at least one domain. Five studies failed to report adequate blinding of the outcome assessor and were judged to be at high risk of bias in this area (Allen et al., 2002; Chumbler et al., 2012; Chumbler et al., 2015; Fido, 2010; Frank et al., 2000; McKenna et al., 2015; Polatajko et al., 2012; Robinson et al., 2008). A systematic review conducted by Hróbjartsson et al. (2013) suggests that treatment effects may be exaggerated in trials where unblinded outcome

assessors are used to assess subjective outcomes that rely to some extent on their own judgement of a participant's condition. The results of the studies identified as being at high risk of bias in this domain should therefore be interpreted with caution. Several of the studies were at high risk of bias in the blinding of participants and personnel domain. However, it may be difficult if not impossible to blind participants and personnel in RCTs of complex interventions, particularly if the intervention is compared to usual care or a wait list control (Higgins and Green, 2011). It may not be relevant to place emphasis on this risk of bias domain with regards to the methodological quality of the RCTs included in this review.

Three studies were judged to be at high risk of attrition bias due to incomplete outcome data (Fido, 2010; Polatajko et al., 2012; Sabariego et al., 2013). This is problematic as those participants missing from the analysis may vary systematically from those who are included (CRD, 2009). For example, more withdrawals in the intervention arm of the study may be due to an unintended negative effect of the treatment. Excluding these participants from the analysis, may make the treatment appear more favourable (Jüni et al., 2001).

Another methodological weakness apparent in the trials identified was the selective reporting of outcome measures. Two studies were at high risk of bias in this domain (Chumbler et al., 2012; Chumbler et al., 2015; Harwood et al., 2012). Reviews of outcome reporting suggest that treatment effectiveness is likely to be exaggerated by selective outcome reporting as the outcomes chosen to be reported are generally those that reach statistical significance (Chan and Altman, 2005; Dwan et al., 2013). The results of the studies identified as being at high risk of bias should also be interpreted with caution.

Limitations of the review

The diversity of the interventions identified highlights the uncertainties that still remain about the optimum way to deliver self-management interventions in stroke care. As previously stated, there is no gold standard definition of the term 'self-management'. This review aimed to be as inclusive as possible of potential self-management interventions, however, it may be criticised for being overly inclusive of interventions that did not explicitly identify themselves as 'self-management'. There is significant overlap between some standard features of stroke rehabilitation provided by

occupational therapists and components of self-management interventions. For example, goal-setting and problem solving is an integral part of occupational therapy (Legg et al., 2007a). However, it is unclear if such interventions should be included in reviews of self-management as their focus is generally upon regaining physical independence, as opposed to targeting the psychosocial impact of the condition, something which has been suggested as a key component of self-management (Jones et al., 2013; Barlow et al., 2002). Occupational therapy interventions comprised a significant proportion of studies in a stroke self-management review by Taylor et al. (2014). In contrast, a stroke self-management review protocol by Fryer et al. (2013) restricted interventions to those targeting quality of life outcomes only. This would exclude many occupational therapy interventions that target the performance of ADL (Legg et al., 2007a).

These contrasting approaches highlight the uncertainties that remain about the delivery of self-management in stroke, and whether such interventions should focus upon one aspect of self-management (e.g. physical functioning), or address the management of the condition as a whole (e.g. physical, psychological and social functioning). Given the complexity of the difficulties faced by stroke survivors (McKevitt et al., 2011), a case may be made for a holistic approach to be taken, and for multiple aspects of self-management to be targeted within one intervention. A focus solely upon physical functioning may also be of limited relevance to stroke survivors with communication difficulties (Boger et al., 2013; Wallace et al., 2017a).

Interpretation and implications for future research

Despite being recommended as an approach that should be offered to all stroke survivors (Intercollegiate Stroke Working Party, 2016; Department of Health, 2007), this review highlights how stroke survivors with communication difficulties, particularly those with moderate to severe communication difficulties, are underrepresented in trials of self-management. This may lead to a systematic lack of evidence for the feasibility, acceptability and efficacy of this approach for this sub-group of stroke survivors. The systematic exclusion of this population of stroke survivors is not only discriminatory, but may also lead to health inequalities due to a lack of evidence regarding the effectiveness of self-management interventions for this population. Future trials of self-management should clearly report the population targeted, including the inclusion or exclusion of stroke survivors with communication difficulties and the rationale for the inclusion or exclusion of this population. A number of strategies have been developed

to facilitate the inclusion of stroke survivors with communication difficulties in research, for example, the adaptation of consent procedures and written information (Dalemans et al., 2009; Jayes and Palmer, 2014; Luck and Rose, 2007). However, in addition to proactive recruitment strategies, it is likely that the inclusion of stroke survivors with communication difficulties will require careful consideration and adaptation of self-management approaches as a whole. The ways in which self-management approaches may need to be adapted are explored in further detail in the next two chapters.

Conclusion

The evidence base for self-management in stroke is growing rapidly and an additional 11 trials of self-management have been identified since the Lennon et al. review in 2013¹. As self-management has been recommended as a core component of longer-term care (Intercollegiate Stroke Working Party, 2016; National Stroke Strategy, 2007), it is important that such interventions are accessible to stroke survivors with communication difficulties or that an alternative form of longer-term support is developed for this population. In the next chapter, a comprehensive systematic review and synthesis of qualitative literature is undertaken to understand the needs of stroke survivors with communication difficulties in relation to longer-term care. The findings of this review and the current review are drawn together in Chapter Three, in order to explore whether existing self-management interventions address the needs of stroke survivors with communication difficulties, and considering this, whether such interventions are likely to be an appropriate means of supporting this population in the longer-term.

¹ Additional work was undertaken on this review for publication that included a meta-analysis of stroke self-management interventions (Wray et al., 2017). This was not relevant to the focus of this thesis upon self-management for stroke survivors with communication difficulties and so the decision was made not to include this work in this thesis. The work undertaken for this publication did not alter the conclusions of the review presented in this chapter.

Chapter Two: Sub-review two (Qualitative studies)

This chapter reports upon the second systematic review undertaken as part of the EPPI centre mixed methods approach; A systematic review of the qualitative literature exploring the longer-term needs of stroke survivors with communication difficulties.

2.1. Introduction

Qualitative research provides in-depth accounts of the views, meanings and experiences of patients, and is increasingly seen as an important contributor to complex intervention development (MRC, 2008; NICE, 2007; NIHR, 2014). In the wider stroke literature, systematic reviews and syntheses of qualitative literature have been conducted (Salter et al., 2008; Satink et al., 2013; Walsh et al., 2015). However, Walsh et al. (2015) and Satink et al. (2013) noted the lack of studies involving stroke survivors with communication difficulties, and therefore it is unclear if the findings from such reviews can be generalised to this population. More recently, researchers have developed novel strategies to ensure that, wherever possible, those with communication difficulties can be included in qualitative research (Dalemans et al., 2009; Luck and Rose, 2007; Simmons-Mackie and Kagan, 1999). There is a growing body of qualitative literature that highlights the insider perspective on living with a post-stroke communication difficulty (Simmons-Mackie and Lynch, 2013). However, to date there has been no systematic review and synthesis of these studies to utilise this knowledge in order to understand what stroke survivors with communication difficulties may require from longer-term care.

Systematic reviews of qualitative research draw together study findings, allowing a greater level of conceptual or theoretical understanding than can be gained by looking at one study in isolation (Britten et al., 2002; Campbell et al., 2003). Qualitative synthesis aims to go beyond a descriptive summary or aggregation of study findings and create an overall interpretation of the literature. This review uses thematic synthesis (Thomas and Harden, 2008) which clearly distinguishes between synthesis at a descriptive and interpretive level. Two types of themes are developed: Descriptive themes which are a summary of findings across included studies and analytical themes

which translate or interpret study findings with regards to the research question. By creating an overall interpretation of the literature in relation to a particular research focus, the findings can inform future intervention development, clinical practice and policy (Britten et al., 2002; Campbell et al., 2003).

It was important to synthesise qualitative research findings to better understand the requirements for longer-term care from the patients' perspective. In this review, the requirements for longer-term care were conceptualised as 'needs'. This review aimed to explore the needs of stroke survivors with communication difficulties in relation to longer-term care. As healthcare services strive to meet individual and population level health requirements and maximise the efficiency of finite resources, the concept of health 'need' is gaining increasing importance (Asadi-Lari and Gray, 2005). It is proposed that designing services according to need is essential to providing patient centred care and to improving patients' quality of life (Asadi-Lari et al., 2004). Mobilising resources according to need is also proposed to have an inherent cost saving implication, another benefit of taking this approach (Asadi-Lari et al., 2004). Linked to the development of needs based healthcare services is the active involvement of patients and members of the public in service design and intervention development. For example, NICE (2007) recommend that complex behaviour change interventions should be based upon a 'needs assessment' with the target population. This is not only required to set out which behaviours are to be targeted and why but also to assess potential barriers to change. Understanding patients' needs is thus suggested to be a crucial component of intervention design (NIHR, 2014; MRC, 2008; NICE, 2007).

It is important to note there is no agreed definition of health 'need' and there is substantial variation in existing definitions of this concept (Asadi-Lari et al., 2003). Culyer (1998) suggests that 'It may be an illusion to suppose that there might ever be a consensus about the meaning of "need"...' (p. 77). Health economists have defined need as 'the capacity to benefit from healthcare' (Stevens and Gillam, 1998) (p.1448), however, this definition may be criticised as it assumes that need only exists where there is capacity to benefit from healthcare, and risks focusing upon needs which can be addressed easily by healthcare services (Asadi-Lari et al., 2003). The World Health Organisation (WHO) define health needs as:

"Objectively determined deficiencies in health that require health care, from promotion to palliation" (WHO, 2016).

However, as noted by Bradshaw (1972) perspectives of need may differ from person to person: From normative needs (those from the perspective of the healthcare professional) to felt needs (wishes, wants, or desires of the patients) to expressed needs (those vocalised by patients). Therefore to 'objectively' determine need may be difficult. For the purposes of this review, a pragmatic approach is taken and the following definition of need was adopted:

“What patients – and the population as a whole desire to receive from health care services to improve overall health.” (Asadi-Lari et al., 2004) (p.2).

This definition of need may be criticised for lacking the economic perspective on need, for example, in relation to resource rationing and cost containment. However, in line with the aims of this review, the patients' perspective of need was prioritised.

2.2. Review objective

1) To identify and synthesise qualitative research relating to the longer-term needs of stroke survivors with communication difficulties.

2.3. Method

A systematic review and thematic synthesis (Thomas and Harden, 2008) of qualitative research relating to the longer-term needs of stroke survivors with communication difficulties living in the community was undertaken.

Eligibility criteria

Study design:

Studies published in English, employing qualitative methodology and qualitative methods of data analysis.

Population:

Adults (aged 16+) with communication difficulties following stroke (aphasia, dysarthria or apraxia of speech).

Outcomes:

The perceived or expressed needs, views or experiences of stroke survivors with communication difficulties in relation to the day-to-day management of their condition following hospital discharge (including studies in which carers, friends or relatives shared their perspectives upon the needs, views or experiences of stroke survivors). Studies were excluded where the focus was upon the delivery or evaluation of a specific communication intervention.

Search terms

Search terms were developed with an information specialist using an iterative process including scoping searches and repeated piloting. In traditional reviews of effectiveness, methods and filters for identifying RCTs are well established. However, qualitative research is often indexed inconsistently across databases and is difficult to pick up using free text search terms due to the use of creative titles and focus upon findings (as opposed to methods) in abstracts (Evans, 2002). This poses difficulties when identifying qualitative research systematically (CRD, 2009; Flemming and Briggs, 2007; Shaw et al., 2004). Some argue the use of a broader approach by not including any filter in relation to qualitative methodology (Gough et al., 2012). However, in this case a qualitative filter (Wong et al., 2004) was applied due to the unmanageable numbers of citations (48 000) initially returned. This potential limitation was addressed by ensuring that multiple search strategies were used. Search terms were initially developed and run in Ovid Medline and then adapted according to the capabilities of each database. A copy of the search terms is available in Appendix B.

Information sources

The following databases of published literature were searched: MEDLINE, EMBASE, PsycINFO, CINAHL, The Cochrane Library, International bibliography of the social sciences (IBSS) and AMED. To limit publication bias, the following grey literature sources were searched: Index to Theses (UK dissertations and Theses), ProQuest (international dissertations and theses) and Web of science conference proceedings. Searches were conducted week commencing 2nd February (Week 5, 2015) and databases were searched from inception. To ensure that the search was comprehensive, other search strategies were also implemented including;

- Hand searching the reference lists of studies meeting inclusion criteria.
- Reverse citation search of studies meeting inclusion criteria

- Reference list check and reverse citation search of an existing systematic review of qualitative literature in stroke care (McKevitt et al., 2004).

Study selection

All citations identified were exported to Endnote X7 bibliographic management software (Clarivate Analytics, 2013) where duplicates were removed. Studies were screened and selected firstly based upon title and abstract review, and then selected following full text review. Title and full text screening and selection was performed independently by the first author and another researcher for all studies. Discrepancies were resolved by consensus with the author's supervisors.

Data extraction

Data were extracted using a template. Data extracted included study aim(s), participant characteristics (age, gender, type of communication difficulty, time post-stroke), sample size, country, study setting and methodology (method of data collection, method of analysis). Findings of included studies were also used to inform the thematic synthesis (see data synthesis). Double data extraction was completed for 30% of the included studies and compared to ensure agreement levels were high.

Quality Assessment

There is substantial debate concerning the criteria that should be used to determine study quality in qualitative research (Mays and Pope, 2000). The National Institute for Health and Care Excellence (NICE) public health guidance qualitative appraisal checklist was used to assess methodological quality in this review (NICE, 2012). NICE created this checklist based upon the broad issues that are generally accepted to affect validity in qualitative research. The checklist comprises of 14 domains including theoretical rationale (appropriateness, clarity), study design, data collection, trustworthiness (role of the researcher, context, reliable methods), analysis (rigorous, rich data, reliable, convincing, relevance to aims), conclusions and ethics. The researcher may endorse the presence or absence of the domain characteristic or mark as unclear/not reported. The checklist also has an overall assessment of study quality which can be marked (++) 'All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter' or (+) 'Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter' or (-) 'Few or no checklist

criteria have been fulfilled and the conclusions are likely or very likely to alter'. Due to the communication difficulties experienced by the target population, adjustments were made when considering the presentation of 'rich' data in the included studies. Illustrative quotations were assessed based on the meaning they conveyed and in conjunction with contextual information provided by the authors to aid interpretation (e.g. use of gesture, topic being discussed). Richness was therefore weighted towards assessing the richness of interpretation in contrast to the richness of the illustrative quotations. In addition to being completed by one researcher, quality assessment was performed by a second researcher for 30% of the included studies. Discrepancies were resolved by discussion and consensus by a third reviewer and remaining quality assessments were revised in line with the discussion to ensure consistency.

Quality assessment was not used to exclude studies but to highlight potential limitations of the research. Although all studies were included in the data synthesis, the findings of lower quality studies were reviewed to ensure that they did not contradict the findings of higher quality studies and to ensure that they did not make a disproportionate contribution to the development of the thematic synthesis.

Data synthesis

There is no consensus on the most appropriate method for the synthesis of qualitative data (CRD, 2009; Higgins and Green, 2011) and a number of approaches have been developed including qualitative meta-synthesis (Walsh and Downe, 2005), meta-ethnography (Britten et al., 2002; Campbell et al., 2003) and thematic synthesis (Gough et al., 2012; Thomas and Harden, 2008). In this review, studies were combined using thematic synthesis. This method of synthesis was specifically formulated by the EPPI centre to organise findings from qualitative literature to enable reasoned hypotheses about intervention need, appropriateness and acceptability (Barnett-Page and Thomas, 2009). Like meta-synthesis and meta-ethnography, thematic synthesis allows for a deeper exploration of findings that goes beyond narrative summary (Gough et al., 2012; Thomas and Harden, 2008). Unlike meta-synthesis and meta-ethnography, thematic synthesis transparently reports the descriptive and interpretive levels of synthesis; distinguishing between the 'data-driven' descriptive themes and 'theory-driven' analytical themes. In thematic synthesis, the review question provides the theoretical framework to drive the development of the analytical themes. This differs from other methods of synthesis (e.g. grounded theory or meta-ethnography) which

focus upon theory generation without a pre-existing framework and without the explicit intention to inform intervention development (Britten et al., 2002; Eaves, 2001).

Synthesising the data was a four stage process that included:

- Stage One: Coding meaningful segments of data
- Stage Two: Sorting meaningful segments of data in to descriptive categories
- Stage Three: Development of descriptive themes
- Stage Four: Development of analytical themes

Key findings (supported by relevant quotations) from each included study were extracted and free coded line by line using QSR NVivo software version 10 (QSR International, 2012) (Stage One). Groups of descriptive codes were formed based on similarities between the free codes (Stage Two). Through discussion with the author's supervisors, the contents of each of the groups of descriptive codes were explored and further refined to create descriptive themes (Stage Three). Analytical themes were developed through an iterative process that included discussion of the links between the descriptive themes and the implications of these upon the needs of stroke survivors with communication difficulties and future intervention development (Stage Four) (Gough et al., 2012; Morton et al., 2010; Thomas and Harden, 2008). Analytical themes were developed with input from the author's supervisors and by gaining feedback on draft analytical themes from a peer review group in the Academic Unit of Elderly Care and Rehabilitation.

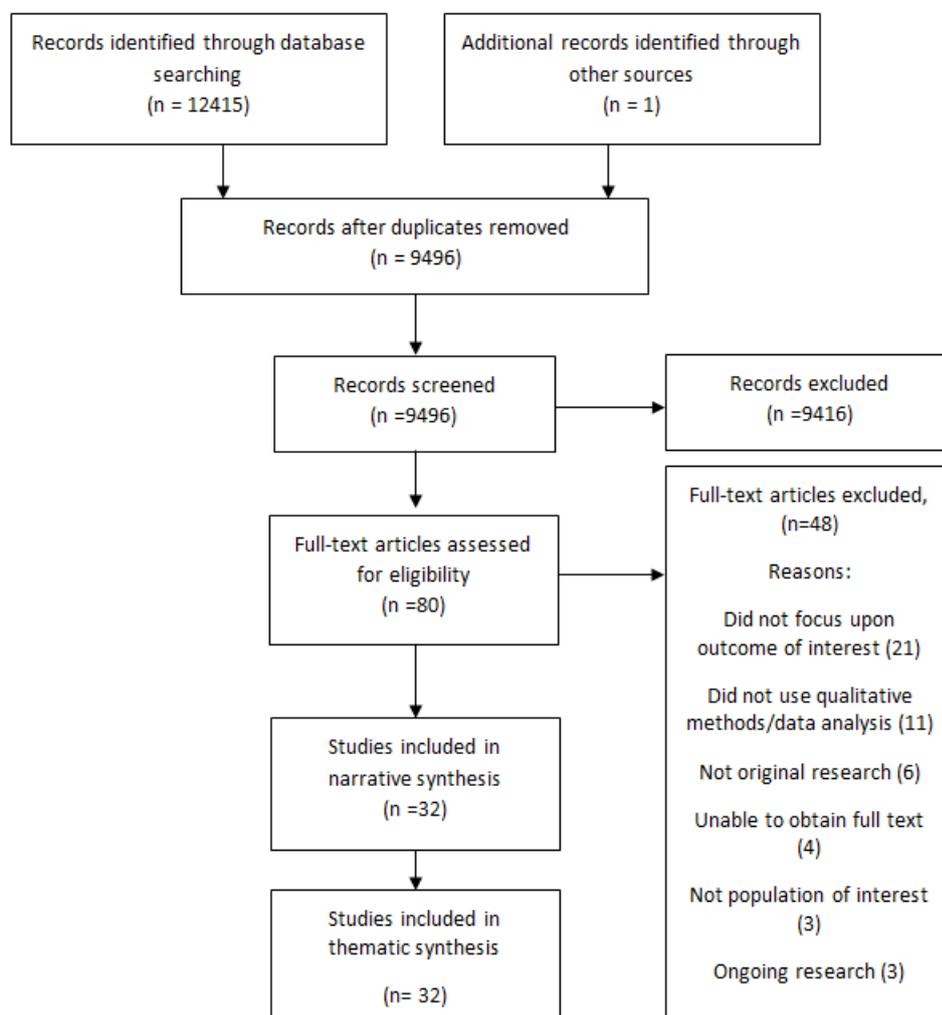
The creators of this approach acknowledge that the process of deriving analytical themes from descriptive themes may be controversial and open to bias (Thomas and Harden, 2008). To reduce bias they recommend transparent reporting of the process and discussion within the wider review team. These principles were adhered to as much as possible during this review. It is also important to note that due to the volume of data at Stage One, it was necessary to add an additional stage of analysis (Stage Two) to that described by Thomas and Harden (2008). Thematic synthesis has been criticised by some for lacking transparency (Pope et al., 2007); in this review this additional stage of analysis should make clearer the process of deriving the descriptive themes from initial coding.

2.4. Results

Study selection

Once duplicates had been removed, a total of 9496 records were screened for eligibility and full text was sought for 80 citations. 48 were excluded; 21 studies did not focus upon the outcome of interest (Ashton et al., 2008; Barrow, 2008; Blonski et al., 2014; Ferguson et al., 2010; Garcia et al., 2000; Greig et al., 2008; Howe et al., 2012; Jones et al., 2008; Legg et al., 2007b; Mackenzie et al., 2013; Mitchell et al., 2011; Morris et al., 2014; Mumby and Whitworth, 2012; Mumby and Whitworth, 2013; Northcott and Hilari, 2011; Nystrom, 2006; Nystrom, 2009; Parr, 1994; Parr, 1995; Pearl et al., 2011; Tregaea and Brown, 2013), 11 studies did not use qualitative methods or qualitative methods of data analysis (Boles, 2006; Carriero et al., 1987; Cruice et al., 2006b; Davidson et al., 2006; Horton et al., 1998; Lemieux et al., 2001; Parr et al., 2006; Simmons-Mackie and Damico, 2001; Skelly, 1975; Wallace, 2010; Zemva, 1999), six were not original research (e.g. were commentaries or book reviews) (Marshall, 1998; Parr et al., 2004; Rolnick and Hoops, 1969; Schnitzer and Goodglass, 1991; Worrall et al., 2007; Worrall et al., 2010), four for which the author was unable to obtain full text (Fretterd, 2014; Kardosh, 2011; Klippi, 2000; Yoshimura et al., 2004), three did not include the population of interest (Ellis et al., 2013; Lanza and Prunier, 2002; Walshe and Miller, 2011) and, three ongoing pieces of research for which the results were not yet available (Anglade et al., 2013; Foster et al., 2013; Van Wijck et al., 2013). Thirty two citations were identified which were eligible for inclusion in the review. The PRISMA flow diagram of study selection is shown in Figure 6.

Figure 6: PRISMA flow diagram (sub-review two) (Adapted from Moher et al., 2009)



Study characteristics

The characteristics of included studies are shown in Table 4. The table is organised alphabetically by study author.

Table 4: Characteristics of included studies (sub-review two)

Authors	Aim of study	Communication difficulty	Size	Country	Setting	Age range	Gender	Time post-stroke	Method of data collection	Time points	Method of analysis	Overall assessment of methodological quality
Baylor et al. (2011)	To explore the similarities and differences in self-reported restrictions in communicative participation across different communication disorders in community-dwelling adults	Aphasia, Apraxia of Speech, Dysarthria	44	USA	Community	37-88	21 male 23 female	Mean 8.2 years (SD 7.4, range 0.5-24)	Interview	One interview	Content analysis	-
Brady et al. (2011a)	To explore the impact of dysarthria on social participation following stroke	Dysarthria	24	UK	Community	34-86	15 male 9 female	Mean (months) 8 (SD 7, range 2-34)	Interview	One interview	Grounded theory	+
Brady et al. (2011b)	To explore the perceptions of people with stroke-related dysarthria in relation to the management and rehabilitation of dysarthria	Dysarthria	24	UK	Community	34-86	15 male 9 female	Up to 3 years (mean not reported)	Interview	One interview	Grounded theory	+
Brown et al. (2010)	To explore from the perspectives of people with aphasia, the meaning of living successfully with aphasia	Aphasia	25	Australia	Community	38-86	13 male 12 female	Mean (months): 71.5 (SD 62.3, range 24-299)	Interviews and participant generated photography	Two interviews	Interpretive phenomenological analysis	++
Brown et al. (2011)	To explore from the perspectives of family members of individuals with aphasia, the meaning of living successfully with aphasia	Aphasia	24	Australia	Community	40-87	9 male 15 female	?	Interview	One interview	Interpretive phenomenological analysis	++
Brown et al. (2013)	To explore the perspectives of 25 community dwelling individuals with chronic aphasia on the role of friendship in living successfully with aphasia	Aphasia	25	Australia	Community	38-86	13 male 12 female	Mean (months): 71.5 (SD 62.3, range 24-299)	Interviews and participant generated photography	Two interviews	Thematic analysis	+

Table 4: Characteristics of included studies (sub-review two) (continued)

Authors	Aim of study	Communication difficulty	Size	Country	Setting	Age range	Gender	Time post-stroke	Method of data collection	Time points	Method of analysis	Overall assessment of methodological quality
Cruice et al. (2010)	To explore how older people with chronic aphasia who are living in the community describe their quality of life in terms of what contributes and what detracts from the quality in their current and future lives.	Aphasia	30	Australia	Community	57-88	14 male 16 female	Mean (months): 41 (SD 25.6, range 10-108)	Interview	One interview	Content analysis	+
Cyr (2010)	To investigate factors associated with resilience in individuals with aphasia	Aphasia	9	USA	Community	47-73	?	?	Interview	One interview	Content analysis	-
Dalemans et al. (2010)	To explore how people with aphasia perceive participation in society and to investigate influencing factors.	Aphasia	13	The Netherlands	Community	45-71	7 male 6 female	Range (years): 1-11	Interview and Diary	One interview. Diary kept for 2 weeks prior to interview.	?	++
Davidson et al. (2008a)	The aims were to describe everyday communication with friends for older people with and without aphasia and to examine the nature of actual friendship conversations involving a person with aphasia.	Aphasia	15	Australia	Community	64-80	7 male 8 female	Mean (months) 42.13 (SD 27.70)	Observation and communication diary (Phase One) Qualitative interview data from simulated recall (Phase Two)	3 separate observations for a total of 8 hours on one week Diary kept on 5 consecutive days	Inductive interpretive analysis (Phase One) Systematic qualitative analysis (Phase Two)	+

Table 4: Characteristics of included studies (sub-review two) (continued)

Authors	Aim of study	Communication difficulty	Size	Country	Setting	Age range	Gender	Time post-stroke	Method of data collection	Time points	Method of analysis	Overall assessment of methodological quality
Davidson et al. (2008b)	To explore the insider perspective on the impact of aphasia on social communication and social relationships, and to explore components of the interactional function of everyday communication that are identified by older people with aphasia.	Aphasia	3	Australia	Community	69-84	1 male 2 female	?	Interviews and Diary data	One qualitative interview, One stimulated recall interview regarding a previously videotaped recording of an interaction with a communication partner, Diary about communication kept for 7 days	Qualitative interview and stimulated recall interview: Framework Analysis Diary: Analysed following guidance by Code (2003)	+
Dickson et al. (2008)	To investigate the beliefs and experiences of people with dysarthria as a result of stroke in relation to their speech disorder, and to explore the perceived physical, personal and psychosocial impacts of living with dysarthria.	Dysarthria	24	UK	Community	34-86	15 male 9 female	Mean (months): 7.07 (range 2-34)	Interview	One interview	Grounded theory	+
Dietz et al. (2013)	To (a) explore the social role changes experienced by people with aphasia, (b) understand the use of communication strategies when attempting to reclaim previous roles, and (c) determine whether discrepancies existed between PWA and their potential proxies regarding social role change changes/adaptations.	Aphasia	3	USA	Community	41-85	2 male 1 female	Range (months): 24-180	Interview	One interview	Interpretative Phenomenological Analysis	+

Table 4: Characteristics of included studies (sub-review two) (continued)

Authors	Aim of study	Communication difficulty	Size	Country	Setting	Age range	Gender	Time post-stroke	Method of data collection	Time points	Method of analysis	Overall assessment of methodological quality
Fotiadou et al. (2014)	To explore the impact of stroke and aphasia on a persons relationships with family, friends and the wider network through analysing blogs written by people with aphasia	Aphasia	10	USA, UK, Turkey	Community	29-69	4 male 6 female	At least one year (mean not reported)	Analysis of online blogs	N/A	Framework analysis	++
Grohn et al. (2012)	To describe the experience of the first 3 months post-stroke in order to identify factors which facilitate successfully living with aphasia	Aphasia	15	Australia	Community	47-90	8 male 7 female	3 months (± 2 weeks)	Interview	3 months post-stroke	Thematic analysis	++
Grohn et al. (2014)	To describe the insiders perspective of what is important to living successfully with aphasia and changes that occur throughout the first year post-stroke	Aphasia	15	Australia	Community	47-90	8 male 7 female	3, 6, 9, 12 months	Interviews	3, 6, 9, 12 months post-stroke	Thematic analysis	++
Hinckley (2006)	The question "what does it take to live successfully with aphasia?" was posed and answers sought within already published accounts written by people living successfully with aphasia.	Aphasia	20	?	Community	?	?	?	Analysis of published personal narratives	N/A	Thematic analysis	+
Howe et al. (2008a)	To explore the environmental factors that hinder or support the community participation of adults with aphasia	Aphasia	25	Australia	Community	34-85	15 male 10 female	Mean (months) 66.6 (SD 34.4, range 10-137)	Interviews	One interview	Content analysis	++
Howe et al. (2008b)	To explore the environmental factors that hinder or support the community participation of adults with aphasia.	Aphasia	10	Australia	Community	35-72	6 male 4 female	Mean (months) 97.1 (SD 29.2, range 51-155)	Observation	Approximately 3 hours of observation	Content analysis	++

Table 4: Characteristics of included studies (sub-review two) (continued)

Authors	Aim of study	Communication difficulty	Size	Country	Setting	Age range	Gender	Time post-stroke	Method of data collection	Time points	Method of analysis	Overall assessment of methodological quality
Johansson et al. (2012)	To explore how people with aphasia experience having conversations, how they handle communication difficulties and how they perceive their own and their communication partners use of communication strategies	Aphasia	11	Sweden	Community	48-79	7 male 4 female	Mean (months) 38 (range 13-75)	Interviews	One interview	Content analysis	++
Le Dorze and Brassard (1995)	(1) To understand the consequences of aphasia in the terms used by aphasic persons and their friends and relatives to describe their experience of this communication disorder (2) To qualitatively analyse and structure the different descriptions with the concepts of impairment, disability handicap and coping behaviour	Aphasia	9	Canada	Community	44-69	5 male 4 female	Mean (years) 5.5 (range 2-14)	Interviews	One interview	Grounded Theory	+
Le Dorze et al. (1996)	To explore with a qualitative approach the experience of auditory comprehension problems from the perspective of aphasic persons and their family and friends	Aphasia	24	Canada	Community	33-71	10 male 14 female	Mean (months) 55.96 (range 4-147)	Focus group	One focus group	Phenomenological	-
Le Dorze et al. (2014)	To explore the factors that facilitate or hinder participation according to people who live with aphasia	Aphasia	17	Canada	Community	51-84	12 male 5 female	Mean (years) 5.7 (range 2-18)	Focus group	One focus group	Content analysis	+

Table 4: Characteristics of included studies (continued)

Authors	Aim of study	Communication difficulty	Size	Country	Setting	Age range	Gender	Time post-stroke	Method of data collection	Time points	Method of analysis	Overall assessment of methodological quality
Matos et al. (2014)	To explore and understand the perspectives of Portuguese people with aphasia, family members and speech and language therapists	Aphasia	14	Portugal	Community	41-80	11 male 3 female	Mean (months) 27.57 (range 3-89)	Group and individual interviews	Participants with mild to moderate aphasia were interviewed as a group and those with severe aphasia were interviewed individually	Thematic analysis	+
Nätterlund (2010)	To describe aphasic individuals' experiences of everyday activities and social support in daily life	Aphasia	20	Sweden	Community	32-70	14 male 6 female	Mean (years) 6.52 (range 3 to 11 years)	Interview	One interview	Content analysis	++
Niemi and Johansson (2013)	To describe and explore how persons with aphasia following stroke experience engaging in everyday occupations	Aphasia	6	Finland	Community	46-75	3 male 3 female	Mean (years) 2.5 (range 1-4)	Interviews	2-3 interviews over two months	Empirical phenomenological analysis	+
Parr (2001)	To describe the consequences and significance of long-term aphasia	Aphasia	50	UK	Community	?	28 male 22 female	Mean (years) 7.7 (range 5-21)	Interview	One interview	Framework method	+
Parr (2007)	To track the day-to-day life and experiences of people with severe aphasia, and to document levels of social inclusion and exclusion as they occurred in mundane settings.	Aphasia	20	UK	Community	33-91	11 male 9 female	Mean (years) 4.67 (range 0.9-15)	Ethnography	Visited and observed 3 times in different domestic and care settings	Framework method	-

Table 4: Characteristics of included studies (sub-review two) (continued)

Authors	Aim of study	Communication difficulty	Size	Country	Setting	Age range	Gender	Time post-stroke	Method of data collection	Time points	Method of analysis	Overall assessment of methodological quality
Pound (2013)	To investigate how people with aphasia understand friends and friendship	Aphasia	28	UK	Community	?	Phase One: 6 male 6 female Phase Two: ?	Phase One: Mean (years) 7.46 (range 1.5-20) Phase Two: ?	Interview	One interview per participant in each Phase	Thematic analysis	++
Pringle et al. (2010)	To gain a greater understanding of the experience of returning home for stroke survivors and their carers.	Aphasia	4	UK	Community	?	?	1 month	Interviews and self-report diaries	One interview and diary	Phenomenological approach	-
Runne (2012)	To examine the relationship between self-efficacy and a person's choice to participate in life roles involving communication by inviting the experts (i.e. people with speech and language disorders) to share their experiences.	Aphasia and Dysarthria	5	USA	Community	51-69	2 male 3 female	Mean (years) 8 (range 3-14)	Interview	One interview	Thematic analysis	-
Worrall et al. (2011)	To describe the goals of people with aphasia and to code the goals according to the ICF.	Aphasia	50	Australia	Community	?	24 male 26 female	Mean (months) 54.9 (SD 43.6)	Interview	One interview	Qualitative content analysis	+

Key: [? : Insufficient information, N/A: Not applicable]

The experiences of 518 stroke survivors with communication difficulties were reported. Studies reporting gender included 249 male and 220 female participants; ages ranged from 29 to 91. Sample sizes ranged from three (Dietz et al., 2013; Davidson et al., 2008b) to fifty (Parr, 2001; Worrall et al., 2011). The majority of studies identified included participants with aphasia (29 out of 32). Only five studies reported including participants with dysarthria (Baylor et al., 2011; Brady et al., 2011a; Brady et al., 2011b; Dickson et al., 2008; Runne, 2012) and one study included participants with apraxia of speech (Baylor et al., 2011). The time post-stroke varied; the participants in 21 studies had a mean time post-stroke of more than 12 months and the participants in five studies had a mean time post-stroke of less than 12 months (Brady et al., 2011a; Dickson et al., 2008; Grohn et al., 2014; Grohn et al., 2012; Pringle et al., 2010).

Methodological quality of included studies

Table 5 shows the results from the NICE public health qualitative appraisal checklist (NICE, 2012). The table is organised alphabetically by study author.

Table 5: Methodological quality of included studies (sub-review two)

		Baylor et al. (2011)	Brady et al. (2011a)	Brady et al. (2011b)	Brown et al. (2010)	Brown et al. (2011)	Brown et al. (2013)	Cruice et al. (2010)	Cyr (2010)
Theoretical Approach	1. Is a qualitative approach appropriate?	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate
	2. Is the study clear in what it seeks to do?	Mixed	Clear	Clear	Clear	Clear	Clear	Clear	Clear
Study design	3. How defensible/rigorous is the research design/methodology?	Indefensible	Defensible	Defensible	Defensible	Defensible	Not Sure	Indefensible	Defensible
Data collection	4. How well was the data collection carried out?	Inappropriately	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately	Not sure/inadequately reported	Appropriately
Trustworthiness	5. Is the role of the researcher clearly described?	Not described	Not described	Not described	Clearly described	Not described	Not described	Not described	Not described
	6. Is the context clearly described?	Unclear	Clear	Clear	Clear	Clear	Clear	Clear	Unclear
	7. Were the methods reliable?	Unreliable	Reliable	Reliable	Reliable	Reliable	Reliable	Not sure	Reliable
Analysis	8. Is the data analysis sufficiently rigorous?	Rigorous	Not sure/not reported	Not sure/not reported	Rigorous	Rigorous	Rigorous	Rigorous	Not rigorous
	9. Is the data 'rich'?	Poor	Not sure/not reported	Rich	Rich	Rich	Rich	Poor	Poor
	10. Is the analysis reliable?	Reliable	Not sure/not reported	Not sure/not reported	Reliable	Reliable	Unreliable	Reliable	Reliable
	11. Are the findings convincing?	Not sure	Convincing	Convincing	Convincing	Convincing	Convincing	Convincing	Not convincing
	12. Are the findings relevant to the aims of the study?	Relevant	Relevant	Relevant	Relevant	Relevant	Relevant	Partially Relevant	Relevant
Ethics	13. Conclusions	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Inadequate
	14. How clear and coherent is the reporting of ethics?	Not sure/not reported	Appropriate	Appropriate	Appropriate	Not sure/not reported	Appropriate	Appropriate	Appropriate
Overall assessment	As far as can be ascertained from the paper, how well was the study conducted?	-	+	+	++	++	+	+	-

Table 5: Methodological quality of included studies (sub-review two) (continued)

		Dalemans et al. (2010)	Davidson et al. (2008a)	Davidson et al. (2008b)	Dickson et al. (2008)	Dietz et al. (2013)	Fotiadou et al. (2014)	grohn et al. (2012)	grohn et al. (2014)
Theoretical Approach	1. Is a qualitative approach appropriate?	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate
	2. Is the study clear in what it seeks to do?	Clear	Clear	Clear	Clear	Clear	Clear	Clear	Clear
Study design	3. How defensible/rigorous is the research design/methodology?	Defensible	Defensible	Not Sure	Defensible	Not Sure	Defensible	Defensible	Defensible
Data collection	4. How well was the data collection carried out?	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately
Trustworthiness	5. Is the role of the researcher clearly described?	Not described	Not described	Not described	Not described	Not described	Not described	Not described	Clearly described
	6. Is the context clearly described?	Clear	Clear	Clear	Clear	Clear	Clear	Clear	Clear
	7. Were the methods reliable?	Reliable	Reliable	Reliable	Reliable	Reliable	Reliable	Reliable	Reliable
Analysis	8. Is the data analysis sufficiently rigorous?	Rigorous	Not rigorous	Rigorous	Not sure/not reported	Not sure/not reported	Rigorous	Rigorous	Rigorous
	9. Is the data 'rich'?	Rich	Rich	Rich	Rich	Rich	Rich	Rich	Rich
	10. Is the analysis reliable?	Reliable	Not sure/not reported	Not sure/not reported	Not sure/not reported	Not sure/not reported	Reliable	Reliable	Reliable
	11. Are the findings convincing?	Convincing	Convincing	Convincing	Convincing	Convincing	Convincing	Convincing	Convincing
	12. Are the findings relevant to the aims of the study?	Relevant	Relevant	Relevant	Relevant	Relevant	Relevant	Relevant	Relevant
	13. Conclusions	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate
Ethics	14. How clear and coherent is the reporting of ethics?	Appropriate	Not sure/not reported	Not sure/not reported	Appropriate	Not sure/not reported	Appropriate	Appropriate	Appropriate
Overall assessment	As far as can be ascertained from the paper, how well was the study conducted?	++	+	+	+	+	++	++	++

Table 5: Methodological quality of included studies (sub-review two) (continued)

		hinckley (2006)	howe et al. (2008a)	howe et al. (2011b)	Johansson et al. (2012)	LeDorze and Brassard (1995)	LeDorze et al. (1996)	LeDorze et al. (2014)	Matos et al. (2014)
Theoretical Approach	1. Is a qualitative approach appropriate?	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate
	2. Is the study clear in what it seeks to do?	Clear	Clear	Clear	Clear	Clear	Mixed	Clear	Clear
Study design	3. How defensible/rigorous is the research design/methodology?	Not Sure	Defensible	Defensible	Defensible	Indefensible	Defensible	Not Sure	Not Sure
Data collection	4. How well was the data collection carried out?	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately
Trustworthiness	5. Is the role of the researcher clearly described?	Not described	Clearly described	Clearly described	Not described	Not described	Not described	Not described	Not described
	6. Is the context clearly described?	Unclear	Clear	Clear	Clear	Clear	Clear	Clear	Clear
	7. Were the methods reliable?	Reliable	Reliable	Reliable	Reliable	Reliable	Reliable	Not sure	Reliable
Analysis	8. Is the data analysis sufficiently rigorous?	Not sure/not reported	Rigorous	Rigorous	Rigorous	Rigorous	Rigorous	Rigorous	Rigorous
	9. Is the data 'rich'?	Rich	Rich	Rich	Rich	Poor	Poor	Rich	Poor
	10. Is the analysis reliable?	Reliable	Reliable	Not sure/not reported	Not sure/not reported	Reliable	Reliable	Reliable	Reliable
	11. Are the findings convincing?	Convincing	Convincing	Convincing	Convincing	Not convincing	Not convincing	Convincing	Not sure
	12. Are the findings relevant to the aims of the study?	Relevant	Relevant	Relevant	Relevant	Relevant	Relevant	Relevant	Partially Relevant
	13. Conclusions	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate	Adequate
Ethics	14. How clear and coherent is the reporting of ethics?	Not sure/not reported	Appropriate	Appropriate	Appropriate	Not sure/not reported	Not sure/not reported	Appropriate	Appropriate
Overall assessment	As far as can be ascertained from the paper, how well was the study conducted?	+	++	++	++	-	+	+	+

Table 5: Methodological quality of included studies (sub-review two) (continued)

		Nätterlund, (2010)	niemi and Johansson (2013)	Parr (2001)	Parr (2007)	Pound (2013)	Pringle et al. (2010)	runne (2010)	Worrall et al. (2011)
Theoretical Approach	1. Is a qualitative approach appropriate?	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate	Appropriate
	2. Is the study clear in what it seeks to do?	Clear	Clear	Clear	Clear	Clear	Unclear	Mixed	Clear
Study design	3. How defensible/rigorous is the research design/methodology?	Not Sure	Defensible	Defensible	Defensible	Defensible	Indefensible	Defensible	Defensible
Data collection	4. How well was the data collection carried out?	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately	Appropriately
Trustworthiness	5. Is the role of the researcher clearly described?	Not described	Clearly described	Not described	Unclear	Unclear	Not described	Not described	Not described
	6. Is the context clearly described?	Clear	Clear	Clear	Clear	Clear	Unclear	Clear	Unclear
	7. Were the methods reliable?	Reliable	Reliable	Reliable	Reliable	Reliable	Reliable	Reliable	Reliable
Analysis	8. Is the data analysis sufficiently rigorous?	Rigorous	Rigorous	Not sure/not reported	Not sure/not reported	Rigorous	Not sure/not reported	Not sure/not reported	Not sure/not reported
	9. Is the data 'rich'?	Rich	Rich	Rich	Not sure/not reported	Rich	Poor	Rich	Poor
	10. Is the analysis reliable?	Not sure/not reported	Not sure/not reported	Not sure/not reported	Not sure/not reported	Reliable	Not sure/not reported	Reliable	Not sure/not reported
	11. Are the findings convincing?	Convincing	Not sure	Not sure	Not sure	Convincing	Not convincing	Not convincing	Convincing
	12. Are the findings relevant to the aims of the study?	Relevant	Relevant	Relevant	Relevant	Relevant	Partially Relevant	Partially Relevant	Relevant
	13. Conclusions	Adequate	Adequate	Adequate	Inadequate	Adequate	Inadequate	Not sure	Adequate
Ethics	14. How clear and coherent is the reporting of ethics?	Appropriate	Appropriate	Not sure/not reported	Inappropriate	Appropriate	Appropriate	Not sure/not reported	Not sure/not reported
Overall assessment	As far as can be ascertained from the paper, how well was the study conducted?	++	+	+	-	++	-	-	+

The majority of studies performed well across the domains. Studies performed less well in domain 5 (Trustworthiness: Role of the researcher). In this domain, only five out of 32 studies reflected upon the role of the researcher in the research (Brown et al., 2010; Grohn et al., 2014; Howe et al., 2008a; Howe et al., 2008b; Niemi and Johansson, 2013). In just under half of the studies (14 out of 32), it was unclear if the methods used for the analysis were reliable (domain 10) (Brady et al., 2011a; Brady et al., 2011b; Davidson et al., 2008a; Davidson et al., 2008b; Dickson et al., 2008; Dietz et al., 2013; Howe et al., 2008b; Johansson et al., 2012; Nätterlund, 2010; Niemi and Johansson, 2013; Parr, 2001; Parr, 2007; Pringle et al., 2010; Worrall et al., 2011). Eight studies were classified as having 'poor' quality data in domain 9 (Analysis: Rich data); failing to provide enough depth and detail to provide convincing insight in to participants experiences (Baylor et al., 2011; Cruice et al., 2010; Cyr, 2010; LeDorze and Brassard, 1995; LeDorze et al., 1996; Matos et al., 2014; Pringle et al., 2010; Worrall et al., 2011). In 11 studies the ethical implications of the research were not adequately reported (Baylor et al., 2011; Brown et al., 2011; Davidson et al., 2011a; Davidson et al., 2011b; Dietz et al., 2013; Hinckley, 2006; LeDorze and Brassard, 1995; LeDorze et al., 1996; Parr, 2001; Runne, 2012; Worrall et al., 2011).

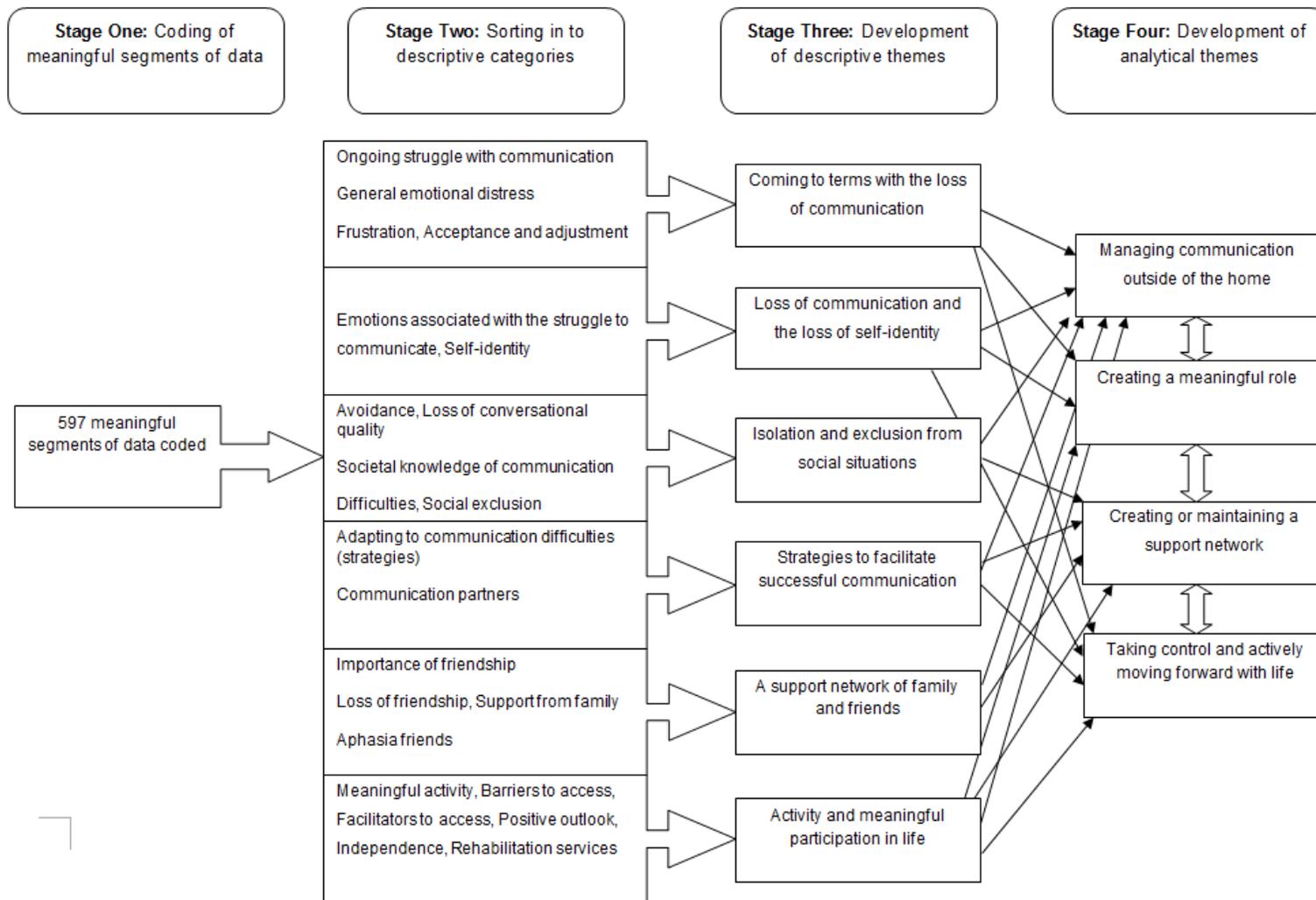
Six studies were scored in the lowest category for the overall assessment (-) (Baylor et al., 2011; Cyr, 2010; LeDorze et al., 1996; Parr, 2007; Pringle et al., 2010; Runne, 2012). Of these, three studies were very narrow in description and lacked richness in the data presented (Baylor et al., 2011; LeDorze et al., 1996; Pringle et al., 2010). The remaining three studies (Cyr, 2010; Parr, 2007; Runne, 2012) were problematic in their overall conclusions. Twenty six out of 32 studies scored in the (+) or (++) categories, suggesting that they scored satisfactorily on most items of the checklist or where they had not, the conclusions of the study were unlikely to be altered.

Thematic synthesis

The progression from descriptive to analytical themes is illustrated in Figure 7. Free coding the findings of included studies produced 597 meaningful segments of data; these were grouped together according to similarity and new descriptive categories were created to capture the meaning of the grouped free codes. For example, free codes which captured emotions (such as loss, anger and sadness) related to the struggle to communicate were grouped to form the descriptive category 'Emotions associated with struggle to communicate'. The initial codes were grouped in to 22 descriptive group categories. Meanings were refined and themes developed by

reassessing the data contained within each category to create descriptive themes. For example, an overlap in experiences was seen between the emotions associated with struggle to communicate and the self-identity category. This developed in to the descriptive theme of 'loss of communication and the loss of self-identity'. Although this review aimed to identify the needs of stroke survivors with communication difficulties, the studies identified did not ask participants directly about their needs and participants did not describe their experiences in terms of need. However, based upon the experiences described, analytical themes were developed which inferred and theorised about the needs of stroke survivors with communication difficulties and the impact this may have upon future intervention development (Gough et al., 2012; Thomas and Harden, 2008).

Figure 7: The development of descriptive and analytical themes (sub-review two)



Descriptive themes

Six descriptive themes were developed and are illustrated in Table 6.

Table 6: Descriptive themes (sub-review two)

	Descriptive Theme	Illustrative quote (s)
Coming to terms with the loss of communication	The extent to which stroke survivors reported being able to come to terms with a communication impairment varied (Brown et al., 2010; Cruice et al., 2010; Cyr, 2010; Dietz et al., 2013; Fotiadou et al., 2014; Hinckley, 2006; Matos et al., 2014; Niemi and Johansson, 2013). For some the struggle to communicate was an ongoing source of emotional distress, triggering feelings of grief, loss and sadness (Brown et al., 2010; Brown et al., 2013; Grohn et al., 2014; Fotiadou et al., 2014; Johansson et al., 2012; Niemi and Johansson, 2013; Pound, 2010; Worrall et al., 2011). Others had successfully come to terms with their communication impairments (Brown et al., 2010; Cruice et al., 2010; Cyr, 2010; Dietz et al., 2013; Fotiadou et al., 2014; Hinckley, 2006; Matos et al., 2014; Niemi and Johansson, 2013). These participants recognised the changes that had taken place in their lives but had been able to adjust to these and find contentment.	<i>'What if you only could! Could talk! That's what I ... Everything'</i> (p. 149) (Johansson et al., 2012) <i>'And I know it'll never be the same as what I was before I had the stroke . . . And as I say I hate to accept it, but I've got to accept it.'</i> (p.1283) (Brown et al., 2010)
Loss of communication and the loss of self-identity	Communication was often linked to participant's sense of self (Baylor et al., 2011; Brady et al., 2011a; Brady et al., 2011b; Cyr, 2010; Davidson et al., 2008b; Dickson et al., 2008; Fotiadou et al., 2014; LeDorze et al., 1996; Niemi and Johansson, 2013; Parr, 2001). Being able to communicate as before was regarded as being 'normal' (Brady et al., 2011a; Dickson et al., 2008) and since stroke some participants described feeling as though a piece of themselves was missing. Stroke survivors were conscious of the deficiencies in their spoken language. The constant monitoring and evaluation of spoken language was also linked to negative self-evaluation when stroke survivors fell short of their own expectations (Brady et al., 2011a; Brady et al., 2011b; Dickson et al., 2008; Niemi and Johansson, 2011).	<i>'at least 50 percent of me vanished when speech vanished that that's how I think about it'</i> (p. 1831) (Niemi and Johansson, 2013) <i>'... I hate myself because I can't speak right...'</i> (p. 143) (Dickson et al., 2008)
Isolation and exclusion from social situations	Participants felt left out of social situations or ignored or excluded specifically due to their communication problems (Baylor et al., 2008; Brady et al., 2011a; Dalemans et al., 2010; Dickson et al., 2008; Dietz et al., 2013; Howe et al., 2008a; Howe et al., 2008b; LeDorze et al., 1996; LeDorze et al., 2014; Niemi and Johansson, 2013). The discomfort others felt in talking to stroke survivors with communication difficulties was apparent to the stroke survivor themselves and led to feelings of social isolation. Participants expressed particular difficulty in taking part in group situations (Dalemans et al., 2010; Fotiadou et al., 2014; LeDorze and Brassard, 1995; LeDorze et al., 1996; LeDorze et al., 2014). As a consequence, people with post-stroke communication difficulties described either withdrawing from or avoiding communication or social situations altogether (Baylor et al., 2011; Brady et al., 2011a; Brady et al., 2011b; Dickson et al., 2008; Dietz et al., 2013; Fotiadou et al., 2014; LeDorze et al., 1996; LeDorze et al., 2014; Matos et al., 2014).	<i>'It's my wife who says I'm antisocial because, even when I visit my in-laws, I'm sick of going to their parties, sit in a corner, and at the end of the party, I get up and leave. I haven't said a damn word in there, and no one was interested, talked to me.'</i> (p.431) (LeDorze et al., 2014)

Table 6: Descriptive themes (sub-review two) (continued)

	Descriptive Theme	Illustrative quote (s)
Isolation and exclusion from social situations (continued)	Feelings of embarrassment and a lack of confidence in communication contributed to participants' avoidance of social events (Brady et al., 2011a). One participant also suggests that fear of stigmatising reactions contributed to avoidance of social situations (Brady et al., 2011a).	<i>'Instead, they would "go into the background and retreat".... and "do the bare amount of talking"...' (p.275) (Baylor et al., 2011)</i>
A support network of family and friends	Family members were discussed as an ongoing support on a practical and emotional level (LeDorze et al., 1996; LeDorze et al., 2014). Although some survivors did rely more on family members for support since having their stroke, reliance on others was not desired by stroke survivors or their carers (Dalemans et al., 2010; Dietz et al., 2013; Fotiadou et al., 2014; Grohn et al., 2012; Johansson et al., 2012; Niemi and Johansson, 2013; LeDorze et al., 2014; Worrall et al., 2011).The importance of friendship and social support outside the family was also expressed by stroke survivors with communication impairments (Brown et al., 2010; Brown et al., 2011; Brown et al., 2013; Cruice et al., 2010 Cyr, 2010; Davidson et al., 2008b; Grohn et al., 2012; Hinckley, 2006; Fotiadou et al., 2014; Nätterlund, 2010; Pound, 2010). However, also prominent was the difficulty maintaining friendships and the loss of friendship post-stroke (Brown et al., 2010; Brown et al., 2013; Dalemans et al., 2010; Fotiadou et al., 2014; LeDorze et al., 1996; LeDorze et al., 2014; Matos et al., 2014; Nätterlund, 2010; Parr, 2007; Pound, 2010).	<i>'The informants mentioned that being dependent on their partners was frustrating. Having their partner always nearby brought security but it also made them feel that they were being a burden.'</i> (p. 150) (Johansson et al., 2012) <i>'...Friends stayed away because they didn't know how to handle the new situation. When time passed by, making contact became even more difficult...'</i> (p. 543) (Dalemans et al., 2010)
Strategies to facilitate successful communication	Some stroke survivors with communication difficulties used their own strategies to help facilitate conversation (Baylor et al., 2011; Brady et al., 2011b; Brown et al., 2010; Dalemans et al., 2010; Dietz et al., 2013; Howe et al., 2008b; Johansson et al., 2012; LeDorze et al., 1996; Runne, 2012). A wide range of strategies were identified including communication aids (Brady et al., 2011b; Brown et al., 2010; Dalemans et al., 2010; Dietz et al., 2013), drawing or writing information down (Brady et al., 2011b; Brown et al., 2010; Johansson et al., 2012) and signalling by raising a hand that they have something to add when in a group situation (Baylor et al., 2011; Brady et al., 2011b; LeDorze et al., 1996). However, some studies identified a stigma attached to using communication aids (Dalemans et al., 2010; Johansson et al., 2012).Strategies used by communication partners of people with post-stroke communication difficulties were also recognised as a facilitator to successful communication (Brady et al., 2011b; Brown et al., 2010; Dalemans et al., 2010; Davidson et al., 2008a; Davidson et al., 2008b; Grohn et al., 2012; Howe et al., 2008b; Johansson et al., 2012; LeDorze et al., 1996; Niemi and Johansson, 2013; Parr, 2001; Pringle et al., 2010; Runne, 2012).	<i>'Interviewer: do you use a communication book? Liv: no, people look strange.'</i> (p. 544) (Dalemans et al., 2010) <i>'Equally important were the degree to which the CPs were able to adapt their speaking behaviour and whether they used supportive conversation strategies. "Then she wrote! Keywords like this. --- She wrote for me, you see. --- That was damn good, and then I understood at once!"...' (p. 1287) (Brown et al., 2010)</i>

Table 6: Descriptive themes (sub-review two) (continued)

	Descriptive Theme	Illustrative quote (s)
Activity and meaningful participation in life	<p>A distinction can be made between stroke survivors who took part in activities they enjoyed or which were meaningful to them and those who no longer took part and remained largely inactive. Where stroke survivors engaged in activities they valued, a sense of achievement, purpose, pleasure and confidence was expressed (Brady et al., 2011b; Brown et al., 2010; Brown et al., 2011; Cruice et al., 2010; Cyr, 2010; Dalemans et al., 2010; Dietz et al., 2013; Fotiadou et al., 2014; Grohn et al., 2012; Grohn et al., 2014, LeDorze and Brassard., 1995; Matos et al., 2014; Nätterlund, 2010; Niemi and Johansson, 2013; Parr, 2007; Pound, 2010). Establishing a routine was important to stroke survivors with communication difficulties. Again this gave stroke survivors a sense of purpose and achievement which was not evident in the experiences of those participants where activity had decreased post-stroke (Brady et al., 2011a; Brown et al., 2010; Brown et al., 2011; Cyr, 2010; Dalemans et al., 2010; Grohn et al., 2012; Grohn et al., 2014; Pound, 2010).</p>	<p><i>'Be involved with everything.'</i> <i>'Have a hobby.'</i> <i>'Live as much as you can; do as much as you can.'</i> (p. 1277) (Brown et al., 2010)</p> <p><i>'When able to establish a routine and engage in activities around the home, participants often obtained a sense of ability, competency, and independence: "I can do everything for myself" and "I can do it myself. Pretty well."</i> (p. 1415) (Grohn et al., 2014)</p>

Analytical themes

Four analytical themes were developed and are described below. It is important to note that the needs highlighted are interconnected and there is significant overlap between themes. For example, the ability to create a meaningful role may be influenced by the availability of a support network or by ability to communicate outside of the home.

Managing communication outside of the home

Managing communication outside of the home was a salient issue for many of the participants in the included studies. Where difficulties with communication arose, these generally occurred away from the safety of the home environment. Many participants were self-conscious about speaking in public and some took steps to hide their communication difficulty by avoiding social interaction completely or by using the bare minimum amount of communication required (Brady et al., 2011a; Brady et al., 2011b; Dalemans et al., 2010; Dickson et al., 2008; Dietz et al., 2013; Fotiadou et al., 2014; Johansson et al., 2012; Le Dorze and Brassard, 1995; Le Dorze et al., 2014; Matos et al., 2014; Parr, 2001; Parr, 2007; Pringle et al., 2010; Worrall et al., 2011). This protected participants from stigmatising reactions and also protected participants self-identity which was questioned when they were confronted with their communication difficulties (Brady et al., 2011a; Brady et al., 2011b; Dickson et al., 2008; Niemi and Johansson, 2013). However, by avoiding communicative situations outside of the home, stroke survivors put themselves at risk of losing friendships and becoming socially isolated (Brown et al., 2013; Brown et al., 2010; Dalemans et al., 2010; Fotiadou et al., 2014; Le Dorze and Brassard, 1995; Le Dorze et al., 2014; Matos et al., 2014; Nätterlund, 2010; Parr, 2007; Pound, 2013).

In contrast, rather than avoiding communication, some stroke survivors identified the active use of strategies to adapt their communication and make themselves understood outside of the home, for example, communication aids (Brady et al., 2011b; Brown et al., 2010; Dalemans et al., 2010; Dietz et al., 2013; Runne, 2012), drawing or writing information down (Brady et al., 2011b; Brown et al., 2010; Johansson et al., 2012; Runne, 2012) or signalling by raising a hand that they have something to add when in group situation (Baylor et al., 2011; Brady et al., 2011b; Le Dorze and Brassard, 1995; Runne, 2012). Other strategies used to facilitate successful communication included sticking to familiar places or people. For example, in one study, when describing the

routine of one participant going out for a coffee this was facilitated by the coffee shop staff's knowledge of that individual (Howe et al., 2008b):

'The individual with aphasia, who reportedly went to the same coffee place every week, indicated that the event was "easy". The employees were familiar with the individual and knew what he usually ordered. To obtain the food items he wanted, the participant only had to say, "Yeah" and pay for the items.' (p. 633)

Successful interaction outside of the home was often facilitated by the stroke survivors close family members, for example, a participant in Brady et al. (2011b) stated '(She) [Wife] deciphers for me' (p. 945). Successful interaction outside of the home could also be facilitated by a competent conversation partner (Brady et al., 2011b; Brown et al., 2010; Dalemans et al., 2010; Davidson et al., 2008a; Grohn et al., 2012; Howe et al., 2008; Johansson et al., 2012; LeDorze et al., 1996; Niemi and Johansson, 2013; Parr, 2001; Pringle et al., 2010; Runne, 2012). Desired characteristics of competent conversation partners included those who gave time and patience during conversation (Brown et al., 2010; Dalemans et al., 2010; Davidson et al., 2008a; Davidson et al., 2008b; Grohn et al., 2012; Howe et al., 2008b; LeDorze et al., 1996; Parr, 2001; Pound, 2010; Runne, 2012). This included the conversation partner slowing down their own speech and giving time for the stroke survivor to respond. Other references identified a need for flexible communication from communication partners. This included a range of strategies to be employed by communication partners such as simplifying the conversation (Howe et al., 2008b; Parr, 2001), being empathetic (Dalemans et al., 2010; Niemi and Johansson, 2012) or using alternative communication methods such as gestures, drawing, or writing information down (Brown et al., 2010; Johansson et al., 2012). An example from Brown et al. (2010) demonstrates the impact an effective communication partner could have on an exchange:

'Equally important were the degree to which the CPs were able to adapt their speaking behaviour and whether they used supportive conversation strategies. "Then she wrote! Keywords like this. – – – She wrote for me, you see. – – – That was damn good, and then I understood at once!"...' (Brown et al., 2010 p. 1287).

Successful interaction helped participants to gain a sense of self-confidence and self-worth:

"It feels really nice that someone ... someone that just wants to speak with you! One feels like a human being. It feels "Wow!"..." (Johansson et al., 2012) (p.148).

Future interventions should support stroke survivors to build confidence in their communicative abilities in order to re-build their sense of self. A staged programme whereby stroke survivors are supported to build confidence in their communicative abilities through setting tasks with increasing difficulty may be appropriate (Abraham and Michie, 2008). For example, the stroke survivor may progress in stages from one to one communication with someone familiar to communicating outside of the home with support to communicating outside of the home alone. Training for friends and family may also need to be considered in order to facilitate optimal communication and communication outside of the home environment (Simmons-Mackie et al., 2016; Simmons-Mackie et al., 2010).

Creating a meaningful role

Stroke survivors who described themselves as living successfully with a communication impairment advocated 'doing things' as being central to their success (Brown et al., 2010; Grohn et al., 2014). Meaningful activity was something that was personal to the stroke survivor and varied across the studies identified. Meaningful activity could be as simple as completing chores around the house, establishing a routine or could relate to activities outside the home. The common theme was that the activity helped the stroke survivor to have a role that they valued, enjoyed or which gave them a sense of purpose (Brady et al., 2011b; Brown et al., 2010; Brown et al., 2011; Cyr, 2010; Dalemans et al., 2010; Grohn et al., 2014; Grohn et al., 2012; Pound, 2013).

Sometimes stroke survivors struggled to participate in meaningful activities they had enjoyed prior to stroke due to their communication difficulties (Cruice et al., 2010; Dietz et al., 2013; Fotiadou et al., 2014; Le Dorze and Brassard, 1995; Matos et al., 2014; Nätterlund, 2010; Niemi and Johansson, 2013; Parr, 2007). However, those who described themselves as living successfully with a communication difficulty sought and took part in other activities that they were able to participate in and found pleasurable. The flexibility to adapt, adjust and take part in meaningful activity in spite of post-stroke communication difficulties is significant. In these circumstances the stroke survivor placed value upon activities that they could participate in as opposed to those they could not (Brady et al., 2011b; Brown et al., 2010; Brown et al., 2011; Cyr, 2010; Dalemans et al., 2010; Grohn et al., 2014; Grohn et al., 2012; Pound, 2013). Brown et al. (2010) suggest that participating in meaningful activity is a process and describe

participants' experiences of finding a balance between the things they could still do and those they were no longer capable of.

"I can't read anymore . . . spelling is horrible since my stroke . . . I can't do whatever I used to do. And I would—I feel that I'm useless . . . [But] I'm not depressed and . . . I laugh . . . And I am finding that I am living successfully with the stroke. Yes . . . I go for a walk. I ride the bike (indicates to exercise bike in lounge) . . . go out shopping with my wife. And go for an overseas trip. And I feel alright—yes." (p. 1279)

This trial and error process may be important to creating a meaningful role and therefore to living successfully with post-stroke communication difficulties.

One barrier to the creation of a meaningful role was the association between meaningful activity and communicative ability. Valued roles were often related to activities outside of the house, which stroke survivors found challenging to manage due to their communication difficulties. For example, a participant in Cruice et al. (2010) describes his reliance on his wife for going out of the house:

'[Communication] affected one man's movements in his community ("C [wife] and I go to town often but I don't go by myself...[aphasia] stops me going out...[it] depends on how people know you")' (p. 336).

This group also experienced other practical challenges common to many stroke survivors such as physical disability, fatigue or a lack of transport (Dietz et al., 2013; Fotiadou et al., 2014; Grohn et al., 2012; Nätterlund, 2010; Grohn et al., 2014) which were additional barriers to participating in meaningful activity. One participant from Grohn et al. (2014) commented:

"If I had the ability to drive...I could do so much better. I could do the shopping. I could go into other pieces [people's] homes. And things like that." (p. 1416).

Future interventions should consider the role of meaningful activity in participants' lives. Establishing a routine or scheduling activities that are valued by the stroke survivor may be key to living successfully with communication impairment. Intervention components to facilitate participation in meaningful activity may include supported activity-focused goal-setting, action planning or problem solving (Abraham and Michie, 2008). Problem solving strategies or adaptations may be needed in order for the stroke survivor to participate in meaningful activity. This may take time and may involve trial

and error process, particularly with regards to participation in activities which were valued prior to stroke and those occurring outside of the home environment.

Creating or maintaining a support network

Participants readily identified the importance of their family and friends for providing support on a practical and emotional level (Grohn et al., 2014; Le Dorze et al., 2014; Brown et al., 2013; Brown et al., 2010; Brown et al., 2011; Cruice et al., 2010; Cyr, 2010; Davidson et al., 2008b; Fotiadou et al., 2014; Grohn et al., 2012; Hinckley, 2006; Nätterlund, 2010; Pound, 2013). As highlighted in the previous two analytical themes it was often necessary for the stroke survivor to have some support from family or friends in order to complete activities outside of the home successfully. This support was highly valued and often enabled participants to manage activities outside of the home which might not otherwise have been possible.

On the other hand, some stroke survivors discussed a lack of support, resulting in feelings of social isolation (Brown et al., 2013; Brown et al., 2010; Dalemans et al., 2010; Fotiadou et al., 2014; Le Dorze and Brassard, 1995; Le Dorze et al., 2014; Matos et al., 2014; Nätterlund, 2010; Parr, 2007; Pound, 2013). In some circumstances, participants had friends prior to the stroke that had drifted away over time (Brown et al., 2013; Dalemans et al., 2010; Parr, 2007). Stroke survivors sensed that their old friends struggled to communicate with them in the same way and adapt to the new situation. The quality of the interaction also changed; some studies reported friends who changed the tone of their conversation, sticking to mundane topics instead of in-depth discussion (Baylor et al., 2011; Brady et al., 2011a; Brown et al., 2010; Brown et al., 2013; Davidson et al., 2008a; Fotiadou et al., 2014; Johansson et al., 2011; Niemi and Johansson, 2013; Runne, 2012). Participants in the included studies described how initially friends had rallied round in the months after stroke but then gradually drifted away over time (Brown et al., 2013; Dalemans et al., 2010; Parr, 2007). Dalemans et al. (2010) describe how friends seemed reluctant to get in contact with the person with communication difficulties. This suggests some level of discomfort in accepting or adapting to the stroke survivors problems with communication:

'...Friends stayed away because they didn't know how to handle the new situation. When time passed by, making contact became even more difficult...' (p. 543).

Stroke survivors also reported either withdrawing from or avoiding social situations due to their communication difficulties (Baylor et al., 2011; Brady et al., 2011a; Brady et al., 2011b; Dickson et al., 2008; Dietz et al., 2013; Fotiadou et al., 2014; LeDorze et al., 1996; LeDorze et al., 2014; Matos et al., 2014). Matos et al. (2014) quote one participants experience:

“I avoid talking to people because one can [shrugs] talk as it should be [...] I even with my children I, all all the time talking to me, but I rarely say something” (p. 783).

A barrier to social participation was the difficulty communicating by telephone; this was coded in six references (Brady et al., 2011a; Davidson et al., 2008a; Dickson et al., 2008; LeDorze et al., 1996; Nätterlund, 2010; Pound, 2010). Brady et al. (2011a) describe how participants' avoidance of the telephone directly impacted on their opportunities for social participation:

‘The avoidance of the telephone not only further restricted the opportunity to communicate with the person on the telephone, but also made it more difficult to create opportunities for social interactions or to make arrangements to meet with family and friends. “I hate the phone because I can hear the faults.” (Female: 69 – moderate) .“In the beginning I was afraid of the telephone. I wouldn’t answer the telephone. I wouldn’t speak on the telephone. I didn’t like it. I avoided it like that plague.”...’ (p. 182)

Future interventions should recognise the value of obtaining and maintaining social support. Stroke survivors with communication difficulties may be at risk of losing friends and having reduced social networks which may impact upon quality of life and lead to social isolation. Social networks may be difficult to rebuild once lost given the communication challenges this sub-group of stroke survivors face. Some stroke survivors had identified communication groups as a means of social support and a way of replacing some of the friends they had lost (Brown et al., 2013; Brown et al., 2010; Brown et al., 2011; Davidson et al., 2008b; Fotiadou et al., 2014; Le Dorze et al., 2014). Stroke survivors expressed a sense of understanding from others in a similar position which was not found through other friends or family members. A focus for future interventions may be to help stroke survivors with communication difficulties to find social support or sustain their existing social networks; where this is meaningful to the stroke survivor. Future interventions should acknowledge the role of social networks and explore how these might be harnessed to further support the stroke survivor and improve quality of life (Reeves et al., 2014).

Taking control and actively moving forward with life

As detailed in the descriptive themes, living with post-stroke communication difficulties had resulted in tremendous change which was often associated with loss for participants compared to pre-stroke life, for example; loss of communication, loss of self-identity, loss of friendship, and loss of previously valued activities. For many stroke survivors the sense of loss was, unsurprisingly, associated with significant emotional distress; triggering feelings of grief, loss and sadness (Brown et al., 2013; Brown et al., 2010; Fotiadou et al., 2014; Grohn et al., 2014; Johansson et al., 2012; Niemi and Johansson, 2013; Pound, 2013; Worrall et al., 2011). Many of these changes were beyond the stroke survivor's control, however, in studies where stroke survivors described themselves as living successfully with the condition, a sense of taking control and actively moving forward was apparent (Brady et al., 2011b; Dalemans et al., 2010; Le Dorze et al., 2014; Grohn et al., 2014). For example, one participant in Grohn et al. (2014) stated:

“But I want to improve myself, even if I wasn't um like I am now and I was back to the way I was, I'd still push myself all the time. But they think that I'm pushing myself too hard sometimes [slight laugh]. But I don't think so. I just think I've got to learn to do these things and I think well I'm going to do it.” (p.1414).

This participant was highly motivated to improve; the authors of the paper state that the participant uses 'improve' in reference to both their communicative and physical abilities. Also apparent within this quote is the participant's belief in their own ability to improve and how the participant 'pushes' to improve on the basis of this belief. A sense of taking control was also linked to independence. Participants in Brown et al. (2010) valued tasks they could complete alone, for example, ordering a meal by themselves at a restaurant;

“If you're going out for dinner . . . make sure that you are . . . you do it. With yourself” (p.1278).

A participant in Grohn et al. (2012) describes how they perceived themselves to be living successfully with aphasia because they were able to do things independently;

“...because I live on my own and that and I get up, I'm gone out of the place, and I get along-do everything myself and that.” (p. 394).

Future interventions should be mindful of the significant loss and emotional upheaval associated with post-stroke communication difficulties and recognise that stroke survivors may be at different stages of coming to terms with the changes to their lives.

Different interventions may be appropriate according to the stroke survivors 'readiness' to accept their communication difficulties and move forward with rebuilding their lives (Cameron and Gignac, 2008; Prochaska and Velicer, 1997). Participants' beliefs in their own ability may also be related to a sense of taking control. Such experiences sit well with self-efficacy theory (Bandura, 1977) which proposes that a person's belief about their capabilities influences their ability to perform a task. Self-efficacy theory was the most commonly cited theoretical rationale for the interventions identified in Chapter One. This synthesis of qualitative literature supports the idea that enhancing self-efficacy or feelings of control may also be important for stroke survivors with communication difficulties and this should be considered in future intervention development.

2.5. Discussion

Summary of main results

The review identified 32 qualitative studies including 518 stroke survivors with communication difficulties from 9 different countries. Synthesising information from the qualitative literature has provided considerable insight into the longer-term needs of stroke survivors with communication difficulties living in the community. The synthesis reveals the ongoing difficulties stroke survivors can face in coming to terms with the loss of communication and in adapting to life with a communication difficulty. By drawing together findings reported in individual studies significant need for longer-term support was identified. Many of the participants who conveyed needs in relation to longer-term care were a number of years post-stroke which suggests that needs may persist over a significant period of time in the absence of resolution. Few studies explored need within the first year post-stroke and further information about how stroke survivors with communication difficulties manage their condition following hospital discharge is required to ensure that difficulties faced during this time period are adequately addressed. Research focusing on the first year post-stroke may help to illuminate how early experiences may shape ability to adjust, adapt and manage life with a post-stroke communication difficulty in the longer-term.

Comparing the findings of this synthesis with previous reviews of qualitative literature including stroke survivors without communication difficulties highlights a significant overlap in experiences (McKevitt et al., 2004; Satink et al., 2013; Walsh et al., 2015).

For example, difficulties regaining valued roles, a sense of self, maintaining social relationships and reintegrating into the community have all been highlighted as problematic in stroke survivors without communication difficulties. However, findings from the current review highlight how post-stroke communication difficulties present a unique barrier, for example, to participation in meaningful activities or maintenance of social networks. Communication plays a central role in maintaining friendship and when difficulties communicating occur, this acts as a barrier to maintaining friendship to both parties (the stroke survivor and the friend). Communication also acts as a unique facilitator and barrier to participation outside of the home, for example; a successful communicative interaction can act as a facilitator to participation in a valued activity and an unsuccessful interaction can act as a barrier to participation in a valued activity. The findings of this review suggest that any longer-term care intervention must address the needs of stroke survivors with communication difficulties and support them to manage the consequences of the communication difficulty itself. The synthesis highlights that the consequences of post-stroke communication difficulties are not only physical; such difficulties can also cause significant disruption to psychological and social wellbeing.

Strengths and limitations of the review

A strength of the review is that a systematic method to summarise and interpret existing qualitative research in relation to a specific research question has been used. Although the themes stay close to the findings of the individual studies; by drawing the findings together, an overall interpretation of the literature in relation to longer-term need was created. Findings were drawn together in a systematic fashion and, based on the weight of this evidence; the synthesis goes beyond a descriptive summary of study findings by identifying the implications for understanding and responding to the longer-term needs of this group of stroke survivors and by making reasoned recommendations for future intervention development.

Thomas and Harden (2008) suggest that analytical themes 'go beyond' a descriptive summary of study findings; firstly, by creating an interpretation of this literature in relation to a particular research question and secondly, by using this interpretation to create reasoned recommendations for intervention development. However, some may question whether either of these features truly represents the higher level of conceptual abstraction and innovation which is typically sought from the synthesis of qualitative data. Consistent with the methods outlined by Thomas and Harden (2008), the

analytical themes developed in this synthesis are transparently derived from the findings of individual studies and stay close to these in creating an interpretation of the literature in relation to longer-term need. Other approaches to qualitative synthesis may interpret the literature with a higher level of abstraction than was demonstrated within the current synthesis. For example, thematic synthesis places an emphasis on descriptively comparing and synthesising the content of the findings from each study. In comparison, an approach such as meta-ethnography is concerned with the key 'concepts' (metaphors or meanings) which can be derived from the findings and how these are related across studies (Noblit and Hare, 1988; Britten et al., 2002; Pope et al., 2007). Meta-ethnography looks for similarities or variations in the meaning of concepts and uses this to translate meaning across studies; transcending individual accounts to provide an explanatory account of the literature as a whole.

In practice this may have implications for the way in which variation between studies is captured and reported using these different methods. Thematic synthesis may describe variation (and contributing factors); however, may not adequately offer explanatory accounts of why and how variation occurs and the implications of this for our understanding of a concept (in this case longer-term need). Reflecting upon the analytical themes created in this review, an area which may have warranted further exploration in the synthesis is the concept of temporality; how longer-term needs exist within or have a relationship with time. This may be an important explanatory concept in terms of achieving a greater understanding of why some people were able to come to terms with their communication difficulties, in what way needs may change or evolve over time, or how biological age or personal biography may impact upon how needs are experienced.

A limitation of this synthesis is that this concept was not systematically explored across studies. However, some inferences about this concept may be made. For example, difficulties coming to terms with the loss of communication appeared to be evident across a number of studies which included participants at a range of timepoints post-stroke (Brown et al., 2010; Cruice et al., 2010; Cyr, 2010; Dietz et al., 2013; Fotiadou et al., 2014; Hinckley, 2006; Matos et al., 2014; Niemi and Johansson, 2013). This suggests that this process may not only be influenced by time post-stroke, but may also be influenced by other factors, such as the meaning of the communication difficulty within the individual's life (Bury, 1982; Charmaz, 1983). For instance, the consequences of post-stroke communication difficulties may be more disruptive for

participants who are younger, who worked prior to stroke, or who have more severe impairments. In turn, this may influence the way in which other longer-term needs are experienced, such as, the extent to which stroke survivors were able to create a meaningful role, or develop strategies to manage communication outside of the home.

The way in which needs may change over time should also be considered. One area in which the synthesis did recognise change over time was in the creation and maintenance of support networks. The difficulty of maintaining friendships over time with a post-stroke communication difficulty was highlighted. In particular, studies described how friends had rallied round in the months after stroke but then gradually drifted away over time (Brown et al., 2013; Dalemans et al., 2010; Parr, 2007). There was also the suggestion that other needs may change or evolve over time. For example, in creating a meaningful role, the findings highlighted how some stroke survivors with communication difficulties continually worked towards improvement such that, if one activity was achieved, this spurred them on to work on another area of personal importance (Grohn et al., 2012; Brown et al., 2010). This suggests that needs and priorities in relation to longer-term care may change significantly over time as more experience of post-stroke life is gained.

Although some inferences about the concept of temporality may be drawn, the systematic exploration of this concept within the findings of the studies reviewed may have yielded additional insights. Miles and Huberman (1994) use a 'meta-matrix' to facilitate the process of looking for comparisons across cases which has been successfully applied to the synthesis of qualitative studies by McNaughten (2000) and Lloyd Jones (2005). Pope et al. (2007) suggest that creating thematic matrices may be one way in which unwieldy amounts of data can be organised and compared in a systematic way. This may be one method which might be considered in the future as a stage between the development of descriptive and analytical themes. This may allow information from the findings of studies to be more easily compared and contrasted and for the basis of variation to be explored. Systematically considering the variation in the studies contribution to the descriptive themes and the meaning of this may facilitate a deeper level of analytical and conceptual understanding to be obtained from the process of thematic synthesis. This may offer additional insights or implications for intervention development.

Three other areas of limitation can be identified in this review. Firstly, the quality of the synthesis of information is inherently limited by the quality and reporting of the original studies (Campbell et al., 2003; Dixon-Woods et al., 2004). For example, full development of the final analytical theme 'taking control and actively moving forward with life' was limited by the lack of contextual information in the reporting of the primary studies. It was therefore difficult to fully explore possible explanations as to why and how some stroke survivors were able to 'take control' in comparison to others who had been unable to do so.

Secondly, the results of the quality assessment highlighted the lack of reflexivity in the included studies. Reflexivity is the researcher's critical reflection upon how their own position within the research may have influenced the conduct or findings of the study (Berger, 2015; Jootun et al., 2009). The lack of reflexivity in the studies included in this review means it is difficult to evaluate levels of bias in the findings of the studies. In the majority of studies, data were collected by researchers who were also qualified speech and language therapists. This may have had some influence on the line of questioning or participants responses.

The final limitation of this review is the difficulty assessing publication bias. It is possible there is a bias towards publishing studies highlighting difficulties post-stroke as opposed to those highlighting more positive experiences. This review identified significant need and this may be a result of biases in publication. It is difficult to quantify the impact of potential publication bias, however, it is important to note that studies were identified in the synthesis which looked at patients who perceived themselves to be living successfully with aphasia and the factors influencing this (Brown et al., 2010; Brown et al., 2011; Grohn et al., 2012; Grohn et al., 2014; Hinckley, 2006). These studies were of high quality and made a significant contribution to the synthesis of information.

Interpretation and implications for future research

The biomedical model of illness assumes that all illness has an underlying physical cause which can be treated through medical intervention (Bodenheimer et al., 2002; Wade and Halligan, 2004; Wade, 2015). Restoration based speech and language therapy approaches typically focus upon treating the specific impairment the patient is experiencing and arguably have their basis in this model (Brady et al., 2016; Sellars et

al., 2005). The findings of the synthesis suggest that the biomedical model of illness is inadequate in understanding the full impact of post-stroke communication difficulties. It demonstrates that the impact communication difficulties goes beyond symptoms of the medical impairment; influencing social relationships, mood and ADL.

The WHO International Classification of Functioning, Disability and Health (WHO ICF) recognises the complex interplay of biological, psychological and social influences which may influence health (WHO, 2002). The WHO ICF framework is a conceptual model for defining and understanding disability and health. According to the framework, health may be impacted by the following domains; body functions and structures, activities and participation and environmental factors. For example, a stroke survivor may have aphasia (bodily impairment) which leads to being unable to speak in public (activity limitation) and therefore being unable to meet with friends (participation restriction). A failure in any of the WHO ICF domains can lead to loss of health and disability. The implication of the WHO framework is that a wide range of factors may influence a person's health and that this must be considered in treatment, research and policy making. Findings from this review support this model and suggest that wider psychosocial factors should be considered in the rehabilitation of post-stroke communication difficulties.

Although the WHO ICF provides a general framework for recognising the factors which might influence the longer-term needs of stroke survivors with communication difficulties, it does not capture the complexities of experience highlighted in this review and synthesis. Drawing together the findings of individual studies highlighted the complex journey stroke survivors go through in adjusting and adapting to post-stroke life. Some were able to come to terms with their communication difficulties, take control and rebuild their lives. Others struggled to adapt and were unable to overcome the loss of previously valued activities and roles. Varying illness courses form the basis of a theoretical model of chronic illness known as the chronic illness trajectory (Corbin and Strauss, 1991; Corbin and Strauss, 1988). The chronic illness trajectory captures the different ways in which patients and families cope with the course of an illness over time and the choices and adjustments made in order to manage the consequences of living with a long-term condition. The notion of an illness trajectory will be critically examined in further detail in Chapter Seven; however, for the purpose of this discussion it is important to consider whether illness trajectories might be shaped so

that stroke survivors with communication difficulties who struggle to adapt are better supported to manage their condition.

Self-management interventions are designed to support patients to cope with the physical and psychosocial consequences of living with a long-term condition (Lorig and Holman, 2003; Barlow et al., 2002). Taking this approach might be one way in which illness trajectories might be shaped by an intervention (Lorig et al., 1999a; Lorig et al., 2001; Lorig and Holman, 2003). Although self-management might be a useful concept, the findings of this review suggest that such interventions must be designed to ensure that they meet the needs of stroke survivors with communication difficulties and support them to manage the consequences of the communication difficulty itself. Existing self-management approaches such as the CDSMP designed by Lorig and colleagues (Lorig et al., 1999a; Lorig et al., 2001; Lorig and Holman, 2003) have been criticised for taking a 'one size fits all' approach to self-management by assuming that one programme is applicable for a range of patients with a range of chronic conditions (Jones et al., 2013; Greenhalgh, 2009). Further research is needed to examine the suitability of self-management approaches for stroke survivors with communication difficulties to ensure this approach to longer-term care matches the requirements of this population.

Conclusions

This synthesis highlights the significant and continuing need for longer-term support experienced by stroke survivors with communication difficulties. Rehabilitation services designed around impairment based models of speech and language therapy may fail to address the psychosocial consequences of post-stroke communication difficulties and may not enable stroke survivors to successfully manage these difficulties within this context (Wade, 2016). Self-management may be a useful approach to facilitate the process of adaptation and adjustment; however, a critical examination of the suitability of existing self-management approaches for stroke survivors with communication difficulties is needed. This is presented in the following chapter.

Chapter Three: Meta-synthesis

This chapter synthesises information from the parallel reviews conducted in Chapter One and Chapter Two in a meta-synthesis to answer the overarching review question: Do existing self-management interventions meet the needs of stroke survivors with communication difficulties in relation to longer-term care?

3.1. Introduction

Pope et al. (2007) describe meta-synthesis as a process of:

‘Building up a mosaic of findings to produce an overall picture from the different pieces of evidence’ (p.112).

This is one of the most innovative aspects of the EPPI approach, however, is the least well developed and tested aspect of this approach to evidence synthesis. Although work in this field is emerging, there are few published examples of how a meta-synthesis should be conducted. In order to guide the development of the synthesis in this review, published guidance from the developers of this approach was used (Oliver et al., 2005; Harden and Thomas, 2005), alongside the published examples of reviews which have utilised the EPPI approach (Clement et al., 2015; Edwards et al., 2014; Lewis et al., 2010; Lorenc et al., 2008; Oliver et al., 2007; Rees et al., 2006; Thomas et al., 2004). Despite the ongoing development of this methodology, the benefit of being able to integrate findings from a diverse range of studies in order to answer a broad review question outweighed the experimental nature of this approach. Oliver et al. (2005) describe this as the ‘added value’ of a mixed methods synthesis in being able to answer questions which could not be answered by reviewing one study type alone.

In order to address the overarching review question, the findings of the studies identified in each of the parallel reviews will be drawn together narratively. The definition of need outlined in Chapter Two is also used in this chapter:

“What patients – and the population as a whole desire to receive from health care services to improve overall health.” (Asadi-Lari et al., 2004) (p.2)

Reviewing the data prior to undertaking the meta-synthesis suggested that two areas were important in answering the review question. The first was the accessibility of self-management interventions to stroke survivors with communication difficulties and the second was the extent to which self-management interventions addressed the longer-term needs (analytical themes) identified in Chapter Two. In order to answer the review question comprehensively, the meta-synthesis was divided according to accessibility and longer-term needs. This information is used to understand whether existing self-management interventions meet the needs of stroke survivors with communication difficulties in relation to longer-term care.

3.2. Objectives

- 1) To explore the accessibility of existing self-management interventions for stroke survivors with communication difficulties.
- 2) To explore the extent to which existing self-management interventions address the longer-term needs of survivors with communication difficulties.
- 3) Considering objectives one and two, to consider the suitability of existing self-management interventions for this population.

3.3. Method

As noted in the introduction to this chapter, the development of the 'meta-synthesis' method is ongoing and has been undertaken in different ways. The most common approach to meta-synthesis is the creation a matrix table of information, juxtaposing results from the findings of the different reviews (Clement et al., 2015; Oliver et al., 2007; Rees et al., 2004; Rees et al., 2006; Thomas et al., 2004). On the other hand, some have taken a purely narrative, textual approach to meta-synthesis (Edwards et al., 2014; Lewis et al., 2010; Lorenc et al., 2008) or used it as a basis to develop a conceptual model (Lewis et al., 2010). The integration of mixed methods data is seen as a 'framework' which can be used flexibly in order to answer the review question (Oliver et al., 2005; Pope et al., 2007). In this review, a narrative (textual) synthesis of information was conducted.

To address objective one of the meta-synthesis, the content of the interventions described in sub-review one, were compared to accessibility requirements arising from the thematic synthesis in sub-review two. To address objective two of the meta-synthesis, the analytical themes developed in sub-review two are used as a framework to explore the self-management interventions identified in Chapter Two in relation to the needs of stroke survivors with communication difficulties. Within each sub-section, the suitability of existing self-management interventions is considered, and based upon this recommendations for future research and intervention development are suggested, addressing the third review objective.

3.4. Results

Accessibility of self-management interventions

Comparing the mode of delivery of the self-management interventions identified and the findings from the qualitative literature review; three areas of concern were highlighted regarding the accessibility of existing self-management interventions for stroke survivors with communication difficulties. The first was the accessibility of group-based self-management interventions. Five out of 20 (25%) of the self-management interventions identified in Chapter One had a group-based format (Aben et al., 2013; Aben et al., 2014; Cadilhac et al., 2011; Kendall et al., 2007; Marsden et al., 2010; Sabariego et al., 2013). However, the findings of the thematic synthesis in Chapter Two suggest that stroke survivors with communication difficulties often encountered problems in a group setting; struggling to keep pace with the conversation or contribute before the conversation had moved on (Dalemans et al., 2010; Fotiadou et al., 2014; LeDorze and Brassard 1995; LeDorze et al., 1996; LeDorze et al., 2014). This raises questions about the accessibility of group-based self-management interventions for stroke survivors with communication difficulties. In addition to difficulties participating in a group based intervention, significant barriers to attending groups were also identified in the qualitative literature, namely, lack of transport either due to difficulties accessing public transport due to communication difficulties or loss of the ability to drive (Dietz et al., 2013; Grohn et al., 2014; Nätterlund, 2010). The qualitative literature also highlighted how some stroke survivors with communication difficulties lacked confidence in their communication and feared stigmatising reactions when communicating outside of the home (Brady et al., 2011a; Brady et al., 2011b; Dickson et al., 2008; Dietz et al., 2013; Fotiadou et al., 2014; LeDorze et al., 1996; LeDorze et al., 2014; Matos et al., 2014). This may also act as a barrier to attending group-based

interventions for this group of stroke survivors. Careful consideration may need to be taken in order to facilitate the delivery of group-based self-management, for example, consideration of restricted group sizes or groups specifically for those with communication difficulties. On the other hand, due to the obstacles identified it may be preferable for self-management to be delivered in an individual or one to one based format for optimal inclusion of stroke survivors with communication difficulties.

The second area of concern with regards to the accessibility of self-management interventions for stroke survivors with communication difficulties was the accessibility of telephone based interventions. Six out of 20 (30%) of the self-management interventions identified included a telephone based component in their mode of delivery (Allen et al., 2002; Allen et al., 2009; Chumbler et al., 2012; Chumbler et al., 2015; Damush et al., 2011; Frank et al., 2000; Johnston et al., 2007). One intervention was delivered exclusively by telephone (Damush et al., 2011) and the others included telephone follow-ups as part of their protocol. However, the qualitative literature review highlighted the difficulties stroke survivors experienced using the telephone (Brady et al., 2011a; Davidson et al., 2008a; Dickson et al., 2008; LeDorze et al., 1996; Nätterlund, 2010; Pound, 2010) and how some stroke survivors avoided using the telephone due to fears of being misunderstood or hearing imperfections in their speech (Brady et al., 2011a). Telephone based interventions may present a barrier to accessibility for some stroke survivors with communication difficulties.

The final area of concern in relation to the accessibility of self-management interventions is the training of the facilitators of this approach. None of the RCT papers identified mentioned any specific training in supported conversation techniques or the experience of their facilitators in relation to this. However, the qualitative literature highlighted the importance of skilled conversation partners in helping stroke survivors with communication difficulties to understand conversation or be understood (Brady et al., 2011b; Brown et al., 2010; Dalemans et al., 2010; Davidson et al., 2008a; Davidson et al., 2008b; Grohn et al., 2012; Howe et al., 2008b; Johansson et al., 2012; LeDorze et al., 1996; Niemi and Johansson, 2013; Parr, 2001; Pringle et al., 2010; Runne, 2012). It is important that intervention facilitators are provided with specialist training in order to facilitate optimal communication with this population. Failure to do so may limit the accessibility of self-management interventions for stroke survivors with communication difficulties.

Suitability of self-management for addressing longer-term needs

Self-management interventions are designed to empower individual's to manage the physical, psychological and social consequences of living with a chronic condition (Barlow et al., 2002; Lorig and Holman, 2003). By this definition, taking a self-management approach appears to fit well with the analytical themes (needs) developed in the qualitative literature review. The themes highlighted how some stroke survivors with communication difficulties struggled to manage the consequences of their condition and this suggests that the underpinning ethos of the self-management approach may form an appropriate basis for an intervention to support stroke survivors with communication difficulties in the longer-term.

The theoretical basis of existing self-management interventions also appeared to fit with some of the longer-term needs identified. For example, eight out of 20 (40%) self-management interventions identified in Chapter One were based upon self-efficacy theory. Self-efficacy is the belief a person holds about their competence to complete tasks and is often associated with feelings of control or self-belief in ability (Bandura, 1977). This concept appears to be well suited to the area of need 'taking control and actively moving forward with life' identified in the qualitative literature review. Targeting self-efficacy as part of a self-management intervention for stroke survivors with communication difficulties may be useful in theory. However, in practice, some of the self-management interventions identified in Chapter One addressed self-efficacy in relation to a specific task, for example, memory self-efficacy (Aben et al., 2013; Aben et al., 2014) or self-efficacy in relation to functional mobility (Chumbler et al., 2012; Chumbler et al., 2015). These interventions do not appear to target self-efficacy in terms of recognising and ameliorating the psychosocial consequences of living with a post-stroke communication difficulty, for example, managing communication outside of the home or creating and maintaining a support network; problems which were particularly salient to stroke survivors with communication difficulties.

Addressing these aims may be more suited to the general self-management interventions identified in Chapter One which targeted broader quality of life outcomes. However, the general self-management interventions identified in Chapter One may also be criticised for failing to address areas of need specific to stroke survivors with communication difficulties identified in the qualitative literature review. Firstly, the general self-management interventions identified appeared to lack any component specifically relating to the management of the communication difficulty itself. This is

perhaps unsurprising given the underrepresentation of this population in the RCTs identified. However, the synthesis of qualitative literature identified this as a significant area of need, particularly for managing communication outside of the home. Difficulty communicating outside of the home often impacted upon other areas of stroke survivors lives, for example, acting as a barrier to participation in meaningful activity or to obtaining social support (Brady et al., 2011a; Brown et al., 2010; Brown et al., 2011; Cyr, 2010; Dalemans et al., 2010; Grohn et al., 2012; Grohn et al., 2014; Pound, 2010). Addressing this need is therefore important in ensuring that a self-management intervention specifically targets and provides support for the challenges faced by stroke survivors with communication difficulties.

Appropriate strategies for managing communication outside of the home should be identified and may include the use of compensatory strategies; for example training in alternative and augmentative ways of communicating (AAC) (Light and McNaughton, 2014). AAC is the use a range of non speech based methods of expression for example, gestures, facial expressions, written words, picture symbols as an alternative to verbal communication. Although such approaches may be used routinely in speech and language therapy, translation of AAC techniques to 'natural' settings has proven problematic (Jacobs et al., 2004). Clinical guidelines suggest that steps should be taken to ensure that compensatory strategies are generalised to day to day contexts (Royal College of Speech and Language Therapists, 2005), however, the qualitative literature identified suggests that further support may be needed to help stroke survivors with communication difficulties in interactions outside of the home environment. Practising compensatory strategies outside of the home environment may be an appropriate component of a self-management intervention for stroke survivors with communication difficulties. However, it is important to note that ability to practise and implement compensatory strategies may vary depending upon the type and severity of communication difficulty which is experienced. For example, due to receptive impairments, a stroke survivor who is experiencing Wernicke's aphasia may find it difficult to recognise errors in their spoken language and therefore, recognise the need for (and implement) compensatory strategies (Potagas, Kasselimis and Evdokimidis, 2017). Similarly, translating compensatory strategies to everyday situations is cognitively demanding (requiring memory, attention and executive functioning). Stroke survivors with aphasia and cognitive difficulties may struggle to implement such strategies independently. On the other hand, it may be possible to train caregivers to prompt or support the use of compensatory strategies in real life contexts (Murray and Myer, 2017).

In addition to practical strategies to manage communication outside of the home, the qualitative literature also suggested that support was needed to encourage confidence in communication outside of the home (Dalemans et al., 2010; Dickson et al., 2008; Dietz et al., 2013; Johansson et al., 2012; Le Dorze et al., 1995; Parr, 2001; Parr, 2007; Pringle et al., 2010; Worrall et al., 2011). In addition to reinforcing compensatory strategies, self-management strategies used to promote confidence in ability for example; goal-setting, action planning, problem solving (Jones and Riazi, 2011) may also translate well to supporting stroke survivors to communicate outside of the home. However, it is important to recognise that the communication difficulties experienced by this group of stroke survivors may make it more difficult for these approaches to be implemented. For example, aphasia and cognitive difficulties are often identified as barriers to collaborative goal setting by healthcare professionals (Sugavanam et al., 2013). Developing the shared understanding required may be facilitated by; supported conversation techniques, time, and the development of accessible materials (Hersh et al., 2012). On the other hand, even with additional support, it may be difficult to achieve the shared understanding necessary to set goals for those experiencing severe Wernicke's or global aphasia. Goal-setting, action planning and problem solving may also require relatively intact cognitive processes which may be problematic for some stroke survivors with aphasia (Murray and Myer, 2017). Again, the involvement of family members may be important for providing support for implementing actions or feeding back on the problems encountered when communicating outside of the home.

Another area of need identified in the qualitative literature which was poorly addressed by existing stroke self-management interventions was the creation or maintenance of social support. Only one of the self-management interventions identified in Chapter One explicitly targeted the mobilisation of social networks as part of the intervention and actively included members of the stroke survivors support network. However, the intervention by Glass et al. (2004) reported the partial exclusion of stroke survivors with communication difficulties. In addition to this, the authors of the study report excluding participants "who had no social network with whom interventionists could collaborate" (p. 889). Given the social isolation and loss of friendship reported by stroke survivors with communication difficulties, finding ways of including stroke survivors without support networks is of importance. The qualitative literature suggested that meeting other stroke survivors with communication difficulties was one way in which participants replaced friendships which had been lost (Brown et al., 2013; Brown et al., 2010;

Brown et al., 2011; Davidson et al., 2008b; Fotiadou et al., 2014; Le Dorze et al., 2014). Facilitating peer support may be one way in which a self-management intervention for stroke survivors with communication difficulties may help participants to build a support network (Lanyon et al., 2013).

The qualitative literature also highlighted how communication acted as a unique barrier to the creation and maintenance of support networks. In order to meet the need to maintain a support network, specific training for family and friends in techniques to support conversation may be necessary (often known as conversation partner therapy) (Simmons-Mackie et al., 2010; Simmons-Mackie et al., 2016). The qualitative literature highlighted the discomfort friends felt in speaking to those with a communication difficulty (Dalemans et al., 2010) and also the importance of competent conversation partners in helping those with communication difficulties be understood (Brady et al., 2011b; Brown et al., 2010; Dalemans et al., 2010; Davidson et al., 2008a; Davidson et al., 2008b; Grohn et al., 2012; Howe et al., 2008b; Johansson et al., 2012; LeDorze et al., 1996; Niemi and Johansson, 2013; Parr, 2001; Pringle et al., 2010; Runne, 2012). Facilitating interaction with existing members of a stroke survivor's support network may be key to enabling the maintenance of social support for stroke survivors with communication difficulties. This need is not currently addressed by existing self-management interventions in stroke care.

3.5. Discussion

There is a substantial policy drive towards incorporating self-management as a part of longer-term care in stroke (Intercollegiate Stroke Working Party, 2016; National Stroke Strategy, 2007). Taking a self-management approach may be appropriate for addressing the longer-term needs of stroke survivors with communication difficulties. For example, empowering stroke survivors to manage the consequences of living with a communication difficulty aligns well with the longer-term needs identified in the qualitative literature which highlighted the extensive physical, psychological and social impact of post-stroke communication difficulties upon daily life. However, the meta-synthesis of literature also highlighted significant mismatches between the longer-term needs of stroke survivors with communication difficulties and existing self-management interventions in stroke. A significant area of need was the longer-term management of the communication difficulty itself; for example, in interactions outside of the home

environment, in participating in meaningful activity or in creating or maintaining a support network. Existing self-management interventions in stroke did not appear to include components or strategies which specifically targeted this need and speech and language specific strategies such as AAC or communication partner training may be needed in addition to standard components of self-management interventions in order to facilitate successful self-management of post-stroke communication difficulties. The mode of delivery of existing self-management interventions (e.g. those using group-based or telephone-based interventions or facilitators who are not trained in supported conversation techniques) may also be inaccessible to many stroke survivors with communication difficulties.

The findings of the meta-synthesis suggest that a 'one size fits all' approach to self-management may not be feasible in stroke and may not be accessible to or address the needs of stroke survivors with communication difficulties. The type and severity of communication difficulty experienced by each individual is likely to have a significant bearing upon which components of a self-management intervention would be appropriate and accessible. For example, training in compensatory strategies may be feasible for some stroke survivors with communication difficulties (e.g. potentially those with Broca's aphasia, dysarthria or apraxia of speech), however, may not be feasible for some stroke survivors with severe Wernicke's or global aphasia. Appropriate strategies to facilitate condition management may also vary substantially according to levels of extralinguistic cognitive impairment. Depending upon these factors, a greater level of involvement from family members may be required. For example, by supporting action planning, problem solving or prompting the use of compensatory strategies in real life situations. It is anticipated that involvement of family or friends to a greater or lesser extent will be an important consideration in intervention development.

Developing a range of components which can be used flexibly within a self-management intervention is of particular importance for this population. Existing self-management interventions have been criticised for their lack of user involvement and for being policy driven 'top-down' approaches as opposed to being driven by the needs and experiences of stroke stakeholders (Greenhalgh, 2009; Jones et al., 2013; Boger et al., 2013; Demain et al., 2014). Stakeholder involvement in the development of complex interventions is recommended by the MRC (2008), NICE (2007) and the National Institute for Health Research (NIHR, 2014). This is of particular importance for stroke survivors with communication difficulties given their exclusion from existing self-management interventions (Chapter One). Further research is needed to develop an

approach which is appropriate for stroke survivors with communication difficulties. Such an approach should be driven by the needs and priorities of this population.

Conclusions

The meta-synthesis suggests that existing self-management approaches are unlikely to be suitable for stroke survivors with communication difficulties without significant adaptation. Further research is needed in order to understand the needs and priorities of stroke survivors with communication difficulties in relation to longer-term care. This work is necessary to ensure that the intervention developed as part of this PhD study is appropriate for this population. In contrast to a 'top-down' policy driven approach, the intervention will be 'bottom-up'; driven by needs and priorities of stroke survivors with communication difficulties and other relevant stakeholders. In the next section of this thesis, qualitative fieldwork is undertaken with key stakeholders to inform the design of the intervention.

Section Two:

Fieldwork

Chapter Four: Methods

This chapter outlines the methods used to collect qualitative data from key stakeholders to inform the design of an intervention to support stroke survivors with communication difficulties in the longer-term.

4.1. Introduction

Existing stroke self-management interventions have been criticised for their lack of user involvement and for being policy driven 'top-down' approaches as opposed to being driven by the needs and experiences of stakeholders (Greenhalgh, 2009; Jones et al., 2013; Boger et al., 2013; Demain et al., 2014). In response to this criticism, it was important that the views and experiences of key stakeholders in relation to longer-term care were used to inform the design of the intervention in this PhD study. Involving stroke survivors with communication difficulties is particularly important, given their previous exclusion from research (Brady et al., 2013; Dalemans et al., 2009), and from RCTs of existing self-management interventions (Chapter One). The exclusion of stroke survivors with communication difficulties is not only discriminatory, but may also lead to health inequalities, if longer-term care interventions are developed which are inappropriate or inaccessible to this population.

Qualitative research provides in-depth accounts of the views, meanings and experiences of participants and is increasingly seen as an important contributor to complex intervention development (NIHR, 2014; MRC, 2008; NICE, 2007). The qualitative research in this PhD study was undertaken to ensure that the intervention designed was informed by the needs and priorities of stroke survivors with communication difficulties and other key stakeholders. There were gaps in the literature concerning the requirements of this population in relation to longer-term care which were likely to be important in informing the design of the intervention. For example, the review of qualitative literature in Chapter Two highlighted a lack of research in the first year post-stroke. Previous research with stroke survivors without communication difficulties has highlighted the importance of the first year post-stroke in terms of adjustment and adaptation (Burton, 2000b). Support and adjustments made during this

time period may influence ability to cope in the longer-term. It appeared that no qualitative studies had explicitly explored how stroke survivors with communication difficulties manage their condition and their needs and priorities in relation to longer-term care within the first year post-stroke. The interviews conducted as part of the fieldwork therefore sampled stroke survivors with communication difficulties during this time period.

Other key stakeholders were also included in the fieldwork (MRC, 2008; NICE, 2007; NIHR, 2014). Given the unique language barriers faced by this population of stroke survivors, specialist input might be required to enable effective self-management or as part of a longer-term care intervention. Although speech and language therapists have traditionally focused upon language deficit, they may be uniquely placed to incorporate principles of self-management to support stroke survivors with communication difficulties (Grohn et al., 2014; Brady et al., 2011b; Worrall et al., 2010). Speech and language therapists (SLTs) views and experiences in relation to longer-term care or self-management had not previously been explored and so they were also included in the fieldwork described in this chapter.

The informal carer or close family relation of the stroke survivor were the final group of stakeholders included in the qualitative fieldwork described in this chapter. The literature reviewed in Chapter Two suggested that post-stroke communication difficulties affect the wider social network of the stroke survivor. This is perhaps unsurprising given how central communication is to relationships (Brown et al., 2011). Carers of stroke survivors with aphasia have been shown to have poorer outcomes in comparison to carers of stroke survivors without aphasia (Bakas et al., 2006). It was therefore important that the views of a carer or close family relation of the stroke survivor were incorporated in this study.

4.2. Aims and objectives of the fieldwork

The overall aim of the fieldwork was to develop an in-depth understanding of the requirements for longer-term care for stroke survivors with communication difficulties. This knowledge is used to develop a rationale for taking a self-management approach and to inform the design of the intervention later in the project.

The objectives of the fieldwork were:

- 1) To understand and explore how stroke survivors with communication difficulties manage their condition (including their speech, language and activities of daily living) in the first year post-stroke including;
 - The needs of this population and the barriers and facilitators to addressing these.
 - Priorities in relation to longer-term care.
 - Behaviours which enable effective management of the condition.

- 2) To understand and explore the requirements for longer-term care from the perspective of the carer/relative of the stroke survivor with communication difficulties, specifically:
 - The carers/relatives experiences in the first year post-stroke (including their perception of the stroke survivors needs and the barriers and facilitators to addressing these).
 - Priorities in relation to longer-term care.

- 3) To understand and explore SLTs views regarding longer-term care for stroke survivors with communication difficulties including:
 - To understand and explore SLTs perceptions of the needs of stroke survivors with communication difficulties in relation to managing their condition in the first year post-stroke
 - To understand SLTs preferences for the design and content of longer-term care and their views of 'self-management' as an approach.

4.3. Methodological orientation and theory

Qualitative research represents a diverse assortment of traditions and methods capturing rich, in-depth accounts or explanations of social phenomena (Denzin and Lincoln, 2011). Due to the wide range of approaches and methods encompassed, qualitative research is difficult to define comprehensively. Denzin and Lincoln (2005) suggest that in many ways it is 'defined primarily by a series of essential tensions, contradictions and hesitations' (p.15). Often qualitative research is described as being concerned with answering 'why' and 'how' questions as opposed to answering

questions of 'how many' or 'how much' (Green and Thorogood, 2004; Ormston et al., 2014). The preference for exploring meaning from the participant's perspective has led some to define qualitative research as interpretive research (Pope and Mays, 2006). Another common feature of qualitative research is its preference for naturally occurring data, often in the form of words or pictures (Silverman, 2000).

The philosophical underpinnings of qualitative research are often positioned in opposition to positivism and the scientific method (Denzin and Lincoln, 2011). Positivism suggests that an objective reality exists which can be studied and understood by empirical investigation. In contrast, constructivist or interpretivist paradigms argue that there is no detached version of reality and that people create their own understandings based upon their experiences and reflections upon the world. Interpretivism and constructivism are closely related schools of thought; interpretivism places emphasis upon the different ways people understand the world and constructivism places emphasis upon the active role people have in constructing their understanding of the world. Methods to access knowledge (epistemology) flow from philosophical beliefs and assumptions about reality (ontology) such as positivism, constructivism or interpretivism (Giacomini, 2011). For example, researchers in the natural sciences believing in positivist ontology seek facts through inductive or falsificationist experiments, believing that the data obtained corresponds to a fixed reality. In contrast, constructivist or interpretivist researchers use interpretive epistemologies, believing that multiple interpretations of a phenomenon are possible and that both the participant's and the researcher's experiences influence understanding of the phenomenon being studied. The divide between positivist and constructivist paradigms is often linked with the divide between quantitative and qualitative research (Pope and Mays, 2006). Due to their varying assumptions about the world, quantitative and qualitative research methods have often assumed to be competing approaches (Bryman, 2006). However, more recently researchers have challenged assumptions of incompatibility, acknowledging that each approach might compliment one another (Barbour, 1999; Bryman, 2006; Pope and Mays, 2006). In health services research many view that the use of either approach in isolation would lead to a deficit in knowledge (O'Cathain et al., 2007).

In recent years researchers have spent much less time embroiled in philosophical battles or so called 'paradigm wars' (Bryman, 2006). Bryman (2006) notes that within research there is generally less concern with ontological/epistemological underpinnings

and more concern with the practical task of undertaking the research itself. Avis (2003) argues that researchers need not justify their philosophical stance in order to conduct rigorous investigations. This approach is also known as pragmatism. Pragmatists propose that the value of research is in its contribution to knowledge, as opposed to its position in relation to a 'real' or 'constructed' world (Giacomini, 2011; Avis, 2003). Pragmatists are unconcerned with ontological and epistemological stances as such beliefs can neither be proven nor disproven (Avis, 2003). According to pragmatists, claims to knowledge must be considered useful or not based upon the advancement of knowledge of the question at hand (Giacomini, 2011). A key facet of pragmatism is the centrality of the research question (Bryman, 2006). Methods are seen as an assortment of tools used to answer a research question and are judged in terms of their appropriateness in answering a research question (Bryman, 2006; Chamberlain, 2000). This is in contrast to positivist or constructionist approaches where philosophical underpinnings influence the choice of methodology, interpretation of data and presentation of findings (Giacomini, 2011; Reeves et al., 2008).

Some argue that without allegiance to a philosophical underpinning, knowledge claims made from qualitative research may lack coherence (Holloway and Todres, 2003). There is seen to be value in consistently pursuing an approach from beginning to end; having a coherent view of ontological and epistemological assumptions, the knowledge sought and using methods which are consistent with these viewpoints (Maggs - Rapport, 2001). Giacomini (2011) claims that attention to philosophical theory yields 'richer findings' and researchers should strive to keep their 'theoretical bearings' (p.146). Strict adherence to a theoretically based method is also claimed necessary to prevent the inappropriate mixing of qualitative approaches referred to as 'method slurring' by Baker et al. (1992). Baker et al. (1992) see the lack of application of the 'pure' form of a method as a demonstration of a lack of rigour. On the other hand, others argue that strict adherence to a particular approach may lead to 'methodolatry' (Chamberlain, 2000) otherwise known as method for methods sake (Holloway and Todres, 2002). The concern with demonstrating the 'right' or 'proper' application of a qualitative approach may overshadow or even constrict the research being undertaken (Chamberlain, 2000; Johnson et al., 2000). Striving for a coherent approach may lead to the rigid application of established methods, stifling flexibility and creativity within the field of qualitative research.

In addition, Johnson et al. (2000) argue that the idea that there is a pure form of any research tradition is an illusion. Within particular traditions there are ongoing debates of ontological and epistemological underpinnings and the consequent methodological approach. For example, in grounded theory, the interpretivist approach assumed by Glaser and Strauss (1967) is different to the constructivist approach adopted by Charmaz (2006) (Ralph et al., 2015). Although some authors may claim the use of a particular approach e.g. grounded theory or phenomenology, the methods reported can bear little resemblance to the tradition claimed (Sandelowski and Barroso, 2003).

The extent to which epistemological and ontological positions are relevant to the conduct of qualitative research is debateable. Although Giacomini (2011) suggests that the use of theory leads to more fruitful findings, there is little evidence to substantiate this belief. Thorne et al. (1997) suggest that justification of philosophical positions was borne out of a past need to defend the use of qualitative research, when approaches to research were typically dominated by quantitative methodology, and when qualitative research was seen as 'the crudest form of inquiry' (p.170). Adding to this line of thought, Sandelowski (2000) postulates that qualitative researchers may be keen to attach themselves to a particular tradition to assert credibility or demonstrate the rigour of the approach taken. This can result in studies claiming a 'hollow allegiance' (p.172) to a recognised qualitative tradition (not reflected in the actual conduct of the study) (Thorne et al., 1997). In the context of health service research, Green and Thorogood (2004) make a useful distinction between 'pure' and 'applied' qualitative research. Many traditional and theoretically rooted approaches are rooted in anthropology or sociology. These 'pure' approaches are focused upon generating an in depth and often theoretical understanding. In applied health research the aim of research often begins with a clinically based problem e.g. How well a service works or what the needs for an intervention are (Green and Thorogood, 2004). Applied research aims may not 'fit' or necessitate the level of understanding associated with 'pure' methodologies, for example, those examining cultural rules (ethnography), exploring a lived experience (phenomenology) or building a theory (grounded theory) (Cooper and Endacott, 2007).

This has led to a rise in the use of a 'generic' qualitative approaches (Cooper and Endacott, 2007; Pope and Mays, 2006). Generic qualitative approaches have been termed in different ways including 'interpretive description' (Thorne et al., 1997) or 'qualitative description' (Sandelowski, 2000). For the purpose of this thesis, Merriam's (1988) definition is assumed; researchers using a generic approach "seek to discover

and understand a phenomenon, a process, or the perspectives and worldviews of the people involved” (p.11) as opposed to, for example, developing an in-depth understanding of lived experience (phenomenology), building an in-depth theory (grounded theory) or cultural understanding (ethnography). Taking a generic approach the methods of data collection and analysis are chosen by the researcher without reference to an established tradition or theoretically rooted approach (Smith et al., 2011). Taking such an approach has been criticised for producing low quality descriptive results described by Seale et al. (2004) as ‘quite stereotypical and close to common sense.’ (p.2-3). However, taking a generic qualitative approach should not be confused with the poor application of qualitative methods. Sandelowski (2010) contend that the use of a generic approach is justifiable and valid and can be used to produce valuable interpretations of qualitative data. This term should not be used inappropriately to label studies which are not well thought out or conducted (Sandelowski, 2010).

The trend towards undertaking generic qualitative research studies is growing, however, further attention is needed to clarify how a generic qualitative study can be conducted rigorously in order to defend criticisms exemplified by Seale et al. (2004) (Caelli et al., 2003; Cooper and Endacott, 2007). Caelli et al. (2003) suggest that transparency is key; Firstly, researchers should clearly articulate that a generic approach was undertaken and demonstrate that this approach is consistent with the questions posed. Secondly, researchers should describe the methods used clearly and consider their congruence within the approach taken. Thirdly, researchers must consider the issue of rigour and choose strategies which based upon their knowledge of the literature and fitting with the approach taken will enhance the rigour of the study. Lastly, researchers should be clear about their own position within the research and explicitly state how this may have influenced their analysis of the data or analysis strategy.

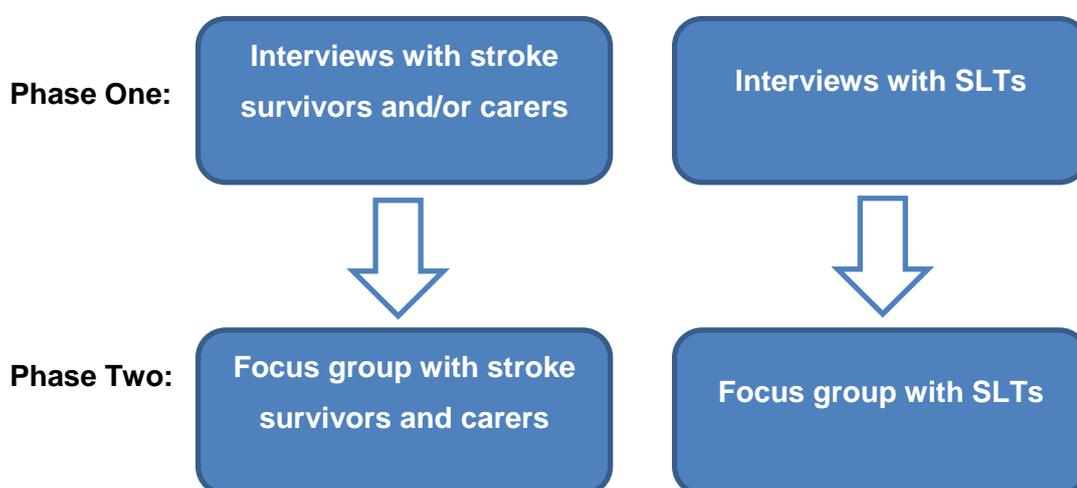
In this study, the author accepts the epistemologies which underpin qualitative research; unlike natural sciences which seek to explain phenomena in an objective manner with rules or laws, human experience can only be explored through participants and researchers interpretations and qualitative methods are appropriate to access this understanding of the social world. This study adopts a pragmatic approach consistent with the applied health research being undertaken. This approach was chosen in line with the aims of the project which did not fit with traditional qualitative approaches, for example, those exploring in-depth lived experiences (phenomenology),

building theory (grounded theory) or exploring cultural understanding (ethnography). Although this may be termed a 'generic' approach to qualitative research this does not necessitate an approach where 'anything goes' (Ormston et al., 2014). Qualitative methods fitting the aims of the project were carefully considered along with methods of data analysis which were consistent with the pragmatic approach. Steps to ensure rigour throughout data collection and analysis were undertaken and are described in further detail throughout the chapter.

4.4. Study design

Figure 8 shows an overview of the study design. The fieldwork was conducted in two phases which involved the collection of interview and focus group data from key stakeholders including stroke survivors, their carers and SLTs.

Figure 8: Overview of fieldwork



In Phase One of the study, interviews were conducted with stroke survivors with communication difficulties, their carers and SLTs. Interviews are a useful tool for generating in-depth accounts of personal experiences (Lewis and McNaughton Nicholls, 2014) and an appropriate way to understand the requirements for longer-term care from stakeholder's perspectives. In Phase Two of the study, a focus group with stroke survivors with communication difficulties and carers and a focus group with SLTs was conducted. Focus groups are a useful method to encourage group discussion such that people's views and experiences are clarified in ways which might not be possible in a

one to one interview (Pope and Mays, 2006). Focus groups were used to enable stakeholders to feedback on the findings of the interviews and to check and refine my interpretation of the interview data (Flick, 1992).

Participant selection

Quantitative research is typically concerned with gaining a sample which is statistically representative of a particular population (Ritchie et al., 2014). In contrast, decisions about sampling in qualitative research are usually concerned with ensuring that appropriate and useful data are generated (Green and Thorogood, 2004). Adequacy is not related to the actual size or representativeness of the sample, rather, its ability to shed light on the research topic in question (O'Reilly and Parker, 2013). The choice of sample is concerned with gaining diversity of experience such that maximum understanding of the topic in question is achieved. This is often referred to as purposive sampling whereby characteristics of the population believed to be salient to understanding the research topic are used to guide sample selection (Ritchie et al., 2014).

Purposive sampling does not rely upon a specific number of participants being recruited and thus an inevitable question arises as to how researchers should judge how many recruits are enough (Guest et al., 2006). The principle of 'saturation' is often used as a criterion to judge if a satisfactory sampling has been achieved (Guest et al., 2006). To reach saturation, participants are recruited in to a study until novel information from the data is no longer gained (Bowen, 2008). The actual number of participants needed for saturation to occur varies upon the research question. The concept of saturation arose from grounded theory where it is more commonly referred to as theoretical saturation (Strauss and Corbin, 1990). Theoretical saturation is the point at which enough data has been obtained to build a rich and complete theory (Morse, 1995). Coding no longer discovers new categories within the data or adds further depth to existing categories of data which contribute to the development of the theory. Although saturation originated in the tradition of grounded theory, the concept has been used more widely and applied to other types of qualitative research (O'Reilly and Parker, 2012). Purposive sample size determined by saturation has become a gold standard for sampling in qualitative research (Guest et al., 2006).

In this study a purposive sampling strategy was used. At the interview stage, the aim was to sample stroke survivors and/or their carers to reflect the 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). Similarly, SLTs were sampled to reflect a range of experience (according to their NHS banding) and services (acute, ESD and community). A mixture of purposive and convenience sampling was used to assemble the focus groups. Whilst a similarly diverse range of experiences was sought as per the purposive sampling strategies used for the interviews, the availability and location of patients and SLTs also played a role in the arrangement of the focus groups.

Participant identification

SLTs were recruited through five NHS speech and language therapy services. A number of recruitment strategies were used to identify stroke survivors and their carers which included identifying potential participants through NHS speech and language therapy services (including hospital and community based services), through charitable organisations and through an existing research register.

Stroke survivors and their carers were identified through the same five NHS speech and language therapy services which were used to identify SLTs. Prior to recruitment, I attended a team meeting with each service to explain the study and answer any questions. 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. At the team meeting I also explained the inclusion and exclusion criteria for identifying stroke survivors and their carers for interviews. The treating SLT approached potential participants face-to-face on my behalf, providing a study information pack containing an invitation letter, summary information sheet, summary information sheet for carers, consent to researcher contact form and pre-paid reply envelope. The SLT explained the study and asked the stroke survivor or carer to get in touch with me if interested in taking part. The consent to contact form was provided with a pre-paid envelope so it could be returned directly. The stroke survivor could also request using the form that initial contact was made with a carer, friend or other family member. There was also space on the consent to contact form for the carer to express their interest in taking part in an interview. The invitation letter and summary information sheet for the stroke survivor were in the accessible format recommended by the Stroke Association guidance (Stroke Association, 2012b).

A similar process was used to identify stroke survivors and their carers through charitable organisations. After explaining the study and inclusion and exclusion criteria, a key contact within the organisation was provided with information packs to approach potential participants face to face. Potential participants were asked to return the consent to contact form directly using the pre-paid envelope if interested in taking part.

An existing research register (held by the Academic Unit of Elderly Care and Rehabilitation and Bradford Teaching Hospitals NHS Foundation Trust) was also used to identify stroke survivors and carers. The database holds records of stroke survivors discharged into the community who have consented to be contacted about participation in future research studies. After meeting the eligibility criteria of being within 12 months post-stroke, the stroke survivor's survival status and living circumstances were checked using the summary care record on the NHS spine portal system. A covering letter providing information about the study, a summary information sheet, summary information sheet for carers and consent to further contact form were posted out to potentially eligible participants. The letter explained that the stroke survivor had been contacted because they have previously given permission to be contacted about future research studies and that the study was looking for stroke survivors who had difficulty speaking since their stroke. Pre-paid reply envelopes were provided to enable potential participants to return the consent to contact form if they wished to be contacted about taking part. The invitation letter and summary information sheet for the stroke survivor were in the accessible format recommended by the Stroke Association guidance (Stroke Association, 2012b).

The consent to contact form specified the participants preferred method of initial contact (telephone, email, written). Contact with either the stroke survivor or carer was made according to the sections of the consent to contact form which had been completed. During the initial contact, I explained the study in full and answered any questions the stroke survivor or carer had. If the stroke survivor/carer was happy to proceed, a date and time for an initial appointment was made. A letter was sent to confirm the appointment and full information sheet. The appointment was not arranged less than three days after initial contact was made to give participants time to consider taking part (unless the participant expressed a wish to take part sooner than this).

Those taking part in the interviews indicated on their consent form whether they would be happy to be contacted about taking part in a future focus group. Those consenting to be contacted were approached about taking part in the focus groups and once contacted, if they were still happy to take part, were sent details of the date, time and location of the event. After I had gained ethical approval for the project, I also became aware of a stroke research event aimed at stroke survivors with aphasia. The organisers of the event actively encouraged researchers to recruit for their projects at the event. Following confirmation from the ethics committee that this would not require an amendment to the existing approval, the stroke event was used to supplement recruitment for the focus group study. The study was explained to potential participants on the day, and those interested in taking part filled out a consent to contact form and were later contacted by the method indicated on the form.

Inclusion and exclusion criteria

Stroke survivors were considered for inclusion in an interview if they were:

- Aged 18+
- 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 or as self-reported by the stroke survivor) and:
- Had the capacity to provide fully informed consent.

Stroke survivors were excluded if they were:

- Residents in nursing or care homes or;
- Receiving palliative care.

Carers were considered for inclusion in an interview if they were:

- Aged 18+
- Able to provide informed consent
- An informal carer to a stroke survivor with a communication difficulty (informal carer as opposed to a paid or voluntary carer) who provides help and support (practical and/or emotional) to the stroke survivor at least once a week.

To be considered for inclusion in a staff interview participants were:

- Employed as a SLT within a recruiting trust
- Have a caseload including adults with post-stroke communication difficulties.

For the staff focus group, participants who had consented to be contacted at interview stage were invited to participate in the focus group. For the patient focus group, participants who had consented to be contacted at interview stage were invited to participate in the focus group. As mentioned previously, recruitment for the patient focus group was also supplemented by approaching participants at a stroke research event. No restrictions on the time post-stroke were placed for participation in the focus group.

Recruitment challenges

A number of recruitment strategies were planned prior to data collection to facilitate recruitment of stroke survivors and their carers. These included recruiting from an existing research register, from local charitable groups and from NHS services. However, difficulties were encountered with recruitment from the research register and from local charitable organisations. With regards to the research register, recruitment for the register had slowed substantially in the time between applying for ethics and commencing data collection. This affected the number of participants who were eligible to be contacted via this method due to targeting stroke survivors who were within 12 months post-stroke. 30 information packs were sent to potential participants inviting them to take part in the project. However, none of the respondents were eligible to take part because of a lack of self-reported communication difficulty. This may reflect two issues; firstly, that participants with aphasia were unable to access the information due to difficulties with reading. Information was presented in an aphasia friendly format; however, it is acknowledged that the inclusion of information for both the stroke survivor and the carer may have caused confusion. Secondly, the lack of responses may reflect a recruitment bias for the research register itself. As highlighted previously, difficulties consenting stroke survivors with communication difficulties has led to their exclusion from research in the past (Brady et al., 2013).

Recruitment from stroke groups also proved challenging. The main difficulty was the time post-stroke as the majority of attendees were a number of years post-stroke (usually 3-4+) and therefore did not meet the criteria of being within one year. The difficulties encountered with recruitment from the research register and from stroke

groups meant a reliance on NHS speech and language therapy services (hospital and community based) for recruitment. One NHS site dropped out of the project a few months in to recruitment citing staff shortage difficulties, and despite ongoing communication and support, another site failed to gain consent to contact any stroke survivors or carers to participate in the project.

Recruitment for the stroke survivor and carer focus groups also proved difficult. Originally, I had planned to approach participants who had consented at interview stage to take part in a focus group. However, due to the geographical spread of participants and that many participants were unable to travel far (due to age or difficulties accessing transport) gathering participants in one local location proved challenging. As mentioned previously, during recruitment for interviews I became aware of a stroke research event and was able to recruit a number of participants who were willing to take part in a focus group from a similar location.

Setting

SLTs were interviewed at their place of work, one to one in a private room (typically a clinic room or meeting room). Stroke survivors and carers were interviewed in their own homes and were given the option to either be interviewed together or separately for the study. The staff focus group was held at the base of one of the community based SLT teams. Stroke survivors and carers who were approached to take part in the focus group stated a preference for taking part in the focus group together and so the author followed these wishes. The stroke survivor/carer focus group was held in a room at a university. All stroke survivors were invited to bring a communication partner to support them if they wished. Care was taken to ensure that the environment was as quiet as possible to facilitate understanding and reduce distraction (LeDorze et al., 1996). For example, if the television was on at home participants were asked if they would mind turning it off during the interview.

4.5. Ethical considerations

The study was reviewed and given favourable opinion by Leeds West Research Ethics Committee (REF:16/YH/0002) (see Appendix C). Separate local approvals were sought and granted at each of the recruiting sites prior to access. The study was conducted in

accordance with the NHS research governance framework for health and social care. A summary of the main ethical issues involved in the research is provided below. Examples of ethically approved documents are provided in Appendix D, E, F, G, H, I, and J.

Informed consent

Informed consent was sought from all participants for each stage of the research (interviews and focus groups). Informed consent was obtained prior to any research procedures being undertaken with participants. Informed consent is seen as a vital component of most ethical codes and is the idea that participation in research should be based upon choice and a full understanding of the risks and benefits entailed (Green and Thorogood, 2004). The participant must be able to make a rational judgement about participating and their choice should not be influenced by coercion or external pressure from others to take part. Stroke survivors with communication difficulties are likely to be considered a vulnerable population, particularly with regards to providing informed consent for research. The challenges stroke survivors with communication difficulties experience make it difficult both to understand information about the research and to express their choice about taking part (Penn et al., 2009). It is important to note that some stroke survivors with communication difficulties may lack the capacity to make fully informed decisions about participating in research. For the purpose of the study, a decision was made not to interview stroke survivors who lacked capacity. This decision was taken as being in the best interests of potential participants who would be unable to contribute meaningfully to the project without understanding of the questions being asked. Past assumptions that all stroke survivors with communication difficulties lack the capacity to consent are outdated (Brady et al., 2013). The capacity to provide informed consent may still be in tact, however, may be obscured by the communication impairment itself (Brady et al., 2013). The study aimed to be as inclusive of stroke survivors with communication difficulties as far as possible and to support participants who retained capacity to provide fully informed consent.

In line with the Mental Capacity Act (2005), in this study each potential participant was assumed to have capacity unless it was established that capacity was lacking. Assessment of capacity in the context of this study meant seeking to determine through informal discussion, that the potential participant could consider information about the study provided by the researcher; that the participant could weigh up what participation in the study would require of them, could retain the information and could then make a

decision about whether to participate in the study and communicate that decision to the researcher. I engaged with SLTs and family members and the potential participant in discussions to determine capacity. The consent support tool (Jayes and Palmer, 2014) was also used to help explore participants' capacity and to determine the format of information that needs to be provided to support informed consent. The tool was used in conjunction with the aforementioned discussions with the stroke survivor, their family and SLT.

If capacity could not be established, the stroke survivor was informed that the interview would not be suitable for them and thanked for their time. However, if the stroke survivor had a carer, they were invited to participate in an interview. If the carer wished the stroke survivor to be present during the interview a consultee declaration was sought. In such cases, the carer or someone who knows the person's wishes acted as consultee. The consultee was advised to set aside their own views and provide advice on the participation of the person who has had stroke in the research, taking into consideration the person's wishes and interests.

In order to support informed consent, information about the study was provided at the appropriate level suggested by the consent support tool (Jayes and Palmer, 2014). For example, if the stroke survivor was able to read full sentences, information about the study was explained with the aid of a standard information sheet (see Appendix D). If the stroke survivor was able to read three key words in a sentence, information about the study was explained with the aid of an information sheet which has been adapted for accessibility according to the Stroke Association guidance (Stroke Association, 2012b) (see Appendix E). If the stroke survivor was able to read two key words in a sentence, information about the study was explained using a 'total communication approach' where each key idea about the study is presented on a separate PowerPoint slide (see Appendix F).

To support the provision of informed consent, I encouraged the stroke survivor to ask questions and also asked the stroke survivor questions to ensure they understood what was being asked of them, for example, will you be interviewed more than once? (yes/no) will the interview be audio recorded? (yes/no), can the interview be stopped at any time? (yes/no). Verifying understanding of the study is of importance for promoting understanding and also to prevent masking effects whereby the stroke survivor may

appear to understand, for example, by nodding or vocalizing in an appropriate way, however, has not actually understood the study (Kagan and Kimelman, 1995).

In line with good ethical practice, the right to refuse participation or withdraw from the research was emphasised as part of the process of informed consent (Webster et al., 2003). All participants were informed of their right to refuse participation in the research without giving a reason and, in the case of stroke survivors, without their medical care being affected. Participants were also informed of their right to withdraw at any point, again without giving a reason. Only when I was certain that the participant had understood the decision they were making did I move forward with signing the consent form (see Appendix G) and then the interview/focus group. When stroke survivors were unable to write, a witness was sought (usually a partner or other family member) to sign the consent form on the participant's behalf.

SLTs were provided with an information sheet prior to the interview/focus group taking place. The information sheet was discussed with SLTs and they were encouraged to ask questions about the project. Written informed consent was obtained from SLTs prior to beginning the interview and focus group.

Interview conduct

The potential for sensitive or upsetting topics being discussed during interviews was considered and strategies to manage this put in place. If participants became upset during the study, I was understanding of this and offered the participant the opportunity to take a break from the interview, to continue the interview at a different time or to withdraw from the study. I also had contact details for the Stroke Association to hand stroke survivors or carers if further advice and support was thought to be appropriate. I was also conscious of the potential for communication fatigue in stroke survivors with communication difficulties. Again, I was sensitive to this throughout the interviews and offered regular breaks and checked ongoing willingness to participate if stroke survivors showed signs of fatigue.

Safeguarding

As a vulnerable population, it was possible that during the interviews, stroke survivors may have disclosed information or I may have had concerns that the individual was experiencing abuse, or was at risk of abuse. If such circumstances were to have arisen,

I would have followed the University of Leeds Safeguarding Adults policy and discussed my concerns immediately with my supervisor and if they were in agreement, the relevant persons would have been contacted as soon as possible (e.g. social services, GP, community care team or the acute trust).

4.6. Data collection

Topic guides

Topic guides were devised prior to the interviews with stroke survivors, carers and SLTs (see Appendix H, Appendix I, Appendix J). Topic guides were used to guide the conversation, however, did not constrain the generation of data and participants were free to introduce any topic(s) they wished. The topic guides for stroke survivors and carers included questions about how they managed when they were first home from hospital, what life was like for them now, how they were currently managing impairments, any problems they had encountered (either ongoing or problems they had solved) and hopes for the future. In order to meet the objectives outlined at the beginning of the chapter, the questions were designed to explore how post-stroke impairments were managed (included resources which had been used to manage them), unmet needs and barriers and facilitators to addressing these. Topic guides were refined on an ongoing basis. For example, after a couple of initial interviews with stroke survivors it became apparent that communication fatigue was more problematic than initially anticipated. In addition to offering regular breaks during interviews, the decision was made to substantially reduce the number of questions in the topic guide. The initial 'ice-breaker' questions, for example, asking participants to describe what happened when they had their stroke were removed. I also piloted the use of Talking Mats™, a system of picture symbols to help participants understand and express their views on health and wellbeing. Talking Mats™ has been used previously to facilitate interviews with frail older people (including those with difficulties communicating due to stroke, dementia and hearing loss) (Murphy et al., 2005) This tool proved useful for gaining insight in to how participants managed their health and wellbeing and began to play a more central role in the interview topic guide (see data collection challenges for further information).

Talking Mats™ was used in the following way: Participants were asked to place a series of health and wellbeing cards under three categories 'managing', 'managing ok',

and 'not managing'. As the interviews with stroke survivors progressed, Talking Mats™ increasingly became the basis for discussion which was used flexibly and in conjunction with questions devised in the original topic guide. Twelve symbols were discussed as part of talking mats including; coping, domestic life, expression, health, leisure (away), leisure (home), learning/thinking, mobility, relationships, self-care and work/education. Blank cards were also available for participants to add any further areas of importance to the mat. An example Talking Mat™ is pictured in Figure 9:

Figure 9: Example of a Talking Mat™ used in interviews with stroke survivors



The topic guide for SLTs included questions about their role, the needs of stroke survivors with communication difficulties, the role of self-management in their practice and how longer-term care could be improved. Minor changes were made to the topic guide as the interviews progressed. For example, questions relating to stroke survivors needs in the original topic guide were focused upon the challenges and difficulties stroke survivors experienced. and I realised it would also be useful to have information about what factors might influence stroke survivors who were able to manage their difficulties well. Therefore, an additional question about this was added to the topic guide: 'What would living successfully with stroke and communication difficulties be like?'. Another change to the topic guide was made in the section about self-management. After a couple of interviews it became clear that few SLTs had come

across this term and so it was difficult to ask the follow-up questions about this. Therefore further questions were added to help explore SLTs perceptions about how stroke survivors managed on a day to day basis: 'How do patients cope with/manage communication difficulties on a day to day basis? Those who are managing well versus those who are managing not so well?'

Interview and focus group conduct

Stroke survivors and carers

Prior to beginning interviews with stroke survivors, I acknowledged the stroke survivors communication difficulties, reassured the stroke survivor that we would try to work around this and that they had plenty of time to speak. Interview questions were flexible, depending upon the stroke survivors' level of understanding. Luck and Rose (2007) describe how, in contrast to a traditional qualitative interview, researchers interviewing those with communication difficulties must take a more active role in the interview process. For example, as opposed to using purely open-ended, non-directive methods of questioning, the researcher may need to offer suggestions or check understanding more often. However, the researcher must also balance this with the need to give the stroke survivor enough time to respond and express themselves as much as possible. Other key strategies employed included; speaking in short sentences using high frequency words, using repetition to aid comprehension, and paraphrasing responses to check understanding (Dalemans et al., 2009; Luck and Rose, 2007). Luck and Rose (2007) showed that the use of such strategies produced richer data in qualitative interviews conducted with those with aphasia than the use of traditional interviewing techniques. Although these adapted methods of interviewing were necessary to collect the highest quality data, the potential for the researcher to introduce bias with their interpretations was considered. During interviews, if a word or interpretation was offered, care was taken to check with the participant that my understanding of their views or experience was correct.

Interviews and focus groups were audio recorded. Fieldnotes were made during and immediately after the interviews and focus groups detailing interruptions or distractions and impressions of the key topics discussed. As the interviews were audio recorded, during the interviews, if communication was unclear, phrases were repeated for the benefit of the recording. I also described non-verbal communication for the purpose of

the tape recording, 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'. Another researcher was present during the focus group to make additional notes about non-verbal communication and impressions of the key topics discussed.

The stroke survivor/carer focus group began with a brief introduction to the project and overview of the tasks that focus group participants would be asked to complete. Participants were reassured at the beginning of the focus group that there were no right or wrong answers and that their experiences and feedback were vital to my project. I also reiterated that everyone in the room had or is with someone who experiences a difficulty communicating, emphasised that we had plenty of time, and encouraged people to communicate in whichever way they wished. Paper and pens were freely available for participants to write or draw their responses if they wished. I asked participants in the focus group to give each other time to speak and to put their hand up if the conversation was moving too fast or if they hadn't understood so I could go back over things. Participants were asked to introduce themselves, stating their name and where they had come from. Carers assisted stroke survivors with this where necessary. The first task participants were asked to complete was a list of three questions on an A3 sheet of paper. This task was intended to be an 'ice-breaker' task to help participants to think about the topics which might be discussed later in the focus group. The questions included:

1. What impact does your communication difficulty have on your day to day life?
2. What has been helpful to you in managing your communication difficulty?
3. What has been difficult for you in managing your communication difficulty?

Questions were presented in aphasia friendly format (Stroke Association, 2012b) and three bullet points per question were presented in the text box. Stroke survivors completed the task individually, or with the help of their carer, and then fed back to the rest of the group. In the second part of the focus group, group participants were presented with picture cards representing support needs which had been identified from the literature and from stakeholder interviews conducted previously. The support need cards were developed and refined through discussion with the supervisory team and a PhD group within the Academic Unit of Elderly Care and Rehabilitation. The cards presented are shown in Figure 10. Each card was presented on an A4 sheet of paper. Participants were then asked to give feedback on the cards and discuss which of the cards were more important or less important.

Figure 10: Support needs presented during focus groups



SLTs

Prior to beginning the interview, I checked that the SLT was comfortable and ready to begin. SLTs were reminded about the confidentiality of the interview and their right to withdraw. Participants were also reminded about this during the introduction to the focus group. The focus group began with a general introduction to the study and an outline of the task that SLTs would be asked to complete. Participants were informed that they were being asked to discuss a very complex subject matter and therefore there were no right or wrong answers. Participants were thanked for their time and the importance of their views and experiences for the project was reiterated. SLTs were asked to introduce themselves at the beginning of the focus group. An A4 handout containing the same support needs as those presented at the stroke survivor/carer focus group was provided to SLTs. Focus group participants were given approximately five minutes to read through and consider the support needs which had been presented. Participants were then asked to give feedback about the needs which they considered to be more or less important and this formed the basis of discussion.

Data collection challenges

Interviewing stroke survivors with communication difficulties is necessarily challenging due to the impact of the disability itself upon the person's ability to express their point of view. In order to maximise the information gained, ongoing adjustments to the topic guide and interviewing approach were made. The first challenge experienced was the inclusion of carers or family members in the interview process. There are mixed views within the literature about whether family members should be included in qualitative research with stroke survivors with communication difficulties. One argument for having a family member present during the interview is the idea that the stroke survivor will feel more at ease and is therefore able to express themselves more easily, generating richer data (Dalemans et al., 2009). Another argument for having a family member present during the interview is that, as the person who knows the stroke survivor well, the family member can aid the interview process by translating or further explaining the stroke survivors' views, again improving the quality of the information gained (Parr, 1994). On the other hand, researchers have found that informal carers or other family members may engage in 'speaking for' behaviours whereby they express what they believe to be the stroke survivors' opinion on their behalf (Luck and Rose, 2007). This can impede the stroke survivors' participation and their motivation to answer further questions (Croteau et al., 2004). In this study, the stroke survivor and informal carer decided their preference for being interviewed together or separately and the researcher took the approach chosen.

In interviews where the stroke survivor was interviewed together with their informal carer, there were difficulties in retaining the focus of the interview to ensure that both parties views were understood. In some circumstances, particularly with stroke survivors with moderate to severe aphasia, the carer dominated the interview and engaged in 'speaking for' behaviour which made it more difficult for the stroke survivor to express their opinion. Strategies to minimise this were employed, for example, ensuring that questions were also directed at the stroke survivor and checking whether the stroke survivor agreed with the carer's translation or opinion, however, the dominance of the carer's voice within joint interviews remained problematic. To address this difficulty, during joint interviews a different approach was used to ensure that the stroke survivors point of view was understood. At the beginning of the interview, I explained that the first task (using Talking Mats™) would be for the stroke survivor to look at, and then in the second part of the interview, I would have some more questions for the stroke survivor and carer to answer together. Talking Mats™ picture cards were used for the stroke survivor to express areas of their health they felt they were managing well with and those they were managing less well with.

Talking Mats™ was an important aid for stroke survivors during the interview process. Talking Mats™ was initially used just for stroke survivors with moderate to severe levels of communication impairment to aid expression. 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). Communication fatigue was more of a challenge for stroke survivors than initially anticipated, which meant the topic guide had to be reduced substantially, to ensure that topics relevant to the research question were covered. Talking Mats™ assisted in keeping the topic of conversation focused and was a useful basis to prompt discussion about managing health and wellbeing. This was in addition to benefits of ensuring the stroke survivors views were heard during joint interviews.

4.7. Data analysis

Interviews and focus groups were transcribed verbatim. All participants were given a participant number and pseudonym and references to places or people were

anonymised. Key quotations used to illustrate themes in the findings were double-checked for accuracy prior to use by listening back to the original recording.

The analysis was conducted on an ongoing basis. This served two purposes, firstly, to highlight key topics that might need further exploration in future interviews and secondly, to reflect upon and improve interview technique. As discussed above, changes to the topic guide/interviewing approach were required in order to capture information as fully as possible.

Approach to analysis

Thematic analysis was used to analyse the interview and focus group data (Braun and Clarke, 2006). Thematic analysis is a technique used to understand and report patterns within data relevant to a particular research question. An advantage of thematic analysis is the flexibility of the approach in being able to answer a broad range of research questions. The analysis is suited to different levels of interpretation depending upon the research question. For example, themes may be related to surface level descriptive summaries, or can explore deeper meanings or conceptualisations of data (Braun and Clarke, 2006). In this study, themes were mostly descriptive except for when the exploration of deeper meanings was relevant to the research aims and objectives and shed light upon the research topic in question. For example, a descriptive aspect of the theme 'obtaining support from healthcare professionals' is that stroke survivors were generally concerned with the physical aspects of managing in the transition from hospital to home and raised few concerns about their speech and language during this time. An interpretive aspect of this theme is that this suggests that the needs and priorities of stroke survivors with communication difficulties were not fixed and changed and evolved over time. Separate thematic analyses were conducted for each piece of fieldwork (interviews and focus groups) and with each group of stakeholders (stroke survivors/carers and SLTs).

Braun and Clarke (2006) suggest six phases are involved in a thematic analysis and these are shown in Table 7.

Table 7: Phases of thematic analysis (From Braun and Clarke, 2006 p.87)

Phase	Description of the process
1. Familiarizing yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

QSR NVivo software (QSR International, 2012) was used to aid the conduct of the thematic analysis. 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 the requirements for longer-term care for stroke survivors with communication difficulties were coded inductively using terms which were close to the original data. For example, in the SLT interviews Lucy stated "Family support makes a big difference if they've got support around them." and this was coded as 'the importance of family support'. A slight variation in the conduct of Phase Three was noted for the interview and focus group data. For each interview, segments of data coded in Phase Two were 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 before looking for themes across transcripts. For example, for the second code of Lucy's data 'the importance of family support' was captured within the label of 'family support' and then more broadly within the theme of 'family involvement in rehabilitation' when themes were identified across participants. As there was only one transcript per focus group, the extra step of labelling data within a transcript before looking across transcripts for themes was not necessary.

Braun and Clarke (2006) criticise some qualitative research for a lack of transparency with regards to how themes are developed from the data. Phrases often used are that themes 'emerged' from the data or were 'discovered'. This study acknowledges the role of the researcher in actively interpreting or selecting data relevant to the aims of the project. Themes were developed to help illuminate the requirements of stroke survivors with communication difficulties with regards to longer-term care. 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. It is acknowledged that the researcher plays a role in interpreting the 'keyness' of the theme in contributing to knowledge on a particular topic (Braun and Clarke, 2006).

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 phase 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 fourth between transcript data and theme organisation was undertaken before the themes were finalised.

Trustworthiness

As the researcher has a role in the interpretation of the data they collect, multiple interpretations of the same data are possible (Graneheim and Lundman, 2004). Given the researcher's role in the interpretation of data, it is necessary to consider the extent to which the findings are credible or truthful. There is no consensus about the best criteria by which to judge rigour in the analysis of qualitative research. Lincoln and Guba's 'trustworthiness' criteria are commonly used and include credibility, transferability, dependability and confirmability (Schwandt et al., 2007; Guba, 1981; Lincoln and Guba, 1985).

Credibility is the extent to which an interpretation of data is representative of the experiences of participants in relation to a particular research question (Schwandt et al., 2007; Lincoln and Guba, 1985; Guba, 1981). It has been suggested that credibility can be enhanced through various means, however, in this study I aimed to ensure credibility through using the following methods: Purposive sampling, peer debriefing and member checking. By using a purposive sampling method, I hoped to ensure that

a range of views were available to create rich data for interpretation. During the analysis I also utilised a PhD group within the research unit for the purposes of peer debriefing. The group was used to discuss themes and check my interpretation of the data. The development of themes was also discussed at supervisory meetings. Finally, the use of focus groups allowed participants to discuss the support needs identified during the interviews. This allowed participants the chance to feedback about my interpretations and check they were relevant to their experiences (member checking).

Transferability is the extent to which findings might be applied or generalised to other participants in similar contexts (Schwandt et al., 2007; Lincoln and Guba, 1985; Guba, 1981). Although issues of transferability are assumed to be the responsibility of the researcher wishing to make a generalisation, the reporting of the analysis in a transparent fashion is done in order to facilitate their judgement. Rich data about the context of the participants is useful in order to facilitate decisions about transferability (Tuckett, 2005). During the analysis I referred to my fieldnotes for additional contextual information which informed the interpretation of the data and to ensure 'thick description' (Krefting, 1991).

Dependability is another aspect of trustworthiness and is the extent to which a researcher's interpretation of data would be consistent if repeated in a similar context with similar participants (Schwandt et al., 2007; Lincoln and Guba, 1985; Guba, 1981). A researcher's interpretation of data may evolve as data are collected over time or as the research question becomes more focused or as additional lines of questioning are explored. To ensure consistency in interpretation, it is necessary to keep an audit trail of the decisions made in relation to the analysis (Krefting, 1991; Guba, 1981). In this study, the use of NVivo software facilitated the clear audit trail from initial coding to final themes. The use of memos aided the production of a clear rationale for the final themes. For the interview data, memos were used to describe my line of thought from the line by line coding to the within subject themes. Mind maps were used to consider the organisation of the final themes and data contained within them. This consideration sometimes led to themes being synthesised or important links between themes being identified (see Appendix K for an example mind map and memo).

The final criterion in considering trustworthiness is confirmability (Schwandt et al., 2007; Lincoln and Guba, 1985; Guba, 1981). Confirmability is related to the concept of

researcher neutrality; the extent to which the findings of the study are free from bias (Krefting, 1991). Guba (1981) suggests that triangulation of data from a number of different sources can help the researcher to evaluate the extent to which their interpretation is justifiable. In this study, I aimed to collect data from different stakeholders and using two different methods (interviews and focus groups). This was intended to help to inform the analysis and to compare experiences which were similar or experiences which were inconsistent. During the analysis, I also strived to find and explore negative (or atypical) cases which contradicted my interpretation of the data (Schwandt et al., 2007). The final way in which I hoped to achieve confirmability in this study was through considering my own influence on the collection and interpretation of data (reflexivity).

Reflexivity is widely considered to be an essential feature of qualitative research (Green and Thorogood, 2004). Reflexivity entails self-awareness from the researcher about how their involvement may have shaped the collection and analysis of data (Finlay, 2002). Rather than eliminating the researchers experience from the process, reflexivity promotes transparency about the researcher's influence upon proceedings. Reflexivity is promoted as a method to enhance the credibility and rigor of qualitative research (Jootun et al., 2009). Neutrality and detachment in relation to the collection and interpretation of qualitative data is accepted as unobtainable. A reflexive statement considering these issues is provided at the end of Chapter Six.

In the next two chapters, the findings from the fieldwork with stroke survivors and carers are presented (Chapter Five), and then the findings from the fieldwork with SLTs are presented (Chapter Six).

Chapter Five: Findings from stroke survivor and carer

fieldwork

This chapter presents the findings from the fieldwork conducted with stroke survivors and carers. In part one, findings from the interviews are presented and in part two, findings from the focus group are presented.

Part one: Interviews

5.1. Overview of interview participants

Consent to contact forms were received for a total of 26 participants (17 stroke survivors and nine carers). One stroke survivor was unable to be contacted (an up to date telephone number could not be found) and two stroke survivor and carer dyads decided they would not like to take part in the study as they were too busy. A total of 21 participants (14 stroke survivors and seven carers) took part in interviews for the project. The majority of stroke survivor and carer dyads (six out of seven) chose to be interviewed together; one dyad chose to be interviewed separately. Fifteen 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 8 shows an overview of participant characteristics; the table is organised alphabetically according to the stroke survivor's pseudonym. 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, I was unable to obtain informed consent for one stroke survivor to participate in an interview (Carol's husband Stan was invited and agreed to take part in an interview and consultee declaration was obtained on behalf of Carol).

Table 8: Overview of participants in stroke survivor and carer interviews

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

* Consultee declaration obtained

5.2. Interview themes

Development of themes

Themes were developed using thematic analysis (as outlined in Chapter Four). The line-by-line coding of interview transcripts created a total of 144 labels across interview participants. The labels were roughly organised according to their topic in order to identify themes. For example, the labels 'loss of independence', 'striving for independence', and 'reliance of stroke survivor upon carer for support' were organised under the draft theme of 'independence'. A total of 10 draft themes were identified which included 'adapting and adjusting', 'ongoing speech difficulties', 'support from friends and family', 'support from healthcare professionals', 'hope', 'independence', 'carers responsibilities', 'confidence', 'meaningful activities', and 'keeping busy'. By reviewing the data within the themes the meaning and content of the draft themes was considered. For example, data contained within the draft themes 'support from friends and family' and 'carers responsibilities', related to the changes in relationship dynamics experienced by stroke survivors and carers, and this developed in to the theme 'coming to terms with relationship changes'. A total of six 'final' themes were developed which are outlined below. An illustrative quote summarising the content of the theme is presented at the beginning of each passage.

1) Managing changes to speech, language and communication

"Oh yeah, oh yeah but it's the fact I can't, I can't use the words so I have to, so I get a problem there, so that's the problem..." (Albert, aphasia, 9 months post-stroke)

The sudden loss of speech and language was described by stroke survivors as a shocking event and an unexpected consequence of stroke. Prior to stroke, speech and language was taken for granted and was performed and understood without thought. However, 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 difficulties speaking upon 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.

*"I just can't express **myself**, I yeah, I just can't express **myself**, yeah."
(Simon, Aphasia, 5 months post-stroke)*

Changes to communication caused restrictions in the activities stroke survivors felt able to perform. Managing changes to speech and language was particularly problematic for stroke survivors when communicating outside of the home environment with strangers who were unfamiliar with their speech and language difficulties. Problems were encountered when strangers spoke too fast or in long sentences or when they did not allow the stroke survivor enough time to respond. Difficulties with communication created problems for stroke survivors who struggled to express their wants and needs in order to perform daily activities.

I: And have you had any situations that have been difficult?

P: Going on bus, for example, yeah.

I: And what happens?

P: From there to down there it's two thirty, expressing...two thirty please, all sorts of trouble, [laughs] yeah." (Simon, Aphasia, 5 months post-stroke)

Some stroke survivors interviewed experienced significant anxiety due to their communication problems. Stroke survivors with receptive difficulties feared that their lack of understanding may cause them to appear rude if they did not respond in the correct way or misunderstood the conversation. Those with expressive difficulties experienced anxiety about being able to produce verbal output when required. In some cases, anxiety about communication caused stroke survivors to restrict their activities.

"Anxiety I think, I just, yeah, no, 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, Aphasia, 12 months post-stroke)

Although Susan's aphasia was relatively mild, her concern about others perceptions if she did not speak 'normally' caused anxiety, and Susan had lost confidence in her ability to communicate outside of the home alone. Confidence was fragile and although none of the stroke survivors interviewed had experienced stigmatising reactions due to their difficulties, this was feared. Stroke survivors also feared the embarrassment of becoming 'stuck' with their communication in a public place.

Restrictions with communication not only caused difficulty with strangers but also with those who were familiar to stroke survivors. Conversations in a group of friends were difficult for stroke survivors to keep pace with both in terms of understanding and in terms of being able to respond with their own thoughts. This change was particularly noticeable for stroke survivors who had been outgoing prior to stroke. For example, James spoke about how he struggled to understand others during a party he had attended with his friends. James' wife Sylvia expressed how she thought that he was quiet during the party.

"I: And is that a change from before the stroke would you say?"

R: Oh yeah yeah, because before it's just life and soul isn't it really ..."
(James, Aphasia, 5 months post-stroke)

In this quote James expresses how before his stroke he was the 'life and soul of the party'. Due to the difficulties he experienced during group conversations, James explained how in group situations, it felt easier for him to withdraw from the conversation rather than attempt to follow it ("...and then I shut up then..."). This account of managing communication difficulties was common amongst the stroke survivors interviewed. Many withdrew from conversation or actively avoided activities which would involve speaking or understanding language.

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 (Dysarthria, 3 months post-stroke) described how the SLT advised slowing down his speech as a strategy, and Gregory (Apraxia of speech, 7 months post-stroke) described how the SLT had advised him to break longer words down in to syllables to help with his communication. Other novel and creative strategies were also evident which 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 speech and language. In order to avoid the embarrassment of being unable to find the correct words, Gregory used humour to diffuse the awkwardness of the situation:

"Well when I get started telling something 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, 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, I'm wearing this, 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 you like rugby?"..." (Sarah, carer-Paul, mother)

In spite of his relatively severe expressive communication difficulties, Paul demonstrates a high level of creativity in learning from the success of a strategy in one situation, and, in adapting it and applying it to another. Cognitive ability may have acted as a facilitator to the development and application of these communication strategies in this context.

The most common strategy stroke survivors used in order to manage difficulties with speech and language was to obtain support from friends and family. 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, Aphasia, 5 months post-stroke)

Simon describes feeling under pressure to communicate if there is a queue behind him in the supermarket. However, having his daughter present takes the pressure off the need to communicate as she is able to provide assistance if needed. Similarly, Nico (aphasia, 8 months post-stroke) struggled to speak with strangers when he felt under pressure to communicate. In restaurant settings, Nico's wife Clara helped to facilitate the conversation by discussing Nico's order with him before the waitress arrived:

"To give the order to the waitress or anything can you, so we've got to have a sort of discussion beforehand..." (Clara, carer-Nico, wife)

Robbie's wife was also available to provide support with communication on the telephone when needed:

"Yeah the... when people ring up, sometimes I can't understand what they're saying, so I have to pass the phone to my wife." (Robbie, aphasia, 1 month post-stroke)

Friends and family also acted as a source of reassurance for stroke survivors with regards to their speech and language. For example, Gregory was placing a card on his 'talking mat' about his expression and changed his mind about placing the card in the 'not managing' section. When asked about why he had changed his mind Gregory stated that his friends being able to understand him had caused him to reflect and re-evaluate his level of speech.

"P: Well it's as good as a tonic.

I:...So that gives you a bit of a boost?

P: Yeah, but I don't think they're saying it for that reason...No, because they say, some would say "Your speech is coming on"..."
(Gregory, apraxia of speech, 7 months post-stroke)

The legitimacy of Gregory's friend's comments about the improvement to his speech was important and Gregory perceived that his friends genuinely believed his speech was improving and were not providing false reassurances. The spontaneity of their comments was related to Gregory's beliefs about authenticity.

Friends and family also provided a sense of normality for stroke survivors. Throughout his interview Simon discusses the difficulty he experiences in expressing himself with people outside of his family and friendship circle. The closeness he felt with his family was of importance to Simon ("closeness is a good thing, yeah..."). Simon's family adjusted the way they spoke to him and gave him time to express himself ("Because time, I given time to speak, yeah.") which allowed him a sense of continuity with his pre-stroke life:

"I: And how do you think that helps?

P: It gets me over what's happened to me..." (Simon, Aphasia, 5 months post-stroke)

Alfred also spoke about the importance of family members treating him as ‘normal’.

“ I: And is there any other way that you think family has helped you or supports you?”

P: Not really, it’s just been normal.

I: They’ve just treated you normally?”

P: Yeah, as though nothing has happened, and I’d prefer it like that anyway because I’ve got to try and get myself right and I’m determined to...” (Alfred, Dysarthria, 3 months post-stroke)

The quote from Alfred suggests his belief that his family treating him ‘normally’ allows him to work towards getting back to normal and increases his determination to do so.

Sometimes the family member themselves used strategies to help the stroke survivor to manage their communication. For example, Clara discusses using a word book to help Nico to express his needs:

“Yeah, and the word book comes out, you know, and then he gets cross and that and he’ll say, “Oh forget it,” and I’ll say, “No, let’s just go back and do it, step at a time,” and I’ve got to then say, “Did you want some crisps or do you want ice cream or do you want a piece of cake?” you know, and we’ve got to go... we go around the thought process till we find the one.” (Clara, carer-Nico, wife)

The quote highlights Nico’s frustration at having to use this alternative method of communication and the effort required to express himself. Clara’s patience helps to facilitate the process in this situation. On the other hand, some family members felt that strategies to facilitate communication were not necessary. For example, despite Carol’s severe communication difficulties, Stan felt he had a good understanding of her wishes and did not require additional aids such as a communication book: “Well we just accept it and try and work out what she’s saying...” (Stan, carer-Carol, husband).

Stroke survivors varied in the extent to which their communication difficulties had restricted their activities. Stroke survivors who were less than six months post-stroke had generally engaged in few activities outside of their home environment which involved speech and language. 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:

“Erm yes yes but 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 important if you can...” (Isobella, Aphasia, 3 months post-stroke)

Once support from rehabilitation services came to an end, 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, 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 facilitate 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, 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, yeah...”

(Paul, 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. For example, in spite of reservations from his family, Paul had recently got on a bus for the first time by himself the week before the interview. This was an important achievement for Paul and a step towards resuming the activities he had enjoyed prior to his most recent stroke. Managing changes to speech and language 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 communication 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.

2) Obtaining support from healthcare professionals

“Because, you know, I mean I can do so much but I just need, just need guidance really...” (Sylvia, carer of James)

Participants’ experiences of obtaining support from healthcare professionals varied. The time post-stroke was associated with the level of support participants were receiving; those who were less than 6 months post-stroke were receiving support from a multidisciplinary stroke team and those who were 6-12 months post-stroke had been discharged from these services and received little ongoing support from healthcare professionals. Participants’ 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 carers 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 carer’s apprehensions.

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

Sylvia valued the healthcare professionals who came in to assist her husband. This continuity was important during a time of uncertainty when Sylvia was figuring out the responsibilities of caring for her husband. The presence of healthcare professionals allowed Sylvia to watch how they physically handled the self-care of her husband so she was able to mimic this in the future. However, the transition from hospital to home was not always smooth and for some obtaining support was effortful. 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...when we saw the consultant after six weeks she said, "and how's the physio going," and I said, "well," I explained to her that we didn't have any, and that we'd gone private. She was shocked, and she said it's a highly funded team and there's no excuse for that."
(Elizabeth, carer-Daniel, wife)*

Elizabeth was proactive in seeking alternative support for Daniel and the couple were in the financially fortunate position of being able to pay for private treatment. Other stroke survivors also noted delays and uncertainties in the provision of healthcare following discharge from hospital. For example, Teddy describes how his daughter had to chase up the care team who did not come as expected when Teddy was first discharged from hospital:

*"Well there were a little, a few ifs and buts at the beginning when they were coming and things like that, you know.... it were just teething troubles at the beginning, you know."
(Teddy, Dysarthria, 4 months post-stroke)*

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, carer-Hideo, wife)*

In the transition between hospital and home, stroke survivors and carers were generally concerned with the physical aspects of being able to manage at home (e.g. washing, dressing, walking), and few concerns were raised about managing speech and language during this time period. James explicitly stated that his immediate priority had been to walk since he was home and speech and language therapy had been a secondary concern. However, since he had made progress in physiotherapy he wished to focus upon his spoken language:

“Really to be honest to start with what... it was to walk properly, and really this sort of... the... much time as we were really because this walking, yeah...speech now is back again to...yeah, yeah” (James, Aphasia, 5 months post-stroke)

This highlights how some of the needs and priorities of stroke survivors with communication difficulties were not fixed during the first year post-stroke and were constantly evolving as rehabilitation progressed. 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 SLT], yeah.” (Simon, 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...and we’re thinking now about him joining a special sort of gym or doing something that way because we don’t want to just stop and I think it’s linked to speech therapy which is a little bit of a concern, because it’s just amazing how, you know, you’re so in this bubble of a stroke that, you know, even me putting his trainers, putting trainers on every day and one of them said, “Get Velcro ones,” well why didn’t I think of that, and it’s like when the speech therapist comes out and she does things and I think, oh well why didn’t I think of that...” (Sylvia, carer-James, wife)

For Simon and Sylvia it was important that when the support that they were currently receiving had ended, that progress with rehabilitation did not stop, and that they could engage with other services. For example, Simon had been referred to computer based speech and language therapy at a local hospital and Sylvia was looking in to a specialist gym for James. For Sylvia the prospect of losing support and guidance from the healthcare professionals was still concerning. The specialist information they

provided was something Sylvia felt she would be unable to obtain or figure out intuitively. For stroke survivors and carers the process of adjustment and adaptation had not ended at the point of discharge from rehabilitation services; many had only just begun to venture outside of their home environment and few had resumed their previous roles or meaningful activities. Stroke survivors and carers therefore had to negotiate this stage of adjustment without support from healthcare professionals. There is also significant uncertainty in Sylvia's account of the discharge process. An explicit discussion about discharge plans appeared to be lacking and Sylvia had inferred from "the way they were talking" that the service may soon be withdrawn. This discussion had taken place with the physiotherapists and Sylvia was unclear if this meant that speech and language therapy would also be withdrawn.

Sarah (carer) felt dissatisfied with support her son Paul (stroke survivor) had received from SLTs 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, carer- Paul, mother)

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 and language.

"So this is why I think it's important to involve if you can do, involve the carers as I say, this is what's happening, try this, try that, you know, and listen, have time 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, carer- Paul, mother)

Sarah perceived that there was a lack of time in speech and language therapy sessions for her to be involved. In the absence of support from SLTs, Sarah had come up with her own strategies to help Paul, for example, creating a colour coded communication board, playing cards or asking Paul to describe what was happening on a television programme. However, in some instances, the SLT told Sarah that the strategies she was using were incorrect. Sarah wished for reassurance from the SLT and information about how she could help Paul, however, in the absence of support she feared that her strategies may have harmed Paul's progress. Sarah also perceived

that speech and language therapy did not cover the practicalities of communicating in a real-life situation:

“...they should have really seen him in settings, would have been nice outside, going for an appointment or I mean I know the sheer practicalities of it, you know...but how would you manage if you were to ask for something in the shops and things like this, so it was the physios that were doing this, whether they were reporting, but they said they were reporting that to the speech therapist, but it’s horses for courses isn’t it, the physios could observe and report back, but are they in a position to offer help and advice to me, I was the one that struggled in so much as am I doing, am I doing anything that’s beneficial, am I helping, am I hindering?...” (Sarah, carer- Paul, mother)

Sarah was unique in her explicit dissatisfaction with the amount and type of speech and language therapy input available to her son Paul. However, Paul was also the only participant in the interview who had previously experienced a stroke which may have impacted upon Sarah’s experiences.

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, carer-Daniel, wife)

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; the decision to discharge rested solely in the hands of the healthcare professional. 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 yet are we?’ (Clara, carer-Nico, wife)

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:

"...but you know, 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, carer-Daniel, wife)

Sarah felt that each healthcare professional had their own speciality and there was a lack of consideration of her son Paul as a "whole person". Sarah felt this was needed to help Paul to come to terms with emotional consequences of having a stroke. Previously, Paul had input from a neuropsychologist which Sarah perceived had been helpful:

"...and she was the first person who wasn't really interested in how his legs were doing, his arm was doing, and his speech, she was looking at him as a whole person, how he was, where he'd come from, what he was doing now and talked about his future, she'd got him to look into his future." (Sarah, carer- Paul, mother)

Due to service reorganisation, this input was no longer available for Paul, and again Sarah had tried to compensate for the lack of professional input by talking to Paul about his future herself.

It is important to note that some stroke survivors and carers 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 deficits who were happy with the progress they had made.

"It's just regarding the stroke and now my speech, and as soon as that's quite happy and [SLT] discharged me from that, which sounds good the next time she comes, I'll be very happy." (Robbie, aphasia, 1 month post-stroke)

Susan had been discharged from speech and language therapy after a few sessions as the therapist stated that her difficulties were not severe enough to require treatment. However, Susan perceived she had a close relationship with the consultant at her local hospital, who regularly reviewed her progress, and provided her with a sense of ongoing support.

"...just to be able to go to my doctor's and to go and see [Name of doctor] just every four months, it doesn't matter, just I know that they're there." (Susan, Aphasia, 12 months post-stroke)

3) Balancing support and independence

“...and they tend to want to go to the bar and I mean they want for me to sit there and they want to, try to I’d say fuss a little bit but they’re meaning well, but I want to do it myself.” (Alfred, dysarthria, 3 months post-stroke)

Stroke survivors obtained support following hospital discharge through healthcare professionals and friends or family. Although stroke survivors and carers accepted that support was sometimes needed, they wished to maintain independence wherever possible. 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, 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, Gregory was determined to manage his self-care independently and managed to do so (with his wife on hand in case of emergencies). Gregory expressed a sense of accomplishment from doing this by himself.

“P: I manage to do all that on my own, well my wife is usually there in case but I’ve managed to do it, I tell her not to help me and my part of my physio and I can now stand up and shave and shower, shave and wash, yeah.”

I: So it sounds like you’re quite keen to do that yourself?

P: Yes! Because it helps me...

I: And how do you think it helps you?

P: Well I’ve got to learn to do things myself, yeah.” (Gregory, apraxia of speech, 7 months post-stroke)

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, apraxia of speech, 7 months post-stroke)

“I’m very erm well you see I’m 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, 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. Isobella’s daughter had been staying with her since she had been discharged; however, was seeking additional support from a home care team in the longer-term. This caused tension as Isobella had previously lived independently (“I have always been a very independent person though”) and was reluctant to accept help:

“...and er you feel then you have to ask other peoples help and they will give it to you sometimes they give you too much and sometimes you get think oo I think everybody’s being a bit stupid about it. So it is a difficult whichever way you have it really I think...” (Isobella, Aphasia, 3 months post-stroke)

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:

“R: Erm... well Kerry more or less does everything I think, you know, I get all words wrong if I want to go on the telephone so I can't make an appointment, you know, for the doctor's or, Kerry more or less does everything, and 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: That's the word! Oh gosh, yeah!” (Susan, 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 spoken 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, Aphasia, 12 months post- stroke)

Some carers used strategies to actively promote their relatives independence. For example, Sarah actively encouraged her son Paul to speak in a cafe by pretending to need the toilet so that he would be required to communicate with the waitress:

“And it's little things like, oh, I go out for a coffee, “I'm going to the loo, if she comes over I'd like a cappuccino, you choose,” he has to do it, it's that sort of thing.” (Sarah, carer- Paul, mother)

Elizabeth strived to enable Daniel to be as independent as possible but this proved difficult due to the severity of his communication difficulties. Elizabeth struggled to find places in the community where Daniel could go for an extended period of time by himself.

“I know it's because it costs money, but somewhere where he could actually go independently, spend the day with other people in a safe environment, practise his speech and just do activities and help other people and get help himself, just interaction with that. Because it's just me and him a lot of the time, everything that he does, you know, and it's a bit limited really, isn't it?...But if there was just somewhere where he could go and do things, but there aren't really things, unless I take him somewhere.” (Elizabeth, carer-Daniel, wife)

Daniel relied upon Elizabeth for many aspects of his daily life including self-care and activities which involved communication. Elizabeth describes a state of constant togetherness which she perceives restricts independence for both parties. Elizabeth

suggests that having a place where Daniel could spend time independently would lessen the sense of restriction.

4) Coming to terms with relationship changes

“I think now we are mainly focusing towards him nowadays....” (Mai, carer-Hideo, 3 months post-stroke)

Stroke survivors and their carers spoke about the changes to the dynamic of their relationship following discharge from hospital. Stroke caused disruption to relationships; the changes often related to the amount of time dyads spent together since the stroke had occurred (spending increased time in each others company) and a shift towards the stroke survivors needs becoming the main focus of the relationship. Stroke survivors recognised the reliance they had upon carers in comparison to their pre-stroke lives:

“Hmm, well I’m just dependant on her [wife-Elizabeth], I am dependant on her, yep.” (Daniel, aphasia, 12 months post-stroke)

Activities which stroke survivors could not manage without their carer often related to those involving communication. For example, it was difficult for stroke survivors to use public transport independently and so they relied upon family members to get out of the house. Other areas which were particularly problematic were activities involving the telephone or communication with strangers. Nico (aphasia, 8 months post-stroke) had significant problems with his communication and his physical mobility which restricted his participation in many of the activities he had done prior to stroke. Nico struggled with his changed relationship role and increased reliance upon his wife Clara. Nico commented: “Used to be the other way around didn’t it?” to highlight how his wife used to rely upon him for support and now he had to rely upon her. Helping Clara with household activities was an important role for Nico prior to stroke; Nico had gone from an active to a passive role and there was a sense of emptiness in the role Nico now played in the relationship.

“Yeah, we did it jointly didn’t we, you could do whatever, you know, we did things together and what not, but now he couldn’t cope doing something like that, you know, even cutting the lawn or anything like that...” (Clara, carer-Nico, wife)

Clara had to cope with her own chronic health problems which also impacted upon the extent to which she felt able to help Nico. Due to back problems, Clara became tired easily, which made it difficult for her to leave the house and she worried about Nico leaving the house with her in case he fell. Clara became upset during the interview when discussing the pressure she felt under as a carer:

"[Cries]. Just feels as if everything is wrong in it wrong but never mind, there's other people worse off, that's what I keep thinking and get on with it, so yeah." (Clara, carer-Nico, wife)

The extra responsibility of managing all household tasks in combination with her existing health problems caused Clara significant stress. An important coping mechanism for Clara was to reflect that other people were "worse off" and to carry on and manage as well as she could.

Although stroke survivors recognised the relationship changes which had occurred, it was those who cared for the stroke survivor who expressed additional pressure and responsibility following hospital discharge. The transition from hospital to home was a particularly difficult and worrying time for caregivers:

"But I felt very, I felt quite panicky really, because I didn't know how I was going to cope." (Elizabeth, carer-Daniel, wife)

"You know, I was worried about him being down here when I went up to bed, but you know, you know, it, it got easier with time didn't it?" (Sylvia, carer-James, wife)

Caregivers also had to cope with some of the hidden consequences of stroke, for example, coping with cognitive difficulties or changes to personality. When Hideo and Mai were interviewed approximately one month post hospital discharge, Mai reflected that "even though look quite okay, he is different", and described how Hideo had become more short tempered and irritable since his stroke. Mai had not anticipated the level of care Hideo would need following his discharge from hospital:

"Actually you know, there are different problems that when he was in hospital I just went to see him by car, to visit two hours up to six hours sometimes, but now I am happy he is here but a different problem has occurred that means he is like a kind of a child." (Mai, carer-Hideo, wife)

Mai uses the simile of Hideo being 'like a child' to express the level of attention and care she felt Hideo needed since being home. There was also a sense that Mai was still coming to terms with these changes and 'figuring out' how best to care for Hideo within their changed relationship. In other carer's accounts of relationship changes, there was the sense that the carer was 'figuring out' the change to relationship dynamics. In taking on the caring role, family members were aware of the stroke survivor's vulnerability. Concerns about the stroke survivor's safety were common amongst carers, in particular falls or anxiety about them having another stroke.

"I used to follow him around about every two inches behind him for months really, worried that he'd fall." (Elizabeth, carer-Daniel, wife)

"...my friend I had to go out yesterday for a couple of hours and I a friend of ours called in came and sat in whilst I was out..." (Stan, carer-Carol, husband)

Sarah spoke about how she had become overprotective the first time her son Paul had a stroke. However, this time Sarah was learning to stand back and allow Paul to become more independent:

"And just letting them go...if he's by himself somewhere and he goes to the bar, and the first time I remember, I said, "Can you go get me a drink," I thought, gosh, he can't carry two pints, and it was upstairs, this was a bar...I thought, "Oh I shouldn't have done that," and he came, down the stairs with one pint, and then he went back up, he came down with the other, and I went, "Oh right," he says, "No, I told them, I've got to... I've had a stroke,"..."

Due to the focus upon the stroke survivors needs, carers sometimes expressed difficulties in having time for themselves. This was mostly expressed by carers who were further post-stroke in comparison to those who were newly discharged from hospital.

"We get on fine, and we muddle along, don't we? So, but it means that we have, we spend such a lot of time together, I don't do the things that I want to do." (Elizabeth, carer-Daniel, wife)

"And he wanted me to go somewhere, and I said, "Paul, I need some time out, I'm going to go back," "Oh okay," "Well I just need a break," and I said, "I just want to do my book, read my book, all I want to do my puzzles or something and I'll get back to you," I said, "but you know, I just need some time out." And they understand, he

understands, and I think it's to be honest, you know, honesty is really important as well." (Sarah, carer-Paul, mother).

Sarah felt that honesty was important and felt free to express her need for a break to her son Paul. However, Paul lived with his father which was a facilitator to Sarah's ability to be able to take some time on her own. In contrast, support for Elizabeth was less readily available:

"And although family are great and everything, they've all got jobs. Everybody we know is working." (Elizabeth, carer-Daniel, wife)

In spite of the disruption stroke had caused to their relationship; survivors and carers still expressed a sense of togetherness in coping with the aftermath of stroke. Some spoke about how they appreciated each other (and life) more since the stroke and had grown closer in the face of the difficulties they experienced.

"Understanding each other...I think more, because our age is getting another year, old more each day, another year, aging." (Mai, carer-Hideo, wife)

5) Hope for recovery

"... it's seven months, and now with these as you say, better, better, I reckon come, sorry, come month, sorry, come a year, yeah, I reckon I reckon that, yeah..." (Paul, aphasia, 7 months post-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 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, aphasia, 1 month post-stroke)

The use of the word "hiccup" suggests that Robbie's aphasia was perceived to be a temporary difficulty and that life would resume as usual once this had been overcome. Robbie's aphasia was mild and the improvements he had seen in his spoken language

so far appeared to contribute to his belief that his spoken language would return to normal. Robbie believed that the exercises given to him by the SLTs had led to improvements in his spoken language, and would contribute to his spoken language returning to normal in the longer-term.

“The therapists have really, really helped...I’m getting back onto the road where I was before, which is a good thing.” (Robbie, 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 language and had set a goal to be “back to normal” by the Christmas following his stroke. Normality was strongly related to returning to work and Simon perceived that he would be unable to regain normality until his language had fully recovered. However, Simon had not progressed as quickly as he had hoped:

“Way, way off that at the moment, yeah, June could see some improvements, back to normal, yeah.” (Simon, aphasia, 5 months post-stroke)

The quote shows how Simon had adjusted his goal of recovering by Christmas to a later date in June. By re-evaluating the date by which Simon expected his language to recover, he was able to sustain hopefulness for recovery in spite of the disappointment of not reaching his goal. Although hopeful, Simon also expresses frustration about the amount of time it was taking to recover. In this extract the author 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 want to know, yeah, I just want to know how it’s doing, how it’s doing.” (Simon, 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. Simon wishes for information about the likelihood of reaching his goals for recovery, but in the same instance appears to hold the view that this information may only become clear through the passage of time (it being “too soon” to tell). Hideo also expresses frustration about the perceived slowness of recovery and his wish to get back to the hobbies and interests he enjoyed prior to stroke:

“But it takes time. I wish I could hurry but it’s not easy...I want this, want this, want this, but slowly on the things and steady.” (Hideo, aphasia, 3 months post-stroke)

The frustrations experienced by Simon and Hideo may be related to a lack of control as recovery is expected to occur naturally over time (as opposed to in direct response to any actions the interviewee takes) and even through the passage of time the extent of recovery is uncertain. Although hopes for recovery were high, frustrations were experienced when recovery did not occur at the expected pace. Without an understanding of what the future may hold, stroke survivors 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 carers delayed resuming pre-stroke activities and roles with the hope that improvements would occur. For example, as previously described Nico had struggled to participate in many of his pre-stroke activities. The couple expressed a sense of emptiness and monotony in their lives but they hoped for improvements to occur in the future.

“Well we just hope things get better and if not well we hope they don’t get any worse don’t we?...” (Clara, carer-Nico, wife)

In contrast to Simon and Hideo, 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, aphasia, 5 months post-stroke). Although James appeared to have come to terms with the fact that his language might not fully recover, it was still important for James to work towards improvements and to come as close to recovering his spoken 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, aphasia, 5 months post-stroke)

Carer’s expressions of hope for recovery were also related to the passage of time. However, the amount of time for recovery or the extent of recovery was often uncertain and in this sense, recovery was not an expected event for carers who took part in the interviews in this study. Hope was often conveyed as a positive outlook which allowed carers to cope with the uncertainty of the situation:

“So it’s still a bit worrying about his future but still on the other hand I am positive moving forward, very slowly and slowly.” (Mai, carer-Hideo, wife)

“So hopefully things might click back in a bit, I don’t know, we’ll just have to wait and see, they can’t tell you these things can you with strokes, it’s what will be will be ...” (Clara, carer-Nico, wife)

6) Adapting activities and keeping busy

“...teaching, I was very involved with pupils... and now it’s gone. Yeah.” (Daniel, stroke survivor, 12 months post-stroke)

Stroke survivors and carers 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 adapt 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. Being unable to drive was often associated with a loss of freedom and a contributor to the loss of activity outside of the home. 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 to take part in daily activities within his home.

“I: So what do you do during the day?”

P: Not a lot [laughs].” (Nico, aphasia, 8 months post-stroke)

As mentioned previously, Nico’s wife Clara also had health problems which left her unable to provide the level of assistance Nico needed to manage his mobility outside

the home and both were concerned about falls which was a barrier to participation in meaningful activity outside of the home.

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... Yeah, for instance, there’s a league game tonight and one chap he’s been very good, yeah.” (Gregory, apraxia of speech, 7 months post-stroke)

Since his stroke, Gregory had been unable to drive. However, a facilitator to his participation in this meaningful activity was the support of his friends in providing transport to the matches. 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 busy, keep busy and activated don’t you?” (Teddy, Dysarthria, 4 months post-stroke)

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

“So that’s why when the 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, carer-Hideo, wife)

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, yeah.” (Gregory, 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 really?” (Albert, aphasia, 9 months post-stroke)

It is interesting to note that 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...” (Albert, aphasia, 9 months post-stroke). 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...”). Both participants felt fortunate in comparison to some of their peers who they perceived to have more significant health problems:

“In that I’m lucky to still be here and when I first had the stroke I could see nothing but cabbage...yeah, because I’ve had one or two friends had a stroke and one close friend he had a bad stroke and he never could speak or anything...” (Albert, aphasia, 9 months post-stroke)

Robbie alluded to getting a balance between keeping busy but recognised this was within the limits of what he could do given his health problems:

“...do as much as I can, but given my disability within the range of what I can do...” (Robbie, aphasia, 1 month post-stroke)

Although Robbie was a younger participant in the sample, he had other health problems, which meant he had already adapted his activities to a certain extent prior to stroke. In this sense, the process of adjustment and adaptation was less dramatic than that required by other stroke survivors, who perceived they had been fit and well prior to stroke.

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 organisation's understanding of the difficulties faced by stroke survivors was also important. For example, Susan had previously worked as a care support worker and wished to return to her previous role but had lost confidence in her abilities due to her aphasia. Susan's manager suggested she came in to the care home on a voluntary basis to make tea and coffee for the residents as a first step towards returning to work. However, human resources stated that Susan would be unable to return to work on a voluntary basis as she was still on sick leave. This was a significant barrier to Susan regaining the confidence in her abilities that she needed to return to work.

"...she [HR representative] sort of like made me like I were an idiot, 'how can you go there when you're still on sick'..." (Susan, aphasia, 12 months post-stroke)

Being unable to return to work contributed to Susan feeling restricted in her activities outside of the home. Susan described feeling "stuck in me own home" and also expressed feelings of worthlessness due to her inability to return to work:

"I've worked all my life and now I feel like I'm in the way, I'm useless..." (Susan, aphasia, 12 months post-stroke)

In contrast, James' work had been supportive since his stroke, for example, by continuing to pay him his full salary and by arranging additional support to aid his recovery e.g. an iPad to practise speech and language therapy and an electronic wheelchair to facilitate mobility outside of the home. James had a senior role within the company, however, he recognised that he would be unable to take regain his managerial role post-stroke due to his communication difficulties. James was still hopeful that he would be able to be involved in seeing customers in the same way he did in his previous role but with less managerial responsibility:

"No, definitely not [being able to go back to the same role]. And with... maybe customers, and such as that maybe..." (James, aphasia, 5 months post-stroke)

James' wife Sylvia felt that his high-pressured job had contributed to the occurrence of the stroke and although she was keen for James to return to work at some time in the future, she was also keen for him to take on less responsibility. It is interesting to note that James' wife Sylvia experienced difficulty in returning to her previous job role. In order to help James, Sylvia had asked if she could reduce her hours but the organisation had been unsupportive:

"...they felt I was a weakness for the team and [laughs] I'd worked there almost ten years, and been there a long time and...on hindsight

because you walk away and think, well I'll just hand my notice, you know, they said I could have meetings but was I actually capable of going back to work and then somebody did suggest maybe counselling and I thought afterwards what I should have said was, "Well no, I just need support from you really, not... I don't need counselling, I need you to be, you know, to just understand..." (Sylvia, carer-James, wife)

Sylvia's experience suggests that it is not only stroke survivors who experience difficulty returning to work but the impact of adjusting activities following stroke also extends to carers.

Summary of interview themes

- Stroke survivors with communication difficulties varied in the extent to which they were able to successfully manage changes to their speech, language and communication during the first year post-stroke. Some had developed novel and creative strategies to aid their communication in different situations. Others struggled to overcome their communication difficulties and had restricted their activities to those which did not involve speech and language.
- Support from healthcare professionals was time limited and some families expressed feelings of abandonment at the point of discharge as they were left to navigate sources of ongoing support on their own or attempted to cope alone.
- Stroke survivors with communication difficulties often strived for independence but this had to be balanced with the need for support from others.
- The dynamic of the relationship between stroke survivors and carers often changed as carers often took on extra responsibility with the stroke survivors needs becoming the main focus of the relationship.
- Stroke survivors with communication difficulties commonly had high hopes for recovery (getting back to 'normal') but varied in the extent to which they believed normality was achievable.
- Some stroke survivors were able to adapt to their circumstances and participate in activities which were meaningful to them and others struggled to do so.

Part two: Focus group

As described in Chapter Four, the purpose of the focus group was to enable stroke survivors and their carers to feedback upon the findings of the interviews and to review and prioritise the needs which had been identified.

5.3. Overview of focus group participants

A total of 7 participants (4 stroke survivors, 3 carers) took part in the patient and carer focus group. An overview of participant characteristics is shown in Table 9. The table is organised alphabetically by the stroke survivor's pseudonym. It had originally been planned for the focus group to include participants who took part in the interviews described previously. However, this proved difficult due to the geographical spread of the participants who took part in the interviews; many of whom were unable to travel due to the distance, a lack of transport or difficulties accessing public transport. Two participants from the interviews who were invited to take part in the focus group also declined due to their communication difficulties; feeling they were not 'ready' or confident enough with their communication to be in a group setting. Two participants who took part in the interviews agreed to participate in the focus group but for unknown reasons did not attend the group on the day.

Table 9: Overview of participants in the stroke survivor and carer focus group

Stroke survivor (Pseudonym)	Age	Communication difficulty	Time post-stroke	Carer (Pseudonym)	Age	Relation to stroke survivor
Colin	66	Aphasia	7 years	Joan	64	Wife
Ethel	79	Aphasia	1 year	Ron	81	Husband
Jack	55	Aphasia	3 years	N/A	N/A	N/A
Jennifer	40	Aphasia	9 years	Harry	66	Father

All participants who took part in the focus group were recruited from the stroke research event described in the Methods Chapter. The majority of participants (except for Ethel and Ron) had met previously through taking part in other research projects and/or attending previous stroke research events.

5.4. Focus group themes

Development of themes

Themes were developed using thematic analysis (as outlined in Chapter Four). A total of 128 codes were created from the line-by-line coding of the focus group transcript. The codes were roughly organised according to their topic in order to identify themes. Seven draft themes were identified and reviewed for meaning and content. All seven draft themes were retained with minor alterations made to the titles. For example, 'communication problems as a hidden consequence of stroke' was amended to 'hidden consequences of stroke', as this better reflected the hidden emotional impact of the stroke as well as the communication difficulties experienced by participants. There was significant overlap in the themes arising from the interview and focus group study. To avoid repetition, a summary of the seven themes developed from the focus group is provided in Table 10. The similarities and differences between the themes developed as part of the two aspects of fieldwork are discussed briefly after the table.

Table 10: Summary of focus group themes (stroke survivors and carers)

Name of theme	Explanation	Illustrative quote (s)
Communicating outside of the home	Participants in the focus group described the difficulties they experienced communicating outside of the home environment, particularly with strangers or people who knew them less well. Barriers to successful communication included; background noise, people talking too fast or understanding people with foreign accents. Facilitators to successful communication included telling the other person you have had a stroke and going to familiar places or conversing with familiar people.	<p>“When I, I always, if I’m somewhere and I’m not, I’ll say “before we start I’ve had a stroke, will you do this?” Well when I first had me stroke I didn’t do that, I just stood there, you know, and I thought “oh I can’t say”, you know, but now I do so they can help me, else you stand there and you can’t get no further can you?” (Ethel, stroke survivor)</p> <p>“But the way you overcome that is by going back to the same dentist and asking to see the same dental person and then gradually that becomes easier then.” (Harry, carer)</p>
Societal awareness of communication difficulties	Others lack of awareness often led to a breakdown in communication and unsuccessful interaction. Participants also spoke about facing stigmatising reactions from members of the public who lacked awareness about stroke and communication disabilities. Large organisations with inflexible systems presented a barrier to stroke survivor’s ability to manage independently.	<p>“And people who have trained in communication with people with aphasia, few or far between, yeah.” (Jennifer, stroke survivor)</p> <p>“But it’s things that would make it easier, just those things, you know, when you go to a counter, if you could just say “I have aphasia” and someone understood.” (Harry, carer)</p>
Hidden consequences of stroke	Hidden consequences of stroke were those which affected the stroke survivor but which might not be immediately obvious to others. These included the communication difficulty itself but also included the emotional consequences of stroke and communication disability.	<p>“Because folks don’t realise and they don’t seem to, I can’t explain, oh you look alright...it isn’t how you feel really.” (Ethel, stroke survivor)</p> <p>Jack described his frustration at being unable to communicate as he wished: “<i>You get frustrating because you cannot say the words you want to say, yeah.</i>”. Colin said “<i>Feel trapped</i>” when asked about the impact of his communication difficulty.</p>

Table 10: Summary of focus group themes (stroke survivors and carers) (continued)

Name of theme	Explanation	Illustrative quote (s)
Keeping busy	Participants in the focus group were in agreement that ‘keeping busy’ was important aspect of their daily lives which was perceived to give them a sense of value and self-worth. Finding enjoyable activities to occupy their time was perceived to be a trial and error process.	<p>“Join group of people. I’ve been, uh, church and Connect group, parents come over to [Name of city] and live, mm...” (Jennifer, stroke survivor)</p> <p>“...there isn’t anything else out there and I think that contact with the universities, no matter what that contact is, has allowed him to have a value. He’s given himself a value to himself because he’s imparting his knowledge of aphasia or stroke, yeah, to other people...” (Joan, carer)</p>
Obtaining support	When discussing the support they had received from SLTs, carers felt that that the stroke survivor had received insufficient support. As a family member, Harry felt a lack of communication from SLTs about his daughter Jennifer’s progress in therapy. Other support had been obtained in the community, for example, through communication groups. However, often these had only been accessed by participants on a short term basis due to service restrictions or changes in service provision. In the absence of other support, support from family member and friends was of great importance.	<p>“But there’s no instructions at all. You’re left to find a way that’s helpful for you.” (Joan, carer)</p> <p>“You didn’t get support. The question I would have, we didn’t understand what support we were getting because nobody explained it. You see it’s no good explaining it to Jennifer or to...” (Harry, carer)</p>
Hope for recovery	Hope for recovery had different meanings to focus group participants. It was a coping mechanism, a desire to work towards improvements (however small) and a positive outlook which participants strived to sustain.	<p>“...if you’ve got no hope, you’ve got nothing, yeah. And it’s that maintaining that hopefulness that this week or next week or next year you will have had achieved so much more.” (Joan, carer)</p>

Table 10: Summary of focus group themes (stroke survivors and carers) (continued)

Name of theme	Explanation	Illustrative quote (s)
Independence	<p>Although independence was desired, stroke survivors and their carers recognised that post-stroke independence may be more restricted in comparison to the level of independence the survivor had prior to stroke. However, it was still important for stroke survivors to strive for independence as far as possible. Working towards independence was an ongoing process for Jennifer, Jack and Ethel. Jack spoke about doing “normal” things which gave him a sense of independence.</p>	<p>“I mean I, um, 39 years old, I went to [Name of town] on my own, brilliant.” (Jennifer, stroke survivor)</p> <p>“Going getting a cup of coffee, yeah? [Chorus of yes's from other focus group participants] Just normal.” (Jack, stroke survivor)</p>

Stroke survivors in both aspects of the fieldwork experienced particular difficulties in communicating outside of the home environment. Similar barriers to successful interaction were identified by both groups of participants. However, more apparent in the experiences of focus group participants was the difficulties caused by a lack of societal awareness of communication difficulties, and this developed as a separate theme. Organisational barriers caused by a lack of awareness were highlighted as particularly problematic by stroke survivors in the focus group. For example, Jennifer's doctors surgery had recently changed their appointments system so patients had to ring up to make an appointment. Previously, Jennifer had been able to make an appointment in person by going in to the doctor's surgery. By changing their system, Jennifer's ability to make an appointment with the doctor was restricted and she had to rely upon her dad Harry to help. Joan had also encountered organisations who insisted they spoke to her husband Colin on the phone; the severity of Colin's communication difficulties made this impossible. Interview participants were earlier post-stroke and many were just beginning to participate in activities outside of the home. This may account for the subtle difference in the experience of organisational barriers between interview and focus group participants.

Focus group participants perceived that they did not receive sufficient support from SLTs following their stroke. In contrast, few participants in the interviews voiced this concern. A possible explanation is that many of the participants in the interviews were still receiving speech and language therapy at the time of the interview, or, speech and language therapy had ended shortly before the interview took place. None of the participants in the focus group were receiving speech and language therapy at the time the group took place and participants were therefore able to reflect back upon the level of support they received. There was also much less uncertainty about obtaining support amongst focus group participants who perceived they were aware of the (limited) support which was available. Common to interview and focus groups participants were the strategies developed to manage post-stroke communication difficulties and the impact upon their daily lives. It is interesting to note that participants in the focus group who were a number of years post-stroke were also still striving to make improvements to their situation, for example, by trying new activities or by regaining independence in small ways.

There was less expectation of full recovery amongst focus group participants in contrast to some interview participants who had high hopes for a full recovery. Again

this may relate to participants time post-stroke with focus group participants gaining more information about the likelihood of recovery though to the passage of time, or, having more time to come to terms with the chronicity of their (or their relatives) condition. Hope was an important coping mechanism for both interview and focus group participants; which allowed them to sustain a positive outlook and work towards improvements.

5.5. Prioritisation of needs

The themes in Table 10 highlight the issues which were salient to participants in the focus group. As described in the Methods Chapter, participants were asked to prioritise the support needs outlined in the picture cards during the focus group. The cards provoked an active and lively discussion. The participants in the group prioritised 'Independence' and 'Hope for recovery' as key support needs. However, participants in the focus group were keen to feedback the complexity of the difficulties they faced in living with (or caring for someone with) a communication disability.

“Jennifer: ...independence.

Harry: But it's such a short sentence that encompasses such a great deal.

Joan: Yes.

Jack: Oh yeah.

Harry: You could see that and probably just... But you've listened to us today, the issues and we've only scratched the surface.”

Joan states that for every support need represented by a particular card, in her mind another ten could be added.

“But for every one, you know, public awareness about communication difficulty, I could add another ten...And so it's a mega-thing that you're attempting to do because there's just an emptiness out there.” (Joan, carer)

Joan felt the number of cards also reflected the lack of support which was available in the community. Participants in the focus group were also keen to note that each person was an individual and may require different types of support. The interaction below

between Jennifer and Harry suggests a need for support to be flexible and tailored to the needs of the individual.

“Jennifer: Um, fine, I got physiotherapy and aphasia support but Jack, he’s, um, say 80 years old. [Laughter]”

Harry: I don’t think that

Jennifer: Yeah. But...

Harry: I think I know where you’re driving to. There’s different levels.

Jennifer: Yeah.

Harry: There’s different levels of what’s required.”

Adding to this point, Harry stated that he felt there was a lack of a co-ordinated approach to support stroke survivors. The fact that the support needs were presented in separate boxes highlighted how he felt services were organised.

“But all this that we’ve got down here is all in little boxes, it’s all over the place, it’s just, it’s, I think it’s by chance that you get, you know, you do this and then you do that.” (Harry, carer)

Harry’s use of the word “chance” in the quote suggests his feeling that there was an element of luck in the way they found out about services relevant for Jennifer. It is therefore important to note that although the issues of ‘Independence’ and ‘Hope for recovery’ were prioritised by participants in the focus group, there was a wider sense that support should be flexible, co-ordinated and tailored towards the needs of the individual and their families.

5.6. Summary

Findings from this chapter highlight how the management of stroke related disabilities (including communication problems) is a complex process. Interview and focus group participants undertook significant work in order to manage the consequences of stroke and communication difficulties on a daily basis. The nature of this work often changed and evolved over time as more experience of post-stroke life was gained and as needs and priorities changed. For example, some interview participants spoke about how initial concerns about coping in the home environment physically, later changed to concerns about recovering speech and language function. The context within which

management work was undertaken also changed, for example, as recovery progressed or as the level of input from healthcare professionals changed.

Stroke survivors and their families varied in the extent to which they were able to successfully work through the problems they encountered and adjust and adapt to post-stroke life. Some developed novel and creative strategies to aid their communication in everyday situations. Others struggled with their communication and withdrew from situations which involved speech and language. A range of factors may have accounted for the variation in the way in which stroke survivors and their families managed. For example, personality factors, confidence and the availability of family support appeared to facilitate the development of communication strategies. The severity of the impairment also contributed to the development of such strategies: Those with milder impairments or those who were cognitively able appeared more likely to develop such strategies to manage their communication. The personal impact of the stroke within the context of the individual's life also appeared to have an impact upon the way in which the consequences of this were managed. For example, older stroke survivors or those with pre-existing health conditions were generally accepting of the limitations imposed by stroke and communication difficulties. However, there were more substantial adjustments to be made by younger stroke survivors with moderate to severe communication difficulties who had been working prior to stroke. Hopes and expectations about recovery may also have impacted upon the work undertaken and may act as a barrier to adaptation and adjustment. A key point in time appeared to be the point of discharge from community rehabilitation services. At this point, some families expressed feelings of powerlessness and abandonment and a sense of uncertainty about how they would manage moving forwards or services which were available to provide ongoing support.

In the next chapter, the findings from the fieldwork undertaken with SLTs are presented.

Chapter Six: Findings from SLT fieldwork

This chapter presents the findings from the fieldwork conducted with SLTs. In part one, findings from the interviews are presented and in part two, findings from the focus group are presented.

Part One: Interviews

6.1. Overview of interview participants and sites

A total of 18 SLTs (recruited from five NHS speech and language therapy departments) agreed to participate in an interview. Participants were assigned pseudonyms following their participation in the interview and site names were also anonymised. Table 11 shows the pseudonyms for each participant, their NHS band and the site to which they belonged. The table is organised by site and then alphabetically by the SLTs pseudonym. A further six participants were scheduled to take part in interviews from Community Team 'D', however, these had to be cancelled due to the author's ill health. The service manager said these could not be rescheduled due to reduced staff numbers through illness and the resulting service pressures. Interviews ranged from 42 minutes to 77 minutes; the mean interview length was 57.14 minutes (SD 10.21).

Table 11: Overview of participants in SLT interviews

Pseudonym	Band	Site
Amy	5	Hospital 'A'
Charlotte	6	Hospital 'A'
Danielle	5	Hospital 'A'
Helen	7/8	Hospital 'A'
Laura-Jo	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'

One participant had a split role encompassing a band 7 and 8. To protect her anonymity, the other three participants who were a band 7 are shown as band 7/8.

The recruited sites included hospital based and community based teams. At Hospital 'A' and 'B' SLTs were based exclusively in the hospital setting and did not see patients in the community. At Hospital 'C' SLTs time was split between seeing patients on the ward and visiting patients in the community. Hospital 'C' ran an ESD service for which Alice provided speech and language therapy input. Sally provided community based therapy for patients who did not meet the criteria for ESD at this hospital. Although SLTs from Community Team 'D' did not describe the service as an ESD service, it is important to note that the service did have hallmarks of ESD (NICE, 2013). For example, SLTs expected that it should provide a smooth and transitional service from hospital to home and provide a similar intensity of therapy compared to the hospital setting. The reasons for the team not being recognised as an ESD were unknown to the SLTs at this site, although they predicted a transition to this label was likely in the future. Hospital 'B' and Community Team 'D' were in the same locality with appropriate patients from Hospital 'B' being referred to Community Team 'D' for onwards rehabilitation. Community Team 'E' were a standalone community team responsible for patients who were discharged from the local hospital. There was no ESD service for stroke patients in this area and they were referred from the hospital directly to the community team.

6.2. Interview themes

Development of themes

Themes were developed using thematic analysis (as outlined in Chapter Four). The line-by-line coding of interview transcripts created a total of 259 labels across interview participants. The labels were roughly organised according to their topic in order to identify themes. For example, the labels of ‘balancing family involvement’, ‘communication difficulties placing a strain upon family relationships’, and ‘supporting families to communicate with patient’, were organised in to the draft theme of ‘family involvement’. A total of 10 draft themes were identified which included; ‘psychological support’, ‘communication outside of the home’, ‘information provision’, ‘longer-term support’, ‘family involvement’, ‘managing expectations’, ‘self-management’, ‘hospital and community transitions’, ‘preparations for discharge’, and ‘societal awareness of communication difficulties’. The draft themes were reviewed for content and meaning before being retained or refined. For example, the draft themes of ‘information provision’ and ‘societal awareness of communication difficulties’ were collapsed in to the final theme of ‘others awareness of communication difficulties’. This better captured the meaning of the data which showed the impact others could have upon stroke survivors with communication difficulties. The draft theme of ‘preparation for discharge’ was integrated with ‘longer-term support’ to become the final theme of ‘support following discharge from rehabilitation’. These themes contained an overlap of data which was better captured within one overall theme. A total of eight ‘final’ themes were developed. An illustrative quote which summarises content is presented at the beginning of each theme.

1) A smooth transition between hospital and community services

“...it can all just feel a little bit disjointed when you hear about people’s journeys and how they’ve kind of found leaving hospital.” (Elizabeth, Band 6, Hospital ‘B’)

Having a smooth transition between hospital and home was perceived to be an important need in relation to longer-term care. Hospital based SLTs observed the limitations of rehabilitation that could be provided within the hospital setting. The hospital environment was perceived to be safe and supportive but at the same time

artificial. Stroke survivors were not obliged to communicate in the same way that might be required once living at home and largely had their needs catered for.

“So it might not be that they need to really ask for things, or say what they want, because they’re in a position where they’re probably getting offered them, or provided with them....” (Amy, Band 5, Hospital ‘A’)

SLTs described the limited opportunities patients had within the ward to practise their communication outside of therapy time. Patients spent much of their time doing very little and opportunities for patients to speak to one another in order to practise social communication were rare. Hospital based SLTs and community based SLTs both agreed that additional challenges and support needs were likely to arise once patients were at home and away from the safety and support of acute care/rehabilitation.

“...because it is a big jump from being in hospital to being back home doing everything that you need to be doing but I don’t think people are always that prepared for it really because you don’t have the same experiences in hospital as you do at home and the same challenges, you know, it’s a very structured environment in hospital and there’s always staff around and there’s always somebody to help if you need it whereas at home it’s very different.” (Katie, Band 6, Hospital ‘B’)

Despite the recognition from SLTs that the transition between hospital and home was a crucial time for support, community service provision varied widely within sites and between sites. Hospital ‘C’ ran an integrated ESD service, however, patients were only eligible for this service if they lived within a certain radius of the hospital and received less intensive speech and language therapy input (e.g. being seen once per week as opposed to three or four times per week) if their postcode was outside of this location. At Hospital ‘A’, two separate community teams were responsible for post-discharge care. Due to a structural reorganisation and ongoing staffing issues, the community team in one area of the town was unable to take new referrals for a number of months which led to a substantial waiting list (of up to one year) to be seen for speech and language therapy in the community. The SLTs at this hospital took their own novel approach to ensuring continuation of therapy by providing speech and language therapy ‘packs’ for patients and families to continue their therapy at home, whilst awaiting treatment from community services. By taking this approach families had something to work on so that rehabilitation did not end abruptly. However, a potential downside was that, left unsupervised, exercises might be done incorrectly or detract from ‘natural’ conversation opportunities.

“We try and give therapy packs that we’ve demonstrated with family of tasks they can do but again, it’s that fear of not wanting to make

family members therapy teams because the number one thing a family should be enjoying that social interaction...because I don't think families often see that them just having a conversation or a chat or discussing photos or what happened on the TV is really important therapy as well." (Laura-Jo, Band 5, Hospital 'A')

A reduction in therapeutic input from hospital to home was highlighted as a problem across sites. SLTs perceived that patients were seen much less often in the community than in hospital and that the intensity of speech and language therapy decreased markedly post hospital discharge. Lack of staff and funding were seen as the main barriers to provision of intensive speech and language therapy in the community.

"I wouldn't say they get enough in our team so if we were going on kind of what they say in the stroke strategy, that somebody would get 45 minutes a day of therapy at home, who is able to do that, 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')

SLTs at Hospital 'A' and Hospital 'B' highlighted how the lack of input which could be provided by community services directly impacted upon decisions to discharge and patients' length of stay. Patients were keen to be discharged from hospital, however, SLTs knew intensive therapy would not continue in the community, and if the patient stayed in hospital they might benefit from input at a higher intensity.

"We're also unfortunately having to decide [about discharge] on the basis of how much therapy people would receive at home, so the community services can't offer daily support and we don't have an ESD in [Name of city] which can offer kind of daily therapy so we're kind of making decisions based on that as well... I would want to give the patient as much as I can do at that time and say, look even if you just stay for a few weeks in the hospital and just get as much therapy as you can here and then we can look towards discharge home with community support." (Katie, Band 6, Hospital 'B')

Helen also describes the difficulty of making decisions about discharging from hospital.

"I know in my heart of hearts that they're improving with their impairment-based therapy. They're improving with lots of input and they'll go home and they won't get anything..." (Helen, Band 7/8, Hospital 'A')

On the one hand Helen describes how her "heart" knows improvements could be made if a patient stays in hospital versus being discharged home with little speech and language therapy. However, in her managerial role as a Band 7/8 Helen also describes

how the rational decision from the hospitals point of view would be to discharge the patient:

*“The hospitals, they don’t like that very much because that would be classed as a ‘bed-blocker’ because the service should be provided...”
(Helen, Band 7/8, Hospital ‘A’)*

In this circumstance, organisational pressures to discharge patients quickly had to be balanced with clinical decisions about benefit to patients in the longer-term.

A facilitator to the provision of intensive therapy provision in the community was the use of therapy assistants. The integrated ESD service at Hospital ‘C’ relied upon therapy assistants to deliver the majority of therapy, supervised by a SLT, who devised an overall therapy plan. Alice was the only SLT on the ESD team and described how she saw patients once per week on average, with an assistant seeing the patient up to four times a week. Although this provided the required intensity of therapy, the assistants on the ESD team were ‘generic’ and were also trained in physiotherapy and occupational therapy competencies. Alice saw the benefits that ‘all in one’ therapy could provide in terms of lessening the burden on the patient who could be seen once in a day for all specialities, instead of having three separate appointments. However, Alice was concerned that sometimes the session could become focused upon physical rehabilitation and speech and language therapy was deprioritised.

*“So that’s sometimes where we’ve come up against a bit of difficulty in that if the focus has then been on say outdoor mobility they haven’t been doing very much of the impairment based work, they’ve been doing supported conversation but actually not naming practise and things like that, so that’s something I’m trying to educate them on at the moment, and we’re working on it, it’s a work in progress that one.”
(Alice, Band 6, Hospital ‘C’)*

The organisation of community teams also acted as a barrier to the provision of intensive therapy. For example, Community Team ‘D’ was commissioned to provide up to ten weeks of therapy following hospital discharge. Lucy describes how she perceived that stroke survivors had the expectation from hospital staff that input would be provided for ten weeks post hospital discharge. Sometimes, Lucy felt this amount of input was not required for milder patients and resources were diverted from moderate or severe cases where the need for input was greater.

“But then at the same time, some people that are quite mild, that don’t need as much will have been told from the hospital that they are getting ten weeks and sometimes think ‘right I will need all of those ten weeks’, and there is this expectation that we will come for the full ten weeks when actually sometimes people don’t need it and we need to be seeing people that do need the full ten weeks.” (Lucy, Band 6, Community Team ‘D’)

Lucy describes feelings of obligation in this circumstance to meet patients’ expectations and provide the “full ten weeks” of speech and language therapy.

Another example of an organisational barrier to providing intensive therapy was the lack of integration of speech and language therapy services with other disciplines in the community setting. For example, in Community Team ‘E’, the speech and language therapy service was part of a general community team which provided adult speech and language therapy across conditions (not exclusively stroke). MDT links between the speech and language therapy team and neurorehabilitation team were not strong and there was a lack of joint working particularly for communication patients who presented with cognitive difficulties.

“There is a neuro rehab team, it’s just a physio and OT, and something that can be a barrier for people with communication problems is cognitive problems and it’s always a bat back and forth between OT and speech saying, ‘Right, whose problem it actually is,’ and it can be a huge barrier for me.” (Emily, Band 5, Community Team ‘E’)

Emily described how she spent time conducting assessments with patients with cognitive problems. When a stroke survivor required onward referral to OT this entailed a lengthy wait to be seen by the neurorehabilitation team, during which time, the progress which could be made within speech and language therapy was limited. In this circumstance, the lack of MDT working was a significant barrier to enabling a smooth transition between hospital and community services.

2) Support following discharge from rehabilitation

“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')

Limited resources for providing speech and language therapy in the community led to services having tight restrictions upon the amount of speech and language therapy provided. All community services conformed to some extent to the notion of providing a set number of sessions for stroke survivors with regards to speech and language therapy. SLTs did have some autonomy to provide further sessions but described how this decision must be justified by proof of benefit to the patient.

"...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')

Decisions about discharge from community rehabilitation were often linked to the concept of reaching a 'plateau' in terms of improvement. Improvement related either to the speech and language difficulty itself, or, the potential for the patient to take on any further alternative communication strategies. Resource constraints were also a factor in the decision to discharge once a plateau had been reached with some therapists describing the need to make rational decisions about discharge. However, making rational decisions about discharge was not always easy. Sally described the difficulty of knowing that a patient was benefiting socially from having a SLT present, however, was making no further improvement.

"We can't see people forever, even if they're benefitting from a social point of view. It often gets to that stage where they're benefitting from you being there but actually it could be anybody being there and talking to them and we can't justify it being a qualified speech therapist, which is very frustrating." (Sally, Band 5, Hospital 'C')

Ruby describes how in the past SLTs would have continued to see patients in a purely supportive role; however, budget constraints forced more careful consideration of resource use.

"...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')

Sally and Ruby's experiences suggest that views of 'benefit' may differ from a patient and service perspective. From a service perspective, benefit to patients is measured in terms of progress with speech and language rehabilitation, however, from a patient perspective, benefit may be obtained through the SLT being present in a purely supportive or social role. Terms such as 'rational' and 'justify' suggest an organisational pressure to maximise the efficiency of resources, and provide maximum benefit from the service perspective, as opposed to the patient perspective. Both Ruby and Sally express their frustrations at the level of support they are able to offer within the constraints of their services.

In SLTs accounts there was an organisational pressure to make the best use of resources. As a consequence SLTs did not wish to be perceived to be seeing patients for too long and wasting scarce resources. However, there was also the sense that some stroke survivors needed further support to cope in the longer-term at the point of discharge from community services.

"I think just they need long-term support and I think that's where we break down, we're very good at the acute support, straight into hospital, straight on with therapy, straight on with the assessment, I think when you get into community you reach a plateau, you kind of either achieve all your goals or you've come to a point where there's sort of limited intervention that could further be appropriate, I think that's where it just drops off and I think that's where things need to be better, supporting people socially and living with long-term implications even if it's just, I don't know, a session a week just to keep, just to feel like you're not on your own..." (Charlotte, Band 6, Hospital 'A')

Charlotte describes how longer-term support is needed for patients both socially and in terms of support to come to terms with the chronic nature of living with a communication disability. The quote from Charlotte suggests that supporting people to live with the long-term implications of communication problems is not a standard part of community rehabilitation, or that the speech and language therapy currently provided is not sufficient to do so. Charlotte suggests that additional support is needed post-discharge to help patients in the longer-term. In contrast, Jessica suggests that support for patients to get back to whatever was meaningful for them in their lives should be integral part of speech and language rehabilitation services as opposed to an additional service.

"I think hospital, if they're relatively well funded services, like, I think people get a very good service but it is the what comes next and, you

know, the active part of participation and inclusion and getting people back to what they feel has meaning for them in their lives. I think that's just what we don't, we don't do very well within health... 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’)

As far as possible (with the limited resources available), community SLTs attempted to provide as much support as possible to clients within their service. However, the majority of SLTs perceived that additional support was required following discharge from community services and that this support was needed to address the longer-term, psychosocial implications of living with a communication difficulty. At the time of the interviews, the majority of support available to patients post-discharge was in the form of peer support groups run by charitable organisations. Support groups were either specific communication 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. Another factor which influenced attendance at groups was confidence. Lucy (Band 6, Community Team ‘D’) and Alice (Band 6, Hospital ‘C’) perceived that many stroke survivors lost confidence with their communication and therefore attending a group was difficult. Other barriers to attending groups included personality factors (not being a ‘group person’) and younger stroke survivors feeling as though they did not fit in at groups with stroke survivors who were older than them.

“...although, 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’)

There was often a lack of communication between NHS services and charitable organisations. Due to their constantly changing provision, SLTs were uncertain about what charities were offering or perceived that the support they could offer had reduced. For example, Holly describes how previously a charity provided one to one support for stroke survivors with aphasia 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')

Changes to provision and the resulting uncertainties about provision were a barrier to SLTs referring patients to charitable organisations. Hospital based SLTs also noted that previously charitable organisations had a presence on the ward, however, more recently had lacked the resources to do so, and again this proved a barrier to onwards referral.

“So we didn't know what was available anymore, whereas, you know, when they came on the ward previously we used to kind of say 'oh by the way I've got such-and-such a person for you that I think is really going to be appropriate for you' and they might tell us about what they were offering.” (Sophie, Band 6, Hospital 'B')

Support from charitable organisations was perceived to be unreliable and restricted to the provision of peer support groups which were inaccessible to many stroke survivors. Although longer-term support was perceived to be necessary, the services currently available (NHS and charitable organisations), were not sufficient to support some stroke survivors with the long term implications of living with chronic communication problems. SLTs accounts suggest that additional support is necessary to equip stroke survivors to cope in the longer-term.

3) Psychological support

“One of the problems we've got at the moment is we don't really have any psychological input, which is really, a real shame, because there's a lot of patients that come up and you think they'd really benefit from it...” (Elizabeth, Band 6, Hospital 'B')

Many of the participating SLTs expressed the need for additional psychological support to help patients with communication problems to come to terms with the consequences of their stroke. Stroke was a sudden, shocking and life-changing event and this necessitated psychological adjustment or the patient 'coming to terms' with the sudden loss of speech and language which had previously been taken for granted. SLTs agreed that a period of adjustment is an expected consequence of stroke and communication problems. However, difficulties arose when a lack of adjustment (often

termed 'acceptance') affected the stroke survivor's ability to engage in speech and language therapy.

"...I suppose a lot of it is whether they have accepted it not, we get a lot of people who struggle to adapt to change in speech or change in mobility and the ones that can kind of accept it earlier on do better than those that can't." (Lucy, Band 6, Community Team 'D')

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. A common perception was that such patients expected to regain 'normal' speech and language following therapy or that therapy would 'fix' their communication difficulties. However, SLTs perceived that in cases where therapy targeting the speech and language impairment was no longer leading to improvement (a therapeutic 'plateau' had been reached), this was unlikely to be achievable. In this circumstance, acceptance of living long-term with communication disability was needed in order for patients to take on board alternative strategies for communication and begin to rebuild their lives. Alice describes her belief that acceptance is key to living successfully with a communication difficulty post-stroke.

"And having a certain amount, not giving up, but having some acceptance, so if they haven't improved completely to how they used to be and they're still having some difficulties but they have an attitude of 'actually, this happens sometimes but I'm OK with that because I know if this happens I just have to use this strategy and it works, or sometimes it just won't work and that's OK too and it's gonna be other people's problems, not mine, if they don't like it', you know, and I'll do the best they can, so feeling confident enough to say that." (Alice, Band 6, Hospital 'C')

"...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')

SLTs identified a number of factors which might influence a patients' ability to accept their communication difficulties. Alice described how if communication was particularly salient to a stroke survivor, for example, was needed for their job role; this could be a barrier to acceptance. Personality factors were identified by some SLTs as facilitators to acceptance; e.g. those who retained outgoing personalities or positive attitude post-

stroke or those with proactive coping strategies. Meeting other stroke survivors in a similar situation was also identified as a facilitator to acceptance. A final barrier to acceptance was a lack of insight into communication difficulties from the stroke survivors due to cognitive problems.

Difficulties with psychological adjustment (or acceptance) were often related to low mood and lack of motivation. These factors were again highlighted by SLTs as those which influenced stroke survivors' ability to engage in speech and language therapy. Lack of motivation to engage in rehabilitation as a consequence of low mood was noted by SLTs in both hospital and community settings. Ruby describes how those struggling with psychological adjustment may miss out on beneficial intervention.

"...at the end of the day, early intervention is where it's at, that there, it says it in the research... you need to get in there quickly and if these things are, 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')

At each of the participating sites, SLTs described a lack of specialist input from psychologists for stroke survivors. None of sites had dedicated input from a clinical or neuropsychologist. SLTs within the hospital setting described how they had learned strategies to encourage patients with low mood to engage in rehabilitation. Helen (Band 7/8, Hospital 'A') discussed how she tried to build a relationship with her patient as much as possible and tried to understand if anything within the environment could be changed to improve their mood, for example, if the patient would like to be in a different position, would like to be in a room by themselves or in a room with other patients. Katie (Band 6, Hospital 'B') described encouraging patients to bring in items from home or go for a coffee off the ward (if able) in order to lift their mood. Personalising speech and language therapy according to the patients' interests in order to increase engagement was also noted as a facilitator to increasing low mood. At Hospital 'A' and 'B' difficulties with low mood were largely managed within the MDT. At Hospital 'B', Sophie described how they had access to psychiatry liaison services, a general service located within the hospital. However, due to their lack of experience with stroke patients with communication difficulties, the encounters had proven unsuccessful.

"...those people don't have a clue how to talk to people with communication deficits so a lot of the time, you know, some of the recommendations that they'll come up with and some of the ways that

they talk to people with aphasia is absolutely laughable really. The, you know, sometimes they possibly even make situations worse because they're saying "oh why don't you, you know, talk to your husband about how you're feeling?" and it's like "have you spoken to this lady?..." (Sophie, Band 6, Hospital 'B')

At Hospital 'A', Helen describes how the identification of mood difficulties had improved due to the use of standardised screening measures. However, without options for onward referral if mood difficulties were identified, this was perceived to be a surface level identification.

"I think people do recognise it more now but it tends to be at a very superficial level, a bit "Oh yeah, they're a bit depressed". We always look at, what are they called, screens for depression things, but then what do you do with that information?" (Helen, Band 7/8, Hospital 'A')

In Community Team 'D', SLTs spoke about referring patients to the local Increasing Access to Psychological Therapy (IAPT) service. However, a barrier was that their criteria restricted referral of patients with more moderate to severe communication impairments. Community Team 'D' could also refer to a neuropsychologist on the community neurology team; however, the patient must be referred for another discipline as well as for psychological input, which restricted access for many patients. Outpatient psychology services could be accessed at the local hospital; however, a barrier to accessing the service was the waiting time of up to a year. In Community Team 'E', SLTs often referred patients with low mood to their GP. In this circumstance, patients were sometimes discharged from speech and language therapy, whilst their mental health problems were addressed.

"... but there've been other people I've sometimes said, you know, "Once you've got this under control more," you know, if they're starting a course of medication or if they're starting talking therapy, "If you want to in future, if it's within a year you can come back and we'll see you." So I try to leave the door open for people..." (Emily, Band 5, Community Team 'E')

Community Team 'E' did not see patients for impairment targeted therapy if they were more than one year post-stroke (although they could be seen to help with AAC strategies). Similarly, within Community Team 'D', patients could not be seen for impairment targeted therapy if they were more than three months post-stroke. Psychological problems were, therefore, a significant barrier to stroke survivors accessing timely speech and language therapy intervention.

The lack of availability of timely, accessible and appropriate psychological services for stroke survivors with communication difficulties was a clear source of frustration for SLTs who wished for their clients to be provided with as much opportunity as possible to benefit from rehabilitation. Within hospital and community settings, there was a sense that SLTs managed 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 patients about psychological problems.

“I have not had any specific kind of training, which I would have liked to have had in terms of counselling. I worked previously in a job that was like debt counselling so I supposed I’ve had experience of working in that kind of situation but 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. I think, because we haven’t got access to psychology or counselling that easily, that we are doing an awful lot of it, a lot of the time.” (Lucy, Band 6, Community Team ‘D’)

The final sentence in this quote demonstrates how Lucy perceives that she steps in to the role of being a counsellor despite lacking training in this area. Some SLTs described how their use of supported conversation enabled patients to open up in a way that might not have been possible with other health professionals and this often led to discussion of mental health problems. Jessica highlights how she perceives SLTs have many of the ‘natural qualities’ to discuss mental health problems with patients. However, Jessica demonstrates a conflict between being able to facilitate a conversation about mental health, and being equipped as a SLT (and not a trained mental health professional), to deal with the thoughts and feelings that may arise as a result of the interaction.

“...I think therapists are pretty in tune to those sorts of things but I think we’re always wary of, you know, we’re not trained psychologists, we have a lot of conversations with people that are really quite difficult so I think we’ve all got natural, well, the natural kind of quality but we’ve also kind of developed our own skills as we go alongside it but equally I think we’re a bit wary of sometimes opening up boxes that we necessarily can’t contain or not wanting to be seen to crossing boundaries, I think therapists are very aware of what we should and shouldn’t do and. So it’s not that we’re not willing to have those conversations, it’s just about making sure that we’re skilled enough to deal with whatever comes up...” (Jessica, Band 7/8, Hospital ‘B’)

4) Family involvement in rehabilitation

“...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')

Many of the SLTs interviewed expressed the importance of family members being involved in the rehabilitation process. Families could be involved in rehabilitation in three ways; firstly, by supporting the stroke survivor 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 the stroke survivor's communication. By involving families in these three ways, SLTs suggested that gains in rehabilitation could be maximised. Although SLTs recognised the potential benefits of involving families in theory, in practice involving families was perceived to be difficult. Facilitators included; chance (whether or not the family member happened to be present on the day of the session), the severity of the communication difficulty (with families more likely to be involved if the stroke survivor's difficulty is more severe), and the family's circumstances or characteristics (e.g. level of motivation to be involved). For example, Lucy's describes her perception that some families 'want' to be more involved in comparison to others:

“Again that varies massively really, so sometimes you have quite a lot of involvement with the carers or partners of people that have had a stroke, and they will want to know lots of things they can do to help or they will help out with any exercises you have given them. They will want to know about strategies they can use to help them. Other times people are a bit less involved really...” (Lucy, Band 6, Community Team 'D')

Lucy's quote suggests that families who are interested or are proactive in obtaining information may have a greater level of involvement in comparison to those who do not. It is interesting to consider the extent to which this is an explicit discussion with the family member, and whether, the family members expectations of the role of the speech and language therapist in terms of being able to 'fix' speech, may impact upon their decision to be actively involved in therapy sessions Both these factors may influence the level of involvement a family member may have within therapy session. . A number of other barriers to family involvement in rehabilitation were identified,

including, the logistics of the family member being present during speech and language therapy, for example, if they worked full time. In the community setting, some SLTs described how family members may use the session as an opportunity for respite from caring for the stroke survivor which was also a barrier to involvement.

“...so I've had a lot of patients where the families have said, “oh, can you just, while you do your therapy I'm just going to go to the shops”, or, “can I just have a break while you're here”, kind of thing, “I'm not going to sit in on your session”, because you know, a bit of respite really...” (Charlotte, Band 6, Hospital 'A')

SLTs often held ambivalent views about family involvement in therapy sessions. On one hand, SLTs identified how family involvement could help facilitate patients' engagement in rehabilitation and increase their quality of life in the longer-term. On the other hand, SLTs raised concerns about involving family members. One concern was that family members sometimes became too focused upon completing therapy tasks and pushed the stroke survivor to complete them even when they were too tired or not motivated. Family members becoming focused upon completing therapy tasks could also detract from spontaneous conversation opportunities which were perceived to be important for rehabilitation. SLTs also raised concerns about therapy exercises being done in a way which was unhelpful to the stroke survivor, for example, some family members were described as taking on the role of 'teacher' and completing therapy tasks in a way which belittled the stroke survivor. Family members who took this role were perceived to inadvertently demotivate the stroke survivor, for example, Alice discusses how some family members talk to their family member “like they are a child” and how the immediate reaction of the stroke survivor is to disengage “you can see the person rolling their eyes”. Alice elaborates further on this point later in the interview:

“Well sometimes there's a strange boundary between what is therapy and what is like teaching in a classroom, and there's a strange kind of boundary as to when one merges into the other...I'm always saying 'actually, you've got these therapy worksheets but if you have an opportunity to go out and talk to people in a coffee shop I'd rather you do that....Because that's what we're doing isn't it, we're supporting them to get back to going out and having a conversation and we're not supporting them to be able to fill in that worksheet!’ (Alice, Band 6, Hospital 'C')

Alice highlights how some families may become too focused upon therapy tasks and may lose sight of the importance of practising ordinary conversation in context. SLTs associated the involvement of family members with some level of risk which may prove

a barrier to SLTs involving families in rehabilitation. There is the suggestion that although SLTs wished to involve families in therapy, the type and amount of involvement was key to maximising benefit. . In this sense SLTs were happy for families to be involved but wished to retain some level of control over the amount or type of involvement. These steps to control involvement were taken in order for the family member to provide support in a which would be most helpful for them and the stroke survivor:

“Quite a lot of family members want something to do and then the challenge is kind of giving them enough to do so they feel like they’re supporting their family member but not too much that they then are kind of delivering a therapy for you...” (Laura-Jo, Band 5, Hospital ‘A’)

“Sometimes I actively encourage it, so sometimes I will say ‘please come and sit in’. I have had occasions where it has, they’ve talked for the patient and so I’ve had to say ‘actually this time, we’re just gonna work one-to-one so you don’t need to sit in’...” (Alice, Band 6, Hospital ‘C’)

In addition to involvement in therapy sessions and the completion of therapy tasks, SLTs highlighted the importance of educating family members in strategies to support the stroke survivor’s communication. Families sometimes struggled to adapt or understand the stroke survivor which caused distress for both parties. Training in communication strategies for families was not provided in any consistent format across sites. Sometimes, training was provided in the hospital setting; however, SLTs suggested that this may not be appropriate in all circumstances. Elizabeth describes how some families needed time leading up to hospital discharge in order to come to terms with the changes to the stroke survivors’ communication.

“...it’s that kind of reality of this is, you know, essentially the two of you will be, you may 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, you know, verbal words, it’s, yeah, it can be quite a difficult realisation for people, that that’s how things are going to be and may not change significantly so...so if you’re kind of trying to push that kind of therapy when it’s, they’re just not in that kind of mind-set, it’s too early.” (Elizabeth, Band 6, Hospital ‘B’)

In the community, time limitations and the logistics of having a family member present during therapy, were highlighted as barriers to communication partner training. Holly

also describes how a lack of involvement may be due to the family's expectation that the SLT would 'fix' the stroke survivors speech and language. Holly perceived that it may take time for families to accept that they may need to think about strategies they could use to help the stroke survivor.

"...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')

SLTs described how involving families in rehabilitation acted as a means by which to prepare families for discharge from speech and language therapy. SLTs described how when the patient reached a 'plateau' in therapy, they expected the family to take over the responsibility of caring for the stroke survivor.

"...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. These are ongoing activities that you can do as a therapy team, we're going to withdraw, because we don't need to be involved anymore," 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')

In SLTs accounts of handing over responsibility to families to care for the stroke survivor, there was often an implicit assumption that families were ready or able to take on this responsibility. It appeared that decisions about discharge largely rested in the hands of the SLT (or with the constraints of the service). The extent to which readiness to take on responsibility was discussed openly with families is unclear. . Kerry questions whether assumptions that the family will be able to cope or were able to take on the extra responsibility were made too readily.

"... I think we also 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')

The importance of stroke survivors having support from family members was highlighted, however, some SLTs also highlighted the need for those without a strong network of family or friends to have additional support. Those who were older or who lived alone were thought to be particularly at risk of becoming socially isolated.

"I think from a communication point of view 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, and so it's just simple things like, you know, being able to ring someone, ring a family member and ask something or just have a chat or go out to catch the bus or go to a shop and ask or something, just all those things really...." (Holly, Band 6, Community Team 'D')

Holly highlights how it could be difficult for stroke survivors with communication difficulties to build a support network once they have become socially isolated. Building a support network may require support in itself, for example, in order to attend a group, a stroke survivor may need someone to find out about the group or someone to phone the organiser on their behalf. Holly suggests that a lack of confidence with communication may also compound a stroke survivors' ability to engage in social opportunities. Lacking a support network was also a barrier to engaging with speech and language therapy, in particular practising speech and language therapy tasks between sessions. Ruby describes how this is particularly applicable to stroke survivors with cognitive difficulties who may not have capacity to practise speech and language therapy tasks or may need to be prompted to use alternative strategies. In this circumstance, families were required to take on more responsibility for rehabilitation and become 'active participants' in the process.

"...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')

Ruby suggests that stroke survivors without support from family and friends may be discharged from speech and language therapy sooner if they are unable to take on board speech and language therapy tasks. In this situation, Ruby perceives she is unable to support patients without a support network stating "there's little that we can do". Resource constraints appear to play a role in Ruby's belief that she is unable to provide support to stroke survivors without a support network of family or friends. Ruby suggests her frustrations that, as a service, they cannot provide or offer further support to stroke survivors in these circumstances.

5) Facilitating communication outside of the home

“Accessing the community, talking to unfamiliar people, talking on the phone especially, well to anyone, but especially to unfamiliar people. I know a lot of my patients feel, have a lot of worry and anxiety over cold-callers or someone coming round to read the gas meter, things that happen all the time in everyday life...” (Emily, Band 5, Community Team ‘E’)

SLTs perceived that facilitating communication outside of the home was an important need in relation to longer-term care. SLTs perceived that stroke survivors were generally able to cope with communication in the home environment as communication was either not required or family members were on hand to provide assistance. However, stroke survivors struggled to communicate outside of their home environment particularly when conversing with strangers. This affected their use of public transport, communication in shops and the use of the telephone. Sometimes other peoples lack of awareness of communication difficulties was a barrier to communicating outside of the home, for example, when strangers spoke too fast or did not allow the stroke survivor enough time to respond (see ‘others awareness of communication disability’ theme). However, the loss of confidence in communication was also identified as a significant barrier to stroke survivors being able to communicate outside of the home environment. SLTs described how a loss of confidence (sometimes in combination with low mood) caused patients to withdraw from or avoid communication altogether which could lead to social isolation or the loss of meaningful activity outside of the home. Stroke survivors were embarrassed about their speech and language or anxious that they would not be understood.

“... I know quite a few people have said if they have problems that they, they choose to pretend that they’re really rude when they’re out in public and they don’t speak to people and they don’t say ‘please’ and ‘thank you’ and they try to ‘uh, uh, uh’ and point because they’re embarrassed to avoid having to, to speak.” (Emily, Band 5, Community Team ‘E’)

Facilitators to confidence included seeing an improvement; either that speech and language itself was improving, or, the successful implementation of alternative strategies or having positive feedback from others (outside the therapy team) about improvements in speech and language. Having support from family and friends was also perceived as a facilitator to confidence. Charlotte (Band 6, Hospital ‘A’) describes how having a support network “who will just pick you up and take you out...” forces

stroke survivors to communicate in unusual situations, and pushes the stroke survivor out of their comfort zone. This could facilitate confidence; firstly, by showing stroke survivors that their communication was not as bad as they perceived or that they could cope in the situation and secondly, by demonstrating that they were able to do 'normal' things in spite of their communication difficulty. SLTs described how having family or friends on hand also facilitated confidence by enabling stroke survivors to feel someone familiar was on hand if they ran in to difficulties with their communication. Other facilitators to confidence included: Attending support groups, having time to come to terms with living with a communication difficulty and carrying a card to inform others they had a stroke and needed more time to communicate.

Having a successful interaction was perceived to be a facilitator to confidence, however, confidence was also perceived to be fragile and Kimberley (Band 7/8, Community Team 'E') describes how as a SLT she facilitates building up confidence in stages. For example if a stroke survivor wishes to use the telephone she might ask them to practise phoning her first, then a family member, then somewhere less familiar. Sally (Band 5, Hospital 'C') also describes building confidence through practising scripts before the stroke survivor goes in to the situation themselves. The fragility of confidence meant that unsuccessful interactions could prove to be a barrier to re-gaining confidence in communication for stroke survivors. Below Charlotte describes how continuing practise and successful interaction is needed to build and sustain confidence in communicating outside of the home.

"...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')

Charlotte perceives that community speech and language therapy teams must have the resources to enable supported practise of communication in context. Charlotte highlights how this process may take time and repeated practise in order to be sustained. Some SLTs highlighted the importance of practising communication in context, for example, going to a coffee shop or on the bus with the stroke survivor in

order to practise communication itself or the use of alternative strategies. This was seen to be essential for building confidence in communication and thus helping patients to rebuild their lives. However, this was not always done as part of speech and language therapy; Lucy (Band 6, Community Team 'D') describes walking to a coffee morning with one of her patients and acknowledges "But we don't get to do that as often as we probably should do...". Time was cited as the main barrier to practising communication in context and the majority of speech and language therapy sessions conducted in the community took place within the home environment. However, it is important to note that some SLTs based their practice around this 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', yeah, I think that's partly to do with my background and my experience, yeah." (Alice, Band 6, Hospital 'C')

It is interesting to note that Alice was less concerned with organisational restrictions upon the number of sessions which could be provided. Although Alice acknowledged that the ESD service lasted for 6-8 weeks officially, she perceived that support could be provided as long as the patient was benefiting or had goals to be achieved. Time and flexibility were facilitators to providing support for communication practise in context. This was in contrast to the service provided in Community Team 'D' which was tightly restricted to the provision of ten weeks of input.

6) Self-management

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')

SLTs were asked directly about their understanding of the term self-management during the course of the interview. The majority of SLTs had not come across the term

before or if they had the term was not understood in a context related to stroke or speech and language rehabilitation. Understandings of self-management were explored and their applications to the SLTs current practice. Hospital based SLTs suggested self-management may relate to patients completing therapy tasks between sessions with minimal supervision. Perceived benefits of taking this approach included that it promoted independence so that patients were not reliant on a SLT for practising therapy tasks. Taking this approach also prepared patients for discharge from hospital when access to a SLT was less readily available. A facilitator to this perceived aspect of self-management was technology. This was useful as it provided immediate feedback to the patient about whether the task had been completed correctly or incorrectly. However, technology to support the completion of therapy tasks between sessions was not available at all hospitals or had limited availability e.g. one iPad was available across two wards. Patient characteristics also influenced the use of this kind of approach. For example, patients needed to be able to understand the task to be completed and remember to do so in their own time which may not be possible for patients with cognitive or memory problems. Some patients also had expectations that the SLT should be present during therapy sessions which acted as a barrier to completion of tasks between sessions. Finally, SLTs perceived that a patient's level of motivation may also impact upon their ability to complete therapy tasks between sessions. Sophie describes how pre-existing personality traits, depression, or a persons life circumstances, may impact upon their motivation to complete therapy tasks between sessions. For example, a person who is of working age and has a family may be more motivated than someone who is older and living in a nursing home.

“And just their kind of expectations and hope about what they are going to get back to basically. If, you know, Mrs Smith who’s 95 has had a stroke and doesn’t, you know, you do sometimes see these like older people who are just, like know that things aren’t right but are just like [sighs], will sometimes say “I’m old and tired like, what, you know, I can’t be bothered”...” (Sophie, Band 5, Hospital ‘B’)

Some hospital based SLTs had a different perception of how self-management could relate to their role as SLTs. Laura-Jo describes how she perceived self-management could relate to general independence on the ward. Laura-Jo perceived that patients lacked independence in their day to day activities on the ward.

“I think some of the patients, I think it’s something I’m probably becoming aware of now that I’ve been here a little bit longer. 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.” (Laura-Jo, Band 5, Hospital ‘A’)

This quote highlights how a lack of independence due to the organisation of the hospital may leave patients ill-prepared for going home and coping in the longer-term. Laura-Jo also describes a lack of opportunity for patients to practise spontaneous, natural conversation. Social areas (for example, the TV room) were described as “not very appealing”. The lack of social opportunity was perceived to impact upon patients’ independence and ability to self-manage in the longer-term.

In the community setting, SLTs view of self-management was also related to practising therapy tasks between sessions. However, in addition to this SLTs also related self-management to an expectation that the patient should begin to take on responsibility for their own rehabilitation. This was in contrast to the hospital setting where patient’s level of control and responsibility for rehabilitation was less evident. SLTs perceived that they promoted self-management by giving patients knowledge to manage their speech and language independently and by encouraging patients to take on board and practise the strategies learnt in speech and language therapy. Self-management was perceived to an inherent aim of rehabilitation which ultimately was focused on preparing and enabling clients to manage in the longer-term, once discharged from the service.

“I think it applies a great deal. For me the patients who do the best are the patients who take on board what you say and do their own therapy, essentially....And, as far as I’m concerned, the more that you can enable a patient to do things for themselves, the better the outcomes going to be, and in every respect, in impairment level testing, in the emotional health, in daily living, inability to communicate your needs, the more you can enable somebody the better.” (Jasmine, Band 7/8, Hospital ‘C’)

In this quote Jasmine endorses a self-management approach and seeks to do this by enabling patients to take on board what is learnt in speech and language therapy and continue it beyond therapy sessions. It is interesting to note a link between Jasmine’s perception of self-management and the patient’s level of compliance; the patients who do the “best” are those who take on board her recommendations. In this quote, Jasmine takes on the role of the expert and the stroke survivor the role of the learner. Many of the SLTs interviewed conformed to the ‘expert’ role and took the lead during therapy sessions. However, this does not mean that the stroke survivor’s wishes were not taken into consideration, rather, that there was an inherent power imbalance within

the relationship due to the SLTs professional status. Taking the lead may be a necessity for SLTs to perform critical aspects of their role, for example, making assessments of speech and language and using clinical expertise to ensure therapy is appropriately targeting specific impairments (in line with the stroke survivor's wishes). However, this may set role expectations within the therapeutic relationship and the subsequent level of responsibility stroke survivors take during rehabilitation.

Some SLTs suggested that their practice was evolving and required the patient to take a more active role within and outside of therapy sessions.

"...the role is more, I think, is 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 actually ultimately, a speech therapist can't fix, it's not a medical approach, we can't fix that problem, we can only guide them and say, actually try this and there'll be a lot that we can do in one session but that one session is great but it is not anything compared to all the hours that a week contains and, you know, that client isn't with the speech therapist so it's very much about them doing the work themselves or having somebody to do the work with, yeah." (Ruby, Band 7/8, Community Team 'E')

Ruby suggests the SLT should take the role of a facilitator, working with the stroke survivor using their clinical expertise to guide them. Due to budget constraints, the number of sessions which could be provided by SLTs in the community team was restricted and Ruby perceived that a shift in the amount of responsibility taken on by both the patient and their families was necessary in order to maximise limited resources. However, Ruby's quote also suggests that with the right guidance and support, stroke survivors and their families can be helped to take on the responsibility for managing in the longer-term. This is an approach which Ruby is keen to endorse.

In community settings, patients' ability to self-manage was linked to their ability to take on board strategies for AAC. This was seen to be an essential part of the tools stroke survivors needed in order to manage their communication independently. However, SLTs described how patients often struggled to take on board AAC strategies or practise AAC strategies between sessions. Cognitive problems were highlighted as a barrier to embedding AAC strategies. Another barrier was a lack of acceptance of the need for alternative strategies. SLTs perceived that patients wished for their speech and language to be 'normal' and accepting that they may need alternative strategies

was associated with a sense of failure or belief that no further improvements to speech and language could be made. Patients also disliked using aids e.g. communication boards which drew attention to the fact they had a problem with communication.

A facilitator to AAC was the patient having a support network to help practise or prompt communication strategies. Those without a support network were perceived to be vulnerable and at high risk of becoming socially isolated or of being relocated to residential care homes. It was perceived that a lack of opportunity to practise alternative strategies due to a lack of communicative opportunities could lead to worse outcome with regards to speech and language. SLTs also spoke of situations where responsibility for self-management was handed over to the family if it became apparent that the patient was cognitively unable to retain AAC strategies or needed prompting to use AAC strategies.

“...others you know that you’ve provided them with these strategies and you say, “Right, when you’re talking you need to think about slowing down, you need to think about really moving your mouth,” and you just know there’s no chance of them doing it themselves, because they don’t have the cognitive ability to monitor their own speech to implement them, but that’s something we’ve got to try, and once we’ve, if we’ve tried that and, say, they’re not showing any signs of being able to self-monitor, that might be at a point where we say, “Look, these are the strategies for family,” or, “These are the strategies that when you’re talking you need to be mindful of them,” but in terms of offering them more functional therapy and offering them to do it alone, it actually might not be feasible.” (Amy, Band 5, Hospital ‘A’)

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 stroke survivor.

A final barrier identified with regards to self-management was the lack of time for stroke survivors to take on board AAC strategies and be supported to practise them in context within community speech and language therapy.

“Part of that I think is, there’s also an issue, I think, from a service perspective is that I don’t think we necessarily have the time that alternative approaches or AAC requires so in order to implement something you need to be able to support an individual on a regular basis to do this and I think that takes a lot of sessions and we’re not able to do that really very well.” (Ruby, Band 7/8, Community Team ‘E’)

A trial and error process of practising AAC strategies in different contexts may be required in order for them to become embedded. Jessica also perceived that the amount of time SLTs spent doing this in the community setting was restricted. Jessica gives an example of community therapists being unable to take stroke survivors to their usual places to practise their communication in a context which was meaningful to them.

“In the community services the things where different therapists aren’t necessarily [pauses] “well I can’t rock up with you to the [Name of community centre]”, I remember doing that with one of the patients that I used to work with, because that’s what’s important to you’re going to the betting shop or whatever it’s going to be and thinking, “Well, why aren’t you doing that?”...” (Jessica, Band 7/8, Hospital ‘B’)

7) Others awareness of communication disability

“Everyone really, I think everyone has a role to play and I think we’re constantly educating people whether it be nursing staff or doctors, relatives, friends, healthcare assistants, anybody we work with I think...” (Charlotte, Band 6, Hospital ‘A’)

Increasing other people’s awareness of communication disability was a need identified by SLTs in relation to longer-term care. SLTs perceived that society’s awareness of post-stroke communication disability was poor, and that increasing others awareness of communication disability may enable stroke survivors’ to engage in the world around them more easily. Although people were aware of stroke in general, they were less aware of the longer-term effects of stroke such as speech and language difficulties, and associated cognitive difficulties. The lack of understanding in the general population led to some stroke survivors having negative experiences when communicating with people in a community setting. Katie describes how a patient had become ‘stuck’ with their communication when asking for something in a shop. The shop assistant had been short with the patient and did not give them enough time to communicate. Katie describes how there was a need for others to recognise the part they had to play in making an interaction successful:

“I think it creates a lot of problems for the person with the communication problem, so they feel like it’s kind of their problem and it’s all on them to fix it and to communicate effectively whereas if they were talking to somebody who had a better understanding of it and

was more supportive in conversation then I think they'd feel kind of less pressure and less like it was their issue because on that occasion it's not the person with the communications problem issue it's the other person really." (Katie, Band 6, Hospital 'B')

The quote highlights how greater awareness or understanding from other members of society could ease the pressure stroke survivors felt to communicate. Jasmine perceived that stroke survivors with communication disabilities were particularly sensitive to an unsuccessful interaction. Stroke survivors had experienced a life-changing event which had "knocked" their confidence. Having a negative experience during an interaction could cause hurt to the stroke survivor and deter them from communicating in the future.

"What might deter people? If people are rude to them, people are standoffish, people don't listen, people ignore them. Then again, I think sometimes that is the case, you know, but then, on the other hand, people ignore me, people are rude to me, but I've got confidence to knock because I haven't just had a massive life-changing event and I know that my communication, largely, is intact. So it becomes quite easy when you're down to be knocked by somebody who's, maybe not out to be rude to that person, but maybe that's the way it's perceived and that could be hurtful, people not giving enough, people enough time, you know, saying a lot, not giving them the time to respond, because you need a bit more time to think, or time to get a word in, but not having any sort of understanding of what's happening and why." (Jasmine, Band 6, Hospital 'C')

Others' lack of awareness was not restricted to strangers in the community and was also evident in the hospital setting. Some SLTs highlighted how staff awareness and consideration of communication disability was not optimal. Problems were identified with staff misunderstanding the level of communication a patient might have, for example, staff assuming that patients have poor receptive understanding if they cannot speak, or, making assumptions that capacity is lacking if speech and language is impaired. A barrier to optimal communication was time, with some staff lacking time to engage in a supported conversation with stroke survivors. Amy describes how staff lacking the time to engage with stroke survivors can have a direct effect upon the stroke survivors' sense of independence.

"I think a lot of people, staff are so busy that they rush in, they do something, they might not explain what they're doing and why they're doing it, and if you imagine with someone who's really dysphasic and doesn't really understand what you're doing, or wants to ask you a question and can't get it out, you're in and out in two minutes, they've

got no chance and it kind of makes them lose their independence and lose their autonomy, whereas if you gave people the opportunity and gave people the chance to communicate, then I think overall that would improve.” (Amy, Band 5, Hospital ‘A’)

There was also perceived to be a wider cultural assumption that it was the SLTs responsibility to communicate with this group of stroke survivors. SLTs spoke about members of staff who avoided communicating with stroke survivors with communication difficulties unless a SLT was present. It was perceived that a major barrier to communication within the hospital setting was fear. Charlotte discusses how the fear was related to staff feeling “awkward” if they were unable to understand what the patient was saying. Sally describes how staff members own fears could lead to patients feeling stigmatised and unsupported. This may have a direct impact upon stroke survivors’ motivation to engage in conversation.

“I think even in healthcare there’s not, you’d assume that everybody would know and everyone would be able to deal with it but they can’t and people are often scared. I think that’s one of the big things. People are scared of people with, who can’t speak or who can’t understand. It’s like, “What do I do with you? I don’t understand,” and I must admit I get scared sometimes, we all do. If you think, ‘I don’t know how to communicate with you, I don’t know how to help you.’ It’s horrible, but I think if people had that awareness it would take away some of that stigma, some of that fear and then the stroke patients would get a lot, lot more out of things, lot more support.” (Sally, Band 5, Hospital ‘C’)

The quote from Sally also demonstrates a perceived lack of understanding from staff about how they could alter their communication in order to support the stroke survivor. All the SLTs who discussed this topic saw it as part of their role to educate other members of staff about strategies they could use to speak to stroke survivors with communication difficulties. However, in some cases staff failed to implement the strategies they had been taught by SLTs. This was problematic as SLTs wished for patients to practise or ‘carryover’ skills learnt in speech and language therapy, however, were unable to do so with other members of staff who were not SLTs.

“...but when you’re trying to rely on somebody to use a communication picture board, the nursing staff, because in my opinion they don’t have enough numbers on the ward, they don’t necessarily think, “Oh, we can carry over the therapy by using that communication board the speech and language therapist told me about.” So you do get people getting quite frustrated very easily and it’s hard then to say, “Oh, no, we can definitely use a communication book, we could look at using an iPad...” ...”(Laura-Jo, Band 5, Hospital ‘A’)

The quote from Laura-Jo highlights how patients' early experiences with alternative communication strategies could influence their willingness to utilise such strategies in the longer term.

8) Managing expectations of recovery

"...it's about being honest with them about what you can achieve and I think traditionally we haven't been. I don't think we've been dishonest, I think we've just been too afraid to say what it is." (Ruby, Band 7/8, Community Team 'E')

It was common for stroke survivors and their families to ask questions about the likelihood of recovery from speech and language difficulties. Throughout the rehabilitation pathway, SLTs described the need to manage patients' and families expectations of recovery. SLTs perceived that managing expectations of recovery was difficult, particularly in the acute setting due to uncertainties about prognosis. SLTs were keen not to mislead patients but also felt uncomfortable about the uncertainty of the information that could be provided.

"A lot of questions of, "Will it come back again? Will they be back to normal? How long will it take? When can they go home?" which are really hard questions to answer, because it's how long is a piece of string?..." (Amy, Band 5, Hospital 'A')

SLTs also perceived managing expectations to be a difficult task due to the potentially life-changing impact of the news if the speech and language deficit was severe, and the likelihood for a full recovery was poor.

"It's really not easy because, obviously, your communication has such a huge impact on so much, you know, every aspect of your life, so the, you know, trying to relay that information to somebody that, especially if it is very severe and you know quite, you know, you sense early on that actually they're going to be living with this for life, yes they're likely to see some changes but this is something that's going to be with them long term, it is quite difficult and often something, I suppose in those early meetings you, usually they're not far from that stroke date, so it's quite early on, so you know that you're hopefully going to see more progress, I suppose it's later on, when that question comes, that it becomes harder to answer..." (Elizabeth, Band 6, Hospital 'B')

On one hand, Elizabeth wishes to convey accurate information about the likelihood of recovery; however, on the other hand, Elizabeth wishes stroke survivors and their families to retain hope for progress. The quote suggests that hope is seen as an important coping mechanism in the face of potentially devastating and life altering news. There is, therefore, a mismatch between the knowledge Elizabeth has about the potential for recovery, and the extent to which this information is shared with stroke survivors and their families. Retaining a sense of hope could be seen as a way of softening difficult news for stroke survivors and their families. Elizabeth's quote suggests she is keen to achieve a balance of delivering accurate information, but retaining some positivity which enables stroke survivors and their families to cope with the bad news. In Elizabeth's quote, hope has also a temporal element; with hope being easier to maintain in the acute setting than later post-stroke.

In SLTs accounts of managing expectations, there was also a distinction between hope and expectation. It was important for stroke survivors and their families to maintain hope in order to engage with rehabilitation and make the best possible recovery. Hope was a sense of positivity, a wish or desire for the stroke survivor to recover. However, problems arose when hope was also an expectation which may not be met and which may lead to disappointment in the longer-term when there was disparity between expectations and achievements.

"I'm always quite honest and say everybody's very different, it's unpredictable, it's very early days. Yeah, I try and be as positive as I can but you don't want to give false hope at the same time either because quite often with aphasia it might get better over time but it's always there with that person." (Katie, Band 6, Hospital 'B')

A common goal SLTs perceived that stroke survivors wished to achieve was to get back to 'normal' with normal representing their communication ability prior to stroke. However, having hopes or expectations which were not 'realistic' was seen to be problematic by SLTs. The process of goal setting often highlighted mismatches between SLTs expectations about what would be realistically achievable and stroke survivors own hopes or beliefs.

"...yeah, it is quite difficult 'cos I think often you might get someone who's really quite impaired and has a lot of word finding difficulties, realistically in the ten weeks you're seeing them they're not gonna get back to normal and realistically probably in the long-term 'normal' isn't really what you're aiming for, so it's quite difficult then to kind of set,

set a goal when they're wanting to be normal and that's probably not achievable. So then it's kind of you've got to try and educate them a little bit and kind of manage their expectations of what they're aiming for as well, so a lot of it, often one of the goals might be, particularly if it's word finding, that they develop some kind of strategies to use when they're experiencing difficulty, so it's kind of saying, 'you know, it might be that this doesn't go back to normal, but what will improve is your ability to deal with it and so that when you're getting stuck there's something that you can do to get past that'..." (Holly, Band 6, Community Team 'D')

Holly describes how the process of addressing an 'unrealistic' expectation may take time and education from SLTs. Holly, Laura-Jo, Amy and Alice mentioned how stroke survivors or their families may be reluctant to "hear" or "take on-board" information which contradicted their hopes or expectations. In the community setting, this often related to the point where the patient had reached a 'plateau' with improvement in impairment focused therapy and where the SLT believed it was appropriate to concentrate on alternative or compensatory communication strategies. As highlighted previously, engaging with AAC strategies once deficit improvements had levelled out was perceived to be of importance in stroke survivors achieving optimal outcomes and quality of life. SLTs used a number of strategies to help the stroke survivor to adjust their expectations, which included, giving stroke survivors time to process the information, or continuing with impairment focused therapy until the stroke survivor reached their own conclusion about needing to look at alternative options. SLTs were keen that when hope or expectation about getting back to 'normal' was not achieved, the stroke survivor was able to retain positivity by focusing on the fact that alternative strategies could be used to overcome speech and language deficits. Alice describes the process of gently adjusting expectations of recovery.

"I also talk to family about what their thoughts are, sometimes it can be that the patients aren't so realistic and sometimes it can be that the families aren't, and I think it's about setting that groundwork from the beginning and making sure everybody's clear that, you know, we can't make any promises, we don't always know how far somebody's gonna get in terms of improving their speech or their language, however there's lots of ways around that and it's about how much are you prepared to adapt to that and use different strategies and, you know, where do you see yourself, say, in six months or a year, you know, where do you want to get to." (Alice, Band 6, Hospital 'C')

The need for expectations to be managed consistently within and across the care pathway was identified. SLTs perceived that stroke survivors and their families were keen to maintain hope for recovery, and so information may easily be misinterpreted, especially if being conveyed by different members of the MDT. This difficulty was also

raised in the community setting. Kerry perceived that a lack of accurate information about recovery was delivered in the hospital setting which led to patients having high expectations of what could be achieved following hospital discharge. Patient's expectations could also inadvertently be raised through re-referral from primary care. In this case Kerry perceived that GPs lacked knowledge about what could be achieved through speech and language therapy.

"...so I don't think it's fair to say that the hospital speech therapy team should be giving them a, you know, a long term prognosis. I think that is our role but I do think that we're often left with delivering the bad news, i.e., very severe dyspraxia, it's notoriously unresponsive to therapy if anything, that kind of exacerbates people's frustration and difficulties with producing anything meaningful. And in spite of lots of evidence we then sort of are at a family setting, people are very resistant to accepting that, but then GPs as well will make referrals based on, you know, somebody being frustrated still, however many years post-event. So I'm not surprised that people have, you know, sometimes their expectations are lifted by the GP goes, "Oh yeah, I'll refer you back to speech therapy," and you think, thanks a lot, 'cos I get to tell them again that..." (Kerry, Band 6, Community Team 'E')

Summary of interview themes

- There is large variation in the way care is provided for stroke survivors with communication difficulties following hospital discharge. Many SLTs expressed considerable frustration about the lack of resources available for speech and language therapy in the community setting.
- SLTs perceived that some stroke survivors need further support to cope with the longer-term consequences of living with a communication difficulty (including psychological and social) following discharge from rehabilitation services.
- SLTs expressed the need for accessible psychological support services to help stroke survivors with communication difficulties to come to terms with the changes to their speech and language.
- SLTs advocated family involvement in rehabilitation, however, this was not always done consistently and a number of barriers to family involvement (including time within sessions, family member's availability and family member's motivation) were identified.
-

- Practise of communication in context was highlighted as being important by SLTs; however, a lack of resources sometimes restricted the extent to which this was performed in practice.
- Self-management was a term which was not recognised by many SLTs. However, SLTs perceived that enabling stroke survivors to manage their condition was an integral part of their role and their actions suggested a number of ways in which they did this as part of their practice. For example, building confidence by encouraging stroke survivors to take on board and practise the strategies learnt in speech and language therapy in daily life and educating carers in the strategies they could use to support their family member.
- SLTs perceived that others awareness of post-stroke communication difficulties (including other members of staff or members of the general public) played a role in successful or unsuccessful interaction, and could influence stroke survivors' confidence in their communicative ability in the longer-term.
- SLTs identified the need to consistently manage stroke survivors' expectations across the care pathway to ensure that their goals were 'realistic', and to avoid disappointment in the longer-term when there was a disparity between expectations and achievements.

Part two: Focus group

The purpose of the focus group was to enable SLTs to feedback upon the findings of the interviews, and to review and prioritise the needs which had been identified from the interviews. Participants were asked to give feedback about the needs which they considered to be more or less important and this formed the basis of discussion.

6.3. Overview of focus group participants

All SLTs who took part in an interview were invited to take part in the focus group. A total of seven participants took part in the SLT focus group. An overview of focus group participants is presented in Table 12. The table is organised by site and then alphabetically by the SLTs pseudonym. All participants had previously taken part in interviews described in part one; participants' pseudonyms are retained from the interview stage. All participants attended the focus group in person, except for Alice

who phoned in to the focus group via teleconference. As described in Chapter Four, a colleague from the department was present during the focus group to take notes and help with the set-up of the room. Another student was also present during the focus group to observe as part of a masters module she was undertaking. Prior to the focus group, all participants were contacted to check that it was ok for the master's student to be present during the focus group. The focus group lasted for one hour and 27 minutes.

Table 12: Overview of participants in SLT focus group

Pseudonym	Band	Site
Amy	5	Hospital 'A'
Elizabeth	6	Hospital 'B'
Alice	6	Hospital 'C'
Emily	5	Community Team 'E'
Kerry	6	Community Team 'E'
Kimberley	7/8	Community Team 'E'
Ruby	7/8	Community Team 'E'

6.4. Focus group themes

Development of themes

Themes were developed using thematic analysis (see Chapter Four for details). A total of 124 codes were created from the line-by-line coding of the focus group transcript. The codes were roughly organised according to their topic in order to identify themes. Six draft themes were identified which included 'psychological support', 'managing expectations of recovery', 'improving care transitions', 'practising communication outside of the home', 'generalising therapy' and 'managing patients with cognitive difficulties'. All themes were retained except for 'managing patients with cognitive difficulties'. There was little data contained within this theme and the data contained did not make any significant contribution to understanding the longer-term needs of stroke survivors with communication difficulties. On balance, the author decided that this theme should be discarded.

There was significant overlap between the themes arising from the interview and focus group fieldwork. To avoid repetition, a summary of the themes developed from the

focus group is provided in Table 13, and a brief discussion of the similarities and differences between the two aspects of fieldwork is presented following the Table.

Table 13: Summary of focus group themes (SLTs)

Name of theme	Explanation	Illustrative quote (s)
Psychological support	Participants perceived there was a lack of psychological support for stroke survivors with communication difficulties. Some felt ill-equipped to help due to a lack of training and fear of crossing professional boundaries. Barriers to accessing psychological support included stroke survivors not meeting the criteria for IAPT services due to their communication difficulties and mental health professionals lacking stroke specific skills. None of the SLTs in the focus group had access to a psychologist within their team and although specialist psychologists were sometimes available in other services, lengthy waiting lists were a barrier to access.	<p>“...but that’s something I feel it does fall to us and when you have people who have communication difficulties we might be some of the few people that they can have any chance of getting the message across with and they wouldn’t be able to access mainstream psychological services anyway.” (Emily, Grade 5, Community Team ‘E’)</p> <p>“...I think we sometimes get from the patients about they can communicate with us to tell us that but then we’re not skilled to do that and we’re kind of almost told, you know, where’s the line and we shouldn’t be crossing that line but then who else is going to take that on...” (Alice, Grade 6, Hospital ‘C’)</p>
Generalising therapy	The idea of therapy being generalised was mainly discussed in relation to the use of alternative communication strategies. Patient’s ability to take on board alternative communication strategies was an area which SLTs felt was problematic in their practice. SLTs felt that families played a key role in supporting patients to generalise what they had learnt in a session. The extent to which this role expectation was clearly communicated to families is unclear.	<p>“It has to be generalised at the end of the day, there’s no point just coming and being a perfect patient for that one session...if the families aren’t embracing it, encouraging it, giving that extra time, those extra bits of support then it just doesn’t work...” (Kerry, Band 6, Community Team ‘E’)</p> <p>“...I think if they haven’t shown up or they invite you in and then they go and sit somewhere else you think okay, they don’t want to be so involved and it’s probably wrong for me to assume that...” (Alice, Band 6, Hospital ‘C’)</p>
Practising communication outside of the home	SLTs agreed that practising communication outside of the home was vital for patients’ recovery in the longer-term. Benefits included increasing patient’s motivation for therapy, increasing confidence in communication and reducing anxiety about communicating outside of the home. However, a number of barriers to taking this approach were also identified which included the time to go out in to the community and the additional preparation required to personalise therapy.	<p>“I think patients are more likely to be motivated doing real tasks that are everyday things...I think gone are the days of sitting there doing impairment based tasks from print-outs from a book...” (Ruby, Band 7/8, Community Team ‘E’).</p> <p>“Because the reality is not as scary as their imagination. [Laughs] So what they think might happen is never quite as frightening as what does happen...”(Alice, Band 6, Hospital ‘C’).</p>

Table 13: Summary of focus group themes (SLTs) (continued)

Name of theme	Explanation	Illustrative quote (s)
Practising communication outside of the home (continued)	Characteristics of the stroke survivor (being psychologically 'ready') also acted as a barrier to this type of therapy. Therapy assistants acted as a facilitator if the stroke survivor had mobility problems.	"...they're just not ready to face that reality when we're with them, it's much further down the line." (Elizabeth, Band 6, Hospital 'B').
Improving care transitions	Problems were identified in the continuation of therapy following hospital discharge. Delays in accessing speech and language therapy in community services were perceived to be related to poorer outcomes for patients. Having support in the transition between hospital and home was perceived to promote patients motivation to participate in therapy, reduce patients risk of mental health problems and increase their independence in the longer-term. Early provision of speech and language therapy was also perceived to maximise gains in terms of neuroplasticity following stroke; Ruby uses the metaphor of "missing the boat" to highlight the need for therapy to be provided in a timely fashion following hospital discharge to maximise the restoration of natural speech and language ability.	<p><i>"...to actually help them with the transition of going home straightaway, you're not leaving someone sat at home for a couple of weeks, couple of months not knowing how to communicate, actually you're straight back out to them, you've already got a relationship with them, you can continue the therapy that you were doing, you're going to get better outcomes."</i> (Amy, Band 5, Hospital 'A')</p> <p><i>"And if you're waiting 6 months to be able to go to the local shops to communicate for the paper, you're going to be a nervous wreck by the time you do it whereas if you get home and within a few weeks you're like, come on, let's go and you do it and you're whipping off like a Band Aid and go right, let's get on with it then..."</i> (Alice, Band 6, Hospital 'C')</p>
Managing expectations of recovery	Participants agreed that in order for patients to manage their condition in an optimal way it was often necessary for stroke survivors and/or their families to accept the idea that they would not be able to communicate in the same way they had prior to stroke and have 'realistic' expectations of recovery. Realistic expectations of recovery were perceived to be necessary for stroke survivor to embrace the use of alternative communication strategies. Emily describes her strategy of-	<i>"...they think you're the big bad wolf telling them that their family member doesn't understand or they can't express themselves..."</i> (Amy, Band 5, Hospital 'A')

Table 13: Summary of focus group themes (SLTs) (continued)

Name of theme	Explanation	Illustrative quote (s)
Managing expectations of recovery (continued)	“planting the seed” with information to manage expectations of recovery. SLTs feared negative reactions from families when conveying news about recovery and some felt they lacked confidence in this area.	<p data-bbox="1144 432 2125 624">“If they know what level they’re at then you can set realistic goals, then the person gets a sense of achievement so they might not feel as negative about the communication and the small steps that way but if they’re wanting to bat higher than what they can do then we’re going to have this unsuccessful communication attempts, negativity, low mood, give up...” (Kimberley, Band 7/8, Community Team ‘E’)</p> <p data-bbox="1144 679 2125 791">“...things don’t usually go back to how things are and I think it’s having the confidence for us to have those conversations as well and not worrying...” (Ruby, Band 7/8, Community Team ‘E’)</p>

There was significant overlap between the psychological support theme developed from the interviews, and the psychological support theme developed from the focus group data. SLTs perceived that a lack of psychological support impacted upon stroke survivors' ability to engage in speech and language therapy, and led to poorer outcomes for stroke survivors in the longer-term. Specialist support from psychologists was either lacking completely, or there were significant barriers to obtaining support for stroke survivors. SLTs expressed that this was an area of support which needed to be addressed and these views were consistent across the interview and focus group data.

'Generalising therapy' developed as a separate theme in the focus group data. However, there is overlap between this theme and the self-management theme developed from the interviews. Both themes covered the practise of AAC strategies, however, in the focus group there was a stronger emphasis on not only practising AAC but generalising the strategies learnt to other contexts. Within this theme there was a strong expectation from SLTs about the role family members took in helping to generalise therapy. Although family involvement in rehabilitation was a theme in the interview data, SLTs spoke about the extent to which families were involved in actual therapy sessions and were less focused upon generalisation to everyday life. In the focus group SLTs expressed the specific need for families to take on responsibility to help generalise therapy to other contexts. However, it was unclear to what extent this role expectation was clearly communicated to families and SLTs expressed making "assumptions" about families' wishes about involvement.

'Practising communication outside of the home' developed as a separate theme from the focus group data. Practising communication outside of the home was discussed during interviews and related to support following discharge from rehabilitation and self-management. However, SLTs spoke in more detail in the focus group about the perceived importance of this aspect of therapy in their practice and the benefits to taking this approach in terms of increasing motivation for therapy, increasing confidence in communication and reducing anxiety about communication. Further depth was also obtained about the perceived barriers and facilitators to taking this approach.

Significant overlap was observed between the interview theme ‘a smooth transition between hospital and community services’ and ‘improving care transitions’. Both were concerned with ensuring the fluid continuation of speech and language therapy in the community setting. However, in the focus group, a stronger link was made between the lack of a continuous service and negative outcomes for patients associated with this. For example, reduced motivation to engage in therapy when it did arrive, reduced levels of independence and increased risk of mental health problems.

Lastly, the theme of ‘managing expectations of recovery’ was apparent in the interview and focus group data. Both themes highlight SLTs perceptions that stroke survivors and their families needed to have ‘realistic’ expectations of recovery in order to progress with speech and language therapy and achieve maximum quality of life. Difficulties in managing expectations were voiced by participants in the interviews and focus group. However, in the focus group SLTs expressed their underlying lack of confidence in relaying information about the prospect of recovery due to fears of negative reactions. This may offer an additional explanation of SLTs actions to subtly “plant the seed” about expectations of recovery or leave stroke survivors and their families to come to their own realisations about recovery over “time” as opposed to providing information about recovery in an explicit manner.

6.5. Prioritisation of needs

The themes outlined above highlight the issues which were salient to participants in the focus group. As described in the Methods Chapter, participants were asked to prioritise the support needs outlined in the picture cards during the focus group. For participating SLTs, the main priority in terms of longer-term care was the increased availability of psychological support for stroke survivors with communication difficulties. Another priority was support for stroke survivors and their families to take over the responsibility of rehabilitation by generalising what they had learnt in speech and language therapy to their day to day lives. However, SLTs in the focus group agreed that optimal timing of support was necessary to underpin these aspects of care. The SLTs stressed the importance of support being available in a consistent and seamless fashion from the hospital to the community setting. Facilitators to the provision of support were the availability of an MDT (including specialist psychologists) and the availability of sufficient funding and staff resources for community services.

“Especially when you’re lacking psychological support, I think and when you’re lacking some of the things that we’ve said...timing, like you say, if you can more of an MDT approach early on, it makes all those things like expectation, having realistic expectations more possible, gains in therapy, you know, better gains. Yeah, I think timing is completely crucial.” (Ruby, Band 7/8, Community Team ‘E’)

The quote from Ruby illustrates the group’s consensus that early intervention in the community setting was key towards improving longer-term outcomes for patients. From Ruby’s perspective, funding greatly impacted upon the timing of support which was available and created a “postcode lottery” for patients in terms of the standard of care they would receive.

6.6. Summary

Findings in this chapter highlight the inconsistent provision of longer-term care for stroke survivors with communication difficulties. SLTs strived to enable stroke survivors with communication difficulties to manage in the longer-term by encouraging them to take on board what they had learnt in speech and language therapy and apply this to daily life. However, SLTs acknowledged the difficulties of building confidence and strategies to manage communication with the limited resources they had for speech and language therapy in the community setting. SLTs also highlighted the complexities of this process; in addition to the severity of the impairment (and associated cognitive difficulties), levels of ‘acceptance’ and ‘hope for recovery’ were also identified as playing a significant role in the extent to which stroke survivors may be ready or able to undertake condition management work during community rehabilitation. SLTs suggested that stroke survivors with communication difficulties and their families may need further support to manage the consequences of living with a communication difficulty in the longer-term. The transition to longer-term adaptation and adjustment was perceived to be challenging. In particular, SLTs identified the need for services to provide ongoing support to manage the psychological and social implications of living with a communication difficulty. At present there are few services available to address these needs beyond peer support groups and significant barriers to attending such groups were identified. In the next chapter the findings of the fieldwork presented in Chapter Five and Six are discussed. Before this, the author reflects upon how her involvement may have shaped the collection and analysis of data presented in the previous two chapters.

6.7. Reflexive statement

Prior to undertaking this PhD, I had little knowledge of stroke or associated communication disability. I was drawn to apply for the PhD due to the applied nature of the research and its potential to benefit stroke survivors in the future. Conscious of my lack of experience in this field, I was apprehensive about engaging stroke survivors with communication problems. In the first year of my PhD, I sought to gain insight in the difficulties this sub-group of stroke survivors may face. In addition to attending training in 'Active Communication' run by the Stroke Association, I volunteered through the Stroke Association at a local communication group. This experience was invaluable in helping me to understand the difficulties faced by stroke survivors with communication disabilities and for practising techniques to support conversation. In addition to my inexperience in stroke research, I also lacked experience in conducting qualitative research. As highlighted in Chapter Four different skills and techniques are required in order to conduct qualitative research with stroke survivors with communication difficulties compared to SLTs. A supportive interviewing style is necessary for stroke survivors with communication disability e.g. offering suggestions or asking shortened or simplified questions (Dalemans et al., 2009; Luck and Rose, 2007). This is in comparison to 'standard' qualitative interviewing techniques where the researcher has less input. In addition to learning and refining my use of 'standard' qualitative interviewing techniques for the interviews with SLTs, I also had to learn the adapted methods for interviewing stroke survivors with communication difficulties. It was, at times, difficult to switch between the two styles of interviewing during data collection with stroke survivors and carers and SLTs. Listening back to the audio files after each interview allowed me to reflect upon moments within interviews with SLTs where I had been too directive or moments within interviews with stroke survivors where I had asked a question which was too complex. I strived to learn from each interview and refine my technique in order to improve it for the next interview.

It is also interesting to consider the impact of my role as a student on the conduct of interviews. Stroke survivors and carers were aware that their participation in the study contributed towards my PhD project. Identifying myself as a student automatically implies an element of learning or lack of knowledge. I am aware that during interviews I often claimed a position of naivety in order to obtain further information. This may not have been possible if I had identified myself as a healthcare professional. I felt this was particularly important in interviews with stroke survivors and carers. When introducing

the project, I was keen to ensure that stroke survivors were aware that I held a separate role to healthcare professionals they may still be in contact with. I felt this facilitated openness and a position from which participants could speak honestly about the care they had received. However, due to the way in which participants were identified (via NHS services), I am aware that even with reassurances, some participants may have felt restricted in the information they provided, particularly if they were still receiving therapy from the aforementioned services.

In accessing sites for the project, I attended a team meeting in order to explain the project and what taking part in the research would entail. It is interesting to reflect upon the fact that SLTs at each site were keen to know my background and interest in stroke survivors with communication difficulties. I explained my background in psychology/health services research and my interest in the topic area. However, I am conscious that their knowledge that I was not a SLT may have influenced the way they responded to questions during the interviews and focus group. In particular, knowing my background in psychology, may have caused this topic to be raised and discussed during interviews or SLTs may have prioritised psychological support during the focus group if they perceived it would be socially desirable to discuss topics which they perceived would match my background and interests. On the other hand, it is important to state that poor access to treatment for psychological problems following stroke has been noted elsewhere in the literature (Hackett et al., 2009) and so SLTs may have raised this issue regardless of their knowledge of my background.

In relation to my background as a non-SLT it is important to consider issues of 'insider' versus 'outsider' perspectives (Hellawell, 2006). Insiders are researchers who share similar characteristics, roles or experiences to those being explored as part of the research (Dwyer and Buckle, 2009). Outsiders do not share membership of the group which they are studying. As a non-SLT, I considered myself to be an 'outsider' throughout the process of data collection with SLTs. The potential limitations of being an 'outsider' included a greater difficulty establishing a rapport with participants due to a lack of common ground or the potential for participants consciously or sub-consciously withhold information or share information less freely in view of my 'outsider' status (Berger, 2015; Ergun and Erdemir, 2010). On the other hand, being an 'insider' also has disadvantages, for example, a researcher who is an 'insider' may be able to relate to the experiences of their participants too closely and thus may find it difficult to separate their own views from the views of their participants (Dwyer and Buckle, 2009).

Another difficulty with being an 'insider' is that participants may not explain their thoughts fully on the understanding that, as a member of the group, the researcher shares their understanding of the topic being discussed (Kanuha, 2000). In relation to the SLT interviews, it is also interesting to consider whether being an 'insider' may have caused SLTs to portray their practice in particular manner in view of the fact that I may have views or experience about the therapy which they should be providing. As an 'outsider' I had little knowledge about the therapy SLTs were providing and this may have been apparent in my line of questioning when I asked for additional explanation about therapeutic techniques or information about the daily routine of a SLT. This lack of knowledge or clinical experience may also have caused me to not fully comprehend information about SLTs practice, or may have led me to interpret the data in a different way in comparison to someone with clinical experience working with this population on a daily basis. However, it is also important to note that being an 'insider' or an 'outsider' is not necessarily a dichotomous position (Dwyer and Buckle, 2009). For example, all SLTs who took part in the interviews were female and the majority were a similar age to me. Although common ground in terms of speech and language therapy was not possible, I shared some common ground with interviewees in relation to broader demographic characteristics including gender, age and level of education. I felt this facilitated the development of rapport prior to and during the interviews.

Finally, it is important to acknowledge that my undergraduate degree in psychology may have had an influence on my interpretation of the data or line of questioning during the interviews. For example, the themes developed highlight the psychosocial consequences of living with post-stroke communication difficulties. These issues may have been explored in more depth during the interviews due to my background which may in turn have influenced the data collected and therefore the overall development of the themes. I was mindful of this during data collection and tried to ensure that my line of questioning was balanced.

Chapter Seven: Discussion of fieldwork findings

This chapter discusses the findings from the fieldwork. The findings from Chapter Five and Six are discussed separately in Section 7.1 and 7.2. The implications of the fieldwork for longer-term care are drawn together in Section 7.3. The strengths and limitations of the fieldwork are explored in Section 7.4. The findings are used to inform a rationale for taking a self-management approach and to inform suggestions for an adapted model of self-management.

7.1. Discussion of findings from SLT fieldwork

Summary of key findings

The fieldwork with SLTs was undertaken to understand and explore SLTs views regarding longer-term care; including their perceptions of 'self-management' as an approach. SLTs highlighted striking inconsistencies in the way longer-term care is currently provided for stroke survivors with communication difficulties. Each site offered a different longer-term care pathway, and the amount of speech and language therapy available in the community varied widely within and between sites. Transitions between services were not smooth and SLTs sometimes felt under organisational pressure to discharge patients promptly in the community setting. SLTs often did not recognise the term 'self-management', however, their actions suggested a variety of ways in which they aimed to enable stroke survivors and their families to manage their condition. For example, SLTs strived to build confidence in communication through translating what had been learned in speech and language therapy to daily life and through educating carers about the best way to support their family member. SLTs also acted as advocates for their clients by educating others (including healthcare professionals) about communication disability. Enabling stroke survivors and their family members to manage in the longer-term was seen as an integral part of rehabilitation. However, SLTs expressed considerable frustration at the amount of resources which were available for speech and language therapy in the community. Community based SLTs suggested that building confidence and strategies for managing in the longer-term was a complex and time-consuming process which was influenced by a number of factors including; severity of language impairment, presence of cognitive difficulties and whether there was acceptance of the longer-term nature of communication difficulties.

Although SLTs took steps to build towards longer-term management, a lack of time and resources were often barriers to meeting these aims in practice. SLTs acknowledged that some may need further support to manage the consequences of living with a communication difficulty at the point of discharge from community services. However, support for stroke survivors following discharge from community services was patchy and SLTs suggested this mainly took the form of peer support groups run by charitable organisations. Such groups were often difficult for stroke survivors with communication difficulties to attend and SLTs cited a range of barriers to accessing these. Increased availability of psychological and social support for stroke survivors with communication difficulties was highlighted as a need in both the interview and focus group studies.

Comparison with existing literature

The lack of a co-ordinated approach to longer-term care is evident across stroke services and is not specific to speech and language therapy. For example, a national audit by the Care Quality Commission showed the inconsistent provision of care in the community across stroke (CQC, 2011). A recommended model of care for stroke survivors being discharged in to the community is ESD. ESD is an evidence based model of care which has proven benefits including reducing the length of inpatient stay, improving the stroke survivor's ability to partake in activities of daily living and increasing service users levels of satisfaction (Fearon et al., 2012). Recent data from the SSNAP survey suggests that 81% of hospitals have an ESD service (Royal College of Physicians, 2016). Only one Hospital taking part in this study had access to ESD. However, the existence of the ESD service did not necessitate access to the service for all stroke survivors in this location and patients were only eligible for input from the ESD team at Hospital 'C' if they lived within a certain radius of the hospital. It is interesting to consider whether the survey by the Royal College of Physicians (2016) adequately captures the complexities of service delivery. Variation in the quality and accessibility of ESD services has previously been highlighted (Fisher et al., 2011; Chouliara et al., 2014).

It is important to consider other rehabilitation services for two reasons. Firstly, many ESD services are time limited (typically providing 2-6 weeks of input) and so referral to other services for ongoing rehabilitation is often required (Royal College of Physicians, 2015). Secondly, only 34% of stroke patients will meet the criteria for ESD and so the majority of stroke patients will require input from non-ESD services (Fearon et al., 2012). The remaining four sites who took part in the fieldwork had no access to an ESD

service. SLTs in these services felt that a similarly smooth and transitional service from hospital to home should be provided for stroke survivors with communication difficulties who did not have access to ESD. However, SLTs consistently cited a lack of resources to provide intensive therapy in the community setting, and highlighted how they felt the transition from hospital to home was therefore disjointed. The lack of resource for speech and language therapy is supported in the SSNAP data for all community services (ESD and non-ESD). The average ESD team has 0.5 whole time equivalent (WTE) SLTs per 100 stroke patients in comparison to 1.2 WTE physiotherapists and 1.0 WTE occupational therapists per 100 stroke patients. The average community stroke rehabilitation team employs 0.7 WTE SLTs per 100 stroke patients in comparison to 1.6 WTE physiotherapists and 1.3 WTE occupational therapists (Royal College of Physicians, 2015).

Resource constraints were cited by many SLTs as an important contributor to the way in which care was provided. In a resource constrained service, allocating more resources to one area automatically leads to losses in another and inherently requires trade-offs to be made by SLTs in their practice. For example, complex cases may require more time to be spent on detailed assessments of speech, language or cognition in order to fully understand the difficulties the individual is experiencing and offer appropriate intervention. However, in a resource constrained service, spending more time on assessment leaves less time for therapeutic work to be undertaken. Another example is the focus of the speech and language therapy itself. An important aspect of speech and language therapy is to improve the impairment itself and to restore speech and language functioning. This is a priority for many stroke survivors and their families (Wallace et al., 2017a) and is often a goal for stroke survivors in the early period post-stroke (Worrall et al., 2011). This requires therapeutic time to be spent to address this aim. However, if this work is undertaken within time limited services, this inherently leaves less time to focus upon other aspects of speech and language therapy (for example, developing and embedding AAC strategies or practising communication outside of the home). There is also uncertainty at the beginning of therapy about the extent to which speech and language functioning can be restored. This requires time to be spent discovering what progress can be made and which aspects of speech and language therapy might be most useful.

SLTs described how the focus of speech and language therapy may need to shift and change over time, depending upon the stroke survivor's response to therapeutic input

provided. SLTs often reported that a key turning point was the point at which improvements in speech and language began to 'plateau'. In these instances, the balance of therapy often shifted to focus upon other facets of speech and language therapy, for example, maximising the use of compensatory or AAC strategies. AAC strategies compensate for a lack of verbal output and include strategies to be used in addition to speech (augmentative strategies e.g. gesture, facial expression, drawing or writing) or strategies to be used as a substitute to speech (alternative strategies e.g. sign language, picture symbols, written words or voice output devices) (Fried-Oken et al., 2012). It is proposed that when verbal output is limited, AAC has the potential to allow stroke survivors with communication difficulties to regain independence, facilitate social relationships or maintain existing social relations and improve overall quality of life (Baxter et al., 2012; Johnson et al., 2006). These approaches were identified by SLTs in the current study as ways in which stroke survivor's participation could be maximised in spite of residual communication difficulties (Simmons-Mackie, 2009; Fried-Oken et al., 2012). However, a shift in approach was not simple. A change in focus often had considerable implications for the stroke survivor who, in order to engage with this aspect of therapy, may have to have some level of acceptance that pre-stroke levels of speech and language may not be restored. SLTs described how this realisation may occur over time; however, in the context of time-restricted services, time may run out before the stroke survivor is ready to try alternative approaches.

SLTs in this study also identified difficulties with stroke survivors 'generalising' the AAC strategies they had learned in therapy to everyday life. A number of factors were identified by SLTs which may influence this process including; the severity of language impairment, the presence of cognitive difficulties, the availability of family support or stroke survivors being ready to accept the longer-term nature of their communication difficulties. The difficulty of 'generalising' strategies is also highlighted in an AAC literature review conducted by Jacobs et al. (2004). Their review highlighted that, although stroke survivors with severe aphasia were able to retain and use AAC during therapy sessions, these findings often did not translate to everyday settings. A complex range of factors may account for a lack of success in this field, for example, whether or not the stroke survivor experiences success with AAC, whether the stroke survivor can overcome the perceived stigma of using AAC, whether the stroke survivors communication partner supports the use of AAC, whether the stroke survivor is emotionally ready to accept the use of AAC, or whether the SLT has time to complete training and follow-up with AAC (Baxter et al., 2012; Johnson et al., 2006). This

literature suggests that embedding AAC strategies may take a considerable amount of time and support.

Some may argue that AAC strategies should not be 'saved' until restorative therapy is complete and should be used as part of a 'total communication approach' which considers the clients communication within the broader context of their life circumstances. Speech and language therapy has been criticised for failing to address wider issues of quality of life and participation for people with chronic communication disabilities (Hilari et al., 2015; Cruice et al., 2003). However, SLTs in this study recognised the importance of supporting participants to live with the broader consequences of post-stroke communications difficulties in the longer-term. For example, a number of SLTs suggested the value of practising communication in real life situations towards meeting this aim. However, given the complexity of difficulties experienced by this group of stroke survivors, building strategies and confidence to manage in the longer-term was also perceived to require a considerable amount of time and resource. SLTs expressed frustration at the amount of resources which were available for speech and language therapy in the community setting. This was often a barrier to undertaking as much work as SLTs would have liked to address the longer-term management of the condition. SLTs often talked about being under organisational pressure to 'justify' the therapy they were providing. The value judgements made by services under pressure to reduce waiting list times may be different to those made by SLTs or those made by stroke survivors and their families. Services may also often wish for benefit to be measurable; this may be more difficult if improvement is related to broader concepts such as quality of life as opposed to impairment focused outcomes e.g. word finding ability.

Resource constraints also influenced SLTs perceptions of the term 'self-management'. SLTs suggested that enabling stroke survivors and their families to manage was an integral part of their practice. This included promoting confidence in communication, and encouraging patients to take on board and practise the strategies learnt in speech and language therapy in daily life. However, in addition to the actions SLTs took to promote self-management, the lack of resources for speech and language therapy also necessitated more active participation of stroke survivors and their families in the rehabilitation process. This was seen as an important part of enabling longer-term condition management and a way to compensate for the lack of session time. Expectations of stroke survivors taking a more 'active' role within speech and language

therapy appeared to change across time. For example, SLTs highlighted the different roles stroke survivors and their families may be expected to take in the hospital in comparison to the community setting. In the hospital setting, SLTs suggested that patients were generally more passive recipients of care. Whilst this role may be expected during the acute stages of illness, the stroke survivor may need to take a more proactive role during rehabilitation in order to maximise recovery (Clark and Smith, 1997). Other research supports the inactive role stroke survivors play in hospital rehabilitation (Bernhardt et al., 2004; Laver et al., 2010). Early experiences of rehabilitation may set expectations for rehabilitation in the community setting and SLTs sometimes expressed difficulties about actively involving stroke survivors in therapy in the community setting.

A key aspect of self-management often described in the literature is the collaborative and empowering relationship between the patient and facilitator of the approach (deSilva, 2011; Lorig and Holman, 2003). Due to healthcare providers' 'professional' status, there is often an inherent power imbalance in relationships between healthcare professionals and patients. There was substantial variation in the role SLTs themselves played within the therapeutic relationship. Many aspects of speech and language therapy may necessitate SLTs to take a leading role within the relationship. For example, assessments of speech, language and cognition and appropriate therapeutic exercises based upon these assessments are necessarily informed by the SLTs' clinical experience and expertise. However, some community based SLTs described the need for the balance of power to shift over time in order for stroke survivors and their families to take on responsibility for managing in the longer-term. This shift required the SLTs' role to change from 'leader' to 'guide' and to ultimately hand over responsibility for managing in the longer-term.

In practice, achieving a collaborative balance within the therapeutic relationship may be difficult. Collaborative goal-setting is used routinely in stroke rehabilitation and was cited by SLTs in this study as a way in which patients' wishes were taken into consideration. However, systematic literature reviews in this area suggest that goals may often be shaped by the healthcare professional, and have less patient involvement than may be optimal (Sugavanam et al., 2013; Rosewilliam et al., 2011). In speech and language therapy, Rohde et al. (2012) found a number of incongruities between the goals of stroke survivors with aphasia and those set with SLTs in practice. These often reflected SLTs' ideas about the boundaries of their practice and goals which were

appropriate to address within speech and language therapy (often goals related to the communication impairment), and those which were not (wider participation focused goals). A meta-ethnography of therapeutic alliances in stroke rehabilitation by Lawton et al. (2016) suggested that the balance of power within therapeutic relationships may often be disproportionately weighted towards the healthcare professional. Lawton et al. (2016) suggest that redressing the balance may require connectedness (a genuine bond) between both parties, a willingness and choice to collaborate, and an ongoing negotiation to ensure that the shared purpose of therapy was maintained.

Whilst collaboration appears to be an integral component of strong therapeutic alliances (Lawton et al., 2016), 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 alliance so that patients not only have a balanced input (sharing the 'control'), but ultimately go on to take the lead in managing their condition (Mudge et al., 2015). Pulverenti et al. (2014) suggest that empowerment goes beyond traditional notions of person-centred care, as the concept of empowerment requires action by the patient, and in the longer-term places value upon the patient's knowledge and experience above the healthcare professionals. In implementing self-management approaches, the literature suggests that tensions may arise for healthcare professionals in relinquishing 'control' and moving away from their traditional 'expert' role (Mudge et al., 2015; Norris and Kilbride, 2014). Whilst some SLTs within the study advocated a more balanced approach, others had a more traditional relationship with patients where the SLT took the lead and role of 'expert' within the partnership.

Establishing a collaborative and empowered relationship may be particularly difficult given the communication difficulties experienced by this particular group of stroke survivors. Communication is the basis for creating a shared understanding of therapy and for creating a shared understanding of what the stroke survivor may wish to achieve (Sugavanam et al., 2013). Severe difficulties in receptive understanding or expressive communication, may hamper the creation of this shared understanding and thus the alliance upon which longer-term management of the condition can be supported and built (Lawton et al., 2016; Rohde et al., 2012). The practicalities of implementing self-management approaches with this population were also highlighted by SLTs in the current study, who suggested that it may be difficult for those with cognitive difficulties to retain and implement self-management strategies in practice. The challenges that may exist in implementing a self-management approach must be

recognised and fed in to training for SLTs in the use of this approach and its specific adaptation for stroke survivors with communication difficulties.

Some may question whether it is possible for a self-management approach to be implemented with those with severe receptive or cognitive communication difficulties given the inherent difficulties outlined above. However, rather than excluding this population, it may require self-management approaches to be adapted. For example, rather than placing sole responsibility with the stroke survivor, there may need to be some recognition of the role family members may take in supporting condition management. Depending upon the severity and type of communication difficulty different 'levels' of self-management may be achievable. Rather than considering self-management as something which stroke survivors are or are not able to do, Satink et al. (2015a) suggest that self-management should be considered as a continuum upon which stroke survivors and their families should be enabled to manage as far as possible. Satink et al. (2015b) found that self-management was described as 'co-management' by stroke survivors who discussed their experiences of self-management during a focus group. Participants in the focus group expressed that family members played a key role in problem solving and supporting them with tasks they could no longer complete independently. Self-management approaches have previously been criticised for failing to take into consideration the social context of the individual and the potential role others can play in enabling condition management (Vassilev et al., 2011; Kendall and Rogers, 2007).

In the current study, SLTs highlighted the importance of the practical and emotional support family members provided to the stroke survivor and yet the extent to which families were involved in therapy sessions varied. SLTs accounts of involving family members were often described as having some element of risk. SLTs were sometimes concerned that if families become involved, this may be detrimental to the stroke survivor if therapy tasks were completed in a way which was discouraging or that an emphasis on completing therapy tasks may detract from ordinary conversation opportunities. There was sometimes ambivalence in SLTs talk; on one hand they expected stroke survivors and their families to take on responsibility for rehabilitation but on the other there were 'risks' they associated with involving families in therapy.

Hallé et al. (2014) interviewed SLTs to gain their views upon family involvement in speech and language rehabilitation. Echoing findings from the current fieldwork, Hallé et al. (2014) found that families were not involved in a systematic way in speech and language rehabilitation. Although SLTs recognised the importance of involving family members, their involvement was generally perceived to be a 'bonus' or an addition to the fundamental approach based around the stroke survivor. These findings are in line with the current study and suggest that without more formalised involvement of family members, their inclusion within speech and language therapy may be perceived as an 'extra' intervention which may only happen if certain conditions are met, for example, if the family member is available, if the family member is willing and if the SLT has time. SLTs accounts suggest that actively involving family members may require a significant investment of resources and a trade-off to be made in terms of time spent focusing on other aspects of therapy. On the other hand, given the scarce resources available, involving family members may be a vital way of supporting condition management (Hallé et al., 2014; Visser-Meily et al., 2006). For example, family members may have a vital role to play in supporting the generalisation of strategies learnt in speech and language therapy to everyday life (Jacobs et al., 2004); something which has been highlighted as potentially problematic in speech and language therapy (Carragher et al., 2012).

The final important finding from the fieldwork with SLTs was the lack of availability of psychological support for stroke survivors with communication difficulties, and in particular, talk based therapies. Clinical guidelines suggest that timely psychological support should be offered to all stroke survivors (Intercollegiate Stroke Working Party, 2016; Department for Health, 2007). It is recommended that a clinical psychologist should be a core member of the stroke multidisciplinary team and that a stepped care model of psychological intervention should be offered to all stroke survivors (Intercollegiate Stroke Working Party, 2016; NICE, 2013). Stroke survivors with communication difficulties have often been excluded from RCTs testing the effectiveness of interventions for post-stroke depression (Hackett et al., 2008). However, having a communication difficulty leads to an increased risk of depression (Hilari et al., 2012; Kauhanen et al., 2000) and emotional distress (Thomas and Lincoln, 2008). Depression has been associated with poorer outcomes for stroke survivors including an increased level of disability, reduced quality of life, increased mortality and an increased length of hospital stay (Ayerbe et al., 2013; Saxena et al., 2006).

Many talking based therapies would be inaccessible for stroke survivors with communication difficulties without adaptation. However, talking based therapies may be preferable due to research suggesting that pharmacological treatments for depression used post-stroke are associated with an increased risk of adverse events (Hackett et al., 2008). A RCT by Thomas et al. (2013) has demonstrated the effectiveness of behavioural therapy for stroke survivors with aphasia. To the authors knowledge this is the only trial of a talking therapy which has been specifically adapted for stroke survivors with aphasia. The intervention was delivered by assistant psychologists under the supervision of clinical psychologist and neuropsychologist and was associated with improved mood at 3 and 6 months follow-up in comparison to usual care. Although the trial by Thomas et al. (2013) demonstrates the feasibility of providing talking based psychological therapies for stroke survivors with communication difficulties, the feasibility of implementing this type of therapy in practice must be considered. None of the sites participating in the current study has access to psychologist as part of their team. Significant barriers were identified for stroke survivors with communication difficulties in accessing neuropsychology services (due to lengthy waiting lists) or mainstream psychological services (due to referral criteria and lengthy waiting lists). The lack of availability of psychological support is supported in the SSNAP data with only 6% of hospitals having access to a clinical psychologist (Royal College of Physicians, 2016) and a median waiting time of 10 weeks to be seen for psychological support in the community (Royal College of Physicians, 2015). Therefore, it seems unlikely that a talking intervention delivered by assistant psychologists like the one described by Thomas et al. (2013) could be implemented in practice, given the resources currently available.

Further research may be needed to explore different therapeutic options for psychological support; however, self-management approaches may also hold some benefit for stroke survivors with communication difficulties in this regard. Definitions of self-management highlight how such approaches are designed to help patients to cope with the physical, social and psychological consequences of chronic illness (Barlow et al., 2002). There are important comparisons to be drawn between aspects of self-management and existing psychological approaches; in particular behavioural therapy. There has recently been a renewed interest in behavioural therapy for the treatment of depression with a number of systematic reviews showing evidence of effectiveness (Ekers et al., 2008; Cuijpers et al., 2007). The basis of behavioural therapy is the premise that engaging in pleasant activities provides positive reinforcement and alleviates symptoms of depression. Behavioural therapy therefore encourages patients

to make the link between their lack of (or avoidance of) activity and low mood and to overcome this by planning and taking part in pleasant activities (Kanter et al., 2010). There is a significant overlap between components of behavioural therapy and self-management. For example, commonly used self-management intervention components such as goal-setting, action planning and self-monitoring appear to be similar concepts to the planning and monitoring of activity undertaken as part of behavioural therapy. A self-management intervention which includes the planning and monitoring of activity may not be sufficient to help all stroke survivors who were identified as needing psychological support by SLTs in the current study. However, the introduction of self-management as part of the currently recommended stepped care model of psychological support may warrant further exploration (Intercollegiate Stroke Working Party, 2016; NICE, 2013).

7.2. Discussion of findings from stroke survivor and carer fieldwork

Summary of key findings

The fieldwork discussed in this section was undertaken to explore how stroke survivors with communication difficulties manage their condition in the first year post-stroke and to explore requirements for longer-term care from the carer's perspective. The interview findings provide a glimpse into the needs of stroke survivors and carers living with communication difficulties in the first year post-stroke. The findings suggest that managing stroke related disabilities including communication problems 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. Some were able to participate in previously valued activities or successfully adjusted and adapted and were content with the new post-stroke life they had created. For some stroke survivors, the process of adjustment and adaptation was ongoing as they tested the limits imposed by their communication difficulties. Others struggled to adjust or adapt and withdrew from social situations and meaningful activity soon after hospital discharge or within the first year post-stroke. Significant adjustment and adaptation was required for many stroke survivors. Much of this work was undertaken following discharge from rehabilitation services with the support of family members/carers and without input from healthcare professionals.

Comparison with existing literature

By focusing upon the first year post-stroke, an in-depth understanding of how stroke survivors with communication difficulties manage during this time period was obtained. The course of stroke survivor's recoveries varied hugely as did the steps taken to manage post-stroke communication difficulties. As described in Chapter Two, varying illness courses have been used as a theoretical framework to obtain insight in to the difficulties associated with managing chronic illness (Corbin and Strauss, 1988; Corbin and Strauss, 1991). Understanding the course of an illness is important for understanding what factors may contribute the management of a condition over time, and at which points further support and resources may be needed to facilitate condition management. This framework is used to interpret the findings of the current study and to locate the findings of the study in relation to existing literature.

Corbin and Strauss have termed illness courses as a 'trajectory' in order to capture the complex journey patients with chronic conditions go through over time. Within a given trajectory there may be a number of 'phases' which a patient may undergo during the course of the illness. The chronic illness trajectory proposes eight phases patients may typically experience:

1. Pre-trajectory- Prior to the onset of symptoms, the phase where chronic illness may be prevented.
2. Trajectory onset- Symptoms are present and may be diagnosed.
3. Crisis- Life-threatening symptoms which require emergency or acute care.
4. Acute- Hospitalisation is required to manage symptoms.
5. Stable- Illness course or symptoms are managed by new treatment regimen.
6. Unstable- Illness course or symptoms are no longer managed by regimen
7. Downward- Deterioration including increased number of symptoms or increased level of disability.
8. Dying- Weeks, days or hours preceding death.

In order to maintain quality of life, patients and families must make choices to manage the problems which occur as a result of living with a chronic illness; for example, adhering to treatment regimens, maintaining social relationships or daily routines such as dealing with housework or financial responsibilities. Significant 'work' is associated

with adapting to and living with a chronic illness and the work undertaken and choices made within the context of an individual's trajectory can shape experience in addition to the severity and natural progression of the illness.

Once discharged from hospital, stroke survivors with communication difficulties may be considered to be in the 'Stable' Phase of their illness trajectories as the acute symptoms of stroke were managed and they were medically well enough to go home. Despite this, many were still coming to terms with the shock and implications of having a communication difficulty, and, there were still significant adaptations and adjustment made soon after hospital discharge and by participants interviewed across time points in the first year post-stroke. Findings from studies reviewed in Chapter Two are also consistent with the findings of this study in suggesting the struggles of participants at a range of time-points post-stroke in coming to terms with the consequences of their communication difficulties (Brown et al., 2010; Brown et al., 2013; Grohn et al., 2014; Fotiadou et al., 2014; Johansson et al., 2012; Niemi and Johansson, 2013; Pound, 2010; Worrall et al., 2011). Corbin and Strauss (1991) suggest that 'subphases' may occur which reflect ongoing fluctuations in condition management within each phase. Arguably, such sub-phases were evident for stroke survivors in this study; soon after hospital discharge, participant's experiences commonly centred on the steps they took to adapt to being back in their home environment (often focusing upon practical and physical aspects of managing within this space). Following these initial adaptations, participants often took steps to regain some sense of normality through daily activities or reacquiring independence in small ways. Participant's experiences were often shaped by the severity of their communication difficulty, and the consequences of this which unfolded as time went by and as they began to gain experience of post-stroke life. Continual adaptations also had to be made as support from healthcare professionals often reduced during this time period.

Across the first year post-stroke, stroke survivors and their families undertook significant work to manage life after stroke and the consequences of living with a communication difficulty. Corbin and Strauss (1985) suggest that three main types of work which may be undertaken in relation to managing an illness trajectory, these include; illness related work, everyday life work, and biographical work. These aspects of work will be considered in turn in relation to the findings of the current study. The first aspect of work which was undertaken by stroke survivors with communication difficulties within the first year post-stroke was managing the biographical

consequences of their communication difficulties. Corbin and Strauss (1988) propose that the illness trajectory takes place within a biographical context which is unique to the individual. Each individual has a biography or narrative of their life, which is consistent with their self-identity and which exists both within time (has a past, present and future) and which fluctuates and evolves across time (over the life course). Biographical disruption calls in to question some aspect of how participants see themselves within or across their life course (Bury, 1982; Charmaz, 1983).

In this study, the loss of speech and language was often linked with a loss of self-identity. In addition to communicating a message, speech and language was also a means by which stroke survivors expressed or reaffirmed their sense of self (for example, by showing their character or personality traits). The loss of speech and language therefore created discontinuity between pre-stroke and post-stroke identity. The loss of speech and language also had broader biographical implications as it often placed restrictions upon activities which held close associations with self-identity, for example, previous occupations or roles taken within the household. The sense of disruption was particularly noticeable for stroke survivors who were younger, who had worked prior to stroke, or, who had outgoing personalities. The sudden disabilities brought about by stroke did not flow with their narratives of pre-stroke life which often included being well, working and socialising without difficulty. Corbin and Strauss (1988) suggest that some of the work associated with managing an illness trajectory is related to reconciling the biographical disruption caused. They suggest that the process of reconciling a disrupted biography is complex, non-linear and often evolves slowly over time. This process involves contextualising or acknowledging the illness within the biography, coming to terms with or accepting the biographical consequences of being ill and rebuilding identity to regain a sense of wholeness in spite of the illness.

It is important to note that not all stroke survivors with communication difficulties experienced high levels of biographical disruption. For some (in particular older participants, those with pre-existing health conditions or those with less severe communication difficulties), stroke did not cause catastrophic disruption to their lives but were perceived as a 'hiccup' on their journey. Others have also questioned the notion that chronic illness necessitates biographical disruption. Faircloth et al. (2004) use the term 'biographical flow' to capture experiences of recovery where stroke is not experienced as disruptive but as one event amongst many in the person's life narrative. Factors such as age, socioeconomic status and comorbidities have been suggested to

impact upon the extent to which stroke is experienced as a disruptive event (Faircloth et al., 2004; Pound et al., 1998).

The extent to which stroke survivors experience biographical disruption is likely to impact upon the amount of biographical work which needs to be undertaken within the illness trajectory. Those who experience less biographical disruption may take less time to reconcile their pre-stroke and post-stroke sense of self and to accept the limitations caused by stroke. The level of biographical disruption did not appear to have a direct association with participants chronological time post stroke; i.e. participants at 12 months post-stroke could experience little or significant disruption and those at 3 months post-stroke could experience little or significant disruption. Where participants are located within biographical time (levels of disruption or reconciliation) may have a significant impact upon how and when other types of trajectory management work are undertaken. For example, a stroke survivor who struggles to accept their communication difficulties may be more likely to manage these by withdrawing from or avoiding situations which involve social participation as opposed to trying out compensatory strategies to manage their communication.

Other types of work associated with managing an illness trajectory include illness related work and everyday life work (Corbin and Strauss, 1988; Corbin and Strauss, 1985). Illness-related work includes regimens which may need to be undertaken to manage symptoms, for example, adhering to medication or engaging in therapy. Everyday life work includes daily tasks such as housekeeping, financial management or maintaining social relationships. In the current study, due to the central role which communication plays in everyday life, there was a significant overlap in the illness related and everyday life work undertaken. The focus of this work also changed over time. When first discharged from hospital, the focus of work was often upon managing practically within in the home environment; for example, managing self-care tasks or adapting the space so it was physically accessible. However, once adaptations in these areas had been made the focus of work changed to managing activities of daily life, including tasks which involved communication. Generally, participants who were less than six months post-stroke had engaged in fewer activities outside of the home environment than those six to 12 months post-stroke. Unsurprisingly, this was influenced by the severity of the impairment, with those experiencing less severe impairments more likely to resume such activities.

An important aspect of the work undertaken by stroke survivors and their family members was the work to 'figure out' which aspects of daily life could be managed independently and which would require more assistance. Burton (2000a) criticises the chronic illness trajectory for downplaying the importance of the trial and error process of experimentation that stroke survivors and their families undertake following stroke. This process has been highlighted in the literature (Burton, 2000b; Doolittle, 1992), however, has mostly related to physical functioning. The findings of the current study extend these findings to include communication and, moreover, highlight the creativity with which some stroke survivors found ways in which to overcome the barriers imposed by their speech and language impairments. This was a complex process which required repeated attempts and adjustments to be made on each attempt to refine the strategy or generalise it to other contexts. For example, for one stroke survivor, starting a conversation with someone by pointing at their t-shirt, evolved to the stroke survivor wearing an interesting t-shirt themselves to start conversation. Several contextual factors may have influenced stroke survivor's ability to engage in this trial and error process of experimentation and the implementation of novel strategies to support conversation. Some cited their outgoing or social personalities or ability to have a sense of humour when a communication attempt was not successful. Professional support and suggestions from SLTs were also cited as facilitators by some, for example, advice to slow down speech or breaking down of words in to syllables. Familiarity of the conversation partner was also cited as a facilitator. Finally, stroke survivors who were able to engage in this process demonstrated high levels of cognitive ability (to adapt, learn and generalise strategies from one context to another) which acted as a significant facilitator.

Family members also 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 within social situations for them to do so. Family members also 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. There appeared to be a balance to be obtained between support and independence; with stroke survivor's highlighting their need for support to be provided in a way which did not restrict their sense of independence or place too much burden upon the family member. However, often in the provision of additional support, family members expressed a shift in the dynamic of the relationship with the family member taking on additional responsibilities to manage everyday life activities including caring

for and protecting the stroke survivor. Despite this, family members did not talk about stroke or post-stroke communication difficulties being a barrier to retaining a sense of closeness or togetherness in their relationship. In contrast to these findings, a qualitative study by Grawburg et al. (2013) suggested that there was a disruption to the sense of closeness felt by family members of stroke survivors with aphasia. The family members in this study suggested that the effort of communicating lead to the avoidance of in-depth and meaningful conversations which impacted upon the sharing of experience within the relationship. Family members in Grawburg et al.'s (2013) study were predominantly several years post-stroke which may suggest that such difficulties may be recognised over time, perhaps as the long-term impact of the condition begins to unfold.

On a similar note, in comparison to the literature reviewed in Chapter Two, loss of friendship or feelings of social isolation were not prominent in the experiences of stroke survivors with communication difficulties who participated in this study. This may, again, be a consequence of time post-stroke and this is supported by some literature which suggests that the reduction of social networks occurs gradually with friends drifting away over time (Brown et al., 2013; Dalemans et al., 2010; Parr, 2007). However, there was some evidence that stroke survivors had encountered difficulty in social situations and in some circumstances had begun to avoid or withdraw from such situations. This may be the beginning of a cycle of withdrawal from social situations which may lead to the loss of friendship over time. The maintenance of friendship is a shared endeavour and maintaining a sense of connectedness within a relationship may be difficult for friends in the face of communication difficulties (Dalemans et al., 2010; Brown et al., 2010). For example, friends may have to adapt their communication style or be accepting of other difficulties (e.g. physical disabilities) which might alter the previous basis of friendship (e.g. if the friendship involved participation in a hobby or work-based friendships).

The preceding section has highlighted the amount and complexity of work which is undertaken in managing the consequences of stroke over the first year. It is important to note that the type of work undertaken was highly dependent upon the context of the individual, for example, the severity of their communication difficulty and the meanings and consequences of their stroke upon their lives. Each type of work undertaken also had a reciprocal impact upon the other and, thus, how the condition was managed over time (Corbin and Strauss, 1991; Corbin and Strauss, 1988). Biographical time (how

stroke and communication difficulties are experienced in the context of an individual's life narrative) and trajectory time (time post-stroke) both had a significant influence upon each individual's experience of condition management. The findings of this study suggest that the management of life after stroke is not undertaken in a fixed or orderly fashion. Participants engaged in a complex balancing act; managing multiple lines of work within a trajectory context which was constantly changing and evolving over time (for example, as recovery progressed, and the level of professional support reduced).

A key point within many stroke survivors' trajectories was the point at which support from rehabilitation services ended. Corbin and Strauss (1991; 1988) suggest that those experiencing chronic illness have a trajectory scheme which is a plan to manage symptoms and handle residual disabilities. At the point of discharge, there was much variation in the trajectory schemes held by participants. This point in time often brought to the forefront concerns about how the post-stroke communication difficulties would be managed moving forwards; some expressed feeling lost or abandoned at this point in time. This appears to be a key time at which further resources may be needed to help stroke survivors with communication difficulties and their families to cope with the transition to longer-term adaptation and adjustment. This timepoint was also highlighted by SLTs as being of significance for the provision of longer-term support. In the next section, the significance of this timepoint is explored further and the implications of this for the provision of longer-term care are discussed.

7.3. Implications for longer-term care

The point of discharge from community rehabilitation services was identified as a key turning point for many stroke survivors, carers and SLTs. From SLTs perspective, resource constraints coupled with the slowing of improvements with speech and language were often a marker to begin the process of discharge. However, SLTs acknowledged that some stroke survivors with communication difficulties may need further support to manage the consequences of their condition at this stage and moving forward. Hersh (2003) interviewed SLTs to explore the strategies they used during the discharge process. Hersh (2003) identified that SLTs tried to gently 'wean' clients from aphasia therapy; a process designed to maintain the therapeutic relationship whilst balancing the need for resource gatekeeping. Hersh (2003) suggests that SLTs attempts to soften the blow of discharge were a demonstration of professional control

in which SLTs held the ultimate decision about when therapy would end and tried to gently bring their clients perspectives in line with their own. In the current study, some stroke survivors and family member's experiences suggested a sense of powerlessness over the discharge process. Hersh (2003) suggests that a more balanced approach to decision making during the process of discharge, including clearer communication and negotiation, may lead to a more satisfying and empowering process of discharge for clients.

However, not all stroke survivors with communication difficulties experienced a sense of disempowerment and abandonment during the process of discharge in the current study. The significance of the point of discharge for stroke survivors with communication difficulties and their family members may also be influenced by the extent to which discharge was concordant with hopes and beliefs about the future course of recovery from stroke (known as a trajectory projection within the illness trajectory framework) (Corbin and Strauss, 1991; Corbin and Strauss, 1988). For example; those who were happy with the recovery they had made during speech and language therapy (usually those with milder deficits), seemed less likely to express concern at the point of discharge from rehabilitation. Corbin and Strauss (1988) suggest that trajectory projections may fade in or out of importance throughout the illness trajectory. For some, the point of discharge from therapy appeared to bring uncertainties about recovery, and whether improvements to speech and language would be made in the future to the forefront. This was often (although not always) the case for participants with more severe language impairments. For these participants, the extent to which further improvements could be made had a significant impact upon their biographies and the way in which their lives would need to change to adapt to and manage residual impairments in the future. Sometimes these participants still wished to work towards improvements and discharge came at a time where therapy was still perceived to be needed to maximise these. Hersh (2009) interviewed stroke survivors with aphasia to explore their experiences of discharge from speech and language therapy. In line with the findings of this study, Hersh (2009) found that perceptions of discharge were strongly interwoven with the meaning of discharge upon participant's biographies, notions of progress during therapy and hopes for future recovery.

Comparing the narratives of stroke survivors, their family members and SLTs suggests that there was often a mismatch at the point of discharge about the extent to which each expected a full or partial recovery from speech and language impairments to be

made. SLTs described the need for patient's expectations of recovery to be managed and to be 'realistic'. However, at the same time SLTs expressed discomfort when discussing recovery; they did not wish to give false hope and feared negative reactions if they took hope away by discussing the likelihood of recovery. Previous work by Wiles et al. (2002) suggests that physiotherapists were also reluctant to be drawn into discussions about recovery and left the prospect of recovery open and ambiguous. In a later study Wiles et al. (2004) suggest that physiotherapists face the "unenviable task" (p.1272) of dealing with patients disappointment at the point of discharge if their expectations of recovery have not been met.

Becker and Kaufman (1995) suggest that the process of adjustment to post-stroke life may be prolonged by an uncertain prognosis. Wallenbert and Jonsson (2005) suggest that stroke survivors face a dilemma during rehabilitation about whether to accept their new situation (and adjust or adapt) or whether to wait and see if there will be any further improvement to impairments. Wallenbert and Jonsson (2005) describe this as 'waiting to get better'. On the other hand, some have suggested that hope for recovery is an important coping mechanism in the process of adaptation and adjustment and so healthcare professionals should not seek to alter hopes even if they perceive them to be overoptimistic (Salter et al., 2008). Wiles et al. (2008) make a useful distinction between 'hope-as-want' and 'hope-as-expectation'. In line with the experiences of SLTs in the current study, Wiles et al. (2008) suggest that hope as a want is a positive outlook but with an understanding that hopes are unlikely to be achieved; whereas hope as an expectation is the idea that hopes will definitely be achieved. Both types of hope may help to sustain patient's engagement in rehabilitation, however, hope as expectation may lead to disappointment if expectations are not achieved.

In the current study, the uncertainty of recovery did appear to prevent some stroke survivors from planning for the future or regaining meaningful roles or activities (Coventry et al., 2014). Some have suggested that education about typical stroke recovery may be needed in order for stroke survivors and carers to adjust their hopes for the future (Laver et al., 2010; Wiles et al., 2008). However, this may be particularly difficult for stroke survivors with aphasia as recovery course and prognosis may be difficult to predict (Lazar et al., 2008). Research generally suggests that most improvement with aphasia occurs within the first three to six months post-stroke (Lazar et al., 2010; Laska et al., 2001; Lendrem and Lincoln, 1984; Demeurisse et al., 1980). Nevertheless, improvements have been shown up to 18 months following stroke

(Pedersen et al., 2004; Laska et al., 2001) and recent systematic reviews suggest that time post-stroke may not be associated with responsiveness to speech and language therapy for aphasia (Allen et al., 2012; Moss and Nicholas, 2006). Initial severity of stroke and size of lesion, have been suggested as predictive factors most strongly associated with the level of recovery in post-stroke aphasia (Plowman, Hentz and Ellis, 2012).

The extent to which recovery information is clearly and openly discussed with stroke survivors with communication difficulties is unclear and may vary across services. Worrall et al. (2010) found that gaining information about recovery (prognosis and what to expect during each stage of recovery) is often a goal for stroke survivors with aphasia. Some SLTs who took part in the fieldwork in this study suggested that their clients were reluctant to hear or take on board information which contradicted their hopes for a full recovery. Worrall et al. (2010) also report cases of stroke survivors with aphasia perceiving that they had not been told this information when they had. Corbin and Strauss (1991) suggest that changing patients ideas of an illness course may require time and for the healthcare professional to 'plant seeds and let them grow' (p. 170). This also fitted with the experiences of SLTs in the current study who either gave stroke survivors time to come to terms with the likelihood that they would not fully recover from their communication difficulties or gently tried to alter their expectations. Struggling to accept the long-term nature of communication difficulties was often associated with a lack of readiness to engage in therapy which introduced compensatory strategies to facilitate adaptation and adjustment, in spite of residual speech and language impairments.

The bereavement model suggests that some stroke survivors may get 'stuck' being unable to accept their disabilities and thus engage in activities to facilitate longer-term adaptation and adjustment. The bereavement model outlines a number of stages which those experiencing grief must typically go through in order to come to terms with their loss (intellectual acceptance, emotional acceptance, adjustment and social reinvestment). This model suggests that acceptance must occur before adjustment. However, Kubina et al. (2013) criticise the linear assumptions of the bereavement model. Findings from their study which explored how stroke survivors re-engaged in meaningful activity suggested that the process of testing the limits aids adjustment and adaptation. This implies that the process of reengaging in meaningful activity should be encouraged even if stroke survivors have not fully accepted their communication

difficulties. Kubina et al. (2013) suggest that engaging in this process will facilitate acceptance and vice versa. Other studies have also suggested the importance of 'doing' in longer-term adjustment and condition management following stroke (Satink et al., 2016). This may be an important aspect of helping stroke survivors with communication difficulties to come to terms with their impairments and find ways in which to manage these in daily life.

As discussed in the Section 7.2, the process of recovery from post-stroke communication difficulties appears to be complex, non-linear and may be influenced by a number of factors in addition to the severity of the impairment, for example, the level of biographical disruption or the resources available to help undertake illness work. It is important to recognise that the extent to which stroke survivors with communication difficulties would be ready at the point of discharge to adjust to and accommodate their impairments into daily life may vary. The preceding paragraphs highlight that 'readiness' may be influenced by a number of factors including the meaning and impact of the impairment within the stroke survivor's life, and hopes and expectations about recovery. It is unclear whether readiness to begin the process of adaptation and adjustment can be facilitated through intervention. For example, could further information about typical stroke recovery or encouragement to reengage in meaningful activity (Kubina et al. (2013) help. Or is this a process which cannot be expedited and must occur naturally with the passage of time. In either case, a longer-term care intervention may need to be flexible both in its timing and in supporting stroke survivors with communication difficulties who may be at various stages of the adaptation and adjustment process. One option for stroke survivors who are not ready at the point of discharge to engage with an intervention which promotes adaptation and adjustment may be to have the option to self-refer back in to a service when they are ready. Another option is that the stage of adjustment is recognised within the intervention and that the components of the intervention are tailored accordingly. For example, the findings of the fieldwork suggest that this adaptation and adjustment is a gradual process and therefore supporting stroke survivors and their families to build towards this in small steps may be important.

Smoothing this transition to longer-term adaptation and adjustment appears to be an important need. The sense of disempowerment and abandonment experienced at the point of discharge from speech and language therapy suggests that further support around this timepoint may be particularly important. At the point of discharge from

speech and language therapy, many stroke survivors had only just begun to negotiate the world with their communication difficulties. Regaining involvement in the social world with communication difficulties may require considerable effort and support. SLTs also suggested that resources to promote this kind of adaptation during speech and language therapy (for example, through practice of compensatory strategies in context) were limited or required a trade-off to be made in terms of focusing upon other aspects of speech and language therapy. An adapted and supported self-management approach may be one way in which stroke survivors with communication difficulties might be supported during this transition. A rationale for taking this approach is presented in Section 7.5. In the next section, the strengths and limitations of the fieldwork are considered.

7.4. Strengths and limitations of the fieldwork

To the author's knowledge, this is the first qualitative study to explore SLTs views regarding longer-term care for stroke survivors with communication difficulties and their understandings of the term 'self-management'. This is also one of few qualitative studies to explore how stroke survivors with communication difficulties and their carers manage their condition, and their needs in relation to longer-term care within the first year post-stroke.

One strength of the fieldwork is the inclusion of a wide range of stroke survivors with communication difficulties, including those with moderate to severe difficulties. This is a difficult to reach population and presents challenges to be overcome in terms of consent and participation in research (Brady et al., 2013; Penn et al., 2009). Careful consideration and adaptation of the methods used (including adaptations to the consent process and adaptations to the qualitative methodology) facilitated the inclusion of this population in the current study. However, difficulties were experienced with recruitment which meant that interview participants were recruited from NHS services only. Interview participants were therefore often (although not always) in receipt of support from SLTs, or had recently been discharged from speech and language therapy services. These participants may therefore not be fully representative of the wider population of stroke survivors with communication difficulties, as those who were not in receipt of support from NHS services, were not approached to participate. This potential limitation was recognised and although attempts were made to

circumvent this issue by recruiting from charitable organisations and a research register, these methods of recruitment proved unsuccessful. A related limitation is that those who declined to participate in the study (stroke survivors, carers and SLTs) may have had different experiences than those who chose to participate in the study.

Recruiting from NHS services necessitated reliance upon gatekeepers; those who hold access to the desired population (Groger et al., 1999; Tuckett, 2004). In this study the gatekeepers were the SLTs who identified and approached potentially eligible participants upon the author's behalf. Reliance upon gatekeepers is problematic as gatekeepers may have their own preconceptions about who is suitable to be approached to participate in research, which may not be in line with the researcher's inclusion criteria (Groger et al., 1999; Tuckett, 2004). This may create sampling bias as the gatekeeper controls who is approached and not all of the potentially eligible participants may be approached to participate due to the gatekeeper's beliefs. Groger et al. (1999) suggest that researchers must consider the influence of gatekeepers upon the recruited sample or in other words "what we didn't learn because of who would not talk to us" (p.829). In the current project, SLTs may have limited stroke survivors they approached to those with whom they had a good therapeutic relationship or those who they considered to be model patients. My background as a non-SLT may also have influenced the participants selected and created bias in the sample recruited. Attempts to reduce gatekeeper bias were made by keeping an open dialogue with sites, by regularly discussing patients who might be eligible, and by gently reminding sites of inclusion criteria.

Another limitation of the sample is 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. Groger et al. (1999) highlight the challenges of achieving a purposive sample whilst navigating the practical realities of recruiting participants from services where access must be negotiated and in the context of time restrictions upon project completion. Although a purposive sample was sought, and continuing efforts were made to ensure that a diverse sample of stroke survivors were recruited, these efforts had to be balanced with the pragmatic need to complete the fieldwork within a set timeframe and with limited resources.

As mentioned previously, a strength of the fieldwork are the adaptations made to facilitate the participation of stroke survivors with communication difficulties in the qualitative research interviews. However, it is important to acknowledge that due to the stroke survivor's communication difficulties it sometimes took time to obtain depth and detail about interview topics. This was not only due to the stroke survivor's difficulties, but the time needed to understand the best way to support the stroke survivor's communication. The number of topics which were discussed was therefore sometimes restricted in comparison to a typical qualitative interview. Stroke survivors varied in the extent to which they could tolerate communicating without becoming fatigued, and in many cases where a limited number of topics had been discussed, prolonging the interview led to diminishing returns and risked the interview becoming burdensome to the participant. Multiple and shorter interviews over a period of time for stroke survivors with communication difficulties may be preferable in future in order to build upon the rapport gained during the first interview, and to gain more depth and detail about topics of interest. Other researchers have used a variety of methods to elicit information about the lives of stroke survivors with communication difficulties including participant generated photography (Brown et al., 2010; Brown et al., 2013), diaries (Dalemans et al., 2010) and observation (Howe et al., 2008b; Parr, 2007). Using combinations of qualitative methods may be preferable where timescales and resources allow.

Finally, a strength of the interview study is that multiple NHS services were used to recruit so views of stakeholders in multiple services were obtained. However, the services were located in one geographical region of the UK and so may not be fully representative of other areas of the country.

7.5. Rationale for taking a self-management approach

At the outset of this PhD study it was unclear whether self-management was a suitable means of providing longer-term support for stroke survivors with communication difficulties. It is important to state that due to the diversity of longer-term needs identified in the fieldwork and literature reviewed as part of this thesis, it is unlikely that any one intervention could be developed to address all of the needs identified. For example, some stroke survivors with communication difficulties will require access to specialist psychological support, and further research is needed to increase the accessibility of such services. Further research may also be needed to facilitate

transitions between hospital and community services or increase societal awareness of post-stroke communication difficulties. However, self-management may be an appropriate intervention to address the difficulties with longer-term adaptation, adjustment and condition management commonly experienced by stroke survivors with communication difficulties. A rationale for designing a self-management intervention to support stroke survivors with communication difficulties in the longer-term is presented below.

Firstly, it is important to note that with the exception of self-management, clinical guidelines and policy documents lack clear recommendations for longer-term care interventions for stroke survivors (Intercollegiate Stroke Working Party, 2016; Department of Health, 2007). An advantage of using self-management as the basis for an approach to longer-term care is that there is a policy drive towards taking this approach both generally, and, more specifically within stroke care (Intercollegiate Stroke Working Party, 2016; NHS England, 2015; Foot et al., 2014; NHS England, 2014; Department of Health, 2007). When developing a complex intervention, it is important to consider the feasibility of implementing the approach in practice (Craig et al., 2008; Michie et al., 2011). The policy drivers towards incorporating this approach are clear and basing an intervention upon a recommended approach increases the likelihood of its implementation in the future. There is also some evidence to suggest the benefits of this approach in terms of increasing self-efficacy and quality of life in the stroke population (Fryer et al., 2016). However, the findings of Chapter One demonstrate the exclusion of stroke survivors with communication difficulties from RCTs of stroke self-management interventions and highlight the need for additional research to explore whether self-management is beneficial for this sub-group. The findings of the fieldwork also suggest that, given the diversity and complexity of communication difficulties experienced, a self-management approach which is adapted to respond directly to the specific needs of this population may be necessary. A clearly defined and structured approach to self-management is needed to ensure that this policy recommendation can be implemented into practice for stroke survivors with communication difficulties.

Secondly, the underpinning ethos of self-management; to empower patients to manage the physical, psychological and social consequences of living with a long-term condition (Lorig and Holman, 2003; Barlow et al., 2002) appears to fit with the longer-term needs commonly experienced by stroke survivors with communication difficulties.

The longer-term needs identified in the literature and as part of the fieldwork highlighted the extensive physical, psychological and social impact of post-stroke communication difficulties upon daily life. A self-management intervention may benefit stroke survivors with communication difficulties and their families by supporting them to adjust to and manage the challenges they face. Although these needs were identified, it is also important to recognise the work that SLTs undertook with the aim of promoting longer-term adaptation and adjustment to post-stroke communication difficulties. SLTs perceived this to be an integral part of their role and sought to help stroke survivors and their family members to generalise what they had learnt in speech and language therapy to daily life, and, by doing so, build confidence in communication. On the other hand, SLTs also highlighted the complexities of undertaking this type of work with stroke survivors with communication difficulties and expressed considerable frustration at the lack of time and resources within community setting to do so. SLTs acknowledged that further support may be needed following discharge to help stroke survivors and their carers to manage the social and psychological implications of living with a communication difficulty. Self-management may be one way of building upon the work already undertaken by SLTs and of justifying the provision of additional resources to support the transition to longer-term adaptation and adjustment.

As suggested previously, needs relating to managing the longer-term psychological and social implications of living with a communication difficulty were identified both in the literature reviewed in Chapter Two and in the fieldwork undertaken. Speech and language therapy interventions were identified which target social participation; for example, conversation partner therapy (Simmons-Mackie et al., 2010) or community groups for stroke survivors with aphasia (Lanyon et al., 2013). However, if used in isolation these interventions focus upon improving a single aspect of social participation. For example, training the conversation partner of a stroke survivor with communication difficulties may not address other commonly identified needs, such as, managing communication outside of the home or participation in meaningful activity. As highlighted previously, research by Rohde et al. (2012) suggests there may be variation in the extent to which wider participation goals are addressed within SLTs practice. The resources available to undertake such work may also vary across services (Northcott et al., 2018).

SLTs who participated in the interview study also identified significant barriers to participation in community aphasia groups for many stroke survivors with

communication difficulties which suggests that such an approach may not be suitable for all. For example, lack of transport, mobility problems, and lack of confidence were all cited as barriers to attending community aphasia groups. Other literature also suggests that those with severe aphasia may struggle to participate in community aphasia groups and may feel excluded due to their communication difficulties making it harder to contribute to or follow a group interaction (Lanyon, Worrall and Rose, 2018). Similarly, it has been suggested that those with severe aphasia may also struggle to engage in the quizzes or pen and paper based activities which are commonly used as part of community aphasia groups (McVicker et al., 2008). On the other hand, some stroke survivors with severe aphasia have expressed feeling valued as part of their community aphasia group and enjoyment from listening to others interact and from the sense of belonging they felt in being around other stroke survivors with aphasia (Lanyon, Worrall and Rose, 2018). Community aphasia groups may vary widely in the way they are delivered and specific contextual factors (e.g. size or location of the group, other participants personalities or mix of aphasia severities) may influence suitability and accessibility for each individual (Lanyon, Worrall and Rose, 2018; Rose and Attard, 2015). In either case, exploring if such groups would be advantageous for stroke survivors with communication difficulties could be a component of a self-management approach. However, this could be part of a range of strategies or options for support which could be offered or supported within the intervention. Self-management may be valuable in offering a broader approach which can be tailored to address a range of needs.

The third advantage of self-management is that the concept is flexible and can be adapted to suit the needs of a particular population. This is demonstrated by the number of ways in which self-management has been applied across a range of chronic conditions (Taylor et al., 2014). It is important to make a distinction between the underpinning ethos and values of the self-management approach and how this is translated to the delivery of an intervention. For example, although self-management has been applied across a range of conditions the approach has also been adapted to include disease specific components e.g. blood sugar control in diabetes or self-monitoring of peak air flow in asthma care (Taylor et al., 2014). The literature reviewed and fieldwork undertaken highlighted how the underpinning ethos of self-management appears to fit with the longer-term needs experienced by stroke survivors with communication difficulties. However, the findings of the fieldwork suggest there are a number of ways in which a self-management intervention might need to be adapted in

order to address the specific problems which arise as a consequence of post-stroke communication difficulties. These are outlined in the next section.

7.6. An adapted model of self-management

As outlined above an advantage of taking a self-management approach is that the intervention can be adapted to be condition specific. There are five ways in which the findings of the fieldwork suggest that a self-management intervention may need to be adapted to suit the needs of stroke survivors with communication difficulties.

Firstly, the self-management approach should support stroke survivors in the trial and error process of experimentation which appears to be important to the process of successful adjustment and adaptation. Lorig and colleagues originally conceived that by teaching patients with chronic conditions a set number of skills over a seven week period that they could become 'experts' in managing their condition (Lorig and Holman, 2003; Lorig et al., 2001; Lorig et al., 1999a). The findings of the current fieldwork suggest that expertise in managing stroke and communication difficulties may continue over a long period of time, and may require a trial and error approach (Kubina et al., 2013; Scobbie et al., 2013). A self-management intervention should not therefore be prescriptive and should not assume that by educating stroke survivors with communication difficulties in a set number of skills that they will automatically become 'experts' in managing their condition. Self-management interventions should support stroke survivors with communication difficulties on their journey to discover how they wish to manage the difficulties they face, within their own particular context. Feeling supported during this period of discovery may help enable stroke survivors with communication difficulties and their families to regain a sense of control and agency, as opposed to feeling that the difficulties that they face are unmanageable. Feelings of control and self-efficacy have previously shown to have positive association with stroke survivors' quality of life, depression and activities of daily living and have been cited as key theoretical underpinnings to self-management interventions (Jones et al., 2011). Some researchers have also theorised about the importance of autonomy as part of the transformative process that stroke survivors undergo in learning about their competence, and re-engaging in meaningful activity (Kessler et al., 2009; Kubina et al., 2013).

The findings of the fieldwork suggest that reengagement in meaningful activity may be a gradual process which occurs over time. Strategies to manage difficulties encountered may also evolve over time as more experience is gained in different situations. The term trial and error is intended to capture the back and forth work of some stroke survivors and their family members in finding out what works and building upon this or applying this to other situations. Although this process may occur naturally for some (for example, the fieldwork showed the creative communication strategies developed by some stroke survivors and their family members), others may require further support. For some stroke survivors with communication difficulties, confidence was fragile and experiencing 'error' or setbacks during this process may be discouraging. A graded programme of support where stroke survivors are supported to build up to a particular activity in small stages may be appropriate (Abraham and Michie, 2008). For example, if the stroke survivor wished to go a café, it may be appropriate to practise what communication might be needed in the home setting first of all. This might progress to the facilitator going with the stroke survivor to the café and then to the stroke survivor going to the café by themselves. Different techniques may be needed depending upon the severity and type of the stroke survivors communication difficulty. Those with Wernicke's aphasia (who may struggle to understand or produce meaningful spoken language) may need a family member or other supporter to be present (and assisted by the facilitator initially) to support communication where necessary. For example, by drawing upon concrete contextual cues such as pointing to the different drink options to choose from in the café (Carlomango et al., 2013; Wilkinson et al., 2003).

Research into errorless learning during naming therapy suggests that stroke survivors with severe aphasia may find therapy more rewarding when the number of errors is reduced during the learning process (Fillingham, Sage and Lambon Ralph, 2006). This finding may relate to increased feelings of competence and confidence which is gained through success. However, those with less cognitive impairment (memory, executive and attentional functioning) responded better to errorful learning (akin to the trial and error process outlined above) during therapy (Fillingham, Sage and Lambon Ralph, 2006). This suggests that cognitive processes may play a role in learning from unsuccessful task completion. Therefore, for those with severe aphasia or cognitive impairments, it may be especially important to find areas where success can be experienced when facilitating reengagement in meaningful activity. However, this may be challenging in real life contexts where success in a given situation may depend

upon the behaviour of others, e.g. a supermarket worker allowing extra time or understanding when communicating.

The second way in which a self-management approach might be adapted is to support stroke survivors with communication difficulties and their families to manage the communication difficulty itself. Support to manage the communication difficulty itself was an important need identified in the fieldwork and literature and appeared to be missing from the self-management interventions reviewed in Chapter One. One way in which the findings of the fieldwork suggested that stroke survivors might be supported to adjust to and manage their communication difficulties is through the repeated practise of AAC strategies in meaningful contexts. This may help stroke survivors with communication difficulties to discover whether such strategies are useful or develop their own ways of managing. Moreover, such work may also help stroke survivors with communication difficulties to reengage in meaningful activities in spite of their communication difficulties.

It is important to recognise the work undertaken by charitable organisations in the community setting which also aims to facilitate confidence in communication and the management of such difficulties in the longer-term. For example, community based conversation partner schemes aim to facilitate access to one to one conversation for stroke survivors with aphasia (McVicker et al., 2008). Such schemes are advantageous in reaching those who may be unable to attend community aphasia groups due to the severity of their aphasia, transport problems or those who are elderly, frail or living in care home settings. The aim of such support is to bring conversation to those who, due to their aphasia, may have difficulty accessing or sustaining social networks. Similarly, community aphasia groups and volunteering opportunities may also be available in some areas (Pearl, Sage and Young, 2011). The work of such organisations is a valuable resource. However, the findings of the fieldwork suggest there may be barriers to accessing such services including awareness, confidence and the communication impairment itself. For example, accessing a community aphasia group may require the stroke survivor to have access to the internet or use the telephone to contact the organiser which may be problematic for someone with language impairments. Similarly, attending such a group may require confidence which may need to be built up gradually in stages. The role of the self-management approach may be to signpost to services within the community setting and provide active support for stroke survivors with communication difficulties to access these; for example, by offering graded

support for a stroke survivor wishing to attend a community aphasia group or engage with volunteering opportunities (Pearl, Sage and Young, 2011). Such organisations are likely to play a valuable role in providing ongoing support in the longer-term.

Hewitt and Byng (2003) suggest that services should strive to create opportunities where stroke survivors with aphasia are not only able to participate, but are also given the opportunity to be and feel valued. Byng and Duchan (2005) suggest that a key way in which to promote engagement and a sense of control amongst stroke survivors with communication difficulties is to discuss clearly which options are available (and what these options offer) and which options are not available. The extent to which this is currently systematically and routinely performed within or at the point of discharge from rehabilitation services is unclear; and may vary depending upon the time and resources available within a given service. Some stroke survivors and carers who took part in the fieldwork suggested they had struggled to navigate support services alone and that there was an element of chance or good fortune in the way in which they had found out about these. For those who may be less ready to engage with a self-management approach, or those who wish to continue working to improve their speech and language, this may mean a clear discussion about services which are available and are not available. For example, further provision of speech and language therapy within the NHS may not be possible, however, computer mediated therapy may be possible (Speak with IT, 2018). Access to this might be facilitated in parallel to other areas of support within the self-management approach (such as support to reengage with meaningful activity).

To support the practise of AAC strategies or communication within meaningful contexts it may also be necessary to recruit family members as 'co-managers' (Satink et al., 2015b). The fieldwork findings suggested that SLTs struggled to involve families in speech and language therapy; however, families were the largest source of support for stroke survivors with communication difficulties and may be vital in aiding the stroke survivor to manage their communication difficulty in the longer-term. Recruiting family members as 'co-managers' also highlights how the term 'self'-management should be extended to encompass those supporting the stroke survivor. The third way in which a self-management approach should be adapted is to recognise the importance of the role of family members in enabling self-management. The complex problems that stroke survivors with communication difficulties face highlight that in many cases it

might not be possible for self-management to occur without support and input from others (either healthcare professionals or family and friends).

The findings of the fieldwork suggested that carers often played a key role in the development of strategies to manage communication and in supporting their family member in communicating outside of the home. Although the development of such strategies may occur naturally within some families, others may need additional support. This may necessitate the family member receiving training in strategies they can use to support the stroke survivor with their communication (Simmons-Mackie et al., 2010). Findings from the current fieldwork suggest that although SLTs recognised the importance of conversation partner training in theory; in practice there were a number of barriers to this and training was not provided consistently within or across services. Delivering this type of training as part of a self-management intervention may provide a more structured approach to providing communication partner training and facilitate the involvement of family members in rehabilitation. As discussed previously, the practise of such strategies in different contexts may be important in finding out which strategies might be useful and in the carer developing confidence in their ability to support the stroke survivor. The findings of the fieldwork suggested there was often substantial shift in the dynamic of the relationship between stroke survivors with communication difficulties and their family members. Sustaining relationships in the face of communication difficulties may be challenging (Grawberg et al., 2013). Including and valuing the input of family members within a self-management approach is important for supporting both parties in their efforts to adapt and adjust to the difficulties faced.

The fourth way in which a self-management approach should be adapted is that the term 'self-management' should not be used dichotomously and self-management should be considered as a continuum upon which stroke survivors with communication difficulties (and their families) should be supported to manage as far as possible (Satink et al., 2015a). As highlighted above it may not be possible for stroke survivors with communication difficulties to manage without support from others. However, by considering self-management as a continuum, those with more severe communication difficulties or co-occurring cognitive deficits (and their families) can also be supported to manage the consequences of post-stroke communication difficulties and will not be excluded from self-management interventions.

Finally, it is important to state that the findings of the fieldwork suggest that stroke and communication difficulties are not experienced as a disruptive event for all. Therefore the extent to which stroke survivors with communication difficulties need to be supported to manage their difficulties will vary. A self-management intervention for stroke survivors with communication difficulties should be flexible in order to accommodate varying levels and types of need (for example, depending upon the level of communication difficulty or co-occurring cognitive problems). A discussion about areas which the stroke survivor with communication difficulties feels they are managing well with and areas they are managing less well with should be incorporated (accessible, aphasia friendly materials and prompts may be required to facilitate this process). As highlighted in Section 7.2, stroke survivors with communication difficulties and their family members undertake considerable work in adapting, adjusting and managing. A key role of a self-management intervention would be to understand, support and build upon this work so that stroke survivors with communication difficulties feel confident about their ability to manage at the point of discharge from community rehabilitation services and moving forwards (Jones et al., 2017).

7.7. Conclusions

Stroke survivors with communication difficulties should be better supported to manage the consequences of their condition in the longer-term. A self-management approach may help to support this population to adjust and manage in the longer-term (Lorig and Holman, 2003); however, the intervention must be adapted to address the specific challenges faced by those with post-stroke communication difficulties. Further work is needed to design a self-management intervention for stroke survivors with communication difficulties and their families. In the next chapter, a theoretical framework of behaviour change is used to inform the design of a self-management intervention.

Section Three:

Intervention design

Chapter Eight: Complex intervention development

This chapter outlines how the research reported in Chapters One to Seven is used in conjunction with a theoretical framework of behaviour change to inform the design of a self-management intervention for stroke survivors with communication difficulties.

8.1. Introduction

The Background Chapter outlined how this project is guided by the MRC (2008) framework for the development of complex interventions. There are three sub-components of the Development Phase; 1) Identifying the evidence base, 2) Identifying and developing theory and 3) Modelling processes and outcomes. So far, the author has identified the evidence base by conducting a mixed methods systematic literature review (Chapters One to Three). Due to gaps in the evidence base, further primary research (fieldwork) was undertaken to develop an in-depth understanding of stroke survivors with communication difficulties requirements for longer-term care (Chapters Four to Seven). The findings from the fieldwork were used to develop a rationale for taking a self-management approach. The second sub-component of intervention development is to design the intervention based upon relevant theory (MRC, 2008). In conjunction with the research reported previously in this thesis, a theoretical framework (the Behaviour Change Wheel) (Michie et al., 2014; Michie et al., 2011) is used to inform the design of a self-management intervention for stroke survivors with communication difficulties.

8.2. Identifying and developing theory

MRC (2008) guidance places a strong emphasis on the importance of theory in relation to intervention development. A theory is commonly known as a system of ideas which helps to explain a particular observation or set of phenomena. A comprehensive definition of theory is provided by Glanz and Rimer (2005):

“A theory presents a systematic way of understanding events or situations. It is a set of concepts, definitions, and propositions that

explain or predict these events or situations by illustrating the relationships between variables.” (p.4)

Those advocating the use of theory in complex intervention development suggest theory helps create understanding of the ‘bigger picture’ of how an intervention works (Michie and Prestwich, 2010). By specifying the techniques which are thought to bring about change, researchers can make reasoned accounts of why an intervention may be effective or ineffective. This enables interventions to be refined and strengthened, and also replicated in different contexts and populations with a better likelihood of success. A systematic review by Webb et al. (2010) identified studies which had used the internet to promote health behaviour change. Such interventions generally had a small effect upon health outcomes, however, using meta-regression the authors found that theory based interventions had increased effect sizes. Other similar reviews have also emphasised the importance of theoretically based intervention components upon overall effectiveness (Michie et al., 2009; Marie et al., 2013), although not all have found evidence to support the use of theory (Prestwich et al., 2014).

The MRC framework has faced criticism with regards to its lack of detail on how theory should be chosen or linked to intervention development (Michie et al., 2011). A narrative review by Michie and Abraham (2004) concluded that many complex interventions were ‘inspired’ by theory, using it as a loose framework, rather than a robust method to develop an intervention (Michie and Prestwich, 2010). In the wider literature, studies using theory often fail to report the components of an intervention hypothesised to facilitate change which creates difficulty identifying the ‘active’ ingredients of successful interventions (Michie and Prestwich, 2010). For example, in a systematic review of behaviour change interventions for obese adults, Dombrowski et al. (2010) were able to determine that such interventions were effective. However, the authors could not provide evidence favouring the use of one method over another, i.e. the specific intervention components which worked to change behaviour. Therefore, despite the large volume of work conducted, recommendations for the content of future interventions could not be made, limiting advances in the field (Dombrowski et al., 2007).

In addition to this, MRC guidance fails to specify how one theory should be chosen over another, stating only that:

“There may be lots of competing or partly overlapping theories, and finding the most appropriate ones will require expertise in the relevant disciplines.” (MRC, 2008) (p.9).

Many health behaviour theories have been developed for example, the health belief model (Becker, 1974), social cognitive theory (Bandura, 1986), the theory of planned behaviour (Ajzen, 1991), the theory of reasoned action (Fishbein and Ajzen, 1975) and the transtheoretical model (Prochaska and Velicer, 1997). Literature has accumulated to support or refute various aspects of each theory (Noar and Zimmerman, 2005). However, more recently researchers have begun to recognise that many of the theories contain constructs which overlap. Noar and Zimmerman (2005) showed how, for example, the construct of attitudinal beliefs (appraisal of the positive and negative aspects of the behaviour and expected outcome of the behaviour) can be found in the health belief model (termed benefits, barriers, health motivators), the theory of reasoned action (termed behavioural beliefs and evaluation of those beliefs), social cognitive theory (termed outcome expectations/expectancies), and in the transtheoretical model (termed pros, cons, decisional balance). Noar and Zimmerman (2005) argue that recognising the similarities between theories can lead to a cumulative knowledge about health behaviour, as opposed to a literature fragmented by the use of different terminology. Michie and Johnston (2012) also argue for developing a “cumulative science of behaviour change” whereby:

“Researchers have access to a definitive set of theoretical explanations of behaviour change and a means of identifying which are relevant to particular contexts” (Michie et al., 2005) (p. 26).

In order to address this gap in the research, Michie and colleagues developed the Behaviour Change Wheel (Michie et al., 2011; Michie et al., 2014); a comprehensive theory based framework for developing complex behaviour change interventions.

8.3. The behaviour change wheel

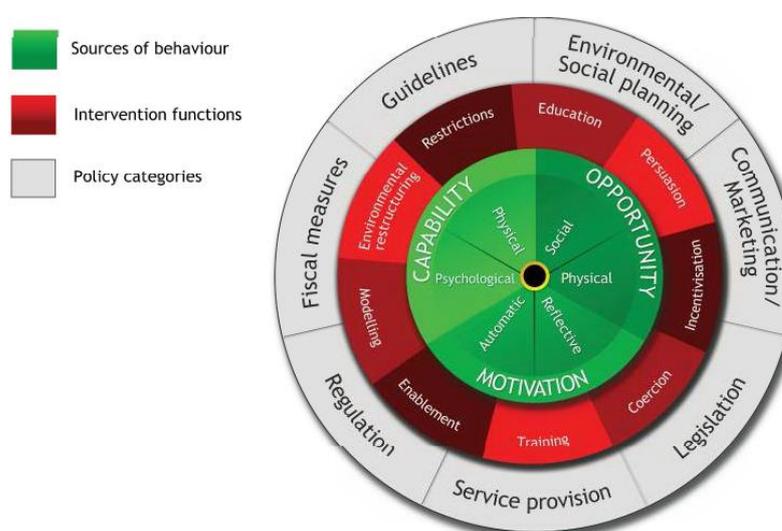
Michie et al. (2011) define behaviour change interventions as “co-ordinated sets of activities designed to change specified behaviour patterns” (p.1). The Behaviour Change Wheel (BCW) was developed to address the weaknesses in the MRC framework outlined above and creates a comprehensive theory based framework for developing a complex behaviour change intervention (Michie et al., 2014). In order to develop the BCW, Michie et al. (2011) conducted a systematic review of other

behaviour change frameworks. Based on the literature, they developed three criteria in order to assess the usefulness of the frameworks identified;

- 1) Comprehensive coverage: The framework must apply to all behaviour change interventions
- 2) Coherence: Categories within the framework must contain concepts of the same type
- 3) Links to an overarching model of behaviour

The review identified 19 existing frameworks for the development of complex behaviour change interventions. None met all the pre-specified usefulness criteria; however, information from the frameworks was synthesised and used to create the three layers of the BCW (sources of behaviour, intervention functions and policy categories). A graphical representation of the BCW is shown in Figure 11.

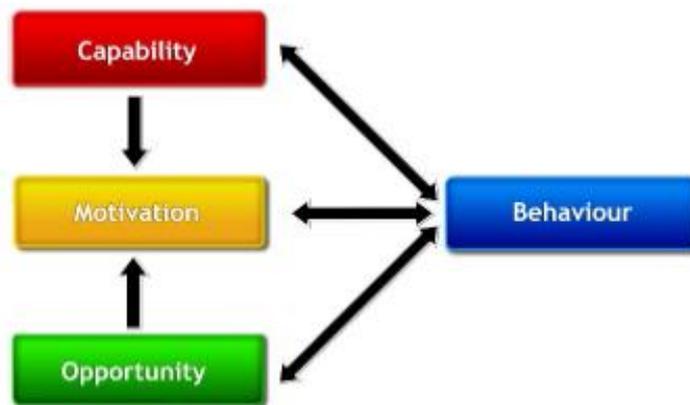
Figure 11: The Behaviour Change Wheel (Michie et al., 2011; Michie et al., 2014)



At the centre of the BCW is the overarching model of behaviour change; the Capability Opportunity Motivation-Behaviour (COM-B) model. In order for behaviour to occur, Michie et al. (2011) propose that three criteria must be met. Firstly, the person must have the capability to perform the behaviour defined as ‘the individual’s psychological and physical capacity to engage in the activity concerned. It includes having the necessary knowledge and skills.’ (p.4). Secondly, the person must have motivation defined as ‘brain processes that energize and direct behaviour, not just goals and

conscious decision making. It includes habitual processes, emotional responding as well as analytical decision making.’ (p.4). Finally, the person must have opportunity defined as ‘all factors that lie outside the individual that make the behaviour possible or prompt it.’ (p.4). The COM-B model is outlined in Figure 12. The arrows demonstrate how each of the components may interact to influence behaviour.

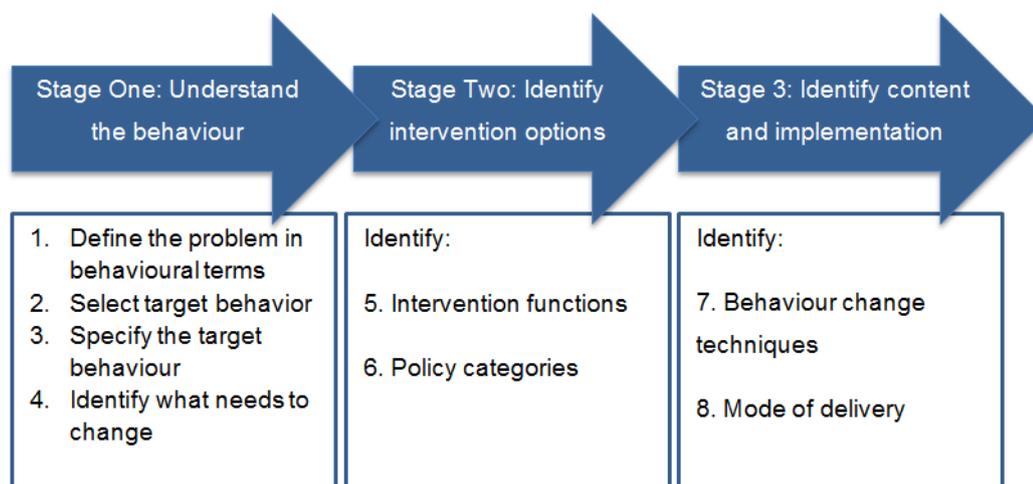
Figure 12: The COM-B model of behaviour (Michie et al., 2011; Michie et al., 2014)



Michie et al. also distinguish different subtypes of capability, motivation and opportunity (Michie et al., 2011; Michie et al., 2014). For example, capability is subdivided into physical capability and psychological capability. Physical capability refers to the individual’s physical skills to engage in a behaviour and psychological capability refers to the individual having the knowledge or capacity to engage in the necessary thought processes to engage in a behaviour. Opportunity is subdivided into physical and social opportunity. Physical opportunity is the opportunity available by the environment and social opportunity is the opportunity available which is afforded by the social environment (i.e. social cues or cultural norms). Finally, motivation is subdivided into reflective motivation and automatic motivation. Reflective motivation is a mental process which involves planning (a conscious intention) and evaluation (reflection about what is good and bad) , and, automatic motivation is a mental process which is driven by emotion (desires, wants and needs) and impulse decisions about engaging in a behaviour which may be driven by associative learning. The intervention may target one or more of the components described in the COM-B model (e.g. capability, opportunity or motivation). The COM-B model provides the basis for intervention development. The BCW guides researchers to choose appropriate intervention components to facilitate behaviour change based upon this model. Michie et al. (2014)

propose three stages of intervention development which are outlined shown in Figure 13.

Figure 13: Behaviour change intervention design process (Michie et al., 2014)



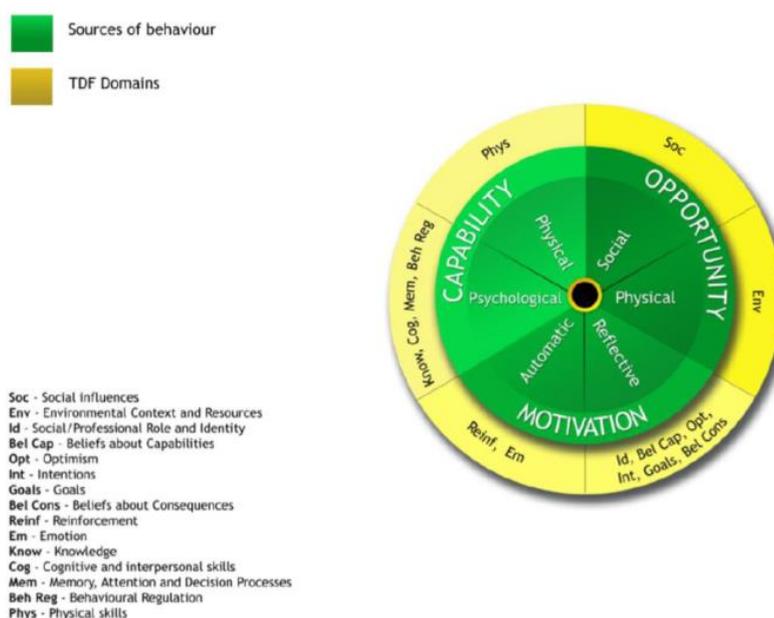
In Stage One, the COM-B model is used to define the problem in behavioural terms. Target behaviours are identified by generating a list of all behaviours which may be relevant to the problem and then prioritising those of most importance. Once the behavioural target has been specified, the behaviour is described in detail (who, what, when, where, how often, with whom) and then in terms of the COM-B model. Areas missing from the COM-B model highlight the changes needed in order for the target behaviour to occur. For example, if the behaviour is obtaining information about stroke, the survivor may be motivated to obtain the information and may have the capability; however, the opportunity to obtain such information may be lacking due to a lack of accessible information, or lack of prompts to request information from healthcare professionals. In this case the intervention would focus upon optimising opportunity.

Michie et al. (2014) propose that the Theoretical Domains Framework (TDF) (French et al., 2012; Cane et al., 2012; Michie et al., 2005) may also be used to aid the 'behavioural diagnosis' in Stage One. The TDF was originally developed to bridge the gap between evidence and practice by encouraging the use of behaviour change techniques in implementation research. The framework aimed to make psychological theories more accessible by creating a simplified classification of theoretical constructs related to behaviour change (Michie et al., 2005). One hundred and twelve Theoretical Constructs (e.g. Action Planning, Illness Representations, Incentives, Perceived

Behaviour Control) were sorted in to 14 Theoretical Domains using an expert consensus method (Cane et al., 2012). The Domains were: Knowledge, Skills, Social/professional role and identity, Beliefs About Capabilities, Optimism, Beliefs About Consequences, Reinforcement, Intentions, Goals, Memory Attention and Decision Processes, Environmental Context and Resources, Social Influences, Emotion, and Behavioural Regulation. The TDF has been used to identify implementation problems and design corresponding interventions in a number of different settings including; acute low back pain management in primary care (French et al., 2012), appropriate prescribing in older hospitalised patients (Cullinan et al., 2015), and in identifying influences on decisions to take up the offer of a health check (Burgess et al., 2015).

Michie et al. (2014) suggest the theoretically derived constructs of the TDF can also be used to elaborate upon the COM-B model (see Figure 14). Figure 14 demonstrates how the TDF can be utilised as an additional layer of the BCW. Steinmo et al. (2015) use the COM-B and TDF domains to propose theoretical 'mechanisms of action' to hypothesise how the intervention has an effect. Steinmo et al. (2015) developed an intervention to facilitate the implementation of the 'sepsis six' care bundle. As part of the intervention, a sepsis six poster was to be placed around wards. The function of the intervention was environmental restructuring and this was achieved by maximising psychological capability and physical opportunity (COM-B model). Elaborating using the TDF, Steinmo et al. (2015) described memory, attentional, decision processes and environmental context and resources as mechanisms of action. Utilising the TDF may be important in developing well defined and reported complex behaviour change interventions with theoretically based mechanisms of action (Michie et al., 2013). However, Michie et al. (2014) describe the use of the TDF as an 'optional step' which researchers may or may not decide to utilise.

Figure 14: TDF linked to the COM-B model of behaviour (Michie et al., 2014)



In Stage Two of development using the BCW, intervention options to address the changes required are identified using the intervention functions in the middle of the BCW (Figure 11). Michie et al. (2014) provide a matrix of links between the COM-B model and intervention functions. For example, if trying to influence opportunity; intervention functions associated with this are environmental restructuring (changing physical or social context), modelling (providing an example for people to aspire to) and enablement (increasing resources, reducing barriers). Michie et al. (2014) also provide a matrix of links between the COM-B, TDF and intervention functions if the TDF has been used at the previous stage. Also to be considered at this stage is policy context and any policies which would support or hinder the delivery of the intervention. Policy categories are identified on the outer circle of the BCW and can be linked to the intervention functions identified previously using a guide developed by Michie et al. (2014). For example, policy functions associated with environmental restructuring are guidelines, fiscal measures, regulation, legislation and environmental/social planning.

In Stage Three, researchers are guided to identify appropriate behaviour change techniques (BCTs) defined by Michie et al. (2013) as:

“An observable, replicable and irreducible component of an intervention designed to alter or redirect causal processes that regulate behaviour...” (p.82)

Or otherwise known as the 'active ingredients' of an intervention. Through expert consensus, Michie et al. (2014) linked the intervention functions described in the BCW to established BCTs. For example, if the intervention function is education, the most frequently used BCTs associated with this function are information about health consequences, information about social and environmental consequences, feedback on behaviour, self-monitoring of behaviour. The TDF has also been linked to BCTs using a consensus method (Cane et al., 2015).

The final step towards developing an intervention is identifying the mode of delivery (Michie et al., 2014). When selecting modes of delivery Michie et al. (2014) recommend that researchers use the APEASE criteria to guide their selection. The APEASE criteria are: Affordability, Practicability, Effectiveness and cost-effectiveness, Acceptability, Side-effects/safety and Equity. Affordability is a criterion to consider whether a service has the means to fund the intervention within its budget. Practicability is the extent to which an intervention could be delivered as intended within the constraints of an existing service. Effectiveness and cost-effectiveness criteria propose that if two interventions are equally effective, researchers should take into account the most cost-effective option. Acceptability is to consider if an intervention is appropriate for the population targeted; side-effects/safety should also be considered when deciding a mode of delivery. The final criterion is to consider if the mode of delivery would increase inequalities between different social groups (equity).

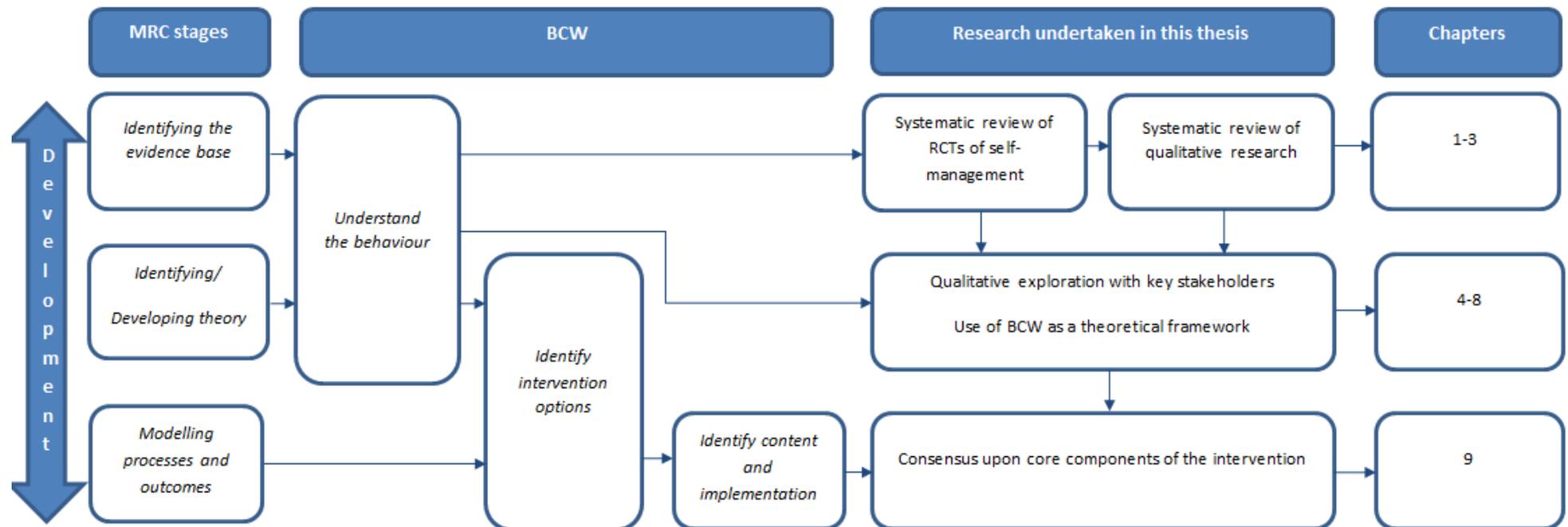
In this PhD study, the BCW is used to inform the development of a theory based self-management intervention. In Chapter One, a significant proportion of the interventions were based upon work by Lorig et al. (2001). The creators of the CDSMP acknowledge that much of their early work was atheoretical, based upon their intuition and experience in clinical practice (Lorig and Holman, 2003). More recently, work conducted by the team has been linked to self-efficacy theory (Bandura, 1977). However, it is unclear precisely how the intervention was developed and a criticism of this work is the seemingly *a priori* linkage to self-efficacy theory. There appears to be no clearly stated reason as to why this theory was chosen and why particular BCTs were chosen in relation to self-efficacy theory. The use of the BCW in this PhD study provides a clear link between an underpinning theory of behaviour and intervention components. Clearly stating this information is important in adding to our understanding of the 'active' ingredients of self-management interventions so that they may be replicated or refined in the future (Michie and Prestwich, 2010).

The BCW also allows the consideration of a wide range of theory based BCTs (Michie et al., 2014). As part of the systematic review conducted in Chapter One, a range of theoretical rationales underpinning the self-management interventions identified were specified including social cognitive theory, theory of planned behaviour, control cognitions theory etc. In considering the development of a self-management intervention, there seems to be no clear logic for picking one theory to base a self-management intervention upon over another, and by limiting intervention design to one theory and corresponding BCTs, the full range of options may not be fully considered. The BCW encourages the researcher to consider a wide range of techniques and options based upon a systematic evaluation of theory and evidence (Michie et al., 2014).

8.4. Designing a self-management intervention using the BCW

In this project, the BCW is used in conjunction with the MRC (2008) guidance. Figure 15 shows how the BCW can be mapped to the MRC (2008) guidance and in relation to the research undertaken in this thesis.

Figure 15: How the MRC guidance and the BCW mapped to the research undertaken in this thesis



Stage One: Understand the behaviour

The first stage of intervention development according to the BCW is to understand the behaviour. Michie et al. (2014) advise researchers to firstly consider what the behaviour is, where the behaviour occurs and who is involved in performing the behaviour. This initial step is a short statement to help researchers focus upon the problem at hand.

- What behaviour: Self-management
- Where does the behaviour occur: Self-management occurs on a daily basis either in or outside the stroke survivor's home environment.
- Who is involved in performing the behaviour: The stroke survivor themselves or with help from their family member or other member of their social network including healthcare professionals.

The next step is to create a list of behaviours which may lead to addressing the problem (Michie et al., 2014). The behaviours must be as specific as possible, for example, if one wished to target obesity, the behavioural target would need to be more specific than 'weight loss' or 'increasing physical activity'. More specific behavioural targets may include 'walking 10 000 steps each day' or 'cycling to and from work' (Michie et al., 2014). Self-management is the overall target for intervention in this study, however, in order to obtain a target behaviour it was necessary to consider a range of more specific behaviours which may lead to self-management. Michie et al. (2014) describe this as a system of behaviours as behaviours generally do not occur in isolation, but within the context of other behaviours (performed by the individual or by others), which may interact with one another.

Relevant behaviours were identified through reviewing the needs of stroke survivors with communication difficulties which were identified in Chapter Two and in the findings of the fieldwork in Chapters Five and Six. The existing self-management interventions identified in Chapter One were also reviewed in order to identify behaviours which may be relevant to the overall target of self-management. The findings of the literature review and fieldwork highlight the variation in the level of self-management stroke survivors with communication difficulties may be able to achieve. It was, therefore, considered necessary for the intervention to target a range of behaviours which might enable a level of self-management which is appropriate to the needs of the individual and their family. Five candidate behaviours were identified and are described below.

1. Communicating outside of the home

Identifying opportunities to communicate outside of the home and being supported to participate in the opportunities identified.

2. Participating in meaningful activity

Participating in meaningful activity which may relate to activities which were previously enjoyed prior to stroke or new activities.

3. Seeking and maintaining social support

Engaging with social network in order to obtain practical or emotional support.

4. Obtaining information about stroke and communication disability

Obtaining information about stroke and communication disability which is accessible and increases knowledge, reduces uncertainty or addresses unanswered questions.

5. Forming a partnership with healthcare providers

Identifying opportunities to form a partnership with healthcare providers in order to obtain appropriate support when needed.

The list of behaviours was not considered to be exhaustive and the behaviours were prioritised as those which the author considered to be most promising as targets for intervention, based upon the literature reviewed, and findings of the fieldwork conducted. Michie et al. (2014) suggest limiting the number of behaviours to be targeted by the intervention, and suggest that researchers use their own (informed) judgement to undertake this process. In this project, the candidate behaviours were also discussed with the author's supervisors and at a peer review group at the Academic Unit of Elderly Care and Rehabilitation. Once the behavioural targets were identified, they were then subject to more precise behavioural specifications (Table 14).

Table 14: Self-management defined by more precise behavioural specifications

Target behaviour	Behavioural specifications			
	What	Who	Where	When
Communicating outside of the home	Using speech and language (or alternative communication strategies).	Stroke survivor (with help or support from facilitator or family member).	An environment outside of the home e.g. shops, restaurants, healthcare settings.	Following hospital discharge
Participating in meaningful activity	Participating in meaningful activity. Meaningful activity will vary according to the individual, for example, it may include hobbies, routines, or housework.	Stroke survivor (with help or support from facilitator or family member).	Any environment (meaningful activity may be inside or outside of the home).	Following hospital discharge
Seeking and maintaining social support	Seeking or maintaining social contact with friends or family.	Stroke survivor (with help or support from facilitator or family member).	Any environment (inside or outside of the home).	Following hospital discharge
Obtaining information about stroke and communication disability	Seeking or being provided with accessible information about stroke and communication disability.	Stroke survivor (with help or support from facilitator or family member).	Any environment.	Any time
Forming a relationship with healthcare providers	Seeking opportunities to form a partnership in order to obtain ongoing support.	Stroke survivor and healthcare provider (with help or support from facilitator or family member).	Healthcare setting (e.g. GP practice, community stroke team).	Any time

Each of the behavioural targets was subject to more in-depth analysis using the COM-B model. This stage is designed to elucidate what might need to change in order for the target behaviours to occur (Michie et al., 2014). The decision was taken to use the TDF in order to gain a more detailed understanding of the behaviours and to identify theoretical mechanisms of action for the proposed intervention (Steinmo et al., 2015; Michie et al., 2014). Each behavioural target is considered with regards to the COM-B model in order to evaluate what capabilities, opportunities or motivation may be required in order for the target behaviour to occur. This process was undertaken for each of the five behavioural targets. An example of the behavioural analysis undertaken is provided in Table 15 for the target of communicating outside of the home.

The behavioural analysis suggests that changes may be needed in the following areas in order for stroke survivors with communication difficulties to communicate outside of the home:

- **Psychological capability:** Individuals may lack knowledge about AAC strategies they could use to compensate for their speech and language impairments. Those with severe aphasia or co-occurring cognitive or memory difficulties may need additional support or prompting to use alternative strategies within an appropriate context.
- **Physical opportunity:** It may be difficult for individuals with co-occurring mobility difficulties e.g. right hemiplegia to leave the home environment, for example, due to difficulties with accessing public transport. Other co-occurring difficulties may also limit ability to leave the home environment e.g. incontinence, dysphagia, visual impairments, fatigue, pain. Physical difficulties may also impact upon ability to communicate outside of the home; for example, ability to write or use gesture as an alternative means of communication may be influenced by the presence of hemiplegia or visual impairments.
- **Social opportunity:** Individuals may have difficulty engaging with others outside of the home environment due to a lack of public awareness about communication difficulties. Those that the individual chooses to communicate with may not know how to support their communication.
- **Reflective motivation:** The individual may lack confidence in their ability to communicate outside of the home environment or may believe that their attempts to communicate would be unsuccessful.

- Automatic motivation: Previous experience of communicating outside of the home may have been associated with a negative outcome. Anticipation of communication outside of the home may automatically cause feelings of fear, stress or anxiety.

Table 15: An example of a behavioural diagnosis for the target behaviour of communication outside of the home

Communicating outside of the home			
COM-B components	TDF	What needs to happen for the target behaviour to occur?	Is there a need for change?
Physical capability	Physical skills	N/A	✘
Psychological capability	Knowledge	Knowledge of alternative and augmentative communication (AAC) strategies.	✓
	Cognitive and interpersonal skills	Has sufficient linguistic and cognitive ability to engage in conversation.	?
	Memory, attention and decision processes	Has sufficient memory or attention to engage in conversation or have support to be prompted.	?
	Behavioural regulation	Be able to monitor speech and language output and adjust communication strategies if necessary.	✓
Physical opportunity	Environmental context and resources	Seek opportunities for communication outside of the home. May need to overcome physical barriers.	✓
Social opportunity	Social influences	Social opportunities must be accessible i.e. conversation partner must engage with stroke survivor.	✓
Reflective motivation	Social role and identity	N/A	✘
	Beliefs about capabilities	Stroke survivor has confidence in their communicative ability.	✓
	Optimism	Being optimistic about being able to communicate outside the home.	✓
	Beliefs about consequences	Belief that communication outside of the home will lead to successful interaction or be resilient if a communication attempt is unsuccessful.	✓
	Intentions	Stroke survivor makes a conscious decision to communicate outside of the home i.e. not driven by others.	?
	Goals	Stroke survivor wishes to achieve the goal of communicating outside of the home.	?
Automatic motivation	Reinforcement	Communicating outside of the home is associated with a positive outcome.	✓
	Emotion	Overcomes emotion associated with communicating outside of the home e.g. fear, stress, anxiety.	✓
Behavioural diagnosis of the relevant COM-B components:	In order to promote communication outside of the home, changes required in psychological capability, physical opportunity, social opportunity, reflective motivation and automatic motivation.		

[Key: ✓ Yes ✘ No ? Unclear N/A: not applicable]

One limitation of the COM-B model during this stage was its ability to capture each individual factor which may account for the occurrence of a particular behaviour. For each stroke survivor with a communication difficulty, a different COM-B model could be created to capture the factors which may influence their ability to communicate outside of the home. For example, Table 15 suggests that knowledge of AAC strategies may influence capability to communicate outside of the home. However, this does not take into consideration the stroke survivor's preference about using such strategies (including their choice not to use them). Although I attempted to account for as much variation as possible, given the heterogeneity of difficulties faced by stroke survivors with communication difficulties, it was difficult within this model to capture the entire range of possibilities. For example, due to their receptive impairments, it may be difficult for someone with Wernicke's aphasia to self-monitor and recognise errors in their spoken language and make adjustments to this; however, this may be possible for someone with Broca's aphasia (Potagas, Kasselimis and Evdokimidis, 2017). Stroke survivors with motor speech disorders (for example, dysarthria or apraxia of speech) may retain the cognitive and linguistic abilities to engage in conversation, however, may be restricted in their ability to convey speech which may impact upon their ability to communicate. It is important to acknowledge that the type and severity of communication difficulty will also impact upon self-management behaviours like communicating outside of the home.

A similar but related difficulty was capturing linguistic capability within the COM-B model. Whilst linguistic ability may fit within the overall category of capability, referring to the definitions provided by Michie et al. (2014) this concept does not seem to be captured fully within the constructs of 'psychological' or 'physical' capability. Some of aspects of linguistic capability fit within the construct of 'psychological capability'; this construct takes account of cognitive functions which may support linguistic processing, for example, memory and attention. However, many stroke survivors with aphasia may have intact memory and attention processes but still struggle with language comprehension and/or production as a result of damage to the language centres of the brain. Linguistic ability is also not a physical skill, although speech production does involve physical processes (e.g. movement of muscles) and these may be affected in the case of dysarthria. A decision was made that linguistic ability fit best within psychological capability as part of the COM-B model, although the limitations of this are recognised. For example, this model does not capture the complexities of when and where a breakdown in language processing may occur for each individual and how this may impact upon their ability to communicate. On the other hand, the focus of the

intervention is not to change linguistic capability but to understand what could be changed to facilitate self-management in spite of residual impairments. Nevertheless, assessments of speech and language are likely to be important in feeding in to the selection of strategies which may be appropriate to support various aspects of self-management.

Another limitation of the COM-B model might be that it places too much emphasis on the individual's behaviour. For example, in Table 15, although others' influence on communication outside of the home is partially captured within social opportunity, this may not fully capture the complexities of supporting a two-way interaction as required outside of the home environment. Success in communicating outside of the home may be dependent upon the skills of the conversation partner in accommodating the stroke survivor's communication difficulties as well as the stroke survivors use of compensatory strategies. Similarly the role of family members in supporting communication outside of the home may also be underplayed in this model. There may be significant overlap between the two behaviours of 'communicating outside of the home' and 'seeking and maintaining social support'. For example, maintaining social relationships may be influenced by ability to communicate outside of the home (e.g. meeting existing friends or developing new relationships) and communicating outside of the home may be influenced by availability of social support from friends or family. The findings of the fieldwork also suggest that developing and sustaining social relationships in spite of communication difficulties (e.g. the sharing of experience, closeness or togetherness) is a shared and reciprocal experience. This is not well accounted for within the individually focused COM-B model of behaviour.

Finally, the COM-B model links reflective motivation with the social role and identity domain of the TDF. Michie et al. (2014) define social role and identity as influences to take action based upon being a member of a collective group (e.g. staff believing it is their role to implement hygiene protocols). This was seen to be a less relevant influence on stroke survivors' behaviour during the behavioural diagnosis as they may not belong to a collective group with a strong identity in the same way as members of staff do. However, the findings of the fieldwork did suggest that self-identity may have an important role in the way in which stroke survivors manage their condition (Bury, 1982; Charmaz, 1983). For example, those who struggle to accept their communication difficulties may be less motivated to communicate outside of the home than those who do not. The disruption to social roles and self-identity inherent in post-stroke

communication difficulties (and the influence on subsequent behaviour) may not be adequately captured within the COM-B model under the current definition of social role and identity.

Stage Two: Identify intervention options

The behavioural diagnosis in Stage One identified areas within the COM-B model which could be altered in order for the target behaviour to occur. In Stage Two of intervention design, principles to create behaviour change are identified which are known as intervention functions. Intervention functions are designed to address the deficits identified by the COM-B model which act as a barrier to the behaviour occurring (Michie et al., 2014; Michie et al., 2011). Intervention functions are broad categories which may be targeted by a behaviour change intervention and are identified before being linked to more specific BCTs (Michie et al., 2014; Michie et al., 2011). The BCW proposes a total of nine intervention functions which are defined in Table 16. Michie et al. (2014) provide a matrix which links the missing components of the COM-B model and TDF with corresponding intervention functions which may address the deficit. In this study, seven potential intervention functions were identified across the behavioural targets which included: Education, Training, Modelling, Enablement, Environmental Restructuring, Persuasion and Incentivisation.

At Stage Two Michie et al. (2014) also recommend that relevant policy is identified to understand if any policies exist which would support or hinder the delivery of the intervention. Policy categories include communication/marketing, guidelines, fiscal measures, regulation, legislation, environmental/social planning and service provision. Definitions of Policy functions according to the BCW are provided in Table 16. Two policy functions were identified which may facilitate the implementation of a self-management approach for stroke survivors with communication difficulties and are applicable across the five behavioural targets identified. The first are guidelines; supportive policy guidelines include those which recommend a self-management approach for all stroke survivors in clinical guidance (Intercollegiate Stroke Working Party, 2016) and as part of the National Stroke Strategy (Department of Health, 2007). Self-management is also at the core of a number of health policy initiatives, for example, the House of Care model (NHS England, 2017), the Self-Care Forum (Self-Care Forum, 2017) and 'Guan Yersel' (Long Term Conditions Alliance and the Scottish Government, 2008). Furthermore, NHS commissioning boards have been mandated by the Department of Health to ensure that patients with long-term conditions are

supported and encouraged to manage their own health and are educated in necessary skills and competencies to do so (Department of Health, 2013). The second policy category identified is service provision; although the policy documents are supportive, the delivery of a self-management intervention as part of the stroke service (either NHS, social services or voluntary sector services) is the only practicable way in which the relevant behaviour targets can be modified. Other policy options, e.g. a mass marketing campaign or legislation were not considered to be practical due to the complexity of the target population and level of individual tailoring required to facilitate self-management.

Table 16: Definitions of intervention and policy functions included in the BCW (Michie et al., 2014 p.111 and p.135)

Intervention function	Definition
Education	Increasing knowledge or understanding
Persuasion	Using communication to induce positive or negative feelings or stimulate action
Incentivisation	Creating an expectation of reward
Coercion	Creating an expectation of punishment or cost
Training	Imparting skills
Restriction	Using rules to reduce the opportunity to engage in the target behaviour (or to increase the target behaviour by reducing the opportunity to engage in competing behaviours)
Environmental restructuring	Changing the physical or social context
Modelling	Providing an example for people to aspire to
Enablement	Increasing means/reducing barriers to increase capability (beyond education and training) or opportunity (beyond environmental restructuring)
Policy function	Definition
Communication/marketing	Using print, electronic, telephonic or broadcast media
Guidelines	Creating documents that recommend or mandate practice. This includes all changes to service provision.
Fiscal measures	Using the tax system to reduce or increase the financial cost
Regulation	Establishing rules or principles of behaviour or practice
Legislation	Making or changing laws
Environmental/social planning	Designing and/or controlling the physical or social environment
Service provision	Delivering a service

Stage Three: Identify content and implementation

In Stage Three, intervention functions are linked to specific BCTs which may facilitate the delivery of the aforementioned intervention functions. Michie et al. (2014) provide a matrix of links between intervention functions and commonly used BCTs. The matrix was developed following an extensive review of the literature and using an expert consensus to sort the BCTs in to groups (Cane et al., 2015; Michie et al., 2013). Michie et al. (2014) suggest that researchers consider all BCTs in relation to a particular intervention function; however, they should use their own judgement to decide which are most appropriate for the situation in which the intervention is intended. Table 17 shows how the design of the intervention progressed from Stage Two to Stage Three for each behavioural target. Possible modes of delivery are also considered at this stage of intervention development.

Table 17: Description of the steps used to identify BCTs and modes of delivery based upon the behavioural diagnosis

Behavioural target	Behavioural diagnosis from the COM-B model	Intervention functions	BCTs	Possible mode of delivery
Communicating outside of the home	Psychological capability	Education, Training, Modelling, Enablement	Information, Feedback, Rehearsal, Self-monitoring	<ul style="list-style-type: none"> Information and training in the use of AAC strategies. Rehearsal of AAC strategies. Feedback on the use of AAC strategies. Self-monitoring of AAC use.
	Physical opportunity	Training, Environmental restructuring, Enablement	Goal-setting, Action planning, Graded support	<ul style="list-style-type: none"> Sets goals for communicating outside of the home. Creating an action plan for communicating outside of the home. Graded support to communicate outside of the home.
	Social opportunity	Environmental restructuring, Enablement	Practical social support	<ul style="list-style-type: none"> Supported to obtain social support to assist communication outside of the home (see seeking and maintaining social support target).
	Reflective motivation	Education, Persuasion, Enablement	Self-monitoring, Feedback, Problem solving	<ul style="list-style-type: none"> Self-monitoring of communication and implementation of AAC strategies as necessary. Feedback on behaviour and outcome. Reflection upon problems which may have arisen and how they may be overcome.
	Automatic motivation	Persuasion, Incentivisation, Enablement	Self-monitoring, Review of goals	<ul style="list-style-type: none"> Self-monitoring of participation in communication outside of the home. Review of goals.

Table 17: Description of the steps used to identify BCTs and modes of delivery based upon the behavioural diagnosis (continued)

Behavioural target	Behavioural diagnosis from the COM-B model	Intervention functions	BCTs	Possible mode of delivery
Participating in meaningful activity	Psychological capability	Education, Training, Modelling, Enablement	Information, Action planning, Self-monitoring, Rehearsal	<ul style="list-style-type: none"> Obtains information about relevant activities. Rehearsal of steps needed to participate in meaningful activity. Self-monitoring of outcome of participation in meaningful activity and problems which may have arisen.
	Physical opportunity	Environmental restructuring, Enablement	Goal-setting, Action planning, Graded support	<ul style="list-style-type: none"> Sets goals for participating in meaningful activity. Creating an action plan for participation in meaningful activity. Obtains graded support in order to participate in meaningful activity.
	Social opportunity	Environmental restructuring, Enablement	Practical social support	<ul style="list-style-type: none"> Supported to obtain social support to participate in meaningful activity (if necessary).
	Reflective motivation	Education, Persuasion, Enablement	Verbal persuasion, problem solving	<ul style="list-style-type: none"> Feedback on participation in meaningful activity and encouragement from facilitator about capabilities. Reflection upon problems which may have arisen and how they may be overcome.
	Automatic motivation	Environmental restructuring, Enablement	Self-monitoring, review of goals	<ul style="list-style-type: none"> Provided with prompts/cues to overcome problems when participating in meaningful activity. Review of goals.

Table 17: Description of the steps used to identify BCTs and modes of delivery based upon the behavioural diagnosis (continued)

Behavioural target	Behavioural diagnosis from the COM-B model	Intervention functions	BCTs	Possible mode of delivery
Seeking and maintaining social support	Psychological capability	Education, Enablement	Information provision, Action planning, Rehearsal	<ul style="list-style-type: none"> • Maps out existing social network in order to identify sources of social support. • Makes an action plan with the steps needed to obtain or maintain social support. • Mentally rehearses the steps needed for social interaction.
	Physical opportunity	Environmental restructuring, Enablement	Goal-setting	<ul style="list-style-type: none"> • Sets a goal to seek or maintain social support.
	Social opportunity	Environmental restructuring, Enablement	Training, Feedback	<ul style="list-style-type: none"> • Training in supported conversation techniques provided to those providing social support to the stroke survivor. • Prompts, cues and feedback provided by facilitator to facilitate communication (graded support which decreases with time and practise).
	Reflective motivation	Education, Persuasion, Modelling, Enablement	Verbal persuasion, Problem solving	<ul style="list-style-type: none"> • Support to review behaviour and outcome. • Encouragement from facilitator and reflection upon problems which may have arisen and how they may be overcome.
	Automatic motivation	Persuasion, Enablement, Incentivisation	Self-monitoring, Feedback on behaviour	<ul style="list-style-type: none"> • Facilitator encourages feedback and encouragement from those providing social support.

Table 17: Description of the steps used to identify BCTs and modes of delivery based upon the behavioural diagnosis (continued)

Behavioural target	Behavioural diagnosis from the COM-B model	Intervention functions	BCTs	Possible mode of delivery
Forming a relationship with healthcare providers	Psychological capability	Education, Enablement	Instruction,	<ul style="list-style-type: none"> Facilitator provides information to stroke survivor about when support from healthcare professionals might be needed and who to contact.
	Physical opportunity	Environmental restructuring, Enablement	Goal-setting	<ul style="list-style-type: none"> Sets a goal to form a relationship with healthcare professional.
	Social opportunity	Environmental restructuring, Enablement	Training, Feedback	<ul style="list-style-type: none"> Facilitator provides social support (or stroke survivor obtains social support) to assist the stroke survivor in building a relationship with their healthcare provider.
	Reflective motivation	Education, Enablement	Review of behaviour, problem solving	<ul style="list-style-type: none"> Stroke survivor and facilitator review encounter with healthcare professional and work together to solve problems which may have arisen.
	Automatic motivation	Persuasion, Enablement, Incentivisation	Self-monitoring, Feedback on behaviour	<ul style="list-style-type: none"> Facilitator obtains feedback about relationship from healthcare professional in order to reinforce stroke survivors' motivation to continue partnership.

Table 17: Description of the steps used to identify BCTs and modes of delivery based upon the behavioural diagnosis (continued)

Behavioural target	Behavioural diagnosis from the COM-B model	Intervention functions	BCTs	Possible mode of delivery
Obtaining information about stroke and communication disability	Psychological capability	Education, Enablement	Information, goal-setting	<ul style="list-style-type: none"> • Provided with information or education about appropriate information sources. • Stroke survivor sets a goal for obtaining information about stroke and communication disability.
	Reflective motivation	Enablement	Review, Self-Monitoring	<ul style="list-style-type: none"> • Information is reviewed and facilitator to assess the need for further information.
	Automatic motivation	Training, Enablement	Self-monitoring	<ul style="list-style-type: none"> • Information is satisfactory

Table 17 outlines the possible BCTs and possible modes of delivery the intervention might take. This is not intended to be a prescriptive list of intervention components to be delivered without tailoring to all participants. It is recognised that certain intervention components may not be appropriate for all stroke survivors with communication difficulties. For example, due to their receptive impairments, it may be difficult for stroke survivors with Wernicke's aphasia to self-monitor and recognise errors in their spoken language (and make adjustments to this) (Potagas, Kasselimis and Evdokimidis, 2017). In these cases, more emphasis may be given to maximising social opportunity or support, including drawing upon principles of conversation partner training to support the stroke survivor's communication (Simmons-Mackie et al., 2010). For example, Supporting Partners of People with Aphasia in Relationships and Conversation (SPPARC) is an established approach to conversation partner training (Lock, Wilkinson and Bryan, 2001). This approach provides tailored training for conversation partners in a range of strategies to facilitate or support communication which may include repeating, emphasising or writing key words, using gesture and picking up on cues from the person with aphasia. There are also established approaches for training stroke survivors in the use of compensatory AAC strategies such as Promoting Aphasics' Communicative Effectiveness (Davis, 2005) or the Total Communication Approach (Lawson and Fawcus, 2001). Drawing upon such approaches may help to guide the information and training which is delivered as part of the self-management approach proposed in this thesis. However, the findings from the fieldwork suggest it is important that such information and training is not delivered in a prescriptive fashion but rather as a means of scaffolding to support the stroke survivor with communication difficulties and their family members in the process of learning how to manage (Satink et al., 2016). The findings of the fieldwork also suggest the importance of testing out such strategies in real life situations. This may not only help stroke survivors and their family members to discover whether or not these strategies are helpful but may also help to support the development of novel or spontaneous strategies which are specific to the individual (Simmons-Mackie and Damico, 1995). This is supported within the proposed intervention by BCTs including goal setting, action planning, rehearsal and problem solving which would be tailored and supported by the facilitator of the approach as appropriate.

Table 17 suggests that a common intervention function to be targeted across the behaviours identified is enablement and an appropriate BCT to promote enablement is goal-setting (Michie et al., 2014). Goal-setting is proposed to be central to person centred care and routinely used in stroke rehabilitation (Rosewilliam et al., 2011). A

decision was taken to base the intervention primarily around the goals of the stroke survivor (and/or family member where appropriate) to ensure that the intervention can be tailored to the individual. It was anticipated that the other BCTs identified in Table 17 could be used flexibly based upon these goals.

Having reached Stage Three of intervention design (identifying content and implementation) according to the BCW, it was necessary to consider in further detail the strategy which had been developed, and to define the mode of delivery in more detail. Michie et al. (2014) recommend that researchers regularly review and amend the intervention based upon feedback. Before further development of the intervention is presented (Chapter Nine), a discussion and reflection upon of the design of the intervention so far follows in Section 8.5.

8.5. Discussion

In this chapter the potential components of a self-management intervention for stroke survivors with communication difficulties were explored. The BCW was used to guide the design of the intervention. In line with this framework, the intervention developed is based upon an explicit theory of behaviour (the COM-B model) and the intervention functions and BCTs clearly link to the underlying theory of behaviour. The TDF is used to propose mechanisms of action which link the BCTs identified to the intervention functions and thus the COM-B model. A strength of this approach is that it provides a coherent link between the underlying theory of behaviour and the BCTs which are used to modify behaviour. Using the BCW framework in conjunction with MRC guidance also addresses criticisms of the MRC approach suggesting a lack of detail about how theory should be chosen or linked to intervention development (Michie et al., 2011). The transparent design process and clear description of the proposed functions of the intervention allows for replication or refinement of the intervention and will progress understanding of the 'active ingredients' of self-management interventions in the future by allowing comparison with BCTs used in other interventions (Michie et al., 2009).

One difficulty encountered in using the BCW framework was the difficulty in specifying precise behaviours as part of the behavioural diagnosis. As a complex population, there is a large variation in behaviour between stroke survivors with communication

difficulties. Previous work using the BCW has often targeted simpler behaviours or those which can be very clearly defined, for example, hand hygiene, condom use or dental hygiene (Asimakopoulou and Newton, 2015; Fuller et al., 2014; Bailey et al., 2015). It could also be postulated that there is greater homogeneity in the groups of individuals previously targeted in relation to a specific behaviour. For example, in many cases the interventions previously developed using the BCW have targeted groups of staff (Connell et al., 2015; French et al., 2012; Steinmo et al., 2015) who are more likely to be similar in their behaviours in the work environment. There is difficulty in defining self-management precisely in behavioural terms as the fieldwork demonstrated that self-management may have different meanings depending upon the context of the individual. The behaviours identified in this study may be criticised for being too broad. However, it was important that the intended target behaviours were not prescriptive, and that the intervention retained a sense of flexibility to ensure that stroke survivors were able to work on areas of importance to them and their families, which would enable them to self-manage in way which is meaningful based upon their circumstances.

The process of identifying target behaviours and conducting a 'behavioural diagnosis' may appear to be an overly simplistic approach. Findings from the fieldwork (discussed in Chapter Seven) suggest that the management of post-stroke communication difficulties was a complex process which involved managing multiple lines of work within a context which was constantly changing and evolving over time. The behaviours identified and analysed using the COM-B model are largely considered in isolation and do not take into consideration the complex and reciprocal way in which one may impact upon another and feed in to the process of managing as a whole. Within this model it was also difficult to adequately capture the diversity of ways in which the type and severity of post-stroke communication difficulties may influence the target behaviours of the intervention. Some aspects of the education and training provided as part of the intervention will need to take into consideration the complex and two-way nature of conversational interactions. For example, training others in techniques to support conversation may require an in-depth analysis of how and when conversation is facilitated and how and when barriers to conversation may occur (Best et al., 2016).

Michie et al. (2014) acknowledge that the BCW is a framework and is not a 'magic bullet' for intervention development or proof of effectiveness in practice. It is important to state that entirely different interventions could be developed given the same starting

problem and there is a degree of subjectivity in the choice and application of the BCTs identified; the broader context of the mode of delivery is also left to the judgement of the researcher. This could create bias in the type of intervention developed which may be shaped by the researchers past experiences or preferences, as opposed to an informed consideration of all the available options. This potential limitation may have been overcome by involving key stakeholders at all stages of the design process; however, this was not possible in this study due to the limited time available.

Some may also question whether similar interventions may be developed without the use of the framework using commonsense, implicit models of behaviour. Although the framework has only been recently developed, there is no evidence to suggest that the use of the BCW framework (or any other complex intervention development framework), leads to the development of more effective interventions. Although the framework does provide a common language by which to define and design behaviour change interventions, at present the researcher also relies upon their own judgement about which BCTs to choose from a list of commonly used techniques. It might be argued that a larger problem to be overcome in behaviour change science is that we do not have comprehensive knowledge of whether some BCTs are more effective than others, for whom and in what context (Pawson and Tilley, 1997). BCTs often only lead to behaviour change for some and the maintenance of behaviour change over time is also problematic (Bull et al., 2014; Ogden, 2016). Without further use and evaluation of the BCW framework it appears that a certain amount of guesswork or best judgement is still used in the development of complex behaviour change interventions. A benefit of using the BCW is that such judgements are theoretically informed.

Another concern about the BCW framework is that it may stifle creativity in the field of behaviour change science. If researchers use existing lists of BCTs it might be argued that the development of new BCTs might be limited (Ogden, 2016). The framework may become a box which constrains the way in which complex interventions are developed; leading to a particular style and type of intervention which does not question the paradigm from which it was created (Ogden, 2016). In defence of their approach Michie et al. (2011) argue that the BCW is a starting point for creating a common language by which to define and develop interventions and should be subject to further testing, evaluation and refinement.

In this chapter, the use of the BCW guided the design of a self-management intervention for stroke survivors with communication difficulties, and, based upon the COM-B model of behaviour, BCTs were chosen to target psychological capability, physical and social opportunity, and reflective and automatic motivation in order to facilitate successful self-management. Although potential behavioural targets were identified, before further development of the intervention was undertaken it was important to seek some consensus and feedback about the components of the intervention developed to date. In addition, although the mode of delivery of the intervention has been considered as part of the development process, there was still uncertainty about this. For example, decisions about precisely where and when in the stroke pathway the intervention would be delivered and who may act as a facilitator for the intervention had not yet been made. Although the findings of the fieldwork suggested that further support around the point of discharge from community services may be important, the findings also suggested variation in 'readiness' to engage with such an approach. It was unclear whether such an approach would be delivered prior to or after discharge from community services or whether preparations to self-manage should begin earlier than this time. In Chapter Nine consensus and feedback upon these issues was sought to refine the design of the intervention.

Chapter Nine: Delphi survey and findings

This chapter reports the findings from the Delphi survey which was used to achieve an expert consensus upon the intervention components developed using the BCW in Chapter Eight and to gain feedback about the way in which the intervention should be delivered in practice.

9.1. Introduction

The Delphi survey technique aims to establish a consensus amongst experts in an area of research where there is uncertainty (Dalkey, 1969). An expert panel is constructed and sent surveys, typically in three 'rounds'. Anonymous feedback is given at each round so that each panel member can compare their responses to the response of the panel as a whole and respond to the emerging data. Findings are commonly summarised and fed back to the panel using descriptive statistics which are sometimes (but not always) supplemented by selected comments from panel members provided in the preceding round. Panel members may choose to revise their responses in the following survey round and are given space to comment upon the reasons for their position. The process of sending out survey rounds is repeated until agreement is reached or until the number of responses diminishes or at the end of the pre-specified number of rounds (Hasson et al., 2000). The repetition of survey rounds is proposed to facilitate the panel to move towards a consensus regarding the issue at hand. The Delphi technique was originally developed by the RAND Corporation in the 1950s to aid research into the future impact of technology upon warfare; however, has since been used more broadly and applied widely in health services research (Hasson et al., 2000; Keeney et al., 2001; Powell, 2003). For example, the technique has been used to develop best practice statements for occupational therapy for Parkinson's disease (Deane et al., 2003); to obtain a consensus upon the principles and indicators of consumer involvement in NHS research (Boote et al., 2006) and to determine core outcome sets for use in clinical trials (Sinha et al., 2011). This method has also been used to develop the Australian Aphasia Rehabilitation Pathway of best practice statements (Power et al., 2015) and to obtain consensus about the key treatment outcomes of importance to SLTs and service managers (Wallace et al., 2017b).

The previous chapter reported how the BCW (Michie et al., 2014; Michie et al., 2011) was used to inform the components of a self-management intervention for stroke survivors with communication difficulties. This approach was used in conjunction with MRC (2008) guidance as part of the development phase of this framework. The final part of the development phase, according to MRC guidance (modelling processes and outcomes), proposes that researchers understand how the intervention would work in practice and identify any potential barriers to implementation. Both the MRC (2008) guidance and Michie et al. (2014) recommend that feedback is obtained about the planned intervention in order to guide the design. To further the design of the intervention, it was therefore important to gain feedback upon the planned intervention. The Delphi technique was utilised in order to achieve an expert consensus upon the intervention components developed using the BCW and to gain feedback about the way in which the intervention should be delivered in practice. By gaining feedback about the intervention from an expert panel, it was hoped the author would be able to gauge the appropriateness of the targets for intervention, and identify unforeseen problems with implementing the BCTs in practice. The Delphi technique was believed to be the best way of obtaining feedback from a range of experts in a timely manner and at minimal cost. Alternative methods, for example, a face-to-face meeting were discounted due to practicalities of arranging the meeting amongst a group of busy individuals who were spread widely geographically and the associated cost of reimbursing travel expenses. Another advantage of the Delphi approach over a face-to-face meeting is that participants are afforded anonymity. The risk of arranging a face-to-face meeting is that one expert may dominate opinion and may cause the group to feel manipulated or coerced into agreeing with their point of view (Hsu and Sandford, 2007; Keeney et al., 2001).

There are a number of uncertainties associated with the Delphi approach which include how expertise is defined, how many panel members are included and what threshold should be set to determine when a consensus has been reached (Hsu and Sandford, 2007; Keeney et al., 2001; Hasson et al., 2000). Other difficulties include the potential for low response rates and the potential for the researcher to introduce bias when selecting comments to feedback to expert panel between survey rounds (Hsu and Sandford, 2007). These difficulties and uncertainties were considered throughout the development and conduct of the Delphi survey and justification for the methods used (and how such difficulties and uncertainties were overcome) is provided in Section 9.3.

This knowledge gained through undertaking the Delphi survey is used to develop and refine the intervention outlined in Chapter Eight.

9.2. Aims

The aims of the Delphi survey were:

- 1) To gain an expert consensus on the key components of a proposed self-management intervention for stroke survivors with communication disability.
- 2) To gain an expert consensus on how the proposed self-management strategy for stroke survivors with communication disability might be delivered in practice.
- 3) To use the knowledge gained from survey responses to refine the design of a self-management intervention for stroke survivors with communication difficulties.

9.3. Method

Study design

A Delphi survey consisting of three rounds was developed. Some Delphi survey's begin the first round with an open question in order to generate information about the key topics to inform the design of the structured questionnaire to be delivered in the second round (Keeney et al., 2006). However, due to the focused aims of the study and previous work undertaken to design the intervention, a decision was made to begin the first round with a structured questionnaire. An example of the questions used in the survey is presented in Appendix L. Participants were provided with a brief introduction to the survey and informed that the author intended the intervention to be used flexibly depending upon the requirements of the stroke survivor and/or their family member (where this was appropriate). The survey was split into two sections; In the first section, participants were asked to rate on a 5 point scale ranging from strongly disagree to strongly agree whether they believed each of the targets for the proposed intervention (communication outside of the home, meaningful activity, seeking or maintaining social support, forming a relationship with their healthcare provider, obtaining information about stroke and communication disability) should be included in a self-management intervention for stroke survivors with communication difficulties. If participants 'strongly agreed', 'agreed' or were 'undecided' for a target they were then asked to rate whether

or not they agreed with the associated BCTs which would be used to address the target for intervention. If participants 'strongly disagreed' or 'disagreed' with the target intervention they were asked to rate the next target.

In the second section of the survey, participants were asked to rate their level or agreement about the way in which a self-management intervention for stroke survivors with communication difficulties should be delivered. There were three questions in this section of the survey. The first, asked participants to rate their agreement on who should facilitate a self-management intervention for stroke survivors with communication difficulties (charitable organisation, trained volunteer, SLT, nurse, family member). The second, asked participants to rate their agreement on how long the intervention should be delivered for (a fixed period or as long as is required by the patients needs). The final question, asked participants to rate their agreement on when a self-management intervention should be delivered (delivered prior to discharge from hospital, delivered prior to discharge from ESD/community services, delivered after discharge from ESD/community services).

It is important to state that there is a lack of agreement about the definition of consensus in Delphi surveys; the researcher is left to gauge an appropriate threshold, depending upon the research question, and there is often no scientific rationale for choosing one threshold level over another (Keeney et al., 2006). Some have allowed the data to decide the acceptable level of agreement to define when a consensus has been achieved (Williams and Webb, 1994). However, using this method may introduce bias as the researcher may choose to set consensus at a level which maximises or minimises consensus, depending upon their preferences. To overcome this limitation consensus was defined *a priori* as $\geq 75\%$ experts 'strongly agreeing' / 'agreeing' or 'strongly disagreeing' / 'disagreeing' with a survey item. This threshold was set prior to the start of the study to reduce the risk of researcher bias if the threshold were set following data collection (Williams and Webb, 1994). 75% was chosen in the current study as it appeared to reflect a good level of agreement on a topic which, given the variety of self-management interventions identified in the literature, was open to much interpretation. This threshold is also in line with that used by a similar Delphi study to agree the key components of ESD interventions in stroke care (Fisher et al., 2011). Items which did not reach consensus during the first round of the survey were retained for the panel to re-rate in the second round, and items which did not reach consensus in the second round, were retained for the panel to re-rate in the third and final round.

Participants

There is significant ambiguity in the literature with regards to how panel members should be identified or the meaning of the word 'expert' in this context. Most agree that expert panel members are a group of "informed individuals" (p.1221) (McKenna, 1994) and that panel members should be "highly trained and competent within the specialised area of knowledge related to the target issue" (p.3) (Hsu and Sandford, 2007).

However, it is left to the discretion of the research team to identify panel members who have appropriate expertise and to develop inclusion and exclusion criteria in relation to these aims (Hsu and Sandford, 2007). The current Delphi survey aimed to include individuals who had specific expertise and knowledge about stroke survivors with communication difficulties and their needs in relation to longer-term care. In order to obtain a consensus about how a self-management intervention might be delivered in UK services, a decision was made to limit the panel to UK based experts. Three groups of experts were sought; these included clinicians (SLTs), academics (SLTs and non-SLTs) and representatives from charitable organisations. Expertise amongst clinicians was defined as those who were Band 7 or above within NHS services and those whose current caseload included stroke survivors with communication difficulties. Expertise amongst academics was defined as those who were at a senior lecturer level or above and whose stated interests included the longer-term care of stroke survivors with communication difficulties. Finally, expertise amongst staff at charitable organisations was defined as those who were at a managerial level within the organisation whose role included the provision of support for stroke survivors with communication difficulties.

Potential participants were identified by conducting internet searches, reviewing key publications in the field and by contacting organisations e.g. the Stroke Association/Royal College of Speech and Language Therapists (RCSLT) to identify suitable potential participants. Email addresses of potential participants were obtained through staff profiles on university websites, through personal contacts or through the organisations identified (for example, the RCSLT). The number of participants needed to make up an expert panel is widely debated and is dependent upon the research question and topic at hand (Keeney et al., 2001). However, generally panels comprise of less than 50 participants, and usually have between 15-20 participants (Hsu and Sandford, 2007). The number of academic researchers, experienced clinicians and

representatives from charitable organisations in this field is relatively small. The project aimed to recruit as many experts as possible and aimed for a panel size of 15-20.

Ethical considerations

The study was granted ethical approval by the University of Leeds School of Medicine Research Ethics Committee (Ref: MREC16-115) (See Appendix M). Confidentiality was considered to be the main ethical issue of the approach outlined above. Three issues in relation to confidentiality are outlined below (including the steps taken to address these issues):

1) Security of online data

Bristol Online Surveys software was used to create and store data collected by the survey; this is a secure software system which is fully compliant with UK data protection laws.

2) Collection of identifiable data

In order to provide individualised feedback for the participant to consider their response to the survey in comparison to the group's response, it was necessary to collect the participants email address as part of the survey. However, this was the only piece of identifiable information which was collected and this was deleted following the final survey round. Participant's email addresses were kept confidential, were stored securely in a password protected file and were not shared with other survey participants.

3) Use of anonymised quotes

Anonymised quotes to free-text answers were used to illustrate points as part of the results of the study. Quotations were anonymised and care was taken not reveal the identity of the participant or their place of work through the quotations used.

Data collection

A weakness which has been outlined by researchers discussing the Delphi technique is the potential for low response rates and the potential for attrition between survey rounds (Hsu and Sandford, 2007; Sinha et al., 2011; Keeney et al., 2001). In order to maximise response rates, I tried to ensure that the approach email and participant information sheet was as clear as possible. Using an electronic survey (Bristol Online Surveys) as opposed to postal questionnaires increased accessibility for participants.

The electronic survey was designed to be as user friendly as possible and included in-built validation features to prompt participants if they had missed a question which was required and automatically directed participants to relevant questions based upon their responses. In order to minimise attrition between rounds, I clearly stated the deadline for completing the round and provided reminder emails between survey rounds. I also included text in the invitation emails to round two and three which emphasised the importance of participants completing the whole Delphi process (Sinha et al., 2011).

Round one

In round one potential participants' were sent an invitation email and link to the online survey. The approach email also contained a participant information sheet. Participants were asked to confirm on the first page of the survey that they had read the information sheet and gave their consent to participate in the survey. The email gave potential participants a deadline of two weeks in which to complete the survey, and those who had not responded, were sent a reminder email one week after the approach email.

Round two

Items which did not reach consensus during round one were re-circulated to participants who took part in the first round in round two of the survey. A personalised feedback sheet was sent to each participant which contained their response and the overall group response to items which had not reached consensus (see Appendix N). Group responses to the items which had not reached consensus were presented in a pie chart with each segment labelled with the percentage of experts which fell into the category contained (i.e. strongly agree, agree, undecided, disagree, strongly disagree). In order to reduce the risk of researcher bias, a decision was made not to include any of the comments which had been provided by participants in the first round of the survey in the personalised feedback forms (Hsu and Sandford, 2007). This reduced the potential for the researcher to unintentionally select comments which reflected their own as opposed to the group's opinion. The invitation email to participate in the second round of the survey contained the link to survey and again gave participants a deadline of two weeks in which to complete. Those who had not responded after one week were sent a reminder email. The second round of the survey began with a brief summary of the items where consensus had been reached and also stated that the comments which had been made during the first round of the survey had been collated and would contribute to the analysis and write-up of the survey.

Round three

Items which did not reach consensus during round two were re-circulated in round three of the survey. A personalised feedback sheet was produced using the same template used in round two. Participants were again given a deadline of 2 weeks in which to complete the survey and those who had not responded after one week were sent a reminder email.

Data analysis

SPSS (version 22) (IBM Corp, 2013) was used to calculate the percentage of agreement and median response to each item for each round. Free text comments were exported to QSR NVivo software version 10 (QSR International, 2012) and grouped according to similarity. The interpretation of the results is complemented by the free text comments provided by members of the expert panel. These comments are used to provide additional insight into the panellist's ratings.

9.4. Findings from the Delphi survey

A total of 577 participants were approached to take part in the Delphi survey. An invitation email was distributed by the RCSLT to all members who were part of clinical excellence networks relevant to stroke (559 SLTs in total). SLTs were invited to participate after identifying themselves as being NHS Band 7 or above (or had equivalent experience) and being involved with a caseload of stroke survivors with communication difficulties. Sixteen UK based academics were invited to take part in the survey and two representatives from UK based charitable organisations. It was difficult to identify participants in charitable organisations as it appeared that few people held managerial roles within the limited number of charitable organisations available.

Round one

A total of 19 participants responded to the first round of the Delphi survey. Participants included nine SLTs, eight clinical academics who were also SLTs, one non-clinical academic and one representative from a charitable organisation. Consensus was achieved on 43 out of 53 items circulated in the first survey; Table 18 shows the items which achieved consensus, the median response, and percentage of experts who agreed or disagreed with the statement.

Table 18: Items which reached consensus in round one of the Delphi survey

	Statement	Median Response	Percentage of experts who agree* or disagree^	Number of respondents
Target for intervention:	A self-management intervention for stroke survivors with communication disabilities should facilitate communication outside of the home.	Strongly agree	94.7*	19
BCTs	Stroke survivor sets a goal for communicating outside of the home.	Strongly agree	94.7*	19
	Facilitator helps the stroke survivor to make an action plan, detailing when communication will occur, where communication will occur, what communication will occur and who communication will occur with.	Agree	98.5*	19
	Facilitator provides information and training in alternative and augmentative communication (AAC) strategies.	Strongly agree	100*	19
	Facilitator and stroke survivor rehearse AAC strategies.	Strongly agree	94.7*	19
	Facilitator and stroke survivor practise communication outside of the home with the facilitator prompting the stroke survivor as necessary to facilitate communication and decreasing support with practise (or ongoing support is provided by a member of the stroke survivors social network who has been trained by the facilitator).	Strongly agree	94.7*	19
	Stroke survivor is supported to self-monitor communication and implements AAC strategies as necessary.	Strongly agree	100*	19
	Facilitator and stroke survivor review behaviour and outcome of behaviour.	Strongly agree	94.7*	19
	Facilitator provides feedback to stroke survivor on behaviour and outcome.	Strongly agree	84.2*	19
	Stroke survivor and facilitator work together to solve problems which may have arisen.	Strongly agree	100*	19
	Goals with regards to communicating outside of the home are re-evaluated.	Strongly agree	100*	19
Target for intervention:	A self-management intervention for stroke survivors with communication disabilities should facilitate participation in meaningful activity.	Strongly agree	94.7*	19
BCTs	Stroke survivor sets a goal for participating in meaningful activity.	Strongly agree	89.5*	19
	Facilitator helps the stroke survivor to obtain information about the available activities.	Agree	79*	19

Table 18: Items which reached consensus in round one of the Delphi survey (continued)

	Statement	Median Response	Percentage of experts who agree* or disagree^	Number of respondents
BCTs	Facilitator helps the stroke survivor to make a plan with the steps needed for activity to take place.	Agree	89.5*	19
(continued)	Stroke survivor is supported to obtain social support to take part in activity (if necessary).	Strongly agree	94.7*	19
	Stroke survivor is supported to take part in activity using prompts or cues (facilitator provides graded support which decreases over time or ongoing support is provided by a member of the stroke survivor's social network who has been trained by the facilitator).	Strongly agree	94.7*	19
	Facilitator and stroke survivor review behaviour and outcome of behaviour.	Strongly agree	89.5*	19
	Facilitator provides feedback to stroke survivor on behaviour and outcome.	Agree	84.2*	19
	Stroke survivor and facilitator work together to solve problems which may have arisen.	Strongly agree	94.7*	19
Target for intervention:	A self-management intervention for stroke survivors with communication disabilities should facilitate the stroke survivor to seek or maintain social support.	Agree	84.2*	19
BCTs	Stroke survivor sets a goal to seek or maintain social support.	Strongly agree	89.5*	19
	Facilitator helps the stroke survivor to map out their existing social network.	Strongly agree	94.7*	19
	Facilitator helps the stroke survivor to obtain information about opportunities for social support.	Agree	89.5*	19
	Stroke survivor is supported to make an action plan with the steps needed to obtain or maintain social support.	Agree	89.5*	19
	Stroke survivor is supported to mentally rehearse the steps needed for social interaction.	Agree	84.2*	19
	Facilitator provides training in supported conversation techniques to those providing social support to the stroke survivor.	Strongly agree	94.7*	19

Table 18: Items which reached consensus in round one of the Delphi survey (continued)

	Statement	Median Response	Percentage of experts who agree* or disagree^	Number of respondents
BCTs	Facilitator and stroke survivor review behaviour and outcome of behaviour.	Strongly agree	94.7*	19
(continued)	Facilitator provides feedback to stroke survivor on behaviour and outcome.	Strongly agree	84.2*	19
	Stroke survivor and facilitator work together to solve problems which may have arisen.	Strongly agree	94.7*	19
Target for intervention:	A self-management intervention for stroke survivors with communication disabilities should facilitate the stroke survivor to obtain information about stroke and communication disabilities.	Strongly agree	100*	19
BCTs	Stroke survivor sets a goal for obtaining information about stroke and communication disability.	Agree	84.2*	19
	Facilitator provides information or education about appropriate information sources.	Strongly agree	100*	19
	Stroke survivor is supported to make an action plan to obtain information.	Agree	84.2*	19
	Facilitator and stroke survivor review information and facilitator to assess the need for further information.	Agree	94.7*	19
Target for intervention:	A self-management intervention for stroke survivors with communication disabilities should facilitate the stroke survivor to form a partnership with their healthcare provider(s).	Agree	79*	19
BCTs	Facilitator provides information to stroke survivor about when support from healthcare professionals might be needed and who to contact.	Agree	89.5*	19
	Stroke survivor is supported to self-monitor the need for input from healthcare professionals.	Agree	94.7*	19
	Facilitator provides social support (or stroke survivor obtains social support) to assist the stroke survivor in building a relationship with their healthcare provider.	Agree	79*	19

Table 18: Items which reached consensus in round one of the Delphi survey (continued)

	Statement	Median Response	Percentage of experts who agree* or disagree^	Number of respondents
BCTs (continued)	Stroke survivor and facilitator review an encounter with healthcare professional and work together to solve problems which may have arisen.	Agree	84.2*	19
Delivery statement:	Who should facilitate a self-management intervention for stroke survivors with communication disabilities?	N/A	N/A	N/A
	Facilitated by a speech and language therapist.	Strongly agree	89.5*	19
Delivery statement:	How long should the self-management intervention be delivered for?			
	The intervention should be delivered for a fixed period.	Disagree	79^	19
	The intervention should be delivered as long as is required by the patients needs.	Strongly agree	89.5*	19

[Key: * combined percentages of strongly agree or agree responses; ^ combined percentages or strongly disagree or disagree responses; N/A not applicable]

The expert panel agreed with the five proposed areas to be targeted by a self-management intervention (communication outside of the home, meaningful activity, seeking or maintaining social support, forming a relationship with their healthcare provider, obtaining information about stroke and communication disability) and the majority of the BCTs proposed to address the aforementioned targets for intervention. The panel did not reach consensus on three of the suggested BCTs. The first was the mental rehearsal of steps needed to take in a meaningful activity. The second was setting a goal to build a relationship with a healthcare provider and the third was obtaining feedback from the healthcare professional in order to reinforce motivation to continue partnership. The remaining seven items which did not reach consensus related to the delivery of the self-management intervention. Panel members did not reach consensus upon whether a charitable organisation, trained volunteer, nurse or family member could facilitate a self-management intervention; however, as shown in Table 18, panellists did agree that a SLT could facilitate this approach. Finally, panel members did not reach a consensus on when a self-management intervention should be delivered (delivered prior to discharge from hospital, delivered prior to discharge from ESD/community services, delivered after discharge from ESD/community services). However, members of the panel did reach a clear consensus about the intervention being delivered for as long as is required by the patients needs as opposed to being delivered for a fixed period. Table 19 shows the items where consensus was not reached and the percentage of panel members who strongly agreed, agreed, were undecided, disagreed or strongly disagreed with each item.

Table 19: Items which did not reach consensus in round one of the Delphi survey

Statements	Responses				
	Strongly agree	Agree	Undecided	Disagree	Strongly disagree
Target for intervention: Meaningful activity					
BCT: Stroke survivor is supported to mentally rehearse the steps needed to take part in the activity.	37%	37%	16%	5%	5%
Target for intervention: Forming a partnership with healthcare provider(s)					
BCT: Stroke survivor sets a goal for forming a relationship with a healthcare professional.	32%	42%	21%	0%	5%
BCT: Facilitator obtains feedback about relationship from healthcare professional in order to reinforce stroke survivors' motivation to continue partnership.	26%	48%	26%	0%	0%
Delivery statement: Who should facilitate a self-management intervention for stroke survivors with communication disabilities?					
Facilitated by a charitable organisation.	10%	58%	21%	11%	0%
Facilitated by a trained volunteer.	5%	58%	32%	5%	0%
Facilitated by a nurse.	5%	16%	32%	47%	0%
Facilitated by a trained family member.	26%	37%	26%	11%	0%
Delivery statement: When should a self-management intervention be delivered?					
Delivered prior to discharge from hospital.	16%	32%	21%	26%	5%
Delivered prior to discharge from ESD/community services.	37%	37%	10%	11%	5%
Delivered after discharge from ESD/community services	32%	26%	16%	5%	21%

Table 19 shows that three BCTs narrowly missed reaching consensus in round one of the Delphi survey (74% of panel members strongly agreeing/agreeing with the statements). Delivering the self-management intervention prior to discharge from ESD/community services also narrowly missed out achieving an agree consensus by 1%.

Round two

All 19 participants who responded to the first round of the survey were invited to participate in the second round. A total of 14 participants responded to the second round of the Delphi survey (74%). Participants included eight SLTs, five clinical academics and one participant who was employed by a charitable organisation. Attrition was highest amongst clinical academics; three of whom dropped out from the first round. One non clinical academic did not participate in the second round and one SLT was also lost from the sample. Consensus was achieved on three out of 10 items circulated in the second survey; Table 20 shows the items which achieved consensus, the median response and percentage of experts who agreed or disagreed with the statements.

Table 20: Items which reached consensus in round two of the Delphi survey

	Statement	Median Response	Percentage of experts who agree* or disagree^	Number of respondents
Delivery statement:	Who should facilitate a self-management intervention for stroke survivors with communication disabilities?			
	Facilitated by a trained family member	Agree	85.71*	14
Delivery statement:	When should a self-management intervention be delivered?			
	Delivered prior to discharge from ESD/community services.	Agree	92.86*	14
	Delivered after discharge from ESD/community services.	Agree	78.57*	

In the second round of the Delphi survey panel members agreed that a trained family member could be used to facilitate a self-management intervention for stroke survivors with communication difficulties. The panel also agreed that a self-management intervention could be delivered prior to discharge from ESD/community services and/or after discharge from ESD/community services.

The panel did not reach consensus on seven of the items which were recirculated. These included the three BCTs the panel were asked to re-rate: The first was the mental rehearsal of steps needed to take in a meaningful activity. The second was setting a goal to build a relationship with a healthcare provider and the third was obtaining feedback from the healthcare professional in order to reinforce motivation to continue partnership. Panel members did also not reach consensus upon whether a charitable organisation, trained volunteer, or nurse could facilitate a self-management intervention. Finally, panel members did not reach a consensus on whether a self-management intervention should be delivered prior to discharge from hospital. Table 21 shows the items where consensus was not reached and the percentage of panel members who strongly agreed, agreed, were undecided, disagreed or strongly disagreed with each item. The responses from the first round of the Delphi survey are also shown for comparison.

Table 21: Items not reaching consensus in round two of the Delphi survey

Statements	Responses									
	Strongly agree		Agree		Undecided		Disagree		Strongly disagree	
	(1 st round)	2 nd round								
Target for intervention: Meaningful activity										
BCT: Stroke survivor is supported to mentally rehearse the steps needed to take part in the activity.	(37%)	22%	(37%)	43%	(16%)	21%	(5%)	7%	(5%)	7%
Target for intervention: Forming a partnership with healthcare provider(s)										
BCT: Stroke survivor sets a goal for forming a relationship with a healthcare professional.	(32%)	14%	(42%)	36%	(21%)	22%	(0%)	21%	(5%)	7%
BCT: Facilitator obtains feedback about relationship from healthcare professional in order to reinforce stroke survivors' motivation to continue partnership.	(26%)	7%	(48%)	36%	(26%)	50%	(0%)	0%	(0%)	7%
Delivery statement: Who should facilitate a self-management intervention for stroke survivors with communication disabilities?										
Facilitated by a charitable organisation.	(10%)	0%	(58%)	64%	(21%)	29%	(11%)	7%	(0%)	0%
Facilitated by a trained volunteer.	(5%)	7%	(58%)	64%	(32%)	7%	(5%)	22%	(0%)	0%
Facilitated by a nurse.	(5%)	0%	(16%)	29%	(32%)	14%	(47%)	57%	(0%)	0%
Delivery statement: When should a self-management intervention be delivered?										
Delivered prior to discharge from hospital.	(16%)	14%	(32%)	28%	(21%)	29%	(26%)	29%	(5%)	0%

Table 21 shows that with regards to the BCTs, panel members appeared to become more split about these intervention components with an increase in 'undecided' responses in comparison to the first round. Little change was observed between the first and second round in response to whether a self-management intervention could be facilitated by a charitable organisation, trained volunteer or nurse. Opinion was also split upon whether a self-management intervention could be delivered prior to discharge from hospital.

Round three

All 14 participants who responded to the second round were invited to participate in the third and final round of the survey. A total of 12 participants responded to the third round of the Delphi survey (86%). Participants included six SLTs, five clinical academics and one participant who was employed by a charitable organisation. Two participants were lost from the second round sample; both were SLTs.

In the third round of the survey, consensus was reached upon three further items which were re-circulated. The first was a BCT; the mental rehearsal of the steps needed to take part in a meaningful activity. 83.33% of panel members agreed or strongly agreed with this statement (median response: Agree). The second was the facilitation of the intervention by a charitable organisation. 75% of panel members agreed or strongly agreed with this statement (median response: Agree). The third was the facilitation of the intervention by a trained volunteer. 83.33% of panel members agreed or strongly agreed with this statement (median response: Agree). The panel did not reach consensus on four of the items which were recirculated in round three. The first two items were BCTs to target forming a relationship with a healthcare provider (setting a goal to build a relationship with a healthcare professional and obtaining feedback from the healthcare professional in order to reinforce motivation to continue partnership). Panel members also did not reach a consensus upon whether a nurse could facilitate a self-management intervention or whether a self-management intervention should be delivered prior to discharge from hospital. Table 22 shows the items where consensus was not reached and the percentage of panel members who strongly agree, agreed, were undecided, disagreed or strongly disagreed with each item. Responses from the second round of the Delphi survey are shown for comparison.

Table 22: Items not reaching consensus in round three of the Delphi survey

Statements	Responses									
	Strongly agree		Agree		Undecided		Disagree		Strongly disagree	
	2 nd round	3 rd round								
Target for intervention: Forming a partnership with healthcare provider(s)										
BCT: Stroke survivor sets a goal for forming a relationship with a healthcare professional.	14%	8%	36%	42%	22%	17%	21%	33%	7%	0%
BCT: Facilitator obtains feedback about relationship from healthcare professional in order to reinforce stroke survivors' motivation to continue partnership.	7%	8%	36%	33%	50%	42%	0%	17%	7%	0%
Delivery statement: Who should facilitate a self-management intervention for stroke survivors with communication disabilities?										
Facilitated by a nurse.	0%	0%	29%	25%	14%	33.5%	57%	33.5%	0%	8%
Delivery statement: When should a self-management intervention be delivered?										
Delivered prior to discharge from hospital.	14%	8%	28%	42%	29%	33%	29%	17%	0%	0%

Table 22 shows that opinion was split across the items which did not reach a consensus in the final round of the Delphi survey. There was little change in the percentage of panellists agreeing or disagreeing with survey statements from the second to third round.

Free text comments from Delphi panellists

Panel members were encouraged to provide free text comments as part of each survey round. In round one, 13 out of 19 respondents provided comments, in round two 8 out of 14 respondents provided comments and in round three 6 out of 12 respondents provided comments.

Positive feedback was obtained from panel members firstly regarding the concept of self-management:

“This survey seems to grapple with very valid issues. Self-management of communication difficulties is one of the most valuable tools that we can use to enable our clients. Good luck.” (Round 1, participant 8, clinical academic)

And secondly about the way in which the intervention had been shaped by the BCW:

“Using the behaviour change framework as a way of shaping the intervention is excellent - I think it's vital we start to see communication training as behaviour change with all the complexities that entails.” (Round 1, participant 19, clinical academic)

Other comments provided across the rounds were organised in to four categories: 1) Timing of the intervention, 2) Flexibility of the intervention 3) Others influence upon self-management 4) Training and supervision of the facilitator and 5) Feedback upon BCTs.

1) *Timing of the intervention*

A consensus was reached in the survey data about the intervention being delivered in the community setting, prior to or after discharge from ESD/community services. However, free text comments suggested that panellists held some reservations about the timing of the intervention. Some advocated the intervention being delivered in the

community setting due to concerns that stroke survivors may not be psychologically 'ready' to self-manage until they are in the community:

"Delivering the self-management intervention prior to discharge from hospital is too early. Many people have a very short hospital stay and have not begun to adjust to life after stroke and aphasia at this point, so may not benefit from a focus on self-management." (Round 2, participant 14, clinical academic)

"A patient is often more ready [in the community setting] both in their psychological, health and understanding to take on self-management tasks." (Round 2, participant 11, SLT)

Other panellists raised concerns that it was "too late" (Round 2, participant 5, clinical academic) to introduce self-management strategies in the community setting, and that self-management should be introduced in the hospital setting (e.g. "It should start asap." Round 2, participant 5, clinical academic). In understanding these contrasting views it may be important to distinguish between introducing the concept of self-management and handing over responsibility for managing the condition. One participant highlights how self-management might be encouraged in the hospital setting without the expectation that stroke survivors are able to self-manage at this stage:

"The process of encouraging self-management should begin immediately, this does not mean that the actual self-management starts very early. Some aspects e.g. self-management of medicines could begin very early." (Round 3, participant 1, employed by a charitable organisation)

Some panellists questioned whether self-management should be introduced at a set time during the stroke pathway and stated the need for flexibility:

"Timing will depend on the nature and severity of the communication difficulty, every patient will be different." (Round 2, participant 6, SLT)

"I think it probably depends on the type of hospital setting and what the patient and family need at that point in time" (Round 2, participant 5, clinical academic)

“It [self-management] could be introduced and reinforced at all points along the therapeutic journey.” (Round 1, participant 13, SLT).

One participant questioned whether self-management should be a single intervention provided at a set time during the stroke pathway, or whether self-management should be a set of values which are promoted across the care pathway.

“Comments in the various sections will have highlighted my doubts about self-management as 'an' intervention, as opposed to self-management as a set of values (e.g. autonomy; self-determination etc.) and principles (e.g. reciprocity; inter-action), to be enacted throughout the stroke pathway” (Round 1, participant 9, clinical academic)

2) Flexibility of the intervention

Although agreement on the areas to be targeted by a self-management intervention was high in the survey data; in their comments panel members highlighted the importance of tailoring the self-management intervention to meet the stroke survivor's needs. Some suggested that the intervention outlined in the survey was too prescriptive:

“We still need to be patient focused in looking at self-management. Guidelines therefore would be more helpful than a prescriptive approach.” (Round 2, participant 11, SLT)

Other panellists suggested that some aspects of the intervention may be suitable for some stroke survivors with communication difficulties but not others and therefore the intervention should be used flexibly to ensure it is tailored to their requirements. The views and context of the individual were perceived to play a central role in determining which areas would be appropriate to be targeted by a self-management intervention.

“Dependent upon the needs of the person” (Round 1, participant 16, speech and language therapist)

“...Self-management requires a strategy of passing responsibility to an individual and possibly (with their agreement) others in their environment. Most of the objectives will be determined by the individual and the strategies (e.g. whether AAC is a good idea) will depend upon the nature and extent of the communication difficulty and the objective chosen by the individual. It is clear that whatever is

chosen needs to be explained clearly, modelled and reviewed but the nature of this will be person and context specific.” (Round 1, participant 11, clinical academic)

“It depends on the needs and goals of the client. Some clients might not have communicated outside the home pre stroke.” (Round 1, participant 10, clinical academic)

3) Others influence upon self-management

Comments from the panel suggested that the intervention might be too narrowly focused upon the actions of the stroke survivor and that the behaviour of others may have an impact upon the stroke survivor; either supporting or hindering the process of self-management. For example, although panel members agreed with the idea that a self-management intervention should facilitate the stroke survivor to seek or maintain social support, they also identified difficulties achieving this in practice. Some highlighted how the approach outlined in the survey underestimated the role others had to play in creating a successful interaction. Other panel members suggested that whilst delivering training to the communication partners of stroke survivors was ideal in theory; there were a number of barriers to doing this in practice, for example, the availability of family members to participate in training.

“This 'neutral' response means here that I have two sets of views: stroke survivor should be provided with facilitation; but also resources for social support (e.g. people; institutions) should simultaneously be mobilised to support the stroke survivor - how it is currently worded implies an individuation that denies / ignores the interaction that is generally inherent in the social world, or one which should be mobilised if it is not” (Round 1, participant 9, clinical academic)

“This is a very challenging area, as many people do not retain or consistently use any training for communication support, it is also extremely difficult to reach everyone who might benefit from training. Even with many revisions and high quality training this area is extremely problematic.” (Round 1, participant 3, employed by a charitable organisation)

Panel members also commented upon the behaviour of others in relation to the intervention target of building a relationship with a healthcare provider. Members of the expert panel highlighted the difficulties of building a relationship based upon the principles of self-management due to inherent power imbalances between healthcare professionals and patients. This demonstrates how the behaviour of healthcare professionals may impact upon the stroke survivor's ability to self-manage. Training may be needed to ensure that both parties are able to work through the challenges of building a relationship of equals.

“The inherent power relationship and imbalance in relationships with MOST healthcare providers can make this challenging.” (Round 1, participant 3, employed by a charitable organisation)

4) *Training and supervision of the facilitator*

There was high agreement in the survey data that SLTs should help to facilitate the delivery of a self-management intervention. Panellists' comments suggested that the facilitator of a self-management intervention should be provided with ongoing training and supervision. Panellists' were particularly concerned that adequate training and supervision should be provided if non-SLTs (i.e. charitable organisations, family members or volunteers) were to facilitate the self-management intervention. Some suggested that charitable organisations and volunteers would only be suitable if provided with ongoing training and support:

“So long as they had the time and appropriate training to do the task justice.” (Round 2, participant 12, SLT)

Panellists' comments also suggested that supervision and training of the facilitator should be provided by a qualified SLT:

“I think an SLT is the most appropriate person to do this but in some situations it could be done by another person with adequate training. This would depend on the degree/type of training, the type of intervention being provided, the nature of the communication difficulty and co-morbidities such as cognitive functioning. In some situations it may be appropriate for a facilitator to be supervised by an SLT.” (Round 1, participant 7, clinical academic)

“Agree to charitable organisation, trained volunteer and family member but with support and training from a speech and language therapist” (Round 1, participant 10, clinical academic)

“With careful management and the input of a speech and language therapist” (Round 3, participant 11, clinical academic)

Some panel members felt strongly that some facilitators would be more appropriate than others. For example, participant 19 advocated the training of family members and volunteers in the assistance of self-management, however, felt charities lacked the knowledge to take a role in this area.

“A trained family member would maximise autonomy, separate communication disability from being 'ill' and reinforce the view that aphasia is everyone's issue. Speech and language therapists have the skills to effectively and efficiently train family members and volunteers (for those who don't have family). Strongly feel charities don't have the necessary knowledge of evidence based training in AAC for aphasia.” (Round 1, participant 19, clinical academic)

Panellists also raised concerns about nurses delivering a self-management intervention which aligns with the lack of consensus in the survey data about this group of professionals delivering the intervention. Panellists raised concerns about whether nurses would have sufficient time and skills to deliver such an intervention.

“They [nurses] don't have the necessary skills in aphasia communication and I can't see the sense in up-skilling nurses when you could use speech and language therapists?” (Round 2, participant 14, clinical academic)

5) *Feedback upon intervention goals*

Some panel members raised concerns about whether some targets for intervention should be explicitly targeted as part of the intervention or whether they should be targeted implicitly as a consequence of taking part in the intervention as a whole. For example, with regards to information provision, one panel member suggested that information should be provided at the start of the self-management intervention so that stroke survivors are empowered to create a plan with accurate knowledge of their

condition. This is in contrast to the method outlined in the Delphi survey where obtaining information is an explicit goal.

*“I would hope that this would have been done with the therapist prior to developing the self-management plan--- the 1st key step is a good understanding of what the problem is before one can self manage!”
(Round 1, participant 11, clinical academic)*

Similarly, some panellists raised questions about which relationship was being targeted as part of the stroke survivor ‘forming a relationship with their healthcare provider’, and suggested that forming a relationship with a healthcare professional might not need to be considered an explicit ‘goal’:

“Forming a beneficial relationship with a healthcare professional is essential, for both parties, (in terms of therapeutic alliance) and the patient needs to be empowered to be active agent in the relationship but not sure whether forming the relationship needs to be an active ‘goal’...” (Round 2, participant 4, SLT)

This raises questions about whether it is necessary for some of the targets for intervention to be focused upon explicitly changing the behaviour of the stroke survivor or whether they could be introduced more implicitly, for example, information may be provided as part of an initial discussion with the stroke survivor about the concept of self-management and assessment of their needs. Similarly, forming a relationship with a healthcare professional may be addressed across the care pathway, with the healthcare professional taking the lead in ensuring that a strong relationship is built.

“...relationship-building is central to rehabilitation from the word ‘go’ - early on, it is generally the HCP who takes greatest responsibility for relationship-building; matters evolve over time; there are many organisational and institutional constraints” (Round 1, participant 9, clinical academic)

Summary of Delphi survey findings

Areas to be targeted by the intervention: Communication outside of the home, meaningful activity, seeking or maintaining social support, forming a relationship with a healthcare provider and obtaining information about stroke and communication disability.

BCTs to be used: Information, goal-setting, action planning, feedback, rehearsal, problem solving, verbal persuasion, review of goals, self-monitoring and practical social support.

Who should facilitate the intervention: An SLT, a charitable organisation, a trained volunteer or a trained family member.

How long should the intervention last: As long as required by the participants needs.

When should the intervention be delivered: In the community setting prior to or after discharge from ESD/community services.

Free text comments by panel members provided useful feedback to consider about the way in which the intervention would be delivered in practice. For example, panellists' comments highlighted the importance of ensuring that the facilitator is sufficiently trained to deliver the intervention according to the principles of self-management. This may not only require initial training but also ongoing supervision on a regular basis. They also suggested the flexibility of the intervention was important to ensure that it could be tailored to each stroke survivors needs. By basing the intervention around goal-setting it was anticipated that the intervention could be tailored to each stroke survivors needs. However, feedback from panellists suggested that not all of the targets for intervention may be appropriate to be identified as a 'goal' and may be addressed through other methods as part of the intervention. For example, establishing the need for information or education about stroke or communication difficulties may be part of the initial discussion and introduction to self-management by the facilitator. In the next section, the implications of the Delphi survey for intervention design are considered.

9.5. Implications for intervention design

In Section 9.4 an expert panel agreed the targets for a self-management intervention for stroke survivors with communication difficulties and BCTs which could be used to facilitate behaviour change. Free text comments also provided useful feedback to consider how the intervention outlined in Chapter Eight should be refined and delivered

in practice. Based upon the feedback from the Delphi survey, the research undertaken previously in the project and considering the APEASE criteria (Affordability, Practicability, Effectiveness and cost-effectiveness, Side-effects/safety and Equity) (Michie et al., 2014) recommendations for the design and content of the intervention are outlined below. Recommendations are structured using relevant sections of the Template for Intervention Description and Replication (TIDieR) checklist (Hoffmann et al., 2014)

Mode of delivery

Who provides

Considering the feedback from the Delphi survey, the author proposes that the intervention is facilitated by a SLT in the first instance. This decision was made due to the existing skills of this group of professionals in facilitating communication with the target population. Delivery by a SLT will ensure that the intervention is accessible and also appropriately paced, depending upon the type and severity of communication difficulties of the stroke survivor. If successful, future development of the intervention might include training other facilitators (e.g. therapy assistants) to deliver the intervention whilst being supervised by a SLT (as suggested by the comments of the Delphi survey panel members). A training package and adequate supervision would need to be designed and delivered to enable the SLT to deliver the proposed self-management approach.

How

The meta-synthesis of literature in Chapter Three highlighted the problems stroke survivors with communication difficulties may face in accessing group-based and telephone based self-management interventions. The author proposes that the current self-management intervention be delivered individually and face to face in order to maximise accessibility. This decision was also informed by the fieldwork undertaken which suggested that a self-management approach would need to be tailored to each individual and support them in the trial and error process to manage their communication difficulty within their own context (Scobbie et al., 2013; Kubina et al., 2013). Individual tailoring to this level would be problematic in a group-based setting and this also informed the decision to deliver the intervention on a one-to-one basis.

Where

Chapter Two illustrated the practical challenges stroke survivors with communication difficulties experienced in leaving the home including physical disability, fatigue and difficulty accessing transport (Dietz et al., 2013; Fotiadou et al., 2014; Grohn et al., 2012; Nätterlund, 2010; Grohn et al., 2014). For this reason, the author proposes that the intervention is usually delivered in the stroke survivor's home environment in order to maximise accessibility.

When and how much

The author proposes that the intervention is delivered approximately once per week for six weeks and with sessions lasting for one hour. The facilitator would have discretion to provide booster sessions after this time and these could be provided at any time following the initial six week period and for as long as is required by the needs of the stroke survivor and their family. The initial six week duration of the intervention is in line with existing stroke self-management interventions reviewed in Chapter One. However, as described in Chapter One, stroke survivors with communication difficulties may be underrepresented in such studies. For participants with severe aphasia, more time may be required to convey information and to create a shared understanding of the intervention and the goals to be addressed as part of this (Sugavanam et al., 2013). For this reason, the author proposes that the intervention has some flexibility with regards to the number of sessions to be offered. However, the feasibility of providing an open ended intervention (in line with the consensus reached by the Delphi panel) beyond this point would need to be tested in practice and the length of the intervention refined accordingly.

Delphi panellists reached a consensus about the intervention being delivered in the community setting. The author proposes that the intervention be delivered prior to discharge from community services. This is in line with the findings of the fieldwork which suggested that stroke survivors and their families needed to feel better equipped at this point to cope in the longer-term. Again this aspect of the intervention may need to be subject to further feasibility testing.

Intervention content

Based upon feedback from the Delphi panel, the intervention has been refined so that some aspects, for example information provision and forming a relationship with a

healthcare professional need not be an explicit 'goal', but are addressed implicitly through the conduct of the intervention. For example, information will be provided by the facilitator as part of an introductory session with the stroke survivor and their family (see below for further details). A relationship will be formed with the facilitator as a consequence of participating in the intervention and the facilitator will be able to facilitate contact with other healthcare professionals as required. The author proposes that the self-management intervention is based around four modules which are outlined below:

Module One: Introduction

The introductory session will discuss with stroke survivors and their families the aims of the intervention, how long it would last and what can be expected. This will include information about 'self-management' (for example, the trial and error approach and the role of family members as 'co-managers' where appropriate) and information about the collaborative role of the facilitator (to help the stroke survivor and or family member to discover how they wish to manage the difficulties they may face). During this session the facilitator will ask the stroke survivor and their family member about their journey so far and how they feel they are managing on a daily basis. This will include discussion of areas the stroke survivor and family member feel they are managing well with and areas they feel they are managing less well with. This will be used as a starting point to understand the needs of the stroke survivor and their family member so that the intervention can be tailored to respond to these as far as possible. The facilitator will ask the stroke survivor and their family if they have any questions about stroke, communication difficulties or the intervention and information would be provided in an appropriate format depending upon the requirements of the stroke survivor i.e. verbally or in an accessible written format. The facilitator will help the stroke survivor (and their family member if appropriate) to reflect upon problems they are still encountering and goals they might wish to work towards as part of the intervention. Led by the stroke survivor (and family member if appropriate) areas to work on as part of intervention will be discussed. Based upon the areas identified the facilitator would work with the stroke survivor (and family member) to think about how they may wish to work upon the difficulties identified. The facilitator may draw upon a mixture of the strategies outlined in Modules Two to Four to enable the stroke survivor (and family member) to work upon areas of importance to them.

- Module One BCTs: Information, goal-setting, action planning

Module Two: Coping with communication difficulties

Education about the kind of challenges which might commonly be experienced by stroke survivors with communication difficulties and strategies which might be used to overcome such difficulties may be provided if appropriate. The facilitator may suggest the introduction of strategies e.g. AAC strategies to help overcome communication difficulties and where appropriate, the facilitator will help the stroke survivor (and their family) to practise the strategies identified. This will enable the stroke survivor to discover if such strategies would be useful for them. As part of this process the stroke survivor (and their family) may create an action plan to practise the use of such strategies in meaningful contexts. The facilitator may provide graded support to the stroke survivor and their family member where the facilitator decreases the level of support in a communicative situation gradually over time. The facilitator may provide cues and prompts to aid communication as part of the support. Where problems have arisen the facilitator will support the stroke survivor (and family member) to reflect upon how such problems may be overcome (problem solving). A worksheet may be used with this module which lists 'my communication strategies' and 'my plan to practise communication'. The action plan will be used to enable the stroke survivor to plan what communication will occur, when the communication will occur, where it will occur and who the communication will occur with.

- Module Two BCTs: Information, feedback, rehearsal, goal-setting, action planning, graded support, self-monitoring, problem solving, practical social support, verbal persuasion, review of goals.

Module Three: Moving forward with life

Education about the impact of stroke and communication difficulties upon psychosocial wellbeing, including information about common difficulties experienced after stroke, such as, low mood or withdrawal from social situations may also be provided if appropriate. Vignettes from other survivors with communication difficulties about the steps they took to positively manage their communication difficulties and to rebuild their lives following stroke, may help the stroke survivor and their family to reflect upon their own journey. The vignettes would be available in written and video format to ensure accessibility. The facilitator may help the stroke survivor (and family member) to reflect upon how they feel about their level of participation and areas they may wish to work on as part of this. The stroke survivor (and family member) would be supported to make a plan to manage wellbeing, for example, by scheduling meaningful activities (if this was appropriate to their goals). To support the stroke survivor (and their family

member) to work towards their goal, the facilitator may suggest an action plan. A worksheet may be used in conjunction with this module where the stroke survivor (and family member) can record 'my activities this week' and plan 'my activities next week'. The action plan will be used to support the stroke survivor to plan what the activity is, when the activity will occur, who it will occur with and where it will occur. The facilitator may provide graded support to the stroke survivor (and family member) to participate in a meaningful activity if appropriate.

- Module Three BCTs: Information, feedback, goal-setting, action planning, rehearsal, practical social support, self-monitoring, verbal persuasion, review of goals.

Module Four: My support team

If the stroke survivor has identified difficulties with social participation, the facilitator may help the stroke survivor to explore this in further detail by listing members of their social network who they had seen in the previous month and the kinds of support they provided them. If the stroke survivor finds this useful, the information may be written on a worksheet 'my support team'. This will enable the stroke survivor to reflect upon areas where social support might be needed or problems which had arisen with regards to social participation e.g. difficulty communicating with friends. Led by the areas identified as being problematic by the stroke survivor, the facilitator may suggest training members of the stroke survivor's network in strategies to help facilitate communication (and therefore social interaction) where this is appropriate. Helpful strategies for members of the stroke survivor's social network may be listed on a worksheet detailing 'what you can do to help me to communicate'. The stroke survivor may wish to know about opportunities to participate socially and the facilitator may support the stroke survivor by providing information about local opportunities e.g. peer support groups or by assisting the stroke survivor to find out about other opportunities. The facilitator may assist the stroke survivor to participate in social opportunities by providing graded support which decreases over time or by training a family member or other member or the stroke survivor's social network to provide continuing support in social situations.

- Module Four BCTs: Information, goal-setting, action planning, rehearsal, practical social support, problem solving, verbal persuasion, review of goals.

Tailoring

The modules are organised into the areas which may commonly be problematic for stroke survivors with communication difficulties. However, the facilitator will be led by the goals of the stroke survivor (or family member if appropriate) and the support provided by the facilitator to enable the stroke survivor (or family member) will be based upon their wishes and feedback; for example, if the stroke survivor (or family member) finds a strategy to be useful or not useful. The intervention therefore has flexibility for the facilitator to suggest multiple strategies to assist the stroke survivor (or family member) and/or for the stroke survivor (or family member) to develop their own ways of coping or managing.

9.6. Discussion

Summary of findings

A Delphi survey was used to gain feedback upon the self-management intervention designed in Chapter Eight. Consensus was achieved upon targets for intervention and the BCTs to address these. The way in which the self-management intervention might be delivered in practice was less clearly agreed by panel members and free text comments highlighted areas to be considered for the design of the intervention. Using the feedback gained from the Delphi survey (and research conducted throughout the PhD project), the self-management approach proposed in Chapter Eight was refined and recommendations were made for the design and content of the intervention.

Strengths and limitations of the Delphi survey

An expert consensus on the potential targets for a self-management intervention for stroke survivors with communication difficulties has been achieved using the Delphi survey method. Using this method enabled structured feedback to be provided by expert panel members and highlighted areas to be considered further in the future development of the intervention. The approach allowed feedback to be obtained from experts across the UK in a timely manner and without the cost and logistical challenges of arranging a face-to-face meeting. Another strength of this approach is that panel members give their responses to the survey anonymously and were therefore not influenced by other experts who may have dominated in a face-to-face meeting due to their status or personality traits (Hsu and Sandford, 2007; Keeney et al., 2001).

A limitation of the study is that the expert panel represent a sub-group of the experts approached to participate in the study, and the potential for bias in the panel of experts who chose to participate in comparison to those who chose not to participate must be acknowledged. Keeney et al. (2001) argue that those who are more likely to be affected by the results of the survey are more likely to take part, and therefore the participating sample is a sub-group of experts whose opinion may differ from others who chose not to participate. The composition of the expert panel is likely to have a large impact upon the results of the survey and therefore there is a potential for bias as a result of the self-selecting sample. In this study, it is likely that experts with knowledge or interest in self-management would be more likely to participate and this may have impacted upon the findings of the survey. Those with an interest in self-management may be more likely to agree with aspects of the intervention than those without an interest in this area. In addition, the professional status of the participants is likely to have impacted upon the results. For example, it is perhaps unsurprising that the panel recommended that the intervention be facilitated by an SLT given that the majority of panellists were SLTs themselves.

The Delphi approach has also been criticised in terms of reliability; there is no guarantee the same consensus would be achieved if a different panel of experts was constructed (Keeney et al., 2001). It is therefore important to state that the findings of this study reflect the views and opinions of one group of experts at one point in time. Views and opinions are dynamic; constantly shifting and evolving which may also impact upon the reliability of the findings as the same panel of experts may reach a different consensus if they were asked to complete the survey again (Kennedy, 2004). However, the intention of this study was to aid the development of a self-management intervention and the findings are not considered to be definitive. Hasson et al. (2000) suggest that the Delphi approach should be interpreted as one opinion and be used to encourage debate and discussion or as a platform for further exploration of findings. A further limitation of this approach is that the comments given by panel members could not be discussed in detail or elaborated upon within the constraints of the survey. However, the Delphi survey does identify key areas of importance which can be seen as a first step in the development of knowledge (Hasson et al., 2000).

A final limitation of the survey is the attrition of panel members between study rounds. A decline in response rate is acknowledged to be a common problem in Delphi surveys and a reason why many surveys do not continue beyond three rounds (Keeney et al.,

2001; Hasson et al., 2000). Although steps were taken to minimise the attrition of panel members by sending clear instructions about the deadline for completing the survey and reminder emails between survey rounds, an attrition level of 26% was experienced between the first and second round of the survey. The attrition of clinical academics between the first and second round of the survey may in part be explained by the co-occurrence of a large conference on the deadline for completing the second survey. Two academics sent their apologies and stated that they had missed the deadline for the survey due to the conference. The co-occurrence of the conference was an unforeseen circumstance; however, the tight timescales for the completion of the survey would not have allowed for the second round of the survey to be delayed even if the author had prior knowledge of the event. It may be argued that panellists who disagree with the statements may be more likely to drop out of the subsequent rounds. If this was the case it might be expected that the majority of items recirculated in round two would reach an 'agree' consensus; however, only 3 out of 10 items circulated in the second round reached an 'agree' consensus with $\geq 75\%$ of panel members agreeing or strongly agreeing with the items.

Implications for intervention development

The findings of the Delphi survey were used to refine the approach outlined in Chapter Eight and to propose the design of the intervention and how this may be delivered in practice. Specifying the mode of delivery is an aspect of the BCW which is less well articulated by Michie et al. (2014) and researchers are simply asked to consider the APEASE criteria (Affordability, Practicability, Effectiveness and cost-effectiveness, Side-effects/safety and Equity). The author found these criteria to be less helpful in designing the intervention as they relied upon a subjective judgement or best guess about how the intervention may work in practice. Although the BCW provides a useful framework for outlining the function and BCTs within an intervention, there are many ways in which these might be delivered in practice (Michie et al., 2014). Webster et al. (2015) describe this as the "creative leap" (p.3) between having an outline of an intervention defined by the BCW and designing a fully functioning intervention which is workable in practice. For example, an important aspect of the intervention outlined is the provision of education about self-management. However, the way in which this information is delivered and paced is vital for ensuring accessibility and is likely to depend upon the linguistic ability of the individual. Previous research suggests that stroke survivors and their families may struggle to identify with the term 'self-management' (Satink et al., 2015b). Stroke survivors with aphasia may struggle to understand abstract concepts or low frequency words. Translating this abstract term in

a way which is meaningful for stroke survivors with aphasia may, therefore, be particularly challenging. The strong association between self-management and activity or 'doing' may be one way in which this concept is translated in to more concrete terms. However, input will be required from stroke survivors with communication difficulties in order to understand how this information may be presented in practice to maximise accessibility and meaning.

A limitation of using the BCW is that the intervention is focused upon changing an individual's behaviour and behaviours are considered in isolation of existing service provision until the end of intervention development. It is intended that this approach adds to and builds upon SLTs existing practice (rather than being a substitute for any part of this). However, defining precisely how this approach will fit within existing service provision is an important question which will need to be addressed in the future development of the intervention. Although the author proposes that the intervention is delivered prior to discharge from community services, the extent to which the intervention is delivered 'separate' to or 'integrated' within existing rehabilitation practices, is an important consideration. If SLTs are to deliver the proposed intervention, integrating this approach within existing rehabilitation practices may have important time and cost saving efficiencies (Jones et al., 2016). However, in order to successfully integrate the proposed self-management approach within existing practice, it will need to be clear how the approach fits with and adds to existing practice.

It might be suggested that the proposed self-management approach offers a framework for addressing broader difficulties with adaptation and adjustment including psychosocial wellbeing. However, many SLTs perceive that they already play a key role in addressing the psychosocial wellbeing of stroke survivors with aphasia during rehabilitation and emphasise the importance of person-centred care and holistic goal setting as an integral part of their practice (Northcott et al., 2018; Northcott et al., 2017). On the other hand, some SLTs also express challenges addressing psychosocial wellbeing due to a lack of time and training in specific approaches, particularly those which address psychological or emotional difficulties (Northcott et al., 2018). SLTs may wish to address wider participation goals, however, may also find this difficult to achieve in practice due to resource constraints and a lack of a clearly defined, structured and evidence based approaches to guide this process (Northcott et al., 2018).

Another difficulty which has been raised by SLTs is the generalisation of strategies which have been learnt in speech and language therapy to everyday life (Jacobs et al., 2004). Supporting stroke survivors with aphasia to translate strategies learnt in speech and language therapy to 'natural' settings is an important way in which the proposed self-management intervention suggests that stroke survivors with communication difficulties may be supported. Being supported to practise communication in context with an SLT may allow stroke survivors with communication difficulties to test out strategies learnt in speech and language therapy and gain confidence in using them in daily life or find alternative ways of managing. The extent to which this is currently performed within SLTs practice is unclear and again may vary according to the resources which are available within a given service.

Finally, the proposed self-management approach may also add to existing practice by pushing the boundaries of patient-centred care so that the stroke survivor is supported not only to collaborate with the SLT but is ultimately empowered to take a leading role in managing their condition moving forward (Mudge et al., 2015). This is supported within the proposed self-management intervention by a flexible approach to planning the areas to be worked on, support to engage in experiences which will contribute to learning about how difficulties may be managed in real life situations, and encouragement to reflect upon problems which may have arisen and how these might be solved. It is important to note that there was variation in practice in the role SLTs took within the therapeutic relationship in the findings of the fieldwork in this study. However, literature suggests that the balance of power within therapeutic relationships in stroke rehabilitation may often be weighted towards the healthcare professional (Lawton et al., 2016).

The communication difficulties experienced by this group of stroke survivors may present particular challenges to the development of a collaborative and empowered relationship as communication itself is often the basis of creating a shared understanding what the stroke survivor wishes to achieve during therapy (Sugavanam et al., 2013). Establishing a shared sense of purpose with a stroke survivor who experiences a severe receptive or expressive communication difficulty may be a challenging and time-consuming process (and in some cases may not be possible). Such difficulties may explain why there is sometimes a mismatch between stroke survivors and SLTs goals (Rohde et al., 2012) or why SLTs may take the lead in this process (Norris and Kilbride, 2013; Mudge et al., 2015). Some aspects of the proposed

self-management approach may also require high levels of cognitive ability, for example, in planning and executing actions or engaging in self-reflection and problem solving. This may be problematic for stroke survivors with co-occurring cognitive difficulties.

It is intended that the involvement of family members within the proposed self-management intervention will maximise the inclusion of stroke survivors with severe communication difficulties or co-occurring cognitive problems. The fieldwork highlighted the numerous ways in which family members often shared responsibility for condition management and supported the stroke survivor. SLTs identified that family members were likely to bear much of the responsibility for managing in cases where the stroke survivor had severe receptive communication difficulties or cognitive impairments. However, the interviews with SLTs again suggested variation in practice in the extent to which family members were involved in rehabilitation. The proposed self-management intervention may provide a framework to facilitate the consistent inclusion of family members wherever this is appropriate. Some aspects of conversation partner training may help to enable family members to develop conversational strategies to support the stroke survivor. However, the proposed self-management approach may add to this approach by giving family members additional support to apply these to daily situations and build confidence in managing through supported experience. This may enable family members to feel more prepared at the point of discharge for managing moving forward.

As described above, adopting a self-management approach may not require a radical redesign of rehabilitation services. Jones et al. (2017) suggest that on the surface self-management approaches may look quite similar to usual care; for example, goals are set, actions led by goals are undertaken and some form of feedback is given. However, the subtleties of the way in which this is done as part of a self-management approach may make a substantial contribution to overall experience of rehabilitation and feelings of preparedness to manage in the longer-term. Jones et al. (2017) suggest that the joint development of a plan for action and support for the individual to develop their own ways of managing (there being no 'right' or 'wrong' way to do things) are some of the ways in which confidence is built and individual agency is promoted as part of a self-management approach. Jones et al. (2017) suggest that this is different to usual care where the healthcare professional may lead the plan for action based upon their expertise and measure success based upon impairment focused markers.

Gaining a balance between supporting stroke survivors to take an empowered role within rehabilitation whilst neither leading nor leaving the stroke survivor to feel as though they are being left to manage alone may require significant skill and sensitivity (Jones et al., 2017). Although the BCW recognises the facilitator's role in changing behaviour, a limitation is that it underplays the significance of the training which may be required to help the facilitator enable behaviour change. There is a reciprocal relationship required to enable self-management which requires behaviour change both on the part of the healthcare professional and on behalf of the stroke survivor (or family member). The quality of this relationship and interaction may impact substantially upon the success of the intervention (Ferreira et al., 2013; Oliveira et al., 2012; Hall et al., 2010). The development of training and ongoing support for the facilitators of the self-management approach proposed in this study is important work which will need to be undertaken in the future. This will form a significant part of the iterative process which is required to refine the intervention and make the 'creative leap' towards an intervention which is ready to be tested in practice. Input from the facilitators of the proposed intervention (currently SLTs) will form an integral part of this process. This will also help to refine how aspects of the intervention are translated in to practice and ensure that it is accessible to stroke survivors with communication difficulties. Feasibility testing will be needed to further refine the intervention and ensure that it can be delivered in practice. Further discussion of the intervention and suggestions for how this could be developed in the future will be presented in the next chapter (Chapter Ten).

9.7. Conclusions

In this chapter, an expert panel provided feedback upon the self-management intervention proposed in Chapter Eight and this information was used to refine the design of the intervention. The intervention outlined is still in the early stages of development and further research is needed to ensure that it is acceptable to key stakeholders and feasible to deliver in practice. The next chapter provides a summary of the research undertaken in this thesis; discusses the strengths and limitations of the approach, and makes recommendations for future development and evaluation of the intervention.

Section Four:

Discussion

Chapter Ten: Discussion

This chapter draws together and discusses the overall findings of this PhD study. The findings are summarised and then critically examined in comparison to the existing literature. The strengths and limitations of the study and recommendations for the future development and evaluation of the intervention are also discussed.

10.1. Summary of thesis context

Research has demonstrated the profoundly negative impact that post-stroke communication difficulties can have upon quality of life and social and psychological wellbeing in the longer-term (Hilari et al., 2012; Hilari, 2011; Cruice et al., 2006). Self-management was identified as a possible candidate for providing a structured and clearly defined approach to support stroke survivors with communication difficulties to manage the consequences of their condition in the longer-term. A clear policy drive towards taking this approach in stroke care was identified in the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2016), the National Stroke Strategy (Department of Health, 2007), and health policy documents recommending NHS reform (NHS England, 2014; Foot et al., 2014; Department of Health, 2007). However, it was unclear whether self-management was a suitable approach for stroke survivors with communication difficulties, and research in this area was limited. This PhD study had two aims; firstly, to critically examine (the existing evidence base and explore through empirical study) the suitability of self-management as an approach for stroke survivors with communication difficulties, and secondly, to use this knowledge to make reasoned recommendations for the design of an intervention to support stroke survivors with communication difficulties in the longer-term. MRC (2008) guidance for the development of complex interventions provided a framework for designing the intervention.

10.2. Summary of key findings

A mixed methods systematic literature review explored the suitability of existing self-management interventions for stroke survivors with communication difficulties. The findings of this review highlighted how stroke survivors with communication difficulties are underrepresented in existing RCTs of self-management and suggested that the effectiveness of this approach for this sub-group is unclear. The thematic synthesis of qualitative research highlighted the significant and continuing need for longer-term support experienced by stroke survivors with communication difficulties. Four themes relating to longer-term need emerged which included; managing communication outside of the home, creating a meaningful role, creating or maintaining a support network and taking control and actively moving forward with life. The findings of the two systematic reviews were drawn together in a meta-synthesis. The meta-synthesis suggested that the underpinning ethos of self-management; to empower patients to manage the physical, social and psychological consequences of their condition (Barlow et al., 2002; Lorig and Holman, 2003) aligned well with the longer-term care needs identified in the thematic synthesis. However, it was also clear that existing self-management interventions in stroke failed to address key areas of need identified by stroke survivors with communication difficulties, including the need to manage the consequences of the communication difficulty itself. The meta-synthesis also highlighted that the mode of delivery of existing self-management interventions (e.g. those using group-based or telephone-based interventions or facilitators who were not trained in supported conversation techniques), may be inaccessible to many stroke survivors with communication difficulties. The meta-synthesis suggested that existing approaches to self-management are unlikely to meet the needs of stroke survivors with communication difficulties without significant adaptation.

Findings from the meta-synthesis suggested that further research was needed to explore the needs and priorities of stroke survivors with communication difficulties (and other key stakeholders) in relation to longer-term care. This work was necessary to ensure that the intervention designed was appropriate for stroke survivors with communication difficulties and driven by their needs and priorities. Qualitative fieldwork was undertaken with stakeholders including stroke survivors with communication difficulties, informal carers and SLTs. The fieldwork highlighted how stroke survivors and their carers engaged in multiple and recursive lines of work in order to manage their condition in the first year post-stroke. This work was undertaken within a context

which was constantly changing and evolving over time (for example, as recovery progressed and as support from healthcare professionals changed). The amount and type of work undertaken varied. Some were able to adjust and adapt and developed creative strategies to manage their communication difficulties. Others struggled to come to terms with their communication difficulties and began to withdraw from activities which involved speech and language. Factors which appeared to influence condition management included the time post-stroke, the availability of family support, personality characteristics, and the meaning of the communication difficulty within the stroke survivor's life. A key timepoint within the first year post-stroke was the point of discharge from community rehabilitation services. A sense of powerlessness, abandonment and uncertainty about services which could provide ongoing support was expressed by some. The findings of the fieldwork suggested that further support around this timepoint may be needed.

Many SLTs did not recognise the term 'self-management'; however, supported the idea of enabling stroke survivors with communication difficulties and their families to 'self-manage' and saw this as an integral part of their role and of rehabilitation. The actions SLTs took suggested that they strived to enable condition management in a number of ways; for example, by supporting and encouraging families to apply what they had learnt in speech and language therapy to everyday life and by educating carers about the best way to support their family member. However, SLTs also acknowledged the difficulties of building confidence and strategies to cope in the longer-term and expressed considerable frustration about the limited resources they had to do this in the community setting. Enabling longer-term management was perceived to be a complex process which was not only influenced by the severity of the stroke survivor's communication impairment, but also their readiness to engage with AAC approaches (and whether this was in line with their hopes or expectations about recovery). SLTs acknowledged that some stroke survivors and their carers may need additional support to manage the social and psychological implications of living with a communication difficulty at the point of discharge from community services and moving forwards.

The fieldwork undertaken highlights the complexities of building skills and confidence to manage in the longer-term. Self-management may be a useful approach for some stroke survivors with communication difficulties in smoothing the difficult transition to longer-term adaptation and adjustment at the point of discharge from community services. However, the findings also suggested that such an approach should be

adapted in order to address the specific problems which arise as a consequence of post-stroke communication difficulties. Condition specific adaptations were suggested in Chapter Seven, these included; increased flexibility of the approach, components targeting the management of the communication difficulty itself and including family members as 'co-managers' in the intervention (where appropriate). The BCW (Michie et al., 2014; Michie et al., 2011) was selected to guide the design of a novel, theory based self-management intervention for stroke survivors with communication difficulties. A Delphi survey was used to gain feedback on the design of the intervention by a panel of experts. This feedback was used to refine the intervention and inform how it may be delivered in practice. Recommendations for the design of a self-management intervention were proposed in Chapter Nine. The intervention aims to provide a flexible and tailored approach to support stroke survivors with communication difficulties to adapt to and manage the consequences of their condition in the longer-term. The intervention is at an early developmental stage and requires further evaluation. Plans for the future development of the intervention are outlined later in this discussion (Section 10.7).

10.3. Comparison with existing literature

The CDSMP designed by Lorig et al. (1999a) was one of the first self-management approaches. The CDSMP is a structured, group based programme, delivered by lay leaders and designed for patients with a range of chronic conditions including heart disease, lung disease, arthritis and stroke (Lorig and Holman, 2003; Lorig et al., 2001; Lorig et al., 1999a). Many self-management interventions are based upon this model; however, evidence to support this approach is limited. For example, a Cochrane review by Foster et al. (2007) found no benefit of the CDSMP in terms of increasing psychological wellbeing, quality of life or in reducing healthcare utilisation. More recently, there has been a shift away from mass educational-based interventions like the CDSMP towards individually tailored and disease specific self-management approaches (Taylor et al., 2014). Cochrane reviews have demonstrated benefits of such approaches in diabetes (Deakin et al., 2009), COPD (Zwerink et al., 2014) and asthma care (Gibson et al., 2009). Benefits of self-management interventions have also been demonstrated in stroke. A Cochrane review by Fryer et al. (2016) found a positive effect of stroke self-management interventions upon quality of life and self-efficacy. The authors concluded that self-management interventions are likely to benefit stroke survivors. However, the findings of this PhD suggest that this result should be

interpreted with caution as stroke survivors with communication difficulties are underrepresented in existing RCTs of self-management, and, evidence of the effectiveness of this approach for this sub-group is lacking. The meta-synthesis of literature undertaken in this study suggested that existing self-management interventions may be inaccessible to stroke survivors with communication difficulties and may not address their needs. This suggests that Fryer et al.'s (2016) findings may not be generalisable to all stroke survivors, and that the appropriateness of assuming a 'one size fits all' approach to self-management in stroke care should be questioned.

Existing stroke self-management interventions have been criticised for their lack of user involvement, and for being policy driven 'top-down' approaches, as opposed to being driven by the needs and experiences of stakeholders (Greenhalgh, 2009; Jones et al., 2013; Boger et al., 2013; Demain et al., 2014). In direct response to this criticism, the intervention designed in this thesis was informed by a comprehensive assessment of need from a synthesis of existing qualitative literature and primary qualitative research. Prior to undertaking the research reported in this thesis, little was known about the needs of stroke survivors with communication difficulties in relation to longer-term care. A comprehensive synthesis of qualitative research was undertaken which interpreted the literature in relation to longer-term need, addressing this gap in the evidence base. Comparing the findings of this review with similar qualitative literature reviews including stroke survivors without communication difficulties highlights a significant overlap in experiences (McKevitt et al., 2004; Satink et al., 2013; Walsh et al., 2015). For example, difficulties regaining valued roles, a sense of self, maintaining social relationships and reintegrating into the community have all been highlighted as problematic in stroke survivors without communication difficulties. However, findings from the review conducted in Chapter Two highlight how post-stroke communication difficulties present a unique barrier to participation in meaningful activities or maintenance of social networks. Communication plays a central role in maintaining friendship and when difficulties communicating occur, this acts as a barrier to maintaining friendship to both parties (the stroke survivor and the friend). Communication also acts as a facilitator and barrier to participation outside of the home, for example; a successful communicative interaction can act as a facilitator to participation in a valued activity and an unsuccessful interaction can act as a barrier to participation.

Review findings in Chapter Two highlighted a lack of qualitative research within the first year post-stroke. Interviews exploring the views and experiences of stroke survivors

with communication difficulties and their carers at a range of timepoints within the first year post-stroke were undertaken as part of this PhD study. This is one of few qualitative studies to explore how stroke survivors with communication difficulties and their carers manage their condition and their needs in relation to longer-term care in the first year post-stroke. Five studies were identified in the qualitative literature review in which participants had mean time post-stroke of less than one year (Brady et al., 2011a; Dickson et al., 2008; Grohn et al., 2014; Grohn et al., 2012; Pringle et al., 2010). In contrast to this study, which sampled participants at a range of timepoints within the first year post-stroke, Pringle et al.'s (2010) sample only included participants one month post-stroke and was focused upon experiences of coming home from hospital. Brady et al.'s (2011a) study described the impact of dysarthria upon social participation and Dickson et al.'s (2008) study described the psychosocial impact of dysarthria. In contrast to this PhD study, neither of these studies aimed to explore how participants managed their condition or their needs in relation to longer-term care.

The most comparable to this PhD study is a study by Grohn et al. (Grohn et al., 2012; Grohn et al., 2014). The authors interviewed 15 stroke survivors with aphasia at four timepoints in the first year post-stroke (3, 6, 9 and 12 months) in order to understand what facilitates living successfully with aphasia. The themes identified (engaging in meaningful activity, support, and maintaining positivity) have clear parallels with the themes identified in this PhD study (adapting activities and keeping busy, hope for recovery, obtaining support from healthcare professionals). However, the findings of this PhD study extend the findings of Grohn et al. (2014) by highlighting the importance of the trial and error approach in facilitating successful adaptation and adjustment for stroke survivors with communication difficulties. The importance of this process of experimentation has also been suggested in stroke survivors without communication difficulties (Scobbie et al., 2013; Kubina et al., 2013). As discussed in Chapter Seven, this was a complex process which required a considerable amount of back and forth work. Some stroke survivors and their family members demonstrated considerable creativity in the strategies they developed to manage communication difficulties on a daily basis. The findings suggested that such creativity should be recognised, supported and built upon as part of a self-management approach.

Qualitative fieldwork was also undertaken with SLTs as part of this PhD study. To the authors knowledge this was the first qualitative study to explore SLTs views regarding longer-term care for stroke survivors with communication difficulties and their

understandings of the term 'self-management'. A novel finding of the research was that despite being an approach which is recommended in the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2016), 'self-management' was a term which was not recognised by many SLTs. Although SLTs did not recognise this term (and had not received any training in this approach), they saw enabling condition management as an integral part of their role and described the steps they took to support this. However, building confidence in communication and strategies for condition management was complex and required a significant investment of time and resources. Many SLTs expressed considerable frustration at the amount of resources available for speech and language therapy in the community setting. Resource constraints required SLTs to make difficult decisions about the amount of time they spent on a particular aspect of therapy. For example, time spent focused upon restorative approaches to speech and language therapy inherently meant a trade-off in terms of time which could be spent focusing upon compensatory strategies or conversation partner training. SLTs also suggested that the support which was available following discharge from community rehabilitation services was patchy. This mainly took the form of peer support groups provided by charitable organisations. However, such groups were often difficult for stroke survivors with communication difficulties to attend and SLTs cited a range of barriers to accessing these.

The qualitative fieldwork undertaken in this PhD study highlighted how some stroke survivors with communication difficulties needed further support to adjust to and manage the consequences of their condition in the longer-term. A self-management intervention was designed to address these challenges. The complex intervention described is at a very early stage of development and will require further work to develop the design and ensure feasibility and acceptability to key stakeholders. The proposed intervention is consistent with the underpinning ethos of self-management; to empower patients to manage the physical, psychological and social consequences of their condition (Department of Health, 2001; Barlow et al., 2002; Lorig and Holman, 2003; Taylor et al., 2014). However, it has also been adapted in a number of ways in order to address the longer-term needs of stroke survivors with communication difficulties.

Firstly, the approach moves away from the group based educational approaches (akin to the CDSMP) which were used by a number of the stroke self-management interventions reviewed in Chapter One (Aben et al., 2013; Aben et al., 2014; Cadilhac

et al., 2011; Kendall et al., 2007; Marsden et al., 2010; Sabariego et al., 2013). Group based approaches may be inaccessible to many stroke survivors with communication difficulties. They also illustrate a prescriptive approach to self-management whereby participants work through a series of pre-determined sessions in a set order. This suggests that being educated in a set number of skills in a set order will enable effective self-management. However, the findings of the fieldwork suggested that the best way for an individual to 'self-manage' was often discovered through a trial and error process, which comprised a considerable amount of back and forth work and continued over an extended period of time. This was a complex process which was influenced by a number of factors e.g. the severity of the communication impairment, the cognitive ability of the stroke survivor, personality characteristics and the availability of family support (Kubina et al., 2013; Scobbie et al., 2013). The self-management intervention proposed in this thesis is designed to support stroke survivors with communication difficulties on a one-to-one basis, to discover how they wish to manage the difficulties they face, within their own particular context. Although the introductory session is structured, the overall approach is not prescriptive and is tailored based upon the areas identified as being important to the stroke survivor (and/or family member if appropriate). The facilitator may suggest strategies to enable the stroke survivor but equally the approach is flexible to support the stroke survivor (and/or family member if appropriate) to develop their own ways of managing. This approach is designed to understand, support and build upon the work already undertaken by stroke survivors with communication difficulties and their families so that they feel confident about their ability to manage at the point of discharge from community rehabilitation services and moving forwards.

The second way in which the proposed self-management approach has been adapted is through addressing the management of the communication difficulty itself. None of the self-management interventions identified in Chapter One explicitly addressed this need, however, this was a salient problem identified in both the literature reviewed and fieldwork undertaken. As noted previously, post-stroke communication difficulties present a unique barrier, for example, to participation in meaningful activities or maintenance of social networks. The need to manage the communication difficulty is addressed within the self-management intervention by the potential for the stroke survivor to be supported to practise their communication (including AAC strategies) in meaningful contexts and for members of family or friends to be trained in strategies to support communication. This work will be led by the wishes of the stroke survivor and their family and is designed to support them in the process of figuring out which

strategies may be useful and/or developing their own strategies to manage. The approach taken is likely to depend upon the type and severity of communication difficulty experienced by the stroke survivor and whether they have any co-occurring cognitive difficulties. For example, due to their receptive impairments, stroke survivors with Wernicke's aphasia may find it difficult to self-monitor their spoken language, recognise errors in this, and implement compensatory strategies. Similarly, stroke survivors with communication difficulties and cognitive problems may be unable to generalise compensatory strategies to real life situation if they have deficits in memory or attention. In these cases, a family member might be supported to provide assistance or prompt the stroke survivor as necessary in these situations.

It is important to acknowledge that training in AAC strategies or communication partner therapy may already be part of existing speech and language therapy (Simmons-Mackie et al., 2010; Jacobs et al., 2004). However, SLTs in this PhD study identified how resource constraints were a significant barrier to providing these in practice. The self-management approach provides a framework to ensure that the stroke survivor and their family member are supported to practise these strategies (in meaningful contexts) and discover if they helpful. This may also differ from the AAC or communication partner training delivered as part of speech and language therapy where the approach delivered may be led by the professional's expertise as opposed to being led by the patients (and family's) experience and a process of joint discovery about what works (Barlow et al., 2002; Lorig and Holman, 2003).

The third way in which the proposed self-management approach has been adapted is through the involvement of family members. The majority of self-management interventions identified in Chapter One focused upon the stroke survivor and did not consistently include family members in the intervention. However, the findings of the fieldwork suggested that for many stroke survivors with communication difficulties support from family and friends was vital to manage the challenges they faced. Taking an individualistic approach to self-management underplays the important role others have in supporting and enabling self-management (Satink et al., 2015b). For stroke survivors with communication difficulties, the term 'self'-management should be extended to encompass those providing support and those providing support should be actively included in self-management interventions. It is also important to acknowledge the different levels of self-management which may be achievable depending upon the severity of the stroke survivor's communication difficulty. The findings of this PhD study

support the suggestion by Satink et al. (2015a) that self-management should be considered as a continuum upon which stroke survivors (and their families) should be supported to manage as far as possible. By considering self-management in this way those with more severe communication difficulties (who may require more support from others) are not excluded from the intervention developed in this thesis. The intervention proposed in this PhD study can be tailored to support different levels of self-management (and family involvement) depending on the individual's circumstances.

The CDSMP has previously been criticised for failing to take into consideration the social context of the individual (Vassilev et al., 2011; Kendall and Rogers, 2007). Creating or maintaining a support network was an important need identified as part of the thematic synthesis of qualitative research undertaken in Chapter Two. The self-management intervention designed in this PhD study supports the stroke survivor to consider opportunities for social support and participation if they have identified difficulties in this area. Only one stroke self-management intervention identified in Chapter One explicitly targeted the mobilisation of social networks. However, Glass et al. (2004) excluded stroke survivors with severe communication difficulties and participants "who had no social network with whom interventionists could collaborate" (p. 889). In contrast, the intervention designed in this study would aim to be inclusive of stroke survivors with communication difficulties who had no (or a significantly reduced) social networks. The 'my support team' module allows the facilitator to work with the stroke survivor to identify opportunities for social support and provide active support to enable participation in social opportunities where this is meaningful to the stroke survivor. On the other hand, it is important to recognise that due to the nature of some post-stroke communication difficulties, it may be difficult to build social support in some cases if the stroke survivor does not have an existing support network. For example, those with severe Wernicke's aphasia or cognitive difficulties may need ongoing support and prompting in social situations. If ongoing support cannot be identified, the self-management intervention proposed in this thesis may not be suitable for stroke survivors with communication difficulties in these circumstances.

In Chapter Three, potential challenges with the accessibility of existing stroke self-management interventions for stroke survivors with communication difficulties were identified. The intervention proposed in this thesis has attempted to maximise accessibility. Firstly, by delivering the intervention on a one-to-one basis, different components of the intervention can be tailored depending on the type and severity of

communication difficulty. For example, the accessibility of components of the intervention which aim to facilitate meaningful activities (including communication outside of the home) can be maximised for those with Wernicke's aphasia or cognitive difficulties by training carers on the best way to support their family member in these situations. Secondly, the accessibility of the proposed intervention may also be maximised by having SLTs as facilitators. This will ensure that communication about the intervention is delivered and paced at an appropriate level, depending upon the type and severity of the communication difficulty.

Whilst accessibility has sought to be maximised, the proposed intervention is at an early stage of development and accessibility must be considered throughout the design and implementation of the intervention moving forward. For example, information or materials which might be provided as part of the intervention or prompts to support discussion about self-management must be designed to be aphasia friendly (Stroke Association, 2012b). The expertise of key stakeholders (including stroke survivors with communication difficulties, family members and SLTs) will be key to develop the design and maximise the accessibility of the intervention as it is refined and implemented in practice (see Section 10.7 for further discussion). It is also important to acknowledge that for some stroke survivors with communication difficulties, for example, those with global aphasia or those without a family member or social network able to provide support, it may not be possible to implement the self-management strategies outlined in the proposed intervention.

The self-management intervention designed in this study also differs from the existing literature by using a theoretical framework to design the intervention. The MRC (2008) framework has been criticised for lacking detail on how theory should be chosen or used in intervention development. This potential limitation was overcome by using the BCW; a theory based framework for developing complex behaviour change interventions (Michie et al., 2014; Michie et al., 2011). To the author's knowledge, this is the first time the BCW has been used to develop a self-management intervention in stroke. An advantage of using this approach is that the intervention is designed in a transparent way with clear linkage between the underpinning theory of behaviour and the components of the intervention. Often, the way in which the theory was linked to the components of the intervention was not clearly reported by the stroke self-management interventions identified in Chapter One. This suggests that such

interventions were 'inspired' by theory as opposed to using it as a robust method to design the intervention (Michie and Prestwich, 2010).

However, using the BCW was not without difficulties. Previous work using the BCW has often targeted simpler behaviours, for example, hand hygiene, condom use, or dental hygiene (Asimakopoulou and Newton, 2015; Fuller et al., 2014; Bailey et al., 2015). Defining self-management in behavioural terms was difficult as the findings of the fieldwork suggested that self-management may have different meanings depending upon the individual (and therefore encompass a range of different behaviours). By focusing upon a very specific set of behaviours, there was a danger the intervention would become overly constrained or prescriptive (Odgen, 2016). This difficulty was overcome by defining the target behaviours in broader terms. This allowed some flexibility to ensure that the targets for intervention would be relevant for this heterogeneous group of stroke survivors. However, arguably this does not fit with the precise way in which the BCW recommends that behaviours are specified. The BCW is a relatively new framework and the difficulties encountered suggest that the approach may need to be adapted for use with different populations and contexts (Michie et al., 2011). It is also important to note that the BCW is not a 'magic bullet' for intervention design, and there is some degree of subjectivity in the way in which BCTs are chosen and applied (Michie et al., 2014).

It is important to acknowledge that there is some emerging literature on longer-term care interventions for stroke survivors with communication difficulties. Ryan et al. (2017) recently reported upon the findings of a phase I trial testing the feasibility of the Aphasia Action Success and Knowledge (ASK) programme to promote positive psychosocial adaptation to aphasia post-stroke. There are a number of similarities between the ASK intervention and the intervention developed in this thesis. For example, both concentrate upon supporting adaptation to post-stroke communication difficulties, are based around goal-setting, and are delivered by SLTs. However, there are also important differences between the two interventions. For example, the ASK programme is delivered in the hospital setting, in comparison to the proposal to deliver the intervention developed in this thesis in the community setting. An additional contrast is that although the authors of the ASK approach cite a number of theories which informed the intervention, there is no clear statement of how such theories linked with components of the intervention, or, which components of the intervention were hypothesised to bring about change. It is also surprising that no assessment of

intervention fidelity was undertaken as part of this feasibility study. Training SLTs to implement such an approach (which may require a departure from what might be seen as their traditional role in assessing and treating speech and language impairment) may be a complex process. Although SLTs report that addressing psychosocial wellbeing is an important and integral part of their role, they also report a lack of confidence and training in this area (Nothcott et al., 2018; Northcott et al., 2017). It would, therefore, be important to ensure that any intervention which sought to address psychosocial wellbeing adequately supported SLTs to implement such an approach in practice. Similarly, a lack of resources and time constrained services were also cited as barriers to SLTs addressing psychosocial wellbeing and these may also impact upon the implementation of such an approach in practice (Nothcott et al., 2018; Northcott et al., 2017). If any difficulties with implementation are not identified at the feasibility stage this may impact upon the efficacy of this approach when tested on a larger scale.

In addition to the ASK programme, there is also ongoing work to adapt existing self-management approaches to increase accessibility for stroke survivors with communication difficulties. For example, Patterson et al. (2015) presented a poster about how they adapted a stroke self-management programme to increase accessibility for stroke survivors with aphasia at the Canadian Stroke Congress conference in 2015. The Bridges self-management team also report revising the workbook associated with their intervention to increase accessibility for this sub-group of stroke survivors on their website (Bridges Self-Management, 2017). Increasing accessibility of self-management interventions is of value; however, the extent to which such interventions address the condition specific management of post-stroke communication difficulties is unclear. None of the approaches outlined have been tested for effectiveness in a full scale RCT, but it is important to acknowledge that research in this area is emerging rapidly. Full RCTs of the Bridges approach (Jones et al., 2016) and the ASK intervention (Worrall et al., 2016b) are currently in progress.

10.4. Reflections upon the concept of self-management

In theory, self-management offers an opportunity to break away from traditional biomedical models of care and to empower stroke survivors and their families to manage life after stroke (Holman and Lorig, 2000; Foot et al., 2014). This multicomponent approach is increasingly being advocated as the solution to

addressing the complex interplay of physical, social and emotional influences which may impact upon longer-term adaptation and adjustment following stroke (Fryer et al., 2016; Intercollegiate Stroke Working Party, 2016; Department of Health, 2007). There is an overwhelmingly positive rhetoric concerning the translation and implementation of self-management approaches in stroke. However, despite its promise, it has been argued that the push towards taking this approach is largely professionally and policy driven; a means to save cost and promote compliance with healthcare professionals perceptions about how long-term conditions should be managed (Kendall and Rogers, 2007).

The intervention proposed in this thesis has attempted to retain as much flexibility as possible and to move away from prescriptive approaches to self-management. The proposed intervention is designed to support stroke survivors with communication difficulties and their family members on their journey to discover how best to adjust, adapt and manage the challenges they face. The findings of the fieldwork suggest the numerous ways in which stroke survivors with communication difficulties undertook work to manage their condition and the creativity and resourcefulness with which they did this. In this sense, stroke survivors and their family members did manage their condition and therefore the relevance of the concept of self-management for some members of this population may be questioned. In particular, should the condition management process be facilitated by an intervention or should this work be left to occur naturally so that stroke survivors with communication difficulties and their family members have time to adapt and adjust. The literature reviewed and fieldwork undertaken suggests that further support is desired by some stroke survivors and their families to manage life after stroke with a communication difficulty. The need for further support is also recognised by SLTs. The challenge for the self-management intervention proposed in this thesis may be to ensure that the focus is upon enabling and supporting condition management in a way which is meaningful for the stroke survivor and their family member within their own particular context. This is in contrast to being driven by professional assumptions about there being a 'right' or 'wrong' way to manage or for an ideal of self-management to be imposed upon stroke survivors with communication difficulties and their families.

It is also important to highlight that there was substantial variation in the work that was undertaken by stroke survivors and their families and the extent to which this led to feelings of confidence in ability to manage. For example, whilst some stroke survivors

were able to develop strategies to manage their condition, others struggled and were left with a sense of uncertainty about what they should do next. Undertaking condition management work without support may also have contributed to the feelings of disempowerment and abandonment experienced by many participants at the point of discharge from community services. Feeling supported whilst figuring out how to manage is a key aspect of the self-management approach proposed in this thesis. However, it is important that the support provided builds upon the work already undertaken and does not stifle the creativity of stroke survivors with communication difficulties and their family members in developing their own coping strategies. The role of the facilitator in supporting but not directing condition management will be key. Jones et al. (2017) suggest that letting stroke survivors and their families take the lead in problem solving within a self-management intervention helps to develop feelings of control over ability to manage and skills which can be drawn upon again as needed in the longer-term (once support from the self-management intervention has ended). This may be a particularly challenging task for stroke survivors with communication difficulties who may vary in their readiness and capacity to take the lead in problem solving or condition management. The facilitator must be able to recognise the difficulties which might be presented by the type and severity of communication difficulty and ensure that support is provided in an appropriate way (for example, via the inclusion of family members or tailored AAC strategy suggestions) so that self-management may be enabled as far as is possible.

Some have also suggested that the concept of self-management places too much responsibility on the individual and does not acknowledge how the individual's ability to manage is influenced by the services and resources available to facilitate self-management (Kendall and Rogers, 2007, Vassilev et al., 2010). For example, the self-management intervention proposed in this study suggests that the facilitator may signpost or provide graded support for the stroke survivor to attend community based communication groups. However, this makes an assumption that such services are available within the local area. Greenhalgh (2009) suggests a number of levels at which responsibility for managing chronic illness lies; this not only includes the individual (who should be supported with the right skills and education to manage) but also health professionals and services (which provide accessible and multidisciplinary support) and wider society (which should create the right environment and remove structural and cultural barriers to participation). Although self-management may aim to promote the active participation and empowerment of patients, it should also be recognised that other services and resources must also be available in order to support

the management of the condition. Charitable organisations such as the Stroke Association play a key role in the provision of ongoing support to many stroke survivors with communication difficulties. However, the recent closure of the aphasia charity CONNECT and merger of Speakability with the Stroke Association suggests that the options for the provision of support within the charitable sector may be changing or reducing.

The fieldwork undertaken in Section Two of this thesis repeatedly highlighted the lack of resources not only for speech and language therapy in the community but also for other services such as psychological support. SLTs also highlighted cuts to the support which was available in the charitable sector e.g. one to one support or the availability of communication groups. There is a danger that a self-management approach may be seen as a substitute to adequately resourced rehabilitation services or the provision of other longer-term support services such as those provided by the charitable sector. Whilst self-management may be one component of longer-term care, it is important that this approach sits within a well-defined longer-term care strategy where stroke survivors with communication difficulties are able to access different types of services and support as needed. A self-management approach may play a role in facilitating access to locally available services in a consistent and co-ordinated manner.

10.5. Strengths and limitations

A strength of this PhD study is that it employed a systematic and staged approach to intervention design which was informed by comprehensive and systematic reviews of the literature and the careful consideration of the views and experiences of key stakeholders (MRC, 2008). Stroke survivors with a range of communication difficulties (including those with moderate to severe difficulties) were successfully included in the qualitative fieldwork which helped to inform the intervention. This can be a difficult to reach population and the methods used were carefully considered and adapted in order to facilitate their inclusion (adaptations to the consent process, interview and focus group methodology are detailed in Chapter Four). The intervention is designed to meet the longer-term needs of stroke survivors with communication difficulties. To the author's knowledge, this is the first self-management intervention to be specifically designed for stroke survivors with communication difficulties.

A further strength is that the intervention was designed using a theoretical framework. The BCW provides a coherent link between an underlying theory of behaviour (the COM-B model), the proposed functions of the intervention and the BCTs used to change behaviour. Specifying the BCTs in this way provides a clear hypothesis about the 'active' ingredients of the intervention which allows the intervention to be replicated or subject to further evaluation in the future. This is necessary for improving cumulative knowledge on complex behaviour change interventions in order to better understand which BCTs are likely to be successful, for whom and in what circumstances (Michie and Johnston, 2012). Gaining knowledge about the 'active' ingredients of self-management interventions is important in order to inform the development of effective interventions for stroke survivors with communication difficulties in the future.

The BCW requires target behaviours to be identified and defined precisely as a starting point for intervention development (Michie et al., 2014). As discussed previously, specifying behaviours which would be targeted as part of the self-management approach using the COM-B model was challenging. Reflecting upon this, it is also a process which is perhaps counterintuitive to the findings of the fieldwork. The fieldwork highlighted the diverse range of ways in which stroke survivors and their family members managed; condition management was a highly personal and context specific process. Therefore picking single behaviours which might support this highly complex process did not seem to fit with the way in which stroke survivors and their family members described their experiences of managing multiple and overlapping lines of work. Similarly, it was difficult within the COM-B model to capture how the severity and type of communication difficulty may influence an individual's ability to perform a behaviour. A limitation of the COM-B model is its flexibility to account both for the complex system of behaviours which might make up self-management, and, the heterogeneity of difficulties experienced by stroke survivors with communication difficulties and how these may influence condition management.

MRC (2008) guidance places a strong emphasis on the use of theory in complex intervention development. The COM-B model provides an overarching theory of behaviour and how behaviour change might be facilitated (Michie et al., 2014; Michie et al., 2011). However, this approach also relies on the judgement of the researcher or the research team in conducting the behavioural analysis and in choosing accompanying intervention components. Although this is often informed by stakeholder views and experiences (Michie et al., 2014), it does not necessitate the active

involvement of stakeholders in the actual design of the intervention. Therefore, the intervention may be designed relatively independently of the stakeholders it is aimed at. Although the BCW allows a theoretical understanding of a problem (and theoretical understanding of techniques which may help facilitate change) to be developed, translating this theoretical understanding into an intervention which is both feasible and acceptable to stakeholders in practice will require considerable work.

A limitation of the intervention proposed in this thesis is the lack of stakeholder involvement in the design of the intervention to date. Whilst this is planned for the next stage of development, an alternative method to using the BCW to design the intervention may have been to use a participatory research approach (Cargo and Mercer, 2008). A number of different participatory research approaches have been formulated including; Transdisciplinary Action Research (TAR) (Stokols, 2006), Co-Production (J. Hawkins et al., 2017; Voorberg, Bekkers and Tummers, 2015) or Experience Based Co-Design (EBCD) (Robert et al., 2015; Donetto et al., 2015; Bate and Robert, 2006). Participatory research approaches involve the active participation of the user in service or intervention design (Bate and Robert, 2006; J. Hawkins et al., 2017). Bate and Robert (2007) suggest that such approaches are distinct in co-designing 'with' the patient as opposed to 'around' the patient. Participatory based approaches are, therefore, more applied than collecting participant's views and involve key stakeholders actively working together, using their experience, to re-design or improve a service or intervention. Such approaches recognise the value of the user's knowledge and experience and attempt to harness this in the design of services or interventions (Clarke et al., 2017; Baltaden et al., 2015). Using such approaches to design the intervention proposed in this thesis may have increased the likelihood that the intervention is feasible and acceptable to key stakeholders at an earlier stage of development.

Participatory research approaches advocate the active involvement of patients in service or intervention design and appear to chime well with the underpinning ethos of self-management approaches which advocate the active involvement of patients in their own care and condition management (Lorig and Holman, 2003). The design of self-management approaches has previously been criticised for being 'top-down' and policy driven as opposed to being driven by the needs and experiences of key stakeholders (Greenhalgh, 2009; Jones et al., 2013; Boger et al., 2013; Demain et al., 2014). In response to this criticism, the fieldwork undertaken with key stakeholders in

this thesis played a key role in informing the design of the intervention. However, it might be argued that this does not truly constitute a 'bottom-up' approach to intervention design in the same way as a participatory research approaches such as TAR (Stokols, 2006), EBCD (Bate and Robert, 2006; Bate and Robert, 2007) or Co-production (J. Hawkins et al., 2017; Voorberg, Bekkers and Tummers, 2015). On the other hand, the approach in this thesis has recognised and sought to harness the experiences of stroke survivors with communication difficulties in order to improve longer-term care. It is also important to note that the proposed intervention is at an early stage of development. Principles of participatory research will be used to further develop the intervention and strengthen the voice of the stakeholder within the design of the intervention (see Section 10.7 for further discussion).

Another limitation of this study is that it designed a self-management intervention which is targeted to begin at the point of discharge from community services. This decision was made as a result of the consensus reached in the Delphi survey and the findings of the fieldwork which suggested that stroke survivors with communication difficulties needed further support to manage at the point of discharge from these services. However, it is important to acknowledge that some Delphi panellists and SLTs interviewed suggested that preparations for stroke survivors and their families to 'self-manage' may need to begin in the hospital setting. On the other hand, some Delphi panellists and SLTs interviewed suggested that some stroke survivors and their families may not be ready at this point to engage in such an intervention. The qualitative fieldwork undertaken with stroke survivors and their families also suggested that there may be significant variation in participant's 'readiness' to engage with a self-management approach. Readiness may not be tied to any particular time post-stroke but may be associated with a range of personal and contextual factors (e.g. age and life stage of participant, severity of communication difficulty, impact of communication difficulty upon ability to engage in previous occupations, beliefs about recovery).

Alternative methods may have been used in order to further understand which factors may influence readiness to engage with a self-management intervention. A limitation of the qualitative fieldwork reported in Chapter Five is that stroke survivors and carers were interviewed at one time point within the first year post-stroke. An alternative approach may have been to use a longitudinal qualitative design where participants were interviewed at a number of points over time (McLeod and Thomson, 2009). This design may have been advantageous in helping to further illuminate how transitions to

longer-term adaptation, adjustment and condition management occur over time and which factors may inhibit or facilitate this process (R.J. Hawkins et al., 2017). This may have contributed to the development of the proposed intervention by ensuring it is fully attuned to support individual variation in the process and meaning of recovery. Given the variability in participant's experiences of longer-term adaptation, adjustment and condition management, it may also have been useful to interview participants beyond 12 months post-stroke. This may have provided additional insight into our understanding of 'readiness' and of what type of self-management intervention should be offered and when.

The variability in readiness to engage in approaches which support the management of the condition presents a significant challenge to healthcare services which tend to offer services at fixed time points within a care pathway. Based upon the experiences of stroke survivors and their carers, a more flexible approach to delivery may be needed. One option might be for stroke survivors with communication difficulties and their families to be able to access self-management support at any time post-stroke. However, this approach is likely to require a substantial investment of time and resources which may not be available, particularly within community rehabilitation teams. An alternative approach might be for a self-management approach to be implemented within services at more than one point during the existing care pathway. Previous research has suggested the importance of taking a 'whole systems' approach; implementing self-management approaches within and across services (Kennedy et al., 2007). Cameron and Gignac (2008) devised the 'Timing it Right' framework to highlight how the needs of carers of stroke survivors change over time and how interventions should be staged in order to reflect this. Although it was not possible within the time constraints of a PhD to design a staged intervention, a staged approach to delivering self-management interventions across the care pathway is likely to be appropriate. Further research is needed in order to understand the type of self-management education that could be provided to stroke survivors with communication difficulties in the hospital setting and how the principles of self-management could be implemented across the care pathway.

Finally, a limitation of this PhD study is that the searches for the systematic reviews were undertaken in 2015. Although the literature was scoped more recently as part of preparations to submit this thesis there is the possibility that relevant literature was missed. It is also important to acknowledge that the qualitative fieldwork which was

used to inform the intervention was conducted in a single geographical region and may not be representative of services across the country. On the other hand, the findings of the fieldwork were generally consistent with the qualitative literature reviewed in Chapter Two and this literature was also used to inform the intervention. In addition, the panel of experts who gave feedback upon the intervention in Chapter Nine were based across the UK.

10.6. Reflexive statement

One of the greatest challenges I found in undertaking this PhD was making choices about which research methods to use as part of the project. This was a key distinction between the work I had undertaken previously, and the work I would undertake on this project as an independent PhD researcher. In the first year of my PhD, the options open, and directions the project could have taken, were seemingly endless and somewhat overwhelming. Choosing an established framework for intervention development, such as the MRC (2008) guidance, was a logical choice and offered a concrete structure to guide my PhD project. On the surface this framework is a step by step guide to move from idea to intervention. As a novice researcher, having some guidance on this process was a helpful starting point. However, the difficulties of designing a multifaceted, multicomponent intervention for a highly complex population were evident throughout the project and much more of a challenge than might be suggested by the stepwise progression outlined by this framework. MRC (2008) guidance also places a strong emphasis on the importance of theory in relation to intervention development. However, finding a theoretical framework which could guide the design of the intervention and account for the complexity of the topic (self-management) and population (stroke survivors with communication difficulties) was not easy. Balancing the demands of including theory within the design of the intervention and accounting for the complexity suggested by the findings of the fieldwork was a significant challenge.

As discussed in the preceding section, reflecting upon this process, it may have been preferable to have further involvement from key stakeholders (including stroke survivors with communication difficulties and their family members) in the design of the proposed intervention at an earlier stage. Although there may be challenges of doing so (see Section 10.7 for further discussion), the fieldwork I have undertaken to date

suggests the value of including this group in the research process and the vital contribution understanding their experiences can make to the design of healthcare services. It has been a pleasure to build a relationship with the stroke survivors with communication difficulties and family members who participated in this research. It has also demonstrated how, with adjustments to maximise inclusion and participation, this group can make an important and meaningful contribution to research. It is imperative to harness this group's expertise of living with post-stroke communication difficulty to contribute to the design of the intervention proposed in this thesis moving forwards.

Undertaking this PhD has provided an opportunity to engage with a range of research methods. A significant realisation throughout this process is that the application of particular methods may not have the anticipated outcome in practice. For example, following the MRC (2008) guidance was not a stepwise progression which led to the design of a neat and fully defined intervention. The work needed to get to this stage is more iterative and complex than I could have imagined at the outset of my PhD. Similarly, in undertaking the qualitative synthesis reported in Chapter Two, the method of thematic synthesis was limited in gaining a high level of abstraction and interpretation of the data. A greater level of abstraction may have offered further insights and offered a more nuanced contribution to the development of the intervention. This experience has been a learning process and if I were to conduct a synthesis of qualitative research in the future, I would approach the synthesis in a way which was more mindful of the different levels of interpretation which may be possible. Allowing extra time for the analysis (to compare and contrast the studies included and consider what meaning might be drawn from similarities and differences in their findings) is one way in which I have learned from my experience of this project. As a novice qualitative researcher, I also learned that the collection and interpretation of qualitative data is a considerable skill. Drawing interpretations from qualitative data is not a skill which came naturally to me, and is a process which I found to be challenging and at times frustrating. Being mindful of representing the complexity and nuances of the findings in my interpretation is something which I have learned from this experience and which I will carry forward in the future. Again, allowing more time for deeper reflection during this process may help.

In sum, getting to grips with the methods used in this project has been challenging. However, when I started the project, it was with an intention to learn as much a

possible from the process and step out of my comfort zone as a researcher. In doing so, I feel I have gained significantly in knowledge and skills I will use moving forwards.

10.7. Research recommendations: Intervention development

The intervention designed in this PhD study is at an early stage of development. As discussed previously, further work is required in order to translate the proposed intervention into a fully functioning intervention which is workable in practice. Given the limited amount of stakeholder involvement in the design of the intervention proposed in this thesis, it is imperative that the ongoing development of the intervention involves input from stroke survivors with communication difficulties, carers and SLTs. This will ensure that the intervention is acceptable to the target population and feasible to deliver in practice (J. Hawkins et al., 2017). J. Hawkins et al. (2017) and Connell et al. (2015) used intervention development groups to discuss, refine and agree the design and content of their interventions with stakeholders. Subject to further funding being secured, an intervention development group will be established to progress the intervention proposed in this thesis. It is anticipated that this group comprised of key stakeholders who would meet on a regular basis, over a period time, in order to contribute to the design of the proposed intervention.

The way in which an intervention development group could contribute to the design of the intervention moving forward would need to be considered carefully. Participatory research designs are often based heavily on language and therefore it may be challenging for stroke survivors with aphasia to engage in this process. However, Wilson et al. (2015) cite a number of ways in which they engaged stroke survivors with aphasia in co-designing two computer applications. The authors suggest that simply asking participants what they want is unlikely to be effective but that creative and generative tools are needed to engage the audience in this process. Wilson et al. (2015) describe this as an iterative process of trying and adapting different tasks in order to engage their participants. Successful techniques included using images, gestures and prototypes in order to engage participants. For example, they describe using a gesture game as an ice-breaker task and asking participants to bring photo diaries of their week in order to establish common ground. The creation of tools and tasks for an intervention development group for this PhD study would need to be designed carefully. It may be difficult to achieve a balance between creating tools and tasks which are

accessible to those with severe aphasia, and ensuring that tasks are not perceived to be overly simplistic to those with less severe communication difficulties (Hendriks et al., 2015).

Once the design of the intervention has been developed, it will also be necessary to develop training and support for the facilitators of the approach to deliver the intervention in practice. The content of the training will depend upon the final design of the intervention and the extent to which the approach will be delivered separate to or integrated within existing practice. However, it is likely to including training in a structure by which to implement the intervention and training in key skills (led by feedback about what might be useful from the potential facilitators of the approach) to deliver the intervention. Both aspects of this development work (refining the design of the intervention and developing training for the facilitators of the intervention) will be vital before the intervention can progress to feasibility testing.

Following MRC (2008) guidance, the next stage of intervention development is to assess the feasibility of the proposed intervention. Feasibility studies are used in order to evaluate the viability of the intervention in practice, for example; the willingness of clinicians to participate, the acceptability of the intervention to participants, and in some cases the outcome measure to be used in the main evaluation of the intervention (Arain et al., 2010; Craig et al., 2008). A feasibility study is done in order to inform key features of the intervention or the implementation of the intervention before further testing in a main evaluation (NIHR, 2017).

A key area to be explored as part of feasibility testing in this study is to evaluate who would be best placed to facilitate the intervention. As reported in Chapter Nine, Delphi panellists suggested that it would be preferable for a SLT to facilitate the self-management intervention. However, this finding is likely to reflect the fact that the majority of the panellists were SLTs themselves. Previous research highlights the difficulties of training healthcare professionals to deliver self-management approaches (Kennedy et al., 2014; Norris and Kilbride, 2014). For example, in a qualitative process evaluation of their primary-care based self-management intervention, Kennedy et al. (2014) found that many staff failed to embed self-management approaches in their day to day practice, despite participating in and providing positive feedback about self-management training. Many of the staff in participating practices based their approach

around the biomedical model and the findings suggested that this was a barrier to implementing a self-management approach in practice as staff perceived that the steps they took to manage illness using this model were sufficient and that it was not a legitimate use of their time to discuss self-management within a consultation. Norris and Kilbride (2014) interviewed occupational therapists and physiotherapists who had been trained in a self-management approach and found that although the therapists wished to involve stroke survivors in their own care some found it difficult to relinquish professional control. These studies highlight the difficulties of changing the practice of groups of staff, particularly when this requires a departure from their traditional role.

An added level of complexity in stroke rehabilitation is that SLTs may need to change their therapeutic approach at different time points depending upon the response of the stroke survivor. For example, a recent Cochrane review suggested that intensive, impairment focused therapy is beneficial for improving aphasia (Brady et al., 2016) and clinical guidelines advocate up to 45mins of therapy per day if measurable benefits are being achieved (Intercollegiate Stroke Working Party, 2016). However, when the limits of restoration based therapy have been reached, the SLT may need to step away from impairment focused therapy in order to facilitate self-management and equip stroke survivors and their families to cope in the longer-term. Some may argue that self-management approaches should not be 'saved' until the limits of traditional, impairment focused therapy have been reached (Simmons-Mackie, 2009); however, the two different approaches are likely to require the SLT to take a different 'role' within the therapeutic relationship. For example, in impairment focused therapy it could be argued that the SLT takes the lead with the assessment of speech and language and with appropriate exercises for the stroke survivor to complete (in line with the stroke survivors wishes). However, to take a self-management approach the SLT must collaborate with the stroke survivor and depart from their traditional 'expert' role (de Silva, 2011; Lorig and Holman, 2003).

Organisational barriers are also likely to be experienced if SLTs were chosen to facilitate this approach. The fieldwork conducted as part of this thesis suggested that some speech and language therapists felt under organisational pressure to begin the process of discharge once improvements with speech and language began to plateau. It might be suggested that this reflects an underlying emphasis upon restorative approaches within some rehabilitation services. However, this pressure may also reflect the lack of resources to undertake condition management work within such

services. The importance of providing services underpinned by the biopsychosocial model (as opposed to biomedical model) is well recognised in rehabilitation (Wade, 2015; Wade, 2016). However, addressing all aspects of this model within resource poor or time constrained services may be challenging. In addition, performance may not be judged upon the provision of care based upon this model but upon the quantity of rehabilitation provided or the waiting times to access the service (Royal College of Physicians, 2016; Royal College of Physicians, 2015). Implementing a self-management approach to help equip stroke survivors with communication difficulties and their families in the longer-term may therefore be at odds with the organisation of existing rehabilitation services as benefit may not be measurable in terms of improvement with speech and language but may relate to other concepts such as quality of life (Fryer et al., 2016). Norris and Kilbride (2014) suggest that self-management is often perceived by healthcare professionals as an 'add-on' to routine care that is not prioritised when organisational pressures and time constraints are experienced. The findings from the qualitative fieldwork in Chapter Six suggest that although SLTs were keen that stroke survivors were provided with support in the longer-term, they were often under organisational pressure to 'justify' the therapy they were providing. Self-management may not be seen as an efficient use of scarce resources by some services under pressure to reduce waiting list times (Royal College of Physicians, 2015). On the other hand, the widespread commissioning of the Bridges approach to self-management in the UK suggests that this may be afforded by resource constrained services (Bridges Self-Management, 2017). If this approach is to be successfully implemented, self-management must be recognised as an integral and essential part of stroke rehabilitation at an organisational level (Kennedy et al., 2014).

Due to the professional and organisational barriers outlined above, the potential for a non-healthcare professional to facilitate the intervention should also be considered. Delphi panellists also agreed that a charitable organisation, a trained volunteer or a trained family member could be potential facilitators of a self-management approach. The CDSMP was originally delivered using trained lay leaders (Lorig et al., 2001; Lorig et al., 1999a). An advantage of this approach is that it may promote empowerment and a shift away from paternalistic models of care (Foster et al., 2007). The facilitator may also be more likely to have an understanding of self-management which aligns with the stroke survivors. For example, a systematic review of lay and healthcare professional's views of self-management suggested significant differences in the way that each group understood this concept (Sadler et al., 2014). Healthcare professionals interpreted self-management as a tool to promote compliance or to shift responsibility onto the

patient. Lay people understood self-management in broader terms which included biomedical, psychological and social components. Such differences in understanding may be a significant barrier to engaging patients in a self-management approach which is facilitated by a healthcare professional (Sadler et al., 2014). Having a shared perspective of self-management may be a facilitator to forming the collaborative relationship which is integral to the self-management approach (Lorig and Holman, 2003). Training a non-healthcare professional to facilitate the intervention may help to encourage such a partnership (Sadler et al., 2014). On the other hand, some aspects of the self-management intervention designed as part of this PhD study may require specialist input from a SLT; for example, training in AAC strategies or training family members in strategies to facilitate communication. Providing a non-health care professional with adequate training, organisational access and ongoing supervision to facilitate the intervention may be problematic. Further feasibility testing for this aspect of the intervention is needed.

Another area to be considered with regards to feasibility testing is the proposed duration of the intervention. Delphi panellists reached a consensus that the intervention should be delivered for as long as is required by the stroke survivors needs. Offering open-ended access to support may help to smooth the difficult transition at the point of discharge from community services when families interviewed in this PhD study expressed feelings of abandonment. However, the feasibility of providing an open-ended approach is unclear, and this may have significant implications for the cost-effectiveness of the intervention. On the other hand, in a RCT of a self-management intervention in inflammatory bowel disease, Kennedy et al. (2004) found that open access to outpatients appointments (based upon the patients own assessment of need) did not lead to an increase in healthcare utilisation. Exploring participants experiences suggested that the open access system enhanced feelings of self-control and confidence about their ability to manage their condition (Rogers et al., 2004). The stroke self-management interventions reviewed in Chapter One were all delivered for a fixed duration. The feasibility of providing an open access self-management intervention in stroke is unclear and further feasibility testing for this aspect of the intervention is needed.

It will be important to underpin a feasibility study with the collection of qualitative data to explore implementation processes (Moore et al., 2015). Normalisation Process Theory (NPT) (May et al., 2009; Murray et al., 2010) is a theoretical framework used to identify

barriers and facilitators to the implementation of complex interventions in to everyday practice. NPT is based upon the premise that in order for complex interventions to be successful they must be normalised or embedded in to everyday practice so that they become a seamless and routine part of practice. NPT proposes that the work done to integrate interventions is based upon four factors: 1) Coherence (the extent to which the intervention has meaning or makes sense to the people involved); 2) Cognitive participation (the extent to which the people involved are engaged with the intervention or commit to its implementation); 3) Collective action (the extent to which the people make the intervention work with the context of the other work which is undertaken); and 4) Reflexive monitoring (the extent to which people positively appraise the intervention upon reflection) (Murray et al., 2010). NPT provides a structured and theoretically based approach to identify and think through implementation problems (Finch et al., 2013) and is increasingly being used to understand the complex process of implementation (McEvoy et al., 2014).

The data collected during the feasibility study would be used to refine the self-management approach before it is tested in a pilot study. A pilot study is a miniature version of the main study that is done to ensure that the main study will run smoothly with regards to recruitment, randomisation, and follow-up (NIHR, 2017). This is an important stage of complex intervention development and Craig et al. (2008) suggest that many of the difficulties with recruitment, follow-up rates, and implementation reported by researchers in full scale evaluations could be avoided by adequate feasibility and pilot testing. This is particularly important in the case of the self-management intervention designed in this study given the anticipated complexities of implementing the approach outlined in this section. The self-management intervention will be further refined based upon the pilot study and it is hoped that a full scale RCT evaluation of the self-management intervention will be conducted in the future.

10.8. Other research recommendations

The research undertaken in this thesis highlights the importance of considering all of the heterogeneous population of stroke survivors in the design of interventions. The findings of this PhD identified that stroke survivors with communication difficulties are underrepresented in existing RCTs of self-management. Furthermore, these interventions may be inaccessible to this sub-group of stroke survivors and may not

meet their needs. The repeated exclusion of stroke survivors with communication difficulties from stroke research is likely to lead to gaps in the evidence base concerning the efficacy of interventions for this sub-group of stroke survivors (Brady et al., 2013; Townend et al., 2007). This may lead to health inequalities in the future if interventions are implemented in practice without evidence of feasibility or acceptability for this population. It is important that all researchers in stroke consider and include stroke survivors with communication difficulties in their research wherever possible. As outlined in this thesis, a number of techniques can be used to facilitate the inclusion of stroke survivors with communication difficulties in research. If stroke survivors with communication difficulties have been excluded, a clear rationale for their exclusion should be provided. It is also important that the inclusion or exclusion of stroke survivors with communication difficulties is clearly stated in the reporting of stroke research.

10.9. Clinical implications

The term 'self-management' was often not recognised by SLTs interviewed as part of this study. Although SLTs actions suggested a variety of ways in which they aimed to enable stroke survivors and their families to manage their condition as part of their role, they had not received any specific training in self-management approaches. This is perhaps unsurprising given the plethora of self-management approaches available and ambiguity concerning which aspects of self-management interventions are effective and should be implemented in practice (Fryer et al., 2016). The literature reviewed as part of this thesis showed a diverse range of interventions which included 'self-management' components. Despite its recommendation in the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2016) uncertainty remains about where in the stroke pathway self-management approaches should be introduced, by whom and in what format. Before self-management is introduced in a clinical setting, further development of self-management approaches for stroke survivors with communication difficulties is needed including evidence of the efficacy of taking this approach. Clinical guidelines should be updated in line with emerging evidence to provide a clearer definition of self-management in order to guide future intervention development and the implementation of this approach in practice.

10.10. Conclusions

This thesis highlights the significant and continuing need for longer-term support experienced by stroke survivors with communication difficulties. Self-management may be an appropriate component of a longer-term care strategy and may help to address the difficulties with adaptation, adjustment and condition management commonly experienced by stroke survivors with communication difficulties in the longer-term. However, adaptations to existing self-management interventions are necessary to ensure that such approaches are accessible and condition specific. Using a staged approach (MRC, 2008), informed by behaviour change theory (Michie et al., 2014; Michie et al., 2011), recommendations for a novel self-management intervention designed around the needs of stroke survivors with communication difficulties (and their families) have been presented in this thesis. The next stages of intervention development will include refinement of the proposed intervention, feasibility testing, pilot testing, and large scale evaluation through a RCT. Stroke survivors with communication difficulties should be considered in the design and subsequent evaluation of self-management interventions to ensure this population has equitable access to evidence-based healthcare.

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List of abbreviations

AAC	Alternative and Augmentative Communication
COM-B	Capability Opportunity Motivation model of Behaviour
CDSMP	Chronic Disease Self-Management Programme
CQC	Care Quality Commission
CRD	Centre for Reviews and Dissemination
BCW	Behaviour Change Wheel
BCT	Behaviour Change Technique
EPPI	The Evidence for Policy and Practice Information and Co-ordinating (centre)
IAPT	Increasing Access to Psychological Therapy
MRC	Medical Research Council
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
RCSLT	Royal College of Speech and Language Therapists
RCT	Randomised Controlled Trial
SLT	Speech and Language Therapist
TDF	Theoretical Domains Framework
WHO	World Health Organisation

Appendix A: Search terms for RCT review (Medline)

1. cerebrovascular disorders/ or exp basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or exp cerebrovascular trauma/ or exp intracranial arterial diseases/ or exp intracranial arteriovenous malformations/ or exp "intracranial embolism and thrombosis"/ or exp intracranial hemorrhages/ or stroke/ or exp brain infarction/ or stroke, lacunar/ or vasospasm, intracranial/ or vertebral artery dissection/ or exp hypoxia, brain/
2. (stroke\$ or post stroke or poststroke or post-stroke or apoplex\$ or cerebral vasc\$ or cerebrovasc\$ or cva or SAH).tw.
3. ((brain\$ or cerebr\$ or cerebell\$ or vertebrobasil\$ or hemispher\$ or intracran\$ or intracerebral or infratentorial or supratentorial or middle cerebr\$ or mca\$ or anterior circulation or basilar artery or vertebral artery) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli\$ or occlus\$ or hypoxi\$)).tw.
4. ((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracran\$ or parenchymal or intraparenchymal or intraventricular or infratentorial or supratentorial or basal gangli\$ or putaminal or putamen or posterior fossa or hemispher\$ or subarachnoid) adj5 (h?emorrhag\$ or h?ematoma\$ or bleed\$)).tw.
5. exp hemiplegia/ or exp paresis/ or exp aphasia/ or exp gait disorders, neurologic/ or hemianopsia/
6. (hemipar\$ or hemipleg\$ or paresis or paretic or aphasi\$ or dysphasi\$ or hemianopsia or hemianopia or transient isch\$ or isch?emic attack\$ or TIA or TIAs).tw.
7. ((unilateral or visual or hemispacial or attentional or spatial) adj5 neglect).tw.
8. 1 or 2 or 3 or 4 or 5 or 6 or 7
9. randomized controlled trial.pt.
10. controlled clinical trial.pt.
11. randomized.ab.
12. placebo.ab.
13. drug therapy.fs.
14. randomly.ab.
15. trial.ab.
16. groups.ab.
17. 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16
18. Self Care/
19. (self adj (care or help or manag\$ or led or directed)).tw.
20. self efficacy/
21. Patient Participation/
22. Self-Help Groups/
23. motivation/ or goals/ or problem solving/ or exp decision making/
24. (((behav\$ adj3 chang\$) or (problem\$ adj3 solv\$) or (goal\$ adj3 setting) or (decision\$ adj3 mak\$) or coping) adj5 (patient\$ or consumer\$ or client\$)).tw.
25. 18 or 19 or 20 or 21 or 22 or 23 or 24
26. 8 and 17 and 25
27. exp animals/ not humans.sh.
28. 26 not 27

Appendix B: Search terms for qualitative review (Medline)

1. cerebrovascular disorders/ or exp basal ganglia cerebrovascular disease/ or exp brain ischemia/ or exp carotid artery diseases/ or exp cerebrovascular trauma/ or exp intracranial arterial diseases/ or exp intracranial arteriovenous malformations/ or exp "intracranial embolism and thrombosis"/ or exp intracranial hemorrhages/ or stroke/ or exp brain infarction/ or stroke, lacunar/ or vasospasm, intracranial/ or vertebral artery dissection/ or exp hypoxia, brain/
2. (stroke\$ or post stroke or poststroke or post-stroke or apoplex\$ or cerebral vasc\$ or cerebrovasc\$ or cva or SAH).tw.
3. ((brain or cerebr\$ or cerebell\$ or vertebrobasil\$ or hemispher\$ or intracran\$ or intracerebral or infratentorial or supratentorial or middle cerebr\$ or mca\$ or anterior circulation or basilar artery or vertebral artery) adj5 (isch?emi\$ or infarct\$ or thrombo\$ or emboli\$ or occlus\$ or hypoxi\$)).tw.
4. ((brain\$ or cerebr\$ or cerebell\$ or intracerebral or intracran\$ or parenchymal or intraparenchymal or intraventricular or infratentorial or supratentorial or basal gangli\$ or putaminal or putamen or posterior fossa or hemispher\$ or subarachnoid) adj5 (h?emorrhag\$ or h?ematoma\$ or bleed\$)).tw.
5. exp hemiplegia/ or exp paresis/ or exp aphasia/ or exp gait disorders, neurologic/ or hemianopsia
6. (hemipar\$ or hemipleg\$ or paresis or paretic or aphasi\$ or dysphasi\$ or hemianopsia or hemianopia or transient isch\$ or isch?emic attack\$ or TIA or TIAs).tw.
7. ((unilateral or visual or hemispacial or attentional or spatial) adj5 neglect).tw.
8. 1 or 2 or 3 or 4 or 5 or 6 or 7
9. exp aphasia/
10. language disorders/ or anomia/
11. (aphasi\$ or dysphasi\$ or dysarthri\$ or apraxi\$ or anomia or anomic).tw.
12. ((language or linguistic or communication) adj5 (disorder\$ or impair\$ or problem\$ or dysfunction)).tw.
13. attention/ or arousal/
14. ((attention\$ or concentrat\$ or arousal or alert\$ or vigilance) adj5 (impair\$ or deficit\$ or disorder\$ or problem\$ or diminish\$ or decreas\$ or reduc\$)).tw.
15. (inattention or distract\$).tw.
16. (error adj3 control\$ adj5 (impair\$ or deficit\$ or disorder\$ or problem\$ or diminish\$ or decreas\$ or reduc\$)).tw.
17. (speed adj3 information adj3 process\$ adj5 (impair\$ or deficit\$ or disorder\$ or problem\$ or diminish\$ or decreas\$ or reduc\$)).tw.
18. (mental adj5 (slow\$ or fatig\$)).tw.
19. (cognitive or cognition or attention\$ or memory or concentration or distract\$ or alert\$).tw.
20. ((attention\$ or cognit\$ or scanning\$) adj5 (training or retraining or rehabilitation or intervention or therapy)).tw.
21. language therapy/ or speech therapy/

22. Speech-Language Pathology/

23. ((speech or language or aphasia or dysphasia or dysarthria or apraxia) adj5 (therap\$ or train\$ or rehabilitat\$ or treat\$ or remediates\$ or pathol\$)).tw.

24. remedial therap\$.tw.

25. cognition disorders/

26. ((cognit\$ or memory or mental\$) adj5 (declin\$ or impair\$ or los\$ or deteriorat\$)).tw.

27. (cognit\$ adj2 (abnormal\$ or defect\$ or disorder\$)).tw.

28. (cognit\$ adj abilit\$).tw.

29. or/9-28

30. interview:.mp.

31. experience:.mp.

32. qualitative.tw.

33. 30 or 31 or 32

34. Qualitative Research/

35. 33 or 34

36. 8 and 29 and 35

Appendix C: NHS ethical approval letter²


Health Research Authority
 Yorkshire & The Humber - Leeds West Research Ethics Committee
 Room 001, Jarrow Business Centre
 Rolling Mill Road
 Jarrow
 Tyne and Wear
 NE32 3DT
 Telephone: 0191 428 3444

02 February 2016

Miss Faye D Plummer
 Academic Unit of Elderly Care and Rehabilitation
 Bradford Institute for Health Research, Temple Bank House
 Bradford Royal Infirmary
 Bradford
 BD9 6RJ

Dear Miss Plummer

Study title: Developing care for stroke survivors with communication difficulties living in the community.
REC reference: 16/YH/0002
IRAS project ID: 193003

Thank you for your letter of 02 February 2016. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 01 February 2016

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Letters of invitation to participant [Interview Invitation Letter]	3.0	01 February 2016
Other [Interview invitation letter (register)]	3.0	01 February 2016
Other [Appointment confirmation letter interview study]	3.0	01 February 2016
Other [Appointment confirmation letter interview study carer]	3.0	01 February 2016
Other [Appointment confirmation letter_focus group study]	3.0	01 February 2016
Other [Appointment confirmation letter_focus group study carers]	3.0	01 February 2016

Approved documents

The final list of approved documentation for the study is therefore as follows:

A Research Ethics Committee established by the Health Research Authority

² NHS ethical approvals are in the author's maiden name (Plummer) as they were obtained before the author married and changed her name to Wray.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Leeds Indemnity Certificate]		
Interview schedules or topic guides for participants [Interview Topic Guide (Stroke Survivors) v1.0 05112015]	v1.0	05 November 2015
Letter from sponsor [Email confirming sponsorship]		
Letters of invitation to participant [Interview Invitation Letter]	3.0	01 February 2016
Other [Consent support tool]	n/a	
Other [Supported communication example prompts]		
Other [Appointment confirmation letter_focus group study]	1.0	09 October 2015
Other [Appointment confirmation letter_focus group study carers]	1.0	28 September 2015
Other [Summary Information Sheet]	1.0	07 October 2015
Other [Summary information sheet for carers]	1.0	07 October 2015
Other [Interview Topic Guide (Carers)]	1.0	05 November 2015
Other [Summary information sheet (register)]	1.0	05 November 2015
Other [Staff interviews topic guide]	1.0	05 November 2015
Other [Patient_Carer focus group topic guide]	1.0	05 November 2015
Other [Staff focus group topic guide]	1.0	05 November 2015
Other [David Clarke Short CV]		16 February 2015
Other [Consent to contact form]	2.0	25 January 2016
Other [Participant information sheet two (accessible)_interview study]	2.0	26 January 2016
Other [Participant information sheet_carer interview study]	2.0	25 January 2016
Other [Consultee information sheet]	2.0	25 January 2016
Other [Consultee consent form_interview study carers]	2.0	26 January 2016
Other [Participant information sheet_total communication approach powerpoint slides]	2.0	26 January 2016
Other [Consent form_interview study carers]	2.0	26 January 2016
Other [Participant information sheet_staff interview study]	2.0	25 January 2016
Other [Consent form staff interview study]	2.0	26 January 2016
Other [Participant information sheet one_focus group study]	2.0	25 January 2016
Other [Participant information sheet two (accessible)_focus group study]	2.0	26 January 2016
Other [Participant information sheet_total communication approach powerpoint slides]	2.0	26 January 2016
Other [Participant information sheet_carer focus group study]	2.0	25 January 2016
Other [Consent form patient focus group]	2.0	26 January 2016
Other [Consent form_carer focus group study]	2.0	26 January 2016
Other [Participant information sheet_staff focus group study]	2.0	25 January 2016
Other [Consent form_staff focus group study]	2.0	26 January 2016
Other [Ethics resubmission covering letter]	1.0	28 January 2016
Other [Interview invitation letter (register)]	3.0	01 February 2016
Other [Appointment confirmation letter interview study]	3.0	01 February 2016

Other [Appointment confirmation letter interview study carer]	3.0	01 February 2016
Other [Appointment confirmation letter_focus group study]	3.0	01 February 2016
Other [Appointment confirmation letter_focus group study carers]	3.0	01 February 2016
Participant consent form [Consent form_interview study]	2.0	26 January 2016
Participant information sheet (PIS) [Participant Information Sheet One Interview Study]	2.0	25 January 2016
REC Application Form [REC_Form_29012016]		29 January 2016
Research protocol or project proposal [Protocol]	2.0	25 January 2016
Summary CV for Chief Investigator (CI) [CV_Faye Plummer_Short_10112015]		10 November 2015
Summary CV for supervisor (student research) [CV_Prof_Anne_Forster]		10 March 2015

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

16/YH/0002	Please quote this number on all correspondence
-------------------	---

Yours sincerely



Kirstie Penman
REC Assistant

E-mail: nrescommittee.yorkandhumber-leedswest@nhs.net

Copy to: *Faculty Research Ethics and Governance Administrator*
Mrs Jane Dennison, Bradford Teaching Hospitals NHS Foundation Trust

Appendix D: Example page from standard information sheet for stroke survivors³

Participant information sheet one: interview study [version 2.0 25/01/2016]

Improving care for stroke survivors with communication difficulties

PARTICIPANT INFORMATION SHEET: INTERVIEW STUDY

You are being invited to take part in a study about improving care for stroke survivors with communication difficulties. The purpose of this leaflet is to outline the study and explain what will happen if you decide to talk to us. Please take time to read the following information carefully and contact us if anything is not clear or if you have any questions.

1. WHAT IS THE PURPOSE OF THE STUDY?

The project is looking at how people look after their health and wellbeing after stroke. We hope to use this information to improve the quality of longer-term care for stroke survivors with communication difficulties.

2. WHY HAVE I BEEN INVITED?

We want to find out about people's experiences following stroke to better understand the type of support stroke survivors with communication difficulties would find useful.



1

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³ Due to word limits and page restrictions it is not possible to include all of the information sheet and therefore an example page has been provided.

Appendix E: Example page from accessible information sheet for stroke survivors

Participant information sheet two (accessible): interview study [version 2.0 26/01/2016]

Participant information sheet



1. Study title

Improving



care for stroke survivors



with communication difficulties



Appendix F: Example slides from total communication approach information sheet for stroke survivors

Participant information sheet



Participant information sheet total communication approach powerpoint slides v2.0 26/01/2016

You are being invited to take part in a study



about **improving** long-term **support**



Participant information sheet_total communication approach powerpoint slides v2.0 26/01/2016

Appendix G: Example consent form for stroke survivors

Consent form: interview study [version 2.0 26/01/2016]

Improving care for stroke survivors with communication difficulties



CONSENT FORM: INTERVIEW STUDY

Please initial each box

 	1. I confirm that I have read and understood the information sheet dated [date] (version [number]) for the above study. I have had the opportunity to ask questions . I have had these answered satisfactorily.	
 	2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected.	
	3. I agree to the interview being audio recorded for the research study.	
	4. I agree to anonymous quotes being used in publications, reports or presentations.	
	5. I understand that anonymised information collected about me will be used to support other research in the future . Data protection regulations will be observed. Confidentiality will be maintained unless there are concerns that I, or someone else, is at risk of harm .	
	6. I understand that even if I withdraw from the study, the data already collected from me will contribute to the study unless I specifically withdraw consent for this.	



1



Consent form: interview study [version 2.0 26/01/2016]

	7. I understand the data collected as part of this study may be looked at by individuals from regulatory authorities or the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data .	
	8. I agree to be contacted about a future research group interview .	
	9. I agree to take part in the above study	

Name of Participant Date Signature

Name of Person taking consent Date Signature

Name of witness Date Signature

(if applicable)

(1 copy for the participant and 1 copy for the University of Leeds)



2



Appendix H: Topic guide for SLT interviews

SLT interview topic guide

Opening questions:

Can you tell me about your role/what your job involves on a day-to-day basis?

What a typical day is like

Needs of stroke survivors:

How do you think stroke and language and communication problems affect the patients that you see?

What sort of challenges/difficulties do they experience?

How/who helps them to cope with these?

How well is this population supported to handle these difficulties?

Any other support you think might be useful?

What hopes and goals do patients have for the future?

Role of speech and language therapists:

Can you describe what you think the role of a speech and language therapist is?

In what ways do you feel you help the patient with their care?

What things help you to fulfil that role?

What things hinder you from fulfilling the role?

Role of self-management

What do you understand by the term 'self-management'?

What do you think this could mean?

How is this used in your own practice (if at all)?

Examples of when this has been used in practice

In what situations this may help/when this is not useful

If not used, how do you think this could be used in future? Who would be best to deliver this care?

How would your patients react to this approach?

How confident would you feel to approach care in this way?

Future of stroke care for survivors with communication difficulties

How do you think care for stroke survivors with communication difficulties could be improved?

What long-term support is needed?

Who should deliver this support? What would this look like in practice?

What would help/hinder in the delivery of this kind of care?

Closing questions

Is there anything else you would like to add?

Appendix I: Topic guide for stroke survivor interviews

Stroke survivor interview topic guide

Opening questions

How long is it since you had your stroke?

Can you describe what happened?

Coming home/Rehabilitation

Could you tell me what it was like coming home from hospital?

How did you feel about coming home? Did you feel prepared (why/how)?

What did you think was good/difficult about coming home when you were first discharged? What support did you receive when you first came home?

Could you describe what has happened to you since returning home?

The amount and type of speech therapy received.

Life now

Could you tell me how your stroke affects you now?

Impact of communication impairments

Other health, social, emotional consequences

How have things changed since before the stroke?

Could you describe a typical day now (what you do, how and why)

What would make it a good/bad day?

What things do you enjoy about your daily life/what would you change?

What activities/events do you now find meaningful/important/enjoyable?

How have you found going out and about following your stroke?

Have you tried to return to doing activities/attending events that you previously found meaningful/important/enjoyable? (could you tell me about your experience)

Living with/managing impairments

Do you feel you are able to manage your impairments (give an example)

What do you need support with? What things are you able to do yourself?

How do you feel about your speech/understanding others?

Improvement/lack of improvement since hospital discharge.

Adapted/changed the way you do everyday things? Example

Who/what enabled these changes?

What has helped/hindered this process?

What, if any formal support do you still receive?

Was support offered?

What do you think of the support received?

What was available/not available to you? How did you access this?

What, if any, support do you receive from family and friends?

Problem solving/resolving issues

What do you feel you manage/cope with well?

Have you encountered any problems/challenges following discharge home?

Examples (Mobility, Falls, Incontinence, Pain, Fatigue, Relationships, Activities etc.)

How did you feel/ how have you handled these?

Did you receive support to do this?

How do you think you will manage this/cope with this in the future?

Unmet needs/ongoing problems/issues

What have you found particularly difficult to manage/cope with?

How have you managed/cope with this?

Is there anything you feel you need more support with...

Closing questions

Is there anything else you think I need to know about life after stroke?

Appendix J: Topic guide for carer interviews

Carer interview topic guide

Opening questions

How long it is since [stroke survivor] had their stroke?

What happened when they had their stroke? How did you feel at that time?

Coming home/Rehabilitation

Could you tell me what it was like when [stroke survivor] came home from hospital?

How did you feel about [stroke survivor] coming home? Did you feel prepared (why/how)?

What did you think was good/difficult about [stroke survivor] coming home?

What support did [stroke survivor] receive when they first came home?

Amount and type of speech therapy received

Involvement in speech therapy sessions

Could you describe what has happened since returning home?

Formal and informal support [for the carer/relative and for the stroke survivor]

How have you managed with the consequences of stroke? (communication, health, social, emotional consequences)

Life now

Could you tell me how the stroke affects [stroke survivor] now?

Communication impairments (difficulty speaking/understanding speech)

Do you feel you are able to manage? What do you need support with?

Could you describe a typical day now (what you do, how and why)

What would make it a good/bad day?

What things do you enjoy about your daily life/what would you change?

What activities/events do you now find meaningful/important/enjoyable?

How have you found going out and about following [stroke survivors] stroke?

Have you continued doing activities/attending events that you previously found meaningful/important/enjoyable?

Living with/managing impairments:

How have things changed since you were first discharged home?

Improvement/lack of improvement for stroke survivor?

Adapted/changed the way you do everyday things? Example

Who/what enabled these changes? What has helped/hindered this process?

What, if any support do you still receive? [for yourself/for stroke survivor?]

Was support offered? What do you think of the support received?

What was available/not available to you? How did you access this?

What, if any, support do you receive from family and friends?

Problem solving/resolving issues

What do you feel you manage/cope with well?

Have you encountered any problems/challenges following [stroke survivors] discharge home? Examples (Communication, Mobility, Falls, Incontinence, Pain, Fatigue, Relationships, Activities etc.)

How did you feel/ how have you handled these?

Did you receive support to do this?

How do you think you will manage this/cope with this in the future?

Unmet needs/ongoing problems/issues

What have you found particularly difficult to manage/cope with?

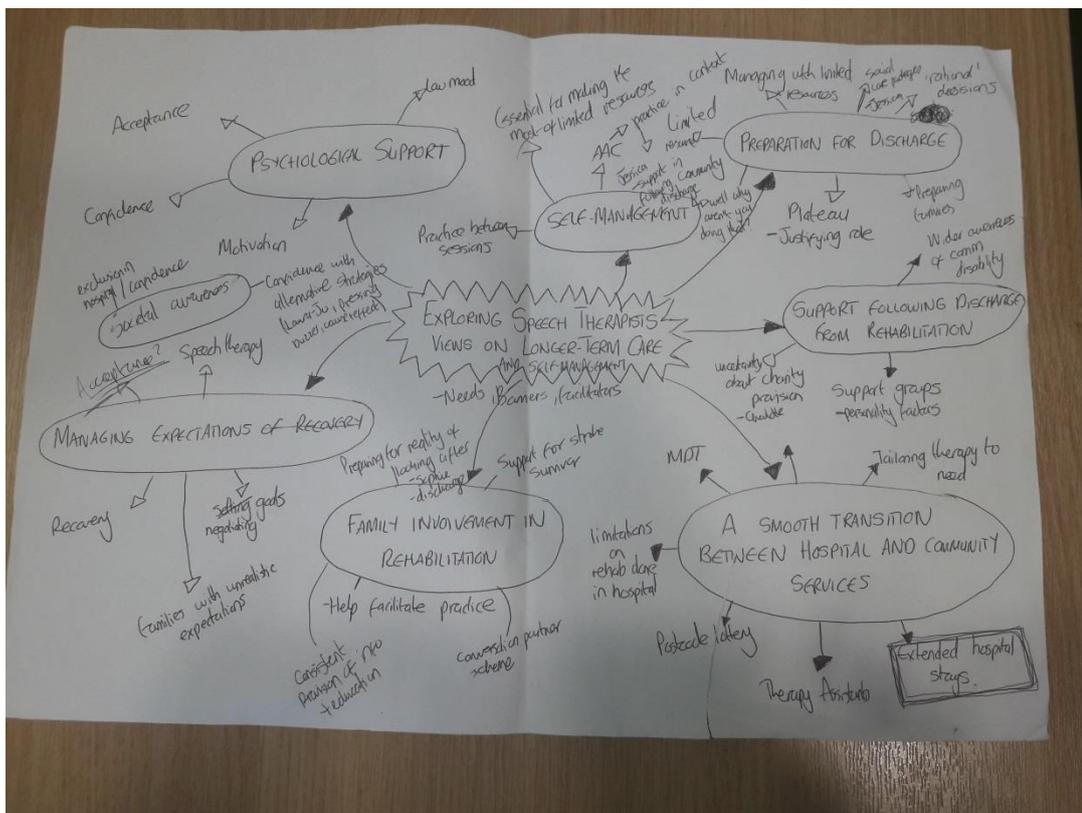
How have you managed/cope with this? How do you feel about this?

Is there anything you feel you need more support with...

Closing questions

Is there anything else you think I need to know about life for relatives of stroke survivors after stroke?

Appendix K: Example mind map and memo



Developing longer-term care for stroke survivors with communication difficulties.nvp - NVivo

File Home Create External Data Analyze Query Explore Layout View

Workspace Open Properties Edit Paste Copy Merge Clipboard Format Paragraph Styles Editing Proofing

Look for: Search In: Teddy Find Now Clear Advanced Find

Teddy

Memos from second code

Loss of confidence since stroke
 - slowly getting back to life as before the stroke, gradually taking on more tasks e.g. gardening, driving, shopping
 - loss of confidence associated with not only changes physically but due to the loss of his wife.
 - Adjustment to life living alone and adjustment to life living with changes to health since having the stroke e.g. being unable to do the shopping or the housework, feeling less confident with walking.
 - Facilitator to having confidence is family support e.g. supporting to drive again, accompanying Teddy to the shops.

Lacking 'zip' since stroke
 - Uncertainty from Teddy about whether how he is feeling is normal, unsure what he should and shouldn't be doing post-stroke.
 - Conflicting information from information booklet e.g. walking 3 miles in 'x' number of minutes and stroke nurses, it takes 3 months+ to recover.

Keeping busy
 - Other health problems a barrier to keeping busy e.g. Crohns disease.

Explaining the cause of stroke
 - Doctors had not explained the cause of Stroke to Teddy, however, he was content with his own explanation of why this had occurred e.g. stress due to caring for wife.

Managing changes with speech
 - Family supportive by treating Teddy as 'normal' when it came to his speech.

Organising support from healthcare services
 - Family support a facilitator

Support from family
 - Despite the support from his family Teddy still felt 'lonely', coming to terms with living alone.

In Nodes Code At

FP: 2 Items Nodes: 0 References: 0 Editable Line: 34 Column: 0 100%

Appendix L: Example question from Delphi survey

Self-management Delphi survey

Welcome

Dear Participant,

Welcome to this Delphi survey to agree the key components of a self-management intervention for stroke survivors with communication disabilities.

Your participation is voluntary and you may withdraw at any time without giving a reason. If you decide to withdraw, the data collected as part of the survey up to the point of withdrawal will be used unless you specifically withdraw consent for this. You may withdraw your data from the survey up to 48 hours after the survey close date. All responses received in the study will be strictly confidential and your identity will not be divulged. Anonymised direct quotes to free-text answers may be used as part of the study report or later Delphi iterations and publications relating to the study. Every effort will be made to ensure that the quotations used do not reveal your identity. You will be asked to provide your email address as part of the survey. This information will be used to provide personalised feedback to survey rounds or identify you should you wish to withdraw your data from the study. This information will be kept confidential and stored in a password protected file on a secure network and separately to your survey responses. Your email address will not be shared with other survey participants.

Please tick 'agree' to confirm that you are happy to participate in the survey and that you have read the Participant Information Sheet (v2.0 22022017). *

Required

I agree to participate

Please click 'next' to begin the survey

Section One: Introduction

"Self-management" has been recommended as an approach which should be offered to all stroke survivors in the UK (National Clinical Guidelines for Stroke, National Stroke Strategy). As part of the PhD work preceding this survey, an adapted model of self-management has been developed through qualitative exploration with key stakeholders including stroke survivors with communication disabilities (aphasia, dysarthria or apraxia of speech), their families and speech and language therapists.

In this section, five areas which could be targeted by a self-management intervention are presented. Behaviour change techniques (identified using the Behaviour Change Wheel; Michie et al., 2011) which could be used to facilitate these aspects of self-management are also presented. You will be asked to rate on a scale from 'strongly agree' to 'strongly disagree' whether you believe the component would be appropriate for a self-management intervention for stroke survivors with communication disabilities. If you agree, you will be asked you to rate on a scale from 'strongly agree' to 'strongly disagree' whether you believe the behaviour change techniques would help to address the aforementioned target for intervention.

It is anticipated that intervention components would be used flexibly and tailored to each individual following a in-depth discussion with the stroke survivor and their family (if applicable) to assess their specific needs. The role of facilitator is deliberately ambiguous in this section of the survey; you will be asked to comment upon who might take this role later in the survey.

1) A self-management intervention for stroke survivors with communication disabilities should facilitate

communication outside of the home * *Required*

Please type any additional comments you wish to make *Optional*

1a) Please rate whether the following intervention components could be used to facilitate **communication outside of the home** * *Required*

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
Stroke survivor sets a goal for communicating outside of the home.	<input type="checkbox"/>				
Facilitator helps the stroke survivor to make an action plan, detailing when communication will occur, where communication will occur, what communication will occur and who communication will occur with.	<input type="checkbox"/>				
Facilitator provides information and training in alternative and augmentative communication (AAC) strategies.	<input type="checkbox"/>				
Facilitator and stroke survivor rehearse AAC strategies.	<input type="checkbox"/>				

Facilitator and stroke survivor practice communication outside of the home with the facilitator prompting the stroke survivor as necessary to facilitate communication and decreasing support with practice (or ongoing support is provided by a member of the stroke survivors social network who has been trained by the facilitator).	<input type="checkbox"/>				
Stroke survivor is supported to self-monitor communication and implements AAC strategies as necessary.	<input type="checkbox"/>				
Facilitator and stroke survivor review behaviour and outcome of behaviour.	<input type="checkbox"/>				
Facilitator provides feedback to stroke survivor on behaviour and outcome.	<input type="checkbox"/>				

Stroke survivor and facilitator work together to solve problems which may have arisen.	<input type="checkbox"/>				
Goals with regards to communicating outside of the home are re-evaluated.	<input type="checkbox"/>				

Please type any additional comments that you wish to make

Appendix M: University ethical approval letter



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Faculty of Medicine and Health Research Office
School of Medicine Research Ethics Committee (SoMREC)

Room 9.29, level 9
Worsley Building
Clarendon Way
Leeds, LS2 9NL
United Kingdom

☎ +44 (0) 113 343 1642

05 May 2017

Faye Wray
Academic Unit of Elderly Care and Rehabilitation
Temple Bank House
Bradford Royal Infirmary
BRADFORD
BD9 6RJ

Dear Faye

Ref no: **MREC16-115**

Title: **Developing a self-management intervention for stroke survivors with communication disability: A Delphi survey**

Your research application has been reviewed by the School of Medicine Ethics Committee (SoMREC) and we can confirm that ethics approval is granted based on the following documentation received from you:

Document	Version	Date Submitted
Ethical Review Form_V3_v6.0_07042017	6.0	10/04/2017
Email from HRA and R&D	1.0	10/04/2017
Approach email (Delphi Survey round 2 and 3) v3.0 07042017	1.0	10/04/2017
BOS self-management survey_v6.0_07042017	6.0	10/04/2017
Example of feedback form_v1.0_01032017	1.0	01/03/2017
Participant Information Sheet (Delphi Survey) v4.0_01032017	4.0	01/03/2017
Reminder email (Delphi Survey) v2.0 22022017	2.0	01/03/2017
Approach email (Delphi Survey round 1) v3.0_24022017	3.0	01/03/2017

Please notify the committee if you intend to make any amendments to the original research ethics application or documentation. All changes must receive ethics approval prior to implementation. Please contact the Faculty Research Ethics Administrator for further information (fmhuniethics@leeds.ac.uk)

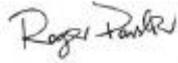
Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

We wish you every success with the project.

Yours sincerely

A handwritten signature in black ink, appearing to read "Roger Parslow". The signature is written in a cursive, slightly slanted style.

Dr Roger Parslow
Co-Chair, SoMREC, University of Leeds

(Approval granted by Dr Roger Parslow on behalf of SoMREC Co-Chairs)

Appendix N: Example Delphi survey personalised feedback sheet

EXAMPLE OF FEEDBACK FORM

[Participant number: XX-XX-XXXX]

Q5: A self-management intervention should facilitate the stroke survivor to seek and maintain social support

Your response: Agree

Group response:

