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Longer-term needs of stroke survivors with communication difficulties living in the community: A systematic review and thematic synthesis of qualitative studies.

Faye Wray*[1] and David Clarke[1]

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CONTACT DETAILS

- Mrs Faye Wray (*corresponding author)

Email: ps10fdp@leeds.ac.uk Tel: 01274 382818

Address: Academic Unit of Elderly Care and Rehabilitation, Leeds Institute for Health Sciences, Bradford Institute for Health Research, Temple Bank House, Bradford Royal Infirmary, BD9 6RJ

- Dr David Clarke

Email: d.j.clarke@leeds.ac.uk Tel: 01274 383441

Address: Academic Unit of Elderly Care and Rehabilitation, Leeds Institute for Health Sciences, Bradford Institute for Health Research, Temple Bank House, Bradford Royal Infirmary, BD9 6RJ

ABSTRACT

Objective: To review and synthesise qualitative literature relating to the longer-term needs of community dwelling stroke survivors with communication difficulties including aphasia, dysarthria and apraxia of speech.

Design: Systematic review and thematic synthesis.

Method: We included studies employing qualitative methodology which focused upon 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. We searched MEDLINE, EMBASE, PsycINFO, CINAHL, The Cochrane Library and IBSS and undertook grey literature searches. Studies were assessed for methodological quality by two researchers independently and the findings were combined using thematic synthesis.

Results: Thirty-two studies were included in the thematic synthesis. The synthesis reveals the ongoing difficulties stroke survivors can experience in coming to terms with the loss of communication and in adapting to life with a communication difficulty. Whilst some were able to adjust, others struggled to maintain their social networks and to participate in activities which were meaningful to them. The challenges experienced by stroke survivors with communication difficulties persisted for many years post-stroke. Four themes relating to longer-term need were developed: 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.

Conclusions: Understanding the experiences of stroke survivors with communication difficulties is vital for ensuring that longer-term care is designed according to their needs. Wider psychosocial factors must be considered in the rehabilitation of people with post-stroke communication difficulties. Self-management interventions may be appropriate to help this sub-group of stroke survivors manage their condition in the longer-term; however, such approaches must be designed to help survivors to manage the unique psychosocial consequences of post-stroke communication difficulties.

ARTICLE SUMMARY

Strengths and limitations of this study

- This is the first systematic review and synthesis of qualitative studies which have included stroke survivors with communication difficulties.
- By synthesising qualitative literature, a greater level of conceptual or theoretical understanding can be gained than by looking at one study in isolation.
- Thematic synthesis is a robust method of synthesis which draws together information from qualitative literature in order to make reasoned recommendations for future intervention development.
- Many of the studies identified did not describe the role of the researcher which may impact upon the data collected and the findings of the synthesis.
- The impact of publication bias in qualitative literature is difficult to assess.

INTRODUCTION

The global burden of stroke is set to rise. It is predicted that by 2030, there will be 12 million stroke deaths, 70 million stroke survivors and 200 million disability adjusted life years lost due to stroke worldwide [1]. In England, it is estimated that 300 000 people are living with moderate to severe disability following stroke [2]. The disabilities stroke survivors face are complex and there is a high prevalence of unmet need in the years following acute onset [3]. Qualitative research has identified that the transition between hospital and community services is difficult and that many stroke survivors feel unsupported and abandoned in the longer-term [4-6]. Although the importance of supporting stroke survivors in the longer-term has been recognised by policymakers, the precise format and content of such support has yet to be established [2 7 8]. Developing an evidence-based care pathway which meets the complex needs of individuals and families coping with the aftermath of stroke remains a challenge [9-11].

Up to one third of survivors will experience communication difficulties post-stroke including aphasia, dysarthria or apraxia of speech [12-15] resulting in difficulties with language comprehension, speech production and difficulties with reading and writing. Research suggests that this sub-group of stroke survivors may have particularly poor longer-term outcome [16], 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 [17].This sub-group are also more likely to suffer from depression [18] and have reduced social interactions [19]. Although stroke survivors with communication difficulties may benefit from longer-term support, the needs of this population in relation to longer-term care have not been explored.

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 [20-22]. In the wider stroke literature systematic reviews and syntheses of qualitative literature have been undertaken [23-25]. However, Walsh et al.[25] and Satink et al.[24] 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 strategies to ensure that, wherever possible, those with communication difficulties can be included in qualitative research [26-28]. There is a growing body of research in this field which highlights the stroke survivor's perspective on living with a communication difficulty[29]. However, to date there has been no systematic review and synthesis of these studies.

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 [30 31]. 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[32] 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 [30 31]. In order to design a longer-term care strategy for stroke survivors with communication difficulties, it is important to synthesise qualitative research findings to better understand the requirements for longer-term care from the patients' perspective. The current review aimed to explore the needs of stroke survivors with communication difficulties in relation to longer-term care.

METHOD

A systematic review and thematic synthesis[32] of qualitative literature relating to the needs of stroke survivors with communication difficulties living in the community was undertaken. A review protocol was developed but was not registered or published.

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 randomised controlled trials 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 [33]. This poses difficulties when identifying qualitative research systematically [34-36]. Some argue for the use of a broader approach by not including filters in relation to qualitative methodology [37]. However, in this case a qualitative filter [38] 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 the online supplementary information.

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; 1) Reviewing the reference lists of studies meeting inclusion criteria, 2) reverse citation search of studies meeting inclusion criteria and 3) reference list check and reverse citation search of an existing systematic review of qualitative literature in stroke care [39].

Study selection and data extraction

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 second and third authors.

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[40]. The National Institute for Health and Care Excellence (NICE) public health guidance qualitative appraisal checklist [41] was used for assessment of methodological quality in the current review. NICE created the checklist based upon the broad issues which are generally accepted to affect validity in qualitative research [41]. 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'. 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 [34 42] and a number of approaches have been developed including

qualitative meta-synthesis[43], meta-ethnography[30 31] and thematic synthesis[32 37]. In this review studies were combined using thematic synthesis [32 37]. This method of synthesis was specifically formulated by the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI centre) to organise findings from qualitative literature to enable reasoned hypotheses about intervention need, appropriateness and acceptability[44]. Like meta-synthesis and meta-ethnography, thematic synthesis allows for a deeper exploration of findings which goes beyond narrative summary[32 37]. 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[30 45].

Key findings (supported by relevant quotations) from each included study were extracted and free coded line by line using QSR NVivo software version 10. Groups of descriptive codes were formed based on similarities between the free codes. Through discussion with a second reviewer and a wider review team, the contents of each of the groups of descriptive codes were explored and further refined to create descriptive themes[32 37]. Analytical themes were developed through an iterative process which 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 [24 32 46]. Analytical themes were developed with help from the wider review team and by gaining feedback on draft analytical themes from a peer review group in the research unit.

RESULTS

[Figure 1: PRISMA flow diagram of study selection]

Thirty-two citations were identified which were eligible for inclusion in the review [47-78]. The PRISMA flow diagram of study selection is shown in figure 1. Once duplicates had been removed, 9496 records were screened for eligibility and full text was sought for 80 citations. 48 were excluded; 21 studies which did not focus upon the outcome of interest [79-99], 11 studies which did not use qualitative methods or qualitative methods of data analysis [100-110], 6 which were not original research (e.g. were commentaries or book reviews) [111-116], 4 for which we were unable to obtain full text [117-120], 3 which did not include the population of interest [121-123], and 3 ongoing pieces of research for which the results were not yet available [124-126].

Study characteristics

Table 1 shows the characteristics of included studies.

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 [59 103] to fifty [73 78] . The majority of studies identified included participants with aphasia (29 out of 32). Only five studies reported including participants with dysarthria [47-49 58 77] and one study included participants with apraxia of speech [47]. 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 [48 58 61 62 76].

Table 1: Characteristics of included studies

Authors	Aim of study	L&C 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. [47]	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. [49]	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. [48]	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. [51]	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. [52]	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	n/a	Interview	One interview	Interpretive phenomenological analysis	++
Brown et al. [50]	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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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. [53]	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 [54]	To investigate factors associated with resilience in individuals with aphasia	Aphasia	9	USA	Community	47-73	?	?	Interview	One interview	Content analysis	-
Dalemans et al. [55]	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. [56]	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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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. [57]	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. [58]	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. [59]	The aim of this phenomenological case study was to (a) explore the social role changes experienced by people with aphasia (PWA), (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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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. [60]	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. [62]	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. [61]	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 [127]	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. [65]	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. [64]	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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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. [66]	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 [68]	(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. [67]	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. [69]	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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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. [70]	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	+
Natterlund [71]	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 [72]	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 [73]	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 [74]	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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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 [75]	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. [76]	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 [77]	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.[78]	The purpose of this study was 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]

Methodological quality of included studies

Table 2 shows the results from the NICE public health qualitative appraisal checklist [41]. A table showing individual study ratings is included in the online supplementary material.

Table 2: Methodological quality of included studies

1.Theoretical rationale: appropriateness	Appropriate 32	Inappropriate 0	Not sure 0
2. Theoretical rationale: clarity	Clear 28	Unclear 1	Mixed 3
3. Study design	Defensible 21	Indefensible 4	Not sure 7
4. Data collection	Appropriately 30	Inappropriately 1	Not sure/inadequately reported 1
5. Trustworthiness: role of the researcher	Clearly described 5	Unclear 2	Not described 25
6. Trustworthiness: context	Clear 27	Unclear 5	Not Sure 0
7. Trustworthiness: Reliable methods	Reliable 29	Unreliable 1	Not sure 2
8. Analysis: Rigorous	Rigorous 20	Not rigorous 2	Not sure/not reported 10
9. Analysis: Rich data	Rich 22	Poor 8	Not sure/not reported 2
10. Analysis: Reliable	Reliable 17	Unreliable 1	Not sure/not reported 14
11. Analysis: Convincing	Convincing 22	Not convincing 5	Not sure 5
12. Analysis: Relevance to aims	Relevant 28	Irrelevant 0	Partially Relevant 4
13. Conclusions	Adequate 28	Inadequate 3	Not sure 1
14. Ethics	Appropriate 20	Inappropriate 1	Not sure/not reported 11
Overall assessment	++ 12	+ 14	- 6

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 [51 61 64 65 72]. 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) [48 49 56-59 64 66 71-74 76 78]. 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 [47 53 54 67 68 70 76 78]. In 11 studies the ethical implications of the research were not adequately reported [47 52 56 57 59 63 67 68 73 77 78].

Six studies were scored in the lowest category for the overall assessment (-) [47 54 67 74 76 77]. Of these, three studies were very narrow in description and lacked richness in the data presented [47 67 76]. The remaining three studies [54 74 77] were problematic in their overall conclusions. 26 out of 32 studies were 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 2. 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 the current 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 [32 37].

[Figure 2: The development of descriptive and analytical themes]

Descriptive themes

Six descriptive themes were developed and are illustrated in table 3.

Table 3: Descriptive Themes

	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[51 53 54 59 60 63 70 72]. For some the struggle to communicate was an ongoing source of emotional distress, triggering feelings of grief, loss and sadness. However, others had successfully come to terms with their communication impairments. These participants recognised the changes that had taken place in their lives but had been able to adjust to these and find contentment.	*What if you only could! Could talk! That's what I ... Everything' (pg. 149)* [66] *'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.' (p.1283)*[51]
Loss of communication and the loss of self-identity	Communication was often linked to participants sense of self. Being able to communicate as before was regarded as being 'normal'[49 58] and since stroke some participants described feeling as though a piece of themselves was missing. Stroke survivors were conscious of the deficiencies in their speech The constant monitoring and evaluation of speech was also linked to negative self-evaluation when stroke survivors fell short of their own expectations.	*'at least 50 percent of me vanished when speech vanished that that's how I think about it' (p. 1831)*[72] *'… I hate myself because I can't speak right…' (p. 143)*[58]
Isolation and exclusion from social situations	Participants felt left out of social situations or ignored or excluded specifically due to their communication problems [47-49 55 56 58-60 64-72 74]. 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[55 60 67-69].As a consequence, people with post-stroke communication difficulties described either withdrawing from or avoiding communication or social situations altogether[47-49 58-60 67 69 70]. Feelings of embarrassment and a lack of confidence in communication contributed to participant's avoidance of social events [49]. One participant also suggests that fear of stigmatizing reactions contributed to avoidance of social situations [49].	*'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.' (p.431)*[69] *'Instead, they would "go into the background and retreat"…. and "do the bare amount of talking"…' (p.275)*[47]
A support network of family and friends	Family members were discussed as an ongoing support on a practical and emotional level [61 69]. 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 [55 59 60 62 66 69 72 78].The importance of friendship and social support outside the family was also expressed by stroke survivors with communication impairments[50-54 56 60 62 63 71 75]. However, also prominent was the difficulty maintaining friendships and the loss of friendship post-stroke[51 55 60 68-71 74 75].	*'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.' (p. 150)*[66] *'…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)*[55]

Strategies to facilitate successful communication	Some stroke survivors with communication difficulties used their own strategies to help facilitate conversation[47 48 51 55 59 64 66 68 77]. A wide range of strategies were identified including communication aids[48 51 55 59], drawing or writing information down[48 51 66] and signalling by raising a hand that they have something to add when in a group situation[47 48 68]. However, some studies identified a stigma attached to using communication aids[55 66] .Strategies used by communication partners of people with post-stroke communication difficulties were also recognised as a facilitator to successful communication[48 51 55-57 62 64 66 67 72 73 76 77].	*"Interviewer: do you use a communication book? Liv: no, people look strange." (p. 544)*[55] *'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)*[51]
Activity and meaningful participation in life	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[48 51 52 54 55 61 62 75].Establishing a routine was important to stroke survivors with aphasia. 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[53 59 60 68 70-72 74].	*'Be involved with everything.' 'Have a hobby.' 'Live as much as you can; do as much as you can.' (p. 1277)*[51] *'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." (p. 1415)*[61]

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 [48 49 55 58-60 66 68-70 73 74 76 78]. This protected participants from stigmatising reactions and also protected participants self-identity which was questioned when they were confronted with their communication difficulties[48 49 58 72]. However, by avoiding communicative situations, stroke survivors put themselves at risk of losing friendships and becoming socially isolated [50 51 55 60 68-71 74 75].

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 [48 51 55 59 77], drawing or writing information down [48 51 66 77] or signalling by raising a hand that they have something to add when in group situation [47 48 68 77]. 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 [64]. Successful interaction was often facilitated by the stroke survivors close family members, for example a participant in Brady et al.[48] stated '(She) [Wife] deciphers for me' (p. 945). Successful interaction could also be facilitated by a competent

conversation partner [48 51 55 56 62 64 66 67 72 73 76 77]. 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!'…" [66] (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[128]. 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[129].

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 [51 61]. Meaningful activity was something which 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 which they valued, which they enjoyed or which gave them a sense of purpose[48 51 52 54 55 61 62 75].

Sometimes stroke survivors struggled to participate in meaningful activities they had enjoyed prior to stroke due to their communication difficulties[53 59 60 68 70-72 74]. However, those who described themselves as living successfully with a communication difficulty sought and took part in other activities which 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 which they could participate in as opposed to those which they could not[48 51 52 54 55 61 62 75]. Brown et al. [51] 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."* [51] *(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. [53] 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")'* [53] *(p. 336).*

This group also experienced other practical challenges common to many stroke survivors such as physical disability, fatigue or a lack of transport [59-62 71] which were additional barriers to participating in meaningful activity.

Future interventions should consider the role of meaningful activity in participants' lives. Establishing a routine or scheduling activities which 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[128] 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 [50-54 57 60-63 69 71 75]. 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 [50 51 55 60 68-71 74 75]. In some circumstances, participants had friends prior to the stroke that had drifted away over time [50 55 74]. Stroke survivors sensed that their old friends struggled to communicate with them in the same way and adapt to the new situation. Participants in the included studies described how initially friends had rallied round in the months after stroke but then gradually drifted away over time [50 55 74]. Dalemans et al. [55] 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)[55].*

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 [50-52 57 60 69]. 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[130].

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 [50 51 60 61 66 72 75 78]. 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 [48 55 61 69]. For example, one participant in Grohn et al.[61] 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. [51] 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. [62] 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[131 132]. Participants' beliefs in their own ability may also be related to the sense of taking control. Such experiences sit well with self-efficacy theory[133] which proposes that a persons belief about their capabilities influences their ability to perform a task. Future interventions may wish to consider components which are targeted towards enhancing self-efficacy.

DISCUSSION

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. 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.

Our findings suggest that the biomedical model of illness is inadequate in understanding the full impact of communication disorders[134]. Traditional speech and language therapy approaches are based upon this model; typically focusing upon treating the specific impairment the patient is experiencing [135 136]. However, this synthesis of qualitative research demonstrates that the impact communication difficulties goes beyond symptoms of the medical impairment; influencing social relationships, mood and activities of daily living. The World Health Organisations International Classification of Functioning, Disability and Health (WHO ICF) [137] recognises the complex interplay of biological, psychological and social influences which may influence health. Findings from the current review support this model and suggest that wider psychosocial factors should be considered in the rehabilitation of post-stroke communication difficulties[115].

Review findings also highlight the complex journey people with communication difficulties go though 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. These findings are consistent with established theories of chronic illness such as the chronic illness trajectory proposed by Corbin and

Strauss[138 139] and Bury's theory of biographical disruption[140] which explain how patients and families cope in different ways with their illness journey and the associated disruption to their lives. It is important to consider whether illness trajectories can 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[141 142]. There is evidence to support the use of self-management interventions in a range of chronic conditions[143-146] and there is a substantial policy drive towards taking this approach in stroke care[2 8]. However, the evidence to support the efficacy of self-management approaches in stroke is mixed[147 148] and a recent systematic review demonstrated that stroke survivors with aphasia are often excluded from RCTs of self-management interventions[148]. A significant proportion of self-management interventions are based upon or adapted from the Chronic Disease Self-Management programme[145]; a group-based patient education programme which has been assumed to be applicable across a range of chronic diseases. However, chronic diseases such as arthritis, diabetes and asthma may follow different trajectories to stroke[139]. Stroke is sudden and life-threatening at onset and causes striking and immediate disruption to patients' lives, in contrast to the more subtle onset and course of other chronic diseases. This suggests that self-management interventions may need to be designed specifically to meet the needs of stroke survivors (including those with communication difficulties) as opposed to being adapted from existing 'one size fits all' approaches[149].

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 priorities of stakeholders[150-152]. Although there is significant overlap with the experiences of the general stroke survivor population[24 39 43]; 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. Although self-management may be a useful concept, the findings

of the current review suggest that self-management interventions must be specifically designed to ensure they meet the needs of stroke survivors with communication difficulties and support them manage the psychosocial consequences of the communication difficulty itself.

Limitations of the review

Two areas of limitation can be identified in this review. Firstly, the quality of the synthesis is inherently limited by the quality and reporting of the original studies [31 153]. 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 [154 155]. The lack of reflexivity means it is difficult to evaluate levels of researcher bias in study findings. 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 participant's responses or the analysis or presentation of results. A second limitation 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. The current 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 current synthesis which looked at patients who perceived themselves to be living successfully with aphasia and the factors influencing this [51 52 61-63]. These studies were of high quality and made a significant contribution to the synthesis of information.

Implications for future research

Future research should explore the possible components of a longer-term care intervention for stroke survivors with communication difficulties and the feasibility of self-management as an approach. Few studies explored need within the first year post-stroke and further information about how survivors with post-stroke communication difficulties manage their condition following hospital discharge is

required to further understand adaptation and adjustment during this time period and inform subsequent care strategies.

Conclusions

Our 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 therapy may fail to address the psychosocial consequences of post-stroke communication difficulties and enable stroke survivors to successfully manage these difficulties within this context[156]. Self-management interventions may be useful to facilitate the process of adaptation and adjustment, however, a critical examination of self-management approaches and their suitability for stroke survivors with communication difficulties is needed to ensure that such interventions meet the needs of this population.

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Contributor statement

FW contributed to the design of the study, acquired the data, analysed the data and drafted the manuscript. DC contributed to the design of the study and reviewed the manuscript for intellectual content.

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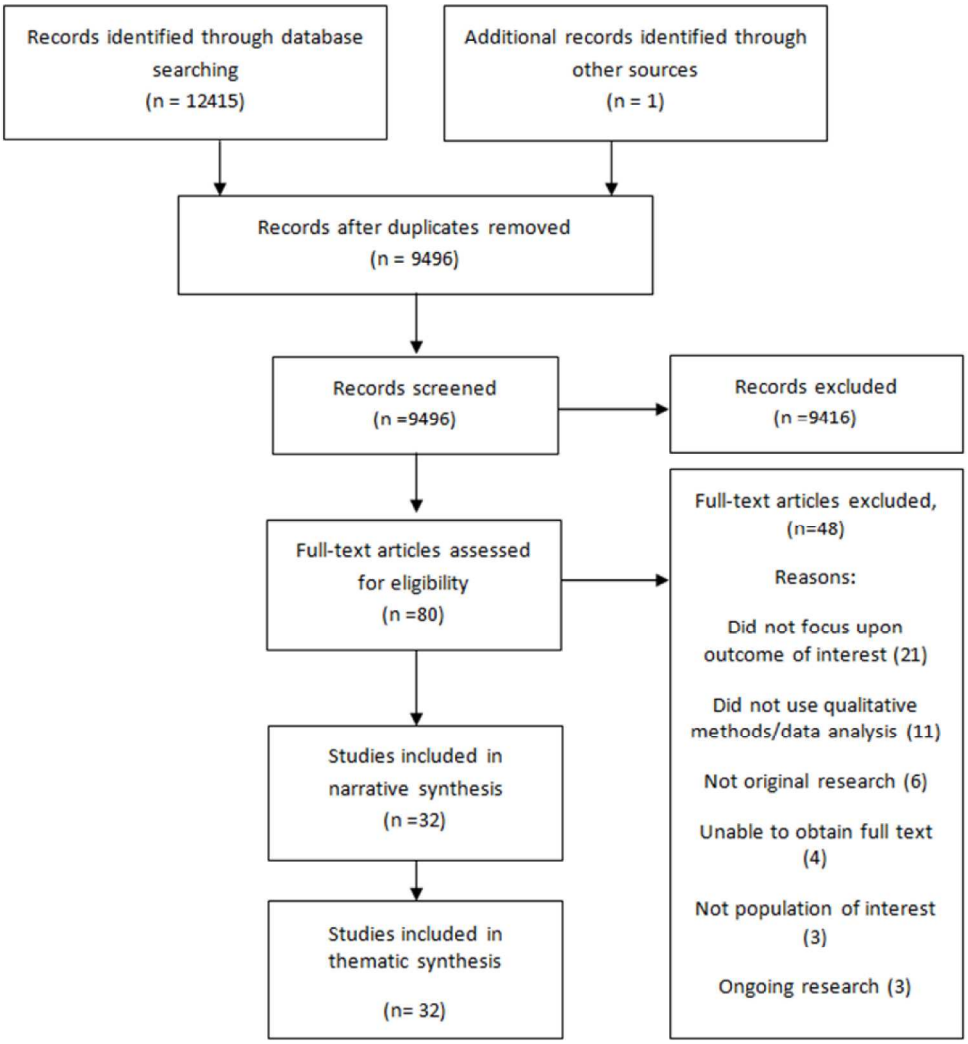

Figure 1: PRISMA flow diagram

279x293mm (300 x 300 DPI)

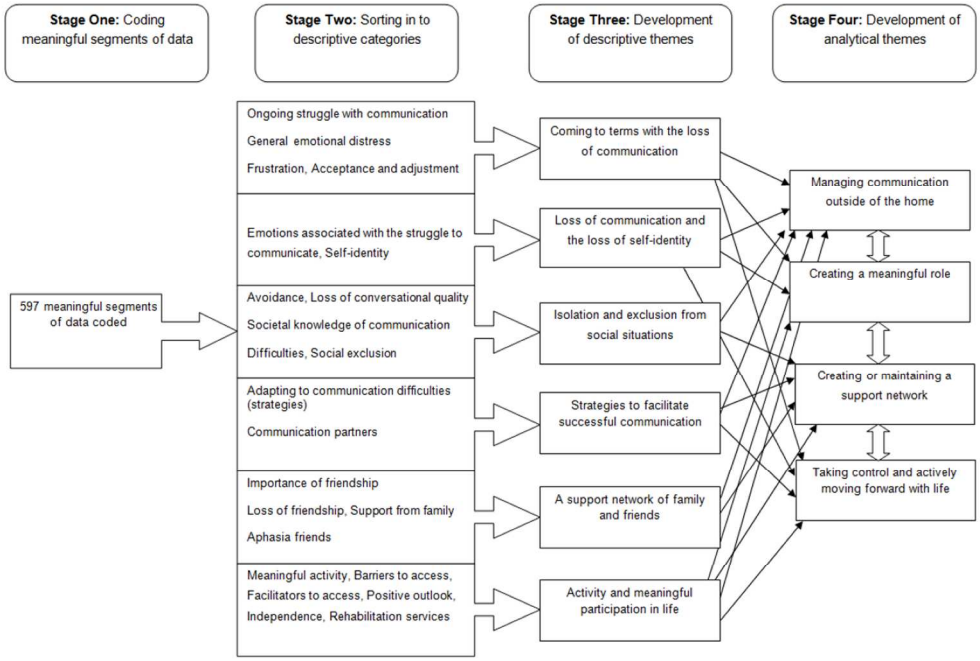

Figure 2: The development of descriptive and analytical themes

265x175mm (300 x 300 DPI)

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4-5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	6
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	See online supplementary information
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A but included equivalent section on quality assessment

PRISMA 2009 Checklist

			p.8
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A qualitative review
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	8/9

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A qualitative review
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A qualitative review
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	10
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	10-17
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	N/A qualitative review
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A qualitative review
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A qualitative review
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A qualitative review
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A qualitative review

PRISMA 2009 Checklist

DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	29
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	31
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	32
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	33

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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BMJ Open

Longer-term needs of stroke survivors with communication difficulties living in the community: A systematic review and thematic synthesis of qualitative studies.

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Longer-term needs of stroke survivors with communication difficulties living in the community: A systematic review and thematic synthesis of qualitative studies.

Faye Wray*[1] and David Clarke[1]

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CONTACT DETAILS

- Mrs Faye Wray (*corresponding author)

Email: ps10fdp@leeds.ac.uk Tel: 01274 382818

Address: Academic Unit of Elderly Care and Rehabilitation, Leeds Institute for Health Sciences, Bradford Institute for Health Research, Temple Bank House, Bradford Royal Infirmary, BD9 6RJ

- Dr David Clarke

Email: d.j.clarke@leeds.ac.uk Tel: 01274 383441

Address: Academic Unit of Elderly Care and Rehabilitation, Leeds Institute for Health Sciences, Bradford Institute for Health Research, Temple Bank House, Bradford Royal Infirmary, BD9 6RJ

ABSTRACT

Objective: To review and synthesise qualitative literature relating to the longer-term needs of community dwelling stroke survivors with communication difficulties including aphasia, dysarthria and apraxia of speech.

Design: Systematic review and thematic synthesis.

Method: We included studies employing qualitative methodology which focused upon 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. We searched MEDLINE, EMBASE, PsycINFO, CINAHL, The Cochrane Library and IBSS and undertook grey literature searches. Studies were assessed for methodological quality by two researchers independently and the findings were combined using thematic synthesis.

Results: Thirty-two studies were included in the thematic synthesis. The synthesis reveals the ongoing difficulties stroke survivors can experience in coming to terms with the loss of communication and in adapting to life with a communication difficulty. Whilst some were able to adjust, others struggled to maintain their social networks and to participate in activities which were meaningful to them. The challenges experienced by stroke survivors with communication difficulties persisted for many years post-stroke. Four themes relating to longer-term need were developed: 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.

Conclusions: Understanding the experiences of stroke survivors with communication difficulties is vital for ensuring that longer-term care is designed according to their needs. Wider psychosocial factors must be considered in the rehabilitation of people with post-stroke communication difficulties. Self-management interventions may be appropriate to help this sub-group of stroke survivors manage their condition in the longer-term; however, such approaches must be designed to help survivors to manage the unique psychosocial consequences of post-stroke communication difficulties.

ARTICLE SUMMARY

Strengths and limitations of this study

- This is the first systematic review and synthesis of qualitative studies to explore the longer-term needs of stroke survivors with communication difficulties living in the community.
- By synthesising qualitative literature, a greater level of conceptual or theoretical understanding can be gained than by looking at one study in isolation.
- Thematic synthesis is a robust method of synthesis which draws together information from qualitative literature in order to make reasoned recommendations for future intervention development.
- Many of the studies identified did not describe the role of the researcher which may impact upon the data collected and the findings of the synthesis.
- The impact of publication bias in qualitative literature is difficult to assess.

INTRODUCTION

The global burden of stroke is set to rise. It is predicted that by 2030, there will be 12 million stroke deaths, 70 million stroke survivors and 200 million disability adjusted life years lost due to stroke worldwide[1]. In England, it is estimated that 300 000 people are living with moderate to severe disability following stroke[2]. The disabilities stroke survivors face are complex and there is a high prevalence of unmet need in the years following acute onset[3]. Qualitative research has identified that the transition between hospital and community services is difficult and that many stroke survivors feel unsupported and abandoned in the longer-term[4-6]. Although the importance of supporting stroke survivors in the longer-term has been recognised by policymakers, the precise format and content of such support has yet to be established[2 7 8]. Developing an evidence-based care pathway which meets the complex needs of individuals and families coping with the aftermath of stroke remains a challenge[9-11].

Up to one third of survivors will experience communication difficulties post-stroke including aphasia, dysarthria or apraxia of speech[12-15] resulting in difficulties with language comprehension, speech production and difficulties with reading and writing. Research suggests that this sub-group of stroke survivors may have particularly poor longer-term outcome[16], 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[17].This sub-group are also more likely to suffer from depression[18] and have reduced social interactions[19]. Although stroke survivors with communication difficulties may benefit from longer-term support, the needs of this population in relation to longer-term care have not been explored.

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[20-22]. In the wider stroke literature systematic reviews and syntheses of qualitative literature have been undertaken[23-25]. However,

Walsh et al.[25] and Satink et al.[24] 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 strategies to ensure that, wherever possible, those with communication difficulties can be included in qualitative research[26-28]. There is a growing body of research in this field which highlights the stroke survivors perspective on living with a communication difficulty[29]. A recent narrative literature review drew together qualitative studies exploring stroke survivor's experiences of community aphasia groups (CAGs)[30]. This review focused specifically upon experiences of CAGs and did not attempt to synthesise broader experiences of living with a communication difficulty. To date there has been no systematic review and synthesis of qualitative research exploring the needs of stroke survivors with communication difficulties in relation to 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[31 32]. 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[33] 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[31 32]. In order to design a longer-term care strategy for stroke survivors with communication difficulties, it is important to synthesise qualitative research findings to better understand the requirements for longer-term care from the patients' perspective. The current review aimed to explore the needs of stroke survivors with communication difficulties in relation to longer-term care.

METHOD

A systematic review and thematic synthesis[33] of qualitative literature relating to the needs of stroke survivors with communication difficulties living in the community was undertaken. A review protocol was developed but was not registered or published.

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 randomised controlled trials (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[34]. This poses difficulties when identifying qualitative research systematically[35-37]. Some argue for the use of a broader approach by not including filters in relation to qualitative methodology[38]. However, in this case a qualitative filter[39] 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 the online supplementary information.

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; 1) Reviewing the reference lists of studies meeting inclusion criteria, 2) reverse citation search of studies meeting inclusion criteria and 3) reference list check and reverse citation search of an existing systematic review of qualitative literature in stroke care [40].

Study selection and data extraction

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 second and third authors.

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[41]. The National Institute for Health and Care Excellence (NICE) public health guidance qualitative appraisal checklist [42] was used for assessment of methodological quality in the current review. NICE created the checklist based upon the broad issues which are generally accepted to affect validity in qualitative research[42]. 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'. 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[35 43] and a number of approaches have been developed including

qualitative meta-synthesis[44], meta-ethnography[31 32] and thematic synthesis[33 38]. In this review studies were combined using thematic synthesis[33 38]. This method of synthesis was specifically formulated by the Evidence for Policy and Practice Information and Co-ordinating Centre (EPPI centre) to organise findings from qualitative literature to enable reasoned hypotheses about intervention need, appropriateness and acceptability[45]. Like meta-synthesis and meta-ethnography, thematic synthesis allows for a deeper exploration of findings which goes beyond narrative summary[33 38]. 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[31 46].

Key findings (supported by relevant quotations) from each included study were extracted and free coded line by line using QSR NVivo software version 10. Groups of descriptive codes were formed based on similarities between the free codes. Through discussion with a second reviewer and a wider review team, the contents of each of the groups of descriptive codes were explored and further refined to create descriptive themes[33 38]. Analytical themes were developed through an iterative process which 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[24 33 47]. Analytical themes were developed with help from the wider review team and by gaining feedback on draft analytical themes from a peer review group in the research unit.

RESULTS

[Figure 1: PRISMA flow diagram of study selection]

Thirty-two citations were identified which were eligible for inclusion in the review [48-79]. The PRISMA flow diagram of study selection is shown in figure 1. Once duplicates had been removed, 9496 records were screened for eligibility and full text was sought for 80 citations. 48 were excluded; 21 studies which did not focus upon the outcome of interest[80-100], 11 studies which did not use qualitative methods or qualitative methods of data analysis[101-111], 6 which were not original research (e.g. were commentaries or book reviews)[112-117], 4 for which we were unable to obtain full text[118-121], 3 which did not include the population of interest[122-124], and 3 ongoing pieces of research for which the results were not yet available[125-127].

Study characteristics

Table 1 shows the characteristics of included studies.

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[60 104] to fifty[74 79] . The majority of studies identified included participants with aphasia (29 out of 32). Only five studies reported including participants with dysarthria[48-50 59 78] and one study included participants with apraxia of speech[48]. 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[49 59 62 63 77].

Table 1: Characteristics of included studies

Authors	Aim of study	L&C 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. [48]	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. [50]	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. [49]	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. [52]	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. [53]	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	n/a	Interview	One interview	Interpretive phenomenological analysis	++
Brown et al. [51]	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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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. [54]	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 [55]	To investigate factors associated with resilience in individuals with aphasia	Aphasia	9	USA	Community	47-73	?	?	Interview	One interview	Content analysis	-
Dalemans et al. [56]	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. [57]	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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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. [58]	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. [59]	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. [60]	The aim of this phenomenological case study was to (a) explore the social role changes experienced by people with aphasia (PWA), (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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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. [61]	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. [63]	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. [62]	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 [128]	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. [66]	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. [65]	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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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. [67]	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 [69]	(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. [68]	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. [70]	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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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. [71]	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	+
Natterlund [72]	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 [73]	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 [74]	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 [75]	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 1: Characteristics of included studies (continued)

Authors	Aim of study	L&C 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 [76]	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. [77]	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 [78]	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.[79]	The purpose of this study was 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]

Methodological quality of included studies

Table 2 shows the results from the NICE public health qualitative appraisal checklist[42]. A table showing individual study ratings is included in the online supplementary material.

Table 2: Methodological quality of included studies

1.Theoretical rationale: appropriateness	Appropriate 32	Inappropriate 0	Not sure 0
2. Theoretical rationale: clarity	Clear 28	Unclear 1	Mixed 3
3. Study design	Defensible 21	Indefensible 4	Not sure 7
4. Data collection	Appropriately 30	Inappropriately 1	Not sure/inadequately reported 1
5. Trustworthiness: role of the researcher	Clearly described 5	Unclear 2	Not described 25
6. Trustworthiness: context	Clear 27	Unclear 5	Not Sure 0
7. Trustworthiness: Reliable methods	Reliable 29	Unreliable 1	Not sure 2
8. Analysis: Rigorous	Rigorous 20	Not rigorous 2	Not sure/not reported 10
9. Analysis: Rich data	Rich 22	Poor 8	Not sure/not reported 2
10. Analysis: Reliable	Reliable 17	Unreliable 1	Not sure/not reported 14
11. Analysis: Convincing	Convincing 22	Not convincing 5	Not sure 5
12. Analysis: Relevance to aims	Relevant 28	Irrelevant 0	Partially Relevant 4
13. Conclusions	Adequate 28	Inadequate 3	Not sure 1
14. Ethics	Appropriate 20	Inappropriate 1	Not sure/not reported 11
Overall assessment	++ 12	+ 14	- 6

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[52 62 65 66 73]. 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)[49 50 57-60 65 67 72-75 77 79]. 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[48 54 55 68 69 71 77 79]. In 11 studies the ethical implications of the research were not adequately reported[48 53 57 58 60 64 68 69 74 78 79].

Six studies were scored in the lowest category for the overall assessment (-)[48 55 68 75 77 78]. Of these, three studies were very narrow in description and lacked richness in the data presented[48 68 77]. The remaining three studies[55 75 78] were problematic in their overall conclusions. 26 out of 32 studies were 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 2. 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 the current 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[33 38].

[Figure 2: The development of descriptive and analytical themes]

Descriptive themes

Six descriptive themes were developed and are illustrated in table 3.

Table 3: Descriptive Themes

	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[52 54 55 60 61 64 71 73]. For some the struggle to communicate was an ongoing source of emotional distress, triggering feelings of grief, loss and sadness. However, others had successfully come to terms with their communication impairments. These participants recognised the changes that had taken place in their lives but had been able to adjust to these and find contentment.	*What if you only could! Could talk! That's what I ... Everything' (pg. 149)* [67] *'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.' (p.1283)*[52]
Loss of communication and the loss of self-identity	Communication was often linked to participants sense of self. Being able to communicate as before was regarded as being 'normal'[50 59] and since stroke some participants described feeling as though a piece of themselves was missing. Stroke survivors were conscious of the deficiencies in their speech The constant monitoring and evaluation of speech was also linked to negative self-evaluation when stroke survivors fell short of their own expectations.	*'at least 50 percent of me vanished when speech vanished that that's how I think about it' (p. 1831)*[73] *'… I hate myself because I can't speak right…' (p. 143)*[59]
Isolation and exclusion from social situations	Participants felt left out of social situations or ignored or excluded specifically due to their communication problems [48-50 56 57 59-61 65-73 75]. 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[56 61 68-70].As a consequence, people with post-stroke communication difficulties described either withdrawing from or avoiding communication or social situations altogether[48-50 59-61 68 70 71]. Feelings of embarrassment and a lack of confidence in communication contributed to participant's avoidance of social events [50]. One participant also suggests that fear of stigmatizing reactions contributed to avoidance of social situations [50].	*'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.' (p.431)*[70] *'Instead, they would "go into the background and retreat"…. and "do the bare amount of talking"…' (p.275)*[48]
A support network of family and friends	Family members were discussed as an ongoing support on a practical and emotional level [62 70]. 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 [56 60 61 63 67 70 73 79].The importance of friendship and social support outside the family was also expressed by stroke survivors with communication impairments[51-55 57 61 63 64 72 76]. However, also prominent was the difficulty maintaining friendships and the loss of friendship post-stroke[52 56 61 69-72 75 76].	*'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.' (p. 150)*[67] *'…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)*[56]

Strategies to facilitate successful communication	Some stroke survivors with communication difficulties used their own strategies to help facilitate conversation[48 49 52 56 60 65 67 69 78]. A wide range of strategies were identified including communication aids[49 52 56 60], drawing or writing information down[49 52 67] and signalling by raising a hand that they have something to add when in a group situation[48 49 69]. However, some studies identified a stigma attached to using communication aids[56 67] .Strategies used by communication partners of people with post-stroke communication difficulties were also recognised as a facilitator to successful communication[49 52 56-58 63 65 67 68 73 74 77 78].	*"Interviewer: do you use a communication book? Liv: no, people look strange." (p. 544)*[56] *'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)*[52]
Activity and meaningful participation in life	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[49 52 53 55 56 62 63 76].Establishing a routine was important to stroke survivors with aphasia. 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[54 60 61 69 71-73 75].	*'Be involved with everything.' 'Have a hobby.' 'Live as much as you can; do as much as you can.' (p. 1277)*[52] *'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." (p. 1415)*[62]

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[49 50 56 59-61 67 69-71 74 75 77 79]. This protected participants from stigmatising reactions and also protected participants self-identity which was questioned when they were confronted with their communication difficulties[49 50 59 73]. However, by avoiding communicative situations, stroke survivors put themselves at risk of losing friendships and becoming socially isolated[51 52 56 61 69-72 75 76].

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[49 52 56 60 78], drawing or writing information down[49 52 67 78] or signalling by raising a hand that they have something to add when in group situation [48 49 69 78]. 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 [65]. Successful interaction was often facilitated by the stroke survivors close family members, for example a participant in Brady et al.[49] stated '(She) [Wife] deciphers for me' (p. 945). Successful interaction could also be facilitated by a competent

conversation partner[49 52 56 57 63 65 67 68 73 74 77 78]. 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!'…"* [67] *(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[129]. 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[130].

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 [52 62]. Meaningful activity was something which 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 which they valued, which they enjoyed or which gave them a sense of purpose[49 52 53 55 56 62 63 76].

Sometimes stroke survivors struggled to participate in meaningful activities they had enjoyed prior to stroke due to their communication difficulties[54 60 61 69 71-73 75]. However, those who described themselves as living successfully with a communication difficulty sought and took part in other activities which 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 which they could participate in as opposed to those which they could not[49 52 53 55 56 62 63 76]. Brown et al. [52] 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."* [52] *(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. [54] 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")'* [54] *(p. 336).*

This group also experienced other practical challenges common to many stroke survivors such as physical disability, fatigue or a lack of transport [60-63 72] which were additional barriers to participating in meaningful activity.

Future interventions should consider the role of meaningful activity in participants' lives. Establishing a routine or scheduling activities which 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[129] 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[51-55 58 61-64 70 72 76]. 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[51 52 56 61 69-72 75 76]. In some circumstances, participants had friends prior to the stroke that had drifted away over time[51 56 75]. Stroke survivors sensed that their old friends struggled to communicate with them in the same way and adapt to the new situation. Participants in the included studies described how initially friends had rallied round in the months after stroke but then gradually drifted away over time[51 56 75]. Dalemans et al.[56] 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)[56].*

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[51-53 58 61 70]. 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[131].

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[51 52 61 62 67 73 76 79]. 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[49 56 62 70]. For example, one participant in Grohn et al.[62] 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.[52] 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.[63] 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[132 133]. Participants' beliefs in their own ability may also be related to the sense of taking control. Such experiences sit well with self-efficacy theory[134] which proposes that a persons belief about their capabilities influences their ability to perform a task. Future interventions may wish to consider components which are targeted towards enhancing self-efficacy.

DISCUSSION

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.

Our findings suggest that the biomedical model of illness is inadequate in understanding the full impact of communication disorders[135]. Traditional speech and language therapy approaches are based upon this model; typically focusing upon treating the specific impairment the patient is experiencing[136 137]. However, this synthesis of qualitative research demonstrates that the impact communication difficulties goes beyond symptoms of the medical impairment; influencing social relationships, mood and activities of daily living. The World Health Organisations International Classification of Functioning, Disability and Health (WHO ICF)[138] recognises the complex interplay of biological, psychological and social influences which may influence health. Findings from the current review support this model and suggest that wider psychosocial factors should be considered in the rehabilitation of post-stroke communication difficulties[116] .

Review findings also highlight the complex journey people with communication difficulties go though 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. These findings are consistent with established theories of chronic illness such as the chronic illness trajectory proposed by Corbin and

Strauss[139 140] and Bury's theory of biographical disruption[141] which explain how patients and families cope in different ways with their illness journey and the associated disruption to their lives. It is important to consider whether illness trajectories can 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[142 143]. There is evidence to support the use of self-management interventions in a range of chronic conditions[144-147] and there is a substantial policy drive towards taking this approach in stroke care[2 8]. However, the evidence to support the efficacy of self-management approaches in stroke is mixed[148 149] and a recent systematic review demonstrated that stroke survivors with aphasia are often excluded from RCTs of self-management interventions[149]. A significant proportion of self-management interventions are based upon or adapted from the Chronic Disease Self-Management programme[146]; a group-based patient education programme which has been assumed to be applicable across a range of chronic diseases. However, chronic diseases such as arthritis, diabetes and asthma may follow different trajectories to stroke[140]. Stroke is sudden and life-threatening at onset and causes striking and immediate disruption to patients' lives, in contrast to the more subtle onset and course of other chronic diseases. This suggests that self-management interventions may need to be designed specifically to meet the needs of stroke survivors (including those with communication difficulties) as opposed to being adapted from existing 'one size fits all' approaches[150].

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 priorities of stakeholders[151-153]. Although there is significant overlap with the experiences of the general stroke survivor population[24 40 44]; 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. Although self-management may be a useful concept, the findings

of the current review suggest that self-management interventions must be specifically designed to ensure they meet the needs of stroke survivors with communication difficulties and support them manage the psychosocial consequences of the communication difficulty itself. There is a paucity of research into the development and robust evaluation (RCTs) of psychosocial interventions for stroke survivors with communication difficulties. However, interest and research in this field is growing rapidly.[154-157]

Strengths and limitations of the review

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

Two areas of limitation can be identified in this review. Firstly, the quality of the synthesis is inherently limited by the quality and reporting of the original studies [32 158]. 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 [159 160]. The lack of reflexivity means it is difficult to evaluate levels of researcher bias in study findings. 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 participant's responses or the analysis or presentation of results.

A second limitation 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. The current 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 current synthesis which looked at patients who perceived themselves to be living successfully with aphasia and the factors influencing this [52 53 62-64]. These studies were of high quality and made a significant contribution to the synthesis of information.

Implications for future research

Future research should explore the possible components of a longer-term care intervention for stroke survivors with communication difficulties and the feasibility of self-management as an approach. Few studies explored need within the first year post-stroke and further information about how survivors with post-stroke communication difficulties manage their condition following hospital discharge is required to further understand adaptation and adjustment during this time period and inform subsequent care strategies.

Conclusions

Our 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 therapy may fail to address the psychosocial consequences of post-stroke communication difficulties and enable stroke survivors to successfully manage these difficulties within this context[161]. Self-management interventions may be useful to facilitate the process of adaptation and adjustment, however, a critical examination of self-management approaches and their suitability for stroke survivors with communication difficulties is needed to ensure that such interventions meet the needs of this population.

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FW contributed to the design of the study, acquired the data, analysed the data and drafted the manuscript. DC contributed to the design of the study and reviewed the manuscript for intellectual content.

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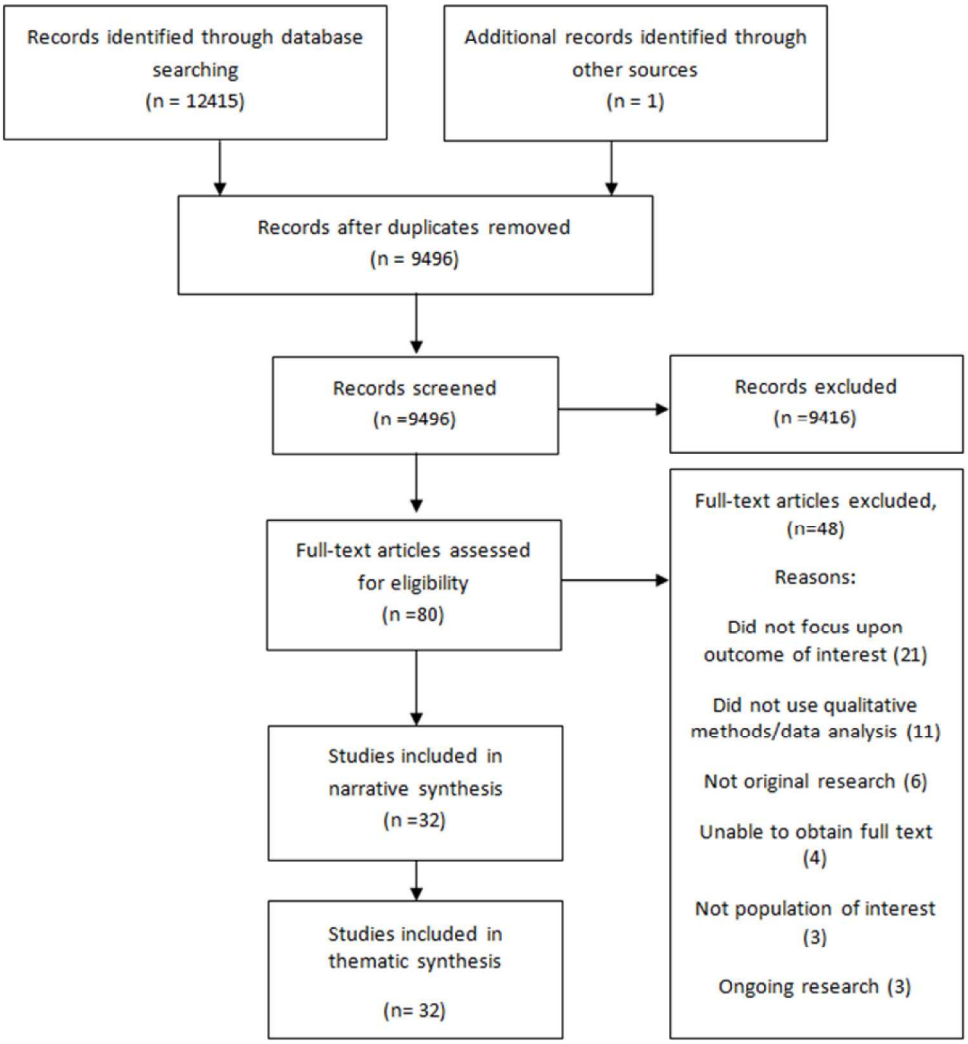

Figure 1: PRISMA flow diagram

279x293mm (300 x 300 DPI)

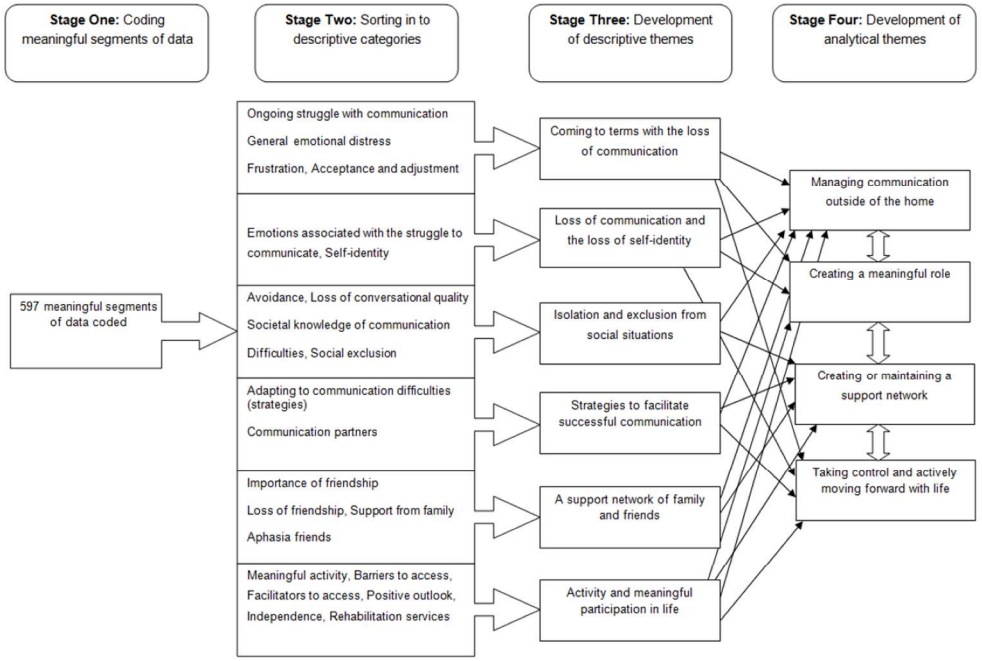

Figure 2: The development of descriptive and analytical themes

265x175mm (300 x 300 DPI)

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	4-5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	6
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	6
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	7
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	See online supplementary information
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	7
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	7
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	7
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	N/A but included equivalent section on quality assessment

PRISMA 2009 Checklist

			p.8
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A qualitative review
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	8/9

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	N/A qualitative review
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A qualitative review
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	10
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	10-17
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	N/A qualitative review
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	N/A qualitative review
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A qualitative review
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A qualitative review
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A qualitative review

PRISMA 2009 Checklist

DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	29
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	31
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	32
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	33

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

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