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Post-stroke self-management interventions: A systematic review of effectiveness and investigation of the inclusion of stroke survivors with aphasia.

Abstract

Purpose

To systematically review self-management interventions to determine their efficacy for people with stroke in relation to any health outcome and to establish whether stroke survivors with aphasia were included.

Method

We searched MEDLINE, EMBASE, PsycINFO, CINAHL, The Cochrane Library and IBSS and undertook grey literature searches. Randomised controlled trials were eligible if they included stroke survivors aged 18+ in a 'self-management' intervention. Data were extracted by two independent researchers and included an assessment of methodological quality.

Results

24 studies were identified. 11 out of 24 reported statistically significant benefits in favour of self-management. However, there were significant limitations in terms of methodological quality, and meta-analyses (n= 8 studies) showed no statistically significant benefit of self-management upon global disability and stroke specific quality of life at 3 months or ADL at 3 or 6 months follow-up. A review of inclusion and exclusion criteria showed 11 out of 24 (46%) studies reported total or partial exclusion of stroke survivors with aphasia . Four out of 24 (17%) reported the number of stroke survivors with aphasia included. In nine studies (38%) it was unclear whether stroke survivors with aphasia were included or excluded.

Conclusions

Robust conclusions regarding the effectiveness of post stroke self-management approaches could not be drawn. Further trials are needed, these should clearly report the population included.

Introduction

Stroke is a prevalent and debilitating condition estimated to affect 152 000 people in the United Kingdom each year [1,2]. The consequences of stroke are long-term with many survivors reporting unmet needs years following the acute event [3,4]. Despite the high prevalence and diversity of difficulties reported, services to address longer-term problems are generally fragmented, uncoordinated or completely lacking [5]. Establishing an evidence-based pathway for longer-term care remains an ongoing challenge [6,7].

Empowering stroke survivors to take an active role in the management of their condition has been suggested as one way of improving longer-term outcomes [8]. 'Self-management' approaches typically teach skills such as decision making, problem solving or goal setting to enable patients to effectively manage the physical and psychosocial consequences of their condition [9,10]. Self-management interventions have shown beneficial effects (such as improving quality of life and reducing healthcare utilisation) in a number of long-term conditions including asthma, diabetes and chronic obstructive pulmonary disease [11-13]. However, stroke falls behind many other long-term conditions with regards to the development and testing of self-management interventions which are comparatively uncommon [14]. In 2013, a systematic review by Lennon et al.[15] identified nine randomised controlled trials (RCTs) in this area. Encouragingly, six of nine trials found significant results in favour of self-management; however, the wide variation in format and outcomes precluded the use of meta-analysis. In addition, the methodological quality of some of the included trials was questionable; two did not report blinding of the outcome assessor and in six trials loss to follow-up was greater than 20%. The authors were therefore unable to reach firm conclusions about the effectiveness of self-management post-stroke.

Despite the limitations of the existing evidence, self-management has been recommended as an approach which should be offered to all stroke survivors in National Clinical Guidelines for Stroke [16] and in the National Stroke Strategy [17]. However, it is unclear where in the stroke pathway self-management should be offered, by whom and in what format and whether such an approach is appropriate for all stroke survivors. Given the heterogeneity of difficulties faced by stroke survivors, concerns have been raised about the feasibility of providing a one size fits all approach to self-management for this population [14].

Approximately one third of stroke survivors will experience aphasia [18] resulting in difficulties with language comprehension, speech production and difficulties with reading and writing [19]. Evidence suggests that people with post-stroke aphasia have particularly poor outcome [20-22]. Stroke survivors with aphasia may benefit from the longer-term support typically offered by self-management approaches. Such approaches may offer an advantage in addressing the psychosocial consequences of stroke lacking in traditional speech and language therapy rehabilitation which is typically deficit focused [23]. However, it is unclear how applicable the evidence is to this population. Stroke survivors with aphasia have previously been excluded from many randomised controlled trials (RCTs) in stroke research [24,25]. The systematic exclusion of stroke survivors with aphasia from research may stem from the assumption that this population lack the capacity to consent to research procedures, however, the view that all stroke survivors with aphasia lack capacity is outdated [24]. Novel methods have been developed to facilitate the inclusion of stroke survivors with aphasia in research, however, it is unclear whether this has translated to the more frequent inclusion of this population [26]. The systematic exclusion of this sub-group of stroke survivors from research examining the efficacy and acceptability of these approaches is a cause for concern. . This issue is of particular importance given the recent recommendations that self-management is offered to all stroke survivors as a key component of longer-term care [16,17].

Due to the rapid growth of research in this field [10] it is now timely to update the Lennon et al.[15] review exploring the effectiveness of self-management interventions post-stroke. The objectives of the review are firstly, to explore the efficacy of self-management for people with stroke in relation to any health outcome (including quality of life, measures of physical disability or measures of mental health) and secondly to explore the inclusion of stroke survivors with aphasia in the trials identified.

Method

A systematic review of post-stroke self-management trials was undertaken. A review protocol was developed but was not registered or published.

Search terms

The development of the search terms was an iterative process which included scoping searches and repeated piloting. A full list of search terms is available in the online supplementary information. Search terms were developed with the help of an information specialist and included a strategy to identify stroke studies developed by the Cochrane Stroke Group. Apart from terms related to stroke, search terms included 'self-management' and synonyms such as 'self-care' and 'self-led'. Other search terms relating to components of self-management e.g. 'goal-setting', 'problem solving' and 'decision making' were also included. The search terms were initially trialled in the Medline database using the Ovid interface.

Eligibility Criteria

Study design: RCTs published in English.

Population: Stroke survivors aged 18+, in any setting (e.g. hospital, home, community-based) and at any time point post stroke.

Intervention: Interventions defined by the authors of papers as 'self-management' or similar terminology such as 'self care' or the intervention comprised some aspect of planning, goal setting or problem solving to facilitate behaviour change and improve participants' quality of life. Interventions could be compared to any control condition and measure any outcome. Self-management interventions solely including stroke survivors with aphasia were eligible for inclusion.

Comparator: Any control condition.

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

Information sources

We searched MEDLINE, EMBASE, PsycINFO, CINAHL, The Cochrane Library and IBSS. The following grey literature sources were also searched: Index to Theses (UK dissertations and Theses), Proquest (international dissertations and theses) and Web of science conference proceedings. Additionally we searched the reference lists of included studies, relevant reviews [15,27] databases of on-going research (HSRProj, UKCRN Portfolio) and clinical trials registers (clinicaltrials.gov, current controlled trials). Databases were searched 2-6th February 2015 (Week 5, 2015) and then later updated to the end of June 2016. All databases searched from inception. Search terms were adapted based on the capabilities of the database.

Study selection and data extraction

Screening for eligible papers involved title and abstract review and then full text review. Screening was performed independently by the first author and another researcher.

Discrepancies were resolved by consensus with the second and third authors. Once agreement on study selection was reached, data extraction was performed.

Data extraction was performed independently by the first author and another researcher. Data were extracted using a template and included participant characteristics (sample size, country, setting, age, gender, time post-stroke, % of participants with aphasia), methods (aim of study, inclusion/exclusion criteria, design of study, unit of allocation), description of the intervention/control, outcome measures and follow-up time points. In order to explore the effectiveness of the self-management interventions, data were extracted for relevant outcomes including means and standard deviations for continuous outcomes and event counts for dichotomous outcomes. We extracted published data only.

Risk of bias

The methodological quality of studies was assessed using the Cochrane Risk of Bias tool [28]. Risk of Bias assessment was performed independently by the first author and another researcher with discrepancies resolved by consensus with a third reviewer. The tool covers six biases which may arise in RCT design. Reviewers are asked to judge if a trial is at 'high', 'low' or 'unclear' risk of bias in these areas. Quality assessment was not used to exclude studies, however, highlighted potential limitations of the research. It was also planned for use in sensitivity analyses; however, insufficient studies were found to conduct such analyses.

Data synthesis

Where self-management interventions were sufficiently similar, data were pooled using the generic inverse variance method in RevMan version 5.3 [29]. Heterogeneity was explored

using the I² statistic. As I² values were low (≤33%), fixed effects meta-analyses models were used. We adjusted for cluster designs in the meta-analyses by calculating the 'effective sample size' [30] using guidance from Cochrane [28]. Where statistical meta-analysis was not possible, due to clinical heterogeneity or lack of comparable outcome measures, results were summarised narratively. In order to address our secondary objective; information from the trials relating to the inclusion of stroke survivors with aphasia was described and synthesised using a narrative approach.

Results

[FIGURE 1: PRISMA FLOW DIAGRAM]

Figure 1 shows the PRISMA flow diagram of study selection. Once duplicates had been removed, 2937 references were screened for eligibility. Full text was obtained for 49 articles of which 16 were excluded. Reasons for exclusion included; six studies did not use a randomized design [31-36], five studies did not include a self-management intervention [37-41], three studies did not include a stroke survivor population [42-44] and for eight studies we were unable to obtain full text [45,46] or the work was ongoing and had yet to be published [47-52]. 27 citations comprising 24 independent samples (studies) were eligible for inclusion in the review [53-79].

<u>Study characteristics</u>

The characteristics of included studies are shown in table 1.

[TABLE 1: CHARACTERISTICS OF INCLUDED STUDIES]

In total, 2921 participants participated in the included studies with a mean age ranging from 53.06 [78][53,54] to 87.5 years [75]. Time post-stroke ranged from 3 days [64,65] to 10 years [70], however, over half of the interventions recruited participants within the first year post-stroke (14 out of 24) [55,56,60,63-69,71,73,74,76,78]. Sample sizes ranged from 20 [72] to 380 [55,72]; just under half of trials (11) were pilot or feasibility studies [57,60,62,64,65,68,70-72,75,76,79]. 69 different outcome measures were used in total. Broadly, they included measures of physical disability (e.g. the Barthel Index, Nottingham Extended Activities of -Daily Living Scale), measures of quality of life (e.g. Stroke Specific Quality of Life scale, SF-36) and measures of mental health (e.g. Hospital Anxiety and Depression Scale, Center for Epidemiologic Studies Depression Scale).

19 out of 24 studies explicitly stated a primary outcome measure. Seven studies chose a quality of life measure for their primary outcome [60,66,69-71,76,78], five studies chose measures of physical disability [58,59,63,67,72,75], three studies chose measures of self-efficacy [53,54,74,79], one study chose a measure of depression as their primary outcome measure [73] and one study chose to measure proactive coping [77].

Intervention characteristics

A descriptive summary of the design, theoretical rationale and content of the self-management interventions is provided in the online supplementary information. The most common theoretical rationale for interventions was self-efficacy theory which was cited in nine studies [53,54,57-60,66,68,69,71,74]. Other theoretical rationales included control cognitions theory (two studies) [62,67], Wagner's chronic care model (two studies) [55,56]

and the psychosocial model (one study) [63]. Eight studies did not state any theoretical rationale for their intervention [64,65,70,73,75,77-79]. The content of the interventions varied; however, they could be broadly arranged into three categories based on their content: 'general self-management', 'occupational self-management' and 'other'.

The majority of studies (14 out of 24) delivered general self-management interventions which focused upon teaching stroke survivors multiple skills such as coping, planning and goal-setting to improve general quality of life [57,60-63,66-71,74,77,79]. Five of the 24 self-management interventions identified were occupational therapy-based interventions which focused upon stroke survivors regaining the skills to perform activities of daily living [58,59,64,65,72,75,76]. These studies met the criteria for 'self-management' as they used aspects of planning, goal setting or problem solving as part of the intervention. However, they were distinguished from other types of self-management interventions as the focus was upon regaining the physical skills needed for self-care as opposed to the broader quality of life outcomes addressed by more general self-management interventions. In addition, all of the occupational therapy-based interventions were facilitated by occupational therapists or physiotherapists.

Of the 'other' interventions, one study was specifically targeted towards improving memory [53,54], one was focused upon problem-solving only [78] and another targeted the prevention of post-stroke depression [73]. Again, these studies met the criteria for 'self-management' as they included aspects of problem-solving, planning and goal-setting. However, they were distinguished from more general self-management interventions due to their specific focus upon a single aspect of stroke rehabilitation. The final intervention was distinguished from the others as it was part of a wider care strategy which involved enhanced-case management and review plus a self-management component [55,56,73].

Risk of bias

The results of the risk of bias assessment are provided in table 2.

[TABLE 2: RISK OF BIAS]

One out of 24 studies was judged to have low risk of bias across all domains [57]. 14 out of 24 studies scored high risk of bias in at least one domain [56,58,59,61,62,66,68-74,76,79]. No studies were judged to be at high risk of bias in the random sequence generation domain. In the blinding of outcome assessment domain, five studies (21%) were at high risk of bias, reporting that the assessor was not blind to the allocation of the participant in the outcome assessment [56,58,59,61,62,71-73]. In the incomplete outcome data domain four studies (17%) were judged to be at high risk of bias [61,72,74,79]. Three of the studies reported substantial losses at follow-up and conducted 'as treated' analysis [61,72,79] and the remaining study reported substantial losses in the intervention arm in comparison to the control arm [74]. In the selective outcome reporting domain 18 studies (75%) were at an unclear risk of bias [53-56,60-65,67-76]. These studies did not reference a study protocol or trial registration which pre-specified outcome measures, therefore, they were judged to be at unclear risk of bias. Three studies (13%) were at high risk of bias in this domain [58,59,66,79] due to discrepancies between measures planned (in the protocol or publication) and those reported in the results of the publication. In the other bias domain, two studies were judged to be at high risk of bias; one due to potential recruitment bias as a result of the cluster design [76] and one due to baseline imbalances between study arms [69].

Evidence synthesis

Efficacy of self-management interventions

Due to the heterogeneous nature of the interventions identified, it was considered inappropriate to pool data across the included studies. Interventions were grouped according to their content (general self-management, occupational self-management, other) and meta-analyses conducted where studies had comparable measures of outcome at comparable time-points. Where meta-analysis was not possible, the efficacy of the interventions are synthesised narratively.

Of the 14 general self-management interventions, five reported significant differences in the intervention group compared to control. At three months, Damush et al.[60] reported improvements in the family roles (p≤0.01, effect size=−0.78) and social roles (p≤0.05, effect size=−0.54) sub-scales of the SSQOL measure in the intervention group in comparison to the control and at six months the intervention group reported significantly higher self-efficacy to communicate with their physician compared to the control (p≤0.04, effect size=−0.59). Harwood et al.'s [66] 'take charge session' significantly improved the physical component score of the SF-36 (p=0.004) and reduced Carer Strain Index scores at 12 months (p=0.03). Johnston et al. [67] found a workbook intervention significantly improved disability recovery at six months follow-up compared to usual care (p=0.019). At nine months, Kendall et al. [69] reported a significant improvement in the self-care sub-scale of the SSQOL in their self-management intervention in comparison to usual care (p=0.05). Finally, Wolf et al. [79] reported that their improving participation after stroke self-management program (IPASS) significantly increased self-efficacy at 6-9 months follow-up (p=<0.05) Data were pooled for activities of daily living (ADL) measured by the Barthel Index and the NEADL at 3 months and measured by the Barthel Index at 6 months. Standardised mean difference (SMD) is reported at 6 months due to the use of differing versions of the Barthel Index. At 3 months three studies (328 participants) contributed data towards the meta-analysis [63,68,71]. The

pooled SMD showed no significant benefit of self-management upon ADL at 3 months follow-up (SMD=0.08, 95% CI -0.14 to 0.30, p=0.48, I²=0%). At 6 months two studies (557 participants) contributed data towards the meta-analysis [63,67]. The pooled SMD showed no significant benefit of self-management upon ADL at 6 months follow-up (SMD=0.12, 95% CI -0.05 to 0.29, p=0.48, I²=0%).Data were also pooled for stroke specific quality of life measured by the SSQOL and SAQOL. Two studies (61 participants) contributed data towards the meta-analysis [68,71]. The pooled SMD showed no significant benefit of self-management upon stroke specific quality of life at 3 months follow-up (SMD=0.01, 95% CI -0.76 to 0.78, p=0.98, I²=54%).

Three out of five occupational therapy interventions reported significant differences in a self-management group compared to control group intervention. Polatajko et al.'s [72] intervention group showed significant improvements in a therapist rated Performance Quality Rating Scale (p=0.02) and in the self-reported performance rated subscale of the Canadian Occupational Performance Measure (p=0.02). Sackley et al. [75] found that participants in care homes who were allocated to the occupational therapy intervention were significantly less likely to have 'poor global outcome' (defined as a deterioration in the Barthel Index or death) compared to those participants in the control care homes at six months follow-up (p=0.03). Finally, Chumbler et al. [58] found increased satisfaction with hospital care at six months in those allocated to a telephone rehabilitation group in comparison to a control group (p=0.029). Data were pooled for global disability (measured by the functional independence measure [FIM]) at 3 months. Standardised mean difference (SMD) is reported due to the use of differing versions of the FIM. At 3 months two studies (63 participants) contributed data towards the meta-analysis [58,59,76]. The pooled SMD showed no significant benefit of self-management upon global disability at 3 months follow-up (SMD=0.16, 95% CI -0.34 to 0.66, p=0.54, I²=0%). Data were also pooled for ADL (measured by the Barthel Index); At 3 months, two studies (81 participants) contributed data

towards the meta analysis [64,65,75,80]. The pooled SMD showed no significant benefit of self-management upon ADL at 3 months follow-up (SMD=0.31, 95% CI -0.14 to 0.75, p=0.18, I^2=0%).

Of the 'other' interventions identified, Aben and colleagues found a significant increase in memory self-efficacy in their intervention group in comparison to the control group at 12 months follow-up (P =0.01) [53,54]. Visser et al.'s [78] problem solving intervention improved task oriented coping (p=0.008) at 6 months follow-up. Robinson et al. [73] reported no significant effects of problem solving therapy upon the prevention of post-stroke depression. In their first trial of a post-discharge model of care Allen et al. [56] found significant effects of the intervention across a range of health profile domains including neuromotor function, severe complications, quality of life, management of risk and stroke knowledge (effect size 0.53, p=<0.0001) at three months follow-up. However, in the second trial of this model at 6 months follow-up Allen et al. [55] only found significant effects in the management of risk and stroke knowledge domains of the health profile (p<0.0003). Due to the heterogeneity of interventions and lack of comparable outcome measures, it was not possible to conduct meta-analyses with data from the group of 'other' self-management interventions.

Inclusion of stroke survivors with aphasia

A review of inclusion and exclusion criteria showed two studies explicitly excluded all participants with aphasia [62,76]. In 10 studies it was unclear whether stroke survivors with aphasia had been included or excluded [55,56,58,59,61,66-68,70,71,75]. Nine studies reported the partial exclusion of stroke survivors with aphasia [60,63,69,72-74,77-79]. Partial exclusion refers to studies where a proportion of stroke survivors with aphasia were excluded. Where partial exclusions were reported, six studies reported the use of a standardized screening tool [60,63,73,77-79], one used the judgement of the treating speech

and language therapist [69], one the judgement of a physician [74]. In the remaining study it was unclear how the exclusion criterion of 'no more than minimal aphasia' was determined [72]. In six out of nine studies, partial exclusions appeared to be related to those with moderate or severe aphasia [78] or severe aphasia [60,63,73,74,79]; the inclusion criteria of remaining three studies were less clear about the level of impairment; 'no more than minimal aphasia' [72], 'Sufficient expressive/receptive English language skills to take part in interviews and the intervention, as determined by the treating speech pathologist' [69] and 'Disturbance in production or comprehension of language (score below 5 on short version of the Aphasia scale of the Dutch Aphasia Foundation)' [77]. One of the studies with partial exclusion criteria reported the number of stroke survivors with aphasia difficulties who did participate [77].

Four out of 24 studies reported the number of stroke survivors with aphasia included. Aben et al.'s sample [53,54] included 11.1% of participants with aphasia, Cadilhac et al.'s sample [57] included 34.27% of participants with aphasia, Guidetti et al.'s sample [64,65] included 42.5% of stroke survivors with aphasia and Tieleman et al.'s [77] sample included 47% of stroke survivors with aphasia. . Although Aben et al.'s [53,54] inclusion and exclusion criteria did not appear to exclude participants with aphasia and the number of participants with aphasia was reported, the authors of the paper describe in their results section the exclusion of three participants due to a 'severe language disorder' suggesting that this population were partially excluded. The authors of the 18 remaining studies which did not report the number of participants with aphasia were contacted by email (where available).Two responses were received; Visser et al.'s [78] sample included 7.8% of stroke survivors with mild aphasia and Jones et al.'s sample [68] included 11.5% of participants with mild aphasia. The rationale for the inclusion or exclusion of stroke survivors with aphasia was not reported in any of the included studies.

Discussion

<u>Summary of main results</u>

The systematic review identified 24 RCTs of self-management in stroke involving 2937 participants. The theoretical rationales, delivery and content of the self-management interventions identified varied widely as did the outcome measures used to determine effectiveness. Just under half of the interventions identified were pilot or feasibility studies. 11 out of 24 of the self-management interventions identified found statistically significant benefits in favour of self-management. Meta-analysis showed no statistically significant benefit of self-management upon global disability or stroke specific quality of life at 3 months follow-up or ADL at 3 or 6 months follow-up. We were unable to perform meta-analysis for any other health outcomes due to a lack of comparable outcome measures at comparable time points. With regards to the secondary objective of this review; only four out of 24 self-management trials identified reported the number of stroke survivors with aphasia included. Just under half of the trials reported total or partial exclusion of stroke survivors with aphasia in their inclusion/exclusion criteria. In just under half of trials, it was unclear whether stroke survivors with aphasia were included or excluded.

<u>Methodological quality of included studies</u>

The methodological quality of the included studies was mixed. 14 out of 24 of the trials identified were judged to be at high risk of bias in at least one domain. Five studies failed to report adequate blinding of the outcome assessor and were judged to be at high risk of bias in this area [56,58,59,61,62,71-73]. A systematic review conducted by Hróbjartsson et al.[81] suggests that treatment effects may be exaggerated in trials where unblinded outcome assessors are used to assess subjective outcomes. Four studies were judged to be at high risk of attrition bias due to incomplete outcome data [61,72,74,79]. This is problematic as

those participants missing from the analysis may vary systematically from those who are included [82] and may make the treatment may appear more favourable [83]. Another methodological weakness apparent in the trials identified was the selective reporting of outcome measures. Three studies were at high risk of bias in this domain [58,59,66,79]. Reviews of outcome reporting suggest that treatment effectiveness is likely to be exaggerated by selective outcome reporting as the outcomes chosen to be reported are generally those which reach statistical significance [84,85]. The results of the studies identified as being at high risk of bias should be interpreted with caution.

Limitations of the review

As a secondary review objective, we chose to focus upon the inclusion of stroke survivors with aphasia. However, we recognise that other groups of stroke survivors may also be underrepresented in trials of self-management, for example, those with cognitive difficulties, care-home dwelling stroke survivors or stroke survivors who do not speak the native language. This is a limitation of the current review.

The current review aimed to be as inclusive as possible of potential self-management interventions however, it may be criticised for being overly inclusive of interventions which did not explicitly identify themselves as 'self-management'. For example, there is significant overlap between some standard features of stroke rehabilitation provided by occupational therapists and components of self-management interventions. For example, goal setting and problem solving is an integral part of occupational therapy [86], however, it is unclear if such interventions should be included in reviews of self-management as their focus is generally is upon regaining physical independence as opposed to targeting the psychosocial impact of the condition, something which has been suggested as a key component of self-management [9,14]. Occupational therapy interventions comprised a significant proportion

of studies in a recent stroke self-management review by Taylor et al.[10]. On the other hand, a review protocol by Fryer et al.[87] restricted the definition of self-management interventions to those targeting quality of life outcomes only. These contrasting approaches highlight the uncertainties which remain about the definition of self-management in stroke.

Interpretation and implications for future research

For studies included in the current review, limitations with study design, the diversity of the interventions identified and the diversity of the outcome measures used, make it difficult to draw robust conclusions regarding the efficacy of self-management for stroke survivors. The diversity of outcomes measured was particularly problematic and reflects a lack of clarity on the outcomes self-management interventions are expected to target [88]. Uncertainties also remain regarding the optimum format, content and mode of delivery of self-management interventions for stroke survivors [15]. Additional fully powered and high quality trials are needed to address these important questions.

The current review also highlights how, despite being recommended as an approach which should be offered to all stroke survivors [16,17], it is probable that stroke survivors with aphasia, particularly those with moderate to severe aphasia are underrepresented in trials of self-management. This may lead to a systematic lack of evidence for the feasibility, acceptability and efficacy of this approach for this sub-group of stroke survivors. The systematic exclusion of this population of stroke survivors is not only discriminatory but may also lead to health inequalities due to a lack of evidence regarding the effectiveness of self-management interventions with this population [24]. A number of well-established strategies have been advocated to promote the inclusion of stroke survivors with aphasia in research, [26,89,90] for example, the adaptation of consent procedures and written information. However, in addition to proactive recruitment strategies, it is likely that the inclusion of stroke

survivors with aphasia will require careful consideration and adaptation of self-management approaches as a whole [17]. Future trials of self-management should clearly report the population targeted, including the inclusion or exclusion of stroke survivors with aphasia and rationale for the inclusion or exclusion of this population.

Since the searches for this study were undertaken a Cochrane review of self-management in stroke has been published [91]. The Cochrane review differed in terms of its inclusion criteria, namely excluding self-management interventions which were not multicomponent in nature. In contrast to the current review, the Cochrane review showed a positive effect of self-management upon quality of life. It is unclear which time points were used to compare studies included in the quality of life meta-analysis in the Cochrane review. In the current review we pooled quality of life data at 3 months follow-up. A benefit of this approach is that data is not compared across varying time points e.g. one month versus 9 month data. However, taking this approach limited the studies eligible for inclusion in our meta-analysis (the analysis undertaken in the current review compared two studies and the Cochrane review analysis compared six). An additional point for comparison is that the Cochrane quality of life meta-analysis included three studies reporting the physical component score of the SF-12 or SF-36. It is important to note that these subscales made a substantial contribution to the meta-analysis and although broadly related to the construct of quality of life, the meta-analysis may be more heavily weighted towards measuring physical aspects of quality of life.

The findings of the current review also support the findings of the Cochrane review [91] in two key ways. Firstly, that the diversity of self-management interventions and outcome measures are problematic for synthesising the evidence available and secondly, that further

research is needed to understand the key features of effective self-management interventions.

Conclusion

The evidence base for self-management in stroke is growing rapidly; an additional 15 trials of self-management have been identified since the Lennon et al. review in 2013 [15], however, further robust trials are needed. Our findings are in line with previous reviews which have highlighted a lack of understanding of the key features of effective self-management interventions and a need for further research in this area [15,91]. As self-management has been recommended as a core component of longer-term care for stroke survivors, it is also important that such interventions are accessible to the whole population including stroke survivors withaphasia . Inadequate longer-term care may be offered if the evidence base is not inclusive of the whole stroke survivor population [24].

Declaration of Interest Statement

The authors report no conflicts of interest

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Table 1: Characteristics of included studies

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age (Mean and SD)	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Aben et al.[54] and Aben et al. [53]	153	11.11% with aphasia	Netherlands	Design: 2 arm, parallel group Unit: Individual randomisation	58 (9.7)	45.1	Mean 54 months	-Memory self-efficacy intervention - Peer support group	- Metamemory-In-Adulthood questionnaire - CES-D -Quality of life-EQ-5D, WhoQol Bref -Memory capacity-Auditory Verbal Learning Test and story recall from the Riverhead Behavioural Memory Test	10 days after the intervention 6 months 12 months	N
Allen et al. [56]	96	?	USA	Design: 2 arm, parallel group Unit: Individual randomisation	Control: 72 (SD not reported) Intervention : 69 (SD not reported)	55.9	Not stated, however, enrolled in to study approximately 48 hours prior to discharge	-Enhanced post discharge care with self-management component -Usual care	-NIHSS -Barthel Index -Stroke Adapted 30-item Sickness Impact Profile -Blood pressure -Appropriate anticoagulation -Stroke Knowledge	3 months	?
Allen et al. [55]	380	?	USA	Design: 2 arm, parallel group Unit: Individual randomisation	Control: 69 (SD not reported) Intervention : 68 (SD not reported)	50	Not stated, however, enrolled in acute unit following confirmation of diagnosis. Intervention participants contacted within 1 week of discharge	-Enhanced post discharge care with self-management component -Usual care	-NIHSS -Timed up and go test -Days hospitalized and death -SSQOL -Blood pressure - CES-D -Medication appropriateness Self-reported falls and incontinence -Stroke Knowledge	6 months	N

Table 1: Characteristics of included studies (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age (Mean and SD)	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Cadilhac et al. [57]	143	34.27% with aphasia	Australia	Design: 3 arm, parallel group Unit: Individual randomisation	69 (11)	59	To be included ⩾3 months post-stroke (70% of sample were >12 months post-stroke)	-Chronic condition Self Management programme and standard care -Stroke Self Management Programme and standard care - Standard Care Only	-Health Education Impact Questionnaire - Assessment of Quality of Life -Irritability, depression and anxiety scales -Health resource utilisation	3 and 6 months	Y
Chumbler et al. [59] and Chumbler et al. [58](Supplementary information obtained from published protocol Chumbler et al. [92]	52	?	USA	Design: 2 arm, parallel group Unit: Individual randomisation	Control: 67.7 (10.0) Intervention: 67.1 (9.5)	2.1%	?	-Multifaceted stroke telerehabilitation (STeleR) - Usual care	-The motor subscale of the Telephone Version of the Functional Independence Measure -The Overall Function Component of the Late-Life Function and Disability Instrument (LLFDI) -Secondary outcomes included the 3 subscales of the LLFDI Function Component: upper extremity function, basic lower extremity function, advanced lower extremity function -LLFDI Disability Component, which evaluates social roles (eg, visiting friends) and personal roles (eg, meal preparation), and evaluates difficulty with task performance and frequency of performance	3 and 6 months	N

Table 1: Characteristics of included studies (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age (Mean and SD)	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Damush et al. [60]	63	?	USA	Design: 2 arm, parallel group Unit: Individual randomisation	Control: 64(8.4) Intervention: 67.3 (12.4)	1.6	1 month	- Stroke self-management programme -Placebo telephone call	- SS-QOL -Self-Management behaviour frequency -Self-efficacy	3 and 6 months	Y
Fido. [61]	29	?	UK	Design: 2 arm, parallel group Unit: Individual randomisation	Overall: 69 (12.30) Control: 67.93 (12.24) Intervention: 70.13 (12.69)	55.17	?	-Diary Plan - No diary plan	-Diary completion - NEADL -Psychological Wellbeing-HADS -Prospective and Retrospective Memory Questionnaire -Motivation for diary keeping	2 weeks	N
Frank et al. [62]	39	Excluded people with aphasia	UK	Design: 2 arm, parallel group Unit: Individual randomisation	Control: 64.35 (14.30) Intervention:63.58 (12.09)	48.7	Workbook group: mean weeks since stroke- 41.42(SD 24.53) Control group: mean weeks since stroke- 37.95 (SD 27.53)	-Workbook based intervention -Wait list control	-Functional limitations Profile -Sickness Impact Profile - HADS -Recovery Locus of Control Scale -Perceived Health Competencies Scale	1 month	Y
Glass et al. [63]	291	?	USA	Design: 2 arm, parallel group Unit: Individual randomisation	Control: 70.4 (11.0) Intervention: 69.3 (11.0)	49.3	Aim to recruit participants within 1 month post-stroke	-Psychosocial Intervention -Usual Care	-Barthel Index -Mini Mental State Exam - CES-D -Barrera's Inventory of Social Supported Behviors -Recovery Efficacy	3 and 6 months	N

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Table 1: Characteristics of included studies (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age (Mean and SD)	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Guidetti et al. [64] And Guidetti and Ytterberg [65]	40	42.5%	Sweden	Design: 2 arm, parallel group Unit: Individual randomisation	Control: 69 (15) Intervention : 66 (14)	57.5	Recruited 3-5 days post-stroke	-Client centred self-care intervention (CCSCI) -Usual Care	-Barthel Index -FIM -Frenchay Activities Index -Stroke Impact Scale -Life Satisfaction Scale -Occupational Gaps questionnaire - Caregiver Burden Scale	3 , 6, and 12 months	Y
Harwood et al. [66]	172	?	New Zealand	Design: 2x2 parallel factorial Unit: Individual randomisation	61.4 (13.6)	52.3	Randomized up to 3 months post-stroke	-Inspirational DVD -Take Charge session -Inspirational DVD and Take Charge session -Control (written information)	- SF-36 -Barthel Index -Frenchay Activities Index -Carer Strain Index -Modified Rankin Score	12 months	N
Johnston et al. [67]	203	?	UK	Design: 2 arm, parallel group Unit: Individual randomisation	Control: 68.79 (12.02) Intervention : 68.96 (12.64)	38.9	Baseline interview within 2 weeks of discharge following hospital	-Workbook based intervention -Usual Care	-Barthel Index -Observer Assessed Disability -HADS -Satisfaction -Recovery Locus of Control Scale -Confidence in recovery -Physical functioning SF-36	8 weeks, 6 months	N
Jones et al. [68]	78	11.5%*	UK	Design: 2 arm parallel group Unit: Cluster	Control: 68.82 (10.28) Intervention : 61.79 (SD 16.03)	42	Intervention: Median 76 days (IQR 44.5-130.5) Control: Median 116 days (IQR 46-170.5)	-Bridges self-management programme -Routine Stroke Rehabilitation	-Stroke and Aphasia Quality of Life (SAQOL) scale -Nottingham Extended ADL (NEADL) -Stroke self-efficacy questionnaire -HADS -SF-12	6 and 12 weeks	Y

Table 1: Characteristics of included studies (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age (Mean and SD)	Gender (% female)	Time post-stroke	Intervention(s)/ Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Kendall et al. [69]	100	?	Australia	Design: 2 arm, parallel group Unit: Individual randomisation	65.96 (10.67)	33	Eligible for inclusion if stroke sustained in the past 'few months'	-Chronic Disease Self-Management course plus stroke specific information session -Usual Care	- SSQOL -Self-efficacy scale	3, 6, 9 and 12 months	N
Marsden et al. [70]	25	?	Australia	Design: 2arm cross-over RCT Unit: Individual randomisation	Control: 73.1 (9.3) Intervention: 70.0 (9.0)	24	Intervention group mean time post stroke: 37.2 (26.7) months Control group: 39.0 (23.6) months	-'Community Living After Stroke for Survivors and Carers' (CLASSIC) -Wait list control (received intervention after study completed)	-Quality of life: Stroke Impact Scale and Health Impact Scale -Modified Rankin Scale -Mini mental state examination -Six minute walk test -Timed Up and Go - Caregiver Strain Index	week 9, week 17, week 21	Y
McKenna et al. [71]	25	?	UK	Design: 2 arm, parallel group Unit: Individual randomisation	Control: 67.38 (10.60) Intervention: 62.18 (13.57)	44	Intervention- mean weeks post-stroke 7.0 (SD 4.45) Control-mean weeks post-stroke 11.38 (SD 12.70	-Bridges Supported Self-Management Programme -Usual care	-Health related quality of life (EuroQol and SSQOL) -Self efficacy (SES and SSEQ) -Functional independence (Barthel Index, NEADL, mood-GHQ-28, community integration SIPSO)	3 months	Y
Polatajko et al. [72]	20	?	USA	Design: 2 arm, parallel group Unit: Individual randomisation	60.4 (SD not reported)	57.9	? (At least 6 months post-stroke)	-Cognitive Orientation to daily Occupational Performance (CO-OP) -Standard occupational therapy	-Performance Quality Rating Scale -Canadian Occupational Performance Measurement	Not stated ('after intervention')	Y

Table 1: Characteristics of included studies (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age (Mean and SD)	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Robinson et al. [73]	176	?	USA	Design: 3 arm, parallel group Unit: Individual randomisation	Escitalopram -61.3(13.7) Problem-Solving Therapy- 67.3 (11.2) Placebo-63.9 (13.3)	40.34	Within 3 months	-Escitalopram -Problem-solving therapy - Placebo	-Structured Clinical Interview for DSM-IV -Hamilton-17 Depression Rating Scale -Hamilton Anxiety Rating Scale -FIM -The Social Functioning Exam	3, 6, 9 and 12 months	N
Sabariego et al. [74]	213	?	Germany	Design: 2 arm, parallel group Unit: Individual randomisation	Control: 59.31 (12.67) Intervention: 55.31 (12.56)	46	Mean days post-stroke for both groups: 150.36 (SD 519.69)	-ICF based patient education programme -Attention placebo control consisting of standardized lectures with information about stroke	-Liverpool self-efficacy scale -WHOQOL -Stroke Impact Scale - EQ-5D - HADS	1 week and 6 months	N
Sackley et al. [75]	118	?	UK	Design: 2 arm, parallel group Unit: Cluster randomisation	Control: 86.3 (8.8) Intervention: 88.6 (6.5)	82.2	?	-Occupational therapy intervention -Usual Care	-Barthel Index -Rivermead Mobility Index -Short Orientation-Memory-Concentration Test	3 and 6 months	Y
Taylor et al. [76]	41	Excluded people with aphasia	New Zealand	Design: 2 arm, parallel group Unit: Cluster randomisation	Control: 63.5 (16.6) Intervention: 58.5 (15.9)	36.7	Intervention group- mean time since stroke (days) 28.1 (SD 25.2) Control group-mean time since stroke (days) 13.2 (SD 5.0)	-Structured goal setting using Canadian Occupational Performance Measure -Usual Care	-SEIQOL-DW -SF-36 - FIM -Patient Perception of rehabilitation	48 hours and 12 weeks	Y

Table 1: Characteristics of included studies (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age (Mean and SD)	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Tielemans et al. [77]	113	47%	The Netherlands	Design: 2 arm parallel group Unit: Individual randomisation	57 (9.0)	47.6	Mean time post-stroke 18.8 months (SD 28.4)	-Self-management intervention -Education intervention	-Proactive coping: Utrecht proactive coping competence (UPCC) -Participation restriction: Restriction subscale of the Utrecht Scale for evaluation of Rehabilitation-Participation (USFR) -Dutch version of the General Self-Efficacy Scale -Stroke specific quality of life (SSQoL12) -Patients and partners frequency and satisfaction with participation in vocational, social and leisure activities-USER Participation self-assessment subscales -HADS -Subjective wellbeing -Caregiver Strain Index	3 and 9 months	N
Visser et al. [78]	166	7.8% with mild aphasia*	The Netherlands /Belgium	Design:2 arm parallel RCT Unit: Individual randomisation	53.06 (10.19)	47	Median time: 7.29 months (IQR 4.9-10.61)	-Problem Solving Therapy -Standard outpatient rehabilitation	-Coping inventory for stressful situations -Social problem solving inventory revised -Stroke specific quality of life scale-12 -EuroQol EQ-5D-5L -Depression CES-D scale	10 days 6 months 12 months	N

Table 1: Characteristics of included studies (continued)

Authors	Sample size	% of participants with L&C difficulties	Country	Design and unit of allocation	Age (Mean and SD)	Gender (% female)	Time post-stroke	Intervention(s)/Control	Outcome measures	Follow-up time points	Pilot or feasibility study?
Wolf et al. [79]	185	?	USA	Design: 2 arm crossover trial Unit: Individual	?	?	?	-Improving Participation after Stroke Self-Management Program (IPASS) -Waiting list	-Chronic Disease Self-Efficacy scale -Participation strategies self-efficacy scale Community participation indicators Reintegration to normal living Activity Card Sort WHOQOL-BREF Stroke Impact Scale	12 weeks and 6-9 months	Y

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

Table 2: Risk of bias

Authors	Selection Bias		Performance Bias	Detection bias	Attrition Bias	Reporting Bias	Other bias
	Random sequence generation	Allocation Concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective outcome reporting?	
Aben et al. [54] and Aben et al. [53]	Low	Low	Low	Low	Low	Unclear	Low
Allen et al. [56]	Unclear	Unclear	High	High	Unclear	Unclear	Low
Allen et al. [55]	Low	Unclear	Unclear	Low	Low	Unclear	Low
Cadilhac et al. [57] (Supplementary information obtained from published protocol by Battersby et al. [93])	Low	Low	Low	Low	Low	Low	Low
Chumbler et al. [59] and Chumbler et al. [58] (Supplementary information obtained from published protocol Chumbler et al. [92]	Low	Low	High	Low	Low	High	Low
Damush et al. [60]	Unclear	Unclear	Unclear	Low	Unclear	Unclear	Low
Fido [61]	Low	Low	High	Low	High	Unclear	Low
Frank et al. [62]	Unclear	Unclear	High	High	Low	Unclear	Low
Glass et al. [63]	Low	Unclear	Low	Low	Low	Unclear	Low

Table 2: Risk of bias (continued)

Authors	Selection Bias		Performance Bias	Detection bias	Attrition Bias	Reporting Bias	
	Random sequence generation	Allocation Concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective outcome reporting	Other bias
Guidetti et al. [64] and Guidetti and Yitterberg [65]	Low	Low	Unclear	Low	Low	Unclear	Low
Harwood et al. [66]	Low	Unclear	Unclear	Low	Low	High	Low
Johnston et al. [67]	Unclear	Unclear	Unclear	Low	Low	Unclear	Low
Jones et al. [68]	Unclear	Unclear	High	Low	Unclear	Unclear	Unclear
Kendall et al. [69]	Low	Unclear	Unclear	Unclear	Unclear	Unclear	High
Marsden et al. [70]	Low	Low	Unclear	High	Low	Unclear	Low
McKenna et al. [71]	Unclear	Unclear	High	Low	Low	Unclear	Low
Polatajko et al. [72]	Unclear	Unclear	High	High	High	Unclear	Low
Robinson et al. [73]	Low	Low	High	High	Low	Unclear	Low
Sabariego et al. [74]	Low	Unclear	Low	Unclear	High	Unclear	Low
Sackley et al. [75]	Low	Low	Unclear	Low	Unclear	Unclear	Low
Taylor et al. [76]	Low	Low	Unclear	Low	Low	Unclear	High

Table 2: Risk of bias (continued)

| Authors | Selection Bias | | Performance Bias | Detection bias | Attrition Bias | Reporting Bias | |
	Random sequence generation	Allocation Concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective outcome reporting	Other bias
Tielemans et al. [77]	Unclear	Unclear	Low	Low	Low	Low	Low
Visser et al. [78]	Low	Low	Unclear	Low	Low	Low	Low
Wolfe et al. [79]	Unclear	Unclear	High	Low	High	High	Low

Figure 1: PRISMA flow diagram of study selection

Please see additional image file. Figure created using Inkscape 0.48.