The key features and role of peer support within group self-management interventions for stroke? A systematic review.

Running Head: Group self-management interventions: A review

Article Type: Systematic review

Ella Clark[1]*, Alison Mac Crosain[2], Nick S Ward[1,3], Fiona Jones[4]

[1] *National Hospital for Neurology and Neurosurgery, Queen Square, London, England,* [2]*School of Psychology, University of Surrey, Surrey England.* [3] *Sobell Department of Motor Neuroscience and Motor Disorders, University College London, London, England,* [4] *Faculty of Health, Social Care and Education, Kingston University and St Georges University of London, London, England.*

*Corresponding Author: Box 146, 33 Queen Square, London, WC1N 3BG**,** e.clark@ucl.ac.uk, 0203 4488774.

The key features and role of peer support within group self-management interventions for stroke? A systematic review.

Abstract

Purpose: To assess the key features of group self-management interventions for stroke and explore the role of peer support in this setting.

Method: A segregated mixed research synthesis was conducted. A literature search was performed in OvidSP, EMBASE, AMED and EBSCO (up to January 2017). Studies were included if they delivered group interventions containing self-management principles to stroke survivors on more than two consecutive occasions. The bias of included studies was assessed using NICE guidelines. Quantitative data were analysed using frequency counts and qualitative data were analysed thematically.

Results: 12 studies were included in the review including a total of 3298 participants (age range 56-89) and eight different self-management interventions. Key features of group self-management interventions were identified as increasing knowledge, collaboration and/or communication, accessing resources, goal setting and problem solving. Peer support facilitated the sharing of experiences, social comparison, vicarious learning and increased motivation.

Conclusion: Future self-management interventions should be designed to maximise peer support and incorporate techniques which facilitate, knowledge building, goal setting, access to resources, problem solving and communication.

Key Words: Stroke, self-management, group interventions, self-efficacy, peer support, chronic disease.

Introduction

Stroke is now acknowledged as a chronic condition, with survivors reporting high levels of unmet needs and feelings of abandonment [1]. Consequently, there have been calls to focus resources on the long-term management of life after stroke [2] and use techniques that have been successfully used to manage other long-term conditions such as arthritis and diabetes [3]. Indeed, the National Clinical Guidelines for stroke now state, "people with stroke should be supported and involved in a self-management approach to their rehabilitation goals" [4] pg. 4].

Self-management interventions aim to support individuals to manage the medical and emotional aspects of their condition in order to maintain or create new life roles [5]. Social cognition theory commonly underpins such interventions and so increasing an individual's self-efficacy or their belief in their ability to complete a specific task is central to the self-management process [6]. How individual interventions increase self-efficacy varies in practice, but the majority use multiple techniques such as goal setting, knowledge building, and problem solving [7].

The interest in self-management for stroke has grown over the past decade as has the evidence base. Two articles reviewing the research to date summaries the key findings. Firstly, a recent Cochrane review found that when compared to standard care, stroke self-management interventions significantly increased self-efficacy (P=0.03) and quality of life (P=0.02) [8]. Secondly, a systematic review focussing on function and participation after stroke found evidence in favour of self-management interventions compared to baseline [5]. The literature also highlights that self-management interventions can be delivered in different formats; one-to-one or group [9]. One advantage of group over one-to-one delivery is that it offers peer support, something highlighted as valuable to recovery by stroke survivors themselves [10].

Peer support is likely to be important to self-management interventions because "maximising the possibilities for social engagement [is] a way of increasing the effectiveness of chronic illness management" [11]. The literature cites many mechanisms of action through which peers may facilitate the management of stroke. Firstly, in a study exploring expectations of a group self-management intervention, stroke survivor's revealed they felt peers may facilitate problem solving and the sharing of experiences as they have the same lived experience of stroke[12]. Secondly, through the validation of feelings[5] peers may also offer emotional support, which 2/10 stroke survivors feel is currently lacking[13]. Finally, qualitative findings from the chronic disease self-management program found peers provided a platform on which social comparison can take place[14].

Despite the growing evidence base that peer support may play a valuable role in the management of stroke, the role of peer support within group self-management interventions is understudied and potentially underutilised. The same problem is found when trying to identify the key features of group self-management interventions. Although attempts have been made to isolate the key components of 1-1 self-management interventions, the same has not been attempted for group interventions. Consequently, because the key features of group self-management are unknown, it is likely this approach is underused [5,8].

Given the increasing importance of group self-management strategies for stroke survivors, the aim of this systematic review is to 1) determine the key features of group self-management interventions for stroke, and 2) explore the role of peer support in this setting.

Method

A segregated mixed research synthesis was used to meet the review aims. A protocol for this study can be found on PROSPERO (CRD42016017351) which details study selection, data extraction, inclusion/exclusion criteria and outcomes of interest. The review was written in

accordance with the PRISMA statement for reporting systematic reviews evaluating healthcare interventions to ensure all relevant information was included [15].

Article Selection Process

The study inclusion criteria were as follows: (1) the intervention was delivered solely in a group setting; (2) the intervention included participants who had suffered one or more strokes (3) participants were aged 18 or over; and (4) the self-management intervention was delivered on more than two consecutive occasions. Studies were excluded if: (1) they were labelled as a pilot, feasibility or a phase 1 study as they would have insufficient statistical power to be representative of the wider stroke population; (2) they were unpublished conference literature; (3) they did not specifically mention 'self-management'. A flow chart illustrating the article selection process is shown in Figure 1.

The search strategy used key terms informed by the aims (e.g. stroke, self-management and group), and was developed using Medical Subject Headings (MeSH) to ensure synonyms were included. Each database was searched from the first available date through to December 2016. The search strategy was used in *OvidS*P to search *EMBASE, AMED* and *PsychInfo* was as follows:*((stroke or strokes or (brain adj3 infarction) or (cerebral adj3 infarction)).ti,ab. or *stroke/ or exp *cerebrovascular accident/ or exp *cerebrovascular accidents/ or *brain infarction/ or *brain stem infarctions/ or *lateral medullary syndrome/ or *cerebral infarction/ or *multi-infarct/ or *infarction, anterior cerebral artery/ or *infarction, middle cerebral artery/ or *infarction, posterior cerebral artery/ or *stroke, lacunar/) and (group or groups).ti,ab. and (("self-management" or "self-care" or "self-treatment").ti,ab. or exp self-care/ or exp self-management/). As other databases recognise different search terms, a separate search strategy was used in EBSCO to search CINAHL (nursing, allied health, biomedicine, healthcare; through Dec 2016; Appendix 2).

Once duplicate papers were removed using referencing software (Zotero), EC and AM screened the papers independently using the titles and abstracts to determine eligibility. Studies that did not meet the criteria were excluded and the full articles of those remaining were read to determine if they were eligible following the same process as above. Any discrepancies were discussed between EC and AM, with the option to involve the whole research team if required (NW and FJ).

Data Extraction

A data extraction template was developed based on the Cochrane Consumers and Communication Review Group's data extraction template [16]. Data were extracted on: (1) sample (size, and condition studied) (2) participants (3) the intervention (content, additional materials, frequency, theoretical underpinning, facilitators, delivery mechanism, group size and whether family and friends could attend) and (4) outcomes. The outcomes of interest were the key features of each group self-management intervention being used (e.g. problem solving or goal setting) and qualitative data which could assess the contribution of peer support to the self-management process.

Quantitative outcomes were extracted in the form of statistical significance (P values) and confidence intervals (CI; if reported) as well as inferences on clinical significance (based on effect size). Qualitative data were extracted in the form of direct quotes from participants. Information relating to the intervention design was also extracted, including length, frequency, theoretical underpinnings and behaviour change techniques. Where information was missing, studies based on established interventions were assumed to include the same content. For example, studies using the Chronic Disease Self-Management Programme (CDSMP) were reported as using the same behaviour change techniques as listed in the original CDSMP publication [3]

Assessing Bias

Studies were assessed for bias using the NICE quality appraisal checklists[17]. Both quantitative (checklist F) and qualitative (checklist H) aspects of intervention studies were assessed. The following items from checklist F were omitted: (i) item 2.4 (Were participants or investigators blind to exposure and comparison?), because the nature of self-management interventions makes investigator blinding at delivery impossible, and (ii) items 2.9 (Did the intervention or control comparison reflect usual UK practice?) and 2.10 (Did the setting reflect usual UK practice?), as the studies were not conducted in the UK. Each checklist assesses bias across five categories; population, method of selection of exposure or comparison group, outcomes, analysis and internal/external validity. The result is a score that indicates the risk of bias as high (-), moderate (+) or low (++). Two researchers were involved in this process, EC assessed all twelve studies and AM assessed two of the studies. EC and AM drew the same conclusions about the risk of bias for two studies so no further assessments were made by AM. Publication bias was accounted for by contacting the authors of the included studies and requesting any unpublished data.

Analysis

A segregated mixed research synthesis was used to assess the primary outcomes of interest, the contribution of peer support and the key features of group self-management interventions. Accordingly, the qualitative and quantitative studies were analysed and synthesised separately, and subsequently combined (see Sandelowski et al for more detail)[18]. Quantitative analysis involved frequency counts of the self-management techniques used in each intervention and the reported values for outcomes of interest. **Some insight into *clinical* significance can be gained from effect size,** and so more weight was given to studies reporting this information when determining the key features of interventions.

Qualitative data were analysed using methods recommended by The Centre for Reviews and Dissemination's guidelines [19]. Thematic analysis was used which ultimately categorises data into key themes [19],[20]. The analysis involved highlighting words or phrases that were relevant to the review aims and coding them as follows; a quote such as, '*Well, what attracted me was that it was in workshop format as opposed to a lecture format, which I saw as an opportunity to exchange ideas with others'*[21] would be coded as 'sharing ideas' and 'delivery format''. As new data were analysed, previously coded papers were re-examined in an iterative process to enable comparison and further analysis [22]. The process continued until no new codes emerged from the data and 'unique and specific themes' began to emerge [23]. For example, data coded as 'motivation' and 'confidence' contributed to the key theme 'vicarious learning. Extracts or quotes were then selected from the coded data to illustrate the themes, creating, "patterns of meaning and issues of potential interest in the data" (pg.15) that address the research question" [23].

A segregated mixed research synthesis is acknowledged as a suitable method for exploring complex health services interventions such as a group self-management interventions for stroke [24]. Qualitative and quantitative aspects of the data were synthesised once they had been analysed separately. In keeping with guidance, the findings are not further reduced but are 'organized into a coherent whole' with qualitative work adding detail to quantitative findings [18].

Results

The most common reasons for study exclusion were: (1) irrelevance, (2) the intervention was not identified as a self-management intervention; or (3) studies were labelled as pilot or feasibility. The study selection process is detailed in figure 1. A total of 12 studies were included (table 1): Eight were quantitative and all utilised pre-post intervention outcome comparisons, three were qualitative and explored reflections post intervention [14,21,25] and

one was mixed methods which utilised both the above techniques to compare two different self-management interventions [26]. Four studies were based in Canada[21,25–27], three in Australia[14,28,29], three in America [3,30,31]one in China [32] and one in Hong-Kong [33]. In total, 3298 participants were included across the 12 studies. The length of time post stroke was reported by nine studies [3,14,21,25,26,28,30,31,33] and ranged from less than three months to 10 years. All studies reported the age of participants with a range of 56 to 89.

Figure 1 to be inserted here.

Nine of the studies used the Chronic Disease Self-Management Programme (CDSMP) or an extension of it. All the self-management interventions were delivered in the community and reported the key features used (see supplementary table 1 for more detail). Each qualitative study discussed the extent to which peer support contributed to self-management. All the studies except one [33], either directly mentioned theoretical underpinning, or stated the influencing programme which has a clear theoretical basis (see table 1). The risk of bias present in each study is indicated in table 1. According to the NICE quality appraisal checklists, all of the studies had good or excellent internal validity rating indicating a low risk of bias.

Insert table 1 here

Key features of group self-management interventions
The number of self-management techniques used per intervention was seven with a range of five to nine (see supplementary table 1). Frequency counts revealed the most commonly used self-management techniques to be education/increasing knowledge which was referenced by nine studies, and collaboration/communication which was referenced by eight. Accessing

resources, goal setting and problem solving were each mentioned by five of the studies. Discussing emotional wellbeing and decision making were the techniques used the least and only utilised by three of the studies. Of the studies that reported clinically significant outcomes [28,31–33], the most commonly used self-management techniques were increased knowledge which was mentioned by three studies, followed by communication/collaboration and decision making which were mentioned by two studies. The least used self-management techniques for clinically significant studies were the discussion of your future self and discussing emotional wellbeing.

Qualitative data revealed that developing skills in goal setting and how to break these goals down into small steps were important to stroke survivors. Both these techniques were discussed in three of the qualitative studies [14,21,26], for example, '*I think what I got most from the programme was the action plans. For me, I have these great huge goals but I don't ever break them down so I had to think about those kinds of things* '[21] p.1142] Enablers echo this sentiment stating the need to; '*break things down into small bits–because if you give yourself a big goal it's too hard, you just don't want to do it*' [14]p. 83].

Two of the three qualitative studies discuss the timing of intervention delivery as a key intervention feature. One study suggested a group self-management intervention could fill the gap in care that many stroke survivors experience once they are discharged from hospital [14], whilst the another reported that the majority of stroke survivors thought the group self-management intervention should be available right away*: 'If I would have taken the course right away I might have been able to recognise more of those chronic things or seen people that might be having some of the same frustrations*' [21] p.1141].

The role of peer support

The role of peer support was explored in all three qualitative studies and the qualitative aspects of the mixed methods study. Four different roles of peer support in a self-

management context were discovered – shared experience, social comparison, vicarious learning and mutual gain.

The four studies with qualitative aspects all reference the role that peer support plays in finding a shared experience and creating empathy[14,21,25,26]: *"There are others out there that are the same as yourself and you feel secure in the fact that we all realise what we've been through"* [14]p. 83]. The practical side of shared experience is illustrated by one participant who said, *"We're all in the same situation here. If one of us gets stared at, everybody gets stared at. We can all wave at them…"* [26]p.514]. Shared experience also helped individuals to, "*not feel so alone in what was going through"* [21]p. 1140] which provided emotional comfort.

The second role that peer support played in self-management interventions was to create a platform for social comparison or being able to compare one's self to other group members[14,21,25,26]. Stroke survivors felt that this helped their own ability to problem solve, for example one stroke survivor said, "*when you talk to other people…you see…how they handle their problems. Yeah, compared to yourself"* [25]p.9]. However, it was seen as important that individuals relate to other members of the group, "*I really actually think it was very beneficial to put folks who have all had strokes together. It would be harder to relate with people in the group if they had a different chronic condition*"[21] p.1140]. The importance of relatability was further highlighted by one participant who felt this was lacking in their group: "I*'m in a group with seniors – their concerns and their abilities are different than mine"* [18, p.1141]. The findings suggest social comparison was found to be important to stroke survivors, and may be affected by how much peers relate to one another.

The third role of peer support was that it enabled vicarious learning which was referenced by three of the four qualitative studies. Vicarious learning can facilitate feelings of mastery and motivation: '*The woman that was going to knit, you know, her aim was to start*

her knitting again. And you could see that she was quite pleased with herself. Like quite pleased. I, ah, consider that as a, a motivation for the group. Because they hey, you know, that's really positive [pause] I can, I can feed on that. Good things are happening in my group [pause]. It, it, it builds confidence I guess'[25]p. 9]. Vicarious learning was identified by three studies as increasing motivation and the likelihood of an individual taking action[14,21,25] *'No matter how badly off I am, someone else has difficult challenges too and they can do it so I can too'* [21]p.1143].

Finally, the concept of mutual gain was identified by three studies and is the result of the reciprocal nature of peer support[14,21,26]. An individual may 'gain' an increase in confidence through helping others -'giving'[21]. The 'gaining' and 'giving' may also happen independently, for example, one participant described how they had 'gained' from peer support, "*Working with other people makes you see not just their strengths but your own strengths better*" [17, p.1143]. Another highlights how they benefitted from 'giving', "*the confidence that comes by knowing that you can actually help other people*" [21]p.1143]. Mutual gain is related to the concept of shared experience, as individuals can offer support to one another when faced with a challenging situation [26]. Shared experience, social comparison, vicarious learning and mutual gain represent the different ways in which peer support contributes to the self-management process in a group setting.

Discussion

The National Clinical Guidelines for stoke suggest that self-management interventions should be used to better support the long-term needs of stroke survivors [4]. Delivering self-management in a group setting can offers benefits such as shared problem solving and social comparison which are a result of peer support. However, attempts to implement group interventions on a larger scale are hampered by limited appreciation of the key ingredients of group self-management and in particular by the role that peer support plays (if any).

Twelve studies contributed to the review, all of which were found to be of high quality. The key features of effective group self-management were increased knowledge, communication/collaboration and decision making. We confirmed previous findings that goal setting and information giving are commonly used self-management techniques [4]. However, there were some differences in our results compared to previous research which identified action planning and homework as the self-management techniques used least in the intervention [4]. Our review found that discussing emotional wellbeing and thinking about your future self were used the least. As our review only explored group based interventions and previous work explored interventions that used both group and one-to-one delivery this may explain the difference in results.

A mixed methods synthesis allowed insight into which components were seen as valuable by stroke survivors. The synthesis thus offers insight into some of the challenges that they may be facing in the chronic phases of recovery. The fact survivors valued goal setting and breaking these up into small steps suggests they may experience a difficulty in knowing how to begin their recovery journey. This is in line with previous results from a survey of 2700 stroke survivors, which suggested that individual's 'don't know where to start' when trying to gather information about stroke[13]. Thus future interventions should focus on offering support that can help stroke survivors feel able to take the first step towards recovery.

It is important to point out that while previous work which explored one-to-one self-management interventions has used statistical significance to indicate an effect, our review incorporated clinical significance which is considered a strength of the work. Studies that present effect sizes alongside p-values when reporting intervention results offer some insight into clinical significance as well as statistical significance. However, future research should liaise with clinicians and the stroke population to determine if they feel the outcomes that effect sizes are reported for are of value to their clinical experience. If this is not done,

researchers are at risk of obtaining a large effect size in an outcome that is not clinically meaningful to stroke survivors.

It is important to note that while we explored commonly used components of group self-management interventions we cannot infer causation. More work would be needed to further understand whether certain components have a direct impact on outcomes, and to what extent. This is important because it may be that although both knowledge and problem solving are commonly used techniques in self-management interventions, only problem solving is able to cause an increase self-efficacy. It may also be that certain components influence some outcomes but not others, for example, problem solving may increase an individual's self-efficacy whilst the development of communication strategies may influence a stroke survivors' quality of life. It is for this reason that future work should also explore peer support as a potential mechansism of change. A study published after this review was completed found no positive effect of the CDSMP[34]. However, this may be because the study explored the wrong outcomes. If the role of peer support had been explored, which the current review highlights could play an important role in group self-management interventions, a different conclusion may have been reached.

Peer support was found to have a number of roles within group self-management interventions for stroke as it facilitated shared experience, social comparison, and learning from vicarious experience. The latter were all identified in previous work by asking what stroke survivors who had not taken part in a group intervention felt the challenges and benefits associated with doing so might be [12]. Peer support also enabled stroke survivors to derive a sense of mutual gain from interactions with peers. The latter enabled a flat hierarchy of interaction to be created which contrasts to the interactions often experienced between patients and health care professionals, even in the context of a self-management setting [35].

Limitations

A potential limitation of this study was the high level of ambiguity and a lack of detail in the reporting of intervention content. For example, although some studies specified how problem-solving skills should be developed during the intervention, ("*problem definition, generation of possible solutions, implementation of a solution, and evaluation of the outcome*" [29]p.737], others merely stated , "*facilitators led problem solving sessions specific to action plans*" [21]p.1138]. A second example is found for setting small steps or action plans, with some studies offering a lot of detail, ('*At the end of each session, participants were asked to make an "action plan" that specified a concrete step they could take to help prevent recurrent stoke. They were encouraged to choose something relevant to what they had learned during the week's session*' [30]p.2] and others merely stating the use of, '*weekly action planning and* feedback' [3]p.7]. A recently published Template for Intervention Description and replication (TIDieR) should be used by future work to overcome this problem but we acknowledge this was published after all but one of the included studies [36].

A second limitation is the heterogeneity in both the interventions and outcome measures used, thereby preventing a full meta-analysis from being conducted. However, it is unsurprising that different outcomes are selected when there is such a wide range of effects reported by self-management interventions [5,8,37]. The complexity of these interventions compounds the issue further and as interventions grow in complexity, so does the likelihood of unexpected mechanisms of change occurring. As a result, researchers are encouraged to use 'a range of measures' to try and capture these mechanisms [38]. The use of mixed methods overcomes this challenge to some extent as it offers a richness of detail which could not have been obtained through a meta-analysis and thus increases the chance that unexpected mechanisms are captured.

A third limitation of the study that that the search criteria restricted studies to those published in English, the majority of studies were set in western societies which limits how representative the findings are. Finally, none of the studies were conducted in the United Kingdom (UK), so their application to the National Health Service (NHS) is limited. However, heterogeneity is sometimes important, as being able to compare studies arising from a range of countries makes the resulting data more representative.

Future Recommendations

Based on the findings of this study, future self-management interventions should maximise peer support if they wish to benefit from shared experiences, social comparison vicarious learning, and mutual gain. Having an understanding of which components were seen as valuable by stroke survivors offers insight into some of the challenges that they may be facing in the chronic phases of recovery. The fact survivors valued goal setting and breaking these up into small steps suggests they may experience a difficulty in knowing how and where to start their recovery journey, and thus future interventions should try and offer support in these areas. It is also important to point out that while we identified commonly used components we did not explore causal relationships.

Future research should explore the whether there any other mechanisms through which peer support can be maximised and ensure future group self-management interventions incorporate the key features identified in this review. In addition, ways to reduce the heterogeneity of content reporting, such as developing comprehensive self-management measures that can capture a range of outcomes, should be explored. Finally, the integration and implementation of group self-management interventions within the UK's NHS should be explored, in particular, whether or not this is feasible.

Conclusion

We have conducted the first mixed methods synthesis exploring group self-management for stroke survivors. The most commonly used components of group self-management interventions were found to be education/increasing knowledge, collaboration/communication, accessing resources, goal setting and problem solving. Future work should determine whether there are any causal relationships between specific components of the interventions and outcomes. Peer support within the interventions was found to facilitate shared experiences, social comparison vicarious learning, and mutual gain. Future interventions should be designed to maximise peer support to enable stroke survivors access to the afore mentioned benefits.

Declaration of interest

References

1. McKevitt C, Fudge N, Redfern J, Sheldenkar A, Crichton S, Rudd AR, Forster A, Young J, Nazareth I, Silver LE, et al. Self-Reported Long-Term Needs After Stroke. Stroke. 2011 May 1;42:1398–1403.

2. O'Neill D, Horgan F, Hickey A, McGee H. Stroke is a chronic disease with acute events. BMJ. 2008 March 1;336:461.

3. Lorig K, Sobel D, Stewart, Brown B, Bandura A, Philip Ritter, Virginia M. Gonzalez, Diana D. Laurent, Halsted R. Holman. Evidence Suggesting That a Chronic Disease Self-Management Program Can Improve Health Status While Reducing Hospitalization: A Randomized Trial. Med Care. 1999;37:5–14.

4. Anon. 2016-National-Clinical-Guideline-for-Stroke-5t-(1).pdf. [cited 2017 June 27]. Available from: https://www.strokeaudit.org/SupportFiles/Documents/Guidelines/2016-National-Clinical-Guideline-for-Stroke-5t-(1).aspx

5. Warner G, Packer T, Villeneuve M, Audulv A, Versnel J. A systematic review of the effectiveness of stroke self-management programs for improving function and participation outcomes: self-management programs for stroke survivors. Disabil Rehabil. 2015 November 6;37:2141–2163.

6. Bandura A. Social foundations of thought and action: A social cognitive theory. Englewood Cliffs, NJ, US: Prentice-Hall, Inc; 1986.

7. De Silva D. Helping people help themselves: A review of the evidence considering whether it is worthwhile to support self-management. The Health Foundation. 2011. Available from: http://www.health.org.uk/sites/default/files/HelpingPeopleHelpThemselves.pdf

8. Fryer CE, Luker JA, McDonnell MN, Hillier SL. Self management programmes for quality of life in people with stroke. Cochrane Database Syst Rev. 2016;22:1–77.

9. Jones F, Riazi A, Norris M. Self-management after stroke : time for some more questions? Disabil Rehabil -Lond Wash- TAYLOR FRANCIS-. 2013;35:257–264.

10. Boger E.J., Demain S., Latter S. Stuck between expectation and hope-the experience of self-management for people recovering from stroke. Int J Stroke. 2012.

11. Vassilev I, Rogers A, Kennedy A, Koetsenruijter J. The influence of social networks on self-management support: a metasynthesis. BMC Public Health. 2014;14:719–731.

12. Clark E, Bennett K, Ward N, Jones F. One size does not fit all – Stroke survivor's views on group self-management interventions. Disabil Rehabil. 2016 December 30;0:1–8.

13. Stroke Association. Feeling Overwhelmed: The emotional impact of stroke. 2013 [cited 2015 May 14]. Available from: https://www.stroke.org.uk/sites/default/files/feeling_overwhelmed_final_web_0.pdf

14. Catalano T, Dickson P, Kendall E, Kuipers P, Posner TN. The perceived benefits of the chronic disease self-management program among participants with stroke : A qualitative study. Aust J Prim Health. 2003;9:80–89.

15. Liberati A, Altman DG, Tetzlaff J, Mulrow C, Gøtzsche PC, Ioannidis JPA, Clarke M, Devereaux PJ, Kleijnen J, Moher D. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate healthcare interventions: explanation and elaboration. BMJ. 2009 July 21;339:b2700.

16. Anon. Consumers and Communication Group resources for authors | Cochrane Consumers and Communication. [cited 2017 June 21]. Available from: /author-resources

17. Anon. Methods for the development of NICE public health guidance (third edition) | appendix-g-quality-appraisal-checklist-quantitative-studies-reporting-correlations-and-associations | Guidance and guidelines | NICE. [cited 2015 October 29]. Available from: https://www.nice.org.uk/article/pmg4/chapter/appendix-g-quality-appraisal-checklist-quantitative-studies-reporting-correlations-and-associations

18. Sandelowski M, Voils CI, Barroso J. Defining and Designing Mixed Research Synthesis Studies. Res Sch. 2006 Spring;13:29–44.

19. Anon. Our guidance - Centre for Reviews and Dissemination, The University of York. [cited 2016 September 23]. Available from: https://www.york.ac.uk/crd/guidance/

20. Green J, Thorogood N. Qualitative Methods for Health Research. London: SAGE; 2013.

21. Hirsche RC, Williams B, Jones A, Manns P. Chronic disease self-management for individuals with stroke, multiple sclerosis and spinal cord injury. Disabil Rehabil Int Multidiscip J. 2011;33:1136–1146.

22. Braun V, Victoria Clarke. Successful qualitative research: a practical guide for beginners. 1st ed. London: SAGE; 2013.

23. Braun V, Clarke V. Qualitative Research in Psychology. Tayloy and Francis; 2006. Available from: http://www.tandfonline.com/doi/abs/10.1191/1478088706qp063oa

24. Tariq S, Woodman J. Using mixed methods in health research. JRSM Short Rep. 2013 May 7;4:1–8.

25. Taylor DM, Stone SD, Huijbregts MP. Remote participants' experiences with a group-based stroke self-management program using videoconference technology. Rural Remote Health. 2011 January;11:1–15.

26. Huijbregts M.P.J., Myers A.M., Streiner D., Teasell R. Implementation, process, and preliminary outcome evaluation of two community programs for persons with stroke and their care partners. Top Stroke Rehabil. 2008.

27. Jaglal SB, Haroun VA, Salbach NM, Hawker G, Voth J, Lou W, Kontos P, Cameron JE, Cockerill R, Bereket T. Increasing access to chronic disease self-management programs in rural and remote communities using teleheaith. Telemed E-Health. 2013.

28. Cadilhac DA. A phase II multicentered, single-blind, randomized, controlled trial of the stroke self-management program. Hoffmann S, Kilkenny M, Lindley R, Lalor E, Osborne RH, Batterbsy M, editors. Stroke. 2011;42:1673.

29. Kendall E. Recovery following stroke: the role of self-management education. Catalano T, Kuipers P, Posner N, Buys N, Charker J, editors. Soc Sci Med. 2007;64:735–746.

30. Kronish I, Goldfinger J, Negron R, Fei K, Tuhrim S, Arneiella G, Horowitz C. Effect of peer education on stroke prevention: the prevent recurrence of all inner-city strokes through education randomized controlled trial. Stroke J Cereb Circ. 2014;45:3330–3336.

31. Wolf TJ, Baum CM, Lee D, Hammel J. The Development of the Improving Participation after Stroke Self-Management Program (IPASS): An Exploratory Randomized Clinical Study. Top Stroke Rehabil. 2016 June 6;23:284–292.

32. Dongbo F., Hua F., McGowan P., Yi-e S., Lizhen Z., Huiqin Y., Jianguo M., Shitai Z., Yongming D., Zhihua W. Implementation and quantitative evaluation of chronic disease self-management programme in Shanghai, China: Randomized controlled trial. Bull World Health Organ. 2003;81:174–182.

33. Sit JWH, Yip VYB, Ko SKK, Gun APC, Lee JSH. A quasi-experimental study on a community-based stroke prevention programme for clients with minor stroke. J Clin Nurs. 2007.

34. Wolf TJ, Spiers MJ, Doherty M, Leary EV. The effect of self-management education following mild stroke: an exploratory randomized controlled trial. Top Stroke Rehabil. 2017 July;24:345–352.

35. Norris M, Kilbride C. From dictatorship to a reluctant democracy: stroke therapists talking about self-management. Disabil Rehabil. 2014 January 1;36:32–38.

36. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, Altman DG, Barbour V, Macdonald H, Johnston M, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ. 2014 March 7;348:g1687.

37. Parke HL, Epiphaniou E, Pearce G, Taylor SJC, Sheikh A, Griffiths CJ, Greenhalgh T, Pinnock H. Self-Management Support Interventions for Stroke Survivors: A Systematic Meta-Review. PLoS ONE. 2015 July 23;10:e0131448.

38. Craig P., Dieppe P., Mcintyre S., Nazareth I., Mitchie S, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. 2006. Available from: http://eprints.gla.ac.uk/42736/1/42736.pdf

Table 1. Description of included studies

Study	Design	Internal validity	Sample *Size Chronic disease*	*Type of control, N*	Time Intervals and Outcomes measured	Results	
						Statistical significance / qualitative outcomes / other	Effect size/ Clinical significance
Cadillac et al. (2011)[28]	Multicentre single blind phase II, randomized controlled trial (RCT).	++	N=143 Stroke	1. CDSMP N=47 2. SSMI N=48	Baseline and 6 months post intervention. Primary outcomes: Recruitment, participation, participant safety. Secondary outcomes: Positive and active engagement in life (ActPos), quality of life (AQoL), Irritability and Depression Assessment (IDA). ,	Primary outcomes: 6 declined before baseline assessments, resulting in 143 (96%) participants randomized. More individuals in the generic group who withdrew reported the programme was not appropriate for their recovery and/or they were no longer interested.11 severe adverse events reported but none attributed to the interventions. Secondary outcomes for SSMI: ActPos, coefficient =0.69 (CI=0.58-0.79), Atoll, coefficient=-0.005 (CI=-0.08-0.07), IDS, coefficient=-1.00 (CI=-3.43-1.42).	ActPos: CDSMP (0.66), SSMI (1.47) AQoL; CDSMP (-1.33), SSMI (-0.90) IDA depression: CDSMP (-1.39), SSMI (-1.04), anxiety: CDSMP (-2.87), SSMI (-1.52)
Catalano et al. (2003)[14]	Longitudinal randomised controlled design	++	N=37 Stroke	None	Five intervals spaced evenly over 18 months following their stroke. A short structured interview designed to elicit perceptions of recovery, loss, and expectations about the future, using four open-ended questions.	6 themes identified: (1) The importance of social contact and comparison, (2) Increased awareness and knowledge about stroke, (3) Motivation to pursue goals and activities, (4) A sense of achievement, (5) Maintenance of gains, (6) The paradoxical nature of social support	N/A
Dongbo et al. (2003)[32]	RCT	+	N=954 Hyper-tension,	Wait-list control N = 428	Baseline (T1), end of program (T2), 6 month follow up (T3)	Treatment group compared with control: Weekly minutes of exercise (P=0.01), cognitive symptom management (P=0.005)	Cognitive symptom management

					Chinese CDSM measure: Exercise, cognitive symptom management, communication with doctor, self-efficacy, self-rated health, health distress, shortness of breath, pain, disability, illness intrusiveness, depression, energy, fatigue, social and role activity limitations. Health care utilization measure: Physician visits, emergency room visits, hospital stays, nights in hospital Cost of programme	communication with doctor (P=0), self-efficacy to manage symptoms and disease (P=0.001), health distress (P=0.31), shortness of breath (P=0.71), pain (p=0.6), disability (P=0.02), illness intrusiveness (P=0.54), depression (P=0.15), fatigue (P=0.12), energy (P=0.83), social role limitations (P=0.36), physician visits (P=0.59), emergency room visits (P=0.93), hospital Stays (P=0.53), nights in hospital (P=0.58). The cost of the programme was just 1/9 of hospital admission savings.	(0.38), depression (-0.1)
heart disease, lung disease, stroke, arthritis, peptic disease, diabetes.							
Hirsche et al. (2011) [21]	Semi structured interviews	++	N=22 Stroke, MS, spinal cord injury.	None	Within a week of programme completion. Experiences of the CDSMP, what was learnt, any changes in the way conditions are managed, and when to introduce the workshop.	5 themes identified: (1) Factors affecting learning opportunities (2) Group (3) Workshop content (4) Pre-programme influences (5) Outcomes.	N/A

Huijbregts et al. (2008)[26]	Longitudinal cohort design Mixed methods	+	N=18 In Moving On after Stroke (MOST)	Living with stroke (LWS). N=12.	Baseline (T1), end of the intervention (T2) and 12 weeks follow up (T3). Participation, Reintegration to Normal Living (RNL), activity specific balance scale (ABC), functional independence measure (FIM), abbreviated Geriatric Depression Scale (GDS), Care Giver Strain Index (CSI), Goal Attainment Scaling (GAS) tested in MOST only, Chedoke McMaster Stroke Assessment Activity inventory (CMSA-AI), cost analysis, focus group (one with carers and patients).	- Participation: significantly more effective when study information received from health professional ($P < .05$). - ABC, RNL, FIM: Between groups change ns. Within group significant changes for MOST (ABC scale (P=0.05), RNL (P<0.05) and FIM (P<0.05). LWS (ns). GDS & CSI: Small sample precluded meaningful examination of change. GAS: 13 met or exceeded their long-term goal, 5 did less than expected. CMSA-AI: Between groups change ns. When exercise participation at T1 accounted for at T3 ($p = .05$). - Both groups were glad to meet other stroke survivors, felt less alone, wanted continued contact with group, said it was beneficial that carers could attend. Both groups said the groups helped them problem solve. - LWS was cheaper to run than MOST.	Not given
Jaglal et al. (2013)[27]	Pre-post comparison design	+	N=213 Lung disease, heart disease, stroke, chronic arthritis.	CDSMP tele-health multi-site N =109	Baseline 4 months follow up. The six-item self-efficacy scale, Stanford disability scale, adapted social role limitations and mental health index. Visual numeric scales for: Pain/physical discomfort, psychological well-being, energy/fatigue, health distress, self-rated health status.	No statistically significant differences in outcomes between single- and multi-site groups except for self-rated health (P=0.05). Within group changes: Self-efficacy (P<0.01), stretching and strengthening (P<0.001), aerobic exercise (P<0.001), cognitive symptom management (P<0.001), communication with physicians (P<0.001), social role function (P=0.015), psychological well-being (P=0.001), energy/fatigue (P=0.04), health distress (P<0.001), self-rated health (P=0.004), disability (P=0.083), pain/ physical discomfort (P=0.191)	Not given

Kendall et al. (2007)[29]	Longitudinal RCT	+	N=73 Stroke	Standard care. N=42	Baseline(T1), 6 (T2), 9 (T3) and 12 (T4) months after stroke. The Stroke Specific Quality of Life scale (SSQOL), the Self-efficacy Scale.	Between group differences, Energy (ns), Language (ns), Vision (ns), Mobility (ns), Fine motor tasks (ns), Mood (ns), Personality (ns), Thinking (ns), Social roles (ns), Family roles (ns), Work productivity (ns)	Not given
Kronish et al. (2014)[30]	RCT	++	N=600 Stroke	Wait list control N=299	Baseline and 6 months follow up, Charlson Comorbidity Index, depressive symptoms, medication adherence, blood pressure (BP), LDL cholesterol	Between groups at 6 months: 3-month stroke prevention measures (P=0.98), LDL cholesterol (P=0.46), BP(P=0.02), systolic BP (P=0.04), taking antithrombotic medication (P=0.61), ddepression (P=0.16).	Not given
Lorig et al. (1999)[3].	RCT	+	N=952 Heart disease, lung disease, stroke, arthritis	Wait-list control N =476	Baseline and 6 months post intervention. Self-rated health scale, disability, psychological wellbeing scale-MHI-5 (from SF36), pain and physical discomfort, the energy /fatigue scale, health distress, duration of exercise, use of cognitive symptom management, communication with physicians, social/role activity limitations Shortness of breath, utilization measures.	Between groups: Stretching and strengthening(P=0.05), weekly minutes of exercise(P=0.0003), cognitive symptom management(P=0.0001), communication with physicians(P=0.006), less hospitalisations (P<0.05), fewer hospital night stays(P=0.01), self-rated health(P=0.02), health distress (P=0.001), fatigue(P=0.003), disability (P=0.002), social activity/social role limitations(P≤0.001), energy/fatigue (P-0.003), pain/physical discomfort(P=0.27), shortness of breath(P=0.56), psychological wellbeing(P=0.1), visits to physicians (P=0.11).	Not given
Sit et al. 2007)[33]	Quasi experimental design	+	N=147 Stroke	Standard care and health promo leaflet N=70.	Baseline (T0) pre intervention one week after (T1) and three months after (T2) the completion of the intervention. Stroke knowledge, self-health-monitoring, medication compliance scale, self-reported Alcohol and cigarette consumption, exercise scale, self-reported Dietary intake	Between group differences for: Medication compliance T1 (P=0.004), treatment seeking response at T1 and T2 (both P<0.001), self BP monitoring at T1 and T2 (both P<0.001), stroke knowledge (ns), consuming salted preserved food (P=0.042), eating thick poultry soup (ns), participation in walking exercise at T2 (P<0.001), alcohol and cigarette consumption not reported.	Stroke warning signs (0.28); medication compliance (0.27); salted preserved food intake (0.22), risk factors (0.55)

Taylor et al. (2012)[25]	Semi-structured interviews	++	N=19 Stroke	None	Post intervention. Interview topics: 1. Previous experiences with groups or video-conferencing; 2. Participation in the discussion portion of Moving On after Stoke Telehealth Remote (MOST-TR) via video-conference; 3. Participation in the exercise portion of MOST-TR via video-conference; 4, Factors enabling or limiting. Participation in the group.	All participants valued access to the programme without having to travel long distances. They felt safe in discussions and when exercising with the group across videoconference. Participants recognized a loss of subtleties in communication and the group facilitators found it difficult to discern whether participants were finding the exercises too difficult or too easy.	N/A
Wolf et al. (2016)[31]	Randomised clinical study	++	N=185 Stroke	12 week wait-list N=86	Baseline (T1), end of the month wait-list period (controls only-T2), end of intervention, (T3), 6-9 months follow up (T4). Primary outcomes: Chronic disease Self-Efficacy Scale (CDSES), participation strategies self-efficacy scale	Between groups CDSES: Exercise regularly (p=0.008), get information about disease (P=0.239), obtain help from others (P=0.045), communicate with physician (P=0.010). Manage: Disease in general (P=0.000), symptoms (P=0.058), shortness of breath (P=0.016), depression (P=0.08), do chores (0.001), social/recreational activities (P=0.122) PS-SES: Managing: Home (P=0.04), community (P=0.000), work and productivity (P=0.043), communication (P=0.314), staying organized (P=0.23), advocating for resources (P=0.002)	Exercising regularly(0.57), obtain help from others (0.44), manage disease in general(0.74), depression (0.66), doing chores(0.75), work productivity (0.37), advocating resources (0.65)

Note: N=number, CDSMP=CHronic Disease Self-Management Program, SSMI=Stroke Self-Management Intervention, CI=Confidence Interval, ns=non-significant