Self-management interventions for adults with stroke: A scoping review

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Abstract

Background: Stroke is a principal cause of mortality and disability globally. Numerous studies have contributed to the knowledge base regarding self-management interventions among chronic disease patients, but there are few such studies for patients with stroke. Therefore, it is necessary to analyze self-management interventions among stroke patients. This scoping review aimed to systematically identify and describe randomized controlled trials (RCTs) of self-management interventions for adults with stroke.

Methods: A review team carried out a scoping review on stroke and self-management interventions based on the methodology of Arksey and O’Malley, following the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). PubMed, Embase, Web of Science, CINAHL Plus Full Text, Medline Plus Full Text, and Cochrane Central Register of Controlled Trials were searched from inception to July 2020.

Results: Fifty-four RCTs were included. The most popular study design is comparing a self-management intervention to usual care or waitlist control condition. Physical activity is the most common intervention topic, and interventions were mainly delivered face to face. The majority of interventions were located in inpatient and multiple settings. Interventions were conducted by various providers, with nurses the most common provider group. Symptom management was the most frequently reported outcome domain that improved.

Conclusions: Self-management interventions benefit the symptom management of stroke patients a lot. The reasonable time for intervention is at least 6–12 months. Multifarious intervention topics, delivery formats, and providers are adopted mostly to meet the multiple needs of this population. Physical activity was the most popular topic currently. Studies comparing the effect of different types of self-management interventions are required in the future.

Keywords: Self management; Intervention; Stroke

Introduction

Stroke is a principal cause of mortality and disability internationally; moreover, the rehabilitation process is very costly. Previous research has revealed that in 2016, 13.7 million people experienced their first
stroke and stroke was the second leading cause of death worldwide (5.5 million deaths, 95% uncertainty interval [UI] 5.3–5.7) behind ischemic heart disease. Additionally, stroke was the second leading cause of global disability-adjusted life years (DALYs), which increased from 1990. There were 2.7 million deaths due to ischemic stroke, while the number due to hemorrhagic stroke was 2.8 million deaths. Furthermore, the worldwide prevalence of stroke in 2016 was 80.1 million, of which 84.4% were ischemic.1,2

Among recurrent stroke patients, the mortality rate is approximately 56%, which is much higher than for initial stroke patients. Prior studies have indicated that up to 43% of initial stroke victims are at risk of stroke recurrence within five years. Consequently, preventing recurrence is an essential strategy for diminishing the mortality rate of this severe illness.2–4 Thirteen systematic reviews indicated that self-management interventions (e.g., telephone calls, behavior therapy, and dissemination of informational materials relating to adherence) among chronic disease patients could significantly improve their survival rate, level of independence, and death rate.5,6 However, there are few studies of self-management interventions for stroke patients. In our literature review, we found that among five meta-analyses and systematic reviews that included 217 innovative studies, there were no reported studies in which stroke patients were participants.7–10 Though there is one systematic review investigating the effects of self-management interventions in people with stroke,11 the target population of which were exclusively those living in the community, and focus mainly on the effects on this population's quality of life.

While several reviews have provided information regarding self-management interventions among patients with chronic disease, many of the studies have attributes that make the results challenging to interpret. For example, several studies were excluded due to deficiencies in the comparison group. Specifically, comparative controlled trials are necessitated to circumscribe the exact impact of a given intervention. To conduct comparative controlled trials, studies focusing on the relationship between self-management and health outcome measures, specific interventions, cost-effectiveness, and combinations of interventions are needed. Importantly, self-management interventions must be effective given diverse patients’ requisites and healthcare contexts.10,12,13

To date, no scoping review reports have focused on self-management interventions among adults with stroke. Therefore, examining self-management interventions among stroke patients is essential. In our study, we implement Arskey and O’Malley’s 2005 scoping review methodology,14 and the goal of this scoping review is to identify and describe randomized controlled trials (RCTs) of self-management interventions in adults with stroke. Concretely, we focus on summarizing the outcomes of these RCTs and the strategies used to promote behavioral change.

Methods

The purpose of a scoping review is to determine what kind of evidence (quantitative or qualitative etc.) is available on the topic and represent this evidence by mapping or charting the data, summarizing the research by time, location, and origin.15,16 This scoping review was conducted in light of the methodology proposed by Arksey and O’Malley,14 which was described in further detail by Levac et al.17 The method consists of five stages: (1) identifying the research question(s); (2) identifying relevant studies; (3) study selection; (4) charting the data; and (5) collating, summarizing, and reporting the results.14 Furthermore, reporting will be conducted according to the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR).18

Stage 1: identifying the research questions

The following research questions were identified to lead our scoping review:

1. What were the principal conclusions of studies of self-management interventions in adults with stroke?
2. How were self-management interventions implemented and measured in adults with stroke?

Stage 2: identifying relevant studies

Six electronic databases, including PubMed, Embase, Web of Science, CINAHL Plus Full Text, Medline Plus Full Text, and Cochrane Central Register of Controlled Trials, were searched from inception to July 2020. We combined the search terms (Stroke OR cerebrovasc* disorders OR cerebrovasc* disease OR cerebrovasc* accident OR brain ischemic OR isch?emi* OR isch?emi* cerebral attack OR brain attack OR intracranial hemorrhage* OR CVA) AND (self-management OR self-care* OR patient-centred care OR self-monitor*
OR self-efficacy OR self-regulat* OR patient-orient* monitor* OR educat* OR promot* OR patient educat* OR teach* OR learn* OR train*). The search was limited to English, with studies involving human adults greater than or equal to 18 years of age and RCTs only, with no time limit. The detailed search strategy is described in Supplementary Table 1. The search phrases, determined in collaboration with the university librarian, follow the fundamental guidelines of each database. Furthermore, the authors examined the reference lists of relevant literature.

Stage 3: study selection

Firstly, two reviewers separately screened titles and abstracts of qualified studies. Afterward, the full text was also assessed by the two reviewers to judge whether or not it was relevant. A third-party was required when discrepancies occurred to resolve disagreements.

The definition of self-management interventions in our research consists of (1) focusing on illness needs (developing knowledge, skills, and confidence; or modifying lifestyle/behavior to manage medical aspects); (2) activating resources (identifying and accessing resources and supports); or (3) living with the condition (learning to cope with the condition and its impact on their lives, and the emotional consequences of the illness, e.g., values, beliefs, attitudes, and motivations, etc.). The inclusion criteria to the studies were: (1) adult patients (18 years or older); (2) diagnosis of stroke (including ischemic stroke, hemorrhagic stroke, or transient ischemic attack); (3) a randomized controlled trial of a self-management intervention; (4) described in the English language; and (5) included an outcome measure of self-management such as medication adherence, behavioral change, or physical activity. Similarly, the exclusion criteria were: (1) stroke as a complication; (2) studies including children or adolescents under 18 years old, adults living in a nursing home, or the hospital who received the patient assisting with the intervention; (3) combined other interventions (which do not involve self-management interventions); (4) conference proceedings, abstracts, and review articles; and (5) targeted only caregivers of stroke patients.

Stage 4: charting the data

To answer the research questions, the data chart (Supplementary Table 2) included the following data for each study: references, publication year, countries/regions, duration of the study, location of RCTs, target population, sample size, providers, delivery formats, intervention topics, intervention details, main findings, and implication for further research.

Stage 5: collating, summarizing, and reporting the results

Reviewers autonomously used a Microsoft Excel spreadsheet to collate the data regarding relevant and excluded information. Excerpts of text were coded deductively by S. Ruksakulpiwat to classify concepts and themes related to the research questions. W.D. Zhou investigated the coding scheme and the themes constructed.

Results

Search results

A total of 6649 references (one from a manual search of relevant references) were identified through the initial search, among which duplicates were found and eliminated by using both Endnote X8 and manual screening. After deduplication, 3618 references were available for screening, of which 3508 articles were excluded during the titles and abstracts screening phase following the application of the inclusion and exclusion criteria (Fig. 1), leaving 110 articles eligible for the full-text screening. During this phase, articles were excluded for the following reasons: (1) being duplicated (n = 1); (2) implementing an intervention not of interest for self-management, or including a particular type of exercise program, treatment, or vocational rehabilitation program (n = 22), such as electrostimulation, treadmill walking, mirror therapy and so forth; (3) not targeting stroke patients (n = 5), e.g., only focusing on caregivers or health professionals; (4) failing to measure the effects of the intervention on healthy behaviors, stroke knowledge, emotional management, or social function and so on (n = 6); (5) not being RCTs (n = 8); (6) other reasons (n = 14). A total of 54 intervention studies met the inclusion-exclusion criteria and were included in the final review.

Description of studies

Most included studies were published between 2014 and 2018 (n = 18; 33.3%) (Table 1). The average duration of the research reported across studies (from the enrollment to the final assessment of one participant) was 7.8 ± 5.9 (1.9–13.7) months. The duration varied
from 1 to 30 months, of which most were 0–3 months and 6–12 months (n = 18; 33.3%, n = 16; 29.6% respectively), and only one was over 24 months. The included RCTs were conducted in 12 countries and regions, including Australia (n = 11; 20.4%), United States (n = 11; 20.4%), China (Mainland) (n = 7; 13%), United Kingdom (n = 7; 13%), China (Taiwan) (n = 3; 5.6%), China (Hong Kong) (n = 3; 5.6%), Canada (n = 2; 3.7%), Germany (n = 2; 3.7%), Sweden (n = 2; 3.7%), The Netherland (n = 2; 3.7%), New Zealand (n = 1; 1.9%), Norway (n = 1; 1.9%), Japan (n = 1; 1.9%), and Multi-country (n = 1; 1.9%). The most common sample size of the control group was 50–100 (n = 17; 31.5%), and the least common were 200–300 (n = 3; 5.6%) and over 300 (n = 1; 1.9%). For the sample size of the experimental group, 50 to 100 (n = 18; 33.3%) was the most common, 200 to 300 (n = 3; 5.6%) and over 300 was the least (n = 2; 3.7%).

Participants characteristics

The target population in the included studies were individuals with stroke, including non-specified types of stroke (n = 31; 29.0%), multiple types of stroke (n = 25; 23.4%), ischemic stroke (n = 20; 18.7%), transient ischemic attack (TIA) (n = 14; 13.1%),
hemorrhagic stroke ($n = 11; 10.3\%$), and other sub-types of stroke ($n = 6; 5.6\%$) (Table 1).

Description of intervention

Table 1 summarizes the characteristics of self-management interventions for stroke patients. Details

Table 1
Overall characteristics of self-management interventions for patients with stroke.

| Variables                        | Count |
|----------------------------------|-------|
| Year                             |       |
| 1999–2003                        | 4     |
| 2004–2008                        | 11    |
| 2009–2013                        | 10    |
| 2014–2018                        | 18    |
| 2019–2020                        | 11    |
| Duration of intervention (months)|       |
| 0–3                              | 18    |
| > 3–6                            | 14    |
| > 6–12                           | 16    |
| > 12–24                          | 3     |
| > 24                             | 1     |
| Non-specified                    | 2     |
| Location of RCTs                 |       |
| Community                        | 9     |
| Home                             | 23    |
| Inpatient                        | 25    |
| Outpatient                       | 21    |
| Multiple locations               | 25    |
| Target population                |       |
| Hemorrhagic stroke               | 11    |
| Ischemic stroke                  | 20    |
| Transient ischemic attack        | 14    |
| Non-specified types of stroke$^a$| 31    |
| Multiple types of stroke$^b$     | 25    |
| Other sub-types of stroke$^c$    | 6     |
| Delivery formats                 |       |
| Electronic                       | 31    |
| Face to face                     | 53    |
| Print                            | 19    |
| Multiple formats                 | 35    |
| Providers                        |       |
| Nurse                            | 28    |
| Pharmacist                       | 1     |
| Physician                        | 13    |
| Psychologist                     | 6     |
| Social worker                    | 4     |
| Therapist                        | 17    |
| Multiple providers               | 26    |
| Others$^d$                       | 16    |
| Sample size ($n$)                |       |
| Control                          | 10    |
| Experimental                     | 8     |
| > 25–50                          | 13    |
| > 50–100                         | 17    |
| > 100–200                        | 10    |
| > 200–300                        | 3     |
| > 300                            | 1     |

Table 1 (continued)

| Variables                        | Count |
|----------------------------------|-------|
| Intervention topics              |       |
| Emotional management             | 29    |
| Medication                       | 20    |
| Nutrition                        | 4     |
| Physical activity                | 35    |
| Social function                  | 15    |
| Stroke knowledge                 | 20    |
| Symptom management               | 18    |
| Others$^e$                       | 31    |

RCTs: Randomized controlled trials.

$^a$ The researcher did not specify the type of stroke in the target population (e.g., stroke or others).

$^b$ The researcher included more than one type of stroke in the target population.

$^c$ Consist of minor stroke, mild stroke, moderate stroke.

$^d$ Consist of stroke association information officer, assistant psychologist, health professional, stroke specialist, researcher, peer leader, facilitator, research assistant, peer dyad, community health coordinators, healthcare assistant.

$^e$ Consist of perceived health status, pain/discomfort, language, vision, handicap, fatigue, quality of life, general health, healthcare utilization, mastery, family functioning, independence, self-efficacy, beliefs and expectations of recovery, cognitive function, risk factor management, engagement in life, perception of the impact of the stroke on life, use of social supports, preparation for caregiving and mutuality, mortality, satisfaction with performance, illness perception.

of the interventions can be found in Supplementary Table 2. In terms of the intervention topic, physical activity ($n = 35; 20.3\%$) was the most common, and nutrition ($n = 4; 2.3\%$) was the least common topic. The most frequent delivery format of the intervention was face to face ($n = 53; 38.4\%$), whereas print was the least common format ($n = 19; 13.8\%$). Interventions were conducted by a variety of providers. The most common group of providers were nurses ($n = 28; 25.2\%$) and multiple providers ($n = 26; 23.4\%$), consisting of nurses, therapists, social workers, peer leaders, and so on. The pharmacist was the least common provider ($n = 1; 0.9\%$). The inpatient and multiple-location settings were the most popular locations for providing the self-management interventions ($n = 25, 24.3\%; n = 25, 24.3\%$, respectively).

Description of research designs, outcomes, and results

The majority of studies ($n = 40; 74.1\%$) compared the self-management intervention to usual care or wait-list control condition. The details are shown in Supplementary Table 2. Two studies compared a self-management intervention to a non-self-management
intervention, ten compared two different kinds of self-management interventions, and one examined the effects of a combined self-management intervention (consisting of two kinds of self-management interventions) compared to one of the two kinds of self-management interventions. One study used three experimental groups to investigate whether the effects of the combined self-management intervention (composed of two kinds of self-management interventions, e.g., A + B) were better than A or B alone.

Most studies (n = 35; 20.3%) measured physical activity outcomes (e.g., Barthel Index, Frenchay Activities Index, and so on). The least common outcomes were nutrition outcomes (n = 4; 2.3%). We categorized the study results descriptively as improved, worsened, unchanged, or have combined results, which indicated the outcome variable was measured more than one time and showed different results (e.g., one measure improved, another had no change). Based on this method of categorization, 82 outcome categories improved, of which 18 were symptom management (improved 100%), 22 were others (improved 71.0%) (e.g., quality of life, general health, self-efficacy, etc.), 15 were physical activity (improved 42.9%), 11 were emotional management (improved 37.9%), 4 were social function (improved 26.7%), 5 were medication (improved 25.0%) and 5 were stroke knowledge (improved 25.0%) (Table 1).

**Discussion**

This is a scoping review of randomized controlled trials of self-management interventions for adults with stroke. The scoping review methodology enabled us to systematically summarize, synthesize, and analyze existing self-management interventions among stroke patients. Moreover, the review allowed us to explore evidence regarding a distinct intervention type and identify areas in need of further study. In this study, we conclusively identified 54 RCTs that examined self-management interventions for adults with stroke, with substantial heterogeneity in countries, study durations, locations, target populations, delivery formats, providers, sample sizes, intervention topics, main findings (whether the outcomes improved after the intervention, worsened after the intervention, were unchanged after the intervention, or had combined results).

We found that most self-management interventions for stroke have been developed, and most studies have been published within the last seven years, i.e., since 2014 (n = 29; 53.7%). This phenomenon is possibly linked to the enhanced perception of the importance of incorporating patients (along with their caregivers) in attempts to address their illness and the importance of encouraging them to take responsibility for their rehabilitation in order to achieve a more satisfying outcome. Furthermore, approximately 86% (n = 48) of self-management interventions were conducted in high-income countries. This finding may indicate that in low-income countries, the limited supplies and the lack of quality and progression of health care may result in inadequate health consequences, which effectively prohibit the invention and implementation of a self-management intervention. To support patients with stroke in these countries, provider-centered care is still principally adopted, instead of the patient-centered care that incorporates self-management.

Nevertheless, one study revealed that in low- and middle-income countries, self-management education (SME) operated by community health workers and peer educators produces major improvements in health promotion, undernutrition, maternal and child health, and epidemic infectious diseases. However, in the case of non-communicable diseases such as stroke, the few studies performed on SME in low- and middle-income countries have unveiled poor outcomes, in contrast to what has been observed in high-income countries.

This study unveiled that over a half of targeted type of stroke is non-specified types of stroke and multiple types of stroke. This could be due to that though the causes vary in different types of stroke, of which the consequences are similar, namely, compromised blood supply to part of the brain, leading to damage of the brain and often impairing functions such as mobility, vision, swallowing, and communication. Therefore, what various stroke populations need to conquer about the consequences of a stroke may be alike. So, the relevant studies commonly did not specify the types of stroke but treated them as a whole instead, or included multiple types of stroke, possibly in an effort to promise generalization of the interventions too.

Additionally, the duration of RCTs ranges from 1 to 30 months, of which most were 0–3 months and 6–12 months (33.3%, 29.6% sequentially), and only one was over 24 months. Likewise, a previous review discovered that the duration of self-management interventions varied from 6 to 12 months. The variability in the duration of studies may be due to diversity in the patient assessment instruments or intervention elements. Although we require confirmation to verify that obtaining results from RCTs requires a relatively long time, this study and the previous study suggest that 6–12 months or more of intervention is required for patients with stroke.
The previous scoping review of a self-management intervention in chronic disease patients indicated that many studies were identified with one or more intervention topics, delivery formats, and providers, which is in line with our study. This is possible due to the benefits of improvement of self-management ability could be reflected in many ways, since the patient is better able to manage the various consequences of the illness, e.g., symptom management, medication adherence, etc. Hence, a multiple intervention topic is needed to explore the multiple benefits of a self-management intervention. As for the delivery format, the use of only one format is limited in the density of the material provided and the method of delivering the intervention (e.g., giving printed educational booklets can only passively motivate the participants to learn and cannot guarantee that all patients will read the booklet, for many patients expect healthcare providers to assume the primary responsibility for patients' health instead of themselves, but this phenomenon could be improved when combined with group talks, etc.). The use of only one format may be monotonous as well, and multiple formats might compensate for the shortcomings of any one format. In terms of the providers, a single provider is mostly specialized in one aspect of the self-management program (e.g., psychotherapists focus on participants' psychological management, physiotherapists focus on teaching them how to improve their mobility), while a single patient may demand or require improvement in many aspects of self-management to be able to manage himself or herself well, and the intervention topic is usually diverse, as argued above. Therefore, multidisciplinary cooperation plays a significant role in supporting stroke survivors' self-management. Although various alternatives to intervention components are helpful if they satisfy the patient's requirements for enhancing their self-management, a larger supply of interventions may produce a vast array of intervention components.

In terms of the intervention topic, physical activity was the most popular topic, which is consistent with the findings of Plow M. et al. One likely explanation for the focus on physical activity may be that stroke is a leading cause of long-term physical disability, its importance is well-known by most people who are taking part in self-management interventions. On account that adherence to exercise plans is unsatisfying for many patients, a major focus of self-management interventions is increasing the level of physical activity of patients by motivating them to be responsible for it using various methods. The most common delivery format for the intervention was face to face (38.4%), and nurses were the primary group of intervention providers (25.2%), a finding that was also noted in the study by Donald et al. Due to the spread of technology in self-management interventions (such as mobile phone applications, websites, videos, etc.), along with technology's convenience and relatively low cost, technology-enabled self-management programs might gain greater popularity in the future. Additionally, the nurse may act as an alternative to a multidisciplinary team when there are insufficient resources to adopt the latter (e.g., in low-income regions).

The majority of RCTs compared a self-management intervention to usual care or wait-list control condition. In recent systematic reviews, stroke survivors who participated in self-management programs demonstrated significantly greater improvements than those who received usual care. Therefore, comparing the effects of an intervention to usual care or wait-list control condition may be an ideal way to show the benefits of this type of intervention. Nevertheless, there is little current evidence on how to support the implementation and integration of stroke self-management interventions better within the clinical practice. As the diversity of self-management interventions increases, with many variations in the types and delivery of self-management programs for stroke patients, study designs that compare the various types of self-management interventions are required to determine which intervention is better for stroke patients. Moreover, of the reported improved outcomes, medication (improved 25.0%) and stroke knowledge (improved 25.0%) outcomes improved the least while symptom management (improved 100%) outcomes the most, which is similar to the findings of a systematic review targeting the effects of self-management interventions on the quality of life of people with stroke living in the community. A primary purpose of self-management interventions is to facilitate better management of the symptoms inherent in living with chronic conditions, and therefore, our findings are consistent with the hypothesized purpose of self-management support programs. Nevertheless, it was reported that self-management interventions have the largest effect on improving medication adherence, which is contrary to one of our findings. This difference could be due to a different number of databases searched, and the results could differ across time since the previously mentioned systematic review was conducted approximately five years ago. Still, further studies are required to explore this outcome. Furthermore, one potential reason for the little improvement
found in stroke knowledge may be that although patients in the control group received a limited amount of information, it may have been sufficient to answer some of the basic questions about stroke, especially when a patient is more educated since learning capacity may be a strong factor affecting knowledge learning.13

Strengths of this scoping review include the application of the widely recognized methodology of conducting a scoping review, following a framework by Arksey and O’Malley14,39; a rigorous search strategy, designed in collaboration with the university librarian, across a range of databases to maximize the likelihood of obtaining the relevant studies; a less partial paper-screening process, composed of the co-selection and co-analysis of studies by two authors, to decrease selection bias and ensure a more comprehensive result. This review may provide the impetus for further research in this area.

Limitations of this review consist of the inclusion of only studies targeting stroke patients and ruling out those that only expose the caregivers (family or health professionals) to the interventions since our primary focus was self-management, in which the patients themselves must learn to take responsibility for their recovery; not reporting the outcomes of the variables regarding the caregivers or other perspectives (e.g., cost-effective analysis, patient’s participation, and satisfaction of the service, etc.), since the patient’s self-management status was our main focus. Thus, we refer the readers to other reviews that target self-management in other populations for further information on those studies that only recruited caregivers as the intervention population and reported outcomes for caregivers and other perspectives.13,30,40

Furthermore, implications for practice are not necessary for scoping reviews.16 This is quite the opposite of systematic reviews, of which these implications are a key feature and are recommended in reporting guidelines for systematic reviews.11 Even if there is a need to make implications for future research and practice in a scoping review based on the researchers’ purpose, the implications may be limited in terms of guiding from a clinical or policymaking, since a formal assessment of the quality of the included sources of a scoping review is not required, and the methodology of scoping review is not naturally aligned to establishing practice or policy recommendations.16

Conclusions

Self-management interventions appear to benefit stroke patients’ symptom management a lot but have little effect on medication and stroke knowledge. The reasonable exposure time for intervention is at least 6–12 months. Multifarious intervention topics, delivery formats, and providers are applied mostly to cater to the multiple needs of this population and promise motivation when managing the stroke themselves. Nevertheless, if there are insufficient resources, technology-enabled, nurse-led self-management programs could be adopted. Physical activity was the most popular topic currently due to its well-known importance among stroke patients. Furthermore, study designs that compare the effect of different types of self-management interventions are required in the future to determine which intervention is best for stroke patients.

Conflicts of interest

None.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.cdtm.2021.03.001.

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