

ORIGINAL ARTICLE

Strategies to enhance chronic disease self-management: How can we apply this to stroke?

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Abstract

Purpose. Social Cognition Theory and the cognitive construct of self-efficacy often form the theoretical basis for many chronic disease self-management programmes. Self-efficacy can be influenced through these programmes and has been shown to be predictive of greater levels of functioning and psychological well-being. Stroke is regarded as a complex chronic disability, and individuals may share many of the same concerns as those living with other chronic diseases such as arthritis and chronic pulmonary disease. However there has been minimal reported research on the utility of self-management programmes following stroke.

Search strategy. To comprehend the composition of chronic disease self-management programmes which could be applied to stroke, this paper examined the theoretical basis of self-management and particularly the evidence relating to interventions which have utilized self-efficacy enhancing strategies. Selected papers were retrieved from an extensive search of literature using Medline, Cinahl, PsychInfo and Web of Science databases and the Cochrane Collaboration. The search request focused on literature that specifically related to chronic disease, self-management and self-efficacy that had been published since 1995. However, seminal literature on self-efficacy produced prior to this date was also included.

Discussion and conclusions. There is strong evidence to support the use of self-management programmes and their effect on self-efficacy and associated health outcomes. While there are differences in the nature of each chronic condition, there are similarities in the core skills required for self-management. Many effective strategies could be incorporated into current stroke rehabilitation programmes or used to develop targeted self-management interventions. Future research which informs stroke rehabilitation should utilize the evidence relating to other chronic conditions. This could be used to develop the most effective methods of equipping individuals following stroke to cope confidently with the transition from being discharged from therapy towards effective self-management in the longer term.

Keywords: *Self-management, self-efficacy, chronic disease, stroke*

Introduction

Research into self-management following stroke falls well behind studies carried out on the utility of self-management programmes for individuals living with other chronic diseases. This is despite the fact that each year in England and Wales approximately 110,000 people will have their first stroke, and stroke is still the most prevalent and complex disability in the UK [1]. The common clinical features of stroke and recovery patterns are well described, but this does not adequately convey the complexity of personal responses to what is often a sudden and distressing life event. Despite an increasing

recognition of the long term psychological and social consequences of stroke and the influence on many different domains, research is heavily dominated by studies of interventions in the acute stage of recovery.

The majority of studies which have examined the longer term post stroke have highlighted the negative psychological and social sequelae, but the results can sometimes conflict. Some studies have reported the prevalence of mood disorders and life dissatisfaction and the link with mortality and morbidity at one year [2,3]. Quality of life has also been found to be highly abnormal at one year following stroke and correlated to depression [4]. However life satisfaction has also been reported to be relatively high in individuals

1–3 years following stroke, which suggests strategies to cope with the consequences of a stroke may improve in the longer term [5]. This suggestion has also been supported in a small number of qualitative studies which have explored the development of diverse and successful self-management strategies in individuals, after discharge from acute services [6–8]. The specific skills required for self-management tasks following a stroke may vary dependent on the complexity of subsequent impairments and activity limitations. However, findings from in-depth interviews carried out with 40 individuals 10 months after their stroke revealed subjects were using a number of active and creative self-management strategies [7]. These ranged from mobilizing informal support, creating new ways of doing things, pacing, relearning specific skills, exercising and developing methods of covering up in an attempt to prevent the disability becoming their total identity.

If there are individuals who will not accept the changes caused by their stroke passively and show creativity and resourcefulness in finding self-management tasks which optimize functional independence, there may be many factors which influence the development of such skills. A key factor may be the belief that an individual holds with regards their own capability to self-manage, particularly after discharge from therapy services. Such belief can be strengthened or reduced through the success or failure of personal efforts. The role of therapists in this process may also be key and their interactions may be highly influential in enhancing and preparing an individual for successful self-management.

Self-efficacy forms a major basis of any decision to act, and is defined as “the belief in one’s capabilities to organize and execute the courses of action required to produce given attainments” [9]. This cognitive construct differs from merely holding a personal belief about a positive outcome and refers to a particular judgement regarding the ability to carry out the skills required to carry out a specific behaviour. Self-efficacy beliefs held by individuals are considered to be a central and persuasive factor in determining the course of action required, the degree of effort put in and perseverance to continue in the face of hindrances and difficulties [9,10]. The acute phase of stroke has been described as a feeling of unreality, and likened to the stages of shock and grief experienced after bereavement [11,12]. Understandably this acute phase is also characterized by the most intense period of acute medical care and therapeutic interventions, but after this an individual is faced with a number of continuing personal challenges and difficulties. These may coincide with the transition of leaving hospital and include

the processes of readjustment and living with their stroke in all aspects of home, family and work. Subsequent events whether successful or not will influence the formation of self-efficacy judgements and future behaviour.

Four main sources of self-efficacy have been described which have been applied to the development of personal efficacy in any action, not just in relation to health behaviour [9]. The first source is *mastery* experiences, which act as an indicator of personal ability, and the confirmation of success in a particular task or skill; *vicarious* experience is another source which is gained through the comparison and modelling of others, it can be beneficial to observe someone perceived to be similar (model) successfully performing the task; *verbal persuasion* forms the third source and serves to increase an individual’s belief about their personal level of skill through the use of persuasion and verification from a significant other (professional or key family member). The final source is *physiological feedback*, in which efficacy beliefs are formed from feedback produced by an individual’s own physiological state. The interpretation of physical and emotional feelings as positive rather than negative is thought to provide an internal feedback which can influence physical self-efficacy [9,13].

Success in the initiation and use of self-management tasks using one or all of these self-efficacy sources could theoretically help an individual to gain more control over some of the manageable aspects of their disease. In chronic diseases such as arthritis, Chronic Pulmonary Disease (COPD), diabetes and Chronic Heart Disease (CHD) the nature of these self-management tasks are well described [14,15]. But many of the tasks have been described as generic and may be as applicable to individuals following stroke as with any other chronic condition [16]. Lorig and Holman described five core self-management skills that should underpin any chronic disease self-management programme. These include: problem-solving, decision-making, resource utilization, collaboration and taking action [17]. The skills should also be something which the individual feels confident that they will achieve, and perceived self-efficacy appears to be at least one of the key mechanisms responsible for improvement in health behaviours following a self-management programme [9,18].

It is no surprise that there are an increasing number of chronic disease self-management programmes which incorporate the training and development of key self-management tasks and are based on Social Cognition Theory, but to date there have been minimal reports of self-management programmes designed for individuals following stroke. To comprehend the composition of chronic

disease self-management programmes which could be applied to stroke, this paper examined the evidence pertaining to interventions which have either utilized self-efficacy enhancing strategies or included self-efficacy as a primary measure. The search request focused on literature that specifically related to chronic disease, self-management and self-efficacy that had been published since 1995. However, seminal literature on self-efficacy produced prior to this date was also included. In view of the scarcity of stroke related research on self-management, the majority of papers presented in the following section relate to self-management interventions for arthritic conditions and COPD.

Application of self-management interventions in other chronic diseases

The ability to exercise some control over self-directed action is a basic human attribute and is fundamental to the processes which underpin the day to day responsibility of living with a chronic condition. Creer and Holroyd describe the key processes of *self-management* as goal selection, information collection, decision-making, action and self-reaction [19]. These processes are in accord with the core self-management skills described by Lorig and Holman [17] and chronic disease self-management programmes which focus on these specific processes and strategies have been found to be more successful than educational strategies alone [20].

However there are a number of study interventions which are not adequately described and do not state the underlying theory, and many deliver a form of educational programme. The Arthritis Self-Management Programme (ASMP) was originally developed along these lines and not on the basis of social cognition theory, but following an analysis of the relationship between health outcomes and self-management behaviours, the mediating effect of self-efficacy became apparent [20]. As a result, the content of the ASMP was modified to include strategies to improve self-efficacy, and the beneficial effects which included a reduction in pain intensity, disability and depression were enhanced in the subsequent programme. More importantly these effects were also found to persist over a follow-up period of four years. The ASMP was the forerunner to the Chronic Disease Self-Management Programme (CDSMP) which included people with different chronic conditions (arthritis, COPD, diabetes and stroke) in one intervention. Both the CDSP and the ASMP have been tested in randomized controlled trials and replicated with populations outside the original study population [16,18,21]. The CDSP is a 17-hour programme led by a lay person with specific personal experience of

a chronic condition and training in self-management. Results at six months showed an increase in exercise, improved coping strategies including symptom management, less fatigue, decreased disability and fewer hospital visits and consultations with medical staff. These results were maintained in subsequent follow-up studies at one and two years [22].

The contribution of programmes such as the ASMP and the CDSP may lie in the fact that self-efficacy is being modified and strengthened rather than previously a focus on the teaching of self-management skills. This has led to a growing recognition of the value of interventions which enable adaptation to chronic disease using a cognitive and behavioural approach and there are a number of examples of this model of self-management [18,20]. Some are disease specific, such as a group intervention for individuals with Ankylosing spondylitis (AS) that aimed to enhance self-efficacy through a series of sessions providing information about exercise and symptom management, combined with techniques to encourage participants to identify their own specific barriers to exercise and problem-solving techniques [23]. Follow-up at six months showed a significant difference between the intervention and control groups in self-efficacy and depression and a trend towards lower disease severity but no long-term change in exercise behaviour or adherence. However a similar group education approach for individuals with rheumatoid arthritis developed by Taal and colleagues found that adherence to exercise was maintained at 14 months post intervention, along with self-efficacy and knowledge about their condition [24]. The results from Taal's study match that of the CDSP and the intervention was designed to follow the ASMP developed by Lorig. The discrepancy in terms of maintenance and adherence to exercise may be explained by the difference in sample populations between the studies, many subjects in the AS study were of working age and results match some of the usual decline in exercise adherence in this age group over time. Subjects in the CDSP had a variety of conditions with different levels of severity, and a mean age of 65 years. In addition, the AS intervention was guided by health professionals as are most self-management programmes, but the CDSMP uses lay tutors with the chronic conditions, this has a particular application to Bandura's second source of self-efficacy (vicarious experience).

Although the evidence supporting the use of self-management programmes in arthritic conditions may conflict in terms of long-term adherence to exercise, the influence on self-efficacy and psychological well-being is well supported in many studies. There have also been several studies which have shown self-efficacy, which is potentially modifiable, to be a key

predictor of pain-related disability [25–27]. Change in functional self-efficacy has also remained significant when adjusting for age, depressive symptoms and disease severity [25]. A significant relationship between self-efficacy function and mood has also been found in a small number of stroke studies, but the predictive value of self-efficacy has not yet been fully examined [28,29]. Although arthritis dominates in self-management literature, there are also a notable number of studies in COPD, in which a primary responsibility of many individuals is the self-initiated and directed behaviours to control and manage breathing in activities of daily living.

Evidence to support self-management interventions for COPD is as yet inconclusive according to a Cochrane review, and many do not name the underlying theory and specifically include self-efficacy enhancing strategies [30]. However a key recommendation by reviewers was that programmes should focus more on enabling behavioural change in the longer term. Self-efficacy may be the key mediating variable in the causal relationship between knowledge and skill in self-management and health behaviour and this was highlighted in a paper by Bourbeau and colleagues which reviewed self-management and behaviour modification in COPD [31]. One of the key factors involved in the success of self-management programmes for individuals with COPD seems to be the need to offer a multifaceted approach which involves specific methods for enhancing behaviour modification. The authors cited the example of an early randomized controlled trial which tested the effect of a self-management intervention which included specific behaviour modification techniques and showed a significant increase in exercise tolerance, health outcomes and self-efficacy judgements in relation to control groups (attention group, and no treatment group) [32].

Some studies have not been designed to include self-efficacy enhancing strategies, but nonetheless self-efficacy is a key variable expected to show change. Toshima and colleagues carried out a two-part study in which 129 individuals with COPD were randomized into a comprehensive rehabilitation programme or a control group [33]. Prior to the intervention (1 year before) physiological performance and disease severity was the strongest predictor of self-efficacy beliefs and physiological feedback was thought to be a key source of self-efficacy judgments about performance. Follow-up measures at 2 months and six months after the intervention showed a significant difference between the groups in terms of exercise tests, fatigue and dyspnoea, but not in self-efficacy judgements. The non-significant change in self-efficacy in the intervention group could be due to how the information is cognitively appraised, subjects may have been basing

their judgements solely on physiological feedback, and not on their own personal mastery. Research shows a stronger effect on self-efficacy when individuals experience performance accomplishment based on a cognitive behavioural intervention rather than a medical model rehabilitation intervention as employed in this study [33]. This has implications for the design of self-management programmes which should include cognitive behavioural methods designed to enhance mastery experiences.

The behaviours necessary for self-management of a chronic disease such as COPD may be multifactorial and this should be reflected in the complexity of self-management programmes. A focus group study of self-care issues from the perspective of individuals with COPD stressed the importance of acknowledging the context for living with and surviving the disease, and many used multiple strategies to self-manage their condition [34]. The relationship between emotional and physical health was also highlighted and how low self-esteem and mood can directly affect physical performance. Subjects ranged in severity and treatment experiences but all subjects had attended either a rehabilitation programme or a support group. The importance of a balance between disease management and finding ways of creatively incorporating self-management activities into life was highlighted, in addition the need to individualize approaches to self-management. Programmes should include methods to encourage individuals to cognitively appraise self-management of their symptoms and encourage resourcefulness and creativity to find self-management strategies. There are parallels to be drawn to stroke and considering the complexity of impairments, the use individualized programmes or group programmes are required to provide flexibility to respond to individual difficulties.

Qualitative research which explored individuals' views following a self-management intervention for COPD found that participants generally had a positive view of the programme and felt an enhanced self-confidence to cope with their condition [35]. This was despite no significant change in Health Related Quality of Life (HRQoL) as measured by the St George's Hospital Respiratory Questionnaire (SGHRQ) in the original randomized controlled trial [36]. Self-efficacy was used as a theoretical basis for the design of this programme, and the changes in disease specific self-confidence are therefore not unexpected. However it also highlights the importance of using measures which are specific and sensitive to the targeted domain, and aspects of perceived self-confidence and personal capability may not be adequately portrayed by the SGHRQ.

The implementation of self-management programmes which include self-efficacy enhancing

strategies is now strongly supported for arthritis and COPD, but it appears that not all programmes adhere closely to Bandura's theoretical framework with regards to self-efficacy sources and utilize appropriate methods of measurement. Although the optimal and specific types of interventions have not yet been identified, it seems sensible to suggest that the value of self-efficacy based interventions for stroke should not be disregarded. There may also be a number of areas of overlap between the strategies required to live with stroke and other chronic diseases, all of which could be amenable to targeted self-management interventions.

Application of principles to stroke self-management

The evidence from the study of chronic disease self-management programmes supports the use of efficacy enhancing interventions over and above educational strategies alone. Some of these strategies may be effective in improving self-management of stroke in the longer term, but as yet there has been minimal report of specific targeted interventions, although stroke was named as one of the chronic conditions included in the CDSP [18]. Further empirical research is clearly required, but there are a number of methods that could be incorporated to enhance self-efficacy in more traditional stroke rehabilitation programmes and this could influence the development of self-management skills in some individuals after stroke.

The main strategic consideration is that self-efficacy to carry out self-management is dependent on an exposure to the four primary sources of self-efficacy information. *Mastery experiences* are the most influential source as they provide the most compelling evidence of what it takes to succeed, and even a small performance success achieved after individual effort can persuade an individual to persevere and accomplish further tasks [9]. The extent to which self-efficacy can be altered through performance experience, may depend on a number of factors including the amount of external help received and the way in which the memories of success or failure in a specific task are cognitively appraised and retained. The use of *specific action plans* is advocated by Lorig and Holman as a key element in skills mastery [17].

Rehabilitation strategies employed following stroke currently utilise a goal setting approach [37] but much of the literature emphasizes the professional guiding the process and individuals may not always fully participate in their own goal-setting process [38]. This approach may not allow practice of some of the key skills necessary for enhancing self-efficacy and self-management and there are a number of further considerations. *The action plan, targets or goals*

need to be very specific and relate to a key achievable activity that can be completed in a short time, e.g., one week. The specific action should also be valued by the individual, and they should be encouraged to rate their level of certainty or confidence with regards to accomplishing the task within a given time frame. Problem-solving is an inherent part of this process, and individuals should be encouraged to use problem-solving techniques to set their own targets and make adjustments if required. If success in the action or target is achieved then a cognitive appraisal of performance and reflection is necessary so that the change is equated with their own personal effort as opposed to an external factor such as the skills of the therapist. However some individuals may have difficulties with this model of self-appraisal particularly if cognitive impairments are apparent. Nonetheless there should be an emphasis on researchers and clinicians to find ways to adapt these principles to be inclusive of all individuals and modify programmes accordingly.

A second application is the use of methods to enable *modelling and vicarious experience*, this may include the use of written or video material which includes stories of individuals that have experienced a stroke and accomplished self-management tasks through their own efforts. In addition the use of peers to teach on self-management programmes has been successful [18], although it might not be necessary to set up formal groups such as the expert patient programmes [39], but to provide opportunities for informal groups of stroke patients to come together, compare experiences, discuss problems and offer suggestions as required.

An additional method of learning to self-manage lies in the ability to *interpret physiological signs* such as fatigue, weakness, stiffness and pain, and provide plausible explanations. The experience of a stroke may result in a number of physical and psychological impairments but if there is a sole reliance on expert opinion to provide answers and solutions to problems, or changes in symptoms then this may be counter productive to enhancing self-efficacy and self-management. Early stroke rehabilitation should not only include regular information-giving about the nature of stroke and ways of managing, but also opportunities for individuals to develop the skills to interpret changes in their function effectively and gain the confidence to determine possible solutions for any problems which may occur.

The final source of self-efficacy advocated is the use of *specific feedback* to highlight personal capability. This involves providing practice opportunities so that if an individual is attempting a self-management task such as an exercise or a particular functional task, they should receive feedback not only about their progress but also about their own personal contribution and

efforts [9]. The persuasion expressed by significant others, e.g., friends, family and other individuals who have experienced a stroke can be an invaluable source of self-efficacy beliefs.

These four sources of self-efficacy often underpin the design of dedicated self-management programmes, but equally could be used as guiding principles to strengthen self-efficacy through the many therapeutic encounters that take place during any stroke rehabilitation programme.

Conclusion

Most of the stroke literature focuses on the acute phase of recovery, and although self-management of stroke begins in hospital, the main process of adjustment and learning to cope with a new disability takes place after discharge [40]. Stroke rehabilitation programmes which are aimed at increasing individuals' perceived self-efficacy to solve problems, make decisions and construct action plans for specific functional targets, could help prevent some of the difficulties which individuals face when discharged from regular treatment. Clearly many individuals will develop their own practical strategies for self-management in the longer term [7], but there are also many individuals who will experience disappointment, when they fail to make a full recovery, and this could place them at a greater risk of developing depression.

Although the majority of evidence to support the use of efficacy enhancing self-management interventions relates to living with chronic conditions other than stroke, there are clearly number of guiding principles which can be applied to stroke rehabilitation programmes. It has also been found that individuals with stroke and other chronic conditions such as arthritis and chronic pain express a similar desire to take charge of living with their condition [40]. However it also necessary to give consideration to the specific cognitive impairments associated with stroke, and modify self-management interventions appropriately. Professionals working with individuals after stroke should also be mindful of making assumptions about an individual's readiness for self-responsibility and insight into their problems. Programmes which acknowledge a contribution an individual can make towards their own self-management however small can still address some of the underlying principles of self-efficacy theory.

Future research which informs rehabilitation practice should have the ultimate aspiration of finding the most effective methods of equipping individuals to cope confidently with the transition from being discharged from therapy services towards effective self-management in the longer term. More work is also required to examine whether the delivery of

interventions needs to be by therapists or through a more collaborative programme which incorporates lay tutors with personal experience of a stroke. The high incidence of depression and life dissatisfaction linked with morbidity and mortality following stroke should provide just incentive for a change in emphasis of research and rehabilitation services which are currently directed to the acute stages. More good quality research using a diversity of methods is needed to fully explore and test a range of targeted self-management interventions for enhancing and improving living with a stroke in the longer term.

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