

## **Tailored stroke self-management: developing and testing a nurse-led, self-management support intervention (TALISSMAN)**

### Study team:

Dr Lisa Kidd (Principal Investigator), Research Fellow<sup>1</sup>

Dr Maggie Lawrence, Stroke Association Senior Training Fellow<sup>1</sup>

Dr Jo Booth, Reader<sup>1</sup>

Dr Anne Rowat, Lecturer<sup>2</sup>

Ms Sian Russell, Research Assistant<sup>1</sup>

<sup>1</sup>School of Health & Life Sciences/Institute for Applied Health Research, Glasgow Caledonian University

<sup>2</sup>School of Nursing & Midwifery, Edinburgh Napier University

This report, written for the Burdett Trust for Nursing, provides a summary of the project findings. Further information is available from the study team on request (please contact Dr Lisa Kidd, [lisa.kidd@gcu.ac.uk](mailto:lisa.kidd@gcu.ac.uk)).

### Acknowledgements:

We would like to thank The Burdett Trust for Nursing Empowerment Programme (Hospital/Community Interface, Level 2 Award) for funding this research study. We would also like to express our sincere appreciation to all the study participants and nursing staff that took part in the study and gave so generously of their time and shared their experiences with us. We would like to thank all members of the Project Advisory Group for their guidance, suggestions and comments throughout the duration of the study.

## 1. Background

Engagement in self-management by individuals with long-term conditions (LTCs), such as stroke, has been suggested as a key to promoting recovery and patient empowerment, and to improving health outcomes as well as a means to manage the escalating costs associated with LTC care. Community nurses are well placed to lead the way in promoting, encouraging and supporting stroke survivors' engagement in self-management. However, there is limited guidance available on the design, delivery and implementation, feasibility and acceptability of stroke self-management interventions, particularly for empowering stroke nurses to take the lead in developing and implementing these in the community. This report describes and presents the findings from a 16 month project, conducted from June 2012 to August 2013, and funded by the Burdett Trust for Nursing Empowerment Programme. The aim of the project was to develop, implement and qualitatively evaluate a nurse-led self-management intervention, underpinned by the concept of 'patient activation', comprising individualised, systematic assessment of stroke survivors' needs, expectations and abilities to self-manage, and aligning the provision of tailored self-management support towards these.

## 2. Methods

The intervention was developed using the UK Medical Research Council's framework for developing and evaluating complex interventions.<sup>1</sup> The project incorporated three phases of data collection which had different aims, used different methods and data sources (Table 1) leading to the development and preliminary testing of the intervention. Ethical approval was obtained from the West of Scotland Research Ethics Committee 3 and research management approval obtained for each of the NHS Boards involved in the study via NHS Research Scotland Permissions CC.

Phase	Aims	Methods/Sources/Analysis
1	To identify the feasibility, acceptability, meaningfulness and effectiveness of self-management interventions for community-dwelling stroke survivors	Systematic literature review. Literature sourced via key health-related databases, published in English language, between 2000 and 2012. Data extracted from relevant studies and quality appraisal conducted. Findings synthesised and presented narratively.
2	i) To understand stroke survivor's perceptions towards self-management and levels of 'activation' ii) To develop prototype of the intervention	Mixed methods. Qualitative semi-structured interviews with 20 stroke survivors & qualitative focus groups/telephone interviews with 11 stroke nurses in three Scottish health boards. Completion of the Patient Activation Measure (PAM). <sup>2</sup> Interviews transcribed and data thematically analysed. PAM data analysed using descriptive statistics. Intervention prototype developed based on the analysed findings from phases 1 and 2.
3	To evaluate the feasibility and acceptability of the intervention	Implementation and qualitative evaluation. Intervention implemented by five stroke nurses in one Scottish health board over a four-week period with five stroke survivors between 1 and 12 months post stroke. Open-ended evaluation questionnaire completed by stroke survivors and qualitative focus group with stroke nurses on completion of the four-week intervention period. PAM data analysed using descriptive statistics, descriptive data from the evaluation questionnaire summarised, focus group transcribed and data thematically analysed.

## 3. The intervention

The 'intervention' was developed based on the findings from Phases 1 and 2 and consisted of a personally tailored self-management action plan created jointly by nurses and the participant in partnership during the nurse's scheduled visits. The personally tailored self-management action plan was presented to individuals in a booklet format and included (and documented) their responses from the PAM, which was completed jointly by the nurse and patient to assess the individual's abilities and confidence to self-manage; motivational interviewing prompts, which were used by nurses to encourage individuals to identify key goals to frame their personal self-management efforts; and activation-specific self-management advice and guidance which was issued by nurses aligning to the individual's specific stage of activation (identified through the PAM and in accordance with individual's personally defined goals). The personally tailored self-management action plan also contained space for writing about the goals that were jointly set with nurses, and spaces for writing down any questions or concerns they wished to talk to their nurse or GP about.

## **4. Results**

### **4.1 Phase 1**

#### **4.1.1 Description of the included studies**

Fifteen studies satisfied the inclusion criteria; eight were RCTs, five were quasi-experiments, and two were other designs (qualitative and cross sectional survey). The studies were conducted in the UK (n=6), Australia (n=4), Canada (n=2), the USA (n=2) and Hong Kong (n=1). All of the studies comprised stroke survivors (n=15); some clearly stated that caregivers (n=8) were also included. Sample sizes ranged from 12 to 205 and the mean ages of the samples ranged from 53-73 years. The interventions were delivered in community settings in varying numbers of sessions, lasting from 4 to 12 weeks in length and comprised different elements including educational, counselling and exercise sessions.

#### **4.1.2 Review findings**

The synthesised evidence demonstrates that self-management interventions (SMIs) for stroke survivors can have a positive impact on: quality of life, psychological and cognitive functioning and self-management behaviours, cognition and knowledge. Less evidence, however, was reported in relation to the feasibility, appropriateness and meaningfulness of SMIs, however, where this was reported it appeared that interventions were feasible and perceived as useful/beneficial in the formats in which they were offered. Consequently since the current evidence base predominantly consists of trial designs little details as to the active ingredients within SMIs are offered. Such designs also tend to ignore the highly subjective and individualised nature of, and context conducive to, self-management. Thus, despite emerging evidence on the overall effectiveness of SMIs for stroke we know little about 'what works, for whom, in what contexts and why' and how these can be feasibly and appropriately integrated and embedded within clinical practice.

### **4.2 Phase 2**

#### **4.2.1 Participant Demographics**

In total 20 participants were recruited; eight from NHS Lanarkshire, six from NHS Fife and six from NHS Highland. Participants ranged in age from 43 to 84 years (mean 64 years). Participants included both males (n=12, 60%) and females (n=8, 40%) and were 1-6 months post-stroke (n=12, 60%) or 7-12 months post-stroke (n=8, 40%). In total, six participants (30%) reported one or more additional comorbidities, 14 (70%) suffered from fatigue and 12 (60%) had cognitive impairments. Half the sample (50%) reported that they had moderate to moderately severe disability/symptoms based on the Modified Rankin Scale (MRS). In total, 11 nurses participated in the focus groups/telephone interviews. Demographic data were not collected on the nurses, other than date qualified (range from 10-37 years) and length of time in post (range from 2 months to 13 years).

#### **4.2.2 Patient Activation Measure (PAM) Scores**

Participant's scores on the PAM were high (median 75.3, IQ range 69, 80), which is comparable with recently published studies on activation levels in the general population.<sup>3</sup> However, it should be noted that since this project involved purposeful sampling to achieve maximum variation, these scores are unlikely to be representative of all stroke patients. There is a lack of published evidence specifically on the measurement of patient activation within a stroke population to be able to compare this against. Analysis of the PAM scores indicates that the majority of the included participants were actively self-managing and were able to maintain this in times of stress, illness or anxiety (stage 4) (n=17, 85%). Of the 3 participants who had lower PAM scores, 2 (10%) indicated that they had understanding of self management, but lacked confidence to actively engage (stage 3) and one (5%) indicated a lack of confidence and knowledge to self-manage (stage 2). All three patients suffered from fatigue and had moderate/severe disability (MRS  $\geq 2$ ). Interestingly, 10 participants gave negative responses (disagree/disagree strongly) to one or more of the PAM statements, suggesting they may have specific needs that are not being addressed and would be missed if the total PAM score/activation scale was used to guide care. Furthermore, we found that 6 participants had difficulty in answering one of three PAM statements, which may be because the tool is not specific to the needs of individual stroke patients.

#### **4.2.3 Qualitative themes**

Key findings from the analysis of the interviews with stroke survivors revealed that self-management meant different things to individuals for example, for some it was about taking responsibility for the management of your condition whilst for others self-management was viewed as an alternative, rather than an adjunct to or part of the

care and support that they were currently receiving and was something that they would do once they were 'better'. Most of the participants perceived that engaging in self-management was important to help them recover from their stroke and prevent a recurrent event. Participants, who appeared to be the most actively engaged self-managers (i.e. those who spoke about personally engaging in a process of reflection and self-management decision making), were those who appeared to have more focussed and established 'goals' as part of their recovery such as, getting back to work or a specific hobby/interest. Participants who spoke of a general desire to 'get better' but who did not identify specific goals or ways to achieve this appeared to self-manage in a more passive style e.g. did not engage in the process of reflection and self-management decision making but followed and adhered only to the advice of medical and allied health professionals. Nurses were viewed as having a pivotal role to play in supporting stroke survivors' self-management but that the support offered needed to be more structured and focussed around their own goals and wishes.

Key findings from the analysis of the focus groups/interviews with stroke nurses revealed that the majority of the nurses perceived patient's self-management similarly; becoming independent, taking responsibility and taking control over their lives. They perceived that their roles were to educate, support, signpost to information and resources and to help individuals to set goals as part of their recovery but that individuals had to be ready, prepared and confident to accept their part in this too. Confusion over terminology was identified as a major barrier to supporting patients' engagement in self-management, particularly when discussing what "self-management" meant with their patients. Other barriers nurses faced included a) a difficulty stepping back and letting patients take control over their self-management, particularly when nurses had traditionally been trained to help care and problem solve *for* people; b) a lack of a supportive infrastructure (e.g. interdisciplinary, interagency working and transport links) in which a culture of promoting self-management could be adopted and; c) lack of a structured process to both assess individuals' needs and priorities and how to personalise self-management support in accordance with these. Findings suggest facilitators are recognised as the individual having specific, realistic goals and a sense of how they could start to work towards achieving these and having someone, be that patient or professional, who could champion a culture of promoting self-management within their health board or local area.

#### **4.2.4 Comparison of the PAM scores and qualitative data from stroke survivors**

Interestingly, the PAM scores indicated that the majority of participants reported having the knowledge, confidence and skills to actively engage in self-management and to maintain this during times of stress, illness or anxiety. However, the qualitative analysis illustrated a different picture; the majority of participants perceived themselves to be lacking in the knowledge, skills and particularly, the confidence to engage in self-management, particularly during times of stress, illness or anxiety. The data suggests a mismatch between the scores on the PAM and the content of the qualitative themes when participants were probed further about their understandings of, and perceptions towards, self-management.

### **4.3 Phase 3**

#### **4.3.1 Participant Demographics**

In total, six stroke survivors participated in the trial of the intervention and returned complete data. Participants ranged in age from 43 to 68 years (mean 58 years), included both males (n=4) and females (n=2) and were all between 1-6 months post-stroke (n=5) except for one man who was between 6 and 12 months post stroke. Five participants reported one or more additional comorbidities. In total, three participants reported slight disability/symptoms based on the Modified Rankin Scale (MRS) with three reporting moderate to moderately severe disability/symptoms. In total, five nurses participated in the focus groups/telephone interviews. Demographic data were not collected on the nurses, other than date qualified (range from 10-27 years) and length of time in post (range from 2 months to 10 years).

#### **4.3.2 Stroke survivor's perceptions of the intervention**

Stroke survivor's set a range of goals with their stroke nurse, as part of the intervention, encompassing examples such as exercising, mobilising independently, lose weight and reduce smoking. Key findings from the analysis revealed that all participants reported that they were happy with the presentation and layout of the tailored self-management plan booklets and found them and the questions they were asked from the PAM easy and straightforward to use. Their comments suggested that they found the goal setting process of particular value. Overall, the participants reported that they felt they had been offered appropriate, relevant and timely self-

management information and advice during the intervention but did not feel that their knowledge, confidence or skills in raising concerns with health professionals had changed any over the course of the intervention.

#### **4.3.3 Nurse's perceptions of the intervention**

The stroke nurses all recognised the push towards promoting engagement in self-management and the need to develop tools that would help them to do this. Key findings from the analysis, however, conveyed that there was still some uncertainty surrounding the concept of 'supported self-management' and the shared meaning of this. Although the nurses acknowledged that their patients wouldn't necessarily use the language of 'goals' per se, the goal setting process was perceived as the most valuable component of the intervention and had a place in their daily clinical practice. They perceived that the process of setting small goals in partnership with their patients helped to document and verbalise patients' personal aspirations and priorities whereas these may not have been revealed otherwise and that these then helped to provide a structure or focus to their subsequent visits and self-management discussions. They perceived that patients setting their own goals helped to motivate them and gave them 'permission' to begin to take self-management action to achieve these. However, it was also acknowledged that the process of 'goal setting' required a degree of motivation on the patient's behalf and that goal-setting based interventions would be less successful with less motivated patients. The PAM was perceived as less useful within the intervention. The nurses commented that participants would frequently give a 'socially desirable' answer placing them at the higher end of the self-management spectrum that did not fit with their true attitudes or behaviours towards engaging in their self-management. They also commented that there was confusion surrounding several of the questions because of the way they were worded and participants did not understand these nor know how to answer them in a Likert scale format (ranging from strongly disagree to strongly agree), rather than with a straightforward 'yes/no' response. One participant commented to their nurse that the questionnaire might be particularly difficult for stroke survivors with communication problems to understand and another commented that more severely impaired stroke survivors may have more specific issues of concern than the questionnaire tended to address.

#### **4.3.4 Issues noted during the implementation phase**

The nurses' comments suggested that implementing the intervention itself did not fit well into their daily clinical schedules. It was perceived by the majority of them as time consuming and resulted in the need for additional visits. However, this may also reflect the 'research process' in that the nurses were responsible for recruitment and consent of participants, therefore, prior to the intervention beginning, the nurses were asked to discuss the study, consent participants and obtain some demographic details from them which may have resulted in the need for an additional visit. The intervention was also viewed by some of the nurses as an adjunct to the on-going care that they were providing to their patients, rather than being readily integrated within their care delivery, which may reflect the difficulties in shared understandings of 'supported self-management'. Three of the nurses described having particularly difficult case loads during the time of the intervention trial which appeared to hinder its integration within normal clinical practice. The nurses commented that the documentation needed to be made simpler, for example, with a one-sided page of check boxes rather than the booklet format in which it was presented.

## **5. Conclusions and implications**

As a result of this Burdett Trust for Nursing funded study, we now have evidence that can be used to enable us to develop and test appropriate self-management assessment tools which capture the issues most important to stroke survivors and which can be utilised within, and more effectively integrated into, clinical practice. As a result of this study, we have further evidence of stroke survivor's self-management support needs. Specifically, some unique findings relating to stroke survivor's and nurses perceptions of goal setting emerged; particularly the nuances of the nature and types of goals that help to motivate people's engagement in self-management activities and the processes of empowering nurses to elicit these from individuals and how best to facilitate them in their progress to achieve these. As a result of this study, we also now have evidence that will enable us to refine the aspects of this intervention that were tested in the current study and how to further refine self-management support interventions to facilitate their integration and embedding within existing practice. In particular, our findings will enable us to further develop and test packages of support and training for nurses in helping to empower them to feel able to promote stroke survivor's engagement in self-management in a tailored and personalised manner and explore further how to integrate these into existing practice most effectively.

The theory behind this intervention i.e. being able to determine how and when stroke survivors engage in self-management, their perceptions towards doing this and being able to assess and respond to their self-management support needs at different stages or times post stroke remains a fundamental basis in empowering nurses to support individual's engagement in self-management in a tailored and individualised manner. Our findings reinforced that there is a continuing clinical need to develop ways for nurses and allied health professionals to do this. The intervention as a whole had limited impact on both stroke survivors' knowledge and confidence to self-manage, and the stroke nurses' ability to deliver tailored stroke self-management support. This may be because the intervention was implemented and the evaluation conducted over a short period of time, over which one may not expect to see a large degree of change in people's confidence or abilities to self-manage. It could also be because of specific aspects of the intervention such as the assessment questionnaire that it was designed to test. Although there was a recognised need for a self-management assessment tool that could be effectively and easily incorporated into nurses' existing practice, the PAM - in its current version - did not appear to be the 'right' assessment tool for this population. Although the clinical utility of the PAM has been suggested in the literature,<sup>2,4,5</sup> our findings suggested that the specific needs of stroke survivors, and indeed subsequent information needed by stroke nurses to inform the delivery of their self-management support, may not be sufficiently captured and addressed within this particular population. This appeared particularly true when using the total PAM score/activation scale was used to guide the provision of self-management support. It could be perhaps that individual questions on the PAM have more relevance and appropriateness to some groups of people with LTCs than others. It is possible that focussing on individual question areas within the PAM provides a more accurate understanding of stroke survivor's self-management support needs than the total PAM score. Further development and testing of the PAM and indeed other assessment tools within a stroke-specific population would be valuable to help ensure that they are fit for purpose, culturally relevant and easy to complete for both stroke survivors and stroke nurses within their clinical practice.

Rather importantly, the evaluation helped to identify the components of the intervention that were successful, most relevant and feasible to both stroke survivors and stroke nurses in clinical practice. It also helped to identify some of the key barriers to the empowerment of nurses in delivering self-management support in practice. The goal setting component, underpinned by motivational interviewing style prompts, was perceived as most useful part of the intervention by both the stroke survivors and stroke nurses who participated. In particular, although many nurses incorporate goal setting within their daily practice, the process evaluation of the intervention revealed that there was a subtle shift between nurse-led and person-centred goal setting. The act of allowing the individual themselves to determine their own specific goal, the personal meaningfulness of that goal and the opportunity to have control over both deciding upon and enacting self-management strategies that would facilitate the achievement of this was undoubtedly a powerful component of the intervention. This process, undertaken in partnership with the nurses, appeared to put patients at the heart of self-management decision making activity and was empowering for both the individuals and the nurses in helping to support effective and meaningful engagement in self-management. Nurses were viewed as being ideally placed to listen to patients' priorities around self-management and help them work towards achieving these. However, further work is necessary to develop training and support that can help to empower nurses to guide and support individual's self-management decision making and activity in a person-centred approach.

All of the nurses involved in the project acknowledged that self-management was a positive approach for their patients and for themselves in helping them to offer more timely and appropriate support to those who need it. The findings highlighted, however, that self-management support continues to be viewed as an adjunct to the daily care that nurses currently provide. Despite an abundance of research in the field of self-management, success in integrating and delivering self-management support within the demands of current practice continues to prove challenging. Numerous barriers related to the resources and infrastructure to support self-management in practice exist. At a conceptual and theoretical understanding there appears to be a lack of a shared vision and understanding regarding the meaning of 'supported self-management' and the use of terms such as 'goals' and 'goal setting' for example amongst nurses and with allied health professionals and with their patients. This is undoubtedly a significant barrier to encouraging engagement in self-management and to the integration and delivery of self-management support interventions in existing practice. Further discussions of 'what is self-management' and 'what is self-management support' would be valuable within (and across) nursing and allied health professional circles, adding an interdisciplinary perspective which would help to ensure continuity and consistency of the messages and

support used to frame self-management. What is meant by self-management is of course also an imperative discussion to have with patients, carers and family members in helping to promote and underpin a culture shift towards person-centred approaches and a shared understanding of how to support engagement in self-management in practice. Such discussions would also inevitably inform the development of better models of care which facilitate nurses' delivery of self-management support but are cognisant of current pressures on them in terms of staffing and resources, time management and workload demands. Further work on how current care delivery systems could potentially be restructured to help further empower nurses to integrate and implement brief self-management support interventions in their clinical practice is important.

## 6. Dissemination of the findings & next steps

The findings from this research project and its implications for future research and clinical practice will be disseminated to a range of audiences and using a variety of approaches, including social media. The project and our findings align very much with current strategic priorities in the fields of stroke care and self-management as well as the priorities of the organisations and NHS boards that have been involved with, and facilitated, the project. As such, the project findings will be disseminated across these avenues. At present the project team are meeting with a range of stakeholders with a remit for policy making, clinical practice and service provision (particularly nurses), academia and representatives from the third sector to present our findings to them and to stimulate discussion around their implications for policy, practice and future research. We are harnessing the potential of social media for reaching wider audiences and disseminating our findings to relevant individuals and organisations who are represented on Twitter etc. We also intend to disseminate the findings via national/international events and through networks that we are members of, for example, the Scottish Stroke Nurse Forum, The Royal College of Nursing and the UK Stroke Nurse Forum. Papers from the project will be prepared for publication in academic stroke journals e.g. International Journal of Stroke as well as in practice journals e.g. the British Journal of Nursing or the Nursing Standard, and British Journal of Community Nursing. Importantly, information about the project will also be disseminated to stroke survivors, their families and carers, and more generally members of the public, at specifically organised events based at Glasgow Caledonian University and disseminated through our networks with third sector organisations including, the Stroke Association, Chest Heart and Stroke Scotland and The Alliance (formerly known as The Long Term Conditions Alliance Scotland) and on our social media pages.

More specifically, the study team intend to apply for follow on funding to undertake further work on the development of self-management assessment tools for stroke survivors, intervention development and delivery in existing practice, and training and support to empower and enable nurses to deliver effective and efficient self-management support in practice.

Please contact Dr Lisa Kidd ([lisa.kidd@gcu.ac.uk](mailto:lisa.kidd@gcu.ac.uk)) for further information or discussion about the project and its findings.

## 7. References

1. Craig P, Dieppe P, Macintyre S, Mitchie S, Nazareth I and Petticrew M (2008) Developing and evaluating complex interventions: the new Medical Research Council guidance *British Medical Journal* 337:a1655
2. Hibbard JH, Stockard J, Mahoney ER and Tusler M (2004) Development of the Patient Activation Measure (PAM): Conceptualising and measuring activation in patients and consumers *Health Services Research* 39:4: Pt 1:1005-1026
3. Greene J and Hibbard JH (2012) Why does patient activation matter? An examination of the relationship between patient activation and health related outcomes *Journal of General Internal Medicine* 27:5:520-526
4. Hibbard JH and Greene J (2013) What the evidence shows about Patient Activation: Better health outcomes and care experiences, fewer data on costs. *Health Affairs* 32:2:207-14
5. Hibbard JH, Greene J and Overton V (2013) Patients with lower activation associated with higher costs; delivery systems should know their patient scores *Health Affairs* 32:2:216-222