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Stroke self-management: what does 'good' self-management support from nurses look like?

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Abstract

Nurses' roles in stroke self-management are particularly pivotal yet there is a gap in our understanding about the perspectives of, and the challenges faced by, stroke nurses in relation to the development, implementation and impact of stroke self-management support services. This article describes the qualitative findings from a recent study which aimed to develop, pilot and evaluate a nurse-led, person-centred stroke self-management support intervention. The findings presented here may help to inform the future design and delivery of stroke self-management support and an understanding of the issues and challenges that nurses face in delivering person-centred self-management support in current clinical practice. The article presents several principles of 'good' stroke self-management support based on the study findings.

Background

It is estimated that there are up to 1.1 million stroke survivors living in the UK (The Stroke Association, 2013). Over half of these have a persistent stroke-related disability, with significant and complex physical, cognitive, and emotional deficits that require continued lifelong care and support to self-manage, for both them and their families (The Stroke Association, 2013). Impairments such as, aphasia, visual and cognitive difficulties including confusion, poor concentration and reduced mental ability – which often go hand in hand with stroke – can affect individuals' health literacy skills, their abilities to see out, interpret and act on complex information, as well as creating challenges with mobility, transport, reading and writing, and confidence with social interaction (Rees et al, 2007). All of these issues are likely to hinder engagement in, and can result in the potential exclusion of, a significant number of stroke survivors from, effective and appropriate stroke self-management (Jones et al, 2013).

Growing evidence on the long-term impact of 'living with stroke' dovetails with the growing policy context around long-term condition (LTC) self-management (Department of Health, 2005, 2007; Scottish Government, 2009a, 2009b), in the UK but also globally (e.g. Canada (British Columbia Ministry of Health, 2007), as well as calls from UK stroke charities for services which specifically address long-term stroke survivor's self-management needs and facilitate health professionals, including nurses, to deliver appropriate, timely and personalised self-management support. This support can be conceptualised and described as the provision of educational and supportive interventions by service providers and the development of mechanisms which help health professionals to facilitate individuals' self-management by helping to develop their personal skills and confidence related to managing, and making decisions about, their own health (Adams et al, 2004; Long Term Conditions Alliance Scotland, 2008).

Examples of well-known existing stroke-specific self-management programmes in the UK include, *Bridges Self-Management Programme* (Jones et al, 2009), which aims to train practitioners to help stroke survivors to develop their personal self-management skills (http://www.bridges-stroke.org.uk) and *The Stroke Workbook* (Joice et al, 2012), a self-management manual based on Leventhal's Self-Regulatory Model. Whilst such programmes have potential impact, a key challenge lies in integrating and embedding such models of self-management support into the 'real-world' setting of clinical practice. Subsequently, this forms the focus of much of the on-going evaluation of these programmes (McKenna et al, 2013). Evidence shows, however, that self-management programmes frequently fail because they do not focus on the individual patients' priorities, preferences nor is there an assessment of their needs or abilities (Kennedy et al, 2007) with which to frame the provision and delivery of self-management support. They can also fail because we, as professionals, can be unwilling to change our practice and because the healthcare system in which we work within does not view the provision of self-management support as a priority (Kennedy et al, 2014) or provide the flexibility required to respond to individuals' needs in what is considered to be a timely, personalised and appropriate manner (Blakeman et al, 2006; Kennedy et al, 2007; Kennedy et al, 2013).

Nurses' roles in stroke self-management are particularly pivotal yet there is a gap in our understanding about the perspectives of, and the challenges faced by, stroke nurses in relation to the development, implementation and impact of supported stroke self-management services and how to support them in implementing the principles of a person-centred, self-management approach. As evidence from the qualitative findings described in this paper shows, the provision of tailored stroke self-management support based on the assessment of individual's priorities, preferences, needs and abilities is valued by both nurses and stroke survivors. Key questions remain, however; what does the provision of 'good' stroke self-management support look like? How can stroke nurses – and in fact, all nurses - be empowered and supported to deliver good self-management support? How do we start to address the challenges that face us in relation to the implementation, integration, long-term roll out, embedding and sustainability of supported stroke self-management programmes and services? Our study aimed to start exploring some of these issues as part of a larger programme of work to increase our understanding about, and develop mechanisms designed to support nurses in, the delivery of stroke self-management support.

Aim and Methods

We conducted a 16-month (June 2012-Aug 2013) mixed methods study, across NHS Scotland, which aimed to develop, pilot and qualitatively evaluate a nurse-led, person-centred stroke self-management support intervention (depicted in figure 1). Theoretically, the intervention was designed to be a collaborative approach - between stroke survivors and nurses – so that individuals' values, concerns and preferences shape the way in which they are supported to live with and self-manage their lives following stroke, underpinned by timely assessment (using the Patient Activation Measure (Hibbard et al, 2004), goal setting, motivational interviewing, and personalized action planning and reflection ('house of care' model) (Coulter et al, 2013).

The study was conducted across three phases (Box 1). The development and evaluation of the intervention itself will be reported in greater detail elsewhere. The findings reported on in this article are derived from the qualitative interviews and focus groups conducted with stroke survivors and stroke nurses in phases 2 and 3. The interviews/focus groups specifically aimed to explore understandings of self-management and self-management support, and, for the nurses, their perceptions towards the delivery and implementation of stroke self-management support within the context of their current clinical practice. Ethical and management approval was sought from the West of Scotland Research Ethics Committee and the NHS Research Scotland Permissions Coordinating Centre. All data were tape-recorded, transcribed and thematically analysed (Braun and Clarke, 2007).

[insert figure 1 here]

[insert box 1 here]

Findings and Discussion

Key findings from the analysis of the interviews with stroke survivors revealed that self-management was generally perceived as important to help them recover from their stroke and prevent a recurrent event. Those stroke survivors, 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. Stroke survivors 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 by stroke survivors as having a pivotal role to play in supporting their self-management but that the support offered needed to be more structured and focussed around their own personal goals and wishes.

Key findings from the analysis of the focus groups with stroke nurses revealed that the majority of the nurses perceived stroke survivors' self-management as becoming independent, taking responsibility and taking control over their lives. They perceived that stroke nurses' 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. They recognized that this could present an atypical role for stroke survivors to expect to assume. Confusion over terminology was identified as a major barrier to supporting stroke survivors' engagement in self-management, particularly when discussing what "self-management" meant with, and to, their patients. The ways in which 'self-management' and 'supported self-management' was conceptualized across stroke nurses themselves as a group also varied, resulting in potential inconsistency in the application of the principles of person-centred supported self-management in the delivery of their care and service provision. Of note, the post-intervention focus group discussions, conducted with stroke nurses who 'tested out' the intervention in practice as part of the study, revealed that 'supporting self-management' was 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; reflecting a lack of a shared understanding of the principles of supported stroke self-management underpinning all care delivery.

It was recognized amongst all of the nurses that the healthcare system had created a degree of patient dependency; constructed through its culture of paternalism and traditional training of the 'health professional as expert'. Stroke nurses voiced a difficulty in stepping back and letting patients take control over their self-management, particularly since their training was traditionally framed as helping care and problem solve *for* people and 'stepping in and doing everything rather than standing back'. Partly, this also appeared to be attributed to a lack of a supportive infrastructure (e.g. interdisciplinary/interagency working, increasing workload demands, and poor transport links) in which a culture of promoting self-management could be adopted and was openly supported. In the post-intervention focus group discussions, all of the nurses voiced concerns over the ever-increasing pressure to complete all of their visits within a specific timeframe as well as deliver self-management support which was seen by some as "not fitting with their daily clinical practice", "time consuming" and resulted in the "need for additional visits".

It was also perceived that delivering stroke self-management support in practice was challenging because of a lack of a structured process to both assess and identify individuals' needs and priorities and to respond to these in a planned and personalized manner in accordance with these. In the post-intervention focus group discussions, stroke nurses identified that the process of 'person-centred goal setting' carried out as part of the intervention would be a valuable adjunct to their repertoire of self-management support tools and skills yet the method through which this was undertaken did not appear to resonate with their current usual practice. They perceived that the process of setting small goals in *partnership* with their patients helped to document and verbalise stroke survivors' 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 where stroke survivors were enabled to set their own goals and where these were personally meaningful and of importance, it significantly 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 individual's behalf and that goal-setting based interventions would be less successful with those who were less motivated.

Conclusion

Success in the implementation, large-scale roll out and potential impact of stroke self-management services and programmes is largely dependent upon the extent to which they focus on stroke survivors' and family members' individualised needs, priorities and expectations to self-manage (and how these change over time). In particular, our findings illustrated the significance of having a 'hook', such as a personally meaningful goal, activity or hobby, which can be used to frame the provision of 'good' individualised stroke self-management support.

Just as important, however, in the design and implementation of 'good' stroke self-management support (and 'good' self-management support more generally) is that it is cognisant of, and congruent with, the attitudes and perceptions of stroke practitioners, commissioners and service providers (across all sectors) towards the concept itself and the implementation of stroke self-management support services, within the larger context of care delivery. A person-centred healthcare system, where individuals are supported to make informed decisions about, and to successfully manage, their own health and care, requires health professionals to have the skills, time and capacity to work in partnership to deliver care that is responsive to people's individual abilities, preferences, lifestyles and goals (De Silva, 2014).

Several principles, as shown in Box 2, can be identified from the findings of this study in relation to what 'good' stroke self-management support might look like and can offer some ideas on how we might start to think about reshaping and restructuring service delivery to encourage, empower, enable and support nurses to deliver care and services in accordance with these.

[insert box 2 here]

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References

Adams K, Greiner AC, Corrigan JME (2004) *Report of a summit. The 1st annual crossing the quality chasm summit – A focus on communities.* National Academic Press. Washington, DC Accessed via http://selfmanagementalliance.org/wp-content/uploads/2013/11/Crossing-the-Quality-Chasm-Focus-on-Communities.pdf

Blakeman T, Macdonald W, Bower P, Gatley C, Chew-Graham C (2006) A qualitative study of GPs' attitudes to self-management of chronic disease. *British Journal of General Practice*. 56,527,407-414

Braun V and Clarke V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3, 2, 77-101

British Columbia Ministry of Health (2007) *Primary Health Care Charter: a Collaborative Approach*. Ministry of Health. British Columbia.

Coulter A, Roberts S, Dixon A (2013) *Delivering better services for people with long-term conditions: Building the house of care*. The Kings Fund. London. Available from: http://www.kingsfund.org, last accessed July, 2014

Department of Health (2005) *Supporting People with Long Term Conditions: an NHS and Social Care Model to Support Local Innovation and Integration*. Department of Health. London.

Department of Health (2007) *National stroke strategy: Improving stroke services – a guide for commissioners.* Department of Health. London.

De Silva D (2014) *Helping measure person-centred care.* The Health Foundation. London.

Hibbard JH, Stockard J, Mahoney ER, 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

Joice S, Johnston M, Bonetti D, Morrison V, MacWalter R (2012) Stroke survivors' evaluations of a stroke workbook-based intervention designed to increase perceived control over recovery. *Health Education Journal.* 71, 1, 17-29

Jones F, Mandy A, Partridge C (2009) Changing self-efficacy in individuals following a first time stroke: preliminary study of a novel self-management intervention. *Clinical Rehabilitation* 23, 6, 522-533

Jones F, Riasi A, Norris M (2013) Self-management after stroke: time for some more questions. *Disability and Rehabilitation.* 35, 3, 257-264

Kennedy A, Rodgers A, Bower P (2007) Support for self care for patients with chronic disease. *British Medical Journal.* 335, 968. doi: http://dx.doi.org/10.1136/bmj.39372.540903.94

Kennedy A, Bower P, Reeves D, Blakeman T, Bowen R, Chew-Graham C, Eden M, Fullwood C, Gaffney H, Gardner C, Lee V, Morris R, Protheroe J, Richardson G, Sanders C, Swallow A, Thomson D, Rodgers A, the Salford National Institute for Health Research Gastrointestinal programme Grant Research Group (2013) Implementation of self-management support for long term conditions in routine primary care settings: cluster randomised controlled trial. *British Medical Journal.* 13, 346, f2882 doi: 10.1136/bmj.f2882.

Kennedy A, Rodgers A, Bowen R, Lee V, Blakeman T, Gardner C, Morris R, Protheroe J, Chew-Graham C (2014) Implementing, embedding and integrating self-management support tools for people with long-term conditions in primary care nursing: a qualitative study. *International Journal of Nursing Studies.* 51, 8, 1103-1113

Long Term Conditions Alliance Scotland (2008) *Gaun Yersel: The Self Management Strategy for Long Term Conditions in Scotland.* Scottish Government. Edinburgh.

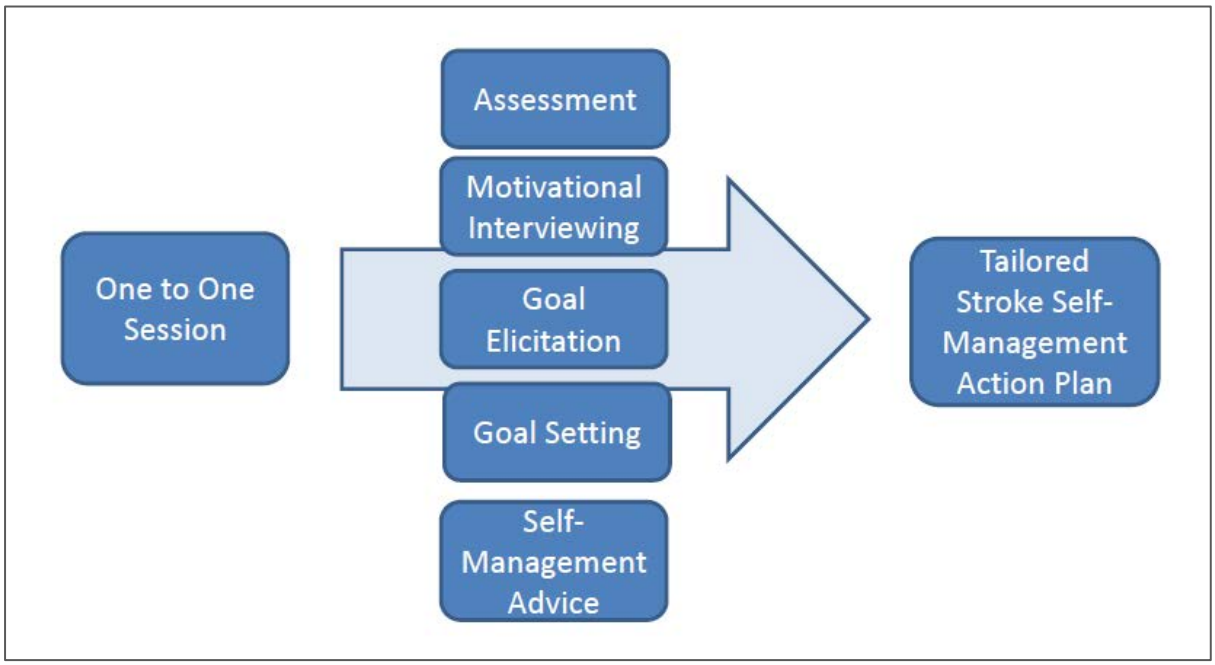
McKenna S, Jones F, Glenfield P, Lennon S (2013) Bridges self-management program for people with stroke in the community: a feasibility randomized trial. *International Journal of Stroke* doi: 10.1111/ijs.12195. [Epub ahead of print]

Scottish Government (2009a) *Improving Health and Wellbeing of People with Long Term Conditions in Scotland: an Action Plan*. Scottish Government. Edinburgh.

Scottish Government (2009b) *Better Heart Disease and Stroke Care Action Plan.* Scottish Government. Edinburgh.

The Stroke Association (2013) *Feeling overwhelmed: emotional impact of stroke*. Stroke Association. London.

Figure 1: The Intervention



Box 1: Aims and methods of the study

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 understand stroke nurse's perceptions towards self-management support and its delivery and implementation in practice iii) To develop prototype of the intervention	Mixed methods. Qualitative semi-structured interviews with 20 stroke survivors & qualitative focus groups with 11 stroke nurses in three Scottish health boards. Completion of the Patient Activation Measure (PAM).[2] 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.

Box 2: Principles of 'good' stroke self-management support

- Understand and acknowledge individuals' perceptions and expectations around self-management and grounds the delivery of self-management support within these
- Conduct a brief targeted assessment, which along with assessing clinical severity and functional status, should include the individual's self-management priorities, preferences, abilities and support needs, and barriers and enablers to their self-management
- Elicit patient-initiated goals through the use of approaches such as motivational interviewing, which is guided by the principle of the client, rather than the counsellor, evoking and voicing their motivations and arguments for change (Miller and Rose, 2009)
- Enable and encourage individuals themselves to identify and articulate 'goals' that are personally meaningful to them, framing them in a manner that they will identify with and respond to, and work in partnership to devise a way in which they might start to work towards these
- Document and record 'goals' and 'self-management action plans' in a systematic manner that will help to guide and structure the delivery of self-management support
- Ensure that self-management support 'fits' with practitioners' daily clinical practice; the principles of person-centred self-management support should underpin care delivery rather than being another 'thing' which results in the need for additional time, visits or added pressure on nurses.
- Ensure that the philosophy of self-management and the provision of self-management support is part of a whole system change which values self-management and supports nurses to deliver stroke self-management support in a timely and person-centred manner, rather than being an individualistic, opportunistic and ad hoc approach