



Stroke self-management: A focus group study to identify the factors influencing self-management following stroke



Emma J. Boger^{*}, Sara H. Demain, Sue M. Latter

Faculty of Health Sciences, University of Southampton, United Kingdom

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ABSTRACT

Background: Self-management refers to the strategies, decisions and activities individuals take to manage a long-term health condition. Self-management has potential importance for reducing both the personal and health service impact of illness. Stroke represents a significant health and social burden, however there is a lack of clarity about the factors that support successful self-management following stroke.

Objective: This study sought to investigate the factors which facilitate or hinder stroke self-management from the patients' perspective.

Design: Nested qualitative exploratory phase within a mixed-methods paradigm. Data were analysed thematically using Analytic Induction to guide development of themes.

Setting: Participants had experienced a stroke and were recruited from rural and urban community stroke support groups based in the South of England.

Method: Five focus groups ($n=28$) using a semi-structured interview guide were conducted. Interviews were digitally recorded and transcribed.

Findings: The term 'self-management' was unfamiliar to participants. On further exploration, participants described how self-management activities were helped or hindered. Self-management was viewed as an important, unavoidable feature of life after stroke. Three key themes identified from the data affect stroke self-management: Individual capacity; support for self-management and self-management environment. People following stroke reported feeling ill-prepared to self-manage. The self-management support needs of patients following stroke are currently often unmet.

Conclusion: Successful stroke self-management consists of features which may be modifiable at the individual level, in addition to the presence of external support and an environment which supports and facilitates people following stroke to self-manage. These findings extend current conceptualisations of stroke self-management.

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What is already known about the topic?

- Successful self-management is an important aim following stroke and is believed to promote effective use of healthcare resources.

- What factors hinder or facilitate self-management from the perspectives of those affected by stroke is unknown.

What this paper adds?

- This research identified the components which contribute to successful self-management following stroke described by three themes; individual capacity, support for self-management and self-management environment.

^{*} Corresponding author. Tel.: +44 02380597898.
E-mail address: e.j.boger@soton.ac.uk (E.J. Boger).

- Individual capacity alone is not sufficient for successful stroke self-management. Support for self-management is required from professionals, families and other services within an environment which facilitates self-management.
- Existing provision for self-management, which focuses upon factors modifiable by individuals, may not support people to adequately self-manage following stroke.

1. Background

Stroke is a major cause of disability and loss of quality of life years world-wide (Mukherjee and Patil, 2011) and represents a substantial health and socioeconomic burden. People living with stroke face enormous challenges, particularly once discharged from acute care, in adjusting to a new phase of life, managing expectations for recovery (Ellis-Hill et al., 2008; Lutz et al., 2011) and regaining autonomy (Kubina et al., 2013). Many people living with stroke rate their quality of life as poor (Sprigg et al., 2012). Depression and anxiety are common after stroke and become more prevalent as time since stroke increases (Lincoln et al., 2013). Many people with stroke report ongoing health needs which are not being met by services over the longer-term (Care Quality Commission, 2011; McKeivitt et al., 2011; Murray et al., 2003). Stroke survivors often find themselves taking on responsibility for the management of their physical, emotional and biographical recovery, coping with their ongoing disabilities, and engaging with secondary stroke prevention with little formal support (Battersby et al., 2009; Joice, 2012). There is clearly the potential to improve the lives of people living with stroke, in addressing the health and social issues associated with life after stroke.

Self-management has been advocated as a means of supporting individuals' coping and continued progress following stroke (Jones and Riazi, 2011; Jones, 2006). Much of the evidence surrounding self-management for long term conditions is based on the Stanford University model, which focuses upon the management by individuals of their treatment, symptoms, lifestyle, physical and psychological consequences of living with a long-term condition (Lorig and Holman, 2003; Lorig et al., 2001). The Stanford model, along with other self-management models such as the Chronic Care Model (Wagner, 1998) and the Flinders model (Battersby et al., 2002) have been applied in various international settings, and across a range of conditions, but the applicability of these models have not yet been tested in stroke self-management. Self-management may help to modify the increased demand on health and social care resources (Bodenheimer et al., 2002a; WHO, 2002), yet findings still remain inconclusive regarding the benefits of self-management (Coster and Norman, 2009; Nolte and Osborne, 2013) with the patient experience of self-management following stroke remaining unexplored.

1.1. Self-management in stroke

Interventions purporting to focus on self-management in stroke, have reported improvements to individual self-efficacy, quality of life and recovery following stroke

(Allen et al., 2004; Harwood et al., 2012; Johnston et al., 2007; Jones et al., 2009; Kendall et al., 2007). Qualitative reports have identified that self-management interventions (SMIs) are important to people affected by stroke as a means of providing psychosocial support (Catalano et al., 2003; Hirsche et al., 2011). Additionally, SMIs may reduce the risk of subsequent stroke, and have positive impacts on resource utilisation (Allen et al., 2004; Cadilhac et al., 2011; Sit et al., 2007). However, the conceptual relationship between the tools used to evaluate SMIs and self-management is uncertain and the psychometric properties of these measures has been shown to be poor (Boger et al., 2013), casting doubt over the reported benefits of stroke SMIs. Uncertainty also exists regarding the appropriate content and delivery of stroke SMIs (Lennon et al., 2013).

To date, no research has explored what self-management, per se, means to people following stroke and the influences upon self-management in the absence of any formal intervention for self-management. This research sought to investigate self-management from the perspectives of people following a stroke.

2. Methods

2.1. Design

This study represents the qualitative phase within a mixed-methods paradigm (Teddlie and Tashakkori, 2008), which sought to develop a new patient-reported outcome measure (PROM) (not reported upon here). The overall research design adopted an exploratory sequential mixed methods approach (Creswell and Plano Clark, 2011). The findings presented in this paper, concern the first exploratory phase, which sought to inform the concepts important to include in the new PROM. Focus group interviews were conducted between July and November 2011. This approach was selected for two key reasons. Firstly, the group dynamics that focus groups afford, potentially facilitate discussion and provide a forum for participants to explore their ideas, beliefs and values about self-management (Barbour, 2007; Rabiee, 2004). Secondly, the reflective and reflexive nature of focus groups means they are particularly appropriate to research involving the exploration of complex and un-researched areas, such as stroke self-management (Morgan, 1997; Powell and Single, 1996).

2.2. Ethical considerations

Ethical and research governance approval (ref FoHS-2011-054) was gained from the Faculty of Health Sciences Research Ethics committee (University of Southampton) which complies with the Code of Ethics of the World Medical Association (Declaration of Helsinki). Participants were provided with written and pictorial information sheets and were asked to sign a consent form in order to participate.

2.3. Sample

A purposive sample of individuals was sought. Participants were recruited by approaching eight community

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