Self-Management and Self-Management Support Outcomes: A Systematic Review and Mixed Research Synthesis of Stakeholder Views

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

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A b s t r a c t

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.

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.

- 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; McKevitt 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 psycho- logical 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. Particiipants were recruited by approaching eight community stroke support groups within a 50 mile radius of Southampton, five of which agreed to allow a researcher (EB) to introduce the study to members. Interested participants were invited to take part in a focus group discussion. Participants were recruited on the basis of socio-demographic variations, in terms of time since stroke, gender, age, ethnicity and level of impairment. This was desirable to reflect a broad range of experience. Focus groups took place in urban and rural areas. Participants were over 18 years of age, not less than three months following stroke, living in the community (but not in nursing or supported accommodation), able to understand English and possess sufficient cognitive ability to provide informed consent. Individuals with communication difficulties were not excluded; those with communication limitations were invited to nominate a person and/or use communication aids to support their participation.

2.4. Measures

The Barthel Index (Mahoney and Barthel, 1965), advocated as a measure of functional independence and physical functioning by the Royal College of Physicians (Royal College of Physicians, 2012) and used widely in stroke research (Quinn et al., 2011; Van Hartingsveld et al., 2006) was used to describe the range and functional abilities of the participants. The Index has a maximum score of 100, indicating optimum independence and function. Scores were assessed at recruitment.

2.5. Procedure

EB explained the purpose of the study – to explore their experiences of managing health and well-being following stroke – to potential participants at group meetings. Subsequent focus groups were held in the usual meeting venues (community halls) at familiar times, to minimise disruption to participants. Reimbursement for travel expenses was provided.

Focus groups were conducted by a registered nurse, trained in focus group methods (EB). An observer (external to research team) was present at each group to record non- verbal communication and additional notes (Kreuger and Casey, 2009; Morse et al., 2002). A semi-structured interview guide, developed following a literature review to identify concepts of potential relevance to stroke self- management, was adopted. Questions aimed to elicit participants' experience of self-management. Examples are illustrated in Fig. 1.

Discussions were digitally recorded. Confirmation was sought from participants with

communication limitations, in relation to comments made by nominees. Contemporaneous reflective notes were made following the conclusion of each focus group and incorporated into analysis (King, 2010).

2.6. Data analysis

Data analysis was conducted using thematic analysis. First, recordings were listened to and written field notes read several times, for familiarity with the content and

Tell me what you've heard about the term 'self-manage' or 'self-management' before?

How relevant do you think self-management is to someone who has had a stroke?

Tell me about the kinds of things you already do as part of self-management?

Fig. 1. Example interview guide questions.

context of the data. Data were transcribed verbatim. Participants, and any other identifiable information, were assigned pseudonyms. An overview of each group, including initial impressions, thoughts and reflections were noted. Codes were generated to describe the data in a literal sense (Mason, 2002).Transcripts were next re-read to identify relationships sufficient to constitute a similar category between the initial descriptive codes, (Gibbs, 2007) (e.g. 'requesting a referral and sourcing aids' become 'navigating resources'). Categories were considered in light of the context of the focus groups and themes identified (Green and Thorogood, 2009). Focus groups were analysed iteratively to enable a sense of emerging salient issues and to inform questioning for subsequent groups.

Analytic Induction (Frankland and Bloor, 1999) was used to assist interpretation of the data. Within Analytic induction, inductive reasoning allows for modification of concepts and relationships between concepts, the goal being to most accurately represent the situation under exploration. During early analysis, theoretical statements were constructed to explain the data, e.g. 'Motivation is required for people to carry out self-management activities' (Pascale, 2011). Statements were then modified and continually revised as analysis progressed, until they reflected the data as accurately as possible and anomalies could be justified. For example, motivation appeared to be affected by additional factors (e.g. responses of health professionals, access to resources to aid self-management). The term 'motivation' was also revised to 'determination', to reflect the language used by participants. The initial statement was thus revised to two hypotheses 'People require determination to navigate self-management resources' 'People's determination to self-manage may depend on the responses of professionals'. Transcripts and theoretical statements were discussed and agreed with co- authors to aid rigour. Data collection continued until saturation was reached, and no new facets of self- management were described.

3. Findings

Group size ranged from four to nine participants and ranged in length from 45 to 90 min. Thirty-one people, recruited from five different community stroke groups, expressed an interest in taking part. Two withdrew due to prior engagements, and one was excluded because of advanced dementia. Two focus groups (FG II and V), were conducted with younger cohorts of people recovering from stroke, (<65 years old). Table 1 illustrates the range of demographic and characteristics of the sample.

Table 1
Summary of characteristics of focus group participants.

	FG I	FG II	FG III	FG IV	FG V	Summary for all groups
No. of participants	9	4	4	6	5	28
Mean age [SD]	80.44 [8.09]	47.5 [8.22]	76.75 [5.56]	64.33 [7.68]	46.6 [7.98]	65.67 Mode 74
Male: Female gender	4:5	2:2	1:3	2:4	2:3	11:17
People with communication impairment	4	2	1	1	0	8
Mean duration since stroke (months) [SD]	83 [95.7]	23.5 [10.21]	43 [15.87]	76 [31.96]	50 [37.93]	57.89 [60.80]
Marital status						
Married	3	3	3	3	2	14
Single	1	0	0	0	0	1
Widowed	4	0	1	1	1	7
Living with partner	0	1	0	0	2	3
Divorced/separated	1	0	0	2	0	2
Mean length of formal education [SD]	13.4 [4.77]	10.5 [0.57]	10.5 [0.57]	11 [2.68]	13.4 [3.57]	11.89 [3.62]
Mean Barthel Index [SD]	76.1 [25.34]	76.25 [7.5]	75 [28.28]	80 [18.70]	87 [29.06]	78.70 [22.34]

Analysis revealed three themes that contribute to self-management following stroke; *Individual capacity, Support for self-management* and *Self-management environment*.

3.1. What 'self-management' means

To facilitate interpretation of the data, it was first necessary to understand what self-management meant to people following a stroke. The term 'self-management' was unfamiliar to most participants in all focus groups. This is perhaps unsurprising considering the term has evolved from the spheres of policy and professional practice and that only one participant had previously participated in a formal self-management intervention. When the term was explored, participant interpretations suggested that self- management was a way of maintaining independence and autonomy:

Researcher: *What do you think it* [self-management] *might mean?*

Felicity: *helping yourself, yeah*

Joy: *getting on and doing it yourself* (FG, IV)

'It's having the ability to look after yourself in the sense that you are able do things for yourself. . .' (Male, 56 yrs, Barthel 75, FG II)

'Well it's survival, isn't it? At the end of the day, you've got to get on yourself and do the best you can. . .I think you just try and be independent. Be it physically or mentally. . .' (Female, 71 yrs, Barthel 95, FG IV)

Self-management appeared to encompass coping, promoting recovery, and maintaining independence. The range of perceptions may partly be reflective of unfamiliarity with the term prior to the participation in the focus groups. Despite this, participants gave a range of physical, psychological and social activities they considered to relate to managing their health post- stroke:

'Coping with stuff like your finances and getting your own care. . .' (Female, 71 yrs, FG IV)
'It's like a day to day routine. How to help yourself and maybe improve your condition. . .' (Male, 45 yrs, FG II)

'It's about taking your pills . . ..' (Male, 77 yrs, FG I) Whilst the majority of participants

viewed self-

management as a positive notion, not all participants agreed. The participant in the extract below, who underwent a 6-week period of multi-disciplinary community-based rehabilitation, suggests that self-management is an implicit part of life after stroke, and something that does not necessarily require a new label:

Well, er [pause] *it's just that it* [self-management] *could be a load of rubbish [laughs] No disrespect, but. . . I mean it's just obvious stuff really. . .silly stuff, you know what I mean? Borders on being really patronising.* (Male, 45 yrs, FG II)

The range of interpretations of self-management voiced by participants highlight a current lack of common understanding regarding what self-management means to people after stroke, despite the term being largely familiar to health professionals and policy makers. Notwithstanding their lack of understanding of this term, participants were able to identify a range of influences on and experiences of what might commonly be classed as 'self-management'.

The next sections consider the three components that support or hinder stroke self-management as suggested by the data; *Individual capacity*, *Support for self-management* and *Self-management environment*. All themes are considered necessary for optimal self-management, with no one theme more important than the others. Analytic hypotheses to describe the data, derived from analytic induction, are first stated and then evidenced using data extracts.

3.2. Individual capacity

The data clearly identified that self-management behaviours were dependent on an individual's self- management 'capacity', which, in this context, refers to an individual's ability or readiness to respond to the demands of self-management following stroke. Individual capacity includes both the presence of skills which facilitate self-management and the absence of barriers. Participant accounts suggested that six key components, detailed in this section, affected individual capacity to self- manage.

3.2.1. Physical impairment

Analytic hypotheses: 1. People with stroke-related impairment experience more challenges to self-management than people without impairment. 2. Stroke-related impairment is not sufficient to predict people's capacity for self-management.

Many participants experienced physical impairments (e.g. reduced mobility, loss of limb function) as a consequence of stroke. These impairments not only resulted in the loss or limitation of previous physical, psychological and social activities, but also on their capacity to perform self-management by presenting practical barriers to accessing self-care support. The participant in the extract below, who was 3 months following her stroke, reported being given plenty of information relevant to self-management upon discharge from an acute stroke unit. However, she was unable to access it due to impairment, suggesting that the resources available for people following stroke to promote self- management are perhaps too generic and do not take account of individual impairment-related needs:

Do you know what I had, as well? I lost my sight. I couldn't even see a phone, let alone phone for help! (Female, 38 yrs, Barthel 100, FG V)

Some participant's impairments were such that they required assistance to perform essential activities of daily living and to facilitate self-management activities, such as performing exercises or practicing reading. In the face of limitations, participants reported that self-management often became more about developing a partnership with carers to enact self-management rather than being solely carried out by the individual. Such adaptation can be viewed as a self-management strategy and an approach to enhancing capacity to perform self-management.

The thing is, if I had to do it [washing and dressing]
myself, I'd be too tired (Female, 64yrs, Barthel 90, FG IV)

Impairment severity alone was not, however, sufficient to predict people's ability for self-management. One participant, who had no verbal speech and communicated during the focus group entirely through pointing at a communication book, writing short phrases and being given support by other group members, lived independently and did all of her own shopping by using public transport. This highlights how other areas of individual capacity, such as determination and communication skills can mediate the influence of impairment upon capacity for self-management, and may be of benefit to target in interventions designed to support self-management.

3.2.2. Self-confidence

Analytic hypotheses: 1. Confidence is important to self- management following stroke. 2. Self-confidence is important to individual capacity for self-management and can be facilitated by other people.

Self-confidence was important to individual capacity for self-management. Participants cited examples where confidence enabled them to engage in activities for self-management, or conversely, where a lack of confidence hindered people from engaging in self- management:

Rihanna: But, sorry [to researcher]*, people* [at the gym] *stare at me. Really really stare at me. and no, no. And erm, men you know stare at me*

Researcher: So how do you handle that, then? Frances: I don't care if people stare at

me Rihanna: well erm [pause] *I cry*

Clare [Rihanna's carer]*: In the summer holidays, with the school children, she wouldn't go at all* [to the gym] [FG II]

Self-confidence was enhanced from different sources such as professionals and support groups. Participants took inspiration from comparison with peers who appeared to be coping with circumstances perceived as worse than their own. However, comparison with peers did not always serve to increase confidence:

Sue*: I think this woman is wonderful* (indicates Margot, who has almost no speech, reduced limb function and is 86). *She does* (pause) *absolutely everything*

Flora: *yeah* (nods) and *she lives alone* (FG I)

But you know at least you're on your feet Rihanna. I'm not even walking with a stick or anything (Female, Barthel 70, FG II)

Reassurance from health professionals during scheduled appointments was also reported as enhancing self- confidence, highlighting the importance of the communication skills of health professionals:

You feel good when he (neurologist) *says how well I am doing* (Male, aged 45yrs, Barthel 75, FG II)

3.2.3. Decision-making

Analytic hypotheses: 1. The ability to be autonomous, and make decisions about self-management is vital to people following stroke. 2. People following stroke are required to make complex decisions about self-management. 3. People following stroke perceive that they are not always given adequate information to make decisions about self-management.

The notion of being an active decision-maker, not a passive recipient, appeared to be an important characteristic of a successful 'self-manager' following stroke. Self- management decision-making was reported as a complex process, frequently undertaken by individuals as they appraised and evaluated the cost or benefit of different options. The ability to make decisions was regarded as the keystone of self-management:

Ron: well, that's the thing, it's having the mind to be able [emphasis] *to control what you want to do and how you want to do it.* (Aged 83, Barthel 95, FG III)

It was apparent that the factors needed for good decision-making, such as adequate information and good communication skills, were often not ideal. For instance, participants, such as the female in the quote below, were asked to make important decisions, some of which had long-lasting consequences on their capacity to self- manage and impacted upon the long-term success of self-management, without necessarily being fully-in- formed of the implications of the decision:

> . . .*when I was in hospital, they* (physiotherapists) *said 'you can either work on your leg or your arm. We can't, we can't do them both'. . .No, so I thought, 'what do you want?' well I thought 'I'd rather be able to walk'. . .because I had two young daughters at home, I'd rather be able to walk, but not use my arm. Because I thought, you know I've still got one arm and I can faff about at home on me own, but there was walking I really wanted, because they said 'your brain can't cope at the time with trying to get your arm going and your leg at the same time'. They said 'we've only got this much time', so we concentrated on my leg.* (Female, aged 59, Barthel 65, FG IV)

The majority of participants felt that informed decision- making was not possible without appropriate information:

> *But I think, self-help, can only kick in, once you've had that initial support. If you then, if you start off by not getting that initial support, how do you find the way to self- help?* (Female, aged 59, Barthel 35, FG V)

Both adequate decision-making skills, and optimum conditions which enable people to make informed decisions, appear to be crucial characteristics that enhance individual capacity for self-management following stroke.

3.2.4. Determination

Analytic hypotheses: 1. Determination is important to individual capacity after stroke and to carrying out activities important to self-management.

Determination appeared to be valued by participants and important to the success of activities key to self- management. Determination helped participants to carry on with self-management activities:

> *Always in the back of your mind is 'well if this is going to help, I'll do it anyway', you know?* (Male, aged 52, Barthel 85, FG II)

> *So you know, I've always tried to be a bit of a fighter* [laughs, pause] *so when I did get up I was trying to walk round the ward, because you know I was paralysed on the right side because I'm left-handed. . .* [pause] *Well I think you have to, you have to put yourself through it. . .* (Male, aged 83, Barthel 95, FG III)

Determination appeared to be a way of creating order and control after stroke but often needed to go hand in hand with adaptation and flexibility:

> Teresa: *You've got to adapt the way you do things at home and maybe you have different you know gadgets to help you and that, or whatever it may be, you know. People say 'it must be hard that you've had a stroke' and I say 'it is hard, but. . .'*

> Joy: *You have to fight it*

> Teresa: *Yes, but it's like everybody else whatever they may have, you know every day is a challenge, but you've got to get through that day* (FG IV)

Some reported that finding the motivation to perform activities important to self-management was often difficult, required persistence and determination and entailed substantial work. Participants reported differing levels of determination for performing therapy exercises; in particular, some felt that trying to continue with exercises without any involvement from health care professionals was challenging, whereas others could sustain the effort despite difficulties:

> Frances: *you know if you are left day to day to your own devices, to do this that and the other every day, I think you can get lazy, don't you?*

Rihanna: *well, No, No* [shakes head in apparent disagreement]

Frances: *well maybe not lazy, but is very easy to say 'ah well, I don't know if I can be bothered to do that today'*

Rihanna: *I does er hand exercises, every night, urm no* [pause, looks up as if thinking] *no 30 minutes hand, every night. So, you know, and it's* [PAUSE] *pissing me off* [laughs]

3.2.5. Communication

Analytic hypotheses: 1. Good communication skills are vital to expressing needs and choices to health care professionals and family members. 2. Communication skills are required to feel informed regarding the treatment and management of stroke

Communication skills were identified as an important influence on individual capacity for self-management in order for the person affected by stroke to seek support and find out information:

You don't know what's going to happen (after stroke)*, and you don't know where it's going to go. So without actually talking with somebody who's actually had a stroke, you're at a loss* (Male, aged 43, Barthel 100, FG V)

Despite self-management being something participants undertook largely independently of health professionals, at times the input of professionals, family members and carers was required. To obtain this support, participants were required to have good communication skills. For example in being able to discuss appropriate management strategies with professionals:

I said 'I'm not sleeping too well' She [stroke nurse] *said 'er, try taking some paracetamol at night, you'll probably sleep better' and I thought 'nah, that don't work'.* [shakes head] *So I actually went back to my consultant at xxx* [hospital]*, and I said to her, 'look, I'm not sleeping too good, is that normal?' and she said 'it can be, but I'll refer you to a psychologist'* (Male, aged 46, Barthel 100, FG V)

Communication was often hindered by temporary or permanent impairment (e.g. aphasia). Dave, initially lost his speech after his stroke, and felt reliant on family members to communicate his needs. The following quote indicates how communication difficulties hindered Dave from expressing choices about self-care whilst in hospital:

Dave: *I couldn't. . . say anything. . .*

Sue (wife and carer of Dave): *He couldn't say anything*

Researcher: *Did you try to talk to any of the staff* [to Dave]*?*

Dave: *Yes! Because I . . .a bath and I couldn't get. . .them to put me in* (the bath)*. Me mate put me in* (the bath)*. . . in the end* [FG IV]

Speech impairments were not the only limitation to effective communication. Some people appeared unable or reluctant to question healthcare decisions and actions. This prevented them from being fully informed about treatment, to express their needs or to enact self-care:

I had a thing stuck in there (points to arm) for a week. Just a big thing, I don't know stuck in there for a week I
couldn't move it or even read [a book]*. . . but I didn't know what it was all about (pause) but it was probably to get some stuff in you quickly. . .I didn't want to ask.* (Female, aged 87, Barthel 60, FG I)

However, others demonstrated how good communication skills, along with determination to find an adequate answer to their concerns, could result in for patients' wishes being taken into account, suggesting that interventions focusing upon enhancing communication skills may be of benefit to self-management:

When I got to the appointment for the Botox, they turned round and said 'no, we're not gonna give it to you this time, but we haven't written you off' and I found that quite patronising, [moves arm in

sweeping gesture] *so said 'why not now? Either tell me I'm going to have the bloomin stuff or tell me to go', and they soon changed their tune!* (Female, aged 63, Barthel 70, FG II)

3.2.6. Finding resources

Analytic Hypotheses: 1. Resources needed to support self-management following stroke are difficult to identify and access.

The ability to identify and pursue appropriate resources appears to be a precursor to effective self-management. Participants used terms such as 'finding out information' and 'finding services', for example in relation to finding out about stroke specific exercise classes, or identifying which professionals were most helpful for specific issues. Often there was a sense of not knowing where to start seeking resources for self-management:

I think it would be good to hear about information that you can, er which I know that you can make your hand move much better. . .or your leg move much better. . .but unfortunately they are not available. (Male FG I)

There's kind of loads of that (information) *at the start, isn't there? But it all peters off basically and then you don't know where to go.* (Male, aged 45, Barthel 75, FG II)

Participants reported that once discharged from formal care, provision for stroke was rationed, often leaving them with feelings of uncertainty regarding how best to manage:

Because you just start getting there and it stops. And then you have to do it yourself, and you're not sure you're doing it the right way or wrong way. Because I couldn't walk 'til the end (of inpatient stay) *so I just had two sessions to walk up and down the pole. Then I was sent home, so I've had to sort of learn myself.* (Female, aged 67, Barthel 80, FG IV)

The timing and nature of information also affected how an individual responded to it. People reported that information was often provided too early in the process, often being given a large, un-tailored information pack on discharge from hospital. These were then discounted if they were not ready to receive it:

When it (stroke) *first happened, you know I was given all these leaflets* (about support services)*, and I just dismissed the whole lot. I thought 'I am not* [emphasis] *going out looking like this'. . .* [Female, aged 38, Barthel 100, FG V]

These findings highlight the importance of revisiting the provision of information and resources for self-management once people are no longer in receipt of formal stroke services.

3.3. Support for self-management

The study findings suggest that the term self-management can be misleading, implying that it is about what people do on their own to maintain their health and wellbeing. These data highlighted that appropriate support was crucial to the way in which people were enabled to self-manage. 'Support for self-management' refers to the collective elements that appear to be precursors to successful self-management. Three components of this theme were identified.

3.3.1. Role of professionals

Analytic hypotheses: 1. Involvement of health professionals after the acute phases of stroke is vital to successful self-management following stroke.

Health professionals were viewed as a key resource to support self-management.

I think you have to, you have to erm. erm rely on their (health professionals) *knowledge. You have to trust in them, don't you really and their experience, that they know what they are doing with you.* (Male, 56 yrs, Barthel 75, FG II)

People with stroke reported that healthcare professionals could enhance or hinder the way people engaged in self-management strategies, for example in how information was provided, or therapy goals were set. Support from professionals was vital for continued progress after stroke. The following extract suggests that it was not sufficient for professionals

to tell people what to do; people also wanted to know the justifications underpinning advice:

> *You know how important it is to keep doing things, coz they* [physiotherapists] *just tell you to do it, but they don't tell you why. I think that's one of the most important things to change for people coming out* [qualifying as a health professional]. (Female, aged 67, Barthel 80, FG IV)

Self-management thus appeared to be more than passive adherence to recommendations, instead being an active process that required understanding of the rationales behind treatment recommendations and a concordance between professionals and patients. Paradoxically, many participants still felt the need for formal sanctioning from health professionals for activities related to self- management and professional support was seen as important for ensuring correct engagement in the 'right' self-management practices. For example, questioning the point of continuing exercises if performed incorrectly and the perception of potential harm, or deterioration without professional guidance:

> *She does all this stuff herself, but often it will really hurt. You know perhaps a physio could say 'strap this up and do it like this' or whatever, but instead she doesn't know how far to go and she ends up over-doing it and having tendonitis or some associated thing when really You need the guidance. She could be laid off for a few weeks and go backwards.* [Relative of aphasic participant, FG II]

> *If you're doing it in your own way, you're probably doing it wrong* [Female FG IV]

Participants needed to feel confident in the skills of professionals and their ability to provide support or to sign-post them to appropriate resources. Some participants suggested that some professionals lacked the skills (in the example below, an apparent focus upon physical status), empathy or perhaps resources and time, necessary to support self-management:

> *I think a lot of the problem is, that a lot of the nurses and that that come out to you, they're sort of like programmed that a stroke is a stroke, but everybody's* [stroke] *is so different to one another. . .But they don't seem to have the time, or the ability. I had the stroke nurse came out to me once* [emphasis, pause] *and she looked at me and said 'oh you're back at work then' I said 'yeah' and that was it. Never came back again. I was going through such like psychological problems.* [Male, 43 years, Barthel 100, FG V]

3.3.2. Resources

Analytic hypotheses: 1. People following stroke express the need for resources to support their self-management, such as equipment, professional advice and expertise and therapy. 2. People following stroke perceive current resource provision to be inadequate and difficult to access. Many participants reported that the support they had anticipated was not available, be it a lack of therapy, lack of equipment or difficulty in arranging appointments with appropriate professionals. The data raised questions regarding the adequacy and quality of existing resources to facilitate self-management.

> *I think the follow-up, I think in general the follow-up to stroke sufferers is diabolical.* (Female, aged 82, Barthel 95, FG III)

Attempts to seek resources entailed substantial work and resulted in feelings of uncertainty and frustration:

> *If it's going to help, I'll try my best', you know? I waited and waited a couple of weeks to hear back from xxx* [therapist] *or the xxx* [rehabilitation centre] *and not a word, so I phoned the receptionist. . .and she says 'well, you'll have to get to yer GP and get a new referral to whoever is taking over'. So, I did that, waited three weeks, to get to see my GP and not a thing. I don't even know where this piece of equipment is supposed to be coming from.* (Female, aged 63, Barthel 70, FG II)

Many participants felt abandoned by services following the end of formal care. Participants found the intermittent provision or limiting of services without adequate explanation unsettling and frustrating. In response to dissatisfaction with their experiences, participant accounts reveal how they often sought their own resources. This is arguably a self-

management strategy, although may be associated with additional burden for the person affected by stroke.

> Jim: *Things could've got better ages ago if they'd carried on with physio, but they just stopped it. Then they started it again with a different one* [physiotherapist]*, and after I just got used to it, they stopped it again. Now I've found me own, it's going along all right again.* (Male, Barthel 55, aged 62, FG IV)

The findings highlight that the resource-related barriers to enabling people to self-manage may originate from health systems and provision in the context of finite resources.

3.3.3. Role of carers

Analytic hypotheses: 1. Informal carers are important to the self-management of people following stroke. 2. Informal carers may limit self-management opportunities by undertaking self-management activities on behalf of the person affected by stroke.

'Carers' refer to those individuals who provide formal (from social or third sector organisations) or informal (usually family members or friends, often unpaid) care. The role of informal carers was applauded by all participants and identified as crucial to supporting self-management. Informal carers often provided personal care, emotional support, plus practical support to enable a person to engage in important self-management strategies, and were often, therefore, crucial to stroke self-management. Often, carers acted as advocates for the person affected by stroke, particularly in light of stroke-related impairment:

> *And when we did finally get someone to come out, they said 'you can have a ramp, but we won't know until April whether we've got the money, and then we'll have to get a builder in'. And this was November. So you know she'd've been stuck indoors all that time. So we built ramps ourselves, and all the handrails.* [Husband of aphasic participant, FG IV]

People did not always view self-management as being about the individual, but about the family unit managing health together, a characteristic important to consider in different approaches to self-management support. Engaging support from carers can be viewed as a strategy to assist self-management:

> *Well not so much the self* (pause) *But erm you can't* (sighs) *no I can't, I don't do* (pause) *meds* [sorting out medication] (pause) *my wife has to do that* (Male, aged 77, Barthel 100, FG I)

The focus group conversations suggest that there was a tension about whether 'doing it all yourself' was the best way to self-manage or whether an active decision to use carer support was also part of self-management. The examples below illustrate the intricate interplay that can ensue and reflects the tensions faced by people following stroke in deciding whether to continually push themselves, or to sometimes make life easier.

> *Every time they* [formal carers] *come in I have to tell 'em what to do* (laughs from others) *So I give up!* (more laughs) *however* (shrugs) (Female, Barthel, 60, lives alone, FG I)

> Researcher: *Would you like to be doing more yourself?*

> John: *I do agree, I can do some of it* [washing and dressing] *myself. But it's quicker, and I like to be on time, regardless of where I've got to be* (Male, lives with spouse, Barthel 65, FG IV)

That carers can potentially facilitate or hinder self- management, highlights the complex nature of stroke- related impairment and the impact of stroke upon family structures.

3.4. Self-management environment

Participant accounts suggest that neither individual capacity nor support for self-management were sufficient to self-manage effectively; an environment that is supportive of self-management is also required. In the context of the findings, environment refers to the additional circumstances necessary, beyond the individual, family and health service, for self-management to be successful.

3.4.1. Others' response to impairment

Analytic hypotheses: 1. People following stroke wish to feel accepted and integrated back into community life. 2. Negative responses of others towards stroke-related impairment dissuade people from pursuing self-management activities, whilst positive responses enable people to feel more confident about self-management.

Returning to 'normality' following stroke appeared to be an important self-management goal for many participants. The female in the extract below reflects on a need to seek environments that are not focused upon stroke in order to feel 'normal':

> *Work is very important. Because I go there, and don't always talk about strokes. We talk about everyday things, your family, what you're doing at the weekend, it's not all strokes.* [Female, aged 59, lives with dependents, FG IV]

Stroke-related impairment is often visible to others (although the causes underlying the impairment may be unknown). How impairment is perceived by others within the community impacted upon peoples' ability to self- manage. Participants discussed how the negative responses of others impacted on them carrying out strategies important to self-management:

> Tim: *One lady in XXX* [community centre] *up here, she just thought I was drunk because of the way I walk, that you know was her thing, she didn't think about anything else it could be.*

> Researcher: *How did that make you feel?*

> Nathan: *Embarrassed!*

> Tim: *It made me want to leave* (FG II)

Conversely, positive experiences encouraged people to feel more integrated into the community and/or to pursue self-management activities in public environments. The response from the community appeared important to promoting individual confidence to self-manage, and to enable individuals to feel valued. While reactions to impairment from others may not be easy to modify, interventions may wish to focus on enabling people with stroke to learn how to cope and manage negative reactions.

3.4.2. Political influences

Analytic hypotheses: 1. People following stroke are aware that political influences affect self-management resources. 2. Political influences are used by people following stroke as a way of rationalising reduced access to self-management resources.

Participants did not explicitly refer to politics or policies (nor were explicitly asked about them). However, participant accounts often made reference to issues which could be viewed as operating within a political arena. For example, the perception of a lack of access to treatment, technology or stroke services:

> Sharon: *You have to press* [for referrals]*, don't you?*

> Clive: *That's right*

> Sharon: *That's what's wrong though, you are always having to push* (FG V)

Where there was a perception of limited services/ resources, participants reported that emphasis was placed on them to actively develop and engage in their own self-management strategies, potentially creating additional burden. Some participants could be said to have become activists in promoting self-management:

> *It's a case of, so this whole self-help, self-management thing, I think is a great thought* [pause]. . .*because that's what we're* [people following stroke] *doing already, but I think it's been executed pretty badly because there is nothing out here. Which is why we've set up this group* [stroke club] (Male, aged 43, FG V)

Some participants reflected more overtly on the political context of self-management, in that self-management can be viewed as a way of encouraging the person affected by stroke

to take responsibility for their health, (although it was not possible to tell if the participant in this extract was critical of this view or not):

> *yeah, I suppose you should've* [emphasis] *done it yourself. The government would say 'help yourself'* (Male, Barthel 100, aged 46, FG V)

Overwhelmingly, participants were frustrated with the current state of support for self-management, and felt that 'decision-makers' and politicians had the ability to improve this.

3.4.3. Peer support

Analytic hypotheses: 1. Peer support is important to self-management and is gained from a range of sources such as stroke clubs, work, friends and interests. 2. Stroke clubs enhance self-management by creating an environment that acknowledges a shared experience of stroke.

Participant accounts suggested that peer support contributed to an environment which fostered self- management. Peer support appeared to be drawn from different guises. Attendance at stroke clubs was recognised as a useful source of peer support. This appeared, in part, to be from being in an environment that acknowledged a unique shared experience which encouraged and enabled people to try new management strategies:

> Tim: *Hopefully you can come here* [the stroke group], and see people's improvement over time. . .*that will hopefully encourage you to do stuff as well, so you know.*

> Nathan: *Well, coz they actually know what they're on about* [someone who's experienced a stroke] [FG II]

The groups also provided opportunities to collectively engage in activities that could enhance self-management:

> *well we've* [the group] *done a sponsored walk. We did one last year, we did a good one last year didn't we?* [Group organiser, Barthel 95, FG IV]

The nature of the groups also provided support for decision-making in relation to health care and self- management and provided impetus to take healthcare actions:

> Macy: *I've moaned about this eye, since it* [stroke]
> *happened. My eye is not right*

> Alex: *You should phone them up, get the GP* [family doctor] *to refer you*

> Clive: *There's your self-help there, like we were saying!*
> [laughs] (FG V)

Participants often accessed organisations for them- selves, which may be viewed as a self-management strategy. However, the need to find out about such services independently was often accompanied by a sense of frustration and created additional burden:

> Sue: *But at least now* [we've joined a charity support group] *he's* [husband with aphasia] *having regular exercises of two hours a week. . ..but you know that's having to go outside of the NHS* [looks to ceiling, appears exasperated]. . ..*obviously couldn't afford it privately* [looks to ceiling] *uhmm, but under the XX* [charity] *banner. . .*

> Teresa: *But you had to do that yourself, did you? You had to find all that yourself?* [FG IV]

4. Discussion

This study focused on the key elements which contribute to stroke self-management. Self-management from the perspectives of people with other long-term conditions has previously been considered (Corser and Dontje, 2011; Kielmann et al., 2010; Söderhamn et al., 2011), but to date the perspectives of people with stroke has not been specifically explored. This research then constitutes the first exploration of stroke self-management and the factors which facilitate and hinder it from the patients' perspective.

We propose that stroke self-management consists of three conceptual layers all with equal importance to optimal self-management following stroke; *Individual capacity*; *Support for self-management* and *Self-management environment*. Each component has the potential to facilitate or hinder successful self-management. The absence of any one component may limit an individual's success at self-management, or may mean that other components are required to a greater extent to promote self-management. For example, in the presence of impairment, access to resources and confidence to seek them, may become more predominant components to enable self-management.

Our findings highlight the importance of additional factors, *Support for self-management* and *Self-management environment*, as well as the components which may be considered to focus on the individual *(Individual Capacity)*, for stroke self-management. This is resonant of the Chronic Care model (CCM), based on the premise that effective long-term condition management programmes are delivered in partnership with health systems and communities (Bodenheimer et al., 2002b). The Flinders model advocates 'systemic and organisational change' and 'Health professional change' in order to provide effective self-management support (Battersby, 2014). Similarly the more recent WISE model (Whole system Informing Self-management Engagement) advocates that self-management cannot be separated from an individuals' socio-cultural environment, health services, family and the wider community (Kennedy et al., 2007). The findings resonate with the social ecological model (Bronfenbrenner, 1979) which posits that the environment is inextricably linked to human well- being. Similar to our findings, Bronfenbrenner's model consists of several 'layers', with the individual placed centrally (resonate of the theme of individual capacity) to social–structural levels, such as social (resonant of the theme of support for self-management), institutional and

cultural contexts (resonant of self-management environment). In contrast, the predominant Stanford model (Lorig et al., 2001) does not focus upon the role of societal or health systems support, instead concentrating upon the individual developing self-management strategies.

The contribution of social influences on health may not currently be adequately acknowledged in existing self- management support (Paterson et al., 2001; Taylor and Bury, 2007; Vassilev et al., 2011; Wilkinson and White- head, 2009). Participants in our study overwhelmingly reported that the level of resources and services following stroke did not meet their self-management needs. Self- management was hindered by a lack of resources and access to appropriate professional support. System related barriers to self-management and feelings of abandonment by health services have been reported by people with respiratory conditions (Kielmann et al., 2010). Similar support system failures have also been documented in stroke (Hart, 2001). Harts' study highlighted how failures thought, from a medical model perspective, to be due to patient factors such as 'lack of motivation', were actually a failing of the health systems themselves. A paradox then exists between the increased policy focus upon self- management, and the reality that the support and resources to enable patients to effectively self-manage following stroke are largely absent. Questions exist for future research and practice with regard to how the "self", in self-management, should be perceived by stroke services and providers. Current conceptualisations of self-management focusing upon the role of the individual in managing their long-term condition (Bandura, 2005; DoH, 2010; Lorig et al., 2006), appear inappropriate for stroke self-management. That carers are vital to stroke self-management is an important finding. The impact upon informal care-givers following stroke, and how they facilitate self-management, remains largely unexplored and represents an important avenue for future research and clinical practice.

Even within a focus on the individual alone as responsible for self-management, the factors reported in this study which contribute to successful stroke self- management may have been under-represented in previous research. Improvements in physical function (PF) are most often assumed to be indicative of successful stroke self-management (Boger et al., 2013), however, the degree to which PF relates to, or is indicative of self-management following stroke has not been clearly articulated. Our findings suggest that PF does impact on the ability to perform self-management; poor function presented practical barriers to performing activities important to self- management. However, PF was not the only arbitrator of successful self-management. Our data suggested that people

with impairment were able to self-manage effectively, if they had the right support (from informal or formal sources) skills and attributes (such as confidence and determination). Such interpretations of impairment should be considered in the design and evaluation of future stroke SMIs.

Aside from PF, self-efficacy has also been considered an important factor both in stroke self-management (Jones et al., 2013; Lennon et al., 2013) and other long-term conditions (Brady et al., 2013; Yoo et al., 2011). Our findings suggest that self-efficacy, or *confidence* as expressed by participants, is an important component of individual capacity for self-management. However, the findings imply that self-efficacy alone is not a sufficient intermediary of stroke self-management, identifying that other attributes such as decision making, communication skills, determination and finding resources were also valued and contributed to individual capacity for self- management. The identification of these additional factors, valued to people following stroke, is important since, to date, these have not been specifically targeted or measured in stroke self-management interventions (SMIs) (Boger et al., 2013). All represent new areas for researchers and clinicians to target in future interventions.

The implications for health services in relation to individuals unable to self-manage to their full potential are yet to be quantified, but may include a general decline in health, including physical and emotional well-being, leading to a continued demand on health and social services, and a risk of further complications. Despite policy direction which supports self-management, and aims to foster equal sharing of power and decision-making between health professionals and patients (Battersby et al., 2010; DoH, 2008; Ministry of Health and Long- Term Care, 2007), the experiences of participants in this study show that the promotion of self-management following stroke may still appear to favour professional and health system agendas, similar to the findings of others (Norris and Kilbride, 2014). Our data indicate that currently, support systems and healthcare structures may not meet the expectations of individuals to give genuine choice following stroke. In addition, our findings highlight that the term 'self-management' was unfamiliar to people following stroke and was not viewed as uniformly positive. Some participants expressed the view that self-management implies trying to cope independently in the absence of alternative adequate support, a view also expressed elsewhere (Demain et al., 2013). As such, it should be acknowledged that self-management may be viewed as a pejorative term by some individuals. The future use of the term self-management should be adopted with caution, according to context.

This study is not without limitations. The strategy of sampling via stroke support groups may mean that the views of participants who demonstrate effective self- management skills are over represented. Alternatively, it may be that people who do not attend stroke groups are successful self-managers, and therefore do not seek additional support. Nonetheless, participants contributed perceptive and reasoned comments about their experiences of self-management. Participants in the focus groups knew each other. As such they spoke within a specific context, of being an established group, meaning the data may have been influenced by pre-existing group dynamics. The inclusion of carers, in three of the focus groups, may have affected the data by influencing how other participants responded, or by limiting the extent to which the direct views of people with communication impairment were captured. However, without their inclusion the views of people with communication impairment, an under-represented group in stroke research, would have been difficult to elicit. Participants in this study spoke within the context of being in a group. It is possible that social desirability affected expression of certain individual perspectives and hence the data does not represent every facet of stroke self-management. Given the potentially sensitive and complex nature of stroke self-management, individual interviews may be helpful to further develop understanding of self-management in stroke. Finally, the sample was not ethnically diverse. As patient experience of self-management may be affected by ethnicity and cultural background, further studies are required to assess appropriateness of the findings for cross-cultural transferability.

5. Conclusions

This study has implications for the discourse around self-management support for stroke and related policy initiatives. We developed a new understanding of stroke self-management informed by perspectives of those affected. We argue that this perspective needs to be considered in the design of future interventions and services aimed at providing people following stroke and their families with support for self-management. The themes identified in this study can assist the development of effective interventions; the identification of outcomes and patient-reported outcome measures which are patient-centred to assist evaluation. Such interventions and outcome measures must represent the complexity of stroke self-management by including appropriate issues and items which have relevance to people with stroke.

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