

A qualitative exploration into the concept of service users as ‘Physical Activity Champions’ to support stroke survivors participate in community based exercise.

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Authorship Declaration

I, Gillian Hutton confirm that this thesis is entirely my own work and has been produced by me as the result of my own original research.

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Abstract

Background

Peer support can facilitate exercise following stroke however limited evidence exists in relation to incorporating individual peer support interventions. A possible method of providing individual peer support in a community based exercise programme could involve the concept of 'Physical Activity Champions' (PAC). This could involve individuals who have completed an exercise programme providing one to one peer support to other, newly referred stroke survivors however exploration of this concept is needed.

Aim

The aim of this study was to explore the concept of PAC with stroke survivors and professionals involved in a community based exercise programme.

Methodology

This was a qualitative study based upon a grounded theory approach. A purposive sample of six stroke survivors and three exercise professionals participated in the study undertaking one to one semi-structured interviews and a focus group respectively. The data collected were transcribed and analysed through initial and focused coding allowing key messages to be identified.

Results

Three key messages and subsequent sub-messages were identified. These were: 'Benefits of peer support' with sub-messages of 'fear of the unknown' and 'all in the same boat'; 'Thoughts on the role' with sub-messages of 'a good idea but not for everyone', 'the right person', 'the job they could do' and 'say it as it is'; and 'The sooner the better'. The PAC concept was found to benefit stroke survivors through psychological and peer support. Information on aspects of the PAC role and its clinical application were also highlighted.

Conclusion

The study offers suggestive evidence supporting the concept of individual peer support provided by a PAC in a community based exercise programme for stroke survivors.

Further clinical evaluation and research would however be required to investigate and evaluate the concept once implemented.

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Abbreviations used

- **PAC:** Physical Activity Champion
- **EAS:** Exercise After Stroke

Chapter 1: Background

1.1: Introduction

Stroke is a significant global health care issue (Brogardh and Lexell, 2012; Galvin et al, 2009). Worldwide, 15 million people a year suffer a stroke (World Health Organisation, 2004). In the UK, there are approximately 115,000 strokes every year (Feigin et al, 2014). The effects of stroke include a range of neurological deficits resulting in stroke being a prominent cause of long-term disability, with stroke survivors often having reduced levels of functional independence (Billinger et al, 2014; Mead and Bernhardt, 2011). The impact of stroke is therefore significant, with the estimated economic costs of stroke in the UK being around £9 billion a year (Saka et al, 2009). Supporting the recovery of stroke survivors is therefore essential and this includes ensuring long-term support is provided to optimise the quality of life of people living with stroke (Scottish Government, 2014).

1.2: Stroke and physical activity

A key area of long-term support is encouraging stroke survivors to participate in various types of physical activity (Scottish Government, 2014). Internationally, the World Health Organisation (WHO) and European Stroke Organisation (ESO) guidelines recommend regular physical activity to reduce the risk of stroke (WHO, 2004; ESO, 2008). In addition, the American Heart Association/American Stroke Association Recommendations (Billinger et al, 2014) promote physical activity following stroke. Within the United Kingdom several clinical guidelines exist which aim to promote physical activity following stroke. These include: Scottish Intercollegiate Guidelines Network (SIGN) (2010); National Clinical Guideline for Stroke (Intercollegiate Working Party, Royal College of Physicians, 2012); and the Scottish Government's 'Stroke Improvement Plan' (Scottish Government, 2014). These guidelines consistently recommend that stroke survivors should be encouraged to engage in physical activity and suggest that services, including stroke specific exercise programmes, should be available to help facilitate this.

The recommendation that stroke survivors should participate in regular, long-term physical activity is due to the recognised physical and functional benefits (Morris et al, 2012). Indeed, literature including clinical guidelines, structured literature reviews and randomised controlled trials exist supporting the feasibility of exercise training for

ambulatory stroke patients and the benefits of exercise following stroke (Billinger et al, 2014; Mead et al, 2007; Morris et al, 2012). The evidence highlights that physical fitness training can improve aspects of physical function such as functional capacity, exercise ability, walking and balance (Billinger et al, 2014; Mead et al, 2007; Saunders et al, 2013). Exercise training has also been shown to benefit functional ability improving stroke survivors' ability to perform activities of daily living and aiding quality of life after stroke (Billinger et al, 2014; Poltawski et al, 2015). Furthermore, regular physical activity reduces the risk for subsequent cardiovascular events, promotes recovery and is beneficial to an individual's general health (Billinger et al, 2014; Morris et al, 2012; Poltawski et al, 2015).

Despite this evidence, there is an awareness that stroke survivors do not undertake regular physical activity and indeed, often display reduced levels of physical activity following stroke (Billinger et al, 2014; Mead and Bernhardt, 2011; Rimmer et al, 2008). Recent research has therefore focussed on gaining an understanding of the reasons for this lack of activity through exploration of the barriers and facilitators to exercise following stroke (Nicholson et al, 2014; Rimmer et al, 2008). A variety of barriers have been highlighted in the evidence relating to both environmental and personal factors (Morris et al, 2012; Rimmer et al, 2008). Environmental barriers include transport requirements, lack of access and cost (Jurkiewicz et al, 2011; Nicholson et al, 2014) whereas personal factors include lack of time, lack of control and lack of motivation (Jurkiewicz et al, 2011; Nicholson et al, 2014; Rimmer et al, 2008). The literature has however also identified facilitators and motivators that may help people to undertake exercise following stroke (Damush et al, 2007; Nicholson et al, 2014; Poltawski et al, 2015; Simpson et al, 2011). Some commonly reported perceived motivators include high self-efficacy, the beliefs and benefits of exercise, the necessity of routine behaviours and planned activities to fill an empty schedule (Damush et al, 2007; Nicholson et al, 2014). Social support from family, friends, exercise instructors and healthcare professionals has also been shown to facilitate physical activity following stroke (Damush et al, 2007). In addition, social support has been illustrated as a beneficial aspect of stroke specific community based exercise groups (Damush et al, 2007; Patterson and Ross-Edwards, 2009; Reed et al, 2010; Simpson et al, 2011). Consideration of the barriers and facilitators to exercise following stroke is therefore a key aspect in encouraging stroke survivors to engage in physical activity. Furthermore,

interventions which address the barriers and facilitators to exercise such as social support and community based exercise programmes will provide a vital means of supporting exercise following stroke.

1.3: Social support and peer support

Social support has been identified as an important facilitator to exercise following stroke. Indeed, social support involving social relationships are widely associated with health and well-being (Boothroyd and Fisher, 2010; Dennis, 2003; Parry and Watt-Watson, 2010; Ravenek and Schneider, 2009). Social support is considered to involve an exchange of resources between people, occurring within an individual's social network (Funnell, 2010; Hildingh et al, 1995). The resources provided by others can be in different forms and include emotional support, instrumental support, appraisal support and informational support (Colella and King, 2004; Funnell, 2010; Hildingh et al, 1995;). Social support and social relationships have been identified as beneficial in a variety of long-term conditions (Boothroyd and Fisher, 2010; Dennis, 2003; Hildingh et al, 1995). This is due to the positive effect on health, with social support influencing psychological adjustment and facilitating recovery from chronic disease (Colella and King, 2004; Parry and Watt-Watson, 2010).

A specific type of social support is peer support. Peer support involves the provision of support by an individual who shares similar characteristics and knowledge gained through shared experiences (Colella and King, 2004; Dennis, 2003; Parry and Watt-Watson, 2010). A peer is therefore able to provide their own experience of managing a disease. This enables individuals to better relate to peers as they can identify with each other's feelings and experiences (Clark et al, 2012; Colella and King, 2004; Funnell, 2010). Similar to social support, peer support incorporates emotional, appraisal and informational support (Dennis, 2003). Emotional support includes empathetic interaction as a peer can express encouragement and re-assurance which can subsequently improve self-esteem and confidence (Dennis, 2003; Parry and Watt-Watson, 2010). Informational support from a peer can increase knowledge and coping through the provision of advice and feedback (Dennis, 2003; Parry and Watt-Watson, 2010). Finally, appraisal support involves communication that can re-assure individuals that their emotions, thoughts and behaviours are appropriate (Dennis, 2003). Peer support can therefore benefit individuals psychologically (Funnell, 2010).

It can help individuals to cope with their situation and also support them with behaviours needed for positive health change and condition management (Clark et al, 2012; Colella and King, 2004). In addition, peer support can benefit service delivery as it has been shown to be accessible, cost-effective and efficient (Boothroyd and Fisher, 2010; Clark et al, 2012). It is therefore a method that can complement and enhance health care services, resulting in it being a key aspect of quality health care delivery (Boothroyd and Fisher, 2010; Dennis, 2003).

Providing peer support in health care can be achieved through a variety of different interventions, including support groups, individual interaction and online communities (Dennis, 2003; Richardson et al, 2010). Peer support interventions have been found to be beneficial in a variety of conditions such as diabetes, cancer and cardiovascular disease (Boothroyd and Fisher, 2010; Parry and Watt-Watson, 2010). In particular, peer support delivered through group intervention has been found to be a successful support strategy in the cardiac population (Hildingh and Fridlund, 2004; Hui et al, 2006). Similarly, within the stroke population, peer support has been identified in relation to the support obtained through group interventions (Damush et al, 2007; Patterson and Ross-Edwards, 2009; Schouten et al, 2011). The social interaction from the group intervention has been identified as a facilitator to exercise with stroke survivors reporting that meeting other people with stroke provided psychological and social support (Nicholson et al, 2013; Nicholson et al, 2014). More specifically, the opportunity to interact with fellow stroke survivors has been highlighted as a potential motivating factor to exercise (Damush et al, 2007; Simpson et al, 2011). Individual peer support interventions have been found to be beneficial in maintaining and improving physical activity levels in patients with heart disease (Clark et al, 2012), spinal cord injury (Latimer-Cheung et al, 2013) and following cardiac surgery (Parent and Fortin, 2000). Previous research with the stroke population has suggested individual peer support strategies to support exercise such as a “buddy system” (Kopunek et al, 2008, pp499) or “buddying support” (Morris et al, 2012, pp18), however this has not been investigated further in patients with stroke. Further research is therefore essential to investigate individual peer support and it is this area that the current study will focus on.

1.4: Current services supporting exercise following stroke

Applying the evidence and recommendations supporting stroke survivors to exercise is therefore an important aspect of service delivery. This has been undertaken through the implementation of community based exercise after stroke services (Mead and Bernhardt, 2011; Nicholson et al, 2013). In Edinburgh and the Lothians there is a well-defined exercise pathway for stroke survivors. This pathway includes an evidence based, stroke specific community exercise programme; ‘Exercise After Stroke’ (EAS) (Lothian stroke managed clinical network, 2013). This programme was established to allow evidence based exercise to be provided to stroke survivors by a stroke trained exercise instructor within the leisure service. The Edinburgh service runs through collaboration between the NHS and a council leisure provider and requires exercise referral to be made by healthcare professionals. The class is specific to stroke survivors who may present with a variety of stroke related impairments. Due to this, the class is facilitated by a specialist exercise instructor which allows individuals to be supported in the class. The service is continually being developed with methods to increase uptake and improve public engagement with the service being considered. This development includes the consideration of methods to incorporate individual peer support within the service. It was recently proposed that recruitment of individuals to undertake a peer support role may be beneficial to recruiting stroke patients and providing ongoing support and motivation to take part in EAS. It was suggested that this could involve incorporating individuals who have completed the programme as possible ‘Physical Activity Champions’ (PAC), individuals who could ‘buddy’ or ‘mentor’ other stroke survivors who have been newly referred to the programme. It is thought that this concept might offer a sustainable method to positively develop the EAS programme however further research is required. Therefore, the current study aims to investigate the concept of a PAC with stroke survivors and exercise professionals involved in the EAS programme. The study will explore individual’s views on the concept enabling increased information to be gained regarding individual peer support being incorporated within a stroke specific community based exercise programme.

1.5: Summary

Interventions which support stroke survivors to exercise are therefore an essential aspect of promoting long-term recovery following stroke. The incorporation of

individual peer support within stroke specific exercise groups may provide a positive intervention facilitating exercise following stroke. More specifically, the concept of a PAC has been suggested as a method to implement individual peer support within an established community based exercise programme. This concept however requires further research thus justifying the focus of the current study. In addition, a systematic review of the literature is required in order to analyse the current evidence relating to the use of peer support facilitating exercise following stroke and is presented in chapter 2.

Chapter 2: Literature Review

2.1: Introduction

The purpose of the literature review was to determine whether peer support has been used to support stroke survivors to exercise. A systematic review of the literature was undertaken with the aim to analyse literature that had incorporated peer support in stroke rehabilitation. The results identified studies that highlight group peer support (Amarshi et al, 2006; Patterson and Ross-Edwards, 2009; Reed et al, 2010; Schouten et al, 2011; Simpson et al, 2011) and recommend peer support for supporting stroke survivors to exercise (Blonski et al, 2014; Damush et al, 2007; Kopunek et al, 2008). However, no studies were identified that specifically investigated individual/one to one peer support and exercise within the stroke population.

It was therefore necessary to further investigate the literature around individual and group peer support in other clinical conditions. A subsequent literature search was undertaken with the focus on cardiac conditions and peer support. Cardiac conditions were deemed relevant due to similarities with stroke in relation to vascular co-pathology, identified risk factors and need for secondary prevention. In addition, exercise is a key focus for management within the cardiac population and group exercise is commonly undertaken (Clark et al, 2012; Hui et al, 2006). These aspects of cardiac rehabilitation are therefore similar to aspects of stroke rehabilitation thus justifying its inclusion in this literature review. This review found some studies in relation to peer support and cardiac conditions. A literature search was also undertaken with the focus on other neurological conditions and peer support. Neurological conditions were chosen due to their complex presentation and long-term nature, characteristics which are similar to that of the stroke population. In addition, exercise is a common constituent in the management of neurological conditions (National Institute for Health and Care Excellence (NICE) (2006); National Institute for Health and Care Excellence (NICE) (2014). This aligns with the stroke population and justifies the relevance and inclusion of this clinical group. The incorporation of literature searches within stroke, cardiac and neurological conditions, in relation to peer support and exercise, ensured that a thorough and comprehensive search of relevant literature was achieved.

2.2: Methods

2.2.1: Literature review objective

The question this literature review aimed to address was: Has peer support been used to support exercise within stroke, cardiac or other neurological conditions?

The objectives of the review were to investigate:

- The definition of peer support and the types of peer support used.
- The type of exercise peer support is applied to.
- The attitudes towards peer support.
- The feasibility and efficacy of peer support to facilitate exercise.

2.2.2: Search strategy

2.2.2.1: Databases searched

A search of academic databases Medline, CINAHL (Cumulated Index to Nursing and Allied Health Literature), AMED was last searched on 26 November 2015. Additional databases of PubMed, Cochrane Library and PEDro (Physiotherapy Evidence Database) were also searched for stroke literature. As the review focused on clinical conditions, it was anticipated that the research of interest would be found mainly within clinical journals which would therefore be captured within these clinical databases.

To increase the likelihood of identifying all relevant studies the reference lists of relevant articles and systematic reviews were searched to ensure any additional useful references were captured. Furthermore, if several included articles were by the same author, an author search was undertaken to identify any further published research by that author not identified in the electronic search. Finally, for sensitivity and precision, hand searching of two years of key journals relating to rehabilitation was undertaken to ensure the articles found from the online search match those found by hand. The journals selected were 'Disability and Rehabilitation' and 'Clinical Rehabilitation'. This aimed to ensure that a high level of sensitivity and precision had been achieved within the literature search.

2.2.2.2: Inclusion and exclusion criteria

The inclusion criteria for this review were: adults; male or female; aged 18 years and over; English language articles only; published literature only; quantitative or qualitative research (any study design); systematic reviews; human studies; participants with stroke, cardiac conditions or other neurological conditions for the stroke, cardiac or neurological searches respectively.

The exclusion criteria were: subjects aged under 18 years; not English language and unpublished literature including conference proceedings and letters due to the lack of reporting detail.

2.2.2.3: Search terms

Three search terms were selected for the stroke search: 'Stroke'; 'Exercise'; 'Peer Support'. For the cardiac and neurological searches, the key word 'Stroke' was replaced with 'Heart' and 'Neurological' respectively. These search terms were chosen as they reflected the relevant clinical population and the focus of interest. For the purpose of the literature review peer support was defined as support provided by individuals with a similar clinical diagnosis through either one to one contact or in a group setting. This was based on the concept of peer support described within the context of social support by Funnell (2010, p18) who states:

“peer support connects two or more people who have the same disease and often the same frustrations, so they can relate to each other’s feeling and anxieties.”

The term peer support therefore relates to individual and social support hence it was considered suitable to identify relevant research (Clark et al, 2012; Dennis, 2003; Funnell, 2010).

The search terms were expanded to form the key words and alternative key words (synonyms), which are shown in Appendix 1. Where appropriate, subject index terms (MeSH) were used in the search. Key words were also exploded where relevant and terms were truncated as required to ensure that the various ways of spelling the words, plurals and synonyms were captured (Kable et al, 2012). The use of Boolean operators and truncation are shown in Appendix 1. The key words relating to 'Stroke', 'Heart'

and 'Neurological' were derived from search strategies used by the Cochrane stroke group (2016) and from two Cochrane review articles (Coggrave et al, 2014; Taylor et al, 2014). In addition, the university librarian who has expertise in systematic review methodology provided valuable guidance and information towards building a robust search strategy. These key words were considered appropriate to ensure literature on the topic of interest was effectively identified.

2.2.2.4: Selection of articles

The titles of the results were initially screened and articles with irrelevant titles were excluded. The remaining articles were then retrieved and assessed for relevance by reading the abstract. Articles were excluded at this stage if the abstract revealed that the content of the paper was not relevant to stroke, cardiac or other neurological conditions, peer support and exercise. The articles that appeared relevant to the review were then read in full. Each article was also entered into a reference management system (Endnote X7, May 2013). Articles that met the inclusion criteria and which were specific to peer support were identified as suitable for the literature review.

2.2.2.5: Quality appraisal of retrieved literature

A quality appraisal of the relevant included literature was then undertaken. The critical appraisal was conducted using the Critical Appraisal Skills Programme (CASP) 2014 critical appraisal tools. The CASP critical appraisal tools include a set of checklists to facilitate the reading of research (Critical Appraisal Skills Programme, 2014). The checklists incorporated in this review included the CASP randomised controlled trial checklist; CASP qualitative checklist; CASP case control checklist; CASP cohort study checklist and CASP systematic review checklist (Critical Appraisal Skills Programme, 2014). These checklists were used to assist the author in the quality appraisal process, in particular, to establish the methodological quality of the articles found. This ensured that only articles with appropriate methodological quality were included in the literature review. No articles were excluded based on the critical evaluation process and articles of varying study design remained included.

2.2.2.6: Data extraction and synthesis

Relevant data were extracted from the included articles. This data focussed on the methodological approach used and the results obtained in each study. This process aided the analysis of the studies reviewed. A narrative synthesis of the data was undertaken. The studies were likely to be heterogeneous due to the diversity in participants, interventions, outcome measures and results (Booth et al, 2015). In addition, both qualitative and quantitative research designs were included therefore, a meta-analysis of the data was not suitable (Booth et al, 2015). A descriptive summary of the data is therefore provided.

2.3: Results

The results from the combined search terms for the Stroke, Cardiac and other Neurological searches are shown in Appendix 2. To optimise the quality of the literature search, ensuring it identified as many relevant articles as possible, the sensitivity (completeness) and precision (relevance) of the search was considered (Cochrane Collaboration, 2011). The resulting sensitivity level and precision of electronic searches compared to hand searching was 100% and 0.009 respectively. The database searches identified a total of 1,661 citations. After the removal of duplicates, 1,614 citations remained. 1,432 were excluded after screening the title. A further 139 were excluded after screening the abstract. 43 publications were retrieved as full text articles and an additional 11 articles were retrieved following additional author and reference searches. The results from these additional searches are shown in Appendix 3. A total of 54 studies were therefore retrieved as full text articles and reviewed. Of the 54 studies, 40 articles were excluded mostly because they were not specific to peer support or exercise. The excluded articles and the rationale for exclusion are shown in Appendix 4. Of the remaining 14 articles that met the inclusion criteria, 8 articles related to stroke (Amarshi et al, 2006; Blonski et al, 2014; Damush et al, 2007; Kopunek et al, 2008; Patterson and Ross-Edwards, 2009; Reed et al, 2010; Schouten et al, 2011; Simpson et al, 2011), 4 to cardiac (Clark et al, 2012; Hui et al, 2006; Isaksen and Gjengedal, 2006; Parent and Fortin, 2000) and 2 to other neurological conditions (Latimer-Cheung et al, 2013; Ravenek and Schneider, 2009). The flow of information for this process is shown in Appendix 5. The details of the characteristics and results of these included studies are shown in Table 2.1 (qualitative studies) and Table 2.2 (quantitative and mixed methods studies).

Table 2.1: Characteristics and findings from 10 qualitative studies that explored exercise strategies for stroke survivors (n=8), and support for participants who had a myocardial infarction (n=1) or Parkinson’s disease (n=1) who were all community dwelling.

Author Year Country	Sample (n) Demographics Inclusion criteria	Physical Activity/Support	Method	Results
Amarshi, F. Artero, L. Reid, D. 2006 Canada	Stroke (n=12). 7 males, 5 females. Age: 63-82 yrs. 1-9 years post stroke. 8 mobile; 4 wheelchair users.	Participation in community social and leisure activities such as swimming, walking and stroke support groups.	Grounded theory. Face to face interviews.	4 themes: a different life, what limits me from participating, what I need to participate, continuing on with life. Peer group support was needed to allow participation in social and leisure activities.
Blonski, D et al. 2014 Canada	Stroke (n=10). 6 males, 4 females. Age range: 50->70 yrs. 2-5 years post stroke. Mild, moderate or severe aphasia.	Barriers, facilitators and strategies for joining and participating in community group exercise programmes.	Descriptive. Face to face interviews.	Facilitators: communication, environmental and personal. Barriers included accessing and participating in exercise programmes.
Damush, T et al. 2007 USA	Stroke (n=13). 8 males, 5 females. Age: 47-72 yrs. Less than 12 months post stroke. Slight or moderate disability.	Barriers and facilitators to exercise after stroke.	3 focus groups.	3 facilitators: motivation, social support, activities to fill a schedule. 3 barriers: physical impairment, lack of motivation, environmental factors. Peer support may enhance physical activity.
Kopunek, S et al. 2008 USA	Stroke (n=29). 16 males, 13 females. Age: 45+ yrs. > 6 months post stroke. Mild to moderate gait deficits.	Motivating factors for participating and completing a 6 month treadmill exercise study.	2 focus groups or telephone interviews.	Themes that influence exercise participation: personal goals, psychological benefits, physical benefits, encouragement received, social support, improved ADL’s, self-determination, research associated exercise benefits.
Isaksen, A.S. and Gjengedal, E. 2006 Norway	Cardiac: myocardial infarction (n=25), from hospital admissions (n=10) and community exercise groups (n=15). 21 males, 4 females. Age: 40-71 years.	Positive and negative experiences of fellow patients both inside and outside hospital.	Descriptive. 5 focus groups.	Found positive support in peer interactions: support from others in same situation, humour, true understanding/ consideration, practical assistance, knowledge and experience, increased motivation. Negative experiences: noise, disturbances and situations where peers got worse/died.

Patterson, S. Ross-Edwards, B. 2009 Australia	Stroke (n=10). 6 males, 4 females. Age: 42-72 yrs. Time since stroke not specified.	Views on a stroke maintenance exercise group.	Face to face interviews.	3 themes: insight into post stroke difficulties; group provision of exercise opportunity, information and social support. Outcomes of increased confidence, motivation and participation. Peer group support found.
Ravenek, M.J. and Schneider, M.A. 2009 Canada	Early Parkinson's disease (n=7). 4 males, 3 females. Age: 45-59 years.	Influence of social support on physical activity participation.	Phenomenology. Questionnaire and face to face interviews.	3 types of support: instrumental, informational, emotional. Each had a positive effect on physical activity participation.
Reed, M et al. 2010 UK	Stroke (n=12). 5 males, 7 females. Age range: <60-73+ yrs. 15-20 months post stroke.	Needs and perceptions of a community exercise group and education scheme.	Phenomenology. Face to face interviews.	Needs found: confidence and sense of purpose, responsive services, an informal support network. The scheme met some needs through exercise, goal setting and peer group interaction.
Schouten, L. Murray, C. Boshoff, K. 2011 Australia	Stroke (n=7). 4 stroke survivors: 3 males, 1 female. Age: 65-85 yrs. 18 months – 18 years post stroke. Complex stroke needs. 3 staff members: 3 females.	Perceptions about participation in a community exercise group and rehabilitation programme.	Interpretive. Face to face interviews.	6 themes: a place to go, diversity of the group, group design, awareness of ability through doing, relationships over and above. Peer group interaction found.
Simpson, L. Eng, J. Tawashy, A. 2011 Canada	Stroke (n=11). From a rehabilitation centre and community groups. 8 males, 3 females. Age: 59-80 yrs. 5-11 years post stroke. All ambulatory.	Perceptions of exercise.	Exploratory. 2 focus groups.	6 themes: mobility, balance, self-efficacy, outcomes, support and exercise as part of active lifestyle. Identified facilitators including peer support and barriers.

Table 2.2: Characteristics and findings from 3 quantitative studies and 1 mixed method study that investigated group peer support for participants with heart failure (n=1) and individual peer support for participants who had heart disease (n=1) or a spinal cord injury (n=1) or cardiac surgery (n=1).

Author Year Country	Sample (n) Demographics Inclusion criteria	Method	Type of physical activity and measurement	Results
Clark, A.M. et al. 2012 UK	Heart disease patients who consented to peer support (n=79). 50 males, 29 females. Mean age: 65.0yrs. Control: heart disease patients who did not join peer support programme (n=30). 25 males, 5 females. Mean age: 66.2yrs	Longitudinal pre-test post-test design. Community group exercise programme with or without individual peer support provided by former patients who had completed cardiac rehab 1 to 2 years previously.	Physical activity levels of moderate and vigorous intensity exercise per week measured at baseline and 12 months by self-report and pedometer.	<ul style="list-style-type: none"> • Peer support group was significantly older (p<0.001). Mean age: 66yrs, control mean age: 59yrs. • Significantly more females (88%), compared to males (66%) joined peer support group (p=0.04). • Control had a significant decrease in total physical activity levels over 12 months, mean reduction from baseline of 211mins in an average week (p=0.003). • Intervention group showed a slight increase in total physical activity levels over 12 months, mean of 48.9mins increase in an average week. • Total step count per week at 12 months was higher in the control group (mean: 65,802) compared to the peer support group (mean: 43,561) but not significant (p=0.16) • Average steps per day at 12 months was higher in the control group (mean: 9400) compared to the peer support group (mean: 6223) but not significant (p=0.16).
Hui, E. et al. 2006 Hong Kong	Heart failure (n=37). Recruited from hospital admissions. 25 males, 12 females. Age: 60+ yrs (mean: 73.5yrs). All ambulant.	Mixed method Pilot study. Pre-test post-test design. 12 week community programme of education and exercise completed with peer support from other group members.	Attendance rate. Physical status at baseline and 12 weeks (6min walk test, dynamometry for biceps and quadriceps strength). Symptom improvement, disease knowledge and psycho-social aspects measured by questionnaires at baseline and 12 weeks. Value of mutual support assessed by structured questionnaire and focus group.	<ul style="list-style-type: none"> • High attendance rate (mean 91%). • High satisfaction rate (81% would attend similar course again). • Significant changes from baseline to 12week measures in self-reported quality of life questionnaires (HADS: p<0.001; MOS-SS: p<0.002; CHQ: p<0.001). • Significant changes (p<0.001) from baseline to 12week measures in physical capacity (6min walk test mean increase of 30.13meters). • 7 themes of experiences including: more motivated to exercise in a group and gained psychological support and social contact.

<p>Latimer-Cheung, A.E. et al 2013 Canada</p>	<p>Spinal Cord Injury resulting in paraplegia (n=12). 5 males, 7 females. Age: 27-59 yrs. Manual chair users n=9.</p>	<p>Quasi experimental pilot study. Pre-test post-test design. Home visit by a trainer and peer delivering home based strength training session. Peers were individuals with paraplegia.</p>	<p>Baseline and 4 week measurements. Self-efficacy measured by social-cognitive and behavioural questionnaires. Frequency and duration of strength training activities. Intervention acceptability questionnaire.</p>	<ul style="list-style-type: none"> • Significant increases in: task frequency self-efficacy (p=0.023), barrier self-efficacy (p=0.027), intentions (p=0.007), action planning (p=0.003). • Significant increases in strength training frequency (p=0.0011), duration (p=0.023) and volume (p=0.012). • All were satisfied with the trainer and peer. They could relate to the peer and having the peer was helpful.
<p>Parent, N. and Fortin, F. 2000 Canada</p>	<p>Cardiac surgery: First time, elective coronary artery bypass graft (n=56). All males. Age: 40-69 yrs.</p>	<p>RCT. Randomised by coin toss. Experimental group (n=27): Routine information plus 3 supporting individual visits 24hours before surgery, 5 days and 4 weeks post surgery by a volunteer former patient who had recovered from cardiac surgery. Control group (n=29): routine information only.</p>	<p>Anxiety 48 and 24 hours before surgery and 5 days and 4 weeks post surgery measured by self-reported score. Self-efficacy expectation and self-reported activity 5 days and 4 weeks post surgery measured by self-report instruments.</p>	<ul style="list-style-type: none"> • Anxiety level significantly higher in experimental group than control before intervention (mean score: 46.6 compared to 39.8). • Significant decrease in experimental group anxiety from 48hrs (mean score: 46.6) to 24hrs (mean score: 29.2) before surgery after first peer visit (p<0.01). • Anxiety remained significantly lower in experimental group compared to control group at 24hrs (mean scores: 29.2 compared to 38.8) and 5days (mean scores: 25.2 compared to 36.1) and 4weeks (mean scores: 25.3 compared to 31.4). • Significant difference in self-efficacy expectation between experimental group and control group on discharge for general activities (p=0.002); walking (p=0.001); climbing stairs (p=0.015). No significant difference at 4weeks. • Self-reported activity significantly higher in experimental group compared to control group at discharge for general activities (p<0.01) and walking (p<0.01). Significant difference remained at 4 weeks for general activities (p<0.05).

2.3.1: Included studies

The fourteen included studies were conducted between 2000 and 2014; six in Canada (Amarshi et al, 2006; Blonski et al, 2014; Latimer-Cheung et al, 2013; Parent and Fortin, 2000; Ravenek and Schneider, 2009; Simpson et al, 2011), two in the UK (Clark et al, 2012; Reed et al, 2010), two in the USA (Damush et al, 2007; Kopunek et al, 2008), two in Australia (Patterson and Ross-Edwards, 2009; Schouten et al, 2011), one in Hong Kong (Hui et al, 2006) and one in Norway (Isaksen and Gjengedal, 2006).

Of the fourteen studies ten were qualitative in design (Table 2.1). Of these, eight related to stroke, one to cardiac and one to other neurological conditions. Six studies used interviews (Amarshi et al, 2006; Blonski et al, 2014; Patterson and Ross-Edwards, 2009; Ravenek and Schneider, 2009; Reed et al, 2010; Schouten et al, 2011), three used focus groups (Damush et al, 2007; Isaksen and Gjengedal, 2006; Simpson et al, 2011), and one used both interviews and focus groups (Kopunek et al, 2008).

Three studies were quantitative in design (Table 2.2): one was a longitudinal design (Clark et al, 2012), one was a randomised control trial with participants randomly assigned to either a control or experimental group (Parent and Fortin, 2000) and one was a pilot study (Latimer-Cheung et al, 2013). There was one mixed method (Table 2.2), pilot study relating to group rehabilitation for patients with chronic heart failure (Hui et al, 2006).

2.3.2: Participants

Of the fourteen studies, eight studies focused on stroke participants. Total sample size was 104, ranging from 7 to 29 participants. In 5 studies the age range was 42 to 85 years (Amarshi et al, 2006; Damush et al, 2007; Patterson and Ross-Edwards, 2009; Schouten et al, 2011; Simpson et al, 2011) whereas in the remaining 3 studies the upper age limit was not specified (Blonski et al, 2014; Kopunek et al, 2008; Reed et al, 2010). Time since stroke onset ranged from 6 months to 18 years, one article specified only less than 12 months (Damush et al, 2007) and only one article did not specify time post stroke (Patterson and Ross-Edwards, 2009). Four studies focused on cardiac participants. Total sample size was 230 participants with age range of 29 to 85 years. The studies included participants with heart disease (Clark et al, 2012), heart failure (Hui et al, 2006), myocardial infarction (Isaksen and Gjengedal, 2006) or cardiac

surgery (Parent and Fortin, 2000). Two studies focused on participants with other neurological conditions. One study focused on spinal cord injury with 12 participants, age range 27 to 59 years. (Latimer-Cheung et al, 2013). One study focused on Parkinson's disease with 7 participants, age range 45 to 60 years. (Ravenek and Schneider, 2009).

Severity of deficit in terms of mobility varied across the included studies. Most participants were ambulant however wheelchair users were included (Amarshi et al, 2006; Latimer-Cheung et al, 2013). In thirteen of the fourteen studies, participants were community dwelling. One study included participants both during and after hospital admission (Parent and Fortin, 2000).

2.3.3: Recruitment of participants

Recruitment of participants varied across the studies. Several studies recruited participants from existing groups (Amarshi et al, 2006; Clark et al, 2012; Patterson and Ross-Edwards, 2009; Ravenek and Schneider, 2009; Reed et al, 2010; Schouten et al, 2011). Recruitment also occurred from other research studies (Damush et al, 2007; Kopunek et al, 2008). Recruitment was limited in one study with 116 participants being ineligible for the peer support programme due to being unable to undertake physical activity independently and due to lack of an available exercise facility (Clark et al, 2012).

2.3.4: Types and measurement of physical activity

Types of physical activity were wide-ranging. Five studies included group exercise programmes that incorporated a diverse range of exercises including aerobic training, weight training and yoga (Blonski et al, 2014); upper and lower limb strengthening and aerobic dance (Hui et al, 2006); balance and strength exercises and functional activities (Patterson and Ross-Edwards, 2009); treadmill training, walking and circuit training (Schouten et al, 2011) and a structured exercise programme (Reed et al, 2010). Individual exercise was included in two studies that involved strength training (Latimer-Cheung et al, 2013) and treadmill aerobic exercise (Kopunek et al, 2008). General physical activity tasks were included in three studies including walking, climbing stairs (Parent and Fortin, 2000); work and leisure related physical activity (Clark et al, 2012); social and leisure activities (Amarshi et al, 2006).

Three qualitative studies examined participants' perceptions of exercise and physical activity but did not define a specific type of exercise or physical activity (Damush et al, 2007; Ravenek and Schneider, 2009, Simpson et al, 2011). One study did not define physical activity or exercise type (Isaksen and Gjengedal, 2006).

A variety of outcome measures related to exercise were included in the quantitative and mixed method studies (Table 2.2). The measures incorporated for physical activity levels are highlighted here as they are of most relevance to this study. Physical activity levels were measured by self-report questionnaires in two studies (Clark et al, 2012; Parent and Fortin, 2000). Self-report questionnaires were also used in one study to measure self-efficacy to exercise (Latimer-Cheung et al, 2013). Physical activity was also measured with participants keeping a diary and objectively, by pedometer (Clark et al, 2012). Physical ability was also measured objectively using the six-minute walking test and hand-held dynamometry in one study (Hui et al, 2006). Compliance with exercise programmes was measured with attendance rate in one study (Hui et al, 2006) and with recording of frequency and duration of training in one study (Latimer-Cheung et al, 2013).

2.3.5: Definitions and types of peer support

Only 2 studies gave definitions of peer support (Clark et al, 2012; Parent and Fortin, 2000). Clark et al (2012, pp389) defined peer support as 'lay mentoring' and peer support interventions included "former patients or service users who act as mentors to support current patients". Parent and Fortin (2000, pp390) defined peer support as:

"the vicarious experience in which a former patient models the active life he or she is leading can act as a source of efficacy information to encourage rehabilitation in the observing patients".

The type of peer support provided was specified in four studies and this varied between these studies (Table 2.2). Individual peer support from people who had had similar experiences was incorporated in three studies (Clark et al, 2012; Latimer-Cheung et al, 2013; Parent and Fortin, 2000). Clark et al (2012) incorporated peer support through participants being matched with a 'peer' who were former patients participating in community based physical activity. This mentor supported attendance at a community

based exercise programme by meeting participants on their first exercise session and introducing others in the group. Parent and Fortin (2000) used one to one support consisting of three visits by a volunteer former patient during which emotional and informational support was given. Latimer-Cheung et al (2013) incorporated individuals who had had similar experiences to provide one to one support consisting of one home visit to deliver a home based strength training programme. Training was provided to the 'peers' in all three studies (Clark et al, 2012; Latimer-Cheung et al, 2013; Parent and Fortin, 2000). Group peer support was demonstrated in one study, this involved mutual support provided from fellow participants in a rehabilitation programme (Hui et al, 2006).

Peer support was highlighted in the ten qualitative studies in which a variety of areas were explored (Table 2.1). Four studies explored barriers and/or facilitators to exercise (Blonski et al, 2014; Damush et al, 2007; Kopunek et al, 2008, Simpson et al, 2011). Three studies explored participants' experiences and perceptions of group exercise (Patterson and Ross-Edwards, 2009; Reed et al, 2010; Schouten et al, 2011). One study explored participation in group exercise (Amarshi et al, 2006). One study explored the significance of fellow patients (Isaksen and Gjengedal, 2006) and one study explored the influence of social support on physical activity (Ravenek and Schneider, 2009).

2.3.6: Results from included studies specific to peer support

2.3.6.1: Qualitative studies

The qualitative results are summarised in Table 2.1. Of the 10 qualitative studies that met the inclusion criteria, 6 identified the benefits of peer support within the group setting (Blonski et al, 2014; Patterson and Ross-Edwards, 2009; Ravenek and Schneider, 2009; Reed et al, 2010; Schouten et al, 2011; Simpson et al, 2011). Exercising in a group was found to provide information and exercise opportunities (Patterson and Ross-Edwards, 2009) and could help stroke survivors to reconstruct their lives positively (Reed et al, 2010). Group exercise was also found to provide peer support (Patterson and Ross-Edwards, 2009). Relationships were found to develop between group members and group rehabilitation allowed peer comparison and increased patients' insight into their potential (Schouten et al, 2011). Group peer support was found to be an important factor in facilitating exercise as it influenced the decision to participate in physical activity (Ravenek and Schneider, 2009), motivated

participants to exercise (Simpson et al, 2011) and was a strategy to aid access and participation (Blonski et al, 2014). In addition, the benefits of involvement with other individuals who had similar experiences were found to “foster a sense of community” (Blonski et al, 2014, pp370). One negative aspect of group peer support identified was that groups of peers were only found to be beneficial when participants could relate to each other regards disease progression. (Ravenek and Schneider, 2009). However, this finding related to individuals with Parkinson’s disease and may therefore be specific to individuals with a progressive neurological condition (Ravenek and Schneider, 2009).

Peer support was also found out with group rehabilitation programmes. Four studies reported the benefits of peer support in relation to social support (Amarshi et al, 2006; Damsuh et al, 2007; Isaksen and Gjengedal, 2006; Kopunek et al, 2008). Social support was found to be an important factor in re-establishing continuity in social and leisure participation (Amarshi et al, 2006), in motivating individuals to exercise (Kopunek et al, 2008) and in providing a support system that could potentially improve health and well-being (Isaksen and Gjengedal, 2006). Peer support was highlighted as a key aspect of social support and found to be beneficial (Amarshi et al, 2006, Kopunek et al, 2008). Positive support was gained from peer interactions (Isaksen and Gjengedal, 2006) and social support from peers may enhance physical activity (Damsuh et al, 2007). In addition, one study supported peer support during lone exercise (Kopunek et al, 2008). It may not be necessary therefore for peer support to be provided solely through group based exercise when informal contact with fellow stroke survivors has been shown to be motivational to participation in exercise (Kopunek et al, 2008).

2.3.6.2: Quantitative and mixed method studies

The results are summarised in Table 2.2. Two quantitative studies and a mixed method study demonstrated that individual and group peer support had a positive impact on physical activity levels compared to baseline (Hui et al, 2006; Latimer-Cheung et al, 2013) and compared to control groups who did not receive individual peer support (Parent and Fortin, 2000). However, the findings of the study by Clark et al (2012) are slightly less clear as although they found peer support to be beneficial to physical activity levels, there was no increase in physical activity levels of the intervention group only a reduction noted in the control group (Clark et al, 2012). However, peer support does seem to significantly increase attendance and satisfaction with exercise

programmes (Hui et al, 2006). Individual peer support programmes were also found to significantly sustain physical activity levels beyond the cardiac rehabilitation programme (Clark et al, 2012). A one to one peer support intervention was also found to significantly reduce anxiety, improve self-efficacy expectation and accelerate recovery after cardiac surgery compared to the control group as well as improve self-reported activity after cardiac surgery (Parent and Fortin, 2000).

2.3.7: Recommendations of peer support

Five studies made recommendations regarding the application of peer support (Damush et al, 2007; Hui et al, 2006; Isaksen and Gjengedal, 2006; Kopunek et al, 2008; Reed et al, 2010). Consideration of a “buddy system” was suggested as a method to maintain social support (Kopunek et al, 2008, pp499). “Peer educators” were illustrated as an option to give participants more control (Reed et al, 2010, pp24). The use of “patient leaders” was also suggested (Hui et al, 2006, pp1496). Involving former patients and encouraging physical activity in groups was suggested as a method to aid patients’ health and well-being (Isaksen and Gjengedal, 2006) and incorporating peer support was highlighted as a method to promote and sustain exercise following stroke (Damush et al, 2007).

2.4: Discussion

This literature review found that peer support was beneficial within stroke, cardiac and other neurological conditions. Peer support was found to have a positive effect on exercise. The initial purpose for this review was to determine whether peer support has been used to support stroke survivors to exercise. The literature retrieved presented no evidence specific to one to one peer support within exercise after stroke. However, research that investigated aspects of group exercise following stroke consistently supported the benefits of peer support (Blonski et al, 2014; Patterson and Ross-Edward, 2009; Reed et al, 2010; Schouten et al, 2011). Furthermore, literature was found which recommended the incorporation of peer support within exercise after stroke programmes (Damush et al, 2007; Kopunek et al, 2008; Reed et al, 2010). The studies included and evaluated in this systematic review of the literature demonstrate peer support facilitates and motivates individuals to exercise and that it has the potential to be applied in a variety of exercise environments. This research therefore confirms the inclusion of peer support in group exercise following stroke will increase physical activity levels, improve confidence with exercise activities and has the potential to sustain exercise beyond the stroke specific exercise programmes. However, there is no research in relation to one to one peer support within the stroke population and although the concept of peer support has been highlighted further research is required to determine whether this would be feasible and/or acceptable to stroke survivors undertaking the exercise programme.

2.4.1: Evaluation of the included literature

The limited research found specific to peer support in the stroke population resulted in the searching of literature within the cardiac and other neurological conditions populations. Although relevant literature was found, the variety of clinical conditions included in these studies adds to the complexity of the results, as the studies contrast significantly in the populations investigated. Few similarities exist between individuals with a cardiac condition or a progressive neurological condition or a spinal cord injury which makes general conclusions and applications about individual peer support challenging. In addition, the cardiac conditions were all different including a range of conditions such as heart disease, heart failure, myocardial infarction and cardiac surgery, and limitations therefore exist in the ability to extrapolate the results as the samples were not representative of the general cardiac population (Clark et al, 2012;

Hui et al, 2006; Isaksen and Gjengedal, 2006; Parent and Fortin, 2000). Despite this, it could be argued that the differences in the clinical conditions investigated in the research illustrate the flexibility of individual peer support and therefore in fact support the potential application across other clinical populations, including stroke. Although these studies provide valuable insights into the positive value of peer support, it is not yet known whether these findings are generalisable to the stroke population and further research is required with stroke survivors.

There is therefore a lack of evidence related to the efficacy of peer support and this is accentuated by the nature of the literature found. All the included studies that recommended peer support in group exercise were qualitative studies exploring exercise following stroke (Amarshi et al, 2006; Blonski et al, 2014; Damush et al, 2007; Kopunek et al, 2008; Patterson and Ross-Edwards, 2009; Reed et al, 2010; Schouten et al, 2011; Simpson et al, 2011). Establishing confidence in the qualitative results, and the quantitative and mixed method results, is dependent on consideration of a variety of methodological aspects:

Firstly, the sample sizes of the qualitative, quantitative and mixed method studies were small and purposeful, variation and convenience sampling strategies were used. This is however appropriate in qualitative research and therefore not considered a limitation of the qualitative research included (Parahoo, 1997). The small sample size is also appropriate for the mixed method studies as it was a pilot study (Adams, 2015). However, the validity of the quantitative and mixed methods findings are reduced by the lack of randomisation (Clark et al, 2012) and lack of a control group (Hui et al, 2006; Latimer-Cheung et al, 2013). In addition, participants were unable to be blinded to interventions allowing for a potential placebo effect and also reducing the validity of the findings (Clark et al, 2012; Hui et al, 2006; Latimer-Cheung et al, 2013; Parent and Fortin, 2000). The samples in the qualitative stroke studies were mainly limited to participants who were ambulant or who had mild to moderate impairment (Damush et al, 2007; Kopunek et al, 2008; Simpson et al, 2011). This therefore limits the ability to apply the findings to stroke survivors who are non-ambulant or have more significant impairments. Despite this, anecdotal evidence based on the author's clinical experience, would suggest that the mild to moderate level of impairment is typical of the population included in the Lothian community based exercise programmes. This is of particular

relevance within the stroke population as stroke survivors with mild to moderate impairment are likely to experience fewer barriers to participation in exercise than those with moderate to severe stroke impairment (Morris et al, 2014). In turn, this may affect the level of support needed by individuals to participate in community based exercise. Further research with the wider stroke population is therefore required to determine whether a peer support individual would widen the access to exercise after stroke programmes. Although, the participants in the stroke studies displayed little variation in their impairment level, there was a variation in the length of time from stroke onset (Amarshi et al, 2006; Damush et al, 2007; Schouten et al, 2011; Simpson et al, 2011). However, it is likely that the barriers and facilitators to exercise will change over time due to issues such as changing health or a change in setting (Rimmer et al, 2008). Therefore, studies that included a range of time from stroke onset ensures that the results are pertinent to both initial and long-term exercise participation, which is particularly relevant to promoting adherence to exercise within the stroke population. In contrast, only including participants within one year of stroke onset provides little information regarding the perceptions of individuals further down the stroke recovery pathway. Considering the findings from the included studies in combination however, would suggest that peer support may motivate individuals at all stages of recovery post stroke. This is therefore a positive finding when considering methods that will help to engage stroke survivors in long-term exercise.

Second, there were differences between studies in how the participants were recruited. Several studies included recruiting participants from existing groups and other research studies involving exercise (Amarshi et al, 2006; Clark et al, 2012; Damush et al, 2007; Kopunek et al, 2008; Patterson and Ross-Edwards, 2009; Ravenek and Schneider, 2009; Reed et al, 2010; Schouten et al, 2011). In order to explore individuals' experiences of group exercise, it is necessary to include participants who are involved in these groups as they have the required experience to be able to provide relevant knowledge, views and experiences (Mauk, 2015; Parahoo, 1997). However, individuals who are already involved in an exercise group or research study may have different views on exercise participation. They may already be more motivated to undertake exercise, they may be more positive towards exercise from the outset and potentially more likely to continue ongoing exercise (Nicholson et al, 2013; Simpson et al, 2011). In addition, they may have already gained social support from attending

an exercise group (Patterson and Ross-Edwards, 2009). This has the potential to limit the meaningfulness of the findings as the results are not meaningful to individuals who are not involved in group exercise. Indeed, it could be argued that the population of individuals who are not participating in established group exercise should be the priority to focus research on given the established benefits of exercise in long-term conditions and that this group is possibly where encouragement of long-term exercise is most needed. Additional research would therefore be beneficial, particularly to allow a comparison of results between individuals who attend exercise programmes and those who do not (Patterson and Ross-Edwards, 2009).

Third, there were different definitions, types and measurements of physical activity in the included studies. A lack of consistency existed between the included studies in the terms 'physical activity' and 'exercise'. Therefore, participants' views and ideas may differ in relation to the definition of physical activity both amongst themselves, and between themselves and the researchers (Nicholson et al, 2013). Participants undertook a wide range of physical activities including aerobic training, strength training, balance exercises and functional activities (Blonski et al, 2014; Hui et al, 2006; Patterson and Ross-Edwards, 2009; Schouten et al, 2011). In particular, one study focused specifically on treadmill exercise following stroke (Kopunek et al, 2008). The findings are therefore only relevant to treadmill exercise, which is not a common form of exercise for stroke survivors, particularly with regards long-term exercise participation which reduces the relevance of these findings (Mehrholz et al, 2014). The methods of physical activity measurement also varied in the quantitative studies and included self-report measures or questionnaires which are subjective and therefore may have reduced accuracy and reliability (Clark et al, 2012; Latimer-Cheung et al, 2013; Parent and Fortin, 2000). Pedometers were also used to measure activity level by step count which was considered a more accurate and objective measure, however are not totally reliable due to the potential for error if applied incorrectly (Clark et al, 2012). The measurement of change in physical activity was also affected by the follow up periods used in the quantitative and mixed method studies. Only one study had a follow up period longer than twelve weeks and therefore long enough to show change in physical activity that could be considered applicable to longer term continuation of exercise (Clark et al, 2012). This requires consideration in future research studies due to the benefits of ongoing, long-term exercise in long-term conditions (Billinger et al, 2014). Furthermore,

studies that include a reasonable follow up period are therefore likely to be more relevant to current evidence based guidelines (SIGN, 2010; Intercollegiate Working Party, Royal College of Physicians, (2012); Scottish Government, 2014). Future research should therefore include appropriate follow up periods and more accurate measurement of physical activity levels.

Finally, the differences between data collection, interventions and data analysis methods between the included studies need to be considered. Data were collected in the qualitative studies by a combination of interviews and focus groups. These techniques are well established however limitations may exist in relation to their application with the stroke population (Kvale, 2007; Holloway, 2010). Stroke survivors may present with communication and cognitive impairments, aspects that should be considered in relation to data collection techniques (Clearly et al, 2014). Obtaining verbal information from participants with communication impairments is challenging but this was highlighted in only one of the included studies that included participants with severe aphasia (Blonski et al, 2014). This difficulty was particularly true in this study as severe aphasia included receptive aphasia (difficulties with understanding), which could therefore affect the accuracy of the data collected. Furthermore, the researchers interpreted non-verbal responses during the interview and took steps to reduce the impact of this, but they did not discuss the recognition of researcher bias that may be present as a result of communication problems after stroke (Blonski et al, 2014). Group discussions may also provide a challenging environment for many stroke survivors, particularly for individuals with cognitive impairments. The interventions used in the quantitative and mixed method studies included very different applications of peer support. Peer support was provided within group exercise (Clark et al, 2012; Hui et al, 2006) but, also in the home (Latimer-Cheung et al, 2013) and hospital environments (Parent and Fortin, 2000). The findings from the quantitative and mixed method studies involving group exercise may therefore relate more closely to peer support being used to support community based exercise after stroke programmes (Clark et al, 2012; Hui et al, 2006). It is of note however that providing one to one support out with the exercise setting may still have a positive effect on an individuals' physical activity level that strengthens support for the peer support concept. The role that the peer volunteer undertook also differed in these studies. Therefore, a lack of consistency exists in relation to the nature of the peer support provided by the peer

volunteer and that experienced by the participants. This variation may reduce the reliability of the findings and limits comparison of peer support interventions across the studies. One aspect that was similar among all three studies was that the peers who provided the support all undertook some form of training prior to their involvement in the study (Clark et al, 2012; Latimer-Cheung et al, 2013; Parent and Fortin, 2000). This may result in an improved level of support being provided which may link to the positive results found in the studies. The different types of individual peer support used in these studies does however limit the ability to form an opinion on an optimal method of one to one peer support rather it can only be determined that there is a place for individual peer support in supporting exercise in a variety of conditions.

Despite the potential limitations regarding data collection, most of the included studies demonstrated sound data analysis methods. The strengths of the qualitative data analysis process included involving more than one person in data coding (Blonski et al, 2014; Damush et al, 2007; Isaksen and Gjengedal, 2005; Kopunek et al, 2008; Reed et al, 2010; Schouten et al, 2011), application of a rigorous data analysis method (Amarshi et al, 2006; Kopunek et al, 2008; Patterson and Ross-Edwards, 2009; Simpson et al, 2011) and the use of field notes and debriefing (Isaksen and Gjengedal, 2005). Data saturation was also reported in several studies, which gives confidence that all relevant themes were discovered (Amarshi et al, 2006; Damush et al, 2007; Kopunek et al, 2008; Patterson and Ross-Edwards, 2009). These aspects strengthen the rigour of these studies. A further consideration relating to data analysis is researcher bias. An awareness of researcher bias is important in qualitative research as the researchers own beliefs and values can affect the interpretation of the data (Parahoo, 1997). Reducing researcher bias will again enhance the study's rigour and this is acknowledged in some studies (Patterson and Ross-Edwards, 2009; Reed et al, 2010; Schouten et al, 2011). Rigorous data analysis methods will enhance the credibility of the results therefore allowing meaningful findings to be obtained.

Despite the methodological limitations of the included qualitative, quantitative and mixed methods studies, the review has enabled a comprehensive picture of peer support and exercise to be developed which may be applicable to supporting the EAS programme. In addition, it has illustrated current gaps that exist in the research, particularly a lack of either qualitative or quantitative research investigating one to one

peer support within the stroke population, and further research is therefore required in this area.

2.4.2: Strengths and limitations of this literature review

The author is not aware of any systematic reviews researching peer support. This is therefore a strength of this review as this is a topic which has not been analysed in the existing research. In addition, a systematic method was used in the review which ensured a robust search for data was undertaken and ensured the method was reproducible and enabled relevant literature to be found (Booth et al, 2015). A limitation of this review is that only English language articles were searched for therefore studies in languages other than English may have been excluded. The large number of irrelevant titles and articles found may result in errors with screening resulting in potentially relevant articles being missed.

2.5: Conclusion

The purpose of this literature review was to determine whether peer support had been used to support stroke survivors to exercise. The objectives were to address the definition of peer support and the types of peer support used, the type of exercise peer support was applied to, the attitudes towards peer support and the feasibility of peer support to facilitate exercise.

This review has demonstrated that there is evidence supporting the use of peer support in relation to facilitating exercise with three different clinical populations including stroke. It also illustrated that positive attitudes exist towards peer support. It is clear however, that the definition of peer support and the types of peer support used vary considerably within the research. There is also no specific exercise type that peer support has been applied to. In addition to this, there is minimal research that has investigated the impact of one to one peer support within the stroke population. At present, the only quantitative research that exists in this area relates to other clinical conditions and is therefore unlikely to be replicable in the stroke population. There was also a lack of qualitative research specifically exploring the concept of peer support within the stroke population. Therefore, further qualitative research exploring peer support, particularly individual peer support, within stroke would provide valuable information and allow an increased understanding of individuals' thoughts, experiences

and perceptions of peer support to be obtained. Gaining the views of stroke survivors and exercise professionals would also enable a theoretical framework for the incorporation of individual peer support in stroke to be developed. This would be an important first step to determine the need for, and feasibility of a full-scale quantitative study, such as a clinical trial to determine if peer support is more effective than usual care in exercise after stroke.

2.6: Chapter summary

The conclusion from this systematic literature review therefore justifies the need for a qualitative study to explore individual peer support within the stroke population and it is this area that the current study aims to explore. The specific aims and objectives of the current study and the method by which these will be addressed will be presented in chapter 3.

Chapter 3: Methodology

3.1: Study aim and objectives

The aim of this study is to explore the concept of PAC with stroke survivors and professionals involved in a community based exercise programme to:

- Explore if stroke survivors think a PAC would be beneficial in helping to support the EAS programme?
- Examine how support from a PAC could affect stroke survivors' experience of community based exercise?
- Discuss whether stroke survivors would consider undertaking a PAC role and if so how would they define that role?
- Explore if exercise professionals think a PAC would be beneficial in helping to support the EAS programme and if so what is the role?

3.2: Study design

This was a qualitative study based upon a grounded theory approach. Qualitative research focuses on the experiences of individuals, and uses words and an inductive approach to gain data (Bryman, 2004; Parahoo, 1997). It involves research that produces findings based on the qualities of entities rather than by quantification and statistical methods (Strauss and Corbin, 1990). The aim of qualitative research is to understand and interpret phenomena in terms of how it is perceived by individuals and the meaning that individuals assign to it (Denzin and Lincoln, 2005; Holloway, 2010). A qualitative design was selected for this study to enable individual's perceptions about the concept of peer support in exercise after stroke to be explored. A qualitative design was necessary to allow concepts and themes regarding supporting exercise following stroke to be explored thus enabling the study's research question to be addressed.

In addition, the researcher's ontological position was considered in determining the design of this research study. Consideration was initially given to a quantitative design particularly as the researcher's experience relates more to quantitative research. A quantitative design was not however deemed suitable due to the lack of evidence of peer support within exercise following stroke (as discussed in chapter 2). The focus of this study needed to determine service users' perceptions, views and experiences of incorporating peer support with an EAS class.

Therefore, in order to answer the research question and explore this area in sufficient depth, a qualitative design was required. A qualitative study design was therefore selected rather than a quantitative study design.

A key aspect of qualitative research is the underlying theory and epistemology with which the researcher approaches the world (Denzin and Lincoln, 2005). Denzin and Lincoln (2005) highlight that researchers have a set of ideas (theory) from which a set of questions (epistemology) is specified. How the researcher then approaches these aspects relates to their philosophical position and the interpretive standpoint they adopt within the research process (Birks and Mills, 2015; Denzin and Lincoln, 2005). The set of beliefs the researcher has will therefore guide how they approach their research (Birks and Mills, 2015). These beliefs can be described and related to interpretive paradigms which structure qualitative research (Denzin and Lincoln, 2005). Lincoln and Guba (2005) highlight five main interpretive paradigms: Positivism; Post-positivism; Critical Theory; Constructivism; Participatory. The philosophical position of the researcher within this study leads to a constructivism approach being applied. Constructivism assumes that there are multiple social realities, that knowledge and understanding are created by both the knower and responder, and sets its methodological procedures in the natural world (Charmaz, 2005; Denzin and Lincoln, 2005). The constructivism position has become more recognised in relation to the grounded theory approach used in qualitative research. Charmaz (2006, pp130) describes a constructivism approach in grounded theory as one which:

“places priority on the phenomena of study and sees both data and analysis as created from shared experiences and relationships with participants”.

This approach is centred in the interpretive tradition of qualitative research (Charmaz, 2006). It considers that the theory gained from participants in the research process is as a result of how the researcher interprets the information (Charmaz, 2006). Furthermore, it suggests that it is through the interaction of the researcher and participant that data is generated (Birks and Mills, 2015). This is in contrast with the original methodological position of grounded theorists who applied a positivism position (Charmaz, 2005). This position views the data objectively and

believes that the researcher is separate from the participants (Birks and Mills, 2015). This approach therefore removes the influence of the researcher and considers the data to be facts which will be uncovered from following systematic methods (Charmaz, 2006). The interpretive paradigm used with grounded theory can therefore vary and will depend on the position taken by the researcher.

3.3: Research approach

The previous section highlighted that the qualitative research design of this study was based on a grounded theory approach. Grounded Theory was originally formulated as a research design by Glaser and Strauss (1967) and later further developed by Strauss and Corbin (1990). The method proposed by Strauss and Corbin (1990) promoted inductive, deductive and verification elements rather than a purely inductive process within grounded theory (Holloway, 2010). The adaptation by Strauss and Corbin (1990) was preferred by the researcher for this study as it enabled identification of a specific area and research problem to be investigated (Holloway and Galvin, 2015). This allowed for a more detailed literature review to be undertaken which was a key aspect of this research study. Being able to incorporate both inductive and deductive processes was considered easier to follow by this researcher and therefore beneficial due to the researcher's lack of experience with the grounded theory method. Grounded Theory is based on the theme of new theory being generated from data obtained from research (Birks and Mills, 2015; Glaser and Strauss, 1967). A grounded theory will therefore start with a phenomenon of interest and the theory will develop from that topic (Strauss and Corbin, 1990). This is similar to other qualitative methods such as phenomenology that start with a phenomenon however is in contrast to the qualitative approaches that test an existing theory or a pre-determined hypothesis deductively from the data collected (Birks and Mills, 2015; Charmaz, 2006; Holloway, 2010). The perceived benefit of undertaking research in the grounded theory manner is that it ensures the emerging theory will be suited to and applicable to the phenomenon studied (Glaser and Strauss, 1967; Strauss and Corbin, 1990).

The process of grounded theory requires the researcher to systematically use a set of grounded theory methods (Charmaz, 2006; Strauss and Corbin, 1990). These methods include concurrent data collection and analysis; initial coding of data; constant comparative methods; memo

writing; theoretical sampling and theoretical sensitivity (Birks and Mills, 2015; Charmaz, 2006). Incorporating these methods result in a flexible process that will allow a grounded theory to be inductively developed through the research (Strauss and Corbin, 1990). In addition, constant analysis of the data allows the researcher to highlight emerging themes which can then be incorporated into subsequent data collection (Strauss and Corbin, 1990). Relevant themes evolve during the process and are inductively developed until no new themes are evident and the theory is formed (Strauss and Corbin, 1990). This allows the theory to be built systematically and results in the theory being grounded in the data collected by the researcher (Glaser and Strauss, 1967; Strauss and Corbin, 1990).

The purpose of the grounded theory method is therefore to generate theory through an inductive process (Strauss and Corbin, 1990). Research which aims to develop new knowledge or where little is known about a particular area will therefore suit the application of the grounded theory method (Birks and Mills, 2015). This study aims to explore the concept of stroke survivors supporting fellow stroke survivors in community based exercise. There is currently limited theoretical understanding of incorporating peer support in community based exercise with a stroke population (as discussed in chapter 2). Basing the research on the grounded theory method will allow this area to be explored in a systematic way and enable new knowledge to be obtained from those with experience of stroke and exercise. It will also allow theory building to occur through an iterative process which will evolve as the information is gathered which is consistent with the purpose and method of grounded theory (Birks and Mills, 2015; Strauss and Corbin, 1990). Undertaking this research in an inductive way will enable a theoretical understanding of the concept of PAC to be gained.

This study is therefore based on the grounded theory method. It does not however attempt to adopt a pure grounded theory approach. A key consideration to this was the completion of a literature review. Some grounded theorists do not recommend undertaking a literature review as it may restrict the development of new theory and constrain the researcher to established theoretical frameworks (Strauss and Corbin, 1990). The researcher however felt that completing an initial literature review would enable knowledge of peer support and exercise to be gained. It would also provide the foundation for this research and enable the researcher to gain a valuable learning experience.

3.4: Method

3.4.1: Sample

A purposive sample was used to select participants. This method of sampling is used commonly in qualitative research and is based on the researcher deliberately selecting individuals who can provide relevant data (Parahoo, 1997). In order for this study's research question to be answered, participants were required to provide information on the topic of exercise following stroke in relation to the EAS programme. The sample group had to therefore be selected from individuals who had experience of the phenomenon of exercise following stroke. A purposive sample was therefore the most suitable selection method for this study. Furthermore, to enable the best possible sample to be achieved, participants were selected from different leisure venues, males and females were included and participants of varying ages were selected. This allowed a broad range of participants to be selected and included in the study. The researcher is aware that sampling in this way limits the ability to generalise the findings to the wider population. However, in qualitative research, the findings aim to be generalisable to theory rather than generalisable to relevant populations or settings as is the case with quantitative data (Bryman, 2004). Purposive sampling therefore remains an appropriate choice for the qualitative design of this research study.

3.4.2: Participants

The study consisted of two population groups: (1) stroke survivors attending EAS, (2) professional staff who were involved in delivery of the EAS programme.

3.4.3: Inclusion and exclusion criteria

The inclusion criteria for stroke survivors were: Adults over 18 years of age; a diagnosis of stroke; had been referred and accepted to the EAS programme; had no significant cognitive or communication impairment (were able to follow complex commands and can understand verbal and visual instruction). The inclusion criterion for professional staff was: staff who had delivered the EAS programme.

The exclusion criteria for stroke survivors were: Individuals with significant cognitive or communication impairments which prevented them understanding complex commands or instructions. No exclusion criteria were required for professional staff.

3.4.4: Recruitment of participants

The recruitment of participants was undertaken separately for each population group. The stroke survivors were recruited by the researcher and exercise instructor who facilitated the EAS programme. The researcher made a face to face request to the group of individuals who were participating in the EAS programme. This was done by through conversation with the stroke survivors prior to their EAS class. The instructor provided individuals who were interested in participating with the potential participant information sheet (see Appendix 6). Individuals were given one week to digest the information. The details of individuals who volunteered to undertake the study were then collected by the exercise instructor and their information was provided to the researcher. The researcher then contacted them directly by telephone to arrange an interview. Recruitment occurred from the current EAS classes that are run over three different leisure centre locations. The recruitment of professional staff was done by a face to face request for voluntary participation in the study. They were given the potential participant information sheet (see Appendix 7) and one week for consideration. If they wished to participate in the study they were asked to contact the researcher by email.

3.5: Ethical considerations

In all research it is vital that ethical principles and issues are considered to ensure research participants are protected when involved in the research process (Bryman, 2004). The ethical practice for this study is described below and was undertaken as per the guidelines provided in Edinburgh Napier University's Code of Practice on Research Integrity (2013).

3.5.1: Ethical approval

The study was approved by the Edinburgh Napier University Ethics Committee on 23rd October 2015. The ethical approval letter can be seen in Appendix 8.

3.5.2: Confidentiality

To ensure confidentiality was maintained, no personal information was used in the study. All information about participants and the data collected was treated confidentially. To achieve this, the participants' personal details gathered by the researcher were immediately anonymised with a participant number and then a pseudonym. This ensured that it was not possible for

participants to be identified from the data gathered. It was also not possible for participants to be identified in any reporting of the data gathered and that participants would be anonymous in publication. To ensure data protection, participants' personal details were stored on a password protected computer and any information in paper form was stored in a locked cabinet in a locked room. All the data that was collected in the study was kept in a secure place (paper copies of the interviews/focus groups were kept in a locked cabinet in a locked room and electronic data was stored on a password protected computer). Access to this data was strictly limited to the researcher and research supervisors. This information will be destroyed at the end of the examination process. It was highlighted to participants that the results may be published in a scientific journal or presented at a conference or in a report. In this case, participants would not be identified in these publications by any of the information given, as stated in the participant information sheet (see Appendices 6 and 7).

3.5.3: Risks to participants

The potential risks associated with the study include psychological or emotional distress to participants who undertook the interview or focus group process. In order to manage this, participants were able to stop the interview or focus group at any time if required. The debrief session also ensured that any issues that occurred following participation were raised and provided an opportunity for participants to ask further questions. If any emotional distress occurred with the stroke survivors group, the researcher discussed with the participant if they would like their Chest Heart & Stroke Scotland Liaison Nurse or GP to be informed as an appropriate source of support. If any issues were raised with the professional group, the researcher advised them to contact the stroke Managed Clinical Network (MCN) lead for Training and Education for stroke. This information and the contact details for these individuals were provided in the participants' debriefing form (see Appendix 9).

3.5.4: Risks to researcher

The potential risks to the researcher associated with the study were undertaking individual interviews. In order to manage this risk, interviews were undertaken in public leisure centres and leisure centre staff were advised of the location and timing of the interview.

3.5.5: Consent

A participation information sheet was provided to participants prior to them agreeing to take part in the study. The information provided was specific to each population group. Contact details for the researcher, supervisor and an independent advisor who knew about the study but was not involved in the study were included. A consent form was completed by participants if they agreed to take part in the study (see Appendix 10). The signed consent form was kept by the researcher.

If an individual did not want to continue to participate during the interview/focus group, then the interview/focus group was stopped and the participant offered to leave. Participants could withdraw from the study at any time, they did not have to give a reason and it would not affect their treatment (if applicable). If participants withdrew from the study, it was clear to participants that any data they provided would be safely destroyed and would not be used in any publication.

A debrief session was undertaken following participation in an interview or the focus group and the debrief form (see Appendix 9) was completed. This ensured that any issues that were raised during the interview or focus group were captured and managed appropriately. It also ensured that the participant still agreed to the information that they provided being used in the study and that this was recorded.

A letter of confirmation from Edinburgh Leisure agreeing to the use of Edinburgh Leisure premises, staff and for the recruiting of participants was obtained (see Appendix 11) in conjunction with the requirements for ethical approval.

3.6: Study procedure

3.6.1: Stroke survivor interviews

One to one semi-structured interviews were undertaken with the stroke survivors. Qualitative interviews are considered a key method of collecting data on individuals' knowledge, perceptions and experiences (Kvale, 2007). In addition to gaining rich data, interviews also ensured appropriate privacy for individuals who may be discussing sensitive topics (Polgar and Thomas, 2000). Furthermore, participants may have mild communication or cognitive

impairments following their stroke. Because of this, individual interviews were deemed the most suitable data collection method as they would allow participants to have time to communicate with the researcher enabling improved engagement in the interview process (Cleary et al, 2014). Participants were interviewed once and recorded by tape recorder. The duration of the interviews ranged from 30 to 40 minutes. This length of time was suitable, as qualitative interviews can vary in duration with shorter interviews being appropriate, to allow rich information to be gained (Bryman, 2004). All the interviews were conducted by one researcher and undertaken at the leisure venue where the individual attended EAS. Rooms were available to book within the centres. The setting was consistent with where participants undertook EAS and the EAS class that they were recruited from. This ensured the setting was familiar to the participant, the aim being to help them feel more comfortable and therefore encouraging improved interaction with the researcher (Cleary et al, 2014). An interview guide was used to aid the structure of the interview. This is provided in Appendix 12. A small number of demographic details were collected initially by the researcher to establish basic background information, particularly in relation to their stroke and exercise history. The qualitative interview then incorporated open-ended questions which aimed to gain the participant's views on the concept of PAC thus enabling the study's aim to be addressed.

3.6.2: Professional staff focus group

A focus group was undertaken with the professional exercise staff and recorded by tape recorder. A focus group was used as it is a suitable method of gaining information from professionals who share a common experience and it allowed them to express their individual views (Holloway, 2010). A potential disadvantage of the focus group method however related to the group dynamics, as a professional hierarchy existed amongst the participants. This may have caused individuals to influence others or result in some participants feeling unable to express their views freely (Parahoo, 1997). The topics discussed were however not sensitive topics and the researcher was able to encourage discussion and debate which aided the generation of valuable data (Barbour, 2008). The duration of the focus group was approximately 60 minutes. The focus group was undertaken at an Edinburgh Leisure office. The focus group was facilitated by the researcher and a research assistance. A focus group guide was used to aid discussion in the group. The focus group guide is provided in Appendix 13. Open-ended questions were used to facilitate discussion in order to obtain the participant's views on the concept of PAC.

3.6.3: Data collection

The interviews and focus group were carried out over a 3 month period with the focus group occurring after the first interview. The researcher recorded field notes after each interview and after the focus group. This allowed the researcher to record observations, non-verbal aspects and immediate reflection of the interaction with the participants (Birks and Mills, 2015). Memo writing was also undertaken by the researcher throughout the data collection period. This enabled initial analysis of the data as the researcher's thoughts and insights were noted in relation to the data (Birks and Mills, 2015). Undertaking data collection in this way allowed for concurrent data collection and analysis to occur. Subsequently, the content of each interview changed and developed depending on the findings from the previous interviews. It also allowed information to be gained from a stroke survivor that could then be used to facilitate discussion within the focus group. The focus group information could then be used within the subsequent individual interviews. Applying this procedure ensured an iterative approach was taken. This is in keeping with the grounded theory approach where themes develop and questions evolve as questions are built upon (Strauss and Corbin, 1990). In addition, constant comparison of the data enabled a degree of theoretical sampling to occur within the data collection process. The information that was obtained from the interviews guided the researcher to the next data source (Birks and Mills, 2015). For example, age was identified in an interview as a relevant concept, which in turn led the researcher to interview a younger stroke survivor.

3.7: Data analysis

3.7.1 Data transcription

The initial step in the data analysis process was to transcribe the interview and focus group data. The researcher transcribed the recorded data which allowed initial reflection and review of the information gathered (Cleary et al, 2014). To ensure the data were prepared appropriately, the researcher followed a sample protocol documented by McLellan et al (2003). This aimed to ensure the transcription was done in a systematic and structured way that would subsequently aid data analysis (McLellan et al, 2003). The digital recordings were transcribed verbatim allowing the data to remain in the words of the participant (Bryman, 2004). This included non-verbal sounds, such as sighs and laughter, and background noises. Non-verbal gestures were also documented based on the researcher's corresponding field notes. Mispronounced or incorrect words were recorded as pronounced by the participant. Furthermore, colloquial or slang terms were not changed. Filler words such as "mhhh" were

also transcribed. Information considered sensitive was removed and a label inserted. To ensure accuracy, the researcher checked the final transcription against the recording and any revisions were made (McLellan et al, 2003). The researcher aimed to transcribe each set of data as soon as possible following data collection and prior to the next interview in keeping with the grounded theory approach (Strauss and Corbin, 1990; Charmaz, 2006). Timely transcription aimed to improve the accuracy of the process however this was not always possible.

Data transcription by the researcher was a lengthy process. The benefit of this was that it resulted in the researcher being immersed in the data. This allowed the researcher to gain an overall picture of participants' thoughts and experiences. This in turn enabled the researcher to begin initial data analysis. It enabled concepts to be generated, which could be taken forward to subsequent interviews resulting in continuous and interlinked data collection and analysis. This immersion was therefore beneficial, a belief that is supported in the literature as it allows the researcher to "become sensitive to issues of importance" (Holloway, 2010, pp 282). A further advantage of researcher transcription was in relation to the researcher's abilities in data collection. Data transcription allowed the researcher to reflect upon the interview content and style of questioning used, awareness of which helped to further develop and improve the researcher's interview technique. This is substantiated by Kvale (2007) who states that researchers who transcribe their own interviews will learn about their own interviewing style.

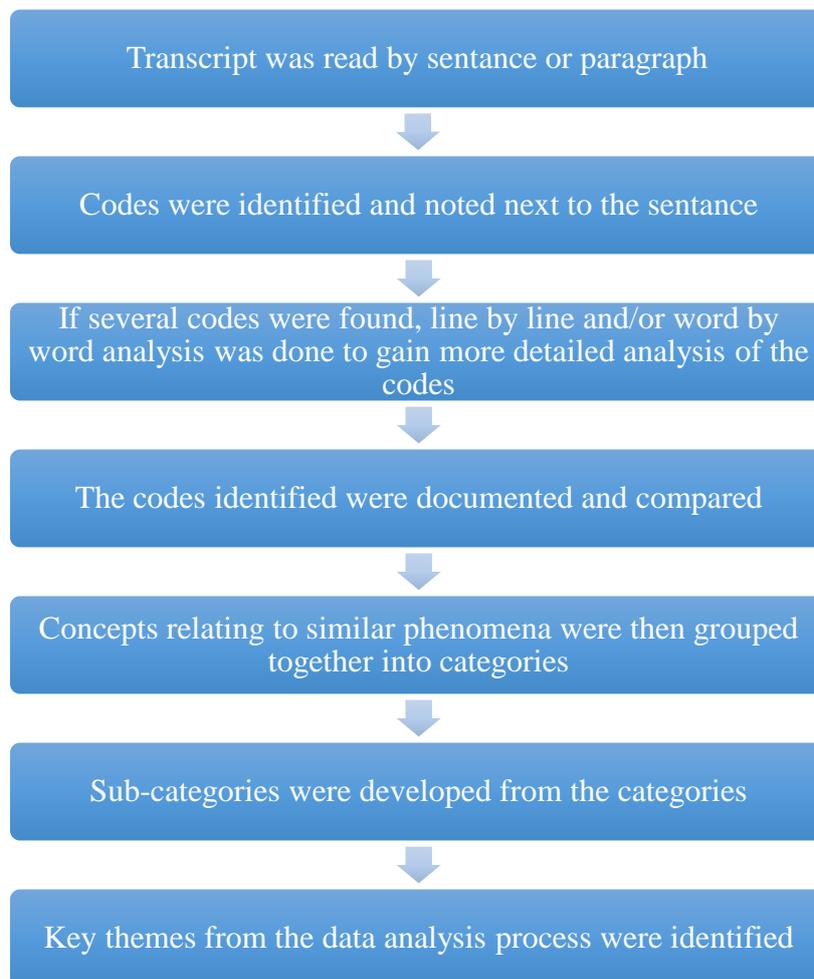
3.7.2: Data analysis process

The process of analysing the data was based upon the method proposed by Charmaz (2006). The main component of the data analysis process involved coding. This is a key component of grounded theory and central to generating theory (Bryman, 2004; Strauss and Corbin, 1990). It involved developing initial codes, which related closely to the data, into more abstract categories, which theorise the phenomenon of interest (Bryman, 2004). The process of coding involved two phases: initial coding and focused coding (Charmaz, 2006).

The first stage of coding undertaken by the researcher was initial coding. This stage involved detailed analysis of the data to develop numerous, provisional codes which linked closely to the data (Charmaz, 2006). The data were analysed in an open way so that as many codes as

possible could be identified. Comparison of similarities and differences in the data was also undertaken to allow initial analysis of participants' views (Charmaz, 2006). The second stage of the coding process involved focused coding. This stage allowed further synthesis of the data and was done by analysing the most frequent or significant codes identified in the initial coding phase (Charmaz, 2006). The codes were compared against each other and concepts that seemed to relate to a similar phenomenon were grouped together into categories. This allowed the most revealing codes to be used to categorise the data into more selective concepts (Bryman, 2004; Charmaz, 2006). These categories were then developed into sub-categories that were linked to the categories. Doing this allowed the relationships between categories to be explored and the categories to be developed further (Bryman, 2004; Charmaz, 2006; Strauss and Corbin, 1990). Finally, key themes were developed from the data analysis process and the main overarching themes were identified. It is recommended that the two coding phases be applied concurrently in the data analysis process and link to on-going data collection (Charmaz, 2006; Strauss and Corbin, 1990). The researcher attempted this however this level of data analysis was not always completed prior to further data collection. Throughout the coding process however the researcher made comparisons and asked questions, two analytical procedures considered fundamental to the coding process (Strauss and Corbin, 1990). This is important as constant comparative analysis in conjunction with on-going data collection aids category development resulting in an iterative analytical method being applied (Birks and Mills, 2015). Figure 3.1 shows the coding process performed by the researcher.

Figure 3.1: Steps taken by the researcher in the coding process based upon the process of coding described by Charmaz (2006)



3.7.3: Theoretical saturation

The processes of initial and focused coding should continue until theoretical saturation has occurred (Charmaz, 2006; Strauss and Corbin, 1990). This is the point where no new concepts are identified and categories cannot be developed further (Birks and Mills, 2015). The researcher cannot be confident that data saturation occurred in this study due to limitations with theoretical sampling and concurrent data collection and analysis. The small sample size used in the study also limits the ability to achieve theoretical saturation.

3.7.4: Theoretical sensitivity

A further consideration in the data analysis process was theoretical sensitivity. Theoretical sensitivity is the researcher's ability to recognise meaning in the data (Birks and Mills, 2015).

A key aspect of this was for the researcher to consider their assumptions and experiences in order to ascertain their baseline position (Birks and Mills, 2015; Strauss and Corbin, 1990). Tools and strategies can then be applied to enhance theoretical sensitivity during data analysis (Birks and Mills, 2015). Consideration of the researcher's personal and professional history illustrated that the researcher had established ideas and perceptions about exercise following stroke. The researcher had close links and knowledge regarding the services involved which made it difficult to accept criticism of the services. The researcher was also keen for individuals to have a positive experience of the services provided therefore was liable to defend services when they were criticised. The researcher was therefore mindful of this position and memos were written in respect to these aspects. The use of memo writing is an important aspect of the grounded theory approach to ensure quality in the process (Birks and Mills, 2015). It also helped the researcher to think out with their professional experience, which in turn enabled an improved interview technique and a better understanding of the data.

A further consideration related to the completion of a literature review prior to data generation. The researcher was aware of the potential for concepts to be generated from the literature and applied to the data. It was important therefore that the researcher recognised and challenged any biases or assumptions made during the data analysis process, a strategy Strauss and Corbin (1990, pp 91) call "waving the red flag". Consideration of these aspects and applying the appropriate strategies allowed theoretical sensitivity to be developed. Subsequently, this resulted in the generation of more meaningful concepts and a more theoretical level of data analysis to be achieved (Strauss and Corbin, 1990).

3.7.5: Reflexivity

In addition to the tools incorporated to enhance theoretical sensitivity, the researcher also aimed to apply the strategy of reflexivity to enhance the rigour of the research study. Reflexivity involves the researcher considering their own values, methods, biases, behaviour and those of the respondents (Bryman, 2004; Parahoo, 1997). The researcher therefore reflected on these aspects during data collection and analysis. Reflection on the data collection method highlighted that, as a novice researcher, it was challenging carrying out the interviews and focus group due to lack of experience. In addition, the researcher was mindful that participants were aware of the researcher's professional role as a physiotherapist, which may affect the

interaction or information given during the interviews. These aspects may have an influence on the richness and validity of the data gathered (Parahoo, 1997). In addition, only the researcher undertook data analysis. Reflection on this highlighted that the findings are therefore subjective to one individual only. Validation of the data by another researcher examining the transcripts or by asking the participants to validate the data could have therefore been beneficial (Parahoo, 1997).

The process of data collection and analysis ultimately however allowed the interview and focus group data to be refined and conceptualised (Charmaz, 2006). This enabled theory on the concept of PAC to be developed and ensured these theories were integrated and grounded in the data obtained. The key themes identified will be discussed in chapter 4.

Chapter 4: Results

4.1: Introduction

The methodology of this study is based on the grounded theory method. A grounded theory was however not fully achieved due to limitations in theoretical sampling and data saturation, which are discussed further in chapter 5. The final stage of theory formulation was challenging due to the lack of data comparison that subsequently limited theory generation and hypothesis confirmation (Bryman, 2004). The resulting methodology therefore incorporated features of grounded theory however as not all procedures were undertaken fully, a final grounded theory could not be generated (Bryman, 2004). With hindsight a thematic analysis would have been a reasonable approach to analyse the findings, as it would have allowed in-depth data analysis that was sensitive to the experiences reported by the study's participants (Bryman, 2004). Although the data was coded and clustered into important key areas, further analysis to draw out themes from the data did not occur due to lack of researcher experience and time constraints (Lathlean, 2015). As a result themes that encompass the flavour of the findings and a final theory were not fully realised (Lathlean, 2015). Despite this, data analysis resulted in three key messages being established, which include 'Benefits of peer support', 'Thoughts on the role' and 'The sooner the better', which will be presented and discussed in detail below.

4.2: Results

Six individual interviews were conducted with stroke survivors, one with a family member present. Of the nine participants who volunteered for the study, two were excluded as they had professional links with the researcher and one was unable to be interviewed due to time restrictions. Six participants were therefore included, three were male and three were female. The age range was 45 years to 89 years. All six participants were stroke survivors who were currently undertaking the EAS programme at three different leisure centres. Table 4.1 shows the demographics of the stroke survivor participants.

Table 4.1: Demographics of stroke survivor participants

Participant pseudonym	Gender	Age	Time from stroke onset	Length of EAS attendance	Exercise undertaken pre-stroke
Ethel	Female	89	1 year	3 weeks	Regular home exercises. Always conscious of exercise.
Andrew	Male	85	2 years	15 months	Going for walks. No other exercises.
Susan	Female	57	1 year	6 months	No exercise.
Frank	Male	65	5 years	4 years	No exercise.
George	Male	78	4 months	7 weeks	Gym member. Golf 3 x week
Julie	Female	45	1 year	3 months	Walking

One focus group was also conducted with a sample of professionals involved in the programme. Three members of staff volunteered to participate. One participant was male and two were female. All the participants had been involved in the delivery of the EAS programme. In addition, they had worked in the EAS programme for a minimum of 4 years resulting in them being very experienced with the programme. Table 4.2 shows the demographics of the professional participants involved in the focus group.

Table 4.2: Demographics of professional participants involved in the focus group

Participant pseudonym	Gender	Age	Time working with leisure provider	Time working with EAS	Role undertaken with EAS
Peter	Male	31	10 years	4 years	Exercise Instructor. Health development projects co-ordinator.
Sarah	Female	41	5 years	4 years	EAS Instructor.
Claire	Female	34	13 years	8 years	Co-developed the pathway. Manage referrals. Source and support instructor.

The first semi-structured interview was carried out on 2nd December 2015. The focus group was then undertaken on 17th December 2015. The final five semi-structured interviews were undertaken between 6th January 2016 and 22nd February 2016 (see section 3.6.3 for rationale).

4.3: Key messages

The interview and focus group transcripts provided rich data relating to the concept of incorporating a PAC to support exercise following stroke. Following data analysis three key messages were identified; 'Benefits of peer support', 'Thoughts on the role' and 'The sooner the better'. The results from the stroke survivor group and the professional group are reported together here as similar themes emerged for both groups. Quotations are used within these results that are representative of the findings. The raw data selected was typical or especially poignant to best represent the key messages (delete) and the perceptions of participants. Selecting quotes in this way is considered appropriate for illustrating themes found through data analysis and ensuring the key elements are highlighted (Holliday, 2007). The results are discussed below under the three key messages. The key messages are discussed separately however there are aspects which overlap between areas and the corresponding quotes.

The three key messages identified were:

- Benefits of peer support
- Thoughts on the role
- The sooner the better

The main message of 'Benefits of peer support' is further broken down into; 'fear of the unknown' and 'all in the same boat'. The main message of 'Thoughts on the role' is broken down into; 'a good idea but not for everyone', 'the right person', 'the job they could do' and 'say it as it is'. The last main message is 'The sooner the better'.

4.4: Benefits of peer support

4.4.1: Fear of the unknown

Stroke survivors and professionals illustrated that an individual may be fearful when undertaking a new exercise class following a stroke. Fear was associated with a lack of knowledge and experience of an exercise after stroke class. Stroke survivors commonly reported that individuals might feel nervous and anxious about coming to the class. Physical and emotional stroke impairments contributed to individuals being unsure if they would be able to cope with the class. Coupled with this was reduced confidence which many stroke survivors reported following their stroke. These

concerns were reported by stroke survivors who had previous experience of exercise as well as those with no previous experience of exercise. The variety of concerns individuals may have, is illustrated in this quote from Susan who describes her feelings about starting the class.

“Now.....I was quite anxious about it because....just the whole stroke thing you know, you lose your confidence and it’s not just a weakness, it’s just lots of other things you know.” (Susan, stroke survivor).

Similarly, professionals were also aware that it may be daunting attending the class and that they have little understanding in how individuals perceive the class prior to starting. Peter explains this in the following quote.

“It think it’s really setting (pause) I suppose expectations and guidance cause actually on a phone call you getting introduced that your gonna come to an exercise after stroke class but really on the other end of the phone what does that mean to them?” (Peter, professional).

The concept of a stroke survivor providing support was however viewed as a method of reducing this fear. Many participants believed a PAC could facilitate individuals attending the class. This was because the PAC could conceivably provide re-assurance, confidence, emotional support and general information to individuals attending the class.

The professional participants also hoped that the PAC could support stroke survivors to undertake an additional exercise session out with the EAS class. They felt it would be beneficial if the concept could be developed so that stroke survivors could increase their frequency of exercise, through additional gym attendance or functional activities such as walking, with the PAC. Using the PAC to aid stroke survivors’ transition from EAS to other leisure classes was also highlighted. Professionals felt that stroke survivors may be less fearful of progressing to exercise that is not in a stroke specific class if they had a fellow stroke survivor to go with. The stroke survivors had mixed views on whether a PAC would benefit this. Some felt that it might aid themselves or other stroke survivors to be motivated to participate in additional exercise. One stroke

survivor however was not keen on this, as she would not want to be depended upon by another individual and felt that this level of commitment was too great.

4.4.2: All in the same boat

This key message refers to the appreciation of many stroke survivors that they have had a shared experience with other stroke survivors. They were aware that they had all had a stroke and, although they acknowledged that strokes affected individuals differently, they felt that they had all been through a similar experience. This was indicated by Frank when he described what he would tell people who are starting the class.

“...everybody has had a stroke, we’re no all looking at you, ken your no an outcast, we’re all the same and we do like a wee laugh eh.” (Frank, stroke survivor).

This shared experience linked closely to the concept of the PAC. Stroke survivors widely believed that it was important that someone who had had a stroke undertook the role. A fellow stroke survivor would have the experience of a stroke and therefore have a better understanding of the challenges facing stroke survivors. It was reported that this would ensure a more personal approach. In addition, contact with an individual who had been through a shared experience could provide re-assurance, which might encourage stroke survivors to attend the exercise class. The significance of incorporating a stroke survivor in the PAC role is described by George.

“Well, it is important that the person you talk to has had experience. It’s no good sending someone along who’s sat in an office and ticking boxes and they’ve been given some role to go along and be this, taking over this role, but they must have had some first hand knowledge.” (George, stroke survivor).

This belief is supported by the following quotes from Frank and Susan.

“Aye well, to have somebody that’s had a stroke’s better somebody like that than somebody who’s no had a stroke telling them eh...or supporting them.” (Frank, stroke survivor).

“...so it’s good for somebody who’s went through all the issues that they’re going through to say that is how I felt, you’re gonna be fine.” (Susan, stroke survivor).

Many stroke survivors also reported the benefits of exercising with fellow stroke survivors. Several stroke survivors reported that it allowed them to compare themselves to other stroke survivors. This comparison included how stroke had affected others and the level of recovery other stroke survivors had made. Being able to see others improve through exercise was considered to be motivating to individuals. Some stroke survivors also felt that being able to speak to individuals who could substantiate the benefits and progress they had made at EAS would encourage them to continue with the exercise class. This is illustrated in this quote from Andrew who describes the possible support gained from a fellow stroke survivor.

“It might be because if someone ah, particularly someone who has done it and has found it successful you know and beneficial to go and meet the person and convince them that the exercise really well worthwhile...(pause)...that could be a motivating factor which would help.” (Andrew, stroke survivor).

Peer support provided by fellow stroke survivors was therefore strongly supported. The perceived shared experience explained the view that a stroke survivor should undertake the PAC role and was considered to be a facilitator to exercise following stroke.

4.5: Thoughts on the role

4.5.1: ‘A good idea but not for everyone’

This key message refers to participants’ views on the suggested idea of a PAC supporting stroke survivors. The majority of stroke survivors and professionals felt the concept was a good idea. Stroke survivors’ reported that it would be useful to have somebody to talk to about the class who had already attended. They also felt a PAC could provide beneficial support and information substantiating the concept as a positive idea. Typical responses supporting the idea of a PAC from stroke survivors were:

“That’s a good idea that.” (Frank, stroke survivor).

“I think that would be a great support from somebody” (Susan, stroke survivor).

Most of the professionals also voiced positive views on the idea. They reported that they had experienced positive results using similar concepts within other services. They felt that the concept has potential to be used within the EAS service and perceived that the benefits could be providing a more person centred approach, aiding participant retention in EAS and improving the transition between EAS and other leisure services.

Nobody thought the concept was a bad idea, however it was not deemed suitable for everyone. Some stroke survivors felt it was not needed for them personally. Some stroke survivors reported that support from a stroke survivor was not needed for them as an individual and that they would rather get support from the instructor. In addition, some stroke survivors and professionals felt that a level of informal support already existed in the classes. They felt that support was provided naturally therefore doubting the need for further support to be provided by a PAC. Ethel describes her feeling that this would not be helpful to her:

“Well.....personally I wouldn't particularly go for that.” (Ethel, stroke survivor).
Ethel expands on this by saying. *“I would feel probably eh, that a member of the class or somebody wouldn't have enough, lets say um background knowledge to support me.” (Ethel, stroke survivor).*

The feeling that the concept would not be needed for everyone is further supported by Andrew as the following quote illustrates:

“A little bit doubtful because you know going by my own experience I just came to the class, [instructor name] introduced it and off we went. That was it. The people were very friendly and I think that helps, em but I didn't find any lack of help or any need from that point of view.” (Andrew, stroke survivor).

Although some stroke survivors felt it was not needed for them individually, they did all perceive that it might be a good idea for others. It was widely appreciated that everyone who has had a stroke is different and that different people benefit from different things. Even if individuals felt that a PAC would not be needed for themselves, they were appreciative that it may be beneficial to others. This view is described by Julie:

“Yeah that would be good. It’s not a problem for me anyway but, well for me personally it’s not a problem but yeah that would be a good thing for probably a lot of people.” (Julie, stroke survivor).

Susan emphasises the potential benefits of the idea for individuals as she described her experiences of her first session.

“I got so worked up and all upset and anxious about coming so that would be a brilliant idea.....because if there was somebody there I would probably never have got so upset.” (Susan, stroke survivor).

In addition to viewing the concept as a good idea, three participants also speculated that they would volunteer to undertake the role if asked. The key reason for volunteering for the role related to being able to provide help and support to others in a similar situation. In addition, one stroke survivor perceived personal benefits of having a role to do and gaining on going motivation to continue to exercise. Some stroke survivors reported that they would not want to undertake the role. The reasons for not volunteering were lack of time and concern that they may find it difficult due to their impairments following stroke. The professional participants thought that stroke survivors may volunteer to undertake the role. They felt the reasons for volunteering may be to help others who have had a similar experience and to “give something back” to the service or to others attending the class.

This key message therefore illustrates participants’ opinions on the concept of a PAC supporting stroke survivors to exercise. The majority of participants considered it to be a good idea. The potential benefits were suggested however the perception of individuals was that it might not be desired by everyone. Overall, both stroke survivors and professionals felt that offering this support to individuals attending EAS would be beneficial. Individuals could then decide if they wanted to engage with it or not. This would allow a PAC to be accessed by those who need it whilst not imposing it on those who do not.

4.5.2: ‘The right person’

The ‘right person’ refers to the type of person who could undertake this role. Both stroke survivors and professionals alluded to the idea that certain individuals would be better in the PAC role than others. Several traits were mentioned with the key areas relating to an individual’s personality and an individual’s level of impairment and recovery following their stroke. The personality required for an individual to be the ‘right person’ included a variety of different personality traits. These included a sense of humour, intelligence, being outgoing, confident, easy going, caring, patient and friendly. Sarah summarises this ‘right person’ as:

“naturally a people person.” (Sarah, professional).

For the concept of a PAC to be successful and beneficial it was suggested that the individual should ideally demonstrate qualities such as these. It was highlighted that it would not be easy to find the ‘right person’. Some stroke survivors reported a reduction in confidence following a stroke and that this might prevent them considering such a role. Similarly, professionals identified that not every stroke survivor would be the ‘right person’, which may pose a challenge in how to recruit to this role. Most professionals and some stroke survivors felt that a process should be in place to ensure appropriate individuals are selected for the role however how this would be done was not defined.

The potential difficulties of finding the ‘right person’ are summarised in this quotation from George.

“In getting somebody that’s going to be up and chatting, able to stand up and say I’m here to help you, you’ve got to be a wee bit outgoing for this and eh to get that right person, I think you’d maybe only get about one in twenty that’s had a stroke.”

(George, stroke survivor).

Some stroke survivors mentioned the level of impairment and stage of recovery following stroke as they felt that this might influence an individual’s desire to undertake the role of PAC. It was acknowledged that physical impairment following a stroke can vary and that individuals who attend the classes are at different stages in their recovery

following stroke. Although some felt this may influence an individual to volunteer for the role, participants did not appear to suggest that it would influence an individual's ability to perform the role.

4.5.3: 'The job they could do'

This relates to the practical aspects of the concept of a PAC. Participants suggested possible duties that the role could encompass. Some of the professional group had a clear vision of the role that the PAC could undertake. They suggested that the individual could 'meet and greet' new participants, providing information on how the class runs, practical aspects of the leisure centre such as changing facilities and providing a link contact for the new participant. Claire describes this role as being a "friendly face" allowing "the softer stuff" to be provided. These suggestions were based on the belief that increasing the communication before starting the class would allow participants to have accurate expectations of the class and help them to feel more at ease. Peter demonstrates this belief when he said:

"I think it's setting that boundary and I think that for most people coming into new any type of exercise it's expectations that worry them most that they're going to fail or they can't achieve what we're kinda asking them to do already in a way so I think it's quite nice that prior to the class they're getting the changing room scenario stuff but also it's about the class this is what we do in the class so they already have an understanding before the instructor just kicks off." (Peter, professional).

One professional expanded this response and highlighted that it was important for the role to be well defined. This was to ensure that it provided more than what happened naturally already.

In line with the professionals, the stroke survivors had similar thoughts on what the role could undertake. Stroke survivors broadly agreed that being offered the opportunity to meet a volunteer prior to starting the class would be beneficial. They felt that this would allow information about the class to be shared in respect to what the class is like, how the class works and what the volunteer's experience of the class had been. The benefits of incorporating the PAC in this way were that it would enable a more personal approach to be applied. In addition, it would provide knowledge and re-assurance to

individuals undertaking a new activity. These benefits are described in the following quote from George.

“Well, it would be much more personal, it would give you a....you’re coming into the unknown for this. Not that it is anything high powered, I mean if you’ve not been used to things you think oh god are they all in leotards and they’re all jumping about, have I got to put shoes on, what, I’ve never had a tracksuit in my life have I got to.....they’ll just tell you all that it would be far easier. Come and speak to me or I’ll talk to you on the phone that would certainly bring it a lot closer.” (George, stroke survivor)

Both groups highlighted the importance of boundaries for the role. Many participants felt that the PAC should not be involved in helping directly with the exercises during the class. It was widely viewed that the individual did not have the expertise, knowledge or training for this task and that this was the role of the exercise instructor. Some stroke survivors however felt it was suitable for the PAC to provide encouragement and support during the exercises if this was acceptable to the individual. This was supported by most professionals who suggested that the PAC could provide support by shadowing an individual around the class, undertaking the same exercise at the same time. Some professionals also felt that the individual could provide exercise reminders to stroke survivors who needed this. However not everyone agreed with this response. Some stroke survivors tended to have a more negative view to a PAC providing support as they felt that it was important to undertake the exercises independently.

Challenges with the implementation of the PAC role were also described. Participants were unsure as to how the concept would be applied to the current EAS service. These logistical challenges raised questions such as whether a PAC would be linked to one class or whether a PAC would cover more than one class or if a PAC would be linked to each individual. Furthermore, some stroke survivors believed that differing ages and genders should be considered in implementing the role. They believed that matching individuals of similar age and/or gender would enable optimal support to be provided. A further aspect that was discussed related to the size of the class. The role of a PAC was considered by some stroke survivors to be required only in larger classes. The

challenges described were seen as uncertainties by participants in relation to the job the PAC would do.

4.5.4: ‘Say it as it is’

This key message refers to the suggested title of PAC. The stroke survivors broadly agreed that this title was not suitable. They felt this title could be off putting, in particular the word ‘champion’, which they felt might infer a competition or an individual excelling at something. Indeed, most stroke survivors felt that a title was not required and that having a very informal approach would be better. They felt that the best method was to describe the person for what they are which the researcher has conceptualised as ‘say it as it is’. This is described by Susan who said:

“Yeah, I don’t know I don’t think it needs a title because if.....if you....in the....see when I was coming here if [instructor name] had said to me oh we’ve got the sort of champion or a volunteer or supporter that would put me off probably I would just think well we’ve got this is [name] or [name] or somebody they’re recovering from a stroke can you know, do you want to have a cup of tea or a blether, keep it....I would just want to keep it like that.” (Susan, stroke survivor).

In contrast, there was one stroke participant who viewed the title positively. This belief was due to the word champion highlighting a feeling a success and achievement associated with recovering from a stroke. She explained why she thought it was a good title:

“Because we have em succeeded in em carrying on after a stroke rather than just sitting doing nothing, it’s good to keep going or given the opportunity to keep going rather cause it’s sometimes hard to get motivated to do it yourself.” (Julie, stroke survivor).

The views from the professional participants were less defined with regards the title. They were familiar with the term champion and aware that it was well used and topical within the current exercise setting, which appealed to one of them. However, they were very considerate of the feelings the stroke survivors had made and most felt it would be best if the stroke survivors and service users created the title themselves.

Both groups were however willing to suggest alternative titles to PAC. These were “*supporter*”, “*mentor*”, “*buddy*” and “*physical support person*”.

4.6: ‘The sooner the better’

This key message was illustrated in relation to exercise following stroke in general. It is less specific to the concept of PAC but was raised by several stroke survivors so deemed relevant to this research. It refers to the need to access exercise as quickly as possible following a stroke. Some participants reported that they felt it was key to be able to begin exercise as soon as possible. They believed that this would optimise their chances to recover following a stroke. In order to achieve this, it was important that an efficient process existed in accessing a programme like EAS. It was also highlighted that receiving information regarding the service would be helpful. Some stroke survivors voiced frustrations in the process they had undergone prior to starting EAS as they felt this had delayed them starting the class. This is described in the following quote from Andrew who explained his experience of accessing the exercise after stroke class:

“Researcher: So it just took a little bit of time to get started?”

Andrew: Which was unfortunate because I think the earlier you start, the more effective they are. So that delay is really quite important in my opinion.” (Andrew, stroke survivor).

Efficient access to supportive services was therefore determined to be a key factor in facilitating exercise following stroke.

4.7: Summary

Three key messages were identified in relation to the PAC concept and exercise after stroke in general. These were: ‘Benefits of peer support’, ‘Thoughts on the role’ and ‘The sooner the better’. Participants’ perceptions on whether there is support for the concept and aspects that may facilitate or challenge implementation of the concept have been gained. In addition, there is an indication that this concept may have benefits in facilitating stroke survivors to exercise. Overall, these messages provide valuable information on the concept of incorporating a PAC to support exercise following stroke. These findings will be discussed further in chapter 5.

Chapter 5: Discussion

5.1: Introduction

This chapter will discuss the findings from this study and consider them in relation to relevant existing literature identified in chapter 2. The importance of the findings will be discussed in relation to their clinical significance, the implications for service delivery and further research. The contribution of the findings to the evidence base will also be discussed with consideration given to the strengths and limitations of the study. The objectives of the study will be discussed with consideration to the three key messages, ‘benefits of peer support’, ‘thoughts on the role’ and ‘the sooner the better’, and the findings as a whole and their relationship to barriers and facilitators to exercise considered throughout. Although the objectives will be discussed individually there is a degree of overlap between them.

5.2: Benefits of a peer support

5.2.1: Support for the PAC concept

The findings from this study show that both stroke survivors and professionals support the concept of incorporating a PAC to support exercise following stroke. However, only stroke survivors feel that it would not be deemed suitable or indeed required for every individual as highlighted by ‘a good idea but not for everybody’. This was due to individuals’ feeling they would rather be supported by an exercise professional and that an informal level of support already existed in the class due to the nature of group exercise. This study therefore illustrates that stroke survivors have unique individual needs with regards the level of support required to participate in community based exercise. This issue is highlighted by Poltawski et al (2015) who found that stroke survivors have varying preferences and needs in relation to exercise support. Therefore, the introduction of a PAC could allow more flexible and specific support for individuals. This also reflects the views of the exercise professionals who thought a possible advantage of the PAC concept would be that the service could be developed to allow provision of a more personalised approach for individual stroke survivors. This is reinforced by existing evidence that highlights the need for community based exercise services for stroke survivors to be flexible, person-centred and responsive (Morris et al, 2015; Reed et al, 2010). As a result, the introduction of a peer support could potentially allow the EAS service to become more tailored to individual needs with support being available at an individual level as required.

5.2.2: Provision of peer support

The findings show that stroke survivors consider it to be essential that the PAC is a fellow stroke survivor. This belief is strongly linked to peer support and the perceived shared experience stroke survivors have with one another. This is illustrated in the ‘all in the same boat’ message which interestingly, has been previously reported by Mead (2005) in relation to stroke survivors undertaking exercise. Mead (2005) also used the term “in the same boat” to emphasise the benefit of social interaction gained by participating in a shared activity. The current study findings support that stroke survivors feel that shared experience is a key aspect to ensuring optimal exercise support is provided. This is also in agreement with findings from Amarshi et al (2006) who reported that stroke survivors benefit from relating to others with similar experiences, particularly as this enables an opportunity to share similar issues that other stroke survivors are experiencing. Furthermore, there is evidence that some stroke survivors feel ‘connected’ to other stroke survivors, and enjoy the opportunity to share personal stories about their stroke experience (Schouten et al (2011)). Although providing peer support from a fellow stroke survivor is considered useful, it could be argued that the shared experience stroke survivors perceive as being beneficial may already be happening through group participation rather than individual support. Indeed, the current study findings highlight that some professionals feel a level of informal peer support already exists in the exercise class. This is consistent with previous literature, which widely supports the benefits of social support through exercising with other stroke survivors (Kopunek et al, 2008; Morris et al, 2012; Nicholson et al, 2013). Group exercise has been shown to provide social support to individuals facilitating exercise, social and leisure participation following stroke (Amarshi et al, 2006; Kopunek et al, 2008; Poltawski et al, 2015). In addition, qualitative research by Patterson and Ross-Edwards (2009) highlighted the strong connection stroke survivors can develop with each other through group exercise thereby creating a sense of belonging and community for individuals. It is apparent therefore that social support and the perception of a shared experience occur through participation in group exercise. Although participants in this study viewed the PAC concept positively, further work is required to establish if introduction of the PAC would add support to individual’s experience of the programme.

The findings from the ‘all in the same boat’ message also illustrate the perceived benefit of stroke survivors being able to compare themselves to other stroke survivors during group exercise. Participants highlighted that seeing how stroke has affected others; the recovery others have made and seeing others improve through exercise were motivating aspects of the EAS class. These results are consistent with those found in other qualitative research studies that found the benefits of increasing self-confidence and self-identity through group exercise (Reed et al, 2010; Schouten et al, 2011). Comparison to others therefore appears to occur during group exercise and can provide motivation and encouragement to attempt new exercises and activities (Patterson and Ross-Edwards, 2009). Therefore, a PAC could potentially voice the progress they have made and highlight the benefits of exercise they themselves have experienced, to encourage participants who are starting or being encouraged to start the EAS programme. This would also allow individuals an opportunity to compare themselves directly to a fellow stroke survivor thus accentuating the benefits of peer comparison and ultimately facilitating exercise participation. Overall, the benefit of peer support in both group exercise and at an individual level is therefore further supported by the findings of this study.

5.3: Effect on stroke survivors’ exercise experience

5.3.1: Psychological benefit

Both stroke survivors and professionals illustrated that fear of the unknown may be experienced in relation to attending EAS. Psychologically, the majority of stroke survivors acknowledged they were fearful when undertaking a new exercise class following stroke. However, the findings show that a PAC could provide re-assurance, improve confidence and reduce fear/anxiety. One of the main benefits of a PAC would therefore be the provision of emotional support to individuals. These findings are therefore extremely positive as they suggest that a PAC could conceivably reduce the barrier of fear and ultimately act as a facilitator to exercise.

The ‘fear of the unknown’ message found was also associated with a lack of knowledge and experience of stroke specific exercise classes, coupled with the concern of the varied physical and emotional impairments that individual stroke survivors manage day to day. Anxiety and vulnerability have been reported previously as a psychological

barrier to physical activity with stroke survivors' feeling concerned about getting out the house and socialising (Carin-Levy et al, 2009). It is not uncommon for stroke survivors to have negative feelings after stroke including being uncomfortable, fearful, self-conscious and socially anxious which can limit participation in physical activity (Morris et al, 2012; Nicholson et al, 2014). Concern regarding not knowing how to perform or not feeling capable of performing exercises has been highlighted as preventing engagement in physical activity (Damush et al, 2007; Simpson et al, 2011). In addition, reduced physical ability can lead to lack of confidence to undertake exercise (Simpson et al, 2011), lack of participation in exercise (Nicholson et al, 2014) and difficulties engaging in social activities (Reed et al, 2010). Therefore, participation in a new exercise class presents stroke survivors with an unknown situation where they may be concerned about their own abilities and whether they are capable of performing the required exercises resulting in a perceived feeling of fear. In addition, pre-stroke experience of exercise appeared to make little difference to the participants' confidence to exercise post-stroke which further illustrates the negative impact stroke has on stroke survivors' ability to participate in exercise. It was felt by all participants that the presence of a PAC would perhaps be able to reduce the fear of the unknown thus enhancing the stroke survivor's experience of community based exercise and potentially improving engagement. This finding was indeed important to all participants in the current study who had all had the experience of attending a new exercise class and therefore can provide credible evidence.

A strength of this study is that it is the first to determine that stroke survivors feel that having increased support from a PAC could be beneficial for individuals who lack confidence. The findings highlight that stroke survivors commonly feel reduced confidence more generally following stroke, a perception that is closely associated with the 'feeling of fear'. This is similar to findings by Reed et al (2010) who found that stroke survivors reported reduced physical and psychological confidence that limited them to regain their social role and perceived purpose in their community. Indeed, reduced confidence has been documented to impact directly on exercise participation and engagement following stroke (Morris et al, 2012; Morris et al, 2015). Previous research has demonstrated that attending a stroke specific rehabilitation programme can provide an opportunity to increase confidence for stroke survivors (Patterson and Ross-Edwards, 2009; Schouten et al, 2011). However, the evidence from this study differs

slightly from this, as improved confidence was not linked solely to participating in an exercise class. Stroke survivors highlighted that incorporating a PAC in addition to the peer support provided from group exercise could be beneficial for individuals who lack confidence. The level of support identified by the stroke survivors was therefore closely linked to how confident they felt following stroke. However, the findings should be considered with caution due to potential bias from the participants, as the stroke survivors in this study are already participating in an exercise class. Obtaining the view of stroke survivors who are not yet involved in stroke specific exercise programmes would therefore be warranted and a consideration for future research.

As stated above feeling anxious, concerned about one's abilities and having reduced confidence is very likely to affect an individual's participation in exercise following stroke. The findings of fear and reduced confidence are compatible with previous research (Morris et al, 2012; Nicholson et al, 2014; Reed et al, 2010). However, there have been several other psychological barriers to physical activity identified in the literature that were not found in this study such as: lack of motivation, lack of control and health concerns (Damush et al, 2007; Morris et al, 2012; Nicholson et al, 2013; Nicholson et al, 2014). Although these do not conflict with the findings from this study it shows that there are significantly more psychological barriers to physical activity than those identified in this study. This may be due to the fact that this study explored the specific concept of a PAC rather than general barriers and facilitators to physical activity. Furthermore, the stroke survivors were currently undertaking exercise suggesting they may not have been affected or have already overcome other psychological barriers identified in the literature.

5.3.2: Supporting additional exercise

The findings highlight that professionals hope a PAC could support individuals to undertake additional exercise out with the EAS class. They viewed increased frequency of exercise as beneficial for stroke survivors' recovery. This is supported by evidence, which recommends regular engagement in exercise/physical activity two or three times a week (Billinger et al, 2014). In addition, they hoped that experience of exercise out with the EAS class could aid transition to exercise opportunities that are not specific to stroke survivors, thereby helping to sustain exercise after the stroke specific programme had finished. Interestingly, the stroke survivors had mixed views on undertaking

exercise out with the class with a fellow stroke survivor. Some participants' felt it could be positive, aiding their motivation to exercise where as others felt it would be too great a commitment. This is similar to previous research that suggests transition to mainstream classes may not be desired by every stroke survivor and some prefer stroke specific programmes (Poltawski et al, 2015). However, current services experience financial and capacity limitations so a key aspect of service delivery involves considering transition to other mainstream services and encouraging long term participation in physical activity (Rimmer, 2012). Therefore, methods to improve individual exercise participation are important. Sustaining motivation through social support has been shown to be an external factor in maintaining commitment to exercise (Poltawski et al, 2015). Furthermore, research by Poltawski et al (2015) explored factors that influence the motivation of long term stroke survivors to engage and maintain involvement in physical exercise. They highlight the individual variation in preferred exercise methods by stroke survivors. For instance, for some the group setting was preferred compared to individual exercise whereas for others this was off-putting for a variety of reasons including not wanting to mix with other disabled people and concern about the impact of their physical impairments in a group setting (Poltawski et al, 2015).

Providing on-going peer support was deemed extremely important by stroke survivors in sustaining motivation to exercise (Poltawski et al, 2015). Service delivery methods that may aid participants to sustain motivation were also discussed such as increased self-management strategies, signposting and transition to mainstream exercise classes and on-going programmes (Poltawski et al, 2015). Sustaining exercise is a complex issue, however, it was clear from the findings that transition to mainstream exercise is unique to individuals which makes service delivery challenging. Although, providing support from a fellow stroke survivor could be an option, this study's findings indicate that it is not appropriate for everybody. It is therefore unclear whether a PAC would be effective in supporting additional exercise and further research following implementation of a PAC would be beneficial to determine whether it would sustain exercise longer term post stroke.

5.4: The PAC role

5.4.1: Who would undertake the role?

The PAC should be a stroke survivor, as discussed in section 5.2.2. The findings also highlight that both stroke survivors and professionals have perceptions on the type of person who would be appropriate for this role and described potential difficulty recruiting a suitable individual to undertake the role. It would appear that finding ‘the right person’ may therefore prove to be a challenging aspect of the PAC concept. The findings from stroke survivors and professionals that there are desirable attributes for individuals who are providing support is to some extent supported by existing research. A randomised controlled trial by Parent and Fortin (2000) selected peer volunteers based on their ability to encourage individuals by sharing their enthusiasm and achievements after cardiac surgery. A strength of the current study is that it has illustrated additional characteristics that are sought after by stroke survivors and professionals such as having a sense of humour, intelligence and being confident, patient and friendly. As this study focussed specifically on the concept of individual peer support this may have enabled the concept to be explored in greater depth, which may account for this more detailed finding. Gaining this knowledge is extremely useful in that it may assist professionals in the recruitment of the most appropriate individuals for the PAC role.

In addition to the desirable characteristics, the findings highlight that a process of selection would be required to recruit stroke survivors to the PAC role. Stroke survivors and professionals thought that the option of volunteering should be offered to all individuals who have had a stroke and have participated in the EAS class. Individuals who then volunteer to undertake the role should be considered by the exercise professionals to determine their suitability for the role. Consideration of training suitable individuals would then need to be considered as existing literature highlights that for peer support interventions to be successful, training of peers is required to ensure they are competent in the peer support role (Colella and King, 2004). The nature of this training is not however well understood (Funnell, 2010). Therefore, variation in training exists in the literature and has included aspects such as development of communication skills, how to deliver an exercise intervention, peer roles and responsibilities and principles on interaction with the participants (Clark et al, 2012; Colella and King, 2004; Latimer-Cheung et al, 2013; Parent and Fortin, 2000). The

need to train individuals was not found specifically in this study, although one concern raised was the lack of knowledge individuals might have. Based on the evidence however, provision of training would appear to be an area that needs to be considered if the PAC role is to be implemented. In addition to this, the exercise professionals highlighted the need for volunteers to complete the appropriate government documentation and checks to ensure safety. This process and the cost that is associated with it is a potential barrier to the recruitment process. These aspects would therefore need further investigation to ensure appropriate clinical application of the concept.

Therefore, although both stroke survivors and professionals thought that some form of selection process was indicated, the findings only provide a suggestion of how this could be done. This is shown in figure 5.1.

Figure 5.1: Suggested process for recruiting a PAC based on the current study's findings.



The findings do not however provide specific information on all the aspects which need addressed in the recruitment of a PAC. This is consistent with previous research where limited information regarding the recruitment of peer volunteers is provided (Clark et al, 2012; Latimer-Cheung et al, 2013; Parent and Fortin, 2000). Further consideration by service providers together with further research on the PAC concept is therefore required.

5.4.2: Why would an individual undertake the role?

The findings highlight a mixed response from the stroke survivors on whether they would undertake the role. Being able to help others in a similar situation, having a role to do and maintaining motivation to exercise were voiced as reasons to be a PAC. This was similar to the professionals who also thought that an individual may want to help

other stroke survivors and ‘give something back’ to a service that has benefited their recovery. Reasons for not undertaking the role were lack of time and the impact of stroke impairments, which may make the role challenging. The potential for stroke survivors to volunteer for the PAC role is therefore likely to vary depending on an individual’s levels of motivation and their perceived barriers to exercise. This is in line with previous research that has shown that maintaining motivation to exercise is challenging for stroke survivors (Poltawski et al, 2015). It is also consistent with evidence that illustrates lack of time and the influence of physical impairments to be barriers to exercise (Jurkiewicz et al, 2011; Nicholson et al, 2014; Rimmer et al, 2008). Despite this, a benefit of the PAC role may be that it facilitates motivation by offering individuals with a specific role. Research has indeed highlighted that individuals’ report a perceived lack of purpose and loss of social and professional role following stroke (Reed et al, 2010). Provision of purpose and role within an exercise programme may therefore be beneficial, a finding supported by Nicholson et al (2014) who highlighted social role and identity as a perceived facilitator to exercise. However, this would need to be researched further with individuals who would consider undertaking the PAC role.

5.4.3: What would they be called?

The ‘say it as it is’ message identified, highlights that the suggested title of “physical activity champion” is widely rejected by the stroke survivors. The professionals illustrated mixed views related to the title, but ultimately felt that any title should be based on the stroke survivors’ views. Although alternative title suggestions were provided such as: supporter, mentor and buddy, the findings highlight that stroke survivors feel a title for this role is not needed. Previous research that incorporated individual peer support has used the terms “peer mentor” (Latimer-Cheung et al, 2013) and “lay mentor or peer” (Clark et al, 2012). The term “buddy” has also been documented in the literature in relation to suggested methods of providing support (Kopunek et al, 2008; Morris et al, 2012). However, this is the first study to explore the views of stroke survivors and professionals in this area who both feel a title is not required.

5.4.4: What would the role involve?

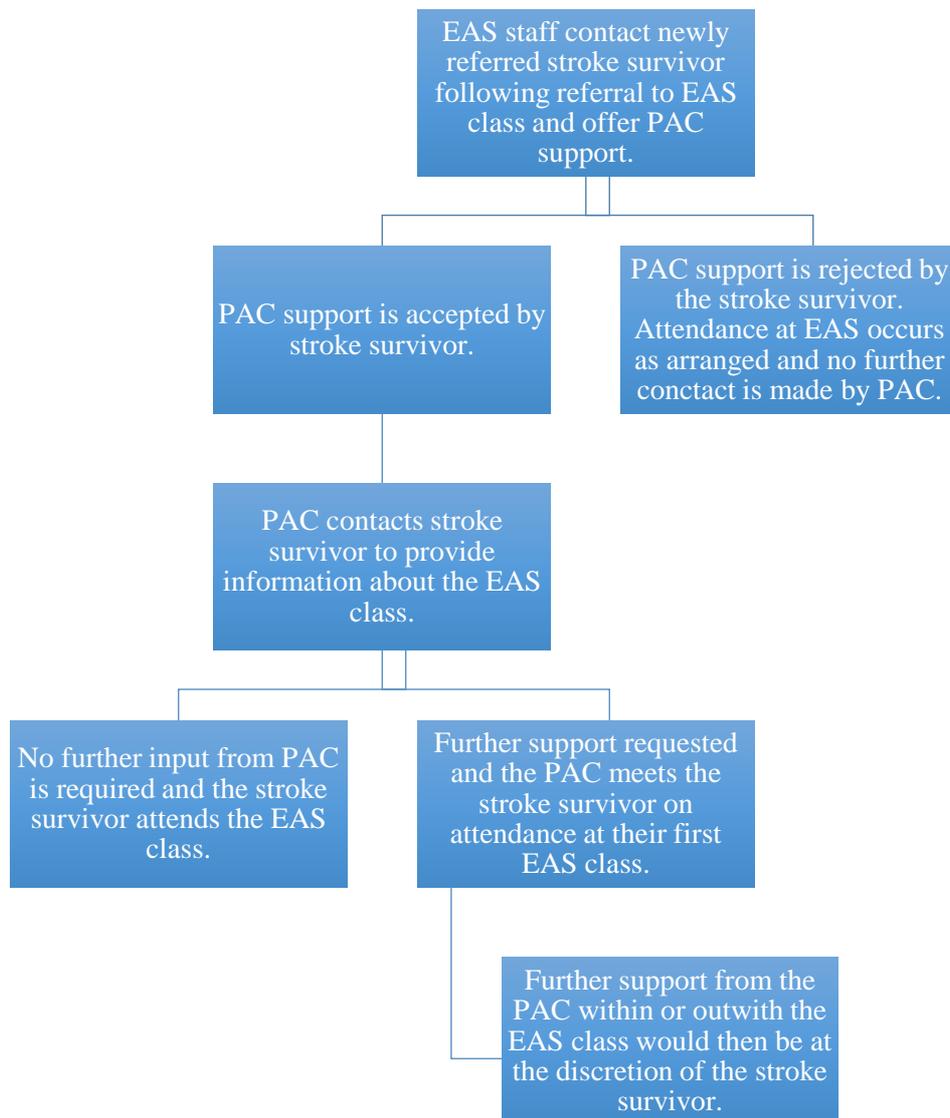
The findings show that both stroke survivors and professionals have clear views on the possible duties and responsibilities of a PAC. Both groups thought that the PAC could provide practical support to stroke survivors. It was also suggested that stroke survivors who are newly referred to EAS could be offered contact from the PAC with the option to accept or reject the offer on an individual basis. It was felt that the PAC might initially contact the stroke survivor prior to their first session to offer useful information that would enable individuals to be better prepared for attending the class. Meeting the individual before their first session would also provide a friendly face prior to starting the EAS programme. This may aid individuals to have increased knowledge and accurate expectations thus facilitating engagement in exercise after stroke. This is consistent with the literature as knowing what to do appears to be a significant influence on stroke survivors' attendance at exercise programmes (Morris et al, 2012; Rimmer et al, 2008). Indeed, a lack of knowledge has been reported as a barrier to physical activity as stroke survivors do not know where or how to exercise (Brogardh & Lexell, 2012; Rimmer et al, 2008; Rimmer, 2012;). In addition, a qualitative study stated stroke survivors perceived exercise being too difficult and exercise not improving their condition as barriers which would negatively affect their participation in physical activity (Rimmer et al, 2008). Other barriers to community based exercise include lack of information on accessible facilities and programs and the general perception that fitness facilities are unfriendly environments for people with disabilities (Rimmer, 2012). This is consistent with the opinion that services should focus on interventions which increase knowledge about exercise centres and physical fitness following stroke to encourage ongoing exercise once stroke rehabilitation has been completed (Brogardh and Lexell, 2012). Incorporating the PAC to provide friendly, practical information could potentially reduce these barriers aiding participation and possibly longer term transition to exercise in the community.

The findings also identify that potential boundaries should be associated with the role. Both stroke survivors and professionals feel that the PAC should not be involved in exercise prescription or instruction. However, the professionals feel that there could be the option for the PAC to go round the class with the stroke survivor to provide encouragement. This might only be undertaken for the first session and further involvement would then be on an individual basis dependent on an individual's desires.

These findings are consistent with findings by Poltawski et al (2015) who highlighted that stroke survivors preferred trained exercise professionals to supervise exercise due to their knowledge and understanding of stroke. In addition to the boundaries of the role, the ‘job they could do’ message illustrates potential challenges associated with the PAC role. Both stroke survivors and professionals were unsure as to how best to implement the role across the EAS service with various logistical issues raised. Further consideration and research of aspects relating to implementation of the role would therefore be required.

Gaining this information on the role of the PAC is extremely useful when considering how the concept could potentially be incorporated in the current EAS service. Although it is possible to draw some tentative conclusions on the role of the PAC it should be highlighted that both stroke survivors and professionals had difficulties in forming defined views on how best to implement and carry out the role due to the hypothetical nature of the concept. However, the findings do offer views of how a PAC could be implemented in a community based exercise programme as shown in figure 5.2. Further discussion would however clearly be needed with service providers to ensure this is practical and realistic.

Figure 5.2: Suggested method of how the PAC concept could be implemented in the EAS class.



5.5: Service delivery considerations

5.5.1: Timely access

The findings show that early access to an exercise service following stroke is highly valued by stroke survivors. They feel that this would enable them to start exercise as soon as possible and that this in turn will help their ability to recover from their stroke. Despite the clear view of stroke survivors illustrated in ‘the sooner the better’ message, this issue was not raised by the professionals. The PAC may enable additional communication with the stroke survivor however it is unlikely that it will affect the speed of access to the EAS service. Despite this, the experiences of the stroke survivor participants in this study highlight a desire for responsiveness and ease of access in

relation to community based exercise services. This relates to existing recommendations for service delivery for long-term stroke rehabilitation that identify the importance of access to specialist, evidence-based, stroke specific community services that allow on-going physical fitness training (SIGN, 2010; Scottish Government, 2014). Furthermore, the value of community exercise programmes in facilitating community participation and helping stroke survivors to positively rebuild their lives has been demonstrated (Patterson & Ross-Edwards, 2009; Reed et al, 2010). Considering the well-established benefits and the national recommendations, it is reasonable therefore to anticipate that these services should be delivered in a timely fashion. These are therefore aspects that should be considered by service providers to allow delivery of the EAS service to be optimised.

5.5.2: Feasibility of a PAC

This study provides a suggestion for how to incorporate peer support within the community exercise setting with the findings providing practical knowledge and understanding supporting its application and theorising its implementation (see section 5.4). Establishing the feasibility of this concept is however difficult as implementation has not been tried before. The literature does however provide evidence for peer support facilitating exercise in both stroke and other conditions (Damush et al, 2007; Hui et al, 2006; Isaksen & Gjengedal, 2006; Latimer-Cheung et al, 2013; Patterson & Ross-Edwards, 2009; Ravenek and Schneider, 2009; Simpson et al, 2011), which suggests that the PAC concept should be taken forward. However, there is no evidence of an existing model within the stroke population and marked differences exist between stroke and the other clinical populations explored in the research (Simpson et al, 2011). The challenges of the stroke population relate to the complexity of stroke impairment including the potential for significant physical, cognitive and communication difficulties (Simpson et al, 2011). The findings from the current study highlight that implementing the concept within the EAS service may however pose fewer challenges as in order to undertake the programme stroke survivors need to have a moderate level of mobility and minimal cognitive or communication impairments. It is therefore arguable that this environment may be the most suitable for implementing the PAC concept. Indeed, if the PAC concept has the potential to increase confidence, as discussed in section 5.3.1, it may result in it being an effective addition to a stroke community exercise programme. Therefore, it would appear that a PAC is a feasible

option to support stroke survivors to undertake community based exercise however further research would be needed to determine whether the PAC would improve health and well-being and long term outcomes after stroke.

5.6: Study strengths and limitations

The findings from this study must be considered in light of the research's strengths and limitations. Firstly, this study is unique in exploring the views of stroke survivors and professionals on a potential method of individual peer support in a community based exercise programme. The author is not aware of any other research with regards individual peer support and exercise following stroke therefore this is a strength of the study. Second, although the study sample size is small and used a purposive sample, it is appropriately aligned to the qualitative study design as it ensured participants could provide relevant data (Parahoo, 1997). However, it should also be acknowledged that the sample is restricted to the population of stroke survivors currently participating in a community based exercise group. These individuals may have a more positive view towards taking part in exercise and group exercise following stroke compared to those that do not participate. Further, the sample was limited to only those stroke survivors that responded to the request to volunteer for the study. Individuals who did not respond and are attending EAS may have different perceptions and experiences of exercise and the PAC concept. Therefore, the sample may not be fully representative of stroke survivors participating in community exercise thus limiting the resulting theory to a specific group of stroke survivors. Further research with individuals who are not participating in community exercise would therefore be beneficial to explore this concept fully. In addition, the sample includes only stroke survivors who are independently mobile with minimal cognitive and communication impairments. Although this was reflective of the patients who are currently recruited to EAS, further work is required to determine if the PAC could help to widen the access to exercise programmes. Another strength of the sample is that it includes participants who ranged from four months to five years post stroke onset. This enables the findings to be representative of the views of stroke survivors participating in exercise in the community longer term. The small sample size resulted in data saturation being unlikely to occur as new properties or insights may have been found with ongoing data collection (Birks and Mills, 2015; Charmaz, 2006). Further interviews may therefore have strengthened the study and enabled greater confidence to be gained in the

emerging theory (Birks and Mills, 2015). Despite this, using data collection methods of both qualitative interviews and a focus group with different population groups enabled rich data to be gathered (Mauk, 2015). In addition, the focus group was strengthened by the use of a second researcher and data was discussed following the focus group with confirmation of content aiding the reliability of the findings and therefore the rigour of the study (Ivey, 2012). It is also recognised that the quality of the interviews and focus group may have been affected by the researcher's limited experience, particularly as interviewing individuals on a hypothetical concept proved challenging. However, a pilot interview was undertaken using the interview guide. This aided the researcher's interview preparation as it enabled evaluation of the interview technique and identification of any potential issues (Dougherty, 2015; Turner, 2010). Despite this, the grounded theory method would have benefited from the focus group occurring mid-way through the interviews to allow evolving data to be included. Pure theoretical sampling was also not achievable in the study due to time constraints and availability of participants. Full transcriptions were therefore not coded prior to each interview thus limiting concurrent data collection and analysis. However, preliminary analysis was undertaken after each interview in combination with the recording of field notes and memos. This allowed relevant meaning to be extracted from the data and then used to inform the next interview therefore strengthening the grounded theory method (Birks and Mills, 2015; Strauss and Corbin, 1990). Finally, the analytical approach used involved only one researcher therefore different interpretations of the data are possible. Revision of the results by another researcher or the participants would have enabled improved data analysis to occur thus strengthening the validity of the data generated (Ivey, 2012). In addition, researcher bias cannot be ruled out therefore the results may be affected by the researcher's personal or cultural perspective (Greenhalgh and Taylor, 1997). However, the researcher was aware of the potential influence of her own perspective, using memo writing and reflection to reduce this bias therefore improving the validity of the study's findings (Greenhalgh and Taylor, 1997).

5.7: Implications for clinical application and further research

Overall, the findings therefore support the clinical application of a PAC within the current EAS programme. A strength of the study is that it has highlighted the following aspects in relation to clinical application of a PAC, including: who would undertake the

role; why they would undertake the role; what they would be called; what the role would involve; and the feasibility of integrating the PAC within current practice. However, the findings do not demonstrate whether the PAC would support additional exercise, how they would be selected and the type of training and documentation required to ensure safety. Consideration and further research of these aspects would therefore be needed prior to the implementation of the PAC concept within the EAS programme. Further discussion with the service provider would also be essential to ensure the clinical application of a PAC is practical and achievable.

Clinical application of a PAC could however enhance service delivery and the findings from this study have the potential to positively impact exercise after stroke services. Indeed, the findings clearly support that introduction of a PAC could provide stroke survivors with the support they need to engage in exercise. In particular, offering individual peer support could aid uptake and participation of the EAS programme. The benefit of this would be that it would help stroke survivors meet the current recommendations for exercise, thus enabling them to obtain the health and social benefits associated with sustaining long-term regular exercise (Morris et al, 2012). This would go a long way towards bridging the gap between services and the current evidence base. In addition, this could enable the service to be developed more cost effectively and efficiently. Although the findings relate specifically to an exercise after stroke service that is delivered locally, the research is relevant more widely throughout Scotland, nationally and internationally, particularly as exercise and self management have been identified as top ten research priorities relating to life after stroke by patients, carers and health professionals (Pollock et al, 2014). Furthermore, the findings are relevant to those with other conditions, including those with cardiac and other neurological disease (Clark et al, 2012; Hui et al, 2006; Latimer-Cheung et al, 2013; Parent and Fortin, 2000; Ravenek and Schneider, 2009).

It is recognised that in order to assess if the PAC would have beneficial effects on service delivery, further quantitative research evaluating the implementation and effectiveness of the concept would be essential. This would enable further information to be gained with regards its suitability, demand and impact on exercise after stroke services. The findings also illustrate other areas for further research. This would include qualitative research exploring the views of stroke survivors not currently

involved in community based exercise. In addition, research exploring methods to support stroke survivors with more significant physical, cognitive and communication impairments to exercise would ensure that the exercise after stroke programmes are more generalisable to the majority of stroke patients.

5.8: Dissemination of findings

Dissemination of research findings is an essential aspect of evidence based practice (Brown and Schmidt, 2015). Dissemination is defined by Brown and Schmidt (2015; pp. 505) as:

“the communication of clinical, research and theoretical findings for the purpose of transitioning new knowledge to the point of care.”

Therefore, knowledge gained from research must be passed on to enable it to be applied within the health care setting (Gerrish, 2015). This involves ensuring the evidence is available to a variety of audiences including healthcare professionals, academics, patients and the general public (Gerrish, 2015). To achieve this, different methods of dissemination can be used such as poster presentations, article publication in academic or professional journals, conference presentations, oral presentations and public reports (Brown and Schmidt, 2015). Consideration of how the current study’s findings will be communicated is therefore essential to allow the knowledge gained to be applied to the clinical setting.

It is therefore important that the findings from the current study will be disseminated in a variety of ways. The findings will be published in clinical journals such as ‘Stroke’, ‘Journal of Advanced Nursing’ and in the practice journal ‘Physiotherapy’ and/or ‘Nursing Standard’. Communication of the findings will occur through dissemination at relevant stroke conferences and events both nationally and internationally, including the National Stroke Forum and European Stroke Organisation Conferences. In addition, the findings will be disseminated to stroke specific clinical groups and healthcare providers such as, the Stroke Managed Clinical Networks, Stroke research network, Allied Health Professional and Stroke Nurse Forums, and government working groups with a remit in stroke. The findings will also be relevant to professionals developing best practice statements and clinical guidelines. To ensure

the research is communicated with the stroke population and the general public a layman summary will be disseminated through Chest Heart and Stroke Scotland and the Stroke Association, including patient involvement groups and exercise clubs and via social media.

5.9: Chapter summary

Within this chapter, the benefits of a PAC have been highlighted. The results have clearly identified that the PAC concept could offer psychological and peer support to stroke survivors participating in community based exercise. The role of the PAC has also been explored, with information gained regarding who the PAC would be, what they would be called, what they would do and how it concept could be applied clinically. The potential challenges of the concept and aspects that could not be fully explored have also been highlighted, along with the need for further research in key areas. A conclusion of this study will be provided in chapter 6.

Chapter 6: Conclusion

This qualitative study provided an opportunity to explore the concept of a PAC with stroke survivors and exercise professionals. Interventions that facilitate exercise are an essential aspect when considering the development of long-term community services for stroke survivors (Patterson and Ross-Edwards, 2009). Establishing a method of providing increased support that is tailored to individual stroke survivors' preferences and needs could enable improved engagement in exercise following stroke (Morris et al, 2014). The findings from this study offer suggestive evidence supporting the concept of individual peer support provided by a PAC in a community based exercise programme for stroke survivors. The PAC could provide increased support on an individual basis thus offering a flexible and person-centered intervention supporting exercise participation. The findings suggest that the concept could benefit stroke survivors experience of community based exercise through psychological and peer support. The potential psychological benefits illustrated by this research are increased confidence, improved motivation and reduced fear. In addition, a PAC would provide increased peer support, allowing individuals to share similar experiences and the ability to compare themselves to fellow stroke survivors. The findings also suggest that exercise professionals perceive the concept positively highlighting similar potential psychological benefits as those stated by stroke survivors. They also perceive that it could aid increased frequency of exercise and transition to mainstream services however this is a tentative conclusion and further research would be needed to determine the efficacy of a PAC within stroke exercise programmes.

In addition to establishing participants' views on the effects of the PAC concept, the findings also offer valuable insight regarding the PAC role. It is clear that the PAC role should be undertaken by a stroke survivor although consideration should be given to the type of individual as both stroke survivors and professionals illustrated preferred personality traits and characteristics deemed necessary for a suitable PAC. It would also appear that a title for the PAC is not required and that maintaining an informal approach to the intervention was preferable to most stroke survivors. Furthermore, exploration of the PAC role has highlighted potential challenges associated with the concept regarding the practical implementation of the role. Consideration of these findings as a whole does however allow a potential method for incorporating a PAC within the EAS programme to be suggested as shown in figure 5.2. These findings provide evocative evidence that implementing a PAC is feasible to support stroke

survivors undertake community based exercise. Incorporating peer support in the EAS programme in conjunction with consideration of ways to ensure early access, where appropriate, could therefore enhance service delivery. In addition, it could provide essential support for stroke survivors who often feel scared or feel unable to undertake exercise and therefore warrants further consideration by service providers. In conclusion, the present study provides important information on a hypothetical intervention aiming to support stroke survivors to undertake community based exercise. The findings demonstrate that incorporation of a PAC may reduce some of the barriers faced by stroke survivors that limit exercise participation, whilst facilitating exercise engagement through the provision of individual peer support. The PAC concept therefore has the potential to provide a beneficial approach that positively supports stroke survivors to exercise. Confirmation of the conclusions of this study would be however be recommended through further clinical evaluation and research to determine the effectiveness of the PAC to deliver and sustain exercise after stroke. Facilitating exercise following stroke would enable stroke survivors to achieve the long-term benefits associated with physical activity and ultimately support recovery and improve quality of life following stroke.

6.1: Key messages

What is already known about this topic

- Encouraging physical activity is an essential aspect of the long-term management of stroke.
- Social support can facilitate exercise following stroke and although there is a suggestion that peer support may be particularly beneficial in motivating stroke survivors to exercise, this requires further research.

What this study adds

- The PAC concept is supported by stroke survivors and professionals involved in a community based exercise programme.
- The PAC should be a fellow stroke survivor who has completed a stroke specific exercise programme.
- Individual peer support, provided by a fellow stroke survivor, could provide a method to increase support and facilitate sustainable participation in a community based exercise programme.

- The PAC would benefit stroke survivors' experience throughout the community based exercise programme by providing psychological and practical peer support.
- The PAC concept could benefit the individuals who undertake the role as it may facilitate their motivation to exercise by offering them a specific purpose within an exercise programme.

Implications for service delivery and further research

- Consideration should be given to the implementation of the PAC concept in the current EAS programme due to the potential for the concept to positively impact the service.
- Further discussion is required regarding the training needs of peer volunteers.
- Detailed consideration of the practical and ethical issues in relation to the role are needed to ensure the concept is implemented appropriately and safely.
- Further quantitative research would be required to investigate and evaluate the PAC concept once implemented within the exercise after stroke pathway.

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Appendix 1: Search terms for Stroke, Cardiac and other Neurological conditions search

Stroke literature search keywords

Medline

- S1 stroke* or poststroke* or cva*
- S2 cerebrovascular* or cerebral vascular
- S3 cerebral or cerebellar or brainstem or vertebrobasilar
- S4 infarct* or isch?emi* or thrombo* or apoplexy or emboli*
- S5 S3 AND S4
- S6 carotid*
- S7 cerebral or intracerebral or intracranial or parenchymal
- S8 brain or intraventricular or brainstem or cerebellar
- S9 infratentorial or supratentorial or subarachnoid
- S10 S7 OR S8 OR S9
- S11 haemorrhage or hemorrhage or haematoma or hematoma or bleeding or aneurysm
- S12 S10 AND S11
- S13 transient isch?emi*
- S14 aphasi* or dysphasi* or dysphagi* or hemianop* or hemiplegi* or hemipar* or aprax*
- S15 S1 or S2 or S5 or S6 or S12 or S13 or S14
- S16 (MM "Motor Activity")OR Physical Activit*
- S17 (MM "Physical Fitness")
- S18 fitness train*
- S19 (MM "Exercise+")
- S20 (MM "Exercise Therapy+")
- S21 aerobic exercise*
- S22 cardiorespiratory train*
- S23 strength train*
- S24 mixed train*
- S25 (MM "Rehabilitation")
- S26 S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25
- S27 S15 AND S26
- S28 (MM "Social Environment+")
- S29 (MM "Peer Group") OR peer support
- S30 "champions"
- S31 "buddy" OR buddies
- S32 supported participation
- S33 barrier* OR motivat* OR facilitat*
- S34 S28 OR S29 OR S30 OR S31 OR S32 OR S33
- S35 S27 AND S34

Cinahl

- S1 stroke* or poststroke* or cva*
- S2 cerebrovascular* or cerebral vascular
- S3 cerebral or cerebellar or brainstem or vertebrobasilar

Appendix 1

S4 infarct* or isch?emi* or thrombo* or apoplexy or emboli*
S5 S3 AND S4
S6 carotid*
S7 cerebral or intracerebral or intracranial or parenchymal
S8 brain or intraventricular or brainstem or cerebellar
S9 infratentorial or supratentorial or subarachnoid
S10 S7 OR S8 OR S9
S11 haemorrhage or hemorrhage or haematoma or hematoma or bleeding or aneurysm
S12 S10 AND S11
S13 transient isch?emi*
S14 aphasi* or dysphasi* or dysphagi* or hemianop* or hemiplegi* or hemipar* or aprax*
S15 S1 or S2 or S5 or S6 or S12 or S13 or S14
S16 (MM "Motor Activity")OR Physical Activit*
S17 (MM "Physical Fitness")
S18 fitness train*
S19 (MM "Exercise+")
S20 (MM "Therapeutic exercise") OR exercise therapy
S21 aerobic exercise*
S22 cardiorespiratory train*
S23 strength train*
S24 mixed train*
S25 (MM "Rehabilitation")
S26 S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25
S27 S15 AND S26
S28 (MM "Social Environment+")
S29 (MM "Peer Group") OR peer support
S30 "champions"
S31 "buddy" OR buddies
S32 supported participation
S33 barrier* OR motivat* OR facilitat*
S34 S28 OR S29 OR S30 OR S31 OR S32 OR S33
S35 S27 AND S34

Amed

S1 stroke* or poststroke* or cva*
S2 cerebrovascular* or cerebral vascular
S3 cerebral or cerebellar or brainstem or vertebrobasilar
S4 infarct* or isch?emi* or thrombo* or apoplexy or emboli*
S5 S3 AND S4
S6 carotid*
S7 cerebral or intracerebral or intracranial or parenchymal
S8 brain or intraventricular or brainstem or cerebellar
S9 infratentorial or supratentorial or subarachnoid
S10 S7 OR S8 OR S9
S11 haemorrhage or hemorrhage or haematoma or hematoma or bleeding or aneurysm

Appendix 1

S12	S10 AND S11
S13	transient isch?emi*
S14	aphasi* or dysphasi* or dysphagi* or hemianop* or hemiplegi* or hemipar* or aprax*
S15	S1 or S2 or S5 or S6 or S12 or S13 or S14
S16	(MM "Motor Activity")OR Physical Activit*
S17	(MM "Physical Fitness")
S18	fitness train*
S19	(MM "Exercise+")
S20	(DE "EXERCISE THERAPY")
S21	aerobic exercise*
S22	cardiorespiratory train*
S23	strength train*
S24	mixed train*
S25	(MM "Rehabilitation")
S26	S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25
S27	S15 AND S26
S28	(DE "Social Environment+")
S29	(MM "Peer Group") OR peer support
S30	"champions"
S31	"buddy" OR buddies
S32	supported participation
S33	barrier* OR motivat* OR facilitat*
S34	S28 OR S29 OR S30 OR S31 OR S32 OR S33
S35	S27 AND S34

Cardiac literature search keywords

Medline

S1	(MH "Myocardial Ischemia+")
S2	(myocard* N (ischaemi* or ischemi*))
S3	((ischaemi* or ischemi*) N heart)
S4	(MH "Coronary Artery Bypass+")
S5	coronary
S6	(MH "Coronary Disease+")
S7	(MH "Myocardial Revascularization+")
S8	(MH "Myocardial Infarction+")
S9	(myocard* N infarct*)
S10	(heart N infarct*)
S11	(MH "Angina Pectoris+")
S12	angina
S13	(MH "Heart Failure+")
S14	(heart N failure)
S15	(HFNEF or HFPEF or HFREF or "HF NEF" or "HF PEF" or "HF REF")
S16	(MH "Heart Diseases+")
S17	(heart N disease*)

Appendix 1

S18 Myocard*
S19 Cardiac*
S20 CABG
S21 PTCA
S22 (stent* and (heart or cardiac*))
S23 Heart Bypass, Left/ or exp Heart Bypass, Right/
S24 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR
S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23
S25 (MM "Motor Activity")OR Physical Activit*
S26 (MM "Physical Fitness")
S27 fitness train*
S28 (MM "Exercise+")
S29 (MM "Exercise Therapy+")
S30 aerobic exercise*
S31 cardiorespiratory train*
S32 strength train*
S33 mixed train*
S34 (MH "Rehabilitation")
S35 S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34
S36 S24 AND S35
S37 (MH "Social Environment+")
S38 (MH "Peer Group") OR peer support
S39 "champions"
S40 "buddy" OR buddies
S41 supported participation
S42 barrier* OR motivat* OR facilitat*
S43 S37 OR S38 OR S39 OR S40 OR S41 OR S42
S44 S36 AND S43

Cinahl

S1 (MH "Myocardial Ischemia+")
S2 (myocard* N (ischaemi* or ischemi*))
S3 ((ischaemi* or ischemi*) N heart)
S4 (MH "Coronary Artery Bypass+")
S5 coronary
S6 (MH "Coronary Disease+")
S7 (MH "Myocardial Revascularization+")
S8 (MH "Myocardial Infarction+")
S9 (myocard* N infarct*)
S10 (heart N infarct*)
S11 (MH "Angina Pectoris+")
S12 angina
S13 (MH "Heart Failure+")
S14 (heart N failure)
S15 (HFNEF or HFPEF or HFREF or "HF NEF" or "HF PEF" or "HF REF")
S16 (MH "Heart Diseases+")

Appendix 1

- S17 (heart N disease*)
- S18 Myocard*
- S19 Cardiac*
- S20 CABG
- S21 PTCA
- S22 (stent* and (heart or cardiac*))
- S23 Heart Bypass, Left/ or exp Heart Bypass, Right/
- S24 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23
- S25 (MM "Motor Activity")OR Physical Activit*
- S26 (MM "Physical Fitness")
- S27 fitness train*
- S28 (MM "Exercise+")
- S29 (MM "Therapeutic exercise") OR exercise therapy
- S30 aerobic exercise*
- S31 cardiorespiratory train*
- S32 strength train*
- S33 mixed train*
- S34 (MM "Rehabilitation")
- S35 S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34
- S36 S24 AND S35
- S37 (MM "Social Environment+")
- S38 (MM "Peer Group") OR peer support
- S39 "champions"
- S40 "buddy" OR buddies
- S41 supported participation
- S42 barrier* OR motivat* OR facilitat*
- S43 S37 OR S38 OR S39 OR S40 OR S41 OR S42
- S44 S36 AND S43

Neurological conditions literature search key words

Medline

- S1 (MM "Central Nervous System Diseases+")
- S2 (MM "Brain Diseases+")
- S3 (MM "Movement Disorders+")
- S4 (MM "Demyelinating Diseases+")
- S5 (MM "Neurodegenerative Diseases+")
- S6 (MM "Neuromuscular Diseases+")
- S7 S1 OR S2 OR S3 OR S4 OR S5 OR S6
- S8 (MM "Motor Activity") OR physical activit*
- S9 (MM "Physical Fitness")
- S10 fitness train*
- S11 (MM "Exercise+")
- S12 (MM "Exercise Therapy+")

Appendix 1

S13 aerobic exercise*
S14 cardiorespiratory train*
S15 strength train*
S16 mixed train*
S17 (MM "Rehabilitation")
S18 S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17
S19 S7 AND S18
S20 (MM "Social Environment+")
S21 (MM "Peer Group") OR peer support
S22 "champions"
S23 "buddy' OR buddies
S24 supported participation
S25 barrier* OR motivat* OR facilitate*
S26 S20 OR S21 OR S22 OR S23 OR S24 OR S25
S27 S19 AND S26

Cinahl

S1 (MM "Central Nervous System Diseases+")
S2 (MM "Brain Diseases+")
S3 (MM "Movement Disorders+")
S4 (MM "Demyelinating Diseases+")
S5 (MM "Neurodegenerative Diseases+")
S6 (MM "Neuromuscular Diseases+")
S7 S1 OR S2 OR S3 OR S4 OR S5 OR S6
S8 (MM "Motor Activity") OR physical activit*
S9 (MM "Physical Fitness")
S10 fitness train*
S11 (MM "Exercise+")
S12 Therapeutic Exercise OR exercise therapy
S13 aerobic exercise*
S14 cardiorespiratory train*
S15 strength train*
S16 mixed train*
S17 (MM "Rehabilitation")
S18 S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17
S19 S7 AND S18
S20 (MM "Social Environment+")
S21 (MM "Peer Group") OR peer support
S22 "champions"
S23 "buddy' OR buddies
S24 supported participation
S25 barrier* OR motivat* OR facilitate*
S26 S20 OR S21 OR S22 OR S23 OR S24 OR S25
S27 S19 AND S26

Appendix 2: Results from the combined search terms for Stroke, Cardiac and other Neurological conditions searches

Stroke search

Stroke** search terms	Exercise search terms	Support search terms
S1 stroke* or poststroke* or cva* S2 cerebrovascular* or cerebral vascular S3 cerebral or cerebellar or brainstem or vertebrobasilar S4 infarct* or isch?emi* or thrombo* or apoplexy or emboli* S5 S3 and S4 S6 carotid* S7 cerebral or intracerebral or intracranial or parenchymal S8 brain or intraventricular or brainstem or cerebellar S9 infratentorial or supratentorial or subarachnoid S10 S7 or S8 or S9 S11 haemorrhage or hemorrhage or haematoma or hematoma or bleeding or aneurysm S12 S10 and S11 S13 transient isch?emi* S14 aphasi* or dysphasi* or dysphagi* or hemianop* or hemiplegi* or hemipar* or aprax* S15 S1 or S2 or S5 or S6 or S12 or S13 or S14	S16 motor activity or physical activit* S17 physical fitness S18 fitness train* S19 exercise S20 exercise therapy S21 aerobic exercise* S22 cardiorespiratory train* S23 strength train* S24 mixed train* S25 rehabilitation S26 S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24 or S25	S28 social environment S29 peer group or peer support S30 champions S31 buddy or buddies S32 supported participation S33 barrier* or motivat* or facilitat* S34 S28 or S29 or S30 or S31 or S32 or S33
Final (Stroke) n: 661,254	Final (Exercise) n: 327,084	Final (Support) n: 835,810
Final search for stroke (S15) and exercise (S26) = 14,339 (S27) Final search for stroke and exercise (S27) and support (S34) = 827 (S35) Limited to Adult/English/Human (S36) = 423 (Medline = 263, CINAHL = 121, AMED = 39) Removal of duplicates = 396		
Read = 70		
Total in review = 22		

**Adapted from Cochrane Stroke group for EBSCO search strategy and stroke terms: The Editorial Team.

The Cochrane Stroke Group. In, The Cochrane Library, Issue 5, 2013. Chichester: Wiley.
<http://onlinelibrary.wiley.com/o/cochrane/clabout/articles/STROKE/frame.html>. Accessed June 26 2015.

Cardiac search

Heart*** Search Terms	Exercise search terms	Support search terms
S1. exp Myocardial Ischemia/ S2. (myocard* N (ischaemi* or ischemi*)) S3. ((ischaemi* or ischemi*) N heart) S4. exp Coronary Artery Bypass/ S5. coronary S6. exp Coronary Disease/ S7. exp Myocardial Revascularization/ S8. Myocardial Infarction/ S9. (myocard*N infarct*) S10. (heart N infarct*) S11. exp Angina Pectoris/ S12. angina S13. exp Heart Failure/ S14. (heart N failure) S15. (HFNEF or HFPEF or HFREF or "HF NEF" or "HF PEF" or "HF REF") S16. exp Heart Diseases/ S17. (heart N disease*) S18. Myocard* S19. Cardiac* S20. CABG S21. PTCA S22. (stent* and (heart or cardiac*)) S23. Heart Bypass, Left/ or exp Heart Bypass, Right/ S24. S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24	S25 motor activity or physical activit* S26 physical fitness S27 fitness train* S28 exercise S29 exercise therapy S30 aerobic exercise* S31 cardiorespiratory train* S32 strength train* S33 mixed train* S34 rehabilitation S35 S26 or S27 or S28 or S29 or S30 or S31 or S32 or S33 or S34 or S35	S37 social environment S38 peer group or peer support S39 champions S40 buddy or buddies S41 supported participation S42 barrier* or motivat* or facilitate* S43 S38 or S39 or S40 or S41 or S42 or S43
Final (Heart) n: 1,641,226	Final (Exercise) n: 442,633	Final (Support) n: 912,187
Final search for heart (S24) and exercise (S35) = 33,918 (S36) Final search for heart and exercise (S36) and support (S43) = 1,333 (S44) Limited to Adult/English/Human (S45) = 684 (Medline = 495, CINAHL = 189) Removal of duplicates = 671		
Read = 71		
Total in review = 13		

***Adapted from Cochrane search strategy in Cochrane review article:

Taylor RS et al (2014). Exercise-based rehabilitation for heart failure. Cochrane Database of Systematic Reviews 2014, Issue 4.

<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD003331.pub4/abstract>

Accessed September 17 2015.

Neurological conditions search

**** Neurological Search Terms	Exercise search terms	Support search terms
S1 Central nervous system diseases S2 Brain diseases S3 Movement disorders S4 Demyelinating diseases S5 Neurodegenerative diseases S6 Neuromuscular diseases S7 S1 or S2 or S3 or S4 or S5 or S6	S8 motor activity or physical activit* S9 physical fitness S10 fitness train* S11 exercise S12 exercise therapy S13 aerobic exercise* S14 cardiorespiratory train* S15 strength train* S16 mixed train* S17 rehabilitation S18 S8 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S16 or S17	S20 social environment S21 peer group or peer support S22 champions S23 buddy or buddies S24 supported participation S25 barrier* or motivat* or facilitate* S26 S20 or S21 or S22 or S23 or S24 or S25
Final (Neurological) n: 1,452,810	Final (Exercise) n: 327,406	Final (Support) n: 765,392
Final search for neurological (S7) and exercise (S18) = 21,166 (S19) Final search for neurological and exercise (S19) and support (S26) = 1,080 (S27) Limited to Adult/English/Human (S28) = 554 (Medline = 381, CINAHL = 173) Removal of duplicates = 547		
Read = 41		
Total in review = 8		

****Adapted from Cochrane search strategy in Cochrane Review article:

Coggrave M, Norton C, Cody, JD (2014). Management of faecal incontinence and constipation in adults with central neurological diseases. Cochrane Database of Systematic Reviews 2014, Issue 1.

<http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD002115.pub5/abstract>

Accessed 26 November 2015.

Appendix 3: Additional searches**Table 1:** Additional databases searched within Stroke literature search and the results from these searches.

Database	Keywords	Number of articles found	Number of abstracts reviewed	Number of articles appropriate for review and read in full	Number excluded	Number included	Reference of article included in literature review
PubMed	Stroke AND Exercise AND Support	133	3	0	N/A	N/A	N/A
Cochrane Library	Stroke AND Exercise AND Support	11	2	2	1	1	Saunders et al (2013).
Pedro	Stroke AND Exercise AND Support	64	6	0	N/A	N/A	N/A

Table 2: Results of articles found from searching the reference lists of key articles within Stroke, Cardiac and other Neurological conditions literature searches

Search strategy	Number of articles found	Number of articles appropriate for review and read in full	Number excluded	Number included	Reference of article(s) included in literature review
Stroke search	2	2	0	2	Amarshi, F et al (2006) Beckley, M.N (2007)
Cardiac search	4	4	0	4	Colella, T & King, K (2004) Hildingh, C.R.N (1995) Hildingh, C & Fridlund, B (2004) Parry, M & Watt-Watson, J (2010)
Other neurological search	0	N/A	N/A	N/A	N/A

Table 3: Results of articles found from searching key authors within the Stroke literature

Name of author searched	Number of articles found	Number of articles appropriate for review and read in full	Number excluded	Number included	Reference of article(s) included in literature review
Morris, Jacqui	2	2	0	2	Morris, J et al (2012) Morris, J et al (2014)
Nicholson, Sarah	0	N/A	N/A	N/A	N/A
Damush, Teresa	1	0	N/A	N/A	N/A
Rimmer, James	9	2	0	2	Chen, M-D & Rimmer, J (2011) Rimmer, J (2012)

Table 4: Journals searched by hand within Stroke literature search

Journal Title	Edition searched (year and volume)	Number of new articles found	Were previously identified articles found?
Clinical Rehabilitation	2007: 21(6)	0	Yes
Clinical Rehabilitation	2010: 24(1)	0	Yes
Disability and Rehabilitation	2009: 31(11)	0	Yes
Disability and Rehabilitation	2014: 36(22)	0	Yes

Appendix 4: Table of excluded articles from literature search

Reference	Year	Reason for Exclusion
<p>Antypas, K. Wangberg, S. An internet and mobile based tailored intervention to enhance maintenance of physical activity after cardiac rehabilitation: short term results of a randomized controlled trial. <i>Journal of medical internet research</i>; 16(3): 77</p>	2014	Investigation of different types of internet and mobile support on physical activity. Focus not specific to peer support.
<p>Aubrey, G. Demain, S. Perceptions of group exercise in the management of multiple sclerosis. <i>International journal of therapy and rehabilitation</i>; 19(10): 557-565</p>	2012	Explored how an exercise group was perceived. Not specific to peer support.
<p>Beckley, M.N The influence of the quality and quantity of social support in the promotion of community participation following stroke. <i>Australian occupational therapy journal</i>; 54: 215-220</p>	2007	Not relevant to exercise.
<p>Brogardh, C. Lexell, J. Effects of cardiorespiratory fitness and muscle resistance training after stroke. <i>Physical medicine and rehabilitation</i>; 4: 901-907</p>	2012	Review of exercise effects following stroke. Barriers and motivators discussed however not a specific review of peer support and exercise.
<p>Chen, M-D. Rimmer, J. Effects of exercise on quality of life in stroke survivors: a meta-analysis. <i>Stroke</i>; 42: 832-837</p>	2011	Provides support for exercise following stroke but not specific to peer support.
<p>Clark, A. Mundy, C. Catto, S. MacIntyre, P. Participation in community based exercise maintenance programs after completion of hospital based cardiac rehabilitation.</p>	2011	Peer support highlighted as beneficial in group setting however specific to cardiac rehabilitation and not a specific investigation into effect of peer support on exercise.

<i>Journal of cardiopulmonary rehabilitation</i> ; 31: 42-46		
Colella, T. King, K. Peer support. An under-recognized resource in cardiac recovery. <i>European journal of cardiovascular nursing</i> ; 3: 211-217	2004	Review of current literature. Not an investigation into peer support.
Crizzle, A. Newhouse, I. Themes associated with exercise adherence in persons with Parkinson's disease: a qualitative study. <i>Occupational therapy in health care</i> ; 26(2-3): 174-186	2012	Examined motivators to exercise adherence in older adults with Parkinson's disease. Not a specific investigation into peer support.
Driver, S. Social support and the physical activity behaviours of people with a brain injury. <i>Brain Injury</i> ; 19(13): 1067-1075	2005	Review article.
Duncan, K. Pozehl, B. Staying on course: the effects of an adherence facilitation intervention on home exercise participation. <i>Progress in cardiovascular nursing</i> ; 17: 59-65	2002	Focus not relevant to peer support and exercise.
Farley, R. Wade, T. Birchmore, L. Factors influencing attendance at cardiac rehabilitation among coronary heart disease patients. <i>European journal of cardiovascular nursing</i> ; 2: 205-212	2003	Topic not relevant to peer support. Examined predictors and reasons for not attending cardiac rehabilitation and demographics of those who attend.
Galvin, R. Cusack, T. Stokes, E. To what extent are family members and friends involved in physiotherapy and the delivery of exercises to people with stroke? <i>Disability and Rehabilitation</i> ; 31(11): 898-905	2009	Focus is on family members providing support for stroke rehabilitation therefore not specific to peer support.
Gerhardt, A. Weidner, G. Grassmann, M. Everyday physical activity in ambulatory heart transplant candidates: the role of expected health benefits, social support and potential barriers. <i>International journal of behavioural medicine</i> ; 21: 248-257	2014	Social support examined within a cardiac population but was not specific to peer support.

Harrington, R. Taylor, G. Hollinghurst, S. Reed, M. Kay, H. Wood, V. A community-based exercise and education scheme for stroke survivors: a randomised controlled trial and economic evaluation. <i>Clinical Rehabilitation</i> ; 24: 3-15	2010	Evaluation of a stroke rehabilitation service. Volunteers used to facilitate delivery of the programme however unsure if they were stroke survivors and this aspect of peer support not specifically assessed.
Hildingh, C. Fridlund, B. Segesten, K. Social support in self help groups as experienced by persons having coronary heart disease and their next of kin. <i>International journal of nursing studies</i> ; 32(3): 224-232	1995	Not specific to exercise.
Hildingh, C. and Fridlung, B. Participation in peer support groups after a cardiac event: a 12-month follow-up. <i>Rehabilitation Nursing</i> ; 28(4); 123-127	2003	Evaluation of a group programme. Not a specific evaluation of peer support and exercise.
Hildingh, C. Fridlund, B. A 3-year follow up of participation in peer support groups after a cardiac event. <i>European journal of cardiovascular nursing</i> ; 3: 315-320	2004	Comparison of participants who attended or did not attend a peer support group for cardiac conditions. Not a specific investigation of individual peer support and exercise.
Hillsdon, K. Kersten, P. Kirk, H. A qualitative study exploring patients' experiences of standard care or cardiac rehabilitation post minor stroke and transient ischaemic attack. <i>Clinical Rehabilitation</i> ; 27(9): 845-853	2013	Participants were minor stroke survivors undertaking cardiac rehabilitation and study was not a specific investigation into peer support.
Jones, M. Greenfield, S. Jolly, K. Patients' experience of home and hospital based cardiac rehabilitation: a focus group study. <i>European journal of cardiovascular nursing</i> ; 8: 9-17	2009	Investigation of home versus hospital cardiac rehabilitation therefore not a specific investigation of peer support.
Jurkiewicz, M. Marzolini, S. Oh, P. Adherence to a home-based exercise program for individuals after stroke. <i>Topics in stroke rehabilitation</i> ; 18(3): 277	2011	Investigation of adherence to exercise following stroke finding superior adherence during group exercise and highlights social support as a motivator. Not a specific assessment of peer support and its effect on exercise therefore not relevant to review.

<p>Learmonth, Y. Marshall-McKenna, R. Paul, L. Mattison, P. Miller, L. A qualitative exploration of the impact of a 12-week group exercise class for those moderately affected with multiple sclerosis. <i>Disability and Rehabilitation</i>; 35(1): 81-88</p>	2013	Study explored experiences of an exercise class for multiple sclerosis. Not a specific exploration into peer support.
<p>Mead, G. Bernhardt, J. Physical fitness training after stroke, time to implement what we know: more research is needed. <i>International journal of stroke</i>; 6: 506-508</p>	2011	Leading opinion on physical activity and stroke. Discussion of need to understand perceived barriers and motivators to exercise after stroke. Not specific to peer support.
<p>Morken, I. Norekval, T. Isaksen, K. Munk, P. Karlsen, B. Larsen, A. Increased confidence to engage in physical exertion: older ICD recipients' experiences of participation in an exercise training programme. <i>European journal of cardiovascular nursing</i>; 12(3): 261-268</p>	2013	Highlights perceived benefits of peer support in group based exercise within cardiac population. Not however an exploration into peer support and exercise.
<p>Morris, J. William, B. Optimising long-term participation in physical activities after stroke: exploring new ways of working for physiotherapists. <i>Physiotherapy</i>; 95: 227-233</p>	2009	Literature review. Focus on physiotherapists' role in support provision rather than peer support.
<p>Morris, J. Oliver, T. Kroll, T. MacGillivray, S. The importance of psychological and social factors in influencing the uptake and maintenance of physical activity after stroke: a structured review of the empirical literature. <i>Stroke research and treatment</i>; vol 2012</p>	2012	Structured literature review.
<p>Morris, J. MacGillivray, S. Mcfarlane, S. Interventions to promote long-term participation in physical activity after stroke: a systematic review of the literature.</p>	2014	Systematic review of literature. Not specific to peer support.

<i>Archives of physical and medicine and rehabilitation</i> ; 95: 956-967		
Morris, J. Oliver, T. Kroll, T. Joice, S. Williams, B. From physical and functional to continuity with pre-stroke self and participation in valued activities: a qualitative exploration of stroke survivors', carers', and physiotherapist' perceptions of physical activity after stroke. <i>Disability and Rehabilitation</i> ; 37(1): 64-77	2015	Focus on perceptions of physical activity. Not specific to peer support.
Natterlund, B. Ahlstrom, G. Experience of social support in rehabilitation: a phenomenological study. <i>Journal of advanced nursing</i> ; 30(6): 1332-1340	1999	Study participants had muscular dystrophy. Study not specific to exercise or peer support.
Nicholson, S. Sniehotta, F. Van Wijck, F. Greig, C. Johnston, M. McMurdo, Dennis, M. Mead, G. A systematic review of perceived barriers and motivators to physical activity after stroke. <i>International journal of stroke</i> ; 8: 357-364	2013	Systematic review of literature. Peer support highlighted as a motivator to physical activity. Paper does not investigate peer support and exercise therefore not relevant.
Nicholson, S. Donaghy, M. Johnston, M. Sniehotta, F. Van Wijck, F. Johnston, D. Greig, C. McMurdo, M. Mead, G. A qualitative theory guided analysis of stroke survivors' perceived barriers and facilitators to physical activity. <i>Disability and Rehabilitation</i> ; 36(22): 1857-1868	2014	Focus is on barriers and facilitators which are highlighted. Social support found to be a motivator but it is not specific to peer support from fellow stroke survivors.
O'Brien, M. Dodd, K. Bilney, B. A qualitative analysis of a progressive resistance exercise programme for people with Parkinson's disease. <i>Disability and Rehabilitation</i> ; 30(18): 1350-1357	2008	Focus of study was to explore aspects of an exercise programme rather than an exploration of peer support and exercise.
Parry, M. Watt-Watson, J. Peer support intervention trials for individuals with heart disease: a systematic review. <i>European journal of cardiovascular nursing</i> ; 9: 57-67	2010	Systematic review of literature. Focus peer support on health outcomes and heart disease. Not a specific investigation into peer support.

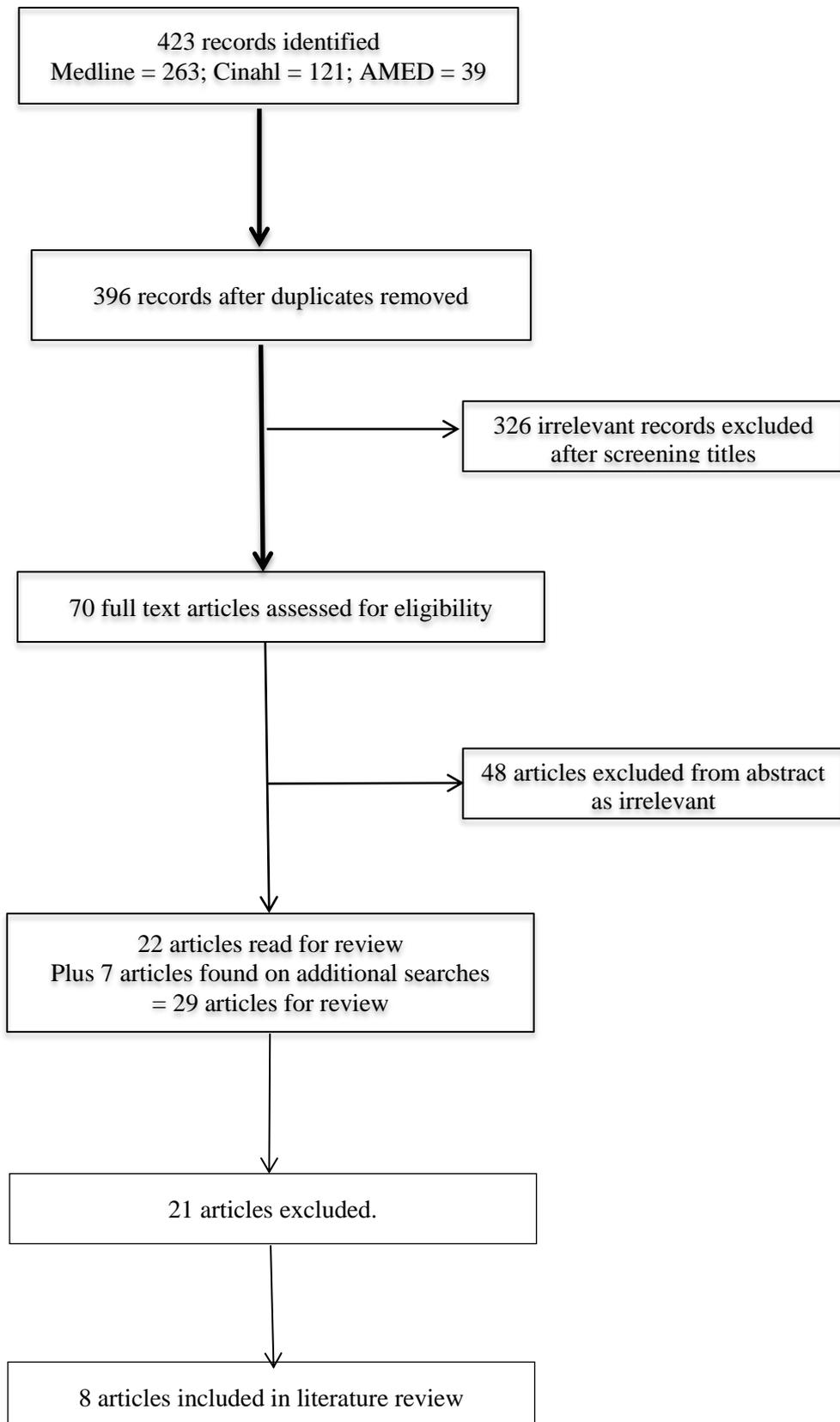
<p>Poltawski, L. Boddy, K. Forster, A. Goodwin, V. Pavey, A. Dean, S. Motivators for uptake and maintenance of exercise: perceptions of long-term stroke survivors and implications for design of exercise programmes. <i>Disability and Rehabilitation</i>; 37(9): 795-801</p>	2015	Exploration of factors that affect motivation to exercise. Not a specific exploration of peer support.
<p>Richardson, C. Buis, L. Janney, A. Goodrich, D. Sen, A. Hess, M. Mehari, K. Fortlage, L. Resnick, R. Zikmund-Fisher, B. Strecher, V. Piette, J. An online community improves adherence in an internet mediated walking program: part 1: results of a randomized controlled trial. <i>Journal of medical internet research</i>; 12(4): 71</p>	2010	Focus is on the content of a web based programme and the effect on physical activity adherence. Not specific to peer support.
<p>Rimmer, J. Wang, E. Smith, D. Barriers associated with exercise and community access for individuals with stroke. <i>Journal of rehabilitation research and development</i>; 45(2): 315-322</p>	2008	RCT investigating barriers to exercise therefore content not specific to peer support and exercise.
<p>Rimmer, J. Getting beyond the plateau: bridging the gap between rehabilitation and community based exercise. <i>Physical medicine and rehabilitation</i>; 4: 857-861</p>	2012	Not specific to stroke. Not specific to peer support and exercise.
<p>Rochett, A. Racine, E. Lefebvre, H. Lacombe, J. Bastien, J. Tellier, M. Ethical issues relating to the inclusion of relatives as clients in the post-stroke rehabilitation process as perceived by patients, relatives and health professionals. <i>Patient Education and Counseling</i>; 94: 384-389</p>	2014	Investigation of family involvement in the stroke rehabilitation process. Not relevant to peer support or exercise.
<p>Saunders, D. Sanderson, M. Brazzelli, M. Greig, C. Mead, G. Physical fitness training for stroke patients. <i>Cochrane database of systematic reviews</i>; issue 10.</p>	2013	Cochrane systematic review. Focus on effects of physical fitness training after stroke not specifically peer support.

Appendix 4

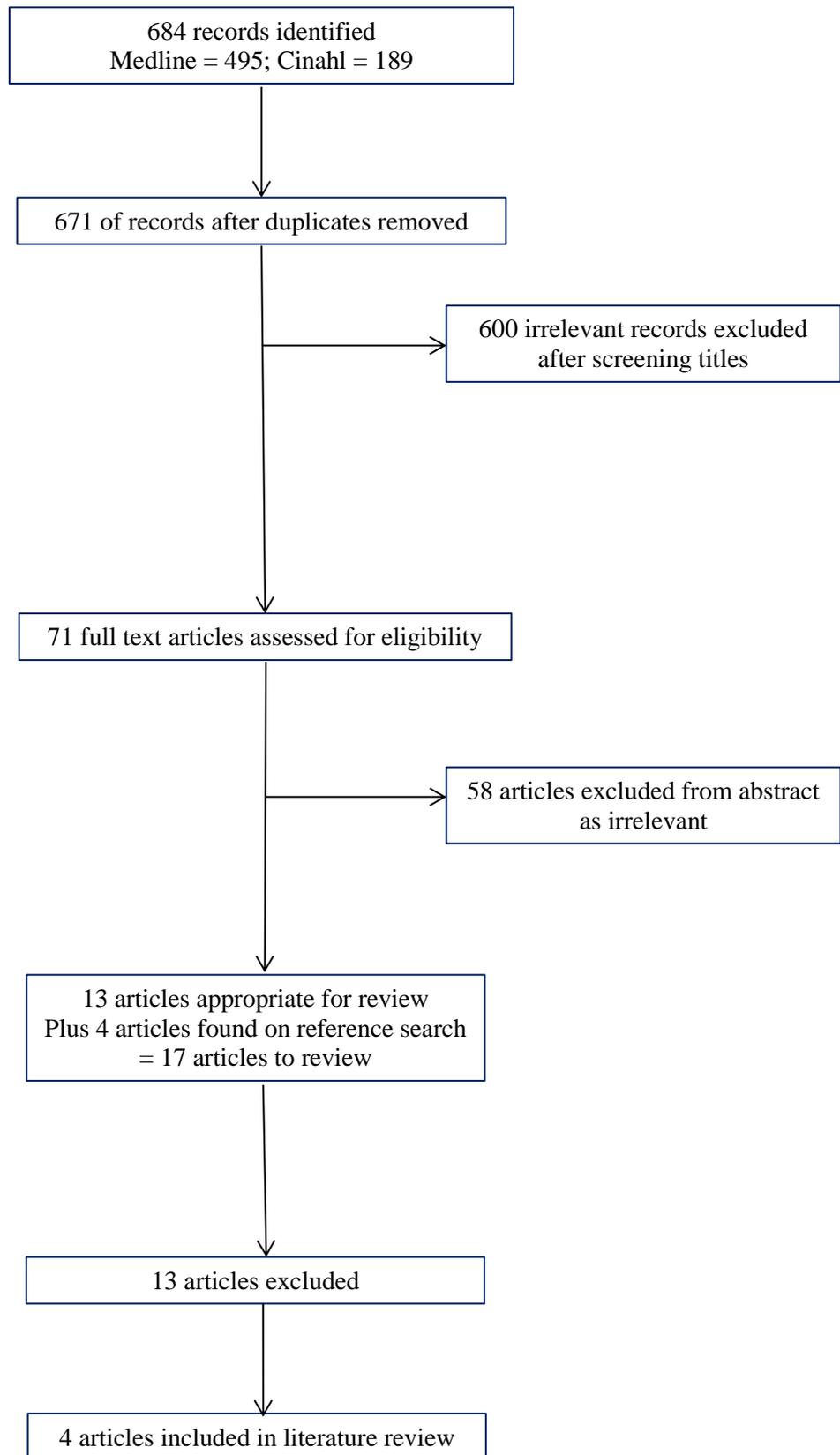
<p>Schweier, R. Romppel, M. Richter, C. Hoberg, E. Hahmann, H. Scherwinski, I. Kosmutzky, G. Grande, G. A web based peer modelling intervention aimed at lifestyle changes in patients with coronary heart disease and chronic back pain: sequential controlled trial. <i>Journal of medical internet research</i>; 16(7): 177</p>	<p>2014</p>	<p>Peer support provided through website patient narratives and outcomes not specific to exercise.</p>
<p>Taskinen, P. The development of health enhancing exercise groups adapted for hemiplegic patients: a pilot study. <i>Neurorehabilitation</i>; 13: 35-43</p>	<p>1999</p>	<p>Focus not relevant to peer support and exercise.</p>

Appendix 5: Flow of information for Stroke, Cardiac and other Neurological conditions systematic review

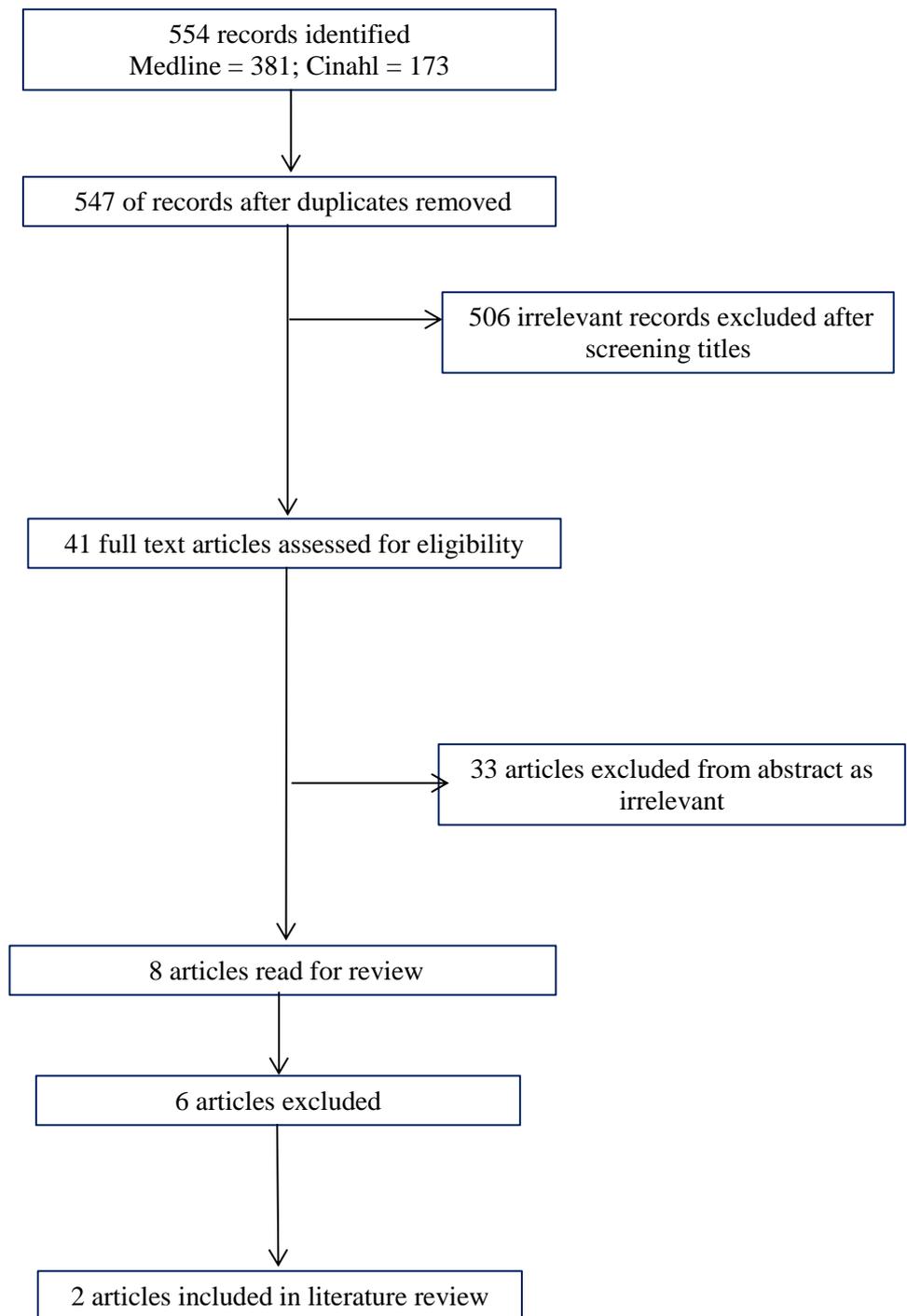
Stroke systematic review



Cardiac systematic review



Neurological conditions systematic review



Appendix 6: Information sheet for potential participants: group 1

Project Title: An exploration into the concept of service users as “Physical Activity Champions” to support stroke survivors participate in community based exercise.

My name is Gillian Hutton and I am a research student from the School of Nursing, Midwifery and Social Care at Edinburgh Napier University. For my postgraduate degree, I am undertaking a research project for my Masters by research qualification. The title of my project is: An exploration into the concept of service users as “Physical Activity Champions” to support stroke survivors participate in community based exercise. This study aims to find out whether someone who has had a stroke could support others, following stroke, to participate in community based exercise.

Invitation to take part

This is an invitation to take part in a research study. Before you decide if you want to take part, it is important that you understand why the project is being done and what it will involve. Please take time to read the following information. Please ask if there is anything that is not clear or if you would like more information.

Aim of the project

People who have had a stroke are encouraged to undertake exercise following their stroke. This is because exercise is believed to be beneficial for people who have had a stroke as exercise can help improve balance, mobility and physical fitness levels. It can also be beneficial for improving future health. There is a lot of research that has investigated exercise after stroke. It has shown that several barriers can exist which prevent people who have had a stroke undertaking exercise. It has also shown that there are factors that may help motivate people to exercise following a stroke. One thing that can help to motivate people who have had a stroke to exercise is support from another person. I would like to find out whether this support could come from a fellow stroke survivor. I am therefore aiming to explore whether people who have had a stroke and are attending the ‘Exercise After Stroke’ programme at Edinburgh Leisure

would find it helpful to have support from someone else who has had a stroke. I will also be exploring how these people could be identified and what role they could undertake.

The findings of the project will be useful because it will help us to get information from stroke survivors who use the 'Exercise After Stroke' programme to help us determine if incorporating this type of support would be beneficial.

Why have I been invited?

You have been invited because you have had a stroke, are over 18 years of age and have been referred to the 'Exercise After Stroke' programme at Edinburgh Leisure. You may have recently started the programme or you may have already completed the programme.

What will the study involve?

If you agree to participate in the study, I will ask you to complete and sign a consent form. You will then be asked to take part in a tape recorded interview where we will discuss the idea of incorporating stroke survivors to provide support at the 'Exercise After Stroke' class. The interview will take place at the Edinburgh Leisure Centre where you were referred for the 'Exercise After Stroke' class. The interview should take no longer than 40 minutes but it will be flexible to suit you and you can stop at any time if you feel tired or unwell. You will be free to withdraw from the study at any stage, you would not have to give a reason, and it will not affect your treatment (if applicable).

What are the possible risks of taking part?

The researcher is not aware of any risks associated with the process. If you find that the interview upsets you, we can stop. You may also choose not to answer certain questions. A short debrief will take place once you have participated in the study to ensure any issues raised are managed appropriately.

What will happen to the information you collect about me?

If you are willing and eligible to take part in the study, all information about you and the data collected from you will be confidential. No personal information will be used. Any personal details gathered will be immediately anonymised, but you may be identifiable from tape recordings of your voice. Your name will be replaced with a participant number or a pseudonym, and it will not be possible for you to be identified in any reporting of the data gathered. All data collected will be kept in a secure place (paper copies of the interview will

be kept in a locked cabinet in a locked room/electronic data will be stored on a password protected computer). Access to data will be strictly limited to the researcher and research supervisors. These will be kept until the end of the examination process, following which all data that could identify you will be destroyed.

The results may be published in a scientific journal or presented at a conference or in a report. You will not be identified in these publications by any of the information given.

Do I have to take part?

It is entirely up to you whether you decide to take part in the study. Participation in the study is entirely voluntary. You can decide not to take part without giving a reason to the researcher. If you decide to participate, you can withdraw from the study at any time, you would not have to give a reason, and it will not affect your treatment (if applicable). If you decide to withdraw, any data you have provided will be safely destroyed and will not be used in any publication.

Concerns

If you have any concerns or questions about any aspect of this study, please ask to speak to myself, Gillian Hutton (email: 40189971@live.napier.ac.uk) or the study supervisor, Dr Anne Rowat (email: A.Rowat@napier.ac.uk, Tel: 0131 455 5670).

If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Dr Norrie Brown. His contact details are given below.

What happens now?

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please sign a consent form. Please then return the consent form to your Edinburgh Leisure 'Exercise After Stroke' instructor who will ask for your contact details. They will provide me with your details and I will contact you by telephone to arrange a suitable time for your interview.

Thank you for taking the time to read this information.

Contacts

Name of research student: Gillian Hutton

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Name of independent person: Dr Norrie Brown, Senior Lecturer

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Email: N.Brown@napier.ac.uk

Telephone: 0131 455 5712

Appendix 7: Information sheet for potential participants: group 2

Project Title: An exploration into the concept of service users as “Physical Activity Champions” to support stroke survivors participate in community based exercise.

My name is Gillian Hutton and I am a research student from the School of Nursing, Midwifery and Social Care at Edinburgh Napier University. For my postgraduate degree, I am undertaking a research project for my Masters by research qualification. The title of my project is: An exploration into the concept of service users as “Physical Activity Champions” to support stroke survivors participate in community based exercise. This study aims to find out whether someone who has had a stroke could support others, following stroke, to participate in community based exercise.

Invitation to take part

This is an invitation to take part in a research study. Before you decide if you want to take part, it is important that you understand why the project is being done and what it will involve. Please take time to read the following information. Please ask if there is anything that is not clear or if you would like more information.

Aim of the project

People who have had a stroke are encouraged to undertake exercise following their stroke. This is because exercise is believed to be beneficial for people who have had a stroke as exercise can help improve balance, mobility and physical fitness levels. It can also be beneficial for improving future health. There is a lot of research that has investigated exercise after stroke. It has shown that several barriers can exist which prevent people who have had a stroke undertaking exercise. It has also shown that there are factors that may help motivate people to exercise following a stroke. One thing that can help to motivate people who have had a stroke to exercise is support from another person. I would like to find out whether this support could come from a fellow stroke survivor. I am therefore aiming to explore whether people who have had a stroke and are attending the ‘Exercise After Stroke’ programme at Edinburgh Leisure

would find it helpful to have support from someone else who has had a stroke. I will also be exploring how these people could be identified and what role they could undertake.

The findings of the project will be useful because it will help us to get information from stroke survivors who use the 'Exercise After Stroke' programme to help us determine if incorporating this type of support would be beneficial.

Why have I been invited?

You have been invited because you work for Edinburgh Leisure and have been involved in delivering the 'Exercise After Stroke' programme.

What will the study involve?

If you agree to participate in the study, I will ask you to complete and sign a consent form. You will then be asked to take part in a tape recorded focus group where we will discuss the idea of incorporating stroke survivors to provide support at the 'Exercise After Stroke' class. This will take place in November 2015 at the Edinburgh Leisure Vantage Point. The focus group will last no longer than 60 minutes but it will be flexible to suit you and you can stop at any time. You will be free to withdraw from the study at any stage, you would not have to give a reason.

What are the possible risks of taking part?

The researcher is not aware of any risks associated with process. If you find that the focus group upsets you, we can stop. You may also choose not to answer certain questions. A short debrief will take place once you have participated in the study to ensure any issues raised are managed appropriately.

What will happen to the information you collect about me?

If you are willing and eligible to take part in the study, all information about you and the data collected from you will be confidential. No personal information will be used. Any personal details gathered will be immediately anonymised, but you may be identifiable from tape recordings of your voice. Your name will be replaced with a participant number or a pseudonym, and it will not be possible for you to be identified in any reporting of the data gathered. All data collected will be kept in a secure place (paper copies of the focus groups will be kept in a locked cabinet in a locked room/electronic data will be stored on a password protected computer). Access to data will be strictly limited to the researcher and research

supervisors. These will be kept until the end of the examination process, following which all data that could identify you will be destroyed.

The results may be published in a scientific journal or presented at a conference or in a report. You will not be identified in these publications by any of the information given.

Do I have to take part?

It is entirely up to you whether you decide to take part in the study. Participation in the study is entirely voluntary. You can decide not to take part without giving a reason to the researcher. If you decide to participate, you can withdraw from the study at any time, you would not have to give a reason. If you decide to withdraw, any data you have provided will be safely destroyed and will not be used in any publication.

Concerns

If you have any concerns or questions about any aspect of this study, please ask to speak to myself, Gillian Hutton (email: 40189971@live.napier.ac.uk) or the study supervisor, Dr Anne Rowat (email: A.Rowat@napier.ac.uk, Tel: 0131 455 5670).

If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Dr Norrie Brown. His contact details are given below.

What happens now?

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, I will ask you to sign a consent form. I will then take your details and contact you by email to arrange the focus group session.

Thank you for taking the time to read this information.

Contacts

Name of research student: Gillian Hutton

Address: School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Room 2.B.48
Sighthill Campus
Edinburgh, EH11 4BN.

Email: 40189971@live.napier.ac.uk

Name of research supervisor: Dr Anne Rowat

Address: School of Nursing, Midwifery, and Social Care
Edinburgh Napier University
Sighthill Campus
Edinburgh, EH11 4BN

Email: A.Rowat@napier.ac.uk

Telephone: 0131 455 5670

Name of independent person: Dr Norrie Brown, Senior Lecturer

Address: School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Sighthill Campus
Edinburgh, EH11 4BN

Email: N.Brown@napier.ac.uk

Telephone: 0131 455 5712

Appendix 8: Ethical approval letter

Neades, Barbara

Hello Gillian,

Thank you for your prompt reply and updated PI sheet and I can now confirm your approval to proceed with your study.

Best wishes with this.

Regards,

Barbara

Appendix 9: Debriefing form

Project Title: An exploration into the concept of service users as “Physical Activity Champions” to support stroke survivors participate in community based exercise.

Thank you for participating in this study. The study aims to explore whether people who have had a stroke and are attending the ‘Exercise After Stroke’ programme at Edinburgh Leisure would find it helpful to have support from someone who has also had a stroke – a “Physical Activity Champion”. The interview or focus group that you have undertaken will provide me with your thoughts on whether support from a stroke survivor would be beneficial or not. It will also provide me with information on what the role could be and how these “Physical Activity Champions” could be identified. The findings of the project will be useful because it will help us to determine if incorporating this type of support in the ‘Exercise After Stroke’ programme would be beneficial. I hope that the information from this study will help us to understand how services can best support people who have had a stroke to exercise.

Following participation, it is important that you have the opportunity to ask any questions and give any feedback regarding the study. Also, please let the researcher know if any issues have been raised during this process. The contact details for Chest Heart and Stroke Scotland and the contact for the Managed Clinical Network for training and education for stroke are below.

If there is any further information you require, please don’t hesitate to ask. The contact details for the researcher and research supervisor are below. Please feel free to contact them if you would like any more information. Also, please provide the researcher with any other feedback you would like to give following participation in the study.

Thank you for participating in the study.

Name of participant: _____

Date: _____

Contact details

Chest Heart and Stroke Scotland (CHSS): Telephone Advice Line Nurses: 0808 801 0899

CHSS nurse: Audrey Bruce, CHSS Lead Stroke Liason Nurse, Edinburgh
Telephone: 537 9085

Managed Clinical Network (MCN) for Training and Education for Stroke:

Mark Smith, Consultant Physiotherapist, NHS Lothian

Email: Mark.Smith@nhslothian.scot.nhs.uk

Name of researcher: Gillian Hutton

Address: Research Student, School of Nursing, Midwifery and Social Care
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Email: 40189971@live.napier.ac.uk

Name of research supervisor: Dr Anne Rowat

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Telephone: 0131 455 5670



Appendix 10: Consent form

Project Title: An exploration into the concept of service users as “Physical Activity Champions” to support stroke survivors participate in community based exercise.

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason and this will not affect any future care.

I understand that if I withdraw from this study, any data I have provided will be safely destroyed and will not be used in any publication.

I agree to participate in this study.

Name of participant: _____

Signature of participant: _____

Signature of researcher: _____

Date: _____

Contact details of the researcher

Name of researcher: Gillian Hutton

Address: Research Student, School of Nursing, Midwifery and Social Care
Edinburgh Napier University
Sighthill Campus
Edinburgh, EH11 4BN

Email: 40189971@live.napier.ac.uk

Appendix 11: Letter of confirmation from Edinburgh Leisure

Subject: Research Project with Exercise After Stroke.

Hi,

I was hoping you would be able to help with an administrative aspect for the Masters by research project which we discussed at our meeting on 2nd July 2015.

As you are aware, I am hoping to explore the experience of exercise of stroke survivors who have completed the 'Exercise After Stroke' programme and to explore the concept of "Physical Activity Champions" to support stroke survivors exercise in the community.

In order to undertake this research I would like to recruit participants for the study from Edinburgh Leisure's 'Exercise After Stroke' Programme and undertake focus groups and interviews on Edinburgh Leisure premises. I am aiming to submit my ethics application in August and for this I require written permission from Edinburgh Leisure.

I would very much appreciate an e-mail from yourselves to give me permission to recruit participants via Edinburgh Leisure and permission to conduct research on the premises of Edinburgh Leisure.

If you require any further information, please don't hesitate to contact me. Any help would be greatly appreciated.

Thanks,

Gillian.

Gillian Hutton
Research Student
Edinburgh Napier University.

To: Gillian Hutton

Morning Gillian,
[Name omitted] got back to me and is ok for this to proceed. When considering the focus group she would be keen to look over the discussion guide to get a wee idea of what will be asked during these sessions.

So what's the next steps from now?

[Name omitted]

Appendix 12: Interview guide
Semi-structured interview: group 1

Introduction

Thank you for agreeing to participate in this study.

Introduce self. I am a researcher doing a postgraduate masters degree and my study is exploring exercise following a stroke.

The study aims to find out how best to support people who have had a stroke to undertake exercise.

I would like to get *your* thoughts and experiences, so there are no right or wrong answers.

I will ask you a few questions and we will talk about what you think. It will take around 40 minutes.

Re-assure the format:

- If you would like to have a break, or stop the interview at any time, please let me know.
- If there are any questions you don't want to answer, please just let me know.
- I will be recording the interview so I can get a record of what was discussed. As stated on the information sheet, all the information you provide will be treated confidentially.
- You can also ask me any questions you have at the end or you can get in touch with me or the research team in the future.
- Do you have any questions before we begin?

“Physical Activity Champion” Questions

In this study, I am looking into whether someone who has had a stroke and has completed the Exercise After Stroke classes could support people who are new to the class. I have called these people “Physical Activity Champions”.

- What do you think about the idea of “Physical Activity Champions”?
[If nothing is said: Do you think this is a good or bad idea? What are the pros and cons of this concept? Does this idea make sense to you?]
[Prompt: If you think back to when you started the class, would this have been helpful or not helpful?]
- What do you think a “Physical Activity Champion” could do?
[If nothing is said: If you think of when you have been at the class, is there anything you would think a “Physical Activity Champion” could do?]
- What people do you think would be good at being “Physical Activity Champions”?

[If nothing is said: If someone was to be at the class to give support, what things would make them good or bad at this?]

- How do you think we could find “Physical Activity Champions”?
[If nothing is said: Do you think people would volunteer to do this? If you were asked to be a “Physical Activity Champion” what would you like to know?]
- From your experience of coming back to exercise after having a stroke, is there anything else you think could help people to exercise after a stroke?

Conclusion

- I have no further questions. Is there anything else you would like to bring up, or ask about, before we finish the interview?

That is the interview finished. Thank you for taking part.

Do you have any questions or comments about anything we have discussed?

To make sure you are still happy to provide the information from the interview, I have a short debrief form.

Appendix 13: Focus group guide

Focus group: group 2

Introduction

Thank you for agreeing to participate in this study.

Introduce self.

The study aims to find out how best to support people who have had a stroke to undertake exercise.

I would like to get *your* thoughts and experiences, so there are no right or wrong answers. We will discuss a few questions, please feel free to say what you think. It will take around 60 minutes.

If there are any questions you don't want to answer, you don't have to contribute. You can also ask any questions at the end or get in touch in the future. Do you have any questions before we begin?

“Physical Activity Champion” Questions

In this study, I am looking into whether someone who has had a stroke and has completed the Exercise After Stroke classes could support people who are new to the class. I have called these people “Physical Activity Champions”.

- What do you think about the idea of “Physical Activity Champions”?
[If nothing is said: Do you think this is a good or bad idea? What are the pros and cons of this concept?]
- What do you think a “Physical Activity Champion” could do?
[If nothing is said: From your experience of running the class, is there anything you would think a “Physical Activity Champion” could do?]
- How do you think we could find “Physical Activity Champions”?
[If nothing is said: How would you identify a “Physical Activity Champion”, Do you think people would volunteer to do this?]
- What people do you think would be good at being “Physical Activity Champions”?
[If nothing is said: If someone was to be at the class to give support, what things would make them good or bad at this?, Can you think of people who could do this role?, Is there attributes that would either lend themselves or be less desirable to being a “Physical Activity Champion”]
- From your experience of supporting people to exercise after having a stroke, is there anything else you think could help people exercise after a stroke?

Prompts

- If an individual has not contributed, ask if they have any additional comments.

Conclusion

- I have no further questions. Is there anything else you would like to bring up, or ask about, before we finish the focus group?

That is the focus group finished. Thank you for taking part.

Do you have any questions or comments about anything we have discussed?

To make sure you are still happy to provide the information from the focus group, I have a short debrief form.