Coventry & Warwickshire
Cardiovascular Network

Evaluation of the Thistle Lifestyle Management Course for stroke patients

"We're all rowing on the same boat in the middle of the bloody Atlantic trying to get somewhere as a team overall."

Final Report
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Executive Summary

Stroke is one of the leading causes of morbidity in the UK, with over 100,000 people experiencing a stroke each year, causing significant physical and cognitive impairment in many patients who survive. Up to 75% of patients who survive a stroke will have significant cognitive impairment, including problems with memory, attention, language and perception as well as organisation of movement and thoughts. Psychological mood disturbance is associated with higher rates of mortality, long term disability, hospital readmission, suicide and higher utilisation of outpatient services if left untreated. Many of those who develop depression or anxiety post-stroke remain undiagnosed or inadequately treated. In addition, caregivers of stroke survivors often develop similar mood disturbances attributable to the strain of taking care of the patient.

One way to improve psychosocial recovery post-stroke, and in line with a growing movement away from acute and episodic care, is to promote self-management. Empowerment and involvement of patients is high on the NHS agenda in the current climate and self-management of long term conditions (LTCs) may provide a route to improved patient outcomes. A stepped care approach is recommended by NICE guidelines for people experiencing common mental health symptoms such as depression and anxiety. The case for psychological interventions for people with LTCs is made in the DH Good Practice Guide for the national Improving Access to Psychological Therapy (IAPT programme).

The Thistle Foundation Lifestyle Management Course

The Thistle Foundation Lifestyle Management Course is designed to support stroke patients who might be dealing with difficult life. The purpose of the course is to help people gain control over their situation by making use of and building on their own coping and recovery strategies and by boosting confidence and self esteem.

Aims and objectives

The aim of this evaluation was to conduct a clinical and effectiveness audit of a “best documented” course service provision for stroke patients.

Objectives

1. To evaluate a newly commissioned service devised and delivered jointly by the Thistle Foundation and the Coventry & Warwickshire Cardiovascular Network (CWCVN), which has been specifically designed to be accessed in an NHS treatment mode by stroke patients.
2. To undertake a structured enquiry, involving observations, interviews and questionnaires, of the course to encourage emulation and comparison in other treatment centres.

Methods

The evaluation was a mixed methods design incorporating observer reports, quantitative questionnaires and focus groups. Two courses were delivered.

Key Findings

We found that by the end of the course stroke patients who had attended at least 60% of the course reported improvements in stroke self-efficacy (confidence), stroke cognitions and hope (goal motivation and goal planning). Some of these improvements emerged at approximately the midpoint of the course.

Some patients specifically mentioned during the group discussions that the course helped with their depression and stress. Patients (and caregivers) described some of the group therapeutic factors (e.g. group cohesion, universality, altruism, instillation of hope) which provided the foundation upon which the improvements in self-efficacy, cognitions and hope quantitative, outcome data occurred. Patients were more likely to look to the future with hope and courage and had were more socially engaged. They were more goal focused and determined in working towards achieving their "best hopes"

Patients were using a range of lifestyle and self-management techniques to help them recover from their stroke including, diaphragmatic breathing, pacing and mindfulness.

Caregivers also found that being around others with similar experiences was beneficial and helped them to cope with their own challenges. Caregivers also benefitted from actively participating on the course.

Stroke patients and caregivers greatly valued the interpersonal style (warmth, empathy, care, compassion) of the tutors, which encouraged them to adopt and maintain stroke recovery lifestyle and self-management techniques.

Recommendations

Given the findings of the evaluation the following recommendations are made to support the sustainability and spread of the Thistle Lifestyle Management Course.

Recruitment & referral

- All recruitment and course correspondence literature should address the patient by forename and surname rather than "stroke survivor"
- The recruitment literature should clearly describe the course aims and content and also describe the benefits of attending for patients and also caregivers.
- Personal testimonies (short video diaries) of previous course patients and caregivers to create demand should also be included in any recruitment literature/ to place on NHS Local YouTube and Facebook, to engage the public, commissioners and providers.
- Recruitment from informed and enthusiastic health practitioners/referrers should be the preferred recruitment method over postal recruitment.

Psychological stepped care

- Stroke staff should be trained to use a simple depression screening tool and refer on to the stroke course.
- IAPT should refer stroke patients at Level 1 (sub threshold psychological problems) and Level 2 (Mild/moderate psychological problems) on to the course.

- Pre and post-course measures should be routinely used to recruit and monitor course participants. Patients who do not improve should be "stepped up" to more specialist, psychological care

Targeting limited resources more effectively

- Improvements in self-reported outcomes (stroke self-efficacy, stroke cognition, hope) emerged at mid course (week 6) with further smaller improvements occurring between week 6 and course end. The course could be reduced in length to a 6-8 week course which would be less resource intensive but which would still improve key patient outcomes.
- A review of the delivery order of the course topics should be undertaken and repetition of the weekly review and physical exercise activity reduced.
- Stroke patients and caregivers (former course participants) could be involved in co-delivering with stroke health professionals some of the course activities
- Course reunions should be scheduled to consolidate and refresh patient and carer stroke recovery management.

Ongoing support and tailored training for clinicians

- The 2 day brief solution focused tutor training should be reduced to 1day and reinforced with a self-directed e learning online training package
- Tutors should develop action learning sets to consolidate and further refine and improve their facilitation and course delivery skills.

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Introduction

Stroke is one of the leading causes of morbidity in the UK, with over 100,000 people experiencing a stroke each year, causing significant physical and cognitive impairment in many patients who survive [1]. Up to 75% of patients who survive a stroke will have significant cognitive impairment, including problems with memory, attention, language and perception as well as organisation of movement and thoughts [2]. Psychological mood disturbance such as anxiety and depression is common post-diagnosis [3]. If left untreated mood disturbance is associated with higher rates of mortality, long term disability, hospital readmission, suicide and higher utilisation of outpatient services [4-6]. Many of those who develop depression or anxiety post-stroke remain undiagnosed or inadequately treated. In addition, caregivers to stroke survivors often develop similar mood disturbances attributable to the strain of taking care of the patient.

The physiological symptoms of stroke are well addressed medically, and are known to be largely affected by the speed at which the patient is admitted into the system of care. However psychological and social symptoms may not always receive adequate attention and care provision [7]. The speed of access and quality of care in psychosocial recovery can have a significant bearing on the overall outcome for stroke patients. The Care Quality Commission review of stroke services 2011[8] demonstrated that there was a great deal of room for improvement in stroke services and in particular the provision of psychological care for stroke survivors and their families.

Both the Royal College of Physicians (RCP) National Clinical Guidance 2008 and the British Psychological Society briefing paper “Psychological services for stroke survivors and their families guidance” recommend that patients should be routinely screened for depression, anxiety and for cognitive problems to ensure that they receive the emotional support they need.

One way to improve psychosocial recovery post-stroke, and in line with a growing movement away from acute and episodic care, is to promote self-management. Empowerment and involvement of patients is high on the NHS agenda in recent years [9] and self-management of long term conditions (LTCs) may provide a route to improved patient outcomes. A stepped care approach is recommended by NICE guidelines for people experiencing common mental health symptoms such as depression and anxiety [10]. The case for psychological interventions for people with LTCs is made in the DH Good Practice Guide for the national Improving Access to Psychological Therapy (IAPT) programme [11]. An adapted Improving Access to Psychological Therapies stepped care model for psychological interventions for stroke patients describes a hierarchy of three levels of mood disorders [1] (see figure 1). These range from 'sub-threshold' transitory mood/cognitive problems (level 1) experienced by many patients, which may not always be diagnosed clinically and which can be dealt with by peers and stroke specialist staff. Mild/moderate symptoms (level 2) which can be addressed by non-psychology stroke specialists supervised by clinical psychologists. Severe and persistent disturbance (level 3) which requires immediate and specialist care provide by specialist stroke clinical psychologists.

This stepped care approach describes the potential for self-management and lifestyle management interventions to help support stroke patients assessed to be at level 1 and level 2 of the model. Stroke self care and self-management are a key priority nationally (National Stroke Strategy [12]; Accelerated Stroke Improvement (ASI) Programme [13]; and Quality Improvement Productivity Prevention Long term conditions and Urgent Care [14].

A systematic review and meta-analysis involving nearly 7,500 LTC patients who attended lay-led self-management programmes (SMPs) reported small improvements in several outcomes including depression and self-efficacy [15]. Many of the SMPs included in the systematic review were derivatives of the Stanford University's Chronic Disease Self-Management Course (CDSMC; known in the UK as the Expert Patients Programme (EPP)). Coventry & Warwickshire Partnership Trust deliver the generic EPP people living with a range of LTCs. However, a national evaluation of the EPP [16] showed that few stroke patients attended the programme. Kendal et al., [7] evaluated the CDSMC for stoke patients in Australia and found that attendance on the course led to improvements in functional self-care outcomes but not psychological or self-efficacy outcomes suggesting a self-management programme tailored to the needs of stroke survivors might be more warranted.

The Thistle Foundation Lifestyle Management Course

The Coventry and Warwickshire Cardiovascular Network together with local clinical psychology services identified that psychological care and support for patients following a stroke was poor. The two organisations worked collaboratively to identify and review courses being offered nationally that might be suited to meet the needs of stroke patients locally. Having reviewed the courses offered, the Thistle Foundation Course was identified as best suiting the needs of stroke patients and carers.

The Thistle Foundation Lifestyle Management Course is designed to support anyone who might be dealing with difficult life situations or living with a long term health condition. The purpose of the course is to help people gain control over their situation by making use of and building on their own coping and recovery strategies and by boosting confidence and self esteem. The course is supported by 2 trained group leaders and consists of 10 group based sessions, each lasting three hours. Sessions are planned in advance with appropriate rest breaks and involve discussions, safe and appropriate exercise, relaxation and mindfulness training. Prior to this evaluation, 2 courses had been delivered to 20 stroke patients in Scotland.

Aims and objectives

The aim of this study was to conduct a clinical and effectiveness audit of a "best documented" course service provision for stroke patients.

Objectives

- To evaluate a newly commissioned service (self management course) by the CWCVN delivered by The Thistle Foundation
- To undertake a structured enquiry involving observations, interviews and questionnaires of the course to encourage emulation and comparison in other treatment centres.

Design

The evaluation was a mixed methods design incorporating quantitative questionnaires, qualitative interviews, focus groups and observations and included two work packages (WP)

- **WP 1** involved obtaining feedback stroke workforce who attended a 2 day training workshop in solution focused training
- **WP 2** involved conducting an outcome and process evaluation of the Thistle Lifestyle Management Courses from the perspectives of stroke patients, caregivers and facilitators.

WP1 Evaluation of the solution focused training workshop

Solution focused brief therapy training (SFBT)

The course was aimed at health care professionals working with stroke survivors. Health care professionals from across the disciplines, who attended, were taught to use a range of strategies to facilitate brief therapy with stroke survivors:

- Engagement - by seeing the person not the problem
- Listening - by the use of constructive listening
- Best hopes - what does the stroke survivor hope to achieve in terms of working together with a facilitator
- Focusing on the future/preferred future by stroke survivor
- Introducing conversations around self management with stroke survivors
- Eliciting stroke survivors own views about resources and self management strategies
- Focusing on small improvements, learning and insights
- Relapse management
- Giving information
- Negotiating end of support
- Future contingency planning

To publicise the course; flyers, posters, registration forms were developed and circulated widely across the NHS provider units across Coventry and Warwickshire.

22 staff registered for the course. The full 2 day course was completed by 17 staff from across Coventry, Warwickshire and Solihull from a range of services: occupational therapy, speech and language, clinical psychology, IAPT, physiotherapy. All staff completing the two day course received a certificate of attendance.

All staff completing the SFBT course were asked if they would be interested in being involved in the 10 week lifestyle self management course. Having basic insight into SFBT and 'belief' in the approach were felt to be important factors in facilitating delivery of the self management course.

Method
All facilitators completed a training feedback questionnaire comprising ten questions about the quality and usefulness of the training. The questionnaire was administered at the end of the second day of training. Of those who attended the training session, four healthcare professionals went on to become course facilitators; one speech and language therapist, two occupational therapists and one assistant practitioner

Data analysis
All data were input into and analysed using PASW v.17. Frequencies and group means are reported.

WP2 outcome and process evaluation of the Thistle Lifestyle Management Course

Sample
A purposive sample of patients who had suffered a stroke were contacted by post by the Coventry and Warwickshire Cardiovascular Network with details of the course. A leaflet was enclosed with an information sheet and the patients were invited to attend a consultation with the evaluation team and a Thistle Foundation representative.

Patients were also referred on an ad hoc basis by consultant neuropsychologists who were aware of the evaluation and had suitable candidates. This method was particularly used in round two when the healthcare professionals were more involved in recruitment and could identify patients and speak to them personally.

Inclusion criteria for being contacted were having had a stroke, and being physically and cognitively able to participate in the course (Some participants self referred having received the information packs in the post about the course and returned the willingness to participate in the course reply slip, whilst those for course 2, facilitators working directly with stroke patients made them aware of the course and distributed packs and those interested then returned the reply slip.
Caregivers were also invited to attend.

Detailed criteria can be found below:

<u>Inclusion criteria</u>

- 3 months post stroke prior to starting the course(admitted to UHCW between March, April, May 2011)
- Living in Coventry or Warwickshire

- Aphasic, but could communicate with carer support
- Psychologically 'struggling' in some way (self recognition that they needed to learn how to deal with this)

Exclusion criteria

- Those with dementia or learning disabilities
- Those unable to communicate in English
- Living outside Coventry and Warwickshire
- Patients admitted June, July, August 2011 (not 3 months post stroke)
- Living in a Nursing Home or in residential care.

Procedure

Course 1

One week prior to course start date, all participants were invited to a 1:1 consultation with the course provider, course facilitators, CWCVN project lead and a researcher from Coventry University. These meetings served several purposes; to enable the participants to find out more about the course, ask questions and reach a decision with support from the course provider as to whether they felt the course would be beneficial to them, for the participants to see the venue and ensure that they were able travel to and from the venue; to meet the team; to be briefed about the content of the course and establish what they hoped to achieve from attending the course (their "best hopes"); to consent to take part in the evaluation and complete baseline questionnaires.

Course 2

A similar format was followed, but the CWCVN project lead provided support from a 'distance' from the outset to enable the newly trained facilitators to take on more leadership responsibilities.

The Thistle Foundation Lifestyle Management Course

The Thistle Lifestyle Management Course is designed to support anyone who might be dealing with difficult life situations or living with a long term health condition. The purpose of the programme is to help people gain control over their situation by making use of and building on their own coping and recovery strategies and by boosting confidence and self esteem. The course is supported by 2 trained group leaders and consists of 10 group based sessions, each lasting three hours. Sessions are planned in advance with appropriate rest breaks and involve discussions, safe and appropriate exercise, relaxation and mindfulness training.

Two courses were delivered and evaluated. Feedback from observations of the first course, and feedback from patients, caregivers and facilitators was used to adapt the second course. The first course was run as the standard 10 week course. The second course was reduced to 8 weeks but retained the same overall content. One of the aims of the project was to 'trial' the 10 week course and see if it could be reduced in length without it impacting on quality given NHS resources are

limited. Moreover, it soon became evident that recruiting staff to deliver the course over a 10 week period proved problematic which in itself would have added to the difficulties of trying to get the service formally commissioned.

The full 10 x week course content and breakdown of each week's discussion topics and delivery order for is included in Appendix 3.

Methods

Outcome measures were selected by a steering group made up of researchers, representatives from the CWCVN and consultant neuropsychologists. The outcome measures used by the Thistle Foundation for previous course evaluations were reviewed. Patient burden in completing several lengthy outcome measures was cited as a reason for very low response rates. It was therefore decided to use a parsimonious battery of outcome measures. The Hospital Anxiety and Depression Scale and the Beck Depression Inventory were rejected by the steering group due to concerns that clinical depression may be indicated through their use and there was no adequate referral pathway should this be the case.

A review of the existing stroke rehabilitation and self-management research was conducted by Coventry University. The project steering group reviewed the outcome measures and selected three described below. The outcome measures reflected both the theoretical underpinning of the course and the aims of the course (e.g. improve confidence to manage stroke, improve stroke cognitions and improve goal motivation and planning) were selected.

Stroke self-efficacy

Self Efficacy was measured with the Stroke Self-Efficacy Scale [17]. The Stroke Self Efficacy Scale (SSES) is a validated 13-item self-report measure designed to assess the ability to carry out day-to-day tasks which are commonly affected by stroke, such as eating with both hands and walking without assistance. Each task is marked on a scale of 0 to 10 (giving a total possible score of 130) where a higher score indicates greater confidence.

Stroke cognitions

Stroke cognitions were measured using the Stroke Cognitions Questionnaire Revised Version (SCQR) [18]. The SCQR consists of 21 items: 9 positive statements and 12 negative statement. For each item, patients indicate whether they have had the thought 'often', 'sometimes', 'rarely' or 'never' in the past month. Responses are scored on a 0 – 3 scale, with 0 = never and 3 = often for negative items and scores reversed for positive items. Total scores are in the range of 0 – 63, with a higher score indicating that the patient has relatively more negative cognitions and less positive cognitions.

Hope

Hope was measured with the Adult State Hope Scale [19]. The scale comprises 6 statements which represent pathways and agency thinking. Participants indicate the extent to which they agree with each of the 6 statements applies to them at the present moment on a 1 ("definitely false") to 8 ("definitely true"). Total hope scores range from 6 to 48 with higher scores indicting higher levels of hopeful thinking.

Best hopes

During their initial consultations, patients were asked to define some specific personal "best hopes" (stroke recovery goals) they wanted to work towards while attending the course and after completing the course. These hopes were elicited by facilitators and recorded by researchers. Patients were asked to rate their progress towards achieving each best hope (goal) on a scale of 0-10 at each data collection point where 0 = no progress made toward goal and 10 = achieved goal.

Baseline questionnaires were administered prior to the beginning of the course, where possible, and on the first week of attendance for participants who had not been able to attend consultations. Questionnaires were then administered at six weeks (mid course), course end (at 10 weeks for course one and 8 weeks for course two), and at four months follow up. The four month follow up data collection for both courses is ongoing and the data are not included in this report Mid course questionnaires were introduced to provide information about any improvements emerging at 6 weeks, which is the traditional length of self-management programmes in the UK (e.g. Expert Patient Programme). These data would assist the Project Steering Group in deciding the optimum length ("dose") of subsequent courses in terms of benefits to stroke patients and the likelihood of being commissioned in light of the resources (e.g. staff time, venue hire) required to deliver the course.

Analysis

Data were analysed using PASW v.17 and an alpha value was set at 0.05. A repeated measures ANOVA test was conducted on course completers (defined as attending 6 of the 10 sessions for course 1, and 5 of the 8 sessions for course 2) for all outcome variables to determine whether any differences occurred as a result of attending the course. Pairwise comparisons (baseline & mid course comparison; mid course and post-course comparison) were conducted to determine at what stage of the course any improvements might occur.

Post-course focus groups

A post-course focus group (FG) was held for both courses. The FGs were conducted one week post-course completion. A semi-structured FG schedule was devised which explored both the course process and content.

Analysis

Focus groups were digitally recorded with the permission of each participant and were transcribed verbatim. The data were analysed using thematic analysis [20].

Post-course facilitators feedback

Course facilitators' feedback was gathered using an open-ended questionnaire. The questionnaire prompted facilitators for their thoughts on the course style and content, as well as the length of each session and overall. Questions also focused on how prepared the facilitators felt, how well supported they felt before and during course delivery, and how their involvement in the course had affected their usual practice.

RESULTS

WP1 feedback from solution focused training workshop

Facilitator training

A total of 17 healthcare professionals attended the two day solution focused therapy training event and 14 completed the feedback questionnaire. Results showed that on the whole, participants were satisfied with the content of the course and the teaching methods, but that they did not necessarily feel prepared to become involved in course delivery at the end of the training (see Table 1).

Table 1: Facilitator responses to selected questions following the two day brief solution focused therapy training (N=14)

	'Very satisfied' (%)	'Somewhat satisfied' (%)	'Somewhat dissatisfied' (%)	'Not at all satisfied' (%)
How satisfied were you with the content of the training?	50	42.9	7.1	
How satisfied were you with the teaching methods?	42.9	42.9	14.3	
How satisfied were you with the course length?	14.3	78.6	7.1	
Overall, how satisfied were you with the training that you received at the Thistle Foundation course?	57.1	42.9		
How satisfied were you with the venue?	100.0			
How satisfied were you with the course materials?	57.1	35.7	7.1	
How satisfied were you with the tutors?	64.3	35.7		
How satisfied were you with the catering and refreshments?	50.0	42.9	7.1	
	'Very well prepared'	'Somewhat well prepared'	'Somewhat ill prepared'	'Not at all prepared'
How well prepared do you feel to be involved in the delivery of a 10-week	11.1	88.9		

course to patients?				
	'Very useful'	'Somewhat useful'	'Not very useful'	'Not at all useful'
How useful do you think the content of this training will be in terms of applying it to your own practice?	36.4	63.6		

Qualitative comments which were captured through open-ended text boxes included in the questionnaire revealed that importance was placed by many respondents on the benefits of using solution focused questions in eliciting hope. This style of working represented a difference from their usual method of questioning in practice. Some participants cited the role playing activities as being a valuable learning tool. However, other participants felt this part of the training was the least useful, took up too much time and were repetitive. Participants generally agreed that the lack of an agenda made the course difficult to follow at times and felt the sessions could have been more structured.

"Could have used an agenda to know exactly what would be covered in the two days"

"Too long spent on role plays, but more theory would be helpful"

In summary the results suggest that the training was extremely useful but that the format of the course may need improving. Suggested improvements would be to reduce the training to one day and provide a clear agenda at the beginning. Role plays could be reduced to improve engagement from participants and avoid repetition.

WP2 outcome and process evaluation of the Thistle Lifestyle Management Course

Figure 1 shows the recruitment and retention process throughout course one; figure 2 shows the process throughout course 2.

Figure 1: recruitment and retention figures for course one

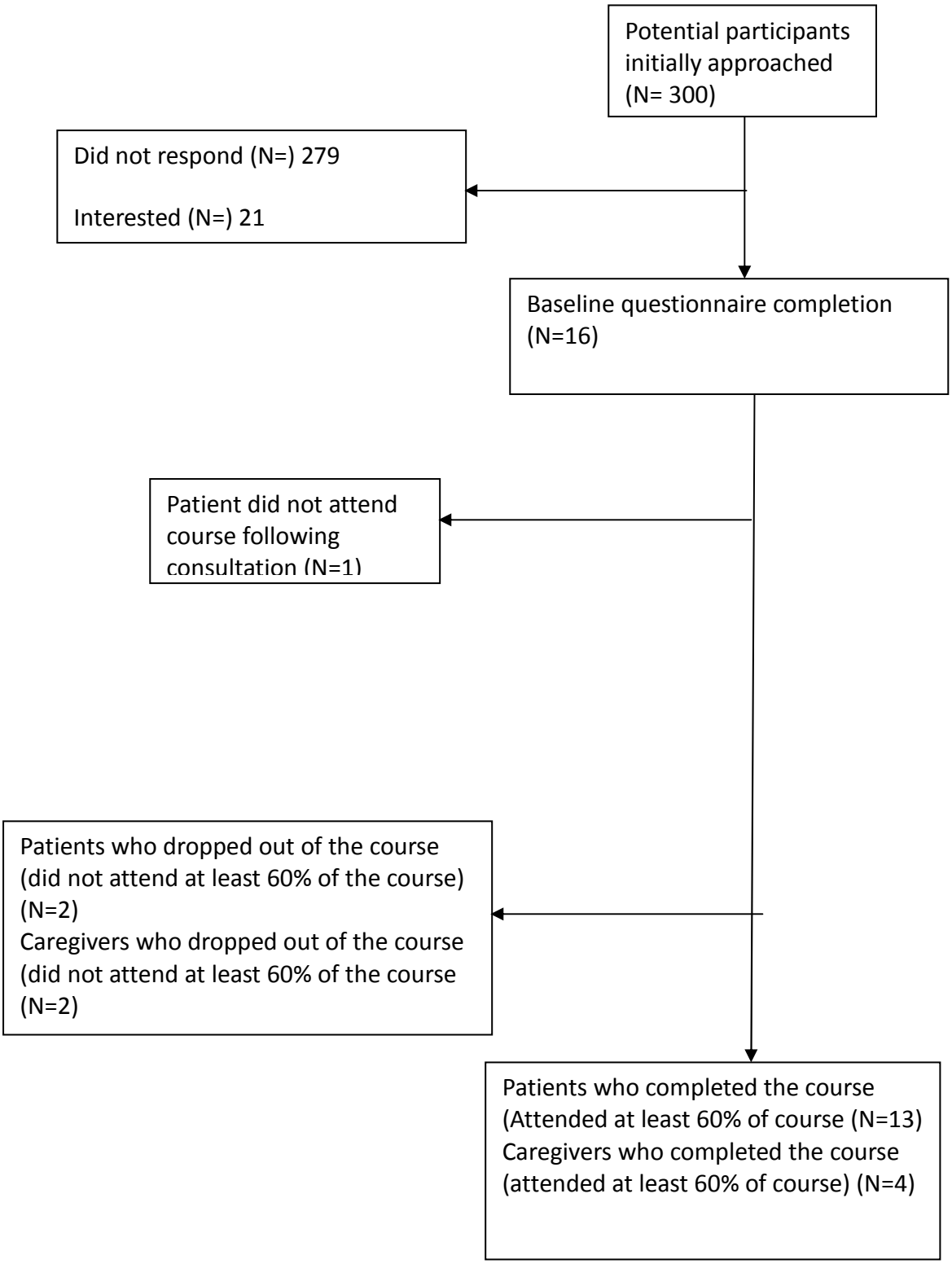
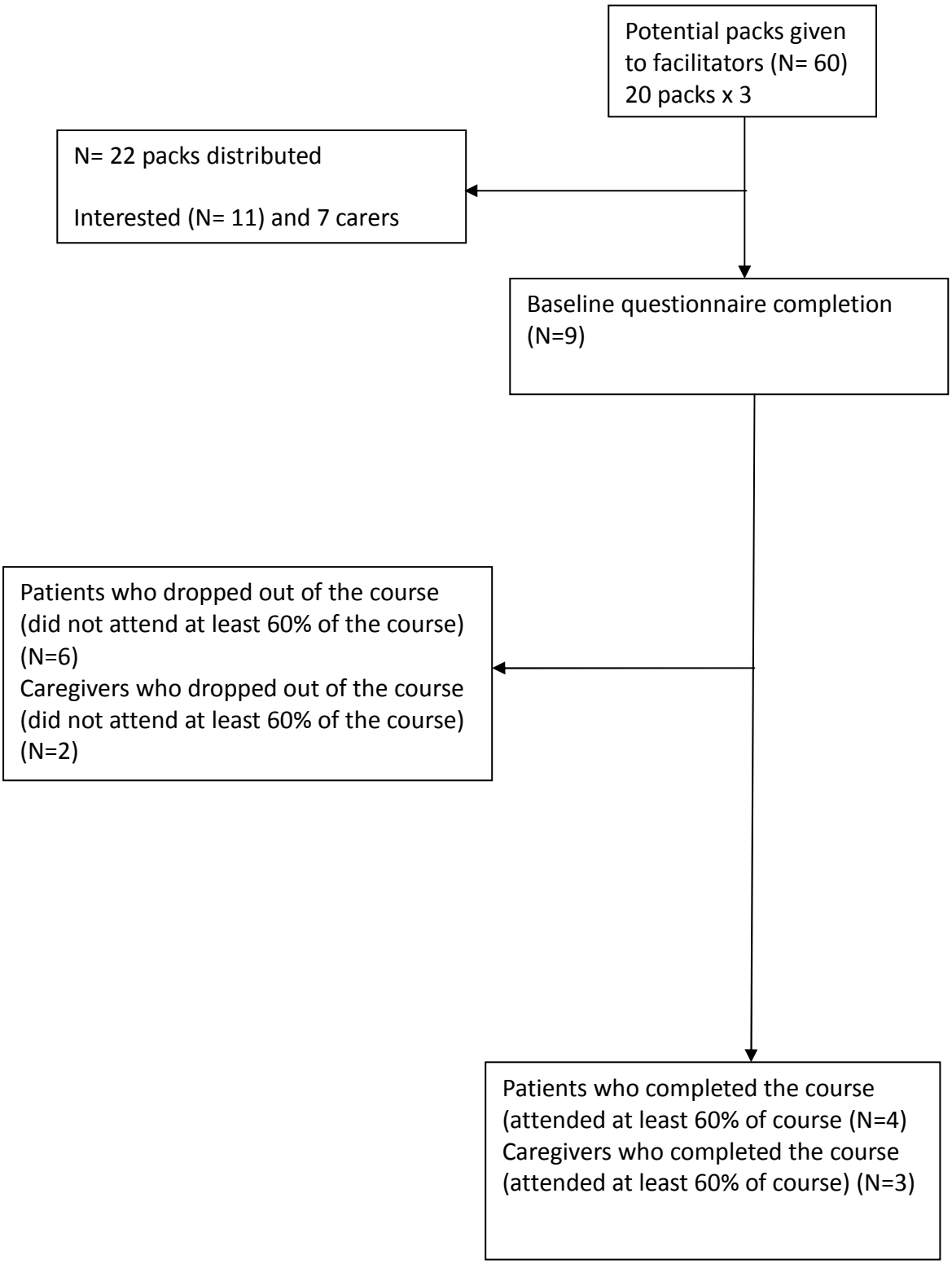


Figure 2: recruitment and retention figures for course two



Although reasons for drop-out were not routinely captured some participants provided reasons:

- 2 patients unfortunately suffered another stroke in the early weeks of course 1. Both were invited with their caregivers to attend course 2; one took up the offer and attended every week of course 2 however the other was not well enough.
- One patient and her caregiver attended one week of course 2 but felt unable to cope with communication difficulties which led to a perceived barrier in taking part in the group discussions and activities.

Table 2 shows how many patients and caregivers attended each course and the frequency of attendance. In course 1, 13 patients completed the course (defined as having attended at least 60% of sessions), and four patients completed course 2

Table 2: Course attendance in total weeks for patients and caregivers

Number of sessions attended	**Course one**		**Course two**	
	patients	**caregivers**	**patients**	**caregivers**
10	5	2	-	-
9	5	1	-	-
8	2	1	2	1
7	1	0	0	3
6	0	0	0	0
5	0	0	2	0
4	0	0	2	1
3	1	1	0	0
2	1	1	0	0
1	0	0	1	1

Table 3 shows the demographic makeup of each group of patients. This information was not collected from caregivers and therefore is not summarised. Slightly more female patients attended the courses than male patients (54. 4%. The mean age of patients was 64.5 years. The mean time since having a stroke was 11.3 months) (days) and the mean time patients spent in hospital following their stroke was 28.9 days. The majority of patients were white (90%).

Table 3: Demographic data for patients attending course course 1 and course 2

Characteristics	All (N=22)	LMC 1 (N=13)	LMC 2 (N=9)
	mean (SD = standard deviation)		
Age	64.5 (11.5)	62.77 (11.6)	67.11 (11.4)
Time since stroke (months)	11.3 (9.5)	12.3 (11.2)	9.8 (6.9)
Time spent in hospital following stroke (days)	28.9 (32.2)	17.0 (12.907)	43.50 (42.584)
	%		
Gender Male Female	 45.5 54.4	 46.2 53.8	 44.4 55.6
Ethnic origin White	 90	 92	 88
Questionnaire completion rates Time 1 Time 2 Time 3	 100 73 59	 100 92 77	 100 44 33

Patient outcomes

A repeated measures ANOVA showed an overall improvement in mean stroke self-efficacy scores ($p<0.001$). Pair wise comparisons suggest a statistically significant improvement in mean totals from baseline to mid course ($p<0.001$) and a further improvement from mid course to post-course ($p=0.044$) (Table 4).

A repeated measures ANOVA showed an overall improvement in mean stroke cognition scores ($p=0.003$). Pair wise comparisons showed a trend towards improvement in scores from baseline to mid course ($p<0.060$). There was a non-significant improvement between mid course and post-course ($p=0.314$) (Table 4).

A repeated measures ANOVA showed an overall improvement in mean Hope scores ($p= <.001$). Pair wise comparisons suggest a statistically significant improvement in mean scores from baseline to mid course ($p=0.004$) and a trend towards improvement from mid course to post course ($p=0.068$) (Table 4).

Table 4: Baseline, mid course and post-course outcomes for patients who completed (attended at least 60% of the sessions) the course (N=11)

Outcome measure	Baseline Mean (SD)	Mid-course Mean (SD)	Post-Course Mean (SD)	P value*
Stroke Self Efficacy Questionnaire (0-130; ↑ = better)	96.9 (25.1)	108.2 (23.2)	114.6 (15.5)	<.001
Stroke Cognitions Questionnaire Revised (0-63; ↓ = better)	23.2 (13.3)	14.9 (7.0)	13.5 (7.2)	.003
Adult State Hope Scale (8-48); ↑ = better	34.6 (8.5)	40.0 (5.7)	42.5 (4.2)	<.001

*Repeated measures ANOVA

Best hopes (goals)

Patients' best hopes were the result of open-ended questions and as such were varied. However, some core themes emerged within the hopes; several patients expressed that they hoped to improve their confidence in some way, some hoped to have more energy and/or improve their sleep pattern, and many patients hoped to rectify cognitive and/or mood disturbances such as poor memory, anger management and stress. Relaxation was also a common theme within best hopes. Table 1, Appendix 2, shows the progress for each participant throughout the course in terms of self-reported best hope scores. On the whole, participants progressed towards achieving at least one of the best hopes and many patients progressed towards achieving all of their hopes. Not all participants completed the questionnaires at all time points therefore the data are not complete.

Patient and carer experiences of attending the course

Nine stroke patients and 3 caregivers from course 1 attended the post-course focus group Three stroke patients and 3 caregivers attended the course2 FG. Only course 1 data are presented below as the audio file for course 2 FG had not been transcribed at the point of writing this report.

Topics explored during the FG are themed and reported below under the following headings:

- Reasons for attending
- Lifestyle and self-management techniques
- Improved outcomes
- Group curative factors: hope, universality, group cohesion, altruism

Reasons for attending

For some course participants the decision to attend the course was borne out of a general curiosity to find out what it was about and whether it could help them recover from their stroke. Other participants said that the invite letter and consultation provide them with hope for the future as well as a stimulating their curiosity.

It must have just been curiosity and a bit of hope. (R4)

One participant attended the course as a way of addressing the social isolation and boredom after having her stroke. Several participants felt that the course was an opportunity to receive support and advice for specific stroke-related problems. One participant was struggling to cope with his emotions (clinical depression) and another participant, after repeatedly reading the invite letter and struggling to see whether the course would be of any use to him, thought that maybe it could help him manage his anger. Similarly, another participant, despite realising and admitting that he desperately needed help recovering from his stroke, was not convinced that the course would help and only attended on the insistence of his GP.

I got the letter and left it for 10 days, having read it and put it down too many times, and then decided that what I saw in it possibly was the fact that I had anger problems, which was a result of the stroke, and that maybe just I might get out of the course a control of my anger issue. (R3)

I think I was at rock bottom when I saw this, I looked at and thought can't see that helping, but the doctor said I urge you to go, and I'm thankful that I did. ... the only thing that made me come was my doctor saying I would urge you to go...I'd got to do something about it or I would just go under. And things have looked up since then. R9)

One participant felt more motivated to attend the course after his consultation with the course facilitator and that his attendance on the course provide him with motivation to become more active and engaged. His attendance also offered him the opportunity to share his experiences with and offer support to other stroke patients.

...and I thought I've got something I can give here as well. I can start to participate in things instead of being this vegetable stuck at home (R1).

One of the caregivers described the importance gaining an understanding of the problems facing their partner and actively participating in the course so that they could better support their partner.

I was absolutely delighted when I was allowed to stay because it's so important, I think the other caregivers will agree, that we go to every course, every part of the course, then we fully understand what's going on and we can participate in it and do it together (R7 caregiver).

Overall, participants were quite critical of the recruitment/invite letter feeling that it lacked sufficient information about the course content and the benefits of attending and that it also addressed participants impersonally (e.g. Dear "Stroke survivor"). These issues possibly explained why there was such a poor response to the letter.

Well the one thing about the letter that I didn't like, and I don't know what words they could have used, was stroke survivor, because I think that's absolutely awful, I think. … a bit angry I think that they used those words. ... When you pick that letter up, you're just kind of getting, well coming to terms perhaps with your situation or whatever it might be, you get this letter and you think stroke survivor, urgh. … It didn't encourage you to come. (R):

Lifestyle and self-management techniques

All participants were using the lifestyle and self-management techniques they were introduced to on the course. These included relaxation and stress management techniques mindfulness, prioritising/pacing, goal setting, communication and sleep hygiene. What was noticeable during the FG was how participants often vividly recalled and described the lifestyle management activities and techniques which involved highly interactive and visually interesting and stimulating teaching methods such as the "sand and the stones" (prioritising/pacing) and the "raisin" (mindfulness). Often these were also described as being the most useful and enjoyable activities.

R4: I think it was the actual physical activity that he did with putting the sand and stones in the jar. R5: You see it work. R1: It's the seeing of isn't it? R3: The visual was essential to get the point across.

A R5: It was mindfulness wasn't it really...it was like a simple raisin, there were big juicy ones weren't there, and like we had to hold it in our mouth for about 15 minutes... played with it in your fingers and smell it and feel its aroma and everything. R1: It was feel the texture, look at the wrinkles on it. R5: It was part of meditation. R1: the smell and everything, it made me so aware of a raisin.

Several participants described the usefulness of the planning and pacing ("boom and bust") activity for helping them to manage their energy levels, look after their health (blood pressure) and prioritise important activities over less important activities.

Well it's helped me with my boom and bust because I was that, very much that way anyway, because I worked full time, a Saturday I had to get my house done top to bottom, no matter if I was on my knees at the end of the day, I had to get it done. Now... I'm not as obsessional about the house, about work, it will still be there, I'm the important one, it's made me realise that plan, prioritise, and just do what you ca (R1).

My blood pressure now, effectively the lower figure sits just about 70, whereas pre the stroke it was bordering between 98 and 105. And that's a little bit down to exercise, and a little bit down to the course in just stop, let go and just breathe because the breathing controls yourself. (R3)

Many participants spoke about the simplicity and usefulness of the deep breathing/relaxation techniques such as diaphragmatic/belly breathing and progressive muscle relaxation (body scan). Participants used these techniques successfully to help with better sleeping and overcome feelings of stress linked to cooking for her family and having grandchildren stay over. Often, participants

used the relaxation CDs give out on the course to assist their relaxation practice.

> *I mean as you know I had problems with sleeping, oh very bad sleeping, insomnia, and it helped me an awful lot with that. It just relaxed me enough to go off to sleep and that's it. Quite often my partner used to come up and take my earphones out because I was fast asleep with it still running [relaxation CD].*

> *Just before we dished I had a funny turn, lie down, the first thought was the breathing, was I getting all stressed because of my entertaining, put them into gear and straightaway and I had another funny do so I went to bed and did the breathing in bed. I think before that would have escalated out of control, I would have had a really bad turn without the breathing, I couldn't do without it.*

Some participants described how they used the breathing techniques to manage their anxieties about returning to work after their stroke. One participant was even encouraging her work colleagues to use the breathing technique to manage their own stress.

> *I was scared, it was a job I knew inside out and I was scared. And I thought come on take time out, breathe, it's only your job, nothing can go wrong, don't react. And it really helped me, really really helped me. And I do it when I'm sitting at my desk, in fact I tell some of my colleagues because one of my colleagues in my office, four in seven out, or five in nine out. (R1)*

One participant described using deep breathing during a serious panic attack to manage a potential life threatening situation.

> *"...and the only thing that kept me going, the doctor came in was just breathing, just breathing kept me going to the end... But without that...I think I would have just died on the floor, you know. (Patient R11)*

Another participant described how her ability to express herself improved over the course of the course.

> *Well I guess my expression that, my self expression improved, and I think it's still starting, it's continuing to get better, it's more and more doing it makes me able to express myself better. And generally, in general conversation now I can not have any problem whatsoever now, so I think that is a big step forward.*

The physical exercise sessions consisted of gentle circuit repetition exercises such as seated leg raises, step-ups on a small raised platform, and light weight lifts. This activity, which was repeated throughout the course, received more mixed views compared to all the other course activities. Several patients commented that they were not appropriate for everyone and therefore it was not necessary for them to be included each week. One patient thought that the exercise sessions were more appropriate for those who were more physically impaired. Participants generally agreed that it would have been sufficient to cover exercise during one week and then build progress into

discussions rather than continue to practice the exercises during the course.

> *But I mean I didn't think it did anything for me. Obviously it did, obviously may do for other people but not for me. I try to do my own exercise anyway. (Patient R8)*

> *I think some of the physical activities I saw, and I went on none of them here, are for people who either (a) aren't necessarily taking any, or are a little more severely disabled and/or are of the slightly older persuasion (R3)*

Some participants suggested that this activity was the one they would take out if the course was to be reduced in length. However, the strong consensus, albeit among those patients who were retired or, who at the time of attending the course had not returned to work, was that the course should remain at 10 weeks as each weekly session was useful in some way.

> *I don't think there's any topic that is irrelevant. I think there are always going to be topics that you would find more interesting than another one. But none of them were irrelevant; there was something you could take from every single one of them. (R6)*

Some participants felt that there was too much repetition of the weekly opening activity where participants worked in groups of three (interviewer, interviewee and observer) to recall and describe things that they have noticed had improved over the previous week.

R4: The only thing for me that I got, I thought oh no we're not doing this again, was the group activities. R1: Oh yeah. R4: Yeah. R3: What have you done since last week? R4: Yes, I don't think we needed to do those so much. R1: What's been good about last week? R2: Last week, what's changed? R3: The observer, the watcher and the speaker. R1: Yeah, I think doing it once or twice is fine, but we were getting to do it regular and like two or three times in a session. And it was like move around, like I can't keep repeating myself, I don't want to keep repeating myself. R4: And it got to the stage with me that I wasn't listening, I thought oh no. R1: I was switching off. R4: Switching off because I thought I've got to think about what to say, so I was switching off. Yeah, it's my turn next, I've got to talk, ah.R4: What can I find, what can I drag up to talk about. R1: Yeah. R5: That's an individual thing though isn't it, some people find that easy and some people don't.

Participants suggested moving the mind/body connection activity nearer to the beginning of the course. This concept was unfamiliar to several participants and the fact that it underpinned a lot of the course activities they felt it warranted greater prominence at the beginning of the course. Participants thought that they may have grasped other topics more quickly or more thoroughly had this activity been introduced earlier in the course,

> *I would have put mind and body higher up, so that there was an understanding right at the beginning that your mind and your body are connected in all these topics. Because whether you're talking about sleep, stress, pacing, it's about your mind and your body working together to get yourself to sleep, get yourself less stressed, pace yourself. (R6)*

Some participants felt similarly that communication should also be introduced earlier in the course.

If you're going to keep communication in, I'd bring it nearer the top, at the beginning of the course. (R9)

Improved outcomes

Better at managing emotions

All participants reported at least one area of improvement as a result of attending the course, and many participants reported several improvements. Many participants described some of their difficulties in the past tense, suggesting that they felt that these were behind them or at least reduced. Increased relaxation and getting 'back to normal' appeared to be the key outcomes for most people, along with reduction of emotional problems, anxiety, depression and stress.

I was clinically depressed, I had an urgent meeting with the doctor and after that tablets, but this has been much more helpful. (R9)

One participant was crying much less that she was before and during the course. This patient had frequently become emotional in the early sessions of the course and pre-course consultation. During the FG she described feeling more hopeful and less emotional and attributed this to applying the relaxation techniques

I hardly ever cry now, so that's good. (R1)

The patient who had attended the course to resolve his anger management issues had become calmer in his outlook and spoke positively about having learned to control his temper, both at home and in the workplace. This improvement had caused him to feel generally more optimistic and relaxed.

For me, as I said earlier on, it was just to be able to control my anger, because since I've had the stroke anger was an immediate thing. Yes, I breathe completely and I do suddenly hit this brick wall quite deliberately and I go fine, and I just stop and nothing moves me, and I just don't care. So in that terms it's taught me to manage myself, and therefore relax.... It's made me refocus and made me more optimistic. (Patient R3)

One of the female patients who had found her emotional state particularly difficult to deal with since her stroke had spoken previously about wanting to return to her 'pre-stroke self'. She felt that the course had helped with this and although she did not feel completely back to normal, she recognised that she had made significant progress and spoke of feeling more complete. She attributed this to being taught how to marry her physical and mental wellbeing together.

I think it's made you feel complete again, whole again (R4).

Less socially isolated

Some participants described how since having a stroke they had become socially isolated with a lack of purpose and motivation to interact with others and maintain old friendships and/or make new ones. This often created a downward spiral of guilt, remorse and lack of confidence. Attending the course helped break this negative spiral.

I wanted to believe in myself again, and I do now. I was lost, I felt a bit lost, I wasn't, apart from my family and friends who came to see me, I wasn't communicating with people; I wasn't integrating with people, I wanted to be part of something. (R1)

I'd cut myself off, so this has made me come out more, well go and visit other people more. So you believe in yourself. I've still got some way to go to get back to how I was, but it's certainly, you know, it's made a big leap. (R4)

Improved confidence, hope and positive outlook

Some participants described how working towards achieving their pre course hopes and goals for recovering from stroke by attempting to achieve their "best hopes" through goal setting and action planning had given them a renewed sense of self-belief and confidence (self-efficacy).

The course has been beneficial because you set yourself goals, and you try and achieve those goals, and it gives you an outlook. Whereas previously you're inward looking and thinking the case is hopeless, but now you're able to look out into the broader world if you like and say I can cope.

I just don't think about those triggers no more, I just think well I had a stroke and I've got on with my life. So we look forward to the future. You've got to set your goals, the course teaches you to set goals, and go for them. So as you try to look forward, don't bother looking back anymore now.

It's give you thought to how to work towards it, whereas before you would have no, no, I'm not doing it because I'm too scared, but now you're thinking maybe I could.(R1)

Some participants described how the course had given them confidence to at least confront, if not entirely master, activities which had been extremely challenging and anxiety provoking such as catching a bus into town alone. The participant described movement towards her ultimate goal.

I won't go into town on the bus on my own. I'll go with someone else, I mean I have been on a bus but it's either been home, to my home, where I knew I was going to be safe, or I went to my daughter's to meet my granddaughter, and I knew that there was going to be someone there. (R2)

Participants often felt unable to deal with the emotional disturbances which are part of stroke recovery, such as anxiety and becoming tearful, which had impacted on confidence. This was improved following the course. One participant had felt a loss of confidence before attending the course which she had linked to sleep deprivation and lethargy. She reported having been able to take up daily exercise which in turn helped her sleep better at night, resulting in increased confidence and ultimately a return to work.

It gave me confidence, because I was concerned how I'd react to the public and being with the public and yeah, once I was back [at work] *I was fine. It was just an anxiety in myself which I didn't need to have. (Patient R8)*

The course encouraged forward, hopeful thinking and coping strategies, which participants

enthusiastically embraced. One carer spoke of a shift from inward thinking to a positive outlook and an increase in coping abilities which in turn led to a more satisfying life.

> *So it's been beneficial to us because you tend to get lethargic, lack of exercise, you just sit there, you know, and the sense of, because you're in that environment and it's a hopeless environment that you bicker and there's misunderstandings. So yeah, the course has been beneficial because you set yourself goals, and you try and achieve those goals, and it gives you an outlook. Whereas previously you're inward looking and thinking the case is hopeless, but now you're able to look out into the broader world if you like and say I can cope. Well <patient name>'s been able to say she can cope more to persevere, and I've seen her persevere, and I've seen a great improvement, not only in her but in everybody on the course actually. (caregiver R10)*

> *It offers you your courage, it offers you a chance to put your courage back to go and see and do things again that you might, that you've shrunk from. (Patient R3)*

Participants described how they positively reframed their limitations and challenges and described how they now tended to focus on what they could rather than could not achieve. The activity which focused on reframing of negative automatic thoughts (NATs) to positive automatic thoughts (PATs) helped with this shift from a "glass half empty" to a "glass half full" approach and outlook.

> *Effectively what it does is it teaches you to believe, and there's no reason to be otherwise, that you don't have a disadvantage any longer. You can drive, you can walk, you're back at work, you're happy and getting better going into public places, and so it goes on. Actually no way are we really disadvantaged, it's the side of the coin that we look at. R4: Yes, what I was saying, the positive rather than the negative. (R3)*

> *It's really helped me look towards the positive more, even though I was the type of person that my glass was half full, it was never half empty, it was half full. But when I had the stroke my glass was totally empty, and it was, in fact I struggled to get a grip out of it. And now my glass is half full again. (R1)*

Some patients began to feel in themselves and see in others an improvement occurring between weeks four to seven. Much of this improvement was attributed to a combination of the emerging application of some of the lifestyle and management techniques and the presence of group curative factors (e.g. hope, universality, group cohesion) described below. However, there was recognition that for patients with greater cognitive and/or physical impairment the improvements may have taken longer to emerge and that shortening the course would mean that activities would be rushed.

> *I can honestly say by week four and five I was really comfortable, the first few weeks I know there was a lot of people that struggled, especially the ones who had the cognitive side of the brain and their speech and all that, and I think it took two or three weeks for it all to settle down (patient R1)*

> *I personally felt that it would have been better should it have been an eight, not a 10. I like*

to see what I call efficiency of things going on. I don't disagree with the ladies who say 12 weeks, but I do think if it had been 12 weeks there wouldn't be a great deal more that could be said, so all we're doing is reiterating over older subjects like homework and bringing it back up. (R5)

Some participants suggested that the course should be kept at its current length of 10 weeks and others even suggested it should be extended to twelve weeks

There was so much to cover and the time in between each topic, each week, to absorb it, to practice it, get into it before the next week, and I thought 10 weeks was absolutely right. I certainly wouldn't see it being any shorter, there's so much to cover. (R7)

Recovering from a stroke was discussed in the context of a "journey", and participants placed themselves at various stages of the recovery process:

I've still got some way to go to get back to how I was, but it's certainly, you know, it's made a big leap. (R4)

All of the participants appeared to feel that they had made progress during the courses, and all patients had at least partially achieved their "best hopes". There was recognition that the journey would be ongoing and that the onus was now on them to continue practicing what they had learned. One participant shared the fact that she had begun to practice the exercises every day since the final week as she realised that the course was ending and that she must take responsibility for the exercise herself:

Five or six days ago I made up my mind, this has been done for us and somebody's done this for us, I'm going to do it. … I think the thought of the course finishing was making me feel a bit, that's my way of carrying it forward. (R9)

Group curative factors: hope, universality, group cohesion, altruism

Irvin Yalom [21] has described several curative factors which create therapeutic improvements in groups and which help promote psychological improvement. Several of these curative factors were found to be particularly helpful for the stroke patients and their caregivers. These included hope, universality, group cohesion and altruism.

Hope

Participants described feeling more hopeful during and after the course, which contrasted with their feelings of hopelessness prior to attending. The fact the course existed at all was something that gave patients and caregivers a renewed sense of hope due to feeling that there were people who wanted to offer help and support.

The fact the course exists gives people hope. Because, you know, you're not cast aside, there's people that want to help you get through what's happened to you. (Caregiver R5)

Participants often mentioned the positive attitude that underpinned the course. Problems were

seen as challenges to be overcome, and the general atmosphere was one of encouragement, support and solidarity. Participants described how some of the most, positive, inspiring and hopeful aspects of the course occurred whilst witnessing others, particularly those who were more severely affected by their stroke, improving and overcoming their limitations.

> *Because you've got the problems that these people have, or so much, but you see how much they're getting better, it spurs you on to get better as well. (R7)*

Several participants described the improvement of one of the patients as something which was both incredibly impressive and inspiring. This particular patient was quite physically limited from the outset but during the course his gradual improvement (e.g. posture, speech) became noticeable to others. This patient later went on to share photographic evidence of achieving one of his best hopes/goals (gardening). This physical recovery journey was repeatedly cited by other group members as an inspirational factor in their own progress.

> *AR1: And it's the hope and aspirations of everybody that can empower you as well. Seeing the change in people, not saying physically but in their eyes, how they're brighter. R3: I would agree with that, because you take [participants name removed]Herbert, he's the one with the tricycle. At first came in and said absolutely nothing. R1: And his head was always down wasn't it? R3: He's down with wife and carer alongside him. R2: They used to hold hands, didn't they? R3: Yeah, they would sit there holding hands for the whole meeting, and he would only get up to go to the bathroom or maybe have something to drink if he was lucky. By the time he was halfway through the course. R4: He started participating.R3: He was up. I don't mean up, standing up, but he was sat up.R4: His head was up. R3: His eyes were bright and he was giving his interjections. So everyone noticed that. R3: And especially when he brings the photographs of him standing outside the wall of his house for the first time, putting his plants in, and everybody got to see them.*

Universality

Participants felt reassured that other group members and the facilitators understood and normalised their own illness experiences, and they appreciated the camaraderie that developed over the 6 weeks. Several participants spoke of the experience of being with others in the group and sharing common experiences ('universality') as one the most valuable aspect of the course. This perspective normalised many experiences which allowed participants to make progress. Patients found humour in shared difficulties which allowed them to open up to one another.

> *Whichever end of the spectrum they're at, that end or that end or in the middle, the commonality has to be there, they all see it with each other. And it's made this bond. Yeah, we're all rowing on the same boat in the middle of the bloody Atlantic trying to get somewhere as a team overall. R3)*

> *But just meeting other people helped a lot as well.... but when you come on the course and there's people young and old who are in similar situations, some have got worse problems than you and some have got better problems, but 90% of them are emotional.*

> *For a short time I think I touched on being clinically depressed. And I think coming on this course helped me lift out of that fairly quickly, and I could see around the room that there were other people going through a very similar kind of turmoil. (R6)*

One participant emphasised the importance and benefit of being with and sharing similar experiences with other stroke patients, which contrasted sharply with his less satisfactory experiences of being in a stress management group where no other members were stroke patients.

> *My doctor referred me to a stress management course. It was awful to be honest, nobody else obviously in the group had had a stroke, they were all suffering from stress to different degrees, and I thought this is not for me, and I just couldn't communicate with them. But with here it's been totally different, because we all know what it's like, and you can appreciate things an awful lot better. But as I say the stress management group didn't help at all.*

Group cohesion (care and compassion)

Feeling that they were valued and important members of the group were strong motivating factors for continuing to attend and to persevere with their recovery from stroke. Participants and displayed genuine care, compassion and empathy towards each other, and often became emotionally connected to each other when witnessing others overcome challenges and make progress. Participants often supported one another during difficult emotional periods of the course.

> *Well, I think it's nice how everybody cares about each other as well. (R4)*

> *R4: Well I think it's nice how everybody cares about each other as well. R2: That's the other thing. R1: For an example, I was really pleased for* [patients name removed] *when she first done a trip on her own, and she was really emotional about it but she'd done it. And like* [patients name removed] *waiting for her electronic stimulation, and I thought about her last Thursday and I thought I hope it's going well. And other things that have happened, when* [patients name removed] *has come in and he's perhaps had a bad day at work at this place, his own business, and so many things*

Altruism

Participants enjoyed and valued the opportunity to be able to help, guide and support each other, whether it was through being invited to facilitate small group discussions and feedback other member contributions or simply commenting on how other group members were progressing.

> *R1: It was nice to feel that you could make somebody else feel empowered. R2: Yeah. R5: You said that much earlier on didn't you, that was one of the big points really yeah. R3: It distances you I think between being what people classified as being disadvantaged and human again if you want to be like that. So that you talk to someone and say how well they're doing, and you feel better because of that. The person who's receiving it, if it's said the right way picks it up the right way and feels better, and therefore everybody, you're not sitting on the blocks any further, you're all the way up here, giver and receiver. R1: It's a case of saying it of not what you say, it's not what you say it's the way you say it. R1: As well as being helped, I've contributed and helped people as well. R2: It's taken out and put back in really haven't you.*

As a way of repaying a debt of gratitude for being able to attend course1, several participants came up with suggestions to help promote the benefits of the course to other stroke patients and health professionals. These included attending course2 to provide personal testimonies about their positive experiences and inform the participants about how and why the course helped them. Another participant felt the GPs would be more informed and better able to refer their patients onto the course if they were to hear personal testimonies from their patients about how the course benefits stroke patients. One participant thought that the personal testimonies should be included as a standard part of the stroke care discharge process. Another participant encouraged his dentist to inform any of his patients who he knew had had a stroke about the course.

> *Well yeah, but the GPs to get to know, they've got so many people who've been on the course to tell them how good it is. It's no use seeing people saying well we've got a bit of a course here, we could recommend you send some people on it, but because they don't know. But if they've got people in their surgery who have been, and they're coming back to them saying that course is brilliant, it's really helped me.*
>
> *If it became a standard that one of the questions that you were asked when you were in hospital was would you like to participate in this follow up course or begin in six weeks time on lifestyle management, then I think what you said about testimonials is absolutely key, but we're not there.*
>
> *I think at least three of us have said that we're going onto the next course and just talk about our experiences. R2: Put back into the pot what we've taken out hopefully, yeah.*
>
> *I went to the dentist last week, gave him the sheet and said if you've got anybody you know who perhaps has had a stroke, this is for them. (R)*

LMC facilitators

Overall, participants were extremely positive in their comments about the both the interpersonal skills of the facilitators (Thistle and UHCW facilitators), the delivery style when introducing the activities, and the way in which they encouraged full participation from each participant. Participants felt that the facilitators showed great respect, understanding, empathy and concern, which allowed participants to learn at their own pace.

> *It's like an education but it's relaxation at the same time. (R3)*
>
> *Jill R5: I think the main thing to me was that they were totally unhurried and made sure that you understood what they were saying. So I think Ross and Lindsay made sure that we were listening to them, we were taking it in, and I think in a completely unhurried way so you weren't panicking or trying to catch or going through your notes or anything like that. And regarding the length of time, I thought initially that this is going to be far too long, you know, we're not going to be able to cope. It's three hours, how are we going to cope with that length of time? But at the end it just went didn't it?*

Participants greatly valued the fact that facilitators were passionate, firmly believed in what they were delivering and at the same time felt part of the team ("blended") who did not 'tell', but gently encouraged each member to find their own path. Patients enjoyed the informal nature of the sessions and reported finding pleasure and relaxation in attending the course.

A R5: And I think they believed in what they were doing. R3: Yes they did. R5: Well the passion for. They made you feel at ease, they made you feel comfortable; they made you feel that you wanted to participate. R1:R1 They didn't want to be seen as tutors though, Ross and Lindsay; they were part of the team that were leading the team. R1: They were involved with you, whether it was relaxation, exercises, scenarios, in the topic groups, they got involved with you. They sat with you, they put their points forward. So you didn't feel like you were being questioned. R2: It wasn't them and us was it? R4: But they were also in control. R1: They were yeah. R2: And we respected them didn't we- R3: I think in a nutshell, without being funny, the word I would use is they blended.... So they sympathised with you, or empathised with you if you like, and got the best out of you all the time without making you feel like a silly schoolboy or a silly schoolgirl or whatever, everything came out. And it was with a little bit of maybe prompting, or a little bit of encouragement somewhere.

During the last session (week 10), participants are invited by the facilitators to highlight positive aspects about each other and what they learned from other members of the group and/or valued about each other. Participants were then presented with a "certificate" of achievement detailing the positive aspects which others had noticed about them. For some participants, particularly those who subsequently shared these observations with their family, this was an extremely uplifting and moving activity.

R2 And I've read that two or three times, mine since, and I also gave it to my daughter to read. And she said "oh mother", that's what she said, she didn't say anything else, and it's lifted me up. This is what other people said and that's good that, I mean you said didn't you, you're glad you met me, and that yes, brings tears to my eyes. R1: Yeah mine, I cried but in a nice way. R3: Sense of achievement, you had a sense of achievement in that certificate, it was a sense of achievement and you were proud and you wanted your nearest and dearest to see it.

Course facilitator feedback

Four newly trained facilitators completed open-ended questionnaires which revealed a number of key points on which facilitators were in agreement are summarised below.

Before beginning the first course (after attending the brief solution focused therapy training), facilitators did not feel ready to lead and did not know what to expect from the course. They felt an understanding of the principles of the solution focused approach but did not understand at that point what the course itself would entail.

"It wasn't until the 10 week course began and we observed the Thistle facilitators actually delivering the course that I began to fully understand the role of the facilitator and the philosophy behind the course." (Facilitator 2)

Working as a team, and the support received from Thistle facilitators (in particular the debrief sessions) was considered to be invaluable. This was particularly evident in the first course when the new facilitators were learning how to deliver the sessions and how to maintain solution focused support for participants.

“The facilitators encouraged us to participate and rightly so it worked. It became easier as we got to know the participants.” (Facilitator 2)

Confidence in course delivery was something that developed over time. Being able to observe a full 10 week course before delivering the sessions was a key factor in development, and allowed the facilitators to see 'the big picture' before taking responsibility for course delivery. This also allowed sufficient time to become engaged with aspects of the course in their own time and with little pressure, which was seen as a benefit.

“The first course I was mainly observing and very nervous to get involved. We took the second course on from the beginning and took ownership of it – my confidence grew each week” (facilitator 1)

Facilitators felt strongly that the course should remain as a 10 week course and that the gradual build-up of knowledge, topics and techniques was an important element to its success. Facilitators thought it might be possible to reduce the amount of physical exercises, and/or to incorporate the topic of mind and body into other activities.

“The mind body connection session – not because it is less important but can be taken out more easily as a discrete session” (Facilitator 3)

In relation to the changes made in the course structure (reducing the overall length from 10 weeks (course1) to 8 weeks (LMC2) and the ensuing changes in content which were at the facilitators' discretion), facilitators felt that this impacted negatively on the quality of the sessions and the success of the course as a whole. Facilitators felt strongly that the course should retain its original 10 week structure and content in order to replicate the same positive effects seen in patients from course one – they perceived that the results were less positive in course two although they did not expand on why.

“The course is designed to follow on from one week to the next constantly building and reinforcing what the participants have already learnt. It's all vital.” (Facilitator 2)

“We attempted to shorten the second course but it was not successful. It is difficult to take out elements – everything builds, week on week. The course doesn't flow very well if sessions/parts of sessions are missed out – also it is stressful for facilitators.” (Facilitator 3)

Facilitators felt that being involved in the course had a positive effect on their own practice, and did not perceive any negative effects. Some did however feel that they had begun to feel differently toward paperwork and “problem focused” techniques required in their daily work. They now identified that some of the required techniques used in their usual practice ran counter to the solution focused principles learned during their time with the Thistle Foundation.

“I'm less 'expert'. I empower patients more by [solution focused questions]. I try to spend longer on hopes rather than on problems. … I now find it difficult to use regular paperwork as it's problem focused” (Facilitator 1)

Summary

We have presented findings from a service evaluation of the Thistle lifestyle management courses (LMCs) delivered to stroke patients and their caregivers. The evaluation explored the stroke patients and caregivers reasons for attending; whether the course was successful in improving key patient outcomes; patients and caregivers experiences of attending the course and the facilitators experiences of delivering the course.

Reasons for attending

Participants attended the course to help manage their emotions (e.g. depression, anger) and out of a general sense of curiosity about the course and a hope that it could help them or that they could help other stroke patients. Referral (urging) from a GP was a deciding factor to attend for one participant. There was a poor response to the recruitment/invite letter which was mailed to over 300 stroke patients. Feedback from participants strongly suggested that the current recruitment procedures are in need of improvement. Sources of confusion and frustration generally centred on the recruitment letter not adequately describing the course aims and content. course1 participants also felt that it was not clear that caregivers could also attend with their partners. Several participants felt that addressing them as 'dear stroke survivor' was inappropriate and insensitive

Lifestyle and self-management techniques

Both patients and caregivers were using several self-management techniques. Relaxation (belly/diaphragmatic breathing, body scanning) techniques were extremely valued and in some cases potentially life saving. All participants (both caregivers and patients) described at least one occasion where breathing and relaxation had helped either in a transient capacity (e.g. anxiety attacks), or with an ongoing issue (e.g. improving duration and quality of sleep). Planning/pacing and prioritising and mindfulness were also popular among patients and caregivers. Patients and caregivers tended to more easily recall and describe interactive activities (e.g.“sand and stones” and “raisin”).

Participants suggested that the “mind and body” and communication activities should be introduced earlier in the course because of their importance in helping to understand and appreciate other course activities.

Some participants felt that there was to much repetition of the opening activity where they formed smaller groups to review improvements from the previous week. Some participants found the physical exercises to be the least useful aspect of the course. These participants tended to be those who already had an established and progressive exercise regime and did not participate in this aspect of the course However, there was a recognition that some patients who had greater physical impairment greatly benefitted from these sessions.

Improved outcomes

Stroke patients

Stroke patients who completed the course (attended 60% of the sessions) reported statistically significant improvements in stroke self-efficacy (confidence), stroke cognitions and hope (goal agency and pathways). The fact that some of these improvements emerged at 6 weeks is extremely encouraging and consistent with early improvements found in brief cognitive behavioural therapy [22] and some of Coventry University's other self-management programme evaluations [23-24]. Higher self-efficacy has been linked with better quality of life and lower depression and [25] and greater independence in activities of daily living and a reduced falls [26]. At the end of the course patients reported relatively more positive stroke cognitions than negative cognitions. This is an important finding because it has been shown that patients who report more positive cognitions are less depressed [18]. Improvement in hope demonstrates improved motivation to set and meet goals. Research has shown that people who are hopeful are less likely to be depressed [27].

The course is similar in content and process to well established and evidenced based interventions (e.g. CBT and group psychotherapy) for people with common mental health problems including anxiety and depression. Some patients specifically mentioned during the FG that the course helped with their depression and stress suggesting that the course might be useful as Level 1 or Level 2 stepped care psychological intervention. The FG data also highlighted some of the group curative factors which provide an explanation for the self-reported improvements in self-efficacy, cognitions and hope outcomes. Patients were more likely to look to the future with hope and courage and had become more socially engaged. Wolfe et al., [28] found that the social networking that occurs in group programmes decreases isolation and hopelessness. Participants spoke about their plans to continue to meet up after the course finished and several participants were keen to assist with recruitment strategies for the second course. They were more goal focused and achieving their "best hopes" fostered a sense of pride and participants were inspired and instilled with hope when witnessing others work towards achieving their "best hopes". Instillation of hope, universality (realising you are not alone), group cohesion, and altruism which were evident in the participants accounts are what Yalom [21] has described in the group psychotherapy literature as "therapeutic curative factors". A key feature appreciated by many stroke patients participants was being in the presence of other stroke patients and tutors in a hopeful, supportive, caring environment. Yalom [21] suggests that group programmes present a powerful source of hope because some participants who are successfully coping role model hope and for other participants who are coping less well.

Yalom [21] has found that depressed patients reported improvements in self-esteem after realising that their contributions in were important and valued by other group members. Several patients enthusiastically described their wish to be involved in promoting the course and some participants intended to attend the second course to describe their positive experiences. Research has shown that providing rather than receiving help can be more beneficial to health [29]. Untrained paraprofessionals chosen for their warmth and empathy can promote client improvement equal to that obtained by trained therapists, suggesting that the mechanism of change may common non-specific (relationship/alliance) factors, rather than technical competence. In self-management Lorig et al., [30] have similarly shown that lay tutors achieve similar participant outcomes to health professionals (e.g. occupational therapists, physiotherapists, rheumatologists).

Carers

Caregivers also found that being around others with similar experiences was beneficial. Caregivers acknowledged that the experience of living with someone recovering from a stroke carries common problems and concerns which are often difficult to deal with alone. Common challenges included communication (more specifically problems such as understanding what the patient is trying to say when their speech and language is impaired), the difficulty of 'role reversal' in the home (particularly evident in cases where the female in the relationship was the patient and the male was forced to take responsibility for household tasks). Other challenges included changes or reduction in hobbies and other pleasurable activities (due to either not being able to do things together or not being able to leave the patient in order to do things). Caregivers reported a gradual improvement in all of these issues due to attending the course. Communication became easier through active listening, new responsibilities in the home were made easier through pacing and forward planning and pleasurable activities were also increased through pacing techniques. The pacing learned on the course seemed particularly useful for two reasons; applying a strict timetable for activity and resting/relaxation allowed caregivers to become more able to get important tasks done without impacting on leisure time, and this technique also allowed patients to contribute.

Stroke patients and caregivers greatly valued the interpersonal style (warmth, empathy, care, compassion) of the tutors, which encouraged them to learn and practise stroke recovery lifestyle and self-management techniques. Therapeutic alliance has been shown to be a stronger predictor of improvement in CBT compared to specific therapy techniques and models.

There are limitations to this evaluation of the Thistle course for stroke survivors. First, the sample size is small. Second, the absence of a control group mean that any conclusions about the usefulness of the course should be treated with caution. Larger trials comparing the Thistle course against other forms of self-management, counselling, CBT and other forms of group support are required. The analysis on completers is likely to present the most favourable estimation of outcomes as it focuses only those participants who received a high dose of the programme.

Despite these caveats the course shows promise for helping stroke patients and their caregivers recover from stroke. The following quote shows that the improvements patients and caregivers reported are due to a combination of all the different components of the course including the group relationships, the lifestyle and management techniques and the course manual.

> *Well I think that although we've said that meeting other people, but then once you've met the other people and the course kicks in, there are different things about mindful thinking and sand and rocks, all this, it all helps again, it gets you one step further. I mean you can read the book but you can't get, you get some idea from the book but it's the way it's put across to you as well. It's all very good, it registers better.*

Recommendations

Based on the project findings the following recommendations are made:

- All recruitment and course correspondence literature should address the patient by forename and surname rather than “stroke survivor”
- The recruitment literature should clearly describe the course aims and content and also describe the benefits of attending for patients and also caregivers.
- Recruitment from informed and enthusiastic health practitioners/referrers should be the preferred recruitment method over postal recruitment.
- Stroke staff should be trained to using a simple depression screening tool (currently being trialled by Professor Gill Furze in another HIEC project) and refer Level 1 (sub threshold psychological problems) and Level 2 (Mild/moderate psychological problems) on to the course.
- IAPT should refer stroke patients at Level 1 (sub threshold psychological problems) and Level 2 (Mild/moderate psychological problems) on to the course.
- Pre and post-course measures should be routinely use to recruit and monitor course participants improvements. Patients who do not improve should be “stepped up” to more specialist psychological care
- Personal testimonies (short video diaries) of previous course patients and caregivers to create demand should also be included in any recruitment literature/ to place on NHS Local YouTube and Facebook, to engage the public, commissioners and providers.
- A review of the delivery order of the course topics should be undertaken and repetition of the weekly review and physical exercise activity reduced.
- Improvements in self-reported outcomes (stroke self-efficacy, stroke cognition, hope) emerged at mid course (week 6) with further smaller improvements occurring between week 6 and course end. The course could be reduced in length to a 6-8 week course which would be less resource intensive but which would still improve key patient outcomes.
- Course reunions should be scheduled to consolidate and refresh patient and carer stroke recovery management.
- The 2 day brief solution focused tutor training should be reduced to 1day and reinforced with a self-directed e learning online training package
- Stroke patients and caregivers (former course participants) could be involved in co-delivering with stroke health professionals some of the course activities
- Tutors should develop action learning sets to consolidate and further refine and improve their facilitations skills

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APPENDIX 1

Course 1: 10 weeks

- Week one:
    - Welcome/ getting to know each other exercise
    - Discussion – what do you hope to get out of this course?
    - Discussion – expectations
    - Discussion – communication skills
    - Explanation of the theory behind the course
    - Relaxation
- Week two:
    - Welcome
    - Relaxation
    - Small group discussion – experiences during relaxation
    - Discussion – what do we want the facilitators to do?
    - Small group discussion – active listening
    - Physical exercise
    - Relaxation
- Week three:
    - Relaxation
    - Review of last week
    - Small group discussion – talking/listening/observing skills
    - Discussion – feedback from small group task
    - Physical exercise
    - Discussion – stress
    - Relaxation
- Week four:
    - Relaxation
    - Review of last week
    - Small group discussion – listening skills/ getting to know you
    - Discussion – what has been better?
    - Physical exercise
    - Discussion – sleep and lethargy cycles
    - Relaxation
- Week five:
    - Relaxation
    - Review of last week
    - Circuit Exercises
    - Discussion - exercise
    - Relaxation
- Week six:
    - Relaxation
    - Review of last week
    - Small group discussion – what has been better?
    - Circuit Exercises
    - Discussion – pacing

    - Relaxation
- Week seven:
    - Relaxation
    - Discussion – how to deal with a difficult week
    - Small group discussion – solution focused questions
    - Discussion – positive and negative automatic thoughts
    - Relaxation
- Week eight:
- Week nine:
    - Relaxation
    - Review of last week
    - What has been better?
    - Discussion – setbacks
    - Relaxation
- Week ten:
    - Write down 5 things you have gained from the course
    - Group activity – 'steal without shame'
    - Discussion – what would you tell others about this course?
    - 'Golden Star Awards'
    - Discussion – forward planning

Course two:

- Week one:
    - Welcome/ getting to know each other exercise
    - Discussion – what do you hope to get out of this course?
    - Discussion – what makes a good listener?
    - Introduction to solution focused approach
    - Discussion – stages of grief and recovery
    - Relaxation
- Week two:
    - Relaxation
    - Review of last week
    - Small group discussion – active listening
    - Discussion – what has been better?
    - Introduction to physical exercise
    - Discussion – sleep and lethargy cycles
    - Relaxation
- Week three:
    - Relaxation
    - Review of last week
    - Small group discussion – talking/listening/observing skills
    - Discussion – stress
    - Relaxation
- Week four:
    - Relaxation
    - Review of last week
    - Small group discussion – active listening
    - Small group discussion – small changes
    - Discussion – pacing
    - Relaxation
- Week five:
    - Relaxation
    - Review of last week
    - Small group discussion – solution focused questions
    - Discussion – planning and putting recovery first
    - Physical exercise
    - Discussion – exercise
    - Relaxation
- Week six:
    - Relaxation
    - Review of last week
    - Circuit Exercises
    - Discussion – communication skills
    - Discussion – positive and negative automatic thoughts
    - Small group discussion – communication and handling setbacks
    - Relaxation
- Week seven:
    - Relaxation

    - Review of last week
    - Small group discussion – coping scales
    - Circuit exercises
    - Discussion – setbacks
    - Relaxation
- Week eight:
    - Relaxation
    - Review of the course
    - Small group discussion – what would you tell people about this course?
    - ‘Golden Star Awards’
    - Discussion – forward planning

Appendix 2: Patients' best hope

Participant	Best Hope 1	T1	T2	T3	Best Hope 2	T1	T2	T3	Best Hope 3	T1	T2	T3	Best Hope 4	T1	T2	T3	Best Hope 5	T1	T2	T3
1	Gain info to share with stroke group				Improve ability to find work															
2	Sensation/ darts ability (10=perfect form)	5	7	9	Expressing self	7	8	9	Determining what people are saying (communication)	5	9	9	Holiday							
3	More energy (to lose weight)	7	6	9	To laugh at things/let things go overhead	4	9	10	Confidence to talk to people more	5	8	10	Getting used to voice	7	9	10	Stop knee trigger thoughts	2	6	8
4	Self confidence	4	8	8	Improve memory	3	5	6	Increase alertness	4	6	7								
5	Offer something to the group	6	9	9	Reaffirm lifestyle changes are the right ones	7	9	10	Embed lifestyle changes	6	9	8	Balance work and life							
6	Patience	5	7	9	Frustration control	5	7	9	Concentration	4	8	8	Memory	6	9	10				
7	Confidence	6	7	9	Empowered	5	7	9	Emotional health	6	7	9	Physical ability							
8	Easy meeting people (thought of having to do it)	5	5	8	Reducing anxiety	4	6	7	Being treated/talked to 'normally'	4	5	8	Increase confidence travelling further	3	6	8	Motivation e.g. creative things, writing etc	4	5	8
9	Confidence	8	8	7	Travel on bus on own	5	7	5	"Back in control of me"	9	8	7			8	7				
10	To realize progress made	7	8	8	For husband to learn daughters comm. strategies	8	7	8	To communicate change in a way which promotes calm	6	7	8			8					
11	To show	2	5		Confidence	4	9													

Appendix 2: Patients' best hope (continued)

	commitment and ability to others																			
12	Exercise	2	8		Relaxation – sleep more at night	0	7		To be more energetic, go back to work	1	7									
13	A return of my pre-stroke self confidence	1	8	7	An understanding of my own feelings	1	8	8	Control of my feelings	8	8	7	Physical tips/help or where to obtain it from	2	5	8				
14	Increase confidence – do more, get out more	2			Communication skills – speech, use phone	3														
15	Get confidence back – walk w/o stick, walk daughter	7			Eat with a knife and fork in hand	7			Get up out of chair more spontaneously	6			Back to gardening	0						
16	Increase confidence in larger groups	5	5		Feel more relaxed, less frustrated	5	4		Improve pattern of sleep	5										
17	Speak more clearly	6	5	7	Sleep better/ more consistently	5	5	9	Get to 9am mass 5 out of 7 days	3	10	8	Be able to concentrate better	6	6	5				
18	More confidence walks, driving, less reassurance	8	9	9	More energy/ stamina	5	7	9	Better memory/ speech	7	8	8								
19	Improve confidence – go out more,	5			Gain control over fears & emotions –	0			More confident with people – speak better,	4										

Appendix 2: Patients' best hope (continued)

	cook meals				peaceful sleep				feel happier											
20	Confidence	5			Be more happy/ content	3			To feel physically better	3			To both (+husband) feel better with life	2						
21	Confidence	6	10	8	Independence (shopping on own)	0	8	2	Social life would like to be more involved	6	6	7	Things better for husband	7	9	6				

T1 = baseline; T2 = mid course; T3 post-course

Appendix 1

Week 1	Introduction to lifestyle management
Week 2	Sleep management
Week 3	Stress management and relaxation
Week 4	Pacing and energy management
Week 5	Getting active
Week 6	Pacing and time management
Week 7	Effective communication
Week 8	The mind body connection
Week 9	Preventing, minimising and recovering from setbacks
Week 10	Review and forward planning