

# 'Integrating a self-management programme into stroke rehabilitation - can it be done?'

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and  
Dr Matthew Liston



## Before we start...

### Sources of Funding

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### Disclosures

FJ is Founder and Director of the Social Enterprise Bridges self-management limited



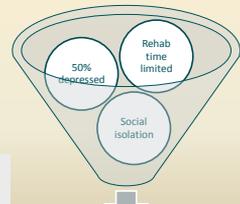
## 2 years in 40 minutes...



## Why Stroke?



'the absolute number of people who have a stroke every year, stroke survivors, related deaths, and the overall global burden of stroke are great and increasing' Feigin et al 2013



'Societal costs of £8.9 billion a year, treatment costs 5% of total UK NHS costs' Saka et al 2009



6/19/2014

## Why self-management?

- Small emerging evidence base (systematic reviews and RCTs) on the utility of changing self-efficacy to increase independence.
- One way is promote self-management skills through individual or group-based programmes.

'All patients should be offered training in self-management skills, to include active problem-solving and individual goal setting'



## Why self-management?

Self-management support has been emphasised as a **top priority** for health and social care in most developed countries (Kings Fund 2013)



## BUT WHAT SHOULD IT LOOK LIKE?



### What is it?

Not leaving people to 'get on with it' on their own....

...but supporting them to build the skills and behaviours needed to live with their long-term condition

informa healthcare

'DIY or 'co-management?'

Disability Rehabilitation  
An international, multidisciplinary journal  
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RESEARCH PAPER

How is self-management perceived by community living people after a stroke? A focus group study

Ton Sattink<sup>1,2</sup>, Edith H. C. Cup<sup>2</sup>, Bert J. M. de Swart<sup>1,2</sup>, and Maria W. G. Nijhuis-van der Sanden<sup>2</sup>

### What is this self-management programme about?

Supporting self-management skills

- Patient held workbook
  - Reflecting on progress
  - Recording Aspirations/hopes
  - Small targets
- Interactions
  - Encouraging problem solving
  - Enabling use of personal resources
  - Changing focus of therapy

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### What were our aims?

1. Test the **feasibility** of training community stroke teams to deliver a SMP to integrate into practice.
2. Monitor **fidelity** of SMP according to predetermined quality markers in control and intervention teams.
3. Explore the **acceptability** of the SMP to patients, carers and clinicians
4. Explore the **impact of SMP** on QOL, Mood, ADL, Self-efficacy
5. Evaluate the **economic impact** of the SMP on health and social care costs
6. Use the data to inform a **power calculation** for a fully powered cluster randomised control trial

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### A word about fidelity....

'The degree to which programs are implemented as intended by the program developers' Dusenbury et al 2003

or

'What you do and what you say' Drummond 2011

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### 'Wise people are full of doubts' (Russell, 1950)

- Everyone needs to be trainable and receptive to training
- Do you check that they are capable and can appropriately use and provide the SMP prior to letting them loose?
- Can you be sure they won't slip back into their old ways?
- How much of the time are they using the SMP?
- Do they use the SMP in some people and not in others?
- Why would they do this?

Professor Stanton Newman UCL  
<http://www.city.ac.uk/health/staff-directory/professor-stanton-newman>

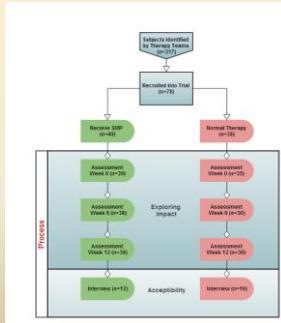
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### What was our worry about all this...

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### How do you test the feasibility of integrating self management into post stroke rehabilitation....

- **Study Design- 4 clusters/teams**
- **Trial Set up- 4 months (approvals and processes)**
- **Recruitment – stroke teams, then stroke participants**



### Measuring feasibility...

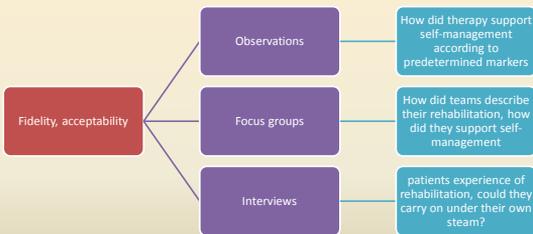
#### Clinical Outcomes at 3 time points

- QOL-Stroke and aphasia QOL scale
- Mood- HADS
- Functional capacity- NEADL
- Health outcome- SF12
- Self-efficacy- SSEQ

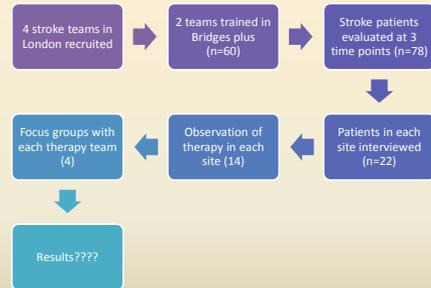
Are these the right measures to capture change?



### Acceptability + fidelity



### The numbers...



### Bridges training 'integrating SM not adding on'



1. 4 x half day sessions (14 hours)
2. Involving ALL staff
3. Theory, research, practice strategies
4. Using the workbook, and carers booklet
5. Lots of work to devise and practice ways to integrate our '7 key principles'



### During the trial...how to sustain and maintain fidelity?

- Reminders and refreshers about key principles
- Sustaining the Intervention
- Checklists and Reminders
- "Thought of the Day"





### Observations- problem solving, goal setting

1. 'Patient said he experienced tiredness and stiffness- they were shown a story on p31 and encouraged to think of ways around the tiredness. OT asked how she had got around other problems and whether she could use these skills again'

2. He says he wants to drive again "I know that it's a big goal" the physio says it's OK to have big goals, he could write it down and she'll help him to think of ideas towards it next time. She thanks him for having ideas about what to do in the session.



### Observations

1. He felt that he could do to do 70% of the tasks required by his job, but didn't know what else was achievable. Physio says she and the OT need to do more assessments before making a prediction.

2. Patient shows all exercises to the physio. She tells him the plan for progressing these exercises at the next session. Physio explains how these exercises will help with his difficulties e.g. "we're strengthening your hip muscles to help with your balance"

3. To wrap up the session the Physio summaries what exercises she wants him to do.



### Acceptability + fidelity



Bridges Teams	Control Teams
Way of team working	Way of team working
Person-centred self-management	Therapy related self-management
Person-centred goals	Realistic goal-setting
Self-discovery & progression	Managing progress
Tools for self-management	Skills for health professionals
Limitations	Limitations

"And I think its really helpful, to pose them a problem, but don't tell them the solution straight away, give them the opportunity to come up with the solution. And you might need to guide them in the right direction for the solution."



### Acceptability + fidelity

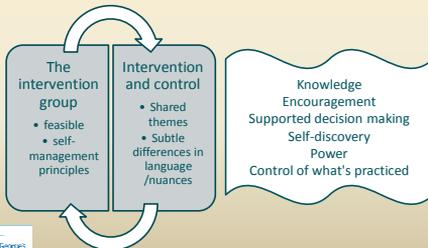
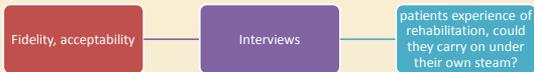


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"So managing their condition and I would read it happens after they've been discharged, managing, so self-management, with the skills they have picked up along"



### Acceptability + fidelity



### What is the role of the therapist in supporting self-management



Every time she came in she would say 'can you do this?' and 'Can you do that?' and if there was an improvement she would count the sections that I did, and the seconds I could balance and tick it off on her list'



### What is the role of the therapist in supporting self-management



"I was directing it but they were pointing me in the right direction. They listened...They said 'right what do you want to do?'- 'Drive' 'Well lets break it down' "



### Summary



- Validity of self-management programme has been shown
- Integration of SM is possible
- Training possible, but needed refreshers because of staff turn over
- Bridges gave a structure to self-management



### Next steps?



- Explore whether it can be used over shorter time period
- Address barriers/inequity (mood/cognition etc)
- Understanding implementation



### Learning from 11 large scale programmes, Health Foundation 2014

- People are different...tailor interventions
- Offer people a range of support options
- Tools alone are not enough
- Changing professional roles, behaviours and mind sets is not impossible
- Involve voluntary and community sector
- Use a whole systems approach to implementing change
- Consider sustainability from the outset
- Evaluation should be incorporated into programmes from the start

### Our wish list, learning from trial

- Greater accessibility/equity
- Groups or individualised or both
- The workbook should not be a barrier
- Start early-pathway wide
- Joint training. Co-produced
- Organisational processes, change management
- Champions, refreshers, bands 1-4
- PROMs/PREMS + bespoke questions tailored to local context



### 'Integrating a self-management programme into stroke rehabilitation - can it be done?'



### What's next?

- Fully powered trial?
  - Assess effectiveness
  - Understand change process
  - Assess cost effectiveness
- Implementation?
  - Surveillance and monitoring
  - Long term follow-up
  - Dissemination



## Thank you for listening, and thanks to the SESAME research group

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