Stroke - what is the current picture?

‘Although age-standardised rates of stroke mortality have decreased worldwide in the past two decades, the absolute number of people who have a stroke every year, stroke survivors, related deaths, and the overall global burden of stroke (DALY’s lost) are great and increasing’ Feigin et al 2013

Low-middle v high income countries

What are the issues for stroke?

- Evidence of unmet needs in the long term post stroke (McKevitt, 2011; CDC 2011)
- Stroke is a sudden event and adjustment may be different than for other LTCs. Changes in identity can be long lasting (Taylor et al, 2011)
- Frequency of depression is 30%, but it is dynamic and continuous (Ayerbe, 2011)
- Evidence of social isolation, access to community groups and support can be limited for some individuals (Salter, 2009; Daniel 2009)

Why self-management?

The number of people with multiple long-term conditions is predicted to rise by a third over the next ten years. Almost one in three of the population in the UK live with one or more long term conditions

Self-management support has been emphasised as a top priority for health and social care in most developed countries.
**Direction of travel..**

**Bodenheimer's model** - professionals are experts in the disease, and patients are experts about their lives: the expertise is shared (Bodenheimer et al, 2002)

**Health Foundation model** - a shift from teaching information and skills based on the clinician’s agenda to collaborative agendas, where patients and clinicians share their agendas and collaboratively decide what information and skills are taught (Health Foundation, 2008)

**Why?**
- Practice has not followed aspiration as widely and consistently as hoped
- Services and approaches developed for acute healthcare conditions are neither appropriate nor sustainable for management of long term conditions (Health Foundation, 2013)

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**Self-management involves a sharing of expertise**

**But...**
- Both parties must be committed
- Clinicians recognise that patients can be competent decision makers

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**Which programme works best?**

- Lay led/professional
- Generic/disease specific
- Group based/ individualised
- Formal content/informal set up

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**Health foundation synthesis of 600 studies on self-management interventions published in the UK and internationally (De Silver, 2011)**

- Supporting self-management can improve quality of life, clinical outcomes and health service use.
- Very little evidence about the best way to provide support and engagement can be limited.
- Initiatives can be categorised along a continuum, from passive information provision about healthy behaviours to behaviour change methods that seek to change and increase self-efficacy.
- Difficult to make direct comparisons between different interventions and the impact over time very few longitudinal studies have been carried out.
- Low intensity didactic interventions are least effective.
People are different… tailor interventions
Offer people a range of support options
Education and not enough
Changing professional roles, behaviours and mind sets is not impossible
Involving 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

What about stroke and self-management?

15 studies - Significant treatment effects in favour of the self-management intervention in 6/9 randomized controlled trials, and 3/6 non-randomized trials. 4 randomized controlled trials n=100

Outcomes include measures of disability, confidence in recovery, stroke specific quality of life, short form SF-36 Score, self-efficacy, mood.

The wide range of outcome measures used prevented comparison across studies.


What is Bridges?

An evidence-based, individualised self-management programme based on self-efficacy principles

MDT Practitioner workshops
One-to-one sessions with stroke survivors
Stoke workbook and carers booklets

What are we trying to do?

Develop a self-management programme
Specific to stroke
That can be delivered as part of stroke rehabilitation
What is Bridges?

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

Why self-management programmes may fail...

- Fail to take the patient perspective into account
- Professionals unwilling to change
- Services lack flexibility to change

(Kennedy et al, Vol. 335. BMJ 2007)

Research findings.... 2008-current

Proof of Concept - single case studies
- People different stages after stroke
- Changed self-efficacy
- Favourable effect on mood, activity, participation

Feasibility and acceptability, pilot RCT (Belfast)
- Favourable changes in outcomes (QoL, self-efficacy)
- Flexible to use in practice
- Acceptable to patients and carers

Organisational/Individual experience
- Pathway evaluation
- Changes in attitudes and beliefs
- Shared philosophy on goal setting

Bridges where are we so far?

- Improves continuity in goal setting
- FTP: Acute setting
- HCPs change perspectives
- Acceptable to patients and carers
- Bridges
Current research: Cluster feasibility trial – completed January 2014

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.

Cluster feasibility - is it possible to integrate a SMP into rehabilitation?

- 4 stroke teams in London recruited
- 2 teams trained in Bridges plus (n=60)
- Stroke patients evaluated at 3 time points (n=78)
- Observation of therapy in each site (14)
- Focus groups with each therapy team (4)
- Patients in each site interviewed (n=22)

Results will be published in June.

Who is the ‘perfect’ participant?

How can we stop gate keeping?

What is stopping us supporting self-management earlier?

- Health beliefs
- Self-discovery
- Past skills
- Small successes
- Learning from others
Bridges in the acute setting- pilot project June-December 2013 (38 staff trained)

Aiming for a ‘provider based model’ where the support is embedded into the clinical practice of the MDT (therefore needs doctors to be active also!)

not

a ‘patient based model’ where a patient goes off and attends sessions and self-management is separate to your role

Future goals

• Groups v individual or both?
• Bridges for other groups- TBI?
• Training for other settings- acute, community, social care, voluntary sector
• Engaging key professional groups- Medical staff?
• Other forms of workbook- digital platforms?
• Measuring what matters to patients
• Impact of carers booklet

Thank you for listening

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