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For everyone concerned with stroke rehabilitation

Investigating the use of Bridges across the stroke pathway with stroke survivors from a Bengali community



Within the UK, adults from ethnic minorities, particularly South Asian and Black, are at higher risk of stroke than the general population (e.g. Gunarathne et al 2008). There is also some evidence to indicate that they may experience poorer quality and access to care; demonstrate reduced engagement with rehabilitation; and show poorer functional outcomes (e.g. Bourke et al 2006, Ottenbacher et al 2008). One possible explanation which specially relates to goal setting is that cultural and traditional beliefs, language barriers, family involvement and cultural differences between therapist and client may impede effective rehabilitation (Becker and Kaufman 1995, Lequerica et al 2009, Kaufman 1988). Because goal setting is a crucial part of the Bridges programme, this may indicate that there are some potential barriers to its use in some stroke survivors from ethnic minorities. However, research investigating whether such barriers exist or not and how Bridges facilitators manage the process is yet to be conducted. Furthermore, it is unknown whether cultural factors may influence the goal setting and rehabilitation process positively.

The broad aim of this project is to explore the experience of rehabilitation professionals in using the Bridges approach with stroke survivors from ethnic minority groups. The current phase is focused in an area of London with a large Bengali population. 14 health professionals across the stroke pathway have been interviewed prior to their Bridges training to ascertain their understanding and use of self management strategies generally and any identifiable barriers and facilitators noted within their community. Follow-up interviews will be conducted after completion of the Bridges course to explore the use of the Bridges programme in the Bengali community specifically. The data collected will be analysed and key themes will be highlighted.

The results of this phase, alongside other parts of this study, will indicate the extent that Bridges is used with stroke survivors from ethnic minorities and the perceptions facilitators have of its utility. This understanding will inform the development of the approach.

Dr Meriel Norris, Brunel University m.norris@brunel.ac.uk



Being positive and managing your own situation

David Borer has been a member of the Bridges advisory group since 2009. Here he provides his story and what he feels are the important issues for people recovering from stroke.

David had his stroke in May 1999. He describes waking up in the morning and 'losing one side....I just couldn't understand what was happening really because I didn't know what a stroke was like'. I never thought of it being permanent and that I'd always be like that, it just never entered my head. Physiotherapists taught me to walk again which was really difficult. It's hard when somebody says 'how do you walk?'. You don't know how you walk because you don't think about it do you? I mean you learn it when you're a child and that's it.

After Rehab stopped I came home and I realised I couldn't go to work so I had to give up my job. I was working for an American company and we were going to set up a communications network around the UK and Europe and I was taking the lead role. But it all stopped because I just couldn't go to work you know physically let alone mentally because it seems when you have a stroke you're always tired. I still get tired very easily and it's very difficult to concentrate. I can't read books even now very easily. I can just about read a paper and articles from Bridges of course. So I became a retired person.

Over time I became involved in trying to improve services locally for people after stroke. I thought the treatment at the hospital was appalling for stroke patients. I kept complaining and eventually, they decided they needed to do something, so they invited me to join the stroke team of consultants, nurses and physios. They were working on a new stroke pathway through the hospital and I got involved in that and they asked me if I'd like to join the Patients Council so I got involved in that. I got on lots of other committees and I found I was getting involved more and more with things happening in the

hospital. Then they set up what they call the Local Implementation Team and they asked me if I would chair the one for our area. The LIT is responsible for driving forward with the stroke strategy making sure everybody lives up to the standards. So it's a team of consultants, doctors, nurses, physios, OT's and everybody that's involved in treating stroke patients and me as a patient.

I was put in touch with Fiona and the Bridges team in 2009, and she asked if I'd like to join the advisory group. It's helped my interest because I can say things at the meeting which gives a different point of view. One of the consultants in the LIT once said 'none of us have had a stroke, you're the only one whose had a stroke (on the committee) so you'll know more about it than any of us do'. The people on the advisory group I've found interesting. It was the fact Bridges was helping stroke patients get better that made me want to join. In the rehab area particularly because I think rehab is an area which needs a lot of investment.

My one wish for people after stroke is that I would like to see more emphasis given on long term rehabilitation. In some areas its quite good in the short term (up to 6 months) but then after that most people that I've met feel abandoned, and that's when people start getting depressed as well, there's nothing available to help them. I think because I used to work in Marketing I'm a fairly positive sort of person, but I meet quite a lot of people who are not. The stroke has really put them back. It's good to be able to teach people to be positive and manage their own situation. That's so much better rather than letting other people take over and manage their lives and stop them doing things.

David describes waking up in the morning and 'losing one side.... I just couldn't understand what was happening really because I didn't know what a stroke was like'

David Borer and his wife, Maureen

Self-management after stroke: where are we now and what needs to be done?

After working in the area of self-management research and training for the last 5 years, a number of questions have emerged. These have been developed as discussions in workshops and with the Bridges advisory group.

We have also kept a close eye on any emerging research in this field. Some current issues and our questions about stroke and self-management are described below;

Individual responses after stroke are varied; there is a danger of presuming there is a 'one size fit all' self-management programme suitable for people. Stroke is not necessarily a static or progressive disability and many people will continue to make progress over time. A greater understanding of how individual responses influence their self-management is needed. For instance what past skills and experiences do individuals use to support their self-management and do our current methods of rehabilitation make full use of these.

The timeline of an individual's adjustment and reconciliation after stroke may not coincide with the timing of access to a self-management programme. Greater flexibility may be required by professionals to integrate principles or programmes that are more responsive to individual needs. Contrary to some assumptions we have found that Bridges can be introduced to some people in the acute setting. But will depend on individual readiness for the programme and level of support available. So far we have no evidence that there is an optimum time to introduce self-management principles.



We also realise that there may be limitations associated with focusing on a self-management agenda which concentrates solely on behaviour change and fails to acknowledge the role of social networks, peer support, and ways in which selfmanagement strategies can be embedded into everyday life.



Bridges open workshop

Overall our workshops have shown stroke professionals have a readiness to interact in ways which support self-management, and adopt communication methods to alter the balance of professional control during stroke rehabilitation. But professional's experience many organisational barriers to working in this way. These include a perceived lack of time to fully explore personal goals and self-management strategies. They have also told us that more needs to be done to support carers to help with self-management and have methods which are more accessible to people with cognitive and communication problems

We also realise that there may be limitations associated with focusing on a self-management agenda which concentrates solely on behaviour change and fails to acknowledge the role of social networks, peer support, and ways in which self-management strategies can be embedded into everyday life. A Self-management programme could be considered another form of healthcare intervention and professional compliance model. Programmes need to work alongside other forms of activities which promote autonomy and active citizenship

Bridges is an individualised intervention, but at the moment it is only accessed through health and social care professionals. More research is needed to evaluate whether Bridges can be used in a group setting, or delivered through peer support schemes directly to people in the community. Further research is needed on methods to engage the more hard to reach groups, e.g. those with cognitive and communication problems, and new ways of supporting active problem solving and learning by use of different interactive tools

As you can see there is much work to be done!

Fiona Jones

Thanks to Dr Meriel Norris and the Bridges advisory Group



Building Bridges between stroke teams: Improving continuity of care for stroke survivors in Kingston

Results from a pathway-wide training project show Bridges has the potential to improve continuity of care for stroke survivors on the stroke pathway in Kingston.

The Bridges Kingston project, which trained sixty-six professionals from health and social care teams working on the stroke pathway in Kingston, has been completed. Not only was this one of the first times social care teams had ever participated in Bridges training, but it was also the first time practitioners from different teams were trained in the same workshops, with the aim of improving knowledge-sharing and crossteam working within the Kingston stroke pathway. The last workshop took place in September 2011, and the evaluation of the project has now been completed.

Questionnaires completed by participants before and after the training show a change in practitioners' attitudes and beliefs towards self-management, particularly amongst health care assistants, and within the 'reablement' team (part of social services). Over half the participants thought their practice had changed and 71% felt Bridges could be used throughout the stroke pathway. It would improve consistency as everyone would be working towards the same clientcentred goals and would improve communications between teams. All practitioners interviewed after the training thought Bridges could help improve continuity of care for stroke survivors in Kingston in three ways: by giving practitioners on all teams "some kind of shared ethos or philosophy to dip into"; by providing a tool meaning that "hopefully the patient isn't

going to have to start the whole goal-setting process again" each time they move to a new service; and by improving connections of professionals in different teams through the mixed-team training.

Funding is now being sought to investigate the sustainability of the Bridges training in a pathway-wide project like Kingston.



This study was supported by a grant from South West London Academic Health and Social Care System

Self-management: A priority for commissioners in a lean financial climate



Transforming our Healthcare System: Top priorities for commissioners. Kings Fund Report, 2011

In 2013 clinical commissioning groups in England will hold the majority of the NHS budget. These clinical commission groups together with health boards and trusts in other parts of the UK have to deliver a sustainable healthcare system in the face of some of the most challenging financial and organisational environment. A report published by the Kings Fund in May 2011 warns that this task is especially challenging given the ageing population and increased prevalence of chronic disease. They emphasise the need to move away from the current emphasis on acute and episodic care and towards prevention, self-care and more integrated and co-ordinated primary care.

In order to support commissioners to transform the healthcare system, the report has identified 10 priorities for action which include consistent themes of systematic and proactive management of chronic diseases, empowerment of patients, population based commissioning, responsive to local needs and more integrated models of care.

The first priority identified in this report is 'Active Support for Self-Management'. The report highlights the impact that can be achieved by self-management programmes. Benefits include increases in physical functioning, anxiety and confidence. The report also highlights some self-management programs have helped to reduce unplanned

hospital admissions, and adherence to treatment and medication. The report states how many of these interventions are currently delivered by healthcare professionals, but there are also many examples of programmes being delivered by the voluntary sector and patient groups.

The report recommends websites such as www.self-management.co.uk and information from established programmes such as the DESMOND and DAPHNE programmes for diabetic management http://medweb.bham.ac.uk/easdec/prevention/diabeteseducation.htm



3rd Annual Bridges Symposium: Life After Stroke

We are delighted to announce the date of the 3rd Annual Bridges symposium to be held on Thursday 3rd May 2012 4pm-6.30pm





Images from the second Annual Bridges Symposium, 2011

As usual we have assembled speakers who will address key aspects of life after stroke and self-management. Professor Tony Rudd will be presenting an update on the London life after stroke model. We will hear from Portia Woodman regarding research on barriers to participation, she will present her findings together with one of her research participants. Chris Jones (stroke co-ordinator from Kingston) and Nicki Bailey research assistant will present the findings of their study evaluating a pathway approach to self-management. Finally we are delighted that Dr Caroline Ellis Hill will be presenting her work on identity and life threads.

For further information and booking contact Jo Appiah jappiah@sgul.ac.uk www.heicevents.sgul.ac.uk or ring 0208 725 2848

Where and When

St George's University of London Boardrooms 2-4 16:00-18:30

Topics include

London Strategy for Life After Stroke

Barriers to
Participation After
Stroke

Self Management Through the Stroke Pathway

Life Threads and Identity After Stroke

Bridges Workshops

Q. How you feel that the workshop will enhance your practice?

To be there for the patients as support and guidance, rather than someone who instructs them what to do.

Not being so prescriptive – allowing more time for exploration and trial and error

Helped me to be more aware of how to support behaviour change.

Think more about patient-oriented goals and getting them more involved, influencing less and taking more time

Focus more on the patient setting, verbalising and writing their goals

To empower patients who feel like they are left hanging at the end of community team input



Research update

Three articles relevant to self-management and stoke are summarised below

Korpershoek C, Van der Bijl J and Hafsteindottir (2011) Self-efficacy and its influence on recovery of patients with stroke: a systematic review. Journal of Advanced Nursing. 67: 9: 1876-1894.

A systematic review by Korpershoek et al (2011) found individuals post stroke with higher levels of self efficacy had greater mobility, were more independent in ADL and higher quality of life. Lower self- efficacy was associated with higher levels of depression. This indicates the relevance of an individual's self efficacy during daily care and rehabilitation. Applying strategies which support self efficacy within in nursing practice may enhance the effect of interventions. It is also recommended that self efficacy principles be integrated to a greater extent in both undergraduate and postgraduate nursing education.

Levack W.M.M, Gerard Dean S, Siegert R. J and McPherson K.M (2011) Navigating patient-centered goal setting in inpatient stroke rehabilitation: How clinicians control he process to meet perceived professional responsibilities. Patient Education and Counselling (early on-line)

Levack and colleagues explored how patient centred goal setting was being applied in an inpatient stroke rehabilitation setting in New Zealand. Study participants included patients, family members and health professionals. Multiple data sources were analysed, including observation of goal setting interactions, team meetings, and interviews with patients.

The results showed that when patients and family were involved in goal setting it could lead interactional dilemmas. Certain goals were likely to be privileged over others. These often involved goals with a more conservative estimation of outcome, focused on physical functioning, and those which could be achieved in a short time frame. Greater patient involvement appeared not to influence clinical reasoning and choice of goals.

Levack argues that patient centred goal setting may be difficult to achieve in an inpatient rehabilitation setting, and that clinicians need to examine the values they attach to certain goals.

Taylor G.H, Todman. J and Broomfield. N.M (2011) Post – stroke emotional adjustment: A modified cognitive transition model. Neuropsychological Rehabilitation. (early online)

In this article Taylor and colleagues propose a new model of adjustment post stroke. Acknowledging the difficulties faced by some individuals, predicting and understanding adjustment poses a challenge to many professionals working in stroke rehabilitation. The article discusses the background literature which has informed *SCoTS* (Social Cognition Transition model for Stroke), drawing on research on post stroke depression and models of adjustment. The authors highlight the specific differences of applying adjustment models to stroke e.g. the influence of cognitive deficits. The SCoTS model proposes that the content and rigidity of an individual's assumptive world can be fundamental in dictating post stroke emotional adjustment. In addition, confirmation and disconfirmation of assumptions, and stress experienced is influenced by social context and individual differences such as beliefs about past and future self.

The model is described as being cyclical and dynamic and contrary to the bereavement model highlights the evolving nature of adjustment post stroke. This may be a useful model for teams to explore in order to support greater collaboration between individuals and professionals to help successful adjustment after stroke.

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The Advisory Group:

Dr Fiona Jones Project <u>leader</u>

Dr Ajay Bhalla Consultant Stroke Physician

David Borer Stroke survivor

Eileen Collins Stroke survivor

Graham and Sue Davidson

Stroke survivor and carer

Thérèse Jackson Consultant Occupational Therapist in Stroke, NHS Grampian

Dr Cecily Partridge Reader in Physiotherapy **Carole Pound** Former Director of Innovation, LIK Connect

Dr Jane Williams Stroke Nurse Consultant

Register your interest:

For further information, including a copy of our 'frequently asked questions' and a booking form, or to join our mailing list and receive regular updates on the progress of Bridges and a copy of future editions of Bridges News, please contact:

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