March 1, 2010

What is the evidence for using family based interventions to prevent stroke recurrence?

Maggie Lawrence, Glasgow Caledonian University
Caroline McVey
Susan M. Kerr, Glasgow Caledonian University

Available at: http://works.bepress.com/maggie_lawrence/1/
What is the evidence for using family based interventions to prevent stroke recurrence?

Lifestyle factors can make people more susceptible to recurrent stroke. Evidence was gathered on how family members can help influence changes in behaviours.

BACKGROUND

Stroke is a common, long term condition that has a considerable impact on individuals, families and health and social care services (Galimani et al, 2009). The UK has a high incidence, with 111,000 first strokes each year (Scarborough et al, 2009). Stroke recurs in approximately 25% of patients within five years of the original stroke and may result in death or an increased risk of disability and/or the need for long term care (Hankey et al, 2007; Redfern et al, 2006).

Several risk factors for recurrent stroke have been identified. These include transient ischaemic attack, age, hypertension, tobacco use, excessive alcohol consumption, an unhealthy diet and physical inactivity (Galimani et al, 2009). Some of these are lifestyle behaviours that can be modified, but little is known about the effectiveness of behavioural interventions that address lifestyle risk factors for stroke (Lawrence et al, 2009a).

Stroke affects the whole family and a family centred approach is thought to be effective in terms of rehabilitation outcomes (Visser-Meily et al, 2006). Often the family influences lifestyle behaviour (Wright and Leahey, 2005).

The effectiveness of involving family members in behavioural lifestyle interventions has been demonstrated in other specialties such as cardiology (Wood et al, 2008). However, no research has been identified that has adopted a family centred approach to support lifestyle change following stroke (Lawrence et al, 2009a).

We developed a programme of research that aims to implement and evaluate a family centred intervention to address lifestyle risk factors for recurrent stroke.

The programme of work was developed using the Medical Research Council’s (2008) framework for developing and evaluating complex interventions to improve health. The framework describes four phases: development; feasibility/piloting; evaluation; and implementation. Each phase builds on the previous one, developing the evidence base and informing the next phase. The work described in this article represents the development phase of our programme.

THEORETICAL UNDERPINNING

Uniquely, our programme of research has adopted a family centred approach to secondary prevention of stroke. Our focus is on lifestyle behaviour change – we aim to address four lifestyle behaviours: tobacco use; alcohol consumption; diet; and physical activity.

To help us understand how families work and how nurses and other healthcare professionals can develop therapeutic relationships with patients and families, we selected a family systems theory, the Calgary Family Assessment/Intervention Model (CFAM/CFIM) (Wright and Leahey, 2005).

The CFAM framework (Fig 1a) focuses on assessing structural, developmental and functional aspects of family life. In the area of family development, the assessment focuses on changing roles such as those that occur when, for example, a family member acquires a disability and becomes dependent on others. A nurse completes the assessment with the family and together they decide whether an intervention is required.

Using the CFIM framework, the nurse and the family select interventions that aim to promote, improve and sustain behaviour change. This ensures family ownership and demonstrates the family’s intentions and willingness to engage in behaviour change. Wright and Leahey (2005) felt the most influential and sustainable area for change is within the family’s belief system.

Nevertheless, effecting a change in one aspect of family function may also have an effect on other aspects (Wright and Leahey, 2005).

Lifestyle behaviour change is a complex issue, so we also selected the theory of planned behaviour (Ajzen, 1991) (Fig 1b) to inform our work. This theory asserts that an individual’s intention/willingness to engage, or not to engage, in a given behaviour is...
based on their behavioural beliefs (attitudes), normative beliefs (subjective norms) and control beliefs (perceived control). Intention refers to the value the individual places on:
- Performing the behaviour (attitude such as stopping smoking);
- Their perception of social pressure to engage in the behaviour (subjective norms such as pressure from family to stop smoking);
- Their perception of the control that they exert over the resources, and opportunities that enable them to engage in the behaviour (perceived behavioural control such as the ability to attend NHS Stop Smoking Services).

We selected this health promotion model to aid our understanding of the factors that prevent or support lifestyle behaviour change.

Finally, to reflect the relational focus of our work (that is, focusing on interactions, see below), the phenomenological concept of intersubjectivity was selected to form a cohesive theoretical underpinning.

Intersubjectivity is concerned with how people interact with one another, and has been described as “a fundamental characteristic of human existence” (Drew, 2008).

Our research aims to gain a deeper understanding of the factors that influence lifestyle behaviour. In particular, we are concerned with how lifestyle behaviours are influenced by interactions within the family, and by the family members’ interactions with health and social care professionals, as well as patients’ wider social environment.

**AIM AND METHOD**

We aimed to develop a community based, nurse coordinated, family centred behavioural intervention.

We have undertaken a range of evidence gathering and evidence synthesis activities (Box 1) with a view to developing a robust evidence base. This article presents an overview of those activities, focusing on three research studies, which are described briefly here and reported elsewhere in greater detail (Lawrence et al, 2009a; 2009b; 2008).

We are on the verge of starting a further stage of synthesis in which the evidence gathered from these three research projects will be synthesised along with knowledge gleaned from wider reading of relevant literature. Moving further into the development phase described by the MRC (2008), we will consult widely with a range of stakeholders (Box 1). All of these activities will inform the development of one or more interventions, which will be tested and evaluated in future work.

**STUDY 1. SURVEY OF STROKE NURSE PRACTICE**

This study explored stroke nurses’ knowledge and practice in relation to providing secondary prevention lifestyle information following stroke. Cross sectional survey methods were used. Participants were members of the Scottish Stroke Nurse Forum (SSNF). Self complete questionnaires were posted to the 193 eligible members of the SSNF in September 2007. Ninety seven nurses returned completed questionnaires, giving a response rate of 50%. The main results are reported here; full details are given in Lawrence et al (2009b).

The results demonstrated that, while nurses reported that they assessed lifestyle risk factors, they focused on some but not all of these. For example, the majority prioritised initial assessment of alcohol and tobacco use over assessment of diet and physical activity.

Another main result was that, although respondents provided information (written and verbal) and advice to patients and/or their families, their knowledge of guidelines and health related recommendations was limited. Only a small number reported using protocols or guidelines to inform practice and even fewer reported using validated assessment tools.

In terms of adopting a family centred approach to assessment and intervention, many reported involving family members when assessing lifestyle behaviour, particularly regarding diet and alcohol consumption. Nurses also reported involving family members in educational health promotion sessions, usually on a one to one basis, and were most likely to do so regarding alcohol consumption.

**STUDY 2. FOCUS GROUP STUDY**

The focus group study aimed to identify and explore factors that support or hinder lifestyle change following stroke from the perspective of people who have had a stroke and their family members.

In particular, we wanted to find out whether patients and families had received secondary prevention lifestyle information following stroke. If they had, we wanted to ascertain their perceptions of that and any associated support.

Between March and July 2008, eight focus groups were held in a range of urban and rural locations throughout Scotland, with 29 people who had had a stroke, including seven with aphasia (either partial or total loss of the ability to communicate verbally or using written words), and 20 family members. Participants were members of stroke groups or carers’ groups organised by the voluntary sector. The main findings are reported here (for full details, see Lawrence et al, 2008). Most participants said they had received little or no lifestyle information and/or advice post stroke. In particular, they reported a lack of information in aphasia friendly formats and felt that clinicians did not make efforts to ensure that the family members of people with the condition were kept informed.

There was much discussion on the issue of people’s knowledge of healthy living issues. An overwhelming issue for participants was the confusing and sometimes contradictory nature of health promotion messages.

Although some had tried to make lifestyle changes following stroke, many had not, and others had tried and failed. Many people continued to smoke after having had a stroke, even though they had quit during the days and weeks when they were inpatients; some even described “lighting up” as soon as they left the hospital.

Some of the barriers to instigating change that participants identified included the common consequences of stroke such as limited mobility, impaired limb function and depression. The influence of family members on making lifestyle changes was evident, both as a facilitator and as barrier. For example, in some instances, family members encouraged positive changes to diet; in

---

**BOX 1. EVIDENCE GATHERING AND EVIDENCE SYNTHESIS ACTIVITIES**

Evidence gathering activities:
- Scotland wide survey of stroke nurse practice (study 1: Lawrence et al, 2009b);
- Scotland wide focus group study conducted with people who have had a stroke, including people with aphasia, and family members (study 2: Lawrence et al, 2008).

Evidence synthesis activities:
- Systematic review of the effectiveness of secondary prevention lifestyle interventions designed to change behaviour following stroke (study 3: Lawrence et al, 2009a);
- Wider reading of relevant literature;
- Consultation with stakeholders, including people who have had a stroke, family members, health and social care professionals, voluntary sector organisations and local councils.
others, family members’ smoking habits made it difficult for people who had had a stroke to quit.

Participants discussed a lack of accessible services, and some felt this to be a barrier to instigating and maintaining lifestyle changes. For example, those who lived in remote locations described problems associated with having to travel, often considerable distances, to access appropriate services and leisure facilities. One urban group were left without physiotherapy/exercise support when funding was withdrawn.

A number of participants described using support groups as a means of making lifestyle changes. Some used generic stroke groups such as Different Strokes (a support group for young adults who have had a stroke and their families, at www.differentstrokes.co.uk), while others used dedicated slimming clubs or exercise groups. However, many voiced a preference for one to one support as a means of initiating and sustaining lifestyle changes.

STUDY 3. SYSTEMATIC REVIEW OF LITERATURE

Systematic reviews aim to synthesise the results of randomised controlled trials and other experimental studies, and are accepted as the highest level of research based evidence (The Joanna Briggs Institute, 2008).

In 2009, we started work on a systematic review to assess the effectiveness of previously evaluated secondary prevention lifestyle interventions, which address one or more lifestyle risk factors for recurrent stroke. When developing our own intervention, we need to have a clear understanding of any that have been shown to be effective.

The review is in the final stages of completion but initial scoping of the literature identified four papers that reported intervention studies: Joubert et al (2009); Sit et al (2007); Ellis et al (2005); and Ovbiagele et al (2004).

The interventions were provided in acute care, an outpatient clinic and primary care settings. All combined medication compliance with attempts to address at least one of the four lifestyle behaviours that form the focus of our work.

Overall, the interventions in these four studies had little significant effect in terms of behaviour change. The only changes noted were by Joubert et al (2009), who reported a significant improvement in levels of physical activity, and Sit et al (2007) who demonstrated a significant improvement in dietary habits only. However, both studies had aimed to address all four lifestyle behaviours.

Interestingly, only Sit et al (2007) described the theory underpinning their study. None of the interventions adopted a family centred approach.

DISCUSSION

We have presented an overview of a series of evidence gathering and evidence synthesis activities (Box 1, previous page).

A survey of stroke nurse practice found that the majority of stroke nurses appeared to focus on assessing tobacco use and alcohol consumption, and were more likely to refer patients to dietitians and physiotherapists for assessment and advice on diet and exercise rather than focus on these issues themselves.

In line with best practice, nurses reported providing written and verbal information to patients and their families (Smith et al, 2008). However, they showed limited knowledge of contemporary guidelines, which may affect the quality of the information and advice they shared with patients and families. This apparent gap in their knowledge base suggests stroke nurses may have insufficient opportunities to access evidence based resources to inform their practice (Rowat et al, 2009).

Respondents reported adopting a family centred approach to assessing patients’ lifestyle behaviours and the subsequent delivery of interventions, thereby reflecting the appropriateness of using a family systems theory such as CFAM/CFIM (Wright and Leahey, 2005).

Findings from the focus group study demonstrated that patients and families continued to report that they did not receive secondary prevention information before discharge from hospital. However, the survey results showed that stroke nurses reported providing information, both verbally and in writing. The reason for this disparity is not clear. It has been suggested that often patients do not recall having been given information (Smith et al, 2008). Consequently, guidelines recommend that healthcare professionals repeat information as appropriate (Smith et al, 2008). Family members described the difficulties...
associated with obtaining information on behalf of people with aphasia (Mason, 2006); this finding echoes that of Nordenh et al (2006) who found clinicians often failed to communicate effectively with people who had aphasia and their families.

If patients lack appropriate information and education, this will negatively affect their intention to engage or not engage in particular behaviours and their level of perceived behavioural control (Ajzen, 1991).

Focus group participants described the effects of stroke, particularly depression and mobility impairments, as barriers to instigating lifestyle change. These effects of stroke negatively influence the individual’s perception of behavioural control (Ajzen, 1991); therefore, depression should be diagnosed and treated.

In addition, innovative interventions such as home based exercise should be implemented to ensure that even those who are confined to the house and/or have restricted mobility are empowered to take up healthy living options (Wood et al, 2008). Focus group findings revealed that family members often exert considerable influence over each others’ lifestyle behaviour, in both negative and positive ways, demonstrating the importance of social norms in terms of lifestyle behaviour and behaviour change (Ajzen, 1991). This supports our hypothesis that, following stroke, a family centred approach is appropriate when addressing behaviour change, and is an approach that should be fully exploited to benefit patients and families (Wright and Leahey, 2005).

In addition to support from family members, many participants reported benefiting from both generic and disease specific support groups, which shows the importance of peer influence on lifestyle behaviour/behaviour change (Ajzen, 1991). However, when asked what their ideal support would be, several participants identified one to one rather than group based support, such as that provided by a personal trainer.

As described above, the results of the initial scoping for the systematic review suggest the interventions tested to date have been ineffective in terms of achieving sustained improvements in lifestyle behaviour.

This may be because studies that addressed the complex issue of behaviour change have lacked a sound theoretical underpinning. To make lifestyle interventions more effective, we believe it is essential to understand the factors that help or hinder people to make and sustain changes (Ajzen, 1991).

It is also worth noting that none of these interventions adopted a family centred approach; as shown, family members and social peers exert considerable influence over lifestyle behaviour (Wright and Leahey, 2005; Ajzen, 1991).

CONCLUSION
The management of lifestyle risk factors for recurrent stroke is a complex health promotion issue. Previous studies have shown that this has had limited success in changing behaviour.

While it is recognised that family members represent an important influence in terms of lifestyle behaviours, there is a lack of research evidence on the efficacy of family centred approaches to lifestyle change.

Using the MRC’s (2008) framework, in a programme of research underpinned by CEAM/CFIM (Wright and Leahey, 2005) and the theory of planned behaviour (Ajzen, 1991), we aim to develop an intervention that will address the complexities of behavioural change and lifestyle risk factor management for people who have had a stroke and their families.

Further research
We will use the evidence gathered and synthesised in the development phase of our research, along with findings from literature and consultation with stakeholders, to inform the development of a family centred behavioural intervention, the effectiveness of which will be tested in future work. Our aim is to improve healthy living knowledge and support healthy lifestyle choices made by families affected by stroke which, ultimately, may help to prevent its recurrence.

REFERENCES


