

**Title Page**

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## **Abstract**

**Background:** Stroke is a national research priority, however, in the literature there is still minimal systematic investigation of stroke nursing, especially practice. The aim of this study was to explore stroke nurses' research priorities through a series of focus groups.

**Method:** The study was qualitative and involved focus groups (n = 7) with registered nurses working in stroke care settings and who were members of the SSNF with Scottish Stroke Nurse. Data was analysed using a grounded theory approach to identify key categories.

**Results:** Six priority areas for stroke nursing research were described, using categories defined by Kirekvoid (1997) and Booth (2001): Interpretive, Consoling/Supporting, Preventive/Conserving, Restorative, Integrative role of the nurse; and Service Structure/Systems.

**Conclusion:** By consulting stroke nurses we can ensure that future research truly reflects the nature of nursing care and is of particular relevance to stroke nursing practice. The development of research evidence-base in stroke nursing will lead to increase knowledge, a better quality of care and ultimately better outcomes for patients.

## **Introduction**

Stroke is the second leading cause of death and the leading cause of severe adult disability (WHO, 2003). Specialist stroke unit care, provided by a multidisciplinary team who are knowledgeable and interested in stroke, saves lives and reduces the need for long term institutional care (Stroke Unit Trialists' Collaboration, 2007). The components of care that contribute most to the benefits and are the most cost effective are still being rigorously debated. Nurses, who are essential members of the stroke multidisciplinary team frequently spend the highest proportion of time with patients thus it seems reasonable to assume that in some way and to some extent nursing interventions contribute to improving stroke patients' outcomes. However, there still remains a lack of nursing research in the literature, possibly because nursing is a difficult discipline to quantify. Currently, stroke is a research priority therefore it is vital to consult stroke nurses to determine their research priorities of particular relevance to nursing practice (Scottish Government, 2008; Department of Health (DH), 2007). Through consultation with nurses we can ensure that the research truly reflects the nature of stroke nursing care and is of particular relevance to stroke nursing practice.

The role of the nurse is one of "care" and is undoubtedly broad, particularly as nurses are responsible for patients 24-hours a day. The broad discipline of nursing has been categorised in the literature in a number of different ways. Kirkevold (1997) described the therapeutic role of the stroke nurse by dividing it into 4 categories: Interpretative (help patients understand stroke); consoling (provide emotional support); conserving (preventing complications,

maintaining normal functions and meeting essential patient needs); and integrative (helping patients meet rehabilitation goals). However, Kirkevold (1997) found little literature between 1989 and 1995 to support the validity of this framework. By reviewing the literature, Bisnaire (1998) divided stroke nursing into 4 categories by the type of research study conducted by nurses, which included studies about: nurses; the experience of stroke; the caregiver of stroke survivors; and various interventions and their impact on outcome. A more recent qualitative study focusing on the nursing role within stroke rehabilitation found three role categories of the nurse including: the nurse as a caregiver; facilitator of personal recovery; and care manager (Burton 2000). However, stroke care is no longer confined to rehabilitation and should include acute care which aims to prevent damage to the already vulnerable brain (Perry et al, 2004). Nurses need to address the confusion that surrounds their role within the stroke unit multidisciplinary team. One way of doing this is by engaging in nurse-focussed and nurse-led research.

Over the last decade, particularly in Scotland there has been a substantial investment on stroke care. Publication of the Chest Heart Disease (CHD) and Stroke Strategy document of 2002, led to the government promising £40 million for CHD and Stroke over a 3 year period to help implement developments in line with the strategy (Scottish Executive, 2002). At this time the development of Managed Clinical Networks for stroke encouraged NHS boards to look closely at services and stroke service development, and a National Advisory Committee for Stroke was formed (Scottish Executive, 2004). In 2005 the Stroke Research Networks (including the Scottish Stroke

Network) were set up across the country to increase participation in research studies, as well as involving stroke patients and their carers in network activities (UK Stroke Research Network, 2008). Another professional body, the Scottish Stroke Nurses Forum (SSNF), was officially launched in 2003. It aims to disseminate good practice, improve educational opportunity and support stroke nurses by facilitating knowledge and expertise (Scottish Stroke Nurse Forum, 2008). The forum recognised it would require a greater understanding of stroke nurses' clinical practice and their priorities for increased knowledge and awareness.

The aim of this study was to identify from Scottish stroke nurses, issues/topics where they considered clinical ambiguity or uncertainty existed within their clinical practice. It was thought that, by engaging directly in group discussion, stroke nurses' research priorities could be delineated; that nurses would be empowered by involvement in the research process and that some future stroke nursing research projects might be identified.

## **Methods**

### Study Design

Focus groups were selected as the means of collecting data for this study as the format enables the exploration of experiences, ideas and areas of concern amongst groups with shared interests (Barbour and Kitzinger, 1999). A semi-structured interview schedule was used to elicit discussion regarding the nurses' experiences and perceptions of evidence-based practice. Participants were asked to describe and discuss the issues and topics that arose during the course of their daily practice and about which they were uncertain. The aim was to identify aspects of stroke nursing practice for which there was little or no evidence base; essential elements of stroke nursing practice that could be addressed in future research.

### Population and sample

The study sample was drawn from the population of registered nurses working in stroke care settings and who were members of the SSNF. The SSNF has a membership of approximately 200, the majority of whom are registered nurses specialising in stroke or neurological care. A purposive sample of 40 members of the SSNF was recruited to the study. The participants represented a range of contemporary clinical nursing grades (i.e. D to G), worked in a variety of stroke care settings, from acute hospital-based to community-based rehabilitation and worked in a variety of geographical locations, including cities, community hospitals and geographically remote locations. In total, seven focus groups were conducted in various locations throughout Scotland (Table 1).

## Ethics

The SSNF is an independent, self-governing group, the aims of which include the development and sharing of knowledge, expertise and best practice, the incorporation of research-based evidence into practice, and the promotion of research designed to improve outcomes (Scottish Stroke Nurse Forum, 2008). After seeking advice from the Central Office for Research Ethics Committee it was agreed that the only requirement for participants was that they should have SSNF membership and be recruited to the study in that capacity.

## Data Collection

Participants were invited to take part in a focus group by a SSNF representative (committee member). The committee members arranged suitable venues, dates and times for the focus groups. Between three and nine trained nurses participated in each group. All participants provided informed consent prior to participation. An experienced moderator facilitated each focus group; a co-moderator took field notes, which included observations of the interactions between participants. All focus groups began with an introduction and explanation of the purpose of the research, ground rules for the conduct of the group, a reminder of the voluntary and the confidential nature of participation, and an explanation of the tape-recording and note-taking, and the analysis and dissemination of the findings. The focus groups interview schedule was semi-structured to allow flexibility and to ensure that data reflected participants' perspectives. Nurses were asked to describe and discuss the issues and topics that arose during the course of their daily practice and about which they were uncertain. Each focus group lasted between 45 and 90 minutes, and, with the permission of the



participants, was tape-recorded and transcribed verbatim. Data collection was carried out between June and November 2005.

## Analysis

The tapes from the seven focus groups were transcribed verbatim and with field notes, formed the data for analysis. Each transcript was read thoroughly three times. In line with the constant comparative approach described in Grounded Theory, interview data were analysed to identify, name, categorise,, and describe the data line by line and to identify the more general categories and properties (Robson, 2002). Conceptual categories were then identified and compared with each other and with the literature (e.g. Kirkevold, 1997 and Booth (2001). Finally, the themes were integrated into the conceptual framework. Data collection and analysis were iterative, with new data used to assess the integrity and credibility of the evolving conceptual framework.

Further analysis was undertaken by a second researcher, who transcribed and listened to three randomly selected audio-tapes and examined the data to ensure completeness and accuracy of coding and to verify consistency of relationships within and across cases. Any disagreement was resolved by consensus. Finally, members of the SSNF Committee reviewed the findings.

## Findings

Five categories were used to describe the research areas that are of importance to stroke nurses (Table 2): Preventive/Conserving, Supporting/Consoling, Restorative, Integrative and Service structure/systems.

The first four of these categories were derived from the work of Kirkevold (1997) which described the roles/functions of nurses in acute stroke rehabilitation as Interpretive, Consoling, Conserving and Integrative, and the more recent work of Booth (2001) which described 'Preventive' and 'Restorative' aspects of stroke nurse roles. However, some data, whilst substantively focused on nurses' roles are to a degree determined by health and social care systems and therefore a fifth category, 'Service structure/systems', was used to describe these findings. It should be noted that the categories described here are to some extent inter-dependent.

#### Preventive/Conserving

Prevention of another stroke is a priority and central to its success is patients' adherence to prescribed medication and reduction/cessation of lifestyle risks such as smoking. Successful strategies should be identified to enhance patient's concordance, support optimum outcomes and also to prevent post-stroke complications such as shoulder pain, depression, fatigue, nausea and malnutrition. Maintaining normal functions and meeting essential needs such as patient nutrition, meal-time care, oral hygiene and urinary continence were also discussed.

#### Supporting/Consoling

Patients and informal carers receive information in a variety of formats. An evidence base is needed to identify the optimum times and communication strategies that may support discussion of patients' prognosis. Stroke nurses consider some measure of 'depression' to be a normal response to the trauma

of stroke, but how best to support patients and alleviate their psychological distress is unclear.

#### Restorative

Absence of one universally-accepted definition of 'rehabilitation' is problematic and specific roles of multi-disciplinary team members are sometimes unclear. For example physiotherapists and occupational therapists are not available at weekends so nurses have to ensure that patients continue rehabilitation in their absence; participants identified the need to research roles, responsibilities and the impact of these on patients' care.

Stroke nurses consider that young people post-stroke have specific needs related to disability, rehabilitation, employment and housing and that research should explore these needs to maximise rehabilitation. Sexual needs of all ages of patients and their partners are seldom acknowledged and nurses find it difficult to provide advice.

#### Integrative

The data in this category overlap with those in the Restorative category, in that the overall aim is rehabilitation, but integrative care ensures that patients are able to function to the best of their abilities in the long term, post discharge. This involves evaluation of multi-disciplinary teams, both in hospital and community settings, to identify strategies by which continuing rehabilitation may best be facilitated.

## Systems and Structures

The structures, both physical and hierarchical, within which individuals live and work may facilitate and/or constrain the actions that they are able or willing to take and Giddens (1984) uses the term 'structuration' to suggest an interplay between individual 'agency' (i.e. ability to initiate and take action) and 'structures'. Our data analysis found that nurses seek evidence evaluating the extent to which NHS and social services structures and systems facilitate and inhibit nurses' ability to deliver care and the impact that this has on patients' hospital care and long-term rehabilitation.

One example is that twelve hour shifts are said to impact negatively on time available for teaching and learning. The impact of Agenda for Change (DH, 2004) on patient care needs to be researched as it entails increased annual leave for some staff, the consequent need to employ agency and bank staff and potential disruption to continuity of stroke-specific care.

Some stroke nurses' remit includes working in areas geographically remote from central services. They identified the need to evaluate the expense of travelling (in time as well as fuel) against the cost of potentially valuable technology such as teleconferencing and to research the psychological and social impact of adopting 'distant' contact between nurses and patients.

## **Discussion**

The role of stroke nurse is diffuse and complex (Booth, 2005; Burton, 2000). Overall nurses identified research categories that could be aligned with Interpretive, Consoling, Conserving and Integrative roles of the stroke nurse (Kirkevold, 1997). We also identified new research categories, including: Preventive, Supporting, and Restorative roles of the stroke nurse; and Service Structure/Systems. It was not possible to identify one core category/basic social process within this small scale study although an over-arching theme in the data is that development of stroke-specific assessment tools for all activities of daily living post-stroke are a necessity.

Several priority areas for research were identified by stroke nurses, including the use of integrated care pathways, discussing sexual health, rehabilitation goal setting, appropriate information provision, managing bladder incontinence and meal-time care after stroke (see Box 1). However, some research areas identified by nurses already had an evidence base, for example “.....when is the optimum time to use PEG tubes” (Dennis et al, 2005). Although some participants identified the Scottish Intercollegiate Guidelines Network (SIGN) and/or the National Clinical Guidelines for Stroke (RCP, 2008), in some areas there was an obvious lack of knowledge of research findings and best practice guidelines. Nurses described issues associated with the dissemination of research findings and/or the ability and motivation of individuals to locate these with a view to incorporating them in practice. Pressures of work and inability to attend education events and sources of information such as libraries were identified by some groups as

barriers to accessing research-based evidence. In addition, many of the stroke nurses who participated in this study considered that they lacked the infrastructure, the research culture and the incentive to undertake research.

### Limitations

This study sought to elicit the clinical information needs of members of the SSNF. However, those who seek out membership of SSNF are likely to differ from the general stroke nurse population and, as we gathered opinions from only 20% of the SSNF members, may not be representative of all SSNF members and therefore the results may not be applicable to the larger group. Also, the focus groups were a mixture of nursing grades and therefore it is likely that focus group members' willingness to express their views or opinions may have been influenced by others in the group. Arguably, the fact that different facilitators conducted the focus groups may represent a limitation of the application of the method. However, the use of semi-structured focus group schedule may have promoted the homogeneity of the approach, whilst having two different facilitators may have prevented uni-directional bias in the data collection process. Ideally focus groups would have been held in all NHS boards but this was not possible due to resource limitations.

### Conclusions

SSNF members' information needs range from specific issues relating to the practical management of stroke patients management to the general management of stroke patients and carers and self-development. Nurses are under increasing pressure to keep up to date with and base their clinical

nursing skills, on current best scientific evidence. However, few nurses have the necessary skills or time to do this. It is vital that SSNF members and other nurses working in stroke know that any uncertainty that they have with regard to their practice often results from the difficulties associated with accessing the evidence based literature and other evidence-based resources such as clinical guidelines, best practice statements and internet-based resources such as The Stroke Therapy Evaluation Programme (<http://www.effectivestrokecare.org/>). We would therefore recommend a systematic search of the literature (for example using Cochrane methodology) before formulating research questions (Clarke et al, 2007; Greenhalgh, 1997). It is also important to listen to the perspectives of service users in research (Scottish Executive, 2003; Goodare and Lockwood, 1999). By consulting individuals who have had experience of stroke we can ensure that future stroke research is of particular relevance to stroke patients and their relatives in order to improve quality of life and health care for other stroke victims.

#### Key points

- Stroke research that reflects the nature of nursing care and is of particular relevance to stroke nursing practice is a national priority.
- Priorities for research identified by Stroke nurses could be aligned with Interpretive, Consoling/Supporting, Preventive/Conserving, Restorative, Integrative role of the nurse; and Service Structure/Systems.
- Nurse involvement in the research process identified future stroke nursing research projects.

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**Table 1: Focus Group Timetable**

<b>date</b>	<b>place</b>	<b>number of participants</b>
June 2005	Falkirk and District Royal infirmary, Falkirk	3
June 2005	Victoria Hospital, Kirkcaldy, Fife	6
June 2005	Edinburgh Royal Infirmary, Edinburgh	9
June 2005	Borders General Hospital, Melrose	5
August 2005	Stobhill Hospital, Glasgow	4
November 2005	Argyll and Bute Hospital, Lochgilphead	5
November 2005	SSNF Conference, Stirling	8
<b>total</b>	<b>7</b>	<b>40</b>

**Table 2: Framework for Stroke Nursing Research Questions**

Research categories	Research topic
Preventive/Conserving	<p><i>Modifiable risk factors:</i>            Are there any interventions for modifiable risk factors (such as smoking, blood pressure) that are best for my patient? And is it worth the cost and effort involved?</p> <p><i>Secondary prevention:</i>            What are the effects of non-adherence of medications/therapy on clinical outcomes?            What are the determinants of adherence of medications/therapies?</p> <p><i>How can nurses prevent complications, such as:</i>            Shoulder pain            Pain on affected side            Post stroke nausea            Depression            Fatigue            Malnutrition            Urinary Incontinence</p> <p><i>Nutrition:</i>            How do we provide stroke-specific training to pass of NG tubes?            What are the best methods for keeping feeding tubes in place?            What are the perspectives of patients and carers about the acceptability of enteral feeding tubes?            When should it be the nurses' decision to pass NG tubes and how can nurses be best guided in their decision making?            What are the best strategies to prevent delays in passing enteral feeding tubes?            What is the optimal time to institute percutaneous endoscopic grastostomy (PEGs) feeding?            How can nurses recognise problems of malnutrition post discharge?</p> <p><i>Meal-time care:</i>            What are the patient/carers opinions on modified diets?</p>

	<p>Would it benefit patients to sit away from their bedside (e.g. at a dining-room table) to eat their meals?</p> <p><i>Oral hygiene:</i>  How can we improving training in oral hygiene, particularly for nursing students?  What are the opinions of carers toward providing oral hygiene for their relatives?  What factors are associated with altered saliva production?</p> <p><i>Urinary Continence:</i>  How effective is intermittent catheterisation and catheter valves for post-stroke incontinence?  Does catheter insertion help improve quantity and quality of rehabilitation over and above the risk of complications?  How does long-term incontinence effect patients and carers post-discharge?  How do nurses improve attitudes related to incontinence post stroke?</p>
Supporting/ Consoling	<p><i>Supporting:</i>  What are the effects of information provision on stroke patients and caregivers?  When is the best time to provide information?  What is the optimum amount of information for patient and carers?  What are the benefits of an on-call service for information giving and should it be available on the weekends?  Are patients and caregivers needs being met?  What are the overall attitudes of patients and carers to stroke unit care?</p> <p><i>The nature of stroke:</i>  When can we give patients/relatives an indication of the maximum amount of recovery after different types of stroke?</p> <p><i>Advocate:</i>  When should volunteers/organisations be contacted to talk to patients and what are the benefits?</p> <p><i>Ethics:</i>  How can we improve team decision-making regarding feeding post-stroke?</p>
Restorative	<p><i>Young people:</i>  What are the specific needs of young people who have a stroke?</p> <p><i>Sexual function:</i></p>

	<p>What factors are associated with sexual dysfunction following stroke?          What is the impact of sexual dysfunction on people's quality of life and relationship stability, regardless of age (i.e. it is not just about younger patients)?          How can we provide better ways to communicate with patients/carers about sexual problems after stroke?          What is the best time to discuss sexual problems after stroke?          Is there any education/training for staff on how to talk to patients/carers about sexual health post-stroke?</p> <p><i>Other therapies:</i>          What are the benefits of complementary therapies?          When is the best timing to start counselling for post-stroke psychological problems?          What treatment for fatigue is going produce the best results?          What are the roles of different occupational groups in stroke rehabilitation?</p>
Integrative	<p><i>Rehabilitation and goal setting:</i>          What constitutes effective multidisciplinary goal setting for stroke patients?          Do delays in therapy effect outcome?</p> <p><i>Nursing roles:</i>          How can I continue to be an efficient and effective nurse?          What is the efficacy of the specialist stroke nurses?</p> <p><i>Documentation:</i>          What are the effects of integrated care pathways for the management of stroke survivors on a range of outcomes?</p>
Service structure/systems:	<p>What is the optimum stroke unit environment for patient care, e.g. unpacking the black box of stroke unit nursing care?          What is the Impact of shift patterns on continuity of care and/or knowledge of stroke nurses?          Does the routine care of night shift affect recovery?          What is the impact of technology e.g. teleconferencing on patient/nurse relationships and on budgets?</p>

**Table 3: Priority areas for research identified by stroke nurses**

- integrated care pathways
- nursing roles and structures/culture
- rehabilitation goal setting
- nutrition and meal-time care
- bladder incontinence
- sexual health
- complications of stroke
- complementary therapies
- information provision
- secondary prevention