Improving Patient Involvement in Stroke Care

Keywords:
Communication, patient involvement, patient led developments, stroke, rehabilitation

Duration of project:
November 2007-June 2010

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Summary of project:
This project was carried out in conjunction with staff and patients from the stroke unit at Manchester Royal Infirmary. The project aimed to develop new ways of working in the stroke service that recognised the contribution patients could make to improving care through communicating their needs to healthcare staff. Staff and patient discussion groups were held to listen to the views of staff and patients on communication and patient involvement in care decisions. Key areas for development were identified including communication, involving patients in decision making and the introduction of volunteers. Improvements have been achieved in all areas but there is recognition that work needs to be ongoing.

Introduction
The stroke unit at Manchester Royal Infirmary involved in this project consists of an acute stroke ward and a stroke rehabilitation ward. Both wards have integrated multi-disciplinary teams that care for patients in the acute and rehabilitation phase of their illness. At the outset of the project, all the project team were members of the multi-disciplinary teams.

To inform the development of the project, the project team initially carried out a review of relevant evidence and policy drivers.

In 2001 the Health and Social Care Act placed a new duty on NHS institutions to make active arrangements to involve and consult patients and the public in planning and providing services. In 2003 the Department of Health undertook a national choice consultation, “Building on the Best-Choice, Responsiveness and Equity in the NHS”. The aim of this national consultation was to find out what changes would do most to improve the experience of healthcare for patients, users and carers. One of the themes that emerged from this consultation was the view that health needs are personal and health services should be shaped around those needs and the message to health care professionals was, “listen to what the public and patients are telling us, and then act” (Department of Health, 2003, p7).

There was general agreement from those consulted, which included individuals, NHS bodies, voluntary organisations and staff that patient and public involvement improved patient experience and service delivery and in 2004 this view was supported by underpinning evidence provided by the Department of Health paper, “Patient and Public Involvement in Health: the Evidence for Policy Implementation”. This paper synthesised evidence from 12 research projects and amongst its key findings were:
• Patient involvement increases patient satisfaction. Benefits also include greater confidence, reduction in anxiety, greater understanding of personal needs, improved trust, better relationships with professionals and positive health effects
• Communication skills contribute to increased patient satisfaction, participation and health care behaviours. Everyone who ‘deals’ with users, including support staff, has an important communication role

A survey carried out by the Healthcare Commission (2005) provided an assessment of the experiences of people who have received treatment for a stroke in England. The survey asked questions on all aspects of in-hospital care including questions on communication with staff and patient involvement in care. This survey found that 31% of patients reported that nursing staff only sometimes answered questions in a way that could be understood and 6% of patients said they could not understand answers at all; the figure for doctors was almost identical. On the question of involvement, 52% said that they had not been involved as much as they wanted in decisions about their care and treatment in hospital (including 19% who said they were not involved at all). However, more than a third (36%) thought that it was only discussed to some extent, and 16% said that their diagnosis was not discussed with them at all. Communication and engagement with patients following a stroke is generally more challenging than with the wider patient group due to specific communication and cognitive problems. This presents a challenge to those working in stroke services to be more pro-active when communicating and engaging with their patients.

These national policy drivers and evidence were influential in engaging the project team to consider how strengthening patient involvement and engaging with service users could influence care given to stroke patients. Local evidence on communication and engagement was available through surveys undertaken in the hospital and of users of the stroke service. A trust wide audit of patients undertaken in 2006 from all specialities revealed that around 30% of patients felt they did not have input into the care they received or feel able to contribute to how care is given. An earlier survey undertaken by the Trust stroke specialist nurse in 2005, and specifically for stroke patients, suggested communication was better in the acute and rehabilitation stroke unit but could still be improved upon. This survey was of particular interest as it asked patients for suggestions on how care could be improved. Many interesting suggestions were made but one quote stood out: “This place has to be fun and well decorated so we get enthusiastic about life or where is the inspiration?”

The project team therefore set out with an open mind on how patients could best be helped to be involved in improving the stroke care they received on the acute and rehabilitation stroke unit.

Aim of the project
The overall aim of this project was to develop new ways of working in the stroke service that recognised the contribution patients could make to improving care through communicating their needs to healthcare staff.

Objectives of the project
To enable the project to achieve its aim the following objectives were identified. To:

• Engage with patients and provide a forum for them to express their views
• Engage staff to share their views on how patient ideas could be incorporated into new ways of working
• Educate staff on the benefits of patient involvement
• Provide staff with strategies to improve the way they communicate with patients
**Methods and approaches**

A number of approaches were used to facilitate the changes in practice. These included:

- Staff discussion groups
- Patient discussion group
- Education programmes

The project team believed that to develop practice those who would be affected by the change needed to be involved. The stakeholders in this project were both patients and staff and the project team made a commitment to involve both these groups from the outset in the framing, delivery and completion of the project.

**Staff discussion groups**

The first stakeholder discussion groups were organised for staff and were held in May 2008.

The project team adopted the claims, concerns and issues approach developed by Guba and Lincoln (1989) when working with the staff groups. Claims are positive thoughts and feelings about the topic; and concerns are unfavourable thoughts and feelings about the topic and its implementation. Issues normally arise out of concerns and are questions that are practical and technical in nature and help crystallise people’s thoughts and in the experience of the project team were very useful in giving the project a practical framework to work from.

The groups were facilitated by Terence Kelly and Sally Timmis using a template in Dewing and Titchen (2007). This template was very useful in facilitating and managing the groups and drawing out the claims, concerns and issues pertinent to the staff.

For the purpose of these group discussions, staff from both wards were combined. Two groups were held within the same week using the same template to get as many staff involved as possible. The staff that attended were:

- 2 Ward Managers
- 1 Consultant Physician
- 2 Senior Occupational Therapists
- 2 Senior Physiotherapists
- 3 Ward Sisters/Charge Nurses
- 10 Staff Nurses
- 8 Healthcare Assistants
- 1 Speech and Language Therapist
- 2 Rehabilitation Assistants

Overall a positive feeling was generated before and during the group discussions. Comments were captured on flip chart paper and following the group, they were themed within the claims, concerns and issues categories. The emergent themes were identified as:

**Claims**

Improving patient involvement will:

- Improve communication
- Lead to sharing of goals
- Find out patient’s needs and wishes
- Be realistic
• Agree appropriate goals

Concerns
Improving patient involvement will:
• Be challenging to staff
• Be time consuming
• Make us unable to meet expectations
• Benefit some vocal patients

Issues
• How do we ensure all patients can be involved?
• How can we make time to involve patients?
• How do we know what patients want?
• How can we gather the right information about patients?

Patient discussion group
The next stage of the project was to invite a group of patients to share their views. The project team planned this discussion group to take place soon after the staff groups to ensure patients’ views were recorded contemporaneously with those of staff. This meeting was held on the 18th of June 2008. The project team identified patients from a cohort of patients that had been through the stroke service and filled in the survey referred to earlier (see introduction). Within this survey, there was a question that asked patients if they would be happy to attend the hospital and share their views on how care could be improved. We contacted 25 patients by letter inviting them to attend the discussion group and in the event, 9 patients and carers attended the group discussion.

The project team decided to use a process based on discovery interviews to inform the discussions. Discovery interviews were developed by the NHS Heart Improvement Programme in 2000 and have since become widely used in the UK National Health Service as a service improvement tool and patient involvement mechanism. This approach seeks to help teams understand what it is like to be a person — rather than a patient — or carer of a person, with a particular condition or in receipt of a particular set of services (Bridges, Gray, Box and Machin, 2008). The aim of the discovery interview within the context of this project was to set up a framework within which the patient could tell their story. The project team used the onset of stroke through to being discharged home as the framework for patients to tell their story in.

At the beginning of the day the patient group was given an overview of the discovery interview process and informed of the rationale for carrying out this type of data collection. The project group asked for volunteers to take part in the interview process. 3 patients were keen to tell their story and gave their verbal consent. The interviews took place within the seminar room booked for the day in the presence of the other patients and members of the project team. The interviews were carried out by Melissa Brechin who is skilled and experienced at carrying out this type of interview. Each of the volunteers was interviewed in turn and handwritten notes were recorded by the project team. Following the interviews, the project team opened up a discussion for the rest of the patient group and encouraged them to comment on what they had heard relate it to their own experiences and thoughts. Written notes were taken of the group discussion by the project team.

The information provided through the interviews and subsequent discussion with patients was extremely helpful and in some ways humbling. The project team hoped to get some ideas from the patients’ perspectives but in fact got a level of insight and understanding that was not really expected. On reflection two of the project team were new to the discovery interview process and had not experienced the depth
and wealth of information patients can reveal in these circumstances. The process also revealed the intense personal thoughts and feelings that patients don’t usually reveal when they themselves are in hospital.

The information from the patient interviews and subsequent group discussions was themed by the project team and checked with the patient group for accuracy at the end of the day. The key themes that emerged from patients were they:

- Wanted to be more involved in setting their goals and be active participants in rehabilitation
- Felt staff should have more training in communication
- Felt they should have more information on stroke and how to prevent further strokes
- Wanted more interaction and activities whilst on the ward to engage them and prevent apathy and boredom
- Wanted more support on discharge, a common recurring theme was one of “abandonment” once discharged home

**Determining priorities**

Following on from the staff and patient discussion groups, the project team agreed that the areas that needed to be concentrated on were:

- Communication - particularly focusing on the skills of staff to communicate with patients
- Involving patients in making care decisions
- Developing a volunteer service that would help patients to engage with others and motivate them during long periods of in patient activity

These priorities were determined from the themes that had arisen in the group discussions and the project team felt that there was a good prospect of addressing these priorities within the scope of the project.

**Communication**

It was clear from the discussions with patients that some healthcare staff had difficulty in listening to and finding out the needs of patients. In some circumstances this can have detrimental effects on the health and well-being of patients. One simple example provided by a patient highlights this problem. The patient had a moderate degree of aphasia and could communicate if given time as the speed at which he processed information and responded to questions was diminished following his stroke. He revealed his intense frustration as he was unable to get a cup of tea without sugar as the staff giving drinks out didn’t give him time to talk. This continued for some days until one member of staff actually took the time to stop and listen to him and could then respond to his needs. Training staff in communication was therefore identified as a key priority and the project team agreed this training should be for all staff that came into contact with patients, not just clinical staff. Consequently, all staff including domestic and administration staff have undergone training in communication with stroke patients (approximately 50 staff in total).

The training courses were run over a full day and consisted of a morning session that addressed the theory of how communication is affected by stroke and how strategies can be adopted that promote more effective communication. The afternoon sessions involved staff developing communication skills by discussing scenarios with patients with aphasia as teaching facilitators to give feedback to staff on how they communicate and hints on how to improve their communication. Good support for the training was
received from nurse and therapy managers which allowed staff to attend the study days. Two training days were held within the hospital which captured most of the staff and other staff attended the training days off site at venues provided by the Greater Manchester Stroke Network. The communication training days were provided by Connect a charity that aims to support patients with aphasia and by the Stroke Association, another charity that provides support and advice to patients following a stroke. Some of the training days were provided free of charge by the Greater Manchester Stroke Network, others were supported by funds provided by the Foundation of Nursing Studies to support the project.

The feedback from staff on these days has been excellent. The teaching facilitators from Connect and the Stroke Association collected evaluations of the training and sent them on to the project team once they had collated them. Many staff commented that they gained in communication skills but also gained insight and empathy into the needs of patients with communication difficulties. Staff also developed skills in the use of aids to communication such as picture books (a number of which have been purchased for the ward) and the use of written communication as well as looking for non-verbal cues from patients. Following the training the project team were able to observe staff communicating with patients and it was clear that they had enhanced communication skills. They gave patients more time to communicate and made greater use of communication aids and non-verbal communication. The project team also questioned a selection of staff on how stroke could affect communication and all were able to identify receptive and expressive dysphasia, reduced processing speeds when listening to communication and slower expression of speech as potential barriers to communication and were able to articulate strategies to circumvent these problems.

**Involving patients in care decisions**

Involving patients in care decisions can take many forms from deciding on diagnostic tests to deciding on where to live when being discharged from hospital. The stroke unit is a progressive unit and in many ways was good at identifying patient and carers needs and working with them to reach decisions in their best interests. The ward teams of nurses, doctors and therapists are closely integrated and decisions about care needs are taken as team decisions that consider the patient holistically. Family meetings are held regularly to pass on information and try and reach decisions in patients own best interests. No system however is perfect and this project has made the project team recognise the vital importance of the patient themselves. Greater effort is now made to include the patient as much as possible in taking care decisions. Staff actively communicate with patients and to this end patient centred goals are included in the integrated stroke pathway. Questions have also been included that prompt staff to pass information to patients and gain consent for care decisions.

This project also coincided with the introduction of new legislation in the form of the Mental Capacity Act (2005). This act provides a framework to empower and protect people who may lack capacity to make some decisions for themselves. The act has five key principles that all healthcare staff have a legal obligation to follow. These principles, but in particular the first principle: “every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise,” (Department of Constitutional Affairs, 2007, p 19) have made a big impact on how decisions are made in hospitals.

This national and trust wide change of practice did influence this particular objective of the project, helping the project team to ensure patients were involved in care decisions. When patients lack capacity and they do not have friends or family our patients are appointed an independent mental capacity advocate who will represent the patient’s wishes and best interests in care decisions. In the case of those patients lacking capacity who have family meetings are arranged that allow family to represent the patient. Of course where patients do have capacity to make decisions we ensure their wishes are represented even if there are communication barriers.
Some practical changes have been made to documentation in the integrated stroke care pathway that prompted staff to involve patients. For example, there is now a patient goal setting sheet which records the patient’s own personal goals and incorporates them into a care plan. There is also a section for medical staff to ensure they discuss diagnosis and prognosis with patients and discuss stroke risk factors and lifestyle changes.

It could be argued that this project has contributed towards the improvement in involving patients in care decisions in two specific ways:

1. The project engaged with staff to raise their awareness of patients’ need to be involved in their care and the benefits that involvement could bring
2. Making practical adjustments to documentation has put a greater emphasis on including patients in discussions and decisions.

During the course of the project, one of the project team (Terence Kelly) was working as a practice development nurse. He was able to observe how staff tried to involve patients and their carers in care decisions through multidisciplinary meetings, family meetings and one to one interaction. Terence now has a new role as a trainee advanced practitioner in stroke care and is now responsible for putting the principles of involvement into practice and using the experience gained from this project to inform care of patients.

Volunteer service

“Sitting around all day, nothing to do, the highlight of the day is mealtimes”. This is a comment from one of the patient representatives that attended the patient discussion group. Other patients described how they could go for long periods of the day feeling alone, not talking to others and feeling apathetic and demotivated at times. They were keen to have interaction and activity built into their day.

The project team decided to explore the possibility of developing a volunteer service on the stroke rehabilitation unit to address some of these issues. There is a volunteer co-ordinator within the hospital but before this project, volunteers were not working in ward areas. In conjunction with the volunteer co-ordinator, the multidisciplinary team that cares for patients on the wards wrote a role description for volunteers who wanted to work on the stroke unit; this was an essential first step to take before volunteers could work on the ward. The main roles described in this document are talking to patients, reading and playing board games with patients and taking those that are able to the hospital shop, or out for walks. Provision has also been made to enable those volunteers with additional specialist skills to be able to use them. For example, one of the volunteers is skilled in hand massage and verbal feedback from patients and ward staff is that this is a service that is greatly appreciated by the patients. The volunteers were recruited by a hospital volunteer co-ordinator as part of a hospital programme to develop a volunteer service. The stroke specialist nurse interviewed these volunteers with the volunteer co-ordinator as part of a general interview not specifically for the stroke service.

Volunteers attending the ward are directed by the rehabilitation therapy assistants who try and match the work of the volunteers with the rehabilitation needs of patients. One of the frustrations of this project however was the inability to fully develop the volunteer service. The project team had no option other than to use the hospital service and as that service itself was in development, the provision of volunteers was patchy. One volunteer continues to visit the ward regularly 1-2 days a week. Other volunteers have worked for short periods only and the actual numbers now attending is minimal. Many of the volunteers are students and are transitory meaning the service on the unit has not been developed as would have been liked. It is also the case that the stroke specialist nurse post has been vacant for a long time and of the original three members of the project team only one still works in the service and in a role that doesn’t
allow him time to now follow up the project work. On a positive note a stroke specialist nurse is now in post and the multidisciplinary team are keen to continue to develop a volunteer service. There is still a will to develop this service and the work done in this project can provide a platform on which to build.

Discussion
Undertaking a project such as this is not a straightforward linear process with a defined start and end point. The focus of the project shifted once the project team had spoken to patients and staff in the stroke unit. This was a positive development as it meant the project could address the real issues that concerned them. The use of the claims, concerns and issues framework was very helpful in drawing out what was important to the people involved.

The original timescale for the project was extremely optimistic as it underestimated the length of time it takes to arrange group discussions; theme the notes from the discussions and clarify meanings with the participants. This was particularly the issue with the patient group. The project team wanted this project to be a practical development rooted in the reality of the experiences of patients’ and staff and in this, the project team would argue that they largely succeeded.

To evaluate this project the following questions can be posed:
- Are patients more involved in decision making?
- Do staff have the skills to communicate with patients?
- Are there volunteers that help patients?

There is evidence from documentation in the new stroke care pathway that communication with patients and carers is taking place and this was directly but not solely influenced by this project work. All ward staff have undertaken communication training to enhance their communication skills with patients who have had a stroke. The project team are aware however that there needs to be continuation of this training for new staff and updates for existing staff. There is a limited volunteer service and the project team would like this to be built upon in the future by the current ward team using the infrastructure developed during this project. Having the support from the Foundation of Nursing Studies was invaluable to get this new way of working embedded but it needs to be sustained. For the project team, this project certainly made all the team members think differently; in particular helping them to see things from a patient perspective. All members of this project team have now moved on to different roles but have taken the skills and learning from the project with them.

Recommendations
For professionals
- Develop a system of ongoing communication training to ensure skills are up to date and that all team members have the skills to communicate effectively with patients
- Work in close partnership with the volunteer service to explore new ways to engage with and motivate patients

For future research and development work
- Develop a system whereby patients views can be heard and incorporated into the professional development of the service
- Repeat audit of patients views on how they are communicated with and their level of involvement in care decisions
- Audit documentation to monitor how communication with patients is documented
References


