A stroke staff training programme involving expert patients: a case study of its impact on staff and service development

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Submitted for publication: 15th January 2013
Accepted for publication: 4th July 2013

Abstract

Aim: To explore the long term impact of an interprofessional staff training course involving expert patients addressing the psychological, communication and cognitive needs of stroke patients.

Methods: Thematic framework analysis of focus group and interview transcripts from a convenience sample of course participants, which identified key overarching analytical themes.

Findings: Participants discussed the impact of the course on their understanding and awareness of, and empathy with, patients and their needs, up to six years after course attendance. Involvement of expert patients was key to this. However, despite their perceived development of awareness and skills, participants felt team and systemic barriers obstructed practice change.

Conclusions: A long term qualitative service evaluation of a staff training course involving expert patients helped staff to develop a holistic outlook, improving their understanding of patients with psychological, communication and cognitive problems, and awareness of their needs. However, training alone was perceived to be insufficient to achieve the practice change required to improve patient care.

Implications for practice:

• Involving expert patients in staff training could improve staff’s awareness and understanding of patients and their needs
• Actively involving expert patients in staff training could bring positive changes to workplace culture and person-centred practice
• Multidisciplinary, practical, workbased, reflective courses with quality manuals and workbooks are valued by staff
• Training alone is not sufficient to ensure practice change or implementation of newly acquired skills, even if staff are highly motivated. Systemic and team barriers need to be addressed
• Long term qualitative and quantitative evaluation of staff training courses involving expert patients should be undertaken to provide in depth and measurable outcomes of training

Keywords: Patient public involvement, expert patients, staff training, service evaluation, staff development, barriers to change

Introduction

Patient involvement in training and development is well established within undergraduate education, health research and service design and provision (Department of Health, 1999a; Boote et al., 2002; Department of Health, 2004; Baggott, 2005; Towle et al., 2010). However, despite recognition that
patient and public involvement in the UK NHS is fundamental to a responsive, equitable and choice based service (Department of Health, 2004), the participation of patients as experts in the training and development of practising healthcare professionals is limited (The Health Foundation, 2011).

The concept of ‘expert patients’ first emerged in the UK in 1999 (Department of Health, 1999b). An expert patient is defined in the literature as someone who, because of their wisdom and experience, understands their disease better than the doctor and is therefore an effective partner in care (Donaldson, 2003). Two relevant issues emerge from the current literature concerning the use of expert patients in healthcare professionals’ training and development: first, most work is done at undergraduate level (The Health Foundation, 2011); and second, evaluations are predominantly short term (Towle et al., 2010; Terry, 2012; Jha et al., 2013). The self-reported short term benefits of involving patients in undergraduate training are greater sensitivity to patient needs, improved attitudes towards disability and illness, and increased confidence in clinical skills (Towle et al., 2010; The Health Foundation, 2011). Meanwhile, reassessment of students up to two years later highlighted long term undergraduate impacts of increased empathy, improved interpersonal skills and the development of an individualised approach to care (The Health Foundation, 2011).

The few existing self-reported short term evaluations of postgraduate health professional studies involving expert patients identified benefits including improved clinician-patient relationships (McCreaddie, 2002) and opportunities for staff reflection (Terry, 2012). Thus, patient involvement in training is still predominantly at undergraduate level (The Health Foundation, 2011) and, where it does involve staff, long term evaluation is missing (Chamney et al., 2012; Terry, 2012; Jha et al., 2013). Determining the long term impact of training involving patients is crucial for three reasons:

- To address the gap identified in the literature regarding the long term effects of patient and public involvement in staff/postgraduate training programmes (The Health Foundation, 2011)
- To assess the value of allocating NHS resources to such training (Brown et al., 2002; The Health Foundation, 2011)
- To allow for the refinement of training programmes to improve quality and effectiveness (Hutchinson, 1999)

In 2004 the Royal College of Physicians stipulated that all staff should be trained in the recognition and management of emotional, cognitive and communication difficulties following stroke (Royal College of Physicians, 2004). However, the UK stroke literature suggests this is not commonplace despite staff requests for such training (Craig and Smith, 2008). Stroke training focuses on visible difficulties such as moving and handling issues (Edwards, 2006) and does not often involve patients in course design or delivery (Repper and Breeze, 2007; The Health Foundation, 2011). Given the impact expert patient involvement has been shown to have on empathy, individualised care and clinician-patient relationships with undergraduates in non-stroke settings, it could be usefully employed in training to help address the psychological, communication and cognitive needs of patients after stroke.

In an attempt to tackle these issues, one UK hospital embarked on a practice development initiative, designing and delivering an interprofessional two day training course on the psychological and communication aspects of stroke. It was rooted in clinical practice and experience, and expert patients helped deliver the training. These patients were stroke survivors with the language disorder aphasia who had experienced the stroke care pathway.

The course facilitated learning and provided time and space for personal reflection. Starting in 2004, it ran twice yearly for six years and was informally evaluated immediately after each course with confidence rating scales and knowledge questionnaires (Ross et al., 2009). Its long term impact, however, had not been established, as is the case with many staff training courses (The Health Foundation, 2011). So, six years after its inception, a service evaluation exploring the ongoing impact of the course on staff participants was undertaken. Service evaluation is defined as:
An evaluation of the effectiveness and efficiency of an existing or new service/practice that is evidence based, with the intention of generating information to inform local decision making’ (Healthcare Quality Improvement Partnership, 2009, p 5).

The purpose of this paper is to present the themes that emerged from focus groups and interviews regarding the course participants’ perceptions of the long term impact of the training course and expert patient involvement on their knowledge, confidence, skills and delivery of patient care, as well as their views on the course design.

Setting
The setting for the course was a large NHS foundation trust teaching hospital in a socio-economically and ethnically diverse UK city. The five site hospital employs more than 13,500 staff and treats more than a million patients each year. At the time of the evaluation, the stroke care pathway consisted of inpatient acute and rehabilitation care on two sites, and a rehabilitation service provided by a community NHS trust in people’s own homes, care homes, nursing homes or outpatient settings.

Course design and format
The course was designed and delivered by three senior members of the rehabilitation team: a speech therapist, an occupational therapist (first author, JR) and a clinical psychologist. It is described in full by Ross and colleagues (Ross et al., 2009). The training was highly practical in nature, focusing on stroke survivor needs, feelings and experiences rather than on theoretical constructs. Its aims were:

• To increase staff knowledge, confidence and skills in identifying and managing the psychological, cognitive and communication difficulties post stroke
• To develop a person-centred approach to care, improve the patient experience and reduce the psychosocial consequences of stroke

The course ran over two days – the first day in the classroom, a half-day in the workplace and a half-day follow-up six weeks later. The expert patients were involved in the classroom session. These patients were all stroke survivors who had responded to a request for volunteers at local stroke support groups or from community speech and language therapists. No longer term follow-up or retraining sessions were available due to resource constraints. Staff of all disciplines and grades working within the city’s stroke care pathway could attend and all participants received a course manual and workbook.

Classroom session: This full day of training, facilitated learning and reflection contained little formal teaching. It used experiential learning, case studies, video recordings, group discussions and a one hour expert patient panel session. During these panel sessions, course participants had the opportunity to interact in an informal question and answer session with four to six people with post stroke aphasia who had experienced the stroke care pathway. The panel members answered participants’ questions and shared their feelings, opinions and perspectives about their experiences of aphasia after stroke and the care and rehabilitation they had received. They were encouraged to highlight positive aspects of their care and recommendations for improvements.

Four hour workplace session: This time was self-directed and arranged by the participants themselves. It could be taken as one block or split over several days or weeks. During this time participants had to complete and reflect on the nine practical tasks listed in their workbook; these included locating a cognitive assessment in a patient’s notes and reviewing its findings, and having a conversation with a patient who had communication difficulties.

Half-day follow-up: The aim of this session was to provide an opportunity for course participants to share and reflect on their practical experiences, homework tasks and learning, including successes and failures. It culminated with each participant setting a personal pledge regarding a change to their clinical practice.
Evaluation method
A qualitative service evaluation (Healthcare Quality Improvement Partnership, 2009), was undertaken by the study authors. It used focus groups to obtain participants’ perceptions of the long term impact of the course in relation to its aims. These aims were:

- Improved staff knowledge, skills and confidence in working with patients with psychological, communication and cognitive problems after stroke
- The provision of person-centred care
- Improved patient experiences

Focus groups enable data to be collected quickly from a large group of participants in natural environments – ‘everyday conversations’ as opposed to more formal and superficial interview settings (Wilkinson, 2004). The groups were facilitated using a semi-structured topic guide (Krueger, 1998), which contained topics based on the aims of the course, with one question and several prompts allocated to each section. Each question was carefully designed and positioned according to Krueger’s (1998, p 2) ‘questioning route’ in order to encourage discursive flow. Opening questions that were non-specific and non-challenging were followed by transitional questions that encouraged group members to start thinking about the concepts in question. Key questions were then posed that addressed issues fundamental to the evaluation and were followed by ending questions that closed the session and gave participants an opportunity to raise any issues and add any comments not already addressed. The topic guide was piloted with a stroke clinician to ensure questions were understandable and that they would elicit useful data. Study validity was maximised using a variety of methods. The first author (JR) kept a reflexive diary to reflect on the researchers’ impact on data collection and analysis (Richards, 2005). Respondent validation was employed (Mays and Pope, 1995): the co-facilitator recorded key discussion points during the focus groups and these points were checked with participants at the end of the session to ensure they were a true reflection of their views. Methods were made transparent using an audit trail (Mays and Pope, 1995). Where course participants could not attend the focus groups, one to one semi-structured interviews were offered using the focus group topic guide.

Participants
Eligibility and Sampling
The original population of course participants consisted of 125 members of staff who had attended the course over its six year duration. All were clinicians working at various sites within the stroke care pathway; no managers had chosen to attend the course. Nursing staff, support workers, physiotherapists, occupational therapists, speech therapists, psychologists and social workers were represented (see Figures 1 and 2). Of the 125, 54 could not be traced as they had moved on leaving no forwarding details. Taking a pragmatic approach, a convenience sampling method was used, selecting participants on the basis of availability (Bryman, 2008).
Recruitment
All contactable course participants (n=71) were sent a personalised email informing them of the study and inviting them to take part, with a reminder email sent three weeks later. Once staff members had expressed an interest in participation and given permission for the author to seek agreement from their line managers, they were invited to attend one of two focus groups. If they could not attend either, they were invited to an informal semi-structured interview at a time and place most convenient to them. Participants received an information sheet three weeks before the focus group. They signed a written consent form and completed an anonymised demographic data collection sheet at the start of the focus group or interview.
Twelve of the course participants were eligible and agreed to participate in the study, giving a response rate of 17 per cent. Within this sample population of 12, six attended the first focus group, four came to the second and two were interviewed separately as they were unable to attend the groups because of work commitments. The groups were of mixed professional background and no hierarchy existed between participating staff. This and the absence of managers minimised issues of power and voice (Esterberg, 2002, pp 109-110). For the sample group and whole original population, the length of time since course attendance averaged 3.5 years but the sample was not representative of the original population with regard to work site and professional mix; it was dominated by staff from one of the three clinical settings. No psychology staff were present and therapy and social work staff were over-represented (see Figures 1 and 2 above, and Table 1). No comparison of staff grade could be made as this data did not exist for the original population.

Table 1: Participant characteristics (n=12)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Profession</th>
<th>Work site</th>
<th>Time since course</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Male</td>
<td>46-55 Social work: care manager</td>
<td>Stroke unit, northern site</td>
<td>2 years</td>
</tr>
<tr>
<td>P2</td>
<td>Female</td>
<td>36-45 Nursing: ward manager</td>
<td>Acute neurology, central site</td>
<td>5 years</td>
</tr>
<tr>
<td>P3</td>
<td>Female</td>
<td>18-25 Therapy: therapy assistant</td>
<td>Elderly wards, central</td>
<td>3 years</td>
</tr>
<tr>
<td>P4</td>
<td>Female</td>
<td>36-45 Therapy: physiotherapist</td>
<td>Stroke unit, central</td>
<td>6 years</td>
</tr>
<tr>
<td>P5</td>
<td>Female</td>
<td>26-35 Nursing: senior staff nurse</td>
<td>Stroke unit, central</td>
<td>5 years</td>
</tr>
<tr>
<td>P6</td>
<td>Male</td>
<td>18-25 Therapy: occupational therapist</td>
<td>Surgical wards, central</td>
<td>4 years</td>
</tr>
<tr>
<td>P7</td>
<td>Female</td>
<td>56+ Social work: care manager</td>
<td>Stroke unit, central</td>
<td>4 years</td>
</tr>
<tr>
<td>P8</td>
<td>Female</td>
<td>46-55 Therapy: technical instructor</td>
<td>Neuromedicine, central</td>
<td>2 years</td>
</tr>
<tr>
<td>P9</td>
<td>Female</td>
<td>46-55 Therapy: technical instructor</td>
<td>Stroke unit, central</td>
<td>3 years</td>
</tr>
<tr>
<td>P10</td>
<td>Female</td>
<td>36-45 Therapy: radiographer</td>
<td>Radiosurgery, central</td>
<td>2 years</td>
</tr>
<tr>
<td>P11</td>
<td>Female</td>
<td>36-45 Nursing: support worker</td>
<td>Acute neurology, central</td>
<td>3 years</td>
</tr>
<tr>
<td>P12</td>
<td>Male</td>
<td>46-55 Therapy: therapy assistant</td>
<td>Stroke unit, central</td>
<td>3 years</td>
</tr>
</tbody>
</table>

Procedure

Focus groups

Two 50 minute semi-structured focus groups were undertaken using a topic guide designed to follow Krueger’s (1998, p 2) ‘questioning route’. The opening question was factual, chosen specifically to ease participants into a group discussion. They were asked to discuss ‘the psychological, communication and cognitive problems of stroke’ rather than personal attitudes and beliefs. It also set the scene and established participants’ current understanding and knowledge of these issues. The transitional second topic ‘changes to the attendee’ aimed to highlight what changes each individual had experienced as a result of the course, moving them towards the key questions and demonstrating to the group the views of all present. Key topics regarding ‘the feelings of those with psychological, communication and cognitive problems’ and ‘the patient experience’ were then explored. This was where personal attitudes, feelings and thoughts were expected to arise. As these issues were key to the study, in addition to the planned questions, participants were asked to write perceived patient experiences on sticky notes, rate them on one flipchart and discuss the outcome as a group. The last topic, ‘additional comments’, was designed to ensure there was nothing the focus group had missed and then bring the group to a close. Within each topic, simple open questions were devised that did not provide examples or ask ‘why’, to allow participants to offer their own thoughts and reflections.
(Krueger, 1998). Predetermined prompts were used if needed. The groups were facilitated by the two authors, one of whom had been part of the training course (JR) and one who was independent (RP). The group sessions were audio recorded with key discussion points paraphrased and documented on flipchart paper during the group’s duration by one of the authors (RP). During the session, as a means of validation, participants reviewed these key points to confirm they represented the ideas expressed (Mays and Pope, 1995).

**Interviews**

Forty minute semi-structured interviews were completed and audio recorded by one of the authors (JR) with course participants who could not attend the focus groups. They were structured using the focus group topic guide.

**Data analysis**

The focus group and interview recordings were transcribed verbatim and analysed as a whole by one of the authors (JR). The five stage thematic framework analysis process was used, as detailed by Richie and Spencer (1994). First the author gained familiarity with the whole dataset. The data were then used to create a coding framework, and the whole dataset was indexed accordingly. The data were charted and abstracted to allow overarching analytical themes to emerge. The final stage mapped and interpreted the data in order to describe the findings (Richie and Spencer, 1994). The second author (RP) oversaw the process via regular team meetings and discussions. NVivo software (QRS International, 2008) was used during this process to store and manage the data.

Demographic data regarding each participant’s professional background and workplace location were collected to determine the representativeness of the sample.

**Ethics**

The study obtained ethical approval from the University of Sheffield. It was also registered as an NHS service evaluation in accordance with the simple rules toolkit set out by the Healthcare Quality Improvement Partnership (2009).

**Results**

Four overarching themes regarding the impact of the course emerged from the thematic framework analysis of participant data. These were:

- Holistic thinking
- Clinical development
- Barriers to implementation
- Reflections on the course

The development of these themes is shown in Table 2.
<table>
<thead>
<tr>
<th>Main themes (4)</th>
<th>Sub themes (18)</th>
<th>Original themes (37)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Holistic thinking</strong></td>
<td>Empathy</td>
<td>Patients’ feelings improved? (3)</td>
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<tr>
<td></td>
<td></td>
<td>Patients’ emotions</td>
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<tr>
<td></td>
<td>Awareness</td>
<td>Knowledge (of the psychological, communication and cognitive problems; techniques available; of the patient as person)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Patient experiences (on ward)</td>
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<tr>
<td></td>
<td></td>
<td>Patients’ life (past, present, future)</td>
</tr>
<tr>
<td></td>
<td>Insight</td>
<td>Putting self in a patient’s position</td>
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<tr>
<td></td>
<td>Attitude development</td>
<td>Attitudes towards psychological, communication and cognitive problems, and to patients with these problems</td>
</tr>
<tr>
<td><strong>Clinical development</strong></td>
<td>Knowledge</td>
<td>Knowledge of the psychological, communication and cognitive problems post stroke and their impact on patients</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Knowledge of techniques</td>
</tr>
<tr>
<td></td>
<td>Awareness</td>
<td>Awareness of patient as person</td>
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<tr>
<td></td>
<td></td>
<td>Awareness of self and practice</td>
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<tr>
<td></td>
<td></td>
<td>Awareness of other professionals’ roles</td>
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<td></td>
<td></td>
<td>Awareness of psychological, communication and cognitive problems</td>
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<tr>
<td></td>
<td>Insight</td>
<td>Insight into a patient’s experience</td>
</tr>
<tr>
<td></td>
<td>Confidence</td>
<td>Confidence in working with patients with psychological, communication and cognitive difficulties</td>
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<tr>
<td></td>
<td>Skills</td>
<td>Skills</td>
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<tr>
<td></td>
<td>Behaviours</td>
<td>Behaviours</td>
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<tr>
<td></td>
<td>Feelings about job</td>
<td>Feelings about job</td>
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<td></td>
<td>Ward functioning</td>
<td>Practical changes required</td>
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<td></td>
<td></td>
<td>Management of change</td>
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<td><strong>Barriers to implementation</strong></td>
<td>Lack of awareness</td>
<td>Own experiences</td>
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<td></td>
<td></td>
<td>Own values</td>
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<td></td>
<td></td>
<td>Lack of skills</td>
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<td></td>
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<td>Lack of knowledge</td>
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<td></td>
<td>System priorities</td>
<td>Tasks</td>
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<td></td>
<td>Discharge planning</td>
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<td></td>
<td></td>
<td>Loss of services</td>
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<td></td>
<td></td>
<td>Management attitudes</td>
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<td></td>
<td>Time</td>
<td>Unable to spend time with patient</td>
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<tr>
<td></td>
<td></td>
<td>Unable to spend time reflecting</td>
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<td></td>
<td></td>
<td>Staffing levels</td>
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<tr>
<td><strong>Reflections on the course</strong></td>
<td>Provision</td>
<td>Provision of training</td>
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<tr>
<td></td>
<td>Suggested changes</td>
<td>Suggested changes to training</td>
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<tr>
<td></td>
<td>Highlights of training</td>
<td>Time provided to learn/develop</td>
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<td></td>
<td></td>
<td>Expert patient panel</td>
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<tr>
<td></td>
<td></td>
<td>Resource pack</td>
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<td></td>
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<td>Training techniques used</td>
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</tbody>
</table>
Holistic thinking
This theme recurred throughout the data. It was clear that the course had helped the participants to develop a holistic approach to their work. They now thought of the stroke patient as a ‘human being’ rather than a ‘job’. They could identify with them as people, empathising with their thoughts, feelings, experiences, wants and needs, contextualising them not as ‘patients’ within the work environment, but as ‘people’ within life – individuals with a past, present and future, and hopes, fears and feelings. Participants’ candid insights into how the course achieved this are set out below.

‘The course made me think actually, these people are human and they do have feelings... even though they might not be able to talk as proper people’ (participant 3).

‘Yeah and it’s not just your job, it is a person there... and they’ve still got feelings, they can still hear you, they know what’s going off around, just because they can’t physically at that moment in time tell you, they still know what’s happening... and it’s only when you go on the course and you’re working with people that it actually sinks in’ (participant 11).

‘I think it [the course] made me think more and more and more about the people I am seeing, the patients I am seeing... the person not the patient. Not the person who’s had a stroke – the person’ (participant 12).

The data suggest that the key to this was the expert patient panel. All participants commented on the effect it had on them, agreeing that it played a significant role in improving their understanding of stroke survivors with psychological, communication and cognitive problems and their needs. They reported the development of a holistic outlook and an ‘enlightenment’ with regard to these patients, saying they became more empathetic as a result. Some of the participants explain this:

‘Actually having the people, having the patients there who had been through it, explaining their side of things... they had obviously been through it and they know what problems they had when they were in hospital... and it just made you understand it’ (participant 1).

‘I thought the expert panel was really useful and being able to communicate with a broad spectrum of people with different difficulties... I hadn’t realised it was just a complete blackout for them and just how difficult that might be’ (participant 10).

‘Having the opportunity to go on the course and see examples of that and speaking to survivors, it just brings it all home really’ (participant 6).

Indeed, results suggest the expert panel had been a powerful mechanism in achieving a better understanding of stroke survivors with psychological, communication and cognitive problems. Participants had an opportunity to see and hear at first hand the ‘human’ side of the stroke experience – to see stroke patients in a different context and then reflect, think and discuss the effects of this contact. The strength of this training mechanism is indicated by the fact that the specifics of the meetings could be recalled many years later:

‘There was one lady in particular who actually couldn’t speak and had still not got her voice back, and she to this day sticks in my head’ (participant 11).

‘I think the part of the course when you have the experts panel and that gentleman came in, and he was quite a youngish gentleman, and I can still remember him now and he said he was in hospital and he was desperate, absolutely desperate to communicate with someone, someone to understand him’ (participant 9).
Another indication of how strong this part of the course was comes from an examination of the words and phrases used to describe it. Terms like ‘powerful’, ‘stuck’, ‘brings it home’, ‘taken on board’, ‘impact’ and ‘icing on the cake’ are used. Participant 12’s words summarise this:

‘I think it was powerful training in the sense that I think it made an impact... then you’ve kind of put the icing on the cake and you had people who’ve experienced strokes.’

Clinical development

The data suggest participants felt that the course helped their clinical development in three ways: they acquired new skills and knowledge, developed their confidence and had an opportunity to reflect on their practice.

New skills and knowledge: Participants discussed the skills they learned on the course. These included the ability to communicate effectively with post stroke patients experiencing communication, cognitive and psychological problems, and the ability to identify their less visible, more subtle needs and adapt treatment plans accordingly. They also felt that the course had provided them with a flexible problem solving approach to communicating with such patients, and highlighted the importance of spending time with them and explaining things fully.

‘It’s opened up other avenues, other ways of being able to pick up signs from patients, I found that very helpful’ (participant 7).

‘Now I try and explain absolutely everything before I even do it... and so I do think I tend to go that little one step further now if I can’ (participant 11).

‘Taking time with people and... trying not to rush questions and all that sort of stuff, take time’ (participant 1).

Confidence: Most participants mentioned that the course had given them an increased confidence in working with this patient group. It had made them feel confident using their newly acquired skills and knowledge, and given them a new positivity about interacting with such individuals.

‘Maybe before [the course] I probably would not have tried again [to communicate] because I’d have thought I don’t know how to do this’ (participant 9).

‘I always used to think if I couldn’t understand [what the patient was saying] I’d failed and that was really bad, but now I try another tack and get to communicate properly and not be worried... try different avenues’ (participant 10).

‘I’m just being more confident. I mean I’m probably at the younger end of the scale... and being thrown into a stroke ward, when you are not confident, it’s well out of your comfort zone... it’s a lot better being able to speak to somebody and have a conversation with those who’ve had a stroke’ (participant 3).

Self-reflection: The data suggest that the course provided time out of a busy working life for staff to reflect on and question their own practice and motivations. For example, participants 6 and 2 explain how the course assisted personal reflection:

‘I think it’s helped me going on this course... because it always reminds me, it helps me remember why I’m doing what I’m doing, in a sense how I’ll approach patients’ (participant 6).
‘Looking at what you do and how you do it – are you an effective listener? And are you an effective communicator? The course really heightened my awareness of that’ (participant 2).

**Barriers to implementation**

Results indicated that although the course facilitated a holistic approach and clinical development, participants felt that it did not always impact on their ability to meet the needs of those with psychological, communication and cognitive problems following stroke. This was because barriers were felt to exist. The data suggest two types of barriers were present: ‘systemic barriers’ that resulted in processes and systems preventing trained staff from meeting these patients’ needs; and ‘team barriers’ that meant untrained colleagues and managers restricted participants’ opportunities to instigate change.

**Systemic barriers:** The data suggest that the system did not prioritise the psychological, communication and cognitive needs of stroke survivors and that staff who had attended the course could not overcome this despite a newly acquired desire and ability to do so. Indeed, participant 9 stated she was ‘helpless’ to meet the psychological, communication and cognitive needs of her patients because of such barriers. It was felt that the system prioritised tasks, reducing length of stay and what were perceived as cost improvements, over the needs of stroke survivors.

Participants felt that priority given to practical tasks or paperwork prevented them from protecting the time necessary to identify and meet the psychological, communication and cognitive needs of patients. Participants 11 and 2 explain this, and participant 4 describes how if she did prioritise psychological, communication and cognitive needs, she would not be able to get her job done:

‘On days where you’ve constantly got buzzers, you’ve constantly got poorly people going off. It’s [feelings of depression] not going to get picked up as much, so maybe they don’t get that care they should do because you’re too busy to actually sit and have a chat with them – that’s how it gets picked up you see’ (participant 11).

‘In the business of every day, you lose those listening skills or you don’t necessarily lose them, but you put them down the list of importance’ (participant 2).

‘I try and utilise those [rehabilitation files] more and try to write things but I do find it challenging with time, I’d like to be able to use it more... but if I do that every day I’m seeing less people’ (participant 4).

Participants felt that the priority given to reducing length of stay and efficiency savings negatively affected their ability to meet the psychological, communication and cognitive needs of stroke survivors. The following comments exemplify this, as they concern patients being moved too quickly through the system for their needs to be addressed, an inability to refer on to a psychology service or adjustment group because they no longer existed, and difficulty trialing a medication management system.

‘There’s such a huge emphasis on length of stay’ (participant 2).

‘But... like you were saying sometimes it’s better to keep them longer for their mental health... to actually progress with therapy, because I know a lot of the time people are down, they refuse therapy don’t they, and they don’t feel like doing it today... So they need to get over that, to get on with therapy, the time is ticking isn’t it?’ (participant 5).

‘I don’t quite understand why they’ve taken the psychologist away when figures show so many stroke patients suffer from depression... because I’ve been on this course I can pick up the signs... but now even if I pick up the signs... I’m helpless aren’t I? I can’t do anything at all for this patient.'
I can’t improve the quality. I’m sure I can in other areas but I can’t do anything to help them with their mood’ (participant 9).

‘One of my big problems... is the medication... I could have got the medidose boxes... to trial on my ward... the pharmacist won’t fill ’em... because they say they’ve not got enough staff to fill ’em’ (participant 1).

Team barriers: The attitudes and knowledge of colleagues and managers who had not attended the training course were felt to impact on the ability to meet the psychological, communication and cognitive needs of stroke survivors in two ways. First, as they had not been on the course, they were felt to lack the awareness, understanding, skills, knowledge and confidence necessary to address such needs. Second, this lack of training and awareness meant trained staff did not feel supported or encouraged to identify, prioritise and address non ‘systemic’ factors.

‘I think it [changes to practice following the course] is individual personally... unless it’s really backed by management and encouraged by management, it’s not going to have a team effect... I don’t think on our ward, I can’t say for other wards obviously, that what we learn is encouraged to be used’ (participant 5).

Reflections on the course
The data provided some useful reflections on the course itself, suggesting that it was valued, beneficial and of good quality. Particular training methods were identified as effective tools in achieving staff development. These were:

• The provision of a course manual and workbook
• The practical, workbased nature of the course
• The use of mixed training methods
• The mixed professional background of trainers and participants
• The use of the expert patient panel

The following quote summarises why the course was valued:

‘I think it’s invaluable training. It’s definitely the best training I’ve had since I’ve been with the Trust... It’s interactive; you felt you were actually sitting down with people, as opposed to just being talked at or given handouts or looking at a screen or something’ (participant 12).

Participants also made suggestions for future courses. They felt training should be compulsory, with regular updates provided, that other professionals should be included in the training team, that the manual should include a laypersons’ reading list and that the course should include carer communication.

Discussion
The evaluation of a workbased, multidisciplinary, practical staff training course involving expert patients demonstrates that it achieved self-reported, long term changes to participants’ ability to empathise, and their awareness of, attitudes towards and confidence in working with people with psychological, communication and cognitive problems post stroke. Participants reported the course had also assisted their clinical development and enabled them to move from viewing patients as a job or task to identifying with them as people, with the expert patient panel appearing to be key to this.

The results of this study mirror those found by evaluations of undergraduate courses involving patients (Towle et al., 2010; The Health Foundation, 2011). This suggests training involving expert patients benefits staff in the same ways it does undergraduates. The results of this long term evaluation also mirror those found in short term studies (Towle et al., 2010; The Health Foundation, 2011). This study found that the self-reported, short term impacts of increased sensitivity to patient needs, development
of attitudes towards disability and illness, improved confidence, awareness of an individualised approach to care and opportunities to reflect (Towle et al., 2010; The Health Foundation, 2011; Terry, 2012) were still present up to six years after attendance.

This study’s findings suggest that active involvement of patients in training is important. Participants explained that having the opportunity to interact with expert patients and being able to hear their stories first hand was a powerful factor in terms of developing their understanding and empathy. McCreadie’s (2002) work offers an explanation for this. She demonstrates that face to face interactions engender a strength of emotion and provide the theory with a real life context that makes understanding and empathy changes marked and enduring.

This study suggests that active patient involvement in staff training can help staff to develop a holistic approach to care and increased awareness of patient needs. It enables staff to view the patient in the context of the patient’s whole life, to develop and maintain a positive approach to their work and to develop good communication and listening skills. They were more accepting and understanding of stroke patients with psychological, communication and cognitive problems and their needs. These skills could contribute towards the provision of person-centred care and effective workplace culture, according to the work of Christie et al. (2012) and Manley et al. (2011). Christie et al. state that patients being accepted, listened to and understood are three of the six core values essential for the provision of person-centred practice. Manley et al. identify person-centred practice as an essential attribute for an ‘effective workplace culture’, a culture that achieves evidence-based care as well as person-centredness.

However, a holistic approach, awareness of patient needs and positive attitudes are not enough to ensure practice change. This study’s findings suggest that participants felt that the psychological, communication and cognitive needs of stroke survivors were not fully met and the quality of person-centred care was compromised by systemic and team barriers. The literature explains that if new positive practices are to endure, systemic and organisational values need to be aligned to these new ways of working (Manley et al., 2011) and social structures and patterns need to be facilitative (Dewing et al., 2011).

Notably, the system and organisation must share the same values and culture required for service development (Dewing et al., 2011; Manley et al., 2011). This is important because if a service aims to meet all the needs of all patients, training alone does not appear sufficient. There needs to be a willingness to address systemic barriers such as funding, staffing levels, service priorities, lack of time and task orientated practice (Gillespie et al., 2004; West et al., 2005; Dewing et al., 2011; Kirkley et al., 2011), and team barriers (social structures and practices) such as low morale, and lack of managerial support and understanding (Gillespie et al., 2004; West et al., 2005; Kirkley et al., 2011). This study’s results support the view that organisational barriers require organisational facilitators. Line management and NHS trust level endorsement and support are essential if post course changes are to influence the workplace and be maintained (Edwards, 2006). It is proposed that as the expert patient panel achieved such effective and enduring empathetic changes and heightened awareness of patient needs in clinicians, its use should be evaluated for the development of the managerial understanding and support necessary to address the systemic and team barriers discussed.

Limitations
It is recognised that as this is a case study of training at one hospital trust, results of this service evaluation are context specific and cannot be generalised. There are also several limitations. First, the low response rate (17 per cent) prevented piloting the topic guide within a group setting and achieving theoretical saturation (Bryman, 2008). Second, researcher bias was present because of the role the first author (JR) had in relation to the course and the stroke care pathway. As co-designer and lead for the course and senior stroke unit therapist, she had trained all of those who had participated in the
study and was a colleague to many. This pre-existing relationship could have affected how participants behaved and what they disclosed (Bryman, 2008). Finally, the sample was biased towards the site at which the author worked (central) and her professional background (therapy) as shown by Figures 1 and 2 above, suggesting researcher bias may have influenced recruitment.

Objective measurement of the long term impact of training is needed according to The Health Foundation (2011). Outcomes in this study and most other evaluations in the literature (Towle et al., 2010; The Health Foundation, 2011; Chamney et al., 2012; Terry, 2012) are self-reported, not objectively measured. Jha et al. (2013) attempted to address this with their pilot randomised controlled trial involving post registration doctors who attended training involving patients. They explored what objective measures could be used within a quantitative methodology. Their findings suggested that some of the pilot measurement tools were not sensitive enough to pick up differences between the intervention and non-intervention groups. Further development of objective measures is therefore required.

Despite these limitations this study does provide case study evidence that adds to and supports the literature regarding patient involvement in health professionals’ training and person-centred care. In addition, the results were locally important. They provided suggestions for enhancing course impact and further developing practice, and for improving the patient experience.

Conclusion
This study demonstrates that staff felt the course had assisted them in developing a holistic outlook and increased their understanding of stroke survivors with psychological, communication and cognitive needs. Results suggest that involvement of expert patients was key to this. However, despite being trained to provide skilled, empathetic holistic care, staff perceived that systemic and team barriers prevented them from fully meeting the needs of these patients.

This study contributes to the literature in three key ways, by suggesting that:

- Staff benefit from patient involvement in training in the same way undergraduates do
- Short term benefits are maintained in the long term
- Actively involving patients in staff training programmes could assist in developing person-centred care and an effective workplace culture if systemic and team barriers are addressed

It is clear that patient involvement in staff training had a beneficial impact on staff members’ awareness and understanding. It is therefore suggested that there should be an evaluation of the impact of user/patient involvement in NHS leadership and management training with regard to reduction of the systemic barriers that restrict culture change. Further, larger scale, mixed method research exploring the long term impact of users/patients in clinical and leadership training is recommended.

References


**Acknowledgements**

The authors would like to thank all the staff that participated in the evaluation. The project was supported by co-course designers and leads Sarah Ross and Dr. Jane Barton, Stroke nurse consultant Amanda Jones and clinical audit development manager Jean Schofield. In addition, NIHR CLAHRC for South Yorkshire are thanked and acknowledged for supporting the preparation of this paper.

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