Patient, carer and staff experience of a hospital-based stroke service

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Abstract

Objective. Here, the aim is to study the experiences of patients, carers and staff throughout a hospital stroke care pathway.

Design. Focus groups of patients, carers and staff followed a semi-structured format to elucidate experiences. The groups were recorded, transcribed and subjected to thematic analysis. Analyses were verified by researchers and participants.

Results. Patients and carers produced four overlapping themes: ‘information’, ‘staff attitudes’, ‘availability of care/treatment’ and ‘considering the whole person in context’. The carers’ group produced two additional themes: ‘accommodation of patients’ individual needs’ and ‘burden of care’. Their experiences were complex and multi-faceted; positive views of the whole service co-existed with negative views of some aspects. The staff groups produced six themes: ‘specialist service’, ‘split service’, ‘availability of care’, ‘consistency of care’, ‘staff morale’ and ‘wish for change’. Positive views of the specialist service were tempered by problems with physical and professional separation, staff shortages and ‘hierarchical practice’ that reduced collective decision-making.

Conclusion. Some of the patients’ and carers’ perspectives have not been previously reported in the stroke literature, including a desire for individualized treatment, the consideration of wider, non-physical needs and the carers’ sense of burden. In addition, the study revealed how staff, carers and patients viewed each other and the service and demonstrated the concordance of their perceptions. However, staff showed little insight into the users’ need for information and negative experiences of care. In contrast with previous research, lack of emotional care, poor continuity of care and lack of staff knowledge and skills were not identified as problems.

Keywords: stroke, health care quality assessment, quality of health care

Patients and carers are expected to contribute to monitoring and planning health care [1], and their views reflect care received in hospital [2, 3]. Studies of stroke patients and carers [4–9] have reported high overall levels of satisfaction with inpatient care, especially when provided in specialist stroke units [4]. But a substantial proportion of patients were dissatisfied with at least one aspect of care and there was variability in the service received. Problem areas included amount of therapy, staff knowledge and skills in stroke, personal care, emotional care, information, patient and carer involvement in decisions and support of carers. Interviews with patients about experiences of acute stroke care identified ‘being valued and cared about’, ‘clinical care’, ‘nursing care’ and ‘information’ as important components of care [10]. In a study of carers of inpatients, 44% were satisfied but 23% were dissatisfied and support from staff was an important factor [11]. Studies of various health conditions reveal the importance of interactions with staff in shaping patients’ experiences of services and have highlighted staff attention to emotional, personal and non-physical needs [12, 13] and staff’s inter-personal skills [14].

Despite the importance of staff–patient relationship in determining recipients’ response to care, the experience of staff in the provision of stroke care has been relatively neglected by research. Tyson and Turner [8] included an ‘open-ended’ staff questionnaire and staff reported being unaware of service shortfalls, but acknowledged lack of knowledge and skills in some areas and felt that staffing levels were too low. Studies of nurses have found that lack of training, time and skills were perceived as barriers to providing effective care for depressed stroke patients [15] and that nurses identify three separate aspects of their role: caregiver, facilitator of personal recovery and care manager [16]. Studies of staff and patients in mixed hospital wards have demonstrated that staff satisfaction/morale [12, 17] and doctor–nurse collaboration [18] are associated with patient satisfaction.

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The study was designed to describe patients’, carers’ and staff’s experiences in a specialist hospital stroke service and to make links between the experiences of these key groups. Qualitative focus groups were used to capture complexity and participants were encouraged to report experiences rather than global opinions, since the latter may hide specific shortfalls [19] and can be subject to judgemental biases [20].

Method

Ethical approval

All participants received an information sheet and signed a consent form. The project was approved by the Trust’s Audit Review Panel.

The service

The focus of the study was the National Health Service provision for stroke in a major city. It consisted of a 26-bed acute stroke unit, and, on a separate site, two adjacent 24-bed stroke rehabilitation wards. Each unit had a multidisciplinary team with all the relevant professions.

Participants

A list of 80 discharges from stroke rehabilitation over 3 months was obtained. Exclusion criteria were severe communication difficulty, severe cognitive impairment or no carer. The remaining 54 carers and patients all received a letter about the study and were telephoned until 11 patients (maximum group size) and 6 carers agreed to participate at the arranged time. One member of each group was unable to attend.

Lists of members of staff in the stroke service were obtained and three groups formed: one group of therapists, a separate group of nurses (qualified nurses and health-care assistants) and medical staff from rehabilitation, and a single group covering as many professions as possible from the acute ward. Senior staff, managers and medical consultants were not included in these groups, since team members indicated this would inhibit discussion. Members of staff were contacted to obtain provisional consent, going down lists until each group was full (11 members) or the end of the list. All consenting participants were sent an information sheet and the interview questions in advance. Owing to constraints of shift patterns and staff shortages, not all professions could be represented for each unit.

Procedure

The two group facilitators were graduate psychologists with no previous experience of the service. They received training in focus groups from an experienced researcher. Recordings were made and transcribed. All groups lasted for ~1.5 h and followed a semi-structured format. A demographic questionnaire was given at the outset.

Patient and carer groups

The interview questions followed a chronological sequence from the stroke to discharge.

Staff groups

Questions included the nature of the service, strengths, weaknesses, shortfalls, possible improvements and helpful and difficult factors.

Analysis

Following the guidelines of Hayes [21], transcripts were read and salient items and issues were noted and sorted into groups. Each group was examined to produce a preliminary label and definition of the theme. Transcripts were then re-examined for further material relevant to each theme. Themes were considered to determine whether they were hierarchically related, but no hierarchy emerged. Two analysts (the facilitators of the focus groups) conducted this analysis independently and discussed their results to reach an agreement. The results were then discussed with members of the original groups, theme by theme, for verification. In all groups, there was a close agreement with the themes. Finally, the two facilitators and the principal researcher examined the themes across all three groups for overlap; this resulted in combining four of the patient and carer themes. Points of similarity and contact between the users’ themes and those of the staff were noted for discussion.

Results

Participants

Patient and carer groups. See tables 1 and 2.

Staff groups. To preserve anonymity only grouped demographic data are presented.

Staff Group 1 (rehabilitation therapists). Staff Group 1 had six staff: five female and one male. The average age was 31 years (range 26–48) and average years of work with stroke patients was 3 years 8 months (range 6 months to 8 years). Their professions were speech and language therapist, psychologist, social worker, dietician, physiotherapist and occupational therapist.

Staff Group 2 (acute unit staff). Staff Group 2 had five female staff. The average age was 45 (range 34–56), and average experience of work with stroke patients was 9 years 4 months (range 6–11 years). There was one each of dietician, nurse, occupational therapist, physiotherapist and healthcare assistant.

Staff Group 3 (rehabilitation doctors and nurses). Staff Group 3 included four female staff: two medical staff (one Senior House Officer and one House Officer), one health care assistant and one nurse. The average age was
31 years (range 26–43). The two nursing staff had 20 and 10 years experience of stroke working each, and the two medical doctors each had 6 weeks experience of the stroke service.

Patients and carers’ themes

Patients and carers have different roles and experiences of the service. It was, therefore, surprising that the four themes were shared. Two additional themes emerged in the carer group: accommodation of patients’ individual needs and burden of care.

Each theme will be described in turn and illustrated with selected quotes. To enable separate identification of carers’ and patients’ quotations for the shared themes, they are labelled [C] and [P], respectively. Many themes represent a dimension of relevance to participants rather than a specific state of affairs; several are illustrated by quotations giving positive and negative exemplars.

Information. Information provision was widely discussed by patients and carers, and experiences varied; some received excellent information, whereas others felt it was inadequate.

“... the Doctors and the consultants were absolutely fantastic ... really, really good, and explained everything to us, took [the patient] off on his own and any questions we wanted to ask, they were fantastic ...” [C]

“... my husband couldn’t get any information even when I’d been in a week or 10 days, still couldn’t get anybody to speak to who either would say anything or could say anything...” [P]

Individual information about the stroke and treatment and what to expect after discharge were highlighted as problem areas and lack of information engendered anxiety.

There were attempts to explain the lack of information.

‘... I don’t think in the hospital they work as a team... they didn’t show any joined up, or any passing on information to each other ...’ [C]

Table 2 Carer group characteristics

<table>
<thead>
<tr>
<th>Carer</th>
<th>Patient’s age</th>
<th>Gender of carer</th>
<th>Time since stroke</th>
<th>Time in hospital</th>
<th>Acute and rehabilitation wards</th>
<th>Communication impairment</th>
<th>Wheel-chair or walking</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>78</td>
<td>Male</td>
<td>7 months</td>
<td>6 months</td>
<td>Combined</td>
<td>No</td>
<td>Wheel-chair</td>
</tr>
<tr>
<td>2</td>
<td>83</td>
<td>Female</td>
<td>5 months</td>
<td>2 months</td>
<td>Combined</td>
<td>No</td>
<td>Walking</td>
</tr>
<tr>
<td>3</td>
<td>70</td>
<td>Female</td>
<td>First stroke, 3 years 5 months</td>
<td>1 year (first admission)</td>
<td>Separate</td>
<td>Yes</td>
<td>Walking</td>
</tr>
<tr>
<td>4</td>
<td>73</td>
<td>Male</td>
<td>5 months</td>
<td>3.5 weeks</td>
<td>Combined</td>
<td>No</td>
<td>Walking</td>
</tr>
<tr>
<td>5</td>
<td>45</td>
<td>Female</td>
<td>1 year 6 months</td>
<td>8 months</td>
<td>Combined</td>
<td>No</td>
<td>Wheel-chair</td>
</tr>
</tbody>
</table>

*Carer 1 was a son caring for his mother, the others were all spouses.*
Staff attitudes. Patients and carers made numerous comments about the high level of commitment of staff.

‘... I just want to sing their (Physiotherapists) praises, ... I thought they went out of their way to help me. ... my personal experience was that they seemed to really work hard to encourage me to just get [going] on all the therapy that they provide and it was just fantastic, ...’ [P]

However, the patient group believed that a small minority of nurses or healthcare assistants was poorly motivated:

‘... there were one or two here that I thought didn't really put much effort into things ...’ [P]

Availability of care/treatment. The availability of staff to provide care and treatment was discussed at length by both groups, particularly the availability of nursing/care staff. Toileting was identified as a particular problem:

‘... I needed toilet and wanted...so you'd ring and you'd [...][...] then and they'd say “oh well just go in your bed” but we got pride...’ [P]

Participants explained shortfalls in care in terms of staff shortages:

‘... I wanted to take my hat off to many of the staff here, because they seem to be under incredible pressure often because of shortages of staff, and O.K there are problems ... ... ... , and you could see where things weren't necessarily going right, but by and large I felt I just wanted to just sympathise with them’ [P]

Finally, they believed more therapy was required, and lack of therapy was thought to be related to setbacks in the recovery process.

Considering the whole person in context. Patients and carers felt that broader human needs were not met and that care was overly narrow and focussed on physical care:

'[I wanted to say]...look at what you're doing, these are people, these are people, yet you see them as [just] patients in bed ...’ [P]

A number of participants felt that their need for family contact should be given greater consideration:

‘... [because of] how awful it was and on the wards, the children did not want to come in ..., when they did come in there was nowhere for us to go, ... and he missed the children so much,' [C]

Finally, many participants commented on the lack of stimulation and its impact on morale:

‘... I just wish there was more things to do, I wasn't very well stimulated, I felt brain dead after about a couple of months (agreement) you need something to occupy your mind ...’ [P]

Accommodation of patients’ individual needs. The carer group believed that patients’ care was often too standardized and not delivered in a way that met their individual needs.

‘... they [patient notes] don't get read though, [the patient] had notes of how he should be positioned in bed, the physio and OT spent a long time doing it, and I know the people that put him to bed didn't look at it and I just thought “what a waste of time”...’

‘... I was always writing things down to give them [nursing staff] an insight into what he could do. ... and it [the note] was just, well put under clothes or whatever in under the locker and I thought “well that was a waste of time”...’

Burden of care. Carers felt they needed to compensate for the perceived shortfalls in the care of their relatives by providing it themselves. In some cases, this extended to the care of other patients:

‘... if I wasn't there he wouldn't have been able to eat because the lids weren't taken off the plates, the sandwiches weren't open, and [it would have been] too far away and I helped loads of people on that ward with their food, ... because there was no staff there to help...’

This sometimes brought them into conflict with staff.

Staff groups’ themes

Analysis of the staff focus group transcripts produced six themes. Quotes are identified by the group in parenthesis: DN, doctors and nurses, rehabilitation; T, therapists, rehabilitation; A, acute ward.

Specialist service. All three staff groups described ways in which the dedicated stroke service and care pathway were key strengths.

‘... it's good that they can access everything on one site as we have got our own physios, OTs, [...] assessments, everything can be generated from the one spot so to speak, ...’ [DN]

Staff develop expertise in stroke care, which benefits patients and carers through the provision of tailored input:

‘... the therapists are very used to the stroke patients, I think that's a positive thing for them, ...’ [DN]

The dedicated wards were also seen to provide emotional support, through access to others with common experiences.

‘... there seems to be a bit of camaraderie between the patients and because they're in the same situation, providing support for one another ...’ [DN]

Split service. Where there were physical or professional separations in the service, problems occurred:

‘... there are two philosophies of care in place, and ... it's made people incredibly anxious and defensive in their practice and quite a blaming culture has grown up ... so there seems to be a kind of reciprocal relationship of blame between THE nurses and THE therapy team ...’ [T]
This was experienced by some staff as difficulty in joint working:

‘... it just is a continuous struggle ... it’s very hard, it’s very aggressive confrontational kind of relationship that it would be very hard to work with to get the best for the patients at the end of the day ...’ [T]

The doctors’ focus on physical factors was seen as a source of problems:

‘... I think some of it is the problem is that obviously the Doctors just look at the medical side don’t they, they don’t actually see the broader picture at all...’ [A]

There were positive observations, however, where staff worked across units and held flexible roles:

‘... just to say about the stroke coordinator role, I just think [...] fantastic in kind of going between the two wards, and getting us together and I find her a great motivation...’ [T]

‘... blurring of the roles actually, is a good sort of supporting mechanism. ... people are willing to talk with each other and adding different bits and listening ...’ [T]

Availability of care. The major concern for all groups was the availability of nursing staff and its impact on rehabilitation.

‘... porters will come to take patients to physio and OT but they haven’t been washed, ... because of all the staffing problems, so that means that they’re not having their physio and OT that day, so lose their slot...’ [DN]

‘... you can always think of lots of things that we could be doing or should be doing to help, ... they [the therapists] will say if you could walk so and so out, ...[that takes] two nurses and... it is just a nightmare and you’re going to go for the easy option...’ [DN]

Consistency of care. Staff in all three focus groups raised concerns about the consistency of care and identified failure of inter-professional communication as one major factor and lack of time and resources (going for the easy option and just doing the basics) as another.

‘... it’s confusing for the patients and the relatives because one person you know, one nurse is doing something completely different to what the therapists are doing ...’ [T]

‘... confusion, one minute they’re told they can go home, then they’re told that they can’t cos they haven’t seen the physio, and the OT needs to do this, and they get quite angry and get quite upset and everybody gets irate and then the Doctors say they can go home anyway, and then we get annoyed. ...’ [A]

All three groups identified aspects of the service that facilitated greater consistency, including working in close proximity, shared patient notes and multi-disciplinary and discharge planning meetings.

Staff morale. All staff groups described a sense of powerlessness. Nursing staff related this to staffing shortages and lack of opportunity to use all their skills.

‘... they’ve [nurses] got the skills the majority of them... they just don’t have the time to... [you just] do the basics. ’’ [DN]

The therapists felt that their skills and knowledge were not recognized and decisions were not collective:

‘... I know that the hierarchical kind of structure has affected the way in which I work, and I know I’ve found it, it’s not a team in which you can really effectively challenge very well if somebody is saying something that you possibly don’t agree with...’ [T]

‘...you can offer your professional opinion but you won’t be heard, there will be a decision made that you’re then expected to go along with...’ [T]

In the verification session, there was a strong agreement with this theme.

Wish for change: recommendations. Recommendations for change were made: better selection of appropriate stroke patients for the wards, a daily multi-professional ward round to improve communication, more mixing of staff between units, improved consistency of care, better staff training opportunities, better considerations of patients’ individual needs, especially ‘hidden’ needs such as cognitive disabilities, and better nursing staff ratios. Some staff felt that external mediation might be necessary to bring change.

Discussion

Patients and carers

Consistent with previous research [19, 22], experiences of the service were complex and multi-faceted; appreciation of the service as a whole was tempered by complaints about service shortfalls and performance. The carers generated two themes that were not expressed by the patients. The experience of burden in carers is a well-documented phenomenon, but the carers’ focus upon individual needs and the absence of this theme in the patients’ group was initially surprising. However, there is frequently a tension between professional carers and family carers about how to provide individualized care [23], and the emergence of this theme for carers may reflect this.

Patients and carers needed more individual information about stroke and their care, and information about discharge was a particular problem, echoing previous findings [24]. Surprisingly, this deficit persists despite strong new guidelines [25]. Lack of information produced anxiety and problems with adjustment post-discharge. Both the groups explained the shortfall as limits of medical knowledge and poor communication between staff. Interactions and relationships with staff were another major theme, and as in previous research [12], staff were seen as vital in providing emotional support and encouragement as well as care.
Insufficient therapy and lack of attention to unpredictable events such as toileting needs contributed to carers’ sense of burden and patients’ experience of unmet needs. Users maintained a generally positive view of individual staff by pointing to service deficits such as low staffing levels, pressures on staff and problems in staff management. The ‘considering the whole person in context’ theme captured several areas of experience, where there was incongruence between users’ expectations and the service provided. The issues centred around the narrow focus of care and an emphasis on physical needs to the exclusion of broader human needs such as stimulation, variety and family contact.

Previous studies have identified service shortfall in staff knowledge and skills about stroke and emotional care [e.g. 4–6, 13, 26]. The establishment of the specialist stroke service may explain the absence of problems with staff knowledge and skills in this service. The emergence of emotional care as a factor in previous research may stem from problems with how it was defined. For example, the Healthcare Commission study [4] may have exaggerated the problem by including cognitive problems with emotional problems. In the current study, important facets of emotional experience were captured by the ‘individual needs’ and ‘whole person in context’ themes. This illustrates the need to consider users’ views when framing survey questions so that they address issues and dimensions that are both cohesive and important to them.

Except for the ‘whole person in context’ theme, which suggested an overly narrow focus on physical needs, carers and patients were not generally critical of the philosophy and rationale of care, in contrast with the finding of Röding et al. [22] with young stroke patients.

**Staff groups**

The staff groups valued the specialist stroke pathway and opportunities to develop specialist knowledge, skills and resources. Physical and professional divisions between parts of the service were considered to reduce cohesive working and to hamper the effectiveness and consistency of care, but where staff had a chance to work across teams, it was felt to be beneficial. Differing priorities of doctors and therapists resulted in inconsistent care, especially around discharge and post-discharge support. Patients and carers also commented on this, and this finding provides further evidence of the link between the quality of doctor–staff communication and users’ satisfaction [18].

As in previous research [27], staff shortage, particularly of nursing staff, was perceived to hinder the nursing role and to act as a barrier to skills training and staff development. Contrary to Bennett [15], skills and knowledge deficits were not perceived to be as important as having the time to use existing skills. Staff shortages put nurses under pressure to perform only a limited range of care-giving roles and made them unable to contribute to broader personalized recovery plans. This was reflected by the users’ experience of the narrow focus of care and adds support to the findings of Burton [16] with regard to the limitations of nurses’ roles.

Despite the importance of the nurse–patient relationship as a determinant of patient experience [28], nurses in this service felt relationship building was not facilitated by the service.

Lack of opportunities to use skills and to contribute to team decision-making made staff feel undervalued. Adams and Bond [29] similarly found that ‘hierarchical practice’ had a negative impact on staff morale. Despite this, staff continued to be committed to the service and made recommendations for service improvement; prominent among these were procedures to facilitate better communications between units and professions.

**General Conclusions**

There were several patient and carer themes that had also emerged strongly in previous research (lack of information, therapy and personal care), as well as a number of new themes with a focus on individualized care and attention to wider, non-physical needs and the carers’ sense of burden. This was the first qualitative study to investigate staff’s experiences of a stroke service as a whole, and the six themes encapsulated views of service performance (availability of care, consistency of care) as well as perspectives on service processes and organization (specialist service, split service, staff morale and recommendations). The study reveals the striking degree of overlap between staff, patient and carer experiences. This is surprising since each group has a different role and position within the service. Several of the patients’ and carers’ themes were strongly reflected in the staff groups’ themes: ‘availability of care/treatment’, ‘accommodation of individual needs’, ‘considering the whole person in context’ and ‘consistency of care’. But the staff did not demonstrate insight into the patients’ and carers’ needs for more information or their perception of poor attitudes and performance. All groups held positive views of many aspects of the service while pointing to gaps in care. All went beyond description to attempt to explain their experiences. The staff groups generated a sophisticated model incorporating process factors: the separation of teams, staffing issues, hierarchical decision-making and professional demarcations. The patients and carers focused on issues such as the shortage of nursing staff and an organizational orientation that did not include individuality and attention to wider non-physical human needs. Staff’s perceptions of the users’ experiences and the users’ experiences of the staff were characterized by sympathy and mutual understanding and positive regard rather than blame.

Staff’s perceptions of the effectiveness of specialization are congruent with the Healthcare Commission study of hospital services [4]. Consolidation and development of the stroke speciality could further strengthen staff morale, but these findings suggest a tension between specialization and fragmentation; increasing specialization should not be at the cost of service cohesion. Staff perceived inter-professional and inter-team cooperation and shared decision-making as important determinants of their capacity to deliver
an effective service and of their morale. This suggests that interventions to improve team-working would improve services, but more research is required to determine whether the relationship between staff morale and positive patient experiences is a direct effect of staff morale or whether staff morale and patients’ experiences are jointly determined by other factors such as fragmented services or resources.

The current study suffered from a number of limitations. In common with many health services, there were few males to participate. There were no independent measures of process or ‘objective’ outcome measures against which to assess the technical quality and efficacy of the care provided. Patient and carer group members were necessarily a self-selected group, and none had been discharged straight from the acute unit. Patients with severe communication or cognitive problems or without carers were not included. The most senior staff in the service, the medical consultants, managers and the stroke co-ordinator were not able to participate, despite being supportive of the study. Staff felt this allowed them to feel less inhibited in discussion of sensitive issues, but their absence may have impeded discussion of the wider context of the service and the influence of clinical and policy guidelines.

Future research could examine the links between staff morale, patients’ and carers’ experiences and high-level determinants of service provision; philosophy of care, clinical and service guidelines, inter-professional working and service configuration.

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