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Challenges in building interpersonal care in organised hospital stroke units: the perspectives of stroke survivors, family caregivers and the multidisciplinary team.

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ABSTRACT

Aims

To explore the organised stroke unit experience from the multiple perspectives of stroke survivor, family carer and the multi-disciplinary team (MDT).

Background

Organised stroke unit care reduces morbidity, mortality and institutionalisation and is promoted globally as the most effective form of acute and post-acute provision. Little research has focused upon how care is experienced in this setting from the perspectives of those who receive and provide care.

Design

The study utilised a qualitative approach, employing Framework Analysis. This methodology allows for a flexible approach to data collection and a comprehensive and systematic method of analysis.

Method

Semi-structured interviews were undertaken during 2011 and 2012 with former stroke unit stroke survivors, family carers and senior stroke physicians. In addition eight focus groups were conducted with members of the MDT.

Results

One hundred and twenty five participants were recruited. Three key themes were identified across all data sets. Firstly, two important processes are described: responses to the impact of stroke; seeking information and stroke specific knowledge. These are underpinned by a third theme: the challenge in building relationships in organised stroke unit care.

Conclusions

Stroke unit care provides satisfaction for stroke survivors, particularly in relation to highly specialised medical and nursing care and therapy. It is proposed that moves towards organised stroke unit care, particularly with the emphasis on reduction of length of stay and a focus on hyper-acute models, have implications for interpersonal care practices and the sharing of stroke specific knowledge.

Why is this research needed?

- The advantages of organised stroke units are well documented, but little qualitative research has been carried out to explore the experience of receiving or providing care from multiple perspectives.
- Research which seeks to understand the inter-relationships between the multidisciplinary team (MDT), stroke survivors and their families/carers has the potential to contribute to improved practice.

What are the key findings?

- Stroke survivors and families reported satisfaction with medical and nursing care.
- Stroke survivors and families identified challenges in being able to receive information and support in a timely and appropriate manner.
- Multi-disciplinary team staff reported frustrations in not being able to develop relationships and provide information and reassurance in the context of organised stroke services, particularly in the context of organisational pressures to discharge stroke survivors earlier from hospital.

How should the findings be used to influence policy/practice/research/education?

- Stroke services have developed significantly in recent years and the benefits of this are clear. It is important, however, to continue to explore the impact of these developments on the interpersonal experiences of staff, stroke survivors and families.
- Organisational pressures around the discharge of stroke survivors earlier from hospital following stroke have implications for the interpersonal practices of the MDT and may have consequences for the quality of the transfer home.

KEYWORDS
Stroke
Interpersonal care
Hospital Care
Nursing
Family caregivers
Qualitative research

INTRODUCTION

Organised hospital stroke unit care reduces mortality, morbidity and prevents admission to institutionalised care (Stroke Unit Trialists 2013). This evidence has contributed to the development of comprehensive evidence based clinical guidelines in England; Australia; USA and New Zealand and growth in the number of organised stroke units in developed countries, with calls for the same to happen on a global scale (Intercollegiate Stroke Working Party 2012; National Stroke Foundation 2010; Jauch *et al.*2013; Stroke Foundation of New Zealand Guidelines Group 2010; Lindsay *et al.* 2014).

Background

The components of organised stroke care include: immediate specialist assessment; early interventions; appropriate staffing/patient ratios; multi-disciplinary team (MDT) working; organised assessment; intensive specialist rehabilitation therapy and effective discharge planning (Langhorne *et al.* 2002; Ringelstein *et al.* 2013). Furthermore, evidence suggests a growing emphasis upon acute and hyper acute models of provision (Vickrey & Thrift 2014). Hyper-acute care is defined as up to the first 72 hours of care, and involves immediate specialist assessment, close physiological monitoring, diagnosis and possible cause of the stroke, and initiation of necessary treatment which could involve thrombolysis. This contrasts other forms of organised care such as acute and rehabilitation stroke units. Research focusing upon experience of care from the perspective of the patient, family carer and MDT is limited. McKevitt *et al.* (2004) highlighted the experience of psychological crisis in the first week of stroke and others have noted that responding to patients needs at this time is a challenge (Kitson *et al.* 2013). Others have noted patient appreciation and satisfaction attributed to medical and nursing staff (Tholin & Forsberg 2104; Harrison *et al.* 2013). Similar themes have emerged from work exploring patient experiences of acute stroke care and hospital rehabilitation, findings include: the need to improve information provision; the promotion of autonomy and the significance of relationships with staff (Andersson & Hansebo 2009; Mangsett 2008). With the advent of evermore acute and 'hyper-acute' models of stroke provision, the ways in which these relationships are played out has come under some scrutiny. Tutton *et al* (2012) carried out a mixed methods study of the notion of 'hope' in stroke unit care, whilst Morris *et al* (2007), identified several themes including: recognition of commitment; a failure to view the 'whole' person and limited resources. Others have suggested that the nursing role may be inhibited by spatial and time related factors in organised stroke care (Seneviratne *et al.* 2009). This paper seeks to draw upon the views of stroke survivors, family caregivers and members of the MDT in exploring experiences of organised stroke care. Specifically it concentrates upon the time spent between stroke survivor's admission and discharge. The work builds on two other papers published from the same study, one looking at emergency admission (Harrison *et al.* 2013), the other focusing on palliative stroke care (Gardiner *et al.* 2013).

THE STUDY

Aims

The aim of this study was to explore stroke survivor, family carer and staff experiences of receiving or providing care within seven organised hospital stroke units in a northern region of the UK.

Design

Due to the exploratory nature of the research aims and the limited existing evidence base a qualitative study design was adopted. Specifically Framework Analysis (Richie & Spencer 2000) was used to enable a comprehensive and systematic examination of the data alongside a semi-structured approach to data collection.

Setting & Participants

All participants had received or provided stroke care at one of seven regional hospitals including one large teaching hospital, three district hospitals and three community hospitals. The organisation of stroke services differed between hospitals, and included hyper-acute (n=1), acute (n=3), rehabilitation (n=3) and combined (rehabilitation and acute) (n=1) stroke units. Former adult patients with a diagnosis of stroke who had been treated in a participating hospital and who were able to provide written consent were eligible for inclusion in the study. Stroke survivors with communication and cognitive impairment were invited to participate providing they could understand three 'information carrying words' in a sentence on the Consent Support Tool (Jayes & Palmer, 2013). Self-identified primary informal carers of someone meeting the above criteria were also eligible. Purposive sampling strategies were employed. Stroke survivors were sampled to ensure diversity across the following: the length of time since discharge, length of stay, proportion of admission spent on the stroke unit and whether they had a communication impairment. A member of the administrative team, not known clinically to stroke survivors, in each of the hospitals identified stroke survivors from the unit's databases and discharge records and subsequently contacted them about the study. Stroke survivors who wished to participate in the study contacted the research team independently. Stroke survivors were asked to nominate a family carer where appropriate. All clinical staff whose primary role was in the field of acute stroke care in one of the participating sites were eligible for the study. Staff participants were identified from those working on stroke units, and were purposively sampled on the basis of their discipline and grade to incorporate a diverse range of professional experience. Senior medical and specialist nurses at each site helped a member of the research team to identify potential staff participants. Each participant was approached independently and it was made clear that their participation was voluntary.

Data Collection

Data were collected during 2011 and 2012 in northern England, by two researchers (MH and CG) trained in qualitative research methods. Interviews with stroke survivors and family carers occurred between two and 50 weeks post-discharge and explored their experience of stroke and the clinical care received in hospital. The interview schedule (Figure 1) for the stroke survivor and family carer interviews was shaped by UK stroke guidelines (Department of Health 2007) and themes from existing literature and aimed to explore the patient's journey from the stroke event to the point of discharge from hospital. Dyadic interviews with both stroke survivors and caregivers were offered which allowed a joint narrative to emerge allowing a more complete description of the post-stroke hospital experience (Morris 2007). Demographic data were collected from the stroke survivor and family carer participants once consent to take part had been granted, post-stroke dependency was also assessed (McKevitt *et al.* 2004). Interviews were conducted in participant's homes, with the exception of one which took place at the participant's workplace.

Focus groups were conducted with medical, nursing and allied health professionals working on the specialist stroke units, whilst senior staff including medical and nurse consultants were invited to take part in semi-structured interviews. This was to allow junior staff to share their experiences, particularly those that related to perceived weaknesses of the service that they provided. The staff interviews and focus groups followed a separate interview guide (Figure 2) to facilitate the exploration of strengths and weaknesses of the services provided and how well the service meets the needs of stroke survivors and family carers. Staff interviews and focus groups were conducted at the participant's place of work.

All interviews and focus groups lasted approximately one hour, and were audio recorded and transcribed verbatim. Transcripts were not returned to participants for checking and correction. However, for the purpose of dissemination and respondent validation a series of five feedback events were held with staff from six of the seven participating stroke services. A combined event was also held for all stroke survivors and family carer participants (n=29). Findings from early analysis were presented at these events and feedback was sought for the purpose of clarification and to enable the research team to validate their interpretation of the data.

Ethical Considerations

The study received ethical approval from Bradford research ethics committee (11/YH/0098). Research governance and access permissions were obtained from all hospitals involved in the study

Data Analysis

Ritchie and Spencer's framework method was used to undertake a thematic analysis of the data (Ritchie & Spencer 2002). The stroke survivor and family carer data were analysed separately to the staff data in the first instance. Once all data had been coded into the thematic framework similarities, and differences between the data sets were considered. These initial thematic frameworks provided the basis of this paper and additional sorting and iterative comparison allowed for further interpretation of the data in order to develop coherent themes common to both data sets.

Rigour

For both datasets three of the authors (TR, MH and CG) independently familiarised themselves with a subsection of the data (five transcripts) and developed an initial coding framework. The three frameworks were amalgamated through discussion and the resultant thematic framework was entered into NVivo9 which was used to manage the analysis of the remaining transcripts. As additional themes and sub-themes emerged from the data they were discussed by the team at regular meetings and added to the thematic framework.

FINDINGS

In total 32 interviews were conducted with 31 stroke survivors and 28 family carers. Most interviews were dyadic (N=27), others were stroke survivor only (N=4) and family carer only (N=1). Stroke survivor and family carer participant characteristics are described in Table 1. Some participants experienced a range of organised stroke unit care from acute to rehabilitation units, whilst others received care from a single setting. Eight focus groups and nine interviews were conducted with 66 staff working in stroke services. Of the 66 participants 11 (17%) were male. Staff from a diverse range of disciplines and grades took part in the study, see Table 2. All of those staff invited to participate took part in the study after receiving an information sheet and providing informed consent.

Three themes are presented here. Firstly, two processes are described: ‘So frightening’: responses to the impact of stroke on the body and; seeking information and stroke specific knowledge. These two processes are shaped by the stroke unit context. With this in mind a final theme was identified: the challenge in building relationships in organised stroke unit care.

‘So frightening’: Responses to the impact of stroke on the body

Upon admission stroke survivor participants were able to describe a range of responses to both their arrival in the acute setting and the feelings about the stroke event. Feelings of shock, confusion and panic were emphasised in the accounts shared by stroke survivors. Being *‘in a state’*, *‘in a tizzy’* and there being *‘an awful lot to take in’* were compounded by events overtaking them and things *‘happening too fast’*. These initial experiences act as a helpful insight into the period following admission but perhaps more powerful are those accounts of the period beyond these early moments. Stroke survivors realisation that they had suffered a stroke and that their function, movement or speech was impaired provide a potent recognition of the impact of stroke. Participants reported bodily and functional changes and outlined the implications this may have had for them and their future.

‘The fact that you can’t communicate as well and it’s so frightening, so frightening, isn't it, when you can’t make yourself understood at all, you know, it’s an awful feeling, I were so frightened and so -, I’d lost all confidence.’ [Stroke survivor24]

‘I said the most frightening part of the stroke (was) when they brought me something to eat and the nurse said to me ‘I’ll be here in a minute to feed you, love’ and I thought oh God, it’s affected me that bad that I can’t even feed myself, you know, what am I going to do?’ [Stroke survivor25]

Within these data the relationship between the plight of a changed body and the threat that this poses for one’s physical identity are apparent. The once reliable body is no longer present, creating uncertainty about the future. Further implications for mood and psychological well-being are apparent. The effect on stroke survivor’s confidence, their emotional state and the beginning of an uncertain future are noted.

Seeking information and stroke specific knowledge

The pursuit of information and knowledge about the nature of stroke and the changes that had occurred is a prominent feature of the stroke survivor and family carer data. This desire to understand the body and the bodily changes responsible for loss of function and movement occurred in addition to the aforementioned need for immediate reassurance and from the MDT via appropriate interpersonal practices or attempts to build relationships through enhanced communication. Occasions when this requirement for knowledge was met were identified as well as instances when stroke survivors experienced disappointment at not being able to access information. Some participants reported waiting until a follow up meeting long after discharge had occurred, others described receiving written information after discharge. The respondent below demonstrates that information provision was perceived as a strategy which can contribute to meeting the informational needs of stroke survivors. The respondent also demonstrates a degree of trust, affinity and openness with the nurse responsible.

'I think the biggest part of it were when you were in hospital weren't it? They explained everything, ... I think it were the charge nurse ...and you could speak to him as easy as anything. All you wanted to know, he says 'come to me' and explains everything. He were good.' [Family Carer 25]

Other participants receiving accurate, trustworthy information were also able to identify the investment in time required and the importance of the opportunity to question knowledgeable members of the MDT. In this sense staff were responsive and able to provide information. Different experiences were reported by other's who felt that information sharing was unidirectional by nature. The respondent below felt that information was requested on a regular basis, without reciprocation. Information was shared at discharge, but this was perceived as being ill-timed.

'I mean, they came and talked to you and asked you your symptoms but never -, I don't recollect.. that anyone sat down and explained to [Name 1] anything that had gone off, you know, I mean, the nurse on the discharge, the ward Sister I think it was, on the discharge, she explained things a lot and went through the folder and all that sort of stuff, but I don't think, there were never much explanation of what a stroke was and how it did it until the discharge.' [Family Carer 18]

These data describe a set of conditions whereby stroke survivors may be fearful and uncertain about their current and future selves, and are seeking to both understand what has happened to their body and be reassured about their future. Coupled with this, those responsible for their care are also seeking to provide a supportive role through the development of relationships and the provision of a more holistic service. The excerpt below demonstrates one Occupational Therapist's frustration in the light of organisational pressures.

'I find that we rush them out when they're still trying to ... and their families are trying to get their heads around that actually I've had a stroke and it's affected me for life yet ... and obviously we care as much as we ever did, but you think well I've got to get them out and you haven't got time to sort of think oh well what happens next week when they can't manage for whatever reason'
[Occupational Therapist 8, Combined Stroke Unit]

The challenge in building relationships in organised stroke unit care

Stroke survivor, family carer and staff participants identified the existence of stroke unit care as being an important feature of the response to the challenges of stroke. In particular '*expertise'* and '*specialist'* medical and therapy knowledge, the inclination for staff to be able to recognise what '*patients were feeling'* and teams '*working day in and day out'* in the field of stroke were viewed as being particularly important. These particular features of organised stroke care were perceived as contributing to successful outcomes for stroke survivors and family carers. For staff participants working within stroke services a number of additional aspects of the organisation of services also contributed to improved outcomes. These include: improved collaborative working with essential services outside of the stroke unit (for example radiology); clarity of goal and purpose within the staff team ('*being on the same page'*); the reliability of information provided by colleagues; close geographical proximity to fellow stroke specific specialists.

Whilst the importance of stroke units can be stressed these data also suggest that the nature of the environment had a significant impact upon the capacity for both stroke survivors and members of the MDT to build relationships, offer reassurance and provide stroke specific information at the right time. The impact of stroke upon stroke survivors coupled with the potential risk of isolation from family and one's familiar home environment places stroke survivors at risk of poor psychological health. The need for *reassurance* was stressed, particularly within what they termed *'the first few hours'*. An approach of this nature was something identified by professional participants as being important, but not always possible:

'At the moment you're lucky to get through the shift. And I would love to give that interaction, just that little bit more, cos then you'd be providing holistic care. You'd be meeting all their needs as opposed to just what you can get through on that shift.' [Staff Nurse 55, Rehabilitation ward]

For some participants moving beyond essential medical care was desirable. The transient nature of the relationship between stroke survivors, family carers and members of the clinical team was also noted as both were seen as '*passing through'*. For the participants below the emphasis centred on task rather than relationship, with little opportunity for individual consideration:

'They put me in a bed, I got changed, you know, they checked my blood pressure, you know, and they gave me tablets I had, I had checks, I think twice a day for my blood and had my tablets and my food, that's all I had.' [Stroke survivor32]

'For somebody to just have a little word with them and just say 'we're going to monitor you all night, you're not on your own, don't worry, you know, you've had a stroke but it's all in hand and whatever' and I'd have slept instead of being awake all night worrying and thinking.' [Stroke survivor27]

Members of the clinical team noted the shortcomings of this interpersonal aspect of their work, citing the increasing pressure on time and resources as an obstacle and subsequent failure to address *holistic* needs. With reference to psychological support one clinical psychologist observed:

‘There are things that could be done that could potentially make the patient’s stay more pleasant .....It’s not that people don’t want to or don’t try, it’s just that there’s a real pressure.’ [Clinical Psychologist 34, Acute & Rehabilitation Ward]

The struggle to achieve the type of service envisioned by nursing and other staff is apparent in these data. The Ward Sister below notes that for the most part a service which provided excellent care, including person-centred approaches is achievable, but in the context of a busy organised stroke unit not all of the time:

‘We go through periods where we have to go back to basics just to make sure that what you are doing is good and there’s no room for the niceties that we know we would like to do. It doesn’t happen all the time, but there are times when it’s like that.’ [Ward Sister 38, Rehabilitation ward]

This is not to say that all stroke survivors and family carers felt that they did not receive support in response to their emotional consequences of stroke. The respondent below contrasts his experience in two very different environments, citing limited time and resources in one of the hospitals as the explanation for the range of his experiences.

‘They [hospital 2] were wonderful, because I think they realised that I were finding it difficult to accept so, you know, they were really lovely… they talked to you a lot more than the [hospital 1] staff. I mean I’m not saying they were any better because I suppose the [hospital 1] staff had more on their mind because they had more patients than down there, so they might have got more time to be more conversational. I think it brought you out of your shell a bit more, you know.’ [Patient 3]

Similarly other participants spoke about being offered reassurance, amid the demanding ward environment. In particular the provision of information tempered with a realistic assessment of outcome was identified as being significant to patients and family carers at this critical time.

Foremost for members of the MDT were the pressures to achieve particular targets relating to Early Supported Discharge (ESD). The imperative placed upon the MDT to facilitate the discharge of patients is a notable theme. The ward manager below describes the impact she feels that this has on the quality of communication within the team and with patients and their families:

‘I think it’s a challenge for the nurses to be able to sort of make contact with the patient and be able to build a relationship in a very short amount of time at a very stressful time. So I think that’s always a challenge and that’s a challenge to the nurses. You know, to ensure that one’s communication is at its best, you know, that everybody knows what’s going on, that we’re all working together, you know, as a team and we’re feeding back to patients and relatives and reassuring them.’[Senior Nurse 24, Acute & Rehabilitation ward]

A senior nurse also referred to ESD as having a significant impact upon the patient experience:

‘So yeah so I think there’s rushing the patients through and the emphasis on getting patients out probably impacts on how the patients feel at times.’[Senior Nurse 12, Acute & rehabilitation Ward]

The recollections of the family carer below are indicative of the challenges faced by many relatives in preparing for the discharge of a loved one following stroke. Preparedness is an important part of becoming a family caregiver and it would appear that in this case once the patient had demonstrated mobility he was considered able for discharge, with little attention given over to the emotional as well as pragmatic demands placed on his wife:

'He [husband] phoned me…. and he said I can come home', I went 'you're joking!', I couldn't believe it that he could come home and then I were really worried thinking, ….. so it were a shock.' [Family Carer 27]

It was not only families and patients who considered the discharge process to be expedited at times. Staff, whilst under pressure to discharge, were aware at times that the quality of the process was being undermined and they were concerned for the future lives of the family:

'It's a huge thing. And to us it is what it is, you know you've had a stroke and this how you are, but to prepare that family member that you're now going to be their main carer, however simple it might be ….and you don't have a choice sometimes. You have to be quite sort of ... put a bit of a face on really, "oh you'll be fine", when really you think "oh god".' [Occupational Therapist 8, Combined Stroke Unit]

Whilst these pressures of time are present throughout the acute phase, staff participants were also able to highlight specific segments of the pathway where particular objectives were viewed as an organisational priority. The burden felt through undertaking these tasks impacted upon the capacity to carry out what might be termed 'person-centred' aspects of the role. The first 72 hours of the admission were singled out as being particularly important. The targets referred to below are those identified within these first 72 hours:

'I guess it's understandable because that's where the funding for the service comes from so if you don't get those results they don't get the funding for the service but because everything gets so focussed on these targets there's lots of other things, good ideas, good things that people might do that get lost on the way because we've got to prioritise.' [Clinical Psychologist 34, Acute & Rehabilitation Ward]

The stroke unit pathway was described by one staff respondent as *'a bit like a roller coaster ride'* for some stroke survivors, whilst another provided a revolving door analogy. The emphasis upon reducing length of stay is clear within the data and whilst this is often viewed as an aspiration for all concerned, the implications for the quality of the discharge process and preparation for a life with stroke are noted.

DISCUSSION

This paper focused on the views of former patients, their family caregivers and members of the MDT within eight organised stroke units across seven services in England. The study is unique in that it brings together these multiple perspectives at a time when organised stroke care has undergone significant change and modernization, both in the UK and around the world. The study highlighted two important themes: responses to the impact of stroke upon the body; seeking information and stroke specific knowledge. Each of these themes is understood via a third central theme entitled: the challenge in building relationships in organised stroke care. Information seeking is not new and several other papers have already noted this perennial issue (Smith *et al*,. 2009). Lawrence and Kinn (2011) regard the exchange of information as a central feature of person-centred stroke care, whilst Wellengren *et al* (2010) point to the importance of family informational needs. Reciprocity in the field of information giving is identified here as being important to patients and as such relational and interpersonal aspects of care are implied. Further, the challenges that the changed physical self provides for the stroke survivor and their families is understood within the context of transient relationships mediated via the monitoring of the patient's medical status, especially in acute stroke units. In a similar vein Morris et al (2007) noted the importance of responding to the 'whole' person and by implication the psychological as well as physical. These data suggest that being able to achieve this effectively in the context of current organised stroke care is a challenge. We are reminded of Hartrick-Doane & Varcoe (2007) and the importance of understanding the situational aspect of interpersonal practices. Indeed there is evidence to suggest that the growth in 'hyper-acute' services, some of which were included in this study, has resulted in a shift towards a focus on physiological monitoring and medical care (West *et al*. 2013), potentially at the cost of person centred or relational care. Further, the increasing expectation that rehabilitation services are provided in a community context may also influence the ways in which hospital staff now see their role. It might be argued that a shift towards such acute and hyper-acute models of stroke unit organisation has contributed to there being reduced opportunities for interpersonal aspects of care and the informational needs of patients and family carers. Indeed West *et al* (2013) point to greater levels of patient and family carer participation in rehabilitation and care in combined stroke units when compared with hyper-acute services. The challenges around the development of supportive relationships in acute environments are compounded by an ever-shortening hospital length of stay in the UK (Intercollegiate Stroke Working Party 2010) and elsewhere (Langhorne *et al.* 2014). Whilst laudable, and often consistent with patient aspirations, these data suggest that there are implications for the nature of the acute experience. Williams *et al* (2009) note how the nature of nurses 'relational practice' can be affected by organisational pressures such as those observed via ESD, highlighting an emphasis on 'pace' and 'processing' over 'complexity' and 'authenticity'. Furthermore, organised stroke care identified here as a factor in hindering relational and interpersonal aspects of care relates to the imposition of work tasks linked to organisational need. Whilst such work may be deemed necessary in order to measure activity, a broader perspective may conclude that change cultures within the NHS in the UK in hospital are predominated by attention to the achievement of targets and management of metrics rather than the nurturing of relationships between clinical staff and patients (Patterson *et al.* 2011).

STUDY LIMITATIONS

This study is derived from qualitative data, relying upon a relatively small number of participants. At no time have the authors sought to make generalisations to a wider population. The study did, however, utilise a purposive sampling approach and hence a broad range of perspectives were gathered. Readers will note that staff participants have been categorized through the setting within which they work. This was not possible in the case of patients and carers as they often experienced more than one form of organised stroke care. Two potential limitations stem from the method of recruitment of participants and the timing of the interviews. First, the research team had little control over who was approached to take part in the study as this was undertaken by third parties. As such these data might be subject to selection bias and we do not have accurate information on the number of patient participants contacted to take part in the study from all settings. Second, it should be noted that the nature of the patient and family carer data is reliant upon recollection and reconstruction of events and experiences. As such it must be recognised that these may represent an interpretation of the time spent in hospital.

CONCLUSIONS

This study has sought to bring together the views of a range of participants and critically reflect upon the nature of stroke unit care in a region of England. In doing so the participants described a range of transitions relevant to their care and clinical practice. Stroke survivors recognised the bodily changes which occurred following stroke and the attempts made to seek support in the form of interpersonal care. They also sought information about the nature of their stroke. Members of the MDT reported frustration at not always being successful in their attempts to meet with these demands, citing an increasing emphasis on hyper-acute models of care and increasing organisational task oriented demands as the source of this. It is argued that the changes that have occurred in stroke acute care may have compromised the potential to maintain high quality interpersonal practices.

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Figure 1: Stroke survivor/carer interview schedule

1. Where did you have your stroke?
2. Could you describe how the nurses communicated with you?
3. Could you describe how the doctors communicated with you?
4. What help did you require with your personal care (e.g. washing, dressing, toileting, eating meals) whilst in hospital?
5. What psychological support did you get after your stroke (for example, did you see a psychologist, a counsellor, a social worker, a mental health worker or did one of the nurses or doctors spend time with you talking through any problems you might be having)?
6. Could you describe an example of when you were/ were not treated with respect and dignity whilst you were in hospital?
7. Did you get help for any specific difficulties, such as mobility, communication, swallowing, dietary, respiratory, cognitive or emotional issues? What help did you get?
8. How did staff involve you in setting goals during your rehabilitation? (For example, activities you might want to be able to do again)
9. What have been your main sources of information about stroke?
10. How were you involved in planning your discharge from hospital?
11. What changes could have improved the service for you?

Figure 2: Staff focus group interview guide

1. Could you describe the services provided on this stroke unit?
2. If you have been working with stroke patients for some time, do you think any changes have occurred in stroke care, following recent changes in policy?
3. What do you consider to be the main strengths of your service?
4. Where are there gaps in the service?
5. Does the service provide high quality end-of-life care to stroke patients?
6. How well does current provision meet the needs of patients and carers?
7. Do you feel equipped to provide the specialist care required by stroke patients?
8. What education and training do you receive/ have you received to enable you to provide the specialist care required by stroke patients?
9. How effective do you find existing interdisciplinary and interdepartmental links and communications?
10. How could the current provision be improved?
11. What would make these improvements possible? And what barriers might prevent these improvements?

Stroke Survivor characteristics (N=31)		
Male	18 (58%)	
Mean age	66 (range: 45 to 83)	
Mean length of stay	22 days (range: 1 to 89)	
Mean time between discharge and interview	171 days (range: 14 to 349)	
Recovery outcome measure: do you feel that you have made a complete recovery from your stroke?	Yes No	7 (23%) 24 (77%)
Dependency outcome measure: in the last 2 weeks did you require help from another person for everyday activities?	Yes No	11 (35%) 20 (65%)
Communication impairment as reported by the stroke survivor	Yes (remaining) Yes (resolved) No	5 (16%) 10 (32%) 16 (52%)
Carer characteristics (N=28)		
Male	9 (32%)	
Mean age	62 (range: 21 to 79)	
Relationship to stroke survivor	Spouse/ partner Former spouse Daughter Daughter-in-law Granddaughter Brother	N=21 (75%) N=2 (7%) N=2 (7%) N=1 (4%) N=1 (4%) N=1 (4%)

Table 1. Stroke survivor and carer participant characteristics (N=59)

Job title	**Number**
Consultant/Registrar working in stroke care	N=9 (14%)
Nurse Consultant	N=2 (3%)
Other qualified nurse	N=20 (30%)
Nursing assistant/ support worker	N=6 (9%)
Physiotherapist	N=8 (12%)
Speech and Language Therapist	N=6 (9%)
Occupational Therapist	N=6 (9%)
Radiologist	N=2 (3%)
Dietician	N=2 (3%)
Others	N=5 (8%)

Table 2. Job titles of staff participants (N=66)

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Conflict of Interest

No conflict of interest has been declared by the author(s)

Declaration of Interest

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