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Patients' and carers' experiences of gaining access to acute stroke care: a qualitative study

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ABSTRACT

Background Rapid access to acute stroke care is essential to improve stroke patient outcomes. Policy recommendations for the emergency management of stroke have resulted in significant changes to stroke services, including the introduction of hyper-acute care.

Objective To explore patients' and carers' experiences of gaining access to acute stroke care and identify the factors that enabled or prevented stroke from being treated as a medical emergency.

Methods Qualitative semi-structured interviews were conducted with 59 stroke survivors and carers who had received care at seven UK centres. The interviews were recorded and transcribed verbatim and thematic analysis was undertaken.

Results Themes emerging showed that participants recognised signs and symptoms, they were satisfied with access to emergency medical services (EMS), they experienced setbacks in the emergency department and delays caused by the lack of availability of specialist services outside normal working hours. Awareness of the importance of time to treatment was generally attributed to the UK stroke awareness campaign, although some felt the message was not sufficiently comprehensive. This awareness led to increased frustration when participants perceived a lack of urgency in the provision of assessment and medical care.

Conclusions The stroke awareness social marketing campaign has contributed to public knowledge and was perceived to assist in reducing pre-hospital delay. It has also resulted in an enhanced knowledge of the significance of rapid treatment on admission to hospital and raised public expectation of EMS and stroke services to act fast. More research is required to assist organisational change to reduce in-hospital delay.

INTRODUCTION

Background

A number of national policy making bodies have recently developed guidelines which emphasise the emergency nature of stroke and the significance of stroke unit care provision.[1-4] Such guidelines promote speedy hospital admission and the safe use of time-sensitive interventions including blood pressure management, and in the case of ischaemic stroke, thrombolysis with alteplase.[1] Time between symptom onset and hyper acute care arrival is critical, and attempts to improve the patient experience by reducing pre-hospital[5] and in-hospital delay[6] are ongoing.

Increasing public awareness of the symptoms of stroke and the importance of seeking urgent medical attention is viewed as an essential component of these strategies[7]. In the UK and elsewhere guideline promotion around emergency admission has been augmented by social marketing campaigns delivered to raise awareness of stroke[8,9] and encourage people to recognise the signs of stroke and to feel confident when accessing emergency services.[10]

A systematic review of observational studies highlighted several barriers to emergency care and the delivery of thrombolysis, including failure to recognise stroke symptoms, use of intermediaries, poor triaging practices and inefficient process of in-hospital acute stroke care.[11] However the quality of the literature reviewed was variable, and the evidence base with regard to identified barriers to addressing emergency stroke care remains limited.

The 2007 UK National Stroke Strategy[2] set out the changes needed in the emergency management of stroke to improve patient outcomes. However evidence relating to the patient experience of policy driven changes in stroke management is limited. This study sought to explore pre-hospital and post admission experiences of former stroke patients and their caregivers in an attempt to identify facilitators and barriers in accessing emergency stroke care. To our knowledge this is the first UK study of its kind in the post National Stroke Strategy era.[2]

Aim

To explore patients' and carers' experiences of gaining access to acute stroke care and identify the factors that enabled or prevented stroke from being treated as a medical emergency.

METHODS

Design

Little is known about the experiences of patients and their families in their endeavours to access such services following the onset of stroke symptoms. As a result semi-structured interviews were used to explore the stroke patient's journey from symptom onset to the time of discharge from hospital. This paper focuses specifically on the patient's hyper acute journey from symptom onset to reaching the stroke unit. Joint interviews with patients and carers were offered to allow the development of a joint narrative.[12]

Setting

The study took place during 2011/2012 in Yorkshire, UK. Interviews were conducted with 31 patients, and 28 carers of patients who had been cared for in seven regional hospitals including one large teaching hospital, three district general hospitals and three community hospitals. All hospitals provided specialised stroke care in units including: hyper-acute stroke units (where timely imaging, expert clinical assessment and the ability to deliver intravenous thrombolysis are available 24 hours a day),[2] acute stroke units (that accept patients acutely but discharge early), rehabilitation stroke units (that accept patients after a delay and focus on rehabilitation) and combined stroke units (that do not separate acute and rehabilitation beds).[13] Call handling and ambulance responders were provided by the regional emergency service.

Participants

Patients were identified from the stroke units' databases and discharge records. A purposive sampling strategy was applied to ensure a diverse range of experience amongst patient participants. A summary of these participant characteristics can be found in Table 1.

Patients with communication or cognitive impairment were included in the study providing they could contribute meaningfully to the interview and give informed consent. A consent support tool ensured the information provided matched the language ability of the participant.[14]

Data collection

The interviews were conducted by two trained researchers (MH, CG) in the participant's own home, with the exception of one interview held at the participant's workplace. An interview topic guide was developed based on themes from previous literature and current stroke guidelines and aimed to explore the patient's journey from the moment the stroke occurred. The interviews were recorded and transcribed verbatim. In addition, a short interview pro-forma was used to gather descriptive data including two questions to assess recovery and dependency post-stroke.[15]

Analysis

The framework method[16] was used to undertake a thematic analysis. Three researchers (CG, MH, TR) read five transcripts and independently developed an initial coding framework. The three frameworks were compared and any differences were resolved through discussion. This framework provided a basis for the subsequent analysis of the remaining transcripts which was managed using NVivo qualitative data analysis software.[17] Further themes and sub-themes that emerged from the data were added to the initial coding framework as the analysis progressed and were discussed at regular meetings.

RESULTS

Thirty-two interviews were conducted with a total of 59 participants, of these 27 were joint patient and carer interviews, four were patient only interviews, and one was a carer only interview. The total sample of 59 participants comprised 31 patients (18 men, 13 women) and 28 carers (9 men, 19 women). Table 1 outlines the patient participant's characteristics.

Patient characteristic	**Participants (n= 31)**
Mean age of patient participants	66 (ranging from 45 to 83)
Mean length of stay in hospital during stroke admission	22 days (ranging from 1 to 89 days)
Mean time between discharge and interview	171 days (ranging from 14 to 349 days)
Point of admission to stroke pathway (as reported by patient)	Emergency department = 17 Emergency admissions unit = 4 Stroke unit = 7 Hospital outside the UK = 2 Unknown = 1
Recovery outcome measure: Do you feel that you have made a complete recovery from your stroke?	Yes = 7 (22.6%) No = 24 (77.4%)
Dependency outcome measure: In the last 2 weeks did you require help from another person for everyday activities?	Yes = 11 (35.5%) No = 20 (64.5%)
Communication impairment as reported by patient	Yes (remaining) = 5 (16.1%) Yes (resolved) = 10 (32.3%) No = 16 (51.6%)

Table 1. Patient characteristics

The mean age of carer participants was 62 years (range 21 to 79). The majority of carer participants were the patients spouse or partner (n= 21), other relationships to the patient included former spouse (n=2), daughter (n=2), daughter-in-law (n=1), granddaughter (n=1), and brother (n=1).

Four themes are described in this paper. Data concerning a broad range of experiences is included.

Recognising signs and symptoms: Taking action

The fieldwork was undertaken in the context of mounting stroke awareness. The recognition of symptoms was often attributed to the FAST campaign[10] or prior experience of stroke, particularly prior family experience. Knowledge of FAST provided participants with the vocabulary to articulate their symptoms, whereas those participants who did not refer to the campaign often provided vague descriptions of their symptoms, such as something being “wrong” or feeling “weird”. The FAST campaign equipped many participants with the knowledge required to recognise symptoms and seek help fast.

> “It was obvious, you know, when you watch the adverts on television, you know, he couldn’t move, he couldn’t stand up, he couldn’t speak, his mouth went on one side, you know.” *Carer, 21.*

In most cases carers rather than patients were the first to recognise the symptoms of stroke, although they often struggled to convey the seriousness of the situation to the patient. Carer participants described visual or auditory symptoms, such as facial paralysis or communication impairment, of which the patient was unaware or lacked insight about.

> “Well, [name of carer] was convinced I’d had a stroke, I wasn’t.” *Patient, 29.*

Those patients who had typical stroke symptoms but did not recognise the stroke provided justifications for this. These included assimilating the stroke symptoms into an existing condition or allergy, not having seen the FAST campaign, and younger participants being unable to relate the information from the adverts to someone of their age therefore failing to recognize candidature.

> “She didn’t think there were ‘owt wrong with her.” *Carer, 8.*

In contrast, those who did not have the common symptoms of stroke depicted in the FAST campaign were frustrated because it did not provide them with information they needed to recognise the stroke. These data help to question the comprehensive nature of the FAST acronym.

> “I didn’t know what was the matter because, I mean it’s wrong really, you know the FAST that they show. That didn’t apply to [patient’s name] at all. So I mean I knew something was radically wrong. But I wouldn’t have said from that that it was a- [stroke], I think that’s quite misleading actually.” *Carer, 6.*

Some participants described a period of waiting prior to seeking help with the expectation that symptoms may fade. Several patients chose to lie down or ‘sleep on it’ before they sought help. Patients were more reluctant to seek help than the relative or carer.

> “And all I wanted to do were go and lay down and it’d go away, I felt it’d go away, you see, if I went and laid down, so we had a bit of a disagreement, didn't we?” *Patient, 24.*

Several participants initially sought help from an intermediary such as a General Practitioner (GP) or neighbour. In most cases GPs or members of the local community health services stressed the urgency of contacting EMS or contacted them on behalf of the patient. In some cases, however, GPs organised home visits delaying treatment.

> “I just waited in the bottom of the bath and I shouted the wife up and she got me daughters and they phoned the doctor’s and I think the doctor said ‘no, you’re wasting time phoning me, it’s a paramedic you want’.” *Patient, 22.*

Accessing Emergency Medical Services (EMS)

Participants seeking help from EMS were satisfied with their response. Speed of arrival was a key factor in participant's satisfaction with the acute care experience. Some participants noted concerns that their call may not be justified, but knowledge of stroke symptoms provided by the FAST campaign provided them with confidence.

> "I thought I could be putting all these people to a lot of trouble...I were 99% sure but the other 1% thought I could be wrong, but actually I weren't. But it's true, I'd seen it on there [pointing to the television]." *Carer, 30.*

One participant who had been misdiagnosed with a transient ischaemic attack (TIA) following a stroke and had a series of TIAs over the following week told her daughter not to phone for an ambulance because she was worried about wasting the paramedic's time.

> "You can't keep ringing 999, you know, every time this happens, you can't just keep ringing them." *Patient, 26.*

Practices employed by call handlers were recognised as providing re-assurance at a time of great anxiety for participants.

> "The operator stayed on with me, yeah, told me all the way what to look for, what to do." *Carer, 33.*

Arriving in the Emergency Department

The FAST social marketing campaign appeared to contribute to participants' knowledge of the symptoms of stroke but also heightened their sensitivity to the passing of time. As such their existed the perception that each delay in receiving care contributed to a poorer outcome for patients. Some participants noted that hospital services were able to respond to the necessity for rapid access to services, such as imaging, on arrival.

> "There were two doctors [...] and he said 'stop there, we'll not be long, we're just taking her for a scan' and they come back, and they took her straight up onto the ward. Very quick, yeah." *Carer, 25*.

Despite examples of good practice it was noted that delays did occur in the emergency department. Such delays were understood by participants to occur as a result of the poor availability of specialist staff or space and bed resources. There was an appreciation of the stresses of the emergency department, but a sense that opportunities were missed at this stage and that stroke was not treated with the priority it merited.

> "[Stroke] should be treated like a heart attack, a medical emergency." *Patient, 24.*

> "No sense of urgency at all. I mean, you know, better part of an hour sat in A & E waiting room" *Carer, 18.*

> "I know A&E is a busy place but I think certain illnesses, or what have you, should have priority." *Carer, 21.*

The awareness that stroke requires time-sensitive treatment increased participant frustration with the delays experienced during the admission process.

> "I hate to think that we missed out on some possible early intervention because of the time that it took to get through the system, that's the major thing to me anyway." *Carer, 18.*

One participant whose speech had been affected by the stroke perceived there to be a lengthy delay on arrival in the Emergency Department. The communication difficulties faced by this participant compounded the sense of isolation felt at this perceived delay.

> "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 awful feeling, so I stopped there." *Patient, 24.*

"You'll have to wait 'til Monday"

Participant's experiences of acute stroke care in hospital differed significantly depending on whether they were admitted to hospital during working hours or out-of-hours (e.g. outside of 9.00-17.00 Monday-Friday). Participants arriving during normal working hours were able to describe a very positive experience. One area of dissatisfaction was, however, the delays caused by poor availability of some specialist services outside normal working hours. One participant admitted at the start of a public holiday was sent home, despite being informed that he had suffered a stroke and had on-going symptoms.

> "So I said I'm really not happy at this and the specialist stroke nurse, a man, he said 'you'll be all right, he's better off in his own bed with his own cooking and come back on Tuesday for an MRI scan'. So I had no option but to bring him home." *Carer, 4.*

Participants expressed disappointment when being informed that they would not be receiving medical input, imaging and other assessments, until the next working day, which in some instances was up to four days over a public holiday. Furthermore, participants reported that the delays in scanning for some threatened the prescription of thrombolytic medication. The increased awareness that stroke needs to be treated quickly has created an expectation that hospitals will be able to provide emergency medical care.

> "The main one was this one that you see on the television about getting people and saving as much of the person, I really couldn't get over that, that really made me so cross because I thought, well this is what we're doing and it didn't seem to be happening." *Carer, 19.*

Two participants had a second stroke whilst in hospital and described a slow response from staff. Given that expectations had been raised by the FAST campaign this perceived lack of urgency was a source of dissatisfaction.

> "But it were quite upsetting that, you know, the television things say this FAST, you know, and one of them is timely and three hours and everything and he were actually in hospital when he had it and not being able to see anybody." *Carer, 32.*

DISCUSSION

This paper draws upon the experiences of former patients, relatives and caregivers to explore the ways in which admission to emergency care is undertaken and initial stroke services are accessed in the UK. Use of emergency services is a significant component in the 'stroke chain of survival'.[1] The important role played by EMS in 'shaping' the remaining acute experience in stroke has already been demonstrated.[18] Efforts to gain access to EMS are evident within these data as are a failure by some participants to recognise the urgency of stroke signs and symptoms. The importance of caregivers and relatives in facilitating access to EMS is therefore also apparent.

Reference to the UK FAST social marketing campaign was made in many of the experiential accounts. The effectiveness of social marketing in raising stroke awareness is currently equivocal.[9,19] Other evidence suggests that knowledge increases during the life of a marketing campaign.[20] This data indicates that public health interventions have helped the public to recognise the signs of stroke and take appropriate action. Participants were often able to relate their own symptom experience with the formal signs of stroke, although not in every case.

Positive experiences upon arrival in acute care are described here and are testament to the developments made within service provision since the publication of key guidelines and policy initiatives in the UK.[2,4] However, the message about the significance of time pervaded subsequent service experience and was used as a benchmark for the remainder of the process. It is in the delays experienced when participants had arrived in the acute care settings that frustration is notable. These 'systems induced setbacks'[21] hindered efforts to make speedy progress within the admissions process and frustrated some patients whose expectations had been shaped by the FAST campaign.

Meretoja et al[6] have described a series of organisational changes undertaken within an acute setting in Norway which have contributed to a reduction of in-hospital delay and an increase in the proportion of patients receiving thrombolysis. These changes include the education of EMS personnel who take the patient history and pre-notify the hospital, the CT is pre-ordered and the patient transferred straight to the CT table on arrival where rapid neurological evaluation is performed, stroke physician interprets the scan and alteplase is delivered on the CT table. The implementation of organisational changes such as these in the UK may allow patients expectations, raised by the FAST campaign, to be met.

Strengths and limitations

The use of a purposive sampling strategy ensured a diverse range of acute stroke experiences were captured. Also the broad range of hospitals each with their own systems will have increased the representativeness of the data, although all hospitals were served by the same regional ambulance service. As this was a qualitative study undertaken in a single region of the UK, findings may not be generalisable. Patients frequently remembered only small sections of the acute experience, as such the data relies heavily upon information provided by carers. It would be interesting to conduct a similar study immediately after the acute event.

Conclusions

The data suggests that the stroke awareness social marketing campaign launched in the UK in 2009 has contributed to public knowledge, although it fails to describe comprehensively the signs and symptoms of stroke experienced at onset. Satisfaction with EMS was expressed, indicating that recommendations made as part of the UK National Stroke Strategy to improve emergency management, have begun to be implemented effectively. Whilst FAST awareness has assisted in reducing pre-hospital delay, it has also resulted in an enhanced knowledge of the significance of time following admission to hospital. In-hospital delays continue to be reported by stroke patients leading to frustration and the potential for poor outcomes. More research is required around the implementation of organisational change to reduce in-hospital delay.

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Competing interests None.

Ethics approval This study was approved by Bradford Research Ethics Committee (11/YH/0098) and appropriate research governance was obtained from all Trusts involved. Informed consent was obtained from all participants.

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