Managing the Flow?

A review of the care received by patients who were diagnosed with an aneurysmal subarachnoid haemorrhage

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SUMMARY

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Managing the Flow?

A review of the care received by patients who were diagnosed with an aneurysmal subarachnoid haemorrhage.

A report by the National Confidential Enquiry into Patient Outcome and Death (2013)

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Principal recommendations

The clinical presentation of aneurysmal subarachnoid haemorrhage should be highlighted in primary and secondary care education programmes for all relevant health care professionals, including the guidelines for the management of acute severe headache published by the College of Emergency Medicine. (Local Education and Training Boards/Deaneries, Medical, Surgical & Nursing Royal Colleges and Specialist Associations)

Formal networks of care should be established, linking all secondary care hospitals receiving subarachnoid haemorrhage patients to a designated regional neurosurgical/neuroscience centre. (Medical Directors)

Standard protocols for the care of aneurysmal subarachnoid haemorrhage patients in secondary care should be developed and adopted across formal networks. These should cover, as a minimum, initial assessment and diagnosis, management, referral, transfer to a neurosurgical/neuroscience centre and subsequent repatriation to secondary care, including rehabilitation. These protocols should take into account existing guidelines where relevant. (Medical Directors)

Relevant professional bodies should develop a nationallyagreed and audited protocol for the management of aneurysmal subarachnoid haemorrhage in tertiary care that addresses initial assessment, multi-disciplinary management and documentation, informed consent, timing of interventions, peri-operative care, management of complications and rehabilitation. (*Royal Colleges and Specialist Associations*) The nationally-agreed standard ('National Clinical Guideline for Stroke') of securing ruptured aneurysms within 48 hours should be met consistently and comprehensively by the health care professionals who treat this group of patients. This will require providers to assess the service they deliver and move towards a seven-day service. (Medical Directors)

PRINCIPAL RECOMMENDATIONS

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Appropriately funded rehabilitation for all patients following an aneurysmal subarachnoid haemorrhage should include, as a minimum, access to information for patients and relatives, specialist subarachnoid haemorrhage nurses and comprehensive in-patient and out-patient rehabilitation services including appropriate neuropsychological support. (Specialist Associations, Medical Directors and Commissioners)

Introduction

Subarachnoid haemorrhage, resulting from the rupture of a cerebral aneurysm (aSAH), accounts for about 5% of all cerebrovascular events in the UK.¹

Subarachnoid haemorrhage may also be caused by head trauma, vascular malformations, hypertension or coagulation disorders, but aneurysms (aSAH) are the most common cause, accounting for approximately 85% of cases.^{2,3}

Autopsy studies have reported that between 3.6% and 6% of the population have unruptured intracranial aneurysms. There is an increased rate of aSAH in first degree relatives of aSAH patients (relative risk 3.7–6.6). The risk of rupture increases with age and is greater in women (ratio 3:2). It is also more common in patients with connective tissue disorders or polycystic kidney disease. Hypertension and smoking are significant risk factors for aneurysmal rupture.⁴

The annual incidence of aSAH in the UK is in the order of 8-12/100,000 and at least 800-900 patients undergo either endovascular coiling or surgical clipping each year in England alone.⁵

In contrast to more common types of stroke, aSAH often occurs at a relatively young age: half the patients are younger than 60 years. The outcome of patients with aSAH is generally poor: half the patients die within one month of the haemorrhage, and of those who survive the first month, half remain dependent for help with activities of daily living (walking, dressing, bathing etc.). Thus only 25% of patients can expect to return to a relatively normal life.⁶

Aneurysms may be treated surgically by clipping the base of the aneurysm, or by endovascular coiling, placing a platinum coil in the aneurysm via an intra-arterial catheter to initiate a thrombosis of the aneurysm. The principal aim of either treatment is to prevent further bleeding.

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Due to the profound effects of the haemorrhage and the risk of early re-bleeding and hydrocephalus, aSAH patients are routinely admitted to an intensive care unit and are cared for by a multi-disciplinary team including neurosurgeons, neurointensivists, neuroanaesthetists and interventional neuroradiologists. The intensive care stay of aSAH patients ranges from a few days to a few weeks and is frequently accompanied by multiple medical complications.²⁻⁷

In addition to the damage caused by the initial bleed or a re-bleed from the aneurysm, further complications include delayed cerebral ischaemia, which can occur 4 to 10 days after the haemorrhage and hydrocephalus. These complications require further intervention and can contribute to a poor outcome.

Although re-bleeding is a feared complication, there is some debate about the timing of treatment. Data from a recent international study indicates that time to treatment in the United Kingdom may be significantly longer than in other developed countries.^{8,9} Although a 2001 meta-analysis of the limited randomised controlled evidence suggested that the timing of surgery is not a critical factor in determining outcome¹⁰, this data was derived prior to the introduction of modern methods of therapy, particularly endovascular coiling. Currently, most UK neurovascular surgeons advise intervention within 48 hours in good grade patients to minimise the chances of a devastating re-bleed as defined by the RCP Stroke Guidelines.⁶ However, the timing of treatment of patients with poorer grades of aSAH is less clear.⁹

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Figure 1. WFNS SAH grading scale

Grade	GCS	Motor deficit
I	15	-
II	14-13	-
III	14-13	+
IV	12-7	+/-
V	6-3	+/-

The severity of a bleed is graded on a 5 point scale. The World Federation of Neurological Surgeons (WFNS) scale (Figure 1) is based on the Glasgow Coma Score (Figure 2) and the patient's motor deficit. Lower WFNS grade patients are associated with a better outcome.¹¹

Definitive treatment for aSAH in England, Wales and Northern Ireland is performed in 27 regional specialist neurosurgical/neuroscience centres (NSC). Thus patients presenting with this diagnosis in primary and secondary care are subsequently transferred for treatment when this is appropriate. However, in patients with a poor WFNS grade/poor neurological function or with

Figure 2. Glasgow Coma Scale

Figure 2. Glasgow Coma Scale			
Catagory		Best response	
Eye opening			
Spontanious To speech To pain None		4 3 2 1	
Verbal	(Modified for infants)		
Oriented Confused Inappropriate words Moans None	Babbles Irritable Cries to pain Moans None	5 4 3 2 1	
Motor			
Follows commands Localises to pain Withdraws to pain Abnormal flexion Abnormal extension None		6 5 4 3 2 1	
Glasgow Coma Score			
Best possible score Worst possible score		15 3	
If tracheally intubated then verbal designated with "T"			
Best possible score while intubated Worst possible score while intubated		10T 2T	



significant co-morbidities an unsatisfactory outcome associated with either treatment means that conservative management may be the most appropriate treatment option.

There is concern that some patients are not referred for treatment and that in others treatment may be delayed for non-clinical reasons. Nevertheless, a cohort of poor grade patients are managed conservatively in secondary hospitals and are not transferred to a NSC.

Patients suffering an aSAH may make an excellent neurological recovery but may not recover their premorbid state due to cognitive and psychosocial deficits leading to difficulties with reintegration into the social environment. The rehabilitation of patients should include both physical and psychological programmes. The cognitive and behavioural impairments caused by an aSAH are often more disabling than the physical symptoms. Neuropsychological assessment and treatment should play an important part in all phases of recovery, including the initial phase after aneurysm rupture and surgery. Early inpatient rehabilitation should be provided for all patients. Following discharge from hospital, the rehabilitation should not end. Community based specialist rehabilitation such as Early Supported Discharge can provide better outcomes for people with moderate disabilities.¹² It is also important to make arrangements for follow up assessments, which will allow the team to evaluate the patient's progress and social functioning as well as to gather valuable information to be used in planning further stages of rehabilitation for aSAH survivors.

Previous studies have largely assessed outcomes in patients who have been admitted to a specialist unit following a decision to treat. This provides relatively poor information on outcomes for patients in general and it does not allow an assessment of the decision making process that determines whether patients are referred for intervention, or provide information on any delays that might occur prior to referral, or on the exclusion criteria for referral that might be applied to patients with this condition. Any attempt to improve the quality of care for aSAH patients must be based on a sound understanding of the whole patient management pathway.

In an attempt to investigate remediable factors in the current service, this study examined the whole acute phase of the patient pathway from the time of arrival to secondary care hospitals until discharge from an NSC. This included data about the quality of the initial assessment, diagnosis and management of patients and the reasons for conservative management when this was selected and in those patients who were transferred to a specialist centre, to examine delays in this process and in the subsequent intervention. Finally, for patients that survived to discharge from a tertiary centre, the provision of rehabilitation services was also assessed.

1 – Method and Data returns

Expert group

A multi-disciplinary group of experts comprising consultants from neurosurgery, neurocritical care, neuroanaesthesia, neurovascular radiology, neurology, neuroscience nursing, acute medicine, and a lay representative contributed to the design of the study and reviewed the findings.

Aim

To explore remediable factors in the process of care of patients admitted with a confirmed diagnosis of aneurysmal subarachnoid haemorrhage (aSAH), including patients that underwent an interventional procedure and those managed conservatively.

Objectives

Based on the issues raised by the Expert Group, the objectives of the study were to collect information on the following aspects of care:

- 1. Organisational factors in the management of aSAH patients in secondary and tertiary care
- 2. Initial Assessment:
 - a. Evidence that diagnosis was delayed/overlooked
 - i. In primary care
 - ii. In previous presentations to secondary care
 - b. Presentation to secondary care
 - i. Quality of initial assessment, delays
 - ii. Delays in investigation
- 3. Description of referral pathway (where appropriate) including:
 - a. The decision to transfer/ manage conservatively
 - b. Delays in referral
 - c. Delays in transfer
 - d. Quality of care during transfer

4. Quality of care in the group of patients managed conservatively

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- 5. Details of admission to a neurosurgical unit, assessment and quality of care during this period
- 6. Adequacy of any further investigations and detail of delays
- 7. Adequacy of decision making process: documented treatment plan, multi-disciplinary team (MDT) meetings, appropriateness of decision to operate
- 8. Assessment of the quality of pre-operative care including appropriate adjuvant therapy
- 9. Details of the intervention
 - a. Appropriateness of intervention: endovascular or surgical approach
 - b. Appropriateness of grade of surgeon/radiologist/ anaesthetist
 - c. Delays
- 10. Detail of issues surrounding the consent process
- 11. Appropriate management of adverse events/ complications
- 12. Quality of post-operative care
 - a. Appropriate level of care
 - Recognition and management of complications; secondary ischaemia, re-bleeds, avoidable complications, delays in recognition and management
 - c. Discharge destination, functional status at discharge, rehabilitation plan
 - d. Appropriateness of end of life care
 - i. Documented DNA-CPR/end of life care/death
 - ii. Discussion with relatives
 - iii. Discussion at Morbidity/Mortality meeting
 - iv. Organ donation
- 13. Follow-up quality of care post discharge
- 14. Overall quality of care



Study Population

Adult patients (aged 16 and older) presenting to secondary care after suffering an aSAH during the study period: 01/07/2011- 30/11/2011.

Hospital participation

Hospitals within Acute Trusts in England, Wales and Northern Ireland were expected to participate, as well as hospitals in the independent sector and public hospitals in the Isle of Man, Guernsey and Jersey. Within each hospital, a named contact, referred to as the NCEPOD Local Reporter, acted as a link between NCEPOD and the hospital staff, facilitating case identification, dissemination of questionnaires and data collation. A study contact and/or neurosurgical lead was appointed in each neurosurgical centre to promote the study and aid the Local Reporter to chase outstanding data.

Exclusions

Non-aneurysmal SAH and cases wrongly coded that were not SAH e.g. subdural bleed, admissions for rehabilitation only.

Case identification

NCEPOD Local Reporters retrospectively identified patients who had had a subarachnoid haemorrhage during the study period, based on ICD10 coding on admission (Figure 1.1). A spreadsheet was completed with basic data from the hospital electronic records. This included admission date and source, discharge date and destination, details of the admitting consultant and the date and details of any listed interventional radiology or neurosurgical procedures. These data were collected in the first instance during a one-year period (1/10/2010-30/9/2011) to ascertain an idea of the required study period to achieve the necessary sample size. It was found that a three-month study period gave a sample of approximately 1500 admissions which was a sufficiently large enough sample to allow for cases lost through exclusions of non-aneurysmal SAH (estimated as being 25% of cases), the linking of cases (where the same patient is admitted to more than one hospital –see below), admissions for rehabilitation only and limiting the number of cases to four per consultant. This gave a sample of approximately 700 cases.

- 160.0 Subarachnoid haemorrhage from carotid siphon and bifurcation
- I60.1 Subarachnoid haemorrhage from middle cerebral artery
- 160.2 Subarachnoid haemorrhage from anterior communicating artery
- 160.3 Subarachnoid haemorrhage from posterior communicating artery
- 160.4 Subarachnoid haemorrhage from basilar artery
- I60.5 Subarachnoid haemorrhage from vertebral artery
- 160.6 Subarachnoid haemorrhage from other intracranial arteries
- 160.7 Subarachnoid haemorrhage from intracranial artery, unspecified
- 160.8 Other subarachnoid haemorrhage
- 160.9 Subarachnoid haemorrhage, unspecified

Figure 1.1 ICD10 codes for SAH

Questionnaires

There were two clinician questionnaires associated with this study. A questionnaire was sent to the admitting consultants in secondary care hospitals. This followed the care of the patient from presentation in the emergency department (ED) to transfer to tertiary care or conservative management within the secondary care hospital (whichever was applicable). A tertiary care questionnaire was sent to the admitting neurosurgeon in tertiary care centres. Both questionnaires also gathered the clinician's opinion on the adequacy of care in the primary care setting prior to admission.

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Because ICD10 coding does not distinguish between aneurysmal and non-aneurysmal SAH, consultants were asked to exclude non-aneurysmal cases through their clinical knowledge of the case and these were removed from the dataset.

An organisational questionnaire was sent to all hospitals that had cases in the study or that admitted patients as an emergency, to collect information on the facilities and resources available for the management of patients with aSAH. It was also divided into sections to be completed concerning the management of patients in secondary care and specialist neurosurgical tertiary care (where applicable). For the purposes of this study, 'organisation' was defined as a hospital rather than a Trust as a whole.

Case notes

For each admission, case note extracts were requested covering the whole admission. The following documents were requested:

- Inpatient and outpatient annotations
- Nursing notes
- Observation charts
- Operation notes
- Anaesthetic charts
- Radiology results
- Fluid balance charts
- Haematology (full blood count), and biochemistry (liver function tests & urea and electrolytes) results
- Resuscitation documentation (DNACPR forms)
- Discharge summary

Cases where a patient was transferred from secondary to tertiary care were linked by NHS number and date of birth. Questionnaires and case notes from the two different hospitals were combined and reviewed as one case by the Advisors.

Advisor groups

A multi-disciplinary group of Advisors was recruited to review the case notes and associated questionnaires.

The group of Advisors comprised clinicians from the following specialties: neurosurgery, neuroradiology, acute medicine, emergency medicine, neuroscience nursing, neurology, neuroanaesthesia/neurocritical care. All questionnaires and case notes were anonymised by the non-clinical staff at NCEPOD. All patient identifiers were removed. Neither Clinical Co-ordinators at NCEPOD, nor the Advisors had access to such identifiers.

After being anonymised each case was reviewed by one Advisor within a multi-disciplinary group. The Advisors assessed the cases by completing a structured Advisor assessment form, allowing both quantitative and qualitative data to be collected. At regular intervals throughout the meeting, the Chair allowed a period of discussion for each Advisor to summarise their cases and ask for opinions from other specialties or raise aspects of a case for discussion. Throughout the Advisor assessment questionnaire, where the Advisor felt that there was insufficient information available in the case note extracts present to make a judgment decision, there was the option to select 'insufficient data'.

The grading system shown in Figure 1.2 was used by the Advisors to evaluate the overall care that each patient received:

Good practice – a standard that you would accept for yourself, your trainees and your institution Room for improvement – aspects of clinical care that could have been better Room for improvement – aspects of organisational care that could have been better Room for improvement – aspects of both clinical and organisational care that could have been better Less than satisfactory – several aspects of clinical and/or organisational care that were well below that which you would accept from yourself, your trainees and your institution Insufficient data – Insufficient information submitted

to NCEPOD to assess the quality of care

Figure 1.2 NCEPOD Overall grading of quality of care



There were three types of cases reviewed by Advisors: 1) Cases where data had been collected from the secondary care hospital only (case notes plus a secondary care clinician questionnaire, when returned). These were patients who were managed conservatively in secondary care or who died before transfer

2) Cases where data were collected only from the tertiary neurosurgical centre (NSC) (case notes, including transferred clinical annotations from referring hospitals and a tertiary care clinician questionnaire). This group was comprised mainly of patients who were not formally admitted to a secondary care hospital ED before being transferred to a NSC

3) "Linked cases" were patients identified from the spreadsheet data as being formally admitted to a secondary care hospital then transferred and admitted to a NSC. Data were collected from both the secondary care (referring) hospital and the NSC (case notes plus secondary care and tertiary care clinician questionnaires).

Quality and confidentiality

Each case was given a unique NCEPOD number so that cases could not easily be linked to a hospital.

The data from all questionnaires were electronically scanned into a preset database. Prior to any analysis, the data were cleaned to ensure that there were no duplicate records and that erroneous data had not been entered during scanning. Any fields in an individual record that contained spurious data that could not be validated were removed.

Approval under S.251 of the NHS Act (2006) was obtained.

Data analysis

The qualitative data collected from the Advisors' opinions and free text answers in the clinician questionnaires were coded, where applicable, according to content to allow quantitative analysis. The data were reviewed by NCEPOD Clinical Co-ordinators and a Clinical Researcher to identify the nature and frequency of recurring themes. Case studies have been used to illustrate particular themes and were developed from multiple similar cases.

All data were analysed using Microsoft Access and Excel by the research staff at NCEPOD.

The findings of the report were reviewed by the Expert Group, Study Advisors and the NCEPOD Steering Group prior to publication.

Data returns

Over the three month period 1694 admissions for SAH (1457 patients) were reported to NCEPOD. In order to limit the burden on individual clinicians, the number of questionnaires sent out was limited to a maximum of four per clinician. This meant that 159 cases (145 separate patients) were not included as the named clinician had more than four cases assigned to them. There were 380 admissions (for 346 patients) for non-aneurysmal SAH excluded, and 307 admissions (from 279 patients) excluded for reasons other than non-aneurysmal SAH. These are presented in Table 1.1.

Table 1.1 Reasons for exclusions

Reason for exclusion of case	n
Non-aneurysmal SAH	380
Patient did not have a SAH	118
Patient was admitted outside study period	12
Patient was under 16 years of age	7
Duplicate record	16
Admission for rehabilitation only (non- "linked" case)	154

Figure 1.3 shows the data returns for the study.



Identified

1694 admissions

(1457 patients)

Not included:

clinicians limited to

maximum 4 cases

145 patients

Patients selected

In total 319/391 (82%) secondary care questionnaires and 344/438 (79%) tertiary care questionnaires were returned to NCEPOD. Copied extracts of the case notes alongside the completed questionnaires were returned in 490/687 (71%) cases.

In a number of cases questionnaires were returned blank or NCEPOD was informed of problems in terms of questionnaire completion; the most common reasons for this were case notes being lost or difficulty in retrieving case notes, and the consultant in charge of the patient at the time of admission no longer being at the hospital. Furthermore, in some cases, the case notes that were returned were too incomplete or were returned after the deadline so they could not be assessed by the Advisor group.

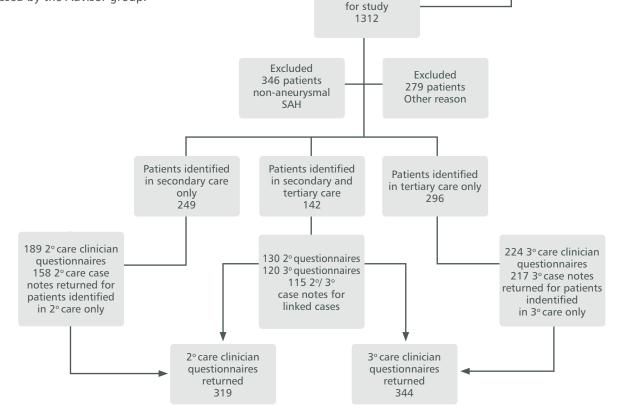
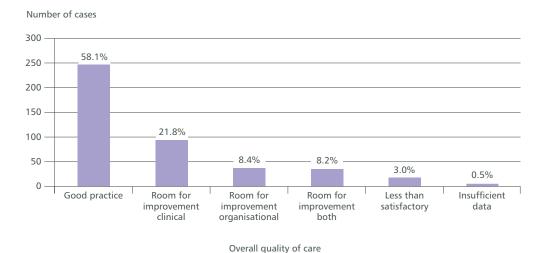


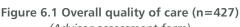
Figure 1.3 Data returns

2 – Overall quality of care and summary

Overall quality of care – secondary and tertiary care

All cases reviewed by study Advisors had their overall quality of care assessed according to a scale ranging from: good practice, room for improvement either in clinical or organisational aspects of care or both clinical and organisational aspects of care, or less than satisfactory. The results of this review are summarised in Figure 6.1. In 58.1% (248/427) of patients the overall standard of care was considered as good. Conversely there was room for improvement or the care was unsatisfactory in 41.5% (177/427) of cases. These figures followed a similar pattern if split between the cohort managed conservatively in secondary care, and those admitted to tertiary care, although the proportion of cases rated as 'good practice' was greater in the conservatively managed group (85/124 (68.5%) compared with 163/303 (53.8%)), and the proportion of cases rated as 'room for improvement in organisational aspects of care' was greater in the cohort that was admitted to tertiary care (34/303 (11.2%) compared with 2/124 (1.6%)).





(Advisor assessment form)

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Summary

This study examined the care of patients with aneurysmal subarachnoid haemorrhage (aSAH) from the time they present with symptoms until they are discharged from hospital following treatment, or they die.

There are important lessons highlighted in each step of the patient pathway starting with a need for a higher index of suspicion, in both primary and secondary care, that patients might have had an aSAH. Simple guidelines, if followed, should avoid delays in the diagnosis and management of acute severe headaches.

There are many opportunities to improve the quality of initial care provided to aSAH patients, such as avoiding delays in performing CT scans and subsequent transfer to a specialist neurosurgical/neurosciences centre (NSC) when this is appropriate. Better lines of communication between secondary care and the NSCs need to be established to avoid delays in contacting the appropriate person in the NSC and to expedite transfer of patients. The administration of nimodipine (which is of proven benefit) was not uniform following diagnosis in secondary care. Standard operating protocols for the management of patients are needed to ensure patient outcomes are optimised and delays abolished. Following transfer to a NSC definitive treatment should be carried out earlier to particularly reduce the risk of rebleeding and the development of "other" complications. To ensure timely treatment within 48 hours as recommended by the Royal College of Physicians, an increased neuroradiology service may be required in all NSCs accepting emergency referrals.

Despite prompt and appropriate treatment complications will occur following aSAH and there is undoubtedly an urgent need to improve rehabilitation services for survivors of aSAH, both within hospitals and in the community, following discharge from the hospital environment.



Key findings and recommendations

Key findings - Organisational data

Secondary care only

32.1% (52/162) of secondary care hospitals had no protocol or policy for the investigation and treatment of acute onset headache.

29% (38/131) of secondary care hospitals used the WFNS subarachnoid haemorrhage grading to assess patients.

84.4% (130/154) of secondary care hospitals are within 50 miles of a neurosurgical/neuroscience centre.

85.3% (133/156) of secondary care hospitals are within one hour of the nearest neurosurgical/neuroscience centre by road.

70.7% (118/167) of secondary care hospitals did not have formal transfer protocols.

Tertiary care only

22/27 of neurosurgical/neuroscience centres did not have a policy defining the optimal timing of treatment of aneurysmal subarachnoid haemorrhage patients.

20/27 of neurosurgical/neuroscience centres did not have a policy for pre-operative care of aneurysmal subarachnoid haemorrhage patients.

17/27 of neurosurgical/neuroscience centres did not have interventional radiologists available seven days a week.

Both secondary and tertiary care

88.1% (177/201) of hospitals were not part of formal networks of care.

90.5% (190/210) of hospitals could perform CT scans twenty-four hours/day, seven days/week.

25.5% (52/204) of hospitals were not able to perform lumbar punctures twenty-four hours/day, seven days/ week.

75.4% (126/167) of hospitals undertaking lumbar punctures did not have a policy defining who should perform them.

97.5% (178/182) of hospitals had a policy for organ donation and 96.1% (171/178) of hospitals had an intensive care team member to facilitate it. (see key finding on page 93 of the full report with regard to how this policy was actually used)

80.8% (105/130) of hospitals did not participate in regional audit or multi-disciplinary team meetings.

39.1% (63/161) of secondary care hospitals offered neuropsychological support to in-patients, repatriated post procedure and 36% (58/161) could offer neuropsychological support post-discharge.

20/27 of neurosurgical/neuroscience centres could offer neuropsychological support for in-patients and 12/27 could offer neuropsychological support post-discharge.

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Recommendations - Organisational data

- Formal networks of care should be established, linking all secondary care hospitals receiving subarachnoid haemorrhage patients to a designated regional neurosurgical/neuroscience centre. (Medical Directors)
- 2. All hospitals should undertake regional audit or multi-disciplinary team meetings, in order to share learning that could improve the care provided to aneurysmal subarachnoid haemorrhage patients. (Medical Directors and Clinical Directors)
- 3. The availability of interventional neuroradiology services should be such that hospitals can comply with the 'National Clinical Guideline for Stroke' stating that patients should be treated within 48 hours of their aneurysmal subarachnoid haemorrhage. (Medical Directors and Clinical Directors)



Key Findings - Secondary care

32/75 patients in primary care had their diagnosis of aneurysmal subarachnoid haemorrhage overlooked in the view of the Advisors; they considered that this could have affected the outcome in 23 of these patients.

18% (62/344) of patients did not have a neurological examination performed, or documented, in secondary care at the time of their initial assessment.

Initial assessment was delayed in 7.4% (25/336) of patients in secondary care; the Advisors considered that 7 of these patients could have had an altered outcome as a result.

12.8% (49/383) of patients in secondary care did not have a timely diagnosis of aneurysmal subarachnoid haemorrhage, in the view of the Advisors. It was further stated by the Advisors, that in 10 of these patients their outcome was adversely affected.

51 patients in secondary care, experienced a delay related to their CT scan in the view of the Advisors. Most commonly this was in requesting and performing of the CT scan. As a result of these delays, it was also the Advisors' view that 7 patients deteriorated and in 4 the outcome was affected (3 of these patients did not survive to discharge).

67.9% (203/299) of patients in secondary care did not have a CT scan within one hour of admission.

46.4% (143/308) of patients did not receive nimodipine in secondary care following the diagnosis of an aneurysmal subarachnoid haemorrhage, despite the *'National Clinical Guideline for Stroke'* stating that this should be prescribed for all patients. 16.5% (47/284) of patients did not receive intravenous fluids in secondary care despite 7 of these patients being haemodynamically unstable.

Advisors felt that the decision to manage patients conservatively in secondary care was appropriate in 94.1% (127/135); this included 23 patients who were not discussed with a neurosurgical/neuroscience centre (not meeting the 'National Clinical Guideline for Stroke').

Delays in the referral of patients from secondary care occurred more frequently out of hours, 5.5% (9/165), than during normal working hours, <1% (1/127), as did finding a contact in a neurosurgical/neuroscience centre, 7.4% (12/162) and 1.6% (2/129) respectively, in the view of the Advisors.

The care of patients with aneurysmal subarachnoid haemorrhage in secondary care was considered good by the Advisors in 68.8% (247/359) of patients.



Recommendations - Secondary care

- 4. The clinical presentation of aneurysmal subarachnoid haemorrhage should be highlighted in primary and secondary care education programmes for all relevant health care professionals, including the guidelines for the management of acute severe headache published by the College of Emergency Medicine. (Local Education and Training Boards/Deaneries, Medical, Surgical & Nursing Royal Colleges and Specialist Associations)
- 5. All patients presenting with acute severe headache in a secondary care hospital should have a thorough neurological examination performed and documented. A CT scan should be performed immediately in this group of patients as defined by the 'National Clinical Guideline for Stroke'. (All doctors)
- 6. Standard protocols for the care of aneurysmal subarachnoid haemorrhage patients in secondary care should be developed and adopted across formal networks. These should cover, as a minimum, initial assessment and diagnosis, management, referral, transfer to a neurosurgical/neuroscience centre and subsequent repatriation to secondary care, including rehabilitation. These protocols should take into account existing guidelines where relevant. (Medical Directors)
- 7. All patients diagnosed with a subarachnoid haemorrhage should be commenced on nimodipine immediately as recommended in the *'National Clinical Guideline for Stroke'*, unless there are contraindications to its use. (All doctors)



Key findings - Tertiary care

95.1% (270/284) of patients were admitted to an appropriate level of care following transfer to the neurosurgical/neuroscience centre and 96.2% (250/260) after definitive treatment.

12.1% (35/289) of patients had deficiencies in their examination and 8.3% (24/289) in their management planning when first assessed in a neurosurgical/ neuroscience centre, in the view of the Advisors.

35.4% (87/246) of patients did not have a review by a consultant neurosurgeon within 12 hours of admission to neurosurgical/neuroscience centre according to the tertiary care clinician questionnaire. The timing of the consultant review was unknown in a further 93 cases.

86.3% (239/277) of patients, who had a procedure, were treated by endovascular techniques.

52.7% (156/296) of the patients in neurosurgical/ neuroscience centres, who had an intervention, did not have the decision on their treatment method made in a multi-disciplinary team meeting.

23.2% (67/289) of patients who had an intervention did not have their treatment decision (either from an MDT or from discussions between the responsible clinicians) recorded in the case notes.

9.6% (24/250) of patients admitted to a neurosurgical/ neuroscience centre had a delay in treatment planning in the view of the Advisors.

13.9% (34/244) of patients had deficiencies in the consent process identified by the Advisors. These included poor documentation of risk (16/34) and limited or poorly documented discussion with the next of kin (15/34).

20.5% (42/205) of patients who gave consent may have had impaired mental capacity to do so.

72% (108/150) patients admitted to a neurosurgical/ neuroscience centre Monday-Thursday had their aneurysm treated within 24 hours of admission, compared with 28% (42/150) of patients admitted Friday-Sunday.

Consultant neurosurgeons and neuroradiologists were present for all interventions.

8.5% (26/307) of procedures were performed by trainees. These were all supervised by a consultant. This low percentage raised questions about training opportunities.

18.8% (49/260) of patients did not receive in-patient rehabilitation (e.g. physiotherapy, occupational therapy and neuropsychology) in neurosurgical/neuroscience centres. Furthermore 21.3% (35/164) of patients had no rehabilitation plan at the time of discharge.

16.5% (28/170) of patients received neuropsychological support as an in-patient in a neurosurgical/neuroscience centre, and 12.4% (21/170) of patients received it post-discharge.



Recommendation - Tertiary care

- 8. Relevant professional bodies should develop a nationally-agreed and audited protocol for the management of aneurysmal subarachnoid haemorrhage in tertiary care that addresses initial assessment, multi-disciplinary management and documentation, informed consent, timing of interventions, peri-operative care, management of complications and rehabilitation. (Royal Colleges and Specialist Associations)
- 9. Mental capacity of aneurysmal subarachnoid haemorrhage patients to give their own consent should be reviewed and a consensus document developed (with consideration of the Mental Capacity Act 2005). (Royal Colleges and Specialist Associations)
- 10. The nationally-agreed standard ('National Clinical Guideline for Stroke') of securing ruptured aneurysms within 48 hours should be met consistently and comprehensively by the health care professionals who treat this group of patients. This will require providers to assess the service they deliver and move towards a seven-day service. (Medical Directors)
- 11. Neurosurgical/neuroscience centres must ensure that trainees in neurosurgery and neuroradiology develop the appropriate competencies for future consultant practice. (Local Education and Training Boards/Deaneries, Royal Colleges, Medical Directors and Clinical Directors)

12. Appropriately funded rehabilitation for all patients following an aneurysmal subarachnoid haemorrhage should include, as a minimum, access to information for patients and relatives, specialist subarachnoid haemorrhage nurses and comprehensive in-patient and out-patient rehabilitation services including appropriate neuropsychological support. (Specialist Associations, Medical Directors and Commissioners)



Key finding - End of life care in secondary care and tertiary care

Organ donation did not occur in 43/87 of potentially suitable donors. After excluding refusal by next of kin more than half of the remainder (11/19) did not occur because medical staff did not pursue this option. (see key finding on page 38 of the full report with regard to the availability of this policy)

Recommendation - End of life care in secondary care and tertiary care

13. Organ donation rates following fatal aneurysmal subarachnoid haemorrhage should be audited and policies adopted to increase the frequency with which this occurs. (*Medical Directors*)

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