

A national confidential enquiry into care of patients with aneurysmal subarachnoid haemorrhage notes areas for improvement, including greater use of specialist nurses

# Improving subarachnoid haemorrhage care

## In this article...

- › Incidence of aneurysmal subarachnoid haemorrhage
- › Delays in diagnosis and treatment
- › The need for better communication with patients and families

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A report from the National Confidential Enquiry into Patient Outcome and Death on the care of patients with aneurysmal subarachnoid haemorrhage (aSAH) has found that, while many people receive high-quality care, there is substantial room for improvement. aSAH is a relatively uncommon condition and patients can experience delays in diagnosis, investigation and receiving appropriate drug and interventional treatment. The report calls for access to specialist nursing for all patients with aSAH and for better communication with those patients and their families.

**A**neurysmal subarachnoid haemorrhage (aSAH) is a relatively uncommon condition, accounting for about one in 20 (5%) of all strokes (Stroke Association, 2013). A National Confidential Enquiry into Patient Outcome and Death (2013) report on the care of patients admitted after having an aSAH has identified ways in which care needs to improve. The report highlights a need for more specialist nurses and for better information for patients and families.

### Incidence and outcomes

The annual incidence of aSAH in the UK is around seven per 100,000, with around 800-900 patients in England having surgical clipping or endovascular coiling each year (NCEPOD, 2013). Surgical clipping

involves locating the aneurysm and placing a metal clip to seal it. Endovascular coiling involves inserting a catheter into an artery in the leg or the groin, locating the aneurysm and then passing platinum coils through the catheter into the aneurysm to prevent it from growing or rupturing.

Aneurysmal subarachnoid haemorrhage often occurs at a relatively young age: half the patients studied by NCEPOD (2013) were under 60 years of age. The outcome of patients with aSAH is generally poor: half die within one month of the haemorrhage and, of those who survive the first month, half remain dependent on help with activities of daily living. Only 25% of patients can expect to return to having a relatively normal life (NCEPOD, 2013).

### The NCEPOD study

The aim of the NCEPOD study was to explore the process of care experienced by patients admitted after having an aSAH. Expert reviewers assessed the care of 427 patients with aSAH presenting to hospitals in England, Wales and Northern Ireland between 1 July and 30 November 2011. Hospital notes were reviewed and questionnaires were sent to secondary and tertiary care. All notes were anonymised.

Data collection for this study involved a range of personnel:

- › Each trust had an NCEPOD local reporter and ambassador within the hospital who identified the aSAH cases that should be reviewed;
- › Doctors who were treating patients completed questionnaires;
- › A group of clinicians working in the field was recruited to advise NCEPOD on what to assess during the study;
- › A multidisciplinary group of senior

## 5 key points

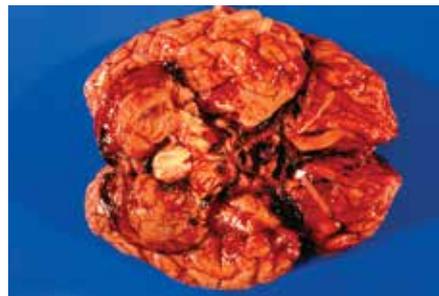
**1** Aneurysmal subarachnoid haemorrhage (aSAH) accounts for about 5% of all strokes

**2** Interventional procedures are performed on 800-900 patients with aSAH in England per year

**3** aSAH often occurs at a relatively young age, with many patients aged under 60 years

**4** Only 25% of patients can expect to return to a relatively normal life following aSAH

**5** A full-time GP will see only one case of aSAH every seven to eight years



A subarachnoid haemorrhage can result in blood clots forming on the brain's surface

## BOX 1. RECOMMENDATIONS

The National Confidential Enquiry into Patient Outcome and Deaths (2013) report recommends the following:

- Primary and secondary care education programmes should cover aneurysmal subarachnoid haemorrhage (aSAH) for all relevant health professionals, including guidelines for the management of acute severe headache published by the College of Emergency Medicine
- Neurosurgical centres (NSCs) must ensure trainees in neurosurgery and neuroradiology develop appropriate competencies for consultant practice
- Formal networks of care should link secondary hospitals to NSCs
- Standard protocols of care in patients with aSAH should be adopted and developed across formal networks. These need to cover, as a minimum, initial assessment, diagnosis, management, referral and transfer to NSCs. Nearly a fifth (62 out of 344) of patients studied did not have a neurological examination

recorded in secondary care

- Relevant professional bodies should develop a nationally agreed and audited protocol for the management of aSAH in tertiary care that addresses initial assessment, multidisciplinary management and documentation, informed consent, timing of interventions, perioperative care, management of complications and rehabilitation
- The nationally agreed standard of securing ruptured aneurysms within 48 hours will require providers to assess the service they deliver and move towards a seven-day service
- Appropriately funded rehabilitation for all patients after they have had an aSAH should include, as a minimum, access to information for patients and relatives, specialist aSAH nurses and comprehensive inpatient and outpatient rehabilitation services, including neuropsychological support

nurses and doctors including me – known as the advisers – peer reviewed the data and identified themes.

Each case was looked at individually. The final report, *Managing the Flow? A Review of the Care Received by Patients who were Diagnosed with an Aneurysmal Subarachnoid Haemorrhage*, was published in November 2013 (NCEPOD, 2013).

### NCEPOD's findings

The NCEPOD report outlines its findings in key areas including:

- » Diagnosis;
- » Investigations;
- » Treatment;
- » Rehabilitation.

### A suspected diagnosis of aSAH

There needs to be a higher index of suspicion among health professionals in primary and secondary care that patients may have had an aSAH.

The management of headache in primary care is challenging. A full-time GP with 2,000 patients will see, on average, one person with a headache every week, but only one aSAH every seven to eight years (Duncan et al, 2008), therefore making diagnosis extremely difficult.

When reviewing 75 out of 427 patients who saw their GP in relation to their symptoms of aSAH, NCEPOD found that in 32 out of the 75, the diagnosis was either delayed or overlooked.

Headache affects about 90% of the general population at some time. The most common causes are migraine and episodic tension-type headache. A small proportion of patients present acutely to a primary care doctor, and the main objective is to identify those who require urgent investigations (Ducros and Boussier, 2013). Investigation of a patient who has a headache but no neurologic deficits is a potentially difficult clinical decision.

Headache also accounts for approximately 2% of all accident and emergency department visits, and while aSAH is one of the most serious diagnoses, it accounts for only 1-3% of these headaches (Perry et al, 2013).

### Avoiding delays in diagnosis

Simple guidelines are needed so that delays in the diagnosis, treatment and management of acute severe headaches can be avoided.

Ambulance personnel need training to ensure appropriate patients are taken directly to A&E departments. Most (95%) people have their first symptoms outside of hospital. It is vital that members of the public and health professionals – GPs and their receptionists, telephone advice line nurses, paramedics, A&E staff – can recognise stroke as early and accurately as possible to facilitate the patient receiving the appropriate emergency care (Royal College of Physicians, 2012).

Current guidelines from the National Institute for Health and Care Excellence state that aSAH should be considered in any patient presenting with sudden onset, severe and unusual headache, with or without any associated alteration in consciousness (NICE, 2008). Protocol-driven investigation of headache can reduce misdiagnosis in this patient group (Beithon et al, 2013).

### Avoiding delays in investigation

Delays need to be avoided in performing computerised tomography scans and subsequent transfer to specialist neurosurgical or neuroscience centres (NSCs).

Guidelines recommend that CT scans be carried out within one hour of arrival in hospital in patients suspected of having a subarachnoid haemorrhage (Bederson et al, 2009). However, CT scanning was found to be delayed in 11% of patients studied – a total of 32 out of 299.

### Better lines of communication

NCEPOD says better lines of communication are needed between secondary care and NSCs, to avoid delays in contacting the appropriate personnel and patients being transferred.

A high suspicion for aSAH during the initial evaluation in the A&E department or by the primary care physician increases patients' chance of early intervention and reduces mortality and disability (Simpson and Deshaies, 2013).

### Administration of nimodipine

The administration of nimodipine needs to start in secondary care when diagnosis of aSAH is made. Nimodipine relaxes and widens blood vessels and reduces the risk of damage after a subarachnoid haemorrhage (NCEPOD, 2013).

The RCP's intercollegiate stroke working party recommends that every patient diagnosed with aSAH should be started on nimodipine 60mg four-hourly unless there are specific contraindications (RCP, 2012). Nimodipine treatment was only documented in 126 out of 269 patients (46.8%) in the NCEPOD review.

### Early treatment

After transfer to an NSC, treatment needs to start early to reduce the risk of re-bleeding and the development of other complications. To ensure timely treatment, an increased neuroradiology service may be required in all NSCs that accept emergency referrals.

While the ideal timing of coiling or clipping after aSAH is not certain, there is

evidence to support the practice of early aneurysm treatment, with the RCP working party stating that this should be done within 48 hours (RCP, 2012). The study showed that 43 patients out of 246 were coiled in under 48 hours.

Rebleeding following aSAH occurs in 5-10% of cases in the first 72 hours (Fujii et al, 1996); early repair of aneurysms reduces the risk of this occurring (NCEPOD, 2013). Untreated ruptured intracranial aneurysms carry a high rebleeding rate, which is quoted in the literature to be 4% on the first day after rupture, 15-20% in the first two weeks and reaching a risk of 50% at six months. Early treatment is therefore crucial (Grunwald et al, 2014).

### Rehabilitation services

There is an urgent need to improve rehabilitation services, both within hospitals and within the community after patients have been discharged.

Evidence suggests that provision of high-quality acute stroke care is both clinically effective and cost effective. Patients with stroke should be assessed and managed by:

- » Stroke nursing staff and at least one member of the specialist rehabilitation team within 24 hours of admission to hospital;
- » All relevant members of the specialist rehabilitation team within 72 hours.

Documented multidisciplinary goals should be agreed within five days of stroke (RCP, 2012).

Aneurysmal subarachnoid haemorrhage is associated with both high mortality and morbidity. Even in those patients who survive, a poor functional outcome is common and the requirement for rehabilitation services will be significant and protracted. Some of these patients will be unable to live independently in the future (NCEPOD, 2013).

The NCEPOD (2013) report suggests that among patients who died, organ donation did not occur in 49% of potentially suitable donors (43 of 87). After excluding refusal by next of kin, medical staff did not pursue this option in more than half of the remainder (11 of 19). NCEPOD's (2013) report recommends auditing organ donation rates after fatal aSAH and introducing policies to increase the rate.

### Specialist nurses

Specialist nurses provide a level of care and support that thousands of people in the UK really cannot do without. In a national survey of health advocacy groups (Royal College of Nursing, 2009), patients

consistently rated specialist nurses higher than any other health and social care professional in:

- » Understanding patients' needs;
- » Designing and implementing care pathways;
- » Obtaining patient feedback;
- » Being transparent and honest.

Neurovascular specialist nurses are



required to deal with the linked psychosocial issues that are costly and disruptive to families and services (Pritchard et al, 2009). Clinical and financial outcomes are improved significantly by identifying patients at risk, monitoring for complications and having acute care nurse practitioners to manage the patients (Russell et al, 2002).

### Consent

Consent to treatment is the principle that patients must give their permission before they receive any type of medical treatment or examination. The principle of consent is an important part of medical ethics and international human rights law (NHS Choices, 2014).

The NCEPOD (2013) report emphasises that the mental capacity of patients with aSAH to give their own consent needs to be reviewed and a consensus document developed that takes into consideration the Mental Capacity Act (2005).

As nurses looking after many patients who are neurologically compromised, we need to ensure patients and families do understand the procedures required.

As emphasised in this report, it is also important to involve patients and their carers in discussions wherever possible. These discussions require health professionals to have expertise and experience, as well as the ability to communicate effectively and with compassion (Department of Health, 2013).

### Conclusion

The NCEPOD report has highlighted the need for not only more specialist nurses within neuroscience specialties, but also more access to information for patients and families. Now the report is publicly available, hopefully it will become a powerful negotiating tool with service providers. It is now for those who fund

healthcare to implement the recommendations and use the information gathered to establish new national standards and guidelines (NCEPOD, 2013). **NT**

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