Establishing a clinical nurse specialist for headache

In this Future Hospital Programme case study, Professor Carl Clarke describes how the Sandwell and West Birmingham Hospitals NHS Trust trained Julie Edwards, a senior ward sister, as a clinical nurse specialist for headache.

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Developing the workforce

Key recommendations

- By introducing a headache nurse specialist, it can reduce the time consultants need to spend with simple headache disorders.

- The specialist nurse can improve the quality of service for patients (including reduced waiting times and quicker access to specialised treatments for cluster headache and chronic migraine).

- By reducing the number of patients referred for imaging, pressure is relieved from imaging and costs are reduced.

Local context

Sandwell and West Birmingham serves a population of around 500,000.

The challenge

A huge proportion of our referrals at Sandwell and West Birmingham Hospitals NHS Trust (SWBH) were headaches (39%). In Neurology, headaches have always been a problem; this is because some general practitioners (GPs) are not sufficiently confident to diagnose/treat a variety of headache disorders. At SWBH, screening had previously been conducted by a general physician. When he retired, we decided we needed to do something different to cope with the increasing number of referrals and follow-up appointments we were receiving. With an experienced senior ward sister in our team, we decided to train her to screen for headache disorders.

At the time, the service was a unique idea. It was inspired by discussion on how we could use the resources we had in the best way. Most headaches are a simple diagnosis. We couldn't afford to recruit another consultant so we had to be more creative.

Our solution

Starting in 2004, we began to train the senior ward sister, Julie Edwards, in the differential diagnosis of headache disorders. Over 6 months, patients with non-acute headache disorders were seen separately by the nurse and one of three consultant neurologists; both performing a history and neurological examination. Julie and the consultants were responsible for reaching an independent diagnosis for the various headache disorders. There was excellent agreement between the nurse and the neurologist, so we created a diagnostic headache nurse (band 7) specialist service.

Julie conducts six clinics per week, seeing 20-25 new and 34-40 follow-up patients. Each new patient has at least 30 minutes (more if necessary) and follow-ups have 15 minute appointments. Administration time is approximately 16 hours per week, but this includes self-development, teaching etc. During her post Julie has completed a Master's in chronic pain management and is on a pre-PhD development course. She will be having supervised teaching once per week, with a consultant neurologist with a specialist interest in headaches from University Hospitals Birmingham. Training for staff is ad hoc (at their request) and Julie will be teaching student nurses in March 2016 on headache. Additionally, medical students sit in on clinics during their neurology placements.

Julie does not have any ward duties and her clinics are paid at nurse level. The service is now contracted with our clinical commissioning group (CCG) as an integral part of the neurology service. Julie is highly autonomous and independently runs a dedicated headache service at SWBH.

Developing the workforce

Julie is extremely busy, seeing vast numbers (800+) of new patients per year. Her workload is certainly comparable to a consultant outpatient load. In addition, she:

- runs a cluster headache service
- advises GPs on the management of follow-up patients
- attends GP meetings and teaching sessions
- receives referrals directly from GPs
- mentors and teaches student nurses, medical students, headache nurses, GPs and other specialist nurses. Teaching is individualised for each group, as are the learning outcomes. Therefore, each session is different and often specifically built.

Julie is not a prescriber, but we have protocols agreed with the consultant neurologists on treating common headache disorders based on the British Association for the Study of Headache (BASH) and NICE guidance. As such, GPs are given recommendations on using triptans for migraine and cluster headache. GPs are not allowed to order oxygen after changes to the regulations; therefore Julie arranges home oxygen for cluster patients with local agreement and support of the respiratory physiology team. For example, Julie arranges the Home Oxygen Order Form (HOOF) A and the respiratory team convert to HOOF B and follow-up as required.

> *'Julie is highly autonomous and independently runs a dedicated headache service at SWBH.'*
> Professor Carl Clarke, Sandwell and West Birmingham Hospitals NHS Trust

Outcomes

When conducting the training, we knew cases of serious headache disorders would be unlikely. Therefore we trained a series of role players to present to the nurse and consultant. These 'actors' were specifically trained to present with either benign or sinister headaches.

Consultants diagnosed 239 patients with:	The nurse agreed with the consultant in:
• tension-type headache (47%)	• 92% of cases of tension-type headache
• migraine (39%)	• 91% of those with migraine
• other headache disorders (14%).	• 61% of other diagnoses.

Where the nurse did not agree with the diagnosis, most would have been referred for a consultant opinion. Furthermore, the nurse specialist and the consultant misdiagnosed the same three out of 13 role players.

For the next 5 years we audited our experience. Julie saw 3,655 new patients with headache disorders with good patient satisfaction levels and no complaints from patients or GPs. 14.5% (530 of 3,655) patients underwent cranial imaging. From these results we were confident the nurse was capable of working independently and she has been ever since.

Methods

The diagnostic headache nurse specialist service was introduced to our sub-regional neurology unit to:

- diagnose migraine, tension-type headache and medication overuse headache
- advise GPs on the treatment of these disorders
- collaborate with consultant neurologists in managing more complex headache disorders.

An unexpected outcome

From feeding back the information we had gathered regarding the proportion of patients referred for imaging by each consultant, we saw an unexpected change in consultant behaviour.

Developing the workforce

We saw there were large differences in the proportion of patients referred for imaging by each consultant (three in total, and excluding myself). These differences disappeared once they received feedback on their behaviour; a change which reduced the numbers of patients being imaged.

During the trial phase, all patients were seen by Julie and one of three consultants and we tracked the percentage of patients that were imaged by the consultants.

Once full time clinics started, Julie worked with a consultant neurologist alongside her. Any patients who Julie felt needed to be discussed, needed imaging or needed a diagnosis to be agreed, she would take to the neurologists next door to agree. Initially, this was around 50% of patients, but this has reduced over time and with experience. Julie now books her own investigations and will only discuss a case with a consultant if there was something she is concerned about or if there is a secondary neurological issue that needs clarification (eg a seizure).

Consultants A and C had relatively low percentages of imaging referrals (16.9% and 27.8% respectively). However, consultant B imaged 59% of patients. Only the consultant made a decision on imaging. These patients were typically 'yellow flag' (those where there was cause for concern, but not an emergency). These percentages reflect the collaborative decision being made by the specialist nurse and consultant. Before commencing the 5 year audit, we made these results available to the team of consultants and specialist nurse. The team were able to review the proportion of patients that had imaged and found nothing compared with the number of patients they had imaged and found something. As a group we felt reassured that patients did not need imaging at the rate that was currently being undertaken by the department.

Practice within the team really did change overnight. The most dramatic change was shown by consultant B who went from 59% to 17.7% in the first year, to a low of 15.5% in the second year of patients imaged. This experience taught us that when a consultant is directly compared with his peers, we see quick results. As imaging is a costly process, we have seen savings in the department. I believe this outcome is testament to the power of influencing people by feeding back relevant results.

> *'It's a little known medical condition and there are very few experts out there, so I'm very lucky to have seen Julie.'*
> Kevin Crook, headache patient

Barriers and levers

The key barrier to setting up this service was funding. It required a great leap of faith from our Trust, that has always been good at looking at new ways of working. This role was an example of this, and one which was beneficial to them. Therefore, we found it wasn't difficult to persuade them as it was in line with their goals at the time to reduce waiting time and minimise expense. It was a key directive of SWBH to reduce outpatient waiting times. However, the Trust couldn't afford another consultant. When the idea of a nurse taking over this role was suggested, the Trust was extremely enthusiastic and could clearly see the patient and Trust benefits of the secondment. Since the nurse was able to be seconded, this meant we received the necessary financial support.

Patient feedback

Julie has been nominated for the NHS Heroes award and The Pride of Nursing Award.

When Kevin Crook nominated Julie for The Pride of Nursing Award he admits he had never experienced pain like it until he suffered from debilitating cluster headaches. 'It's a little known medical condition and there are very few experts out there, so I'm very lucky to have seen Julie,' he explains. 'She told me she has a plan A and a plan B. For me, and people like me, she is a godsend,' added Kevin.

Developing the workforce

Next steps

The service has won a number of awards, internally and externally. Julie herself has also been nominated for and won a number of awards.

There is no typical patient referred to the headache service. With up to 350 different types of headaches, our patients cover all ages, personalities, job roles and personal circumstances. With relatively few headache specialists found in the UK, Julie is a high profile nurse who regularly runs GP training sessions and has even hosted a headache advice session on local radio. The effect of Julie's role has been provided as evidence to an All-Party Parliamentary Group on Primary Headache Disorders.

Resources

Clarke CE, Edwards J, Nicholl DJ, Sivaguru A. Imaging results in a consecutive series of 530 new patients in the Birmingham Headache Service. J Neuro 2010;257:1274-78

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