Headache Disorders -
not respected, not resourced

A Report of the All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD)
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Based on evidence given to the Group during 2008-2009

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Chairman’s Foreword

As Chairman of the All-Party Parliamentary Group on Primary Headache Disorders (APPGPHD), I am delighted to introduce the Group’s first authoritative, evidence-based Report entitled: “Headache Disorders - not respected, not resourced”

Headaches are an unglamorous disability - the Cinderella of the medical profession, under-rated and often ignored. In the list of leading causes of disabling conditions headache is 12th for women and the 19th most disabling condition for men, according to the World Health Organisation’s recent research. It is a very common reason to visit the GP. One in 7 people in the UK population – that is to say over 6 million people - are affected. That is 1 in every 7 of our constituents are sufferers of headaches and migraine to at least a degree serious enough to visit a GP. That widespread level of need and experience should certainly alert each and every politician.

More people suffer from headaches than the combined number of those who suffer from diabetes, epilepsy and asthma.

The APPGPHD has had an active two years. It has made presentations to the APPGPHD, worked in various capacities in headache and migraine management and/or research.

In addition to the suffering imposed by a migraine attack, the economic burdens impose financial costs on individuals and society. The NHS costs of migraine are £150 million per year, whereas the cost of absenteeism through migraine alone cost £2.25 billion in the UK. The indirect costs of man hours lost almost certainly considerably outweigh the direct costs of treatment. Investment in better health care for migraine sufferers can therefore demonstrate a direct return on investment – a case that was well made by Dr Tim Steiner.

In particular, I am extremely grateful to Professor Goodisby who has overseen, edited and set out some wise recommendations to tackle the problems caused by these widespread and debilitating conditions.

Health service research was another area of discussion. There are regional disparities in neurological services and a lack of coordination between the different sectors of the health service. How can care be managed across the NHS, what skills are required and what interventions are needed? These are questions that this report has asked – and gives some clues as to the answers.

The Group heard from Dr Richard Hargreaves, Merck & Co., Inc. and Professor Peter Goodisby, who both lamented the lack of research into the causes and treatment of headaches in the UK. Pharmaceutical research provides hope for the future with exciting work that is now being undertaken in the USA.

In particular, I am indebted to Headache UK whose support funds the administration services for the Group. I believe that the thrust of this report should have real impact in urging policy- and decision-makers to turn their attention to this pressing, widespread issue which is capable of solutions that will increase the wellbeing of our constituents and fellow-citizens.

This needs to be done with urgency, not least as the need to catch up the time lost by the relative neglect of this area of clinical practice to date, means all of us owe so much to all the millions of sufferers across every part of the United Kingdom. I commend this Report to you.

Stephen O’Brien MP
Chairman, All-Party Parliamentary Group on Primary Headache Disorders
March 2010
1. The Economic Cost

The economic cost of migraine and other headache disorders in the UK

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Added to all of its other unwanted effects, illness imposes financial costs upon society. These arise in two ways. Direct costs are essentially the health-care costs: the use of resources to diagnose and treat illness; where these fall upon a tax-funded health service, they are a societal cost. Indirect costs are the value of the consequential losses attributable to illness. Whilst these costs may be borne by individuals, they are frequently shared by society. Indirect costs may outweigh direct costs: investment in health care, whilst increasing the latter, may offset the former to an extent that is cost-saving overall.

This is the context in which I explore the cost of migraine and other headache disorders to the UK economy. The estimates are inexact because some of the data supporting them are imprecise, but the numbers are such that the message they give rise to is unambiguous. It should inform and direct policy.

Migraine – the statistics

Today in the UK, 190,000 people are in the throes of a migraine attack. The number yesterday was the same, as it will be tomorrow, and the day after. This is a condition which affects 5.85 million adults in the country - 14.3%, or one in seven, of the population. It leads to 100,000 people missing work or school every working day, a huge loss of time and productivity.

Two key characteristics of migraine identified here – it is both very common and often seriously disabling – combine to generate a heavy public burden with major economic impact. Research shows that more than half of people with migraine experience the symptoms of an attack at least once a month; but some are affected far more often, so that the average frequency across the UK is 24 attacks a year. Each attack typically lasts a full day, although some are quite a lot longer. Crucially, the great majority of people - 80% - report severe or extremely severe pain. Many in addition experience the other, associated symptoms: three-quarters report nausea, phonophobia and photophobia (in which ordinary levels of noise and light cause discomfort). These are all disabling symptoms, so it is not in the least surprising that, during an attack, most people find it difficult to function; three-quarters need always to lie down for at least part of the attack, and half need to take some time off work.

A third key feature of migraine, magnifying its effect, is the way in which its prevalence is age-related. Migraine is most common between the ages of 30 and 50 years, when people are generally at their most productive, furthering their careers and raising children.
The Economic Cost

A fourth feature is that the individual impact of migraine is not restricted to the attack. Anxiety over the next occurrence leads to avoidance of activities or situations that would be enjoyed but are feared as possible triggers. Whilst migraine attacks are episodic, these lifestyle-compromising consequences are present for much if not all of the time. More than three-quarters of sufferers find their normal day-to-day activities to some extent limited by migraine, half report damage to family and social relationships and a small but very important minority – one in every seven – feel chances of promotion at work are adversely affected. This last consequence has cumulative effects over an entire lifetime.

And finally, the impact of migraine spreads beyond the person who actually has it. When a person is ill, family members must take on increased shares of chores and responsibilities. A UK survey noted that almost half of people, during a migraine attack, rely on others for some form of help. Employers lose the services of those they are paying to work, whilst colleagues may be called upon to provide cover.

The economic cost

The NHS costs of migraine in the UK are of the order of £250 million per year – around 3.5% of what headache disorders impose in total. Industry and employers should be more aware of the considerable costs to them in terms of lost productivity. More should be done to assist employees who suffer from headache.

The Department of Health should recognise that migraine and other headache disorders are a major public-health issue and respond accordingly, organising primary-care based services with a health-care budget allocation raised substantially above the current estimated £250 million.

Recommendations

The World Health Organization ranks migraine in the top 20 causes of disability (and headache disorders collectively are almost certainly amongst the top ten). Headache disorders impose a large humanitarian burden; but, in addition, costing an estimated £7 billion a year, they clearly present the UK with a major economic burden. The Government should acknowledge this.

It would be highly cost-beneficial – cost-saving, in fact – to address and reduce the effects of headache in the UK, quite apart from the humanitarian benefit this would achieve.

Industry and employers should be more aware of the considerable costs to them in terms of lost productivity. More should be done to assist employees who suffer from headache.

The Department of Health should recognise that migraine and other headache disorders are a major public-health issue and respond accordingly, organising primary-care based services with a health-care budget allocation raised substantially above the current estimated £250 million.

References


2. Improving Management

Headache - Improving Management in Primary Care

Based on a presentation by Professor Leone Ridsdale and Dr David Kernick

Background

Headache (including migraine) is in the World Health Organisation's top ten causes of disability and has a high impact at home, work and school. As 95% of headache consultations present to primary care, this setting offers important opportunities to reduce the burden of headache in the UK. The majority of headache patients can be treated in primary care and this setting is more appropriate to address not only co-morbidities but the complex psycho-social factors that are often an important factor in the pathogenesis of headache.

Community studies suggest that headache is the most common symptom experienced in the population but not a major reason for consultation with a GP. Despite a substantial burden, the needs of headache sufferers are frequently unmet. For example, less than 50% of migraine patients are satisfied with their current treatment. The majority use non-prescription medication and do not seek medical help. When they do so, the diagnosis is often incorrect and the condition is poorly managed. Only 50% of migraineurs have ever seen a doctor and of those who have, the minority are under continuing care. The majority of patients self medicate and this can gradually escalate into medication overuse.

What is happening in primary care?

Headache is the commonest neurological symptom presented to GPs and 4% of all adults consult a GP for headache each year. 2% of these cases are referred to neurologists and 1% to other specialties. In children and adolescents, headache is also the most common primary care neurological symptom and the most common cause of pain. Although 11% of children have migraine and 20% of children have headache that bothers them once or more times a week, only 1.6% of children consult their GP each year. The referral rates are much higher than in adults. 25% of consultations being referred to a paediatrician.

This may reflect the uncertainty and concern of GPs when dealing with paediatric headache.

The health seeking behaviour of children with headache reflects the adult population. Research is needed in this area to explore why this is the case but reasons given in children are belief that nothing could be done, not wanting to reinforce illness behaviour or not realising a child had migraine. As migraine tends to run in families, it is likely that parental health seeking patterns of behaviour are transferred to their children.

Do all headache sufferers need a referral to a neurologist?

Twenty-five per cent of new referrals to neurologists are for headache, a level that may be difficult to justify. Patients referred to a neurologist do not have more severe headache but are likely to be more anxious about it. Unfortunately neurologists are not always interested in the area and evaluations have suggested dissatisfaction with hospital consultations in a high proportions of patients.

There is often cause for concern by both practitioner and patient that headache may reflect an underlying pathology and in particular a brain tumour. Investigation should only be undertaken if there is a high likelihood of an underlying problem as incidental findings can lead to long standing anxiety. Although investigation may be effective in the short term to alleviate patients' concerns, studies show that patient anxiety returns over the longer term.

The Royal College of General Practitioners headache initiative

In order to strengthen the focus on direct clinical care, the RCGP has nominated a number of key clinical areas of which headache is one. This offers important opportunities for one of the presenter/authors (DK) to work with stakeholders to raise the profile of headache, encourage research, develop guidelines and educate healthcare professionals and students. This three year programme commenced in 2009. An important area will be developing General Practitioners with a special interest in headache to improve both service delivery and education of primary care health professionals. This approach is endorsed by the Royal College of Physicians and Association of British Neurologists in their guideline on the role of neurologists in the next decade.
2. Improving Management

Migraine in women: is it all in the hormones?

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Introduction

Migraine affects more than 1 in 7 of the UK population - over 6 million people - and is more prevalent than diabetes, epilepsy and asthma combined. These figures mask the fact that migraine is a predominantly female disorder compared with men, 1-year migraine prevalence is nearly 3-fold higher (17% vs. 6%) in women and lifetime incidence is more than 2-fold higher (43% vs. 18%).

Research by the World Health Organization has established migraine as a leading cause of years of life lived with a disabling condition - 1.2% of women, compared to 1.9% for men. Migraine can impose a large personal burden for sufferers, their friends and family, and employers, as well as high economic costs for society. More than three quarters of migraineurs experience at least one attack each month, and more than half experience severe impairment during attacks. Living with or being related to a migraineur decreases non-migraineurs’ ability to participate in home/family life (moderate/great impact 47%); social/leisure activities (moderate/great impact 49%) and social/leisure activities (moderate/great impact 47%).

Despite this burden of illness, migraine is often not diagnosed or treated effectively. Further, specific hormonal events such as menstruation, hormonal contraception, pregnancy, the menopause and hormone replacement therapy have variable, but often predictable, effects on the frequency and severity of migraine. At each stage, there are specific opportunities to intervene and relieve the burden of migraine.
3. Migraine in Women

Contraception

Most women use contraception at some stage in their lives. Hormonal contraception, particularly combined hormonal contraceptives, is a popular and effective method, with additional non-contraceptive benefits. For many women, migraine improves or they report change in migraine frequency or severity.

As with headache, migraine, typically without aura, occurs during the hormone-free interval. In a retrospective study on patients on combined hormonal contraceptives (CHCs) with unwanted withdrawal symptoms (35% reporting headache as a symptom), almost all side effects were found to be significantly worse during the 7-day hormone-free interval compared to the 21 days to be significantly worse during the 7-day withdrawal symptoms (35% reporting headache without aura). This suggests that many women with this type of migraine are denied CHCs. In some cases, this stems from misdiagnosis of premonitory symptoms as aura. In other cases, just the diagnosis of migraine can result in withholding CHCs. Clearly, there is a need to provide contraceptive providers with a better understanding of migraine to ensure that women are receiving optimum contraceptive options.

These findings need to be viewed in the context of the low absolute risk of ischaemic stroke in young women. Additional risk factors, including use of CHCs, further increase risk. On this basis, most authorities consider migraine with aura to be a contraindication to use of CHCs. Effective contraception need not be compromised since progestogen-only and non-hormonal methods, several of which are more effective than CHCs, are not associated with increased risk. However, there are a number of barriers to effective care. Despite there being no concern regarding use of CHCs in women with migraine without aura, clinical experience suggests that many women with this type of migraine are denied CHCs. In some cases, this stems from misdiagnosis of premonitory symptoms as aura. In other cases, just the diagnosis of migraine can result in withholding CHCs. Clearly, there is a need to provide contraceptive providers with a better understanding of migraine to ensure that women are receiving optimum contraceptive options.

Pregnancy and breastfeeding

Up to 80% of women with migraine experience fewer attacks compared to pre-pregnancy, in around 20% attacks completely disappear. Improvement is more likely with a history of menstrual or menstrually-related migraine. If migraine is still occurring by the end of their first trimester, it is likely to continue to occur throughout pregnancy and postpartum. Women can be reassured that migraine, with or without aura, does not have any adverse effect on the outcome of pregnancy if they are otherwise healthy. Despite this, women with migraine should be monitored during pregnancy since there is a co-morbid increased risk of arterial and venous thrombosis, pre-eclampsia and gestational hypertension. Most drugs and other teratogens exert their greatest effects on the fetus in the first trimester, often before pregnancy is confirmed. Healthcare professionals need to be aware of women with migraine who may be planning to conceive soon. It is important to consider that these strategies for treating migraine can be discussed. Drug use during pregnancy should only be considered if the potential benefits to the woman and fetus outweigh the potential risks.

Women with migraine receiving assisted conception would particularly benefit from support and advice on management, as fertility treatment is frequently associated with headache. It is also important to consider that headache can be symptomatic of emotional stress. Frequent pre-pregnancy headache is a strong predictor of poor general and emotional health during pregnancy and should alert the healthcare professional to assess these women for depressive disorders.

Headache is common in the week following delivery, affecting around 30% to 40% of women. Of relevance to women with migraine is the finding that a history of migraine headache is strongly associated with stroke. Breastfeeding is generally associated with improvement in the clinical course of migraine during the postpartum period. A longitudinal prospective study found that the headache index during the first 3 postpartum months was similar for patients who breastfed to the headache index during the second trimester of pregnancy. These data likely suggest that the improvement of migraine commonly seen during the second trimester of pregnancy continues into the postpartum time period if breastfeeding is maintained. A more recent study reported that migraine recurred within the first postpartum month in 100% of women who bottle-fed and in only 43.2% of those who breastfed (P = 0.0003). Although recent studies suggest that the number of women choosing to breastfeed is rising, there is also evidence that women do not initiate breastfeeding or discontinue because of their concerns about taking medication. Unfortunately, many women and healthcare professionals rely on information in the package inserts, which may not be accurate. Milk supply can reduce within 48 hours without full and repeated emptying of the breast. Therefore, advising a mother to interrupt breastfeeding for even a few days can destroy her milk production. Hence, maintaining breastfeeding during drug treatment is increasingly recommended. Healthcare professionals should be informed about which migraine treatment can safely be used at this time.
3. Migraine in Women

Menstrual migraine

By mid 30s to 40s, migraine is three times more prevalent in women than in men. Migraine is one of the most significant risk factors for migraine, and 50% to 60% of female migraineurs experience attacks of menstrual migraine. The risk of migraine, notably migraine without aura, is increased among women during a 5-day perimenstrual window that starts 2 days before the onset of menses and continues through the first 3 days of menstruation. The International Headache Society recognises two types of menstrual migraine: menstrually-related migraine, which is migraine without aura that regularly occurs on or between day −2 to +3 of menstruation, with additional attacks of migraine with or without aura at other times of the cycle; and pure menstrual migraine, which is migraine without aura that occurs only on or between day −2 to +3, i.e. with no attacks at any other time of the cycle. To confirm the diagnosis, migraine attacks during the day −2 to +3 window must occur in at least 2 of 3 menstrual cycles to establish a relationship that is greater than chance alone. Relying on the history to confirm the diagnosis can be misleading. Use of a 3-month diary to record migraine patterns can reveal the predictable patterns associated with menstrual migraine, aiding diagnosis. According to a number of studies, menstrual attacks have distinctive clinical features such as more associated symptoms, longer duration, greater severity, greater susceptibility to relapse, greater resistance to treatment, and greater disability than migraines occurring at other times during the menstrual cycle. In a population-based study involving more than 1000 women, 84% of women with menstrual migraine engaged in fewer social activities, 59% had to limit family activities, 55% could not engage in sports, and 45% had work-related disability. Work-related disability is more often reported for perimenstrual migraines than for non-menstrual attacks (P < 0.001). Similarly, time spent at less than 50% productivity is greater for menstrual than non-menstrual attacks (P = 0.01). This disability is important as it does not only affect the individual but extends to the family and work environment.

Menopause and hormone replacement therapy

The perimenopause should be considered in women presenting with perimenstrual headache together with other recognised climacteric symptoms such as hot flushes and a change from a regular to an irregular menstrual cycle. Headache is a common but under-reported complaint in perimenopausal women. In one study, migraine was associated with significant disability with 80% of women affected reporting attacks more often than once a month, 75% reporting severe attacks and 50% reporting attacks lasting longer than one day. In 1000 women attending a Leicester menopause clinic, 85% reported recurrent attacks of which 73% reported headache more often than once a month. Management should be directed to treating the menopausal symptoms, which may include hormone replacement therapy. Studies suggest a significant association between migraine and current use of HRT. An understanding of the effects of different types of HRT is important as some studies suggest that a history of worsening migraine at menopause is a factor in predicting worsening migraine with HRT. However, the regime of HRT, route of oestrogen, and type of progestogen may all have a significant impact on migraine. Physicians treating the menopause should be aware that non-oral routes are less likely to have a negative effect on migraine than oral formulations of oestrogen replacement and continuous combined appears to be better tolerated than cyclical combined HRT.

Conclusion

The effects of hormonal changes on migraine provide healthcare physicians with specific opportunities to identify and manage migraine in women. Under-treatment – as well as causing unnecessary disability and suffering – is not economically cost-effective in terms of time lost from work and burden placed on the families of sufferers. More effective health care would alleviate much of the suffering and therefore reduce both the personal and financial costs of migraine. In particular, ineffective management of migraine in women has significant implications and personal costs for women, their families and their employers. Such consequences would in turn result in greater healthcare costs as most of these patients are referred to tertiary care. Education of healthcare professionals, greater recognition of migraine, and support of research are important strategies for reducing the total costs associated with migraine in women.

References

3. Migraine in Women


3. Migraine in Women


4. Related Syndromes

Headache, migraine and related syndromes in children and adolescents

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Clinical headache disorders in children:

Episodic tension-type headache (ETTH):

This is the most common cause of headache in children affecting about one in five schoolchildren. The headache is mild to moderate in severity, dull in nature and has no other associated features. Attacks are usually short and respond well to simple painkillers.

Chronic Tension Type Headache (CTTH):

CTTH is defined as a frequent headache disorder with attacks occurring on at least 15 days per month and each attack may last for at least 30 minutes. Around 1% of schoolchildren have CTTH. The headache is mild to moderate in intensity and there are no associated symptoms of nausea, vomiting or intolerance to light and noise. CTTH is associated with some emotional and psychiatric co-morbidity such as anxiety, depression and stressful life events.

Migraine without aura:

This is a common migraine disorder in children defined as episode of headache lasting between 2 – 72 hours that has two of the following features: (a) severe enough to interfere with some or all activities, (b) unilateral in location, (3) pulsating in character and (4) worse on walking or physical activity. It is also associated with any 1 of the following: (a) Nausea and/or vomiting and (b) light intolerance, noise intolerance.
4. Related Syndromes

Special consideration for migraine in children and adolescents

Typical migraine attacks are described as a throbbing unilateral headache, accompanied by anorexia, nausea, vomiting, intolerance of light and noise. It can last one to two days. The attacks can be relieved by rest, sleep and simple painkillers. Between attacks the child is well and healthy. However, it is common for children and adolescents to have migraine attacks that do not follow the above description as seen in adult migraine patients.

In children and adolescents migraine attacks differ from those in adults by being often shorter in duration, with 10 per cent of attacks lasting less than one hour. Although throbbing headache is characteristic of migraine, most children with migraine (60 per cent) have difficulty describing pain in general and headache in particular and many children will describe the headache as “just sore”. Also unilateral pain is less often reported by children than adults and the pain is commonly described as affecting the forehead. The severity of headache is best described in children by its effect on the child’s behaviour and normal activities. The headache can be described as mild if it does not interfere with normal, moderate if it stops some but not all activities and severe if the child has to lie down during headache is unable to carry out and activities at all. Nausea and vomiting are more often reported by children than by adults during attacks of migraine 90% and 60% respectively.

Only one in three children with migraine can identify a trigger factor for their attacks. The common trigger factors are anxiety, stress, excitement and exams. Food triggers of migraine are only occasionally reported in children.

Migraine with aura is a special type of migraine that affects around one in four children with migraine. The aura symptoms consist of visual disturbances, sensory impairment, motor weakness or a speech disturbance. The symptoms are transient and resolve completely before or soon after the onset of headache. Migraine in children may present with a wide variety of clinical features, in which headache is not the most prominent symptom. The following syndromes are of particular relevance to children:

- **“Alice in wonderland” syndrome**
  This is a special type of “migraine with aura” that is characterised by intense visual disturbances that mimic the characters of the children’s fictional story “Alice in Wonderland”. The patients have a frightening experience of distorted images, micropsia (objects look smaller than reality), macropsia (objects look larger than reality) and a feeling of déjà vu. The intense visual aura may precede, accompany or occupy the whole of the headache phase.

- **Confusional migraine**:
  Young children experience intense headache, dizziness, confusion, vomiting and lethargy following a minor head injury. Migraine attacks can imitate intracranial bleeding and children commonly attend the accident and emergency departments in acute phase requiring brain scans.

- **Childhood syndromes related to migraine or migraine variants**:
  - **Benign idiopathic paroxysmal torticollis (BIPT)** –
    This is a relatively rare syndrome, but has a clinical and epidemiological association with migraine and is likely to have a common genetic link to migraine. The syndrome is characterized by frequent episodes of unexplained head tilt in children under the age of 3 years. The episodes are painless and may last between a few hours to a few days and the child is normal between attacks. The diagnosis is made after exclusion of serious intracranial brain disorders. As children grow older they stop having the episodes of torticollis and may start to have typical migraine episodes. Some children with paroxysmal torticollis have a family history of hemiplegic migraine and some children have positive tests for the genetic mutation CACNA1A commonly found in patients with familial hemiplegic migraine.
  - **Cyclical vomiting syndrome (CVS)** –
    CVS is a syndrome related to migraine and may affect up to 2% of schoolchildren. Young children present with recurrent episodes of severe, discrete episodes of intense nausea, vomiting, pallor, lethargy and possibly headache or abdominal pain. Between attacks the child makes complete recovery and returns to normal. The diagnosis becomes apparent after a few episodes when no other causes can be identified such as infections or metabolic disorders. The episodes last from a few hours to 3 days and long episodes may result in dehydration and may require hospital admission.
  - **Abdominal migraine** –
    Recurrent abdominal pain is common in children and about 4% of schoolchildren have episodes of abdominal pain that fulfils the criteria for the diagnosis of abdominal migraine. The abdominal pain is dull in nature and is severe enough to interfere with normal daily activities. The pain is periumbilical in location and is associated with any two of anorexia, nausea, vomiting or pallor. Each attack lasts between 1 hour and 3 days with dear onset and resolution. During attacks the child looks ill, pale, withdrawn and may complain of nausea, vomiting and headache. The child feels better after rest and deep Analgesia may help reduce pain. Anti-migraine drug Pizotifen was shown to reduce the number and severity of attacks and can be used as a preventative treatment.
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- **Benign paroxysmal vertigo** –
  Vertigo is an unreal sensation of movement of the patient or the surrounding environment. It affects young children between two to five years of age. During episodes the child feels sudden unsteadiness, becomes frightened and may fall. Children cling to adults or furniture to avoid falling to the floor if standing and may just lie down. The episodes may last between a few minutes to a few hours. The child looks pale and unwell but recovers spontaneously. The Disorder can be confused with epilepsy and it should be excluded.
  No treatment is necessary. Children may grow to have typical episodes of migraine.

The impact of migraine

**School education**

Headache is a major cause of school absence. Population-based studies showed that children with migraine missed up to 82 days of school per year (an average of 2.7 days) and headache is the leading medical cause of school absence in children who missed at least 20% of schooldays per year due to illness. Among children attending specialist clinics for headache, the numbers of schooldays missed due to headache are much higher (between 32 days and three months per year).

**Level of disability**

Paediatric migraine disability Assessment (PedMIDAS) is a tool to measure the impact of headache on school (school day absences; partial day absences; and functioning at 50% or less ability). Among children attending specialist clinics for headache, the numbers of schooldays missed due to headache are much higher (between 32 days and three months per year).
4. Related Syndromes

• Quality of life

Children with migraine were shown to score lower than children without migraine against measures such as the Paediatric Quality of Life (PedsQL;4.0), which assesses physical and psychological health, emotional, social and school functioning (Powers et al., 2004). Children’s self-reporting of quality of life questionnaire was in close agreement with parents’ reporting of headache impact on their children with a clear reduction in quality of life.

Management of headache and migraine:

The management of headache in children has not been standardised and varies greatly between individuals. Also headaches are managed differently by different doctors making it important to have appropriate nationally agreed guidelines for the management of headache in children on similar lines to the SIGN guidelines for the management of headache in adult patients.

At least 40% of schoolchildren, over the age of 11 years, use over-the-counter painkillers to treat their own headache. Also it is common for parents to treat their children’s headaches, though, on many occasions, inappropriately. A study of 100 caregivers showed that only 30% were able to determine the correct dose of paracetamol and to accurately measure the intended dose. Some parents do not seek medical advice for their children due to the mistaken belief that there is no effective treatment. Other parents may seek advice from a wide variety of medical professionals (general practitioners, general paediatricians, paediatric neurologists, neurosurgeons, child psychiatrists, ENT surgeons and ophthalmologists) or alternate therapists.

The common reasons for seeking medical help are:

• Headache has been going on over a long time
• Headache is interfering with school attendance
• Headache has been too often
• Headache is no longer responding to treatment
• Concerns about a possible sinister cause for the headache

Management of the headaches and migraine starts with a good medical diagnosis of the headache disorder and reassurance of child and parents about the benign nature of migraine.

Advice on healthy life style is an important first step in management and includes an advice on regular meals, regular sleep and regular exercise and rest. Children are advised to take adequate amounts of water and avoid excessive amounts of caffeine containing drinks.

Acute attacks of migraine may build up gradually in severity and therefore the earlier the treatment is given the more likely the treatment to be successful. For that reason children are advised to seek help as early as possible after the onset of headache, have rest in an appropriate environment and take appropriate dose of simple painkiller such as paracetamol or ibuprofen. Specific anti-migraine treatment such as sumatriptan nasal spray is licensed for use in children over the age of 12 years and can be a useful addition to the control of migraine attacks.

Prophylactic treatment is indicated in children with one or more attacks per week and in those with prolonged and disabling migraine attacks. Several drugs are available including pizotifen, propranolol, topiramate and amitriptyline.

Doctors and parents need to liaise with school teachers and school nurses in order to develop a treatment plan for headache attacks that occur during school hours. The plan needs to be individualized and medical treatment is made available for use as early as possible. Children need to be supported during stressful life events and the help of clinical psychologist may be of great value.

Prognosis of migraine:

A small number of children grow out of migraine, but the majority of children continue to suffer from migraine into adult life. The natural course of the disorder is that of “good spells” of no or a few attacks and “bad spells” of frequent and severe attacks.

Future development in childhood migraine:

Most of the current evidence on treatment is derived from research studies on adult patients. Research into childhood headache is needed in order to achieve better understanding of the disorder and provide better treatment strategies for children. The following areas are of particular priority:

• Research into effective treatments of acute migraine attacks
• Research into effective preventative treatment of migraine
• Research into the impact of migraine on children’s education, social development and emotional wellbeing
• Production of national guidelines on the diagnosis and management of headache in children utilizing the best available evidence

Conclusion

• Children can suffer from a range of headache disorders which are often undiagnosed and untreated, leading to a poor quality of life and a negative impact on wellbeing and educational attainment.
• This problem lacks adequate recognition, adversely affecting two of the Every Child Matters (ECM) outcomes – Achieving and Staying Healthy. In addition, children with migraine are often unable to access their medication whilst at school which results in longer, more painful attacks.
• Parents and carers are also adversely affected, having to leave work or home to collect an unwell child from school which results in lost productivity.
• The development of national guidelines for the management of headache and migraine in children such as those of NICE and SIGN will greatly raise awareness of the problem, improve diagnosis and treatment and encourage research on many aspects of the impact of headache on children and their families.

Headache UK calls for the Department for Children, Schools and Families and the Department of Health to undertake a review of education provision for migraine sufferers in line with the ECM agenda and Healthy Schools Programme. It also calls for schools to recognise migraine as equal to other chronic conditions such as asthma or diabetes.
5. Health Service Research

UK Health Service Research
Dr David Kemick

Background
Health service research asks the question how can we draw upon social and medical sciences to deliver health care that is effective, efficient, equitable and affordable. From the perspective of headache care, it addresses the issues of how care should be managed across the NHS, what is the most suitable skill mix to deliver this care and what interventions should be delivered. Health service research seeks to inform policy makers and managers at an organisational level and clinicians at an individual patient level.

Health service research - what is happening?
The first stage in any health service research is to establish the current situation. Epidemiological research has identified that there is a regional disparity in neurological services and there is a paucity of evidence in this area but it has been suggested that there is a need for change in the research process. By contributing their experiential knowledge they can make research more relevant to their needs and therefore to the needs of the NHS.4 Although this principle is well established, the practicalities of involving lay people have prevented their involvement in many areas of health service research.

Conclusion
Health service research complements the development of bioscience. Despite significant potential for health gain, there is a paucity of evidence to inform clinical and organisational delivery of care.

References

6. Company Research

“Are we taking research into Headache Disorders and Migraine seriously?”
Dr Richard Hargreaves, BSc PhD
Vice President, Neuroscience Worldwide Head of Discovery Research, Merck Research Laboratories, West Point, Pennsylvania

According to the World Health Organisation, headaches or headache disorders, are among the most common disorders of the nervous system, and can cause substantial levels of disability. Migraine is one of the most widespread headache disorders and in the UK is estimated to affect nearly six million people and cause 190,000 migraine attacks every day2. Though not linked to mortality, headache disorders have a profound negative effect on people’s social and work lives. Often debilitating, headache disorders can lead to substantial sickness, absence from work, and loss of productivity with a major economic and health impact1. To tackle this problem, there need to be breakthroughs in research, with leadership and infrastructure to conduct translational headache research and translating problems into research-based solutions for patients. We will take academic infrastructure, improvements in training for physicians in headache medicine, and research. The 1990s saw breakthroughs in headache research and the development of new treatment strategies, including the discovery and development of new medicines. The ‘briptan’ medicines advanced acute migraine headache care. However, the general level of research into headache disorders now appears to be dwindling.

Pharmaceutical companies have a role to play in funding research, developing new medicines and contributing their expertise on these. Merck & Co., Inc., has been committed to innovative headache research over the last 20 years, and discovered one of the first in a new class of migraine medicines in the UK in the early 1990s. We believe in the importance of collaboration with academic and clinical colleagues, such as Professor Gooddy and our neuroscience research work continues with him in the USA today. Merck & Co., Inc. also provides the opportunity for investigator-initiated grants to support researchers studying headache mechanisms in the laboratory and migraine patients clinically.

There is a pressing need for a more extensive and coordinated approach to the study of headache in the UK which goes beyond single companies. An approach is required that brings together industry, academia, government and regulatory organisations to do what has become known in the US as ‘big science’. Some examples of these consortia, thought of as ‘big science initiatives’, may provide some ideas that could be developed in the UK.

First, the Foundation for the National Institutes of Health that was established by the US Congress to support the mission of the National Institutes of Health (NIH), on improving health through scientific discovery. The Foundation identifies and develops opportunities for innovative public-private partnerships involving industry, academia, government and the philanthropic community, and is a non-profit charitable organisation. It is now probably the world’s leading foundation for public private biomedical partnerships. Merck & Co., Inc. has provided funding for several Foundation initiatives to translate research to medical practice. For example, one of the programmes is the Alzheimer’s Disease Neuro-imaging Initiative (ADNI). This initiative aims to develop improved methods for clinical trials that could lead to more effective treatments for Alzheimer’s. Another example is the Biomarkers Consortium that aims to help accelerate the discovery of new technologies, medicines and therapies for prevention, early detection, diagnosis and treatment of disease.

Biomarkers are the essential elements of predictive, preventative and personalized medicine.
6. Company Research

Secondly, in the US there are new leadership initiatives underway to try to redress the deficits in headache research and medicine by creating Specialized Accelerated Research Consortiums for Headache (SPARCs). These consortia will study headache patients, translate their findings to fundamental laboratory and clinical research, and then translate this research back to clinical practice to improve patient care. The intention is that the SPARCs will promote interdisciplinary and collaborative research that is bidirectional and translational. In addition, they will train doctors for the current and future care of patients with disabling headaches. It is envisaged that SPARCs will comprise of academic centres with experimental research capability in headache, academic centres doing translational clinical research based on laboratory findings, and chemical advances from the pharmaceutical industry and clinical centres capable of evaluating new medicines and training physicians in headache medicine.

A significant example of a translational medicine strategy led to the discovery of a novel class of therapy (called CGRP antagonists), with some promising compounds now being examined in clinical trials by several pharmaceutical companies. The work started following clinical observations that levels of a particular protein were increased in cranial venous blood during migraine and cluster headache attacks. It was found that these protein levels could be normalized by some of these neural pathways, then we will be able to understand their therapeutic actions. The third example is the recent launch of the National Institutes of Health Blueprint for Neuroscience Research. This is a collaborative framework that includes the NIH Office of the Director and the 15 NIH Institutes and centres that jointly support neuroscience-related research with the aim of accelerating discoveries and reducing the burden of nervous system disorders. One of the key areas for funding in 2009 was the ‘Grand Challenge on Pain’. This was the study of the transition from health to disease, understanding the changes that occur during the transition from acute to chronic pain. The idea of the Blueprint is to bring together groups of basic and clinical pain researchers and non-pain neuroscientists who would not normally interact to capture new insights that could lead to opportunities to prevent, or reverse nervous system changes that lead to chronic pain. One could envisage that this might include the transition from acute to chronic migraine and perhaps even the study of medication-overuse headache. The hope is that this Blueprint for research may provide new avenues to explore in headache research.

Most recently, I have been interested in using functional brain imaging techniques to determine the dysfunctional neural pathways that lead to migraine susceptibility, which are activated during headache attacks. Identification and manipulation of the neuroanatomical hubs that modulate headache pain signalling and altered sensory sensitivity are critical steps in moving towards prevention and treatment of headache pain. Once we understand these neural pathways, then we will be able to study the pharmacodynamic effects of existing and potential new medicines to evaluate and understand their therapeutic actions.

The opportunity to combine brain imaging with drug discovery to have a better understanding of patients and drug actions, is an exciting area of research. However, the complexity of the brain in health and disease poses huge challenges, and our understanding of the neural circuits that underlie many human behaviours is still in its infancy. There are undoubtedly practical challenges in the use and acceptance of neuroimaging to characterise patients, monitor drug actions, understand response and non-response, link to simple migraine phenotypes and so define and improve therapeutic outcomes. There is, therefore, a clear opportunity for partnerships between different organisations with a research interest to define the place of neuroimaging in studying headache patients and supporting the development and registration of new headache therapeutics. This may be a fruitful area for future research here in the UK since neuroimaging is a research strength.

Some highlights of this migraine imaging research that we can see to date include the imaging of the trigeminal pathways that mediate migraine headache pain. We can see functional, structural and chemical changes in the migraine brain interictally (that is between attacks), and ictally (during an attack) that differ from healthy individuals. This indicates that the migraine brain is predisposed to exaggerated sensory activation as a result of changes in specific brain pathways that signal and modulate headache pain and its perception, together with the sensory emotional and cognitive disturbances that are often associated with an attack.

There is a clear need to build on existing research expertise to develop innovative new treatment strategies, to help relieve the pain and suffering of people with migraine and headache disorders. By looking at models of research collaboration, and making headache a ‘Big Science’ project, there is progress that can be made on a global scale. Merck & Co., Inc., together with other pharmaceutical companies, is committed to working with academia, medical researchers and the health service to help speed the development of safe and effective new approaches to prevent and treat the headache pain that has such enormous personal and economic consequences.
The case for academic and research growth in the UK
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Conclusions
Headache disorders range from the life-destroying consequences of migraine and cluster headache to the less troublesome, very prevalent tension-type headache. Migraine in particular is a complex brain disorder that is both very common and highly disabling. Cluster headache affords the sufferer with the worst pain known to humans. Sections of this report recognise the cost and burden of these disorders; the specific problems of headache and adolescents and the very real issues faced daily at the coal-face of the National Health Service in general practice. The basis for any attack on headache disorders must be education, yet there is little or no infrastructure to teach doctors about the problem. The principle of improving health for the future must be rooted in research, yet when the All-Party Parliamentary Group met to review UK spending on headache research, there was none to identify and the funding bodies could not even be bothered to turn up and explain the issue.

Why are we not teaching healthcare professionals about headache?
The very simple reason why headache care is so lacking is that the teachers are not available. Academic medicine, indeed academic neurology, who should be taking the lead on teaching medical students; our future doctors, and allied healthcare professionals, have simply too few teachers. There has only ever been one university chair made available for headache and that had almost no support with it- the incumbent had therefore to move elsewhere. It is axiomatic that if we do not teach students, whatever their background, we sow a seed of despair for the future and will reap a harvest of lost opportunity. Such is the state of academic progress in headache in the UK. There is no point resourcing the untrained since they will simply squander the resources. Any progress must be sustainable and produce incremental benefit year on year – such would be the effect of providing support for academic headache in the UK.

How did we forfeit the lead in headache research?
By the mid-1990s the UK had begun to establish the fresh shoots of a renaissance in headache teaching and research. The triptans, serotonin receptor agonists that targeted highly specific structures in the head to have their positive effect in migraine, began to emerge. The first was developed at Glaxo in Stevenage, the second at the Wellcome Foundation in Bedekenham, the third at Merck in Terlings Park, the fourth again at Glaxo in Stevenage, the fifth in Spain and the sixth at Pfizer in Sandwich. The greatest single advance in migraine management in the last half of the twentieth century and almost all but one of its descendents were developed in the UK but who has reaped the benefit? Fully one-third of Swedish patients, and perhaps a little under twenty per cent of North American migraine sufferers are treated with triptans, yet only eight per cent of UK patients. How much of this world boon was turned back into utility for the NHS and better management for patients—clearly too little. Why is the next major advance being developed in the US rather the UK and why is no research being targeted at migraine in the UK?
Furthermore, consider cluster headache at about one in one thousand of the population, a still substantial and horribly debilitating condition. The UK lead the way in understanding the condition and in the conduct of clinical trials. However, research funding bodies have deemed the problem too trivial to take an interest in supporting. The UK forfeited the lead in headache by not nourishing the buds of what was a potential for considerable advancement. Research brings leadership, interest, competitiveness and investment- ignoring a field has the effect of smothering innovation.

How are comparators fareing in Europe and North America?
The European Union launched an initiative to fund collaboration in headache research and a project called EuroHead delivered new genes for migraine disorders. This modest funding that provided collaboration between The Netherlands, Italy, UK, Germany, Belgium and Denmark yield more than what had ever gone before, and certainly more than the US had produced, yet now sadly it is stopped.

The funding situation is not much better in the United States. Although the prevalence rates are comparable with migraine affecting about one-third of adult Caucasian women, and costing tens of billions of dollars only about 36 cents per patient per year is allocated to all headache by the National Institutes of Health (Figure 1).

What can be done?
The way forward is clear; simple and relative to the several billions of pounds in lost productivity, highly cost-effective. The UK needs to prioritise headache by establishing a suitable academic focus to-
• Involve properly and completely both primary care, secondary care and allied health professionals as well as patient groups in the conduct of research and teaching in headache.
• Co-ordinate translational research in headache- the NHS is the most wonderful opportunity that humans have to advance headache, especially for common conditions- why not use it in a joined-up, intelligent way to get developments in science into practice for the good of all.
• Involve properly and completely both primary care, secondary care and allied health professionals as well as patient groups in the conduct of research and teaching in headache.

The best way to establish such a crucial development would be policy initiative lead by Government to instruct the Medical Research Council to seek to create an MRC Headache Unit to achieve the above goals. Headache is neither impossible nor intractable and with a small investment can be an area in which the UK leads the world and provides value to patients and to society ignoring a problem that effects more than ten million people cannot be correct, nor can it be a strategic option for the future.
References


7. Conclusion