ECONOMIST IMPACT

The challenge of migraine in South Africa

Complex, misunderstood—and surmountable

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Introduction

Often regarded as simply a bad headache, migraine is in fact a recurrent, often life-long, condition with a range of symptoms. It is also the second-leading cause of disability worldwide.[1] Around one in ten people are affected by migraine, with a higher prevalence among women by a factor of about 2:1. In addition, the impact of migraine has increased in recent years.[2,3]

Lacking a diagnostic scan or blood test, detection of migraine is often reliant on primary-care providers who lack training in diagnosing neurovascular conditions. As such, migraine is often under- or misdiagnosed and under- or mistreated. The impacts on sufferers' family, work and social life are significant, as are the broader socioeconomic impacts, especially in terms of productivity losses.

This report assesses the impact of migraine in the social, economic and health-system context of South Africa. As with elsewhere in Africa, there is relatively limited data on the prevalence and impact of migraine. In addition, deficient, poorly managed funding and health-system constraints, especially in rural and poorer areas, mean that accessing care is difficult. Meanwhile, the private healthcare system—in a country where unemployment runs at about 30% and poverty is high—is prohibitively expensive for many.[4]

Ultimately, many South Africans suffer with migraine without accessing treatment. This has a significant impact on their own lives and those of their families, as well as the country's socioeconomic landscape. Yet, the problem is far from insurmountable—as long as a comprehensive focus can be placed on sustainable, efficiently funded care, education, and a focus on prevention.

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Defining migraine and its impacts on individuals, society and the economy

Migraine is an often-misunderstood condition, regarded by many as simply an intense headache. The reality is more complex—migraine is a recurrent, often life-long neurological condition with multiple possible symptoms. There are also different types of migraine, and people are affected in different ways. Symptoms often last for hours and recur a small number of times per year, but they can also last for days and recur several times a month, waging a disabling impact on sufferers' home, social and family life. Unlike many disabling conditions, migraine disproportionately affects relatively young people, and especially women.

What is migraine?

There are two major types of migraine: migraine with aura and migraine without aura. Migraine without aura manifests in attacks lasting 4-72 hours.[5] These headaches tend to be moderate or severe and take place in one side of the brain, often with a pulsating quality. Migraine without aura is also characterised by nausea/vomiting and/or oversensitivity to light or sound.

Migraine with aura begins with a range of possible visual, sensory, speech or language, motor, brainstem, and retinal symptoms that can last for minutes or hours. These are then usually followed by (but can overlap with) moderate-to-severe headache. Visual aura (flashes of light, blind spots, bright spots, and blurred or loss of vision) are the most common, followed by sensory aura, often in the form of pins and needles.[5]

Migraine can be episodic or chronic and can progress from the former to the latter, especially if not treated properly.[6] Although episodic migraine may occur only about once a year, migraine is considered episodic in people who have as many as 14 headache days per month. Chronic migraine causes more than 15 headache days per month and can be extremely debilitating.

"A major challenge is the concept of migraine as just a headache. It is so much more. There is a whole spectrum of non-pain, clinical manifestations of migraine," says Dr Patty Francis, a South African neurologist and President of the Neurological Association of South Africa (NASA). According to Dr Francis, due to the compounding impact of symptoms before, during and after the pain phase, "patients are faced with the double burden of forcing themselves to think harder, focus harder and work harder through this increasingly severe pain."

"[If migraine attacks happen] once a week and you lose two or three days due to that, a third or even half of your life goes up in smoke"

Dr Johan Smuts, Neurologist, vice president, South African Headache Society.

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Table 1. ICHD-3 diagnostic criteria for migraines

Migraine without aura	Migraine with aura	Chronic migraine
5 or more attacks	**2** or more attacks	**15** or more days with headache **per month** for more than **3 months**
Headache lasting **4-72 hours** Headache with **2-4** of the following: • unilateral location • pulsating quality • moderate to severe intensity of pain • causing dispersion of routine physical activity Headache with **1 or more** of the following: • nausea and/or vomiting • sensitivity to light	Headache with **1 or more** of the following aura symptoms: • visual • sensory • motor • brainstem • retinal • speech and/or language Headache with **3 or more** of the following: • aura symptoms over 5 minutes • 2 or more aura symptoms in succession • aura symptoms lasting 5-60 minutes • 1 or more aura symptom is unilateral • aura accompanied by headache within 60 minutes	**5 or more** attacks for **8 or more days a month** over **3 months** with any of the following: • criteria for migraine without aura • criteria for migraine with aura • relieved by a triptan or ergot derivative

Source: Adapted from: Vincent T. Martin, Alexander Feoktistov & Glen D. Solomon (2021) A rational approach to migraine diagnosis and management in primary care, Annals of Medicine, 53:1, 1969-1980, DOI: 10.1080/07853890.2021.1995626

How prevalent is migraine—and who does it affect?

Migraine affects about one in ten adults worldwide. Total prevalence has been estimated at 11.6%, with the level slightly lower in Africa, at 10.4%.[3] Notwithstanding high prevalence rates, the impact of migraine is most striking when assessed in terms of disability. In terms of years lost to healthy life due to disability (YLDs), migraine is consistently among the top causes. In the 2019 Global Burden of Disease (GBD) study, migraine was the second highest source of YLDs, responsible for almost 5% of the total and second only to lower-back pain, a broad category encompassing a variety of conditions—often, along with neck pain, associated with migraine.[3] About 8% of people with migraine have chronic migraine.[1] However, discussion of prevalence is subject to one caveat: migraine is consistently under- and mis-diagnosed, meaning that the true burden is likely to be higher.

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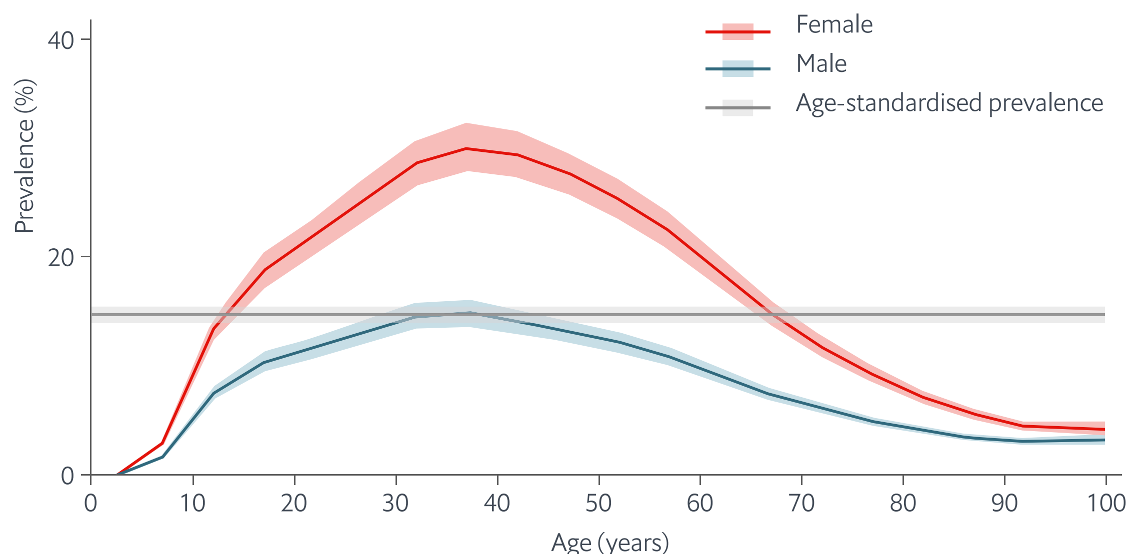
Figure 1. The global age-standardised prevalence and the global prevalence of migraine by age and sex



Shaded areas show 95% uncertainty intervals. Values are plotted at the midpoint of 5-year age categories.

Source: Ashina,Messoud,Katsarava,Zaza,Do,Thien Phu et al. The Lancet. Migraine: epidemiology and systems of care. 2021.[10]

In terms of demographic impacts, migraine is unusual because it disproportionately affects a relatively young, active proportion of the population—primarily those aged 25-55, with a peak among 35-39-year-olds.[7] Another striking demographic trend of migraine is that it primarily impacts women. Women are affected at a ratio of about 2:1 compared with men (prevalence is 13.8% among women, versus 6.9% in men), and migraine is the leading cause of disability among women aged 15-49, accounting for 8% of YLDs.[1] This is because variations in levels of oestrogen, which plays a key role in menstruation, can make the impact of migraine worse—"oestrogen desensitises the brain to pain," explains Dr Elliot Shevel, medical director at the Johannesburg-based Headache Clinic. Urban dwellers are also more impacted than people who live in rural locations. This may be the result of lifestyle differences, including variations in aspects such as sleep schedules, exercise, stress levels and meal schedules.[1]

Overall, about 20% of people experience migraine at some point in their life, regardless of race, location or income. In South Africa, a country of over 59m people, this 20% proportion equates to over 11.8m people.

Overall, about 20% of people experience migraine at some point in their life, regardless of race, location or income. In South Africa, a country of over 59m people, this 20% proportion equates to over 11.8m people. An estimated 25m working days are lost worldwide each year due to migraine. As such, many sufferers are rightly fearful of losing their jobs because of their condition. "Many are

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suffering with migraine and not saying anything," says Dr Francis while speaking about how patients are often reluctant to share the diagnosis with their employer, "[when patients are asked] Do you need a medical certificate? They say no, I took leave. I didn't want [my employer] to know. And for the ones who get hospitalised, they often ask not to put the diagnosis, just that they were in hospital."

Comorbidities and risk factors

Migraine, especially chronic migraine, has a wide range of comorbidities. It is associated with both depression and anxiety, and depression can also increase the risk of migraine becoming chronic.[1] Stress can also be a factor. And, given the impact that migraine can have on a person's life, stress levels can increase as a result of migraine, meaning that the two become mutually reinforcing. According to research by the Migraine Research Foundation, 71% of sufferers feel that their mental health has been affected by migraine.

"Stress is one of the biggest triggers for migraine. Migraine is related tremendously to muscle tension in the neck and jaw. And the more you stress, the more stressed your muscles are."

Dr Elliot Shevel, medical director at the Johannesburg-based Headache Clinic.

There are also links between cardiovascular events, such as ischaemic heart disease and stroke, especially in relation to migraine with aura, while epilepsy and obesity are also comorbidities of chronic migraine.[7] These comorbidities are generally more strongly associated with chronic migraine, which makes identifying risk factors (and therefore opportunities for prevention) of migraine progression easier to identify. However, the data on migraine comorbidities, as with much of the migraine field more generally, are inconsistent.

The prevalence of migraine has risen in recent decades, a trend that should be viewed in the context of the worldwide rise in non-communicable diseases, which includes many migraine comorbidities, such as chronic pain, sleep disorders, depression and hypertension.[3]

Genetics also play a major role in the development of migraine in individuals. Genes shared with family members can make people more sensitive to changes in their environment, such as lifestyle factors and migraine triggers.[3]

The socioeconomic impacts of migraine

Beyond the raw impact of migraine symptoms, the condition, especially in its chronic form can have a severe impact not only on the lives of those affected, but also on those closest to them. According to one US-based study, 33% of migraine sufferers reported that migraine had affected their career, almost half said that they would be a better partner without migraine and almost 40% said that it had affected their ability as parents; 3% said that their plans to have a family had been impacted by migraine.[3]

In terms of the impact of on work and employment, 90% of migraine sufferers report not being able to function normally at work during an attack, and migraine is the second most common cause of lost work days in the UK, responsible for an estimated 43m lost work days per year.[8] According to the US-based Integrated Benefits Institute, employers incur costs of almost US$9,000/year per employee related to absenteeism, healthcare spending and disability.[9] Indirect costs linked to people in the US continuing to work while suffering with migraine (known as presenteeism) have been estimated at US$5bn.[10] The fact that migraine impedes people's ability to work raises very real fears among migraine-affected workers that they may lose their jobs.

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One blind spot in terms of data and research on the impact of migraine is that waged on the families of sufferers, not only in terms of strained relationships, but also on the lives of partners and family members—a European study found that partners suffer losses linked to their own work and social activities.[3]

All in all, the consequences of migraine can be extremely significant. "There's a massive impact in terms of impairment and in terms of disability," says Dr Michael Huth, a specialist neurologist and Education Committee member at the International Headache Society. "I've seen people whose lives have been destroyed by chronic migraine."

According to the US-based Integrated Benefits Institute, employers incur costs of almost US$9,000/year per employee related to absenteeism, healthcare spending and disability.[9]

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Treating migraine

The challenge of treating migraine starts with diagnosis. Migraine is a difficult condition to pin down, manifesting as a range of possible symptoms, often with crossover to other headache disorders. The pathophysiology of migraine (the processes that cause symptoms) is shrouded in uncertainty. As such, diagnosis is reliant on what is essentially a checklist of systems used by primary care physicians and nurses who often have only a limited background in neurological or headache disorders.

"We all understand what a migraine is. But medically speaking, it's meaningless, because 'migraine' is a set of symptoms. [Diagnosis] is actually not telling you where the pain is coming from and what's causing it."

Dr Elliot Shevel, medical director at the Johannesburg-based Headache Clinic.

Once migraine has been diagnosed, there are two main approaches to treatment—acute and preventive treatments. Acute treatments tend to be drugs-based: in South Africa, as elsewhere, pharmacotherapy—usually in the form of specialist migraine drugs called triptans or more common painkillers such as paracetamol and ibuprofen—accounts for most of the direct costs related to treating migraine.[11]

A large range of drug treatments are also available for preventive treatment to reduce the frequency, severity and duration of attacks before they occur. These are largely repurposed from other conditions, including epilepsy and depression, although specialist drug treatments have recently come to the market. These drugs, calcitonin gene-related peptide (CGRP) antibodies, are the first targeted preventive drugs for migraine. This development is good news, says Dr Huth. "I think that there's a lot more advantage [to migraine-specific medications]," he says, likening the use of other medications to treat migraine—a condition that is still not fully understood—as throwing a dart and hoping that it hits.

In addition, a range of injections and device-based treatments can be used to modify nerve function (either to stimulate specific nerves or dull their function). Botulinum toxin, a bacterial derivative (marketed, especially in cosmetic surgery, as Botox) is used to treat a variety of neurological conditions, including migraine.

Behavioural treatments are one aspect of migraine management that is relatively underexplored. These can include stress management, biofeedback (learning to recognise and react to early signs of migraine) and cognitive behavioural therapy

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(CBT).[12] Biofeedback is also used to manage comorbidities such as depression and anxiety, demonstrating that the overlap with these conditions extends to prevention. Lifestyle interventions in general can have an impact, says Dr Smuts, even where the link is not obvious. "Stress is not the reason why people get migraines," he says. "But if you are a migraine sufferer and you stress a lot, you most certainly will have a lot more [attacks]. If you don't sleep well, it is likely that it might unmask something. So I'm very much advocating healthy lifestyle; I think we think that is not important, but it is tremendously important."

Looking to the future, the pathophysiology of migraine is becoming increasingly better understood, and the increasing availability of new migraine-specific preventive treatments such as CGRP antibodies bodes well. In addition, a range of non-pharmacological treatments have demonstrated positive impacts—as well as CBT these include physiotherapy and acupuncture.[13] For migraine sufferers, their families, employers and health services currently spending relatively large sums on acute treatment, the move towards targeted, preventive treatment must be regarded as positive.

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Migraine care in South Africa

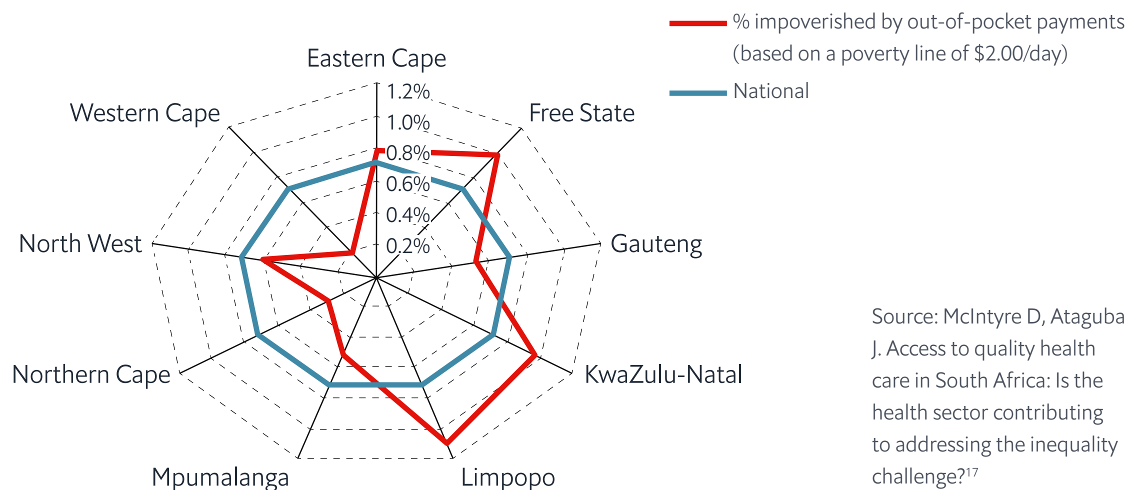
The fundamental trends of South Africa's health system, which is split between a state-funded service and a (primarily insurance-funded) private service, are relatively positive: spending has risen steadily both in GDP terms and per capita over the past two decades, as has government spending, and out-of-pocket (OOP) spending has fallen.[14] However, these overall trends hide inequity and underfunding within the system.

While OOP spending has fallen, it is higher on a per capita basis than in 2000, meaning that uninsured people pay more in OOP costs.[15,11]

Private healthcare is generally expensive in South Africa—it serves less than 20% of the population yet consumes almost half of the health spend—and costs are increasing.[16] Inequity in public healthcare—in some cases linked to Apartheid-era funding frameworks—also persists in regional spending, with wealthier, metropolitan areas receiving larger sums.

In terms of migraine care, all of this has two clear impacts: the primary care services upon which most sufferers should be able to rely for diagnosis and initial treatment are under-resourced or

Figure 2. Impoverishment associated with out-of-pocket payments by province in South Africa, 2005/06[17]



Source: McIntyre D, Ataguba J. Access to quality health care in South Africa: Is the health sector contributing to addressing the inequality challenge?[17]

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inaccessible; and secondary or specialist treatment costs too much to be widely accessible. "Insurers have not recognized migraine as a chronic disorder. And so, they don't approve any funding for migraine medication," says Dr Francis.

Many of the drugs used to treat migraine, including the preventive, migraine specific CGRP antibodies, which are not yet available in South Africa, are not funded by the public or private systems. "If you have to see a specialist, it might be too expensive," says Dr Smut. "If you look at the state system, there is a significant problem in terms of manpower. For the majority of patients, you can make a very good clinical diagnosis. But the dilemma comes with the level of treatments that you could provide."

Part of the consequence, says Dr Huth, is a broad lack of recognition of migraine as a serious condition, as well as a poor health-seeking culture—linked to limited public health access and expensive private costs—even for conditions that are more widely recognised as serious. "The burden and the disability of migraine in South Africa is grossly underestimated and under-recognised," he says. "And this has led us over the last 10-20 years to be behind the developed world in terms of treatment and management."

This hints at another aspect that is lacking in South Africa when it comes to migraine: education. Primary healthcare providers even in the most well-resourced countries often have minimal training in neurological and headache-related conditions, and in South Africa this is exacerbated by the fact that primary care services are under-resourced.

At a higher level, health decision-makers in the public and private sectors lack knowledge on how to efficiently manage migraine at a society level. For example, although some treatments are expensive on a per-case basis, says Dr Huth, they don't need to be prescribed to every (or even relatively many) migraine sufferers. "We're not asking for every GP to be able to treat a migraine with any drug and get funding; we want to start off [by saying that] if a neurologist signs the script for the expensive migraine specific treatment, please fund it."

Limited information is also available about how to seek help for migraine. Equally, lifestyle-related prevention is another area where knowledge is lacking, both in terms of research and publicly available information. Employers, too, would benefit from better understanding the burden and treatment options linked to migraine.

"[Employers] don't really understand how Migraines can stop you from working or performing at work or can cause you to be continuously absent," says Dr Huth. "There's just not that level of awareness, knowledge or education for employers to understand that this is a separate illness to headache that causes a lot of problems and needs to be taken seriously."

"It may not be lack of knowledge as compared to an allocation of priority," says Dr Francis, adding that the experience of covid-19 showed what can be done when there is a whole-of-government response.

"The burden and the disability of migraine in South Africa is grossly underestimated and under-recognised, and this has led us over the last 10-20 years to be behind the developed world in terms of treatment and management."

Dr Michael Huth Specialist neurologist, Education committee member, International Headache Society, president, South African Headache Society.

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Looking Ahead

Clearly, migraine is a difficult condition to manage—even countries with well-equipped, equitable health systems struggle to do so effectively. In South Africa, universal challenges are bolstered by an under-funded, inconsistently resourced health system that is reluctant to fund the most effective migraine treatments, as well as a broader lack of knowledge around migraine. Yet the worst impacts—if approached in an appropriate way, from the individual to the health-system and socioeconomic level—are preventable, and the burden manageable.

Affordability and use of treatments

Cost is a limiting factor in migraine treatment in both the public and private health sectors in South Africa. Often this is related to a concern by decision-makers that spending will spiral if more treatments are made available. Yet this misunderstands the complex nature of migraine—and the fact that most people will not require expensive drugs or specialist treatment.

"What is important to understand is that this is a multifaceted thing, and to try and think of it as one symptom, one treatment is absolutely ridiculous," says Dr Smut. "Yes, it affects many people. But you start off with the most basic things and you reserve the most high-end things for a very small number of people. And by doing that, you make a tremendous difference to society as well."

"We try to approach [payors] and say 'look, huge amounts of the population actually have migraine, very few of them are going to doctors, and even fewer of them are ending up with neurologists,'" says Dr Huth.

Another area of focus should be primary care. To manage the overall burden efficiently, and to ensure that people can be treated without

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costs increasing unsustainably, more equitable resourcing of primary care services would enable as many patients as possible to access the level of care that they require, whether basic, lifestyle-related advice or specialist neurological or psychological treatment.

Despite access, diagnostic and reimbursement barriers, people suffering from migraine should be encouraged to seek support from a specialist, as the appropriate treatment can significantly improve quality of life.

"Because of the frequency of occurrence, [Migraine] is often self-diagnosed and self-medicated," says Dr Francis. "[Self-medication] predisposes people to other types of headaches such as medication overuse headaches and side effects, and delays their introduction to, or consultation with a specialist. Contact with the appropriate specialist should begin the appropriate evidence-based medication, which will give the patient a better quality of life, not just coping with the pain." Dr Francis adds that while accessing a neurologist may be challenging, "there is about one neurologist to 500,000 of population", other specialists such as physicians, psychiatrists and anaesthetists, who are pain specialists, can also support.

Elevate the importance of lifestyle-based prevention

Given the impact that migraine attacks have on the lives of sufferers, and the consequent burden that this places on families, healthcare providers and employers, there are clear benefits to approaching migraine in terms of prevention. Lifestyle-related approaches to prevention can reduce the likelihood and impact of migraine attacks and limit the chances of episodic migraine becoming chronic. Given the strong links between migraine and stress, stress management, biofeedback and mindfulness-linked CBT offer a way to head off the worst impacts of migraine.

"Diet and lifestyle play a major part in the wellbeing of patients," says Dr Smuts. "And if you can address that … you don't need to spend a cent on anything [and] you actually start saving on medical costs."

Employers have a duty here, too, adds Dr Smuts—not least because their businesses are reliant on healthy workers. He also adds that self-diagnosis tools such as questionnaires can help people to decide whether they need to approach healthcare professionals.

Dr Huth also points to technological solutions to help people self-manage migraine. "There's an app called Migraine Buddy, which allows you to track your symptoms, your sleep, your diet; your headache duration, what medication you took. You can also go on to forums and support groups and get information there."

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Education

The keystone that will enable people, health workers, health decision-makers and employers to overcome the burden of migraine is education. In South Africa and beyond, migraine is a widely misunderstood condition—in terms of its pathophysiology, how it manifests, how it impacts on people's lives and how it can be treated.

A large part of education efforts should be focused on the health sector. Primary care providers must be better supported to recognise migraine and take appropriate approaches to treatment (including referral to specialist care where necessary). Health decision-makers must be shown that migraine does not impact all patients equally, is rarely a costly condition to treat, and is far better treated than left to cause broader health and social impacts.

Outside of health services, greater awareness must be created about the complex characteristics of migraine, the impacts on people's lives, and the benefits that can be gained by individuals and society as a whole if it is understood and managed correctly.

A key part of a push to educate people about migraine will be advocacy and research. This, suggests Dr Huth, will involve "dedicating a specific society, such as the recently formed South African Headache Society, to the treatment of headaches … that will put together consensus statements and ideas and guidelines on the best practice for treatments." He adds that part of the solution should be specialist headache centres (seen in Europe and the US), with targeted treatments and multidisciplinary teams. "We want to promote concepts behind understanding the disability behind migraine … That is kind of the future for the next five to ten years."

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Economist Impact would like to thank the following experts for sharing their insights and experiences:

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