

## Review article

## Barriers to headache care in low- and middle-income countries

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## ABSTRACT

Headache disorders are a common cause of disability globally and lead not only to physical disability but also to financial strain, higher rates of mental health disorders such as depression and anxiety, and reduced economic productivity which negatively impacts gross domestic product (GDP) on a national scale. While data about headache are relatively scarce in low- and middle-income countries (LMICs), those available suggest that headache disorders occur on a similar scale in LMICs as they do in high-income countries. In this manuscript, we discuss common clinical, political, economic and social barriers to headache care for people living in LMICs. These barriers, affecting every aspect of headache care, begin with community perceptions and cultural beliefs about headache, include ineffective headache care delivery systems and poor headache care training for healthcare workers, and extend through fewer available diagnostic and management tools to limited therapeutic options for headache. Finally, we review potential solutions to these barriers, including educational interventions for healthcare workers, the introduction of a tiered system for headache care provision, creation of locally contextualized diagnostic and management algorithms, and implementation of a stepped approach to headache treatment.

## 1. Introduction

Headache disorders are one of the most common medical conditions worldwide and are associated with significant disability. The 2019 Global Burden of Disease (GBD) study ranked headache disorders as the third most common cause of disability globally, after back pain and depressive disorders, with migraine the top cause of disability in adults under 50 years of age [1]. According to the 2016 GBD study, almost 3 billion people worldwide are living with headache disorders. Tension-type headache (TTH) affects 1.89 billion, and ranks as the third commonest disease worldwide behind only dental caries and tuberculosis [2]. The rising prevalence estimates of headache disorders may be an artefact of better recent population-based studies, but their effect on disability demonstrates that headache is a major global public health concern. However, despite the unquestionably high global burden of headache, health care provision for headache, including the quality of care delivered and rates of utilization, are consistently poor across all world regions, countries, cultures, and settings, but this is especially true

in low- and middle-income countries (LMICs) [3].

In this review, we highlight common barriers to headache care for people living in LMICs, including clinical, political, economic, and social barriers, as well as their consequences (Table 1). Subsequently, we review potential solutions to these barriers that may be applicable in LMIC settings (Table 1).

## 2. Clinical barriers to headache care in LMICs

Ineffective delivery systems for headache care in many countries, regardless of economic stratum, combine such that only a small proportion of people who could benefit from appropriate pharmacological treatment of their headaches actually access that care. Even in high-income countries (HICs), with greater numbers of healthcare providers available to their populations, many people with headache disorders are not evaluated in medical systems. A survey of adults with migraine from the United Kingdom, France, Germany, Italy, and the United States found that consultation rates with physicians were unexpectedly low

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**Table 1**

Summary of common barriers that individuals with headache disorders in LMICs face in obtaining proper diagnosis and management of their headache disorders as well as potential solutions for each identified barrier.

Barriers	Potential Solutions
(a) Clinical barriers to headache care	
Shortage of neurologists and neurology training programs	Increase opportunities for formalized neurology training programs
Misdiagnosis	Healthcare worker education programs targeted at healthcare workers of all levels
Lack of validated algorithms to identify patients at highest risk for secondary headaches who need more extensive evaluations	Locally contextualized research to develop structured diagnostic questionnaires and treatment algorithms based on local epidemiology
Increased rates of medication overuse headache	Public education regarding therapeutic options for headache
(b) Political/economic barriers to headache care	
Ineffective healthcare delivery systems	Development of structured headache services such as the three-tiered system
Inadequate treatment or therapeutic mismanagement	Improved education of health care personnel and general providers
Neuroimaging may be unavailable, unaffordable or delayed	Healthcare worker education programs targeted at healthcare workers of all levels
Reduced access to CSF diagnostics	Advocacy within health ministries and government policy makers to improve access to diagnostic services
	Improved training of healthcare workers to limit inappropriate utilization of diagnostic testing during headache evaluations
	Advocacy within health ministries and government policy makers to improve access to diagnostic services
(c) Social Barriers to Headache Care	
Community misperceptions regarding headache	Public education regarding the nature of headache disorders
High rates of secondary headache disorders in regions with high HIV burden	Healthcare worker education programs targeted at healthcare workers of all levels
High refusal rates of lumbar puncture	Increase opportunities for formalized neurology training programs
	Public education on the indications, risks, and benefits of lumbar puncture

[4]. In India, fewer than one-quarter of those with headache had consulted a physician for their headache in the preceding year [5]. In China, barely half of those with migraine or medication overuse headache (MOH) and only 40% of those with TTH had consulted with a physician. While headache disorders are a major public health concern in sub-Saharan Africa (SSA) [6], literature on neurological diseases in this large region is scarce. Therefore, it is unclear what percentage of individuals with headache disorders in SSA undergo formal evaluation by a provider [7].

Even among individuals who are evaluated by a healthcare provider, misdiagnosis and inadequate treatment of headache disorders are common. A World Health Organization (WHO) global survey of healthcare providers identified lack of training in diagnosing and managing headache disorders as a key reason for inadequate headache management, leading to misdiagnosis and inappropriate treatment for those who do seek medical care for headaches [3]. Accurate diagnosis of headache disorders presupposes that healthcare workers have received adequate headache education, which data have shown is generally not true in most settings, especially LMICs where a great proportion of healthcare is provided by non-physician healthcare workers [3].

An efficient headache care delivery system relies on adequate education and training in headache diagnosis and management by healthcare providers at all levels. In such a system, primary care providers should be able to provide optimal management for the great majority of people with common headache disorders, since neurologists are not

needed for most headache care. However, most undergraduate medical programs do not offer in-depth teaching in current headache practices. As a result, practicing general physicians are not well equipped either to provide good pharmacological and non-pharmacological treatment options for headache or to understand the negative impact headache disorders can have on individuals' productivity and quality of life [8].

Neurologists are the specialists most likely to receive training in the diagnosis and management of headache disorders and to encounter large numbers of patients with headache disorders in their clinical practice, in LMICs as elsewhere. For example, headache disorders constituted 21% of the diagnoses made in a Ugandan outpatient neurology clinic [9], and 27% of diagnoses in a Tanzanian neurology outpatient clinic, where it was the most frequent neurological diagnosis [10]. However, neurologists are in short supply in most LMICs. The 2017 *WHO Atlas of Country Resources for Neurological Disorders* showed the European Region had a median of 6 neurologists per 100,000 population while the African and South-East Asia Regions reported medians of 0.10 and 0.04 respectively [11]. The *Atlas* emphasized the striking deficiency of adult neurologists in low-income (median of 0.03 per 100,000 population) and lower-middle-income (median of 0.13) compared to upper-middle-income (median of 1.09 per 100,000 population) and high-income (median of 4.75) countries [11]. Unfortunately, many LMICs also suffer from a shortage of neurology training programs. Of 19 countries surveyed in SSA, respondents from only nine reported the existence of postgraduate neurology training in their countries [12]. The consequences are not only fewer neurologists available to care for patients with headache but also fewer neurologists available to train other healthcare personnel in good headache management.

Lack of healthcare providers well-versed in headache management, paucity of available headache prophylactic medications, and ease of obtaining over-the-counter analgesics for pain have combined to result in high rates of MOH in many LMICs, as in Ethiopia [13] and Zambia [14]. In these settings, easy access to analgesics from private-sector pharmacies may provide temporary relief from headache while lessening incentive to seek formal medical assessment of their headache – a pathway likely to increase the burden of MOH over time. This is especially true in urban areas where over-the-counter analgesics are even more accessible. For example, in Zambia, the prevalence of MOH in rural areas was 2.1% compared to the striking urban prevalence of 14.5% [14].

### 3. Political/economic barriers to headache care in LMICs

LMICs suffer from a shortage of physicians who are well-trained in primary headache disorder recognition, leading to high rates of misdiagnosis and inadequate or inappropriate treatment [15]. Lack of local expertise limits headache awareness campaigns, opportunities for continuing medical education activities focused on headache, and advocacy efforts within healthcare policy sectors. The dearth of local experts also means less locally driven research to address these policy gaps.

Furthermore, LMICs suffer from a knowledge gap regarding the ill-health consequences of headache disorders. For instance, the prevalence and attributable of headache disorders in both adult and pediatric populations in SSA are largely unknown. Because health policy decisions are often – and to a large extent should be – based on the perception of ill-health burden, this knowledge gap makes it difficult for uninformed policymakers in LMICs to recognize headache disorders as a public health concern, accord due priority to them, develop policies and structures for improving access to good headache care, and implement changes that would improve diagnosis and treatment of headache disorders and thereby reduce their associated disability. Yet, in SSA countries where data are available, such as Zambia and Ethiopia, prevalence of headache disorders is comparable to that in HICs [13,14]. In Zambia, the one-year prevalence of any headache among the adult population is estimated at 61.6%, and of individual headache disorders

at 22.9% for migraine, 22.8% for TTH, and 11.5% for headache disorders characterized by headache on  $\geq 15$  days/month, including 7.1% for MOH [6]. Surveys in Zambia and Ethiopia also revealed an association between headache-associated disability and economic loss at national level, with indirect costs of headache estimated at 1.6% loss of gross domestic product (GDP) in Ethiopia [13] and a similar 1.9% loss of GDP in Zambia [6].

In addition to barriers to diagnosis of headache disorders, LMIC settings often have substantially fewer pharmacologic options available for headache management when compared to HICs. While therapeutic options differ by country, basic medications are available in most countries. In a WHO survey, countries were asked to report on the availability of at least one medicine (acetylsalicylic acid, ibuprofen, paracetamol, or propranolol) used for the treatment of headache disorders at both primary-care and hospital levels. Of the 117 responding countries, 108 (92%) reported consistent availability of at least one medication in primary care and 110 (94%) at hospital level [11]. The *Pan-African Medical Journal* published a formal consensus statement developed by a multinational group of authors on widely available medications for acute first and second-line headache treatment, as well as prophylaxis [16]. This first expert consensus making recommendations for the management of migraine in African adult patients was created as a practical guideline for healthcare practitioners to adapt to the medical resources most commonly available in their local settings within SSA.

Affordability of expensive tests such as neuroimaging is an additional challenge. Many LMICs lack personal health insurance options, especially for the poorest segments of their populations, resulting in medical tests such as neuroimaging being accessed through out-of-pocket payments. For example, in Cameroon, an estimated 40% of the population live below the poverty line, and 96–98% do not have any form of financial protection for healthcare-related expenses. In such circumstances, out-of-pocket payments as the main means of accessing CT imaging often leave patients and their families financially debilitated [17]. Data from the World Bank indicate that each drop in World Bank income group is associated with a 29% decrease in the share of the population who can afford a given test [18]. The WHO defines catastrophic health expenditure as health-related out-of-pocket expenditure of  $>40\%$  of disposable household income [19]. In most low-income countries surveyed, only the top 10–20% of income earners in the population were able to afford tests without catastrophic health expenditure [18]. In surveyed lower middle-income countries,  $>40\%$  of the population, on average, could not afford neuroimaging tests [18].

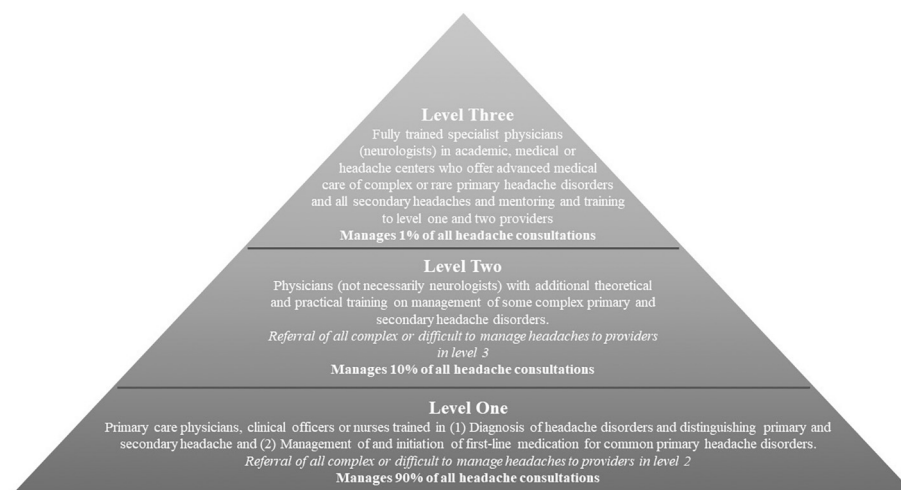
#### 4. Social barriers to headache care in LMICs

Cultural beliefs have a huge bearing on headache health-seeking behaviors in communities [20]. Beliefs that headache is caused by social or emotional problems, visual impairment, exposure to very bright light, or supernatural forces are common in many cultures. Entrenched reliance on traditional healers is also common in many cultures, not infrequently coupled with distrust of modern medicine. These myths and behavioral preferences often result in delayed, missed or erroneous diagnoses of headache disorders, and failure to receive medically proven treatments. Community perceptions of headache in LMICs often erroneously attribute it to hypertension, or, in regions with high rates of tropical diseases such as malaria, typhoid and meningitis, to an infectious process [4,21]. When this occurs, mismanagement is the result.

#### 5. Barriers to identifying secondary headaches in LMICs

When managing headache disorders in both HICs and LMICs, healthcare personnel at all levels of the healthcare system must be able to differentiate between primary and secondary headache disorders. In general, secondary headache disorders due to infectious disease are more common in low-resourced settings than in HICs, so a high degree of clinical suspicion for secondary and infectious causes of headache must be maintained in these settings [4]. However, current algorithms designed to aid clinicians in determining which individuals should undergo more extensive evaluation for secondary headaches are often not applicable to LMIC settings. One major reason for their poor transportability to LMICs is that HIV infection is often an absolute indication for neuroimaging in these algorithms [22], while  $>90\%$  of people living with HIV reside in LMICs [23], where neuroimaging is often unavailable and unaffordable – and certainly not to be performed without clear need. At the same time, headache is one of the most common complaints in this patient population [24]. Thus, contextualized and validated algorithms for identifying patients at highest risk for secondary headaches in regions with a high burden of HIV infection are urgently needed.

To the extent that evaluation of potential secondary causes of headaches requires additional diagnostics – not only neuroimaging but also examination of cerebrospinal fluid (CSF) – limited access to these diagnostics, especially neuroimaging such as computed tomography (CT) and magnetic resonance imaging (MRI), creates barriers in many LMICs. In a study conducted in the West African subregion in 2015 and 2016, a severe deficit of MRI facilities was identified, with only 84 MRI units serving a combined population of over 370 million people [25]. Even when facilities are available in a LMIC, they are often limited to a



**Fig. 1.** Three-tiered system for headache healthcare provision proposed by the Global Campaign against Headache [29]. This system is reliant on improved training of healthcare providers at level one and reserves limited specialist care for individuals with the most complex and difficult to treat headache disorders.

few hospitals within the country, usually in urban centers not geographically close to where many patients reside [18].

Imaging results are also often delayed in LMICs. In urgent situations, only about 15% of patients in low-income countries can obtain CT imaging for stroke evaluation within 4.5 h of symptom onset, compared to 100% in high-income countries [18]. The resultant delays in initiation of appropriate treatment can be devastating for individuals with headaches secondary to infectious or inflammatory etiologies.

Obtaining CSF via lumbar puncture (LP) is a key diagnostic step in some patients with headache in order to rule out infectious and inflammatory causes. However, in resource-limited settings, LP may not be utilized because of inadequate staff training, lack of proper equipment, and inaccurate analysis of CSF. For example, although LPs are performed in a rural hospital in Mosango, Kwilu Province, in the Democratic Republic of Congo, even basic CSF diagnostics such as glucose and protein concentration cannot be obtained, limiting the utility of the investigation in determining headache etiology [26]. This clinical scenario is not uncommon in many LMIC settings.

High refusal rates for LP in some regions further limit its utility in the evaluation of secondary headaches. In a study of inpatient pediatric care in 14 district hospitals in Kenya, no LPs were performed on 46 patients presenting with symptoms and signs of meningitis, despite 13 hospital laboratories having capacity for CSF microscopy [27]. A survey of clinicians practicing in urban medical centers in Nigeria, Malawi, and Zambia found that half of respondents reported LP refusal, often attributed to patients' and relatives' preexisting belief that the procedure would cause death [27]. While this was a major barrier to clinical care in these countries, provider-level factors, including inadequate staffing and training, and unavailability of prior neuroimaging to assess risk of herniation, also contribute to LP non-performance in resource-limited settings [28].

## 6. Potential solutions to improve headache care in LMICs

While barriers to good headache care are plentiful in many LMICs, so too are potential solutions. For example, the development of structured headache services in LMICs could rectify the under-diagnosis and undertreatment of headache in these regions. One possible strategy is the three-tiered system advocated by *Lifting The Burden: the Global Campaign against Headache*, in collaboration with the European Headache Federation (Fig. 1) [29]. This system assumes that approximately 50% of all those with headache should be able to manage themselves, such as those with episodic TTH or less frequent migraine. However, this necessitates improved public education about the nature of headache disorders and how to manage these episodes. Of the remaining 50%, who need professional care, level-1 healthcare providers would manage the great majority (~90%). Level-1 providers are intended to be primary care physicians, clinical officers, or nurses who are expected to be capable of diagnosing and managing common primary headache disorders, as well as recognizing important secondary headaches, after completing a concentrated short training course. Level-2 providers are physicians (not necessarily neurologists) with additional theoretical and practical training in headache medicine and would be expected to manage more complex primary headache disorders as well as some common secondary headache disorders. Finally, level-3 providers are fully trained specialist physicians in academic medical centers who manage highly complex or rare primary headaches and the full range of secondary headache disorders [30]. The purpose behind this structure is to reduce unnecessary demand upon specialists and reserve higher levels of headache care for those who truly require it [29]. In the absence of a structured system of headache care, the unmet healthcare need for people with headache will almost inevitably persist. By developing a structured headache healthcare system, LMICs can ensure people with headache have contact with a healthcare professional at the appropriate level, with headache knowledge adequate for that level, and receive appropriate diagnosis and management.

Improving education of primary care providers is a vital step in improving the global burden of headache and is also a prerequisite to developing a tiered headache care system. Educational interventions have been shown to be beneficial in LMIC settings. For example, in Estonia, an education model was created to improve headache care delivered by general practitioners [31]. Primary providers attended an educational program delivered as two six-hour courses on headache medicine. As a result of the intervention, participants referred fewer patients to specialists, used more specific headache diagnoses, ordered fewer unnecessary diagnostic tests for headache, and were more likely to initiate headache treatment than they were prior to the intervention. In Senegal, there are "neuro caravans" where neurologists travel to rural regions to train local providers in management of common neurologic conditions [32]. Similarly, the Disease Relief Through Excellent and Advanced Means (DREAM) health program created an initiative to educate >10,000 African personnel, including clinical officers, doctors, and nurses, in 11 countries in SSA on how to manage communicable and non-communicable diseases, including headaches from primary and secondary causes [33]. This initiative allowed more patients to be evaluated and receive treatment for their headaches without needing to be seen by a specialist.

Training generalists and nonphysician providers, especially in rural regions, in the basic management of highly prevalent neurologic conditions such as headache disorders is an appropriate response to the shortage of neurologists in LMICs. But it is insufficient. There is a paucity of formalized neurology training programs in LMICs, and a need to increase their number, quality and availability. International collaborations, whereby experienced external individuals and organizations help to establish such programs, provide one means of achieving this in LMICs with pressing requirements for more neurologists [15]. For example, the National Autonomous University of Honduras and the World Federation of Neurology (WFN) collaborated to develop a curriculum in Honduras, which continues to undergo internal and external evaluation [15]. Their curriculum includes research and teaching skills, and has led to increased epidemiologic studies in Honduras and public health interventions. Similar interventions could be applied to other LMICs to tackle headache disorders and other neurologic conditions.

Especially in LMIC settings, where the majority of primary headache care is likely to be provided by non-physician healthcare workers, improving headache diagnosis and management may begin with implementation of structured diagnostic questionnaires and treatment algorithms. Among potential tools are the *Aids to management of headache disorders in primary care*, developed by the Global Campaign against Headache and providing comprehensive guides on diagnosis and management of headache disorders in primary care together with assessment instruments [34]. The latter can be administered by medical or trained lay interviewers and include questions based on diagnostic criteria of the International Classification of Headache Disorders, 3rd edition. There are separate modules such as a headache diary that assists diagnosis and a headache calendar that supports follow-up [34]. A pre-treatment Headache-Attributed Lost Time in 90 days (HALT-90) index and post-treatment Headache-Attributed Lost Time in 30 days (HALT 30) index quantify one important impact of an individual's headache disorder – on productive time. The Headache Under-Response to Treatment (HURT) questionnaire measures the outcome of treatment while offering guidance on how treatment might be modified for better effect [34]. Advantages of these instruments in busy clinical settings are that they are short questionnaires, and can be self-administered and scored. Although these aids to management were designed for use in European countries, adaptations for use in LMICs are possible owing to unlimited free accessibility to content and translation protocols.

Improving availability of medications for good headache management in LMICs is also imperative. The therapeutic intervention for headache associated with the greatest population-level health gain is acute, stepped-care management using aspirin plus sumatriptan [35]. This approach was developed using a WHO model for cost-effective

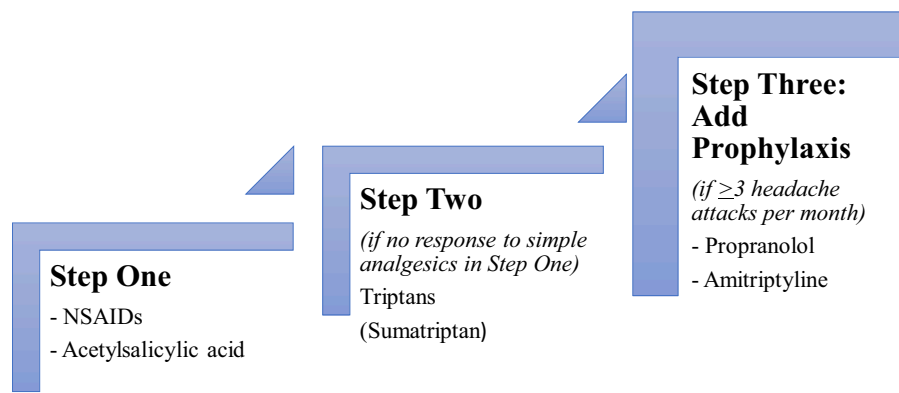


Fig. 2. Illustration of the stepped care approach for headache treatment which has been shown to be cost-effective using modeling analyses based on available data from China, India, Russia and Zambia.

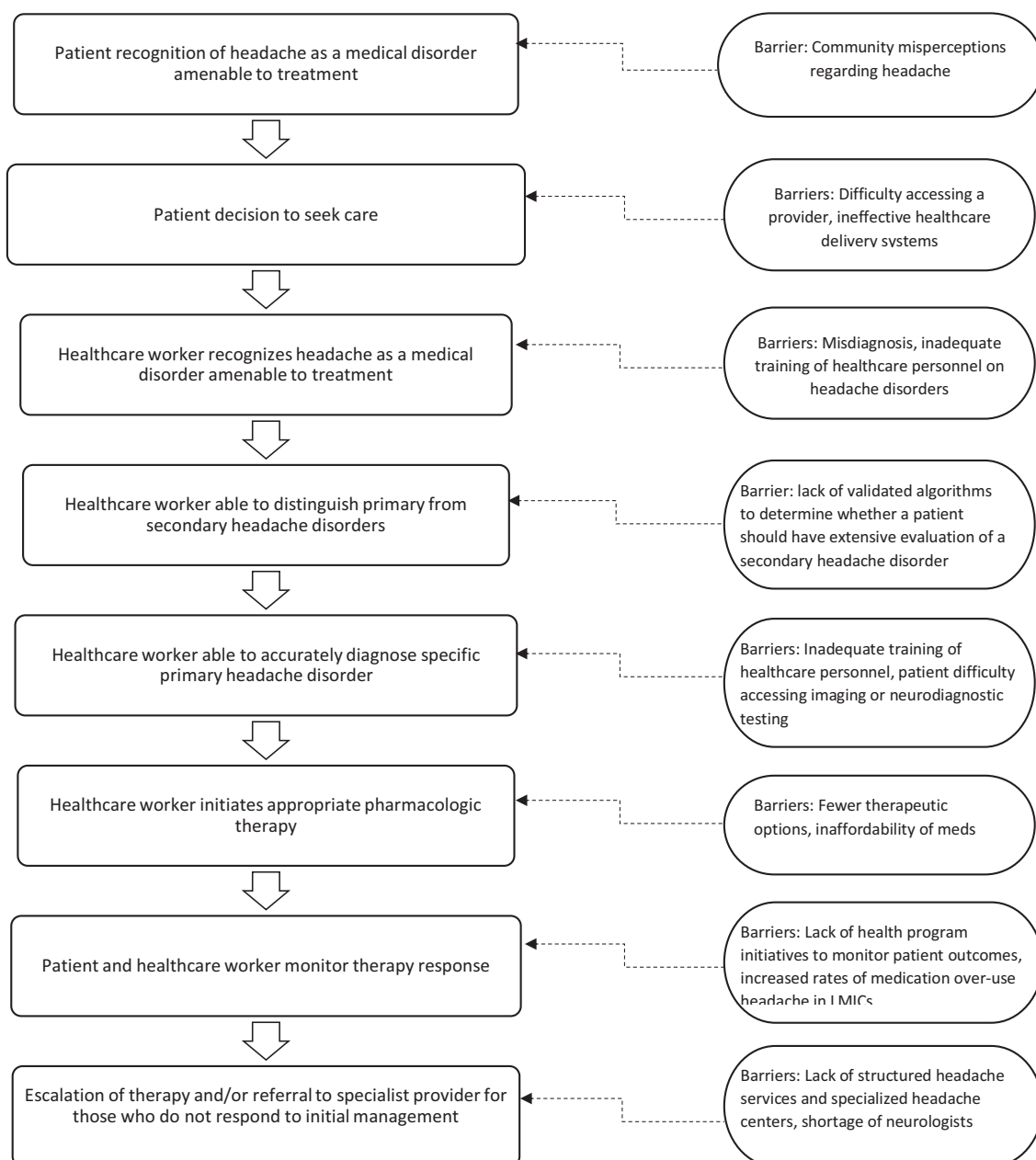


Fig. 3. Typical patient pathway to headache care with barriers with the potential to impact each step in the care pathway noted to the right.

analysis focusing on a core set of intervention strategies for migraine that were theoretically applied to the general populations of China, India, Russia, and Zambia (Fig. 2) [35]. This model assumed that triptans were used only by non-responders to simple analgesics such as aspirin in a stepped care treatment paradigm. Other model assumptions were that acute treatment is initiated at headache onset and is used once per attack, while prophylaxis would be offered only to people with 3 or more migraine attacks per month. When this model was theoretically applied to the four countries, implementation of aspirin and sumatriptan as abortive therapy resulted in a gain of 700–1600 healthy life years (HLYs) per one million population. A combination of acute management and prophylaxis also offered sizeable health benefits. While these would not be fully realized in the population because of incomplete coverage and adherence [35], both of these can be enhanced by the educational initiatives that are an essential part of structured headache services [29].

Among therapeutics used for acute care, aspirin is widely available globally, and has been shown to be highly cost-effective. In the same WHO model of cost-effectiveness applied to the same four countries, use of aspirin in this treatment paradigm cost less than US\$100 per HLY gained [35]. Paracetamol/acetaminophen is one of the most common medications actually used for acute management of headaches in many LMIC settings, and similarly inexpensive, but, it should be noted, less effective [36]. Of note, the WHO's Essential Medicines List includes a core set of drugs known to be effective and cost-effective for migraine management, including aspirin (ibuprofen for children) and sumatriptan, along with propranolol as a preventative medication [37]. However, whether drugs on the Essential Medicines List are included on national formularies varies by country, and policy and advocacy work will be required in many LMIC settings in order to increase access to this basic set of essential headache medications.

While limitations in neuroimaging affordability and accessibility are unlikely to be resolved quickly, improved training of primary care providers on headache management often results in the ability to avoid the cost of CT imaging altogether [38] by allowing providers to feel more confident that this is not indicated when the patient's history is reassuring and neurologic examination shows no abnormalities. This is also true in LMICs, where the yield of correctable abnormalities from routine CT imaging in individuals with headache who have normal neurologic findings and an absence of concerning clinical features is low [38]. Therefore, it is likely to be more cost effective to train healthcare workers to obtain a detailed history and undertake physical examination so that limited imaging resources can be reserved for patients with a high suspicion for intracranial lesions or those with poor response to initial management [38,39].

## 7. Conclusions

Headache disorders, such as migraine, TTH, and MOH contribute significantly to the global burden of disease, impact quality of life, and can be financially penalizing as a result of lost workdays and productivity. Yet, individuals with headache disorders in LMICs face multiple barriers to accessing appropriate headache care, including lack of community and healthcare provider awareness of headache disorders, limited headache education of healthcare workers, lack of access to specialist services and basic investigations for headache disorders, inadequate treatment availability, and an absence of data regarding the best way to screen for secondary headaches in populations with a high prevalence of HIV infection (Fig. 3). Low funding and poor health policies for headache care in LMICs, compounded by under-recognition of the burden of headache disorders in these settings, further deter advancements in care [40]. Improved patient education and provider training in headache management in addition to partnering with policymakers for the systematic development of structured headache services and stepped management of headache disorders are essential. Increased local research is also needed in LMICs to understand the full burden of headache disorders in these settings, investigate factors that

contribute to poor headache management, and develop locally relevant diagnostic and therapeutic algorithms. In doing so, healthcare systems can develop locally contextualized and effective diagnostic and therapeutic approaches to tackle this very substantial public-health problem that accounts for a major proportion of the global neurologic burden of disease.

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