



Review article

Advocacy for patients with headache disorders

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ABSTRACT

Primary headache disorders are worldwide highly prevalent and burdensome and should be therefore considered as a global public health priority. However, too many patients with primary headache disorders still do not receive satisfying care. The most likely identified reasons for such a scenario - lack of public awareness, stigma, lack of trained professionals with inadequate healthcare systems and policies - are remediable. Despite the progresses that were made in headache advocacy, these efforts have not yielded substantial improvements in research funding or access to specialty care and even standards of care. The situation is more complex in Low and Middle Income Countries (LMICs) where headache advocacy is urgently needed given the magnitude of the difficulties that patients with primary headache disorders face in accessing care. The growing emergence of coordinated, collaborative, patient-centered advocacy efforts with improved patient-clinician partnership is an opportunity to enhance progress in advocacy for a satisfying life and optimal and equitable care for people with primary headache disorders. LMICs can benefit greatly from coordinating these efforts on a global scale. The recent organization of a training program on headache diagnosis and management for healthcare professionals in Africa is a concrete example.

1. Advocacy – articulated goals

Migraine is second among the world's causes of disability, and first among young women (1). The age groups during which primary headache disorders tend to be most troublesome in patients are 15–64 years-old, an age group that accounts for about two thirds (66%) of the world's population (2). It has been estimated that a global average of about 15% of adults aged 15–64 have migraine disease and 80% of those are significantly disabled through pain and associated symptoms (3). Accordingly, per every million people worldwide, 80,000 adults (12% of the 660,000 aged 15–64 years) need care because of migraine-attributed disability (2) and patterns indicate a rising global migraine prevalence (4).

Numerous studies have been conducted around the world and increasingly provide more accurate data on the characteristics of primary headache disorders (3,5,6). These studies highlight a higher

prevalence of primary headache disorders in LMICs than previously estimated (7–9), with important economic and disability-associated burden (10). Discrepancies have been identified between earlier estimates and The Global Campaign “Lifting the Burden” estimates in several LMICs (7–10). According to GBD, sub-Saharan African countries generally were described as having the very lowest migraine prevalences (11). In Zambia, The Global Campaign “Lifting the Burden” migraine prevalence estimate was 22.9% in 2015, at least comparable to the rest of the world (7). GBD prevalence estimates used to rely on studies with disparate methodologies, and frequently selected populations surveyed. Global advocacy efforts should then be inspired by “Lifting the Burden approach” and be focused on correcting pivotal estimates that guide global health policies, to ensure equitable public health and advocacy resource allocations in Africa and other LMICs.

Patients living with headache disorders still face many challenges in obtaining medical care and treatment, particularly in LMICs. Less than

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one-third of even the most severely affected receive a diagnosis (3) and only 8.5% of those with episodic and 1.8% of people with chronic migraine surmount the four barriers to receiving optimal care – namely, appropriate medical consultation, and receiving an accurate diagnosis, minimally appropriate acute and preventive treatments, and education around the avoidance of acute medication overuse (12). Worldwide, approximately half of the headache disorders population relies on self-treatment (6,13).

The growing body of data showing the burden of headache disorders in LMICs (7–10,14–16) contrasts with the magnitude of the difficulties that patients with headache disorders face in accessing care in these countries. Advocacy for people with disabling headache disorders is therefore urgently needed in LMICs. Patient organisations have been actively advocating for headache disorders in higher income countries with increasing success (17–19). Advocacy efforts need to be initiated at multiple levels in LMICs, addressing individual, interpersonal, and institutional barriers and encompassing local, national, regional and global levels (20).

To optimize the impact of advocacy efforts, advocacy stakeholders must recognize articulated advocacy goals: educate and empower patients, drive public awareness and reduce stigma, mandate headache education in medical school curricula, increase access to care and treatment, drive funding and promote headache research, impact payor coverage and policy support, and educate healthcare providers. Each goal builds on the other, effecting a cascade of success. As patients are educated and empowered, for example, they are able to drive public awareness and reduce stigma. Likewise, as stakeholders are able to drive funding and promote headache research, new and innovative treatments will lead to patient demand for access to and payer coverage for such treatments. The realization of each of these objective goals requires a unified effort of healthcare providers, pharmaceutical and device manufacturers along with other treatment industry representatives, payer and policymakers, and patient advocates.

Using an original approach based on a patient personal journey from being patient to becoming globally active advocate, and through an overview of the situation in Africa and other LMICs, this paper intends to underline the need for headache advocacy, particularly in LMICs, and provides suggestions for how headache advocacy could contribute in these countries in particular, referring to concrete examples. This collaborative work benefited from the combined insights of patients, researchers, health professionals and advocates from diverse cultural backgrounds.

2. From patient with headache disorder to global advocate: A personal story (by Audrey Craven)

Picture a mother with 3 young children lying on a floor unable to function due to a migraine attack from what is generally regarded as only a headache! I was that young woman and, once I obtained a proper diagnosis and treatment plan, my life improved enormously. Family and close friends became vital caregivers all through those dark years -their role should never be underestimated or taken for granted. The burden of migraine is determined by the severity and frequency of attacks. I learned to keep a headache diary and recognize triggers early and changed lifestyle to include regular sleep, rest, exercise, food, and hydration. This hard-earned experience led me on a journey of headache patient advocacy.

Back in 1994, I contacted Ireland's best-known broadcaster to say I was planning a public meeting with a medical doctor as guest speaker. Hundreds turned up and so the Migraine Association of Ireland (MAI) was founded to raise awareness and gain recognition for headache disorders. Thanks to a small group of committed volunteers including medical advisers, we set about providing accurate, reliable information and support to all. This work (pre internet) involved a Helpline, composing leaflets and newsletters, and organising public seminars. We partnered with other stakeholders in the field of neurology and gained

respect as the “go to” organization for primary headache disorders. In 1998, due to lobbying, the first Headache/Migraine clinic in Ireland was opened in a major teaching hospital to great publicity on the national airwaves. Then in 2000, MAI was granted annual funding by the Irish Government's Department of Health, which meant full time staff could be employed, and the Association grew to be one of the most respected in Europe. Outreach increased through use of new technology and digital platforms based on the founding principle of “putting the person living with migraine at the centre.” Peer to peer support is vital when building trust and educating patients, which leads to better self-management and quality of life. An informed patient is an empowered patient and, working with a team of multi-disciplinary healthcare providers to publicise the importance of seeking an accurate diagnosis and appropriate treatment plan, the message began to permeate society at large. Invitations to speak on numerous platforms about headache disorders based on published evidence helped to make the organization a trusted third party. Respect for a strong patient voice grew, not just advocating for a medical model but treating the whole person. In addition, seventeen national patient organisations joined forces to form the Neurological Alliance of Ireland with the purpose of improving the public health system. This coordinated approach led to an increase in the number of Hospital Consultant Neurologists being appointed from nine to twenty-four.

Ireland's story shows that advocacy is a vital tool for increasing research, care and treatment for patients living with headache disorders. However, it should be noted that success takes time – and even more time for countries with income and resources less than Ireland's. Ireland's advocacy efforts started in 1994 and still continue. This demonstrates an imminent incentive for advocacy to begin in LMICs. And a coordinated and collaborative approach among nations will be required to facilitate and hasten progress – people suffering cannot and should not be required to wait for generations for eminently achievable outcomes to occur. The sooner advocacy efforts begin, the sooner success can be achieved.

3. Drive public awareness and reduce stigma/ educate and empower patients

As noted above, a principle goal of headache advocacy is driving public awareness and reducing stigma. People with headache disorders, especially migraine, experience stigma globally and at multiple levels. (17,20–23). The feeling of social exclusion is greater in people with chronic migraine than in people with epilepsy (21,22). Stigma is multidimensional (17,20–23). Patients with headache disorders experience public stereotypes and negative attitudes that prevent them from seeking treatment and adopting effective self-care. They experience structural stigma with inadequate and discriminating policies, laws and organizational practices (17,23). When internalized, stigma negatively impacts on perceived quality of life and worsens chronic pain (22,23). Literature in this area is scarce in LMICs. If we consider Multiple Sclerosis (MS), as with other chronic diseases, patients depend heavily on the public support and healthcare system. People with MS might experience social stigma at different levels and discrimination in the workplace (24). The use of Atlas of MS and the World Brain Day 2021 Stop MS global campaign data raised awareness of MS and supported individuals to improve health outcomes (25,26). Although there is no direct comparison between MS and migraine advocacy efforts, it is clear that these two chronic conditions can inspire each other and still require efforts to understand, de-stigmatize and manage. In HIV positive persons, peer mentorship programs for adolescents and adults led in Zambia have shown improvement in internalized stigma and in viral suppression (27). This was preceded by a set of studies that provided a detailed description of the manifestations, impacts and risk factors of stigmatization in this country for persons living with HIV (28–30). Results from teacher trainings interventions, in sub-Saharan schools were promising regarding the decrease in HIV stigma among school teachers (31).

Further studies are needed to describe attitudes and beliefs towards headache disorders and patients with primary headache disorders in these countries, and the influence of stigma on access and quality of care and policies (32,33).

Destigmatizing primary headache disorders is one major focus of advocacy (17,19,20,23). As a preliminary matter, self advocacy can help in fighting against stigma (17). People with headache disorders should be able to access relevant knowledge (17,34), become empowered, and also be trained to self-advocate. This should be supported by patient advocacy organisations (17) and healthcare professionals (34). Destigmatization efforts should also include raising awareness for respect and work accommodations for patients with headache disorders in the LMICs. (35) This is a relevant area of focus given the peak prevalence and impact of migraine between the second and sixth decade (1).

Educational campaigns are key and can include patient education programs (workshops, group sessions, and individual sessions) and more broadly general public educational sessions, and communication campaigns (television, schools, and workplace communication campaigns) (23,35). Patient education provided by health care professionals regarding their headache management could be provided at relatively low cost in LMICs (36). Additionally, collaboration with traditional healers can be considered in contexts where they are respected and trusted in their communities and are in significant number compared to specialists or trained health professionals (37).

Political engagement of organisations of patients or advocates in particular, in wealthier countries, has helped to reduce institutional stigmatization towards persons with headache disorders (17). This has allowed in the USA, for example, the issuance by the Social Security Administration of the first ever ruling to guide migraine claimants on filing Social Security Disability Insurance (SSDI) claims under current regulations (17). Although there is still some way to go, this approach could be inspiring in LMICs and in Africa in particular.

4. Increase access to care and treatment/ educate and empower patients

Access to care and to effective treatment is challenging for persons with headache disorders in the United States (3,5) and in many higher income European countries (6). In LMICs, the situation is even more dire, due in part to the scarcity of trained physicians (13,32,38–41) and healthcare facilities. In countries where rural areas are prevailing, access to health services is even more difficult than in urban areas due to mobility constraints related to long distances to health facilities (with poor or potentially inexistent roads) (37) or to geographical barriers (8). Local/regional epidemiological conditions also may exacerbate constraints on access to appropriate care in LMICs with limited resources and poorly equipped health facilities, and with highly prevalent HIV infection (42–45).

In addition to limited healthcare facilities, great variations of health literacy among patients is found across LMICs (46). Low health literacy among patients can prevent patients from seeking appropriate treatment. Patients with migraine or tension-type headache disorders may not easily understand their condition as a neurobiological disease. Further, they may not fully accept that, although their condition is treatable, initial treatment options may fail. They may also struggle to make effective and safe health decisions (47).

Traditional or ethnomedical practices can be widespread in LMICs (48–50). As reported in Nepal (8), medicinal or traditional herbs alone or in addition to analgesics are used in LMICs to manage headache disorders (50). Other traditional methods are also used, including bloodletting (51), blood cupping with small skin incisions (52) (Hijama), cauterization treatment (using hot bicycle spokes or pieces of iron for example) by a traditional healer or by the person himself (48,49), applying raw butter on the head (48,49), and putting a tight scarf around the head (48,49,52).

Motivation for using such practices, whose effectiveness and safety

have yet to be determined, is multifactorial. In a study led in Kuwait, 70% of patients with primary headache disorders used traditional medicine (blood cupping, head banding, herbal medicine, diet modification) before consulting a headache clinic. This rate rose to 100% in those with chronic migraine. In this study, the first reason for seeking traditional medicine was cultural/ religious (Islamic tradition) beliefs, followed by ineffective medical treatment, and intolerance/ fear of medical treatment (52).

Access to conventional and effective medication is also challenging. Self-medication can be frequent (7–9). Headache disorders are among the first complaints for which over-the-counter drugs are consumed in Sub-Saharan Africa (53). Preventive treatments are almost never used (54), some treatments such as triptans are still exceptionally used, and the range of drugs used frequently are limited to simple analgesics such as paracetamol or aspirin (41,54). The high prevalence of medication overuse headache in some of these countries, mainly in urban regions, correlates with a difficult access to trained professional health care (7,9).

Patient and population educational programs are needed when barriers to treatment access are related to cultural/ religious belief(52) or knowledge gaps. These efforts will improve health literacy in these countries, improving the capacity to interpret, obtain, understand and make appropriate health decisions from management options. Optimally, such education will prevent medication overuse headache in countries with the lowest health literacy, or in areas where trained practitioners are scarce or absent.

5. Drive funding and promote headache disorders research

Research is key in advocacy (17,18), as it generates the essential knowledge on which the different components of advocacy can be built. The Global Campaign “Lifting the Burden” against headache disorders and consequent development of a standard methodology for burden assessment increased the availability of data and the visibility of burden globally in LMICs, with locally adapted tools (3,5–10,13–15). This should help increase awareness for primary headache disorders, inform and drive policymakers, and orient resource allocation (9,35). This is essential in LMICs with limited resources.

The American and International Registries for Migraine Research supported by the American Migraine Foundation (55) are another initiatives directed to improve the understanding of headache epidemiology and patients' needs, locally and globally. Even though implementing such initiatives and ensuring its sustainability require significant resources, opportunities for adapting them at lower cost should be considered, particularly for LMICs.

Advocacy should stress the need to encourage and fund research that provides more locally accurate knowledge. This would effect modifications in guidelines that are practical and contextually aligned with current guidelines in LMICs. Nonetheless, efforts should be made to ensure that proper resources are available to optimize headache management according to evidence-based guidelines, including for specific populations and specific contexts (e.g. HIV+ people presenting with headaches in LMICs) (42–44).

Advocacy efforts are also needed in LMICs to encourage and fund research for evidence-based data that evaluates local practices and traditional medicine approaches, as well as accurately analyzing patients' motivations in seeking traditional medicine. This research will provide evidence-based and culturally/locally-appropriate communication campaigns and minimize the potential health hazards of some traditional or ethnomedical practices.

6. Impact payor coverage and policy support / increase access to care and treatment

Financial issues hinder access to treatment (6). Having health coverage or health insurance is one of the predictive factors of good headache/migraine management (3,5). In Africa, there are large

discrepancies in health coverage between and within countries (56). In countries without health insurance programs, prescribed medication is hardly affordable for those with low health coverage. This contributes to the difficulty of access to health services for patients with headache disorders when they are expected to be the primary payers (out-of-pocket) for their treatment. Patients with headache disorders may have to choose between spending money on headache treatment or on other family expenses. Advocacy efforts are needed to adapt policies and health coverage programs to better support care for patients with headache disorders, especially in LMICs, and decrease out-of-pocket payments by families.

Simple and low cost strategies for treatment and prophylaxis can be effective in LMICs (36). Their rapid implementation should be considered, given that policy adjustments may take longer and that even in poor settings, patients may be willing to pay for the management of their headache disorders (57). Collective bargaining for medications should also be considered in order to lower medication prices in lower income countries (37).

Promoting agile and contextualized adaptations of the healthcare services is needed, especially in LMICs. A model for structured headache services refining older proposals with vertical integration between care levels (primary, secondary and tertiary) was recently developed (2). This locally adaptable model with headache services based in primary care and embedded in the broader national or regional health services could be considered and adapted to LMICs, tailored according to local needs, infrastructure and resources.

Task shifting (meaning that specific medical tasks can be transferred from specialists to newly trained individuals), is a relatively affordable adjustment to the health system to improve access to care with a more efficient use of available human resources in contexts where specialists are scarce (37,58–60).

In the United States, for example, advanced practice practitioners (APPs) which include nurse practitioners (NPs) and physician assistants (PAs) provide medical care and education in headache and migraine under the supervision of a licensed doctor. In Africa and other LMICs, task shifting experiences have been led in for other clinical situations showing its feasibility and potential benefits (37,60). They are currently being considered for the management of neurological conditions including headache disorders in LMICs (59). Through including community workers, for example, task shifting can also help tackle problems of access to health services, such as long distances, travel or commuting difficulties. Community workers must be properly trained beforehand. They can, for example assist in providing educational support to patients.

Further help in addressing geographic and mobility barriers to care access could rely on mobile health technology (37,61–64). This technology can in turn help in task shifting in these settings, while bearing in mind certain precautions, notably resources availability (37,61).

7. Education of healthcare providers

A significant barrier to the care and treatment of patients living with headache disorders is the fact that, across the globe, most patients do not receive a proper diagnosis of their condition. A fundamental obstacle to receiving proper diagnosis is the lack of headache disorders-trained healthcare providers and headache disorders specialists. According to the Atlas of Headache Disorders And Resources In The World by the World Health Organization and Lifting The Burden, of 101 countries surveyed, 75% reported that among changes that would improve the care of people with headache disorders, professional education is by far the highest on the list (13). While this problem is significant in high-income countries (65), it is even more dire in low-income countries. Frontline healthcare providers have often received minimal training in neurology in general and in the diagnosis and management of headache disorders in particular (13,32,41). Many LMICs lack a neurological society, and some countries do not have a neurologist at all (39,66). In

addition, within those countries great geographical discrepancies in regard to distribution may be found. As an example in Tunisia: 125 / 179 neurologists are located in 5 regions out of a total of 24 Tunisian regions (40).

As experience has shown, however, patient advocacy organisations can play a vital role to remedy the lack of healthcare providers educated in headache disorders and its treatment. In a “first of its kind” event, IHS-GPAC (International Headache Society – Global Patient Advocacy Coalition), the African Academy of Neurology (AFAN), the World Federation of Neurology (WFN) and the International Headache Society joined efforts to present a two-day education program entitled “Education in Headache to Healthcare Providers In Africa.” The program was held on August 21, 2021 and on September 4, 2021 to initially introduce headache disorders and then build into content with a focus on migraine. Importantly, patient advocates were an integral part of the planning and faculty for this meeting. Thirteen different sessions featured various topics such as methods for approaching patients with headache disorders, evaluation of migraine and diagnostic criteria, management of migraine, and the global impact of patient advocacy (67).

The “Education in Headache to Healthcare Providers In Africa” event registered 551 registrants from 71 countries. A post-event evaluation survey indicated that the program was successful in its endeavor. Table 1 indicates the results of the 52 attendees that responded to the survey (67).

Based on its success, the “Education in Headache to Healthcare Providers In Africa” program should not be the last of its kind. The program has proven that joint efforts between clinicians experienced in headache disorders diagnosis and treatment and patient advocates can do much to advance education in countries where social constraints and economic disparities mean that medical care is not freely accessible or feasible. Such programs should be offered again to include other African countries and further expanded to other continents.

It is important to note, however, that of the 551 registrants, 224 reported expertise in neurology; in contrast, 129 reported to be in general healthcare practice. As the ultimate goal of programs such as “Education in Headache to Healthcare Providers In Africa” is to provide citizens of low- income countries greater opportunities for diagnosis and treatment of headache disorders by healthcare professionals, future programs should drive attendance towards general practitioners, as there are likely to be more general practitioners in a community or country than neurology or headache experts. As noted by Timothy J. Steiner and Jes Olesen (18), primary care physicians can easily manage the five essential components of headache healthcare: awareness of the problem; correct recognition and diagnosis; avoidance of mismanagement; directing appropriate lifestyle modifications, and informed use of cost-effective pharmaceutical and other remedies.

While programs such as “Education in Headache to Healthcare Providers In Africa” can address the present-day problem of the dearth of physicians trained in headache medicine, headache advocates also can direct their efforts to the void of such training in medical schools. Worldwide, formal undergraduate medical training commits on average only four hours to headache disorders (13). Postgraduate training

Table 1
Post-event survey key findings (67).

Attendees statements: “As a result of attending the program, ...	Percent of attendees
... they can distinguish migraine from other headache disorder”	55%
... their confidence to make a correct diagnosis of migraine and other types of headache disorders had increased”	48%
... their understanding of the underlying biology and pathophysiology of migraine and other headache disorders had improved”	37%
... their confidence in treating and managing migraine and other headache disorders had increased”	28%

typically does not overcome this shortfall in education. This does little to generate interest among medical students to pursue headache medicine (68), and it does little to encourage established health care professionals to become proficient in headache treatment further in their career. Primary headache disorders are not often perceived as serious among healthcare providers (69) as they are often episodic, are not contagious, and do not cause death. Patient advocates in higher-income countries, now aware of recent pharmaceutical and device treatments available for headache disorders, are motivated to urge medical schools to adopt new attitudes towards headache disorders and training. This can also be of benefit to patients in LMICs, for instance, through the return of some of the practitioners trained in higher income countries.

8. Conclusion

Despite recent success, further headache advocacy is needed in high income countries while advocacy efforts are urgently needed in LMICs given the magnitude of the difficulties that patients with headache face in accessing care in these countries. Advocacy for appropriate headache care and greater access to treatment will benefit from cohesive collaboration among numerous trained advocates, including patients, healthcare practitioners, industry representatives, payors, and policy makers. The Global Campaign “Lifting the Burden” for headache disorders is successful, and the core contents are universally applicable. However circumstances and realities in LMICs make a comparison impossible. Initiatives such the “Education in Headache to Healthcare Providers In Africa” programs should be expanded and encouraged. Advocacy at all levels is the core, but resources, targets and medical background vary. The delay in advocacy efforts in LMICs should be seen as an opportunity to learn from and build on the successes of advocacy efforts in high income countries (18), and adapt to local structures, needs and resources.

Declaration of Competing Interest

None.

References

- On Behalf of Lifting The Burden: The Global Campaign against Headache, T. J. Steiner, L.J. Stovner, R. Jensen, D. Uluduz, Z. Katsarava, Migraine remains second among the world's causes of disability, and first among young women: findings from GBD2019, *J. Headache Pain* [Internet] (2020 Dec), <https://doi.org/10.1186/s10194-020-01208-0> [cited 2021 Dec 19];21(1). Available from:.
- T.J. Steiner, R. Jensen, Z. Katsarava, L.J. Stovner, D. Uluduz, L. Adarmouch, et al., Structured headache services as the solution to the ill-health burden of headache: 1. Rationale and description, *J. Headache Pain* [Internet] (2021 Dec), <https://doi.org/10.1186/s10194-021-01265-z> [cited 2021 Dec 19];22(1). Available from:.
- D.W. Dodick, E.W. Loder, A. Manack Adams, D.C. Buse, K.M. Fanning, M.L. Reed, et al., Assessing barriers to chronic migraine consultation, diagnosis, and treatment: results from the chronic migraine epidemiology and outcomes (CaMEO) study, *Headache J. Head Face Pain*. 56 (5) (2016 May) 821–834.
- Y.W. Woldeamanuel, R.P. Cowan, Migraine affects 1 in 10 people worldwide featuring recent rise: a systematic review and meta-analysis of community-based studies involving 6 million participants, *J. Neurol. Sci.* 372 (2017 Jan 15) 307–315.
- R.B. Lipton, D. Serrano, S. Holland, K.M. Fanning, M.L. Reed, D.C. Buse, Barriers to the diagnosis and treatment of migraine: effects of sex, income, and headache features, *Headache J. Head Face Pain* 53 (1) (2013 Jan) 81–92.
- Z. Katsarava, M. Mania, C. Lampf, J. Herberhold, T.J. Steiner, Poor medical care for people with migraine in Europe – evidence from the EuroLight study, *J. Headache Pain* [Internet] (2018 Dec), <https://doi.org/10.1186/s10194-018-0839-1> [cited 2021 Dec 19];19(1). Available from:.
- E. Mbewe, P. Zairethiama, H.H. Yeh, R. Paul, G.L. Birbeck, T.J. Steiner, The epidemiology of primary headache disorders in Zambia: a population-based door-to-door survey, *J. Headache Pain* [Internet]. (2015 Dec), <https://doi.org/10.1186/s10194-015-0515-7> [cited 2021 Dec 19];16(1). Available from:.
- K. Manandhar, A. Risal, T.J. Steiner, A. Holen, M. Linde, The prevalence of primary headache disorders in Nepal: a nationwide population-based study, *J. Headache Pain* 16 (2015) 95.
- M. Al Jumah, A.M. Al Khathaami, S. Kojan, M. Hussain, H. Thomas, T.J. Steiner, The prevalence of primary headache disorders in Saudi Arabia: a cross-sectional population-based study, *J. Headache Pain* [Internet]. (2020 Dec), <https://doi.org/10.1186/s10194-020-1081-1> [cited 2021 Dec 19];21(1). Available from:.
- M. Zebenigus, R. Tekle-Haimanot, D.K. Worku, H. Thomas, T.J. Steiner, The burden of headache disorders in Ethiopia: national estimates from a population-based door-to-door survey, *J. Headache Pain* [Internet]. (2017 Dec), <https://doi.org/10.1186/s10194-017-0765-7> [cited 2021 Dec 19];18(1). Available from:.
- World Health Organization, The Global Burden of Disease: 2004 Update 146, 2008.
- D.C. Buse, C.E. Armand, L. Charleston, M.L. Reed, K.M. Fanning, A.M. Adams, et al., Barriers to care in episodic and chronic migraine: results from the chronic migraine epidemiology and outcomes study, *Headache*. 61 (4) (2021 Apr) 628–641.
- World Health Organization and Lifting The Burden, Atlas of Headache Disorders and Resources in the World 2011, WHO, Geneva, 2011.
- T.J. Steiner, G.L. Birbeck, R. Jensen, Z. Katsarava, P. Martelletti, L.J. Stovner, Lifting the burden: the first 7 years, *J. Headache Pain* 11 (6) (2010 Dec) 451–455.
- M. Zebenigus, R. Tekle-Haimanot, D.K. Worku, H. Thomas, T.J. Steiner, The prevalence of primary headache disorders in Ethiopia, *J. Headache Pain* 17 (1) (2016 Dec) 110.
- M. Chraa, L. Adarmouch, T. Steiner, K. Najib, Headache yesterday in Morocco: prevalence and impact, *J. Neurol. Sci.* 381 (2017 Oct) 428.
- R.E. Shapiro, What will it take to move the needle for headache disorders? An Advocacy Perspect. *Headache* 60 (9) (2020 Oct) 2059–2077.
- T.J. Steiner, J. Olesen, Advocacy for patients with headache, in: T. Wijeratne, S. Crewther, D. Crewther (Eds.), *Advocacy in Neurology* [Internet], Oxford University Press, 2019 [cited 2022 Jan 15], pp. 339–346. Available from: <https://doi.org/10.1093/med/9780198796039.001.0001/med-9780198796039-chapter-29>. Available from:.
- K. Gvantseladze, T.P. Do, J.M. Hansen, R.E. Shapiro, M. Ashina, The stereotypical image of a person with migraine according to mass media, *Headache*. 60 (7) (2020) 1465–1471.
- D. Dodick, L. Edvinsson, T. Makino, W. Grisold, F. Sakai, R. Jensen, et al., Vancouver declaration on global headache patient advocacy 2018, *Cephalalgia*. 38 (13) (2018 Nov) 1899–1909.
- P.M. Estave, S. Beeghly, R. Anderson, C. Margol, M. Shakir, G. George, et al., Learning the full impact of migraine through patient voices: a qualitative study, *Headache*. 61 (7) (2021) 1004–1020.
- W.B. Young, J.E. Park, I.X. Tian, J. Kempner, The stigma of migraine. *Preux PM*, editor, *PLoS One* 8 (1) (2013 Jan 16), e54074.
- S.K. Parikh, J. Kempner, W.B. Young, Stigma and migraine: developing effective interventions, *Curr. Pain Headache Rep.* 25 (11) (2021 Dec 6) 75.
- R. Dobson, D.R. Rice, M. D'hooghe, R. Horne, Y. Learmonth, F.J. Mateen, et al., Social determinants of health in multiple sclerosis, *Nat. Rev. Neurol.* 18 (12) (2022 Dec) 723–734.
- C. Walton, R. King, L. Rechtman, W. Kaye, E. Leray, R.A. Marrie, et al., Rising prevalence of multiple sclerosis worldwide: insights from the atlas of MS, third edition, *Mult Scler Houndmills Basingstoke Engl* 26 (14) (2020 Dec) 1816–1821.
- T. Wijeratne, E.C. Jones, W. Grisold, W.M. Carroll, Global advocacy in action: world brain day 2021 dedicated to stopping multiple sclerosis, *Neurol. Clin. Pract.* (2022 Jan 20), <https://doi.org/10.1212/CPJ.0000000000001151>.
- J.A. Denison, V.M. Burke, S. Miti, B.A.S. Nonyane, C. Frimpong, K.G. Merrill, et al., Project YES! Youth engaging for success: a randomized controlled trial assessing the impact of a clinic-based peer mentoring program on viral suppression, adherence and internalized stigma among HIV-positive youth (15–24 years) in Ndola, Zambia. Price MA, editor, *PLoS One* 15 (4) (2020 Apr 2), e0230703.
- J.R. Hargreaves, S. Krishnaratne, H. Mathema, P.S. Lilleston, K. Sievwright, N. Mandla, et al., Individual and community-level risk factors for HIV stigma in 21 Zambian and south African communities: analysis of data from the HPTN071 (PopART) study, *AIDS Lond. Engl.* 32 (6) (2018 Mar 27) 783–793.
- H.S. Jones, S. Floyd, A. Stangl, V. Bond, G. Hoddinott, T. Pliakas, et al., Association between HIV stigma and antiretroviral therapy adherence among adults living with HIV: baseline findings from the HPTN 071 (PopART) trial in Zambia and South Africa, *Trop. Med. Int. Health TM IH* 25 (10) (2020 Oct) 1246–1260.
- J.A. Parsons, V.A. Bond, S.A. Nixon, “Are we not human?” stories of stigma, disability and HIV from Lusaka, Zambia and their implications for access to health services, *PLoS One* 10 (6) (2015), e0127392.
- R. Martin, C. Ashimosi, W. Nyandiko, A. Chory, J. Aluoch, M. Scanlon, et al., A systematic review of interventions to reduce HIV-related stigma among primary and secondary school teachers, *AIDS Care* 34 (1) (2022 Jan 2) 1–6.
- M. Ashina, Z. Katsarava, T.P. Do, D.C. Buse, P. Pozo-Rosich, A. Özge, et al., Migraine: epidemiology and systems of care, *Lancet Lond. Engl.* 397 (10283) (2021) 1485–1495.
- K. Ravishankar, Barriers to headache care in India and efforts to improve the situation, *Lancet Neurol.* 3 (9) (2004 Sep) 564–567.
- K.N. Arca, A.J. Starling, Advocacy in headache medicine: tips at the bedside, the institutional level, and beyond, *Curr. Neurol. Neurosci. Rep.* [Internet] (2020 Nov), <https://doi.org/10.1007/s11910-020-01073-z> [cited 2022 Jan 14];20(11). Available from:.
- D.W. Dodick, M. Ashina, F. Sakai, W. Grisold, H. Miyake, D. Henscheid-Lorenz, et al., Vancouver declaration II on global headache patient advocacy 2019, *Cephalalgia*. 40 (10) (2020 Sep) 1017–1025.
- M. Linde, T.J. Steiner, D. Chisholm, Cost-effectiveness analysis of interventions for migraine in four low- and middle-income countries, *J. Headache Pain* [Internet]. (2015 Dec), <https://doi.org/10.1186/s10194-015-0496-6> [cited 2021 Dec 19];16 (1). Available from:.
- Institute of Medicine (US) Forum on Neuroscience and Nervous System Disorders, Systems of Care for MNS in Sub-Saharan Africa, in: *Mental, Neurological, and Substance Use Disorders in Sub-Saharan Africa: Reducing the Treatment Gap, Improving Quality of Care: Workshop Summary* [Internet], National Academies

- Press (US), Washington (DC), 2010 [cited 2022 Jan 5]. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK53427/>.
- [38] J.H. Bower, G. Zenebe, Neurologic services in the nations of Africa, *Neurology*. 64 (3) (2005 Feb 8) 412–415.
- [39] J.A. Aarli, A.G. Diop, H. Lochmüller, Neurology in sub-Saharan Africa: a challenge for world Federation of Neurology, *Neurology*. 69 (17) (2007 Oct 23) 1715–1718.
- [40] République tunisienne Ministère de la Santé, Santé Tunisie 2019. Démographie des professionnels de santé 2019. [Internet] [cited 2021 Dec 10]. Available from: <http://www.santetunisie.rns.tn/images/statdep/DMOGRAPHIES-2019.pdf>, 2020.
- [41] D. García-Azorín, M. Molina-Sánchez, P. Gómez-Iglesias, C. Delgado-Suárez, I. García-Morales, M. Kurtis-Urra, et al., Headache education and management in Cameroon: a healthcare provider study, *Acta Neurol. Belg.* [Internet] (2021), <https://doi.org/10.1007/s13760-021-01620-6>. Feb 10 [cited 2022 Jan 7]; Available from:.
- [42] S. Evers, B. Wibbeke, D. Reichelt, B. Suhr, R. Brilla, I. Husstedt, The impact of HIV infection on primary headache. Unexpected findings from retrospective, cross-sectional, and prospective analyses, *Pain*. 85 (1–2) (2000 Mar) 191–200.
- [43] K.E. Kirkland, K. Kirkland, W.J. Many, T.A. Smitherman, Headache among patients with HIV disease: prevalence, characteristics, and associations, *Headache*. 52 (3) (2012 Mar) 455–466.
- [44] S. Sohail, G. Nakigozi, A. Anok, J. Batte, A. Kisakye, R. Mayanja, et al., Headache prevalence and its functional impact among HIV-infected adults in rural Rakai District, Uganda *J. Neurovirol.* 25 (2) (2019 Apr) 248–253.
- [45] M.E. Bigal, R.B. Lipton, The differential diagnosis of chronic daily headaches: an algorithm-based approach, *J. Headache Pain* 8 (5) (2007 Oct) 263–272.
- [46] H.F. McClintock, J.M. Alber, S.J. Schrauben, C.M. Mazzola, D.J. Wiebe, Constructing a measure of health literacy in sub-Saharan African countries, *Health Promot. Int.* 35 (5) (2020 Oct 1) 907–915.
- [47] Institute of Medicine (US) Committee on Health Literacy, in: L. Nielsen-Bohman, A.M. Panzer, D.A. Kindig (Eds.), *Health Literacy: A Prescription to End Confusion* [Internet], National Academies Press (US), Washington (DC), 2004 [cited 2022 Jan 17]. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK216032/> [cited 2022 Jan 17]. Available from:.
- [48] R.T. Haimanot, Burden of headache in Africa, *J. Headache Pain* 4 (S1) (2003 Mar) s47–s54.
- [49] R.T. Haimanot, S. Yu, K. Ravishankar, M.F.P. Peres, L.P. Queiroz, Traditional treatments for headache, in: P. Martelletti, T.J. Steiner (Eds.), *Handbook of Headache* [Internet], Springer Milan, Milano, 2011, pp. 701–719 [cited 2021 Dec 19]. Available from: https://doi.org/10.1007/978-88-470-1700-9_54 [cited 2021 Dec 19]. Available from:.
- [50] E.K. Frimpong, J.A. Asong, A.O. Aremu, A review on medicinal plants used in the management of headache in Africa, *Plants*. 10 (10) (2021 Sep 28) 2038.
- [51] H. Tandeter, M. Grynbaum, J. Borkan, A qualitative study on cultural bloodletting among Ethiopian immigrants, *Isr. Med. Assoc. J. IMAJ* 3 (12) (2001 Dec) 937–939.
- [52] J.Y. Al-Hashel, S.F. Ahmed, F.J. Alshawaf, R. Alroughani, Use of traditional medicine for primary headache disorders in Kuwait, *J. Headache Pain* 19 (1) (2018 Dec 4) 118.
- [53] R. Kawuma, R.S. Chimukuche, S.C. Francis, J. Seeley, H.A. Weiss, Knowledge, use (misuse) and perceptions of over-the-counter analgesics in sub-Saharan Africa: a scoping review, *Glob. Health Action* 14 (1) (2021 Jan 1) 1955476.
- [54] F. Ojini, N. Okubadejo, M. Danesi, Prevalence and clinical characteristics of headache in medical students of the University of Lagos, Nigeria *Cephalalgia* 29 (4) (2009 Apr) 472–477.
- [55] T.J. Schwedt, K. Digre, S.J. Tepper, N.M. Spare, J. Ailani, M. Birlea, et al., The American registry for migraine research: research methods and baseline data for an initial patient cohort, *Headache*. 60 (2) (2020) 337–347.
- [56] E. Barasa, J. Kazungu, P. Nguhiu, N. Ravishankar, Examining the level and inequality in health insurance coverage in 36 sub-Saharan African countries, *BMJ Glob. Health* 6 (4) (2021).
- [57] C. Lampl, T.J. Steiner, T. Mueller, E. Mirvelashvili, M. Djibuti, M. Kukava, et al., Will (or can) people pay for headache care in a poor country? *J. Headache Pain* 13 (1) (2012 Jan) 67–74.
- [58] World Health Organization, PEPFAR, UNAIDS, Task Shifting: Rational Redistribution Of Tasks among Health Workforce Teams: Global Recommendations and Guidelines [Internet], World Health Organization, 2007, p. 88. Available from: <https://apps.who.int/iris/handle/10665/43821>.
- [59] A.C. Villegas, D. Saylor, M. Kvalsund, M. Atadzhyanov, C. Chiluba, L. Chishimba, et al., Task-shifting to optimize outpatient neurological care in Zambia, *Hum. Resour. Health* 19 (1) (2021 16) 88.
- [60] S.L. Leong, S.L. Teoh, W.H. Fun, S.W.H. Lee, Task shifting in primary care to tackle healthcare worker shortages: an umbrella review, *Eur. J. Gen. Pract.* 27 (1) (2021 Jan 1) 198–210.
- [61] R. Braun, C. Catalani, J. Wimbush, D. Israelski, Community health workers and mobile technology: a systematic review of the literature. Bullen C, editor, *PLoS One* 8 (6) (2013 Jun 12), e65772.
- [62] M. Mokaya, F. Kyallo, R. Vangoitsenhoven, C. Matthys, Clinical and patient-centered implementation outcomes of mHealth interventions for type 2 diabetes in low-and-middle income countries: a systematic review, *Int. J. Behav. Nutr. Phys. Act.* 19 (1) (2022 Jan 6) 1.
- [63] A. Feroz, M.M. Kadir, S. Saleem, Health systems readiness for adopting mhealth interventions for addressing non-communicable diseases in low- and middle-income countries: a current debate, *Glob. Health Action* 11 (1) (2018 Jan) 1496887.
- [64] W.A. Odendaal, J. Anstey Watkins, N. Leon, J. Goudge, F. Griffiths, M. Tomlinson, et al., Health workers' perceptions and experiences of using mHealth technologies to deliver primary healthcare services: a qualitative evidence synthesis, *Cochrane Database Syst. Rev.* 26 (3) (2020), CD011942.
- [65] O. Begasse de Dhaem, R. Burch, N. Rosen, K. Shubin Stein, E. Loder, R.E. Shapiro, Workforce gap analysis in the field of headache medicine in the United States, *Headache J. Head Face Pain*. 60 (2) (2020 Feb) 478–481.
- [66] J.H. Bower, A.G. Diop, R. Gouider, E. Schmutzhard, Addressing neurologic needs in sub-Saharan Africa: an opportunity for multisociety cooperation, *Neurology*. 83 (13) (2014 Sep 23) 1207–1209.
- [67] IHS-GPAC, Education in Headache to Healthcare Providers in Africa- Program Report, 2021, pp. 1–2.
- [68] H. Huang, M.T. Minen, S. Mehla, C. Chiang, D.G. Mehta, P. Patel, et al., Eleven reasons people decide to choose headache medicine: there may be a headache medicine provider shortage but there are ways to Foster interest, *Headache J. Head Face Pain*. 60 (8) (2020 Sep) 1846–1852.
- [69] S. Rutberg, K. Öhring, Migraine—more than a headache: women's experiences of living with migraine, *Disabil. Rehabil.* 34 (4) (2012) 329–336.