Factors Associated With, and Mitigation Strategies for, Health Care Disparities Faced by Patients With Headache Disorders

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Neurology® 2021;97:280-289. doi:10.1212/WNL.0000000000012261

Abstract

Objective

To review contemporary issues of health care disparities in headache medicine with regard to race/ethnicity, socioeconomic status (SES), and geography and propose solutions for addressing these disparities.

Methods

An Internet and PubMed search was performed and literature was reviewed for key concepts underpinning disparities in headache medicine. Content was refined to areas most salient to our goal of informing the provision of equitable care in headache treatment through discussions with a group of 16 experts from a range of headache subspecialties.

Results

Taken together, a multitude of factors, including racism, SES, insurance status, and geographical disparities, contribute to the inequities that exist within the health care system when treating headache disorders. Interventions such as improving public education, advocacy, optimizing telemedicine, engaging in community outreach to educate primary care providers, training providers in cultural sensitivity and competence and implicit bias, addressing health literacy, and developing recruitment strategies to increase representation of underserved groups within headache research are proposed as solutions to ameliorate disparities.

Conclusion

Neurologists have a responsibility to provide and deliver equitable care to all. It is important that disparities in the management of headache disorders are identified and addressed.

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Go to Neurology.org/N for full disclosures. Funding information and disclosures deemed relevant by the authors, if any, are provided at the end of the article.

Glossary

AAN = American Academy of Neurology; **ACE** = adverse childhood experience; **AIAN** = American Indian and Alaska Native; **ED** = emergency department; **HEAL Initiative** = Helping to End Addiction Long-term Initiative; **IOM** = Institutes of Medicine; **LGBTQ** = lesbian, gay, bisexual, transgender, and queer; **mTBI** = mild traumatic brain injury; **OR** = odds ratio; **SES** = socioeconomic status.

In 2003, the Institutes of Medicine (IOM) defined disparities in health care as "racial or ethnic differences in the quality of healthcare that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention."[1] Since then, health disparities in headache medicine have been documented across race, socioeconomic status (SES), and geography.[2] In addition to the IOM definition, poor access to care may also be a source of disparity.[2] Headache disorders are among the most prevalent neurologic conditions. Migraine itself is the second leading cause of disability globally.[3] To receive appropriate care, patients with headache must have access to a health care provider and receive an accurate diagnosis and appropriate treatment plan. In the case of migraine, only 26.3% of adult patients with episodic migraine[4] and fewer than 5% of adult patients with chronic migraine[5] traverse all health care barriers and obtain appropriate acute treatment (in the case of episodic migraine) or acute and preventive migraine treatment (in the case of chronic migraine). Significant disparities affect the ability of certain groups to navigate these steps, which affects diagnosis, prevalence rates, treatments, and outcomes, amplifying unmet needs. In this article, we summarize available literature regarding racial/ethnic, socioeconomic, and geographic disparities as well as social determinants of headache outcomes and use this information to suggest solutions that could improve equity and reduce disparities in headache treatment.

Methods

We conducted a series of searches between June 2020 and August 2020 on PubMed and Google Scholar with an unrestricted date range and combinations of the following terms: headache, migraine, disparit*, race, equity, gender, socioeconomic, and traumatic brain injury. Literature was reviewed for key concepts underpinning disparities in headache medicine.

Content was refined to areas most salient to our goal of informing the provision of equitable care in headache treatment through discussions with this group of 16 experts from a range of headache subspecialties.

Headache Disparities

Race (Racism)

When discussing race and ethnicity, consideration of language is imperative. In this article, the terms outlined by the National Center for Health Statistics are used, including Hispanic or Latino, American Indian or Alaska Native (AIAN), Black or African American, and White (cdc.gov/nchs/nhis/rhoi/rhoi_glossary.htm). We recognize that there are ongoing discussions in academic and community circles regarding preferred racial/ethnic nomenclature, such as use of the terms Black versus black versus African American, Latinx versus Latino or Latina versus Hispanic, Indigenous versus Indian versus Native, and White versus white.

Whereas races are not inherent biological categories, race is a social construct that as a vehicle for systemic racism has profound health effects. Throughout the literature, it is apparent that race plays a role in the appropriate diagnosis and treatment of headache disorders. Although recent population studies have found the prevalence of severe headache and migraine is roughly equal among White (15.5%), African American (15.0%), and Hispanic (14.9%) groups in the United States,[6] differences exist in diagnosis, treatments, and outcomes. African American and Hispanic patients are less likely (25% and 50%, respectively) to receive a migraine diagnosis than White patients.[6]

African American men receive the least care for headache diseases nationwide,[6] and are less likely than White patients to present for ambulatory care for migraine disorders.[7,8] African American patients visiting emergency departments (EDs) with headache were 4.8 times less likely than White patients presenting with the same complaint to receive CT to diagnose the etiology of their headache.[9] Similarly, in a prospective study on headache in the ED, White children were 3 times more likely to receive imaging compared to children of other races.[10]

African American patients with headache disease report more headache days per month, higher pain intensity, and poorer quality of life than White patients, who are more likely to receive a primary headache diagnosis in headache subspecialty clinics.[11] African American patients also report more allodynia compared to White patients.[12] Despite more severe disease in tertiary care settings, African American patients are twice as likely to discontinue specialty clinic–based headache treatment than White patients, after adjusting for SES.[13] African American patients were also less likely than White patients to utilize health care settings for migraine treatment (46% vs 72%), less likely to have been given a headache diagnosis (47% vs 70%), and less likely to get prescribed acute migraine medication (14% vs 37%). African American patients may have distrust in the medical community as well as a less positive perception of physician communication, which may

Table 1 Clinical Considerations and Strategies to Address Inequality in Headache Care

Telemedicine: Telemedicine can mitigate geographic disparities without sacrificing efficacy of care
1. Support providers in developing comfort with telemedicine by ensuring access to information technology services and providing adequate staffing support
2. Advocate for policy-level changes that improve insurance coverage for telehealth visits, including both video and telephone visits
3. Connect patients to resources to improve access to technology, build technological skills and literacy, and ease challenges with use of telehealth platforms
4. Ensure availability of translating services for telehealth visits
5. Pursue funding for telemedicine expansion
Care in a primary or secondary setting: Insufficient headache providers coupled with geographic maldistribution presents challenges in accessing specialized care
1. Provide telementoring and web-based educational opportunities to support primary care providers in gaining comfort for treating headache
2. Create tools to support these providers in making decisions about headache diagnosis and treatment
3. Develop population-level interventions that rely on a range of providers (primary care physicians, school nurses, etc.) to improve treatment for individuals
Screening: Inequity cannot be addressed if it is not made known; consistent screening affords the greatest chance of determining unmet needs
1. Collect a variety of patient information (housing stability, language, insurance, income, dependents, demands on time, barriers, etc.) to improve understanding of patients' experiences
2. Intentionally screen for past and current trauma and adverse childhood experiences and connect patients to appropriate resources
3. Utilize school nurses and health aides to screen students for migraine and promote the use of migraine action plans
Accessibility: Even for patients under specialist care, accessibility may affect treatment adherence and success
1. Ensure instructions for medication are understood by using simple and direct language and encouraging patients to explain these instructions to the provider
2. Minimize assumptions around degree of understanding and familiarity with the health care system and provide more information than is needed to minimize patient experiences of judgement
3. Allow patients to attend appointments with an individual who can offer support either in person or via telephone or video

lead to fewer physician visits for migraine care or migraine medication prescriptions.[14]

Non-White children and adolescents presenting for headache care in a large health system were less likely to receive acute medication compared to White children and adolescents.[15] Inadequate headache treatment can result in greater disease activity that is more refractory to treatment. Pervasive bias against prescribing effective analgesics to non-White patients disadvantages patients of color. Ineffective analgesics for pain control were reported as the most pervasive inequality for people of non-White racial/ethnic backgrounds compared to White patients across different treatment locations and presenting pain types.[16] However, certain prescribing practices for White patients may lead to inappropriate headache care for White patients with migraine, with several studies showing higher rates of prescribing non-recommended medications (e.g., opioids or barbiturate-containing medications) for White children, adolescents, and young adults with headache compared to other races.[15]

The undertreatment of pain in African American patients compared to White patients has historical relevance as African American patients have been falsely viewed as more biologically pain tolerant compared to White patients. Recent findings suggest that even among those who have medical training, erroneous beliefs regarding differences in biology between African American and White patients influence medical judgement, which leads to racial disparities in assessing pain and treatment of pain.[17]

There are limited data with regards to Latino headache disparities, pain comorbidities, or pain experience.[18] Although Latino patients report similar or higher rates of headache compared to non-Latino White patients,[18] Latino patients are 50% less likely to receive a migraine diagnosis than White patients.[19] In addition, Latino ethnicity has been identified as a predictor of limited access to chronic pain care.[20] Latino patients are less likely to receive clinically significant high-quality prophylactic headache medications in US ambulatory care.[7,8]

Native/indigenous people in America, including AIAN, have the highest prevalence of migraine and severe headache in the United States (19.2%)[6] and are more likely to experience allodynia.[12] There is a paucity of headache outcome studies in

Table 2 Professional Training and Educational Considerations

Educational opportunity: Addressing the lack of representation of underrepresented groups across the field of medicine begins with educational opportunity
1. Develop mentorship programs for younger students of underrepresented groups to encourage interest in pursuing specialized headache medicine
2. Address financial barriers for individuals from historically marginalized groups who may have less familial wealth/resources
Faculty and provider representation: Many factors may contribute to insufficient specialists to provide optimal care for patients with headache, particularly specialists serving underrepresented communities or representing these communities themselves
1. Improve institutional support around career development for junior faculty and clinician investigators from underrepresented backgrounds, including internal faculty development programs, institutional awards, salary support, and protected time
2. Increase incentives (e.g., recruitment/retention packages, opportunities for career advancement) for individuals from underrepresented backgrounds to attract a diverse group to training
3. Continue mentorship opportunities throughout training to provide support for individuals as they advance in their careers
Educational and training modifications
1. Provide training and educational experiences that intentionally consider participant and provider social factors
2. Train providers to display cultural humility and deliver equitable care
3. Promote implementation of antiracism initiatives across institutions and levels of career development
4. Continually engage providers in antiracism education and initiatives to ensure that changing societal needs are reflected across current practice.

this ethnic group, but allodynia often predicts poor treatment outcomes.[21]

There are also limited data on Asian Americans with regard to headache disparities and the pain experience. Asian American patients are not appropriately represented in research as, when accounted for, they are often lumped together under the broad designation of "Asians." Typically, Asian subgroups are not acknowledged on their own (for example, Pacific Islanders, Laotians, Bangladeshis). Prevalence estimates for severe headache have been reported to be lowest among Asian patients at 10.1% and 13.2% in Native Hawaiians or Pacific Islanders; however, the estimates for this subgroup are not reliable due to the small number of participants within the subgroup.[6]

Racial and ethnic disparities also exist in concussion and mild traumatic brain injury (mTBI), which often presents to neurology with refractory and persistent posttraumatic headache for management. African American children compared to non-Latino White children are less likely to have ED visits for pediatric sports-related head injuries and less likely to receive a concussion diagnosis.[22] In addition, compared to non-Latino White children, Latino children have a higher likelihood of having a decline in quality of life outcomes (social, academic, or physical functioning) 3 months after mTBI in children who present to an ED.[23] For mTBI and headache, Latino and African American patients receive less intensive rehabilitation after a traumatic brain injury.[24] There is a dearth of literature describing the experience of non-White patients regarding posttraumatic headache diagnosis and management.

Socioeconomic and Insurance Status

Low socioeconomic status is an independent predictor for worse health outcomes[25] and migraine prevalence is strongly associated with annual household income.[26] Thus, populations of color that are of low SES are doubly at risk for health disparities. Some research has been done in migraine looking at both income and insurance status as proxies for SES, but there is a paucity of other studies in headache that examines this relationship. There is a 60% higher rate of migraine in lower income groups (<$10,000) compared to higher income groups (>$30,000).[26] Low income or uninsured patients are less likely to receive acute migraine treatment.[27] Ineffective acute treatment is associated with progression of disease and increased risk of chronic migraine.[28] The prevalence of migraine is highest in those reporting the lowest incomes/incomes below the poverty level and the uninsured (17.1%) or those using Medicaid (26%) compared to those with private insurance (15.1%).[5] Two hypotheses have been proposed to help explain the inverse relationship between SES and migraine prevalence: social selection and social causation (these theories are not mutually exclusive). Social selection suggests that individuals may be unable to perform their regular educational and occupational responsibilities, leading to a decline in social status as a result of migraine disability; social causation suggests that low SES is linked to increased stress, which causes an increased duration or incidence of disability.[29] Low SES may negatively influence migraine onset, attack frequency, disease progression, and chronicity.[8] SES is also likely associated with sequelae noted 6–12 months from mTBI, such as novel psychiatric disorder and declines in health-related quality of life.[23]

Geography

Geographic disparities also present a challenge to appropriate access. Not only are there not enough headache specialists to treat patients with headache, but the distribution of headache fellowship programs and practice locations that fellows subsequently move on to are unevenly distributed. Fellowship

Table 3 Addressing Systemic Disparities and Inequities in Headache Research

Research process: Engaging individuals of marginalized communities early in the research process will direct research toward their specific needs[1]
1. Utilize qualitative studies, mixed methods research, and community-based participatory and community-engaged research[1]
2. Consider use of focus groups in the research development process[1]
Topics of research: Research should systematically examine the role of social inequity in the experience of patients with headache in marginalized communities
1. Determine whether and to what extent inequities exist across samples (including treatment effects)
2. Examine the role intersectionality across multiple social identities
Recruitment: Study samples should include historically underrepresented populations (non-White racial/ethnic groups, non–national language–speaking populations, LGBTQ populations, people experiencing poverty, people with lower levels of education, people living in rural communities, and other communities that often have difficulty accessing medical/mental health services)
1. Stratify recruitment of study samples to include higher proportions of historically underrepresented populations
2. Report inclusive and specific demographic data
3. Consider multisite studies to increase sample diversity
Barriers: Barriers to participation in research differentially affect individuals from marginalized communities
1. Examine systemic barriers to headache treatment access, particularly behavioral interventions, as need for nonopioid treatment increases
2. Minimize these barriers to allow improved access to research participation
Intervention development: Design and evaluate interventions for marginalized populations that account for unique circumstances and barriers
1. Develop, implement, and evaluate the implementation of programs targeting marginalized communities
2. Ensure communication is appropriate for individuals across varied levels of health literacy and educational attainment
Dissemination and implementation: Work to ensure novel findings do not only reach individuals under care of a specialist provider
1. Target primary care providers in publications that increase knowledge about the efficacy of interventions to improve care for individuals not seen by neurologists
2. Provide training and specific literature for generalist providers (primary care providers, school nurses, behavioral health providers in primary care, community mental health providers, school counselors) in evidence-based headache management, including behavioral headache management
3. Develop advocacy and public health initiatives to increase headache awareness and reduce disability

Abbreviation: LGBTQ = lesbian, gay, bisexual, transgender, and queer.

programs are mostly located in urban areas, specifically the larger cities in the Northeast and mid-Atlantic, and the majority of headache fellow graduates stay in the vicinity in which they trained.[30] The density of headache specialists is lower in rural states and there are no training programs in the Western and Plains states.[30] In general, rural Americans fare worse as they tend to be older, have a lower median household income, and have lower educational levels and health literacy. Social stigma and privacy concerns act as barriers to health care access in rural communities where there is little anonymity.[31] Patients also face obstacles related to transportation as median travel time and distance is longer for patients in rural communities compared to those in urban communities.[31] Rural patients with headache have longer wait times and a greater loss of income due to time taken off work to attend visits for headache.[32]

Other

There are also considerations that may exist in the lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ) population, including biases of health care practitioners and lack of knowledge regarding how hormonal therapy may affect migraine disorder and dictate treatment and other research. To our knowledge, many of these considerations have not been examined in the headache literature, but biases among health care professions students and providers toward LGBTQ patients have been documented in the health care literature.[33] LGBTQ patients also report discrimination from health care providers and are more likely to delay or avoid necessary medical treatment compared to heterosexual patients.[34] More work needs to be done within headache medicine to assess for disparities and address as appropriate.

Social Determinants

Discrimination

The 2003 IOM report on racial and ethnic health care disparities identified 3 significant factors driving these disparities: racial discrimination, health care systems management, and the legal and regulatory environment in which these health care systems operate.[1] Unconscious bias (or implicit bias), defined as "associations outside conscious awareness that lead to a negative evaluation of a person on the basis of irrelevant characteristics such as race or gender,"[35] plays a large role in the persistence of racial and ethnic health disparities, along with systemic structural or institutional racism, which are synonymous terms in the social science research literature.[36] Institutional or systemic racism is defined as those "processes of racism that are embedded in laws (local, state, and federal), policies, and practices of society and its institutions that provide advantages to racial groups deemed as superior, while differentially oppressing, disadvantaging, or otherwise neglecting racial groups viewed as inferior."[36] Segregation of all types is a significant factor in determining SES as it greatly reduces employment and educational opportunities and adversely affects health outcomes.[37] Federal, state, and local policies have supported racial residential segregation within the United States.[37] An example of this is redlining, which was a form of systemic housing discrimination at the federal level, resulting in de facto neighborhood segregation due to loan availability. Racial segregation has been associated with African American disadvantage even within the realm of health care (preterm birth, maternal depression, mental health issues, and cancer are more common among residents of previously redlined areas) and generally,[38] there are poorer health outcomes in segregated communities of people of color.[37]

In addition to the discriminatory practices that have created a system of inequitable care, underserved populations also face discrimination by health care professionals. More than 1 in 5 AIAN individuals reported experiencing discrimination in clinical encounters, while 15% avoided seeking health care for themselves or family members due to anticipated discrimination.[39] Over one-third of African Americans report discrimination in clinical encounters, while 22% avoided pursuing health care for themselves or family members due to anticipated discrimination.[40] A 2019 study found that 20% of Latinos reported having experienced discrimination when going to a health clinic or seeing a doctor compared to Whites (20% vs 5%, $p < 0.01$; adjusted odds ratio [OR] 3.18) and 17% of Latinos avoided health care for themselves or family members to avoid discrimination or poor treatment (17% vs 3%, $p < 0.01$; adjusted OR 4.98).[41] The authors found that being a US citizen, a college graduate, or of higher SES were not protective against discrimination for Latinos.[41]

Apart from the ethical issues of equity and poorer health outcomes, racial and ethnic health disparities are costly to maintain. Failure to resolve these persistent racial and ethnic health disparities has resulted in tremendous costs for the United States: direct medical costs of nearly $230 million and indirect costs of nearly $1.25 trillion between 2003 and 2006.[42] Furthermore, these unresolved racial and ethnic health disparities create additional economic burdens to these patients, accounting for over 30% of direct medical costs to African American, Latino, and Asian American populations.[43] Correcting racial and ethnic health disparities is not only ethical and humane, it is financially prudent as well. Specific studies are needed to determine the effects of discrimination in patients with headache.

Social Environment

Adverse childhood experience (ACE) exposure can contribute to frequent headache,[44] and more specifically, ACEs are associated with a higher risk of migraine compared to episodic tension-type headache.[45] There is strong evidence that there is a higher burden of ACE in children with neurologic disorders and disabilities. ACEs include physical abuse, emotional abuse, sexual abuse, physical neglect, emotional neglect, exposure to mental illness in the household, witnessing violence against one's mother, being the product of divorce, having a substance-abusing household member, or having an incarcerated relative.[46] Additional ACEs have been identified in more recent research and include exposure to racism, living in an unsafe neighborhood, and experiencing community violence. ACE exposure in early childhood affects the development of the neuroendocrine axis.[47] Increased ACE and its negative effects on neurologic outcomes contribute to disparities in health as communities of color often carry disproportionately higher burdens of ACE exposure and trauma.

Insurance Status

Disparities in insurance status limit the ability of people with migraine to obtain an appointment, receive an accurate diagnosis, and receive evidence-based treatments. Uninsured adults with migraine are twice as likely and publicly insured adults 1.5 times more likely to fail to receive evidence-based treatment compared to commercially insured adults with migraine.[48] Pediatric evidence similarly suggests substandard care for children of low SES with migraine. Children from low-income neighborhoods have lower odds of hospital admission for migraine,[49] despite higher migraine prevalence,[29] suggesting children of lower SES are being undertreated for acute pain flares.

Lack of Specialists

The physician shortage problem is not necessarily one of total supply, but rather geographic and specialty maldistribution, with almost twice as many physicians per capita in metropolitan areas compared to rural areas.[50] This access problem is magnified in specialty care for headache medicine. According to the Healthcare Cost and Utilization Project in 2008, patients living in rural communities overall have higher rates of ED visits (1,425 per 100,000) for headaches compared to those in urban areas (896 per 100,000), indicating a lack of primary prevention.[51] There are 706 headache specialists maintaining United Council for Neurologic Subspecialties certification in the United States, and many states that have 2 or fewer certified headache specialists.[52] As the number of headache fellowship programs has increased over the last 16 years to 45 centers in the country, the total number of certified specialists remains only slightly increased, and most remain where they trained rather than moving to underserved areas. Because of the low number of specialists, and lack of spread, there continue to be specific regions that are grossly underserved. This is not solely in areas with low population density; Vermont, for example, remains relatively well served despite very low density. It may have to do more with bias of training location and support of the early career subspecialist than the demand for specialist care.[30] The data on regional ED utilization do not directly correspond with location of available certified specialists, suggesting large areas of geographic disparity. Furthermore, even within urban centers, geography may limit care. Not all headache centers are easily accessible by public transportation, and medical transport is often limited as to where it can bring patients. This, coupled with low rates of telemedicine within urban and suburban areas, may also lead to balkanization of care.

Lack of Representation in Research

Although national surveillance data summarily dismiss the stereotype that migraine is a disease of the White and wealthy,[19] migraine research is dominated by White, wealthy, female participants. Of the 16 migraine research publications in *Neurology®* over the course of 2019, only 6 reported participant race, and of these 6, only 1 study reported participant race in terms other than White/non-White. Of these participant samples, 74.7%–97% were White. This bias is not due to underlying rates of migraine, but due to the failure of recruitment efforts to obtain representative samples. Consideration of other sources of bias are further complicated by lack of reporting: only 1 study reported any measure of SES; only 1 study reported any measure of educational attainment.

African American, Latino, and AIAN populations have also been underrepresented in clinical trials. This is problematic due to potential safety and efficacy concerns as well as external validity across diverse individuals who are reflective of a heterogeneous population representative of the United States. Underrepresentation in clinical trials could potentially lead to worsening outcome disparities if newer treatments benefit White over non-White patients.[53]

The lack of representation in research is also partly related to the distrust that underserved populations and specifically the African American community have towards the medical system.[13] Historical atrocities such as the Tuskegee Syphilis Study, the testing of mustard gas and other chemicals on African American soldiers during World War II, and experimentation on African American women in gynecologic studies have left scars on the African American community and fueled distrust. Neurologists and their institutions need to make a long-term commitment to regain the trust of African American and other underserved communities.

Potential Mitigation Strategies

Abolishing these racial, socioeconomic, and geographic inequities would require major cultural shifts in US society. To better understand these inequities and develop innovative solutions, a substantial investment in headache research and implementation science is warranted.

Clinical Strategies

The field is encouraged to address inequality by utilizing telemedicine, educating primary care physicians, screening patients for social determinants, of health and addressing issues around health literacy (table 1). In particular, addressing poor health literacy may affect health disparities through increasing awareness and use of headache-specific treatments, decreasing rates of medication overuse headache, improving physician-patient communication, decreasing misperceptions, and leading to earlier health intervention–seeking behavior, which would all improve quality of life and reduce morbidity of headache disorders.[54] Public education and advocacy initiatives may also be helpful to improve awareness of headache disorders, reduce disparities, and decrease disability.

Training Providers

Comprehensive headache education needs to be a core part of medical school education, residency, and continuing education for neurologists to meet the needs of diverse populations. To continue the efforts championed by the American Academy of Neurology (AAN), the field should focus on training providers in cultural sensitivity and competency when treating patients and addressing lack of representation of underrepresented groups in academic medicine and training programs by creating mentorship programs geared towards faculty development for underrepresented groups (table 2). Another knowledge gap is with regard to headache training programs. We would be remiss to not discuss that in addition to the lack of inclusion of underrepresented groups in headache studies, there is also a lack of underrepresented physicians and researchers engaging in clinical care, and designing and conducting the research studies in headache medicine. We need to find ways to recruit and retain faculty from underrepresented groups in medicine, develop programs dedicated towards promoting diversity and inclusion, and attract a wider range of applicants to residency and fellowship programs from underrepresented groups in medicine. Specific strategies have been suggested.[55] Research is needed to understand career trajectories in academic medicine for groups with marginalized and underrepresented statuses. Evidence also suggests that individuals from underserved and underrepresented racial and ethnic groups are more likely to serve the clinical needs of underserved populations, further underscoring the value of enhancing diversity of health care providers.[55,56]

Improving Representation in Research

Considerably more work is needed to evaluate headache disparities occurrence, access to care, accurate diagnosis, and appropriate treatment (table 3). Evidence-based strategies used to explore and ameliorate disparities in other areas of neurology such as community engagement, community-based participatory research, and mixed methods research methodologies can be applied to researching headache disparities and their resolution.[57]

Population-based studies can help capture underrepresented groups in both adult and pediatric headache populations;

oversampling underrepresented groups can be a strategy to better understand headache/neurology disparities. The limited research that has evaluated measurement invariance in headache methodology has found existing measures perform well in both African American and White samples; however, considerably more research is needed to understand measurement invariance in common patient-reported outcomes, headache diaries, and diagnostic algorithms. Headache is comorbid with conditions with known health disparities, including cardiovascular disease and psychiatric diseases.[58] The added effect of vascular and psychiatric comorbidities in particular by race/ethnicity and SES is of great research importance.

Recruitment of underrepresented groups should be improved across all areas of headache research. Current research efforts must contend with the legacy of ethical violations of decades past and actively address distrust of the medical and scientific communities by marginalized groups. This requires a paradigm shift in how headache research is conducted and commitment from funding agencies to support headache research in historically underrepresented groups. Funding by the NIH has historically been greatly disproportionate to disease burden. Despite having a disease burden comparable to digestive disorders, breast cancer, and arthritis, NIH funding for headache and migraine research is a fraction compared to these other conditions.[59] Although the NIH has prioritized pain research through processes like the Helping to End Addiction Long-term Initiative (HEAL), many HEAL Initiative items are focused on understanding the mechanism of the pain disorder or developing new nonopioid treatments. Funding for headache research has been driven largely by the pharmaceutical industry. While this investment in headache research has led to tremendous breakthroughs in headache treatments, novel pharmaceuticals are almost always priced out of the range of government-insured or uninsured patients, further magnifying inequity. Increased support for headache research will encourage increased investment in the field from the research community, providing an opportunity for increased representation of underrepresented groups in headache research.

Discussion

Although headache disorders are prevalent and potentially disabling neurologic conditions, there is a paucity of research in healthcare disparities and the effect of social determinants. Of the available research, headache disparities persist for African American, Latino, and AIAN patients nearly 20 years after the 2003 IOM report first described health care disparities as being caused by racial discrimination, health care systems management, and the legal/regulatory environment in which these health care systems operate. As racial categories are a social construct, structural racism is an important driver of these inequities, which may compound the stigma attributed to headache disorders such as migraine. Among racial and ethnic groups, AIANs have the highest prevalence of migraine and headache disorders, Latinos have the greatest headache/neurologic needs, and African American men receive the least care. Access to care is limited by racism, low SES, and geographical barriers.

We summarized a number of mitigation strategies to address these disparities and the effects of social determinants of health, ranging from provider and trainee education to systematic changes to research and innovation. We encourage readers to view this article as a call for reflection and action at the individual, community, institutional, and societal level, recognizing the need for long overdue change.

Study Funding

Several NIH career development awardees were involved in the drafting of this article, including Dr. Minen (NCCIH K23 AT009706), Dr. Seng (NINDS K23 NS096107), and Dr. Szperka (NINDS K23 NS102521).

Disclosure

J. Kiarashi has no financial disclosures. J. VanderPluym consults for Teva and has a research grant from Amgen. C.L. Szperka receives research support from NINDS (K23 NS102521), has consulted for Teva and Lundbeck, and has received grant support from Pfizer. S. Turner has no financial disclosures. M.T. Minen is on the AAN Guidelines Subcommittee and has received travel funds to attend meetings; serves on the General Board of the American Headache Society and has received travel funds to attend meetings; serves as co-head of the Headache Section of Pain Medicine; and her research is funded by NIHK23AT009706. S. Broner has no financial disclosures. Dr. Finkel's disclosures include the following: consultant: Amgen, Allergan; advisory boards: Amgen, Allergan, Biohaven; and speaker: Allergan, Amgen, Biohaven, Lilly. Dr. Wagstaff and A.C. Ross have no financial disclosures. N. Rosen has been on advisory boards for Allegan, Amgen, Alder, Biohaven, Eli Lilly, Impel, Novartis, Supernus, and Teva; has been a speaker for Allergan and Eli Lilly; has been a site PI for Allergan, Eli Lilly, and Amgen; has received funds for work with American Academy of Neurology, American Headache Society, and Springer for his work as an associate editor for *Current Pain and Headache Reports*; and reports no relevant conflicts of interest for this article. T.S. Monteith has consulted for Amgen, Alder, Lundbeck, Biohaven, and Teva; received educational grant support from Alder, Eli Lilly, and Amgen; and is a site PI for Amgen, Novartis, Teva, Eli Lilly, and Electrocore. S.L. Manrriquez, M. Anto, and M. Marzouk report no disclosures. E. Seng receives research support from NINDS (K23 NS096107 PI: Seng) and has consulted for GlaxoSmithKline, Eli Lilly, and Click Therapeutics. E. Seng has received travel funds from the American Psychological Association, the American Academy of Neurology, the American Association of Pain Medicine Foundation, and the American Headache Society. L. Charleston IV has served as consultant, advisory board member, or has received honoraria from AbbVie/Allergan, Alder/Lundbeck, and Biohaven; is on the advisory board of BrainWeekend and Ctrl M Health; is an Associate Editor of *Headache: The Journal of Head and Face Pain*; and reports no relevant conflicts of interest for this manuscript. Go to Neurology.org/N for full disclosures.

Publication History

Received by *Neurology* August 25, 2020. Accepted in final form April 19, 2021.

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