Improving the Diagnosis, Treatment, and Experience of ME/CFS: An Overview of Existing Policies and Recommendations

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Executive Summary

836,000 to 2.5 million Americans suffer from myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), a poorly understood and devastating chronic disease. Despite the widespread impact of ME/CFS, there exists a lack of infrastructure in our health care system to support patients with this condition. While a potential silver lining of the pandemic has been renewed attention on unexplained fatigue associated with long COVID, there still remains an all-around lack of awareness of ME/CFS due to limited research funding, lack of understanding of the condition's etiology, and inadequate medical training regarding the condition. Consequently, it is extremely difficult for patients with ME/CFS to seek the necessary medical care and support they need, including disability insurance. Moreover, racial inequities exist within the patient population affected by ME/CFS, though this aspect has largely been understudied and unaddressed. In this policy brief, we examine the existing status quo of ME/CFS and provide policy recommendations within four areas: (1) long COVID, (2) medical training, (3) disability insurance, and (4) racial inequities.

Summary of Policy Recommendations

1. Establish a singular, clear definition of ME/CFS in the research and clinical setting.
2. Create a pathway for increased NIH funding dedicated to ME/CFS research to advance diagnosis and treatment.
3. Increase ME/CFS education in medical school curricula via a patient-focused teaching approach.
4. Streamline and increase the flexibility of the disability insurance process for ME/CFS-based claims.
5. Improve awareness of ME/CFS as an evidence-based medical condition that is sufficient for filing a disability benefits claim alone.
6. Form collaborations between ME/CFS advocacy groups and minority health-focused organizations to spearhead a community-based public education campaign on ME/CFS.
7. Uplift the voices of racial and ethnic minority patients with ME/CFS.
8. Feature racial and ethnic minority patients in medical training materials to reflect the true prevalence of ME/CFS.

Background

Recently, countless news articles and medical professionals have focused on long COVID, a chronic illness that can arise from COVID-19 infection. This spotlight on long COVID presents a window of opportunity for new policies and advocacy for similar lesser-known chronic illnesses, especially myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). ME/CFS is a poorly understood, devastating chronic disease that affects the lives of 836,000 to 2.5 million Americans.[1] Common ME/CFS symptoms include profound tiredness, physical and mental fatigue, and brain fog.[2] Additionally, the dominant symptom of fatigue worsens with even minimal physical and mental activity.[3]

ME/CFS DISEASE OVERVIEW

LIVES AFFECTED:
836,000 to 2.5 million Americans

COMMON SYMPTOMS:
Persistent fatigue that worsens with physical and mental activity and cognitive impairment/brain fog

DIAGNOSIS
91% of patients suffering with ME/CFS remain undiagnosed, while those with a diagnosis receive little to no care.

Currently, there exists a lack of infrastructure in our health care system to support patients with ME/CFS. To make matters worse, receiving an accurate ME/CFS diagnosis is nearly impossible as its symptoms are similar to many other illnesses, resulting in the invisibility of patients with ME/CFS.[4] In fact, 91% of patients with ME/CFS remain undiagnosed because of the variable symptoms and their applicability to other ailments, while those diagnosed receive little to no care.[5]

In cases when people are able to receive a diagnosis, there is little to no knowledge, research, and training on how to effectively treat ME/CFS, leading to a long journey of trial-and-error treatments. Specific causes for ME/CFS are also largely unknown and have mostly been attributed to dysfunction of the immune and/or adrenal systems.[6] Discrepancies between characteristics used for diagnosis, such as the Centers for Disease Control and Prevention (CDC)'s focus on physical symptoms versus the World Health Organization (WHO)'s focus on neurological symptoms, also lead to further hardship and confusion for those with ME/CFS.[7]

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[1] "What Is ME/CFS?"

[2] Ibid.

[3] Ibid.

[4] Pilkington et al., "A Relational Analysis of an Invisible Illness."

[5] Bateman et al., "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Essentials of Diagnosis and Management."

[6] Cortes Rivera et al., "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome."

[7] Ibid.

Therefore, this policy brief aims to address the invisibility of ME/CFS and holistically provide recommendations from four angles: (1) long COVID, (2) medical training, (3) disability insurance, and (4) racial inequities. Policy options analyzed will seek to achieve the following policy objective:

- Improve the diagnosis, treatment, and experience of ME/CFS and increase awareness of the condition among providers, stakeholders, and patients, especially for underrepresented groups most affected.

Policy options will be evaluated based on the following three criteria:

- **Effectiveness**: Does this policy option achieve the desired policy objective?
- **Political feasibility**: Can this policy option be easily passed with broad support from various stakeholders?
- **Equity**: Will this policy option achieve the desired policy objective for marginalized and systemically discriminated populations?

Long COVID

While ME/CFS suffers from an issue of invisibility, long COVID has largely captured the attention of the media and the nation's policymakers. For example, in late 2020, Congress launched a four-year, $1.15 billion NIH initiative dedicated to investigating long COVID.[8] Because numerous patients with ME/CFS have similarities with the symptoms associated with long COVID, ME/CFS advocates hope that such increased funding for long COVID research can also result in findings applicable to ME/CFS etiology and treatments.[9] However, the overlap of ME/CFS and long COVID symptoms often causes confusion in diagnosis, elevating the difficulty of differentiating between the two conditions.[10] Consequently, increasing funding for research investigating the two conditions both separately and together would increase the chances of effective research findings for ME/CFS diagnosis and treatments.

Existing Policy Context

As the pandemic progresses, there has been increased interest in researching the etiology, diagnosis, and treatments for long COVID.[11] Simultaneously, existing policies and advocacy efforts have already begun to leverage the connection between long COVID and ME/CFS to

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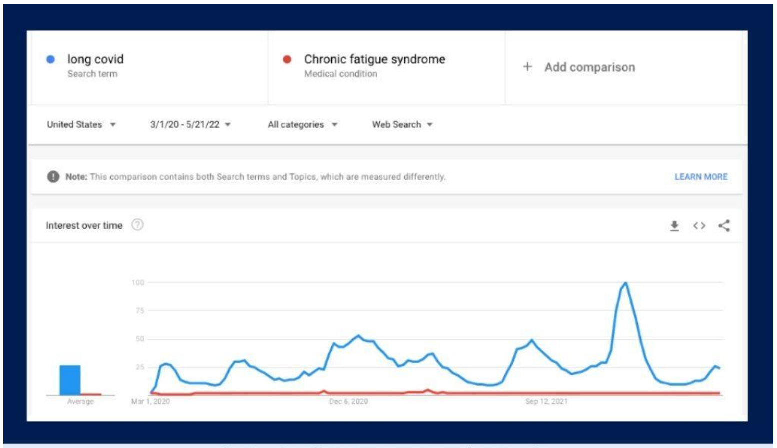
[8] Collins, "NIH Launches New Initiative to Study 'Long COVID.'"

[9] Wong and Weitzer, "Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)-A Systemic Review and Comparison of Clinical Presentation and Symptomatology."

[10] Amanda K. Morrow et al., "Long-Term COVID-19 Sequelae in Adolescents: The Overlap with Orthostatic Intolerance and ME/CFS," *Current Pediatrics Reports* 10, no. 2 (2022): 31–44, https://doi.org/10.1007/s40124-022-00261-4.

[11] "Google Trends Compare: 'Long Covid' v. 'Chronic Fatigue Syndrome.'"

advance ME/CFS research. For example, Solve M.E. launched a long COVID Initiative in April 2020 and called for an NIH budget appropriation for post-viral research.[12] To this latter end, the advocacy group advocated for the passage of the H.R.7057 U.C.S. ME/CFS Act.[13] Although H.R.7057 was revolutionary as the first legislation for ME/CFS research funding ever introduced to Congress, the bill failed to pass.[14] H.R.7057 would have secured $15,000,000 for each of fiscal years 2020 through 2024 with a $60 million total for further NIH investigations of "post-viral chronic neuro-immune diseases" like ME/CFS to support the developing COVID-19 response.[15] Despite its failure to pass, H.R.7057 laid the foundation for the total of $60 million in funding from Congress to the NIH for long COVID research, which led to the NIH's new RECOVER Initiative.[16] Within the RECOVER Initiative, there is an emphasis on studying the prolonged symptoms of COVID-19 infection, many of which overlap with ME/CFS, such as prolonged fatigue, anxiety, depression, and sleep problems.[17]



Note: This comparison contains both Search terms and Topics, which are measured differently.

GOOGLE TRENDS

THIS GRAPH COMPARES GOOGLE SEARCH TRENDS FOR "LONG COVID" AND "CHRONIC FATIGUE SYNDROME." IT ILLUSTRATES THAT WHILE THERE HAS BEEN INCREASED INTEREST IN LONG COVID, THIS HAS NOT SPILLED OVER TO ME/CFS.

Recommendations

With current media attention and policy efforts predominantly focusing on long COVID, a policy window exists for advancing ME/CFS research, diagnosis, and treatment. Therefore, our policy recommendations regarding ME/CFS's relationship to long COVID focus largely on how ME/CFS is defined and increasing funding for ME/CFS research.

Establish a singular, clear definition of ME/CFS in the research and clinical setting. Because there currently exists no one, clear definition, it is more difficult to incentivize, advocate for, and spearhead research on ME/CFS treatments.[18] In order to allow for more consistency in diagnoses, the differences between the clinical and research definitions should be rectified.

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[12] "The Solve Long Covid Initiative."
[13] "Finding Resources and Creating Opportunity."
[14] Raskin, U.C.S. ME/CFS Act.
[15] Ibid.
[16] "RECOVER COVID."
[17] Ibid.
[18] "Understanding History of Case Definitions and Criteria | Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)."

Because there are already definitions in both senses, it is feasible for a singular definition that covers aspects of both to be established.[19] Overall, this recommendation would result in a clearer understanding of ME/CFS, including how to best diagnose the condition and research possible treatments.

Create a pathway for increased NIH funding dedicated to ME/CFS research to advance diagnosis and treatment. ME/CFS research has largely lacked sufficient funding overall, often an afterthought to other diseases like long COVID. Currently, funding allocated to ME/CFS research roughly totals $15 million, which is only double the amount of funding since 2016.[20] Therefore, we recommend that the NIH increase funding for ME/CFS research to roughly $25 million. When comparing ME/CFS to other diseases, we see that research funding can be reallocated to better target diseases with larger prevalence and reach of adverse effects.[21] Although this recommendation may not be as economically sustainable and politically feasible, it is necessary if we are to make strides towards alleviating the burden of ME/CFS for millions of affected people.

Medical Training

Overall, there is a stark lack of medical training for treating patients with ME/CFS. A survey conducted across 132 U.S. medical schools found minimal coverage of ME/CFS clinical treatment, research, and medical school curricula.[22] In fact, only 4 out of 71 schools that responded met all three domains.[23] Another study reviewed 119 medical textbooks and found that only 0.09 percent of pages mentioned ME/CFS.[24] Of the medical textbooks reviewed, only 39 included the etiology of ME/CFS while just 34 included treatments.[25] Relative to other diseases with lower prevalence rates such as multiple sclerosis, ME/CFS was discussed far less in medical textbooks despite affecting more of the U.S. population.[26]

Furthermore, in the UK, 41 percent of 22 medical schools surveyed did not cover ME/CFS in their education at all.[27] The UK's National Institute for Health and Care Excellence (NICE) has also kept the same recommendations for ME/CFS since 2002, signaling little innovative research to improve ME/CFS treatments.[28] Accordingly, over these past 20 years, medical education for ME/CFS has also not changed, revealing how dated and little ME/CFS training medical professionals receive.[29] Often feeling that their symptoms are "invisible" and

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[19] "ME/CFS Disease Criteria and Terminology: Research, Inclusion and Community."
[20] "Estimates of Funding for Various Research, Condition, and Disease Categories (RCDC)."
[21] Ibid.
[22] Peterson et al., "DOI."
[23] Ibid.
[24] Jason et al., "Frequency and Content Analysis of CFS in Medical Text Books."
[25] Ibid.
[26] Ibid.
[27] Muirhead et al., "Medical School Education on Myalgic Encephalomyelitis."
[28] Ibid.
[29] Ibid.

ignored, patients with ME/CFS strongly want their physicians to be more equipped to treat them.[30] Presently, even when patients come with clear statements of their symptoms, surveys have shown that 48 percent of specialists did not feel comfortable diagnosing the patients with ME/CFS while 28 percent did not recognize the condition as a clinical diagnosis.[31]

Overall, if medical professionals are unable to properly learn the general diagnostic criteria and treatments for ME/CFS through their training, they certainly will be unable to properly treat patients. A more defined set of ME/CFS symptoms would not only improve medical training, but also increase the confidence of physicians in their knowledge of ME/CFS.

Existing Policy Context

One advocacy organization called the U.S. ME/CFS Clinician Coalition provides many different options for medical providers to learn more about ME/CFS.[32] Free general courses and courses specific to patients under the age of 18 are listed on the organization's website for medical providers who can take them to earn Continuing Medical Education (CME) credit.[33] However, no courses for medical students or nurses in training currently exist. The organization also provides many resources on ME/CFS diagnosis and management, including key comorbidities, special considerations, and accessing disability benefits and accommodations.

Recommendations

With ME/CFS training largely absent from medical school curricula and only offered as optional CME courses, the existing status quo for ME/CFS medical training is appalling. Consequently, our policy recommendations focus on increasing ME/CFS medical training.

Increase ME/CFS education in medical school curricula via a patient-focused teaching approach. While the current lack of ME/CFS research results in a dearth of information on the condition, platforms like Solve M.E.'s You + M.E. registry exist where patients talk about their own ME/CFS symptoms and experiences.[34] Similarly, ME/CFS patients can volunteer to speak on their symptoms and experiences in learning videos and modules for medical school curricula. Using these patient experiences, U.S. medical schools can also publish textbooks with the latest information on ME/CFS and discuss the condition in more detail. By centering patient testimonials in ME/CFS medical training, patients have more influence and voice while medical professionals gain more insight into direct patient experiences of ME/CFS. Once medical professionals and medical students are more well-informed on ME/CFS, patients will also feel more comfortable talking to their providers about their symptoms for ME/CFS diagnoses.

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[30] "People with Chronic Fatigue Syndrome Want to Be Taken Seriously and to Receive Personalised, Empathetic Care."
[31] Bowen et al., "Chronic Fatigue Syndrome."
[32] "Medical Education."
[33] Ibid.
[34] "A Registry for the ME/CFS + Long Covid Communities."

Disability Insurance

Disability insurance is necessary for patients with ME/CFS due to the condition's extremely debilitating physical and cognitive symptoms that can interfere with work and daily living.[35] However, patients with ME/CFS frequently report challenges in applying for disability insurance, due to difficulties with not only diagnosing the condition, but also objectively documenting its symptoms.[36] According to the Social Security Administration (SSA), disability is defined as "the inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or to last for a continuous period of not less than 12 months".[37] Therefore, as a chronic condition of overwhelming fatigue, ME/CFS should be a sufficient basis for filing for disability insurance alone.

Existing Policy Context

Still, the SSA remains largely skeptical of disability claims filed by patients solely for ME/CFS.[38] In fact, disability claims for ME/CFS are rarely approved at the initial or reconsideration levels, and even at the hearing level, most Administrative Law Judges are reluctant to approve benefits except in the most compelling cases.[39] Tellingly, ME/CFS is absent from the SSA's Blue Book listing of impairments, though Ruling 14-1p does outline how ME/CFS claims should be evaluated by SSA.[40] The current regulations require the submission of listed objective medical signs and laboratory findings to support a ME/CFS diagnosis.[41] Thus, despite the subjective nature of ME/CFS symptoms, self-reported symptoms alone are not enough.[42]

Furthermore, a provider's opinion clearly detailing the patient's work-related limitations is critical to acquiring disability benefits. The SSA's guide for applying for ME/CFS-related disability claims asks for detailed medical reports establishing the "existence, severity, and duration" of ME/CFS, including longitudinal clinical records, all relevant clinical and laboratory findings, and descriptions of functional limitations in work and daily activities.[43] However, due to the lack of awareness of ME/CFS among healthcare professionals, it is difficult for patients with ME/CFS to find a provider willing to diagnose them and file the necessary reports for a disability insurance application. Clearly, filing for ME/CFS-related disability insurance is too

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[35] Hotfelder, "Getting Disability Benefits for Chronic Fatigue Syndrome (CFS)"; Comerford and Podell, "Medically Documenting Disability in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Cases."
[36] Hotfelder, "Getting Disability Benefits for Chronic Fatigue Syndrome (CFS)."
[37] "Disability Evaluation Under Social Security."
[38] Hotfelder, "Getting Disability Benefits for Chronic Fatigue Syndrome (CFS)."
[39] Ibid.
[40] Ibid.; "Disability Evaluation Under Social Security - Listing of Impairments"; Williams, "Social Security Ruling."
[41] Hotfelder, "Getting Disability Benefits for Chronic Fatigue Syndrome (CFS)"; Williams, "Social Security Ruling."
[42] Hotfelder, "Getting Disability Benefits for Chronic Fatigue Syndrome (CFS)."
[43] "Providing Medical Evidence for Individuals with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)."

burdensome with little chance of success, rendering patients with ME/CFS only further marginalized.

Recommendations

When imagining policy solutions to improve the diagnosis and treatment of ME/CFS, we must not only advance care, but also address the coverage barriers that patients face when seeking disability benefits. Accordingly, our recommendations focus on addressing the challenges that ME/CFS patients face when seeking disability insurance.

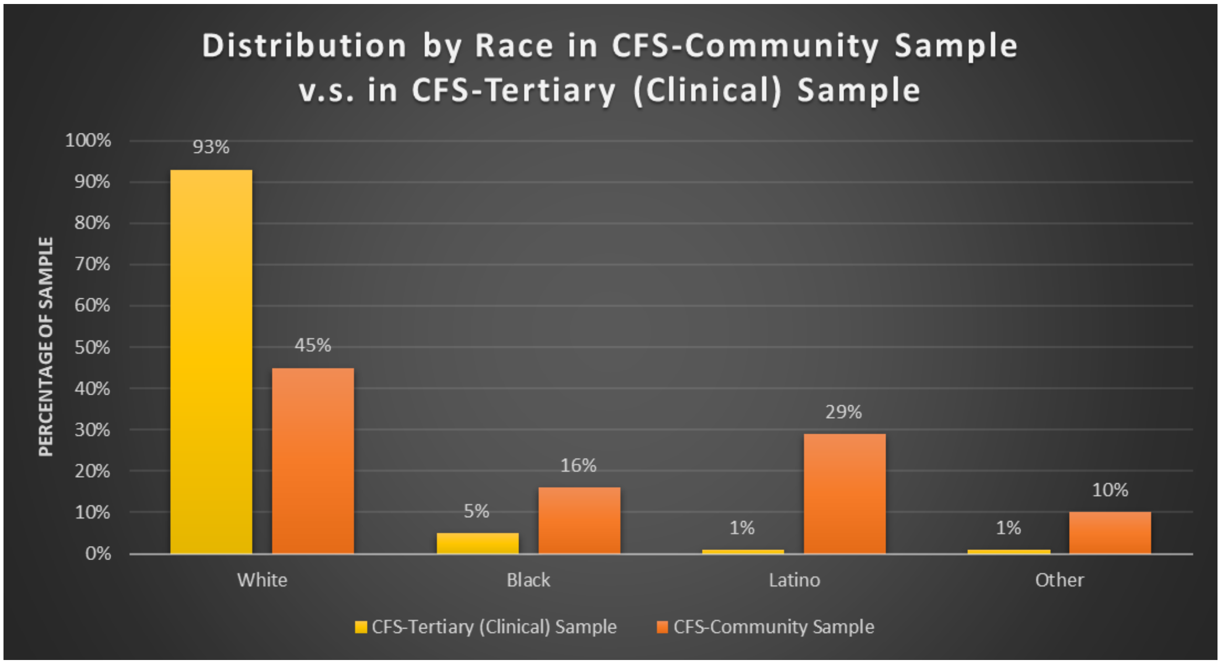
Streamline and increase the flexibility of the SSA disability benefits process for ME/CFS-based claims. This could include creating a Blue Book listing for ME/CFS, which would not only legitimize the condition as a valid impairment for a disability claim, but also simplify the filing process. Additionally, weighing the subjective experiences of patients more heavily within the deliberation of a disability claim is recommended for conditions like ME/CFS, which are inherently subjective in nature. In practice, this could look like considering a patient's daily log of their condition's severity and its debilitating effects on work and daily living more heavily in the absence of laboratory findings for ME/CFS as long as the patient's provider attests to the patient's ME/CFS diagnosis. This increased flexibility should be limited to disability claims based on ME/CFS and other chronic pain or fatigue conditions to decrease the risk of misuse and fraud. This recommendation will be highly effective and equitable in helping patients with ME/CFS better access disability benefits, but it may be less politically feasible due to the existing lack of awareness surrounding ME/CFS and the risks accompanying any increase in process flexibilities.

Improve awareness of ME/CFS as an evidence-based medical condition that is sufficient for filing a disability benefits claim alone. Overall, there is an all-around lack of awareness of ME/CFS among patients, providers, disability insurance companies, disability determination officials, and the general population. Therefore, improving awareness of ME/CFS is necessary to help patients better understand their options for care and financial support via disability insurance and better equip providers, insurance companies, and disability determination officials to assist patients in navigating these processes. Because medical evidence is core to successfully filing for ME/CFS-related disability benefits, improved awareness of diagnosis criteria, symptoms, and SSA-requested clinical and laboratory tests is necessary among medical professionals. This can be implemented through increased training modules for primary care providers, who are most likely to see patients with ME/CFS. Disability insurance companies and disability determination officials should also be better trained on the difficulties facing patients with ME/CFS filing for disability benefits rooted in the condition's complexity and unknown etiology. This can hopefully increase not only their knowledge of the condition's specific challenges, but also their empathy when determining a disability evaluation. Altogether, this recommendation will be highly effective and equitable if successful, though it may be difficult to implement.

Racial Inequities

Severe racial inequities exist within the status quo of ME/CFS diagnosis and treatment. The needs of patients from racial and ethnic minority groups are often overlooked and underserved. Contrary to the stereotypical understanding of ME/CFS as a "yuppie flu" that only affects upper-middle-class white females, racial and ethnic minorities are at least as likely as white individuals to suffer from ME/CFS.[44] Nevertheless, racial and ethnic minorities are much less likely to be diagnosed and treated for ME/CFS than their white counterparts.

Racial inequities exist in participant representation in service-based samples of individuals who have sought medical services and population-based samples of ME/CFS.[45] Simply put, white individuals are significantly overrepresented in samples of individuals who have seen a doctor for ME/CFS.[46] However, racial and ethnic minorities actually possess a higher risk of ME/CFS relative to white individuals, evidenced by researchers' estimates of ME/CFS prevalence within the entire population, regardless of the individual's status of diagnosis.[47]



Data from Jason et al., 2003.[48] Whites are significantly overrepresented in the Tertiary Care Sample, which counts individuals who were able to seek medical care. The proportions of racial and ethnic minorities are much higher in the Community Sample, which counts individuals with ME/CFS in the population who have not necessarily sought medical care.

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[44] Richman, Flaherty, and Rospenda, "Chronic Fatigue Syndrome"; "What Is ME/CFS?"; Bhui et al., "Chronic Fatigue Syndrome in an Ethnically Diverse Population."

[45] Jason et al., "Comparing Symptoms of Chronic Fatigue Syndrome in a Community-Based Versus Tertiary Care Sample."

[46] Ibid.; Reyes et al., "Prevalence and Incidence of Chronic Fatigue Syndrome in Wichita, Kansas."

[47] Jason et al., "Comparing Symptoms of Chronic Fatigue Syndrome in a Community-Based Versus Tertiary Care Sample."

[48] Ibid.

While the direct causes of these racial inequities in ME/CFS have not been well-studied, research suggests that the primary cause lies in the unequal distribution of health care resources among racial and ethnic groups.[49] An Institute of Medicine report examining health inequities concludes that societal-level factors like poverty, racism, discrimination, and concentrated environmental hazards underlie general racial inequities in health outcomes.[50] Moreover, racial and ethnic minorities and low-income individuals are underrepresented in epidemiological research, which only perpetuates the gap in health outcomes.[51]

Apart from this history of systemic racism that relegates disproportionately worse health outcomes to racial and ethnic minorities, the unique characteristics of ME/CFS also disadvantage minority patients in distinct ways. For example, the diagnosis of ME/CFS is heavily influenced by patients' subjective descriptions and interactions with their medical providers. A study of racial inequities in chronic pain management (a condition that also relies on patients' subjective descriptions and disproportionately burdens racial and ethnic minority patients) has found that medical providers might provide unequal care due to implicit bias, racial prejudice, stereotyping, and limited cultural competency.[52] The study also reports the absence of public education initiatives that aim to dispel "counterproductive beliefs about pain".[53] Such beliefs may include that "'pain is an expected part of life; grin and bear it,' 'pain is God's will,' 'pain is only in one's head; it isn't real,' and 'people who succumb to pain are weak'".[54]

A similar absence of public education initiatives to dispel myths about ME/CFS could hinder the diagnosis and treatment of minority ME/CFS patients. Patients may underreport their ME/CFS symptoms due to cultural biases like the model minority myth, which may lead individuals with East Asian backgrounds to attribute their illness to "over-work" or "over-ambition".[55] Additionally, clinicians possessing limited education on ME/CFS may be dismissive towards minority patients due to racial stereotypes, such as falsely believing that African Americans are just being "work-shy".[56]

Existing Policy Context

Currently, there is no government initiative or policy agenda that addresses the racial inequities in ME/CFS. While national institutions like the Office of Minority Health and the NIH have spearheaded initiatives to fund research programs that address racial inequities in COVID-19 response, provider cultural competency, hypertension control, sickle cell disease, and

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[49] Jason et al., "The Prevalence of Pediatric Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in a Community-Based Sample."

[50] Smedley, Stith, and Nelson, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*.

[51] Richman, Flaherty, and Rospenda, "Chronic Fatigue Syndrome."

[52] Mossey, "Defining Racial and Ethnic Disparities in Pain Management."

[53] Ibid.

[54] Ibid.

[55] Darius, "When POC Can't Get a Diagnosis, Go Unseen."

[56] Ibid.

other health conditions, there has not been any attention on racial inequities in ME/CFS.[57] Consequently, these national-level initiatives are unlikely to adequately address the needs of minority patients with ME/CFS, especially given the extremely low funding priority ME/CFS currently receives.[58]

At the community level, ME/CFS advocacy groups also do not have initiatives or programs dedicated to addressing the racial inequities in ME/CFS. While minority patients are occasionally featured on advocacy groups' websites and blogs, consistent and intentional attention to the issue is lacking. Similarly, within advocacy groups that work on minority health and racial health inequities, there have been no campaigns or initiatives that focus on racial inequities in ME/CFS.

Recommendations

Racial inequities in ME/CFS diagnosis and treatment are the products of deep-rooted inequities in the social drivers of health for racial and ethnic minorities. Therefore, thorough reforms are necessary to completely address the racial inequities in ME/CFS. National-level efforts like the NIH's UNITE initiative may slowly ameliorate racial health inequities through increased funding for minority health research and the training of medical professionals from minority backgrounds.[59] However, these efforts are unlikely to translate into progress for racial and ethnic minority ME/CFS patients in the short term, given the extremely low funding priority of ME/CFS on the national agenda.

Thus, we focus our recommendations on community-based strategies. A recent interdisciplinary paper by social scientists and public health experts from Havard and Johns Hopkins suggests that enlisting local institutions and stakeholders in minority communities as agents of change can more effectively address community needs relative to national-level actors.[60] This point has been made more relevant by the COVID-19 pandemic, which saw the growth of community-based organizations, funds, and support networks.[61] With this in mind, we make the following recommendations.

ME/CFS advocacy groups should partner with organizations that focus on minority health to spearhead a community-based public education campaign on ME/CFS. ME/CFS advocacy groups should highlight the relevance of ME/CFS to community-based minority health advocacy groups within the context of long COVID, given that combating racial inequities in the pandemic has been a priority for many minority health advocacy groups. The public education campaign should strive to dispel community- and culture-specific stereotypes in addition to

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[57] "Key Initiatives - The Office of Minority Health"; "UNITE - Milestones & Progress."

[58] Mirin, Dimmock, and Jason, "Research Update."

[59] "UNITE - Milestones & Progress."

[60] Williams and Cooper, "Reducing Racial Inequities in Health."

[61] Travers, "The Hardest Hit."

misunderstandings about ME/CFS to legitimize its severity. The campaign should also publicize information in a variety of languages, such as Spanish and Chinese, which are the two most spoken non-English languages in the US. For instance, publishing information about ME/CFS in Spanish or Chinese newspapers may more effectively reach minority communities. This approach could maximize the use of educational resources and materials already created by advocacy groups, research centers, and medical authorities. Besides expanding the audience of pre-existing educational campaigns, this would build valuable collaborations between ME/CFS advocates and minority community groups to elevate ME/CFS to a higher level of priority for community-based advocacy efforts.

ME/CFS advocacy groups should uplift the voices of racial and ethnic minority patients. Blogs should more frequently feature opinions from minority patients, highlighting their unique experiences and challenges. Lobbying campaigns and other ME/CFS-themed events should also strive to be more inclusive of minority patients. While such increased visibility of minority patients in media and lobbying campaigns would be crucial, it might be relatively less influential for promoting public awareness and informing potentially undiagnosed patients.

Medical training materials on ME/CFS should feature racial and ethnic minority patients to reflect the true prevalence of ME/CFS. This would help dispel the unfounded myth that ME/CFS is primarily a white woman's disease, which produces dismissive attitudes towards minority patients' claims of suffering from ME/CFS. This recommendation would be ideal for building racial equity from the provider end, but given the lack of emphasis on ME/CFS currently in medical training, this may take more time to be implemented.

Conclusion

Overall, this policy brief aims to address the invisibility of ME/CFS and provide policy recommendations from four angles: (1) long COVID, (2) medical training, (3) disability insurance, and (4) racial inequities. When examining the existing status quo of ME/CFS within these four areas, we found that the condition suffers from an extreme lack of awareness, unclear diagnostic criteria, limited research funding, insufficient medical training for providers, burdensome disability claims process for patients, and unaddressed racial inequities. Accordingly, the aforementioned recommendations outline policies that can be implemented at both the institutional and community levels to improve the diagnosis, care, treatment, and overall experience of ME/CFS for patients suffering from the condition.

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