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Reducing Disease Burden for Patients with Migraine Should be a Global Priority

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Cover Letter

October 5, 2021

Raffaella Bosurgi, PhD, MSc
Executive Editor, *PLOS Medicine*

Dear Dr. Bosurgi,

We would like to submit our manuscript titled, “Reducing Disease Burden for Patients with Migraine Should be a Global Priority,” for consideration for publication as a perspective article in *PLOS Medicine*. This article is being submitted in tandem with its relevant research article, “Patient-Reported Care Limitations, Impact, and Stigma of Migraine (PRoCLaImS): A Global Web-based Survey.”

Many epidemiological studies have explored the unmet needs and challenges associated with migraine but have failed to provide practical applications to reduce the burden of migraine. The cross-sectional survey discussed in the corresponding research article highlights the daily experiences and attitudes of patients with migraine in an effort to understand the unmet needs and set the trajectory towards a comprehensive solution. The study found that not only does migraine significantly affect patients’ wellbeing, but there remains a stigma among those involved in the lives of patients with migraine. Patients with migraine have asserted that raising awareness of the disease may therefore be an important part of reducing the overall burden of migraine, through a variety of avenues, including migraine support groups, healthcare professionals who are better educated about migraine, and increasing funding for migraine research. The initiatives that the patients included in this survey recommend could potentially improve the accuracy and timeliness of migraine diagnosis, access to proper care, and overall public awareness of the disease. Through my own experiences with migraine, I am in agreement with the conclusions drawn from this study. Taking these steps to mitigate the burden of migraine would positively impact the healthcare community, as well as those directly affected by migraine, and could help provide direction moving forward to reduce the burden of migraine.

Thank you for your consideration of this article for publication in your journal.

Sincerely,

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Reducing Disease Burden for Patients with Migraine Should be a Global Priority

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Migraine has impacted humanity for millennia. Accounts of its daily burden go as far back as 1200 B.C., when ancient Egyptians lamented painful headaches that gave rise to a myriad of treatment practices, such as one involving a clay crocodile wrapped around the patient's head [1]. Despite substantial advances in migraine treatment regimens in modern times, migraine remains the second leading cause of years lived with disability (YLD) globally [2]. Migraine has an incredible impact on health-related quality of life (HRQoL), as well as multiple facets of daily life, including physical and emotional well-being, personal relationships, social activities, and occupational functioning [3-7]. Although numerous large, epidemiological studies have been conducted to study the burden of migraine [8-11], there remains a dire need to address that burden and to reduce its impact on a more unified global scale.

In this week's issue of *PLOS Medicine** Patricia Pozo-Rosich and colleagues report findings from a cross-sectional survey of patients with migraine from 16 countries across Europe, Asia, Latin America, and Australia. The observational study highlights the day-to-day experiences of patients with migraine and reveals patient attitudes toward treatment to better understand their unmet needs and to elicit recommendations for improving care. Altogether, 59% of participants reported that their quality of life was very much impacted by migraine, most commonly their overall health and wellbeing (69%), social life (60%), work/career (56%), and family relationships (39%). More than 50% of participants identified their partner and children as being the most affected by migraine outside of themselves. Among parents, 44% felt their migraine impacted the general happiness of their children, 60% their ability to provide unconditional parental support, 35% their children's social lives, and 27% their children's school results. Nearly half of the survey participants (49%) reported that their occupational fitness was detrimentally affected by migraine, with 31% of individuals who were not working full time claiming migraine symptoms as the primary cause. Fortunately, 59% of participants reported overall satisfaction with their prescribed medication, and a greater percentage (69%) attested that their healthcare provider was supportive and well-informed on the latest migraine treatments.

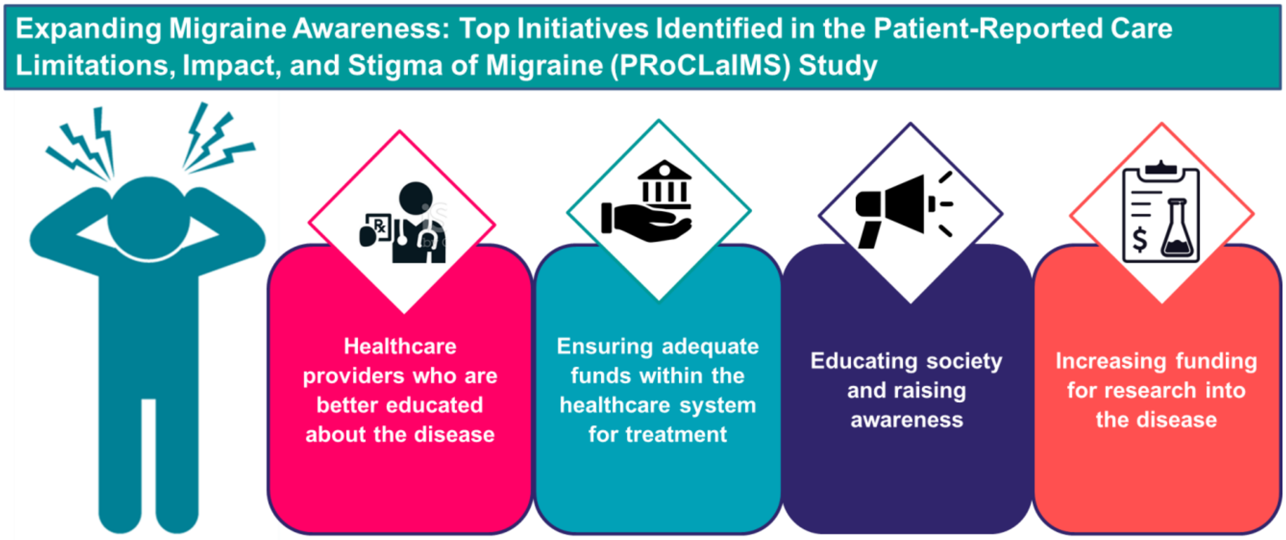
According to the study, despite migraine’s prevalence worldwide, its related stigma remains an issue for many individuals: 46% of the study participants reported having felt the need to hide their migraine at any given time, whether it be from employers (63%), family (49%), or friends (37%). In general, 61% of participants felt that migraine is not taken seriously by their government or society. This finding suggests that raising awareness of migraine may be an integral part of reducing the burden of migraine. Although 54% reported that hearing from other people with migraine and sharing experiences could positively impact their lives, the majority (88%) were not members of migraine patient support groups, mostly because they were unaware that these exist. Moreover, they have deemed that the migraine community could benefit greatly from having healthcare professionals who are better educated about migraine (46%), ensuring available funding for migraine treatment in the healthcare system (41%), educating society and raising awareness about migraine (35%), increasing funding for migraine research (33%), and enacting policies in schools or the workplace for people with migraine (31%).

The findings from this study demonstrating the significant HRQoL, social, and economic burdens associated with migraine support and expand on the results of prior cross-sectional survey-based studies. These include, among others, the Chronic Migraine Epidemiology and Outcomes Study (CaMEO), a longitudinal study with a cross-sectional web-based survey conducted from 2012 to 2013 in the United States [10], and the Eurolight study, another cross-sectional observational survey study conducted in ten European countries between 2008 and 2009 [9]. Demographic and clinical characteristics were generally comparable between prior studies and the study by Pozo Rosich and colleagues. However, the current study is unique in that it not only gleaned patient experience from various countries and regions worldwide but included several previously uninvestigated aspects related to migraine. These include patient perceptions of care, the broader social burden of migraine, including migraine-associated stigma, and exploration into patient recommendations for improving support and care.

Though it provided global perceptions of migraine and unmet needs in this patient population, this study comes with several limitations. Its cross-sectional design precludes any causal inferences from being determined, and the absence of standardization or psychometric validation of the survey limits reliability and replicability. Bias may exist due to lack of medical records, for instance, and given the strict inclusion criteria, the data may not reflect the overall migraine population. Nevertheless, the study’s non-biased sampling methodology, coupled with its global scope, allowed for a comprehensive view of patient perceptions of the day-to-day burden of migraine and potential solutions for addressing that burden. To that point, this survey provides a call to action to expand the awareness of migraine in the broader community, as well as specifically among healthcare providers. If implemented, these initiatives (Fig 1) could promote accurate and timely migraine diagnosis, better access to the proper specialists, and a significant reduction of the social stigma that currently exists owing to a lack of awareness of the gravity of this disease.

As a person affected by migraine, I have had to cope with all the negative experiences that this disease brings throughout my life. I lost a very important career role in a relevant position due to a migraine attack. Life would have been very different for me without migraine, and I and the rest of the migraine community have a high level of frustration because of the lack of support, understanding, misperception and disregard for this disease. We do not want anything special, just our normal rights through a better educated healthcare community, adequate funding of healthcare systems to allow for better access to treatments for all patients, a better informed society, and a high level of research into the disease.

Fig 1. Top migraine-related initiatives according to survey outcomes.



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Competing Interests

No conflict of interest.

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***** Citation pending for survey manuscript ("Patient-Reported Care Limitations, Impact, and Stigma of Migraine (PRoCLaImS): A Global Web-based Survey") submitted concurrently.

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