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The Value of the Patient Perspective in Understanding the Full Burden of Migraine

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Understanding the patient perspective of living with migraine is critically important for a disease that is the second leading cause of disability worldwide.[1] With the recent explosion of headache research, we have more therapeutic choices to offer, including pharmacotherapies, devices, and behavioral interventions. Optimally using the expanding therapeutic armamentarium requires a holistic approach and nuanced understanding of the distinct ways in which migraine impacts our patients' lives.

During two recent migraine clinical trials,[2,3] we began semi-structured interviews by asking participants, "How does migraine impact your life?" Although originally intended to assess participants' experiences in the study, the interviews also richly illuminated the patient perspective and demonstrated the tremendous burden of this common neurological disease. These results are presented in the current issue of *Headache* in our publication "*Learning the Full Impact of Migraine through Patient Voices: A Qualitative Study.*" [4]

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The findings from our large qualitative study, with 81 participants who provided nearly 3300 minutes of recorded interviews across two clinical trials conducted in two cities, highlight how people with migraine experience the disease as a major burden despite widespread treatment availability. Most participants in our study were using acute and/or preventive medications, yet 90% reported that migraine still had a negative overall impact on their lives. Moreover, more than two-thirds reported troublesome effects on specific domains of life.

The magnitude and pervasiveness of these findings shows the enormity of the impact. Though most participants did not have a formal diagnosis of a mood disorder, more than half of the participants reported that migraine had a negative impact on their emotional health beyond typical psychiatric diagnoses such as depression and anxiety. For example, participants described feeling guilty for missed work, family, and social activities, sometimes leading to feelings of frustration and isolation. Our study showed that factors outside of migraine attacks (e.g., interictal factors), such as anticipatory anxiety, fear specifically of the next attack, and avoidance behaviors leading to life restrictions, are major contributors to poor quality of life. Other themes, such as internalized and externalized stigma, underscore the need for societal change in migraine awareness and perception. The ictal effects on cognition and mood reveal the need for future research to better understand if these factors are mediated through pain or if they are more direct expressions of neural dysfunction.

Our study shows that migraine affects many domains of our patients' lives. The depth of responses to the single open-ended question of "How does migraine impact your life?" underscores its importance in clinical practice. Including this question in a patient care interview can serve a multitude of purposes, including: 1) increasing the providers' holistic understanding of disease impact on the patient; 2) providing an opportunity for the patient to acknowledge and express his/her perspective; and 3) improving patient-provider communication.[5,6] Having their experiences heard and validated builds rapport, the foundation of a productive therapeutic relationship. The very process of 'telling your story' can itself be therapeutic for patients,[4] as narrative medicine has significant value.[7,8] Understanding the ways in which migraine is most impacting a patient's life can help providers and patients develop shared agreement on the goals of migraine therapy, help the provider select a therapeutic option targeted to the patient's goals, and improve patient adherence to a collaboratively-developed treatment plan.[9,10] As we work to bring the patient voice into clinical decision making, a knowledge of the general needs and preferences of all patients can help us better understand the needs and preferences of a particular patient before recommending a specific course of treatment.

The patient perspective can be utilized to inform the development and testing of migraine therapeutics [11,12] as well as clinical trial outcomes and endpoints by targeting what is most important to individuals with migraine. [13,14] For example, the awareness of the role of guilt and stigma demonstrates the need to develop validated instruments to capture these effects in migraine. While we have identified migraine's negative impact on well-being in multiple spheres of life (family, social, occupational), we need ways to rigorously and efficiently measure and target all of these domains. In the clinical setting, we can develop standardized approaches and treatment regimens that address the inter-ictal effects of migraine, such as fear of attacks, anticipatory anxiety, and avoidance behavior. The stigma of migraine can specifically be targeted through programs to improve the public's knowledge of migraine, teaching friends, family, and co-workers how to better support those living with migraine.

The results of this study demonstrate the tremendous and complex burden of migraine on adults' lives and highlight areas of further research. While this study heard from treatment-seeking participants interested in non-drug interventions who had significant disease burden, future studies could include a broader population of people with migraine. The focus in this study was on adults with migraine so additional studies are needed to include the voices of children, adolescents, and their families.[15,16] In summary, moving forward as researchers and clinicians, we need to intentionally work to identify and target what matters most to patients to direct future research endeavors and treatment approaches to ensure our work is addressing the needs of those living with migraine.

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