

STROKE MATTERS

WINTER 2023

Minnesota Stroke Association



Letter from the Chief Executive Officer

By David King

Minnesota  Stroke
Association



Welcome, *Stroke Matters* readers,

It's cold outside, and these feet of mine are always chilly! My solution? Fuzzy socks with grips on the bottom, so I can stay warm and not slip and fall in the kitchen. Falls being the leading cause of brain injury in Minnesota. Stroke patients face a significant risk of falls. In the initial week following a stroke, when patients are most vulnerable and still hospitalized, about seven percent experience a fall and up to 37 percent of post-stroke patients fall within the first six months. This

number can rise to as high as 73 percent within the first year following a stroke. So please consider getting a pair of gripper socks. They're good for your toes and your brain!

Such small things bring a sense of protection and well-being to our bodies. But, it's also important to extend that protection to our communities. Certain issues, like strokes, disproportionately impact our communities of color. This edition of *Stroke Matters* looks into the nuances, challenges, and steps we can take to bridge the gaps and ensure every individual, regardless of background, has access to the best healthcare and preventative measures possible.

Our main article explores the recent study out of the University of Minnesota, headed by Dr. Haitham Hussein, that examines ten years of data on stroke in the Hmong population. We spoke with Dr. Hussein and Donna Lindsay of Hennepin Healthcare about the study as well as cardiovascular health in other minority communities. You can read the entire study at www.tinyurl.com/StrokeHmong; trust me, it's fascinating reading.

These disparities in stroke awareness and treatment underscore the importance of advocating for oneself in medical settings. Women, also have historically faced challenges when communicating their symptoms, concerns, and pains to medical professionals. Our own Nancy Christensen shares practical knowledge women can use to ensure they're heard, understood and treated appropriately by doctors and other healthcare providers.

Speaking of being heard, the recent Statewide Stroke Conference was a fantastic opportunity to hear voices from all corners of stroke care and prevention. Over 225 participants registered and attended a day of sessions, covering topics ranging from driving after a stroke, new methods in staff stroke education, spasticity and fatigue, aphasia-friendly educational materials, and more. In addition, Dr. Anjail Sharrief delivered a fascinating keynote on achieving equity in stroke care. We hope to see you at next year's Statewide Stroke Conference.

Finally, as the year comes to a close, we ask you to consider a generous donation to the Minnesota Stroke Association. Your contributions empower us to offer free educational outreach, advocacy training, and brain injury support events. Your gifts give us the flexibility to innovate and plan for the future, without being constrained by financial pressures. Each dollar is a thread in the cozy socks that wrap our community in support and hope. So, as you pull on those fuzzy socks this winter, remember that with every step, together, we're making strides against stroke. Visit strokemn.org/donate and give what you can.

Thank you so much for your support and continued readership.
David King
CEO, Minnesota Stroke Association

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Are They Listening To Me?

By Nancy Christensen,
Administrative Assistant

The first three months after a stroke are, statistically, the most important in terms of recovery and are when patients will see the most improvement¹. It's also the time when a patient's risk of having a second stroke is fifteen times more likely than before². A treatment plan will be set up by the medical team to provide the patient with ongoing steps to healing and recovery but what happens if you are not being heard when voicing your symptoms, concerns and questions?

According to Mahlet Endale, a licensed psychologist based in Atlanta, "Women are less likely to have their pain treated, their symptoms taken seriously or to be given a diagnosis than men. Their bodies, and the conditions that primarily affect them, are less likely to have been studied in clinical trials (which make effective treatments difficult to find) gender bias may be playing a role in whether a woman's reports of pain are believed or not."

Why do so many women struggle to be taken seriously when they go to the doctor? It's a well known fact that men and women tend to express pain whether it be physical or physiological in different ways. Unfortunately, many times women are considered to be "overly dramatic" and oftentimes are dismissed by medical providers³. This can and does lead to deadly consequences. More concerning, women of color appear to be at an even greater risk of being overlooked by their medical teams while facing a disproportionate burden of chronic conditions, including anemia, cardiovascular disease, and obesity, relative to other U.S. women⁴.

So, if a woman who has had a stroke and now has regular follow-up appointments is having difficulty conveying to her team of doctors how she is feeling, what her symptoms are and expressing herself so she can be fully understood and taken seriously, what can she do?

The Huffington Post provided some steps that women may consider to use in preparation for upcoming medical appointments⁵.

Check reviews

There are many social media platforms that are available to women, including specific local women's groups, to provide advice and direction. Ask other women on these platforms if there are treatment providers who have been especially good listeners. When doing so, look for a consensus rather than one person who says a provider is great or terrible. Call the Minnesota Stroke Association Resource Facilitation department at 763-553-0088 and ask for recommendations.

Quantify your issues

When you're planning a visit to your physician, a great tip to getting your point across is by "presenting [your concerns] to your doctor with measurable data," said Jolene Brighten, author of *Beyond the Pill* and founder of Rubus Health, a women's medicine clinic.

So, rather than saying you've been experiencing recurring headaches, you would be able to say "I have three to four headaches a day, typically when I first wake up and then every two hours." Keeping a notebook where you mark down your symptoms as you experience them will help in keeping track of these issues. Speaking of which...

Write it down and don't hesitate to ask questions

Have your questions and concerns ready to go and bring them up at the beginning of your appointment. Waiting to be asked about your concerns frequently leaves them until the end of an appointment. To get the most out of your time, bring up your questions and concerns immediately.

Have it repeated

Have your provider repeat your concerns back in their own words. For example, you might say to your healthcare provider, "Could you please recap my concerns about the persistent tingling sensation in my left hand? I'll feel better knowing we're talking about the same thing."

(continued on next page)

Be your own advocate

If you ever feel like your concerns are being rushed or overlooked, you can address it by saying something like, “I know you’ve got a busy schedule, and I totally get that. But I need to make sure you understand the challenges I’m facing during my stroke recovery. Can we take a bit more time to discuss it, so I can be sure I’m getting the right support?”

Ask a trusted professional to advocate with you

Self-advocacy can be difficult. The Minnesota Stroke Association can help you be a more effective advocate for yourself and your loved ones. Our Resource Facilitators can help you work through your questions and concerns; can arrange group phone calls when talking with providers; and help you find providers who will listen.

It’s always important to have people on your side. Call the Minnesota Stroke Association at 763-553-0088 to talk to a Resource Facilitator in your area.

Bottom line:

*You deserve good care,
remember that!*

1 <https://www.hopkinsmedicine.org/health/conditions-and-diseases/stroke/stroke-recovery-timeline>

2 <https://www.flintrehab.com/second-stroke-survival/>

3 <https://www.washingtonpost.com/wellness/interactive/2022/women-pain-gender-bias-doctors/>

4 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8020496/>

5 Barnes, Stephanie. “Doctors Can Dismiss Women’s Health Concerns. Here’s How To Take Back Some Control.” HuffPost, 14 March 2019, www.huffpost.com/entry/doctors-who-ignore-women-health-concerns-advice_1_5c7020a8e4b00eed0833a29c

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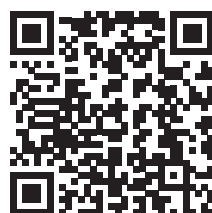
The journey to finding a new normal after a stroke or brain injury is a profoundly personal, yet universally challenging, experience. We understand how hard it can be managing healthcare; advocating for necessary accommodations; and, for families, watching their loved ones grow into and out from their own disabilities. Our goal is to be a steadfast ally through these times.

Your support makes this all possible. It enables us to create spaces where individuals can use their voices to help others and where families can find guidance in an increasingly overwhelming healthcare system.

Thank you for your commitment to the Minnesota Stroke Association and for your continued support!

We invite you to join us in this crucial work by making a donation. Your gift can be made online at strokemn.org or sent to our offices. Each contribution is a step towards empowering those navigating life after a stroke.

Please donate to the Minnesota Stroke Association today. A gift of \$50, \$100, \$250, or whatever is meaningful to you, can help us continue to offer educational opportunities, advocacy training, and volunteer training. YOU make a difference when you include us in your gift giving. Please, donate online at strokemn.org/donate.



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Addressing Stroke Disparities in Hmong Americans

By Phil Gonzales, Public Awareness Associate

In the realm of healthcare, disparities in stroke outcomes among racial minority groups remain an ongoing and concerning issue. These disparities, driven by a complex interplay of socioeconomic factors, healthcare access, and cultural differences, have far-reaching implications for the well-being of these communities.

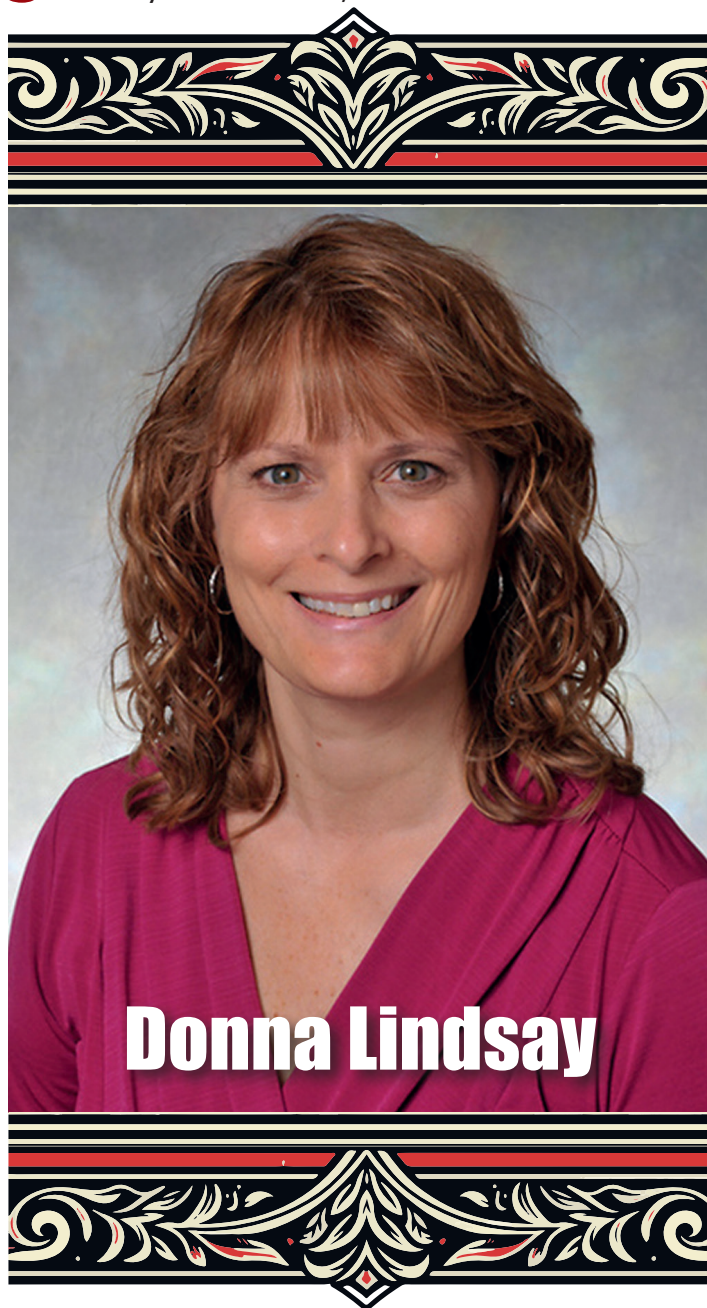
For example, Donna Lindsay, Clinical Nurse Specialist/Stroke Program Coordinator at Hennepin County Medical Center, notes that in the Latino community, the potential cost of an ambulance ride frequently leads to stroke patients driving to the emergency room where, due to language barriers, their stroke might not be immediately recognized.

“So, we’re noticing that more time is passing before the stroke code gets called,” she says. “They register with a non-clinical person, and these people have been trained to know what stroke symptoms look like, but that’s not happening. So, we’re trying to figure out what they’re saying when they present to see if we can bridge that gap.”

But, factors such as language barriers and income are compounded in communities that have more recently arrived in the United States.

Hmong Americans have long experienced unique challenges in navigating the American healthcare system. Originating in Southeast Asia, the Hmong community fled persecution following the war in Vietnam, with many families resettling in America as refugees starting in the Seventies. With their unique language and cultural traditions, including healthcare practices, the Hmong found themselves facing barriers to healthcare that placed them at increased risk for cardiovascular issues, including stroke.

Despite the community’s growing presence in the United States, there has been a glaring gap in our understanding of stroke within the Hmong American population. While prior studies have indicated high rates of vascular risk factors among racial minority groups, very little was known about the specific patterns and outcomes of stroke in the Hmong community. The lack of comprehensive data and research left a critical void in addressing the unique healthcare needs of this population.



Donna Lindsay

However, a recent and groundbreaking study published in the *Journal of the American Heart Association*, titled “Stroke Characteristics in a Cohort of Hmong American Patients,” sheds light on this underrepresented group’s experience with stroke, offering vital insights into healthcare disparities and potential solutions.

At the forefront of this study is Dr. Haitham Hussein, Associate Professor at the University of Minnesota’s Department of Neurology and the President of the American Heart Association board in the Twin Cities. Originally from Egypt, Dr. Hussein pursued his medical



Dr. Haitham Hussein

education in Cairo and completed a combined neurology and psychiatry residency, during which he also earned a master's degree and American certifications to practice in the United States. He then conducted research before undertaking a neurology residency and stroke fellowship at the University of Minnesota.

In a recent conversation with *Stroke Matters*, Dr. Hussein shared the history of the study as well as his insights into the study's findings, emphasizing the importance of primary prevention, cultural sensitivity, and the need for tailored interventions.

"It's always obvious for people in health care that members of racial minority groups usually don't have access to good primary care," he says. "And, that chronic conditions like high blood pressure, and diabetes and high cholesterol are not as well controlled. As a racial

minority myself, I've had my own experiences, but I am privileged. I'm a physician.

"I remember, for example, one nurse telling us about a patient who was coming frequently to the hospital with diabetes complications. The initial impression was that the patient was not compliant. The nurse went to his room one day, prepared to give him a lecture about the importance of being compliant and all of that, only to learn that he had to decide between buying food for the family and buying his medication. So he always bought the food.

"Without talking to the people who we are intending to serve, and getting the story from them, and letting them inform us of the gaps or the difficulties, and letting them participate in the solution, without doing it that way, it's never going to move forward."

However, finding actual numbers was difficult because of how racial and ethnic minorities are tracked. Healthcare organizations use the same general categories as the Census Bureau. These categories don't allow for any kind of granular statistics within the overly broad category of "Asian." Hmong people can't even be categorized by country of origin because the Hmong have historically been a people without a set country.

"Because there isn't a single country of origin for the Hmong people," Dr. Hussein says, "we had to think creatively. Most Hmong individuals come from Laos, but some can be found in Vietnam and Cambodia, among other places. We used their language, which is unique to the Hmong, and their names. Notably, there are 18 distinct clan names among the Hmong, with the clan name serving as their last name. This approach allowed us to effectively combine last names with the Hmong language, ensuring a pure sample of Hmong patients for comparison with White patients.

"It was an interesting approach, although we acknowledge its limitations. While it hasn't been validated by prior studies, we had to accept these methodological constraints."

The study also leveraged data from the institutional Get With The Guidelines (GWTG) database and identified patients discharged with acute ischemic stroke, intracerebral hemorrhage, or subarachnoid hemorrhage between 2010 and 2019. Using clan names and primary language, Hmong patients were specifically identified within the database. The study then conducted univariate analysis – analysis that takes data, summarizes that data and finds patterns in the data – to compare Hmong

patients with their White counterparts, revealing several critical insights.

Among the key findings, it was observed that Hmong patients had a higher prevalence of hemorrhagic stroke compared to White patients. Moreover, in the acute ischemic stroke cohort, Hmong patients were notably younger, experienced delays in emergency department arrival, had a lower rate of thrombolysis usage, and displayed distinct risk profiles. In the intracerebral hemorrhage cohort, Hmong patients again demonstrated a younger age, higher blood pressure, and differing outcomes compared to White patients.

“And that difference is as much as eleven or twelve years,” Dr. Hussein says.

This specific factor, that of stroke and cardiovascular health issues hitting people at a younger age, is statistically noticeable among many non-white populations.

“For instance,” Donna Lindsay says, “the African American population is known to develop high blood pressure at a younger age than other ethnic groups, and their management is often suboptimal. This could be influenced by socioeconomic status and dietary practices. Still, it’s believed that they may respond differently to high blood pressure treatment, suggesting that healthcare approaches might need to be more aggressive.

“The Latino community has a higher incidence of diabetes at a younger age than many other groups, and we’re investigating whether they’re being identified and managed effectively.”

“And, in many populations that have a history of traumatic encounters with authorities, we see decisions to not contact 911. Or participate in research. We see that in the African American and Latino communities and definitely in Somali communities.”



In this context, the “Stroke Characteristics in a Cohort of Hmong American Patients” study emerges as a pivotal first step toward shedding light on the challenges faced by Hmong Americans in the realm of stroke care and, importantly, providing a foundation for targeted interventions and equitable healthcare practices.

Dr. Hussein emphasizes that healthcare interventions for teenagers and children of racial minorities must begin as far back as high school and middle school due to the higher than average prevalence of cardiovascular health issues among their coterie.

“We actually have another study that just got accepted and will be published soon. We looked at the control of blood pressure in people in clinics, not stroke patients, just regular clinic visits. We found that if you divide the patients by age, categorizing them by decades you’ll

find that the worst rate of uncontrolled hypertension, the highest rate, is in the youngest age group.

People in their 20s often have high blood pressure and take it lightly. They lack symptoms or alterations in bodily functions. They can work and socialize without trouble but are unaware that it is causing silent damage to their blood vessels. So, from a public health standpoint, we should focus on primary prevention. We need to work on obesity, lifestyle, smoking, and eating habits starting early. We should provide these kids with the knowledge that they are at a higher risk for stroke.”

Dr. Hussein also stresses the significance of listening to and understanding the challenges faced by racial minority communities. He notes that assumptions about healthcare and interventions often overlook the lived experiences of these communities, leading to ineffective solutions. His

Continued on Page 12



Sidebar: A Conversation With May Deluhery

By Phil Gonzales

In our exploration of stroke prevalence within the Hmong community, we spoke with May Deluhery, a Resource Facilitator with over a decade of experience at the Minnesota Stroke Association. May’s direct insights as the Hmong liaison illuminate the nuances of stroke care and rehabilitation, particularly among higher-risk populations.

Increased Referrals, Varied Demographics: According to May, “I’ve noticed a significant increase in client referrals over time. A growing trend is the influx of younger, male clients from various backgrounds, but many face obstacles. There’s a need for education on the importance of stroke rehab and transportation can be a significant barrier.”

Hmong-Specific Patterns: May highlights that “within the Hmong community, stroke survivors tend to be older or retired, often with younger family members available to support them during appointments. Insurance coverage plays a significant role in their access to rehabilitation.”

Delays in Seeking Care: May notes that “across diverse communities, a common challenge is the delay in seeking medical attention when stroke symptoms manifest. Lack of awareness about the symptoms and hesitance to call 911 contribute to these delays.”

Educational Imperative: According to May, a primary issue is “the disconnect between stroke and brain injury awareness, especially among those who don’t recognize a stroke as a brain-related issue. Education remains a vital component of my work.”

Interacting with Healthcare Professionals: May describes her initial challenges in coordinating care with healthcare facilities, saying “I faced difficulties in referral follow-ups and communication. But professionals are increasingly recognizing the importance of rehabilitation therapy, which is heartening.”

Transportation and Interpretation Challenges: Access to care is further complicated by “transportation and language barriers,” as May elaborates. Overcoming these hurdles often requires “significant effort.”

A Vital Resource: Despite the obstacles, May and the other Resource Facilitators at the Minnesota Stroke Association provide essential guidance and support for stroke survivors and their families. The Resource Facilitation team is there to assist those seeking answers or help navigating the complex stroke care landscape.



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emphasis on cultural sensitivity highlights the need for a more humble and receptive approach that values the input and experiences of those who are intended to benefit from healthcare initiatives.

In addition to cultural and language considerations, Dr. Hussein stresses the challenges faced by Hmong Americans who are war refugees. Trauma has a found impact on healthcare interactions, where even the presence of someone in uniform can evoke distressing memories. These insights emphasize that addressing healthcare disparities is not solely about medical numbers but also about the complex interplay of cultural, psychological, and historical factors.

“It’s not just how well their cholesterol number is on a lab check. It is more complex than that. It really just requires that we sit down and listen and understand and see how we can build that trust.”

While the study serves as a crucial starting point, its scope also points to the need for larger studies to confirm its observations. Dr. Hussein’s call for future research aligns with this perspective, emphasizing the importance of exploring stroke disparities in other racial minority groups. These larger studies can offer a more comprehensive understanding of the factors contributing to healthcare disparities and guide the development of effective interventions.

In addition to research, policy changes and healthcare initiatives are imperative. Dr. Hussein’s insights into the unique challenges faced by racial minority communities, particularly war refugees, underscore the necessity of policy adaptations that consider cultural backgrounds and trauma-related experiences. The healthcare system must evolve to provide the time, tailored care, and cultural competence required to bridge the healthcare disparities gap.

A key aspect of addressing healthcare disparities is the commitment to expanding the research. Future research should not only aim to identify disparities but also inform actionable solutions. Policy adaptations must consider cultural backgrounds, historical experiences, and the impact of trauma on healthcare interactions. Furthermore, targeted interventions should encompass primary prevention efforts that begin early in life, age-appropriate approaches, and culturally sensitive healthcare practices. The lessons learned from studying healthcare disparities should serve as a catalyst for change within the healthcare system.

To pave the way forward, we must commit to equitable healthcare for all communities. Dr. Hussein’s emphasis on primary prevention, cultural sensitivity, and tailored interventions aligns with the urgency of the issue. Closing gaps in primary care, improving stroke health literacy, and adapting policies and healthcare initiatives are critical steps. Future research must expand its horizons, examining disparities in other racial minority groups to inform targeted solutions.

The journey to equitable healthcare is ongoing. By combining the insights from the “Stroke Characteristics in a Cohort of Hmong American Patients” study and Dr. Hussein’s expertise, we can strive for a future where healthcare disparities are addressed comprehensively, and every individual receives the care they deserve, regardless of their background or history.

“There has to be a different approach,” Dr. Hussein emphasizes. “We have to start early. We have to be smart. It’s a multifaceted issue.”

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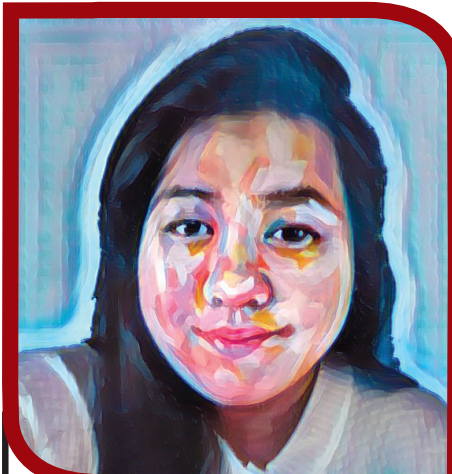
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