



## Narcolepsy Perspectives: A blog about anything & everything Narcolepsy

### 2024 “Sleep Inequities and Inclusion” Panel Recap

*Written by Tatiana Maria Corbitt, MS*

**June 27, 2024** - Hello and welcome back to Narcolepsy Perspectives! The Wake Up Narcolepsy 2024 National Summit near Seattle, Washington, was a smashing success!

Experts in the sleep field, medical professionals and patients alike, sure taught us a lot. Some of my favorite moments during the National Summit included meeting so many Narcolepsy friends in-person for the first time, watching my Narcolepsy service dog perform her duties in a highly-populated environment and speaking on a very important panel!



During the Summit, I had the privilege of sharing my experience living with Type 1 Narcolepsy whilst presenting my story on the **Sleep Inequities and Inclusion Panel**. Other panelists included **Tony Bennae Richard** and **Dr. Michael Grandner**. I will be briefly touching on moments from everyone’s presentations, but encourage you to check out the [full recording](#) to hear from each panelist themselves.

#### **Michael Grandner, PhD, MTR, CBSM, FAASM**

Dr. Grandner shared during the presentation that, “sleep is what brings us all together. It’s something we all have a story about.” He also mentioned that certain populations face systematic barriers that create more problems for them in the area of sleep.



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In 2013, Dr. Grandner published a paper in the *Journal of Sleep Medicine* entitled “Sleep Symptoms, Race/Ethnicity, and Socioeconomic Position,” which discusses sleep inequities within the medical sleep space. This paper states,

“The present study represents the first comprehensive examination of “sleep disparities” relative to demographic and socioeconomic factors to leverage a nationally representative dataset. Sleep symptoms are disproportionately experienced by individuals based on their **race/ethnicity, immigration status, poverty status, education level, access to healthcare, food insecurity, and other factors,**” (Grandner et al, 2013).

### Tatiana Maria Corbitt, MS

During the presentation, I brought up the many barriers to treatment and care based on my own identities and life experiences. As an openly queer and femme person, I have experienced intense poverty, issues with access to healthcare and housing, prolonged food insecurity and more. This is not just my own story, though - this is the case for many vulnerable populations in our community.

I mentioned that there seem to be significant gaps of cultural competency in healthcare providers. According to a research paper entitled, “Health Care Inequities of Sexual and Gender Minority Patients,” LGBTQIA+ people “**are more likely than heterosexual and cisgendered individuals to experience discrimination, bias, and dissatisfaction** with the medical system,” (Arnold E., Dhingra N, 2019).

Gaps in cultural competency heavily impact healthcare outcomes in LGBTQ+ people. According to a research article entitled, “Update on Medical Education, Insurance Coverage, and Health Care Policy for Lesbian, Gay, Bisexual, Transgender, Questioning, Intersexual, and Asexual Patients,”

“There are important gaps in LGBTQIA knowledge, clinical competency, and cultural sensitivity, as well as attitudes among health care professionals, medical educators, and those in the public and insurance policy sectors. These are not only professional deficiencies but also **perpetuate discrimination, limit access to health care, and lead to poor health outcomes.** Research supports the notion that acquiring skills and knowledge through dedicated training programs leads to more compassionate and competent care for LGBTQIA patients,” (Nguyen, 2019).

In addition to struggling to access adequate healthcare, we also experience higher rates of food insecurity. I personally continue to experience food insecurity despite being on



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disability and working and using all community and government resources that are available to me. This isn't uncommon in the LGBTQ+ community. According to a paper published by UCLA: The Williams Institute, "Certain sub-populations within the LGBT community are particularly vulnerable to food insecurity or report relatively high rates of participation in SNAP. These include bisexuals, women, and people of color. While nearly 1 in 4 White LGBT adults (23%) experienced food insecurity at some point last year, the figure was more than 1 in 3 for African-American LGBT adults (37%), more than 1 in 2 for LGBT Native Americans (55%), and more than 3 in 4 for Native Hawaiians (78%)" (Gates, 2014).

### **Tony Bennae Richard**

Sleep inequities are present in many populations, not just the LGBTQ+ population. The Black community, for example, can face extra barriers to care. Tony is a veteran, and a father to a young woman with Narcolepsy named Chloe. Tony discussed "Acres of Skin: Human Experiments at Holmesburg Prison" by Allen Hornblum and "Medical Apartheid," by Harriet Washington, which are books that explain the history of nonconsensual medical research on people of color. Even in modern times, it is difficult for people of color to get access to adequate medical care.

During his presentation, Tony also shared a letter from his daughter outlining the ways in which Narcolepsy affected her life, and continues to. This was a personal essay that she drafted for a school application in which Chloe described her journey to a Narcolepsy diagnosis. She discussed the hurdles that came along with her diagnosis, including fighting with insurance for specialty medication coverage, on top of fighting with her severe Narcolepsy symptoms.

On this, she stated, "For roughly three years, I was a prisoner of war as my brain and immune system battled each other, ultimately leading to my immune system conquering my brain, and subsequently the demise of the neurons that regulated my wakefulness. Unbeknownst to me I had developed narcolepsy, seemingly overnight. Insatiable exhaustion plagued my body. My bed became my cell, the cell that held me. Hallucinations, my cellmate. My responsibility for adversaries and the ignorance regarding my chronic condition became my oppressor. In the blink of an eye, the entire trajectory of my life had changed..."

Later on in the letter, she mentioned that her relationship with Narcolepsy began to shift when she discovered the power of advocacy. She grappled with the reality that she was able to get access to diagnosis and treatment for her Narcolepsy, while many people are



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not able to. On this, she states, “The uninsured, the unsupported, or the underinsured, those with language or financial barriers, those with disability or impairments, those who have no one to advocate for them. How will their voices and needs be heard and valued? How many people continue to struggle with debilitating disorders due to the failures and barriers in the healthcare system?”

Ultimately she described the importance of advocacy and pushing for better change for people with Narcolepsy. Tony states that their journey shifted for the better after they found out about Wake Up Narcolepsy.

The panel concluded with a Q&A session. The first question posed by the audience was, “How do we create positive change in the medical sleep space for minority populations?” The **Sleep Inequities and Inclusion Panel** answered that it is vital to increase awareness and open up discussion around these topics. It’s important to uplift minority patient voices, and support research efforts led by researchers of minority identities. Finally, it would be beneficial to increase and improve the required cultural competency training curriculum for medical and research professionals, including extensive discussions around barriers to proper medical care.

*So how do we make these systems work for us, the people?* That was the question posed to the panel. And while there is no hard and fast answer, per say, we did have a constructive discussion on this topic during the Q&A portion of our panel.

Dr. Michael Grandner made sure to contribute to the conversation here, explaining that people of color are less likely than white people to bring up sleep issues with their doctor, and as a result, are more likely to have higher rates of undiagnosed sleep disorders. He stated that, “People for whom the system is sort of stacked against them in some way, they’re less likely to say ‘my sleep is a problem’ because their sleep is often not even on their radar. They’re solving other problems in their life right now.”

Finally, a representative of the [Narcolepsy Africa Foundation](#) expressed their gratitude for the support that is provided to the LGBTQ+ Narcolepsy community through [WUN’s LGBTQIA+ Narcolepsy Support Group](#), stating they have similar support needs in their community and recognize the importance of our work. Overall, I found this validating and touching.

As a volunteer facilitator for Wake Up Narcolepsy’s LGBTQIA+ Narcolepsy Support Group, I put a lot of effort into cultivating and uplifting and welcoming space for the



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people in our community. I call these people my “Narcolepsy family,” and I truly mean it. We are there for each other, we understand each other, we support each other. We appreciate and honor our similarities and differences. And that is beautiful.



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