Project Sleep Podcast
"Sleep, Race, & Health Disparities"
(Sleep Insights Series Episode 2)

Julie Flygare, JD is the President & CEO of Project Sleep, a leading narcolepsy advocate, speaker, award-winning author, and Stanford Medicine X ePatient Scholar diagnosed with narcolepsy and cataplexy in 2007. She received her B.A. from Brown University in 2005 and her J.D. from Boston College Law School in 2009.

Dr. Michael Grandner is a licensed clinical psychologist, Director of the Sleep and Health Research Program at the University of Arizona, and Director of the Behavioral Sleep Medicine Clinic at the Banner-University Medical Center in Tucson, AZ. His work focuses on translational sleep research and Behavioral Sleep Medicine. Dr. Grandner is also a member of Project Sleep's Expert Advisory Board.

Dr. Carmela Alcántara is an Associate Professor of Social Work at Columbia School of Social Work. She is a clinical psychological scientist with additional expertise in social epidemiology and behavioral medicine.

The Sleep Insight Series invites listeners to learn about this amazing adventure we take every night called sleep. Through these insightful discussions, we examine sleep, and our societies beliefs about sleep, from a variety of angles. We hope you'll learn some cool new facts and analogies that you can use to help us raise awareness about this under-appreciated one third of our lives. This is a written transcription of the podcast "Sleep, Race, & Health Disparities" (Sleep Insights Series Episode 2) from Project Sleep. Transcription provided by Mirela Starlight.

Project Sleep is a 501(c)3 Nonprofit Organization, dedicated to raising awareness and advocating for sleep health, sleep equity and sleep disorders.

All guests and speakers express their own opinions. While medical diagnoses and treatment options are discussed for educational purposes, this information should not be taken as medical advice. Each person's experience is so unique, which is why it's so important to always consult your own medical team when making decisions about your own health.

Julie in intro: What is the connection between sleep, race, ethnicity and health disparities? And what is being done to help reduce these disparities? In this episode, Dr. Michael Grandner provides a wonderful overview of sleep health disparities research, followed by Dr. Carmela Alcántara, highlighting a community engagement intervention in the Spanish-speaking Latinx population.

Julie: We're really excited to have two presenters today, to tell you a little bit more about their work in this space and catch you up in case you're not familiar with this area of research and this body of research.

Dr. Grandner: Thanks. So, I'm really excited to be here and I'm really excited that this is a topic that is gaining increased focus and attention. So my task over what I'm hoping is 10 minutes or less, is to sort of orient everyone to sleep and health disparities research. My goal is mostly to

tell the history of where sleep disparities research has come and sort of where it is now and look— and talking about these policy directives. I want to start with this idea though, that especially throughout the sleep scientific community, sleep is often thought of as something like this— as a biological process or a set of biological processes that are intertwined with each other and have many functions and have mechanisms on health and then— there's a whole breadth and depth to this. But something that I continuously try to remind myself as a sleep and circadian researcher, and the sleep and circadian research community, is encapsulated perfectly in this quote by sociologist Simon Williams, who says, "When we sleep, where we sleep and with who we sleep, are all important markers or indicators of social status, privilege and prevailing power relations." And this reminds us that sleep isn't just a biological process. It's a process that occurs in context, of the world, and it's universal, and it's impacted by all of these things. So a very, very, very brief history— social environmental influences on health have been studied for over 200 years. I mean, you have the first epidemiology studies going back to the 1700s, picking up steam in the 1800s, and even more so in the 19th century and into the 20th century. They start out in Europe, and you have these early and mid-20th century studies that started looking at systematic differences, and particular areas that were looked at were environmental exposures, so this is where you had a lot of dirty cities and air pollution and disease and sanitation issues. Healthcare access and utilization, and also differences in health status and outcomes, based who you were, especially socioeconomically. The racial ethnic health disparities research picked up steam, especially in the 1990s, and culminated with an Institute of Medicine report called "Unequal Treatment". This was published in 2003, and it really defined the term of disparities for the field, and really did set a research agenda. Since then there's been some pick-up in sleep disparities research. The very first study of sleep health disparities that I could find was published by Girardin Jean-Louis and colleagues in 2000. So it was 20 years ago, but still relatively recent compared to other disparities research. And this is sort of the key disparities takeaway finding was that minority men got less— and women to a lesser degree, got less sleep than those who were white. There was some previous work that may have mentioned race or ethnicity differences, but this was really the first time it was a focus of a research publication.

Dr. Grandner: Probably the next key finding in the field was by Hale and Do— Lauren Hale and Phuong Do published 2007 in the Journal of Sleep. And what they did that was particularly groundbreaking here was that they extended findings to a nationally representative sample. So you have blacks and African Americans are more likely to be both short and long sleepers. You had Asian Americans more likely to be short sleepers, and other non-Hispanic Latino adults more likely to be short sleepers. These findings have been replicated since, many, many times. There's a huge uptick. I'm not going to mention all of the studies in this area, but I'm going to mention what I think are a few key ones. First of all, you had Girardin Jean-Louis and colleagues really digging into this issue of ethnicity and sleep, not even just race ethnicity but how some groups, environmental context impacts sleep. This was another groundbreaking study led by Diane Lauderdale that actually extended these results to actigraphy in a large sample. This was a study where we looked at the interaction between race, ethnicity, socioeconomics, and other sociodemographic factors and how they fit together. We now have a number of meta-analysis, there are two in particular, led by Megan Petrov. There's the term sleep disparity— was coined by Nirav Patel in this 2010 paper. You have a growing literature on physiologic and genetic mechanisms, linking some of these disparities' outcomes. You have more integration of sleep disparities focus in other cohort studies. A great study that came out of the HCHS-SOL Project, also showing bridging out from not just looking up blacks and American Americans, even though that's where probably the most robust findings are. And then sort of the modern era of analyzing some of this data and really looking at some of these complex

relationships, linking sleep and race ethnicity, what is the role of socioeconomics, what is the role of racism and discrimination and cultural context, and all of these things sort of fit together.

Dr. Grandner: A socioecological model that we've been using and really is trying to set the discussion for the field of how all this stuff fits together. You have sleep, you have these downstream health outcomes, you have metabolic, cardiovascular, immunologic health, mental health, behavioral health and cognitive health— and all these domains are all integrated with each other, and there's whole lines of research linking sleep with each one of these, but then what is upstream of sleep? If we're going to make an impact on sleep in the real world of public health, we have to understand what's upstream. So we have these individual level factors— these are the things like behaviors, beliefs, and attitudes, genetics, health. These are the things that if you ceased to exist, they would cease to exist. And this is what drives individual sleep behavior. But, what's important is the individual is embedded within a social level. These are things that exist outside of you that you're a part of. Things like your job, your neighborhood, your culture, religion, your social networks, your friends, your family. These are the things that these individual level beliefs, behaviors, and the biology sort of come from. And we can't really extricate ourselves from these. I mean, anybody— think about how your sleep in the past— just in the past week, was dictated by things outside of you like your job, or your neighborhood or your family, or the busy street you live on, or things you need to wake up in the morning for, or stay up late for. And even still, way beyond the basic sciences is the social level, or the societal level. These are things that exist outside of these social constructs, like social networks and friends and jobs and families. These are things like— racism, globalization, technology, public policy, the physical environment and conservation. These are things that actually impact sleep. There was a paper that was just published, looking at wind turbines and wind farms and how that may impact sleep. So there's a whole ecology here— what drives sleep.

Dr. Grandner: And thinking about going forward, there's a paper that recently came out from an NIH workshop that was led by an NIMHD that was focused on sleep health disparities. I was fortunate to be part of this workshop and so are a number of other people in the field. And this is sort of what we set as sort of the agenda moving forward. We need more, to develop and promote integrated research of sleep health disparities, not just looking at it from one perspective. We want further development on understanding the causes and consequences of sleep health disparities, and also interventions to address sleep health disparities. That's something we're a bit behind on. And we also need to help build the research infrastructure and training opportunities for sleep health disparities. Not just funding research, but helping to build the pipeline. And so, led by Project Sleep, we sort of— I was able to help develop some of these ideas. I reached out to and got feedback from a number of people publishing research in this field. And we also got some input and endorsement from the Sleep Research Society and the Society of Behavioral Sleep Medicine, that these ideas were something they will extend behind. There were these five policy initiatives, and this is what they were.

Dr. Grandner: Number one, we want to ensure funding for early career pipeline programs that help individuals of low socioeconomic status and underrepresented racial ethnic minority groups to thrive in the medical and research fields, to help add their voice to the conversation, because they have perspectives that not everybody in the field is going to have. And so we'll get better questions, better science, and better answers if we can diversify the field a little more. We want to ensure dedicated research funding to develop and implement people-centered, community-led interventions to improve community awareness and treatment of sleep disorders and sleep loss. So sleep as a domain of health, as well as disorders like insomnia and apnea, and the focus here is not just treatment of these problems, but also helping to increase awareness. Dr.

Carly mentioned the tax program, which is a great example of this. We want there to be more funding to educate the public health and healthcare providers, on signs of sleep loss and sleep disorder issues. Specifically those impacting racial ethnic minorities and underrepresented groups. I think there's a huge social justice issue here. The people who are not sleeping and having adverse health outcomes are the ones who are already systematically set up for worse outcomes in general. And a lot of the upstream factors have to do with things like, work schedules and multiple jobs and shift work and environmental stressors that we could potentially intervene on. And we want meaningful research and funding to better understand and address these health disparities. And research funding to study how school start times in particular, are impacting low socioeconomic and minority communities. I mean, the school start times issue is probably the lowest hanging fruit as from a policy perspective, because the research is so clear— that this is something that probably needs to be done, and it's important to draw attention to the fact that the communities that are most probably disproportionately impacted by this, are communities that are already stressed. So these are the five policy initiatives that we're talking about putting forward.

Julie: Thank you so much, Michael.

Julie: Dr. Carmela Alcántara.

Dr. Alcántara: Hi Julie.

Julie: Hi! Thank you so much for joining us today.

Dr. Alcántara: Happy to be here. So as Julie mentioned, what I want to do in the short time together is just highlight one of these kinds of community engage interventions. And specifically, this is a Dormir Mejor Trial, which is an ongoing R01 that's a hybrid effectiveness implementation study, but that's focusing on the health disparity population that's important, which is the Latinx population and particularly Spanish-speaking Latinx population. And so to first, you know, to answer this big question, which is what do we know about the state of science of behavioral sleep medicine interventions for health disparity populations— my group and I we conducted this really comprehensive, exhaustive, systematic review that reviewed all of the behavioral sleep medicine randomized control trials from inception to December— where the goals were to examine all the records to examine and identify the socioeconomic characteristics to get a sense of the representativeness of the samples, and then also to really closely look at what kinds of changes, cultural adaptations or tailoring, were made for these specific populations that— I think were highlighted in what Dr. Grandner described before. And then lastly to describe— really qualitatively, intervention effectiveness.

Dr. Alcántara: And what we found from that, is that, over— I think we retrieved 8,000 records, did full deep dives of 800 articles and of those 800 articles that met inclusion of criteria, only 7% of them actually targeted underserved groups that would qualify as a health disparity population. Among this, you know, massive systematic review, what we learned is that of behavioral sleep medicine randomized control trials, none targeted immigrants, none targeted LGBTQ+ populations, linguistic minorities, so non-English speakers— and that only about 9% actually targeted— or included, racial ethnic minorities. In my program of research, I appreciate being called the fixer, I think I describe in point two— and so I'm really interested in how social determinants shape sleep, mental health, and cardiovascular health, but also thinking how do we translate that into interventions. And, you know Michael put in a plug for thinking, not only about individual level interventions, but community interventions. And I've been really interested

in how do I integrate the work on these population based level with both individual, behavioral level interventions. And increasingly focused on insomnia, in the Latinx population. And the reason for that is if you take a temporal view, the prevalence of insomnia among the Latinx population's actually increasing. So in 2002, it's around 16%. In 2012, it's about 19.3%. With insomnia's, we know that in terms of behavioral treatment, CBTI is the first line of defense, and so we know it works really well— but that there's a lot of barriers to actually getting— access, to receive cognitive behavioral therapy for insomnia. And some of those, which we all know— you know, include insomnia's secondary, there's inaccurate beliefs about the importance of sleep, just limited access to qualified providers which when you're referring to underserved groups and non-English speakers really becomes accentuated in terms of who is— having qualified providers to deliver CBTI— in languages that are not English— and in general as that systematic review, the results of that systematic review, underscore— there's been a lack of attention to these contextual language literacy and cultural factors.

Dr. Alcántara: And so with that in mind, you know, I— and colleagues, have been very interested to understand the role of socio-cultural stressors, and it's relationship to insomnia, and other sleep disturbances among Latinx populations, and use these large, population based studies, some of which Dr. Grandner called out, like the Hispanic Community Health Study, to examine what's the relationship between specific socio-cultural stressors and insomnia, and what we have found— in two sets of papers that were published, is that the acculturation stress in particular, which is the stress of adapting and integrating to U.S. mainland culture, seems to be a pretty significant, consistent, and robust correlate of insomnia in the Latinx population. We've also had some— in this work, to show that also ethnic discrimination appears to be an important correlate of insomnia, as well. In addition to, and independent of chronic stress. So this bore out in quantitative, population based epidemiological studies and also in qualitative work that we did, where we directly talked with patients and participants with insomnia. And time and time again in these groups, both in English speaking groups and in Spanish speaking groups, the salience of acculturation stress was actually— very salient, and pervasive. And there's been a lot of promise, it's cool and not intentional, I think I heard in the Pakori talk, there— there was reference to several of these internet based studies or digital health based studies, to address potential CBTI access barriers, particularly because of the supply and demand imbalance that we all know. And there's been a lot of excitement around digital therapeutics, digital treatments, as potentially expanding access for underserved communities. Because of the supply and demand issues, we know that this might be especially helpful amongst Spanish speakers and there might be a potential for faster up-take of behavioral health care because of increased access to digital health for these communities.

Dr. Alcántara: This is just an example, by no means an exhaustive list— not an exhaustive list of various different kinds of digital therapeutics for insomnia that exist, and some of which have a pretty strong evidence base. And so this quantitative literature that I showed you, the qualitative literature, the promise of some of these digital therapeutics, and the strong evidence base for CBTI, in particular— among English-speaking, highest SES communities, really served as a strong foundation to fund for the Dormir Mejor study, which is an AHRQ Agency for Healthcare Research Quality, R01 funded grant that reflects the collaboration between Columbia School of Social Work, Pear Therapeutics, which I'll describe— and also this 11% bilingual English and Spanish community advisory board that includes patient stakeholders and other key stakeholders from the community, and other— respective areas.

Dr. Alcántara: And so with this hybrid type one trial, it's a combined hybrid effectiveness implementation study, as I mentioned, with three aims. The first aim is to culturally adapt an

existing evidence-based digital health intervention and then to conduct a randomized controlled trial. The second aim is to conduct a multi-stakeholder evaluation, to really understand and assess the barriers and facilitators to implementing a digital health CBTI treatment, in primary care for Spanish-speaking Latinx patients. And the third is a cost effectiveness, and we want to know, is it cost effective? How does it compare? So using a rigorous cultural adaptation sub-study, that goes from the early stages of information gathering, and very formative qualitative research, to the final stage— which is this cultural adaptation trial, this randomized controlled trial. We're currently in the stage 3 and stage 4. I do want to say we've been— we have a lot of participant engagement and have been able to conduct focus groups in New York City— in, you know, actually during our search in May, through— virtual platforms and I think that's a reflection of just the community involvement that we've had thus far and are prepared to move to stage 3 and stage 4, but a community advisory board has been involved throughout this entire process.

Dr. Alcántara: So, in this intervention, the digital therapeutic that we are adapting and testing is Somryst. Somryst is— some of you may know, Somryst is the first FDA market authorized prescription digital therapeutic for chronic insomnia, for adult ages 22 years old and up, it's really quite exciting. And so what we're doing is, doing a deep dive, top to bottom— review of Somryst and obtaining both community advisory board and participant feedback on precipitating and perpetuating factors of insomnia— the Somryst vignette characters and stories, the personas, the guideline— really with close attention to health literacy and wanting to make health literacy and numeracy— often numeracy is actually a topic that isn't often discussed, but that— given in digital platforms you're relying on content, wanting to make sure that— that we're attuned to and responsive to health literacy concerns to make sure that the therapeutic concepts are understood. And today in this short and trying time, we've already identified 71 different kinds of adaptations, most of these are what we would refer to as deep level adaptations, or— or tailoring, where it's beyond just the language or more surface level adaptations. And some examples of these adaptations which are either surface or deep, include making sure that the vignette characters reflect the diversity of the Latinx population— that the vignette— the video vignettes leverage cultural values of families, and I can talk more about that later. Really centering the immigrant experience, as I mentioned, acculturation stress in the quantitative work seems to be a major factor in the qualitative work, so making sure that that was foregrounded throughout the content of the digital health intervention. Incorporating culturally relevant examples and proverbs and really again, attuning to health literacy— to reading levels, so all the materials at a sixth grade reading level, and also ensuring that there's captioning in these digital health interventions, which is something that is oftentimes missed.

Dr. Alcántara: So I just want to acknowledge the multiple funding sources here, including AHRQ and NHLBI and also the community partners as I mentioned, I think part of why we had a lot of engagement and sustainment even during— a pandemic, is because of the strong community partnerships with various different consulates in New York City who are listed here, including the consulates of Mexico, Dominican Republic and Colombia— and our community partners like the Hispanic Federation and others here. I'll end there.

Julie: Thank you so much for this amazing presentation. I know it's— I'm inspired, I hope you guys are too, by all this great work. All right, well, thank you again to Dr. Grandner and Alcántara, for being here today and doing this special emphasis panel, it is so important— and I just can't thank you enough, for all that you are doing.

This discussion was originally recorded during Project Sleep's Sleep Advocacy Forum *in October 2021.*