SESSION IV

Autistic People's Sleep Differences

Beth Malow and Zachary Williams* (Vanderbilt University)

Thursday, July 21, 2022 at 2:00pm ET

Course Materials

The purpose of these materials is to help provide an introduction to the INSAR Institute session on understanding autistic people's research priorities. The materials were designed to prepare students and trainees who are unfamiliar with this research with the general background to receive the most educational benefit from the session. Toward this objective, we have prepared the following: (1) learning objectives for this session, (2) key terms and concepts, (3) a selection of recommended resources. These materials are considered supplemental to the presentation.

In collaboration with Beth Malow and Zachary Williams, these materials were developed by Hillary Schiltz (Post Doctoral Scholar at University of California, Los Angeles, USA; hschiltz@mednet.ucla.edu), Sapir Soker-Elimaliah (Doctoral Candidate at City University of New York; elm.sapir@gmail.com), Fathima Muhsina Kodakkadan (Doctoral Candidate at Anglia Ruskin University in Cambridge, UK; muhsinak19@gmail.com), and Michal Cook (Graduate Student at University of North Carolina Chapel Hill; michal.cook@unc.edu). Feel free to contact us with questions/comments. Register for this webinar and other sessions in this series at: https://www.autism-insar.org/page/Institute2022.

Learning Objectives

The INSAR Institute for Autism Research was established in direct response to requests from students and trainees for multidisciplinary training opportunities. The INSAR Institute team is also working to engage stakeholders. The INSAR Institute priorities are to provide a (1) freely available, (2) multidisciplinary training platform for young scientists and others from various backgrounds that (3) allows for international participation. The overarching goal of the INSAR Institute is to expose junior scientists to topics they are not currently engaged in, with the hope that basic scientists and clinical scientists may learn from each other to ultimately advance the understanding of autism.

The current session, *Autistic People's Sleep Differences*, is presented by Beth Malow (Professor at Vanderbilt University) and Zachary Williams (autistic MD/PhD candidate at Vanderbilt University). A team of trainees worked in tandem to prepare this handout and the web presentation. At the conclusion of this session, participants will:

1. **Describe** common sleep concerns in autistic youth and adults.

2. **Identify** research gaps on sleep among autistic people.

3. **Learn** about evidence-based approaches to treating sleep problems among autistic youth and adults.

Key Terms with references:

Bruxism: Bruxism refers to the experience of unconsciously grinding or clenching one's teeth during the day or at night while asleep. Prolonged bruxism can lead to abraded or chipped teeth, facial pain and muscle aches, tooth sensitivity, headaches, and tongue indentations.

(Johns Hopkins - https://www.hopkinsmedicine.org/health/conditions-and-diseases/bruxism)

Continuous Positive Airway Pressure (CPAP) Therapy: Continuous positive airway pressure (CPAP) therapy is a common treatment for obstructive sleep apnea. A CPAP machine uses a hose connected to a mask or nosepiece to deliver constant and steady air pressure to help people breathe during sleep.

(Mayo Clinic - https://www.mayoclinic.org/diseases-conditions/sleep-apnea/in-depth/cpap/art-20044164)

Hypersomnia: Hypersomnia is characterized by recurrent episodes of excessive daytime sleepiness or prolonged nighttime sleep. People experiencing hypersomnia often have difficulty waking up, may often feel disoriented, and may experience other symptoms including anxiety, increased irritation, decreased energy, restlessness, slow thinking, slow speech, loss of appetite, hallucinations, and memory difficulty.

(NIH National Institute of Neurological Disorders and Stroke - https://www.ninds.nih.gov/health-information/disorders/hypersomnia)

Insomnia: Insomnia is characterized by difficulty falling asleep, staying asleep, and/or returning to sleep after awakening prematurely. Insomnia affects a person's energy level and mood as well as one's health, work performance, and quality of life.

(Mayo Clinic - https://www.mayoclinic.org/diseases-conditions/insomnia/symptoms-causes/syc-20355167)

Melatonin: Melatonin is a natural hormone produced by the brain in response to darkness. When released, melatonin aids with the timing of one's circadian rhythms. Melatonin dietary supplements are often taken to improve sleep quality.

(NIH National Center for Complementary and Integrative Health - https://www.nccih.nih.gov/health/melatonin-what-you-need-to-know)

Narcolepsy: Narcolepsy is a severe, long-term brain disorder that leads people to fall asleep unexpectedly. Although narcolepsy may not result in major or long-term physical health issues, it can have a substantial impact on everyday living and be emotionally challenging to manage.

(https://www.nhs.uk/conditions/narcolepsy/)

Obstructive Sleep Apnea (OSA): Obstructive Sleep Apnea (OSA) refers to the experience of interrupted breathing during sleep (i.e., when one's regular rate of breathing is disrupted for longer than 10 seconds at least 5 times per hour throughout the sleep period). OSA can range from moderate to severe depending on the length and severity of interruption.

(Johns Hopkins Medicine - https://www.hopkinsmedicine.org/health/conditions-and-diseases/obstructive-sleep-apnea)

Parasomnias: Parasomnias is an umbrella term for atypical behaviors people experience prior to falling asleep, during sleep, or while awakening. These behaviors range in characteristics, severity, and frequency (e.g., sleepwalking, night terrors, sleep paralysis, etc.).

(Sleep Foundation - https://www.sleepfoundation.org/parasomnias)

Restless Leg Syndrome: Restless legs syndrome, also known as Willis-Ekbom illness, is a common nervous system condition characterised by an intense urge to move the legs.

(https://www.nhs.uk/conditions/restless-legs-syndrome/)

Sleep Efficiency: Sleep efficiency is the proportion of time spent in bed asleep. It is determined by dividing the time spent sleeping (in minutes) by the total time spent in bed (in minutes). A standard sleep efficiency is believed to be at least 85 percent.

(Hypersomnia foundation - https://www.hypersomniafoundation.org/glossary/sleep-efficiency/)

Recommended Readings & Resources

Chen, X., Liu, H., Wu, Y., Xuan, K., Zhao, T., & Sun, Y. (2021). Characteristics of sleep architecture in autism spectrum disorders: A meta-analysis based on polysomnographic research. *Psychiatry Research*, *296*, 113677. https://doi.org/10.1016/j.psychres.2020.113677

Díaz-Román, A., Zhang, J., Delorme, R., Beggiato, A., & Cortese, S. (2018). Sleep in youth with autism spectrum disorders: systematic review and meta-analysis of subjective and objective studies. *Evidence-based mental health*, *21*(4), 146-154. http://dx.doi.org/10.1136/ebmental-2018-300037

Han, G. T., Trevisan, D. A., Abel, E. A., Cummings, E. M., Carlos, C., Bagdasarov, A., Kala, S., Parker, T., Canapari, C., & McPartland, J. C. (2022). Associations between sleep problems and domains relevant to daytime functioning and clinical symptomatology in autism: A meta-analysis. *Autism Research*, 15(7), 1249–1260. https://doi.org/10.1002/aur.2758

Halstead, E., Sullivan, E., Zambelli, Z., Ellis, J. G., & Dimitriou, D. (2021). The treatment of sleep problems in autistic adults in the United Kingdom. *Autism*, *25*(8), 2412-2417. https://doi.org/10.1177/13623613211007226

Henderson, L.M., St Clair, M., Knowland, V. *et al.* Stronger Associations Between Sleep and Mental Health in Adults with Autism: A UK Biobank Study. *J Autism Dev Disord* (2021). https://doi.org/10.1007/s10803-021-05382-1

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MacLean, J.E. & Malow, B.A. (2016, May). *Parent's guide to sleep and melatonin use for children with autism.* Autism Speaks. https://www.autismspeaks.org/tool-kit/atnair-p-melatonin-and-sleep-problems-guide-parents

Malow, B. A., Katz, T., Reynolds, A. M., Shui, A., Carno, M., Connolly, H. V., Coury, D., & Bennett, A. E. (2016). Sleep difficulties and medications in children with autism spectrum disorders: a registry study. *Pediatrics*, *137*(Supplement_2), S98-S104. https://doi.org/10.1542/peds.2015-2851H

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Malow, B., Adkins, K. W., McGrew, S. G., Wang, L., Goldman, S. E., Fawkes, D., & Burnette, C. (2012). Melatonin for sleep in children with autism: a controlled trial examining dose, tolerability, and outcomes. *Journal of autism and developmental disorders*, *42*(8), 1729-1737. https://doi.org/10.1007/s10803-011-1418-3

Malow, B. A., Marzec, M. L., McGrew, S. G., Wang, L., Henderson, L. M., & Stone, W. L. (2006). Characterizing sleep in children with autism spectrum disorders: a multidimensional approach. *Sleep*, *29*(12), 1563-1571. https://doi.org/10.1093/sleep/29.12.1563

Morgan, B., Nageye, F., Masi, G., & Cortese, S. (2020). Sleep in adults with Autism Spectrum Disorder: a systematic review and meta-analysis of subjective and objective studies. *Sleep Medicine*, *65*, 113-120. https://doi.org/10.1016/j.sleep.2019.07.019