NATIONAL INSTITUTES OF HEALTH

FRONTIERS OF KNOWLEDGE IN SLEEP AND SLEEP DISORDERS: OPPORTUNITIES FOR IMPROVING HEALTH AND QUALITY OF LIFE

MARCH 29 and 30, 2004

SUMMARY REPORT

The conference was held in the Natcher Auditorium of the NIH, Bethesda, Maryland and was coordinated by the National Center on Sleep Disorders Research, part of the National Heart, Lung, and Blood Institute.

PARTICIPANTS:

DR. CARL E. HUNT
DR. BARBARA ALVING
DR. RICHARD H. CARMONA

DR. HECTOR BALCAZAR
DR. RUTH BENCA
DR. DANIEL BUYSSE
DR. MARY A. CARSKADON
DR. CHARLES A. CZEISLER
DR. WILLIAM DEMENT
DR. DAVID F. DINGES
DR. ROBINSON FULWOOD
DR. CONRAD IBER
DR. KATHRYN LEE
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DR. W. VAUGHN MCCALL
DR. EMMANUEL MIGNOT
DR. MERRILL MITLER
DR. RUSSELL MORGAN
DR. GREGORY MOROSCO
DR. STUART QUAN
MR. PHILIP RENNER
DR. ROSE MARIE ROBERTSON
DR. TIMOTHY ROEHRS
DR. MARK R. ROSEKIND
DR. THOMAS ROTH
DR. DAVID RYE
DR. JUDITH SANGL
DR. RICHARD J. SCHUSTER
DR. VIREND SOMERS
DR. EVE VAN CAUTER
DR. JAMES K.WALSH
DR. PHYLLIS ZEE

INTRODUCTION

Dr. Hunt, Director, National Center on Sleep Disorders Research, welcomed everyone to the first national sleep conference organized to focus on what is known about sleep and sleep disorders, and what can be utilized and disseminated at the community level to help improve sleep-related public health. Delineating gaps in knowledge and prioritizing recommendations for future research was addressed in the 2003 National Sleep Disorders Research Plan (www.nhlbi.nih.gov/health/prof/sleep/res_plan/index.html) and was not a focus of this conference. Rather, the opportunity to develop strategies to more effectively apply what is known and ready for dissemination and implementation to change clinical and public health practice and, therefore, sleep-related health brought together over 400 individuals from medicine, research, nursing, education, public health, and the general public.

Dr. Barbara Alving, Acting Director of the National Heart, Lung, and Blood Institute (www.nhlbi.nih.gov/), indicated that attendees would hear about how information about sleep and sleep disorders can and should be translated into cost-effective, comprehensive and broadly applied strategies to improve all aspects of sleep-related health care. Dissemination of the existing body of medical knowledge and implementation of expanded clinical practice guidelines is a critical mission for the NIH, she said. Dr. Alving also said that expanding and updating national public health programs is an essential mission for the office of the U.S. Surgeon General and the U.S. Public Health Service, and then introduced Dr. Richard H. Carmona, the U.S. Surgeon General.

Dr. Carmona thanked Drs. Hunt and Alving for organizing the conference. He said that sleep science is among the most important work being done in medicine today and that it also some of the least understood and least appreciated work. He said that the conference would go a long way toward remedying that problem. Dr. Carmona said that chronic sleep loss and sleep disorders have a profound impact on Americans of all ages, and that as many 70 million Americans may be affected at an annual cost of $15 billion in health care expenses and $50 billion in loss productivity.

Dr. Carmona talked about his past experiences, including his military service, recalling that some of his superior officers used to say that sleep was a sign of weakness. He said that prior to performance tests, every man would say that he was "good to go" when asked by an officer, even if he was exhausted. He talked about working as a police officer, a paramedic and a surgical resident, all of which, he said, were demanding jobs that provided little time for sleep. Dr. Carmona talked about the relation of sleep disorders to his portfolio on what is needed to improve the health and safety of the nation.

He said that there were three main areas that currently occupy most of his time. The first area is shifting American society from a treatment-oriented focus to a prevention-minded focus. He said that sleep disorders were responsible for many preventable injuries and accidents. The second area is preparedness, which he said is related to sleep issues because of the huge, rotating workforce called 'responders' who would first handle a terrorist attack. These people need to be well rested and clear-headed for such an event. The third area is health disparities -- minorities typically have less access to health care and have poorer outcomes when they receive care. This is likely also true for minorities with sleep disorders, but there are currently more questions than answers in this area.

Dr. Carmona said that health literacy is also an important problem. American society is largely health-illiterate. Obesity and type-II diabetes are huge problems for Americans and are reaching epidemic proportions without any signs of slowing down. He said that the relationship between these problems and sleep disorders is still not entirely understood and that more needs to be learned.

Dr. Carmona told the conference participants that they were a part of the solution and called on them to continue their work, saying that he needed their help in order to do his job. He expressed hope for many more conferences of this kind.

SESSION 1: NORMAL/ABNORMAL SLEEP: OPPORTUNITIES FOR TRANSLATION

Dr. Czeisler suggested two proposed action items related to characteristics of healthy sleep and circadian rhythms -- education of primary care givers and the public regarding sleep homeostasis; and developing a new understanding of individual or genetic effects on sleep homeostasis and practical application of this knowledge.

Dr. Roth listed two proposed action items related to prevalence of sleepiness and sleep disorders. The first was to define the risk of being 10% overweight and 20% overweight. The second proposed action item was to determine these risks when only sleeping seven hours, six hours, and on down.

Dr. Buysse stressed the importance of educating the public and the physician community that insomnia is more than a nuisance symptom for those affected. He also said it is important to recognize that insomnia is not the same as sleep deprivation and that helping people find the right sleep balance is critical.

Dr. Mahowald concluded that Restless Legs Syndrome (RLS) also needs to be included in the education of health care professionals and the public. He said that many doctors are not familiar with RLS and therefore are unable to diagnose or treat it. He also stated that the public is generally unaware that people do not have to feel tired during the day and do not have to live with untreated insomnia.

Dr. Quan said that Obstructive Sleep Apnea (sleep disordered breathing, SDB) is a common medical condition, that certain populations such as African Americans and Native Americans are at greater risk, and that SDB is only being diagnosed in less than 50% of patients who need treatment. SDB is associated with substantial morbidity, impairment of quality of life and increased health care costs. Dr. Quan said that there is a lack of public and medical awareness, a lack of accurate diagnostic testing facilities and equipment, and poor adherence to effective therapy when diagnosed.

Dr. Mignot concluded his presentation on narcolepsy/hypersomnia with three recommendations. The first was that there is a need to make CSF hypocretin-1 measurements more widely available. He said that the demonstration of a biological basis often facilitates treatment strategies. The second recommendation was to educate physicians on the diagnostic pitfalls and treatment difficulties of hypersomnias without cataplexy. The final recommendation was to better educate physicians on the availability and proper use of a wide variety of novel narcolepsy treatments.

SESSION 2: NORMAL/ABNORMAL SLEEP: WHAT PRICE DO WE PAY?

Dr. Dinges said that the medical community needs to have valid, reliable, practical measures of sleepiness in order to quantify the effects of sleepiness and fatigue on performance including drowsy driving accidents. He said that it is impossible to take every person who is sleepy into a sleep lab and that caregivers need to be given a way to measure for sleep disorders to treat them. Providers also need to have a standard scale system to rate sleep drugs for their side effects. He also suggested developing and validating fatigue prevention, fatigue detection and fatigue management systems within regulatory frameworks.

Dr. Somers said that there are many mechanisms by which SDB can increase risk for cardiovascular disease. Early morning cardiovascular vulnerability during sleep needs to be better emphasized clinically, and prevention strategies need to be implemented as soon as there are better strategies for recognized people at greatest risk and a better understanding of trigger mechanisms.

Dr. Van Cauter said that when self-reported sleep hours and levels of obesity from 1960 were compared to sleep hours and levels of obesity and diabetes today, they are a mirror image. Although more data are needed, restricted sleep schedules and untreated sleep disorders may indeed be important contributors to the contemporary epidemics related to diabetes and obesity.

Dr. Benca proposed two research questions related to mood/quality of life and psychiatric sequelae. Does the treatment of insomnia and sleep disorders decrease risk of psychiatric illness, and are insomnia and depression caused by similar mechanisms? She also suggested that, given the high co-morbidity between sleep and psychiatric disorders, patients with sleep problems or primary sleep disorders should be screened for depression, anxiety, and related disorders.

SESSION 3: NORMAL/ABNORMAL SLEEP: POPULATIONS AT RISK (INCLUDING UNDER-SERVED, UNDER-REPRESENTED POPULATIONS)

Dr. Carskadon said that while children and adolescents are vulnerable to sleep disorders, their youth also offers unique opportunities for intervention. She said that many children have reduced or disrupted sleep and do not have the opportunity to obtain adequate sleep. Dr. Carskadon said that there are a number of resulting negative outcomes that need to be the focus of both professional and public education initiatives.

Dr. Zee reported that we need to better understand the extent to which poor sleep and poor health in older adults contribute to adverse health outcomes. The treatment for SDB needs to be improved and applied to older populations, which is a challenge. Dr. Zee said that it is known that sleep disturbance and excessive

daytime sleepiness effect cognitive function, and this knowledge provides an important opportunity for prevention strategies designed to ameliorate cognitive decline in older adults. Clinical trials of behavioral treatments for insomnia and circadian rhythm sleep disorders are also needed and would also help in ameliorating cognitive decline in older adults. She recommended targeted educational programs to improve knowledge of sleep medicine among health professionals who care for the elderly and medically underserved populations.

Dr. Lee discussed women's health issues related to sleep during the menstrual cycle, during and after pregnancy, and during menopause. She pointed out that progesterone, secreted during the luteal (post-ovulation) phase of the menstrual cycle is soporific and known to potentiate alcohol and could potentiate sleep debt. Shift workers are at risk of anovulatory cycles, and women with polycystic ovaries are at risk of sleep disordered breathing. The risk of Restless Legs Syndrome is high in the third trimester of pregnancy, and women having their first child experience more sleep loss after birth than women who already have other children. She recommended that healthcare providers ask women of any age whether they have difficulty falling asleep or difficulty maintaining sleep and, if so, why. Reasons for sleep problems may be related more to family or environmental and safety concerns than the woman's own physiology.

Dr. McCall summarized the risks for sleep problems in patients with a primary psychiatric disorder. He recommended that physicians should give insomnia separate consideration and management as a symptom of psychiatric disorders.

Dr. Roehrs summarized the risks for sleep problems in relation to substance abuse and alcoholism. Impaired alertness can modulate the self-administration of a stimulant and may contribute to the maintenance of stimulant abuse. He said that disturbed sleep can lead to alcohol abuse as tolerance develops to its hypnotic effects. He also stated that disturbed sleep predicts relapse in abstinent alcoholics.

Dr. Rye recommended getting "sleep" into the medical vocabulary in the education of all health care providers about neurological disorders in general. He recommended that sleepiness should be added as another component of vital signs.

Dr. Iber spoke about chronic medical disorders. Some chronic disorders are associated with an increase in sleep related complaints. He emphasized the fact that the chronic medical disorders which produce complications of sleep are less likely to come to the attention of a sleep specialist, but are more likely to be noticed by the routine care physician.

Dr. Rosekind made a presentation on occupational groups indicating that safety is the primary interest in these settings. There are at least fourteen ways in which work schedules can affect sleep and circadian patterns, including night shifts, travel, early meetings, and unexpected extensions. He > reported that there may be as many as 83 million Americans working outside of the typical 9-5 work schedule whose sleep may suffer as a result. Disrupted sleep patterns among these groups can have particularly significant physical and psychological impacts. A comprehensive approach to address the range of issues is more likely to be effective than a single strategy.

SESSION 4: WHAT IS TRANSLATION AND WHAT IS ITS OBJECTIVE?

Dr. Balcazar said that a translation of sleep disorders from the medical model of clinical services to the population-based model using public health requires a multidimensional approach. He also said that a "one size fits all" approach cannot be used to address the complexity of sleep disorders. He concluded

that tailoring messages and/or interventions to meet the needs of diverse audiences requires a cost-effective plan of action that will first enhance awareness and then lead to behavioral change.

Dr. Sangl suggested focusing on system and organizational levels as well as on the individual level for effective and sustainable changes. She said interventions based on assessment of potential barriers are more likely to be effective, and that multi-faceted interventions targeting different barriers to changes are more likely to be effective than single-faceted interventions. She also said that successful change requires identification of a specific process for change.

Mr. Renner presented another model for translation that uses quality measurement to help drive quality improvement. It could also measure a performance-driven award system. The Institute of Medicine's six aims of the health care system, including Patient Safety, Effectiveness, Proficiency, Patient Centeredness, Timeliness, and Equity, can be used to establish priorities for measurement and improvement. He uses these domains in his organization's HEDIS report, (Health Plan Employer Data and Information Set), which offers sixty standardized process and outcomes measures used to provide quality in care in health plans.

Dr. Schuster recommended measuring physician outcomes and providing the physicians with their results. He also suggested taking a population-based approach in translating research knowledge in order to improve the health of a community.

SESSION 6: FINAL RECOMMENDATIONS AND PROPOSED ACTION ITEMS

GROUP PANEL A: Neurocognitive (Learning and Memory)

Proposed Action Items address population groups "at risk" across the full age spectrum from children to older adults.

PROPOSED ACTION ITEM #1: Be smart, sleep right- a national education program about sleep information addressed to parents, children and adolescents with the aim of improving learning and behavior by improving sleep. The target populations are expectant parents, children, teachers and the health care providers such as pediatricians and nurses.

Implementation steps: Integrate sleep education into the existing prenatal care programs. Develop educational modules for parents, to be delivered by health care providers and day care centers.

PROPOSED ACTION ITEM #2: Increased detection of sleep disorders in students at risk for academic failure. Stakeholders include: School systems, PTAs, family services and agencies (students would be referred to these systems for evaluation), and pediatric health care providers.

Implementation steps: Provide tools for teachers, family members, nurses and counselors to identify children at greatest risk for a sleep disorders. Develop a community referral plan that incorporates a family service network for children with a sleep disorders.

PROPOSED ACTION ITEM #3: Feel good and be productive- a national education program to teach people that lack of sleep impacts cognitive function and performance. Target populations include: General adult populations, CEOs, caregivers, etc. Stakeholders would be employers, public advocacy groups and professional societies.

Implementation steps: National ad campaign showing the effects of daytime sleepiness upon cognitive and decision making processes and improved memory; community education program to inform the public about the impact of sleep upon learning and memory.

PROPOSED ACTION ITEM #4: Recognize untreated sleep disorders as a contributing factor to cognitive impairment. The target populations would be older adults, families, family caregivers and health care providers. Stakeholders would include family, insurance companies, Medicare, family services agencies and other health care providers.

Implementation steps: Provide educational tools for identification of disorders in patients related to presenting signs and symptoms, targeting primary care providers; disseminate sleep disorder-specific materials on the adverse effects on cognitive function for patients, caregivers and families.

GROUP PANEL B: Performance (Drowsy Driving, Work Accidents)

PROPOSED ACTION ITEM #1: Education for high-risk groups. Target populations: High school students, police and other safety personnel, commercial drivers and health care workers. The stakeholders include: parents, teachers, students, athletic coaches, the Department of Justice, local workers, long haul and short haul drivers, commuters, transport companies, patients and insurers.

Implementation steps: Identify and evaluate available resources and create a repository; partner with groups active in worker-fatigue to disseminate information; develop resources and demonstration projects or model programs for health care workers with work schedule-related performance impairments.

PROPOSED ACTION ITEM #2: Apply alertness management principles in the workplace. Target populations: Health care professionals, families, and other high risk work populations. Stakeholders include sleep professionals, management and workers.

Implementation steps: Develop a "top five" list of actions and choices- making sure that people get the requisite amount of sleep; implement and evaluate outcomes for these actions. Expand into worksite fatigue programs.

GROUP PANEL C: Cardiovascular Disease

PROPOSED ACTION ITEM #1: Increase diagnosis and treatment of sleep disordered breathing (SDB) because of its etiological importance in cardiovascular disease. Target populations: Health care providers (cardiologists and other sub specialists, primary care providers, nurse practitioners), undiagnosed patients and the public at large, cardiovascular disease patients (hypertension, congestive heart failure). Stakeholders: Sleep labs and sleep centers, employers, reimbursement payers, and industry/manufacturers of devices for diagnosing sleep apnea, health care providers, professional/patient organizations, patients and spouses.

Implementation Steps: Establish alliances with organizations developing guidelines and patient/professional education to facilitate recognition of SDB. Several organizations should be enlisted as partners in this step, including the AAFP, ACP, ACC, AHA, AAP, and cardiovascular nurses. Implementing these guidelines would help to change the behavior of providers.

GROUP PANEL D: Obesity and Diabetes

PROPOSED ACTION ITEM #1:   Professional education to incorporate sleep history including sleep apnea in patient evaluations, especially in people who are obese or diabetic. Target populations are

overweight and obese children, parents, schools, peers, adolescents (who require different strategies), minorities (for whom their should be a special emphasis), overweight and obese adults, normal-weight adults who are shift-workers, who get less sleep or are drug users, and obese individuals who are undergoing general anesthesia. Stakeholders: Patients, primary care doctors, sleep medicine specialists, companies who diagnose and treat SDB, insurance companies, employers, schools and educators.

Implementation Steps: Incorporate sleep history including questions about sleep apnea in patient evaluations, especially in people who are obese or diabetic.

PROPOSED ACTION ITEM #2: Public education about the relationship between obesity, sleep and diabetes. Target populations include children, families and educators.

Implementation Steps: Partner with teen magazines to promote sleep because of appearance issues, fast food restaurants (BMI charts in establishments), weight loss programs such as Weight Watchers and Jenny Craig, and partner with existing public education groups such as the American Diabetes Association.

GROUP PANEL E: Psychiatric Disorders

PROPOSED ACTION ITEM #1: Promote awareness that sleep is important for mental health and vice versa, and that healthy sleep promotes good health. Target populations include high-risk populations such as economically under-privileged groups, shift workers, substance abusers, professionals, children, the elderly, primary health care providers and mental health professionals.

Implementation steps: Disseminate information through advertising/public service announcements, increased material on sleep disorders in training curricula for mental health provider.

PROPOSED ACTION ITEM #2: Promote “sleep” as a new vital sign. Target populations: Health care providers and educators and parents.

Implementation steps: Develop and implement a brief “sleepiness” scale for clinical use, following the example of how “pain” was made into the fifth vital sign.
PROPOSED ACTION ITEM #3: Develop a standard of care for the diagnosis and treatment of insomnia across the lifespan (from children to elderly). Target populations: General health care providers and specialty health care providers.

Implementation steps: To increase awareness of differential diagnosis of insomnia in relation to other sleep disorders, psychiatric disorders and substance abuse disorders. Develop a treatment algorithm including daytime and nighttime symptoms to address insomnia.

PROPOSED ACTION ITEM #4: Disseminate and implement the established standard of care for the diagnosis and treatment of insomnia.

Final Discussion

There are several general themes throughout the conference, including that inadequate sleep impacts neurocognitive function and performance across all target groups and all age groups, and there is a link between SDB and cardiovascular disorders such as hypertension and heart failure.

Dr. Morgan recommended engaging consumers. The public would like to know things like how much sleep is normal, and would feel more empowered with the knowledge we now have about the science on sleep issues.

Dr. Morosco mentioned the "red dress" campaign that has brought attention to heart disease in women through partnering with the private sector and professional groups. A similar strategy could be very effective with sleep issues. He said that the "tipping point" just has to be found, the point at which people really start to pay attention to sleep and work to make changes.

NEXT STEPS

Distribute the conference summary widely to all potential stakeholders and potential partners in disseminating existing knowledge to improve sleep literacy and implementing changes in clinical and public health practice to improve sleep health.

The recommendations of the 5 action group panels, as modified by the final discussions in Session 6, will be discussed and prioritized at the Sleep Disorders Research Advisory Board meeting on June 23, 2004. An implementation plan for the highest priority public health proposals will subsequently be developed.