

## WORKSHOP REPORT

### EFFECTS OF SLEEP DISORDERS AND SLEEP RESTRICTION ON ADHERENCE TO CARDIOVASCULAR AND OTHER DISEASE TREATMENT REGIMENS: RESEARCH NEEDS

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The following four sections identify 30 research issues critical to understanding both the factors essential for effective adherence to treatments for sleep disorders, and the role of sleep factors in adherence to treatments for non-sleep disorders.

#### **I. Adherence Measurement Needs**

1. Research is needed on multiple approaches to adherence measurement, and on the relationships among adherence measures. Models of adherence should be data driven and based on reliable and valid measures. Objective measures of adherence are needed to enhance the accuracy of adherence studies. Information technologies (e.g., personal organizers; web-based reporting; interactive voice recording) should be studied for their reliability and validity in assessing adherence, and for their potential impact on improving adherence. The usefulness of objective technologies for measuring adherence should be evaluated relative to less expensive measures to justify any additional cost.
2. The development of reliable and valid self-report methods also continues to be important for assessing adherence, especially when technological measures are not possible or practical. Research is needed on ways to improve self-report measures of sleep timing, sleep duration, sleep quality, to improve the validity and reliability of sleep measures in large-scale adherence trials.
3. In light of technological changes in continuous positive airway pressure (CPAP) for obstructive sleep apnea syndrome (OSAS), there is a need for studies of objective adherence to establish whether there has been an improvement in CPAP compliance. Research on CPAP should be continued using the increasingly sophisticated monitoring technology available in some CPAP machines (e.g., smartcards, modem/wireless transmission).

#### **II. Research on Basic Mechanisms of Adherence**

4. Data are needed on the relationship of sleep and sleep disorders to adherence to medical (e.g., pharmacological) and behavioral (e.g., weight loss) interventions for non-sleep-related disorders. To obtain such information, adherence trials should include measures of sleep quantity, quality, and daytime sleepiness using a variety of instruments (e.g., sleep questionnaires, actigraphy).

5. If aspects of sleep are found to clearly be associated with adherence, then the mechanisms by which this occurs will need to be identified. For example, to what extent do sleep loss and sleep disorders induce changes in metabolic responses to food (e.g., insulin resistance) and in eating behaviors (appetite, hunger, cravings)? Do such responses contribute to nonadherence to weight loss and weight management interventions? Do the cognitive effects of poor sleep quality or inadequate sleep result in reduced adherence to treatment interventions? Do the emotional consequences of poor sleep quality or inadequate sleep affect adherence (e.g. lead to hopelessness or depression). Does sleep loss reduce social functioning and thus affect adherence?
6. Research is needed on the potential developmental and neurobehavioral changes that can occur in children as a result of low adherence to treatment for sleep disorders.
7. Studies are needed to identify genetic and other biomarkers that link to susceptibility to the neurobehavioral and physiological effects of OSAS, and how susceptibility relates to reversibility of effects by adherence to treatment. Early identification of the most vulnerable segments will allow more targeted intensive approaches at prevention and intervention adherence.
8. Research is needed on the biological and behavioral bases for stable inter-individual differences in response to chronic sleep restriction, in sleep need, and in vulnerability to the physiological, cognitive and affective responses to sleep loss. What are the adaptive mechanisms in relation to sleep deprivation? Can those most vulnerable to the consequences of nonadherence to treatment for sleep disorders be identified?
9. There is a need to evaluate the effects of environmental factors on behaviors critical to adherence.

### **III. Research on Psychosocial Factors in Adherence**

10. The role of economic factors in adherence needs to be better understood. Does cost of treatment affect compliance? How do other economic pressures influence adherence? What resources support or detract from adherence? Does adherence differ in health systems that are less costly, such as Canada and the United Kingdom? Are economic factors affecting adherence more important in some vulnerable populations, such as the elderly? Do safety net clinics in poor neighborhoods affect compliance?
11. Minority populations, particularly those known to have higher vulnerability to cardiovascular or other medical disorders, should be represented in studies of adherence to permit evaluations of the role of ethnicity in adherence. Lower socioeconomic status is linked to poorer sleep quality, quantity, as well as to

poorer health. Larger studies of minority populations—particularly those known to have higher vulnerability to cardiovascular or other medical disorders—are needed to permit evaluations of sleep as a mediator between economic status and health, as well as to establish whether adherence is a mediator in this relationship as well.

12. Measures of patients' personal perspectives (e.g., personal illness models) on their disease/disorder and on the nature of the intervention should be developed and included in adherence trials to determine what role these personal beliefs have in mediating adherence. What specific beliefs about illness influence adherence? What relationship does adherence have to sleep, health and quality of life, relative to patients' personal perspectives?
13. Studies of interventions for adherence need to be conducted in children, where interventions may be more predictable if administered by a caretaker; changes in outcomes may be more easily identified; and plasticity of the developing child may more clearly reflect reversibility of pathologic changes through adherence. It is also important to study the transition to adolescence, when both sleep and adherence can become more problematic as the shift occurs from parental control to self-management.
14. There is a need for time utilization studies to determine how lifestyle factors influence selected segments of the population to prioritize and utilization time for sleep, work, domestic and leisure activities, etc., relative to adherence to treatments. It is especially important to identify barriers to adherence in selected subgroups (e.g., working aged population; adolescents and young adults; families with small children; night shift workers; etc.).
15. Studies of adherence to interventions for sleep disorders should determine which if any aspects of adherence are influenced by the modality of health care delivery (e.g., sleep specialist versus non-sleep specialist; private sleep clinics versus academic centers; self-referral versus physician referral; insured versus uninsured; single versus multiple-care providers).
16. Research should identify the role of characteristics of individual subjects (e.g., cognitive/behavioral factors; personality traits) in adherence and outcomes relative to the implications for interventions for sleep disorders.
17. Data are needed on the nature of adherence to treatments for sleep disorders in ethnic minorities, especially sleep disorders such as OSAS, which have a higher prevalence in certain minority groups.
18. Data are needed on patterns of adherence to other therapies compared to CPAP treatment in patients with OSA. In other words do patients with OSA adhere similarly to CPAP treatment as they do to other treatment regimens.

#### **IV. Research on Adherence Interventions and Treatment Outcomes**

19. There is a need for a population sleep intervention strategy to determine if sleep behaviors can be improved in large segments of the population, and to identify if there are specific modest changes in sleep behavior that can have substantial impact on adherence or measures of health outcome.
20. Studies to improve adherence to medical and behavioral treatments should include interventions to improve sleep quality and/or sleep quantity to determine if changes in these areas enhance adherence. Interventions seeking to improve adherence using automatic routine behaviors should evaluate the usefulness of intervening during pre-sleep and post-sleep routines.
21. Studies are needed on the effects of circadian and sleep alterations induced by lifestyle (e.g., shift work, prolonged work) on adherence to interventions for medical disorders (cardiovascular, metabolic).
22. Research is needed to identify factors that predict CPAP adherence to develop multifactorial models of adherence. Data are needed on the pre-treatment and intra-treatment factors that influence adherence; on the role of patient acceptance of the diagnosis or its functional consequences; on the role of bed partners in adherence; and on the development of methods designed to promote adherence.
23. There is a need to determine how nightly duration of use of CPAP and long term adherence to CPAP for OSAS affects morbidity, mortality; health-care utilization; health-related physiological processes; cognitive, emotional and neurobehavioral functions; quality of life; and psychosocial outcomes (e.g., school/work advancement). Research is needed on these questions for each stage of development (children, adolescents, young adults, middle-aged adults, older-aged adults).
24. Research is needed on how treatment of OSAS affects cardiovascular outcomes (e.g., atrial fibrillation; hypertension; chronic heart failure), and whether knowledge of improvement in cardiovascular outcomes improves adherence to treatments for OSAS. Research is also needed on whether medications to reduce adverse cardiovascular outcomes related to inflammation (e.g., ASA, statins) can be of benefit in patients being treated for sleep disorder (e.g., those adherent and those nonadherent to CPAP treatment for OSAS).
25. Research in animal models is needed to develop dose-response relationships between the extent of treatment and the degree of reversibility of neurobehavioral and physiological deficits OSAS/hypoxemia.
26. Research is needed on adherence to insomnia interventions. There is a need to adapt techniques from adherence research in other areas to determine how

adherence is measured and interpreted for patients being treated for an insomnia disorder, where the treatment (e.g., sleep hygiene; hypnotic medication; restricting sleep in bed; cognitive-behavioral intervention) is prescribed to be used everyday, or on an intermittent basis.

27. Studies are needed to define relevant measures of adherence to treatments for disorders involving insomnia (e.g., sleep hygiene; hypnotic use; behavioral therapies) and hypersomnia (e.g., scheduled naps; wake-promoting drugs).
28. Studies are needed to determine whether interventions designed around automatic behaviors can improve adherence to treatments for sleep disorders. For example, can interventions based on instructions for visualizing at sleep onset improve adherence to treatments for sleep disorders?
29. Research is needed on adherence to interventions designed to help shift workers cope with shift changes (e.g. work lighting; sleep environment). The need to identify and test strategies that improve adherence to procedures that are contrary to environmental and social work-rest activities.
30. Barriers to obtaining adequate sleep should be identified, including social, cultural and economic barriers, as well as the roles of gender and age in exposure to and consequences from voluntary sleep restriction. Studies are needed to determine whether sleep restriction poses neurobehavioral and physiological risks that affect health and reduce adherence to interventions. There is a particular need to determine the factors essential for being adherent during recovery oversleeping (e.g., on weekends) in health and disease prevention.