



Canadian Sleep Society (CSS)

Société Canadienne du Sommeil (SCS)

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Final Report

Engaging Patients in Sleep Disorders Research

A workshop hosted by the Canadian Sleep Society (CSS)
and the Canadian Sleep and Circadian Network (CSCN)
September 25th, 2015

Funded by the Institute for Circulatory and Respiratory Health (ICRH)



Engaging Patients in Sleep Disorders Research

In September 2015, a half-day workshop was held in Toronto that focussed on **patient engagement (PE)** in research on sleep disorders. Sleep professionals and patients came together to discuss how to integrate patients as partners in the research process in the study of four major sleep disorders: 1. Restless Leg Syndrome (RLS), 2. Obstructive Sleep Apnea (OSA), 3. Narcolepsy, and 4. Insomnia.

Over 25% of Canadians suffer from sleep disorders, a percentage that increases with aging. In each of these primary sleep disorders, poor sleep has both short- and long-term consequences for physical and mental health, productivity, safety and quality of life. In particular, insufficient sleep is associated with increased incidence of obesity, diabetes, and cardio-vascular disease. Given, the high prevalence of sleep disorders, and the significant outcomes for health, research into understanding the mechanisms of disease and treatment is a crucial area of concern for public health.

The workshop was held in conjunction with the biennial scientific conference of the Canadian Sleep Society (CSS), in partnership with the Canadian Sleep and Circadian Network (CSCN). The CSS is a national professional organization committed to improving sleep for all Canadians through: support for research; promotion of high quality clinical care; education of professionals and the public; and advocacy for sleep and sleep disorders medicine (<http://css-scs.ca/>). The mission of the CIHR-funded CSCN group is to “generate new knowledge in sleep and circadian research and bridge gaps between research outcomes and impact on health by accelerating translation of research discoveries into clinical applications, best practices and/or the marketplace and developing, validating and evaluating interventions that change significant aspects of practice” (<http://www.cs-cn.ca/>).

Patient engagement (PE) involves a *partnership* between the researchers/clinicians (who are experts in the disorders), and the patients/families (who have expertise in living with the disorder), which facilitates a better link between health research outcomes and patient needs. PE is recognized as an important and necessary process that benefits from the experience-based knowledge of patients and adds significant value to health research.

The workshop was facilitated by an expert in PE, Dr. Alexandre Berkese, PhD, of the Office of Collaboration and Patient Partnership, Faculty of Medicine, University of Montreal. Attendees included 16 sleep professionals (e.g., clinicians, scientists, health care workers) and 16 patients and family members. Sleep professionals and patients gave presentations on each of the four sleep disorders. Researchers discussed current knowledge and gaps/opportunities for discovery, while patients presented their ideas for areas of improved understanding and management. Small group discussions then took place on co-building research priorities for each of the sleep disorders, and how to involve patients as partners in research. Below is a summary of these discussions.

There were a number of themes that represented overlap between the four sleep disorders. Some examples included:

1) Poor care process

- patients often had limited access to help with striking regional differences across Canada
- patients often had a fractured care process with limited access to the resources they needed even after engaging appropriate clinical advocates
- patients often experienced uncertainty in which branch of the healthcare systems was best suited for their needs
- long wait times to see a sleep specialist

- 2) Perceived trivialization of their condition
 - despite having conditions that have significant medical implications, and demonstrated impaired quality of life, patients felt that most of the community and many medical professionals did not seem to understand their problem and it was often trivialized
- 3) Association among the different sleep disorders and interactions with concurrent medical problems

Restless Legs Syndrome (RLS) Section

Chair, Brian Murray, MD, FRCPC D, ABSM

Emerging themes specific to RLS:

- 1) A need to understand the condition across the lifespan
 - RLS may manifest in children as behavioral and school problems
 - RLS in pregnancy may be severe and impair resiliency
 - RLS becomes more prevalent with increasing age, appears to contribute to cognitive difficulties, and medications can be associated with complications in the elderly
- 2) A need to improve the care path of a common problem
 - public education is needed to help people recognize a condition they may have that may be interfering with their health, and introduce basic interventions that may ameliorate mild cases
 - an urgent need to increase education for health professionals as many clinicians remain unaware of the impact of the condition, associated medical implications, and treatment options
 - increased access to specialists with expertise in the disorder
 - novel diagnostic tools should be developed without RLS being missed in screening for respiratory sleep disorders
- 3) A need for better assessment of non-medical treatments
- 4) Advanced research needs in special situations
 - better understanding of iron deficiency in this disorder
 - better understanding of cardiovascular implications of RLS
 - better familial assessment including genetic panels
 - better options for refractory RLS cases after appropriate interventions

Obstructive Sleep Apnea (OSA) section

Chair, Robert Skomro, MD, FRCPC

Emerging themes specific to OSA:

- One of the most common sleep disorders and chronic conditions
- Rates of OSA on the rise; Canadian population needs are not met
- Wide variety in access to diagnosis and treatment, with vast majority of Canada experiencing poor access with wait times measured in months or years
- Poor recognition at the primary care level
- Lack of care pathway - large discrepancies between provinces in funding of diagnostic testing, CPAP and dental appliance funding
- Poor access to specialists coupled with lack of recognition/knowledge at the primary care level leads to a wide care gap. Fragmented care
- Poor follow up

- Lack of national advocacy group. Poor media presence

Narcolepsy section

Chair, John Peever, PhD

Emerging themes specific to narcolepsy:

- Perceived lack of clinical expertise
- Lack of clarity in how to treat and diagnosis narcolepsy in younger and older patient populations
- How to deal with narcolepsy in the context of school for children/teens and work for mature adults
- How to access resources for securing disability compensation
- Social stigmas associated with sleepiness and cataplexy
- Need to streamline the process of various lines of treatment and post-diagnostic care
- Need to increase education of public and health professionals as many clinicians remain unaware of the impact of the condition, associated medical implications, and treatment options
- Impact of diet on symptoms

Insomnia Section

Chair, Charles M. Morin, Ph.D.

Emerging themes specific to insomnia:

- Patients feel there is a stigma associated with revealing that one has insomnia or is treated for insomnia
- Patients felt that their family doctors should be more aware and better informed of the impacts of insomnia on daily lives (e.g., one patient was on sick leave for several weeks before his GP gave more attention to his sleep difficulties)
- Patients were not well informed about the different treatment options available; most thought that only medications could be used for insomnia; most did not know about Cognitive Behavioural Therapy (CBT)
- Patients felt their care should be better coordinated and that communication amongst health care providers was poor, especially with regard to effects of different drugs on sleep (e.g., with overlapping condition such as chronic pain or cancer)
- Need for support groups (e.g., not aware of La Fondation du Sommeil)
- Patients felt more research was needed about new therapies for insomnia, including non drug therapies. However patients did not know about the evidence supporting CBT. For example, many of their suggestions and recommendations for research avenues are already well documented (CBT, relaxation, etc)
- Knowledge transfer: Primary care physicians should be better informed about sleep disorders during their medical training, learn more about non drug therapies and present these options as valid choices instead of prescribing hypnotics from the outset
- Need to increase knowledge transfer – raise awareness in the general public about insomnia – something like “Talk to your doctor about your sleep”
- Greater use of social media to raise public awareness and share information about treatment resources and sleep clinicians

Future Directions. This first workshop was the beginning of discussions, between researchers/clinicians in the sleep field and patients, regarding the state of science, gaps in knowledge, and priority areas for research. Involving patients in the research process as equal partners in decision making on research design to dissemination will add significant value to the field of sleep research and sleep disorders medicine. The CSS and CSCN both aim to facilitate this process of PE at future national conferences as well as locally across the country.

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