

FINAL REPORT

Understanding healthcare provider barriers to prescribing and recommending non-pharmacological sleep interventions for persons diagnosed with dementia

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Executive Summary

For persons with dementia (PWD), sleeping problems are often unrecognized and undertreated. This is a concern for two reasons: disordered sleep may contribute to the onset of their dementia and a lack of restorative sleep can negatively impact the health and functioning of both the person living with dementia and their family caregivers. Early identification and appropriate intervention for sleep problems can help reduce the risk of dementia onset and/or slow the acceleration of the illness.

Presently, the relationship between sleep and dementia is not well understood by most healthcare providers and family caregivers of PWD. Traditionally, sleep problems have been treated with medication, but this can cause a range of side effects. Although there are evidence-based interventions for sleep disorders that are non-pharmacological these interventions are not routinely recommended known to healthcare workers because of a prevalent research-to-action gap. Consequently healthcare providers lack the knowledge required to make recommendations to family members about pragmatic sleep interventions for PWD. Addressing this gap through evidence-based knowledge translation and exchange (KTE) strategies will ultimately contribute to improved health and quality of life for both PWD and their family caregivers. In turn, optimal health and functioning are positive influences supporting the priority goal of PWD and their family caregivers remaining able to live safely and with quality in their own homes.

The first step in addressing this knowledge-to-action gap is to determine the current state of sleep assessment and intervention practice of healthcare providers working with PWD. Knowing this helps lay a strengths-based foundation for more targeted KTE and educational strategies addressing sleep problems

for PWD. This study, *Understanding healthcare provider barriers to prescribing and recommending non-pharmacological sleep interventions for persons diagnosed with dementia* gathered quantitative and qualitative survey data from 2,027 healthcare providers from across Canada. The respondents to the survey represented a wide range of professional groups working in both institutional and community settings. These findings present a clear picture of current knowledge and practices. Additionally, the findings illustrate what healthcare providers perceive to be barriers and facilitators to applying the sleep and dementia evidence-base to their practice. Finally, and very importantly, the survey highlights what KTE strategies healthcare providers identify as being most effective for helping reduce the sleep and dementia research-to-action gap that currently exists.

The full report reviews the background literature highlighting the impact of disordered sleep on dementia, outlines the study design, presents the findings of the survey and discusses the implications of these findings. A series of **sixteen action points** (Table 13 in the full report and at the end of this report) emerged to help guide further evidence-based action targeting the sleep and dementia KTE needs of Canadian healthcare providers.

Encouragingly, the study shows healthcare providers want to learn more about disordered sleep and non-pharmacological sleep interventions. This is a key strength upon which efforts to address sleep KTE needs of healthcare providers can move forward and thereby improve health and well-being of PWD and their families.

Key Findings

Current Level of Knowledge Related to Disordered Sleep in PWD

Incidence of Disordered Sleep Experienced by Persons with a Diagnosis of Dementia

On the strength of this large sample from across Canada, it appears that healthcare providers underestimate the extent of disordered sleep in PWD. This is consistent with other research studies.

Bi-directional Relationship

There is a lack of awareness about the reciprocal relationship between disordered sleep and dementia. Disordered sleep can result in changes to a person's appetite, falls, problem solving abilities and caregiver beliefs. Not only do these health variables impact a PWD's ability to function at an optimum level, but also a lack of sleep can contribute to the development of their dementia.

Assessment Tools

Knowledge of sleep related assessment tools is limited to caregiver reports, self-reports and sleep diaries. There is a minimal use of standardized tools or other assessment methods.

Effect on Co-morbid Conditions

The relationship between disordered sleep and co-morbid conditions is not well understood among healthcare providers. Co-morbid conditions can negatively impact sleep and sleep problems appear to be a risk factor for many health conditions (such as cardiac disease and diabetes). In particular, the associations between disordered sleep and conditions such as allergies, sensory deficits, endocrine or renal disorders and rheumatic diseases are under-recognized by healthcare providers.

Current Practice Related to Screening for Disordered Sleep in PWD

Present Practice

Disordered sleep is not specifically nor formally assessed on a routine basis. Rather healthcare providers may informally identify sleep problems

during assessments for other conditions or from the reports of other team members and family/caregivers. Routinely administered standardized assessment tools do not include sleep screening questions.

Standardized Tools

Awareness of standardized sleep assessment tools was low, but respondents saw their relevance and did not perceive assessment tools as being impractical.

Non-pharmacological Sleep Interventions (NPSI)

The three most common strategies endorsed by respondents were: have a regular bedtime routine, increase daytime activity and restrict caffeine. Other interventions less frequently endorsed included: have a regular exercise routine, decrease daytime naps and evening noise levels, as well as cut down on evening fluids. Education about sleep surfaces and positions, white noise at night and reduced ambient nighttime light were not well endorsed.

Professional Variability in Awareness of Sleep Interventions

Awareness of different non-pharmacological sleep interventions varied widely between different professions.

Barriers and Facilitators to Recommending NPSI

Barriers

Resource limitations and restrictions in the environment were identified as the most common impediments to utilizing NPSI. Other barriers included characteristics of PWD and their caregivers, knowledge of NPSI and a societal trend to medicalize sleep problems and discount them in older adults.

Facilitators

Characteristics and practice of the healthcare provider (including their education) were identified as the most common facilitators to recommending NPSI. Additionally, but with less impact, identified the facilitators of available resources, family/caregiver characteristics,

environment, access to interventions available other than medications.

Of particular interest is that, although healthcare providers identified a range of influences that facilitated or hindered their use of non-pharmacological sleep interventions, few of these influences involved wider socio-political policy and attitudes about health, aging and dementia. This seems to indicate a lack of awareness about the public health and societal implications of untreated sleep problems in older adults with dementia.

Preferences for Assessment and NPSI Knowledge Translation

Flexible Formats

Respondents' preferences were for printed reports and handouts for knowledge translation. Among the different groups of healthcare workers, there was a high degree of variability of preferences for different types of formats. This indicates that targeted, as opposed to generic, knowledge translation strategies are indicated.

Targeted Topics

Respondents' comments indicated that information should be relevant to the healthcare provider's local work context. Clear, specific knowledge gaps should be targeted.

Implications of the Study:

- There is a research-to-knowledge gap regarding how interventions for disordered sleep can reduce the risk or lessen the severity of dementia, possibly leading to greater independent living in the community.
- Healthcare providers are not well informed about the risk factors of disordered sleep in older adults with dementia..
- The present practice for assessment is not routine, sleep related issues may be followed up if they emerge in other assessments but little awareness of existing, standardized assessment exists.

- Barriers and facilitators exist to incorporating assessment and treatment of disordered sleep into the daily practice of healthcare providers. With knowledge of the range of facilitators and barriers KT strategies can be selected and modified within the parameters of local context so as to increase the likelihood of meaningful change.
- Healthcare providers lack awareness about the public health and societal implications of untreated sleep problems in older adults with dementia.
- Learning new information regarding disordered sleep needs to be contextualized and reflect individual learning preferences.
- Healthcare providers are eager to learn about assessment and treatment of disordered sleep in older adults with dementia with non-pharmacological methods.

This study can inform the topic by:

1. *Targeting specific areas within and across healthcare professions where information is significantly lacking.*
2. *Linking the recommendations to build on the existing strengths of healthcare providers.*

Our findings align with the Canadian Institute for Health Research (CIHR) Knowledge-to-Action Cycle and particularly the taxonomy of barriers and facilitators for knowledge use that Légaré developed based on his review of the extant KT conceptual models. These foundational works helped us identify the key findings from our survey as they relate to the goal of recommendations to increase healthcare providers' knowledge and use of NPSI for persons with dementia.

Summary of Action Points to Improve Sleep and Dementia KTE Outcomes:

- Build sleep problem screening and advocacy capacity in the healthcare providers who spend the most time with persons with dementia.

- Make sleep a higher priority topic for education of healthcare providers.
- Educate healthcare providers about the effect of caregiver beliefs and co-morbid conditions on disordered sleep for persons with dementia.
- Educate healthcare providers about effective non-drug sleep interventions.
- Tailor healthcare providers' education to fill the specific knowledge gaps of each discipline.
- Educate caregivers to facilitate a change in their beliefs and awareness of effective non-drug interventions for disordered sleep.
- Improve sleep screening and assessment by: 1) embedding sleep-related questions in generic elder-care screening tools, and 2) improving access to appropriate sleep assessment tools.
- The priority requirements for delivering effective knowledge translation strategies to reduce the research-to-practice gap are:
 - a. Customize to local context.
 - b. Incorporate a range of formats for learners' preferences.
 - c. Develop strategies based on an awareness of organizational culture.
 - d. Respect and build on prior knowledge.
 - e. Avoid ageist assumptions of communication methods.
 - f. Focus on evidence-based principles for increased health literacy.
 - g. Focus on practicality of the information.

These recommendations can be applied by policy makers and healthcare educators to develop specific educational strategies and care guidelines to improve healthcare providers' ability to provide the best, research informed, care for older adults living with sleep problems and dementia.

For a full copy of the report go to <http://www.sleep-dementia-resources.ualberta.ca> and click on the "New" button on the home page.

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Table 1: Emergent action points for NPSI KT strategies

1. Build capacity for screening and advocacy related to sleep and dementia in professions (nursing, physiotherapy, occupational therapy) whose practices have the highest frequency and duration of patient/family interaction.
2. Prioritize sleep and dementia education by profession so as to build on existing awareness when introducing information. For example, as physicians already report awareness of the relationship between sleep problems and depression and night-time wakefulness, knowledge translation efforts should not focus on these elements. Rather, clear knowledge gaps should be targeted.
3. Education about the relationship between caregiver beliefs and sleep problems in persons with dementia should be a priority for all healthcare practitioners.
4. Education about co-morbid conditions with known association to sleep problems is required across professional groups with particular emphasis on allergies, endocrine conditions and sensory deficits.
5. Embedding sleep-related questions in widely used screening tools for other conditions would be congruent with healthcare providers current practice and promote more routine screening in a practical format
6. Healthcare providers need information about, and access to, appropriate assessment tools for persons with dementia. Particular emphasis should be on actigraphy, Pittsburg Sleep Quality Index, Epworth Sleep Scale and the Sleep Disorders Inventory.
7. Healthcare providers need education about non-pharmacological sleep interventions that is tailored to knowledge gaps within their own profession.
8. All healthcare providers need education about non-pharmacological sleep interventions focused on modifications to the sleep environment and the critical role of passive exposure to daylight.
9. Knowledge translation strategies focused on concerns about shared responsibility between healthcare provider and PWD/family members, on issues related to the quality and reliability of the evidence, and on ease of recall of the information ARE NOT a knowledge translation priority for this issue.
10. Look to stages-of-change theoretical models to guide knowledge translation strategies for modifying values and beliefs. Do not assumptions that opinion leaders are cross-disciplinary or relevant outside of specific contexts.
11. Increase comfort and cohesion between stakeholders by framing new NPSI information as built on, and an extension of, what healthcare providers and family members already know.
12. Focus on placing non-pharmacological sleep interventions on the dynamic continuum of care that values 'this as well as that' as is required for effective management of the complex adaptive human system presented by dementia.
13. Facilitate caregiver change of beliefs and acceptance of non-pharmacological sleep interventions through a focus on practical, observable, patient-centered outcomes; and strategies to enhance motivation that are aligned with kin group and cultural contexts.
14. Avoid ageist assumptions about communication and base design of communication strategies on evidence-based principles for increased health literacy and clearly evident practicality of the information.
15. Develop knowledge translation strategies that incorporate awareness of organizational context and that focus at the level of those stakeholders who are able to influence organizational culture.
16. Deliver knowledge translation with as much local context as possible, in a range of formats that accommodate learners' preferences and that reduce the amount of time spent in learning new technology to access the material as opposed to time spent in learning the new material specifically.