Collaborative Research Grant Initiative: Mental Wellness in Seniors and Persons with Disabilities

Seed/Bridge Final Report

April 2013 – Cary A Brown, PhD

Understanding healthcare provider barriers to prescribing and recommending non-pharmacological sleep interventions for persons diagnosed with dementia.
Executive Summary
For persons with dementia (PWD) sleeping problems are often unrecognized and undertreated. This is a concern for two reasons: the evidence is clear that disordered sleep may contribute to the onset and exacerbation of dementia and that a lack of restorative sleep will negatively impact the physical, emotional and cognitive health and functioning of both the person living with dementia and their family caregivers. Sleep problems are one of the key reasons care providers seek institutional placement for family members with dementia. Early identification and appropriate intervention for sleep problems can help reduce the risk of dementia onset and/or slow the acceleration of the illness. A national survey of 2,027 Canadian healthcare providers identified significant research-to-practice gaps in sleep and dementia knowledge, assessment, and interventions. Encouragingly, these survey participants recognized a knowledge gap exists and indicated they were eager for more information and resources to provide best practice. The survey revealed that the knowledge gaps were not the same in each professional group and targeted, strategic knowledge translation activities are indicated. Additionally, different professions identified different preferences for knowledge translation and this needs to be considered in developing strategies. Academic training programs, professional colleges and regulatory bodies are all able partners to address these gaps.

Research Overview
Objective(s)
The aim of this study was to determine Canadian persons with dementia (PWD) healthcare providers’:
- knowledge about the evidence-based relationship between poor sleep and other significant health conditions,
- awareness of the range of sleep assessment tool,
- experience with sleep interventions, and
- perceived barriers and facilitators to implementing non-pharmacological sleep interventions for persons with dementia.

Background
For persons with dementia (PWD), sleeping problems are often unrecognized and undertreated (Ancoli-Israel, 2009). 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 physical, emotional and cognitive health and functioning of both persons living with dementia and their family caregivers (Ancoli-Israel, 2009; Cricco, Simonsick, & Foley, 2001). 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 these often cause a range of side effects. Although there are evidence-based non-pharmacological sleep interventions (NPSI) (Brown, Berry, Tan, Turlapati, & Swedlove, 2011; Koch, Haesler, Tiziani, & Wilson, 2006) these interventions are not routinely recommended and a research-to-action gap prevails. Consequently healthcare providers lack the knowledge required to assess sleep problems and make recommendations about evidence-based pragmatic sleep interventions for PWD. Addressing this gap through demonstrated 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 reside safely, and with quality of life, in their own homes.

**Approach and Methods**
The first step in addressing the unmet sleep intervention needs of PWD was to determine the specifics and extent of the apparent knowledge–to–action gap. To that end we surveyed Canadian healthcare providers’ awareness of the existing evidence-base related to risk factors for PWD to develop sleep problems and the consequences of untreated sleep problems (see Survey in full report, [www.Sleep-dementia-resources.ualberta.ca](http://www.Sleep-dementia-resources.ualberta.ca)). We also surveyed for knowledge of appropriate sleep assessment tools and intervention practices. To best understand the challenges in changing current practice we asked participants what were the barriers and facilitators for them to employ evidence-based sleep assessment and interventions when working with PWD. Finally, to help future KTE strategic planning we asked participants what KTE approaches they preferred. Knowing this helps lay a strengths-based foundation for more targeted KTE and educational strategies addressing sleep problems for PWD.

This study gathered quantitative and qualitative survey data from 2,027 healthcare providers from across Canada. The survey was piloted and placed on-line in a FluidSurvey ® platform. The invitation to participate was disseminated through 318 healthcare professional groups and organizations across Canada. The invitation was targeted specifically to healthcare providers working with older adults living with dementia. Most of the organizations were contacted by phone to explain the purpose of the survey and to build support amongst the stakeholders. A number of the organizations also posted a link to the research team’s sleep website ([www.Sleep-dementia-resources.ualberta.ca](http://www.Sleep-dementia-resources.ualberta.ca)) designed for family members of persons with dementia.

**Participants:** The survey participants represented a wide range of professional groups working in both institutional and community settings. The participants were distributed across Canada. The highest response rate was 38.7% from Alberta (n=407), followed by 19.7% from New Brunswick (n=235) and 16.9% from Ontario (n=201). The most frequent participants were those working in nursing (60.3%), followed by physiotherapy (9.0%), occupational therapists (8.9%), physicians (4.2%) and psychiatrists (4.1%).

**Data analysis:** Survey data were converted to SPSS (Version 19.0). We performed 2-tailed statistical testing at a .01 level of significance unless otherwise stated (see full report [http://www.sleep-dementia-resources.ualberta.ca](http://www.sleep-dementia-resources.ualberta.ca)). The sample of psychologists, respiratory technicians and care assistants was too small for chi-square analysis and were removed from the data set for questions 4-7, and 10. Postal code data was used to break the responses into provincial categories. The qualitative questions regarding barriers and facilitators to applying evidence-based sleep assessment and interventions into practice were hand coded through thematic analysis to determine the most prevalent themes.

**Key Findings**
The key findings of the survey questions are highlighted in sections 1-5 below for details the full report can be reviewed at [www.sleep-dementia-resources.ualberta.ca](http://www.sleep-dementia-resources.ualberta.ca).

1. **Current Level of Knowledge Related to Disordered Sleep in PWD**
   a) *Incidence of Disordered Sleep Experienced by Persons with a Diagnosis of Dementia*  
   It appears that healthcare providers underestimate the extent of disordered sleep in PWD. This is consistent with other research studies (Ancoli-Israel, 2009).
   b) *Bi-directional Relationship*  
   There was 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.
   c) *Assessment Tools*
Knowledge of sleep related assessment tools is limited to caregiver reports, self-reports, and sleep diaries. They reported minimal use of standardized tools or other assessment methods.

d) **Effect on Co-morbid Conditions**
The relationship between disordered sleep and co-morbid conditions was not well understood among participating healthcare providers. They were mostly unaware that 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.

2. **Current Practice Related to Screening for Disordered Sleep in PWD**
   
a) **Present Practice**
   Disordered sleep was not specifically nor formally assessed on a routine basis. Rather participants would 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 did not include sleep screening questions.

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

c) **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.

d) **Professional Variability in Awareness of Sleep Interventions**
   Awareness of different non-pharmacological sleep interventions varied widely between different professions.

3. **Barriers and Facilitators to Recommending Non-Pharmacological Sleep Interventions (NPSI)**
   
a) **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.

b) **Facilitators**
   Characteristics and practice of the healthcare provider (including their education) were identified as the most common facilitators to recommending NPSI. Additionally, but less frequently, participants 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.

We reviewed Knowledge Translation (KT) models to help us organize and understand the rich survey data with particular emphasis on the relevance for developing effective KT strategies. Knowledge translation and exchange requires a planned-action approach (Straus, Tetroe, & Graham, 2009). We selected Légare’s (in Straus et al (Straus, et al., 2009)) taxonomy of barriers and facilitators for knowledge as a useful applied tool around which to map the barrier and facilitator themes, and related categories, that emerged from the survey’s qualitative data.
Legare’s taxonomy of variables that influence use of knowledge (Straus, et al., 2009) are listed below and key areas where emergent themes from our findings aligned are presented in **bold italics**:

Variable 1 - Knowledge

- **Awareness (or lack of)**
- **Familiarity (or lack of)**
- Forgetting/remembering
  Variable 2i- Attitudes – lack of applicability
- **Agreement**
- **Patient characteristics**
- **Clinical situation**
- Patient/caregiver preference for shared decision making
- **Patient/caregiver support for knowledge**
- **Patient/caregiver values**
- Cost-benefit
- Confidence in developers
  Variable 2ii- Attitudes – lack of agreement in general
- **Flexibility**
- Challenge to autonomy
- Bias
- **Practicality**
- Shared responsibility with patient/caregiver
  Variable 2iii- Attitudes- lack of expectancy
- **Perception about contribution to change**
- **Perception about contribution to improved process**
- Perceived will provoke negative feelings
- Self-efficacy of intended user
- **Motivation of user**
- **Patient/caregiver preferences**
- Variable 3- Behavior
- Patient/caregiver preferences
- Variable 4- Factors associated with innovation
- Trialability
- Compatability
- **Complexity**
- **Observability**
- **Communicable**
- **Uncertainty**
- Modifiable
- Variable 5- Environmental factors
- **Time**
- **Resources**
- **Organizational constraints**
- Access to services
- Reimbursement
- **Perceive risk/liability**

There are twelve clear and concentrated areas where our study’s emergent themes align with Légare’s variables- these areas are presented in **bold italics** in the preceding table. Interestingly, both our facilitator and barrier themes aligned around the same variables. This is important as it highlights where the critical concerns are concentrated and so guides priority areas for action. Additionally it illustrates that barriers and facilitators should be viewed along a continuum as opposed to discrete entities. For example at one end of the continuum “knowledge” (lack of knowledge) is a barrier but at the other end it is a facilitator (the existence of knowledge). The task is to move the balance of many of these areas from the sleep negative to the sleep positive end of the continuum. Visualizing aligned variables on a continuum will help us develop more targeted and relevant KT strategies that build on existing strengths, familiarity and system capacity. The twelve key areas present opportunities for focused KT strategies.

Successful implementation of evidence-based information is often beyond the capacity of individuals and requires KTE strategies that integrate local context and address organizational inertia and culture. Sixteen (16) action points emerged from the discussion of survey findings against the extant KT research:

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, Epsworth 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 have influence and are recognized outside of their own discipline. Also they may not be recognized 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.

Conclusion
Current practice lacks awareness and implementation of the evidence-base related to sleep problems in PWD. Healthcare providers perceive there to be significant barriers and facilitators to applying the sleep and dementia evidence-base to their practice. Different groups of professions have different preferences for KTE strategies to help reduce the current research-to-action gap. The full report (at www.sleep-dementia-resources.ualberta.ca) reviews the background literature highlighting the impact of disordered sleep on dementia, outlines the specifics of the study design, presents the detailed findings of the survey, discusses implications of these findings and presents the evidence-based rationale underpinning each of the 16 action points. Encouragingly, the study shows that 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.
**Implications for Policy & Practice**

- There is a research-to-knowledge gap regarding how interventions for disordered sleep can reduce the risk or lessen the severity of dementia, and possibly lead to greater independent living in the community.
- Healthcare providers are not well informed about the risk factors of disordered sleep in PWD.
- Presently sleep assessment is not routine, and although sleep related issues may be followed up if they emerge in other assessments, 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.
- 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 strategies to address the unmet need for evidence-based sleep assessment and interventions for persons with dementia by:

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

**Directions for Future Research**

Knowledge translation strategies planned in collaboration with identified stakeholder groups and targeting the specific gap areas identified in the study should form the next stage of this research.

**Knowledge Dissemination and Translation Activities**

The findings have been disseminated to all of the individual participants who provided an email address and to the participating organizations across Canada. As of September 2013 this resulted in over 2,100 visits to the [www.sleep-dementia-resources.ualberta.ca](http://www.sleep-dementia-resources.ualberta.ca) educational website.

Many of the participating organizations placed a link to the study report in their internal communication vehicles. We will present the findings at the Glenrose Hospital Care of the Elderly and Geriatric Medicine Physician Group March 15, 2013 and at the Canadian Association of Occupational Therapist ASM in June 2013. Graduate students in the Master of Science in Occupational Therapy (MScOT) program at the University of Alberta are carrying out a further knowledge exchange project based on these findings and we are preparing a manuscript to submit to the journal *Dementia*. Other opportunities will be pursued as they present.

For a full copy of the report go to [http://www.sleep-dementia-resources.ualberta.ca](http://www.sleep-dementia-resources.ualberta.ca) and click on the ‘New’ button on the home page.

**Principal Applicant (Team Leader)**

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<thead>
<tr>
<th>Name</th>
<th>Position Title</th>
<th>Topics of interest</th>
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<tbody>
<tr>
<td>Cary A Brown, PhD</td>
<td>Associate Professor, Dept. of Occupational Therapy, University of Alberta</td>
<td>Dementia, sleep, pain, caregivers, knowledge translation and exchange</td>
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### PROJECT PARTNERS (TEAM MEMBERS)

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<tr>
<th>Name</th>
<th>Position Title</th>
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<tr>
<td>Patricia Wielandt, PhD</td>
<td>Associate Professor, Dept. of Occupational Therapy, University of Alberta (at time of study)</td>
<td>Design, consult on analysis, writing up.</td>
</tr>
<tr>
<td>Donna Wilson, PhD</td>
<td>Professor, Faculty of Nursing, University of Alberta</td>
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<tr>
<td>Allyson Jones, PhD</td>
<td>Associate Professor, Dept. of Physical Therapy, University of Alberta</td>
<td>Design, consult on analysis, writing up</td>
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### PUBLICATIONS AND PRESENTATIONS

The findings of this study and related resources have been disseminated as follows as of March 2013:

- The report is posted on the PI's website [www.sleep-dementia-resource.ualberta.ca](http://www.sleep-dementia-resource.ualberta.ca). This website as of February 2013 was the number one website retrieved in the Google search ‘sleep dementia resource’. Over 750 new visits to the website have occurred as of March 2013 since the report was disseminated to stakeholder groups. As of September 2013 there were over 2,100 visits to the website.

- The report was presented to the Care of the Elderly and Geriatric Medicine Physician Group (Glenrose Hospital, Edmonton - March 2013).


- Brown CA Non-pharmacological sleep interventions for persons with dementia: Pragmatic approaches in the community. Canadian Coalition of Seniors’ Mental Health/Canadian Association of Geriatric Psychology Joint Conference – Banff Alberta Sept 2012. (workshop presentation)


- A manuscript of study findings is in review with the journal *Sleep Disorders*. 
ABOUT THE ALBERTA ADDICTION AND MENTAL HEALTH RESEARCH PARTNERSHIP PROGRAM

The Alberta Addiction and Mental Health Research Partnership Program is comprised of a broad-based multi-sectoral group, representing service providers, academic researchers, policy-makers and consumer groups, working together to improve the coordination and implementation of practice-based addiction and mental health research in Alberta.

The mission of the Research Partnership Program is to improve addiction and mental health outcomes for Albertans along identified research priority themes, by generating evidence and expediting its transfer into addiction and mental health promotion, prevention of mental illness, and innovative service delivery.

The Research Partnership Program sets out to increase Alberta’s excellence and output of addiction and mental health research findings, and to better translate of these findings into practice improvements.
REFERENCES


APPENDIX A

The survey also served as KT tool and we received a number of emails from participants expressing how useful the survey was:

- Thank you - this really made me think about what I need to do to investigate the techniques that I was unaware of.
- I would like to see a patient centered approach - an educational session with patient, family, and invite all care providers of the patient. That way we all get the same message, and all focus on helping the patient instead of each trying individually to work against each other’s ideas and wishes.
- I'm really happy to see that nurses are getting this survey. Gaining knowledge about research and how we can change our practice to better help our patients, especially persons who are often overlooked is so valuable. Thank you.
- Thank you for taking the time to do this survey I have always been concerned about this issue and would love more information and education so I can be more effective with my holistic and hospital practice as a nurse.
- As a home care physical therapist, my practice has a definite emphasis on fall prevention, skin & wound Rx, and palliative symptom relief so I am glad to see that sleep disorders in seniors is being studied and I look forward to hearing more about your work.
- Education and support for in-home caregivers in any format are really needed.
- I did not realize all the assessment tools available. I will be ‘googling’ the list. Studies like this will re-enforce what we should be doing in LTC. Thank You.
- Thank you for raising this issue on-line - it is one I could be spending more time assessing and treating in my practice.
- Thank you this really made me think about what I need to do to investigate the techniques that I was unaware of.