

# Knowledge Network in Rural and Remote Dementia Care

## *Scientific Poster Session*

### Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia

3rd Annual Summit

October 28 & 29, 2010



**Thursday October 28, 2010**  
**Wine and Cheese Scientific Poster Program**  
**7:00 PM – 10:00 PM at the Sheraton Hotel (South Room)**

<b>Poster Number</b>	<b>Poster Presenter</b>	<b>Authors &amp; Poster Titles</b>
<b>1</b>	<b>Leslie Holfeld</b>	Holfeld, L., Morgan, D., Crossley, M., Kirk, A., Stewart, N., D'Arcy, C., Forbes, D., Dal Bello-Haas, V., Basran, J., McBain, L., Cammer, A. & O'Connell, M. Mapping Referrals of a Telehealth-Supported Rural and Remote Memory Clinic
<b>2</b>	<b>Debra Morgan</b>	Morgan, D., Cammer, A., Wickenhauser, J. & Holfeld, L. Factors Influencing Satisfaction With Telehealth Videoconferencing in a Memory Clinic for Rural Seniors
<b>3</b>	<b>Catherine Lacny</b>	Lacny, C., Kirk, A., Morgan, D. & Karunanayake, C. Does Day Length Affect Cognitive Performance in Rural and Remote Memory Clinic Patients
<b>4</b>	<b>Nicole Haugrud</b>	Haugrud, N., Crossley, M., Vrbancic, M. & Jodouin, S. Comparing Qualitative Verbal Fluency Scoring Procedures in Healthy Aging and Early Stage Alzheimer's Disease
<b>5</b>	<b>Margaret Crossley</b>	Crossley, M., Lanting, S., O'Connell, M., Morgan, D., & The Keewatin Yatthé Home Care Team Introducing the Northern Cultural Assessment of Memory (N-CAM): A Dementia Screen for Aboriginal Seniors
<b>6</b>	<b>Megan O'Connell</b>	O'Connell, M., Crossley, M. & Morgan, D. Impact of Technology on a Telehealth-Based Support Group for Rural Spousal Caregivers of Patients Diagnosed with Atypical Dementias
<b>7</b>	<b>Megan O'Connell</b>	O'Connell, M., Dal Bello-Haas, V., Morgan, D. & Crossley, M. Attitudes Toward Physical Activity and Telehealth-Based Exercise in a Sample of Memory Clinic Patients and Their Caregivers
<b>8</b>	<b>Chandima Karunanayake</b>	Morgan, D., Karunanayake, C., Kosteniuk, J., Beever, R., Holfeld, L. & Elash, F. Rural and Remote Memory Clinic - Data Team
<b>9</b>	<b>Sheena Walls Ingram</b>	Walls-Ingram, S., Morgan, D., Cammer, A., Crossley, M., Forbes, D., Innes, A., O'Connell, M., Stewart, N. Dementia Caregiving in a Rural or Remote Setting: Initial Findings from a Longitudinal Needs Assessment of Informal Caregivers
<b>10</b>	<b>Norma Stewart</b>	Stewart, N., Morgan, D., Forbes, D., Karunanayake, C. & Wickenhauser, J. Caregiver Distress Prior to a Family Member's Dementia Diagnosis: Gender and Generational Contrasts

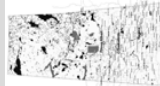
<b>11</b>	<b>Julie Kosteniuk</b>	Kosteniuk, J., Morgan, D., Innes, A., Keady, J., Goins, T., D'Arcy, C., Stewart, N. & Kirk, A. Diagnosis and Management of Dementia: Pilot Study of Roles and Perceived Needs of Rural and Remote Primary Care Providers
<b>12</b>	<b>Julie Kosteniuk</b>	Morgan, D., Innes, A. & Kosteniuk, J. Dementia Care in Rural and Remote Settings: Systematic Review of Formal/Paid Care
<b>13</b>	<b>Lesley McBain</b>	McBain, L., Stewart, N., Morgan, D., Bourassa, C., Cammer, A. & Cyr, C. Personal Care and Special Care Facilities in Aboriginal Communities of Saskatchewan.
<b>14</b>	<b>John Keady</b>	Keady, J. Dementia and Ageing Research Theme (DART): An Overview of Completed and Ongoing Research
<b>15</b>	<b>John Keady</b>	Ferguson-Coleman, E., Denmark, T., Young, A., Woll, B., Atkinson, J., Marshall, J, Rogers, K., Geall, R., Keady, J. & Burns, A. Deaf With Dementia Project
<b>16</b>	<b>Joanne Bracken</b>	Alzheimer Society of Saskatchewan First Link Coordinators First Link: Linking Individuals and Families Affected by Alzheimer's Disease or a Related Dementia to a Community of Learning, Services and Support
<b>17</b>	<b>Duane Minish</b>	Minish, D. & Morgan, D. Strategic Response to Dementia Rates in the United Kingdom - A Country by Country Review
<b>18</b>	<b>Xiangfei Meng</b>	Meng, X.-F., D'Arcy, C. & Morgan, D. Being Mindful: Depression and Dementia Among Rural and Urban Seniors - Epidemiological Studies
<b>19</b>	<b>Tracy Danylyshen Laycock</b>	Danylyshen-Laycock, T. Implementation and Sustainability of an Educational Program in LTC: Utilization of the PARIHS Framework to Guide the Way
<b>20</b>	<b>Charlene Chipeur</b>	Charlene's poster is not included in the booklet due to printing time constraints. For a copy of her poster please contact Debra Morgan at <a href="mailto:debra.morgan@usask.ca">debra.morgan@usask.ca</a>

# Mapping Referrals of a Telehealth-Supported Rural and Remote Memory Clinic

L. Holfeld<sup>1</sup>, D. Morgan<sup>1</sup>, M. Crossley<sup>2</sup>, A. Kirk<sup>3</sup>, N. Stewart<sup>4</sup>, C. D'Arcy<sup>5</sup>, D. Forbes<sup>6</sup>, V. Dal Bello-Haas<sup>7</sup>, J. Basran<sup>3</sup>, L. McBain<sup>8</sup>, A. Cammer<sup>1</sup>, M. O'Connell<sup>2</sup>

<sup>1</sup>Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan; <sup>2</sup>Department of Psychology, University of Saskatchewan; <sup>3</sup>College of Medicine, University of Saskatchewan; <sup>4</sup>College of Nursing, University of Saskatchewan; <sup>5</sup>Department of Applied Research, University of Saskatchewan; <sup>6</sup>Faculty of Nursing, University of Alberta; <sup>7</sup>School of Physical Therapy, University of Saskatchewan; <sup>8</sup>First Nations University of Canada

## Background

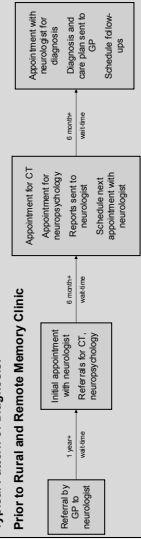


- Introduction:**
- Rural and Northern Saskatchewan have a low population density resulting in large travel burden for medical visits
  - Rural SK is older, on average, than urban and is home to many older adults
  - Risk for dementia increases with age

**New Emerging Team (NET) Grant:**

- NET grant, "Strategies to improve the care of persons with dementia in rural and remote areas", was developed to:
  - Improve the **availability** of specialized personnel and services providing assessment and management of dementia
  - Improve the **accessibility** of programs supporting formal and informal caregivers of persons with dementia
  - Improve the **acceptability** of services for persons with dementia and their caregivers

**Typical Pattern of Diagnosis:**



It was like climbing a mountain to get a diagnosis.

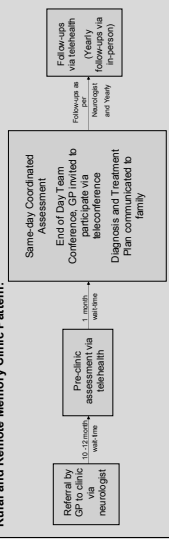
"Strategy for AD and Related Dementias in Saskatchewan" (2004), focus group comment.

## Rural and Remote Memory Clinic

**Clinic Goal:**

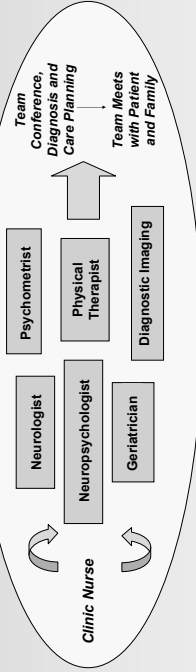
- To develop and evaluate a **streamlined integrated clinic** for patients from rural and remote Saskatchewan for diagnosis and management of dementia and to evaluate telehealth as a means of delivering follow-up care

**Rural and Remote Memory Clinic Pattern:**



- Pre-clinic assessment of patient and caregivers is conducted via telehealth to prepare them for the one-day assessment, familiarize them with the clinic nurse who will be their care liaison, order blood work or other tests, and gather information to assist with planning the one-day assessment
- Coordinated assessment** takes place in Saskatoon, is approximately 8 hours, and involves the patient and their informal caregivers

## Full-Day Coordinated Assessment

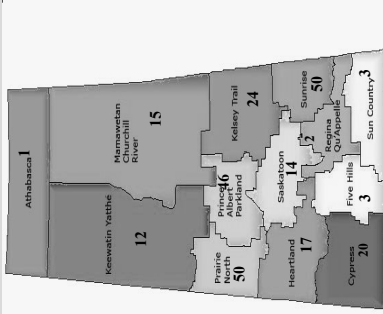


## Saskatchewan Telehealth Sites



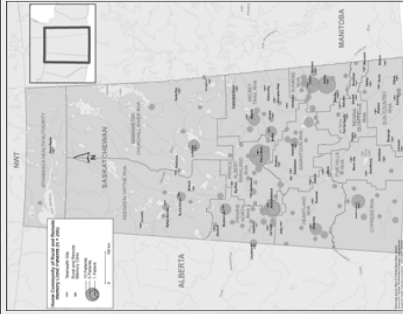
Comparison of travel time and distance saved:  
 Mean distance from home to Telehealth = 37.4 km  
 Mean distance from home to Saskatoon = 250.8 km  
 Distance saved by Telehealth = 213.4 km

## Patient Referrals per Rural Health Authority



Patients seen in Rural & Remote Memory Clinic as of Nov 2009, by RHA (n = 257)

## Patient Referrals per Home Community (n=256)



Funding and in-kind support is generously provided by:



All follow-up appointments are now via telehealth. This process was implemented in December 2008 based on research showing high patient and family satisfaction with telehealth.



# Factors influencing satisfaction with telehealth videoconferencing in a memory clinic for rural seniors

Debra Morgan<sup>1</sup>, Allison Cammer<sup>1</sup>, Joe Wickenhauser<sup>2</sup>, & Leslie Holfield<sup>1</sup>

<sup>1</sup>Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan, CANADA, <sup>2</sup>York University, Toronto, Ontario, CANADA



## Background

- The province of Saskatchewan, Canada:
  - 652,000 km<sup>2</sup> (252,000 mi<sup>2</sup>), population 1 million people
  - 13 health regions with population density of 0.1 to 9.2 people per km<sup>2</sup>
  - Rural communities have more seniors (22%) compared to cities (15%)
  - Risk for dementia increases with age

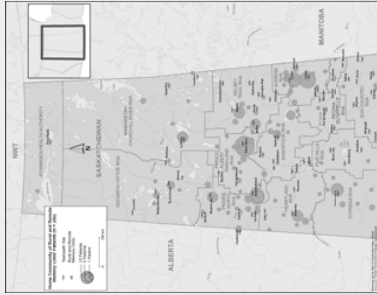
## Rural and Remote Memory Clinic

Providing specialized services to sparsely populated areas is challenging. To address the needs of rural seniors with dementia we have developed a **Rural and Remote Memory Clinic**, that incorporates:

- **1-stop interprofessional clinic** in a tertiary care centre: neurologist, neuropsychology team, physical therapist, nurse, geriatrician, and CT
- **telehealth videoconferencing** for pre-clinic assessment & follow-up

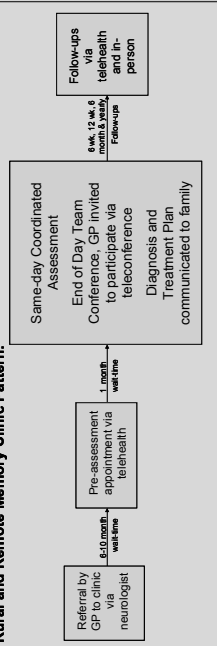


Telehealth Session



Research Team in Telehealth Unit

### Rural and Remote Memory Clinic Pattern:



## Aims and Methods

- The Rural and Remote Memory Clinic study was implemented in 2004.
- The aim was to evaluate **feasibility and acceptability** of:
  - (1) **one-stop interprofessional clinic** and (2) use of **telehealth videoconferencing** for pre-clinic assessment and follow-up.

### PREVIOUS FINDINGS IN THIS STUDY:

- Equal satisfaction with Telehealth and In-Person follow-up BUT Telehealth significantly more convenient
- High Telehealth Satisfaction Summary scores:
  - mean score 42 out of possible range 12 to 48
  - **Strong endorsement of telehealth using structured scales**. BUT we don't understand patient and caregiver experiences and how we can improve them.



### CURRENT STUDY (to date; study is on-going)

AIM is to help interpret findings from structured satisfaction scales and to identify areas for improvement.

METHODS: Theoretical sampling, semi-structured telephone interviews with primary caregiver, digitally recorded, transcribed, thematic analysis



### PARTICIPANTS to date: 19 primary caregivers

11 spouses, 5 patients, 2 daughters, 1 patient/caregiver

## Results: Themes

- **Overall high satisfaction with telehealth**
  - "I wish that there were other aspects of the health-care system that would use it too"
- **Convenience is main factor (time, cost, stress)**
  - "There's not as much time and travel involved. So in organizing things at home and getting to appointments, and organizing work... if [telehealth] is certainly more helpful that way"
- **Face-to-face is ideal BUT telehealth is good alternative**
  - "If it wasn't a 3-hour drive both ways, in-person [would be preferable], but it [telehealth] is a very satisfactory alternative"
  - "The in-person is best, but since getting to [the city] is such a job for us, I guess we have to go telehealth."
- **Combination of TH and IP works well**
  - "I feel they both go together you know"
  - "I think the combination works well... It's helpful to actually go [to city] and meet face-to-face... for those appointments that maybe aren't quite as long-able to do that through telehealth"
  - "I think that to see the people, at first anyway, and then go into the telehealth"

## Results continued

- **TH good for follow-up, not initial in-depth assessment**
  - "To keep in touch with them [telehealth] is probably a good thing. And if they [team] have any suggestions"
  - "The assessment is better person-to-person, face-to-face. Following the patient then it [telehealth] has a definite place"
- **Factors influencing satisfaction with telehealth**
  - age and health of patient & caregiver, stage of dementia, ease of traveling, distance saved by telehealth, frequency of appointments.
  - presence of family members living in the city
  - type/length/purpose of appointment: "For any appointment after the initial assessment I think it is very good"
  - Comfort with technology
    - "Dealing with the camera—I know it made my mom nervous... she was just a little intimidated maybe... a little hesitant about dealing in front of the camera, the anonymity of it"
    - "They [parent] don't do so well with telehealth, they find it a little odd I think talking to the camera. And they don't tend to say much"
    - "To me, seeing your doctor is a personal experience... there is a human aspect that you can't replace"
- **Other findings:** Some participants perceived that:
  - the telehealth appointment was for benefit of Dr/team
  - the patient was the focus, thus reluctant to raise caregiver concerns
  - they felt pressure to respond quickly on telehealth
  - they had less input/control into the session



## Implications & Conclusions

- Most patients and caregivers were satisfied with telehealth.
- TH is working for the purpose we planned BUT there are things we can do to better prepare patients and families.
- Explain that purpose of the appointment is to assess patient and caregiver, that it is appropriate to bring up any concerns & that they could bring a list of questions. Team should invite questions.
- Planned growth in number of TH sites is positive (benefit of TH decreases as distance to TH increases).
- Future: continue interviews using theoretical sampling, including those who discontinued.

Funding and in-kind support is generously provided by:



# Does day length affect cognitive performance in rural and remote memory clinic patients?

Catherine Lacny<sup>1</sup> BSc, Andrew Kirk<sup>2</sup> MD FRCPC, Debra G. Morgan<sup>3</sup> PhD, Chandima Karunanayake<sup>3</sup> PhD

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## Introduction

Natural light is an important environmental cue influencing circadian physiology. Early studies on light focused on intensity, generating hypotheses on the contribution of light exposure to human physiology that were based on bright light exposure. More recent studies suggest that natural light exposure also affects humans, as circadian systems have been shown to respond to low intensity natural lighting as well<sup>1</sup>. The pattern of depression and remission seen in patients with seasonal affective disorder (SAD) suggests that environmental illumination is a factor in the etiology of the syndrome, and cognitive function tests have demonstrated summertime improvement in SAD patients who are in remission.<sup>1,2</sup>

Sundowning denotes the clinical phenomenon of disruptive or agitated behaviour worsening in late afternoon or evening in dementia patients. While the mechanism is unclear, it has been suggested that sundowning is the result of disturbed circadian rhythms caused by Alzheimer's disease and related dementias<sup>3</sup>. Currently, there is insufficient evidence to assess the effect of natural light exposure on dementia patients<sup>4</sup>.

## Objective

Our objective is to determine whether day length affects cognitive performance in rural and remote memory clinic patients. Saskatchewan is an ideal location for this investigation as day length varies both seasonally and geographically.

## Methods

• The Rural and Remote Memory Clinic (RRMC) in Saskatoon, Saskatchewan provided an opportunity to examine how cognitive performance on the Mini-Mental State Exam (MMSE) is influenced by day length.

• Following an initial assessment by the RRMC team, patient follow-up appointments were performed either in-person or via telehealth videoconference.

• At each follow-up appointment the clinic neurologist administered the MMSE. The relationship between day length and MMSE scores at the 6-week follow up appointment was analyzed in 154 patients.

• Ethical approval was granted by the University of Saskatchewan Behavioural Research Ethics Board and all patients and their families gave informed consent prior to participation.

• Climate data was obtained from the Canadian Weather Network, Environment Canada, the National Research Council Canada and Natural Resources Canada databases (See Table 2).

• Bivariate correlation and linear regression analyses were conducted.

**Table 1: Demographics and clinical characteristics of participants**

Total number of patients in study, n		154
Age at initial clinic day, years	Mean ± SD Range	73.9 ± 9.8 42 to 91
Gender, n (%)	Male Female	59 (38.3%) 95 (61.7%)
Neurologist diagnosis, n (%)		Alzheimer's disease (AD) 86 (55.8%) Mild cognitive impairment <sup>a</sup> 23 (14.9%) Frontotemporal dementia <sup>b</sup> 12 (7.7%) Dementia with Lewy bodies 10 (6.5%) Vascular dementia 7 (4.5%) Mixed Dementia – AD/vascular 5 (3.9%) Vascular cognitive impairment 4 (2.6%) Normal pressure hydrocephalus 2 (1.2%) Head injury 1 (0.6%) Sequelae of coronary artery bypass graft 1 (0.6%) Vitamin B12 deficiency 1 (0.6%) Parkinson's disease 1 (0.6%) Huntington's disease 1 (0.6%)
MMSE score	Mean ± SD Range	20.95 ± 6.16 0 to 29

<sup>a</sup> Mild cognitive impairment (MCI) includes MCI, MCI due to other and MCI amnesic diagnoses.

<sup>b</sup> Frontotemporal dementia (FD) includes FD frontal variant, FD semantic, and FD progressive non-fluent diagnoses.

**Table 2: Descriptive statistics of climate data**

Day length (min)		739.6 ± 196.4 417 to 1046
Mean temperature (°C)	Mean ± SD Range	2.1 ± 12.3 -25.2 to +25.0

## Results

There was no significant correlation between MMSE score and day length or mean temperature. The statistical analysis was repeated on patients with scores less than the median score, 22 (SD ±6.1; n=72), in order to focus our analysis on patients with more severe dementia. Again, there was no significant correlation between MMSE score and day length or mean temperature. We carried out multiple linear regression with day length and temperature in the model. We did not find any significant relationship (See Table 3).

**Table 3: Correlation and multiple linear regression analysis**

	MMSE Score			
	All (n=154)		MMSE score ≤22 (n=72)	
	Estimate	P value	Estimate	P value
<b>Correlation coefficient</b>				
Day length	-0.058	0.477	0.056	0.642
Mean temperature	-0.048	0.554	-0.079	0.512
<b>Multiple linear regression (±SE)</b>				
Day length	-0.002 ± 0.004	0.693	0.008 ± 0.005	0.115
Mean temperature	-0.004 ± 0.066	0.958	-0.130 ± 0.078	0.101
R <sup>2</sup>	0.003		0.042	

<sup>a</sup> P value from 2-tailed T test

<sup>b</sup> R<sup>2</sup> is multiple coefficient of determination for regression.

## Conclusion

Our statistical analysis of the effect of day length and temperature on MMSE scores of RRMC patients strongly indicated that there was no significant association. Further research is needed to determine if natural light exposure is a useful treatment in improving cognitive performance and modulating circadian rhythm disorders.

## References

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- Sullivan B, Payne TW. A comparison of seasonal and nonseasonal depression. *Am J Psychiatry*. 2007;164:1663-1667.
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# Comparing Qualitative Verbal Fluency Scoring Procedures in Healthy Aging and Early Stage Alzheimer's Disease.

N. Haugrud, M. Crossley, M. Vrbancic, & S. Jodouin



## Introduction

- **Two component model of verbal fluency**<sup>4</sup>:
  1. **Clustering**: production of words in a phonemic or semantic subcategory, presumed to rely on temporal lobe processes
  2. **Switching**: a shift between clusters, presumed to rely on frontal lobe processes
- **Summary of Previous Research**:
  1. **Older adults** produce fewer total words, switches and novel and repeated clusters than **younger adults**<sup>2,3</sup>
  2. Individuals with **Alzheimer's disease** (AD) produce fewer switches and smaller cluster sizes than normals<sup>3</sup>
- **Limitations of previous research**: Traditional scoring procedures use of single words, errors, and perseverations in calculations of cluster size and switching rates.
- **The present studies** examined multiple methods<sup>1,2,4</sup> of calculating clustering and switching during semantic and phonemic verbal fluency in young, middle aged, and older adults with equivalent estimated verbal ability, and in individuals with early-stage Alzheimer Disease (AD).

## Methods

### Participants

#### Study 1

- 30 young (mean age 27.9 yrs)
- 30 middle (mean age 51.1 yrs)
- 30 old (mean age 71.3 yrs)

#### Study 2

- 26 AD group (mean age 70.6 yrs)
- 26 healthy older adults (mean age 70.5 yrs)

### Measures

- Phonemic fluency – FAS (three 60-sec trials)
- Semantic Fluency – Animal Naming (one 60-sec trial)
- Estimates of Verbal Ability
  - Study One: Peabody Picture Vocabulary Test-Revised
  - Study Two: Wide Range Achievement Test (WRAT-III)

### Computer Scoring Program

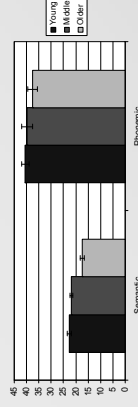
- Calculated clusters of words based on Troyer et al. (1997) clustering rules. Modifications to scoring:
  - Phonemic fluency: clusters were calculated based on the same first two letters
  - Semantic fluency: superordinate category was used if a word could be included in multiple clusters

## Procedures

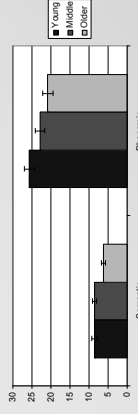
- **Phonemic clusters**: successively generated words that begin with the same two letters
- **Semantic clusters**: successively generated words that belong to the same semantic subcategory (e.g. African animals)
- **Mean cluster size**: summation of size of each cluster divided by number of clusters
- **Number of switches**: number of transitions between clusters
- **Number of hard switches**: number of transitions between two single words or a single word and clustered word
- **Number of cluster switches**: number of transitions between clustered words
- **Number of novel clusters**: number of new subcategories accessed
- **Number of repeated clusters**: number of subcategories returned to during a trial

## Results: Study One

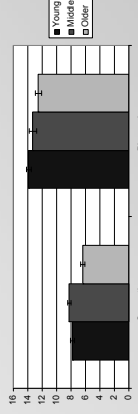
Age Group Differences in Total Words Produced



Age Group Differences in Number of Hard Switches



Age Group Differences in Number of Novel Clusters

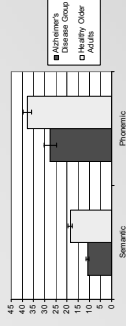


## Discussion: Study One

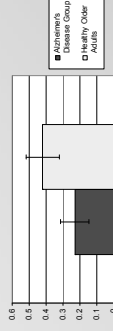
- **Age Group**: Strongest age group effects observed on total words produced, number of switches (specifically hard switches) and number of novel clusters, with older age group producing lower scores than young and middle groups
- Supports executive function (i.e. search and retrieval) and processing speed decline with healthy aging.

## Results: Study Two

Group Differences in Total Words Produced



Group Differences in Overlapping Clusters



## Discussion: Study Two

- **AD participants**: AD group produced fewer total words, switches (larger effect for cluster switches), semantic cluster size, novel clusters, and fewer overlapping clusters (i.e. word at end of cluster that prompts a new cluster)
- Supports decline in effective strategy use (i.e. effective search and retrieval of words and the use of prior words to cue new responses) and semantic memory in AD

## General Discussion

- Total word production declines both with healthy aging and AD, but due to different underlying processes
- Supports use of multiple methods of examining verbal fluency production

### References

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4. Troyer, A. K., Moscovitch, M., & Winocur, G. (1997). Clustering and switching as two components of verbal fluency: Evidence from younger and older healthy adults. *Neuropsychology, 11*, 138-146.

# Introducing the Northern Cultural Assessment of Memory (N-CAM): A Dementia Screen for Aboriginal Seniors

M. Crossley, S. Lanting, M. E. O'Connell, D. Morgan, & The Keewatin Yatthé Home Care Team

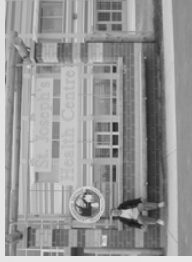


## Introduction

- Performance on mental status screening tests (e.g., MMSE) is influenced by culture, language, and education.
- Culturally appropriate assessment protocols are needed to advance knowledge about normal aging and the prevalence of dementia among Aboriginal seniors.
- The development of assessment and consultation services for Aboriginal seniors who reside in remote and Northern communities must occur in collaboration with local front-line healthcare workers and decision makers.
- The Northern Cultural Assessment of Memory (N-CAM) was developed through a partnership between faculty and graduate students from the University of Saskatchewan, Rural and Remote Memory Clinic, and home-care staff and health managers residing and working in the North (Keewatin Yatthé Regional Health Authority).

## Methods

Neuropsychology faculty and graduate students traveled to Ile a la Crosse to participate in a series of four full-day working groups (2008-2010) with home care staff and managers with the Keewatin Yatthé Regional Health Authority.



**Figures:** Screening instruments need to reflect the culture and environment of Aboriginal seniors who live in remote communities

## Foundational Work

- 1) Key informant interviews with Aboriginal seniors (Saskatoon Community Clinic Grandmothers' Group) and fieldwork in Northern communities guided test development and modification (Lanting et al., 2007).
- 2) Case study analyses of modified screening tools (Community Screening Interview for Dementia, Hall et al., 1993; Cognitive Abilities Screening Instrument, Teng et al., 1994) used with Aboriginal seniors in the Rural and Remote Memory Clinic identified strengths and limitations (Lanting et al., 2008).

## Early Findings and Future Directions

- Pilot work indicates that the N-CAM can be completed with relative ease in the home environment by trained home-care staff, and that the protocol is well-received by front-line health workers, family caregivers, and by Aboriginal seniors with memory difficulties.
- The N-CAM can be completed within one hour, and can be easily scored and interpreted by well-trained front-line health care staff.
- The protocol generates measures of **functional status**, based on the caregiver interview, and **cognitive scores** that are comparable to the MMSE and other commonly used cognitive screens.

## Next Steps:

In an ongoing partnership between faculty and students at the University of Saskatchewan and health care staff from Keewatin Yatthé Regional Health Authority, research with the N-CAM will continue to ensure acceptability and ease of performance by healthy Aboriginal seniors without formal education or exposure to urban culture, and to establish the sensitivity of the N-CAM to cognitive impairment and early-stage dementia.

## Funding Support







# Impact of Technology on a Telehealth-Based Support Group for Rural Spousal Caregivers of Patients Diagnosed with Atypical Dementias

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## BACKGROUND

High need for caregiver interventions specific to atypical non-Alzheimer dementias such as frontotemporal dementia or other early-onset dementias

- Spousal caregivers of patients diagnosed with atypical dementias (e.g., FTD) experience more psychological distress than carers of spouses of patients diagnosed with Alzheimer disease<sup>1</sup>
- Few specific interventions have been developed to address their needs<sup>2</sup>

### Rationale for Specialized Group Intervention

➢ Spousal carers of individuals diagnosed with atypical dementias can obtain both practical information and support from others who are experiencing similar troubling behaviours in their spouse<sup>2</sup>

### Problem

➢ In rural and remote regions it is difficult to find many carers of individuals diagnosed with these uncommon atypical dementias – cannot connect

### Solution

- Innovative use of telehealth videoconferencing to connect 10 caregivers from 6 regions of the province
- Once monthly group 1 ½ hr meeting for spouses
- Emotion processing focus of group rather than psycho-education
- Many members have been in this group for 1 ½ years

### Evaluation of Effectiveness

- Questionnaires on technology, neuropsychiatric behaviours and distress, caregiver burden, caregiver psychological distress, and coping methods
- In-person focus group held after 1 year in group



## Use of Telehealth Technology

- Use of telehealth versus in-person group therapy substantially reduced travel burden
- caregivers saved between 262 and 534 km travel per session
- use of telehealth provided access to an intervention not otherwise feasible for these rural caregivers

## Impact of Technology

- Impact of technology on the group was assessed after the first few sessions, at 6 months, at 12 months, and more recently at an in-person workshop, which was the group's first face-to-face meeting
- Group members described developing strong bonds via the telehealth videoconferencing technology; nevertheless, participants felt meeting in-person added a depth to their interactions

➢ Group members stated a preference for in-person group interventions, but ranked telehealth-based group interventions as a close second

- Prospective questionnaire data suggest that the following aspects of group process were initially rated as 'good' by all respondents, but there was more variability in these ratings (from poor to excellent) when measured at 6 and 12 months
  - reciprocal non-verbal communication
  - ability to emotionally connect with others
  - ability to spontaneously add to group discussions

## DISCUSSION

### Impact on Group Process

- As the group intervention became more emotionally charged, the limitations of virtual communication became more apparent
- Use of technology may have drawbacks for group processes, but overall satisfaction with use of technology was high for this remotely delivered group intervention

## FUTURE DIRECTIONS

### Description of Effectiveness

- Caregivers report this intervention is helpful and consider the bonds created over telehealth to be important for their coping and mental health
- Individualized comparisons of distress, coping, and burden over time

### Intervention Template

- Continue our collaboration and partnership with support group members to identify the key ingredients to this specialized and novel intervention
- Share this template with clinicians, researchers and community organizations to implement on a wider scale

## ACKNOWLEDGMENTS

- We acknowledge our caregiver partners and collaborators without whom we would not have been able to develop this intervention
- We have received great support from Telehealth Saskatchewan & received a Canadian Centre for Health and Safety in Agriculture knowledge translation grant

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# Attitudes Toward Physical Activity and Telehealth-Based Exercise in a Sample of Memory Clinic Patients and Their Caregivers

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## BACKGROUND

### Importance of Physical Activity and Exercise

- Physical exercise
- reduces cognitive aging<sup>1</sup>
- delays onset of dementia risk<sup>2</sup>
- is recommended for patients diagnosed with dementia<sup>3</sup>

### Rationale for Intervention

- Despite importance of physical activity and exercise, adherence is difficult
- Group-based interventions promote adherence and social engagement
- In-person group-based interventions not possible with our Rural and Remote Memory Clinic patients who exclusively live outside the major urban areas
- Use of telehealth videoconferencing allows these rural and remote patients to participate in an exercise intervention

### Objectives of Study

- Assess Memory Clinic patients and family caregivers:
  - attitudes toward telehealth exercise
  - attitudes toward physical activity for individuals with memory problems
  - general attitudes toward exercise with the multifactorial Older Person's Attitudes Toward Physical Activity and Exercise Questionnaire (OPAPAEQ)<sup>4</sup>

### Method

- Author developed questionnaires consisting of engagement and attitudes toward: physical activity and exercise (OPAPAEQ), telehealth and exercise, exercise for individuals with memory concerns mailed to all Memory Clinic patients and caregivers
- 77 questionnaires returned with complete data for interest in telehealth (54% response rate)
  - 42 patients
  - 35 caregivers

## RESULTS

### Interest in Telehealth Exercise Intervention

- Of the sample (N = 77), 51 (66%) stated that they would be interested in a telehealth exercise intervention
- Patients (n = 42) and caregivers (n = 35) were equally likely to express interest in participating in the telehealth exercise intervention
- Interest in the telehealth intervention was predicted by respondents' willingness to participate in a group-based exercise
- Interest in the telehealth intervention was **not** predicted by
  - belief in the importance of exercise for individuals with memory problems
  - general attitudes toward physical activity (via OPAPAEQ)

### Attitudes Toward Exercise

- 86% of the sample agreed physical activity and exercise is important for persons with memory concerns
- Responses on sub-scales of Older Person's Attitudes Toward Physical Activity and Exercise Questionnaire (OPAPAEQ) were similar to published normative data for the overall sample

#### Subscale measures on OPAPAEQ are:

- belief exercise provides tension release
- belief exercise is important for health promotion
- belief in need for vigorous exercise
- belief in the social benefits of exercise

- Memory Clinic patients and caregivers responded similarly on the OPAPAEQ factors assessing belief that exercise releases tensions, belief in importance of vigorous exercise, and belief in the leisure and social benefits of exercise
- In contrast, Memory Clinic patients and their caregivers differed on belief of the health benefits from exercise, with patients less likely to endorse belief in health benefits

## DISCUSSION

- Group-based telehealth exercise interventions appear acceptable to Memory Clinic patients and their caregivers
- To improve rural patients' engagement in technology-based exercise interventions, additional delivery formats that include an opportunity for individual interventions are needed
- Memory clinic patients were less likely to endorse beliefs regarding the health benefits of exercise
- any exercise intervention for Memory Clinic patients should include didactics regarding the health benefits of exercise



## ACKNOWLEDGMENTS

- We would like to thank the RRMIC patients and their caregivers who participated in this study
- We would like to thank Telehealth Saskatchewan for their support
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# Rural and Remote Memory Clinic - Data Team

Debra Morgan, Chandima Karunanayake, Julie Kosteniuk, Rob Beaver, Leslie Holfeld & Freda Elash

## Introduction

The Rural and Remote Memory Clinic (RRMC) evaluation project maintains an integrated database that includes patient and caregiver data **across time** from first contact until patient discontinues or moves to a nursing home or location outside SK and **across clinical disciplines** (e.g., neuropsychology, neurology, physical therapy).

Once a year the Data Team produces a Data Release (DR) that includes all of the data collected for each study participant to date. The data are de-identified, carefully cleaned, and checked to ensure accuracy and anonymity.

All data analyses use the most current Data Release, to ensure that all analyses are conducted using the most current and accurate data, with the maximum sample size.

In the RRMC database there are 125 questionnaires covering 9 time points from PreClinic Assessment to Year 4.

## Preparing for a data release

- Freda (Research Assistant) enters RRMC data into the main database
- Freda imports the following databases into the main database
  - Tracking data entered by Leslie (Clinic Nurse)
  - Physiotherapy data entered by Flo (Physical Therapist)
  - Neuropsych data entered by Memory Clinic Team
- After Freda imports the above databases into the main database, Rob (Data Analyst) and Freda do a "Supercheck" after each database is imported to ensure all data is imported correctly.
  - \* A supercheck involves comparing birthdates and appointment dates from the new main database with the database from Leslie, Flo or the Memory Clinic with the patients' files
- Freda exports the data into SPSS for cleaning
- Rob cleans the data, runs the syntax for the embedded scales, and prepares the data for the Data Release
- Chandima (Statistical Consultant) is involved with syntax writing, the SF-12 scale, and statistical analysis for the team
- Debra (Principal Investigator) and Julie (Postdoctoral Fellow) give support with every stage in the Data Release

## Sample Sizes and Data Release Dates

**DR1** 151 patients (October 2007)

**DR2** 188 patients (December 2008)  
**N increased by 37 from DR1**  
 Physiotherapy data added

**DR3** 230 patients (January 2010)  
**N increased by 42 from DR2**

- 105 questionnaires/layouts, covering 8 time points from PCA to Year 3 (does not include tracking information)
- Variables in SPSS database = 7828

**DR4** 273 patients (anticipated February 2011)  
**N increased by 43 from DR3**  
 and by 122 from DR1



# of Patients seen by the Memory Clinic either at In-Person or Telehealth Visits February 2004 to July 2010

	# of patients
Pre-clinic	273
Clinic day	248
6 week follow-up	181
12 week follow-up	177
6 month follow-up	165
1 year follow-up	128
2 year follow-up	84
3 year follow-up	43
4 year follow-up	16

# of Patients, Family Members/Caregivers Present at In-Person and/or Telehealth Visits October 1, 2009 to September 30, 2010 (12 months)

	# of patients	# of family members/caregivers
Pre-clinic assessments with Nurse & Neuropsychologist	30	32
Full day assessment with inter-professional team	38	60
In-clinic follow-ups with Neurologist	18	19
Telehealth follow-ups with Neurologist	113	128
Half-day annual follow-up assessments with full team	38	45
TOTAL	237	284

Graduate students in clinical psychology are assigned to the RRMC for clinical practicum training (Sept - May), summer clerkships (May - August) and predoctoral residency rotations (Jan-Aug), and medical residents periodically attend full day or half-day follow-up assessments. During the past 12 months, an average of 2 students attended each clinic with a range of 0 to 3 students. Three visitors attended full day assessments or half-day annual follow-up assessments during 2009-2010.

## Timeline of Questionnaires

### Pre-Clinic Assessment (90/130/180/270 Day)

- 18. Modified Clinical Best of Seniors
- 19. Behavioral Rating Scale (9 year)
- 20. Physical Activity Scale for the Elderly (PASE)
- 21. Performance Oriented Mobility Assessment
- 22. AMCS Scale (9 year)
- 23. GDS-SM (9 year)

### Clinic Day (90/130/180/270 Day)

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### 4 Week Follow-up (6 weeks)

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### 12 Week Follow-up (12 weeks)

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8 months before the next participant 1 year after the Neurophysiology clinic, ahead of time if they will see the patient and sometimes only the Neurologist will see them.



# Dementia Caregiving in a Rural or Remote Setting: Initial Findings from a Longitudinal Needs Assessment of Informal Caregivers



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## Background

The purpose of the CIHR Applied Chair program, *Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia* is to improve the health and quality of life of individuals with dementia and their formal and informal supporters in rural and remote communities.

The current project addresses the specific objective, (1.1) To identify the support and service needs of rural and remote dementia patients and their caregivers.



Caregivers of Rural & Remote Memory Clinic patients routinely provide questionnaire data regarding their health, stress, and burden, yet we have not systematically investigated their specific needs and experiences prior to this study.

## Study Design

This study is a longitudinal needs assessment – we are interviewing informal caregivers at 3 points over the year following their first Rural & Remote Memory Clinic visit:

**Clinic Day** : initial in-person interview

**6 Months later**: telephone interview

**One-Year follow-up appointment**: in-person interview

The interviews are being analyzed using a Grounded Theory analysis. Interviews are coded concurrently with data collection, with revisions to the interview guide as themes emerge.

## Data Collection to Date

16 Initial (Clinic Day) Interviews have been conducted, involving 25 participants.

Eight 1-person interviews; Seven 2-person interviews; One 3-person interview

Six spouses; 14 children; 2 other family; 1 friend of RRMC patient

## Preliminary Findings

Early analysis suggests caregivers experience common stages in the period between when they first noticed symptoms in their family member, and the day of their first visit to the Clinic for diagnostic assessment. Preliminary themes are highlighted within these stages.

### First Signs

Caregivers typically notice first signs of problems in patients ~ 2 years prior to initial RRMC visit.



### Questioning

Some caregivers **second-guess** their suspicions and question whether the patient's symptoms are just "normal aging". Some use a family history of dementia confirm their own suspicions

### Seeking 1<sup>st</sup> Help

Caregivers report varying degrees of success with approaching the patient's family Dr. with concerns, with some being very satisfied and others **getting stuck** and **taking charge** at this initial stage.



"...just to know that this is what it is and this is how it's going to progress, and then we'll deal with it."  
Wife & caregiver of RRMC patient

## Process continued

### Getting a Referral

Caregivers often report **taking charge**. The path of care/referral is not always clear to the caregiver, but getting a referral to the RRMC is typically a relief.

### Waiting for: Initial RRMC Visit

The interim between referral and initial Clinic visit ranges in experience among caregivers from a maintenance of the **status quo**, to an **escalating crisis**, including safety concerns and caregiver burnout. Almost all caregivers spend this stage **anticipating** and **planning** amidst unknown circumstances. All are **seeking answers** with a great deal of urgency. Caregivers report that the diagnosis is important, and is a climax in this first part of the caregiving journey.

"...we felt, that at least there was something happening."  
Daughters of RRMC patient

## Acknowledgements



# Caregiver Distress prior to a Family Member's Dementia Diagnosis: Gender and Generational Contrasts



Norma Stewart<sup>1</sup>, Debra Morgan<sup>1</sup>, Dorothy Forbes<sup>2</sup>, Chandima Karunanayake<sup>1</sup>, Joseph Wickenhauser<sup>3</sup>  
<sup>1</sup>University of Saskatchewan <sup>2</sup>University of Alberta <sup>3</sup>York University

Gerontological Society of America 63<sup>rd</sup> Annual Scientific Meeting, New Orleans, Nov. 19 – 23, 2010

## Objective

In this analysis, we compared family caregivers according to their gender (male vs. female) and relationship (spouse vs. child) on measures of burden, severity of distress and health (mental and physical) at the initial in-person visit to a rural and remote memory clinic (RRMC) for diagnosis of early dementia.



## Methods

A family member, who accompanied the person referred to the RRMC interprofessional team for assessment, completed three questionnaires about their caregiving experiences and their general health.



Ethics approval was obtained and family members signed an informed consent form.

Of 175 caregiver participants, there were 66 wives, 49 daughters, 42 husbands, and 18 sons.

The caregiver self-report data were collected prior to the end-of-day meeting in which team members provide feedback to the patient and family about the assessment and diagnosis.



Analysis of Variance was used in a factorial design to compare these four caregiver groups as two factors (gender x relationship) on each of four indicators of distress and health.

## Results

We found that women (wives + daughters) reported significantly more caregiver burden ( $p < .0001$ ), greater severity of distress ( $p < .0001$ ), and lower mental health ( $p < .05$ ) than men (husbands + sons).

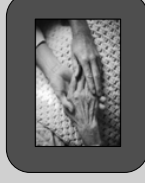
In the relationship analysis, spouses (wives + husbands) reported greater severity of distress ( $p < .05$ ) and lower physical health ( $p < .05$ ) than children (daughters + sons).

There was no interaction between the gender and relationship factors.



## Conclusion

These results are consistent with earlier research that has found differences in caregiver burden and distress in relation to gender of caregiver and type of relationship with the person diagnosed with dementia.



Differences in physical health between spouses and children may reflect age-related deterioration for spouses and suggests that differing needs for support exist based on type of caregiver.

The next stage of the present analysis will be to examine changes over time as caregivers continue to support their family member with dementia at home.



**Table 1:** Clinic Day Means and Standard Deviations.

Relationship	Caregiver Burden (n=171)	Severity of Distress (n=166)	Health-Mental (n=169)	Health-Physical (n=169)
Husband	8.2 (8.5)	49.2 (9.8)	55.3 (8.7)	43.3 (10.6)
Wife	15.3 (9.7)	55.0 (8.9)	50.1 (10.2)	44.5 (12.1)
Son	10.8 (6.7)	45.2 (10.8)	54.7 (7.5)	49.3 (11.4)
Daughter	16.5 (7.5)	52.1 (9.4)	49.6 (9.3)	48.9 (13.3)

**Table 2:** Clinic Day Analysis of Variance Results.

	Caregiver Burden (n=171)	Severity of Distress (n=166)	Health-Mental (n=169)	Health-Physical (n=169)
Gender (G)	<0.0001	<0.0001	0.002	0.881
Relationship (R)	0.181	0.039	0.732	0.012
G x R	0.593	0.688	0.957	0.725
Skewness*	Skewed Right	Skewed Right	Skewed Left	Skewed Left

Note: Results (p values) in **bold** are statistically significant  
 \*Kolmogorov-Smirnov test for normality

## Acknowledgements



# Diagnosis and management of dementia: Pilot study of roles and perceived needs of rural and remote primary care providers



Julie Kosteniuk<sup>1</sup>, Debra Morgan<sup>1</sup>, Anthea Innes<sup>2</sup>, John Keady<sup>3</sup>, Turner Goins<sup>4</sup>, Carl D'Arcy<sup>5</sup>, Norma Stewart<sup>6</sup>, and Andrew Kirk<sup>7</sup>  
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## Background

### The problem of dementia care in Canada

- According to the Third Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (CCCDTD3), most patients with dementia can be assessed and managed adequately by family physicians.
- However, many family physicians are not entirely confident with providing dementia care, and specialist referral rates among dementia patients are high (Pimlott et al., 2006)

### The problem of rural and remote dementia care

- Familiarity with patients and stigma of dementia may hinder detection and diagnosis (Cahill et al., 2008).
- There is limited availability of specialist services locally and it is difficult for patients to travel to urban centres (Teel 2004).
- Limited access to support programs and services such as home patient care, nursing, day-care, and respite care (Bradford Dementia Group and Commission for Rural Communities 2008, Alexander & Fraser 2008).
- Only 16% of family physicians and 2% of specialists provide services in rural Canada, which comprises 21% of the nation's population (The Society of Rural Physicians of Canada, 2005).

### 2004 baseline survey of 31 Saskatchewan family physicians

- Physicians saw a median of 6 patients per month with Alzheimer's Disease or dementia, diagnosed dementia in a median of 3 patients (range 0-40) per year, and referred a median of 3 patients (range 0-20) per year to specialists.
- 83% of physicians affirmed that they required more continuing medical education on dementia, particularly concerning diagnosis and initiating treatment.
- 50% of physicians identified a need for increased patient and caregiver support services in their community, with long-term care beds, respite beds, and support groups topping their list of support needs.
- 62% were comfortable with diagnosing and managing dementia patients, 51% were comfortable with driver's license issues, and 43% were comfortable with competency assessment.

## Objectives

- To identify the roles and support needs of Saskatchewan primary care providers (Family Physicians and Nurse Practitioners) in the assessment and management of people with dementia
- To further explore primary care providers' perceptions of barriers to providing dementia care.

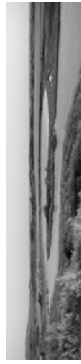


Photo: Shutterstock.com

## Findings

### Participants

- N=14
- 9 participants were Family Physicians (FP), and 5 were Nurse Practitioners (NP).
- 8 participants practiced in rural settings, and 6 practiced in urban locations. Rural settings included communities considered moderate, weak, and no MIZ (metropolitan influenced zones), as well as northern communities. Urban locations included census agglomerations and census metropolitan areas. Given that urban FPs and NPs often have a substantial proportion of rural and remote patients, the present analysis explored the views of urban as well as rural participants.

### Role in caring for patients with dementia

When asked to define their role in caring for patients with dementia, participants focused on the following roles:

- diagnostician
- care co-ordinator
- "I think a primary role in the family physician is to make sure that all the multidisciplinary services are available, so setting up appointments with specialists, cat scans, occupational therapy, home care, going through the CPP, the financial aspects, going through the end of life issues." (Family Physician)
- medications manager
- providing resource assistance
- "I would like to be a good resource for them and be able to see that they have access to whatever support is possible." (Family Physician)

### Perceived needs to provide dementia care

In order to provide better dementia care, participants indicated that they had needs related to practice, training, information, and referral:

- Practice needs included more time to spend with patients and more staff to help with assessments
- Training on diagnosis and management
- Information to distribute to family members about what to expect as the disease progresses
- Information on new assessment and diagnosis tools, pharmacological and non-pharmacological treatment, behavioural management, and how to provide support to caregivers
- Multi-disciplinary teams of specialists where patients can be referred
- "It would be great if we had one location where you could just send people and everything got done. But I suppose that's a dream world right." (Family Physician)
- More specialists and greater access to therapies
- "...access to therapies, access to lab tests and occupational therapy and physiotherapy is not what it ought to be in our community, we probably have half as many professionals as we need." (Family Physician)

### Barriers to providing dementia care

- Isolation from other health professionals
- "And always having to connect with people like you just couldn't go next door right? It either had to be a phone call or wait until they came out or you know some delay at times." (Nurse Practitioner)
- Difficult referral process
- "I refer under the auspices of my visiting physician. We're still trying to get that changed...if I refer, the specialist can take that referral from me but would not get paid his premium wage." (Nurse Practitioner)
- Shortage of health care professionals in rural areas

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## Acknowledgements

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# PERSONAL CARE AND SPECIAL CARE FACILITIES IN ABORIGINAL COMMUNITIES OF SASKATCHEWAN

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## Introduction

There are many gaps in the provision of health care services for Aboriginal seniors, especially for elderly residents living in rural and remote areas. A particular area of concern is the lack of long-term care facilities, which means that those seniors requiring more comprehensive care must leave their community. The Saskatchewan Patient First Review Commissioner's Report calls for development of linkages and partnerships with First Nations and Métis run services to better integrate care. However, it is unclear what facilities are currently available for Aboriginal seniors in their communities. The purpose of the pilot project is to establish an inventory of long-term care homes in Aboriginal communities of Saskatchewan. The project will also map and examine the distribution of these facilities in the province.

## Definitions

The term "Aboriginal" includes Indian, Inuit, and Métis peoples who are identified as the Aboriginal people of Canada in the Constitution Act of 1982, Sec. 35 (2).

### Special Care Homes (SCHs):

An SCH is a facility that provides long-term care to meet the needs of individuals that cannot be met through home-based/community services. Regional Health Authorities (RHAs) may operate an SCH directly or through affiliation/contract.

The government funds SCHs through RHAs and pays approximately 80% of the overall cost of long-term care. Residents pay an income-tested charge ranging from \$982-\$1866 per month; Indian and Northern Affairs Canada's Assisted Living Program pays this resident fee for adults who live on reserve and are admitted to an SCH.

Individuals are assessed by RHAs and are admitted and prioritized for placement to SCHs on the basis of need. The person with the greatest need and living at the greatest risk is offered the first available bed, which may not necessarily be in the preferred facility or community.

### Personal Care Homes (PCHs):

PCHs are privately owned and operated facilities that offer accommodation, meals, and supervision or assistance with personal care to people who generally do not need or do not want the level of health services provided in SCHs.

Residents do not have to demonstrate need to be admitted to a PCH, but rather are admitted because they choose that service option. In PCHs, residents pay the full cost of their care, which ranges from approximately \$900-\$3500+ per month.

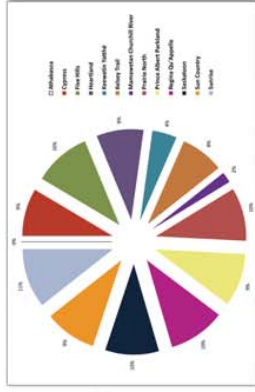


Figure 1: Percentage of SK LTC Beds Allocated per Health Region (per 1000 Individuals Aged 65+)

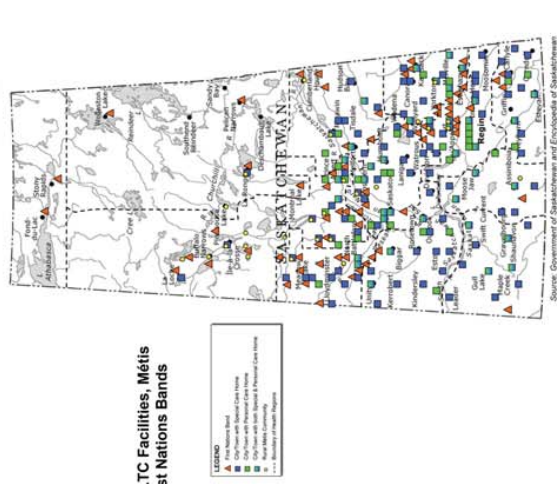


Figure 2: Map of SK LTC Facilities, Métis Communities and First Nations Bands

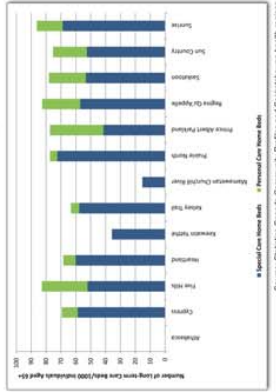


Figure 3: Distribution of LTC Beds in SK by Health Region

## Initial Observations

The regional health authorities with the highest percentage of First Nations and Métis individuals (Keewatin Yatthé, Athabasca, Mamanawak Churchill River) have the lowest proportion of long-term care beds (4%, 0%, 2% respectively) for seniors over the age of 65. These three regions combined offer 37 special care home beds and no personal care home beds. In these regions, special care homes are limited to the larger communities (La Ronge, La Loche, and Ile-a-la-Crosse) so residents in other areas of northern Saskatchewan must relocate to receive long-term care. If the 37 beds are full, individuals in these northern regions who require long-term care must move to another health region and wait to be transferred to their preferred facility when there is an opening. Since there are no personal care homes in these northern health regions, residents who do not require special care homes but still need more care than community or home care services provide do not have an option for long-term care.

The distribution of special care and personal care homes indicates a lack of facilities in northern Saskatchewan where approximately 80% - 95% of the population is of Aboriginal ancestry. Of particular note is the lack of personal care homes. This is not surprising given that Northern Saskatchewan is one of the poorest regions in Canada and where houses are in far greater need of major repairs than those in the south. The result is two-fold. Firstly, the paucity of houses in good condition limits the number of homes that are available for use as a personal care homes. Secondly, even if there were an adequate number of personal care homes, the incidence of poverty means that many Aboriginal people could not afford the cost of care which ranges from \$900 - \$3500 per month in the privately owned and operated facilities.

## Next Steps

Given the lack of facilities in northern Saskatchewan as indicated in our initial observations, our next step is to investigate how the needs of elderly residents requiring long-term care are being met in the three underserved regions. Meeting with health care providers, community leaders, and residents will enable us to obtain a clearer understanding of how people in the north are affected by this lack of services.





## Dementia and Ageing Research Theme (DART): an overview of completed and ongoing research

John Keady

School of Nursing, Midwifery and Social Work. University of Manchester, UK  
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### UK Policy Developments

#### National Dementia Strategy

Department of Health, 2009.  
17 objectives including: increased awareness, early diagnosis, good quality information for people with dementia and carers, increased quality of life, quality of care home and hospital care.

Localities will be supported to meet these objectives nationally and regionally, with joint commissioning of dementia care services a priority.

#### Key UK Dementia Policy Documents / Reports:

Alzheimer's Research Trust (2010) Dementia 2010: the economic burden of dementia and associated research funding in the United Kingdom.

Alzheimer's Society (2007) Dementia UK: the full report.

National Institute for Health and Clinical Excellence (2006) Dementia. Supporting people with dementia and their carers in health and social care. NICE clinical guideline 42.

Department of Health (2005) Everybody's Business. Integrated mental health services for older adults: a service development guide.

Department of Health (2001) National Service Framework for Older People.

### DART Members

Caroline Swarbrick  
Christine Brown Wilson  
Emma Ferguson-Coleman  
Helen Barnes  
Jill Pendleton  
John Keady  
Moirra Attree  
Pamela Roach  
Patricia Lees  
Penny Bee  
Phil Hardman  
Richard Ward  
Ruth Elvish  
Sarah Campbell  
Sean Page  
Simon Burrow  
Xia Li

### Research Clusters

1. Biographical / Narrative Work
2. Psychosocial Interventions
3. Lifestyle and Creative Arts
4. Education

### Overview of Current Work

SDO Transitions and Dementia 2009-2010: with London and Newcastle

Recovery and Dementia Research project

The Banff Collaboration: a three-year cohort study of care for dementia and health outcomes during periods of transition.

Assistive technologies and dementia

Dementia and physical activities evaluation

Deaf with Dementia: working with Deaf people with early-stage dementia

Improving Quality of Care for people with dementia in acute hospital settings: developing an educational training intervention

### Upcoming Work

#### *Hairstyling, image and body work in care services to older people*

28 month study funded by the ESRC First Grant Competition. Start Date: 1 November 2010

**Overview:** An ethnographic study of the provision of hairdressing services within the care system for older people. The project will take account of the relationship between older people who are high level users of health and social care and the hairdressers who visit them in various types of care settings. The proposed methods are qualitative and will combine visual and spoken (interview) data to examine the meanings that older service users attach to their image and appearance. The study will also consider the workplace experiences of care-based hairdressers, their working conditions and the relationships they build with older clients.

### Ongoing Work

#### *REMcare: a study looking at the effectiveness of reminiscence groups for people with dementia and their relatives*

A single-blinded randomised controlled trial funded by the HTA Programme – National Institute of Health Research (2007-2011)

**Overview:** REMcare is a multi-centre, national project which aims to explore the effectiveness of reminiscence groups for people with dementia and their care-givers. The format of the groups is based on Pam Schweitzer and Errollyn Bruce's book 'Remembering Yesterday, Caring Today'. It is group based with around 12 couples (any caregiving dyad) per group. Various senses and modes of communication are used – verbal, touch, dance, art, re-enactment. Weekly sessions trace the life course with themes including childhood, schooldays, working life, holidays.

### Recently Completed Work

#### *The Senses in Practice (SiPs): Working in partnership with care homes to enhance the care of people with dementia*

An 18 month project based in two care homes (one 'for profit' and one 'not for profit' providers).

**Overview:** Using a relationship-centred approach, staff, residents and families were invited to complete questionnaires known as the CARE Profiles, which were developed from the Senses Framework (Faulkner et al 2006). The results of the CARE Profiles were used to develop the staff education programme. The education programme comprised eight sessions of one hour duration exploring the senses of: purpose; achievement; security; significance; belonging; and continuity. Interactive workshops encouraged staff to consider the importance of each 'sense' to their own lives. Staff developed a number of resources for use in each home, including: memory boxes, sensory boxes, personal fact files, 'Creating the senses for' booklet, and a care planning resource.

### Recently Completed PhD

#### *A Family-Centred Study of Younger People with Dementia*

**Pamela Roach**  
[Pamela.Roach@manchester.ac.uk](mailto:Pamela.Roach@manchester.ac.uk)

3 year study funded by the Medical Research Council (MRC) UK

#### Phase 1: Literature Review

Literature review conducted to establish current evidence base of younger people with dementia and family members' experiences.

A main theme that emerged from the review was **Diagnosis and Information Provision:** frequent difficulty experienced obtaining a diagnosis and referral to specialist service provision. Symptoms often initially attributed to stress, menopause or other health-related conditions. Diagnosis can take many months, and in many cases years, to obtain. Increased awareness of common forms of young-onset dementia and presenting symptoms required.

#### Phase 2: Longitudinal Data Collection

Longitudinal, Narrative study. Data Collection over a period of 12-15 months.

- in-depth interviews
- co-construction of family biographies

Completed family biographies made up primarily of family photographs but included text, drawings, song lyrics (written by participants).

Participants Recruited through 2 health care authorities; younger person with dementia recruited initially, then nominated up to five family members for participation.

Narrative, storyline analysis identified six storyline types. These storyline types may be used in a variety of ways by families in order to adjust to their new life with young-onset dementia. The use of these storylines may be indicative of increased clinical support needs and therefore the identification of storylines and use of family biographical data can lead to enhanced clinical decision making.

#### Phase 3: Clinical Staff Interviews

Interviews were undertaken with clinical service providers working with younger people with dementia and their families. Staff reported a reluctance to address relational support needs within family due to uncertainty of professional competency in these areas and recognised that the biographical information of families plays a significant part in clinical decision making.

Development of an exploratory, dementia-specific clinical assessment tool resulted. Designed to facilitate the formal collection, record-keeping, and use of family biographical information in clinical settings. This tool is still in early stages and needs to be piloted in clinical service areas to assess its usefulness and practical application.

*Pamela Roach is currently planning on developing this family-centred work further during a post-doctoral fellowship at the University of Calgary*



Funded by Alzheimer's Society

Emma Ferguson-Coleman<sup>1</sup>, Tanya Denmark<sup>2</sup>, Alys Young<sup>1</sup>, Bencie Woll<sup>2</sup>, Jo Atkinson<sup>2</sup>, Jane Marshall<sup>3</sup>, Katherine Rogers<sup>1</sup>, Ruth Geall<sup>4</sup>, John Keady<sup>1</sup> and Alistair Burns<sup>1</sup>

The University of Manchester<sup>1</sup>, Deafness, Cognition and Language Research Centre, University College London<sup>2</sup>, City University London<sup>3</sup>, The Royal Association for Deaf People<sup>4</sup>

British Sign Language (BSL) is a visual language used by more than 100,000 people in the UK. Lack of awareness of this linguistic minority creates barriers to diagnosis and support which result in health inequalities.

Early identification, accessible information and 'living well with dementia' are key aims of the Government's Dementia Strategy but these cannot be achieved for Deaf people without Deaf-centred research in BSL.

A new research study, with three major elements, will assist with the early identification of dementia amongst Deaf people. This is a three year project funded by Alzheimer's Society.

#### Study 1 (Deafness, Cognition and Language Research Centre)

•Establish the range of normal changes in language and thinking associated with healthy ageing in a population of Deaf signing older people.

•Develop a dementia assessment instrument in BSL that is culturally appropriate.



There are no culturally appropriate assessments in BSL that are known to work well in assessing Deaf people who might have dementia.

The Addenbrookes Cognitive Examination Revised (ACE-R) (Mioshi, Dawson et al. 2006) has been modified in addition to other language, memory and visiospatial tasks, so they are suitable for deaf BSL users.

#### Items that need adapting:

- Verbal fluency looking at handshapes rather than English letters
- Remove English requirement, writing and repetition of complex words
- Pictures to be named due to iconicity of signs
- Name and address not culturally valid
- Clox administration-sign gives away clock face and hands



In October 2010, 250 deaf healthy signers aged between 50-95 will be given these tasks at the England Deaf Derby and Joan holiday in Pontins, where over 800 deaf older adults will attend.

With the collection of data from a number of different age ranges in deaf healthy adults, norms can be developed, so deaf individuals with dementia can be compared against healthy norms for their age and we can determine if they are at risk.

#### Study 2 (The University of Manchester)

Describe the experience of dementia from within the cultural perspective of signing Deaf people with dementia (DWD) and their carers.



This is groundbreaking research in the Deaf community as this is the first time that Deaf BSL users have ever been interviewed directly about their dementia. These documented first-hand accounts are vital to find out:

- What BSL users' priorities and values are in terms of care and support;
- The cultural influences on potential recognition of early-stage dementia;
- What daily life is like for a person, who uses BSL, with dementia;
- Deaf BSL users' experiences with current service provision.

Data will be collected from ten DWD and ten carers twice over a period of 6-8 weeks to measure (if any) differences in the participants' experiences and access to information about their dementia. Video data will be analysed using Interpretative Phenomenological Analysis. (IPA)

#### Study 3 (the University of Manchester, Alzheimer's Society and Royal Association for Deaf People)



Explore /knowledge of and attitudes towards dementia in the Deaf community including its identification, familial/community support, and service need and access to information.

A review of current services available will take place; to identify accessibility and to gain feedback from the Deaf community about their preferences.

Study 3 will incorporate a number of focus groups in the UK with Deaf BSL users who have no direct experience of dementia. These groups will explore what their knowledge and understanding of dementia is; and their perception of service provision in this area. The focus groups will also bring local Alzheimer's Society groups, who have limited understanding of the support needs of Deaf people with dementia, together with Deaf BSL user groups. The study will look at the potential for inclusion and the development of joint working and support. These groups will be brought together by the Royal Association for Deaf People and the Alzheimer's Society and the research developed by the University of Manchester. This feedback will be extremely useful for the development of future provision for Deaf people with dementia and their carers.



## Linking individuals and families affected by Alzheimer’s disease or a related dementia to a community of learning, services and support

**What is First Link® ?**

**Direct Referral**

- Physicians and other health care professionals directly refer patients to the Alzheimer Society

**Early Intervention and Ongoing Support**

- Individuals and families build relationships with support agencies for ongoing access to services, support and learning opportunities

**Community Collaboration**

- Working together to provide access to effective, consistent and timely services

**Progressive Learning Series**

- Provides a comprehensive overview of dementia, coping strategies, resources and support systems
- For people with early memory loss and their care partner
  - *Next Steps*
- For family and friends of a person with dementia
  - *Next Steps for Families*
  - *Care Essentials*
  - *Options for Care*
  - *Care in the Later Stages*

**Benefits to Physicians and other Health Care Professionals**

- Health professionals can focus on the medical aspects of dementia care, while the Alzheimer Society provides ongoing support, education and help in navigating the health care system
- Holistic approach to care results in fewer unplanned visits to physicians and medical facilities

**Benefits to Patients and Families**

- Early and ongoing access to information, services and support
- Early intervention gives people with dementia an opportunity to help plan for their own care
- Caregivers are more knowledgeable about the progression of the disease and more confident in their caregiving role
- Removes barriers for families that are too overwhelmed to link to services themselves
- Reduces incidence and intensity of caregiving crisis situations

**Benefits to the Health System**

- Connects people to local services for a community-based, integrated care continuum
- Early intervention through education and support delays placement in long term care, resulting in significant savings for the health care system
- Agencies work together to provide appropriate services at the right time, identify gaps and reduce duplication of services

**For more information about First Link® or to obtain referral forms, please contact a First Link® Coordinator:**

**Regina & Southern Saskatchewan**  
 Phone: 306-949-4141  
 Fax: 306-949-3069  
 Email: [firstlinksouth@alzheimer.sk.ca](mailto:firstlinksouth@alzheimer.sk.ca)

**Saskatoon & Northern Saskatchewan**  
 Phone: 306-683-0141  
 Fax: 306-683-6391  
 Email: [firstlinknorth@alzheimer.sk.ca](mailto:firstlinknorth@alzheimer.sk.ca)

or

**1-800-263-3367**





# Strategic response to dementia rates in the United Kingdom – a country by country overview

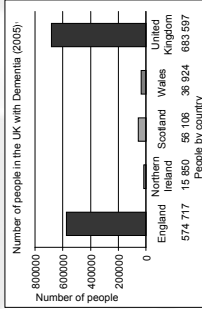
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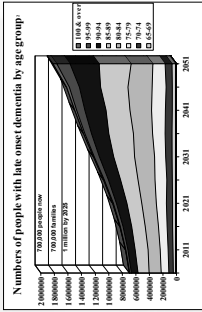


## Background

- Reports and research in the United Kingdom highlight the shortcomings of the current provision of dementia services.
- The level of diagnosis and treatment for those affected by dementia in the UK is generally low compared to other European countries.
- Only one third of people with dementia receive formal diagnosis or have contact with specialist services at any time in their lives.
- With the foreknowledge that the number of people affected by dementia will continue to grow, the countries of the UK are acting now to respond to the impact of dementia on their citizens.



The 2005 population estimate of the UK was 60.2 million.



## Response By Country



### England

- The government of England has made dementia a national priority.
- Published in February 2009, England's National Dementia Strategy is the result of consultations and planning begun in August of 2007.
- This strategy aims to ensure that significant improvements are made across three areas: **improved awareness, earlier diagnosis and intervention, and a higher quality of care.**
- With a focus on local-level changes to healthcare delivery, 17 key objectives are identified which – when implemented – should improve the level of care received by those affected by dementia.
- Integral to the strategy is an implementation plan with £150 million over the next two years of new investment in health and social care to implement all of the objectives.



### Scotland

- Alzheimer Society of Scotland figures place the cost of dementia in Scotland between £1.5 billion and £1.7 billion – £25 472 per person per year.
- The Society's dementia manifesto *Let's make dementia a priority* urges the Scottish parliament to make dementia a national priority allocating a total of £15 million to seven activities to address the impact of dementia.
- The Mental Welfare Commission and the Care Commission co-produce *Remember, I'm still me*. The report is an in-depth look at 30 care homes in Scotland and the individuals with dementia in those homes.
- The two agencies found that some care homes in Scotland have fallen seriously short of best practices. Of the 30 care homes visited:

- Only 24% of people living in a care home had an adequate record of their life history
- About half of the people living in care homes never went outside of the home
- Only a third of care home managers had undergone a recognized training course about caring for people with dementia
- The report has **ten key messages** for care homes and dementia care.

- The Scottish government is addressing the shortcomings outlined in the report, and will build upon these measures to develop a national dementia strategy for Scotland.
- Over the summer of 2009 a wide ranging consultation is gathering recommendations for the strategy including from a specialist dementia forum including the Mental Health Commission, Alzheimer Scotland, the Care Commission, Age Concern & Help the Aged. The strategy is expected to be published by the end of the year.



### Northern Ireland

- The Northern Ireland Assembly Executive has committed to the development of a Dementia Strategy for Northern Ireland.
- The Alzheimer's Society in Northern Ireland calls for the strategy to be similar to the strategy developed in England.
- In Northern Ireland the Alzheimer Society is concerned that within 10 years, more than 20 000 people in the country will be living with dementia.

## In Focus – England

The strategy has three **key areas** in which to improve the quality of life for people with dementia and their carers: **Raising a awareness and understanding** **Ensuring** early diagnosis and support **Providing** a higher quality of care to dementia and lessen the stigma of the for people with dementia, their family and carers.

There are **17 objectives** to be implemented:

<p><b>1. Improving public and professional awareness of dementia</b></p> <ul style="list-style-type: none"> <li>- Raise awareness, reduce stigma, and encourage help seeking behaviours</li> </ul>	<p><b>2. Good quality early diagnosis and intervention</b></p> <ul style="list-style-type: none"> <li>- All people with dementia have access to a "pathway of care" that delivers rapid specialist assessment and sensitively communicated support</li> </ul>	<p><b>3. Good quality information for those with dementia and their carers</b></p> <ul style="list-style-type: none"> <li>- diagnosis and throughout course of care, quality information will be provided</li> </ul>	<p><b>4. Easy access to care, support and advice after diagnosis</b></p> <ul style="list-style-type: none"> <li>- "dementia adviser" will facilitate easy access to care, support &amp; advice for people with dementia and their carers.</li> </ul>	<p><b>5. Development of structured peer-support and learning networks</b></p> <ul style="list-style-type: none"> <li>- "dementia adviser" will facilitate easy access to care, support, and enable people with dementia to take an active role in development of local services.</li> </ul>
<p><b>6. Improved Community personal support services</b></p> <ul style="list-style-type: none"> <li>- Carers have an assessment of their needs, get better support, and short breaks from caring at home with dementia and their carers.</li> </ul>	<p><b>7. Implementing the Carers Strategy</b></p> <ul style="list-style-type: none"> <li>- Carers have an assessment of their needs, get better support, and short breaks from caring at home with dementia and their carers.</li> </ul>	<p><b>8. Improved quality of care for people with dementia</b></p> <ul style="list-style-type: none"> <li>- In general leadership and pathways for general hospitals with specialist older persons mental health teams</li> </ul>	<p><b>9. Improved immediate care for people with dementia</b></p> <ul style="list-style-type: none"> <li>- more care for people with dementia who need help to stay at home.</li> </ul>	<p><b>10. Considering housing related services and telecare</b></p> <ul style="list-style-type: none"> <li>- needs should be considered in the development of housing options, assistive technology, and telecare.</li> </ul>
<p><b>11. Improve the quality of care for people with dementia</b></p> <ul style="list-style-type: none"> <li>- development of explicit leadership for dementia care within care homes.</li> </ul>	<p><b>12. Improved end of life care for people with dementia</b></p> <ul style="list-style-type: none"> <li>- involving people with dementia in end of life care planning.</li> </ul>	<p><b>13. An informed and effective workforce for people with dementia</b></p> <ul style="list-style-type: none"> <li>- health and social care staff have the right skills to provide best care, and get the right training specific to their work.</li> </ul>	<p><b>14. A joint commissioning strategy for dementia</b></p> <ul style="list-style-type: none"> <li>- health and social care services will work together to identify and best meet the needs of people with dementia and their carers</li> </ul>	<p><b>15. Improve assessment and regulation of health and care services and of how systems are working</b></p> <ul style="list-style-type: none"> <li>- there will be better inspection regimes for care homes.</li> </ul>

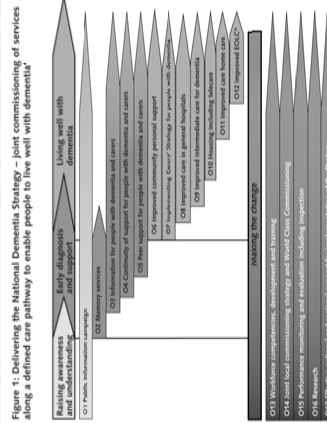


Figure 1: Delivering the National Dementia Strategy – best commissioning of services along a defined care pathway to enable people to live well with dementia

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# Being Mindful: Depression and Dementia among Rural and Urban Seniors- Epidemiological Studies



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## Introduction

### Global burden of dementia and depression

Table 1. Estimated prevalence of moderate and severe disability (million) for leading disabling conditions by age, for high-, middle-, and low-income countries from Global Burden of Disease, 2004.

Ranking	Disabling condition	High income	Low income	World			
Age group	Age group	Age group	Age group	Age group			
15-64	65-74	75-84	85-94	15-64	65-74	75-84	85-94
1	Ischaemic heart disease	7.7	6.4	6.8	13.9	15.2	15.2
2	Stroke	6.4	5.1	5.5	10.9	12.9	12.9
3	Alzheimer's disease	5.8	5.1	5.4	10.9	12.9	12.9
4	Depression	5.8	5.1	5.4	10.9	12.9	12.9
5	Unintentional injuries	2.8	1.1	1.9	4.9	5.0	5.0
6	Alcohol use disorders and problems	2.8	1.1	1.9	4.9	5.0	5.0
7	Alcohol use disorders and problems	2.8	1.1	1.9	4.9	5.0	5.0
8	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
9	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
10	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
11	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
12	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
13	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
14	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
15	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
16	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
17	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
18	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
19	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6
20	Use of anti-depressants	0.8	0.6	0.7	1.4	1.6	1.6

• **Depression**  
98.7 million at 2004  
(GBD)

• **Dementia**  
24.3 million now  
4.6 million/year  
81.1 million at 2040  
(10/66 Dementia)

North Americans aged > 60 yrs have the highest prevalence and incidence rates of dementia in the world (see table 2). WHO projects that dementia will become the most important neurological disorder contributing to disability-adjusted life years.

## WHO (2006)

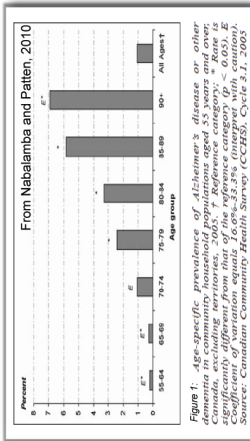
### Canadian seniors

- History.** The aging of the Canadian population is a result of 1947-1966 "Baby Boom". However, there is considerable debate about the impact of Canada's aging population.
- Situation.** Currently, 13% percent of the Canadian population is seniors (>65yrs). This proportion is expected to rise to 25% by 2031.
- Distribution.** A higher proportion of seniors are women; this is especially true in older age groups, due to longer life expectancy among women (Turcotte and Schellenberg, 2006).
- Depression and/or dementia in Canadian seniors**

- Dementia.** The number of Canadians with dementia will increase from approximately 500,000 at present to 1.1 million in the next 30 years (Dudgeon 2010).
- The prevalence of dementia increases with age and almost doubles every decade after 65 years old (Nabalamba and Patten, 2010) (Figure 1).

### Depression

The Canadian Community Health Survey of Mental Health and Well-being (2001) reports more than 5.0% of Canadians 65 yrs and over had a measurable common psychiatric disorder such as depression, mania, panic, phobias or substance dependence (CCHS 2003).



### Relationships between Dementia and Depression

- Is depression a risk factor for the subsequent development of dementia? Does dementia lead to depression? It is suggested that depression and dementia share a common pathophysiology. APOE may also be involved in dementia and depression co-morbidity (Delano-Wood et al. 2008).
- Lifetime history of depression can be considered as a distant risk factor for dementias. Depression also occurs frequently within one year before and after the onset of dementia.
- Psychotropic agents and antidepressant may cause memory problems and/or dementia-like symptoms.

There is little literature on prevalence, correlates, and their trends in depression or dementia among Canadian seniors.

### Research questions

- What are current prevalence, incidence, and trends in depression and dementia in Canada in general?
- Are there rural and urban differences?
- Are there differences among the young-, middle-, and old-old seniors?
- What are major risk factors for dementia or depression? Are there unique risk factors for seniors?
- Do those with co-morbidity have more risk factors? Does a dose-response relationship exist?
- What are the trends in the treatment of depression and dementia among seniors?
- Do additional psychological or physical health problems contribute to depression and dementia occurrence?
- Do Immigrant or Aboriginal seniors have more or less depression or dementia?
- What are the attributes associated with successful aging? What factors provide protection against the onset of dementia/depression?

### Research objectives

- To fill the information gap on the current prevalence, correlates, and their trends for depression and dementia among rural and urban Canadian seniors;
- To find out the existing or potential risk factors for dementia and depression;
- To disseminate information about the attributes associated with successful aging to policy makers and general population.

### Methods

#### Data sources

- National survey data (1994 to 2008)
  - Cross-sectional data:
    - National Population Health Survey (NPHS) cycle 1, 2, 3;
    - Canadian Community Health Survey (CCHS) 1.1, 1.2, 2.1, 3.1
  - Longitudinal data: NPHS cycle 4, 5, 6, 7
  - Administrative health data (2000 to 2006)
    - Population health care utilization data for Saskatchewan
- Statistical analyses

#### Prevalence and incidence

#### Risk factors

#### Protective factors



### What this research adds

- Provides a timely and useful portrait of the current status and trends in depression and dementia among rural and urban seniors in Canada with particular attention to rural populations.
- Examines risk factors for these disorders and looks for potential interventions points that may delay or prevent their occurrence.
- A variety of national health survey data and provincial administrative data sources will be used to look at trends in prevalence, current prevalence rates, and risk factors for depression and dementia, including cognitive functioning.
- The results will provide firm evidence for policy and program development with respect to depression and dementia among seniors.

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# Implementation and Sustainability of an Educational Program in LTC: Utilization of the PARIHS Framework to Guide the Way

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## Background

Within long term care (LTC) facilities across Canada, there are many residents who have been diagnosed with some type of dementia. One of the characteristics of dementia is that individuals may display some type of aggressive behaviour. Front line staff often feel as if they do not have the appropriate skills to be able to manage these behaviours. Training will help staff manage the aggressive behaviour, but it alone does not cause behaviour change. There are many factors that influence the implementation of knowledge. Research utilization and sustainability have been studied within acute care studies, however, there is limited research on the factors that affect research use in LTC.

## Research Purpose

Although the Promoting Action on Research Implementation in Health Services framework (PARIHS) has been utilized in various acute care settings (Brown & McCormack, 2005) little is known about which dimensions of facilitation are most important or how they operate in long term care settings.

The purpose of this research is to develop and understand the concept and process of facilitation in the implementation and sustainability of best practice guidelines in long term care, with a particular focus on an educational intervention for front line staff aimed at management of challenging behaviors by residents with dementia.

## Research Questions

How and in what ways does facilitation impact the uptake of knowledge and the sustainability of evidence based practice in long term care?

What role does facilitation play in relation to context and evidence in the implementation and sustainability of best practice in long term care? How do these concepts interact?

What are the characteristics of facilitation as observed in the selected long term care sites? How do these fit with those proposed in the literature, which is based on concept analysis and research conducted in acute care settings?

The Gentle Persuasive Approaches Program (GPA) uses the train-the-trainer model with on site training conducted by internal instructors who may be from any department in the facility. How and in what ways do these trainers act as facilitators during and after program implementation?

## The Gentle Persuasive Approaches Program

The GPA program is a dementia specific training program designed for all staff in LTC who work with residents with challenging behaviours.

It utilizes the "train-the-trainer" teaching method.

GPA Master Trainers are responsible for training GPA Coaches from the LTC sites.

GPA Coaches then return to their individual sites to provide staff from all departments with this training.

A total of 12 long term care staff are allowed in each training session conducted by the GPA Coaches.

The GPA is a 7.5 hour training course divided into 4 modules

- Module 1: Focuses on resident directed care
- Module 2: Explains how the brain is affected by the dementia process
- Module 3: Introduces how to identify and de-escalate behaviours
- Module 4: Teaches staff how to physically protect themselves in ways that are respectful and safe for the residents in LTC.

## Knowledge Translation

Knowledge translation" can be defined as "...the exchange, synthesis, and ethically sound application of knowledge – within a complex system of interactions among researchers and users – to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system" (CIHR, 2004).

## Promoting Action on Research Implementation in Health Services (PARIHS) Framework

Successful Implementation (SI) is a function (f) of the nature and type of Evidence (E), the qualities of the Context (C) in which the evidence is being introduced, and the way the process is Facilitated (F) (Kitson et al., 1998).

### SI=f(E,C,F)

- Sub-elements :
  - Evidence = research, clinical & patient experience
  - Context = culture, leadership, & evaluation
  - Facilitation = purpose & skills/attributes

Each of these three elements and their sub-elements can be placed on a continuum from low to high.

The higher on the continuum that evidence, context and facilitation fall, the more likely it is that knowledge will be implemented in practice.

## Facilitation

"Facilitation is defined as a process through which one person makes things easier for others by helping them reach their full potential and realize particular goals" (Scott & Snelgrove-Clarke, 2008, pg.27).

The PARIHS Framework recognizes the importance of the facilitation process in the implementation and sustainability of research in the health care system.

It is almost impossible for knowledge implementation and sustainability to occur without some type of facilitation (Kitson, 2008).

## Research Utilization

•There is a significant gap between research and the implementation of new knowledge into practice (Bradley, 2004; Davis et al., 2003).

•There is an expectation that once research is generated, it should be immediately implemented within the health care system (Nuitley, Waller & Davies, 2003).

•For those who work in health care, passive information or educational activities are very poor methods to create change in a system (Davis et al., 2003).

•To improve the uptake of knowledge, the health care system needs to move beyond the simple dissemination of knowledge (Kitson, 2008).

•The health care system is a dynamic, chaotic and ever-changing system where many factors play a role in how knowledge is implemented and sustained (Davis et al. 2003; Kitson, 2008).

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