Knowledge Network in
Rural and Remote Dementia Care

Scientific Poster Session

Healthcare Delivery Across the Continuum
for Rural and RemoteSeniors with Dementia

3rd Annual Summit

October 28 & 29, 2010
<table>
<thead>
<tr>
<th>Poster Number</th>
<th>Poster Presenter</th>
<th>Authors &amp; Poster Titles</th>
</tr>
</thead>
</table>
Mapping Referrals of a Telehealth-Supported Rural and Remote Memory Clinic                                                                 |
| 2             | Debra Morgan           | Morgan, D., Cammer, A., Wickenhauser, J. & Holfeld, L.  
Factors Influencing Satisfaction With Telehealth Videoconferencing in a Memory Clinic for Rural Seniors                                                  |
| 3             | Catherine Lacny        | Lacny, C., Kirk, A., Morgan, D. & Karunanayake, C.  
Does Day Length Affect Cognitive Performance in Rural and Remote Memory Clinic Patients                                                                 |
| 4             | Nicole Haugrud         | Haugrud, N., Crossley, M., Vrbancic, M. & Jodouin, S.  
Comparing Qualitative Verbal Fluency Scoring Procedures in Healthy Aging and Early Stage Alzheimer’s Disease                                              |
| 5             | Margaret Crossley      | 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                                           |
| 6             | Megan O’Connell        | 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                        |
| 7             | Megan O’Connell        | 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                             |
| 8             | Chandima Karunanayake  | Morgan, D., Karunanayake, C., Kosteniuk, J., Beever, R., Holfeld, L. & Elash, F.  
Rural and Remote Memory Clinic - Data Team                                                                                                             |
| 9             | Sheena Walls Ingram    | 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                       |
| 10            | Norma Stewart          | Stewart, N., Morgan, D., Forbes, D., Karunanayake, C. & Wickenhauser, J.  
Caregiver Distress Prior to a Family Member’s Dementia Diagnosis: Gender and Generational Contrasts                                            |
<table>
<thead>
<tr>
<th></th>
<th>Name</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Julie Kosteniuk</td>
<td>Diagnosis and Management of Dementia: Pilot Study of Roles and Perceived Needs of Rural and Remote Primary Care Providers</td>
</tr>
<tr>
<td>12</td>
<td>Julie Kosteniuk</td>
<td>Dementia Care in Rural and Remote Settings: Systematic Review of Formal/Paid Care</td>
</tr>
<tr>
<td>13</td>
<td>Lesley McBain</td>
<td>Personal Care and Special Care Facilities in Aboriginal Communities of Saskatchewan.</td>
</tr>
<tr>
<td>14</td>
<td>John Keady</td>
<td>Dementia and Ageing Research Theme (DART): An Overview of Completed and Ongoing Research</td>
</tr>
<tr>
<td>15</td>
<td>John Keady</td>
<td>Deaf With Dementia Project</td>
</tr>
<tr>
<td>16</td>
<td>Joanne Bracken</td>
<td>Alzheimer Society of Saskatchewan First Link Coordinators</td>
</tr>
<tr>
<td>17</td>
<td>Duane Minish</td>
<td>Strategic Response to Dementia Rates in the United Kingdom - A Country by Country Review</td>
</tr>
<tr>
<td>18</td>
<td>Xiangfei Meng</td>
<td>Being Mindful: Depression and Dementia Among Rural and Urban Seniors - Epidemiological Studies</td>
</tr>
<tr>
<td>19</td>
<td>Tracy Danylyshen Laycock</td>
<td>Implementation and Sustainability of an Educational Program in LTC: Utilization of the PARIHS Framework to Guide the Way</td>
</tr>
<tr>
<td>20</td>
<td>Charlene Chipeur</td>
<td>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></td>
</tr>
</tbody>
</table>
Mapping Referrals of a Telehealth-Supported Rural and Remote Memory Clinic

L. Holfeld1, D. Morgan1, M. Crossley2, A. Kirk3, N. Stewart4, C. D’Arcy5, D. Forbes5, V. Dal Bello-Haas5, J. Basran3, L. McBain8, A. Cammer1, M. O’Connell2

1Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan; 2Department of Psychology, University of Saskatchewan; 3College of Medicine, University of Saskatchewan; 4College of Nursing, University of Saskatchewan; 5Department of Applied Research, University of Saskatchewan; 6Faculty of Nursing, University of Alberta; 7School of Physical Therapy, University of Saskatchewan; 8First 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:
  1. Improve the availability of specialized personnel and services providing assessment and management of dementia
  2. Improve the accessibility of programs supporting formal and informal caregivers of persons with dementia
  3. Improve the acceptability of services for persons with dementia and their caregivers

Typical Pattern of Diagnosis:
Prior to Rural and Remote Memory Clinic
- Referral by GP to clinic via neurologist
- Pre-clinic assessment via telehealth
- Follow-ups via telehealth (Yearly follow-ups via in-person)

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

Clinic Nurse
Neurologist
Psychometrist
Diagnostic Imaging
Geriatrician
Physical Therapist

Team Conference, Diagnosis and Care Planning
Team Meets with Patient and Family

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

It was like climbing a mountain to get a diagnosis.
“Strategy for AD and Related Dementias in Saskatchewan” (2004), focus group comment.

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 Morgan1, Allison Cammer1, Joe Wickenhauser2, & Leslie Holfeld1

1Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan, Canada; 2York University, Toronto, Ontario, Canada

Aims and Methods

Background

TH good for follow-up, not initial in-depth assessment

The province of Saskatchewan, Canada: "To keep in touch with them [telehealth] is probably a good thing. And if they [team] have any suggestions"

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 ongoing)

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

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

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... it [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 think the combination works well... It’s a helpful to actually go [to city] and meet face-to-face... for those appointments that maybe aren’t quite as long—to be 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 perhaps... a little hesitant about dealing in front of the camera, the anonymity of it"

- "They [patient] 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.
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. 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.1,2 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.3 Currently, there is insufficient evidence to assess the effect of natural light exposure on dementia patients.4

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.

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 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 | 59 (38.3%) | Female | 95 (61.7%) |
| Neurologist diagnoses, n (%) | Alzheimer’s disease (AD) | 86 (55.8%) | Mild cognitive impairment* | 23 (14.9%) | Frontotemporal dementia† | 12 (7.7%) | Dementia with Lewy bodies | 10 (6.5%) | Vascular dementia | 7 (4.5%) | Mixed Dementia – AD/Vascular | 5 (3.3%) | Vascular cognitive impairment | 4 (2.6%) | Normal pressure hydrocephalus | 1 (0.6%) | 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 |

* Mild cognitive impairment (MCI) includes MCI, MCI due to other and MCI amnestic diagnoses.
† Frontotemporal dementia (FTD) includes FTD frontal variant, FTD semantic, and FTD progressive non-fluent diagnoses.

Table 2: Descriptive statistics of climate data

| Day length (min) | Mean ± SD | Range |
| 739.6 ± 196.4 | 417 to 1016 |
| Mean temperature (°C) | Mean ± SD | Range |
| 2.1 ± 12.3 | -25.2 to +25.0 |

Table 3: Correlation and multiple linear regression analysis

| MMSE Score | All (n=154) | MMSE score ≤22 (n=72) |
| Estimate | P value | Estimate | P value |
| Day length | -0.058 | 0.437 | 0.056 | 0.642 |
| Mean temperature | -0.048 | 0.504 | -0.079 | 0.512 |

Multiple linear regression (n=72)

Slope of linear regression (SE) | 0.093 | 0.008 | 0.005 | 0.015 | 0.101

R² | 0.023 | 0.032 |

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

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**: 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**
2. Individuals with **Alzheimer’s disease** (AD) produce fewer switches and smaller cluster sizes than normals

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 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: subordinate 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

- **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

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).

**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).

**Qualities of the N-CAM**

The N-CAM was created and modified in collaboration with our Keewatin Yatthé partners, and based on our experiences in the Rural and Remote Memory Clinic.

- The N-CAM does not assume formal education and is administered in the preferred or first language of the senior.
- The N-CAM is administered through home-based interviews by front-line health workers.
- The N-CAM has been designed to incorporate colour, humour, and familiar images and materials to better engage Aboriginal seniors.
- Family caregivers are included in the assessment of activities of daily living to better identify potential changes in functional status.

**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.

**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.

**Funding Support**

...
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 curers of spouses of patients diagnosed with Alzheimer disease

- Few specific interventions have been developed to address their needs

Rationale for Specialized Group Intervention

- Spousal careers of individuals diagnosed with atypical dementias can obtain both practical information and support from others who are experiencing similar troubling behaviours in their spouse

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

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

References

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

M. E. O’Connell1, V. Dal Bello-Haas2, D. Morgan3, & M. Crossley1

1 Department of Psychology, University of Saskatchewan
2 School of Physical Therapy, University of Saskatchewan
3 Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan

BACKGROUND

Importance of Physical Activity and Exercise
- Physical exercise
  - reduces cognitive aging1
  - delays onset of dementia risk2
  - is recommended for patients diagnosed with dementia3

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)4

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 RRMC patients and their caregivers who participated in this study
- We would like to thank Telehealth Saskatchewan for their support
- Funding: Ralston Brothers Medical Research Fund, College of Medicine, University of Saskatchewan

REFERENCES

Introduction

Sample Sizes and Data Release Dates

DR1 188 patients (December 2008)
   - 38 60
   - 113 128
   - 38 45
   - 237 284

DR2 84 patients (April 2009)
   - 3 Year Follow-up
     - 43
     - 84
     - 38

DR3 155 patients (September 2009)
   - 128
   - 122
   - 38

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.

Timeline of Questionnaires

Pre-clinic Assessment (6 weeks following Clinic Day)
   - h1 Telehealth Session Form (Pre-Clinic)
   - i1 Family/Patient Telehealth Session (Pre-Clinic)
   - j1 Telehealth Coordinator Form (Pre-Clinic)
   - f1 Family/Caregiver (Clinic Day)
   - k Family/Caregiver Patient Health History (Clinic Day)
   - g Family/Caregiver 1 day Clinic Satisfaction (family takes home questionnaire and Allison writing, the SF12 scale, and statistical analysis for the team)

Clinic Day
   - c5 Client Interview Follow-up (4 year)
   - l1 Family/Patient Follow-up Evaluation (6 week)
   - f2 Family/Caregiver (6 week)
   - f3 Family/Caregiver (12 week)
   - f4 Family/Caregiver (6 month)
   - f5 Family/Caregiver (1 year)
   - h2 Telehealth Session Form (6 week)
   - i2 Family/Patient Telehealth Session (6 week)
   - j2 Telehealth Coordinator Form (6 week)
   - l2 Family/Patient Follow-up Evaluation (6 week)
   - n2 Neurologist Data Points (6 week)
   - n3 Neurologist Data Points (12 week)
   - n4 Neurologist Data Points (6 month)
   - c6 Client Interview Follow-up (2 year)
   - l3 Family/Patient Follow-up Evaluation (6 month)
   - n5 Neurologist Data Points (1 year)
   - n6 Neurologist Data Points (2 year)
   - n7 Neurologist Data Points (4 year)
   - n8 Neurologist Data Points (4 year)
   - d Family/Client Satisfaction Interview Guide Telehealth Experience (The first possible administration time is 1 year. This is only administered once.)
   - q1 3MS/MMSE (2 year)
   - q2 3MS/MMSE (1 year)
   - q3 3MS/MMSE (6 week)
   - q4 3MS/MMSE (12 week)
   - h3 Telehealth Session Form (1 year)
   - i3 Family/Patient Telehealth Session (1 year)
   - j3 Telehealth Coordinator Form (1 year)
   - l4 Family/Patient Follow-up Evaluation (1 year)
   - n4 Neurologist Data Points (1 year)
   - p2 MRS Patient Data (1 year)
   - u1 Technology Acceptance Survey (1 year)
   - v1 Behaviour Rating Scale (1 year)
   - u2 Technology Acceptance Survey (6 week)
   - v2 Behaviour Rating Scale (6 week)
   - s1 Other Survey (5 years)
   - n9 Neurologist Data Points (2 year)
   - n10 Neurologist Data Points (4 year)
   - j10 Telehealth Coordinator Form (4 year)

1 Year Follow-up
   - c5 Client Interview Follow-up (2 year)
   - l1 Family/Patient Follow-up Evaluation (6 week)
   - c6 Client Interview Follow-up (1 year)
   - l2 Family/Patient Follow-up Evaluation (6 week)
   - c7 Client Interview Follow-up (2 year)
   - l3 Family/Patient Follow-up Evaluation (6 month)
   - c8 Client Interview Follow-up (4 year)
   - l4 Family/Patient Follow-up Evaluation (1 year)
   - c9 Client Interview Follow-up (6 year)
   - l5 Family/Patient Follow-up Evaluation (2 year)
   - c10 Client Interview Follow-up (10 year)
   - l6 Family/Patient Follow-up Evaluation (4 year)
   - c11 Client Interview Follow-up (12 year)
   - l7 Family/Patient Follow-up Evaluation (6 year)

2 Year Follow-up
   - c5 Client Interview Follow-up (2 year)
   - l1 Family/Patient Follow-up Evaluation (6 week)
   - c6 Client Interview Follow-up (1 year)
   - l2 Family/Patient Follow-up Evaluation (6 week)
   - c7 Client Interview Follow-up (2 year)
   - l3 Family/Patient Follow-up Evaluation (6 month)
   - c8 Client Interview Follow-up (4 year)
   - l4 Family/Patient Follow-up Evaluation (1 year)
   - c9 Client Interview Follow-up (6 year)
   - l5 Family/Patient Follow-up Evaluation (2 year)
   - c10 Client Interview Follow-up (10 year)
   - l6 Family/Patient Follow-up Evaluation (4 year)
   - c11 Client Interview Follow-up (12 year)
   - l7 Family/Patient Follow-up Evaluation (6 year)

3 Year Follow-up
   - c5 Client Interview Follow-up (2 year)
   - l1 Family/Patient Follow-up Evaluation (6 week)
   - c6 Client Interview Follow-up (1 year)
   - l2 Family/Patient Follow-up Evaluation (6 week)
   - c7 Client Interview Follow-up (2 year)
   - l3 Family/Patient Follow-up Evaluation (6 month)
   - c8 Client Interview Follow-up (4 year)
   - l4 Family/Patient Follow-up Evaluation (1 year)
   - c9 Client Interview Follow-up (6 year)
   - l5 Family/Patient Follow-up Evaluation (2 year)
   - c10 Client Interview Follow-up (10 year)
   - l6 Family/Patient Follow-up Evaluation (4 year)
   - c11 Client Interview Follow-up (12 year)
   - l7 Family/Patient Follow-up Evaluation (6 year)

3 Year Follow-up
   - c5 Client Interview Follow-up (2 year)
   - l1 Family/Patient Follow-up Evaluation (6 week)
   - c6 Client Interview Follow-up (1 year)
   - l2 Family/Patient Follow-up Evaluation (6 week)
   - c7 Client Interview Follow-up (2 year)
   - l3 Family/Patient Follow-up Evaluation (6 month)
   - c8 Client Interview Follow-up (4 year)
   - l4 Family/Patient Follow-up Evaluation (1 year)
   - c9 Client Interview Follow-up (6 year)
   - l5 Family/Patient Follow-up Evaluation (2 year)
   - c10 Client Interview Follow-up (10 year)
   - l6 Family/Patient Follow-up Evaluation (4 year)
   - c11 Client Interview Follow-up (12 year)
   - l7 Family/Patient Follow-up Evaluation (6 year)

Pre-clinic 273
   - 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
   - After Freda imports the above databases into the main database, Rob (Data Analyst) and Freda do a supercheck involving comparing birthdates and appointment dates from the new main database.

In the RRMC database there are 125 questionnaires covering 9 time points:
   - 84
   - 38
   - 45
   - 237
   - 32
   - 12
   - 22
   - 17
   - 60
   - 33
   - 33
   - 12
   - 13
   - 25
   - 6
   - 16
   - 3
   - 1
   - 4
   - 9
   - 1
   - 1
   - 1

Debra Morgan, Chandima Karunanayake, Julie Kosteniuk, Rob Beever, Leslie Holfeld & Freda Elash
Dementia Caregiving in a Rural or Remote Setting: Initial Findings from a Longitudinal Needs Assessment of Informal Caregivers

Sheena Walls-Ingram¹, Debra Morgan¹, Allison Cammer¹, Margaret Crossley¹, Dorothy Forbes², Anthea Innes³, Megan E. O'Connell¹, Norma Stewart¹

¹University of Saskatchewan ²University of Western Ontario ³University of Stirling

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 to confirm their own suspicions.

- Seeking 1st 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.

- 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.

Acknowledgements
Caregiver Distress prior to a Family Member’s Dementia Diagnosis: Gender and Generational Contrasts

Norma Stewart1, Debra Morgan1, Dorothy Forbes1, Chandima Karunanayake1, Joseph Wickenhauser1
1University of Saskatchewan 2University of Alberta 3York University

Gerontological Society of America 63rd 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.

Table 1: Clinic Day Means and Standard Deviations.

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Caregiver Burden (n=171)</th>
<th>Severity of Distress (n=166)</th>
<th>Health-Mental (n=169)</th>
<th>Health-Physical (n=169)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Husband</td>
<td>8.2 (8.5)</td>
<td>40.2 (9.8)</td>
<td>55.3 (8.7)</td>
<td>43.3 (10.6)</td>
</tr>
<tr>
<td>Wife</td>
<td>15.3 (9.7)</td>
<td>55.0 (8.9)</td>
<td>50.1 (10.2)</td>
<td>44.5 (12.1)</td>
</tr>
<tr>
<td>Son</td>
<td>10.8 (6.7)</td>
<td>45.2 (10.8)</td>
<td>54.7 (7.5)</td>
<td>49.3 (14.4)</td>
</tr>
<tr>
<td>Daughter</td>
<td>16.5 (7.5)</td>
<td>52.1 (9.4)</td>
<td>49.6 (9.3)</td>
<td>48.9 (13.3)</td>
</tr>
</tbody>
</table>

Table 2: Clinic Day Analysis of Variance Results.

<table>
<thead>
<tr>
<th>Factor</th>
<th>Caregiver Burden (n=171)</th>
<th>Severity of Distress (n=166)</th>
<th>Health-Mental (n=169)</th>
<th>Health-Physical (n=169)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (G)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship (R)</td>
<td>0.181</td>
<td>0.039</td>
<td>0.732</td>
<td>0.012</td>
</tr>
<tr>
<td>G x R</td>
<td>0.933</td>
<td>0.688</td>
<td>0.957</td>
<td>0.725</td>
</tr>
</tbody>
</table>

Skewness*:
- Skewed Right
- Skewed Left

Note: Results (p values) in bold are statistically significant.

*Kolmogorov-Smirnov test for normality

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.

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

Julie Kosteniuk¹, Debra Morgan¹, Anthea Innes², John Keady³, Turner Goins⁴, Carl D’Arcey⁵, Norma Stewart⁶, and Andrew Kirk⁷

¹Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan, ²Applied Social Science, University of Stirling, ³School of Nursing, Midwifery, and Social Work, University of Manchester, ⁴Community Medicine, West Virginia University, ⁵College of Medicine, University of Saskatchewan, ⁶College of Nursing, University of Saskatchewan, ⁷College of Medicine, University of Saskatchewan

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, 2000).

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, 51% were comfortable with driver’s license issues, and 43% were comfortable with competency assessment.

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
• medications manager
• providing resource assistance

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

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.

Methods
Sample
• 235 family physicians were invited to participate, from the total population of Saskatchewan family physicians (N=189)
• All Nurse Practitioners were invited to participate (approx. 115 NPs licensed to practice in SK)

Data collection
• January – May, 2010
• Telephone interviews with a semi-structured interview guide
• Participants received a $50 honorarium

Analysis
• Constant comparative method of analysis, with simultaneous data collection and analysis

Results
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.

References
Bridford Dementia Group and Commission for Rural Communities, Services Needs and Delivery Following Dementia Diagnosis: Evidence Based Review, Central Lancashire Primary Care Trust, 2000; 239-2949.
Bridford Dementia Group and Commission for Rural Communities, Services Needs and Delivery Following Dementia Diagnosis: Evidence Based Review, Central Lancashire Primary Care Trust, 2000; 239-2949.

Acknowledgements
This research is supported by:
• Dr. Debra Morgan’s Applied Chair in Health Services and Policy Research (2009-2014), funded by CIHR and the Saskatchewan Health Research Foundation for the research program Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia.
• The CIHR Strategic Training Program in Public Health and the Agricultural Rural Ecosystem (PHARE) and Partner Institutions including the University of Saskatchewan, University of British Columbia, Institute of Child Health and Research, Institute of Circulatory and Respiratory Health, Institute of Infection and Immunity, and the Institute of Public Health and Public
Dementia care in rural and remote settings: Systematic review of formal/paid care

Debra Morgan1, Anthea Innes2, Julie Kosteniuk1

1Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan, 2Applied Social Science, University of Stirling

Introduction

- A growing number of countries have developed, or have committed to developing, national dementia strategies to improve dementia services. England’s 2009 National Dementia Strategy is the benchmark for other countries.
- The rise in numbers of people with dementia is related to the “graying” of the population, as prevalence roughly doubles every five years over age 65 [1].
- Rural areas are aging faster than urban areas [2-4], leading to more people at risk for dementia in rural areas.
- Health and social care services to people with dementia and their caregivers living in rural and remote settings is neglected globally [5].
- Meeting the needs of people with dementia in rural and remote areas is challenging, given the difficulties of providing and accessing services in rural areas [6].
- Urban models of care are often applied to rural areas but do not account for access issues related to distance from services.
- Future research into rural dementia care must improve our understanding of dementia, services, and social inclusion in relation to rurality [5].

Objectives

- Critically evaluate the available evidence from the published scientific literature on dementia care and service provision in rural and remote settings from the perspective of formal/paid caregiving
- Assess the current state of knowledge, policy and practice implications, and make recommendations for future research in rural and remote dementia care.

Methods

Search strategy: Seven databases were searched between January 22, 2010 and January 27, 2010. Search terms included (dementia or Alzheimer*), (rural or remote), and (care* or support or service or nurs* or tele*). An asterisk indicates that all terms that begin with that root were included in the search. The search was limited to English studies published between 1990 and 2010.

Inclusion criteria: Peer-reviewed original articles were included in the review. Dissertations, editorials, book chapters, book reviews, letters to editors, and commentaries were excluded from review. Only studies that involved formal or paid care were included in this review.

Data extraction: The data were extracted from each study by one reviewer, JC, and verified by CM and AI. Extracted data included details regarding the sample, study objective, definition of rural/remote care/service providers, major findings, and study recommendations.

Results

Figure 1 Flowchart for the selection of studies

| 627 records identified | 350 duplicates removed | 277 articles screened | 158 abstracts included (after full-text review) | 46 articles included in review |

Summary of findings

Six themes were identified in the 46 studies included in this review, including diagnostic processes, service provision, service models and programs, staff education and support needs, use of technology, and long-term care.

Diagnostic processes

- Recommendations from the reviewed studies focused on the following strategies to improve diagnosis and assessment in rural areas:
  - offer dementia-specific continuing education opportunities, training that improves early recognition and diagnosis of dementia by rural GPs and outreach strategies
  - improve access to local community-based services, such as the Alzheimer's Association
  - offer alternative assessment services such as memory clinics

Service provision issues

Four main themes emerged in relation to service provision:

- Barriers included the perception of rural people as self-sufficient and distrustful of outsiders, stigma of dementia, lack of awareness of services, lack of availability and choice in services, cost, travel, lack of transport, and providing culturally sensitive care to diverse populations
- Identification of case management and referral as strategies to address a number of these challenges
- Increase collaboration, partnerships, and integration of services
- Recruitment, retention, and training of formal care providers in rural communities

Service models and programs

Most studies focused on case management and referral:

- Identification of case management and referral as strategies
- Use of technology
  - Telehealth has been shown to be effective for pre-assessment and follow-up and for distance consultation for rural nursing home patients
- More research is needed to evaluate the validity and reliability of telehealth compared to in-person care
- To evaluate patient and provider satisfaction

Long-term care

- The demand for specialized dementia care environments in rural nursing homes may increase due to the desire of rural seniors to stay in their communities
- The physical environment might be improved without developing special care units by decreasing meaningless stimulation and increasing quality stimulation, providing more environmental clues, developing dementia-specific programs, providing more education opportunities for staff, and attending to staff workload issues
- The smaller scale of rural than urban nursing homes and the personal relationships between staff and residents may be a solid base for quality dementia care
- More attention needs to be placed on the absence of specialist end of life care and pain management
- More research is required on rural palliative care

Conclusions

- There is a need for more basic and continuing dementia-specific training of formal caregivers who provide services in rural communities, including family physicians, nurses, and other allied health professionals, and home care and nursing home staff
- Given the limited number and types of services available in sparsely populated rural areas, it may not be possible to provide a full range of separate specialized services for those with dementia
- Thus developing the capacity of rural providers is critical to ensuring their comfort and competency in delivering high quality care across the different types of service provision
- Formal caregivers play a key role in supporting patients and family caregivers and must have the necessary skills to fulfill this role
- There is also a need for integrated and coordinated care across the continuum from early diagnosis to end of life care
- The concept of case management emerged as a strategy to ensure that available services are used
- While outreach programs and technology help to reduce travel burden for episodic specialist care, the challenge remains to provide appropriate support and services in the rural community across all stages of the dementia trajectory

Acknowledgements

Debra Morgan is supported by an Applied Chair in Health Services and Policy Research (funded by the Canadian Institutes of Health Research and the Saskatchewan Health Research Foundation). Anthea Innes is supported by the University of Stirling research travel fund.

Julie Kosteniuk is supported by a Canadian Institute of Health Research Pre-Doctoral Scholarship through the Public Health in the Agricultural Rural Ecosystem (PHARE) Strategic Training Initiative in Health Research.

References

PERSONAL CARE AND SPECIAL CARE FACILITIES IN ABORIGINAL COMMUNITIES OF SASKATCHEWAN
L. McBain, N. Stewart, D. Morgan, C. Bourassa, A. Cammer, C. Cyr
First Nations University of Canada; University of Saskatchewan

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 who 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 $762 to $1,886 per month; Indian and Northern Affairs Canada's Assisted Living Program pays the 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.

Initial Observations

The regional health authorities with the highest percentage of First Nations and Métis individuals (Keewatin Yathé, Ashbasca, Mousel助推 Churchill River) have the lowest proportion of long-term care beds (4% - 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 Re-a-la-Croix) 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 hospitals are in far greater need of major repairs that those in the south. The result is two-fold. Firstly, the paucity of homes 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
John.Keady@manchester.ac.uk

UK Policy Developments
National Dementia Strategy
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:

DART Members
Caroline Swarbrick
Christine Brown Wilson
Emma Ferguson-Coleman
Helen Barnes
Jill Pendleton
John Keady
Moir Ali
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
Hairdressing, 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 relationships 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 Emronly 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

A 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’ 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

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
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) (Micoli, Dawson et al. 2006) has been modified in addition to other language, memory and visuospatial 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, family/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

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

or

1-800-263-3367
Strategic response to dementia rates in the United Kingdom – a country by country overview

D. Minish, D. Morgan
Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan

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 illness.
- With the foresight 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.

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 £50 million over the next two years of new investment in health and social care to implement all of the objectives.

Scotland

- The Mental Welfare Commission and the Care Commission co-produce Home, Health, Final Illness. 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 eat outside of the home.
  - Only a third of care home managers had undergone a recognised training course about caring for people with dementia.
  - The report highlights ten key messages for care homes and dementia care.
- The Scottish government is addressing the shortcomings outlined in the report, and will build upon those measures to develop a national dementia strategy for Scotland.
- Over the summer of 2009 a wide ranging consultation is getting underway to develop the strategy for Scotland.

Wales

- The government of Wales has a draft plan for a national dementia strategy.
- It is also of the recommendations made in the National Dementia Strategy for England, and focuses on actions taken by the Welsh health service.
- Currently in a consultation process, the Welsh government has accepted feedback on the document until September 15, 2009.
- The vision is to transform Wales into a dementia supportive community on a local and national level. The plan focuses on five major areas for consequent changes: (1) strengthening individuals, (2) strengthening communities, (3) improving infrastructure and access to services for all, (4) making structural changes to economic cultural and environmental conditions.
- There are 20 objectives in the strategy that aim to address these four areas.

Northern Ireland

- The Northern Ireland Assembly Executive has committed to the development of the 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 Focus – England

The strategy has three key areas in which to improve the quality of life for people with dementia and their carers:

- Raising awareness and understanding of dementia and lessen the stigma of the disease.
- Ensuring early diagnosis and support for people with dementia, their family and careers.
- Providing a higher quality of care to people who live well with dementia.

There are 17 objectives to be implemented:

1. Improving public and professional awareness of dementia and reducing stigma, reducing discrimination, and improving help-seeking behaviours
2. Good quality early diagnosis and intervention for all, all people with dementia have access to a ‘pathway of care’ that delivers specialist support and individually tailored support.
3. Good quality information for those diagnosed with dementia and their carers.
4. Easy access to care, support and advice after diagnosis.
5. Improved quality of care for people with dementia in general hospitals with specialist mental health teams.
6. Improved Community personal support services, appropriate range of service to support the needs of those living at home with dementia and their carers.
7. Implementing the Green Strategy.
8. Improved quality of care for people with dementia in care homes.
9. Improved quality of care for people with dementia who need help to stay at home.
10. Improved immediate care for people with dementia.
11. Improved quality of care for people with dementia in general hospitals with specialist older persons’ mental health teams.
12. Improved quality of care for people with dementia in care homes.
13. Improve the quality of care for people with dementia who need help to stay at home.
15. Improved immediate care for people with dementia.
16. Improved quality of care for people with dementia.
17. Improved support and learning for dementia.

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

Canadian Comparison

Out of a population of 33.5 million, an estimated 300,000 Canadians live with dementia. Canada is without a national dementia strategy. Funds to support more and better research are being directed through CBHR, but no direct support to those affected by dementia.

References

- Dementia UK – The Full Report (2007) {image adapted from report}
- National Dementia Strategy for England, and focuses on four major areas for concentrating changes: (1) strengthening individuals, (2) strengthening communities, (3) improving infrastructure and access to services for all, (4) making structural changes to economic cultural and environmental conditions.
- An informed and effective workforce for people with dementia.
- Health and social care staff have the right skills to provide best care, and can work together to identify and meet the needs of people with dementia and their carers.
- The Northern Ireland Assembly Executive has committed to the development of the Dementia Strategy for Northern Ireland.
- The government of Wales has a draft plan for a national dementia strategy.
- The Mental Welfare Commission and the Care Commission co-produce Home, Health, Final Illness. 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 eat outside of the home.
  - Only a third of care home managers had undergone a recognised training course about caring for people with dementia.
- The Scottish government is addressing the shortcomings outlined in the report, and will build upon those measures to develop a national dementia strategy for Scotland.
- Over the summer of 2009 a wide ranging consultation is getting underway to develop the strategy for Scotland.

Number of people in the UK with Dementia

- Number of people with dementia by age group

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Number of people with dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>65-69 years</td>
<td>800000</td>
</tr>
<tr>
<td>70-74 years</td>
<td>600000</td>
</tr>
<tr>
<td>75-79 years</td>
<td>400000</td>
</tr>
<tr>
<td>80 years+</td>
<td>1200000</td>
</tr>
</tbody>
</table>

The 2005 population estimate of the UK was 60.2 million.

- Only one third of people with dementia receive formal diagnosis or have contact with specialist services at any time in their illness.
- With the foresight 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 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 £50 million over the next two years of new investment in health and social care to implement all of the objectives.

- The Mental Welfare Commission and the Care Commission co-produce Home, Health, Final Illness. 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 eat outside of the home.
  - Only a third of care home managers had undergone a recognised training course about caring for people with dementia.
- The Scottish government is addressing the shortcomings outlined in the report, and will build upon those measures to develop a national dementia strategy for Scotland.
- Over the summer of 2009 a wide ranging consultation is getting underway to develop the strategy for Scotland.

- Only one third of people with dementia receive formal diagnosis or have contact with specialist services at any time in their illness.
- With the foresight 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 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 £50 million over the next two years of new investment in health and social care to implement all of the objectives.
Being Mindful: Depression and Dementia among Rural and Urban Seniors—Epidemiological Studies

Xiangfei Meng1,2, Carl D’Arcy1 & Debra Morgan2
1 Applied Research/Psychiatry, College of Medicine; 2 Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan

Introduction

Healthy burden of dementia and depression

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

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

- Dementia
  - 24.3 million now
  - 46 million by 2040
  - 81.1 million at 2040

Canadian seniorss

- 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% of the Canadian population is seniors (>65 yrs). 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 Schellengren, 2006).

Depression and/or dementia in Canadian seniors

- Depression
  - 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 yrs old (Nabila and Peaten, 2010) (Figure 1).

- Dementia
  - ... (Table unstated)

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, 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: Descriptive analysis
  - Risk factors: Sample weights
  - Protective factors: Multivariate regression analysis

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 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.

Acknowledgement

This research is supported by A CIHR Strategic Training Postdoctoral Fellowship in Public Health and the Agricultural Rural Ecosystem (PHARER).
Implementation and Sustainability of an Educational Program in LTC: Utilization of the PARIHS Framework to Guide the Way

Tracy Danylyshen-Laycock, Behavioural Consultant, Saskatoon Health Region
Doctoral Student, Health Sciences
University of Saskatchewan

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?

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).

The Gentle Persuasive Approaches Program (GPA) 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.

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.

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 (Nutley, Walter & 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).

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).
For additional information contact:

Debra Morgan, PhD, RN  
Professor  
CIHR-SHRF Applied Chair in Health Services and Policy Research  
College of Medicine Chair, Rural Health Delivery  
Canadian Centre for Health & Safety in Agriculture (CCHSA)  
University of Saskatchewan  
103 Hospital Drive, Box 120, RUH  
Saskatoon, SK  S7N 0W8  Canada  

Telephone: (306) 966-7905  
Facsimile: (306) 966-8799  
Email: debra.morgan@usask.ca  
http://cchsa-ccssma.usask.ca